

Developing Research Priorities for Palliative Care of People with Intellectual Disabilities in Europe: A Consultation Process using Nominal Group Technique

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For which topic were research priorities identified?

palliative care of people with intellectual disabilities

In which location was the research priority setting conducted?

Europe

Why was it conducted at all?

Empirical knowledge around palliative care provision and needs of people with intellectual disabilities is extremely limited, as is the availability of research resources, including expertise and funding.

What was the objective?

to develop an agenda for research priorities for palliative care of people with intellectual disabilities in Europe

What was the outcome?

a ranking list of 4 research topics

How long did the research prioritization take?

2 days

Which methods were used to identify research priorities?

workshop

How were the priorities for research identified exactly?

Step 1: workshop: round table presentations of the participants' research to date followed by discussions about perceived gaps in knowledge and methodological, practical and ethical issues of collecting data around death, dying and palliative care for people with intellectual disabilities, followed by identification of research priorities with nominal group technique: silent generation of research priorities by asking participants: What are the research priorities for palliative care of people with intellectual disabilities in Europe?, followed by round robin recording of research priorities, 40 research topics were proposed, topics were then clarified and collapsed into 11 research topics, participants were then asked to select the 5 most important research topics and rank them in order of importance

Which stakeholders took part?

Academics, clinicians in the field of palliative care and intellectual disability. 16 participants.

How were stakeholders recruited?

The participants were academics and clinicians who had been involved in research projects related to aspects of palliative care for people with intellectual disabilities within Europe. The group was convened through networking and included members of the EAPC Taskforce on Intellectual Disabilities as well as participants and presenters of scientific papers.

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.