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*National Institute for
Health Research*



Patient and Public Involvement

CASE STUDIES IN PRIMARY CARE RESEARCH



**September
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This publication is a result of the collaboration between the following organisations:

- NIHR Clinical Research Network Primary care (NIHR CRN Primary care)
- NIHR INVOLVE
- NIHR Research Design Services (NIHR RDS)
- NIHR School for Primary Care Research (NIHR SPCR)
- National Association for Patient Participation (N.A.P.P.)
- Primary Care Research in Manchester Engagement Resource (PRIMER)
- Society for Academic Primary Care (SAPC)



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contents

.....

Introduction	1
Case Study 1: The Primrose Programme	2
Case Study 2: The MOSAICS study	9
Case Study 3: Undergraduate medical education in general practice	12
Case Study 4: The ISiS Project: Identifying, Signposting and Supporting Carers	14
Case Study 5: ‘Critical friends’	17
Case Study 6: Improving community health networks of people with severe mental illness	19
Case Study 7: A Qualitative Study Investigating the Psychosocial Impact of Urinary Incontinence on People with Vascular Conditions (PHIEBI)	23
Case Study 8: Developing a new intervention for patients with severe Chronic Fatigue Syndrome/ME; a collaborative approach based on patient and public involvement	26
Case Study 9: Understanding the cost and consequences of patient and public involvement in primary care research	29
Case Study 10: Primary Care Research PPI – an example	31
Case Study 11: Patient, carer and public perspectives during study recruitment and delivery phase	33
Acronyms	36
Organisational profiles	38

forewords

Paul Wallace

Patient and public involvement (PPI) has come to play a key role in both the generation and the delivery of research studies. Those of us involved in working to promote the delivery of high quality research in primary care settings have seen a major increase in activity in recent years, with more than 700,000 patients recruited to studies by primary care professionals in England since the establishment of the NIHR Primary Care Research Network in 2006, and over 50% of general practices engaging with research delivery. It is my firm view that PPI has been a key factor in this success.

To many clinical researchers, understanding exactly what constitutes PPI and how it can benefit research can sometimes seem something of a mystery. This collection of accounts of PPI initiatives addresses this, providing a clear illustration of how PPI actually works and the value it can add to the quality, performance and experience of research.

As the National Specialty Lead for Primary Care for the NIHR Clinical Research Networks, I warmly welcome this publication and strongly recommend it to all those with an interest in improving the quality of research and making it more relevant to people's needs.

Paul Wallace FRCGP FFPHM, National Specialty Lead for Primary Care for the NIHR Clinical Research Networks.

Richard Hobbs

Embedding Patient and Public Involvement in primary care research is pivotal to an ethos of inclusivity and participation. This can be facilitated in every step of the research process by finding common ground between researchers and the public and relaying research results back to the core stakeholders.

I hope this exciting new collection of unique case studies will further establish PPI principles across primary care research. They provide the reader with some useful insights, which may be applicable to their own future research engagements and offer a glimpse of how PPI can be incorporated into various research contexts. I am hopeful they will inspire and influence researchers, practitioners and the public as they embark on working together in the future.

The SPCR would like to congratulate the contributing researchers who have not only highlighted conceptual and methodological positions but have done so in an open and candid manner. These case studies illustrate the NIHR and SPCR's commitment to our involvement in and support of PPI.

Richard Hobbs, Director, NIHR School for Primary Care Research.

Simon Denegri

I am delighted to introduce this publication showcasing examples of public involvement in research in primary care settings.

The wealth of good practice and insight contained herein is evidence of just how much health professionals in primary care are increasingly at the forefront of the way we do research in the UK.

This can take many forms - from identifying research priorities and designing research, to asking patients and carers to take part in potentially life-saving clinical studies.

What is clear from this helpful booklet is the important role played by patients and carers as partners in this process. Also, how strong approaches to public involvement can have an important impact on research delivery in terms of value, effectiveness and efficiency.

I hope it will serve as a source of motivation, encouragement and good ideas to others setting out on the path of conducting best research for better health.

Simon Denegri, Chair, INVOLVE & NIHR National Director for Public Participation and Engagement in Research.

glossary



The examples in this publication will be of interest to researchers, research funders and commissioners and members of the public interested in public involvement in research. The glossary includes some of the terms frequently used within the publication - details of other commonly used research terms can be found in the INVOLVE jargon buster: <http://www.invo.org.uk/resource-centre/useful-information/jargon-buster/>

Action research - a form of research carried out by people on their own work and/or lives, sometimes with the help of an external facilitator.

Behavioural - Involving, relating to, or emphasizing behaviour.

Cognitive - The process of knowing and perceiving, including attending, remembering, and reasoning; also the content of the processes, such as concepts and memories.

Empirical - Based on or verified by testing or experience rather than theory or logic.

Grant application - in a research context, this is an application to a grant making organisation to secure funding for a research study or project.

Intervention - An intervention is something that aims to make a change and is tested through research. For example, giving a drug, providing a counselling service, improving the environment or giving people information and training are all described as interventions.

Long term condition - defined by the Department of Health as “those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies. The life of a person with a LTC is forever altered – there is no return to ‘normal’.”

Meta ethnography – Meta ethnography is a method for combining data from qualitative evaluation and research, especially ethnographic data, by translating concepts and metaphors across studies.

Protocol - A protocol is the plan for a piece of research. It describes in great detail what the researchers will do during the research. Usually, it cannot be changed without going back to a research ethics committee for approval.

Risk - The measure of the association between exposure and outcome (including incidence, side effects, toxicity).

Risk score - The risk assessment is evidenced-based and consists of seven questions. It uses a points system to identify if a person is at low, moderate, or high risk of developing a condition. Based on this score, appropriate advice is provided in the form of lifestyle changes or a GP referral.

Service user (SU) - A service user is someone who uses or has used health and/or social care services because of illness or disability.

Systematic review - Systematic reviews aim to bring together the results of all studies addressing a particular research question that have been carried out around the world. They provide a comprehensive and unbiased summary of the research.

Validate - Check or prove the validity or accuracy.

introduction

In 2013 representatives from a range of organisations with a responsibility for, or an interest in, patient and public involvement (PPI) in research in the primary care setting formed an informal interest group. With a shared experience of collaborating with patients and carers around study design, development and delivery we knew the value this can add to the quality, performance and experience of research. We were keen to see how we could join up involvement and engagement activities to facilitate greater continuity for patients and carers along the lifecycle of a study. We also recognised that we had similar agendas with regards to promoting access to research and an interest in working with external patient led organisations such as the National Association for Patient Participation N.A.P.P.

In November 2013 we asked researchers via INVOLVE for examples where PPI has made a positive impact on research in primary care and were delighted to hear back from eleven research teams across England. The examples present a rich tapestry of how patients and carers have been involved in the development of a range of research studies. There is also a range of different ways of involving people which have been included from virtual online groups to established forums. We enjoyed reading the case studies and wanted to share them wider to inspire others to be creative and dynamic in the way they involve patients and carers.

Thank you to all the members of the group listed under Organisational Profiles who all contributed to producing this publication by collaborating on the design, content and editing. Special thanks in particular to the members of PRIMER who reviewed the document to check use of plain English and ensure it is accessible to a wide public audience and to the School for Primary Care Research for publishing and printing the document.

What is Patient and Public Involvement?

INVOLVE defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants. Find out more.

Case Study 1:

The PRIMROSE Programme

Alex Burton and Ben Gray

About the study

This 5 year programme aims to find ways to reduce cardiovascular risk in people with severe mental illness by developing an intervention for use in primary care. It began with two years of development work. This included a systematic review, the development of a new cardiovascular risk score and a series of focus groups with health professionals, service users and carers. The findings have informed the design of the new intervention. This intervention will be tested in a clinical trial during the final three years of the Programme. The Primrose study is funded by the National Institute for Health Research (NIHR) under the Programme Grants for Applied Research (PGfAR) scheme (Grant Reference Number RP-PG-0609-10156).

Alex's experience

How have service users and carers been involved in the project?

We've had service user input since before the project started. There was a co-applicant who was part of the grant development. She informed some of the key decisions, but we lost her - unfortunately she passed away. That was all before I joined the project.

There was also a lot of involvement from the Service User Research Forum (SURF) at the local Trust. The project was presented to them a few times and their feedback was incorporated into the application.

We also worked with Rethink on the grant application, through to the development stage. We employed Ben, a research officer through Rethink who is also a service user researcher. He's been inputting into the development work and he's been coming to our meetings and helping with the focus group analysis - so it's been at all levels of the project really.

What difference did the involvement make in the early stages?

With SURF, they thought the research was important and we got an endorsement from them. They helped by saying the project was meaningful and worthwhile and something we should be getting funding to do.

They had another comment about one of the interventions for managing cardiovascular risk, which is the prescription of statins. There was some concern from SURF that the study shouldn't just focus on drug treatment and there should be more of a discussion with clinicians. The shape of the grant did change so that more behavioural interventions would be offered, and more emphasis would be placed on the communication between the clinician and the service user. So it shouldn't just be 'You're at risk, here's your drug - off you go'.

What impact has the Lived Experience Advisory Panel (LEAP) had on the project?

Rethink set up a Lived Experience Advisory Panel (LEAP), a panel of service users and carers who help steer the project. The panel is co-ordinated by Ben. 27 people have joined the LEAP, so it's a good resource to draw on. They can contact Ben whenever

they have an idea and if we've got something we want to share with them, then we can quickly send it out. It works quite well. I've also attended their meetings so I've heard the feedback first hand.

Their feedback has been at all levels really. We've shared our logo, and our acronym to find out whether service users think that is relevant and appropriate. We shared the focus group protocol with them and they suggested that we involve carers, so we ran an additional group with carers. They also suggested that we don't just focus on urban areas, so we included rural GP practices, in case people's experiences are different there.

The Intervention Development Group, made up of a smaller number of LEAP members, has made a big difference to the intervention, especially around the work we've planned with nurses. The Group suggested we include the topic of stigma in the nurses' training programme and also that we ensure that practice nurses feel comfortable working with people with severe mental illnesses. So the mental health side of things is being included in the training and the intervention. This is where there's often a divide – between physical and mental health – and by linking it all together, there has been a real emphasis on holistic care, rather than dividing people up into separate illnesses.

How has having a service user researcher on the team made a difference to the research?

Ben has been co-ordinating our links with Rethink and his remit has been to organise the meetings with the LEAP. He makes the personal contacts with them. He emails them and they come back to him with individual comments as well as via the group forum.

He was also meant to be co-ordinating and facilitating the focus groups with service users – but unfortunately he became unwell. He helped facilitate one group and then he had to stop. We really wanted to have a service user doing that research, so we had to quickly try and identify somebody to replace him. We found a service user from another project in our department who was willing to come and help us. We ran five groups with service users but only three of those had a service user facilitator.

He's better now and still co-ordinates the LEAP. He inputs into the written documents we've been producing following the development work. He was attending team meetings up until the time he became unwell. As he's still in recovery, he's stepped away from coming to the meetings, but we try to feedback the minutes and he comments that way. We try to keep him on board as much as possible – but it's been quite difficult to manage at times.

