
Exploring public involvement in research funding applications

About this project

This project aimed to develop a series of examples illustrating how researchers are involving members of the public in their National Institute for Health Research (NIHR) funding applications and to explore the views of the researchers on the impact public involvement had on the development of their research funding application.

The examples demonstrate the different approaches used to involve members of the public and the uniqueness of each project.

INVOLVE is interested in gathering **evidence** about the impact of public involvement on research and these examples contribute to this work. A further six examples on the impact public involvement has on **research quality** have also recently been published (www.involve.nihr.ac.uk/wp-content/uploads/2013/08/invoNETexamples2013.pdf).

We would like to thank the researchers who shared their experiences, Kristina Staley from TwoCan Associates who carried out the interviews and the project advisory group for their support and guidance.

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Example 1: Bridging the gap between memory decline and medication in Parkinson's disease (PD)

About the research

Lead researcher: Professor Nicky Edelstyn, School of Psychology, Keele University.

Funder: National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB) Programme.

Project aim: To explore the impact of medication on memory decline in Parkinson's Disease (PD).

Type of research: Clinical research.

Duration: Two years - started in April 2013.

Who we spoke to

We interviewed the lead researcher Nicky Edelstyn. Her comments are in blue below.

About the involvement

How patients influenced the research question

In a previous, small-scale study looking at the effects of timing of medication on PD, patients commented that their memory was better when they were off medication, that is first thing in the morning before taking their first dose. This anecdotal evidence was supported by the data. The research team therefore decided to investigate this effect in more detail, to understand the implications for treatment and care.

Patient / carer involvement prior to applying for funding

Nicky first talked to the Research and Development (R&D) facilitator in the local trust about seeking funding for the project.

“ The R&D facilitator opened up this big area of support which I had been unaware of and put me in touch with the Research Design Service (RDS). The RDS encouraged me to involve patients and carers in the research design and helped me obtain an RDS bursary to fund the involvement ”
Nicky

She then met with a group of four or five patients and carers who were recruited via the Secretary of the local branch of the Parkinson's Association. They met for a pub lunch and discussed the project proposal in the afternoon. The RDS bursary covered people's travel expenses and lunch.

“ We met in a pub as the office was too formal and might have been off-putting. The local café was too noisy. We also wanted somewhere that was an equal distance from where everyone was coming from.

It worked very well. We drank soft drinks, had a meal and chatted about who we were and why we were there, what we hoped to get out of it, and what they felt about talking to us. Afterwards everyone felt more relaxed and I presented the design of the project as it was then and asked for their comments. I had a note taker with me so I could focus on talking to them. ”
Nicky

Impact of the early involvement

The patients and carers influenced the **outcome measures**. The researchers had only considered the effects of medication on memory performance. They had not previously considered the effects of memory impairment on the patients’ day-to-day activities, their confidence and self-esteem. In response to the patients’ and carers’ comments a quality of life measure was added to the study.

The patients and carers also commented on the **practical arrangements** for participants. For example they advised that having two assessments in one week was too much and that patients needed time in between to recover (each assessment requires a period without medication). They also advised on the additional support that patients might need during the period off-medication. This led to the development of a care package for the participants.

Continuation of involvement following funding

One person who came to the first meeting said they are interested in joining the study Steering Group and continuing to work with the project. Nicky is currently discussing their potential role with them.

“ I’m going to explain what I would like them to do and find out what they would like to do so I make it clear that it’s an even playing field. I’ve got some funding for training to build their knowledge and understanding of research. ”
Nicky

Most of the group didn’t want to be involved in a more formal way or commit to regular meetings. This highlights one of the advantages of meeting in a pub - it enabled patients and carers to share their ideas without having to go into a research environment.

Lessons learnt

“ I would have involved patients and carers much earlier because I wasted time putting my application together before I spoke to them. Then it required all of this modification following their input. It improved the application – there was no doubt about that. Now I involve people much earlier. I’ve learnt from my mistakes.
I don’t know why I had previously overlooked involving patients. It was a sort of Road to Damascus experience. What’s the point of doing a very researcher-led

study when you've got this wealth of experience and knowledge just sitting there, not being tapped? ” Nicky

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Project website: Under development

References:

Edelstyn, N M J, Shepherd, T A, Mayes, A R, Sherman, S M & Ellis, S J (2010). Effect of disease severity and dopaminergic medication on recollection and familiarity in patients with idiopathic nondementing Parkinson's. *Neuropsychologia* 44(6), 931-938.

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Shepherd, T A, Edelstyn, N M J, Mayes, A R & Ellis, S J (2013) Second Generation Dopamine Agonists and Recollection Impairments in Parkinson's disease. *Journal of Neuropsychology*, 7, 284-305.

Reference: INVOLVE (2013) Examples of public involvement in research funding applications: Bridging the gap between memory decline and medication in Parkinson's Disease (PD). INVOLVE, Eastleigh

Example 2: Resources for Living (R4L) pilot: Exploring the potential of progressive cuisine for quality of life improvement for head and neck cancer survivors

About the research

Lead researcher: Dr Duika Burges Watson, School of Medicine, Pharmacy and Health, Durham University.

Funder: National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB) Programme.

Project aim: To find out if progressive cuisine (innovative cooking techniques and ingredients) can help survivors of head and neck cancer treatment to overcome difficulties related to food and eating.

Type of research: Action research.

Duration: 30 months - started July 2013.

Who we spoke to

We interviewed the project's Patient and Public Involvement (PPI) lead, Dr Sue Lewis at Durham University. Her comments are in blue below.

About the involvement

Patient / carer involvement prior to applying for funding

The lead researcher initially invited a group of academics to meet and discuss developing the proposal for this project. At the suggestion of the NIHR regional PPI officer from the local Research Design Service, they also invited a survivor of head and neck cancer, John Buckley, to meet them. He was a member of a support group run by one of the researchers.

