



**National Institute for
Health Research**



**School for Primary
Care Research:
Public Involvement
Case Studies**



April 2018

This publication is a result of the collaboration between the School for Primary Care Research partners:

- University of Bristol, Centre for Academic Primary Care (CAPC)
- University of Cambridge, Cambridge Primary Care Unit (PCU)
- Keele University, Research Institute for Primary Care and Health Sciences
- University of Manchester, Centre for Primary Care
- Newcastle University, Institute of Health & Society
- University of Nottingham, School of Medicine, Division of Primary Care
- University of Oxford, Nuffield Department of Primary Care Health Sciences
- University of Southampton, Primary Care & Population Sciences Academic Units
- University College London, Research Department of Primary Care and Population Health (PCPH)

An independent public contributor, Mari James, helped edit the finished document.

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Contents

Forewords.....	4
Introduction.....	6
Involvement within the SPCR.....	6
Current and Completed Projects.....	7
Wessex Public Involvement Network (Wessex PIN).....	7
Database Study (Clinical Practice Research Datalink).....	7
Mixed Methods Interview Study and Priority Setting Partnership.....	10
Protocol development and testing.....	10
Co-producing patient and clinician resources.....	12
Evidence Synthesis of Clinical Study reports.....	13
Intervention development.....	14
Feasibility and Pilot study.....	15
Exploratory Research.....	16
Recently awarded projects.....	17
Systematic review and meta-analysis.....	17
Training.....	18
For Trainees.....	18
For New Starters.....	19
For Contributors.....	20
Encouraging Early Involvement.....	21
Panel and participation event.....	21
Workshops.....	21
Embedding Involvement.....	22
Primary Care Research in Manchester Engagement Resource (PRIMER).....	22
Research User Group.....	22

Forewords

Director

Richard Hobbs

Embedding public involvement in primary care research is key to designing and running good quality healthcare research. This can be included 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 collection of case studies from School researchers will further champion public involvement 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 involvement 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 our researchers and their contributors, who have not only highlighted conceptual and methodological positions, but have done so in an open and candid manner. These case studies illustrate the SPCR's commitment to public involvement in our research.

Patient and Public Involvement Officer

Emma Palmer-Cooper

The NIHR School for Primary Care Research set out a list of goals and objectives for a 2015-2020 plan to develop patient, public and carer involvement at a strategic and project level. This moved involvement away from tokenistic, 'box ticking' exercises, and towards high-quality, meaningful involvement of public, patient and carer contributors, and promotion of co-production across the lifecycle of research projects.

A key part of this plan was the review of current involvement practices across our nine partners, which demonstrated SPCR-funded researchers are conducting good quality involvement in most fields. It also highlighted barriers that all public involvement communities (involvement leads, contributors and researchers) perceive to hinder quality involvement activities, and where there is room for improvement.

Along with a number of ideas for future development, this review has provided examples of high-quality involvement plans across the breadth of research, from systematic reviews to database studies, to mixed methods studies. It also demonstrates the value placed on providing support for SPCR staff and trainees at all levels of project development. This document contains some of the best examples of research involvement and training from across the SPCR.

Academic Lead for Patient and Public Involvement - School for Primary Care Research

Peter Bower

The case for patient and public involvement is well recognised in primary care research, and the benefits are significant. However, it is important that we in the primary care research community do not rest on our laurels in this regard. We may have consensus on the importance of good patient and public involvement, but we still have much to learn: how best to engage with our patient and public contributors, how to deliver high quality involvement at all stages of the research process, and how to achieve this across the different types of research that underpin the delivery of high quality primary care.

This compendium of public involvement case studies is designed to showcase our progress in this area, and highlight good practice across our member departments. Most importantly, it can act as a stimulus to help us improve our involvement activities. Reflecting on what we have achieved so far can help us learn from our mistakes, maintain quality in our ongoing involvement, and encourage our staff and patient contributors to try fresh approaches and new ideas.

Public Editor

Mari James

The School would like to thank our Public Editor for her help in designing the structure, language and scope of this booklet. The changes made as a result of public input have made this publication clearer, and better demonstrated the SPCR's commitment to high-quality public involvement.

Introduction

Public involvement and engagement is a means of improving research and its dissemination, rather than an end in itself. The NIHR supports and encourages involvement and engagement in all the research that it funds, on the basis that this can lead to better research that is more focused on the needs of patients, public and carers (hereafter referred to as ‘the public’). Engagement of the public during the dissemination of research can accelerate the transfer of evidence into practice.

There are many different ways that the public can be involved in research and its dissemination as contributors and co-applicants. Most often this is in partnership with others (such as researchers, academics, clinicians, methodologists, statisticians, health economics and research managers) and includes:

- helping to select research that is important and relevant
- helping to design research projects
- helping to develop understandable information sheets for people taking part in research
- joining a research management or advisory group
- training to carry out some of the research (for example interviews)
- helping to interpret the results of the research
- helping to make sure the research is reported in understandable ways
- helping to make sure good research is heard about

Involvement within the SPCR

The School for Primary Care Research manages various research programmes, and applicants are encouraged to actively involve the public in identifying research questions and preparing applications. Applicants are also encouraged to actively involve patients in the research they propose. This is promoted through the use of a specific section of the funding application form dedicated to public involvement ‘SECTION F – Patient and Public INVOLVEMENT’.

The School also asks all personal award holders, and collaborative award PIs, to report on involvement and engagement activities in their research when submitting annual and final reports. This enables the School to monitor the level of public involvement in the research it funds, and also serves to establish expectations the NIHR has about public involvement in the research that it supports. A review of current and future planned public involvement activities within School funded research has been carried out using these reports.

The following document lays out examples of best practice public involvement and engagement in current and planned future research, in a range of research methodologies, as well as training, and schemes developed by the School to promote best practice for research involvement.

Current and Completed Projects

Wessex Public Involvement Network (Wessex PIN)

Jackie Seeley

- University of Southampton

Background

The Wessex PIN was established in March 2017, with the aim of improving collaboration and best practice in Patient and Public Involvement (PPI) across the National Institute for Health Research (NIHR) organisations in the Wessex region. Members include; The Wessex Institute (WI), Southampton Clinical Research Facility and Biomedical Research Centre (SCRF and BRC Southampton), Research Design Service South Central (RDS SC), School for Primary Care Research University of Southampton (SPCR UoS), Wessex Collaboration for leadership in Applied Health Research (CLAHRC), Southampton Clinical Trials Unit (CTU) and the Wessex Clinical Research Network (CRN). Wessex PIN meetings are held every two months chaired by Claire Ballinger (Strategic Lead) and Tina Coldham (Consultant Public Contributor and Chair of INVOLVE).

