

Training case study one

Training for researchers – a workshop designed by a virtual working group

Summary

This was a workshop on patient and public involvement in research with the aim of raising awareness of public involvement among researchers. It was led by patient and public involvement (PPI) managers in the National Institute for Health Research (NIHR) Trainees Coordinating Centre, NIHR Central Commissioning Facility and NIHR Evaluation, Trials and Studies Coordinating Centre. It was offered both as a one-day workshop and as a shorter breakout workshop within a two-day meeting for NIHR trainees (researchers with an award for research training from the NIHR).

What was the aim of the training?

The aim was to raise awareness of PPI in the research community by targeted activities setting measurable objectives, enabling participants to:

1. Identify the reasons for involving patients and the public in the design and conduct of their research
2. Fulfil the expectations of funders and sponsors of health related research
3. Identify a range of resources and approaches to developing PPI in their research projects

Who was the target audience?

The training was developed to be delivered to Trainees Coordinating Centre doctoral award holders. It was delivered at a dedicated one-day workshop in July 2011 and as two

workshop modules during the NIHR TCC Trainees' meeting in September 2011. This was a pilot to test suitability of materials and methods with this group with a view to wider development and dissemination.

What did the training involve?

The full day workshop covered:

- Why is it important to involve the public in research?
- Public involvement in the research cycle – a mapping exercise for participants
- Examples of involvement in one area of clinical specialism
- Changing the culture – involving people effectively
- How do funders involve the public in their work? – case studies and group activities
- Action planning

The facilitators encouraged open discussion about participants' experience with PPI and 'reality checks' to draw out concerns and reservations. They invited researchers to approach the research from a patient or member of the public's perspective and included an NIHR public contributor as part of the design and delivery team. They provided participants with additional materials and signposting for advice and information, and encouraged discussion about the ways in which they might argue in favour of PPI with sceptical or uncertain colleagues.

The facilitators subsequently ran the workshop as a short module within a one-day meeting. In this case, they covered topics including: 'What can PPI do for you?', 'Key challenges in PPI' and 'PPI throughout the research cycle'.

What were the outcomes?

1. The event objectives were achieved
2. The initial workshop was adapted into two PPI workshop

modules quite easily but with limitations

3. Materials from the workshop could easily be adapted and used by others in the NIHR.

Who developed the training? Were members of the public involved?

The training was developed by a project team through a virtual network using WebEx conferencing, email and telephone conferencing. The group was chaired and managed by Jo Powell, Senior Manager, Personal Award Team, NIHR Trainees Coordinating Centre, Leeds – who had originally identified the need for the training. Project team members included the PPI manager at the NIHR Central Commissioning Facility and the PPI manager at the NIHR Evaluation, Trials and Studies Coordinating Centre, two TCC award holders providing the researcher perspective, and a NIHR public contributor.

Who delivered the training? Were members of the public involved?

The training was delivered by the two PPI managers identified above, with input from a manager from the Personal Award team at TCC, a doctoral award holder and other members of the team including the public contributor.

How did you support participants after the training?

Participants were invited to develop an action plan at the end of the training, which the facilitators emailed to them three months after the workshop in order to remind them of the work they had done and plans they had developed.

Have you evaluated the training?

Feedback from participants on the day included positive comments about the interactive sessions, presentations and information about funders' requirements. In commenting on what could be improved, they suggested the need for more practical

examples.

Learning points

- It was useful to organise the participants into groups according to their level of experience with PPI.
- The shorter workshops were less successful because they gave limited opportunity for participants to develop understanding or apply principles to their own area of research.
- Participants would have liked more practical examples, but found the mix of interactive sessions and presentations useful.
- The two main presentations that formed the introductions to the morning and afternoon sessions of the one-day course were delivered by Jonathan Tritter of Warwick University. It will not be possible to replicate this at future events, although the slides and exercises that formed part of his presentations could be used or adapted by other presenters.

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Training and support for project steering group member

Steering groups are made up of experts and it is good practice for them to include at least two members of the public. A steering group oversees a research project to ensure that protocol is followed and provides advice and troubleshoots where necessary. This section describes the training and support that helps to maximise the benefits of this approach and enables people to be successful in this role. It covers:

- [What is a steering group?](#)
- [Training for steering group members](#)
- [Issues to think about before you start – training](#)
- [Support for steering group members](#)
- [Issues to think about before you start – support](#)

Training case study 17

Training and support for service user researchers

Summary

This is a flexible six-day training course for service users becoming involved in a research project, or to equip them to

carry out their own small-scale projects. Run by an independent service user researcher, it can respond to the needs of the project or of the individuals.