“ As a group of researchers we weren't convinced that on our own we'd be able to come up with a workable research question or project design. We needed to be sure that the way we conducted the research would be acceptable to survivors. We also wanted their help in identifying what kinds of foods would be most useful to investigate – what would be most relevant to their everyday life. ” Sue

The team worked with John and his wife to develop a strategy for further involvement in working up the proposal. They applied for funding for PPI from the Wolfson Research Institute at Durham University. This enabled them to run three workshops with survivors and their partners. These workshops introduced the idea of progressive

cuisine and gave survivors opportunities to sample innovative foods. John helped to plan the workshops and recruit participants.

Impact of the early involvement

The discussions at the workshops helped to refine the **methods** used in the research.

“ We wouldn't have been able to put the proposal together without the involvement. It gave us confidence that the workshop format would be acceptable to survivors. We also needed some of the study participants to undergo further tests to see how easy the new food would be to swallow. The survivors at the workshops confirmed that asking people to undergo these tests would be acceptable. ” Sue

The idea for a Resource for Living also came from the workshop, helping to define the **project outputs**.

“ The idea of the Resource is that it provides advice to other survivors – it will probably take the form of a recipe book that also includes lifestyle tips. There will be sections that highlight different survivors' stories – what kinds of problems they've experienced, what kinds of foods they can or can't eat and the changes they have found useful. ” Sue

Working with survivors also changed the **attitudes of the researchers** and the **functioning of the research team**.

“ As a team, it helped us to work in an interdisciplinary way. Having other kinds of experts working so closely with us, made us much more open to different ideas. It made us focus on the issues that are most important to survivors. We got a much deeper understanding of their experiences and a greater appreciation of the problems and frustrations they face, for example how difficulties with eating have a much wider impact on families and socialising with friends. ” Sue

Continuation of involvement following funding

John Buckley became a co-applicant on the grant and continues to work with the project team. The workshop participants have also been invited to join an expert group to help with developing the Resource for Living over the remainder of the project.

During the time between being awarded the grant and starting work on the project, the team have run further workshops with the same participants and kept in touch through regular newsletters / updates. This has helped to keep people engaged and motivated to stay involved.

Lessons learnt

“ Before this experience, I would have thought good PPI was about getting people in early and making space to talk to them but now I think you can be more creative than that. If you give people more time and meet with them

more than once you can open the floodgate to a whole new set of ideas and possibilities. It will also give you confidence that you have a viable project to take forward. In the long run I think it will make me a better researcher – I now wouldn't consider putting together a project without taking PPI very seriously.

It's important to allow adequate time and resources for involvement, not just for meetings, but also to respond to the feedback. We had to put back the submission date for our application when we realised we needed more time to develop the proposal and to include all that we'd learnt. You need to give involvement the priority that it deserves. ” Sue

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References:

INVOLVE Autumn 2011 Newsletter – [John's Cheese Sandwich](http://www.involve.nihr.ac.uk/posttypenewsletter/autumn-2011/)
www.involve.nihr.ac.uk/posttypenewsletter/autumn-2011/

Link to film of John: <http://vimeo.com/29369805>

Reference: INVOLVE (2013) Exploring public involvement in research funding applications: Resources for Living (R4L) pilot: Exploring the potential of progressive cuisine for quality of life improvement for head and neck cancer survivors. INVOLVE, Eastleigh

Example 3: Optimising adult mental health service configurations across health and social care

About the research

Lead researcher: Professor David Challis, Personal Social Services Research Unit (PSSRU), University of Manchester.

Funder: National Institute for Health Research School for Social Care Research (SSCR).

Project aim: To provide local commissioners and providers with evidence to inform the reconfiguration of local mental health services. The focus is on the needs of service users receiving inpatient and community mental health team services.

Type of research: Service evaluation.

Duration: 13 months – started April 2013.

Who we spoke to

We interviewed Jane Hughes, Lecturer in Community Care Research at the PSSRU, University of Manchester. Her comments are in blue below.

About the involvement

Patient / carer involvement prior to applying for funding

The team were asked by Pennine Care NHS Foundation Trust to carry out this study. At a meeting with operational service managers, the researchers met the Chair of the Trust's Service User and Carer Mental Health Forum, who invited them to a Forum meeting to discuss the project.

At the Forum meeting the researchers asked for feedback on their outline proposal and also requested further involvement in developing their bid for funding. It was agreed that they would hold a consultation meeting.

“ The Trust was supportive of it, so they provided a venue, refreshments and paid people's travel expenses. They sent an email invitation to all Forum members and nine people came. The meeting lasted about two and a half hours. We discussed people's experiences of accessing and using local services and the challenge of disseminating the findings to large numbers of local organisations.

The Forum members were asked to give their time free of charge and they were fine to do it as a one-off, although I did say the involvement in the research would be fully funded. I do that as a researcher sometimes - you give your time to develop a proposal and it's a bit of a lottery as to whether anything comes from it. ” Jane

Impact of the early involvement

The feedback from service users and carers at the consultation meeting shaped the development of the bid, in particular strengthening the **user involvement** and helping develop a local **dissemination strategy**.

“ After the consultation, I came back to the rest of the team and said ‘We’ve got a large body of expertise out there and we have to tap into it because it’s value added’. Originally we had thought to have only a small reference group, but we subsequently decided to include a lay panel as well. This will help us reach a wider constituency. We plan to communicate with them by email and phone, rather than meetings.

It challenged us to be crystal clear about the role of user involvement in the project and about payment for members of the reference group, not only for attending meetings but also in helping us in carrying out the research. We were careful about getting that correctly funded. ” Jane

The researchers were also keen to ensure that the project’s findings would reach the wide range of local organisations with a role in providing care to mental health service users and carers. The Forum agreed to take responsibility for this task.