What difference has it made to have a service user researcher co-ordinating the LEAP?

Because Ben is a service user researcher, people feel more comfortable speaking about their experience. He's collected quite a lot of information through people sharing their stories. Being based at Rethink - they have the resources and the networks where they can contact people – and they have good models of involvement. They don't just play lip-service to it – it's worked really well the way that they've set this up. If I'd tried to do it I wouldn't have known where to start.



This is where there's often a divide – between physical and mental health – and by linking it all together, there has been a real emphasis on holistic care, rather than dividing people up into separate illnesses.



It's also been really helpful having a bit of separation from the project and having someone else leading that. Having people on the outside is quite useful – it's fresh eyes and an independent view.

The LEAP members are very honest as well because they are a group of people who are comfortable with each other. We've had some very honest views about how we should be doing something or what we shouldn't be doing.

How have you made sure that the LEAP's views influence the project?

I attend part of the LEAP meeting, but the service users also discuss things without me being there, as I might influence the things they feel they can say. Our service user researcher is always present and he will write up the notes and send them through to me – so that we've got documentation of everything.

Recently we've been pulling together all of the development work into evidence tables. Within those tables we've also got all the notes that have been taken at the team meetings and key suggestions from the LEAP – so that we can come to an overall decision about what the intervention should include. We make every effort to ensure that everything is considered at least, but it might not all be taken on board.

Some of the feedback that people have given us hasn't been realistic. Some suggestions have been ones that we can't deliver in the project. I manage that by documenting what the research team has said in the meetings and gathering the responses to the LEAP's comments. Then I can go back and say 'This was considered, but we felt it was not possible', as well as describing the process as to how we reached our decision. I can answer questions or justify why we haven't included what they said.

Have there been any challenges?

The main challenge was when Ben became unwell. Unfortunately it wasn't something that we'd planned for, so we didn't have a contingency plan. The service user aspect of the development work was on hold for

the few months he was in hospital until we identified other people to meet our short-term needs. But it wasn't ideal because continuity is always better. Now he's back, it's just about managing whatever he feels comfortable with doing. You want to involve him in every level of the project in the way that you set out to do, but at the same time, you have to respect that he might not feel ready to come to meetings. We've met with him and asked how he wants to take things forward. His strengths are really the writing and running the LEAP. So he's focusing on that side of things.

Part of the challenge was that it happened so unexpectedly. We weren't aware there was a problem and there was a bit of a breakdown in communication. I think it's important to have those conversations early on, even though it's difficult when someone is well. Asking questions like 'If you become unwell how do we manage that?' and emphasising 'We want you to feel comfortable telling us if things are getting too difficult'.

How will you continue to involve service users and carers in the remainder of the project?

We hope to have the manual prepared for our intervention before the next LEAP meeting. We are going to share that with them and get their feedback on whether it's what they envisaged, and see if it sits comfortably with them. We might try out the intervention with some of the users there and see how it works in practice.

We have to give some thought as to how best to involve LEAP members from here on. We need to work out whether we need a trial management group with service users and how we involve them productively and meaningfully. It will probably be about the recruitment to the trial and how we could encourage service users to take part in the research. We're going to try to have service users involved in the training of health professionals and again Rethink have a network of service user trainers that we're hopefully going to work with.

Ben's experience

How have you been involved in the project so far?

I've mainly been involved in co-ordinating the LEAP. It has taken a hell of a lot of work to co-ordinate 27 people. But it's been really good to bring people together. It's good to have a strong interpersonal relationship with the people on LEAP to understand where they are coming from and their difficulties, and if they are unwell, to try to find ways for them to participate and feel included. It can be very lonely and isolating for people otherwise.

I've also been supporting the Intervention Development Group. It has 8 members and has been oversubscribed. So we have 5 people as core members to keep continuity and then we invite a different 3 people according to what's being discussed. So people can opt in from the main LEAP and take part in different activities as they want.

What difference do you think the LEAP has made to the project?

The first recommendation they made was to have a blog where people could post their stories and which could act as a project newsletter online. So I've been managing that. That's been a very successful way of keeping people abreast of what's happening and keeping people engaged and included.

Since then LEAP has acted as a critical friend to the project - so it offers pragmatic advice on the research design and ways of increasing opportunities for collaboration. For example, LEAP members commented on the topic guide for the focus groups at the beginning of the project. They took the jargon and complicated words out to make it simpler and more accessible. They also suggested having more time at the beginning and end of the focus groups to have a general discussion - rather than jumping in to specific questions - to relax people and allow them to tell their stories and to bring the group together.

The Intervention Development Group has also helped to make the intervention more acceptable and meaningful for service users. One of the great barriers is that people just don't turn up to these interventions in primary care - so we've been looking at ensuring LEAP's expertise and experience inform that development, so that we get a good uptake.

LEAP members gave examples of good and bad practice in their experiences of primary care - what worked for them and what didn't. Some had found that their GPs lacked an in-depth knowledge of mental health and the side-effects of anti-psychotics, and were concerned that the attitudes of primary care staff had to change. So they suggested that service users and carers should be involved in training the nurses - to address the issues of stigma and exclusion.

“

Asking questions like 'If you become unwell how do we manage that?' and emphasising 'We want you to feel comfortable telling us if things are getting too difficult'.

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The Group has made eleven recommendations and nine of those are thought to be feasible - we hope they will get incorporated into the clinical intervention and professionals' training.

What helps the LEAP to work well?

The group is chaired by Alison Faulkner, who is an independent service user consultant who has worked widely in mental health. She's outside the research team so that the LEAP has its own identity and can make recommendations without having to doctor them. That adds a critical edge. LEAP can then give an external and critical perspective that it might otherwise lack. We don't just tell the research team what they want to hear.

With Alison as the chair, everyone has their say at the meetings. We do invite members of the research team to come and talk to us and tell us what the state of the work is. They stay to field questions and then leave so we can have our discussion amongst ourselves - to ensure questions aren't shut down and are explored from everyone's perspective. We need close collaboration but also some independence.

It also makes a difference to have a service user co-ordinating the group, as I have much more empathy and understanding of mental health. I didn't really appreciate the suffering of people until I'd experienced it myself. It gives you a good perspective on how valuable it is to include people.

We also pay people for their time. We've been using INVOLVE guidelines on payments. We either pay £100 in a one-off payment or in £20 vouchers. That enables people on benefits to take part and not lose their income. The majority of members are on benefits - and we want them to be able to come and take part.

Have there been any challenges?

It's a challenge to get everyone together at a certain time and date because we have to arrange everything for them - from train tickets through to paying them. We have to chase people up to make sure they'll attend, particularly if they're not doing well. That has been difficult for me as I still have negative symptoms

of schizophrenia, so it takes quite a lot of effort. It's been worth the effort and Rethink has been very supportive. They have let me have administrative help to get people to the meeting.

Then unfortunately last year I became unwell again and had 2-3 months off work, spending 1-2 months in hospital. During that time the team were extremely supportive. I continued being paid and my manager was saying they really wanted me back. He said 'You've got great research experience and lived experience that none of us have. You've made a great contribution to Rethink and to the LEAP, so come back as soon as you're ready'. That really motivated me to get better and come back.

What further benefits do you hope to come from your involvement?

It's not just about doing research but also communicating research - getting it out there so people can know about it and implement it. That's where me working at Rethink is very helpful because we have a very good Campaigns and Communications team. I've been working with them already to go to conferences and develop the project web pages.

We're also tying this research into campaigns being run by Rethink. There's a campaign for physical health champions and our '20 years younger campaign' which is raising awareness of the fact that people with mental health problems die 20 years younger from preventable diseases like diabetes and heart disease. This fits with one of the LEAP's recommendations - that we need service user champions to raise awareness of what works and what matters. So I hope my involvement in the project will help with linking into campaigns and activities that go beyond the research, and actually try to change practice.

A LEAP member's experience

What difference has being involved made to you personally?

For me it's huge - in lots of different ways and on different levels. It's something that I feel really matters - the shocking statistic of people with severe mental illness like myself - the fact that our life expectancy is so dramatically reduced. It feels really important in that way for all service users. It also matters to me personally because I'm trying to reduce my own risk factors for cardiovascular disease. For example, I smoke at the moment and I'm trying to stop, so I am thinking about that.

It's also making good use of my own experiences with mental illness - using it to benefit other people. It's really empowering and helping me to make sense of everything that I've been through and continue to live with. I feel quite emotional saying it - but it does feel really important and valuable. I feel that when I'm in a LEAP meeting, by being part of LEAP, it's not just me I'm representing, but the people I've met, particularly from the psychiatric wards I've been on. I've met some incredible people with severe mental illness who don't necessarily have a voice, so hopefully I can bring some of their voices to this research.

It's still vitally important to me to have contact with other people who talk openly about having mental illness. I really value talking to other people with mental illness - and there's carers involved in LEAP as well, so I'm getting that perspective.

But it's also important to me professionally. In the past I was in the medical profession. Now I'm retraining to re-enter the health service. In-between I've been a patient in psychiatric hospitals and supported by community mental health teams. I have to say I got quite disillusioned with the professionals, particularly with how they dealt with people like me and mental health in general. I do feel like some of my confidence has been regained through being involved in LEAP. There are clearly medics who are interested in what we have to say and who

actually think it matters, and more than that are actually taking action in response. That's really vital professionally as it's something I believe in and want to have in my own practice.

What difference do you think the LEAP has made to the research?

I'm not sure. Maybe that's part of my scepticism. There are a few things that have been passed on, but I'm not sure how they've been received - and am not sure if that has shaped the intervention being proposed at the moment.

There was also quite a lot of discussion about where we can contribute next. We want a bit more involvement. We're getting a bit bolder in a way which was really nice - but whether that makes a difference we'll have to see.

There's a meeting coming up so hopefully at that stage things will be clarified. I expect an update and suspect it's a timing thing.

What has helped your involvement to work well?

Rethink's involvement is really valuable. I trust them and their values and I think that's really crucial. I was wary initially because of my past experience of the medical profession. I was quite critical. But



Rethink's involvement is really valuable. I trust them and their values and I think that's really crucial.



because Rethink was involved it felt less tokenistic. That's something I am wary of with service user involvement. It's a term that trips off the tongue but can be reduced to tokenism.

The way they facilitate the meetings means it works well. One of Ben's real strengths in the meetings is that he's really good at drawing out themes, summarising and pulling it all together – those practical skills are really useful. He does a fab job at keeping us updated in between and encourages us to be involved in other ways as well. It makes a difference that Ben is a service user – there's no two ways about it. That shared experience for me helps with the trust. I feel that he gets it and I feel he adds integrity in a different way.

It's really important that there isn't always someone from PRIMROSE at the meetings. I think we've started to get a bit wider and bolder in our thinking – we are freer to be critical even at a sub-conscious level – so that is very clever in a way. Little things like that matter.

Could anything be done to make it work better?

I would value more communication. I think it goes back to that fear that user involvement might be tokenistic. There's nothing specific to make me feel that about LEAP. I don't mind if things put forward by LEAP don't shape what happens – but I need to hear that there is good logic. I think we deserve that feedback - otherwise it's meaningless and just a gesture really. I need to feel the information flow is more two-way.