Cross-cutting work is carried out by these partners and is delivered through the following task and finish groups: Diversity and Inclusion, Growing Capacity, Communications, Exploring Impact and Learning and Development. Each member organisation participates in at least one of these task and finish groups information collected by each of the Wessex PIN organisations about their public contributors as well as input from a PPI panel of public contributors. The panel provided input about the phrasing and order of the questions as well as the appropriateness of the questions and answers. They also provided additional advice about disseminating the questionnaire amongst public contributors.

Each Wessex PIN organisation (excluding those within the Wessex Institute as these are National organisations and therefore not representative of the local community) circulated the diversity monitoring questionnaire amongst their public contributors. We received 120 responses to our anonymised questionnaire. The results were analysed and compared against an audit of the demographics of the local population.

The results showed that we are failing to involve enough men, young people who are in employment and some ethnic groups are not represented at all. In contrast, we have an over-representation of people aged 66 and over and on average our public representatives have achieved higher levels of education compared with the local population.

What would we do differently?

When we started to analyse the results of the questionnaire, we were surprised to see that we have a good representation of disabled people involved in our research. However, one of our public contributors who has worked for many years promoting equality for disabled people noted that we did not distinguish between people with a lifelong disability and those who developed an impairment and long term health conditions later in life. These two sub-groups might have very different experiences but based on how we asked this question we failed to collect this information. Also, as we have a greater representation of people aged 66 and over involved in our research it is possible that we are predominantly involving public contributors who have developed impairments later in life and not people with a lifelong disability. Because we failed to include a public contributor for disabled people until after the questionnaire was released the data which we collected around disabled people is of limited value. This highlights the importance of including people with the required expertise and relevant experience from the very beginning of a project. If we repeat the questionnaire in the

future we would review this question beforehand.

Next steps

The preliminary work completed so far by the group has helped us to identify the communities and groups of people currently underrepresented in our local PPI activities. We are currently liaising with a number of community organisations who are already working with some of these underrepresented groups. Working with these community leaders we are exploring how we can engage with these communities in a sustainable, long term and more meaningful way.

We aim to repeat the diversity monitoring questionnaire in 2 years time and hope that we have a more proportional representation of the community involved in our research at that stage. This would also help to monitor the success and impact of our community diversity strategy.

Benefits and Impact of collaborative working

One obvious outcome of this work is that we have been able to identify the groups and communities which we are not currently involving in our research. Armed with this information we are reviewing our methods of public involvement and engagement. We have started to work with community leaders and organisations who work with some of our underrepresented groups to ensure our future involvement opportunities are more meaningful and inclusive.

In terms of diversity, the group were keen to ensure a minimum baseline standard across all Wessex PIN organisations with reference to diversity. To achieve this, we arranged standard diversity training for all PIN members (both staff and public contributors) and we developed a minimum data collection form about public contributors for use by Wessex PIN organisations. As a result of our collaboration we have ensured a basic standard across the organisations but also

we have improved our working relationships, frequently reaching out to colleagues from other PIN organisations for support and expertise when needed.

Finally, as a result of our work to date we have established a 'diversity group' which includes both PPI staff and public contributors with a broad range of knowledge and expertise which will be a valuable asset to our ongoing diversity and inclusion programme of work.

Acknowledgement

A note of thanks to all of the Wessex PIN members for their continued support and hard work. A special thank you to Ranjita Aujla-Singh (intern working with Southampton CRF and BRC) who analysed the results of the questionnaire.

The diversity task and finish group includes: Giselle Atkinson (SCRF & BRC Public Contributor), Caroline Barker (SCRF & BRC Southampton PPI Officer), Aniqua Nishat (RDS SC Public Contributor), Megan Barlow-Pay (RDS SC PPI Officer), Hazel Patel (SPCR UoS Public Contributor), Jackie Seely (SPCR UoS PPI Officer), Tess McManus (NETSCC Public Contributor), Kate Sonpal (INVOLVE).

For a copy of the Diversity monitoring questionnaire please contact Jackie Seely j.seely@southampton.ac.uk

Database Study (Clinical Practice Research Datalink)

Dr Dahai Yu

- Keele University

Predicting individual risk of future hip and knee replacement for osteoarthritis

About the study

Our research plan reflects the interest expressed by the public in a James Lind Alliance (JLA) Priority Setting Partnership (PSP) about in [early hip and knee osteoarthritis](#), led by researchers in Oxford, and focuses on developing a tool to predict individual risk of future hip and knee replacement for osteoarthritis.

Initial Involvement

Two members of the Keele [Research User Group](#) (RUG), with personal experience of osteoarthritis, were sent a short summary of the proposal to review. They then met for a 2 hour face-to-face discussion with researchers, which focussed on the research question, potential benefits and unintended consequences of a risk prediction tool, as well as the importance of the context a prediction tool might be used.

Feedback from Patient contributors

Contributors were supportive of the proposal and agreed with the potential benefit to patients of this while highlighting that other factors beyond the scope of this project would have a major contribution. Potentially negative consequences could be eased by ensuring that messages to patients were appropriate.

There was not support for the future development of a patient self-completed prediction tool, instead preferring a tool to be used by primary care professionals such as practice nurses, with patients.

Contributors identified potential factors that might indicate a person's risk of future need for joint replacement (e.g. weight, injury) supporting the proposal to involve them in discussions about which risk factors to consider for inclusion.

Whilst the plain English summary was approved by RUG members, suggestions to remove all jargon from the project title were made, and taken up by the research team.

Ongoing contributions:

Contributors are now co-investigators in the project. The nature of this involvement was discussed with them and agreed that this would centre on the following activities:

- addition to, and selection from the list of possible risk factors to be included in the risk prediction tool;
- reviewing progress at 6 monthly project team meetings;
- interpreting the findings of the study;
- contributing to the design of appropriate dissemination materials and choice of channels.

