

Development of Advance Care Planning Research Priorities: A Call to Action

Johnson et al. (2013)

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For which topic were research priorities identified?

advance care planning

In which location was the research priority setting conducted?

international

Why was it conducted at all?

Most terminally ill elderly patients value quality of life. They do not want to prolong their lives by resorting to medical technologies, and they do not wish to be a burden to their families. They want to place their trust in their physicians, have ready access to their physicians, be given honest information about their condition, and be offered help with making difficult decisions about care. However, there are challenges to be faced in delivering high-quality end-of-life (EOL) care to such patients. Advance care planning (ACP) may be a solution to such challenges. It is a process in which people determine and consider their options related to future healthcare decisions and perhaps assign a substitute decision maker who will act on their behalf if they find themselves incapacitated due to injury or illness. Accordingly, effective implementation of ACP strategies is considered a high priority in the effort to improve EOL care. However, important questions about the best way to implement ACP, the barriers to ACP implementation, and the impact on patient and economic outcomes still need to be addressed.

What was the objective?

to develop a national, prioritized research agenda for advance care planning

What was the outcome?

a ranking list of 9 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

focus group; survey

How were the priorities for research identified exactly?

Step 1: focus groups: brainstorming research questions in small groups, questions then presented to larger group, questions refined, and finalized, final list of 17 research topics formulated. Step 2: determining criteria for prioritization, interviews with stakeholders to confirm criteria, further interviews and focus groups to refine prioritization criteria, 9 criteria determined. Step 3: assignment of importance weights: survey asked participants to rate importance of each of the criteria. Step 4: rating research topics: survey: participants were asked to rate each of the ACP research topics against each of the prioritization criteria. Step 5: result analysis: combining importance weights of criteria with topic ratings

Which stakeholders took part?

Key decision makers (clinician leaders, administrators, policy analysts, and government consultants), practitioners, researchers. Focus group: 20 participants. Survey: 62 participants: 20% researchers, just under 40% decision makers, less than 1/3 clinicians: physicians (67%), nurses (20%), spiritual care (13%).

How were stakeholders recruited?

Participants were recruited via ACP meetings. E-mails were sent out inviting 100 individuals to participate. Of these 100, 62 replied and agreed to participate.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.