Ben is pivotal in that and does a fab job – but I don't feel like I have a full grip on where we fit into PRIMROSE. It would be good to have more updates on progress.

Also it takes me a long time to process things sometimes – so if we only get a verbal update in the meeting, I can't always think about everything there and then, to respond to it or to question. It would be good to have the information further in advance. For me it adds to the fear that maybe the research project is all going on regardless of what LEAP are doing over in a separate bubble.

Have there been any surprises?

Personally - just how rigidly I sometimes thought about things. I'm also not very good at on the spot thinking. It's also given me a re-awareness that everyone's lived experience is different, in terms of mental health issues and cardiovascular risks. There's still a wide variety within that – some reflected in the LEAP – which is really valuable.

What would you say to other service users about being involved in research?

That if done well it really makes a difference – both personally and in practice. It's that empowerment in forcing change – closing the gap that exists between theoretical research and practice. It's about people and their context and what's in everyone's best interest. The process of being involved is very empowering.

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Project blog: <http://primroseleap.blogspot.co.uk/>

Case Study 2:

The MOSAIC study

Clare Jinks, Adele Higginbottom, Carol Rhodes, Pauline Ong and Krysia Dziedzic.

About the study

A team from the Arthritis Research UK Primary Care Centre at Keele University were given funding by the National Institute for Health Research to undertake a programme of work (over 5 years) to find out how to best deliver care for patients with Osteoarthritis (OA) in primary care. One study within this programme is the MOSAICS study which stands for Management of Osteoarthritis in Consultations. The study method is a trial and four general practices delivered a new consultation for OA and a further four practices carried on with what they usually provided. The new consultation included a new way of recording information about OA by the GPs, use of a guidebook for patients, GPs and nurses, and a new nurse clinic where patients could see the nurse up to four times about their OA.

The Arthritis Research UK Primary Care Centre at Keele is committed to taking an explicit and systematic approach to involving patients and the public in research. The Centre has a written framework for involvement (based on guidance from INVOLVE) and this helps researchers to think and plan involvement in their projects.

The Centre has established a Research Users' Group (RUG) which has 60 members. For the MOSAICS study the Research Users' Group worked in collaboration with researchers on a wide range of tasks. These tasks have focused on aspects of

research design, management and dissemination. Some examples of involvement are outlined:

Development and design of a guidebook for use in the OA consultations

This was a major piece of work which has been published collaboratively by one of the researchers and one of the patients involved. The OA guidebook differs from conventional patient education materials in that it contains lay as well as biomedical evidenced-based, knowledge. Five members of the RUG helped to shape the content of the guidebook. They reviewed a summary of qualitative research of people's experiences of living with OA to identify information needs, drawing on their own lived experience to suggest what information was required to meet newly diagnosed patients' information needs, and review draft materials. The guidebook was then used as part of the new intervention in the trial. (See Grime J, Dudley B. Developing written information on osteoarthritis for patients: facilitating user involvement by exposure to qualitative research. *Health Expect.* 2011 Nov 10. doi: 10.1111/j.1369-7625.2011.00741.x. [Epub ahead of print]).

Involvement in and advice gained for a Delphi consensus study

The aim was to ask patients what they think should happen / be done when older people with joint pain consult a GP for the first time. A one hour meeting was held to explain the consensus exercise and

discuss aspects of consultations. RUG members then completed two postal questionnaires which listed all the possible things that could happen during the consultation, and decide which they think should be included. They were asked to think in the first questionnaire that time was no object. In the second round they were asked what should be included in an initial ten minute consultation. RUG members then returned for a follow up meeting to discuss items on the questionnaires and give feedback on the consensus method.

(See Porcheret M, Grime J, Main C, Dziedzic K. Developing a model osteoarthritis consultation: a Delphi consensus exercise. *BMC Musculoskeletal Disord.* 2013 Jan 16;14:25. doi: 10.1186/1471-2474-14-25).

Advice on content of a population questionnaire

The aim of patient involvement here was to assess the content, layout and order of a postal questionnaire to be used as part of the trial. As a result of the feedback changes to the consultation questionnaire were made.

Development of quality indicators for general practice consultations

A quality indicator describes the performance of something. It could be an action or task (e.g. GP recording information) or a health outcome (e.g. lower blood pressure or reduced pain). Quality indicators are used to measure standards of care and whether they are consistent with what is thought to be best care. A list of quality indicators (QIs) for the content of general practice consultations for the MOSAICS was pulled together by a researcher from a systematic review. This list was taken to the RUG and translated by the RUG into questions that could go into a questionnaire to ask about experiences of the new consultation being tested. Some of the questions in this “consultation questionnaire” therefore are patient defined questions – using the words suggested by RUG members. In collaboration with

Norwegian and Danish colleagues results of patient involvement across countries are being compared. The format developed by the RUG was found to be almost identical to a format being tested for OA Quality indicators in Norway which also included patient partners.

Involvement in developing training for health care professionals

- At a RUG meeting in November 2011 researchers introduced members to 4 pieces of qualitative data from a previous study which looked at how people with knee pain self-managed their pain. These pieces of data were considered by researchers as good examples to use in training of nurses of how people cope with joint pain and adopt self-management approaches. The RUG discussed their thoughts on how patient experiences could influence a model OA consultation and if these examples would be suitable to help nurses to see the patients’ view. The results of this were fed into the training programme for the trial.
- 4 members of the RUG recorded extracts of patient stories for the trial intervention practice training video (December 2011).
- The MOSAICS intervention practice training, which the RUG helped to develop, has now been adapted for an eLearning OA module on the Royal College of General Practitioner’s website which is sponsored by Arthritis Research UK and is freely accessible to anyone, and not just GPs. Photographs of RUG members and text from quotations are included in the module.

Steering Committee Membership

Two members of RUG sit on the overall programme grant steering committee.

MOSAICS is a complex study and this creates challenges for the patients and researchers. This has been managed by (1) the generation of a glossary which is available to all patients (2) support to patients at meetings by a PPI co-ordinator and User Support Worker (3) production of lay summaries in advance of meetings (4) continued feedback to patients who have been involved (5) offering training (e.g. Contributing Assertively in Meetings).

The MOSAICS study is one study at the Arthritis Research UK Primary Care Centre where patients have been involved. To date the Centre has had involvement in 58 studies some of which have been written up for publication. For example:

- Carter P, Beech R, Coxon D, Thomas MJ, Jinks C (2013): Mobilising the experiential knowledge of clinicians, patients and carers for applied health-care research, *Contemporary Social Science: Journal of the Academy of Social Sciences*, DOI:10.1080/21582041.2013.767468
- Strauss V, Carter P, Ong BN, Bedson J, Jordan KP, Jinks C, in collaboration with the Arthritis Research UK Research Users' Group. Public priorities for joint pain research: results from a general population survey. *Rheumatology (Oxford)*. 2012 Nov;51(11):2075-82. doi: 10.1093/rheumatology/kes179. Epub 2012 Aug 11.

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ISRCTN number: ISRCTN06984617.

NIHR Programme Grant: RP-PG-0407-10386



The aim was to ask patients what they think should happen / be done when older people with joint pain consult a GP for the first time.



Case Study 3:

Undergraduate medical education in general practice

Sophie Park and Nada Khan

About the study

We are currently running two projects which consider the involvement of patients in undergraduate medical education in a general practice setting. These projects are summarised below.

A systematic review

We are conducting an NIHR School for Primary Care Research funded Best Evidence in Medical Education (BEME) systematic review about undergraduate UK general practice medical education. This project aims to summarise and synthesise the existing research evidence delivering undergraduate medical education in general practice. It focuses upon 3 different areas of outcome: patient; student; and teacher. This review has been conducted by a multi-disciplinary and multi-institutional team, including user representatives. We have produced three major outcomes relevant to patient involvement:

1. A descriptive summary of educational activities in undergraduate general practice teaching, including the emotional, behavioural and cognitive changes or learning for patients as an outcome
2. A summary of quantitative independent outcome measures assessing the impact of general practice teaching on patient emotional/affective outcomes and student behavioural and cognitive outcomes
3. A meta-ethnography considering the perspectives of students and patients involved in undergraduate medical education.

Outcomes of the project relating to patient involvement

1. The project will produce a number of descriptive outcomes including, for example, benefits and dis-benefits to patients of involvement in medical education reported within the review
2. Specifically, we are looking at three different areas in terms of impacts on patients participating in medical education teaching. These are:

Cognitive

Do patients gain an increased familiarity or understanding about disease process or absence of disease affecting self; increased knowledge of system; more knowledge about availability of treatments (or lack of) or increased knowledge about possible prognoses as a result of taking part in teaching?

Emotional

Do patients experience a sense of altruism or a sense of reward from participating; anxiety about novice status of students or participating; or increased vulnerability or exposure through questioning during teaching; an increased sense of resolution or acceptance about current illness experience through teaching experience and discussion; or increased confidence to communicate or challenge healthcare professionals through taking part in teaching?

Behavioural

Do patients experience an increased understanding of disease-frameworks and presenting experiences in medical language as a result of taking part in medical education?

Thirdly, the meta-ethnography is exploring how patients (and their relationships with students and clinical teachers) are conceptualised within the literature. We hope that this will provide useful feedback to patients considering involvement in medical education, as well as students and faculty about patient-based teaching.

Patient Participation in UG medical education in general practice (PatMed)

This project follows on from the results of our systematic review and meta-ethnography about undergraduate UK general practice medical education.

The objective of this new project is to inform a set of recommendations for patients, students, teachers and policy-makers about patient participation in medical student general practice teaching. In order to achieve these objectives, we intend to take the findings of the meta-ethnography to patient and student groups and discuss the findings, their potential meanings, and ways of using these findings in practice. We will then conduct interviews with patients involved in medical student teaching in general practice to further explore issues identified within the focus groups and meta-ethnography.

Impact of the project

This project will add to the existing work in this field by exploring the anticipated role and contribution of the patient during the teaching or consultation; the relationship between patient, doctor and student; the sorts of knowledge and experiences which patients would like to share, or feel are relevant to discuss with the students; the impact the patient feels their participation in medical education might have upon their current and future consultations with their GP; and ways patients feel their participation might be improved or developed to support their involvement and strengthen connections between medical schools and their local communities.

Patient involvement

This project seeks to directly translate and develop findings from a meta-ethnography of existing empirical literature using patient and student



We intend to take the findings of the meta-ethnography to patient and student groups and discuss the findings, their potential meanings, and ways of using these findings in practice.



perspectives about undergraduate general practice medical education. Through the research processes in this study, we hope to facilitate an exchange of perspectives between participants and the empirical literature. We anticipate that this will enable contemporary service users' involvement in the interpretation and development of relevant research findings and inform recommendations for future policy and practice.

The PatMed project includes a patient representative as part of the existing, established research team. The patient representative has helped us by providing insight and comments on drafts of the study proposal and study design. The patient representative will be invited to comment on drafts of all study materials (findings from the meta-ethnography, interview schedules and topic guides for focus groups and Interviews). She will also be invited to attend discussions of analysis and emerging themes and comment on drafts of any reports and papers.

