

Patient and public involvement in scope development for a palliative care Health Technology Assessment in Europe

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Background

Although Patient and Public Involvement (PPI) helps to ensure that study findings are useful to end users, it is under-developed in Health Technology Assessment (HTA).

Having experienced the intended and unintended consequences of palliative care services, which vary widely across Europe, patients can provide valuable insights and advice for HTA scope development.

Aims

To establish PPI in six European countries in a palliative care HTA.

Methods

As PPI to assist early scope development in HTA is novel, each country used locally appropriate methods.

One of two advocated methods was used, either a qualitative research approach or 'creating research partners'.

Country	Method	Participants
England 	Individual or group, face-face meetings (notes taken) using EUnetHTA core model as a framework.	Twenty research partners (10 male, 10 female) comprising patients receiving palliative care (n=2), carers (n=2), Ex carers (n=2), patient & carer (n=1) family (n=6), friend (n=2) representing an organisation (n=5). White (n=19) Asian – Indian (n=1). Mean age =66
Norway 	Individual, face-face meetings (notes taken & some recorded) using EUnetHTA core model as a framework.	Five research partners (2 male, 3 female) comprising patients receiving palliative care (n=3) or carers (n=2). White (n=4) 'Other Asian' (n=1). mean age =64.
Poland 	Individual or group, face-face meetings (notes taken) using EUnetHTA core model as a framework.	Eight research partners (all females) comprising 5 volunteers and 3 members of palliative care associations. All White. Mean age = 45.6.
Germany 	Qualitative focus groups and face-to-face interviews were conducted (using nominal group technique and categorical coding procedure informed by a Grounded Theory approach).	Eight research participants (3 male, 5 female) comprising patients receiving palliative care (n=3), ex-patients (n=1) & relatives of patients or ex-patients receiving palliative care (n=4). Age range of patients and relatives = 40-69.
Italy 	Qualitative individual, face-face / telephone recoded, Interviews using EUnetHTA core model as a framework.	Seven research participants (2 male, 5 female), all White Catholic family members of patients receiving palliative care - mean age =42.
The Netherlands 	Interactive evaluation using qualitative face-face interviews (notes taken) and subsequently case reconstruction using constant comparison.	Two research participants (1 male, 1 female) comprising patients receiving palliative care. 1 patient was aged 59. The age of the other patient is unknown.

Findings

- PPI in palliative care requires researchers to have cultural awareness of the acceptability of engaging in discussions around palliative care services.
- Ensuring positive PPI experiences and effective participation by acknowledging patient knowledge and experience is important.
- Establishing a two-way flow of information in the HTA process is essential.
- Key issues for PPI include: partnership working between researchers and patients; stakeholder evaluation; remuneration for research partners.

Conclusions

- PPI was successfully implemented in each country, assisting patient-centred scope development and identification of important issues related to palliative care.
- Methods of PPI engagement require further development.
- All PPI methods have advantages and limitations which must be considered in light of local needs, resources and culture.

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