What is the aim of the training?

To train a group of service users to be able to carry out their own research or to become involved in an established research project. These tend to be small-scale pieces of qualitative research.

What does the training involve?

The training includes work on the following topics:

- different types of research – qualitative versus quantitative research
- why service user led research is different
- critical analysis of research
- potential for emotional impact of research on participants and user researchers
- different methods, for example running focus groups, conducting interviews

The course can be quite specific and focused on whatever approach is being used in an existing piece of research or more general to help a group of users choose their method and overall approach.

What are the outcomes?

The service users gain skills in research and the research project is completed.

Who developed the training? Were service users involved?

The training was developed and is delivered by Jan Wallcraft, who is a researcher and former service user.

How do you support service users after the training?

Ongoing support is provided to ensure the service users 'learn by doing'. For example, groups meeting are facilitated at key points to help the group learn from their experience and plan next steps in the process. They might meet to review the findings from a pilot focus group, to review the transcripts from interviews and plan how they will analyse the data, or to discuss what they will do with the results once they have the findings. This work is ongoing and is tied into the practical aspects of doing the research, which tends to work better than discussing it in theory.

In addition emotional/psychological support is provided by telephone. Service users know there is someone they can contact if things become difficult for them or if they need to talk to someone after an emotional interview.

When is this training most useful? Who is it most useful for?

Organisations/groups/researchers wishing to support or promote user-led research or involve service users as researchers.

Contact for more information:

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Useful reports/documents

Wallcraft J, Amering M et al. (2009). Handbook of Service User Involvement in Mental Health Research, Wiley-Blackwell.

Wallcraft J, Read J et al. (2003). On Our Own Terms: Users and survivors of mental health services working together for support and change, Sainsbury Centre.

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Training case study 16

Training for peer interviewers at Rethink

Summary

This was a five-day training course run by mental health charity Rethink, to prepare a group of mental health service users becoming involved as peer researchers on a qualitative research project exploring recovery for people with severe mental health problems.

What was the aim of the training?

The aim was to equip service users with interviewing skills prior to their involvement in a qualitative research study.

Who were the target audience?

Service users who were recruited to be researchers on the project.

What did the training involve?

The initial training days included training in interviewing and work to develop the interview schedule.

Day 1: Team development and a review of the research topic 'Recovery from mental illness' – including sharing personal experiences.

Days 2 and 3: Interviewing skills. Topics included:

- why peer interviewing is a good idea
- good practice in interviews – the start, middle and end

of interviews

- skills in questioning and listening, probing questions and follow-up questions.

There was role-play in groups of three: one interviewer, one interviewee and one observer to listen and give feedback. People swapped roles so that everyone got a chance to practise interviewing and receive feedback. The participants also discussed how to deal with difficult interviews, coping with distress and asking questions about sensitive topics.

Day 4: Ethical issues: confidentiality, informed consent and protocols for reporting any serious concerns about interviewees. There were further opportunities for role play plus discussions to finalise the interview schedule.

At the end of the four days the trainees took away a copy of the interview schedule and were asked to try it out with a friend. They chose to tape record these interviews themselves.

Day 5: A few weeks later, the group came together again to review their experience of piloting the questions, and their experience of interviewing. They finalised the schedule and received further feedback on their interviewing skills.

Further training was delivered by a member of the Rethink staff to coincide with the phases of data analysis and report writing.

What were the outcomes?

The training helped to improve participants' interviewing skills, and also helped with team-building. By sharing their perspectives about recovery, team members came to understand and respect different points of view, which helped with developing the topic guide used in the interviews.

Who developed the training? Were service users involved?

The training was developed and delivered by Alison Faulkner

who is a trainer with a mental health service user perspective. Alison promoted a shared approach to training, which was based on sharing her own skills and knowledge, but also recognised and built on the skills and knowledge that participants brought. New ideas and tips for others therefore emerged in every training session.

How did you support service users after the training?

The service user researchers were offered telephone support from a member of staff at Rethink throughout the project and had occasional meetings as a group.

Was the training evaluated?

Participants were asked to fill in a self-assessment form to evaluate whether the training had improved their knowledge and research skills generally, as well as specific interviewing and questionnaire design skills. The responses were generally very positive and depended to some extent on their previous knowledge. One participant had an MA in Health Research so her knowledge and skills showed little improvement; whereas others with little or no previous experience found that the training improved their skills and knowledge significantly, particularly their interviewing skills. The training was valued for the opportunity it gave people to learn together and bond as a group.

When is this training most useful? Who is it most useful for?

