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Patient and Public (PPI) Involvement in Hospice research: an example of co-production in action

Brigden C, Goodwin, M, Silsbury, G, Rees-Roberts M, Butler C, Greene K, Hayes C, Hashem F, Gage H, Williams P, Wee B, Barclay S, Wilson P, Mikelyte, R



WHAT IS PUBLIC & PATIENT INVOLVEMENT? 1

Research grant funders require patient and public involvement (PPI) to feature in research projects. There is evidence that PPI can have a favourable impact on many stages of the research process: ensuring research evidence is relevant to patients, improving recruitment success, retention of subjects and the uptake of research in practice.

Co-production takes PPI one step further whereby researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project.

RESEARCH PROJECT DEVELOPMENT 2

A research project was developed to assess optimum hospice at home services at the end of life (OPEL H@H).

PPI supported the preparation of an application for a research grant to the National Institute for Health Research.

The PPI group included bereaved carers who had used H@H services. They provided feedback on the project idea, research question, outcome measures, and recruitment process.

Two members went on to become 'co-applicants' on the project grant to act as members of the research team to provide their expertise.

PHASE I: SURVEY OF HOSPICE H@H SERVICES 3

The survey gathered information on the range of service models and their characteristics.

A consensus meeting enabled co-production which involved joint decision making:

- of the emerging model types
- the selection of research site shortlist to act as case studies for further in depth analysis
- interpreting and generating theories from the emerging data from the survey
- developing a theoretical framework

PHASE II: IN-DEPTH CASE STUDIES 5

PPI activities for the development of phase II included advising on public facing study documents so they were ready to submit for NHS ethics approval, such as:

- Study information sheets
- data collection forms
- insight into appropriate processes for approaching patients and carers

Current hospice patient and hospice at home staff perspectives were also sought. Their input included:

- the language and content of documents
- when and how to follow up participants
- suggestion of a flyer to give out in advance to make approaching patients/carers easier.

6 DATA CODING MEETING

PHOTO: A group of people sitting around a table in a meeting room, discussing data coding.

DATA COLLECTION 7

The researchers and PPI co-applicants worked together to decide:

- the processes and procedures for data collection
- the questionnaire tools to use
- when and how to approach patients and carers as potential participants
- development of interview topic guides and a framework for analysis of the data
- analysis and interpretation of interview data from service providers, commissioners and carers

4 TEAM CONSENSUS MEETING

PHOTO: A group of people in a meeting room, discussing project findings.

CONSENSUS OF PROJECT FINDINGS 8

The work will be finalised at two national consensus events (one in the north, one in the south) where our provisional findings and theoretical framework will be presented and discussed with a range of stakeholders (including service users).

These events will help to validate the interpretation of the findings and refine our understanding of what works, for whom, and under what circumstances.

PHASE III: PROJECT OUTPUTS & DISSEMINATION 9

Guidelines will be developed for service providers and commissioners, supported by the consensus events.

We plan to work with our PPI co-applicants to summarise and present the findings in a way that is more easily accessible to service users and members of the public.

The PPI co-applicants have suggested a newsletter as one form of communication, including sending to the project participants.

10 STUDY SUCCESS

PHOTO: A group of people standing together, celebrating the success of the study.

KEY MESSAGES 11

- PPI has had a positive impact on the design and progress of the study to date.
- success with ethics approval first time
- support with analysing data
- support with study documents
- PPI has kept patients and carers views at the forefront to ensure the work remains relevant to those who benefit from H@H services
- The transition from PPI to co-production ensures that all perspectives are equally included throughout the course of the research project.

WHAT CAN HOSPICES DO TO DEVELOP PPI? 12

- Invite public or service user volunteers to join your research governance committee
- Seek volunteers to get involved in research
- Patients, carers and bereaved carers want to get involved and are very generous with their time.