Mixed Methods Interview Study and Priority Setting Partnership

Research team: Dr Emma Teasdale, Dr Miriam Santer, Dr Jo Chalmers, Dr Anna Lalonde
Contributors: Peter Smart, Julie Hooper
 - University of Southampton

Experience of cellulitis and views about causation and prevention: qualitative interview study and survey

About the study

Cellulitis is an acute, painful and potentially serious bacterial infection of the skin and underlying tissues, usually as a result of breaks in the skin allowing bacteria to get through. Many people with cellulitis go on to have recurrent episodes. There is a limited body of research on the diagnosis and treatment of the disease. Initial treatments aim to cure the infection; longer-term effects on infected limbs are less regularly followed up. This study was designed to explore the views of people who have had cellulitis, about what they believe caused it and what might prevent future episodes.

Our approach

Before exploring a trial of non-antibiotic prevention of cellulitis, the team explored patient and health professional views regarding current prevention practices and priorities regarding research on these, using a mixed methods study. The study ran in parallel with a James Lind Alliance (JLA) Priority Setting Partnership (PSP) about [Cellulitis](#). One question asked about the best *non-antibiotic* intervention for the prevention of cellulitis, and was ranked number 4 in the list.

The PSP was valuable not just in terms of highlighting research that is important to patients and healthcare professionals, but also in identifying a community who are interested in conducting and contributing to cellulitis research.

Patient and Public Involvement

This study planned to define current understandings of cellulitis, information needs and practicality of prevention practices by inviting cellulitis patients to complete a survey and/or take part in a face-to-face interview about their view and experiences. The study was then

jointly designed by researchers and patients with a history of cellulitis.

What we learnt

Patient input was useful in ensuring the survey and interview guide was acceptable and easy for participants to respond to (so people were more likely to complete it), for example by adding additional questions about experiences of diagnosis/treatment which was deemed to be very relevant to patients.

Who was involved?

Peter Smart was a member of both the JLA PSP steering group and the mixed methods study development group. He brought personal experience of multiple episodes of cellulitis, of intravenous and oral antibiotic treatments, and of non-antibiotic treatments to help prevent further episodes.

'[I] hope that I might be able to influence all relevant stages of the research process for the benefit of all sufferers... the questions that I have been asking for the past 20 years are the kind that have recently been identified by the JLA PSP as of priority for research activity.'

What next?

Results of Cellulitis JLA PSP have been published [online](#), in the [British Journal of Dermatology](#) and have been shared with the NIHR NETSCC. A number of research teams are interested in taking forward the 'Top 10' research priorities identified, which should lead to a larger evidence base for this under-researched condition.

The final development group meeting for the mixed-methods study will focus on patient input on key findings, interpretation of results and methods to disseminate findings. This will be helpful for health professionals to understand patients' experiences and understandings of this condition, future trial design, and to improve patient understanding of the condition.

Protocol development and testing

Dr Katerina Kassavou – University of Cambridge

Developing and pre-testing a tailored interactive voice response intervention to support adherence to anti-hypertensive medications

About the study

Many people with hypertension do not take their medication as prescribed. This reduces the effectiveness of their treatment and means that a lot of medicines are wasted. Nurses and doctors in primary care can support patients to take their medication as prescribed but have limited time. Automated interventions, such as Interactive Voice Response (IVR), is one way to support patients between their primary care consultations. Our meta-analysis found that IVR-based interventions can be effective to support adherence to different type of medications, but none of them has been developed and tested within the UK primary care. This study aimed to develop and pre-test a highly tailored IVR intervention within the Primary Care, and involved PPI/E in all processes of the intervention development and pre-test.

First Steps

The project team carried out face-to-face interviews with 20 patients and five nurses from local practices to explore the acceptability of IVR. Patients were enthusiastic about the idea, and nurses felt that it could provide useful support to patients between consultations and made helpful suggestions for intervention content.

Initial Intervention Development

Four PPI contributors provided email advice on the project lay summary and made recommendations for intervention acceptability and message content. Each contributor was followed up with a phone call by the researcher, who obtained views and recommendation on specific elements of the IVR delivery mode and content, such as frequency and timing of the calls, the duration of the intervention, and the messages.

Going Out to Patients

The research team spent a day at Adenbrooke's Hospital Outpatients, where PPI members were asked their view about the IVR intervention and invited to write intervention messages based on scenarios provided.

"Since we are developing an interactive voice response (IVR) system to help people with taking their medications as prescribed, we saw the value in having the patients and public's view on the intervention and the type of messages patients could receive" – Vikki Houghton, Researcher

Recruitment and Questionnaire Development

Two PPI contributors took part in 'think aloud' face-to-face interviews and provided feedback on the recruitment procedures and the development of the theory-based questionnaire. The data informed the decisions about the tailoring algorithm of the intervention.

Trialling the Intervention

Two PPI contributor trialled the IVR intervention for 28 days, during which they provided feedback at four telephone calls with the researcher. PPI contributors completed baseline and follow up questionnaire, and one of them provided further feedback during a follow-up face-to-face meeting. The data refined the intervention content and delivery mode, before piloting the intervention to primary care.

Science Festival

The team took part in a local Science Festival, where they explained the intervention to attendees, and their views and recommendations about the IVR delivery mode were sought, as was messages content. They were also asked to write their own messages, based on scenarios provided.

Co-producing patient and clinician resources

Dr John Bedson, Dr Steven Blackburn, Dr Jonathan Hill, Dr David White, Dr Ying Chen, Dr Simon Wathall, Stephen Dent, Kendra Cooke, Prof Danielle van der Windt
- Keele University

Development and testing of a pain monitoring smartphone application (Keele Pain Recorder) for patients with musculoskeletal conditions (STAMP feasibility study)

About this study

This project aimed to develop and test a smartphone application (Keele Pain Recorder*), designed to record patients' experiences of musculoskeletal pain daily, and determine if such an application was useful and easy to use for both patients and general practitioners. This is the first ever scientific evaluation of such a device that has been undertaken.

Why do we need the Keele Pain Recorder?

Assessing daily change in pain and related symptoms can help in diagnosis, predicting how well patients will fare, and monitoring their response to treatment. These changes are infrequently monitored, and changes are usually reviewed weeks or months after the start of treatment. Paper diaries are often not completed daily, and risk inaccuracy if completed retrospectively. An application that reminds patients to record their pain experience daily would overcome such problems, which we have developed based solely on the experiences and recommendations of patients with musculoskeletal pain.