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Case Study 4:

The ISiS project: identifying, signposting and supporting carer

Sarah Knowles, May Griffiths, Ryan Combs, Sue Kirk, Neesha Patel and Caroline Sanders

About the study

The ISiS study is an ongoing project of research looking at the problem of 'hidden carers', meaning people who make a significant contribution to supporting others with health problems but may not recognise themselves as a 'carer', and consequently be less likely to access the support they need. The original study, which was funded by the Greater Manchester Collaboration for Leadership in Applied Health Research and Care (CLAHRC), was inspired by Mrs May Griffiths, a member of the University of Manchester PRIMER group who was herself a hidden carer for many years. She collaborated with a team of researchers in the Centre for Primary Care to secure funding for a pilot study that qualitatively explored the experiences of carers for people with vascular disease and examined barriers to identifying as a carer which could impede access to support. The project was also supported by a steering group of people with lived experience of caring who influenced the development and analysis of the study.

Integrating PPI inspired research into Primary Care: May and Sarah's stories

May had been a carer for many years for her husband. However, she didn't realise she was a carer until after he passed away. She says: "Joining PRIMER I found a group of people who like myself wanted an outlet to use their life experience and interest in research to work for patient benefit. At PRIMER I was able to introduce a subject – the problem of carers being hidden and not receiving support - that I felt was important. Fortunately I found I was not alone, and with help from my colleagues at PRIMER, both service users and researchers, my germ of an idea has developed into a successful project."

May worked with a team in the Centre for Primary care to develop her idea into a funding proposal and was a co-applicant on the bid. The project was successfully funded by the NIHR Collaboration for Leadership in Applied Health Research and Care Greater Manchester (CLAHRC), as part of a broad theme of research exploring social network support for people living with vascular disease. The exploration of carers' perspectives complemented this theme but also added an unexplored dimension to it, demonstrating how novel ideas from PPI partners can both bring new insights into research but also how research teams can help PPI partners integrate their ideas into existing themes of work.

Sarah, one of May's co-applicants on the study, comments that: "It was interesting to see how a PPI partner can bring a new or neglected idea to your attention, and how then as a researcher you can try to find ways to incorporate it into ongoing research. I think the project shows how PPI partners bring new

inspiration, but I think researchers can be scared that those ideas will be too ‘out there’ or unfeasible. It can be reassuring to see actually the things researchers focus on and the issues that are important to PPI partners aren’t that far apart! The PPI partners bring a different focus but I think any researcher would hope their own research in Primary Care isn’t so divorced from what matters to people that they can’t find a way to integrate the two. In our case, we were already looking at people with long term conditions (LTCs) and the support they get outside the clinic, in their own homes and communities. May’s experience as a hidden carer gave this a new angle, by asking ‘But how prepared are the other people living with them to provide this support, and do they realise they might need support as well?’”

PPI Partners guiding the research as ‘critical friends’

May is very experienced in PPI and in research in general, having completed an MA dissertation that looked at identifying the health effects of carers living with LTCs. This has been immensely valuable as it meant May could contribute at multiple stages of the research and was comfortable attending team meetings with the Principal Investigator (PI) and other researchers. However, we also wanted to make sure that the research was informed by people with lived experience of caring who were new to research and brought ‘fresh eyes’. We approached local carer support groups in Manchester and recruited 8 volunteers to sit on a PPI Steering Group, to guide us on the project as ‘critical friends’ using their insights as experts-by-experience.

The steering group met three times during the project:

- Before data collection started, to consider our recruitment strategies, advise on the ethical issues we should consider, and make suggestions for the topic guides.
- Midway through the study to reflect on progress, specifically to make suggestions for improving recruitment and to discuss the emergent findings to check if they felt any aspects of carer experience were being neglected or were surprising.
- At the end of the project, to hear about our final analysis and reflect on whether it rang true with their experiences, and to identify what next steps needed to be taken to help us begin planning the next phase of the research.

We were not able to include PPI members in the analysis itself or directly in data collection (for example by acting as lay interviewers). This was due to limitations both in our budget and also in the time available. We did not want to ask PPI members to make this kind of contribution without making sure there was sufficient time for them to access training and gain experience, and also if we couldn’t financially reimburse them adequately for their time. We hoped that the structure and timing of the meetings however would mean we were still gaining PPI insight at the various stages of research and analysis. The steering group members were also happy with this arrangement as they would not have been able to commit to actively working on the project itself. This demonstrates the need to recognise the varying levels of PPI input that are possible and how the ‘right’ level for the study is a balance of what is possible or feasible given the resources available and also the specific needs or interests of the PPI members. It shouldn’t be assumed that PPI partners will want a certain level of involvement, and PPI strategies in projects should be sensitive to the interests and expectations of those partners.

Steering Group

The PPI steering group provided significant input in helping us modify materials to be more suitable, for example they identified very early on that the term ‘carer’ could be off- putting (this emerged as a significant theme in the research findings) and suggested that our invitation materials should refer to “helping or looking after someone” rather than “caring for”. They were also able to validate our findings, for example richly describing their own experiences struggling with the term ‘carer’ which were congruent with the experiences of participants in the study. This helped us to refine and focus our analysis and make the struggle with the label of ‘carer’ the overarching theme of the paper.

However, we were not able to accommodate their suggestions in all cases, again mainly due to budget restrictions. For example, we specifically wished to recruit South Asian participants and had costed in the grant for translation costs for this group. Interestingly, the steering group felt that we should also provide materials for other ethnic groups and translate documents into Polish and Chinese. This would have been beyond our capacity, but it was notable to see how the PPI Steering Group considered the perspective of diverse participants and the emphasis they placed on making sure all potential participants would have access to the study.

Getting the word out: Publication and Dissemination

May's role as equal partner on the study is continuing, and she is a co-author on the paper that is currently in preparation. We've also tried to follow best practice in reporting PPI by using the Guidance for Reporting Involvement of Patients and Public (GRIPP) checklist (Guidance for Reporting Involvement of Patients and Public) to guide the references to PPI conduct and impact during the study throughout the paper. This can be challenging at first as often PPI is relegated to the methods section or an appendix, and GRIPP encourages authors to consider how it should be included throughout the manuscript. However, this also means that the PPI input, and May's input in particular, is given the prominence it deserves, and the better reporting of PPI hopefully means the paper will be able to contribute to broader reviews of PPI work, which to date has been limited by inconsistent reporting.

There has also been considerable interest in the study itself as an example of PPI-inspired research. We have been invited to talk about the study at PPI presentations and training events, to give insight into how a PPI inspired project can take shape and what the benefits can be. May has given a key presentation along with a service user colleague at the Research and Development Conference, has been invited to speak at her local 'Healthwatch' conference, and also given a presentation to the Cumbria and Lancashire Comprehensive Local Research Network. She says: "The study has aroused a great deal of interest. We have been able to prove that service users and

researchers working together can introduce a new and relevant perspective into research."

May's networks amongst carers' organisations are also incredibly useful for helping develop the next stage of the research. As we prepare to apply for more funding, we already have various interested stakeholders amongst health and social care and in the voluntary sector who are keen to contribute. For Sarah, this has been one of the most striking aspects of the project. She comments "So often in research it's an uphill struggle to get organisations interested and committed to new studies. The level of interest in this study I think shows firstly how having a PPI champion like May involved can open doors in terms of her already having good relationships with relevant organisations, or because they're more convinced by her enthusiasm than a dry expression-of-interest letter, but also I think it's because clearly the study has hit a nerve. The problem of hidden carers is very important to people and something they're really eager to see more research on. I think that shows why having PPI-inspired research projects is so important, as it makes sure the studies that go forward are really relevant and valuable to the end users."

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Case Study 5:

‘Critical friends’

Rebecca Morris

About the study

The VOCALS study explored the existing and potential role and function of voluntary organisations to support long term conditions (for example diabetes and Chronic Kidney Disease). It was part of the Greater Manchester Collaboration for Leadership in Applied Health Research (CLAHRC). The project examined the role of voluntary groups to long term condition management from the group organisers’ and members’ perspectives. The project was supported by a PPI group with members from the local community in which the research was being carried out. The PPI group influenced the focus of the study and the priorities of research.

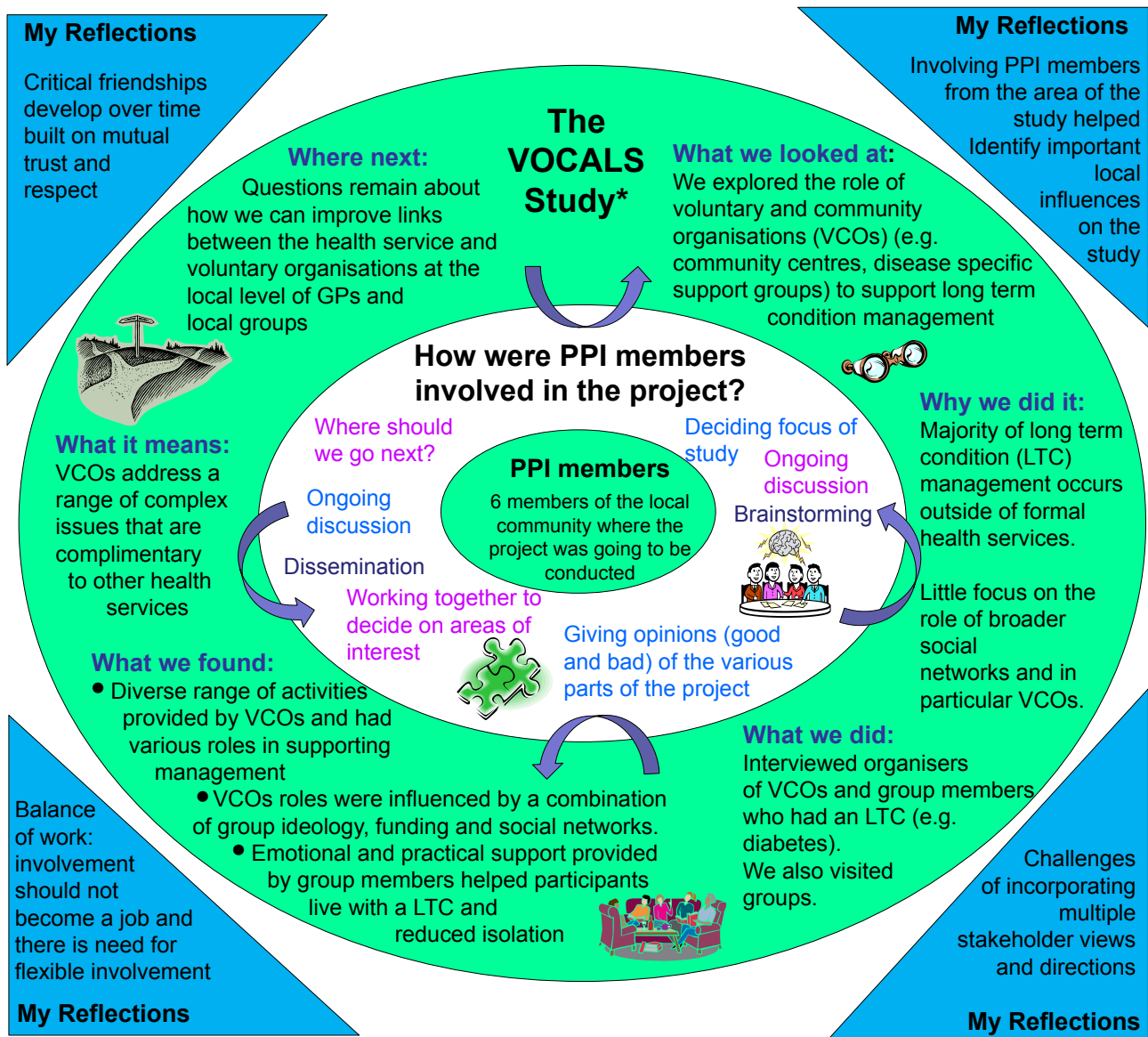
Poster on page 18.