“ They couldn’t understand why I thought dissemination might be a problem. They said ‘We’re in touch with lots of organisations, so if it comes to one of us it’ll be our job to email it out – what are you worrying about?’ ” Jane

Continuation of involvement following funding

Forum members have been invited to join the reference group and lay panel. The Forum’s administrator is helping with the recruitment. It was very important for the Forum to hear how their involvement had made a difference to the bid, and encouraged them to continue to engage with the project.

“ Working with an existing organisation has been a very useful way forward because they have easy access to service user expertise and a network of people they can contact on your behalf. ” Jane

Lessons learnt

“ It was important to hold the meeting on their premises – on familiar territory – then it felt like coming to an ordinary meeting for them. I just went with the flow, which meant I accessed the best of their information.

You have to be very clear about what’s up for negotiation, the parameters of the consultation. Then you need to be flexible and prepared to sit back and listen to what people are saying so you don’t just get what you want to hear. Then you’ll hear some things you weren’t expecting. We heard interesting things about the link between what people want from a service and their age, which made us think through that in planning the research. ” Jane

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Reference: INVOLVE (2013) Exploring public involvement in research funding applications: Optimising adult mental health service configurations across health and social care. INVOLVE, Eastleigh

Example 4: Decision making about implantation of [cardioverter defibrillators](#) (ICDs) and deactivation during end of life care

About the research

Lead researcher: Professor Richard Thomson, Newcastle University.

Funder: National Institute for Health Research (NIHR) Health Services and Delivery Research (HS&DR) Programme.

Project aim: To explore the views of patients, family members and clinicians around making decisions about both implantation of cardioverter defibrillators¹ (ICDs) and deactivation at the end of life. The aim is to improve the information and support given to patients and increase their participation in making these decisions.

Type of research: Clinical research.

Duration: Two years - started May 2013.

Who we spoke to

We interviewed Dr Kerry Joyce, a Senior Research Associate working on the project. Her comments are in blue below.

About the involvement

How patients influenced the research question

The research team submitted three separate grant applications before this study was funded. The third and final version included recommendations from an experienced carer which changed the focus of the project and ensured the research question directly addressed patients' needs.

“ The first two applications focused solely on decision making around implantation of ICDs. They were rejected. Some of the feedback said this was not an area of significant interest or patient need. We took this on board and at the suggestion of one of the cardiologists on our team contacted Trudie Lobban MBE, founder and trustee of the patient organisation, Arrhythmia Alliance (the Heart Rhythm Charity).

Trudie helped us think through the most important issues for patients and family members. She encouraged us to change the focus of the study to cover decisions around deactivation as well as implantation. She raised the issue of

¹ An ICD is a small device which can treat people with dangerously abnormal heart rhythms (from British Heart Foundation website accessed 30/07/14)
www.bhf.org.uk/heart-health/treatment/implantable-cardioverter-defib.aspx

the timing of these decisions, explaining that patients want to talk about deactivation in advance. This way deactivation is addressed as a hypothetical scenario rather than leaving it until the end of life, when it's an emergency situation. If left until then it is often the family / carers who are faced with making the decision rather than the patient themselves causing even more distress at an extremely emotional time. If we hadn't changed the focus of the study, we may not have got funded. ” Kerry

Patient / carer involvement prior to applying for funding

Trudie became a member of the grant writing team and contributed to drafting the funding application in the same way as other team members. In recognition of Trudie's important contributions, she became a co-applicant on the grant.

Trudie was offered payment for her time spent in telephone meetings and reading drafts of the grant application. However she did not take up this offer. She was already working in a paid role in the charity.

Impact of the early involvement

Trudie's involvement at the early stages ensured the project was **relevant and meaningful** to patients. This reassured the researchers that their work was genuinely worthwhile.

Her contributions to the grant application **strengthened the patient voice** throughout.

“ The final application was stronger as a result, as Trudie was able to advise on how to incorporate the patients' views and to emphasise the potential for patient benefit. Specifically she helped write the lay summary and sections on patient and service need. ” Kerry

Continuation of involvement following funding

Trudie has joined the Advisory Group for the project along with another representative from her organisation.

Lessons learnt

“ It's about having a conversation at the outset. If we had engaged Trudie when we were putting the first grant application together then we might have saved a lot of time and effort, and got it right at the beginning.

It takes time to establish relationships, to get beyond the superficial to really identify what's important. It's about having ongoing conversations and establishing a dialogue, not just emailing a draft and saying 'What do you think about this?' You also have to listen to people's comments and remain open, not being blinded by what you think as a researcher. ” Kerry

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References:

Joyce, KE, Lord S, Matlock DD, McComb JM, Thomson R. Incorporating the patient perspective: a critical review of clinical practice guidelines for implantable cardioverter defibrillator therapy. *J Interv Card Electrophysiol.* 2013; 36(2):185-97.

Reference: INVOLVE (2013) Exploring public involvement in research funding applications: Decision making about implantation of cardioverter defibrillators (ICDs) and deactivation during end of life care. INVOLVE, Eastleigh

Example 5: A randomised double-blind [placebo](#) controlled Phase 2B clinical trial of repeated application of gene therapy in patients with Cystic Fibrosis²

About the research

Lead researcher: Professor Eric Alton, Professor of Gene Therapy and Respiratory Medicine, National Heart & Lung Institute, Imperial College.

Funder: National Institute of Health Research Efficacy and Mechanism Evaluation (EME) Programme.

Project aim: To assess the safety and effectiveness of gene therapy for cystic fibrosis (CF).

Type of research: Clinical trial.

Duration: 30 months – started in March 2012.

