

Shared Learning Group on Involvement in Research

Involving people in laboratory based research: a discussion paper

Introduction

Much has been written about involving people in clinical, public health and social care research. Much less has been written about involving people in laboratory based research, or in other types of research where researchers have no direct contact with patients or family members.

In this paper we consider why researchers should involve people in laboratory based research, how they might do this and what the impact of involvement in this type of research can be.

This paper is based on discussions at meetings held in February and June 2016, in response to an initial query and subsequent work by Courtney Coleman from Asthma UK. Thanks to Courtney for starting this discussion.

Involvement or engagement?

INVOLVE defines involvement as situations where patients, carers and/or members of the public are **actively** involved in research projects and in research organisations, and engagement as situations where information and knowledge about research is provided and disseminated¹. Many laboratory based researchers undertake lots of engagement activities.

Within the context of laboratory based research we believe that there is a continuum between involvement and engagement, and that discussions that are interactive, and where researchers are open to change and have (and convey) a sense of accountability to patients, carers and members of the public, can be seen as involvement and not just as engagement.

For example, the Barts MS team is a group of researchers and clinicians based at Barts and The London School of Medicine and Dentistry. They run a popular [blog](#) for people affected by MS, which shares the latest research and clinical trends, and which they say “allows us to reflect on our work, assess its potential impact and plan for the future.” The blog authors engage directly with the MS community in the comments, often asking for people’s thoughts on ethical or contentious issues. One topic frequently discussed is different treatment options for relapsing MS and people’s appetite for risk vs potential benefit. The team also organise an annual Research Day, where again the conversation is a two-way dialogue.

Being clear about the purpose of involvement

As with any other type of research, it is important to be clear about the purpose of involvement. Within the context of laboratory based research, the purpose of involvement might be to:

- Help researchers to take account of patient experience

¹ See <http://www.invo.org.uk/posttypesource/what-is-public-involvement-in-research/>

- Motivate researchers who may have no direct contact with patients
- Help to review findings and identify areas for future study
- Legitimise funding decisions, thereby reassuring potential donors
- Equip people affected by the condition with knowledge about this research

For researchers working with human tissue, the purpose of involvement might additionally be to:

- Maximise the potential benefit from samples
- Help researchers to think about the ultimate beneficiaries of their research
- Help to set outcome measures that are important to patients
- Review information for potential donors
- Help to communicate results of research to people who donated samples and to members of the public
- Review applications to ethics committees and applications to access tissue

How people are involved in lab based research

Methods for involving people in lab based research include:

- Inviting patients/carers to speak to researchers at research meetings
- Matching early career researchers with patients/carers who will take a particular interest in their research to exchange knowledge and monitor progress during the project
- Patients or carers sitting as members of boards, governance or ethics committees
- Researchers having regular contact with patients, carers and members of the public to talk about their research and answer questions about it
- One-off or ongoing discussion sessions
- Service users or carers help researchers to write about their research in plain English (e.g. for a funding application or to report on results)

Experience of member organisations

Alzheimer's Society

Alzheimer's Society involves people affected by dementia in decision-making about the funding of laboratory based research in the same way that it involves people in decisions about other types of research. That is, members of the [Research Network](#) (a network of people affected by dementia) review plain English summaries of applications to decide whether they should be considered for funding. 15 members then meet to discuss the collective reviews of the Research Network, give indicative scores for the applications and agree questions to ask in the funding panel. Four members then sit on the grant making panel alongside researchers to represent the views of the wider Network, with full voting rights.

In 2015/16 the Society undertook a review of this process to decide whether it should continue for laboratory based research. There were a number of drivers:

- The Society had received feedback from Network members who said that they found it difficult to review applications for laboratory based research

- The amount of funding for research has increased substantially, which means that there are opportunities to personalise how people are involved and focus on areas they are more interested in
- Clarify the purpose of lay review of biomedical research
- To reflect on the achievements and challenges of involvement in this type of research to date

The review involved surveys, interviews with lay panel members and biomedical grant board members (including the chair of the biomedical grant board) and with other stakeholders. Findings were encouraging and affirmed that involvement in this type of research was valuable. The input of lay members in reviewing the plain English summary was seen to be of particular value. The Society has therefore clarified that the role of lay reviewers in this type of research is to assess:

- Relevance of the research: does the research answer a relevant question relating to dementia?
- Will the research benefit either people with dementia and/or the dementia field (short or long term)?
- Quality of dissemination plans
- Quality of PPI plans
- If involving human participants: Are these the appropriate methods?

