

# Patient and Public Involvement in Identifying Dementia Research Priorities

Bethell et al. (2018)  
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**For which topic were research priorities identified?**  
dementia

**In which location was the research priority setting conducted?**  
North America - Canada

**Why was it conducted at all?**  
Patient and public involvement in health research is being advocated for on methodological and moral grounds, including by national funding agencies in the United States (Patient-Centered Outcomes Research Institute (PCORI), Canada (Canadian Institutes of Health Research, Strategy for Patient-Oriented Research), and the United Kingdom (National Institute for Health Research (NIHR), INVOLVE <http://www.invo.org.uk/about-involve/>), yet there is still a gap between current clinical research and the priorities of patients, caregivers, and clinicians. The Canadian Dementia Priority Setting Partnership (PSP) was established to engage individuals with personal or professional experience of, or interest in, dementia: including persons with dementia, friends, family, caregivers and health and social care providers.

**What was the objective?**  
to engage persons with dementia, friends, family, caregivers, and health and social care providers to identify and prioritize their questions for research related to living with dementia and prevention, diagnosis, and treatment of dementia

**What was the outcome?**  
a ranking list of 10 research questions

**How long did the research prioritization take?**  
Survey: May 2016 - August 2016. Interim ranking: April 2017 - May 2017. Workshop: 2 days in June 2017

**Which methods were used to identify research priorities?**  
JLA method

**How were the priorities for research identified exactly?**  
Step 1: survey: participants were asked for questions about living with dementia, as well as dementia prevention, diagnosis, and treatment. Step 2: data cleaning: answers categorized, summarized, out-of-scope removed, submissions that could not be formulated into a question and questions that asked only once were excluded, resulting list then checked against available research evidence, list of 79 questions about dementia was created. Step 3: interim ranking: via survey, participants were asked to identify their unranked top 10 priorities, number of times each question was selected was tabulated, ranked list of questions was created. Step 4: additional input from persons with dementia sought out: support group of persons with dementia discussed questions and themes, 3 additional questions added. Step 5: final prioritization: workshop with small and large group discussions and rankings

**Which stakeholders took part?**  
Persons with dementia, friends, family, caregivers, health care providers, social care providers. Survey: 1217 participants. Interim ranking: 249 participants. Workshop: 28 participants: persons with dementia (n=7), friends, family, and caregivers (n=5), health and social care providers (n=9), Alzheimer Society representatives (n=5), and members of an organization representing long-term care home residents (n=2).

**How were stakeholders recruited?**  
The survey was promoted by partner organizations through social media, mailed surveys, and group discussions.

**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 18 members (amongst others 1 person with dementia). The members oversaw and advised the study, promoted surveys and nominated workshop participants.