Who we spoke to

We interviewed the project manager, Tracy Higgins, at the National Heart & Lung Institute, Imperial College. Her comments are in blue below.

About the involvement

How patients influenced the research programme

Thirteen years ago, three groups in the UK – from Edinburgh, Oxford and Imperial College – came together to form The UK CF Gene Therapy Consortium. The aim was to stop duplicating research and to develop a translational programme to get gene therapy into clinical practice. At the beginning the Consortium was funded by The CF Trust.

“ When we set up the Consortium, we also set up a scientific advisory group which included two parent reps – they’ve been with us ever since. We gave them progress reports on an annual basis. They would ask lots of questions and fed their views into the design of the whole programme. ”
Tracy

² A description of some of the terms used in this example such as double blind, clinical trial and placebo can be found in the MRC Clinical Trials Unit glossary www.ctu.mrc.ac.uk/about_clinical_trials/glossary/

Patient / carer involvement prior to applying for funding

The researchers have developed a close relationship with the patient organisation over the years and as a result have got involved in giving presentations to parents' meetings all over the country. This provided a route for more informal feedback.

“ The senior academics gave lots and lots of lay presentations. The people there always asked really good questions and helped refine the details of the trial a bit further. ” Tracy

Impact of the early involvement

Since the aim of the consortium has always been to get to the stage of a clinical trial, the parent reps have had an influence on every aspect of the **trial design**. For example, they have contributed to the development of a placebo, and commented on the acceptability of the gene therapy product.

“ We've been asking them about the process. Patients have to be nebulised (inhaling a mist into their lungs) in a sealed room. The cubicles are tiny – so how long can they bear to sit there for? Also we know there are side-effects. The researchers were worried about some of the symptoms – would people want that once a month? But the parents were saying 'We don't mind – don't worry about it'. That helps to refine the trial design. Then we could be sure patients and parents would accept what we were asking them to do. ” Tracy

The overall impact of the involvement has been to ensure the research team is very **patient-focussed** in all that it does.

“ We've spent a lot of time talking to patients and parents – but it's difficult to pinpoint exactly what difference it's made. It's made us always question everything we do in relation to what the patient would think. When we sit down in the strategy group overseeing the whole consortium – with every question that comes up – we talk about what the patient would think. There is no dividing line. It's not an add-on. That's what helps you reach your goal of getting products into clinic. ” Tracy

Continuation of involvement following funding

Some of the patient / parent representatives who were on the Consortium's original scientific advisory group have now joined the Trial Steering Group. They have commented on the consent forms and patient information sheets. Other people are involved more informally, for example one patient helping with recruitment to the trial using Twitter.

All the people who were involved in the developing the bid had their expenses paid, but were not paid for their time.

Lessons learnt

“ One of biggest challenges is time. Researchers are always working on grant applications up to the last minute and they don't want to send the draft round until they've got the near final version. But if that's 24hrs before you're due to submit... You've got to engage earlier with patient reps when you've got something specific for them to comment on.

This study has been unique because we have been involved with the patient group for so long and as a group they have become really knowledgeable about the research. On another project, our patient rep has found it more challenging - we realised it's because we haven't taken enough time to increase her level of knowledge. With the CF group - their level of knowledge has become that much higher. ” Tracy

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References:

Alton EW, Boyd AC, Cheng SH, Cunningham S, Davies JC, Gill DR, Griesenbach U, Higgins T, Hyde SC, Innes JA, Murray GD, Porteous DJ. A randomised, double-blind, placebo-controlled phase IIB clinical trial of repeated application of gene therapy in patients with cystic fibrosis Thorax. 2013 68 (11): 1075-7

Reference: INVOLVE (2013) Exploring public involvement in research funding applications: A randomised double-blind [placebo](http://www.involve.nihr.ac.uk/resource-centre/useful-information/jargon-buster/?letter=P) (www.involve.nihr.ac.uk/resource-centre/useful-information/jargon-buster/?letter=P) controlled Phase 2B clinical trial of repeated application of gene therapy in patients with Cystic Fibrosis. INVOLVE, Eastleigh

Example 6: Design and optimisation of a saliva-based point-of-care biosensor for non-invasive monitoring of chronic obstructive pulmonary disease (COPD) exacerbations: COPD-SPOC sensor

About the research

Lead researcher: Professor Monica Spiteri, Directorate of Respiratory Medicine, University Hospital of North Staffordshire.

Funder: National Institute for Health Research (NIHR) Invention for Innovation (i4i) Programme.

Project aim: To develop and construct a simple analyser to measure biomarkers for COPD in saliva, to enable patients to monitor changes in their condition from home.

Type of research: Experimental and observational study to support the development of a new device.

Duration: Started April 2012, ending December 2014.

Who we spoke to

We interviewed the lead researcher Professor Monica Spiteri. Her comments are in blue below.

About the involvement

How patients influenced the research question

This project has been driven by patients' needs from the start. People with COPD need to monitor their condition to ensure they take their rescue medication, or increase their usual treatment as soon as their symptoms get worse, or if they develop a chest infection. This typically involves a visit to a GP, an out-of-hours clinic or A&E and often requires blood tests. This places a burden on COPD patients which could be avoided if better monitors were available for use at home.

“ The patients told us they would prefer not to have to give blood samples. They have very fragile skin because they often have to take steroids so they would prefer something non-invasive. Through earlier studies we found out that it's easier for patients to produce saliva at all times, and that saliva was much easier to use than sputum; importantly the biomarkers we're looking for in COPD could be detected in saliva. ” **Monica**

Patient / carer involvement prior to applying for funding

Patients and carers were consulted before and during the two previous studies that led up to this longitudinal research project. Both studies were funded by the NIHR - one by an i4i feasibility grant. Before putting in a second i4i funding application, patients and carers were again consulted about the overall approach and design. These patients / carers were found through a variety of routes - a local Patient Partnership Forum in Stoke-on-Trent, the researchers' database of previous research participants, the local Research Design Service (RDS) at Keele and personal contacts made through work on local groups and committees.