RUG development of the Keele Pain Recorder

A workshop with nine members of Keele [RUG](#) was organised to get the views and opinions of people with experience of living with chronic musculoskeletal pain. During the workshop, attendees advised on appearance, functionality and content. A clinical advisory group of thirteen health care professionals and researchers was also convened, and a combination of their suggestions led to beta-version development. This was designed to examine a patient's daily pain level, pain interference with activity, mood,

medication use, sleep disturbance and possible side effects. An electronic diary stores this information, and also records other thoughts that patients wish to share with their GP. After a 4-week period of testing by RUG members, the final version was developed, and used in the main study to test its accuracy and usability (*shown to the right*).

Testing the Keele Pain Recorder

Over an 18-month period, in four general practices, patients aged over 18 with musculoskeletal pain and prescribed a new strong painkiller were recruited to use the Keele Pain Recorder twice daily, for 28 days to record changes in their experience of pain. The pain recorder was found to be accurate in terms of the pain levels and pain interference it recorded.

Following completion of the study, RUG members were involved in another meeting, where 2 members facilitated a workshop with app users from the study, adding their own experiences of the development of the app.

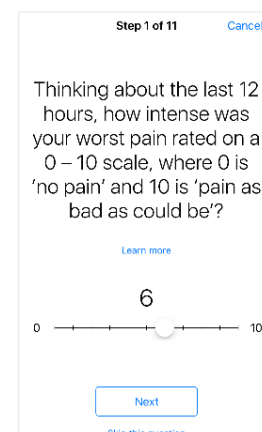
Feedback

The Pain Recorder was reportedly easy to use on phone and tablet devices, causing no interference to with daily life or sleep. It was perceived as a tool to help inform GPs about pain management and contributed to decisions by the GP regarding medication changes. Importantly, it was also felt the app did not directly influence thoughts, feelings or actions related to mood, pain interference, or medication usage.

All four GPs found the app graphs easy to interpret, useful in helping patients make choices about their use of medication, and they would recommend the app to patients for self-monitoring of their condition.

Impact of Involvement

RUG members were an essential part of the Keele Pain Recorder development. The final version of app was their design, and this clearly showed in its usability for patients.



*The Keele Pain recorder is now available to download from both the [Android](#) and [Apple](#) stores.

Evidence Synthesis of Clinical Study reports

Dr Kamal Mahtani

- University of Oxford

DiSCeRN - eviDence Synthesis of Clinical Study reports for non-vitamin K antagonist oral anti-coagulants (NOACs)

About the study

The aim of this project is to find out whether new drugs that are being used to prevent strokes are as good as drugs that are currently being used. The team are gathering all the evidence on this topic, synthesising it and summarising it into a systematic review. This will uniquely include unpublished evidence that has previously been unavailable.

Involvement through online platforms

Feedback was sought from patients who take anticoagulant drugs or have been involved in caring for someone who takes them. A brief outline of the project was posted on the Anticoagulation Europe (ACE) forum, part of the "[HealthUnlocked](#)" online community.

We specifically asked the following questions:

- Do you think this project is a good idea?
- What types of advantages and disadvantages would you be interested in knowing about when considering a new anticoagulant?
- Is there anything else you would like to tell us about that could help with the design of this project?

18 replies were received to our post, offering encouragement and support for our work

"I would certainly be interested in the results of trials that may not have been made public"

"It is useful to review the clinical issues, especially with regard to risk and effectiveness between warfarin and the newer drugs."

The online community felt that more research regarding the safety of NOACs would be very worthwhile. As a result, we modified our protocol, putting greater emphasis on extracting data about harms. It was also useful to read about the experiences of some patients who had tried one NOAC unsuccessfully, and were switched to a different NOAC which suited

them. This highlighted an area for possible future research for us.

Involvement through a face-to-face meeting

Information and feedback was also gathered at a face-to-face meeting with members of the public. A short lay summary of the project was sent via email to a departmental public involvement advisory group, two of whom were able to attend a face-to-face meeting with the research team.

The meeting started with a short researcher presentation, highlighting the importance of systematic reviews, their use in decision-making by clinicians and the NHS, and why it is important to look at all the evidence (illustrated with examples). This was received positively. One public attendee commented about research waste

"it saves re-inventing the wheel to look at the evidence out there already...you want to know that all of it is being looked at by your doctor"

Issues surrounding unpublished data and accessing unpublished study reports were discussed.

"It's incredible that these [unpublished] reports are not available to everyone...releasing the data [by drug companies] should be non-negotiable!"

Armed with a better understanding of the value of systematic reviews in health care, both members of the public were keen to support our work and stay involved. They highlighted the importance of summarising our findings for a public audience and making them openly accessible to all. In keeping with NIHR policy, our findings will be published in an open access journal. We will also publish a lay summary of our work on a public facing platform. As the next phase of our work begins, public contributors have been invited to join the steering committee.

Impact of public involvement

Having the public involved in our project has been instrumental in both endorsing and shaping our work.

Intervention development

Dr Kieran Ayling¹, Dr Lucy Fairclough¹, Dr Paddy Tighe¹, Professor Ian Todd¹, Dr Simon Royal¹, Dr Mark Wetherell², Dr Graziela Figueredo¹, Dr Heather Buchanan¹, Professor Kavita Vedhara¹ - University of Nottingham¹, Northumbria University²

Non-pharmacological approaches to optimising vaccine effectiveness: the development of an effective and acceptable intervention for primary care

About this study

Older people do not always benefit from vaccination. Some studies suggest less than 20% are protected after receiving a flu vaccination. Our research has found that older people with greater positive mood on the day of flu vaccination produce more flu antibodies, which consistently predicts protection from flu. Therefore, an intervention that improves positive mood at the time of vaccination could make the vaccine more effective in more people.

This project aims to:

- 1) Understand which approaches to promoting positive mood are most acceptable to patients and primary care health care professionals (HCPs) with the help of patient focus groups and interviews with HCPs.
- 2) Develop an intervention to promote positive mood
- 3) Conduct a feasibility trial of the intervention

Public involvement prior to the grant

This project continued research carried out during a SPQR studentship (Kieran Ayling). During this studentship, a patient and public involvement group was set up. Contributors consisted of a number of community dwelling adults aged 65 to 85 years, matching the population of interest for this research. The group provided vital input on the design of the work carried out during the studentship. This group played a key part in shaping the research study designs and ensuring their acceptability for potential participants.

Public involvement in the project to date

So far, public input has been instrumental in designing the research undertaken:

- 1) Co-developed focus group and Interview topic guides
This helped to refine qualitative research topic guides and led to significant changes in the specific questions posed in our qualitative work.
- 2) Pre-feasibility Trial Intervention Testing
This resulted in changes to the length of the intervention and the order of selected content.
- 3) We also piloted the intervention with members of the public who were not actively involved as contributors, to get a 'green-lay' perspective.

