CHAPTER 1:

PATIENT AND PUBLIC INVOLVEMENT (PPI) AND THE RESEARCH PROCESS

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CHAPTER OVERVIEW

This chapter defines and introduces the different stages of the research process: from identifying a problem, to reviewing the literature; then developing a research question; designing a study; obtaining funding and ethical approval; recruiting participants; collecting and analysing data; and reporting and disseminating findings. This chapter will outline how users of health services, their carers and family members, and other members of the public can be involved in these different research stages, and demonstrate the impact that this involvement can have. Examples of different ways of involving and engaging public members in research studies are drawn from the Enhancing the Quality of User-Involved Care Planning in Mental Health Services (EQUIP) research programme.

LEARNING OBJECTIVES

By the end of this chapter you should be able to:

1. Understand the different stages of the research process
2. Understand the impact of Patient and Public Involvement in research
3. Understand the different ways you could be involved

INTRODUCTION

The Frascati Manual provides an internationally recognised definition of research. It defines research as:

“

CREATIVE WORK UNDERTAKEN ON A SYSTEMATIC BASIS IN ORDER TO INCREASE THE STOCK OF KNOWLEDGE INCLUDING KNOWLEDGE OF MAN, CULTURE AND SOCIETY, AND THE USE OF THIS STOCK OF KNOWLEDGE TO DEVISE NEW APPLICATIONS.

”

(OECD, 2002, pp30)

Inviting members of the public to offer a lay, non-specialist perspective on the design and conduct of research studies is typically referred to as 'Patient and Public Involvement' (PPI). PPI is a term used to denote meaningful involvement in the design and conduct of a research study. It does not mean a person is involved in a research study as a participant.

At the very least, a research study should be able to evidence consultation with service users, and at best, collaboration and partnership with them as an equal and valuable part of the research team.

Meaningful involvement is not always easy to achieve. One of the most important factors influencing the outcome of involvement is the perspective of different team members, and the different skills, assumptions, values and priorities that each of them brings. Acknowledging and working with these different perspectives is precisely what makes PPI so valuable, but it can also be what limits its success. Effective PPI requires that equal respect is afforded to academic and patient and public researchers, that the perspectives of both parties are equally valued, and that the team as a whole develops and maintains a shared language and goal. It is also important that PPI opportunities are advertised as widely as possible to ensure that they are accessible to a broad range of people from different backgrounds. Adequate training should be provided to ensure that people can be involved in research in a meaningful way (e.g. research methods and how clinical services are organised and commissioned).

Figure 1 Levels of service user involvement

Since the mid-1990s, increasing emphasis has been placed on the importance of PPI. The desire to strengthen the involvement and engagement of service users, carers and members of the public in research has been driven by:

- a.** a strong moral argument that any publicly funded research that aims to benefit health status or health services should be shaped and informed by the people it will affect (Hanley, 2012)
- b.** accumulating evidence of the benefits of patient and public involvement in research (Staley, 2015)
- c.** recognition that service users and carers, by virtue of their lived experience, can bring a wealth of experiential knowledge and expertise to the design and conduct of research studies (Faulkner, 1997; Repper, 2008).

Different roles and opportunities for patient and public members to participate in research have emerged. Some people may wish to act as consultants, advising on multiple projects during the early phases of research commissioning and design. Others may choose to engage in one specific project, joining a project advisory panel who will guide and advise a research team throughout the life of that project. PPI advisory panels (sometimes called a Service User and Carer Advisory Groups (SUCAG) or Expert User Groups) provide an independent viewpoint on research progress, advising on research procedures and challenges as they arise and assisting with dissemination.

Service users and carers may also choose to be researchers. Unlike advisory panel members, these individuals work as trained, integral members of the research team, contributing to the design and conduct of the study, and in some cases, its funding application. Service users and carers can be named as principal investigators or study co-applicants. As principal investigators they might take the lead in managing, designing and carrying out a study, or in forming a collaborative team, in what is sometimes called user-led or user-controlled research.

The EQUIP study was conducted by a mix of researchers from different backgrounds. The different contributions that service users and carers made to the EQUIP research programme are shown in Figure 1. As you can see, service users and carers worked in many different roles and had a range of different experiences, and you will learn more about their personal stories throughout the book. First though, let's take a journey through the research process and look more closely at where and when PPI opportunities can arise.

