

**NIHR Research Design Service for Yorkshire and the Humber  
RDSYH Public Involvement in Grant Applications Funding Award Report**

**Angela Burgin**

**Leeds Teaching Hospitals NHS Trust**

**Contents**

Page 2	Introduction
Page 2	Aim
Page 2	Method
Page 3	The people who took part
Page 4	The contributions made by the group
Page 5	Evaluation of the patient and public involvement
Page 7	How PCPI will be taken forward if awarded funding and when I will find out
Page 8	Difficulties encountered
Page 10	Appendix 1 - detailed breakdown of how the funding was spend

## Introduction

Electronic Prescribing (EP) disrupts the flow of patient and Healthcare professional (HCP) engagement. Research has shown that EP reduces contact between patients and their healthcare teams, and can be damaging to the way that HCPs communicate with patients. These changes, as an unintended consequence of digitalisation, have been found to cause medication errors, poorer patient medicines adherence, and consequently, can affect treatment outcomes. Medicines Optimisation (MO) involves working with patients and other HCPs to create a "...person-centred approach to safe and effective medicines use, to ensure people obtain the best possible outcomes from their medicines...". Working with patients in this way relies solely on HCPs connecting, interacting and communicating with patients. It was felt that further research is needed to understand the cultures and behaviours that are evolving in light of digitalisation in NHS hospitals, with particular consideration of what helps and/or hinders the MO process in the digital age.

The Patient, Carer and Public Involvement (PCPI) group was set up to support the development of the research as part of an application for a HEE/NIHR ICA Clinical Doctoral Research Fellowship grant. The purpose of the PCPI group was to learn whether the proposed research topic was relevant to patients, and if so, to put the patient voice at the centre of the research by ensuring that the group were involved in the research question and methodology design.

## Aim

The aim of applying for the funding was to enable the delivery of PCPI workshops to ensure that;

- Patient experiences and perceptions informed the creation of a project that was patient centred and relevant to patients.
- The patient perception was fully reflected in the final research proposal by sharing and receiving feedback on the research question, patient involvement in the research, the Plain English Summary and dissemination of the research findings.

## Method

To support the development of this research proposal, I needed to find patients, or carers of patients, who take medicines on a long term basis, and who had recently (in the last 12 months) had an overnight stay in hospital at Leeds Teaching Hospital NHS Trust (LTHT).

To recruit patients and their carers, I liaised with the LTHT Patient Experience Department. This enabled access to different forums in an attempt to connect with and recruit people from different backgrounds and of varied socio-economic status. The advertising flyer was shared by email through the LTHT Patient Volunteer Database, by newsletter via

Healthwatch Leeds and the Leeds CCG Volunteer Newsletter, and on the web page of Healthwatch Leeds and Leeds CCG Volunteer Programme.

Patients and their carers contributed to the research grant application by taking part in workshops. I organised and facilitated 2 workshops.

### **Workshop 1 - Exploring patient experiences and perceptions**

Workshop 1 (WS1) was delivered twice, each with a different group of 7 patients and carers. The aim of running WS1 twice was to ensure that a range of patient experience and opinions were sought, and also to identify if any themes emerge.

The workshop had clear aims identified at the start of the session, with background and context given using photographs and the method of storytelling to share the digital journey of LTHT and the NHS. The discussion explored the group's experiences, thoughts and perceptions of changes in relationships with Healthcare Professionals in the digital NHS, and also access to their medicines and information about medicines when they are in hospital.

### **Workshop 2 - Sharing of the research question created, proposed research methods, and the grant application Plain English Summary**

Workshop 2 (WS2) was held 7 weeks after WS1, and was a single meeting which combined both groups from WS1. This was considered an appropriate approach as the patient experiences and perceptions were combined and informed one grant application. Prior to WS2, the Plain English Summary was circulated to the participants to provide the opportunity of reading and reviewing prior to the session if desired.

WS2 briefed the participants on the findings of WS1 and how their contribution in WS1 had fed in to the design of the research question and research methods. The group were asked for their feedback on; validity of the research question, the research method and patient participation, the Plain English Summary and any other concerns they had in relation to the project design.

## **The people who took part**

Fourteen patients and carers were recruited in total. WS1 was delivered twice with 7 participants attending each session. All 14 participants were asked to take part in WS2, but unfortunately not all could attend due to ill health or prior commitments. Of the 14 participants recruited, 8 attended WS2.

