

PB-PG-0407-11227 – NIHR Research for Patient Benefit Programme – Final report

Project title: Community-based evaluation of 'Preferred Place of Care' in the North West of England.

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Plain language summary:

Background: This study aimed to evaluate the PPC, a patient-held advance care planning tool promoted in the NHS. Originally called 'Preferred Place of Care', the current version is named 'Preferred Priorities for Care'. PPC was developed to help people consider, discuss and document their wishes and preferences for care at the end of life. Its questions are designed to stimulate discussion between patients, families and healthcare providers across care settings. At the start of this study very little research or evaluation had been done about PPC.

This study aimed to understand the experiences of patients, families and healthcare staff who have used PPC, and to identify potential barriers to PPC use. Phase 1 consisted of interviews in the community and Phase 2 consisted of anonymous surveys sent to patients, family members and community-based nurses. A final pilot study, a 1-day anonymous public survey about awareness and access to PPC, was based on Phase 2 results.

Findings: Phase 1 findings from 40 nurse and 8 patient/family interviews reveal primary themes of (1) barriers to PPC use or end of life discussions; (2) the decision making process for introducing PPC and initiating end of life discussions; and (3) the need for proper PPC infrastructure and support. In Phase 2, the patient/family survey (445 respondents) shows that 94% of people have never heard of PPC. Regarding their comfort in talking about death and dying, 60% of people indicate that they are comfortable or very comfortable, and 20% report feeling neutral. Survey results from the 153 nurse participants indicate that the factor most chosen (31%) as the most important for influencing the nurses' decision to use or not use a PPC with patient is the nurse's assessment of the patient's willingness or desire to discuss illness and end of life.

The pilot study shows that 21 out of 25 people (84%) have never heard of PPC, and 84% feel that more needs to be done to make the public aware of PPC. People think PPC should be available in GP waiting rooms (96%), hospital waiting areas (84%), and community places (84%).

Conclusions: The findings from this study have strong implications for (a) the need to challenge assumptions about people's lack of willingness to engage with the topic of death and dying, (b) the need for more visible and direct public access to the PPC document, and (c) the need for new and direct flow of information to the public about advance care planning and end of life care.

Keywords: Advance care planning; Preferred Priorities for Care (PPC); palliative care; end of life care; qualitative research; surveys; mixed methods; communication.

Summary of research findings:

BACKGROUND

The Preferred Priorities for Care (PPC) is an advance care plan that since 2005 has been promoted by the NHS End of Life Care Programme to improve patient choice at the end of life. The PPC (initially called 'Preferred Place of Care') is a patient-held document. It was designed to encourage people to discuss, consider, document and communicate their wishes, preferences and priorities for care at the end of life. However, very little evaluation of PPC has so far been done. This mixed methods study was undertaken to evaluate PPC from the perspectives of patients, family carers and healthcare staff in the North West of England where PPC was first developed.

AIMS AND OBJECTIVES

The two primary aims of this research were:

1. To understand the experiences of patients and care professionals who have used PPC.
2. To understand barriers that deter patients and care professionals from using PPC.

METHODS

A two-phased, mixed methods approach was used to gain both depth and breadth in the data; a short pilot study was also undertaken at the end of the project. All components of the research were approved by the NHS Research Ethics Service and relevant NHS Research and Development governance offices. A User Advisory Group and a Management Group each met regularly throughout the study to advise and assist the research team.

Phase 1

Phase 1 was a qualitative study to investigate the experiences of healthcare practitioners, patients and family members who had and had not used PPC. Semi-structured interviews were planned with 40 staff and 40 patients/family members (20 who had used the tool and 20 who had not in each group). In order to recruit the staff (district nurses, community matrons and Macmillan nurses), the researchers contacted nurse managers in each of the 12 participating Primary Care Trusts (PCTs), and attended staff meetings to present the study and distribute written information. Patients/family members were recruited via the nursing staff to protect patient confidentiality; nurses were given packs to hand to patients/family members if they had either used PPC or declined to use it.

Data were collected through semi-structured individual interviews. The interviews were anonymised, then transcribed verbatim and subjected to detailed thematic analysis. Atlas.ti software was used to manage and organise the data. The research team consisting of 3 researchers from different disciplines independently coded the data, iteratively grouping coded fragments into categories and themes. A final thematic coding and code book to define the codes were agreed upon by the research team.

