



**National Institute for  
Health Research**



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



**April 2018**

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

An independent public contributor, Mari James, advised on content and formatting of the finished document.

**To download the document, please visit:**  
**[www.spcr.nihr.ac.uk/PPI](http://www.spcr.nihr.ac.uk/PPI)**

**This document should be referenced as:**  
School for Primary Care Research: Public Engagement Case Studies. NIHR School for Primary Care Research, © SPCR, April 2018

# Contents

|                                  |    |
|----------------------------------|----|
| Forewords .....                  | 4  |
| Introduction.....                | 6  |
| Public Involvement.....          | 6  |
| Engagement to Inspire.....       | 7  |
| Science Festivals.....           | 7  |
| Bespoke events.....              | 9  |
| Engagement to Disseminate .....  | 11 |
| Science Festivals.....           | 11 |
| Engagement for Involvement ..... | 15 |
| Exploratory Approaches .....     | 15 |

# Forewords

## Director

Richard Hobbs

Conducting good quality and innovative public engagement in primary care research is key to disseminating research findings, and generating new research ideas.

This collection of case studies demonstrates the School's commitment to communicating research to the public, particularly those who will be impacted by the findings in a primary care setting. They also act as a guide for the vast array of methodologies that can be used to communicate and engage with the public, regardless of research topic or context.

I am hopeful these examples will inspire and influence future SPCR research, and enable researchers to communicate with key stakeholders to produce impactful and meaningful projects.

The SPCR would like to congratulate our researchers on their dedication to communication and engagement.

## Patient and Public Involvement Officer

Emma Palmer-Cooper

Engaging with the public about the research process and publicising research findings is a key part of the SPCR ethos.

A recent review of public engagement within the SPCR has demonstrated that a diverse range of engagement activities have been planned and carried out by SPCR partners. From Science Stand up to public seminars and science festivals, SPCR partners have demonstrated a dedicated and enthusiastic approach to communicating their research in unique and captivating ways.

We hope these examples it will inspire future engagement activities by partners, and take primary care research dissemination further into the public area.

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

Peter Bower

We all recognise the case for engaging with the public throughout the research process to make sure we do the best health care research. The benefits can be significant for all involved. However, we need to learn the best ways to engage with the public, as well as our patient and public contributors. Finding and adopting the best methods for each audience are key to success.

This compendium of case studies is designed to showcase the School's progress in this area, and highlight good practice across our member departments. Most importantly, sharing examples can help us improve our engagement activities, and help to stimulate innovation in this area. Reflecting on what we have achieved so far can help us encourage our staff and trainees to try fresh approaches and new ideas to get the most out of engagement.

## Public Editor

Mari James

We 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 engaging with the public.

# Introduction

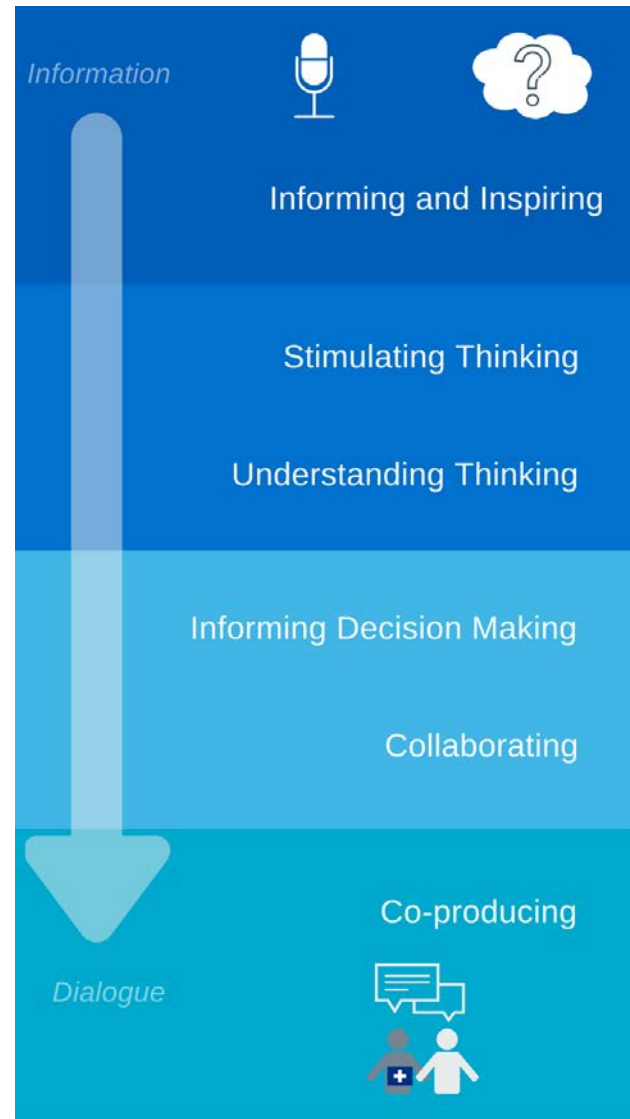
Engaging with the public involves providing the public with information, inspiration and encouraging them to think about a particular topic.