The training was designed to develop the interviewing skills and confidence of service user researchers within a qualitative research study. Similar studies involving service users as peer interviewers may find it helpful to adopt this approach.

Who commissioned this training?

The research project and training was commissioned by Rethink.

The project was funded by Astra Zeneca.

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The service user researchers' summary of the findings:

[Recovery insights: Learning from lived experience](#)

Full report: [Getting back into the world](#)

May 2012

Training case study 15

Training in critical appraisal skills: Making sense of the evidence in dementia – the ALOIS community

Summary

This one-day skills workshop was for carers of people with dementia. It was linked to a specific engagement project managed by the Cochrane Dementia Group, which recruits and trains lay volunteers, specifically targeting carers and former carers of people with dementia, to update and maintain an online register of controlled dementia trials. This trials register is called ALOIS after Alois Alzheimer. The ALOIS

community volunteers read reports of dementia research and extract key pieces of information to enter into the trials register, a task referred to as 'coding'.

What was the aim of the training?

The workshop had dual aims:

1. to enable carers to understand more about research and specifically how to tell good research from bad
2. to recruit volunteers to the ALOIS coding task, as described above.

People could take part in the workshop regardless of their intention to volunteer for the coding task. Also, taking part in the training was not a requirement for volunteering – many of the volunteers have access to this opportunity through other avenues.

Who was the target audience?

Although the target audience were carers and former carers of people with dementia, the workshop was open to anyone with an interest in dementia research. All members of the Cochrane Dementia and Cognitive Improvement Review Group (the team which set up the trials register) took part in the workshop, learning alongside the carers.

What did the training involve?

The workshop used a step-by-step approach to build up participants' confidence in critically appraising research articles. The trainers approached the workshop on the basis that people already have critical skills and the workshop was to help them learn how to apply these skills to research reports. The workshop activities are outlined below:

Step 1

Using a spoof example, participants were asked to think about

their views of research and the core principles required when reporting research. The example was a (pretend) new wonder drug for hangovers called 'LOMA – Less of the Morning After'. The aim was to make the first session accessible and fun.

Step 2

Using examples of real research which had been reported in the national press, the session continued discussion about how to critique research and focused on how these real examples stood up to further scrutiny. Participants were asked to think about what else they would want to know about the research if they read about it in the newspaper, such as what was missing in the report that would enable them to decide if it was good quality or would be useful to them.

Step 3

Using the standard Critical Appraisal Skills Programme (CASP) [11 questions for randomised controlled trials](#), participants worked in small groups to critique a published research paper, which had been referred to in Step 2.

Other workshop content included:

- thinking about why good quality research is important to carers of people with dementia
- a 'map' of a research article – getting orientated to research articles and the different elements you expect to see
- practical information about how the coding task would be carried out for the ALOIS community.

What were the outcomes?

About half of the carers taking part in the workshop decided to volunteer for the ALOIS project – reading trial reports and extracting information such as number of participants, type of intervention and diagnostic criteria. Their contribution is

improving the ability of the Cochrane review team to undertake the systematic review in a timely way as the trial reports are entered into the database more quickly.

As people become more confident with the task, they are encouraged to undertake other tasks for the Cochrane Dementia Group, such as acting as consumer referees of the Group's reviews and protocols, which is an integral part of the Cochrane peer review process.

Who developed the training?

Sally Crowe was the trainer commissioned to deliver this workshop. She has many years' experience of training members of the public in critical appraisal skills and has developed materials with Amanda Burls at CASP. The content of this workshop was influenced by feedback received from participants in previous workshops.

How do you support carers after the training?

Those carers who volunteered for the coding task are supported by the ALOIS study manager, Anna Noel-Storr. A comprehensive ALOIS coding manual gives step-by-step guidance for new volunteers and they submit their coding to Anna, who gives detailed and constructive feedback via email on how they've done. She also makes any corrections needed to the record and then publishes it on ALOIS. The number of corrections needed falls dramatically as volunteers get familiar with the task. For many volunteers Anna no longer checks their records in detail before publishing them.

Online e-learning materials are being developed both to encourage people to volunteer and to support volunteers. These materials include an online coding tutorial using a real dementia research paper as a worked example. There are more details about the e-learning materials below.

Was the training evaluated?

