Training case study seven

National Institute for Health Research (NIHR) Cancer Research Network (NCRN): Support for lay members of the Consumer Liaison Group and Clinical Studies Groups

Summary
Part of the work of the National Institute for Health Research (NIHR) Cancer Research Network (NCRN) is to support the running of 22 Clinical Studies Groups whose role is to oversee the development of clinical trials as part of the NIHR Research Portfolio in the UK. Each Clinical Studies Group has two lay members working alongside researchers as part of each. Peer support for their roles is provided through their membership of the Consumer Liaison Group (CLG).

As part of the NIHR Clinical Research Networks' Patient and Public Involvement (PPI) Programme, the NCRN Coordinating Centre offers a package of support for lay members involved in the **Consumer Liaison Group** and Clinical Studies Groups. Some of the ways in which they do this include coordinating an email group, encouraging peer mentoring between new and existing members; as well as pairing lay members with a scientific mentor to assist with matters associated with their Clinical Studies Group.

1. Email group

The email group is coordinated by the NCRN PPI Lead through the University of Leeds JISC mail service (a group email facility). It has nearly 100 members in total, about 15 of whom are research staff. Although it is overseen by the

Coordinating Centre, the email group is largely self managed.

What is the email group for?

The email group is intended primarily as a communications tool, to notify people about meetings, to share policy and best practice guidance, and generally for keeping people in touch, informed and updated. People can get advice and help through this group; for example there is a thread running at the moment on definitions and understandings of rarer cancers. If people are to present on behalf of the group, they can ask for help and advice and will sometimes work together on presentations. Sometimes requests come from research teams across the country for members of the public to be involved in their research.

The email group is primarily intended for support in relation to lay people's roles as members of the Consumer Liaison Group and Clinical Studies Groups. Support for wider issues is encouraged to take place through other channels, for example through personal contacts and emails.

Training in use of the email group

The use of the email group is introduced as part of routine induction training. Guidance is given to people on how to use it, how to word things, how to use headers to alert people to the purpose of a message, when to use 'reply to all', and how to give clear information, for example about deadlines.

Have you evaluated the email group?

The email group has not been formally evaluated but it is active and well used, suggesting that people find it useful. People will often mention that it is helpful when they attend meetings of the Consumer Liaison Group.

2. Peer mentoring

The NCRN encourages all of its lay members to support each

other through a system of peer mentoring. New members are put in touch with existing members, as part of induction training and through regular attendance at CLG meetings, in order to learn from each other. Consumer Liaison Group members have access to a contact list to support ongoing communications with each other too.

Peer support is embedded in the role profile for lay membership of the Clinical Studies Groups and Consumer Liaison Group. As part of this, lay members are strongly encouraged to keep in touch with and support each other for advice, information and problem-solving; this takes place by email and for some via face-to-face and telephone contact.

There is an item on PPI at every Clinical Studies Group meeting. Some new members may be unsure how to use that slot; more experienced members can help with this and give examples of how they have used it. They can work together so that they do not feel so isolated.

Have you evaluated peer mentoring*?*

Informally, the NCRN asks people at meetings how it is going. They also carry out an annual survey to ensure that they get feedback on the views and experiences of lay members, including experiences of peer and scientific mentorship. The results help the NCRN PPI Lead to work with others to improve things. The mentoring is largely seen as positive – some use it a lot, others less so. However, as an overall indicator of the Consumer Liaison Group's popularity with members, nearly all lay members opt to extend their membership after the initial three years.

3. Scientific mentoring

Each lay member also has a scientific mentor, who is a member of their Clinical Studies Group. Clinical Studies Group Chairs work through the PPI Lead to ensure that scientific mentors are identified for each new lay member joining the Group,

helping them to more easily navigate the information discussed at meetings. The Clinical Studies Group Chairs are directly involved in recruiting new lay members and so are aware of the skills and expertise they can bring, which in turn helps them to identify appropriate scientific mentors.