This could be about a specific research project, or a more general area of research. The NIHR supports and encourages public engagement in all the research that it funds, on the basis that this can accelerate the transfer of evidence into practice, and improve public awareness of healthcare innovations and knowledge.

There are many different ways that researchers can engage with the public, and includes going to public events to talk about research and running events for specific community groups to talk about upcoming research, or future projects. However, there is no right or wrong way to run a public engagement, as long as research is communicated in an understandable way.

## Public Involvement

Public involvement is just one part of the wider concept of public engagement, and involves creating more of a dialogue with the public about research. The SPCR has developed a booklet of case studies that specifically reports examples of research and School-wide public involvement<sup>1</sup>, and training related to this. The current document will report activities that are related to informing and inspiring the public, or activities designed to recruit new members of the public as contributors for future projects, termed 'Engagement for Involvement'.



<sup>1</sup> School for Primary Care Research: Public Involvement Case Studies. NIHR School for Primary Care Research, © SPCR, April 2018

# Engagement to Inspire

## Science Festivals

### Curiosity Carnival

School for Primary Care Research

#### Background

Public involvement comes in all shapes and sizes! The SPCR supported the 'Knit a Neuron' event at Oxford University's 2017 Curiosity Carnival.



Held on European Researchers Night (Friday 29 September 2017) the whole event aimed to showcase the world leading research taking place at Oxford to a large and diverse audience through a programme that included live experiments, debates, bite-sized talks and other activities.

'Knit a Neuron' was the brain child of Dr Anne Cooke from the University of Bristol as 'a collaborative, knitting, art project'. Since its inception in 2010, events have spread throughout the UK and beyond, as a fun and creative way to engage the public with science. Researchers from across the University of Oxford came along to help knit neurons and talk science. Everything from basic neuroscience to treating mental health patients in primary care.



#### The Event

Emma Palmer-Cooper and Karen Morecroft (SPCR), along with Oxford University colleagues Anne Ferrey (Primary Care), Anna Mitchell (Experimental Psychology), Amanda Kerr (Population Health), Vasiliki Economopoulos (Oncology), Liz Tunbridge and Sally-Anne Vincent (Psychiatry), and Alison Brindle (Medical Sciences), and NIHR colleagues Polly Kerr (Oxford BRC).

They worked with members of the public to make neurons, and create a giant neural network in their 'Make a Memory: Neural Knitwork' installation. Attendees attached their neurons to make new connections, or memories, and were able to take a neuron home to keep the memory alive. Members of the public from aged 4 years and upwards sat with scientists to learn about healthcare research.



## Science Busking

University of Manchester

As part of the Manchester Science Festival, the University hosts a Science Spectacular. This event uses the Science Busking scheme to support researchers in developing and running their own science engagement events. Members of the SPCR have taken part in this event to communicate their work and the importance of healthcare research to the public.



### *What's Wrong with Teddy?*

Members of the public were asked to don a white lab coat, glasses and gloves and use scientific equipment to help investigate which teddy is sick. They were able to test samples of their 'blood' using chromatography, a method that is commonly used in the lab, as well as being showcased regularly on shows like CSI. The public were also able to perform a 'lab' test for diabetes.



### *Complex Life of Sugars*

In this event, members of the public learned about the importance of sugars in their daily life (not just in their diet). Using giant building blocks they built their own sugar as it is created by cells in their body. Attendees were also able to learn about what happens when things go wrong. This event was designed to help change public perspectives on these essential miniature treats.