Participants were contacted to give feedback about their experience of the workshop. They enjoyed the day and of those who have gone onto code research reports for ALOIS, enjoy this task also. Some sample quotes from participants include:

“Rewarding”...“interesting”...“informative”...“challenging”...“educational”

“...a great way to become and stay more informed about the current research that is being done in the area of dementia and cognitive enhancement”

“I feel that I am making a contribution to a very important cause and a very worthwhile project”

Learning points

- When training members of the public in critical appraisal skills, the choice of topic for the practice session is important.
- Sometimes it can be helpful to use research examples that are different from the participants’ specific area of interest – this enables people to get really engaged with the critical appraisal process, rather than get distracted with the topic of the paper.

Contact for more information:

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Links to useful reports/documents

See further information about the [e-learning materials](#) that are being developed.

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Training case study 14

Integrated training for members of a research panel

Summary

At the Musculoskeletal Research Unit at the University of Bristol, there is a dedicated group of members of the public who meet on a regular basis with researchers to discuss research ideas and projects. This group is called PEP-R: the Patient Experience Partnership in Research. Group members bring with them knowledge and experience of living with musculoskeletal conditions. At group meetings, researchers and group members discuss ideas and projects. The sessions are funded by North Bristol NHS Trust and through the National Institute for Health Research (NIHR) Research Studies into the Orthopaedic Experience (RESTORE) programme.

What is the aim of the training?

The aim of the training is to provide the chance for members to find out about research methods and processes so that they can best contribute to the research. The aim of PEP-R is to enable people with musculoskeletal conditions to contribute to research projects at the Unit, to contribute their ideas for research and to work alongside researchers to identify research priorities.

What does the training involve?

The ethos behind the training and development is to place information about research methods and process within the context of real examples of the Unit's ongoing and planned research. In this way training and development are integral to the ongoing work of PEP-R. Training and development for group members takes place in three ways:

1. It is built into sessions when discussing projects
2. It is included in some dedicated timeslots within the sessions
3. It takes place in specialised meetings for group members interested in particular topics.

Training and development topics are identified by research staff and by group members in response to questionnaires asking them to prioritise areas that they would like to learn more about. PEP-R members are provided with additional materials including information about research design, examples of blank funding application forms and INVOLVE's [jargon buster](#).

In dedicated information sessions held separately, PEP-R members have visited the Unit during working hours. These visits have provided the chance for them to find out about and discuss sensory testing equipment and laboratory research. These information sessions took place with the Unit's research staff who are using such equipment and working in the laboratories on an ongoing basis.

What are the outcomes of the training?

To date the PEP-R group have found out about a range of topics within the regular meetings when discussing projects. For instance, PEP-R have been able to input into several proposed and ongoing randomised controlled trials. To make this possible, randomisation and the reason for trials were discussed with the group. Dedicated slots within the sessions

have enabled PEP-R to discuss topics such as qualitative research methods with researchers. Larger scale studies have also been discussed, again within the context of examples of the Unit's research.

Who organised the sessions?

The content of PEP-R sessions is worked out by a planning group. This is made up of research staff, a Communication and Patient and Public Involvement (PPI) Manager and a member of PEP-R.

How do you support group members?

Training and development is integral to the whole approach of PEP-R and Amanda Burston, the PPI Coordinator, is the key contact person for group members. Members regularly receive feedback on the projects they have discussed so that they can see how their input has influenced research at the Unit.

Have you evaluated the training?

The planning group is currently conducting an evaluation of PEP-R as a whole. Group members and researchers are being asked to describe how PEP-R has impacted on them and whether it has met their expectations.

When is the training most useful? Who is it most useful for?

This approach is a valuable way of providing training in an integrated way into meetings of a panel of service users to enable them to provide input on research projects.

Learning point:

- Don't underestimate the value of integrating training into existing activities of service user groups

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May 2012

Training case study 13

Preparing people for involvement in research using the Patient Learning Journey model

Summary

The Pressure Ulcer Research Service User Network (PURSUN UK) at the University of Leeds used the Patient Learning Journey model to prepare service users for involvement in research. This approach was used to support a new service user network, with the aim of developing patient and public involvement (PPI) in a previously poorly understood area of healthcare research.

What was the aim of the training?

There were previously no service user/carer groups or indeed charities with a specific focus on pressure ulcers. The Pressure Ulcer Programme of Research (PURPOSE) team at Leeds Clinical Trials Research Unit (CTRU) identified a need to develop PPI in their own studies as well as in the field more generally. They appointed Delia Muir as part time PPI officer to facilitate training to meet this need. Workshops based on the Patient Learning Journey model were chosen as preparation for new network members.

Who was the target audience?

The PPI Officer brought together a group of six service users with some personal experience of the prevention or treatment of pressure ulcers, some of whom had experience as carers.

What did the training involve?