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“Critical friends”: the experience of integrating and developing patient and public involvement in an exploratory study of voluntary organisations and long term condition management

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* The Voluntary Organisations, Community Groups And Local Networks of Support (VOCALS) study
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Case Study 6:

Improving community health networks of people with severe mental illness

Vanessa Pinfold, Julie Billsborough and Ruth Chandler

About the study

Policy drivers in mental health to address personal recovery, stigma and poor physical health indicated that new service solutions were required. The aim of this study was to understand how connections to people, places and activities were utilised by people with severe mental illness to benefit health and wellbeing. It was funded by the NIHR HS&DR programme.

A five module mixed method design was undertaken in two study sites. Data were collected from 150 network mapping interviews incorporating the name generator approach and 41 in-depth follow up interviews with participants recruited through GP surgeries; 30 organisation stakeholders and 12 organisation leaders semi-structured interviews; 44 telephone interviews with practitioners. We undertook a three-stage synthesis process including independent lived experience feedback and a public and patient involvement team participated in tool design, data collection, analysis and write up.

Our approach

This NIHR funded study was developed by a team including a service user researcher and carer advisor: the lay summary on the funding application was written by the service user researcher. PPI expertise was included in the project budget. Originally we

planned to employ service user researchers in our two study sites – London and the South West, involving them in local advisory groups, study recruitment and data collection.

Our approach however changed. Firstly, our service user researcher left the team before the study was funded and secondly we decided to change our PPI plans as a result of scoping and pilot work in the two study sites. We did not set up local advisory groups but instead formed a national advisory team including two service user representatives. We did not employ service user researchers but formed a PPI group drawing on expertise and skills beyond the study areas; we worked with six people with lived experience of severe mental illness over the course of the study. This group was vital within the project contributing in the following key ways:

- We recruited one service user in London to support the team in understanding the local geography, mental health landscape and her journey of recovery through a walking tour of the local area. This was really helpful for the researcher who joined the study team from Ireland, knowing nothing of London. The research interviews asked people about the places they went, the people they knew and the activities that supported their wellbeing; having a ‘heads up’ on key places helped ground the interviews in local mental health knowledge
- We had a service user volunteer join the team. They piloted the network mapping interview

schedules and provided lived experience feedback on all the practitioner interviews following a structured feedback proforma to help us interpret these data

- We recruited service user researchers to work on a sessional basis to help with two study modules: in-depth interviews and practitioner telephone interviews. The PPI group helped design and refine interview schedules, assessed interview transcripts and were involved in the analysis process. The in-depth interview module followed Kip Jones reflexive team principles (Jones, 2004). The practitioner module employed a service user researcher to collect the interview data, applying lived experience insights at the data coding stage. Within both these modules the PPI group impacted on our approach to collecting and analysing the data

- The final phase of the PPI group involvement in the study was the most intensive and challenging. We had one synthesis meeting with study advisors and the PPI group to assess the study data. However, this did not sufficiently enable PPI expertise to reflect and discuss the study findings using personal experience as a reflexive lens. We wanted a more comprehensive way of involving the PPI group in the synthesis process and thus we commissioned an independent service user researcher, with no knowledge of the study, to facilitate a reflexive and interpretative reading of the study data. Over a two month period the PPI group used their own recovery journey of living with severe mental illness as a “way in” to viewing the community health networks data sets, and wrote a full report of their insights. This was then used as a formative part of the full study synthesis and had a discernible impact on the conclusions and further recommendations of the study. The independent service user researcher and one of the sessional service user researchers provided critical review of the final report, responded to reviewer comments and participated in the final drafting of the study.



Part of our learning journey has been that it is important to be transparent about what the group can and cannot influence, what the role of PPI is within the study and why.



What we learnt

Our PPI team took time to establish and this was viewed negatively by some members who, coming later to the study, felt they could not shape the study sufficiently as it already had an agreed methodology and REC approval. In an ideal world, it would have been better to have consistency between membership of the PPI team pre and post funding. Part of our learning journey has been that it is important to be transparent about what the group can and cannot influence, what the role of PPI is within the study and why, for example user-control, collaboration or consultation to use a frequently cited framework (MHRN, 2004) and how decisions are taken by the study team.

PPI group membership may change over time with individual member's other work commitments hindering regular participation, periods of illness impacting on engagement and the welfare benefits system acting as another barrier. We paid all PPI group members an hourly rate for working on the

study. Developing contractual agreements with individuals, including a Wellness Recovery Action Plan (WRAP), is best practice; we are putting these in place for future studies.

We have also learned that Lived Experience expertise makes a difference. In the in-depth interview analysis process, one of the substantial themes we explored came from the service user researcher's reading and re-reading of transcripts, identifying aspects of the interview none of the other team members had identified. In the interpretation of findings, the PPI group also identified strengths and limits of the analysis that were not immediately obvious to the research team and added to the quality of the final synthesis. Employing an independent service user researcher with no personal knowledge or investment in the study to facilitate the interpretation introduced another layer of reflexivity into final synthesis and optimised the critical independence of the PPI report which also helped to enhance its usefulness to the study team.

Reflections from Julie

My role was to carry out the practitioner interviews. I was also part of the PPI team, working with five other people to provide feedback from a lived experience perspective. Contributing to the PPI work made me think about my own experiences of mental health services and helped me realise that my own treatment could have been a lot better. Having experience of mental illness also gave me personal understanding of some of the topics practitioners talked about and, at times, gave me a better understanding of their point of view.

For future studies, I think it would be helpful for PPI members to keep a record of their involvement: details of what they did, experiences of being involved, what they found helpful and unhelpful.

Reflections from Ruth

Facilitating the PPI reflexive report was both a challenging and exciting task. I had already developed a critical friendship model of PPI on other studies and in the development of LEAF (Lived Experience Advisory Forum) at Sussex Partnership Foundation

NHS Trust since 2009 (Slade et al 2010). However, all my previous experience has been with service users I had already met and with studies I was already familiar with. Coming into this study was a leap in the dark on both counts and at a period of considerable time pressure for the research team. These unknowns were a strength because they enabled active listening to occur without any filtering through of the hopes and expectations of the study team. They also made us focus on the emotional safety of lived experience experts which is an area often missed for vulnerable adults who are not research participants. The biggest challenge was the sheer volume of data to interpret and reflections from the PPI group to condense into a short report. This was a very stretching task to do in two months and I would not have been able to complete it without having built active involvement of the PPI group within the editing process. I would definitely recommend a slower pace next time.



... unknowns were a strength because they enabled active listening to occur without any filtering through of the hopes and expectations of the study team. They also made us focus on the emotional safety of lived experience experts which is an area often missed for vulnerable adults who are not research participants.



Collaborating on this project has been one of the most meaningful PPI activities I have ever undertaken. It is inevitable in research teams that there are power relationships between different kinds of expertise. This can and has historically resulted in tokenistic approaches to PPI from researchers that struggle to see the added value of coproduction with Lived Experience Experts. There was nothing tokenistic about the PPI in this process which enabled the range of voices in the PPI group to collectively shape the meaning and conclusions of the final study report.

Reflections from Vanessa

I knew from the beginning of the study our PPI programme was not going to be as comprehensive as in other studies I was involved with but I wanted to ensure the elements we introduced were significant. There is no point having advisory groups if you do not take on board their views; there is no point creating a PPI team if the research group are not open and responsive to challenge. Our study collected mountains of information, and inviting the PPI team to explore the data sets and tell us what they thought it all meant was a central part of our synthesis process. We asked what they felt the study had found, what it meant in practice and what might be missing. Meeting the PPI team to receive their report summarising the findings, and hear their feedback on the process was a significant afternoon. I would definitely repeat this reflexive process to aid study synthesis but provide more time for the entire process.

What next?

The team are keen to learn lessons from this study and contribute to research literature on PPI critical experiences and insights. We are particularly interested in looking at moving PPI beyond doing it because it is moral and ethical (Staley et al 2013), though this is important, but because of broader impacts that can improve the quality of health research. Critical approaches to the ethics and impact of service user involvement are only beginning to be understood. We hope our case study will contribute to this on-going debate.

This study was led by Dr Pinfold from the McPin Foundation which is a mental health research charity that is focused on ensuring lived experience is at the heart of all research activities; visit www.mcpin.org for more details including work with peer researchers.

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Case Study 7:

A qualitative study investigating the psychosocial impact of urinary incontinence on people with vascular conditions (PHIEBI)

Ryan Combs

About the study

The PHIEBI study is a qualitative investigation of the emotional and social impact of having a urinary continence problem on people with vascular conditions, identifying barriers to accessing health care services, and exploring the potential for self-management strategies to ameliorate psychological distress. Interviews with up to 30 patients with continence /vascular disease living in Greater Manchester are currently being conducted. Patients have been recruited through continence clinics and the distribution of flyers in places like chemists, community centres, and libraries. PHIEBI is funded by the NIHR CLAHRC for Greater Manchester Research Capability Funding for a period of nine months. Our aim is that the work will lead to further research and the development of appropriate self-management interventions.

How service users have been involved in the research

The PHIEBI study's focus on the emotional and social effect of continence problems was inspired by the personal experiences of a lay member of PRIMER, a PPI group working in partnership with the Centre for Primary Care at the University of Manchester (www.population-health.manchester.ac.uk/primer/). This is the second patient-led project in the Centre for Primary Care, which has developed expertise of managing patient-led projects. Participants were recruited to the PHIEBI PPI group through PRIMER, a continence clinic, and word of mouth. Our PPI group is comprised of three patients. The group is chaired by a lay member and has met regularly throughout the study. Advisory group members have been involved in all aspects of the research, from its inception through to the data collection and analysis. Here are some examples of their contribution:

- A group member inspired the study, is a member of the research team and takes part in all study management meetings
- The group comments on all documentation such as the study's flyers, information sheets, and interview schedule
- One PPI member participated in a pilot interview to test out and help us improve the topic guide
- The group contributes ideas and strategies around improving recruitment

- The group sheds light on our data analysis themes by reflecting on and sharing their personal experience
- Group members have written about their experiences of being involved in the study for the study blog.