### *Marvellous Medicine*

Attendees were asked questions like 'What colour are your eyes?' and 'Can you roll your tongue?', with the aim of the event to demonstrate what makes us all different from each other. The public were able to find out how researchers and doctors use this information about people's differences to make medicine more effective. They were also able to talk to real doctors about their research and jobs.



## Bespoke events

### Images of Care and Dying

Dr Stephen Barclay, University of Cambridge

#### Background

Several SPCR-supported studies were presented at a series of five collaborative and co-produced engagement events, titled 'Images of Care and Dying'. The scheme was designed to enable Palliative Care clinicians and academics to start a dialogue with professionals in film and the visual arts in seminars, for a public audience, and was led by the SPCR's Dr Stephen Barclay.

#### The Collaboration

Clinical practice at the end of life raises many issues which are hard to find ways to feel, think and talk about. This results in a tendency to short-circuit the process, and move quickly into familiar and abstracted debates cut off from the felt and lived realities of daily clinical work.

Screen media is well adapted to the task of allowing questions about illness, death and dying to be articulated, thought through, felt and reimagined. Though representational and fabricated, they offer a sharp way back in to engaging with the bustle, upheaval, misery, tenderness and clarity of clinical work in this area.

"Images of Care and Dying" offered a genuinely innovative interdisciplinary conversation focused around the themes of desire, responsiveness and representation – each of which is needed and difficult in a palliative care context.

#### The Events

The seminars explored the difficult feelings and dilemmas presented by end of life care that are felt in the lived experiences of clinicians. Each seminar examined issues of end of life care through the lens of film, and featured guest speakers bringing together policy and academia.

Notably, the keynote speech was delivered by Mrs Roberta Lovick and members of the Palliative and End of Life Care Research Patient

and Public Involvement group, and focused on "Using patient experience to drive service development and change".

- Revd Dr Derek Fraser, Lead Chaplain at Addenbrooke's, and Nicola Stockley, BBC filmmaker led a discussion on *Caring for the bereaved and caring for ourselves when caring for the dying and bereaved*.
- Professor Bee Wee, National Clinical Director for End of Life Care, NHS England, and Dr Anna Elsner, University of Zurich led a discussion on *Palliative Care after the Liverpool Care Pathway*
- Steven Eastwood, Reader in Film Practice, Convenor, Queen Mary University of London led a seminar titled '*The Interval and the Instant*'.
- Claire Henry, then Chief Executive of the National Council for Palliative Care, and Sarah Cooper, Professor of Film Studies at King's College London also presented a session.
- Finally, Professor Jane Maher (Joint Chief Medical Officer, Macmillan Cancer Support), Professor Bill Noble (Medical Director, Marie Curie), and Emma Wilson (Professor of French Literature and the Visual Arts, University of Cambridge) ended the event with a discussion about '*The present and future agenda of cancer survivorship and palliative care*'.

The audience also had the opportunity to ask questions in a [Q&A](#).

#### Impacts

The events were positively received, and were attended by members of the public, practitioners, service managers and commissioners attending, alongside academics. The organisers have been invited to write two papers for the Lancet "Art of Medicine" section based on this series.



## Research User Group Annual Event Keele University

Engagement includes keeping in touch with existing public contributors. Over 100 members of the public make up Keele University's Research User Group (RUG), and they contribute to over 90 musculoskeletal and mental health research and implementation projects.



Whilst research projects can last years, being involved on a project as a contributor is not often a regular or continuous process, especially whilst data is being collected. To make sure RUG members stay engaged with research, the PPIE team (Patient and Public Involvement and Engagement) holds an Annual Event for RUG members at Keele University's Research Institute for Primary Care and Health Sciences.

Sharing stratified care using mastermind style format at patient conference @PCSciences @stevenawoor



3:17 PM - 13 Oct 2017

In 2017 the theme of this event was 'accelerating the impact of research using patient and public involvement', and was attended by over 80 RUG members, stakeholders and researchers. The event focused on how patient and public power can be better utilised

to improve implementation of research findings, with presentations from both staff and contributors, as well as interactive and innovative sessions to report on project findings and progress.

In addition to presentations, there were networking opportunities and a showcase of research and implementation projects that demonstrated good practice public involvement. This annual event is well received by staff and public contributors, and has fostered new connections and networks of researchers and contributors that will support patient and public power in research implementation.