The Patient Learning Journey model involved facilitated workshops where people were encouraged to tell their stories and reflect upon their personal experiences, expertise and skills as a group. Bringing people together to tell their own stories can facilitate group bonding as they recognise the common themes within their different experiences. It also provided an opportunity for people to vent their feelings about negative experiences in a safe environment, before meeting with professionals.

The next stage was to work with people to identify the learning points from their experiences and think about ways of communicating these learning points to professionals, in a constructive way. People were also encouraged to think about how much personal experience they felt comfortable disclosing when they came to meet professionals in a research context and what type of research activities they may be best suited to. Participants were encouraged to recognise the value of their experience and skills.

Further training with the network has been carried out on an informal basis, as at present there is little funding available to organise it more formally. The PPI officer also helps people to access local training and development opportunities where possible. As the group is widely spread geographically, they may be able to make use of local opportunities through universities or the National Institute for Health Research (NIHR).

What were the outcomes?

Network members who accessed the Patient Learning Journey workshops have gone on to be involved in research in a variety of ways. This has included: being a co-applicant on a funding application, being part of steering committees and project teams and speaking at conferences. The PURPOSE team has taken a flexible, 'asset-based' approach to involvement, which allows network members to take on varying roles depending on their skills, needs and the level of commitment they feel able to give.

Who developed and delivered the training? Were members of the public involved?

The Patient Learning Journey model was developed by colleagues at the Leeds Institute of Medical Education (see Morris et al 2009) looking at involving patients in the education and training of health professionals. This team includes people with a service user / carer background. People who have completed the training themselves can train to co-facilitate future workshops. The training was adapted and delivered by Delia Muir, the PPI Officer.

How do you support participants after the training?

When an opportunity for involvement arises, the PPI Officer is available to meet service users before they meet researchers, to talk through the project with them and help them to think about the contribution they could make. The PPI officer also meets researchers to help them to think about ways of involving people in their work in a supported and meaningful way, which may include organising and facilitating meetings and events. One example of this was a public engagement day to aid service user involvement in the interpretation of data. This involved using role play and videos as well as looking at the written material arising from the research.

The PURSUN UK network also aims to provide an environment where peer support is possible. The Patient Learning Journey

workshops aimed to facilitate this as they helped the network members get to know each other.

When is this training most useful? Who is it most useful for?

The Patient Learning Journey model was originally developed to prepare patients or service users for involvement in the education and training of professionals. However it is a model that can be easily transferred to other areas of public or service user involvement. It is particularly useful in situations where you are bringing together patients or service users who have not previously been involved, whether in research or in training and education.

Learning points

- Start where people are at, know your group and help them to assess their own needs and skills; start with them and their stories rather than what professionals think they need to know.
- When thinking about training, it is vital to work with researchers as well as service users: both groups need to be prepared for collaboration if it is to be a partnership. Researchers need to appreciate that service users may not engage with the research in the same way that they do.
- For people to contribute in a meaningful way, it is important that research activities are fully accessible; the way that you involve people is part of helping them to feel supported. You need to meet people halfway.

Contact for more information:

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Reference:

Morris P, Dalton E, McGoverin A and Symons J (2009) Preparing for patient-centred practice: developing the patient voice in health professional learning. In: Bradbury H, Frost N, Kilminster S, Zukas M, Beyond Reflective Practice. Oxford: Routledge.

May 2012

Training case study 12

Introduction to the research process – Diabetes Research Network

Summary

This one-day introduction to clinical research for service users involved in the Diabetes Research Network (DRN) has a focus on the early stages of research: how to come up with a question and how to develop a research protocol (research design).

Who is the target audience?

The training is intended for service users involved in the work of the Diabetes Research Network. Some are members of regional user groups that meet regularly, and some are members of a national group that carries out all its work virtually.

What does the training involve?

The training provides an overview of how research questions come about and how to design clinical trials, with some presentations and interactive workshop activities. It includes:

- presentation and discussion about where research questions come from
- group activity to see how the design of a blinded, randomised, controlled trial would work in practice
- introduction to research funding and how the process works
- presentation and discussion of ethics committees and what they do
- review of patient information sheets and lay summaries, what they ought to contain and what people need to look for – small group activity
- introduction to research terms and lay summaries, with a focus on the use of plain English
- discussion of what makes a successful study and a comparison of the views of service users, researchers and funders
- presentation from a local researcher about the variety of studies currently being delivered in the region, plus a question and answer session.

Supporting materials are circulated during the training, including a 'Glossary of Diabetes and Clinical Research', and if necessary a 'Glossary of Acronyms and Abbreviations'.

What are the outcomes?