Beginning the research process

The beginning of the research process involves identifying a problem, reviewing the current literature to clarify what is already known and developing a research question to resolve remaining uncertainties or fill knowledge gaps. This is rarely a straightforward process.

Reviewing the literature on a particular topic can help to identify relevant papers quickly, enabling researchers to build upon, rather than duplicate, existing work. It can help to narrow a broad problem down to a specific issue, assess its importance and develop an appropriate and meaningful research question. We will learn more about how to conduct a literature review in Chapter 2.

It is good practice to involve stakeholders in the review process (Rees and Oliver, 2012). In research, the term 'stakeholder' is often used to refer to those individuals, groups or communities who have an interest in, and are likely to be affected by, the conduct and findings of a research project. In mental health research for example, important stakeholders can include service users, carers, wider family members, mental health professionals, service managers and commissioners. Working with stakeholders to define the appropriate focus for a literature review, and identifying and prioritising the research questions that might arise from it, is therefore an important step in making sure any future studies have relevance and applicability to health services (Arksey and O'Malley, 2005). We know that people who use mental health services, carers and professionals have different views about effective care, with professionals often prioritising a clinical model of care, and service users emphasising a social model of care (Rose, 2003). Similarly, they may also have different research priorities.

Service users want research that makes a noticeable difference to their care experiences, both personally and generally (Beresford, 2005). More importantly, they want research that leads to positive improvements in the whole of people's lives, not just in the design and delivery of mental health services (Faulkner and Layzell, 2000). Given these priorities, it's crucial that service users, carers and public members are consulted, or even better, are asked to collaborate in the early stages of the research process, helping to prioritise research ideas and to frame research questions. Involving service users should lead to questions that are more relevant and meaningful to participants. Where service users are not part of the actual study team, this kind of involvement can be achieved through holding focus groups, discussions or local and national stakeholder events.

Designing the study

Having developed a research question, it is important to decide which methods might be the best to answer it. Research generally falls into two types: quantitative research and qualitative research. Quantitative generates numerical data, often through the use of large studies, using methods such as questionnaires and surveys. We will learn more about how to collect and analyse quantitative data in Chapters 3 and 4. Qualitative research explores attitudes, behaviour and experiences through methods such as interviews, focus groups or observation, and we will learn more about this in Chapter 7 and 8.

Once the type of research is set, the study needs to be designed in detail. Collaborating with service users and carers in the design of a research study allows researchers to understand how best to approach potential research participants, why people might drop out of research studies (Goward et al., 2006), why an intervention might work from the user/carer perspective (Allam et al., 2004), what people might find most useful about different interventions and what might be the most appropriate outcomes to measure (Faulkner, 1997).

When evaluating if, and how well, a new intervention works for instance, it is often necessary to ask people to report treatment 'outcomes.' Popular outcomes for mental health interventions might include scales that measures symptoms, recovery, hope or daily activities and functioning. Treatment costs or the need to use other services might also be measured. Interestingly, the most common clinical measures are often the ones that service users like the least, because they do not tap into the priorities of service users themselves (Crawford, 2011). Service users want measures that can capture both the negative and also the positive effects of treatments, and are often willing to complete longer questionnaires to ensure that this is possible (Kabir and Wykes, 2010).

The act of completing questionnaires for service users and carers can in itself be challenging. Collaborating with service users and carers to select and prioritise outcome measures for quantitative research studies is therefore incredibly important, and can help to minimise the number of questionnaires or questions that participants miss out or refuse to answer. It can also help to get feedback on the length of time needed to complete any questionnaires.

Increasingly, service user involvement is also being sought in the design of new outcome measures, for example in selecting possible questions, prioritising questions and/or reducing the number of questions included in a scale, and commenting on ease of response and the emotional impact of its wording (Wiering et al., 2016). Is it too distressing or demoralising for example? Questionnaire development can be a complex and time-consuming process, and we will learn more about this in Chapter 6.

