

The top research questions asked by people with lived depression experience in Alberta: a survey

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Abstract

Background: 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. The aim of the project was to survey patients, caregivers and clinicians/researchers in Alberta about what they considered to be the most important unanswered questions about depression.

Methods: The project adapted the James Lind Alliance Priority Setting Partnership method into a 6-step process to gather and prioritize questions about depression posed by people with lived depression experience, which included patients, caregivers, clinicians and health care practitioners.

Results: Implementation of the project, from initial data collection to final priority setting, took 10 months (August 2016 to June 2017). A total of 445 Albertans with lived experience of depression participated, ultimately identifying 11 priority depression research questions spanning the health continuum, life stages, and treatment and prevention opportunities.

Interpretation: This project is a fundamental step that has the potential to positively influence depression research. Including the voices of Albertans with lived experience will create advantages for depression research for Albertans, researchers and research funders, and for patient engagement in the research enterprise overall.

Depression is a major public health issue in Canada.¹ About 8% of adults aged 25–64 years are projected to experience major depression at some time in their lives.² Depression is estimated to account for at least \$32.3 billion of direct and indirect costs to this nation annually.³ Continued investment in research that explores prevention and treatment is needed,^{4,5} in particular through engaging patients (i.e., people with depression, family members and informal caretakers) in this endeavour to better ensure that research is relevant to their needs. Patient engagement occurs “when patients meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge.”⁶ However, research findings suggest that medical research topics are selected predominantly by researchers and funding agencies, with little input from patients themselves,⁷ and that, even when patients are engaged in setting research priorities, their opinions are sometimes overlooked.⁸ Engaging people with lived experience of a health situation in setting research priorities is one structured way of influencing researchers and research funders to consider their opinions.

The goal of the Alberta Depression Research Priority Setting Project (ADRPSP) was to have patients and clinicians in Alberta identify the most important unanswered questions about depression by answering the research question “What are the patient and clinician priorities for depression research in Alberta?” The project was codesigned and complemented by the Patient Engagement Platform of the Alberta Strategy for Patient-Oriented Research's Support for People and Patient-Oriented Research and Trials Unit, Alberta Health Services' Addiction and Mental Health Strategic Clinical Network and the Alberta Depression Research Hub of the Canadian Depression Research and Intervention Network. In this paper, we describe the process used to survey patients,

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caregivers and clinicians on what they believe are unanswered questions about depression. We report our findings taking into account the Guidance for Reporting Involvement of Patients and the Public checklist criteria for patient and public involvement⁹ and the Checklist for Reporting Results of Internet E-Surveys.¹⁰

Methods

Setting and participant recruitment

The study focused on recruiting people who lived within the geographic boundaries of Alberta. The partner organizations recruited 14 members from their communities to form an ADRPSP Steering Committee consisting of 6 people with depression, 1 caregiver, 4 clinicians, 5 researchers and 2 members of the ADRPSP planning committee (some members represented more than 1 category, i.e., a person with depression who was also a clinician). 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. In an effort to engage populations that have traditionally been voiceless in health research, including Métis and homeless people, 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,”¹¹ with representation from a broad demographic spectrum (e.g., age, ethnicity, immigration status).

Study design

The James Lind Alliance Priority Setting Partnership method brings patient and clinician groups together on an “equal footing” to produce a jointly agreed-on list of research priorities, which are recorded and made available to researchers and funders.¹¹ A “funnel approach” is used: a larger sample of people with lived experience first identifies research questions about a health issue, a smaller sample ranks the questions, and a still-smaller sample prioritizes the final questions.¹¹

The Patient Engagement Platform adapted the 4-step James Lind Alliance method into a 6-step process to ensure that the voices of people with lived experience of depression were included throughout the project. An egalitarian, consensus-building process was used, combining the perspectives of people with lived depression experience and clinicians. The ADRPSP is, therefore, classified on the “Collaborate” level of Patient and Researcher Engagement in Health Research Schematic.¹² The implementation of the project, from initial data collection to final priority setting, took 10 months (August 2016 to June 2017).