# Engagement to Disseminate

## Science Festivals

### Talking about healthy, happy eating: Food Forensics

*University of Oxford*

In June 2017 the Nuffield Department of Primary Care Health Sciences took part in the Oxfordshire Science Festival's Explorazone.

Through a colourful suite of activities, supported by NIHR CLAHRC Oxford, the department's Behavioural Medicine team talked about a number of their research projects with passers. They covered areas of health and eating, such as how much sugar, fat and salt is really in what we eat, and the benefits of making simple food swaps.

As well as discussions there were engaging activities to help get their messages across. Activities included guessing how much sugar is in a range of everyday food products, investigating a typical basket of food for its potential to create healthy, balanced meals, and colouring activities for small children.



The team were also encouraging adults to sign-up for their patient and public involvement group, and to take part in ongoing studies on salt reduction and self-weighing.

Also on the theme of diet was one of Oxford Science Festival's top-billed events, where Professor Susan Jebb interviewed renowned chef and TV presenter Tom Kerridge about his new diet book and connections between emotions, food and weight.



Having a variety of activities relating to the wider research activities ensured there was something for audiences of all ages, and a number of key messages were communicated to the public in a fun and engaging way.

### PreScribed

*University of Bristol*

PreScribed (a life written for me) was performed at the Edinburgh Fringe in August 2017. It explored the alarming statistic that one in five practising GPs suffer from chronic stress and anxiety. The show draws on research into barriers to help-seeking and facilitators to support for the estimated 13,000 UK GPs living with mental ill health. The project "Improving access to support" was led by Ruth Riley with research carried out by Dr Johanna Spiers at the University of Bristol. PreScribed (a life written for me) was written by Viv Gordon and performed alongside Mandy Redmond. It tells the story of a GP nearing breaking point whilst working within the struggling NHS. This emotive show from performance artist Viv Gordon, who has lived experience of mental health, uses verbatim text

from anonymised research interview transcripts, creating a powerful account of the one in five GPs who are currently suffering with chronic stress and anxiety. The show is commissioned and co-produced by the Elizabeth Blackwell Institute at the University of Bristol. Read an editorial published in BJGP: Who cares for the clinicians? The mental health crisis in the GP workforce. Johanna Spiers, Marta Buszewicz, Carolyn Chew-Graham, Clare Gerada, David Kessler, Nick Leggett, Chris Manning, Anna Taylor, Gail Thornton, Ruth Riley.

### Kick the habit: what's the evidence?

*University of Oxford*

At the 2016 Oxfordshire Science Festival staff and students from across the Nuffield Department of Primary Care Health Sciences took to the high street to discuss smoking cessation research with the public.

"Kick the habit: what's the evidence?" used props and games to dispel some of the myths around giving up smoking and initiate discussion between the department's smoking cessation researchers and passers by of all ages.

The event was based on research from the Cochrane Tobacco Addiction Group and the Behavioural Medicine team.

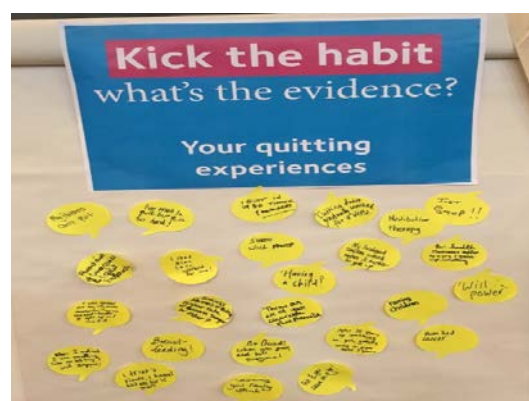


The interactive stall included information about the contents of tobacco smoke, the pros and cons of e-cigarettes, the physiological benefits of quitting, a 20-a-day jar of tar, a smoking cessation strategies game as well

as craft activities for children focused on 'healthy air, healthy lungs'.



Throughout the two days, the public also shared their own experiences of quitting, which were put on display for everyone to see.



