The Palliative and End of Life Care Priority Setting Partnership (PeolcPSP): Determining Evidence Uncertainties from the Perspective of the End User of Research

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Aims The aim of the PeolcPSP is to identify unanswered questions about palliative and end of life care and then prioritise those that people who are likely to be in the last years of life, current and bereaved carers and professionals working with people at the end of life agree are the most important.

Methods The process commences with a survey. People are asked to submit questions or ‘evidence uncertainties’ about care, support and treatment for people with life-limiting conditions who may be in the last years of life and about support for current or bereaved carers.

Survey responses are categorised by an information scientist who also checks whether any of the submitted evidence uncertainties have already been addressed by existing evidence. Priority setting workshops with patients, carers and professionals are carried out to determine the ‘top ten’ evidence uncertainties in any category, using the Nominal Group Technique.

Results The results of the PeolcPSP will inform partners’ research strategies and will allow funding bodies to target limited funds to research priorities of the end user.

We will report preliminary findings on the process and types of questions proposed.

Background Palliative and end of life care research is an under-developed research area [National end of life care strategy, 2008; Rapid Review NCRI, 2010].

The importance of involving patients and clinicians in the setting of research questions to avoid funding research that is of low relevance to the end users of the research findings has been highlighted [Chalmers and Glasziou, 2009].

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