

The Top Research Questions Asked by People with Lived Depression Experience in Alberta: A Survey

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For which topic were research priorities identified?

depression

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

To support patient-oriented setting of priorities for depression research in Alberta, the Patient Engagement Platform of the Alberta Strategy for Patient Oriented Research's Support for People and Patient-Oriented Research and Trials Unit and Alberta Health Services' Addiction and Mental Health Strategic Clinical Network, along with partners in addictions and mental health, designed the Alberta Depression Research Priority Setting Project.

What was the objective?

to survey patients, caregivers and clinicians/researchers in Alberta about what they considered to be the most important unanswered questions about depression

What was the outcome?

a ranking list of 11 research questions

How long did the research prioritization take?

Survey: August 2016 - December 2016. Data analysis: August 2016 - December 2016. Interim ranking: 1 week June 2017. Workshop: June 2017. Knowledge synthesis: July 2017 - October 2017. Knowledge translation: November 2017 - January 2018.

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: collecting research questions: Steering Committee co-designed survey, participants were informed that their participation would help inform the research community on the direction of research, participants were asked to submit questions that matter most to patients, families and others who support Albertans with depression, 1270 questions submitted. Step 2: data processing: duplicates and out-of-scope questions removed, question re-formulated into PICO format, shortlist of 66 research questions across 7 categories created. Step 3: interim ranking: via survey, participants were asked to rate each of the 66 research questions, 25 medium- to high-priority questions identified. Step 4: final prioritization: workshop: participants were asked to prioritize the questions from most important to least important before the workshop, during the workshop: small group discussions with nominal group technique, final ranking. Step 5: literature review: to determine to what extent, if any, the top 11 questions had been addressed by previous research. Step 6: final report disseminated

Which stakeholders took part?

Survey: 445 Albertans with lived experience of depression: 283 persons with depression, 74 family members or caregivers, 28 healthcare professionals, 14 clinicians treating depression and others. Interim ranking: 49 participants. Workshop: 20 participants

How were stakeholders recruited?

A convenience sampling strategy was predominantly used to recruit people with depression, people who care for those with depression and health care professionals who treat people with depression. Participants were recruited via advertisements on social media platforms (Twitter and Facebook), through websites of partner organizations and through network connections of Steering Committee members. A purposive sampling technique was used, employing established connections and relationships through partner organizations (e.g., leveraging positive connections at the Bissell Centre, Edmonton). A sampling frame was developed to address the study objectives by including people with lived experience with depression, who are justifiably considered experts, with representation from a broad demographic spectrum (e.g., age, ethnicity, immigration status).

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 6 people with depression, 1 caregiver, 4 clinicians, 5 researchers and 2 members of the ADRPSP planning committee. The members co-designed survey, were involved in data processing and participated in the workshop