Phase 2

Phase 2 consisted of anonymous quantitative surveys to gather data from a larger and more diverse sample of healthcare practitioners, family members and patients in the North West of

England. Based on Phase 1 data analysis results, we created two surveys: one for patients registered with a GP (and their family members if they wished), and the other for community nurses. Assistance with recruitment for the patient/family survey was provided by the Primary Care Research Network (PCRN), which identified one GP practice in each of the 12 PCTs. The research team provided 200 survey packs for each GP practice, and mailings were sent from GP practices to protect patient confidentiality. Via the PCRN, 200 people who were registered with each GP practice were randomly selected and sent a survey pack. The sole eligibility criterion for patient selection was that they be adults (age 21 and over). Reminder letters were posted 2 weeks later. Surveys were sent with a copy of the PPC document to enable those not familiar with PPC to view it and comment on it.

In order to distribute the staff survey, we contacted the same nurse managers as in Phase 1, and asked them to distribute the survey to their staff. Both paper and online versions of the survey were offered to nurse managers.

Survey data were entered into an SPSS database (PASW Statistics version 18) and analysed. Descriptive statistics, chi-squares, regressions, and latent class analysis were used for data analysis. Free text data were entered and analysed thematically.

Pilot study

The final piece of the study was a pilot to explore the issues that emerged from the Phase 2 findings. A one-page anonymous questionnaire was created to collect the views of members of the public about PPC awareness and availability. The survey, a PPC document and an information leaflet about PPC (produced by the NHS End of Life Care Programme), were distributed and collected via the mobile information service (the iVan) run by Merseyside and Cheshire Cancer Network. Data were entered into an SPSS database and subjected to descriptive statistical analysis.

KEY FINDINGS

Phase 1

Semi-structured interviews were conducted with 40 nurses (20 who had used PPC and 20 who had not), as well as 2 patients and 6 family members (5 who had used PPC and 3 who had not). Due to dependence on the nurses for patient/family recruitment, we experienced significant difficulties in recruiting patients and family members to this phase of the study.

The primary themes that emerged from Phase 1 were: (1) barriers to PPC use or end of life discussions; (2) the decision making process for introducing PPC and initiating end of life discussions, including when and how to introduce PPC; and (3) the need for proper PPC infrastructure and support. Small numbers of patient/family interviews limit the ability to make conclusions from the patient perspective.

Phase 2

Patient/family survey

Two thousand survey packs were distributed across 10 PCTs and 445 completed surveys were returned; this response rate of 22.3% was significantly higher than predicted but nonetheless a low rate. As with most survey research, respondents' self-selection would be expected to influence the results. Respondents have a mean age of 57 (range 16 – 89); and 59% are female. Ethnic origin of participants is 97% white, and religion is reported as 79%

Christian and 18% with no religion. Sixty-five percent reported their health as good or excellent.

Most respondents (94%) have not heard of PPC, and 98% have never seen the document. Most people reported being comfortable/very comfortable (60%) or neutral (20%) about talking about death and dying with someone close, and similarly, with health professionals. Regarding the PPC, less than 5% of respondents think some of the questions are a bit confusing, 71% indicate the PPC seems easy to complete, and only 9% think the design/presentation needs to be improved; 75% think making more people aware of PPC would make more people use PPC or another type of advance care plan.

Nurse survey

Nurse managers report distributing approximately 183 paper copies and 598 emailed electronic survey links (total = 781). A total of 153 surveys, predominantly paper copies, were completed for a response rate of 20%. Respondents have a mean age of 45 years (range 24 – 70), and 94% are female. Similarly to the patient/family participants, ethnic origin of participants is 97% white, and religion is reported as 80% Christian with 15% no religion.

In terms of PPC familiarity, 96% of the nurses have heard of PPC, 71% have initiated a PPC with a patient, and 69% use PPC with patients who have non-malignant disease. Forty-three percent report ever feeling that they should have introduced PPC but left it too late, and 16% are not sure. Thirty-one percent have wanted to introduce the PPC but have not felt skilled enough. The factor most chosen (31%) as the most important for influencing the nurses' decision to use or not use a PPC with a patient is the nurse's assessment of the patient's willingness or desire to discuss illness and end of life.