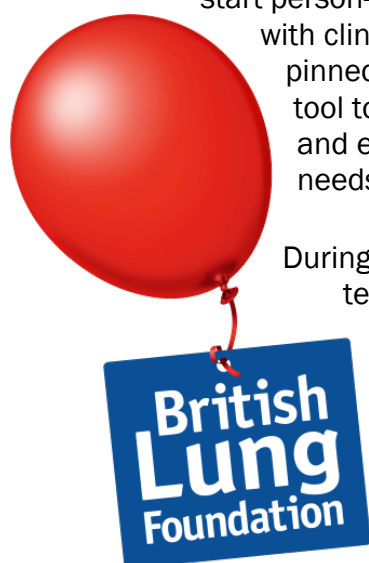
# Working with Charities

University of Cambridge

## Background

Patients with advanced Chronic Obstructive Pulmonary Disease (COPD) have difficulty articulating their support needs to health care professionals, undermining person-centred care and support. A new intervention, the Support Needs Approach for Patients (SNAP), informed by, and modelled on, the evidence-based Carer Support Needs Assessment Tool (CSNAT), has been designed to help patients identify and express their support needs and start person-centred conversations with clinicians. SNAP is underpinned by an evidence-based tool to help patients consider and express their support needs.

During the SNAP1 study, the team had a number of opportunities to engage with the wider public about the study via the British Lung Foundation (BLF).



## Local Events

Having developed relationships with two local BLF patient support groups, the team provided an article about the SNAP tool for each of their newsletters, and presented at a regional BLF Patient Information Event.

## National Events

Nationally the team presented their work to around 20 key members of the BLF staff team at their head office. As a result, Dr Farquhar (study PI) has begun on-going discussions about how the team could work with the BLF to develop the profile of SNAP, and has been invited to contribute to their Task-force for Lung Health, in which the BLF are

working with other stakeholder groups to establish a five-year strategy for lung disease.

During the summer of 2017 the team also presented their work to a combined audience of 40 Marie Curie volunteers in Norwich and Cambridge. In addition, Dr Farquhar was invited to present work on the SNAP tool at a national seminar hosted by Marie Curie in December 2017, where at which approximately 50 Marie Curie staff and public involvement members were present.

Over the course of 2017-2018 the team also presented the SNAP tool at a number of events for clinicians, such as a Specialist Registrar Study Day at Arthur Rank Hospice and Norfolk & Norwich University Hospital Respiratory Team, as well and at a CRN-Eastern East of England flagship event “Ready Steady Research!” and CRN newsletter aimed at primary care practitioners.

## Publications

The SNAP tool also featured in a recent invited Marie Curie [blog](https://www.mariecurie.org.uk/blog/new-research-to-help-people-with-copd/170275)<sup>1</sup> for World COPD Day.



<sup>1</sup> <https://www.mariecurie.org.uk/blog/new-research-to-help-people-with-copd/170275>

## Science Stand-Up

Bethany Bareham, University of Newcastle

Supported by **Bright Club NE**, SPCR Trainee Bethany Bareham performed a comedy set based on her doctoral work at ‘the thinking person’s variety night’ in a local Newcastle comedy venue, The Stand. Her work focuses on alcohol use in later life, with particular attention being paid to risk perceptions and older people’s views of the consequences of drinking alcohol.

### Background

Bethany recognised that the implications of her doctoral work reached beyond the university and health care system, and into societal attitudes and values.

People don’t associate risky drinking with older people, as their patterns of drinking are less visibly excessive, and the increased risks of drinking, associated with the ageing process and medical conditions or medications common in later life, are not well known. Consequently, neither older people, those around them nor their care providers pay any special attention to older people’s drinking.

This issue has been recognised by a small number of academics and service providers, drawing funding to develop an organisation ‘Drink Wise Age Well’. Despite at least 20% drinking in a way that may be a risk to their health, they have highlighted that up to 80% of these individuals have never discussed their drinking with friends, family or professional care providers.

The message - that we need to think and talk more about older people’s drinking - is a message that the wider public need to hear.

### The Event

Bright club is an event which blends comedy with academic research to create an opportunity for the ‘comedian’ to engage the public in their research, and an entertaining and thought-provoking evening for the audience. Several researchers perform their sets across the course of the show, interjected by ‘real’ comedy and public engagement acts.

Bethany faced the difficult challenge of finding the humour in a topic which should usually be taken seriously.

As the event is developed in collaboration with the Bright Club, researchers have access to valuable training and input, with feedback from an expert engagement and other university colleagues. The sets are developed with care and consideration over two and a half weeks from an initial training session, ensuring that the ‘joke’ is placed on the researchers, rather than the populations their work is advocating for.



Photo credits: Luca Cepollaro

Over 100 people turned up on the night.