Service users report increased confidence and enthusiasm about their involvement. At present they are mostly involved in commenting on research at the design stages, and reviewing research protocols and patient information sheets. They have a better understanding of what they can influence, where this will fit into the research cycle, and what researchers are doing.

Who developed the training? Were members of the public involved?

The programme was developed by a number of staff in the DRN –

people skilled in training to ensure that it is interactive and delivers the desired outcomes. The training was developed in response to an identified need: service users were asked about their training needs after some experience of being in their role.

Who delivers the training? Are members of the public involved?

The training is delivered by a combination of local and national DRN staff (including the DRN Training Officer, the DRN Patient and Public Involvement Lead, and a local DRN manager). Experts from the local area often deliver sessions on research ethics and the role of other regulatory bodies. Sometimes a local service user delivers a session describing their experience of assessing protocols and patient information sheets.

How do you support participants after the training?

Participants are asked to be involved in studies soon after the training, to help transfer the theory into practice. Further training is offered to develop other skills or knowledge.

Have you evaluated the training?

Feedback from all participants is very positive. They often comment that the length of sessions and the mix of topics meet their needs, and that the training gives them the skills and confidence to become more involved.

When is this training most useful? Who is it most useful for?

This training is useful for groups or panels of service users who are linked to a research centre, university or research network, who are involved in the early stages of research design.

Is the training accredited?

No – the variation in those delivering some of the sessions, plus the flexibility of the programme to meet local needs, means that we do not meet accreditation criteria.

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May 2012

Training case study 11

Training needs assessment of researchers at the NIHR University College London Hospitals Biomedical Research Centre

Summary

Rosamund Yu is the Patient and Public Involvement (PPI) Manager at the Joint Research Office for University College London Hospitals (UCLH) NHS Foundation Trust, University College London (UCL) and the Royal Free London NHS Foundation Trust. Rosamund was appointed in January 2011 and tasked with developing PPI in biomedical research across the National Institute for Health Research (NIHR) UCLH Biomedical Research Centre (BRC).

Why did you decide to carry out a training needs assessment?

Across the BRC there have been some examples of highly

effective PPI but we wanted to find out more about how examples of best practice could be spread across the Centre. In order to embed PPI in research throughout the BRC, it was necessary to increase researchers' awareness of and develop their skills for public involvement. A survey was used to raise awareness, assess training needs and find out what would attract researchers to training for public involvement (for example topic preferences, time of day, length of sessions and so on).

We planned to integrate training for public involvement for researchers at the BRC into the usual programme of professional development training being offered to research staff at UCL/UCLH. Offering a training programme in public involvement is intended to meet a number of aims for public involvement across the BRC, including:

- helping the researchers develop the knowledge and skills necessary for involvement
- helping researchers feel supported to incorporate public involvement into their research
- showing them it is expected and a normal part of doing research
- improving the quality of public involvement in research at the BRC
- encouraging involvement to be a positive experience for members of the public and researchers.

How were researchers asked about their training needs?

A brief [survey](#) was used to ask researchers about their training needs. Every effort was made to ensure the survey was quick and easy. It was available online and also given out at in-house research events, such as research governance training and a symposium for young researchers. There were few responses to the online survey until it was highlighted in an e-newsletter specifically targeted at biomedical researchers. 102 researchers completed the survey – about half online and

half from events.

What were the main findings from the survey and what is being done in response?

Researchers indicated that training that focuses on the practical aspects of doing public involvement would be most helpful, in particular:

- how to write the PPI section of a funding application
- taster sessions on PPI
- a practical session for planning PPI
- effective partnership working with charities
- leading and managing PPI activities.

They indicated that sessions on general skills (for example chairing a meeting, verbal communication skills and facilitation skills) were less helpful. They preferred at least half-day sessions and most preferred morning sessions.

A training programme is being planned in response to the survey findings.

Contact for more information:

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The BRC has produced a [booklet](#) containing a range of examples of how patients and the public have helped with their research.

May 2012

Training case study ten

Assessing training needs for patient advocates involved with the Diabetes Research Network

Summary

The Diabetes Research Network (DRN) has people affected by diabetes involved in various groups or committees, such as a national committee organised by the DRN Coordinating Centre, and one connected to a DRN Local Research Network centre – they call these people Patient Advocates. The DRN has developed an approach for finding out about Patient Advocates' training needs.

How were Patient Advocates asked about their training needs?

People affected by diabetes who had already been members of research groups for some time were asked what kind of training they would they have found helpful early on in their role. A questionnaire, based on these experiences, was developed. The questionnaire was piloted with local groups and further developed which took some time. It was sent to all active Patient Advocates. The [questionnaire](#) asked about three main areas:

- general skills, for example communication skills, committee skills, computer skills
- knowledge about diabetes and current research areas
- knowledge about research and how it works.