Developing the feasibility trial design and methods

The group contributed to key features of the feasibility trial design including recruitment strategies, data collection methods, saliva and serum sampling procedures, questionnaire items, and approaches to reducing patient drop-out and loss. Participant documentation was also examined and were revised to remove jargon.

Future plans for public involvement

Our public contributors will be consulted regarding the best methods of disseminating the research findings. Members of the group will also be invited to help disseminate the findings from this research, including co-presenting at academic events, GP practices and other suitable forums and producing lay summaries for distribution to study participants, health care providers, and the wider public as appropriate.

Feasibility and Pilot study

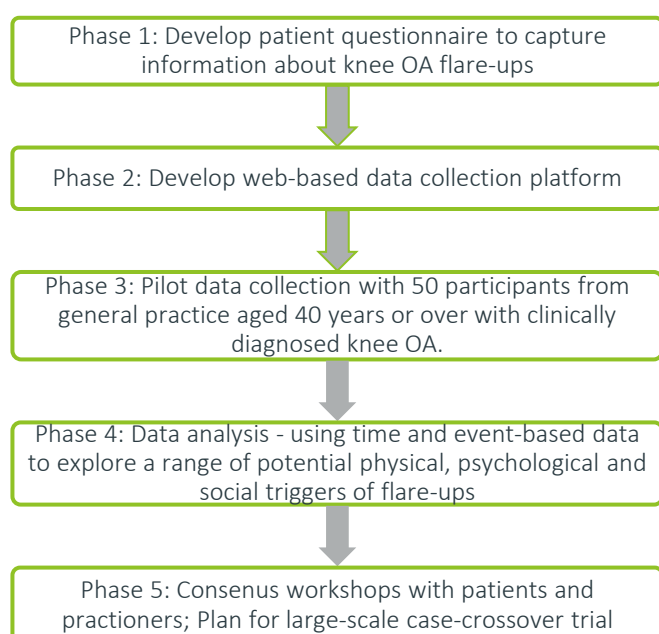
Dr Martin Thomas, Dr Steven Blackburn, Prof George Peat

- Keele University

The ACT-FLARE study

The role of patient and public involvement and engagement has made significant and meaningful contribution to a study aiming to develop and test a new way of capturing patients' experiences of flare-ups of osteoarthritis in real time.

Knee osteoarthritis (OA) affects 25% of adults aged over 50, and leads to over 400,000 general practice consultations in the UK each year. Some patients complain of acute flares that are difficult to cope with, particularly when severe and unpredictable. It is unclear what flare-ups are or what they signify. Existing guidance for patients and practitioners does not address what triggers these flares and how they can be managed and prevented. Therefore, we aimed to develop and test a system for capturing 'real-time' information on acute flare-ups, the things that trigger them, and which patients are most affected. PPIE was instrumental throughout this feasibility study

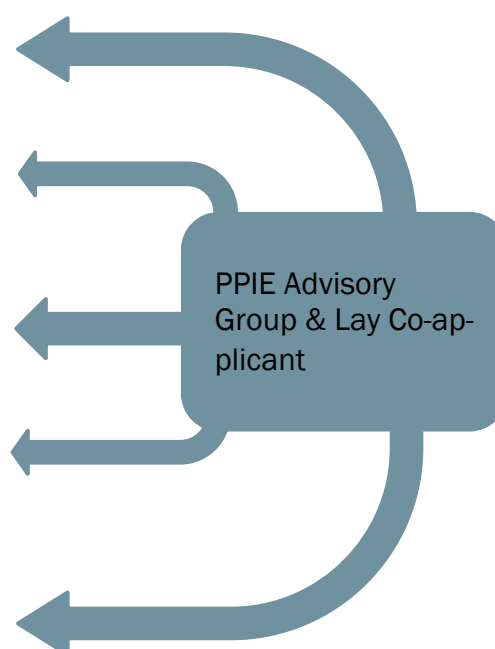


Role of and Impact of Patient and Public Involvement and Engagement

One patient advisor from the Keele University RUG was as a co-applicant on the project. A Patient Advisory Group was also convened, made up of six RUG members, who contributed to the design and content of the questionnaire and web-based data collection tool and the conduct of the study in a number of ways, including wording, layout and terminology for the website and questionnaires; outcome measures; questionnaire layout; acceptability of participating in a web-based data collection tool; production of online video clips on patient experiences; and reflections on the pilot study.

Conclusion

The valuable contribution of public involvement and engagement to this study has helped establish whether a large-scale case-crossover trial is feasible (whereby a case serves as their own control at a different time point in a study). This work forms part of a series of investigations, supported by public involvement and engagement, that we hope will lead to greater recognition of these knee OA flare up and more effective management and prevention of this disabling condition.



Exploratory Research

Dr Susan Hrisos, Prof Richard Thomson, Dr Anu Vaittinen, and Panel Members Mr Dave Green, Ms Judith Hunter, Ms Parveen Rasul, Ms Samina Zia

- University of Newcastle

The ThinkSAFE® study

Background

For most people visiting a general practitioner (GP), practice nurse or pharmacist, their consultation will be safe and harm free, but some will experience an adverse event (2%-25%). Significant advances have been made in understanding the role that patients, their families and carers, can play in improving patient safety whilst in hospital, and how best that role can be supported, such as [ThinkSAFE® programme](#). Understanding of the patient and family role in a primary care setting is limited; little is understood about the primary care staff perspective on involving patients in improving their own safety. This project worked with both groups to explore views on patients and/or families helping to reduce patient risk of harm in primary care, and how best to support them. This study also assessed the appropriateness of the ThinkSAFE® approach to the primary care setting. Findings will inform adaptations and extensions to this co-designed, user-informed approach.

Involvement Model & Roles

1) Public membership of an over-arching Advisory Group (AG):

Provided a 'bigger picture' perspective on the research, and promoted the study at a national level. Membership included representation from [Action against Medical Accidents](#) and a WHO Patient Safety Champion.

2) Public membership of a dedicated public Panel

Contributed to the research process at the most appropriate stages (determined by panel members), and consisted of four public members with diversity in involvement experience, professional background, age, gender and ethnicity.

