

Methodological, ethical and governance issues for Patient and Public Involvement in a European health technology assessment of palliative care.

Louise Brereton ScHARR, University of Sheffield, Sheffield, England.¹

Elizabeth Goyder ScHARR, University of Sheffield, Sheffield, England.¹

Christine Ingleton School of Nursing & Midwifery, University of Sheffield, Sheffield, England.²

Clare Gardiner, School of Nursing, University of Auckland, New Zealand.³

Jim Chilcott, ScHARR, University of Sheffield, Sheffield, England.¹

Gert Jan van der Wilt, Department of Primary and Community Care, Radboud University Medical Centre, Nijmegen, The Netherlands.⁴

Wija J Oortwijn, Health Unit, ECORYS Nederland B.V. Rotterdam, The Netherlands.⁵

Kati Mozygemba, Department of Health Services Research, University of Bremen, Bremen, Germany.⁶

Kristin B Lysdahl, Institute for Health and Society, University of Oslo, Oslo, Norway.⁷

Dario Sacchini, Institute of Bioethics, Università Cattolica del Sacro Cuore, Rome, Italy.⁸

Wojciech Leppert, Department of Palliative Medicine, Poznan University of Medical Sciences, Poznan, Poland.⁹

Background: Patient and Public Involvement (PPI) ensuring that research findings are useful to the end users (patients, families, carers, staff and service commissioners) is widely advocated and well developed in some areas including palliative care. However PPI is under-developed in Health Technology Assessment (HTA). Better understanding of methodological issues relating to PPI in HTA for complex interventions such as palliative care is needed.

Aims: To identify methodological ethical and governance issues for PPI in HTA using palliative care in Europe as a case study.

Methods: Co-ordinators in six countries (England, Germany, Italy, Netherlands, Norway and Poland) engaged PPI using locally appropriate methods. ‘Patient and Public’ includes patients, carers and family. Three countries used a qualitative research approach and conducted 21 individual, face-face interviews which were analysed thematically. Three countries engaged stakeholders as ‘research partners’. An adapted version of the EUnetHTA core model guided 30 face-face discussions. Thematic analysis and conceptual mapping were used to identify key issues.

Results: Challenges for PPI included sensitively identifying credible, legitimate participants and clarifying the aims for PPI involvement. Uncertainty over what constitutes appropriate methods for engaging PPI representatives as research partners; ethical requirements and what constitutes ‘advice’ and ‘data’ and training when using patients as research partners were identified as specific issues.

Discussion: Tailoring methods to the local context by recognising philosophical differences relating to how PPI is best implemented and cultural sensitivities to palliative care enhances successful PPI engagement. However this limits comparability of findings. Ethical guidance needs developing for when patients contribute as research partners.

Conclusion: PPI methods must be further developed in a culturally sensitive way, especially in palliative care.

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