Despite the attempt to recruit from a variety of sources, the people who volunteered and took part were similar in nature. The type of people who took part were all over the age of 45, mostly retired, and were white British. It was clear from the discussion that each individual had worked throughout their life time, and that most employment was at a

professional level. At least half of the total group had been involved in PCPI groups in the past.

### **The contributions made by the group**

The PCPI members and workshops contributed to my personal development and clinical practice, as well as the intended purpose of informing the research question, focus, design and the grant application.

#### Contribution to me as an individual healthcare professional

The PCPI sessions were the most impactful 6 hours of my career. I had always felt that I was in touch with patients and their needs, and always worked with patients to deliver pharmaceutical care specific to them. Hearing the difficulties that patients face with medicines, both during and after their hospital stay, had a huge impact on me as an individual practitioner, and made me see that despite my best efforts, there is more to see in the 'unsaid', and more to consider beyond the hospital stay. The workshops and conversations have provided real insight in to what it means to be a patient with special needs. I realised that my tool kit for supporting patients with medicines was fairly limited and very practical in nature, and as part of this work have identified the need to develop health coaching skills to better enable me to support patients to get the best from their medicines.

In addition to this, I am keen to learn more about PCPI design and delivery, and take this back to the pharmacy department and explore how we might include more PCPI in our service redesign.

#### Contribution to the research design and grant application

Through sharing their experiences, thoughts and feelings, the PCPI group members were supportive of the research area and agreed that it was relevant to patients. Their contributions fed directly into the design of the research.

The workshop content directly informed the research question, the research methods chosen, and also the design of the PCPI element of the research, by sharing what they felt was reasonable and manageable for patients. The PCPI group also reviewed the Plain English Summary for the research grant application and suggested methods of dissemination of the research findings.

At the suggestion of the PCPI group members, the wording of the research question and the Plain English Summary was changed. The group agreed with the research methods proposed, but suggested that different age groups of patients were interviewed in phase 2 of the study.

In addition to the grant application changes, the group also suggested that the proposed Research PCPI Panel have meetings that were longer than the workshops they had attended. The group felt that a little more time was needed and suggested a half day session as opposed to a 3 hour meeting which included breaks. This suggestion was added to the design of the PCPI element of the research proposal.

Finally, group members suggested connecting with other strong PPI groups at LTHT and provided contacts to enable this. Group members all commented on the demographics of participants in the workshops and that wider consultation was needed in further work to include younger members and also members from different ethnic and working backgrounds. If the research grant is successful, both of these suggestions will be followed up and actioned.

### **Evaluation of the patient and public involvement**

Assessing the quality and impact of the PCPI involvement in the design and completion of the grant application was done using the appraisal criteria published by Wright et al (2010). These criteria were also used when designing the PCPI element of the main research project.