Have you evaluated scientific mentoring*?*

This scheme has not been formally evaluated. It has been found to work well for the majority but for some the arrangement does not always work as well as expected. To some extent this depends on the personalities and skills of the people involved as well as the time they have to devote to this activity.

Plans for the future

The NCRN are planning to do further work with the Clinical Studies Groups, through their Chairs, scientific and peer mentors to see what further support may be needed to ensure the groups make best use of PPI and that lay members feel supported in their roles.

As a starting point, the plan is to work with Clinical Studies Group Chairs to encourage further focus on giving everyone an opportunity to speak, listening to people, and ensuring that new members are introduced.

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May 2012

Training case study six

Planning training for involvement in a systematic review

Summary
This training was carried out by researchers at the Medical Research Council (MRC) Clinical Trials Unit (CTU), London and was funded through a post-doctoral grant in Evidence Synthesis. Some funding was also through Medical Research Council funding to the Meta-analysis group at the CTU. The training was not accredited.

What was the aim of the training?

The aim of the training was to enable patients to understand the principles of systematic reviews and meta-analyses so that they could participate in a systematic review being carried out at the MRC Clinical Trials Unit.

Who was the target audience?

The target audience was a small group of women who had experienced chemotherapy and / or radiotherapy for the treatment of cervical cancer, as this was the subject of the systematic review. The women were recruited through two main routes: the charity Jo’s Trust and Cancer Voices. They became known as Patient Research Partners.

What did the training involve?

Initially, a workshop style meeting was held with the women who had been recruited along with the lead researchers who were carrying out the systematic review. The purpose of the workshop was to take the Patient Research Partners through the process of carrying out a systematic review, covering issues

such as:

- What are clinical trials?
- What are systematic reviews and why might they be needed?
- The specific needs of this project
- The benefits of carrying out this systematic review.

The workshop was supported by an information pack.

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

Initially, a small Reference Group was set up. This group included researchers, the Consumer Liaison Lead for the National Cancer Research Network, two experts in consumer involvement in healthcare research, the then Chief Executive Officer of **Jo's Trust** and one former cervical cancer patient. The Reference Group provided advice on the recruitment of women, provision of support and information and on the activities the women might undertake. From this we developed terms of reference and a role description for patients who were to get involved.

Workshop slides developed by the lead researchers were presented and discussed with the Reference Group members and were modified in response to their feedback. The Reference Group also provided initial comments and feedback on the information pack (drafted by members of the meta-analysis group). The information pack was further edited and extra sections were added, based on suggestions of the Patient Research Partners throughout the course of their involvement.

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

Researchers from the meta-analysis group delivered the training.

How did you support participants after the training?

Following the initial workshop, the Patient Research Partners were supported by regular meetings (approximately every six months for the duration of the project); and regular communication, usually by email.

What were the outcomes?

The Patient Research Partners became involved in a number of activities associated with the systematic review, including providing feedback on the detailed information folders; helping to trace contact details for trial investigators; learning about data management and analysis; and contributing to regular project newsletters. Their involvement also led directly to the researchers getting involved in another research project with a greater focus on late side effects of treatment. They were also involved in writing an editorial from the patient perspective. Another outcome was the further development of the information pack which may be used for similar projects in the future.

Have you evaluated the training?

The training itself has not been evaluated but the experiences of the Patient Research Partners and the researchers involved were evaluated at the end of the entire research project. The evaluation (published in the journal **Systematic Reviews**) showed that, for the most part, both researchers and patients appreciated the experience of involvement and the Patient Research Partners felt that the information provided had been thorough and had helped them to participate. There were some reservations about the involvement including: the time taken to manage the involvement of patients; the potential influence that patients can realistically have on a large-scale systematic review; and the need to be well prepared for what could be involved.

Learning points

- Training and supporting people well involves additional resources in terms of funding and time. This project was fortunate in that it had resources to do this, but this should not be overlooked in future projects.
- Preparing people for what might be involved is a vital part of training (for example the potential for research to take a long time; and dealing with discussion of topics or issues that may be sensitive or difficult).