People were asked which of these they thought were important for their current or future roles, what knowledge and experience they already had and where there were gaps and then what training they might need.

When was the training needs assessment carried out?

We aimed to assess training needs within six months of each group being established. Some groups raised this earlier, or even discussed training issues at their first meeting – but it was felt they needed to get a feel for their role before they could fully complete the questionnaire.

What has been done in response to the findings?

By using the questionnaire for each group, it has been possible to tailor the training content to match the particular interests of the members. So far this has gone down very well.

The results of the first batch of questionnaires showed that there was a need to develop training around the research process, to demystify some of the terminology and what actually happens during the planning and delivery of a research study. So, for example, if Patient Advocates were looking at a patient information sheet, they wanted to know more about where that fitted in to the whole research pathway, to know who had been involved in developing that information and what would happen afterwards. This was important to people so they could better understand how their input would make a difference.

A one-day workshop has been developed as an introduction to clinical research. It has a particular focus on the early stages of research – how to come up with a research question and develop a research protocol. See [case study 12](#) for details of this training day. This workshop has now been delivered on numerous occasions, across the country, to a variety of groups.

It is tricky to try to cover everything with the limited resources available – so training days have been delivered by DRN staff members who are experts in their field. Where the required expertise is not available, external trainers have

been sought, for example Sally Crowe was commissioned to run workshops on Critical Appraisal Skills (see [case study 15](#) for an overview of this type of workshop).

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Training case study nine

Informal approach to assessing training needs

Summary

The Arthritis Research UK National Primary Care Centre has a part-time patient and public involvement (PPI) Coordinator and a part-time User Support Worker to support the Research Users' Group (RUG) for the Centre. The two adopted an informal approach to assessing the training needs of the service users involved in the Centre at an annual meeting for the group.

Why was it important to assess service users' training needs?

The aim was to assess the training needs of the service users in the Group in an informal way during an annual meeting: to find out what training people felt they needed in order to contribute meaningfully to research meetings.

The PPI Coordinator feels that it is particularly important to

address the training needs of people who are to attend steering groups as they can lack confidence and believe that they know nothing or fear that they might say something stupid. This can be a barrier to recruiting service users to steering groups.

The PPI Coordinator's view is that public involvement is more likely to have a positive impact if users first receive appropriate training and then subsequently receive continued support.

How were services users asked about their training needs?

Two A3 posters designed like a bar chart with 13 different training options, including one blank bar for suggestions, were placed up on the wall. During the meeting, service users were invited to put yellow post-it notes next to their first, second and third choices for training. These were subsequently collated and used to assess the priorities for training.

What has been done in response to the findings?

Training courses

The most popular topic identified was training on the research process, but people also wanted training in team building, management of meetings, presentation skills, and learning about health organisations. Following this exercise, the training options were split into those associated with the research process and those associated with meeting skills. The following courses have been provided to date:

(i) Contributing Assertively at Meetings: Half-day training course 9.30–12.30 lunch included, with external trainer. Funding from Centre Consortium Fund. (A university course for staff adapted to users.) Main course objectives were:

- to recognise the importance of your contributions to research

- to know and use techniques that will enable you to contribute assertively
- to identify ways that would help you to contribute more effectively.

The course was attended by 13 service users; ten rated the course as excellent, three as good. All attendees were issued with a certificate to say that they had successfully completed the course.

(ii) Systematic Reviews – what are they, why are they so important?

Half-day training course of three hours with an in-house trainer, an expert in systematic reviews. It covered an explanation of evidence based medicine, Randomised Controlled Trials (RCTs) and systematic reviews, the Cochrane collaboration and introduced participants to two Cochrane Review plain language summaries. All participants rated the course as excellent or good and received a certificate to say that they had successfully completed the course.

A further course is planned: **What happens in a clinical trial, what trials are undertaken at the Centre?** This will be a half-day course with an in-house trainer, a clinician with expertise in clinical trials.

Signposting to online Cochrane courses. Those who want to learn more about the research process are directed to the online course on the Cochrane website – [Evidence Based Healthcare](#) by Kay Dickersin and Musa Mayer, which gives further training for users into research process and methodology.

Who developed this approach? Were service users involved?