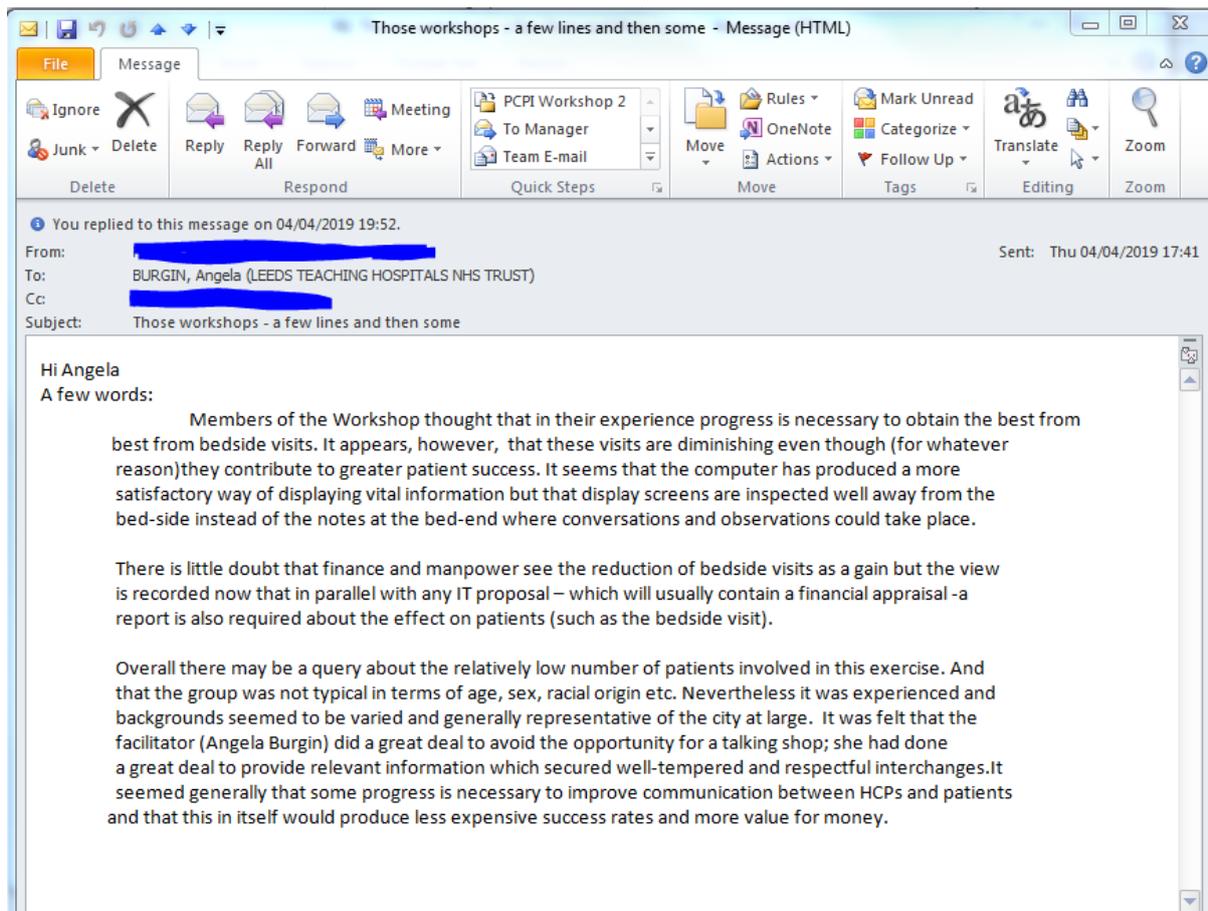
In addition to this, evaluation of the PCPI sessions involved a number of activities;

- Evaluation of the PCPI activities.
  - a. Participants completed an evaluation form at the end of each session.
  - b. 'short account' from a group member.
- Evaluation of lead applicant as facilitator of PCPI activities.
  - a. I completed a reflective log after each workshop.
  - b. Had a 'de-briefing' session with a member of the Trust's Patient Involvement Department who supported with the set up and sat in on the sessions offering support, when appropriate, with facilitation.

#### **Evaluation of the PCPI activities**

Clear aims and objectives were set at the start of each session, and were revisited by the group at the end, to ensure that we had achieved what was set out at the start. Additional feedback was collected through an evaluation questionnaire completed by participants throughout the sessions. The overall feedback from the evaluation questionnaire was that the group was facilitated well and that they enjoyed listening and contributing to the discussion. All participants actively contributed to the workshops in both written and verbal formats. Points suggested for improvement were acted upon for subsequent sessions.

## Participant short account



### **Evaluation of lead applicant as facilitator of PCPI activities**

I have had lots of experience as a facilitator of group conversations during my career, and have previously facilitated focus group discussions which I felt gave me a lot of transferable experience and skills. The PCPI workshops were my first attempt at facilitating discussions with patients, and as such, I wasn't sure what to expect. I felt I needed some support during, and feedback after the sessions. I asked my colleague from the LTHT Patient Experience Department (who has lots of experience at hosting and facilitating such sessions) to come and observe the workshops, helping facilitate if needed. After each workshop, I wrote a reflective log. My colleague from Patient Experience and I, then met to discuss the workshops. We discussed my thoughts, their reflections on the session, and the feedback offered by participants. This was really helpful in both improving my technique and building confidence.

## How PCPI will be taken forward if awarded funding and when I will find out

It is still currently unknown as to whether the award has yet been granted. The timeline for application stages of the award are:

Application stage	Date
Shortlisting	11th July 2019
Stage 2 Application submission deadline	1pm on 5th September 2019
Applicant Interviews	6th and 7th November 2019
PhD start date if successful	1st April 2020

If the grant application is awarded, members of the public will be involved in the research in a number of ways.

1. Research PCPI Panel
2. Involvement in the research by being observed and interviewed in the ward environment as part of data collection
3. Contribution to the design of an intervention

As a **Research PCPI Panel** member, participants will;

- Review patient information literature
- Review and refine patient interview schedules as part of the research
- Ensure that the patient perspective is captured fully by supporting the analysis and reviewing of data
- Will advise on appropriate strategies for, and contribute to, the dissemination of the research through appropriate networks and relevant interest groups
- Review written material for dissemination to relevant public and medical bodies for readability, understanding and applicability
- Contribute to the design of the intervention in the final phase of the study.