“Some of the patients took part in informal discussion groups with tea and cake. But some of them didn't want to take part in a group meeting, so we met them one-to-one and captured their ideas. We funded this work through a patient and public involvement (PPI) grant from Keele University and from funds within our own department. We had to apply for this money.

One of the patients was also a co-applicant. The patients had contributed a lot of good ideas and we thought it was important to acknowledge their input. It shows that they were genuinely part of the research team and they still are.”

Monica

Two people have become involved as PPI leads contributing ongoing advice to the research team. Their time is paid for through the project grants. They helped with writing the lay summary for the second grant application.

Impact of the early involvement

The involvement of patients and carers informed the approach used for **capturing patient data** which aimed to improve the communication between patients and the clinical team.

“ In the previous studies, participants kept paper diaries of their symptoms, which were collected weekly by the nurses. This was cumbersome for everybody. So we wanted to develop an electronic diary that could be completed in 10 minutes and sent to the clinic daily but we weren't sure whether this would be acceptable to the older patients. So we asked them whether they would be happy to use an electronic gadget if given training. Most of them already use mobile phones and were happy with this idea but they wanted something with a large screen interface. They helped us design the layout and the format.” **Monica**

They also contributed to the **practical design** of the study to ensure it would be acceptable to people with COPD. This ensured that the participants were compliant with the requirements of the research.

“ We initially thought about asking participants to complete their diary and also give a saliva sample once a day but the patients we consulted thought daily saliva samples would be too much. They made us think about what information we really needed so in the end we agreed that saliva samples could be collected once a week when the patient was well, but that testing

would be brought forward if people began to feel unwell or the clinic noticed a decline in the scores. ” Monica

Continuation of involvement following funding

The PPI leads continue to provide advice to the project. They helped with drafting the participant information sheet prior to ethical review, and ensured it was accessible to patients / carers. One PPI lead regularly attends the Steering Committee meetings.

“ He offers his very strong opinions on our findings – I mean that in a friendly way he questions us and it contributes to our governance. ” Monica

As the work continues, patients and carers will be consulted at a number of stages along the way. For example, the electronic diary has been developed into an App, and patients will continue to be asked about its design and operability to ensure it meets the needs of the target audience. Similarly they will be involved in determining the final design of the saliva sampler.

Patients and carers will also be consulted about the final dissemination strategy to ensure the findings reach a broad audience.

Lessons learnt

“ If you are trying to develop a device that patients use themselves then they have to be involved at every step of the way and remain engaged throughout. There are a number of redundant devices out there where the patient has been forgotten in the development process.

It's also very important to involve patients in the design of a clinical study – you can sit down and put together a very nice study without them, but your recruitment will be low if the design is not acceptable or practical for the people you want to take part.

You need to think carefully about who is the best person to facilitate group discussions. You need someone who is independent of the research team so the patients can feel more relaxed and free to say what they think, not what they think you want to hear. ” Monica

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Reference: INVOLVE (2013) Exploring public involvement in research funding applications: Design and optimisation of a saliva-based point-of-care biosensor for non-invasive monitoring of chronic obstructive pulmonary disease (COPD) exacerbations: COPD-SPOC sensor. INVOLVE, Eastleigh

Example 7: The RESPONDS Study. Bridging the knowledge and practice gap between domestic violence and child safeguarding: developing policy and training for general practice

About the research

Lead researcher: Professor Gene Feder, School of Social and Community Medicine, Bristol University.

Funder: Policy Research Programme.

Project aim: To develop and evaluate training for GPs that addresses the combined issues of domestic violence and child safeguarding. The broader aim is to improve the care given to women experiencing abuse, and their children.

Type of research: Action research.

Duration: 30 months - started in July 2012.

Who we spoke to

We interviewed the lead researcher, Professor Gene Feder, and his collaborator Professor Nicky Stanley at the University of Central Lancashire. Their comments are in blue below.

About the involvement

How service users influenced the research question

The survivor groups were instrumental in identifying this topic as a priority for research.

“ We were aware that in previous studies we had not addressed the issue of the impact of domestic violence on children. Working with the survivor groups made it clear just how serious a short-coming this was. They encouraged us to pursue this project and not wait another few years. It wasn't simply them saying 'That's a good idea'. They gave us a rationale based on their experience, which is precisely what we wanted. You could do studies on a dozen things... they gave us the reasons to run with this one. ” Gene

Service user involvement prior to applying for funding

The research team has established two groups of survivors of domestic violence (DV). One is in Bristol, supported by a DV organisation called Next Link, and the other is in Cardiff, supported by Cardiff Women's Aid. These groups were set up to provide advice to previous research projects. They have evolved into standing groups that provide input into all new research ideas, and continue to advise on the existing research programme. Both groups were consulted during the development phase of

this project, as part of their regular meetings. In addition, staff at **Hyndburn and Ribble Valley (HARV) Domestic Violence Team**, an organisation that supports young people with experience of DV, were asked to comment on early drafts of the project proposal.

“I wasn't able to meet directly with children, but I did consult HARV. Their staff are very much in touch with young people's issues. I've worked with them on several projects, so I was able to ring them up and ask them to read through the proposal and tell us what they thought.” **Nicky**

Impact of the early involvement

The groups' views influenced the **conceptual framework**, the researchers' thinking on what aspects of the research to focus on.

