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PATIENT AND PUBLIC INVOLVEMENT IN SCOPE DEVELOPMENT FOR A PALLIATIVE CARE HEALTH TECHNOLOGY ASSESSMENT IN EUROPE

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Background Patient and Public Involvement (PPI) helps to ensure that study findings are useful to end users but is under-developed in Health Technology Assessment (HTA). "INTEGRATE-HTA, (a co-funded European Union project -grant agreement 30614) is developing new methods to assess complex health technologies and applying these in a palliative

care case study. Having experienced the intended and unintended consequences of palliative care services, which vary widely across Europe, patients in six countries (England, Germany, Italy, Netherlands, Norway and Poland) provided valuable insights and advice for scope development.

Aims To establish PPI in a palliative care HTA.

Methods As PPI to assist early scope development in HTA is novel, each country implemented PPI methods as appropriate locally. One of two advocated methods was used, either a qualitative research approach or seeking the views of patients, relatives, carers or patient representatives as research partners. Using a qualitative approach, 21 individual, face-face patient interviews were conducted and analysed thematically. When patients were research partners, an adapted version of the EUnetHTA core model guided 30 face-face discussions. Thematic analysis and conceptual mapping identified key issues.

Findings PPI in palliative care requires researchers to have cultural awareness of the acceptability of engaging in discussions around dying in each country. Ensuring positive PPI experiences and effective participation by acknowledging patient knowledge and experience whilst establishing a two-way flow of information in the HTA process is essential. Partnership working between researchers and patients, stakeholder evaluation and remuneration when involved as partners is important.

Conclusions PPI was successfully implemented in each country, assisting patient-centred scope development and identification of important issues related to palliative care. Although there is much to be gained from PPI, 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.