

# Involving Healthcare Professionals and Family Carers in Setting Research Priorities for End-of-Life Care

<https://doi.org/10.12968/ijpn.2017.23.2.56>

## **For which topic were research priorities identified?**

palliative and end of life care

## **In which location was the research priority setting conducted?**

Europe - United Kingdom

## **Why was it conducted at all?**

Palliative and end of life care is an under-researched area and requires greater attention. There are many unanswered questions to be addressed. But with such scarce resources, it is important that researchers and research funders ensure that they address questions which will bring direct and tangible benefits to patients and their carers, families and friends.

## **What was the objective?**

to ask patients, carers and clinicians what the most important unanswered research questions are

## **What was the outcome?**

a ranking list of 10 research questions

## **How long did the research prioritization take?**

December 2013 - November 2014

## **Which methods were used to identify research priorities?**

JLA method

## **How were the priorities for research identified exactly?**

Step 1: setting up PSP: steering group established, stakeholders and partner organizations identified. Step 2: identifying evidence uncertainties: gathering unanswered questions via survey: participants were asked: "What question(s) do you have about care, support and treatment for people who are in the last few years of their lives that could help them to live as well as possible? What question(s) do you have about care, support and treatment for those rapidly approaching the end of their lives?", 1403 responses. Step 3: data processing: refining questions and uncertainties: identifying themes, searching for evidence, transforming questions into PICO format, PICO questions formed, questions reviewed, duplicates combined and checked again for scope checked against evidence, final list of 100 questions formulated, then reduced to 83 by combining similar questions. Step 4: interim ranking: survey asking participants to rate each of the 83 longlisted question, top rated 31 questions identified, steering group then combined questions, resulting in shortlist of 28 questions. Step 5: final prioritization: workshop: participants were asked to rank 28 questions before workshop, during workshop small group discussions and small group rankings, final ranking in plenary

## **Which stakeholders took part?**

Workshop: 24 participants including current and bereaved carers, patients, nurses, palliative care consultants, a social worker and former GP.

## **How were stakeholders recruited?**

The survey was disseminated by stakeholders and steering group members to their networks via email, newsletters, social media, web posts, presentations and stands at conferences, and blogs.

## **Were stakeholders actively involved or did they just participate?**

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of patient and carer representatives, health and social care professionals, and representatives from the funding bodies.