3) Public membership on the study Project Management group (PMG):

One member of the public Panel attended all PMG and AG meetings and fed back to the public Panel. They were also involved throughout the secondary care study, bringing expertise, and are a funding co-applicant.

This model has allowed for reflections on study progress in all groups, as well as emergent findings, advising on issues and challenges faced, and analysis of data. This has fostered a team culture which regards public involvement with equal importance to others, with meetings structured to enable public voices and providing equality of power.

Reflections on public involvement in this study

'...by empowering people in the primary care setting to be aware/alert to patient safety and their role it is more likely a partnership arrangement will be developed between patients and health care professionals.' - Judith

'...members given specific tasks to do and questions to answer [and] their input formed part of a face to face report back session where researchers and PPI members offered critical comment on each other's presentations' - Dave

'...I was also able to bring my experiences during my involvement and was happy to share these with the other panel members.' - Samina

'...as a patient I also know what it is like to be on the receiving side. This has helped me enormously to understand a bit more about the ThinkSAFE™ side of things.' - Parveen

'...the analysis process is usually a relatively solitary enterprise, however in this project we invited the public panel to contribute to the analysis. ... I found the panellists' comments and observations particularly useful' - Anu

What next?

The study is being written up for publication with public panel co-authors, and will include details of their involvement and reflections. The Panel will leading on planning and delivery of a regional dissemination event targeting a range of stakeholders. The event will include engagement and involvement components, designed to address remaining questions relating to the adaptation of ThinkSAFE® to a primary care setting.

Recently awarded projects

Systematic review and meta-analysis

Dr Oghenekome Gbinigie
- University of Oxford

What is the value of diagnostic tests at presentation in the ambulatory care setting to identify serious bacterial infections in older adults?

About the project

Older adults are susceptible to serious bacterial infections, which often present in an atypical fashion, creating a diagnostic challenge for clinicians. There is a lack of clinical guidance to help clinicians in knowing which tests are most useful in diagnosing these infections in older outpatients. This systematic review was designed to answer some of these questions.

Shaping the research question

During an earlier (related) research project, I met with an already established public involvement group. One member of the group had heard about point-of-care tests, and wondered about the role of these tests in helping clinicians to make diagnoses of serious bacterial infections. This response helped to prioritize the current research question. This feedback also confirmed that the proposed work was of value to the public, as well as clinicians.

Formation of a dedicated public contributor group

Departmental and Research Design Service involvement coordinators helped the team develop a public involvement strategy. It was decided that a dedicated public involvement group made up of people interested in the research topic would be useful. Five people were subsequently recruited. Each of the participants was interested in shaping the project. They all also had a lot of personal experience of the topic area; namely, bacterial infections (e.g. chest infections), interaction with GPs, and caring for patients with these infections.

Shaping the grant application- successes and difficulties

Public members read over the lay summary for the grant proposal, and researchers were able to incorporate their feedback. This was very

helpful, as writing for the lay public is very different to writing for a scientific audience.

The main difficulty faced was co-ordinating meetings with PPI members. The group were very flexible, but even so, a face-to-face meeting with the entire group at the same time was not possible. The most important ingredient for success was being organised. As far as possible, PPI members were given plenty of advance notice and choice about future meeting dates and times.

"I realised that one doesn't always have to meet with group members face to face; getting feedback via email from PPI members can also be valuable."

- Oghenekome Gbinigie – Lead Researcher

Future Plans

As the systematic review progresses the findings will be shared and discussed with the PPI group, particularly if we uncover results that are surprising. Once the review has been completed, it is hoped the group will aid in disseminating the findings to the public.

Reflections from Contributors

'I like the idea that the presenters are willing to listen to our comments without being judgemental. At the same time [I like] to hear the others point of view...The results will benefit the [patients] and the health providers.'

Training

For Trainees

Bethany Bareham, Susan Hrisos
- Newcastle University

Postgraduate Researcher Public Involvement Workshop

In addition to supporting research that utilises good public involvement, the School for Primary Care Research is committed to providing learning opportunities for its researchers. The School's trainees meet each September at the trainee conference, where a range of training sessions are provided. The School identified a need for more focussed training, and set up Post Graduate Research training days. The School has PGR students acting as representatives for each of their member institutes.

On Wednesday 7th June 2017, the second of these training days was hosted by the Newcastle University Institute of Health and Society and themed around developing skills in Patient and Public Involvement. Trainee Bethany Bareham led the organisation of this event alongside the University engagement team. Thirty-five students attended the event at the Royal Station Hotel, Newcastle upon Tyne. The vision for the training day was to create a formative opportunity to develop understanding and confidence for PPI in this cohort of early career researchers. Particular emphasis was placed on encouraging creative thinking, and involvement of patients and the public throughout the research cycle.

Keynote talks, workshops, student presentations and a panel discussion filled most of the day. Almost all the participants reported that their plans for public involvement in their project had changed as a result of the training day, and that their understanding and confidence in involvement activities had increased. One student commented:

'It was a delight to hear perspectives and experiences from both established experts in this field and also from students. Very informative and motivating learning experience. And very well organised.'

A comment from one of the public contributors was that the day

'gave us [PPI group members] insight into the difficulties that students may face... [the event] was interesting and thought provoking'.

Mr Peter Michell, presenting as public representative for Rashmi Bhardwaj-Gosling of Newcastle University, took the award for best presentation in a fantastic example of PPI for dissemination. Nadege Uwamahoro won an award for her thoughtful and thorough public involvement plans within her project, which truly embodied the School's philosophy of the importance of public involvement, taking these principles overseas to Malawi.

For New Starters

Karen Postle (Public contributor), Jackie Seely (PPI Officer) and Kate Sykes (Public contributor)
- University of Southampton

Introductory training for PhD students and researchers

The University of Southampton Primary Care and Population Science unit are responsible for delivering PhD Induction training within the Faculty of Medicine. As part of their training, students are offered Patient and Public Involvement (PPI) training. This year the training, which consisted of a two hour session, was co-designed and co-delivered by two public contributors Karen Postle and Kate Sykes and a PPI Officer Jackie Seely.

Co-designing and co-delivering training

The aim of the training was to introduce students to public involvement in healthcare research.

The details and content of the training were agreed through discussions over email, phone and teleconference

The resulting training was a collaborative and complementary method of working.

The presentation and discussions interspersed with examples from Karen, short videos provided by Kate and a couple of short group exercises. One activity included a list of nine examples of involvement or participation and engagement, with attendees deciding which category each example belonged to.

What went well?