“What the groups said very strongly was that they wanted GPs to be more understanding of the dilemmas women face around disclosing their experience of domestic violence and their fear of children's services being involved... They also encouraged us to consult young people during the project, which gave us confidence that this was the right thing to do... It's about the underlying conceptual framework, around making choices about what's going to be in the research – there's no doubt they had quite a strong influence that way.” **Gene**

Continuation of involvement following funding

The groups have continued to be involved since the project started, for example providing their views on the content of the GP training. Some group members have now been working with the research team for four or five years and have become very enthusiastic about research. Their involvement continues to evolve over time. One of the group members has developed further research skills, conducting interviews with other survivors of DV and co-authoring publications.

Lessons learnt

Maintaining a group long-term requires adequate resourcing, not only to cover paying for people's time, travel and expenses, but also to provide sufficient admin support to arrange the meetings. The research group has budgeted for patient and public involvement (PPI) in each study, with overlap between funded studies and those still under development. The researchers have also learnt practical lessons about running the group and getting the most out of discussions.

“Sometimes we overloaded the meetings with us talking too much. Even though the group has strong individuals who have no problems in speaking up, they have felt overloaded with information. So we've designed the meetings to be more interactive. It's not very helpful to just present information and ask for the group's opinion. That's a bit passive and not really using people's talents to the best advantage. It's much better to pose specific questions – then you get very sophisticated and specific answers.” **Gene**

Having a long-term relationship with a group and/or relevant organisations facilitates the process of having discussions at this very early stage of research.

“ Engaging people in the early stages is hard to do cold. It’s easier in the context of an ongoing relationship, where people understand research and their role in developing applications. You don’t want to be making false promises about research which may not get funded. Having a group that understands the stage you’re at, means they come to it in an informed way and you also understand what you can expect from them. ” Nicky

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Reference: INVOLVE (2013) Exploring public involvement in research funding applications: The RESPONDS Study. Bridging the knowledge and practice gap between domestic violence and child safeguarding: developing policy and training for general practice. INVOLVE, Eastleigh

Example 8: Supporting Excellence in End of life care in Dementia – SEED programme

About the research

Lead researcher: Professor Louise Robinson, Institute for Health and Society / Institute for Ageing and Health, Newcastle University.

Funder: National Institute for Health Research (NIHR) Programme Grants for Applied Research (PGfAR).

Project aim: The overall aim is to support professionals to deliver good quality, community-based end of life care in dementia. This will involve identifying which aspects of existing end of life care in dementia are effective and efficient, developing and evaluating an evidence-based integrated care pathway and determining how community-based end of life care in dementia should be organised and commissioned.

Type of research: Wide ranging programme of research.

Duration: Starts October 2013 – five years duration.

Who we spoke to

We interviewed the lead researcher Louise Robinson. Her comments are in blue below.

About the involvement

How patients influenced the research question

Louise is the Lead and Chair of the Primary Care Group (PCG) in the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN). A few years ago the Alzheimer's Society approached the PCG, because they wanted to work with the Group to develop a project that would address one of the Society's research priorities. The Alzheimer's Society had previously asked patients and carers about their priorities for research (http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1804). One of the top five topics was end of life care for people with dementia. The PCG were enthusiastic about taking this work forward as end of life care for people with dementia is often provided within the community setting.

Patient / carer involvement prior to applying for funding

The PCG and The Alzheimer's Society worked together to develop the proposal and write the funding application. They jointly funded this development work and the Alzheimer's Society helped find patients and carers to be involved.

“ We decided to start with a one-day workshop bringing together patients, carers and researchers. We invited people already doing research in this area

as well as some of the carers and people with dementia who had been involved in the priority setting exercise. In the morning we had a few presentations from researchers about what was currently happening and what they thought the potential research questions might be. Then in the afternoon we split into small mixed groups, where researchers, carers and patients could share their views. We asked patients and carers about their thoughts and experiences of end of life care. We had bereaved carers there. So we used the small groups to bring out the personal experiences and to bring the two together. ” Louise

The findings from the workshop were reviewed by a group of academics. This group included members of the PCG and the researcher presenters from the workshop, but no patients or carers. They met for a joint writing day, funded by DeNDRoN, to develop the research proposal. It was agreed that they would apply for an NIHR Programme Grant as the discussions at the workshop had shown that little was known about the current state of end of life care and much research needed to be done.

“ We got the proposal to a point where we could send it back to the Alzheimer’s Society. They had a workshop with patients and carers to discuss it and fed back to us. On the whole they were very supportive. They felt we had addressed some of the key issues that had come up from the initial priority-setting exercise. They also volunteered to become part of a PPI group if the grant was successful. One of the carers became a co-applicant and worked with us on writing up the rest of the bid. The whole process has taken us years - we started this work in 2011. ” Louise

Impact of the early involvement

The involvement of patients and carers helped to keep the researchers’ thinking **grounded in reality**. Most of the previous research in this area had been carried out in other countries and suggested that end of life care for dementia was sub-optimal. The carers reported that their experience hadn’t all been bad.

“Some of the carers said the nurses had been very good in looking after their loved one but that ‘nobody looked after me’. The carers don’t seem to get enough follow-up support. So we realised it would be important for us to observe actual care and to identify local initiatives around the country where there is good practice, which people knew about, but which hadn’t been properly evaluated. ” Louise

The patients and carers also stated their wish to be involved in **developing outcome measures** for the quality of care.

“The carers said ‘You’ve got to talk to us about what are the important outcomes’. So that became another area of research work. We’re planning to look at current literature and policy around outcomes, to talk to people with early dementia and carers about the outcomes they would want services to achieve and compare their views to what’s currently advocated. ” Louise

Continuation of involvement following funding

The original patients and carers have joined the programme oversight board, which meets once a year to review progress.

