

## International experiences of Patient and Public Involvement (PPI) in the INTEGRATE-HTA project

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**Background:** Palliative care aims to enhance quality of life for patients with life-limiting illnesses and their families. Integrate-HTA, an EU-funded project, is developing new methods to assess complex health technologies and using palliative care in Europe as a case study. One key aspect is enabling PPI throughout the project in six European countries.

**Aims:** To share experiences of PPI and the methodological, ethical and governance challenges associated with this.

**Methods:** The countries involved used one of two advocated PPI approaches; either involving patients, carers and family as research partners or engaging them in qualitative research. Using locally appropriate methods, three countries (England, Norway and Poland) engaged stakeholders as 'research partners'. An adapted version of the EUnetHTA core model guided 33 face-face or telephone discussions with individuals/small groups. Three countries (Germany, Italy and The Netherlands) used a qualitative research approach, conducting 17 face-face, individual or focus group interviews. Thematic analysis identified key issues.

**Results:** We found that clarifying the aims and appropriate methods for PPI in each country at each stage of the project is critical. Overcoming uncertainty about methods their advantages and disadvantages, ethical requirements and training needs were identified as specific issues.

**Discussion & Conclusion:** Tailoring methods to reflect philosophical, ethical and cultural differences about PPI and palliative care poses challenges when undertaking cross-national research and comparing findings. Developing culturally and ethical sensitive methods is essential to engaging PPI in international projects involving palliative care.