

"Methodological, Ethical and Governance Issues for Patient and Public Involvement in a European Health Technology Assessment of Palliative Care"

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Background

The INTEGRATE-HTA project is developing new Health Technology Assessment (HTA) methods for assessing complex health technologies and using a palliative care as a case study. Patient and Public Involvement (PPI) ensuring that research findings are useful to the end users (patients, families, carers, staff and service commissioners) is widely advocated¹ 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.

Aim

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 engaged PPI using locally appropriate methods. 'Patient and the Public' includes patients, carers and families. Three countries (Germany, Italy & the Netherlands) used various qualitative research approaches and conducted a total of 17 face-face, individual and /or focus group interviews which were analysed thematically. Three countries (England, Norway and Poland) engaged a total of 33 stakeholders as 'research partners' individually and/or in focus groups. An adapted version of the EUnetHTA core model² guided face-face individual or small group discussions and subsequent organisation of advice to identify key issues.

Findings

- Cultural awareness regarding the acceptability of engaging stakeholders in discussions about palliative care is fundamental to work with stakeholders in this area.
- Clarifying the aims of PPI involvement is fundamental to engaging stakeholders in a meaningful manner as providing data and advice are different activities.
- Sensitively identifying and engaging with credible, legitimate participants is essential, especially as palliative care is an emotive topic.
- Consideration should be given to the philosophy of stakeholder involvement as the principles of partnership working advocated by INVOLVE³ differ to philosophies underpinning qualitative research approaches.
- Appropriate methods for engaging PPI representatives as research partners require further development.
- Careful consideration should be given to ethical requirements for PPI, particularly with regard to identifying what constitutes 'advice' and 'data.'
- Meeting the training needs of stakeholders where required is a priority when using patients as research partners.
- Presenting the information gained using different methods requires consideration.
- Remuneration for stakeholder involvement requires consideration to ensure that this is adequate.
- Stakeholders providing advice may wish to waive their anonymity and be acknowledged in reports.
- Irrespective of the approach used, evaluation of the stakeholders' experience may inform future working with them.

Discussion

Recognising cultural sensitivities to palliative care and the different philosophical differences underpinning advocated PPI methods enhances successful PPI engagement. Additionally, a number of methodological ethical and governance issues require attention for successful PPI in palliative care¹. Using different PPI methods across countries has implications for the comparability of findings. Ethical guidance needs developing for when patients contribute as research partners.

Conclusions

Successful PPI in a European HTA of palliative care requires careful consideration of a number of methodological, ethical, governance and practical issues. PPI methods require further development in a culturally sensitive way, especially in palliative care.

References

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3. What is public involvement in research? <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>

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