### Reflections

*‘I had a great laugh, and I’m pleased to say my audience did too.’*

*‘Bright Club made me think about my research with a new purpose. I now recognise how to engage and inform the public in messages that they need to hear from my research in a way that they find interesting.’*

You can find a video recording of the set [here](#).

# Engagement for Involvement

## Exploratory Approaches

Engaging with mental health research in very late life

*Dr Rachael Frost, UCL*

This public engagement project, funded by UCL Culture, involved running discussion groups in day centres with older people, to discuss the topics of wellbeing in later life and what facilitates or hinders this. This was followed up by a photo project “Smile” in each day centre, where service users were given disposable cameras and were asked to photograph things that made them happy and things that were important to them.

### *Project Aims*

1. To share what is known about how common mental health issues in very late life are and the services that may be available, with service users.
2. Explore what is important to people to maintain mental health in later life and what therapies people might find acceptable or useful at this point in life
3. Discover more effective ways to engage with frailer older people on this topic.

### *Project Details*

Rachael Frost & Pushpa Nair carried out four discussion groups in day centres with 3-6 participants each, to discuss the topics of wellbeing in later life and what facilitates or hinders this. This was followed up by a photo project “Smile” in each centre. The team developed the photos and created a display within each centre, and talked through these with the service users.

### *Impacts from the project*

This public engagement project has informed the context of a systematic review of non-pharmacological interventions for older people with functional limitations and depression or anxiety.



This work has also informed the topic guide and recruitment materials for a qualitative interview study with frailer older people regarding depression and anxiety.

The Team have also develop successful ways to broach the sensitive topic of mental health, highlighted potential areas of difficulty, and informed how the researchers can best explain the study to potential participants.

A number of ideas have emerged from this project. In future, the project team would like to develop more effective ways to engage with older men, who were particularly challenging to engage in this project.



## The Yarnfulness Project

Dr Anne Ferrey and Dr Emma Palmer-Cooper, University of Oxford & SPCR

Following on from the SPCR *Curiosity Carnival event*, Dr Emma Palmer-Cooper and Dr Anne Ferrey applied for and were awarded the Oxford University 'Public Engagement with Research Fund' for the Yarnfulness Project, which will run from January to June 2018.

### Background

After talking to members of the public at the Curiosity Carnival, they realised that there was a strong public belief that creative activities had a positive effect on wellbeing and mental health, and emulated mindfulness and meditation. However, when the scientific literature was searched, the evidence base appeared to be quite small.

### Aims

The project was designed to engage the 'crafting public' in the design of research by:

1. Running online engagement activities to gain community opinion about project ideas (no geographic location)
2. Running face-to-face engagement activities with local (Oxfordshire) community groups to gain research themes and methodology ideas
3. Develop a study protocol with a small group of local community members
4. Educate engaged community members about research evidence and research design

This project will form the basis of future funding applications for empirical research.

### Activities and Events

Both online and face-to-face engagement activities were set up to ensure a diverse range of opinions were heard.

### Online

Online activities were run through the project [website](#). These included quick surveys and

online submission forms for interested members of the public to submit ideas and thoughts. Interested members could also sign up to a mailing list, where an e-newsletter was sent out once a month with project updates and blogs from the research team and public contributors.

### Tea Party

Face-to-face events included a 3-hour 'Tea Party', held at a local (Oxford) art and café venue. This involved nine (female) members of the public from diverse backgrounds coming together to learn about research methodologies and existing evidence. Over tea and cake they were then encouraged to discuss what research would be interesting, and what would be the best way to conduct it, using their newfound knowledge. Attendees were also encouraged to leave feedback and research ideas on the Yarnfulness 'Knitting Tree' (pictured right).



*'Insightful, engaging and exciting discussions. Incredibly interested in the research that could stem from the questions that were posed.'*  
Attendee

*'An absolutely fascinating morning – so many different strands of thought...'*  
Attendee

From this group, three individuals were 'recruited' as public contributors for future research projects.

### Public Events

Other face-to-face events include a Knitting Circle at the Pitt Rivers Museum's (PRM) 'Pitt Fest', which aims to speak with public attendees about community and social activities involving yarn-crafts, and how these could influence wellbeing. A 'Knit-In' event aims to discuss potential collaborative community research projects with PRM staff and their community networks.



# 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 engagement, 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.