The impact of public involvement on the research

Patients are at the heart of the PHIEBI study. Public involvement has been integral and has influenced the research in several ways. Broadly, interacting with the PPI group has allowed the research team to maintain close links with continence patients and other stakeholders. Group members come from a variety of backgrounds and have brought diverse expertise to the table. PPI members have been very open to sharing their experiences and providing us with an independent point of view. As one group member put it, “two heads are better than one.” Specifically, the group has made a substantial contribution to determining the focus of the research, the language used in our study materials, and the way that researchers conduct the interviews. To help improve the information leaflet and poster, the group suggested that we should make changes to reflect preferred usage (e.g. “continence problem” as opposed to “incontinence”), as well as change the title and document layout to improve its readability.



A key point to take away in terms of the PHIEBI study is that everyone who is eligible to take part should be told about the research.



To help the researchers prepare for interviewing patients, a group member participated in a pilot interview. This helped the interviewers to improve their technique, ensuring that the questions were appropriate and succinct and, importantly, helped the researchers to become more confident discussing continence issues. To help the research team better understand the challenges faced in recruitment and to assist us in interpreting the data, the group talked through the issues faced by patients and made suggestions about other places we could go to reach participants. Finally, a PPI member took part in the analysis and the preliminary analysis was presented to the PPI group, followed by a discussion.

The impact of public involvement on research quality

PHIEBI was patient initiated. When a patient brought the idea for the PHIEBI study to the Centre for Primary Care, this ‘hidden’ issue was put on the radar of researchers, who put in a bid for funding. The work may not have been done were it not for this impetus. PPI has given researchers access to perspectives that may have otherwise remained silent. Members of the PPI group point to our openness to patients’ ideas as a key asset that has improved the quality of the research. The patient voice has also helped us keep the study’s momentum going by ensuring that we focus on the key issues according to those who have experienced them.

Personal reflections on public involvement and research quality

PPI advisory group members recommended that researchers and clinicians keep an open mind about who may want to participate in research. At times, well-intentioned researchers and clinicians can be paternalistic to patients, assuming that they will not want to take part in a study or that they will not feel able to be open with their views. However, PHIEBI PPI group members say that patients can feel empowered by having their voice heard, especially in a study like this because you can choose what information you share with a researcher. The key point to take away in terms of the study is that everyone who is eligible to take part should be told about the research.

Problems encountered

The PPI advisory group was smaller than we would have liked. One group member said that the condition can be embarrassing, so it might be hard to speak about continence and less likely that patients will want to take up a PPI role. She also said that the requirements of taking part may have seemed like a lot on paper, but the reality of participating has been much easier.

Recruitment to the study has been very slow and PPI members would like to have seen more people come forward to participate and more people from different backgrounds. This has been a source of frustration and disappointment for members of the group, especially in light of the personal importance of the study. One group member said that she has given a lot of herself to the study, and if the study gets sufficient participation and valid results, it would feel very worthwhile to have been involved. While PPI participants' passion for the topic is positive, it constitutes a risk; patients involved need to be prepared for the potential frustrations of research.

Group members said that although it is a small study, participants' narratives have value. Members of the group said that "it is up to the individual if they want to take part [in research]" but "nothing will ever change if you don't speak out." Another drawback was the short length of the study. Gaining ethics and research governance approvals took up a significant part of the time. PPI members said that if the study had had more time, we may have had access to a wider range of results. This is a danger for patient led research; our current lack of knowledge in these areas may mean that the projects tend to be smaller and of limited impact.

How problems were overcome

On the positive side, the PPI group members said that their experience of taking part in the PPI group was enjoyable, comfortable, easy, and worthwhile. There was flexibility around attendance and the recognition that members of the public have health conditions too. Meetings were held in an accessible

location and were not too long (two hours). The meetings are also not too formal and the organisers used accessible language throughout. Expenses were paid on the day, allowing people to attend. Participants trusted that they could share their views confidentially and that their thoughts and ideas were valued. One participant said "I feel like my contribution has been valued and that I am valued as a person. Doing something to help someone else can make PPI participation worthwhile - if the results can get there and make someone else's life better, it makes participation worth it."

For further information the PHIEBI study has a blog (phiebi.wordpress.com) that reflects on and shares our learning around PPI and engages with the public. The blog contains contributions by both the research team and members of the PPI advisory group.

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Case Study 8:

Developing a new intervention for patients with severe Chronic Fatigue Syndrome/Myalgic Encephalopathy; a collaborative approach based on patient and public involvement

Clare McDermott and Sarah Frossell

About the study

Chronic Fatigue Syndrome/Myalgic Encephalopathy (CFS/ME) is an illness in which individuals experience debilitating mental and physical fatigue, as well as pain and other symptoms. CFS/ME is estimated to affect up to 250,000 people in the UK. The Dorset Bespoke Project for CFS/ME is a Patient and Public Involvement collaboration based in Dorset and Hampshire.

The idea for the project came from previous qualitative work interviewing patients with experience of recovery from CFS/ME. The findings of this study raised the question; “Could the experiences of patients who had recovered or substantially improved from CFS/ME be used as a resource to help current CFS/ME patients?”

The development group brought together:

- individuals with experience of the recovery journey from CFS/ME (‘peer specialists’)
- current patients with CFS/ME
- carers
- specialist doctors and occupational therapists
- medical researchers

The group met in a series of six half day workshops over five months with the goal of understanding and modelling the key elements of the recovery journey from CFS/ME, drawing on the lived experience of patients.

Each session was co-facilitated by Sarah Frossell, a master trainer in Neuro-Linguistic Programming (NLP). Our reason for choosing NLP as the facilitatory approach was based on two reasons:

- NLP focuses on learning new insights through exploring or ‘modelling’ the real life experiences of individuals who have successfully achieved a particular outcome. In this project, we wanted to ‘model’ the experiences of patients who had recovered from CFS/ME in order to learn from their insights.

- NLP looks at the ways that language and communication differs between individuals. We were keen to understand more about how patients themselves communicated ideas around recovery strategies and how this might be important to health professionals when they choose what language to use when working with patients.

The development process was documented by the researcher, Clare McDermott. In addition, many group members captured their own thoughts and ideas on the group process and/or their own recovery journey through a variety of means, including journals, mind maps and diagrammatic models, as well as creative art. These contributions were shared and discussed during group sessions, and were a much valued aspect of the development process.

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The lead consultant and the head occupational therapist from the local NHS specialist CFS/ME service visited to hear from the development group about their experiences and to discuss the ideas that were emerging. Following these sessions, members of the development group and the Dorset CFS/ME service agreed to collaborate to plan research.

A local charity, the Dorset ME Support Group, has played a pivotal role in supporting both research and clinical practice at the Dorset CFS/ME Service over the past 14 years. The charity kindly agreed to provide funding and other support to progress the project further.

With the support of the Dorset ME Support group we held further patient groups, which we titled 'Rebuilding Your Life', based on the original PPI development group. We have now held 5 groups over three years in Dorset and Hampshire, with insights from each successive group used to inform and enhance the work of the next, based on the Action Research concept of 'learning cycles'. These groups have now involved over 40 individuals

with experience of CFS/ME as well as carers. Peer specialists play a central role these groups, contributing first-hand accounts and insights on using recovery skills in practice. Recent groups have been co-facilitated by Sarah Frossell and our lead peer specialist.

We have also completed a research study using an action research approach. In this study the Occupational Therapy Team of the Dorset CFS/ME Service took part in training led by Sarah Frossell based on the PPI development work. The study incorporated qualitative interviews and a focus group with the Occupational Therapy team to reflect on how the training had impacted on their clinical practice.

Severe Chronic Fatigue Syndrome/ME

In its most severe presentation, CFS/ME can lead to individuals becoming housebound, wheelchair or bedbound. Patients with severe CFS/ME are generally unable to attend outpatient appointments and may have severe cognitive difficulties which can affect communications including reading, using a computer, talking face-to-face or by phone. These restrictions can



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present a serious challenge to patients and clinicians in finding ways to improve health and quality of life. Whilst significant progress has been made in researching and treating mild-moderate CFS/ME, successive national reports on CFS/ME have highlighted a serious gap in research evidence and clinical provision for severe CFS/ME.

An unexpected finding from the early development work was that several patients severely affected by CFS/ME asked to be linked into the 'Rebuilding Your Life groups' and subsequently were able to make marked shifts in improving symptoms and gradually resuming activities.

We wished to find out whether this new approach to helping patients with severe CFS/ME might be feasible to deliver within an NHS setting, and whether it would be acceptable and beneficial to patients. In order to investigate this further, we designed 'A feasibility study for a community based intervention for severe CFS/ME'.

The intervention for this study is based on the PPI development work from the bespoke project. Peer specialists, current patients and carers have played a central role in all aspects of the study design.

The PPI development work for the intervention was presented in March 2013 to the All Party Parliamentary Group on ME at Westminster by Clare McDermott, Sarah Frossell and the Chairman of the Dorset ME Support Group, Tim Stirgess. It was also presented by Clare McDermott on local radio (Abbey104) in May 2013 as part of 'ME Awareness Week'.

The feasibility study has received ethical approval and is currently recruiting patients in Dorset and Oxford. Results are expected in 2016.

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The mixed methods design for this study follows the Medical Research Council guidelines on evaluating complex interventions. It has been peer reviewed and approved by the NIHR School of Primary Care Research. This research is supported and supervised by the Department of Primary Care and Population Sciences, University of Southampton and is being conducted as an NIHR funded PhD by Clare McDermott.

Case Study 9:

Understanding the cost and consequences of patient and public involvement in primary care research

Clare Jinks, Steven Blackburn, Antony Chuter, Paramjit Gill, May Griffiths, Adele Higginbottom, Sue Jowett, Phil Kinghorn, Sarah McLachlan, Carol Rhodes, Fiona Stevenson and Sabi Redwood.

About the study

This is a two year project funded by National Institute for Health Research (NIHR) School for Primary Care Research (SPCR). The SPCR is a partnership between eight leading academic centres for primary care research in England. The School's main aim is to increase the evidence base for primary care practice through high quality research and strategic leadership.

patients and researchers. Patients talked about the need to highlight the hidden costs of involvement, and how things that are taken for granted by researchers (e.g. train travel, talking in a meeting) often have costs and consequences for the patients. A gap in knowledge about the financial and economic aspects of PPI was highlighted.

A writing team was organised (lead by Clare Jinks working at the Arthritis Research UK Primary Care Centre at Keele University) and a grant proposal was collaboratively written. Four patients who had attended the workshop reviewed the proposal and advised on the lay summary for the proposal. In addition an independent lay advisor agreed to be part of the team, and two patients from the workshop wanted to be co-applicants.

Pre-protocol work and prioritising topics for research

Researchers with an interest in PPI from the School's member departments were invited to a workshop in February 2011, together with patients, to discuss ideas they all had for research. The workshop was funded by the NIHR SPCR. All 8 members of the school were invited to the workshop, and 6 departments participated. Nearly half of participants at the workshop were patients. Ideas for research were circulated in advance of the meeting. On the day the group discussed each idea and prioritised a project to investigate the meaning, cost and consequences of patient involvement in research as this brought together overlapping suggestions from

The grant application was submitted to the SPCR in funding round four. The project was approved and commenced in November 2012.