Similarly, when it comes to designing focus group or interview topic guides, service users often ask different questions to non-service users (Rose et al., 2004). Gillard et al. (2010) compared 'academic-researcher' and 'service user-researcher' questions and found that the latter were more concerned with 'how things felt' rather than 'what happened next'. They may also ask questions in a different way, using different phrases and words. It is therefore crucial to involve service users, carers and public members in this stage of the research process.

Funding

Depending on their size and purpose, research studies can be expensive. New research proposals will therefore usually be submitted to a funding body. Funders will look to see if the proposed research study is important (from the funder's point of view); that the proposed methods will answer the research question; that the study represents good value for money; that it be conducted safely and in line with ethical guidelines (see chapter 9); and that the research team are the right people to do the work (Aldridge and Derrington, 2012).

Funders will also want to see that the proposal is well structured and is written simply and clearly, including a summary of the proposed research which is accessible and understandable to members of the public (Aldridge and Derrington, 2012). Service user, carer and public member involvement has an obvious role to play in this, and most funding bodies now mandate PPI in the development of research proposals and grant applications. Many funders also seek to actively include service user, carer and public members in the appraisal of funding applications, both as peer reviewers and as panel members participating in the meetings where funding decisions are finally made.

Figure 2

WHAT ARE FUNDERS LOOKING FOR IN A RESEARCH APPLICATION?

Aldridge and Derrington, 2012

- ✓ The research is important
(from funder's point of view)
- ✓ The research will answer the question
- ✓ The proposal represents good value for money
- ✓ The proposal is ethically sound
- ✓ The research team are the right people to
do the research
- ✓ A well-structured and well written application
- ✓ A clearly written proposal
- ✓ Includes a lay summary
- ✓ Incorporates patient and public involvement

Ethics

All research studies, with the exception of service evaluations and audits, need to be approved by a Research Ethics Committee (REC) before they can begin. A detailed protocol, which outlines how researchers will deal with any ethical issues (e.g. confidentiality, informed consent etc.), is submitted electronically to the REC and reviewed by a multi-disciplinary team. Researchers may need to attend an REC, if invited, to discuss their application. Additional permissions to carry out research in specific organisations may also be required. We will learn more about research ethics and governance in Chapter 9.

Informed consent is an important principle of ethical research. This means that all potential participants must be allowed to choose to take part in a research study, without fear of losing care, or worrying about what might happen if they don't. To make sure this decision is an informed one, all potential research participants must be given clear and accurate information about why the study is being conducted and what participation would involve. Service user involvement can help to ensure this information is presented clearly and provides all the details that people might want to know. It can ensure that consent is truly informed by making sure that the right information is accessible (Allam et al., 2004) and that potentially offensive, dismissive or misleading statements are avoided (Rose, 2003). Service users may have different perspectives on what might cause distress and how that should be managed (Nicholls et al., 2003).

Once a study has all the necessary approvals, it can begin to recruit research participants. The precise recruitment strategy that is used will have been outlined in the ethics submission. It could, for example, include recruiting in person at clinics, or via poster display, or via social media. Patient and public representatives who sit on advisory panels can often advise on or act as a conduit to service user networks, potentially increasing access to people who may or may not be in contact with statutory health services. In some instances, the research topic will be sensitive, and in these cases, trained service user researchers can play a valuable role in study recruitment. People from 'seldom heard' or marginalised groups may be more willing to participate in a project involving someone they know (Fleischmann and Wigmore, 2000; Ennis and Wykes, 2013).

Exactly how data is collected will depend upon the methods chosen to answer the research question. As an integral part of a multi-disciplinary research team, service users, carers and public members can be co-investigators with an active role in collecting data (Hanley, 2012). For example, they could help assist someone in the completion of a questionnaire, or they could facilitate a focus group or face-to-face interview. Often this can enhance the richness and relevance of the data that is obtained. Participants may also choose to share a different type or level of information with someone who has had a similar life story or experience compared to somebody who has not.

Figure 4

Analysing data

The move from collecting to analysing data is rarely a linear process, and exactly how and when researchers begin their analysis will largely depend upon their underlying approach. Quantitative studies will involve data-input and some kind of statistical analysis (see Chapter 4). Qualitative studies may involve identifying themes (or codes) from interview and/or focus group transcripts or observational field notes (see Chapter 8). There is evidence to suggest that service users, carers and public members interrogate qualitative data differently, asking different questions of it and interpreting qualitative data in ways that reflect their priorities (Gillard et al., 2010). These interpretations can be fruitfully pooled with other (non-service user) perspectives to provide a more holistic and meaningful analysis.