Pilot study

Twenty-five members of the public completed and returned the questionnaire in the pilot study. The mean age of respondents is 54 (range 18 – 82); 84% are female. Twenty-one respondents (84%) have never heard of PPC, and only 2 have completed one for themselves. However, 84% think more should be done to make the public aware of PPC. In fact, people think PPC should be available in GP waiting rooms (96%), hospital waiting areas (84%), and community places (84%). Several suggestions are made by respondents for additional locations for PPC distribution, such as dentist offices, leisure clubs and colleges/universities.

EXPECTED IMPACT ON THE FIELD

The project team has maintained contact with the National End of Life Care Programme and the National PPC Review Team, and members of both were included in a half-day meeting to discuss the research results and plans for the final pilot study. This research may reinforce the trend for public education about PPC and end of life care, and might influence the ways in which PPC is made available. Results should be conveyed to healthcare professionals in relation to their introducing PPC and advance care planning to their patients. In turn, it is hoped that such information will lead to better communication regarding end of life care wishes and preferences among patients, family members and healthcare providers.

CONCLUSIONS

The findings from this study lead to several conclusions: (a) within the constraints of the limited survey response rate we can conclude that, given the opportunity, the public is willing to engage with the topic of end of life care and is mostly comfortable doing so; (b) there is a need to recognise professionals' potentially blocking role regarding end of life care discussions, and implicit and explicit assumptions about people's lack of willingness to engage with the topic of death and dying need to be challenged; (c) the current version of PPC is not in need of revision at this time; (d) there is potentially a need for more visible and direct public access to the PPC document; and (e) there is a potential public interest in more direct flow of information to the public about advance care planning and end of life care.

Patient and public involvement:

Throughout this project we have defined 'service users' as people who have used or could use the PPC document, such as patients and their family members. We have included healthcare staff in this definition because they, particularly nurses, are often instrumental in facilitating use of the PPC with patients and family members.

User involvement has been integral to this study since its inception. In the early stages of developing the proposal we held a one-off user group discussion to seek the views of patients, carers and staff about key aspects of the research. This was helpful in shaping the development of the proposal and refining our thinking about recruitment of patients and carers into the study. At the start of the study we established a project user group that consisted of four patients (one of whom was also a carer), one other carer and two healthcare professionals (one District Nurse and one senior nurse manager from a cancer support service). The group met every four months throughout the study, and was led and facilitated jointly by the Project Manager and Principal Investigator. Two members of the user group also joined the project management group, which met every six months.

The main purpose of the user group was to provide feedback and input at different points of the research. For example, emerging themes from the analysis of Phase 1 data were discussed and validated by the group, and draft questionnaires for Phase 2 were reviewed and improvements made. User group members also contributed in ways we had not anticipated at the start of the study. For example, during Phase 1 we experienced great difficulties in recruiting patients and family members into the study. This was discussed at one of the user group meetings, whereupon one user volunteered to accompany the researchers to meetings with District Nurses to explain that patients and carers would value the opportunity to be invited to take part in research. With the help of this user, recruitment of patients and family members into the study increased.

The main challenge we encountered with user involvement in this study was in keeping the same people involved throughout the study. Over the course of 2½ years, of the seven original group members, two had to withdraw due to ill health, and another because of other commitments. Not every member was able to attend every meeting. However, four members did continue their involvement throughout the study, and will contribute to dissemination of the findings through their own networks and other organisations with which they are involved.

We have learnt a number of lessons through our experiences of user involvement in this study. In our original funding bid we only budgeted for travel expenses for users, and did not cost in their time, which meant we had to rely on the willingness of individuals to participate voluntarily in the study. Since the submission of our bid, INVOLVE has produced helpful guidance about payment of users, which we would follow in any future funding application. Another change we would make would be to encourage three user group members (rather than two) to join the project management group. This would help to promote better continuity, as well as provide additional support for users, for example on the occasions when one person was unable to attend.

Data sharing statement

See link

[\[https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253\]](https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253) for the NIHR position of the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

Disclaimer

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This project was carried out between October 2008 and March 2011. This final report has not been peer-reviewed. The report was examined by the Programme Director at the time of submission to assess completeness against the stated aims.