



Case study

ECLIPSE: patient workshops for research design

Involving patients at an early stage can be of great value.

Patient safety is a global health issue. 44,000 - 98,000 Americans die each year due to medical error, and one in ten patients in NHS hospitals will experience an adverse event.

As main stakeholders in their own care, and the only people present along the entire care continuum, patient contribution could help with a range of areas related to patient safety, including recognising and reporting adverse events, improving how incident reporting is handled, and putting pressure on policy makers to improve standards.

Introduction

As part of a research project exploring errors and safety in delivering intravenous medication¹, the ECLIPSE team conducted a patient workshop to inform the planned research and improve patient information.

The two main aims were:

1. to establish how to inform and engage potential participants in research, and;
2. use patients' experiences to shape research questions.

What did they do?

The team recruited nine patient representatives through online patient involvement directories and existing contacts, providing the workshop's focus, details and compensation for involvement.

The workshop started with patient experiences to introduce the context and give members a chance to be the 'experts' in the room. They then reviewed patient information sheets in the final session.

"After first splitting into smaller groups for better quality conversations, we followed with lunch so conversations could continue before reporting back to the group," said Imogen Lyons, Research Associate.

¹doi.org/10.1186/s40900-016-0035-x

This project was funded by the National Institute for Health Research Health Services and Delivery Research programme (project no. 12/209/27)

Impact on research

This was used to modify questions in patient interviews, and improve patient information, which improved research design, impact outcomes and public awareness of outputs.

The patients' experiences directly influenced the questions for research interviews. These were broader in scope and grounded in patient experiences, making them more meaningful to research participants at the bedside.

The workshop led to a thorough review of how to engage with patients, highlighting possible sensitivities and how to address these. Importantly, there was a steer away from terms such as 'error' and 'safety' in interactions and patient information, as these terms could worry patients.

Legacy

Following the activity, this input was factored into the research and design, ensuring the project was attuned to patient needs and concerns from the outset.

Patient involvement continued throughout the project, with patient representatives on the steering committee and a wider advisory group. A second patient workshop took place to reflect on the results of the patient interviews.

Lessons learned

- Patients' own interests and expectations may go beyond the scope of the research or workshop. Be clear from the start about the group's purpose and the research boundaries.
- It may not be appropriate to discuss all sensitive medical topics in a group. However, patients with shared experiences are likely to be able to better empathise with one another.
- Facilitation is a skill. Make sure you involve people with experience of facilitating PPI, if you don't have someone in your research group then ask around.

Public focus groups

A public focus group can collect information from a range of people that can contribute to your research. This might be help develop and prioritise research questions, shape research design, or help develop more useful and accessible patient information.

Focus groups can be done cheaply, although factor in venue costs, refreshments, compensation and reimbursing travel. As this format is flexible and requires little of participants' time, it can be an effective way to involve patients – especially when held somewhere familiar and comfortable to them or by working with relevant centres or organisations.

“Our workshop highlighted potential issues and sensitivities we might not have considered, and how to address these.

Patients were able to compare and contrast their experiences, as patients with shared stories empathised with one another. This provided common themes as well as a rich source of variability.

In return, the researchers became more sensitised to patients' experiences and concerns at an early stage of the study.”

*– Dominic Furniss,
Research Associate*



Interested in hosting a focus group?

Contact Dan Taylor, Public Engagement Coordinator
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