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May 2012

Planning support – general overview

The support needed by researchers and members of the public will very much depend on the situation. This section provides an overview of the different types of support that could be useful as well as the different ways of providing this support. A range of case studies illustrate how support has been provided via different approaches in varied situations.

The section covers:

Planning training – general overview

This section provides general advice about planning training. We look at:

- Who benefits from training?
- What should training for members of the public cover?
- What should training for researchers cover?
- Different methods of training
- Issues to think about before you start – training
- Running training events or courses
- Budgeting for training events or courses

Training case study five

Research User Support Worker – Arthritis Research UK Primary Care Centre

Summary
The Primary Care Research Centre had a group of eight service users meeting regularly from 2006 (the Research User Group), but when the work of the Centre increased, it became necessary to support the group further. In addition, a larger pool of

service users was recruited to become a virtual panel of 20 in addition to the Research User Group. At this point it was decided to employ a part-time support worker, initially for three days a week: someone with experience of a musculo-skeletal condition. In 2009 the post was developed into patient and public involvement (PPI) Coordinator and extended to 30 hours per week.

What does the support involve?

The PPI Coordinator, Carol Rhodes, liaises with both researchers and patients. The Research Centre has patients involved in 40 different projects, including clinical trials, qualitative research and PhDs. Carol supports less confident new members by attending meetings with them. When she first started she tried to go to all meetings with the patients, but now she has an assistant User Support Worker who performs this role. The Research User Group (RUG) meets four times a year and they also have an annual meeting for all 28 patients/service users.

Part of the role is as an intermediary in enabling patients to understand the research, which includes liaising with researchers to produce lay summaries. Carol has developed a glossary of terms to help with this, which resulted from sitting in one of the larger steering groups and not understanding a great deal of what was said.

The Research Centre has a PPI request form for the researcher to fill in; this gives a framework with which all parties can understand the task involved. This document draws heavily on INVOLVE guidance and includes clear time scales for consultation and involvement so that service users are given time to read and absorb information. Carol then meets with the researcher and gets them to do a lay summary of the research. She also manages the process of feedback – to ensure that service users get feedback about their contribution whether a project is funded or not. Other issues include raising

awareness among researchers of the best ways to communicate with service users. An example of this is to make sure that researchers know that service users do not necessarily open their emails every day. There can also be a lot of last minute requests which involve ringing round to find someone who can step in.

Much of the day-to-day support is now carried out by the User Support Worker. She organises all of the support needs for someone to attend a meeting (for example parking, payments, ensuring that people get breaks and refreshments) and attends meetings with them. Carol and her assistant consider it vital that more than one patient should attend a meeting.

Who developed this approach? Were members of the public involved?

The approach has evolved over time, starting with the eight-person user group and culminating in the present situation with one PPI Coordinator and one User Support Worker. Both of the workers have personal experience of a musculo-skeletal condition (the support worker is a former member of the RUG) and were active in developing the roles.

What are the benefits of this approach?

Benefits for service users

- This approach is particularly beneficial in helping to bridge the gap between patients and research clinicians in a field where the language and acronyms are often difficult to understand.
- Patients' lack of clinical and research knowledge helps the researchers to produce more patient-friendly paperwork for their research.
- Some service users have grown enormously in confidence through their involvement in research.

Benefits for researchers

- Researchers are guided by the PPI Coordinator to plan ahead and follow best practice as outlined in the framework.
- They can ‘check out’ their ideas with people who understand what it is like to live with a musculoskeletal condition through presenting draft protocols to the Research User Group.
- They have access to a group of people willing to be involved in a range of research tasks.
- Researchers’ awareness of the positive value of service users’ contribution to research ideas and the design of studies has been transformed.

Have you evaluated this approach?

There has been an evaluation of the whole PPI approach taken at the Centre. The response was very positive. Recommendations included: merging the virtual panel and the RUG to become one Research Users Group for clarity; developing an induction pack and/or workshop for new members; and having a regular annual survey of members’ satisfaction. In addition, it was suggested that some PPI activities such as sitting on a steering committee need more support to develop a different set of skills. So the PPI Coodinator is thinking of running a workshop just for those who sit on steering committees, as a training exercise but also as a way of letting them share their experiences with each other.