The Society has also reviewed the involvement of people affected by dementia in monitoring research funding awards. Two or three members of the Society's Research Network are allocated to each laboratory based research project that is funded by the Society. They visit the funded projects once or twice per year to review how the project is progressing, learn from each other and often see demonstrations of the equipment and experiments which are used. A review of this activity, carried out in 2014 concluded that it was particularly valuable to laboratory based researchers and staff employed on these grants, who find the monitoring visits motivating and encouraging.

“It puts your work into perspective, I mean, in the lab day-to-day we don’t see patients but when you see people who have been affected by the disease it’s really nice to be able to see that what you’re doing is going to good use.” James Edgar, PhD Student

Cancer Research UK

Cancer Research UK has representation from people affected by cancer on many of its funding committees, but does not traditionally have patient representatives on its basic research funding committees. Partly this is because until recently there were not requirements for all of CRUK’s funded researchers to include PPI in their applications.

Recently this has changed. Of note is the Grand Challenge funding scheme (making its first award in 2016) which has included PPI throughout the identification of research questions, set a minimum PPI requirement for researchers applying, and has a patient panel feeding into the funding decisions – the Grand Challenge has a strong focus on basic research.

In addition, CRUK’s Experimental Cancer Medicine Centres (ECMCs) and Centres Quinquennial review will include PPI questions (reviewed by a patient advisory panel) as part of the application for ECMC/Centre status. This has previously been included for ECMCs (which lead of early phase clinical trials) but is a new requirement for Centres (which sit in the discovery/basic space). The aim of this is to benchmark current activity, and provide strategic support to ECMCs/Centres in developing 5-year PPI strategies.

Alongside this, the Patient Involvement team at CRUK have been conducting a review of the involvement of people affected by cancer in Cancer Research UK's **population and clinical** research funding committees. This review found that scientific committee members were overwhelmingly positive about this involvement, as it brings a focus on patient benefit. As a result of this review CRUK is now developing supporting materials for staff involving people affected by cancer in funding committees, and is planning to review involvement in their basic research funding committees to see where, and what, PPI could add value.

Parkinson's UK

Members of Parkinson's UK [Research Support Network](#) have worked with lab based scientists who are undertaking research related to Parkinson's. Heather Mortiboys, a Parkinson's UK Senior Research Fellow based at Sheffield Institute of Translational Neuroscience involved people affected by Parkinson's in her research into investigating how the batteries of the cell die in Parkinson's. As a basic scientist, in the laboratory most of the time, under normal circumstances Heather doesn't get to meet people affected by Parkinson's. Heather finds the experience really motivating and it increases her enthusiasm for the research that she's doing by getting people's input at every stage.

Heather involved people with Parkinson's in developing her research question. She did this by visiting and talking with people at local Parkinson's branches around Sheffield. After sharing the information about the research she had done previously, she then spoke to them about ideas for how she could develop future research questions. In particular, they discussed the model that she should be use. While Heather had been considering moving her research into animal models, the people affected by Parkinson's really thought it should be focused on human tissue samples. From those discussions Heather decided to take the project forward using cells from patient material. She submitted a grant application to Parkinson's UK, and received funding.

"Ultimately I am doing that basic science research to have an impact on [people with Parkinson's], and their family and their lives. So finding out what ultimately is important to them, should be helping me to shape all of my future research questions" Heather Mortiboys, Parkinson's UK Senior Research Fellow, Sheffield Institute of Translational Neuroscience

The impact of involvement in laboratory based research

For researchers, involvement can help to:

- Motivate and encourage researchers
- Improve the quality and relevance of research
- Improve communication about research
- Help to boost a REF score
- Improve the chances of gaining funding for a project
- Review findings and identify areas for future study

At a research organisation level, involvement can help to:

- Ensure public accountability for research that is publicly funded
- Consider ethical and governance issues from a patient's perspective
- Ensure that information aimed at patients and the public is communicated in plain English

For a research funding organisation, involvement in lab based research can help to:

- Ensure that funding is focused on patient benefit
- Demonstrate accountability

For people who get involved in this type of research, involvement can help to:

- Increase their hope about the long-term possibilities for a cure/improved treatment
- Offer an interest and/or motivation
- Increase understanding about the importance of laboratory based research

“It’s valuing our experience as carers or as people living with dementia of what we think is going to be helpful for the future. The fact that you can get involved at a stage when you’re still a full-time carer at home, with perhaps limited opportunities for getting out and about, is a plus. You meet new people, you make friends, it’s stimulating, it’s interesting, it’s a learning experience, it’s hopefully keeping my brain working for a bit longer. I’ve actually been able to have a very stimulating life through my involvement.” Angela Clayton-Turner, Research Network member, Alzheimer’s Society

Relevant reading

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