The project

The overall aim of the project is to find out what PPI activity is taking place within the School for Primary Care Research and what the costs and effects of that activity are. By costs we mean the financial costs (for example, payment for time attending meetings and reviewing documents and travel expenses). By effects we mean non-financial costs or other things (good or bad) that might happen because of involvement.

There are three ways in which we are collecting data for the project:

- Questionnaires. We are sending a questionnaire to all researchers who have received funding by the School for Primary Care research to ask about PPI in their projects. We are asking the researchers to pass on questionnaires to patients that they have worked with on their projects
- Watching and listening to what happens in meetings where researchers and patients are discussing research
- Looking in documents to find out what is written about PPI (for example, minutes of meetings, grant applications and project reports).

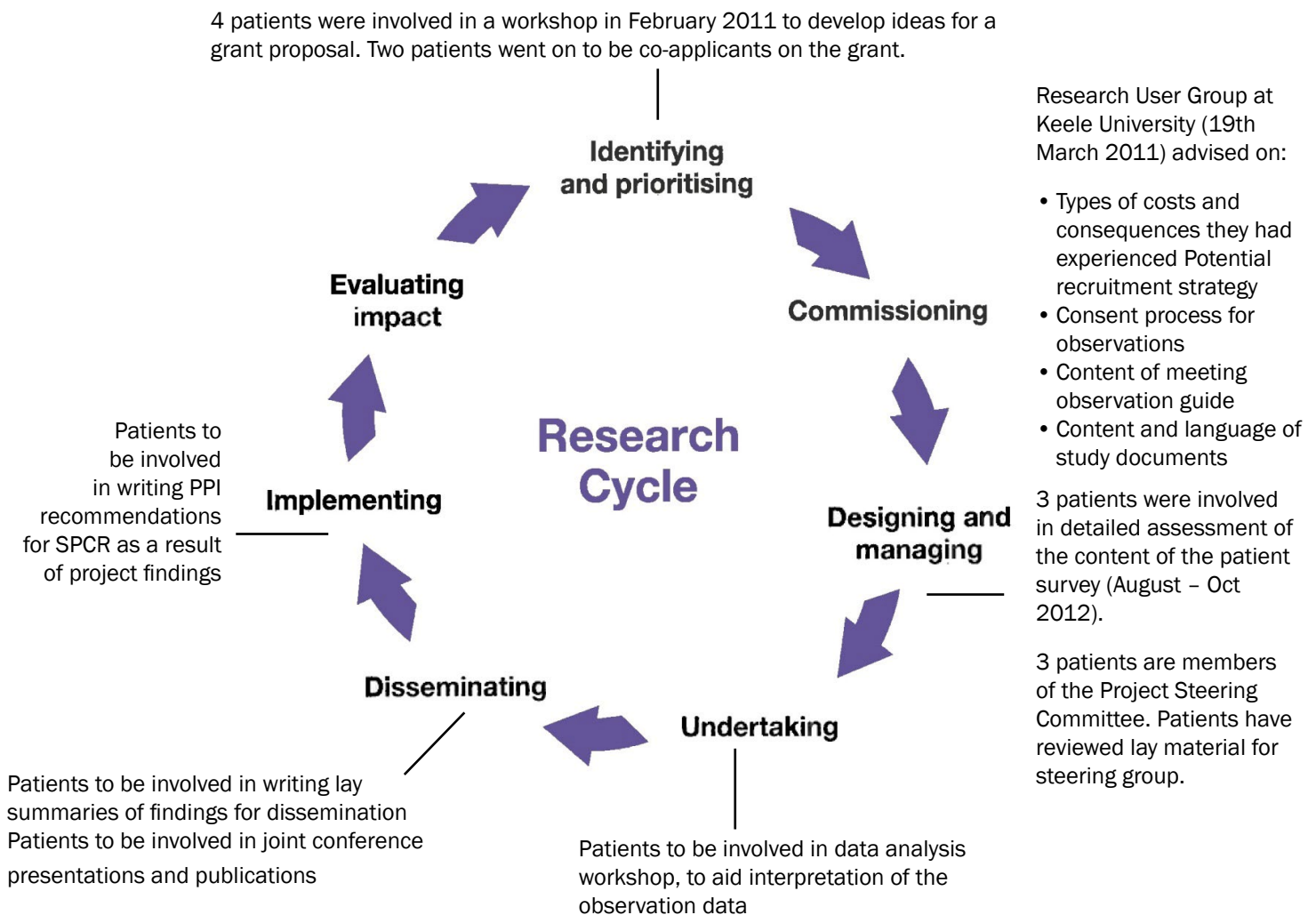
The information we get from the project will then be fed into a sub study which will look at how people

make decisions about the amount they can or are “willing to pay” for either having PPI in their projects or volunteering to be a PPI advisor.

By undertaking this project we will be able to provide a breakdown of what PPI activity is happening and what the costs and effects of this are for patients and researchers. We will also be able to make recommendations to the School for Primary Care Research about PPI in their projects in the future.

PPI in the project

A diagram of patient involvement in the study is below. This shows how patients have been involved in identifying the topic for research, helping to undertake and manage the research, and how they will also be involved in the future.



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Case Study 10:

Primary Care Research PPI – an example

Abi Eccles

About the study

This doctoral research explores the information and decision support needs of people with Multiple Sclerosis (MS). Decision making in MS is characterised by uncertainty due to the condition being highly complex and personalised with largely inconclusive research evidence into prognosis, pathogenic mechanisms and effective treatments. The purpose of this research is to explore the decision making experiences and information use of people with MS, identify changing needs and the ways in which clinicians can provide support.

After attending an INVOLVE workshop at the NIHR School for Primary Care Research trainee days in September 2012 I was inspired to incorporate PPI into my research. With the support of my supervisors I developed a plan to recruit 6 members of the public with long term conditions to a PPI group which would provide valuable input for my doctoral research at various stages. Using guidance from the INVOLVE website I put together a role description outlining planned activities, expectations and desired attributes members would possess. This role description was distributed to interested members of public before they decided to take part.

The novel element of this PPI group is that it exists online. A secure website hosts information about the research and activities available to volunteer for. Members can also ask questions via the secure website or contact the researcher at any time (via email or phone). The online element allows flexibility for PPI members and minimises research costs: activities can be carried out as and when it's convenient, the admin and costs of organising meetings are avoided and involvement is more accessible for those who have disabilities or other responsibilities which may make attending face-to-face meetings difficult.



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Members receive notification of each new PPI activity via e-mail and are given instructions on how to access material, complete tasks and submit completed activities online (or in some cases via post). Members are invited to devote half a day (three and a half hours) to each activity and in return are reimbursed £75 for their time. PPI activities to date have included: providing feedback on research design; amending recruitment literature, participant information and consent forms; carrying out qualitative analysis on an excerpt of interview data (to act as an audit against the researcher's analysis); and identifying which outcomes should be considered most important in a systematic review. Future tasks may include: editing lay summaries; aiding in focus groups; reflecting on experiences of PPI; and help with public engagement activities.

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Case Study 11:

Patient, Carer and Public Perspectives during Study Recruitment and Delivery Phase

Tracey Johns

Once a study is included on the National Institute for Health Research Clinical Research Network (NIHR CRN) Portfolio, and is able to access support from the Clinical Research Network, we actively look for opportunities to continue the involvement of patients, carers and the public. We know that it makes sense to maintain the positive relationships which research teams have built with patients and carers during the design and development of studies and we aim to work collaboratively with our wider NIHR and academic partners.

There are two aspects of our study delivery service where patients, carers and the public can play an important role. Firstly, when a new study is included onto the national portfolio, the network has to undertake a number of checks to make sure that we have the capacity and capability to support the study and also to make sure that it is feasible, or doable, in the real world of the NHS. A patient perspective, along with those of health professionals, clinicians and network staff can really add some value at this point. Patients are able to provide an opinion about whether they think people would want to take part and also to highlight any potential barriers to recruitment which may put people off taking part. Often the issues highlighted can be practical and addressed quite easily. When patients do not like the sound of a study, or understand the information about a study, this could indicate that the study may be difficult to recruit to. We aim to ensure a positive patient experience by anticipating the opportunities and challenges that might impact upon the success of the study and hearing suggestions from patients about how they think the study may be improved.

Secondly, patient insight can help to anticipate and solve problems in recruitment and performance of studies which are struggling to meet their anticipated targets. By involving patients and carers in discussions about study delivery, they can help to improve recruitment strategies, patient facing information and communications. Delivering research on time and on target is essential to make sure that important research questions get answered in a cost effective way and the findings can be used to improve healthcare.



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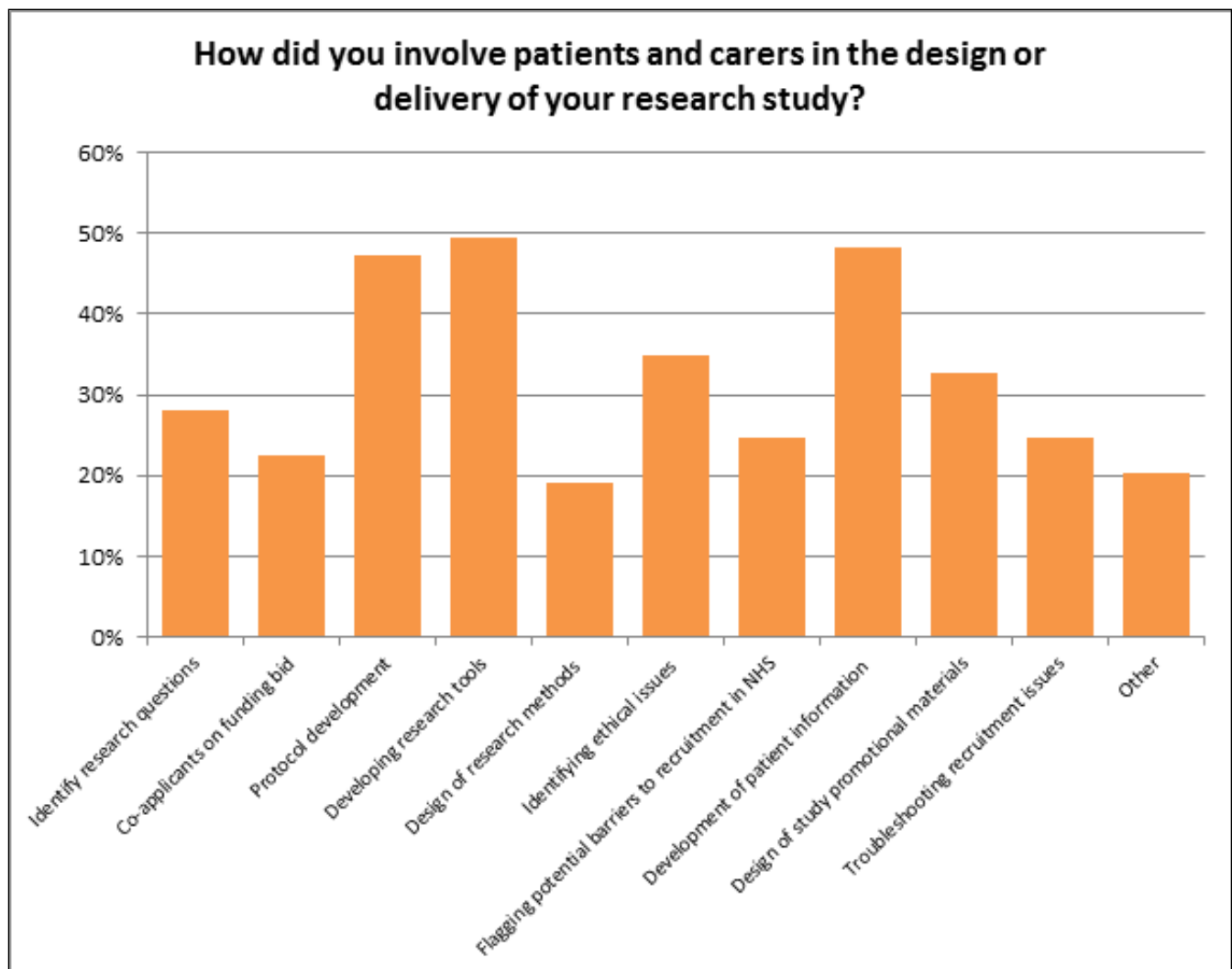