What are the learning points?

- It involves time, hard work and patience from all of those involved: researchers, patients and clinicians.
- People with musculoskeletal conditions need additional consideration when travelling to conferences, for example extra overnight accommodation may be required.
- Patients dislike tokenism and they need feedback on projects and regular updates in order to stay motivated.

“I love my job and I do think patients have a positive impact on the research projects they are involved in. It is not just the research that benefits, but researchers, clinicians and patients benefit by working together and sharing their individual areas of expertise. We can all learn from each other.”
Carol Rhodes, writing in the **INVOLVE newsletter, Winter 2011-12**

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May 2012

Training case study four

Introduction to patient and public involvement in research

Summary
This is a one-day training course commissioned by the National Institute for Health Research’s Clinical Research Network Coordinating Centre (NIHR CCC), with the intention of introducing both researchers and members of the public to patient and public involvement (PPI) in research.

What is the aim of the training?

The aims are to:

- help people to build their understanding of patient and public involvement in research
- enable researchers to start involving patients and public in their research, or to develop their involvement activities if they are already active in this area
- encourage people to learn from each other about what might work in specific contexts
- equip patients and public with an understanding of the opportunities and issues in becoming actively involved in clinical research.

Who are the target audience?

- People working in research who want to involve patients and the public in their work.
- Researchers who are already active in this area, and who would like the chance to reflect on that they do and to share experience and ideas with others.
- Patients and members of the public who are already actively involved in research.

What does the training involve?

This is an interactive course. Issues covered during the training include:

- What is involvement? Defining some of the terms
- How patients and the public are involved in clinical research
- A talk from an involved patient, and time to ask questions
- The barriers to involvement and how to tackle them
- Involvement in different research areas/activities
- Action planning
- Sources of advice, information and support

What are the outcomes?

By the end of the course, participants have:

- an understanding of what is meant by patient and public involvement in research, and why it is important
- thought about the barriers to patient and public involvement, and how to overcome some of them
- started to think about how they might use the information gained on the course in their own work.

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

The training was developed in response to a detailed brief from the commissioners. It was developed by Bec Hanley, Rachel Purtell and Derek Stewart; Rachel and Derek are both service users.

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

The training is delivered by TwoCan Associates and service users are involved in delivering the course both as trainers and presenters.

How do you support participants after the training?

The trainers are not contracted to provide any support or information after the training; there is an assumption that support will be provided by PPI leads from within the Clinical Research Networks at a local and national level. However, as part of the training the facilitators give their contact details and invite people to contact them if they have any queries.

Have you evaluated the training?

An evaluation form is issued to participants at the end of each course. The evaluation of one of the more recent courses (July 2009) showed the following from 28 returned evaluation forms:

- All of the participants thought the course was excellent or good – 15 said it was excellent and 11 that it was good overall. Most people said the course was either useful or extremely useful for their current work.
- All but one person said that they would be likely to change their practice as a result of attending. We think this is the most important piece of feedback.

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

This is a general introduction largely to motivate and enthuse people about public involvement in research. Participants may need follow-up support and information before becoming involved or involving people in practice. This training would be useful for universities, research centres or research networks looking to train their researchers and to encourage and motivate them to involve service users in their work.

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May 2012

Training case study three

Patient and Public Involvement module for researchers in MSc at

King’s College, London University

Summary
This is an innovative development: a 12-week postgraduate module run as part of the Masters in Public Health (MPH) at King’s College London (KCL). Places on the course are also offered to students in the School of Medicine, health professionals, Research and Development managers and other researchers. The training is accredited as part of the MPH; it comprises 15 credits at Masters level; 40 Continuing Professional Development units with the assignment and 30 units without.

What is the aim of the training?