Step 1: Data gathering (online and paper survey)

The Steering Committee codesigned the survey by consensus, with the goal of ensuring that people with lived experience of depression identify their concerns and unanswered questions about depression. A copy of the survey can be found in Appendix 1 (available at www.cmajopen.ca/content/6/3/E398/suppl/DC1). The ISO-27001-compliant Snap Surveys online platform (<https://www.snapsurveys.com/>) was used and was hosted by Alberta Innovates – Health Solutions, with data stored on secured internal systems. Access to the application was limited by site licences, and the application was accessible from onsite/internal systems only. In addition, the Web host function was password protected.

Participants were informed that their participation would help inform the research community on the direction of research, focusing on questions that matter most to patients, families and others who support Albertans with depression. To facilitate data collection, participants were given a specific URL to access the questionnaire. They were not required to provide their name or contact information. The survey took 10–20 minutes to complete. No incentives were provided to complete the survey.

Paper copies of the questionnaire were disseminated to populations who may have had more limited online access: 100 paper surveys were taken to a Métis settlement in Buffalo Lake (9 returned [response rate 9%]), and 25 paper surveys were distributed to homeless people at the Bissell Centre (13 returned [response rate 52%]).

Survey responses were accepted between August and December 2016.

Step 2: Question analysis and review

After excluding responses to the online survey from outside Alberta ($n = 192$), Steering Committee members analyzed the data for diversity of representation. Diversity was analyzed periodically throughout the survey (on a weekly basis for the first 3 months and every other week for the last month) to inform the Steering Committee about representation across responses.

Next, the open-ended questions submitted by people with lived experience were reviewed. Duplicate questions were removed, as were questions that 2 or more Steering Committee members agreed did not meet the purpose of the project. The remaining questions were reviewed by the entire Steering Committee to ensure that they were easy to understand, were worded appropriately (without jargon or acronyms) and reflected the original intent of the questions submitted. In-person meetings allowed the Steering Committee to ensure the questions were being interpreted through a patient lens.¹³ The aim was to fully capture the nuances in language on the list of prioritized questions. A smaller subset of questions was assigned to dyads within the Steering Committee (i.e., 1 person with lived experience and 1 clinician) to formulate the research questions using the PICO (population, intervention, comparator, outcome) format,¹⁴ where possible.

Step 3: Question rating (online survey)

An online rating survey was created and the URL shared on Twitter and through contact networks of the Steering Committee. Over 1 week in June 2017, survey respondents identified

which of the short-listed questions were most important using a 5-point Likert scale: not a priority, low priority, medium priority, high priority or undecided. Data were collected and managed with the use of REDCap electronic data capture tools,¹⁵ a secure and user-friendly application hosted at the University of Alberta. Access to the application was limited by site licences, was accessible from onsite/internal systems only and was password protected. Questions that were most frequently identified as “high priority” were ranked higher than or equal to other questions to establish the order of question importance. This ultimately generated a list of research questions rated in order of importance. No incentives were provided to complete the survey.

Step 4: Question prioritization (in-person workshop)

Twenty participants (11 Steering Committee members and 9 members of the public, including clinicians, health care professionals and people with lived experience) selected by recommendation of the Steering Committee attended a full-day workshop in June 2017 to identify the top 10 questions submitted by Albertans. In addition, 3 facilitators, 3 Patient Engagement Platform members and 2 observers (1 student and 1 evaluator) attended and supported the workshop but did not participate in ranking. This sample fits within the James Lind Alliance recommendation that prioritization workshops not exceed 30 participants.¹¹ Before the workshop, participants were given a ranking tool listing the top-ranked 25 questions from the rating survey and were asked to prioritize the questions from most important to least important. At the workshop, a nominal group technique was used, whereby participants were divided into 3 groups to compare their personal rankings. Each group had a facilitator and a recorder to manage the dialogue and guide the process toward group consensus. After 2 iterative rounds of dialogue and small-group work, the overall rankings of each question were brought back to the collective group for final ranking, and 11 questions were identified (v. the James Lind Alliance suggestion of 10 questions, as 2 questions had equal rating).

Step 5: Knowledge synthesis

The Knowledge Translation Platform of the Support for People and Patient-Oriented Research and Trials Unit searched the available literature to determine to what extent, if any, the top 11 questions had been addressed by previous research (to be reported in a forthcoming manuscript). Manuscripts on the knowledge synthesis and literature search strategies, including the identification of knowledge gaps, are in process.