“ We felt we had to broaden the input because we needed to get some fresh ideas – to have people take a new critical look at the proposed research. Also with a five year programme, we thought not everyone would want to commit to that length of time. So DeNDRoN North-East is holding an event with their regional PPI group to see if we can find any additional patients / carers. We’re trying to find people who can work with their local research group to give direct and immediate feedback. ” Louise

Lessons learnt

“ Involvement helps to ground your thoughts in reality. A lot of the researchers on our team didn’t have experience of clinical practice – so it’s about making sure we keep a balance and remember the impact on patients and carers, and what’s important to them.

It requires investment of time and resources. When we got feedback we got absolutely superb feedback on the PPI section of the programme grant. We scored really highly because we had invested in it. ” Louise

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Reference: INVOLVE (2013) Exploring public involvement in research funding applications: Supporting Excellence in End of life care in Dementia – SEED programme. INVOLVE, Eastleigh

Example 9 : A multi-centre programme of clinical and public health research to guide health service priorities for preventing suicide in England

About the research

Lead researcher: Professor David Gunnell, School of Social and Community Medicine, University of Bristol, working with Professor Nav Kapur, University of Manchester and Professor Keith Hawton, University of Oxford.

Funder: National Institute for Health Research (NIHR) Programme Grants for Applied Research (PGfAR).

Project aim: To provide evidence to inform the National Suicide Prevention Strategy.

Type of research: Clinical and public health research.

Duration: Five years – started April 2012.

Who we spoke to

We interviewed the lead researcher Professor David Gunnell and Rosie Davies, a service user co-applicant on the Programme Grant. Their comments are in blue below.

About the involvement

How service users influenced the research question

This programme of work built on the findings from a previous programme grant, which had involved service users as co-investigators. As the first programme came to an end, the research team held a one-day meeting with all the potential end-users of the research including service users, the Medicines and Healthcare Products Regulatory Agency, the Samaritans, Madeleine Moon MP (Chair of the All-Party Parliamentary Group on Suicide and Self Harm Prevention), the Office for National Statistics, NHS managers and clinicians. This group discussed the priorities for the next grant and helped shape the research questions.

“ The aim of the workshop was first to reflect on what we had learnt so far and then to brainstorm ideas for the next programme. We presented some of our ideas to open up the discussion. It was an extremely valuable meeting which helped us cross off some possibilities from our list and add in others. ”
David

“ One of the things the researchers wanted to look at was self-harm services. I suggested that they needed to include users of those services in that process so not just to look at hard outcomes, but also, for example, how relationships between users and staff influence the quality of care. ” **Rosie**

Service user involvement prior to applying for funding

Rosie was one of the service users involved in the first programme grant and became a co-applicant on the new funding application. She helped write the section on patient and public involvement, and was involved in the same way as other members of the team in commenting and contributing to numerous iterations of the preliminary and full applications. She was paid for this work through funds from the first grant.

“ Rosie had previously provided sound and grounded advice not only on the research itself, but also on maximising user involvement. She had been extensively involved in the previous programme and had contributed to the publications from that work as a co-author. It seemed a natural progression for her to become a co-applicant. This has given her responsibility for an element of the programme. Rosie’s major contribution - she has many - is to advise on the service user involvement in the new programme. ” David

Impact of the early involvement

Rosie’s work on the funding application resulted in a step change in the **service user involvement** in the new programme. There are now more service user research advisors involved at all three project sites, and the role has broadened to include, for example, doing pilot interviews and providing feedback on draft topic guides, question wording and the interview process.

Rosie also helped to develop **policies and practice** around managing the risks of involving service users in this challenging area of research and ensuring people are properly supported.

“ One stream of our work is around investigating lethal methods of suicide. Evidence shows that knowledge of effective methods will influence people’s choice of method and the likelihood they will die from the attempt. So we wanted to ensure we didn’t talk about this topic with potentially vulnerable people, including the service users we involved. We listened to Rosie’s advice about how to manage that, as the last thing we want to do is increase people’s risk or make their mental health worse. ” David

“ Some of the feedback we received on the preliminary application asked about our policies for managing participant distress. That led to discussions about the potential distress of the service users we involve. We then developed more explicit plans about how to provide support to me and the other service user members. ” Rosie

Continuation of involvement following funding

Rosie has continued to be involved in the programme and attends meetings of the research team. Her post is funded through the second grant. Her role has evolved into a more formal advisory role, overseeing a strategic approach to involvement and encouraging researchers to create further opportunities for involvement as the work unfolds.

Lessons learnt

“ There has been some caution about involvement in research. My experience has been generally positive. It’s such an important dimension to the work we do – bringing new insights as to what is most relevant to people and to remind researchers that, at the end of the day, the purpose of research is to improve patient and population health. Without including service users there’s a really important part of the jigsaw missing. ” David

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Reference: INVOLVE (2013) Exploring public involvement in research funding applications: A multi-centre programme of clinical and public health research to guide health service priorities for preventing suicide in England. INVOLVE, Eastleigh

Example 10: Health care innovations from policy to practice: A case study of rapid HIV testing in General Practice

About the research

Lead researcher: Heather McMullen, Centre for Primary Care and Public Health Barts and The London School of Medicine & Dentistry.

Funder: National Institute for Health Research (NIHR) Trainees Coordinating Centre - Doctoral Research Fellowship.

Project aim: To examine health innovations from policy to practice in terms of the ways they get picked up and dispersed across primary care settings - using rapid HIV testing as a case study. A second aim is to explore how national guidance is put into practice.

Type of research: Qualitative research.

Duration: Started January 2013 – three years duration.

Who we spoke to

We interviewed the PhD student who is carrying out this research, Heather McMullen. Her comments are in blue below.

About the involvement

Background

Heather worked as a trial manager and co-ordinator on a large study that explored whether rapid HIV testing in primary care led to earlier and greater detection of HIV. In the trial, the test was offered to some of the patients undergoing a new patient health check at their GP surgery.