The module aims to provide postgraduate training in the theory and practice of involving patients and the public in health and social care research. Students will acquire the skills to be able to understand patient and public involvement (PPI) policy and practice in its historical, social and political context. They will also develop the practical skills required to design and implement patient and public involvement in research.

Who is the target audience?

The target audience is, firstly, students on the Masters in Public Health; they get first refusal for places (there are a maximum of 25 places). After this, it is opened up to everyone in the University. On the first occasion the module was run, four National Institute for Health Research (NIHR) / NHS professionals attended the course along with three Masters students. External students pay £600 for the course.

What does the training involve?

It is a 12-week course of three teaching hours per week, plus a minimum of three hours reading to prepare each week and

three assessments. The topics covered include: the history of PPI; activism and public involvement, individual and collective action; practical – critique of papers; expert patient debate; benefits of PPI; key principles; practical issues (for example communications and skills); and impact of PPI. Students have the opportunity to create an individual PPI plan for a research topic of their choice. For example, one student talked to a group of young people about a research project, and another talked to a mother about maternity services.

What are the outcomes?

The first time it was run (September to December 2011), five students out of the seven passed, and one of the Masters students gained a distinction. (Two of the participants who were not doing the MSc did not complete the assignment due to work pressures). Feedback from students is positive, particularly from the Masters students. The practical part of the course is found to be particularly important in bringing home to the students the value of PPI in research.

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

It was developed by Carol Porteous (PPI Lead for the Research Design Service (RDS), London) and Sophie Auckland (PPI Lead for the Biomedical Research Centre, Guy's and St Thomas's/King's College London) with Dr Christopher McKevitt (Reader in Social Sciences and Health) as module coordinator and with support from Dr Annette Boaz, Lecturer in Translational Science. Having run training sessions for Research Design Services and for the Biomedical Research Centre of two to three hours, they recognised that there was a need for more of a grounding in the philosophy and origins of PPI in research for academic researchers.

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

The module is delivered by Carol Porteous and Sophie Auckland and the academic lead is Dr Christopher McKevitt. In addition, there are a number of external speakers for example Dr Diana Rose, Co-Director of the Service User Research Enterprise, Institute of Psychiatry and Jonathan Boote, University of Leeds/Yorkshire and Humber RDS). Service users are involved in delivering two of the sessions: communications and creating relationships with patients and members of the public, and writing for lay audiences.

Have you evaluated the training?

There has been no formal evaluation to date (April 2012), but in the next month or so, the students will be receiving their marks and will be asked to feedback their views of the course.

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

The coordinators see the module as being useful for anyone doing a research based Masters; it fits with the MPH but would be useful for students in other disciplines, as well as health professionals and research managers unfamiliar with or wanting a greater understanding of PPI in research.

Learning points for the benefit of others

- The first run of the module involved a lot of work and was exhausting for the coordinators. Without a dedicated textbook to support such a course, it was necessary to pull the information together from various sources. There should not be as much work when they run it a second time.
- There was a range of experiences and views across the group which was a challenge for the coordinators to balance out. Some students were not very knowledgeable about research so the coordinators needed to provide some basic tuition about the research cycle. For next time, they will develop the pre-course reading to reflect this.

- Some students needed a lot of one-to-one support. It is important to reiterate that there are still different understandings of PPI and you need to allow time for this intensive support.

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May 2012

Training case study two

Patient and Public Involvement module in an MSc Clinical Research programme

Summary
This innovative module on Patient and Public Involvement in Research was established in 2010 as part of the MSc Clinical Research programme at the Centre for Research in Primary and Community Care (CRIPACC), University of Hertfordshire, Hatfield. The University of Hertfordshire is one of only seven universities in England to be awarded the fully funded contract by the National Institute for Health Research (NIHR) to provide the MSc in Clinical Research. In the context of developing the new Masters programme, it seemed to the course leaders that this was an ideal opportunity to introduce new

clinical researchers to the idea of public engagement in research.

What is the aim of the training?