This approach to assessing training needs was developed by Carol Rhodes, the PPI Coordinator and service user, with Adele Higginbottom who is a long-standing member of the Research

Users' Group. As Adele has been a member of the Group from its inception and has also been a member of the Impact Back team who took part in a Health Foundation training course, Carol felt that she was best placed to act as training advisor to help develop a training plan for the User Group. Together they carried out a consultation exercise from which came the decision to assess the training needs of the Group.

Contact for more information:

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Training case study eight

INVOLVE shared learning groups for public involvement

Summary

The number of people who are involved with promoting and supporting public involvement in research organisations has grown in recent years. As this is often one or two people within an organisation, sometimes working part-time, they can benefit from having specific opportunities to share experiences with others in similar roles and from structured approaches to learn from each other.

INVOLVE facilitates three shared learning groups to bring people together across different parts of the National

Institute of Health Research. Each shared learning group has a particular focus – public involvement in (i) research commissioning, (ii) research design and (iii) translating research evidence into practice.

What is the purpose of this support approach?

A shared learning group is a way to enable people to share experiences, knowledge and ideas, learn about public involvement and provide a peer support network.

The aims (see [sample terms of reference](#)) of the INVOLVE shared learning groups are to:

- facilitate a shared understanding of public involvement in research
- discuss and address issues of common concern
- exchange ideas, strengthen skills and share examples of good (and not so good!) practice
- provide peer support within a safe environment.

Criteria are set for membership with new members being able to join at any point. For each group, the main criterion is simply to have a role in promoting and supporting public involvement in the relevant organisation. In the INVOLVE groups, this usually refers to staff members, but it can also include patients/members of the public. There are around 20 members in each INVOLVE group.

The approach aims to develop a network or community of people with a common interest. A structured element, for example meetings can initiate this with other mechanisms developing alongside as members get to know each other and develop relationships independently.

What does the support involve?

A key feature of the approach is planned meetings of group members. The INVOLVE groups have three full-day meetings each

year. This format suits these groups as members are based across England – travel for a periodic full-day meeting is more efficient than for more frequent shorter meetings.

The meetings are facilitated by INVOLVE staff and include:

- discussion of topics chosen by group members and driven by their current priorities, for example training and support, evidence of impact and diversity
- time for updating each other on recent work and developments
- small group discussions to ‘problem-solve’ particular issues
- talk or presentations from others (when appropriate).

Group members may also decide to take forward specific projects. Members in the research commissioning shared learning group have worked together to produce a [tips sheet](#) for recruiting public contributors.

The main resources required for each shared learning group include:

- venue to hold the meetings – this may be provided by member organisations
- catering – especially if whole day meetings
- time and travel for participants
- staff time from the facilitating organisation.

Who developed this approach?

This approach has evolved over time after a regular meeting for the public involvement leads for research commissioning was established in 1999. INVOLVE has learnt from other approaches such as the [User involvement in voluntary organisations – Shared Learning Group](#) and developed the approach in response to members’ feedback.

When is this support most useful/effective?

This approach is most useful when there is a group of people with a shared interest who may not have naturally occurring opportunities to develop their role and work through peer learning. In these examples, providing a forum for public involvement leads across a set of organisations with similar objectives has been a key feature. This has helped to increase people's capacity and capability for their role/work and reduced duplication of effort as well as a sense of isolation.

This model also suits people who are interested in working with others and have the ability to travel to meetings.

Have you evaluated this approach?

An [internal review](#) of the Research Design Service Involvement Forum was carried out in 2012. A formal evaluation of the other INVOLVE groups has not been carried out but enthusiasm for attending the meetings is high, suggesting that members value them.

Learning points

- Activity between meetings by members of the groups might be low – try not to see this as an indicator that members do not value the group, they are probably just busy in their own roles/lives.
- Continuity of the person facilitating the group is helpful – this enables a 'memory' for the group (especially with changing membership), capitalising on the knowledge generated by the group and building on work carried out previously.
- Be realistic about the time needed for organising and facilitating meetings – INVOLVE estimates at least 15 days of staff time per year for a group that meets three times.

Contact for more information:

Maryrose Tarpey (mtarpey@invo.org.uk) facilitates the Public

Involvement Collaboration Group (research commissioning)

Sarah Bite (sbite@invo.org.uk) facilitates the Patient and Public Involvement in Collaborations for Leadership in Applied Health Research and Care (translating research evidence into practice).

Lucy Simons (lsimons@invo.org.uk) facilitates the Research Design Service Involvement Forum (research design).

Another example is the [User Involvement in Voluntary Organisations – Shared Learning Group](#). This group aims to encourage shared learning about service user and/or carer involvement between voluntary sector organisations working within the UK. It is facilitated by Bec Hanley of [TwoCan Associates](#).

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