Step 6: Knowledge translation

The Patient Engagement Platform developed a final report¹⁶ in conjunction with the Steering Committee and planned, implemented and hosted a media launch that resulted in television, radio and print news coverage, as well as attendance by researchers. A separate paper discussing the patient engagement components of the ADRPSP has been published elsewhere.¹⁷ The Patient Engagement Platform is working with the identified partner organizations to facilitate dissemination and knowledge-translation opportunities by developing a knowledge-mobilization plan.

Ethics approval

The ADRPSP was approved by research ethics boards at the University of Alberta and Athabasca University. The research ethics boards approved “implied consent”; that is, consent was implied by the positive act of completing the survey.

Results

A total of 445 Albertans with lived experience of depression participated in identifying depression research questions (Table 1). Forty-nine people rated the research questions to inform the 25 medium- to high-priority questions.

Table 1 (part 1 of 2): Survey participant demographic characteristics and experience with depression

Characteristic/experience	No. (%) of respondents n = 445
Type of participant	
Person with depression	283 (63.6)
Family member or caregiver of person with depression	74 (16.6)
Health care professional caring for people with depression	28 (6.3)
Counsellor	3 (10.7)
Nurse	7 (25.0)
Psychiatrist	1 (3.6)
Psychologist	4 (14.3)
Social group worker	1 (3.6)
Other	12 (42.8)
Clinician treating depression	14 (3.1)
Other*	46 (10.3)
Sex	
Male	88 (19.8)
Female	354 (79.6)
Did not report	3 (0.7)
Age group, yr	
18–29	76 (17.1)
30–39	108 (24.3)
40–49	116 (26.1)
50–59	95 (21.3)
60–69	40 (9.0)
70–79	8 (1.8)
≥ 80	2 (0.4)
Primary place of residence	
Edmonton	144 (32.4)
Calgary	141 (31.7)
Elsewhere	160 (36.0)
Immigrant status (between 2011 and 2016)	10 (2.2)

Table 1 (part 2 of 2): Survey participant demographic characteristics and experience with depression

Characteristic/experience	No. (%) of respondents <i>n</i> = 445
Ethnic origin†	
Canadian	287 (64.5)
European	150 (33.7)
East European	29 (6.5)
Métis	25 (5.6)
North American	16 (3.6)
First Nation	13 (2.9)
Asian	11 (2.5)
South American	6 (1.3)
African	5 (1.1)
Middle Eastern	5 (1.1)
Central American	3 (0.7)
Inuit	2 (0.4)
Other	6 (1.3)
Prefer not to say	5 (1.1)
Experience with depression (<i>n</i> = 420)	
Lifetime	119 (28.3)
> 5 yr	159 (37.8)
3–5 yr	39 (9.3)
1–2 yr	28 (6.7)
< 1 yr	12 (2.8)
New diagnosis of depression	4 (1.0)
Other	15 (3.6)
Recovered from depression	44 (10.5)
No. of months in year with depression experience (<i>n</i> = 352)	
10–12	164 (46.6)
7–9	32 (9.1)
4–6	62 (17.6)
≤ 3	94 (26.7)
*Nurse educator, certified diabetes educator, bail supervisor, clinical exercise physiologist, clinical scientist, dietitian, holistic nutritionist, counsellor (intern), life coach, massage therapist, medical laboratory technologist, neurologist, paramedic, occupational therapist, registered acupuncturist, senior quality improvement consultant.	
†Some participants self-identified in more than 1 group.	

The ADRPSP was successful in gaining representation from people with lived depression experience at every step. In step 1 (data gathering), more than three-quarters of the respondents (357 [80.2%]) identified as people with depression or as family members or caregivers of a person with depression. Within this population, 159/420 (37.8%) had more than 5 years' experience with depression, and 119/420 (28.3%) identified a lifetime of experience with depression. Nearly all participants (44 [90%]) in step 3 (question rating) identified as having some experience

with depression, as did more than half of participants (12 [60%]) in step 4 (question prioritization).

The summary of outputs of the project across each of the 6 steps is provided in Table 2. The final 11 priority research questions are identified in Figure 1.