The aim of the module is to enable students to understand and critically explore the social and political background against which public involvement in health research has been developed. The course leaders felt that a half-day workshop was not sufficient to cover the depth and complexity of patient and public involvement (PPI) in research and that for a Masters programme it was appropriate to provide a module in which students could fully appreciate both the theoretical and the practical aspects of public involvement.

Who is the target audience?

The majority of students are nursing and allied health professional students taking the module as part of the Masters in Clinical Research and they receive salary replacement costs and course fees from the Department of Health. It is also available as a 'stand-alone' course to health professionals engaged in clinical and health related research, who can self-fund; the fee for this is £540.

What does the training involve?

The module constitutes 15 credits at Masters level on successful completion of a 2,000-word essay. It is run in two blocks of two days over a term and is delivered through four days of mixed lectures, workshops, seminars and tutorials. Topics covered include: historical context/political and policy shifts; notions of citizenship and social movements; issues of power/empowerment; a critical approach to public involvement; the work of INVOLVE Advisory Group; the impact of PPI in research; gathering the evidence base; and patients' and clinicians' perspectives. Group seminars on the role of public involvement in health-related research are presented as a formative assessment. The summative assessment involves

developing a written critical analysis of patient or public involvement in a research issue related to the student's clinical area.

What are the outcomes?

To date there have been three cohorts of students to undertake the module: a total of 46, two of whom have done it as a stand-alone course. The first cohort of students have successfully graduated from the Masters programme. The third cohort of 23 students have just finished attending the sessions and are due to submit their assignment next month.

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

The course was developed by a team of service users and members of the public who are members of the CRIPACC Public Involvement in Research Group (PIRG) alongside academics within the Centre.

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

Members of the Public Involvement in Research Group are actively involved in delivering the module alongside lecturers from CRIPACC and external speakers. The module is led by Dr Jane Smiddy (Research Fellow in Public Involvement) alongside Professor Sally Kendall (Director) and Dr Patricia Wilson (Research Lead – Patient Experience and Public Involvement). External speakers include representatives from INVOLVE, the NIHR, and the James Lind Alliance. Members of the Public Involvement in Research Group also present sessions.

How do you support participants after the training?

No support is offered to students after they have finished the course but service users involved in delivering the course are supported through regular meetings and training opportunities within the PIRG.

Have you evaluated the training?

Yes, the module has been evaluated. Students rated this module as excellent and particularly valued the input from outside speakers. The majority reported that it has transformed their approach to PPI.

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

The course is aimed at health professionals actively involved in a research role and is particularly beneficial for research nurses and so on. This module may also be of benefit to interested people who are not health professionals but who would gain knowledge and critical thinking in relation to public involvement in research.

Learning points for the benefit of others

- Do not assume any prior knowledge of patient and public involvement in health research even with clinicians who have been involved in health research over a number of years.
- Having a variety of outside speakers makes this a dynamic module to attend. Students feel they are receiving “cutting-edge” preparation for PPI activities.

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May 2012

Training and support for peer interviewers

A peer interviewer is a person who has direct experience of the topic being researched and carries out interviews with others with a similar experience. 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 peer interviewer?
- Training for peer interviewers
- Issues to think about before you start – training
- Support for peer interviewers
- Issues to think about before you start – support

Training and support for public reviewer

Members of the public undertake reviews of grant funding applications for research funders. They can draw on their knowledge and experience of a health condition or their use of health and social care services to inform their review. 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 public reviewer?
- Training for public reviewers
- Issues to think about before you start – training
- Support for public reviewers

- Issues to think about before you start – support

Training and support for project advisory group member

Project advisory groups are set up to advise on a specific research project. They are often small groups of four to six members of the public who help with all stages of the research. 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 project advisory group?
- Training for advisory group members
- Issues to think about before you start – training
- Support for advisory group members
- Issues to think about before you start – support

Training and support for research panel member

Research panels are often made up of around a dozen members of the public and are usually attached to a research unit or organisation. They may help researchers develop and design research projects at the early stages. 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 research panel?
- Training for research panel members
- Issues to think about before you start – training
- Support for research panel members
- Issues to think about before you start – support