Supporting Adults Bereaved Through Advanced Illness: Development of a Core Outcome Set (COS)

Luke Cowie, Annmarie Nelson, Fiona Morgan, Anthony Byrne, Sara Pickett, Stephanie Swell, Jim Fitzgibbon, Emily Harrop. Marie Curie Palliative Care Research Centre (MCPCRC), Cardiff University; Specialist Unit for Review Evidence (SURE), Cardiff University; Swansea Centre for Health Economics, Swansea University.

Background A lack of evidence-based guidance on bereavement support (Hudson et al., 2012) and of consistency in the measures used in clinical practice and research to assess bereavement outcomes (Forte et al., 2004) have been identified. The heterogeneity in outcome measures makes it difficult to assess and benchmark clinical services. It is also challenging to combine and compare research results, and draw robust conclusions on effectiveness to inform clinical practice and service delivery. One step to resolving this situation is to develop a core outcome set (COS). This represents the ‘minimum that should be measured and reported in all clinical trials of a specific condition’ (www.comet-initiative.org).

Aim This project, funded by Marie Curie, aims to develop a COS that is specific to bereavement in adults following advanced, progressive illness.

Methods The COS will be developed through a series of distinct methodologies. First, outcomes utilised in the studies identified by systematic review will be mapped into different domains. Second, an expert consensus day will be convened with up to 30 stakeholders to identify any further outcomes and engage in a consensus methodology (Gallagher et al., 1993) designed to identify the most important. Finally, the list of core outcomes will be further refined through an online Delphi survey with items rated over two rounds to reach consensus on which items should be included in the COS.

Results/conclusions The COS will allow research results to be compared, contrasted and combined, and will have additional benefits for clinical practice and the commissioning of services.

REFERENCES