Reporting findings

Researchers often talk about 'dissemination' or 'knowledge transfer.' These terms are used to refer to the mechanisms and strategies by which other groups and communities become aware of, obtain and/or subsequently make use of new research findings (Freemantle and Watt, 1994). Service users may have very different dissemination priorities to academic-researchers, whose main emphasis is often upon publication in peer-reviewed journals or presentations at academic and professional conferences. Service users, carers and public members may publish or present the research in their local communities or groups, ensuring wider reach and understanding of the study and its findings. Service users play an important role in framing research findings, in deciding what implications they may have for practice (Hanley, 2012) and in preparing accessible summaries of projects for dissemination that explain the results in a clear and jargon-free way. Increasingly, academic and professional journals are recognising the value of this input and seeking articles led by or co-authored with service users and carers.

Supporting and equipping people to be involved in research

If you are a patient or a carer, somebody who has used health services in the past or a general member of the public, then you will most likely have a unique viewpoint on health service delivery and research, and a valuable contribution that you can make.

Getting involved in research can be extremely rewarding but it is not always easy to do. Barriers include a lack of awareness about opportunities to get involved in research, language barriers, physical or emotional health, a lack of confidence, the behaviour or attitudes of researchers, or inappropriate timing/location of meetings. Research teams need to make sure that people are and can be involved in a meaningful way. This means making sure that PPI members are properly and regularly supported, and that they are fully recognised for their time and knowledge contributions, as important and integral members of the research team. The EQUIP team has found that offering service users and carers a short course in Research Methods and Design can help to facilitate collaborative relationships and can give members the confidence to play their role in the multi-disciplinary research team.

PPI stories from EQUIP

Next, Andrew and Garry (members of the EQUIP team) reflect on their experiences of being involved in the EQUIP programme of research.

ANDREW'S STORY

Following the first research methods training course I was invited to be a coapplicant on the EQUIP research programme. This meant that I became a member of the research team for the whole of the EQUIP programme, and shared responsibility for the design, management and conduct of the EQUIP studies.

One of my roles was to promote the studies across Nottinghamshire, as this was one of our main research sites. It's been a real privilege to network with local service user and carer groups, who have invited me back time and time again to talk about our work. I've really appreciated their help and support!

I received some practical training in qualitative research methods, and thoroughly enjoyed co-facilitating focus groups and conducting interviews in the

EQUIP programme. It was wonderful to take a lead on the analysis of the service user data, to help write up our findings, and to assist in developing an animation to outline our new model of care planning involvement. It was also really interesting to see how new questionnaires are developed and tested – and it's been great to be part of producing a new measure of service user involvement in care planning, and an audit tool that services can use to improve their care.

Co-delivering the EQUIP training intervention took up a lot of my time, but I absolutely loved it. I was involved in recruiting mental health teams to the trial, in co-facilitating their two days of training and in providing subsequent clinical supervision. It's been a privilege to help Trusts consider how best to implement our training, working with service users, carers and clinicians so that they can go on to deliver the training themselves.

It's been a joy to be able to present at events and conferences, I've loved telling people what we've been finding out. I've had a few mental health 'blips' along the way, but I feel that with the right training and mentorship I've been able to use my lived experience and expertise in a constructive way.

GARRY'S STORY

During the time I've been involved in EQUIP, I've really valued the meetings that have taken place. As a group we've dedicated time to looking at the process of care planning. In the focus groups that I have observed, service users have been very open and very honest, sharing experiences in a safe and supportive setting.

We asked people to talk about their positive experiences, what has worked well for them and also what could be improved. We gathered a great deal of information that has been to the EQUIP

programme and has been published as important research findings. I think focus groups are very good; by helping people to share their feelings and experiences, we can travel a long way towards improving the care that we receive.

REFLECTIVE EXERCISE

- What opportunities are there for members of the public to get involved in health services research?
- Are there any stages of the research process that are of particular interest to you? Why?
- What skills can you offer a research team?
- How might the chapters in this book help you and what other training might you need?

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