

Preferred Priorities for Care: Preliminary results from an evaluation in the North West of England

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Project Partnership

Community-Based Evaluation of 'Preferred Place of Care' in the North West of England

The project is a collaboration between the Lancashire and South Cumbria Cancer Services Network and the International Observatory on End of Life Care.



PPC Project Team

- Dr Mary Turner – Lead Applicant; NHS partner (Lancashire and South Cumbria Cancer Services Network)
- Dr Iris Cohen Fineberg – Principal Investigator (Lancaster University)
- Dr Xu (Suzie) Wang – Senior Research Associate
- Dr Katrina Stengel – Research Associate
- Dr Tom Lynch – Research Associate

PPC Project Team (continued)

- PPC Project Management Group
 - Kath Nuttall, Brian Francis, Les Storey, David Clark

- PPC Project User Group
 - Bill Ryder, Alison Small, Norah Knifton, Irene McGill, Margaret O'Donoghue, Judith Palin, Rita Hewitt

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What's in a name?

PPC is
a patient-held
advance care planning tool
intended to promote
communication and continuity of care.



PPC original name: *Preferred Place of Care*

PPC version 2 (Dec 2007): *Preferred Priorities for Care*

Project Background

- PPC was developed in the North West.
- It is promoted by the Department of Health.
 - End of Life Care Programme (2003 – 2007)
 - End of Life Care Strategy (2008) for England and Wales
- There is minimal research about PPC, and much of it is on a small scale.

Early References

- Storey, L., Wood, J., & Clark, D. (2006). Developing an evaluation strategy for 'Preferred Place of Care'. *Progress in Palliative Care*, 14(3), 120-3.
- Wood, J., Storey, L., & Clark, D. (2007). Preferred Place of Care: an analysis of the 'first 100' patient assessments. *Palliative Medicine*, 21(5), 449-50.

Project Aims

- a) To understand the experiences of patients and care professionals who have used the new version of PPC. For example: ease of use; extent and way in which PPC facilitates communication among patients, family members, professional care providers, and care settings.

- b) To understand barriers that deter patients and care professionals from using PPC. For example: what types of elements – such as discomfort with death and dying, lack of familiarity with PPC, limited communication skills, cultural issues – may impede implementation of PPC in the NHS.

Study Design

- **Phase One:** A qualitative study using semi-structured interviews to provide in-depth data on people's experiences of using PPC and barriers to use of PPC.
- **Phase Two:** A quantitative study using a written survey to gather data from a larger and more diverse sample of people in the same region.

Results from Phases One interviews have been used to inform the development of Phase Two surveys.

Phase One: Study sample

- Setting: Community-based care in 12 Primary Care Trusts (PCTs) in the North West of England
- Intended sample for Phase One interviews
 - 40 nursing staff (district nurses, community matrons, and Macmillan nurses)
 - 40 patients/family members

Phase One: Data collection

- Semi-structured individual interviews took place face-to-face with participants at a place of their choosing.
- Interviews were audio-recorded, transcribed and anonymised.
- Interviewers kept written field-notes related to the interviews.



Phase One: Data analysis

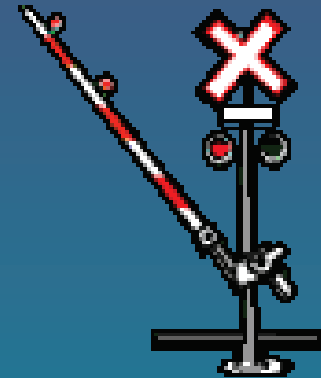
- Interviews were qualitatively analysed using standard thematic analysis.
- Atlas.ti software was used to manage data analysis.
- Analysis was conducted by a multidisciplinary team of researchers using individual coding and iterative theme building.

Phase One Results: Sample

- Nurse participants
 - 40 interviews completed, transcribed and analysed
 - 20 PPC “users”; 20 “non-users”
- Patients and family members
 - 8 patients/family: 6 “users”; 1 “non-user”
 - 6 family members; 2 patients

Recruitment challenges

- Mechanism for access to patients / families
- Problems with the access
- Attempted solutions to increase recruitment



Phase One: Selected results

Three selected themes

1. Barriers to PPC use or end of life discussions
2. Decision making process for introducing PPC and initiating end of life discussions
3. PPC needs proper infrastructure and support

Theme 1: Barriers to PPC use

- Timing – when is the right time to mention it?
- Specific challenges of using PPC with people who have non-malignant diseases
- Staff characteristics (i.e., discomfort, lack of knowledge of PPC, lack of confidence and/or training, lack of time to deal with PPC or end of life discussions)
- Perceived patient characteristics (i.e., denial)
- Family characteristics

Theme 2: Decision making process

Decision making process for introducing PPC and initiating end of life discussions



A. When to introduce the PPC

- When patients are deteriorating
- When patients give cues or open up such topics
- As early as possible
- Get to know patients first and build up relationship
- Hard to know when is appropriate

Theme 2: Decision making process

Decision making process for introducing PPC and initiating end of life discussions

B. How to initiate PPC

- Method
- Managing personal comfort within the team
- Managing patients who do not want to talk
- Using euphemisms to talk about death



Theme 3: Infrastructure & support

PPC needs proper infrastructure & support



- Training for staff
- More promotion to increase awareness
- Staff support
- Central information resource to share ideas and best practice

Phase Two: Anonymous surveys

In progress



Phase Two: Study sample

- Setting: Community-based care in 12 Primary Care Trusts (PCTs) in the North West of England
- Mailing for Phase Two anonymous surveys
 - Estimated 600 Nursing staff (district nurses, community matrons, and Macmillan nurses)
 - 2400 Patients/family members (200 patients from each PCT)
 - Estimated projected response rate: 15%

Phase Two: Data collection

- Nurses

Nursing managers across the 12 PCTs are contacted by phone regarding survey distribution, sent hard-copy surveys and an internet link to an online version of the survey (on SurveyMonkey.com), requested to distribute surveys and the internet link to their staff, and reminded to re-send the link.

Phase Two: Data collection

- Patients/families
 - 200 randomly selected patients from each GP practice
 - One GP practice per PCT
 - Patients receive a hard-copy anonymous survey, a 2nd copy for a family member, and a pen in the post (directly from the GP practice)
 - A reminder letter is sent 2 weeks later
 - Inclusion criterion: patient is age 21 or over

Phase Two: Data analysis

- SPSS (Statistical Package for the Social Sciences) software is used to analyse the data.
- The SPSS database includes both nurses' data and patient/family data.
- Data from the on-line survey will be imported into the database.



Preliminary Conclusions

- People are willing to provide their views about PPC, whether or not they use the document.
- Feedback about PPC is rarely about the document itself but rather its availability, completion process, and implementation.
- The study results will have implications for PPC distribution and use, staff training, and end of life care in the NHS.

In the future

The research results will be used to make recommendations to the PPC National Review Team and the National End of Life Care Programme

(<http://www.endoflifecareforadults.nhs.uk/>)

about the PPC document

(<http://www.endoflifecareforadults.nhs.uk/publications/ppcform>) and its implementation.

Doctorate in Palliative Care

http://www.lancs.ac.uk/shm/study/doctoral_study/phd/palliative_care/

The aim of the course is to equip people working in palliative, hospice and end of life care to undertake advanced study within their chosen field.



International Research Summer School

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The purpose of the International Research Summer School is to provide an 'advanced introduction' to social research methods relevant to palliative and end of life care.