Patients and their carers will be **involved in the research** through observations of the ward environment and one to one interviews. Patients, and/or their carers, will be observed as part of, for example, a ward round. This will be complemented by semi-structured interviews which will probe and explore what has been observed.

Patients and their carers will also be involved in the **design of the intervention** in the final phase of the study. This is to bring the patient needs and voice to the intervention design.

## Difficulties encountered and what I might do differently next time

There were four situations that arose during the design and delivery of the workshops where I felt difficulties were encountered. These were;

- a. recruitment of a variety of patients and carers,
- b. practicalities of organising the session,
- c. the conversation going 'off topic',
- d. a difficult group member.

I reflected on each workshop and developed mechanisms to improve on my performance and the feedback I received. Running more than one session was really useful as it enabled me to practice new approaches in a timely manner. All are strategies that I would employ again for future sessions.

### a) Recruitment of a variety of patients and carers

Whilst I was extremely pleased with the patients and carers enrolled in the PCPI sessions, both myself and group members observed that those involved were all of a certain demographic.

As part of my PCPI development, since designing and running these sessions, I have managed to network further with PCPI specialist outside of LTHT. This has brought new connections and ideas as to how I might run patient recruitment and deliver PCPI sessions differently in the future.

### b) Practicalities of the session

As part of the feedback from the first workshop, group members provided a few practical points to help improve the session. These were areas I felt I had covered as part of the preparation, but I realised that I hadn't fully considered the patient perspective. I was limited with choice of room for the first workshop due to time pressures. The room for the first workshop was not located in close proximity to accessible toilets. Whilst I had done what I could to make sure that accessible toilets were available, they were on the floor above which was accessible by a lift. In addition to this, the room was next to a service corridor, and was also near a loading bay so was extremely noisy at times, and cold (despite heaters in the room). For future sessions, I would plan the session more in advance and make sure that I had a decent room booked which would cater for the needs of the group members. In addition to this, I had provided tea and coffee facilities to be used throughout the session, but forgot to get water. The group members pointed out that medication and radiotherapy had meant that they had limited/no saliva, some had coughs and colds (the meeting was in January), and as such, it was important to also have water available.

Whilst organising the following 2 meetings, I took these practical points in to consideration and made changes.

#### c) The conversation going off topic

There were times, particularly in the first session, where the group members would digress and the conversation would go off topic. Unfortunately this meant that the first session over ran by about 10 minutes. One evaluation suggested keeping the group on track as a means of improving the session.

On reflection, I was afraid of missing an important point or appearing rude by cutting the conversation off. This was my first experience of facilitating a session with patients and carers as group members. After a conversation with the supporting facilitator from the hospital Patient Experience Department, I now feel more equipped to help steer the conversation back on track without appearing rude.

#### d) A difficult group member

The second workshop felt more difficult to facilitate than the first due to a 'difficult' group member. At the start of each session, the group created their own ground rules for the session which included rules around respect and listening. Despite this, there was an individual who frequently interrupted, was abrupt and rude in manner, and often tried to contradict what others were saying when they were describing their own experiences. The feedback on the evaluation forms described the situation and how at times, this individual dominated the conversation. During the session, I did bring everyone in to the conversation, and tried to diplomatically stop the individual from interrupting.

I reflected a lot on this scenario, and spoke at length with the facilitator from the Hospital Patient Experience Department about it. I created some tactics for dealing with the situation should it arise again. These included making the ground rules more visible to the group during the session, reminding individuals of specific ground rules if behaviour began to stray and not feeling afraid to challenge this. Running the final workshop with all group members gave me opportunity to try some of my new tactics, particularly as the individual described came back. The individual behaved in a similar manner, but I employed my new tactics with good effect, mostly. The feedback from this session was positive, the conversation fruitful, and all group members contributed.

<b>Appendix 1 - Breakdown of how the funding was spent</b>
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	<b>£</b>
<b>Catering:</b>	
Workshop 1a	90.00
Workshop 1b	90.00
Workshop 2	99.00
<b>Tea, coffee, water and biscuits:</b>	29.95
<b>Travel reimbursement for participants:</b>	
	100.00
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<b>Total</b>	<b>£ 408.95</b>