Attendees were positive about the training. The collaborative elements worked extremely well, with the team playing to their individual skills and strengths.

The videos provided by Kate about her personal experience of public involvement were practical examples of how the public can get involved in research and the benefits of this involvement.

What could have been improved?

It was difficult to coordinate diaries for everyone to meet at the same time. In future,

more time will be allowed to arrange the training and for public contributors to read the documentation provided.

The attendees had no experience at all of public involvement and this restricted the conversation a little. With hindsight, it would be worth sending out some pre-training material about public involvement with some relevant website links. This way attendees would be able to familiarise themselves with the basic information, and attend the training with questions already in mind.

For Contributors

Lynne Maddocks
- University of Oxford

Summary

Training sessions were for contributors to help them to be as 'research ready' as possible. The sessions aimed to give contributors confidence to ask questions that have most impact on their involvement, reducing the power imbalance within their involvement experience.

The Pilot scheme was offered to local contributors to the Department of Primary Care. In 2017, the department worked with NIHR colleagues at the Oxford BRC and their contributors, and invitations were extended to those living further away.

The Pilot

A pilot of 5 seminars were run in 2016, including sessions on introductions to evidence, clinical trials and the research cycle, quantitative and qualitative research, ethics, and systematic reviews, concluding in a session about 'How can we work together to improve PPI?'; a combination of attendee suggestions from previous sessions.

Further Development

In 2017, the scheme was refined to a series of 6 workshops

- 1) What is being involved? What is the impact of PPI?
- 2) Research terminology and the research cycle
- 3) Ethics – the process within the application and PPI role within it
- 4) Management of trials (including multi-site, phases and styles of research)
- 5) Medical Statistics
- 6) Evidence Based Methodology and PPI role within it

Costs

The pilot scheme cost £464, due to research staff to leading lectures at no charge, free venues, providing basic refreshments, and not all attendees chose to claim their travel expenses. In 2017 community venues were used, as well as external caterers, and more travel expenses were paid, so the cost was much higher.

Evaluation

An evaluation of the pilot was used to redefine the workshops for 2017, including the content, venues, length of sessions and increased inter-activity.

In both schemes the feedback suggested that contributors felt empowered and better informed.

The training also meant research staff were made more aware of contributors, their numbers, and availability. Academics who led the sessions gained a sense of what contributors needed to know, and saw first-hand their enthusiasm for contributing.

Coordinators felt it was very valuable, and an important way to move from email to personal contact with contributors. They also believe it helped to raise the profile of involvement work internally and externally. Several of the delegates were contributors who had not been linked to a project, and it felt very positive during these months to be able to offer the seminars to new recruits.

"...with improved learning and understanding my contribution to any research project would be similarly improved...and secondly a greater appreciation of how research needs to be conducted to secure funding, to achieve outcomes." - Public Contributor

Reflections

Both series had no formal involvement of the public, however sessions were based on contributor feedback.

Both schemes experienced issues with venue accessibility and location. It was noted hosting pilot events out of normal working hours did not attract more working age people.

Conclusions and what next?

A new collaboration between six research and clinical organisations now runs sessions aimed at new recruits, with each organisation hosting and funding one session. A further collaboration with three organisations hosts sessions with 50:50 staff and public input. There are also plans to offer more research topic training for our PPI Contributors in 2018.

Encouraging Early Involvement

In a move to promote best practice in public involvement, the SPCR funded six pilot ‘pre-grant’ involvement workshops to support Funding Round 15 and 16 applications.

Panel and participation event

- University of Bristol

The Centre for Academic Primary Care at the University of Bristol hosted a panel and participation event. The first of two sessions allowed individual researchers to pitch their research idea to a panel of public contributors for feedback. Researchers felt the initial application process helpful in writing to a lay audience. Of the panel event itself, one researcher commented that the public members ‘brought depth to the research’. Panel members commented that they felt able to contribute, whether they had direct personal experience of the research areas covered, or as interested members of the public.

Alternatively, attendees could play ‘Partneropoly’, a customised, innovative and interactive game where researchers and members of the public work together to find solutions to research questions in order to ‘win’ Partneropoly money. Researchers teamed up with members of the public and engaged in multi-viewpoint discussions on how to involve members of the public in primary care research. Discussions were prompted by combinations of stimulus cards and squares landed upon. Researchers were pleasantly surprised at the value of the exercise and the wealth of knowledge and community contacts possessed by the public contributors. Public contributors felt that researchers were interested in what they had to say

‘Partneropoly is a great way of getting academics and the public to interact in a meaningful, ‘level playing field’ way whilst being relatively fun and informal.’ - Public Contributor

Workshops

Researchers from across the SPCR chaired five separate workshops to address specific public involvement themes:

Clinical Trials - online recruitment and electronic health records

Chair Dr Caroline Clarke, UCL

Involving the public, patients and practitioners in general practice workforce research

Chair Dr Sharon Spooner, University of Manchester

Public involvement with children and young people in primary care research

Chair Dr Emma Palmer-Cooper, SPCR Patient and Public Involvement Officer

Research into public involvement: PPI in quantitative research methodologies

Chair Dr Claire Planner, University of Manchester

Diversity in PPI in primary care

Chair Dr Susan Hrisos, Newcastle University

These workshops ran over the course of a day in two 2-hour sessions. The morning sessions included an introduction to the topic, and discussions about related issues. The afternoon then concentrated on projects and recommendations for future work. For example, the ‘Public involvement with children and young people in primary care research’ plan to co-create a young person’s group for involvement in primary care research, to support SPCR funded departments in funding and project involvement activities. One contributor said:

‘[It was] very interesting, everyone very open to comments, wide ranging and freeform discussion.’ - Public Contributor

Reports and recommendations from each group are now available on the [SPCR resources hub](#), and are designed to help researchers plan and conduct public involvement for future funding bids.

The feedback from all attendees was positive. Constructive feedback on these pilot sessions about structure, organisation, and location will now be used to help plan future events.

Embedding Involvement

Primary Care Research in Manchester Engagement Resource (PRIMER)

Dr Claire Planner, Prof Peter Bower and Carole Bennett

- University of Manchester (UoM)

In 2008, the Centre for Primary Care at UoM formed the [PRIMER](#) Patient and Public Involvement and Engagement group; one of the first and longest-standing public involvement groups in the UK to focus on primary care research. PRIMER works with researchers to ensure there is high quality public involvement and engagement throughout their work.