The idea for this PhD project came out of the work that she did on the trial:

“ I was going into the GP practices to train them in rapid HIV testingThis led to a lot of questions about why some practices were able to pick up the intervention and roll it out to good effect and why some practices weren't. ” Heather

For Heather, it was also important to explore the patients' experience of rapid HIV testing in more depth than had been explored in the clinical trial.

“ I was passionate about interviewing patients as part of my study as that was something that was missing. We had looked at providers' experiences of delivering the tests, but not at the patients' experience of being diagnosed within a minute. All the research was designed around the patients, but we hadn't heard from them – not in the write-ups. I wondered what would happen

if the trials showed it's really significant in terms of public health outcomes, and the qualitative studies showed that health professionals found it acceptable and feasible, but the patients found it hugely traumatising. ”
Heather

Patient / carer involvement prior to applying for funding

Prior to submitting her application Heather consulted senior academics, representatives of community and patient organisations and also individual patients - about a dozen in total.

“ I consulted patients and their representatives because I wanted to know that the work I was going to do would be useful. I had academics telling me that it would be, but I wanted policy people and patients to tell me that too. I also knew I had to do it, as a huge part of the application asks you how your study is connected to the people it is meant to help. Finally, I wanted to make sure that patients were involved in my project design, because as I was going to be speaking to patients, I wanted to make sure I got those questions right. ” **Heather**

The patients and organisation representatives were sent a copy of the research proposal and invited to comment by email or by meeting face-to-face. Heather selected local community organisations who were working in the same area of London as well as HIV charities working with more commonly affected groups, including Africans and men who have sex with men.

“ It was easy for me to get access to the right people and fairly quickly because I already had key people on board for the trial and I already knew which organisations had good reputations. I also knew some patients personally, as I had involved them in the training I provided to the GP practices. I had found the patients through the local HIV liaison nurse and local organisations... It was part of my job to talk to everyone involved in the trial, so I could do this consultation alongside other work, which meant the costs weren't an issue for me either. ” **Heather**

The patients who met with Heather received a £10 gift voucher as a thank-you and also had their travel expenses paid. It is unlikely some of the patients would have been able to attend a meeting if they had had to pay for their own travel.

Impact of the early involvement

The involvement helped to increase Heather's **confidence in the relevance and importance** of the research.

“ It helped me nuance some of the perspectives and some of the reasons why the study is important. It also gave me confidence - which isn't easy to measure - but I think it comes through when you're putting in an application and certainly helped me during the interview with the funders. Knowing that you believe in your project and so does your community - that comes through in those moments. ” **Heather**

It also helped to improve the **accessibility and acceptability** of the language used in the written information about the project.

“ How you phrase things is particularly important in HIV – for example you might not use the term ‘gay men’ and use the term ‘men who have sex with men’ instead. I hadn’t written that in my application – but those are the types of things that can be pointed out when working with a community – or they can tell you if you get too medical in your language – it’s invaluable to have that kind of feedback. ” **Heather**

Continuation of involvement following funding

The patients and organisation representatives who were consulted about the application have since joined the study steering committee and will be involved in the rest of the project.

Lessons learnt

“When you talk with patients and their representatives, you have to be prepared for the offshoot conversations. People will ask all sorts of questions. I was mostly equipped to answer those questions because of my experience in the trial. When they asked me questions about things I wasn’t sure about, for example access to care by illegal immigrants, I was able to refer them to the specialist clinic. I knew who else to talk to and where to get the information.

There is a difference between activists and lay patients. There isn’t a universal patient experience. This is very true in HIV because of its political history. I find the activists know loads about it, are already involved in policy decisions and give you one version of the patient perspective. Their experience is different because of the world they’re part of – they are usually comfortable with their HIV status as its part of their job. But with other patients, you may be one of the very few people that know they are HIV positive. It makes sense to go to patient organisations – because that’s an easy point of access – but you need to be aware that you may be accessing a certain realm of experience. It’s particularly highlighted in the HIV field – it might not be the same say for asthma patients... I’m not sure. ” **Heather**

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Further information and resources

INVOLVE describes ‘patient and public involvement’ as an active partnership between patients, members of the public and researchers in the research process. This can include, for example, involvement in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.

INVOLVE’s definition of the term ‘patients and public’ includes: patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services and research (INVOLVE 2012).

For a more detailed explanation of involvement, how it links to and differs from engagement and participation in research see www.involve.nihr.ac.uk/find-out-more/what-is-public-involvement-in-research-2

To help you consider **why** you want to involve people, **who** you want to involve and **how** to involve people in **your** research study view the **INVOLVE Briefing notes for researchers** www.involve.nihr.ac.uk/resource-centre/resource-for-researchers/

Information is also available on:

- **planning and preparation** for public involvement in research [INVOLVE Briefing note five: How to involve members of the public in research www.involve.nihr.ac.uk/posttypesresource/before-you-start-involving-people/](http://www.involve.nihr.ac.uk/posttypesresource/before-you-start-involving-people/)
- **planning a meeting** involving members of the public [INVOLVE Briefing note eight: Getting started www.involve.nihr.ac.uk/getting-started/](http://www.involve.nihr.ac.uk/getting-started/)
- **costing and budgeting** for public involvement in your study [Involvement Cost Calculator www.involve.nihr.ac.uk/resource-centre/involvement-cost-calculator/](http://www.involve.nihr.ac.uk/resource-centre/involvement-cost-calculator/)

The NIHR Research Design Service provides advice and support to researchers developing research proposals for submission to the NIHR and other national, peer-reviewed funding competitions for health and social care research. This includes resources, advice and support on patient and public involvement in the development of proposals. www.rds.nihr.ac.uk/

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