Within the Clinical Research Network: Primary care we have a small national panel of trained lay members who are willing and ready to provide input when required. This panel was originally established as part of a pilot with industry sponsored studies. As part of the pilot the lay members were provided with training, an induction programme and mentoring to support them in fulfilling the role. We learned some important lessons from this which have helped us develop our approach for patient involvement in primary care research delivery, including the need to provide a handbook of tools and training materials. As lay reviewers, people may be involved in taking part in teleconferences with network staff and research teams or providing a written review of study documentation. Increasingly this input is being

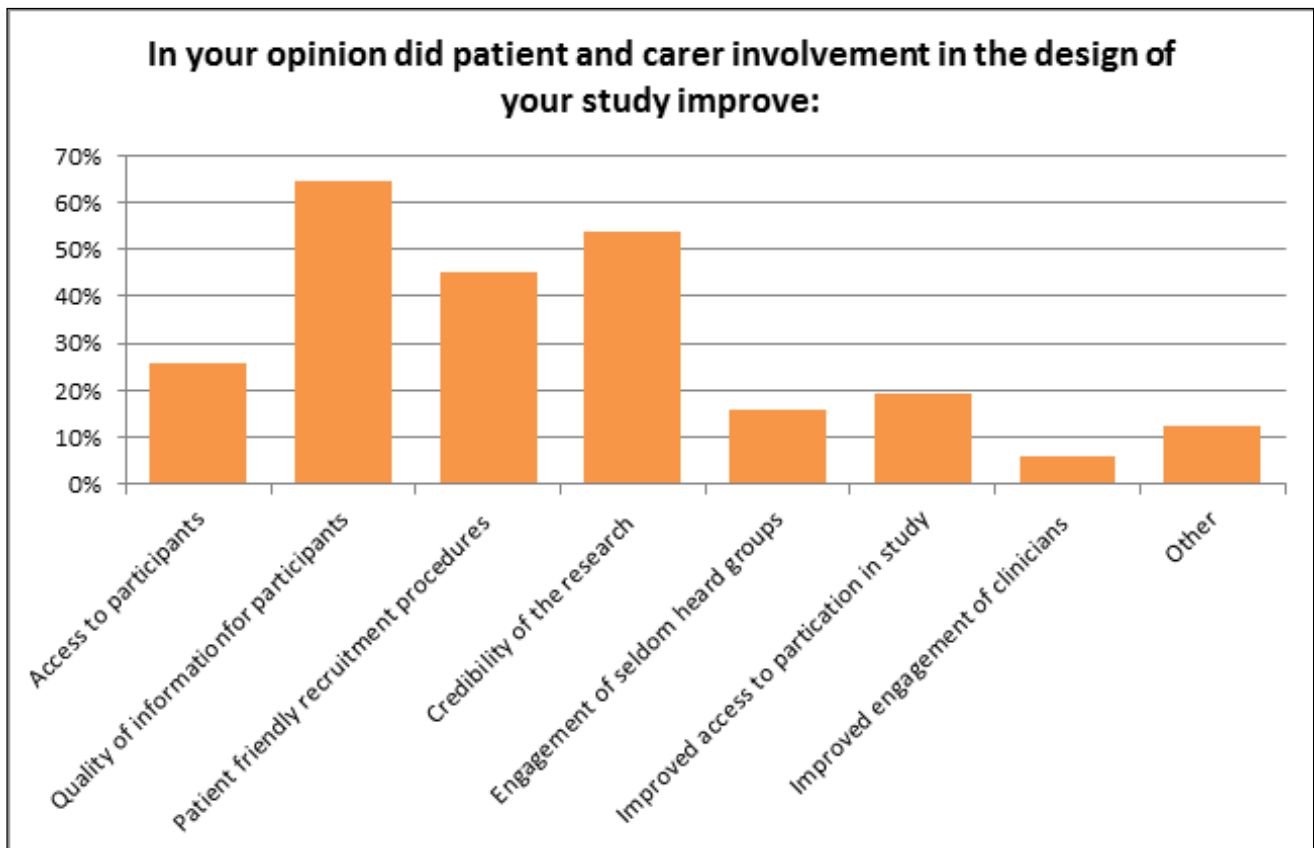
facilitated at a local level and there is a growing network of people with lived experience and interest in particular clinical conditions and types of research who are keen to be involved in this way.

We have received positive responses from study teams who have found this input to be insightful and useful:

“Thanks so much for this – it’s great that reviewer gave such a detailed response and that the others had some positive comments.... I might see if we have time to make some changes though.I very much like the changes to the letter and think we will go with the modified version.I think sending our information sheet out for review would be a good idea at some stage...” (ELONS)



The evaluation results provide evidence of good practice being followed by primary care researchers with regard to ensuring studies are co-designed and developed with patients.



As expected there is recognition of the difference a patient perspective can make to improving the quality of patient information and in ensuring that recruitment methods are appropriate and sensitive to the needs of patients. It is also interesting that researchers valued the potential impact that patient involvement may have in terms of improving the credibility of the research and the research teams with over 50% responding positively to this question.

Once a study closes research teams are invited to complete an online evaluation to provide feedback about the service they have experienced from the network. Included in this survey are questions about patient, carer and public involvement at various stages of the study lifecycle. Below are the responses from 88 responses received from closed studies during the last year (1 May 2013–21 May 2014).

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acronyms



CLAHRC - Collaboration for Leadership in Applied Health Research and Care

INVOLVE - is a national advisory body funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

LEAP - Lived Experiences Advisory Panel

PRIMER - Primary Care Research in Manchester Engagement Resource

RCGP - Royal College of General Practitioners

Rethink Mental Illness - An organisation that provides expert, accredited advice and information to everyone affected by mental health problems.

NIHR PRIMER - Primary Care Research in Manchester Engagement Resource

Acknowledgement:

We would like to thank PRIMER members Maggie Derry, Manoj Mistry and Ailsa Donnelly for their lay review of this publication. We were reminded of the importance of working collaboratively with PPI partners to ensure that this document could be read by a wide audience. Their insights were invaluable in this respect.

PRIMER is a PPI group based at the Centre for Primary Care at the University of Manchester and supported by the NIHR School for Primary Care Research. The group consists of 20 members from various backgrounds with a common aim to support PPI in primary care research. The ethos of the group, now in its 5th year, has always been to share expertise and resources so do visit our website for information and updates: <http://www.population-health.manchester.ac.uk/primer/>

A good idea is a good idea regardless of who it comes from, be it a researcher, healthcare professional, or a user of primary care services. Seeking a variety of perspectives and views on the research we do will help to ensure that research is relevant to users of primary care and is of the highest quality. We all have different talents, skills and experiences and PPI work encourages us to value different types of expertise. We hope this publication encourages you to dip your toes into the world of PPI. It's an exciting place to be!

contributing organisations

INVOLVE

INVOLVE is funded by, and part of, the National Institute for Health Research to support public involvement in NHS, public health and social care research. INVOLVE has a keen interest in developing an evidence base for public involvement in research. These examples of public involvement in primary care research will contribute to building our understanding, knowledge and learning.

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National Association of Patient Participation

N.A.P.P. is the leading national, patient-led organisation working with Patient Participation Groups, the NHS and other key stakeholders to place the patient at the centre of the primary health and social care agenda through active participation at the grass roots of general practice and the local community.

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NIHR Clinical Research Network Primary care (NIHR CRN Primary care)

The primary care specialty is one of 30 specialties which bring together communities of clinical practice to provide national networks of research expertise. Our membership is made up of research-interested clinicians and practitioners at both national and local levels. Our job is to ensure that the primary care studies that are included in our national portfolio of research receive the right support to ensure they are delivered successfully in the NHS.

Working with a wide range of primary care practitioners such as GPs, practice nurses, pharmacists and dentists, we support and oversee research in areas which primary care practitioners have particular responsibility. This includes health promotion, disease prevention, screening and early diagnosis, as well as the management of common and long-term conditions.

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NIHR Clinical Research Network: Thames Valley and South Midlands (NIHR CRN)

The Clinical Research Network: Thames Valley and South Midlands supports the delivery of clinical research in primary and secondary care, across a range of disease areas. Our aim is to produce better treatments, services and care for people with health conditions, through research. Working with patients and members of the public is central to what we do. The Network is Hosted by Oxford University Hospitals NHS Trust and covers Berkshire, Buckinghamshire, Milton Keynes and Oxfordshire.

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NIHR Research Design Services (NIHR RDS)

The NIHR Research Design Service (RDS) supports researchers to develop and design high quality research proposals for submission to NIHR and other national, peer-reviewed funding competitions for applied health or social care research.

The Research Design Service provides expert advice to researchers on all aspects of preparing grant applications for applied research in health and social care, including statistics, quantitative and qualitative research techniques, clinical trials, evidence synthesis, health economics, epidemiology, public and patient involvement, ethics and governance.

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NIHR School for Primary Care Research (NIHR SPCR)

The NIHR School for Primary Care Research is a collaboration between eight universities across England. The School aims to increase the evidence base for primary care practice through high quality research and strategic leadership.

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PRIMER

PRIMER stands for Primary Care Research in Manchester Engagement Resource. PRIMER's aims are to work with researchers to advise on best practice in PPI, to contribute to project development and management, to act as a resource for researchers in Manchester and across the NIHR SPCR, and to provide input into research at an early stage and suggest areas of work for future research.

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Society for Academic Primary Care (SAPC)

Practitioners, researchers and teachers committed to academic primary care through education and research. Our work takes a critical look at how primary care works - what it does well, and what could be done differently. Our goal is to support our members by providing opportunities for the critical, creative, shared conversations which help academic primary care make a difference.

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**Patient and Public
Involvement**

**Case Studies for
Primary Care Research**

www.spcr.nihr.ac.uk/PPI