The core objectives of the Group are:

- Work with researchers to offer best practice advice on PPIE
- Input at an early stage to shape research, and suggest topics for future research
- Network with other PPIE groups to develop best practice
- Contribute to policy within the Centre, the wider University, and the SPCR.

"We work with researchers, so they know what real people want and need from NHS primary care. We help to ensure that research is relevant to our health and well-being." (Carole Bennett, PRIMER Chair)

Background

PRIMER has a lay Chair and Vice Chair and is supported on a day-to-day basis by Centre staff. The group is supported by Professor Peter Bower and Dr Sally Giles.

The group has 16 members with diverse backgrounds, expertise and experiences of using NHS services. Members can be classed as *attending* (10 members) and *corresponding* (work online or by telephone; 6 members) depending on which best suits them and their circumstances. Meetings are held every 6-8 weeks, where researchers present early stage proposals, allowing public input at the very start of the research cycle, and members can remain involved throughout bid development and beyond. Researchers receive support to develop bespoke involvement strategies to meet the specific requirements of the project.

PRIMER members also co-produced and delivered two patient '[Hack Days](#)', run 'Elevator Pitch' days and workshops, help train medical undergraduates, conduct sessions on setting up an Involvement Group and Communication, and have advised on national consultations, such as 'Going the Extra Mile'.

How members are supported

New members are given the opportunity to complete a training needs assessment form, co-produced by PRIMER, and to have a one-to-one training discussion within 3 months of joining to explore opportunities for different types of involvement and training. New members are provided with an experienced member, a PRIMER buddy, for advice and guidance. All members are given access to a University email address, library card and an induction to the library, along with opportunities to join mailing lists advertising seminars, events and training.

'...I can't believe how much I have learnt about the research that is taking place. It's given me hope for the future of healthcare...' (Lindsey Brown, joined 2016)

How researchers are supported

Co-produced training includes an introductory workshop and three masterclasses. Advice clinics are also provided, run on a weekly basis, for researchers and students needing further input and advice. Resources have also been co-designed and are freely available. In 2018 PRIMER launch their Summer School for Patient and Public Involvement, in collaboration with the Coordinating Centre for Involvement and Engagement at UoM.

Impact

PRIMER has advised on over 90 projects and inspired a number of its own research projects and studentships. Members run an annual seminar to raise their profile and engage with research teams. In 2018/19 PRIMER will work up a new strategy for engaging the public in research, and roll out their Mentoring 3D programme and PRIME, supporting Undergraduate medical students to involve the public in their first research project.

Research User Group

Dr Steven Blackburn, Laura Campbell, Adele Higginbottom, Carol Rhodes, Prof Krysia Dziedzic

- Keele University, Patient and Public Involvement and Engagement Team, Research Institute for Primary Care and Health Sciences

Contributing 'expertise by experience' to primary care research

Background

In 2006, the Research User Group (RUG) at the Research Institute for Primary Care and Health Sciences (iPCHS), Keele University, started out with 11 members of the public. It now has over 100 members advising on over 70 different projects. Members contribute their experiences of health conditions throughout the research cycle. Each RUG member is treated as an expert in their own right. This "Expertise by Experience" helps to produce high quality, patient centred, relevant primary care research.

Making a positive impact to research

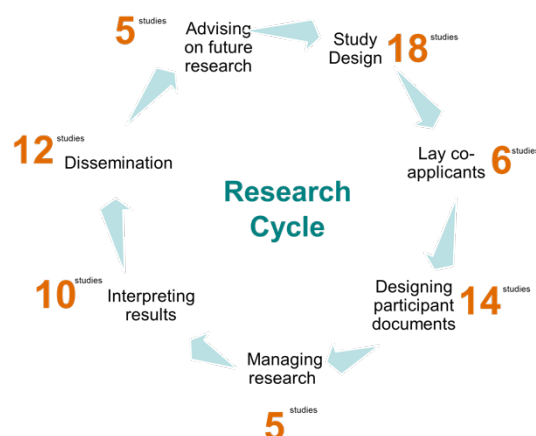
By 2016, over 80% of SPCR funded studies at the iPCHS included public involvement and engagement activities [throughout](#). Key to this meaningful and sustained involvement of patient/public members is leadership and [organizational commitment](#) to PPI.

The RUG and its contribution to our research were instrumental in helping the iPCHS achieve Arthritis Research UK Centre of Excellence status in 2008. Also, RUG members sit alongside NHS partners on the Primary Care Consortium Board to discuss and inform the iPCHS' research strategy.

Supporting Involvement and Engagement

RUG members are supported by a dedicated and enthusiastic Patient and Public Involvement and Engagement (PPIE) team. We have developed a learning and development programme, including training courses for members and researchers, induction events for new members, and guides explaining different elements of research. We also provide a plain language glossary of over 300 research terms and acronyms to assist the involvement of members of the public in research studies.

Supporting research with involvement and engagement



A new addition to the RUG has been the LINK (Lay Involvement in the mobilisation of Knowledge) group which aims to facilitate the transfer of knowledge and innovations originating from research projects into real life healthcare practice. Here, professional, personal and volunteering experiences are combined with knowledge of established networks and real healthcare practice, providing strong guidance to the project teams in the iPCHS' Impact Accelerator Unit, which take research into implementation.

A core team of Knowledge Mobilisers and a PPIE Knowledge Broker work alongside the LINK to ensure that the iPCHS retains a strong patient voice throughout the whole research cycle. The core team also work closely with the LINK group to address any problems or barriers to implementation, and to ensure that the high quality research produced at Keele is maintained throughout the process.

Impact

The RUG patient voice is being heard in incredible places and by influential people. Members have recently advised on the feasibility of rolling out the iPCHS's model osteoarthritis (OA) consultation across Western Europe ([the JIG-SAW-E implementation project](#)).

Members have also spoken about their experiences in healthcare and research at international conferences and with policy-makers. The RUG group's success is down to each of its valued, hard-working and brave members. Their generosity, hard work and willingness to share their most difficult experiences in order to improve healthcare for everyone has helped to shape our research for the better.

Acknowledgements

The School for Primary Care Research would like to thank the researchers, coordinators, and members of the public from each project presented in this document. Without their hard work and enthusiasm for good quality and innovative public involvement, the creation of this case studies would not have been possible.

This document was curated and edited by Dr Emma Palmer-Cooper, SCPR Patient and Public Involvement Officer, with input and guidance from Ms Mari James, Public Editor.