Interpretation

In this study, we used a systematic and collaborative approach to identify 11 priority questions for depression research from the perspective of Albertans with lived experience of the condition. People with lived experience of depression and clinicians were involved in all steps of the research question identification and prioritization process. Aligning patient and clinician interests is challenging. The necessary “social conditions for dialogue” necessary for this alignment do not simply appear; therefore, an appropriate methodology should include strategies for developing mutual trust and commitment from otherwise disparate groups.¹⁸

This strategy presents many advantages for patients, clinicians and researchers and for the patient engagement in research enterprise itself. First, as suggested by the International Association for Public Participation's spectrum of public participation,¹⁹ the higher the degree of participation within research-priority-setting activities, the more accurately the results reflect the community.¹² In the current study, more than three-quarters of the initial respondents identified as having lived experience of depression. The effects of this degree of participation may be illustrated by the extent to which the prioritized research questions span the health continuum, considering different life stages, treatments and prevention opportunities. The comprehensiveness of the questions reflects the complexity of depression and the multiple ways in which it affects the well-being of those affected. Second, the present study presents an opportunity to address research priorities that are meaningful to Albertans. Researchers have suggested that priorities established by people with lived experience are better aligned with the complex experience of living with disease and make it easier to gain broader collaboration from patients across the research activity spectrum.^{18,20} This approach recognizes patient contributions as valuable, acknowledging the expertise brought forward from patients' own experience.^{21,22}

Although the James Lind Alliance Priority Setting Partnership method incorporates a simultaneous review of the literature to validate research uncertainties, the ADRPSP validated research questions through the creation of common themes that emerged from survey respondents, workshop participants and Steering Committee members. Questions were not systematically filtered based on existing research before the prioritization process began; therefore, we believe that the results authentically reflect the voices and perspectives of Albertans, including people with lived experience of depression. The literature on patient engagement suggests several benefits from such meaningful representation, including improved quality of research design, increased participant enrolment and decreased attrition in research studies, wider

Table 2: Summary of process and outputs of the Alberta Depression Research Priority Setting Project for determining top 11 depression research questions

Process	Output
—	<ul style="list-style-type: none"> • 14-member Steering Committee formed
Step 1: Data gathering (participant online and paper survey), August–December 2016	<ul style="list-style-type: none"> • 445 respondents (from Alberta only) • 1270 questions and comments on depression received
Step 2: Question analysis and review (Steering Committee), August–December 2016	<ul style="list-style-type: none"> • 350 questions removed that were submitted by participants residing outside Alberta from how many respondents? • 724 questions removed owing to duplication • 196 questions reformulated into PICO (population, intervention, comparator, outcome) research question format¹⁴ and refined (e.g., removed jargon) • Short list of 66 research questions across 7 categories went forward for final priority setting (in order: diagnosis and treatment; society, culture and environment; medication, biology and physiology; child and youth; access, service, funding and policy; training and education; and family and behaviour)
Step 3: Question rating (participant online survey), 1 wk in June 2017	<ul style="list-style-type: none"> • 49 participants rated 66 research questions (through online survey) • 25 medium- to high-priority questions (most commonly asked) identified
Step 4: Question prioritization (in-person participant workshop), 1 d in June 2017	<ul style="list-style-type: none"> • 20 participants prioritized 11 research questions (3 facilitators, 3 Patient Engagement Platform members and 2 observers attended and supported workshop but did not participate in ranking) • 14 remaining questions not selected in the top 11 were deemed worthy of consideration for future depression research
Step 5: Knowledge synthesis (Patient Engagement Platform and knowledge translation), July–October 2017	<ul style="list-style-type: none"> • 25 rapid reviews of depression research questions conducted
Step 6: Knowledge translation (Patient Engagement Platform and knowledge translation), November 2017–January 2018 and ongoing	<ul style="list-style-type: none"> • Dissemination and knowledge mobilization opportunities • Public report¹⁶ launched to media January 2018

application of research findings and overall improved research effectiveness.^{21,23,24} Therefore, we believe that using the results from our study can assist in closing the knowledge-to-action gap²⁵ by mobilizing timely and relevant data to inform clinical care and research.

Recent research suggests that building collaborative relationships between the patient and researcher requires an informed and compassionate understanding of how to effectively and efficiently involve patients in a meaningful and feasible way.²⁶ The present study helps illustrate outcomes of meaningful patient and researcher engagement, building on other such work in Canada.^{20,27–35} It also contributes to the growth of evidence that people with lived experience are valuable research partners.

Limitations

Several important limitations should be considered when applying our findings. First, the convenience-sampling strat-

egy may have resulted in bias due to over- and underrepresentation of subgroups compared to the population of interest. This inherent limitation was addressed in part by continuous review of demographic characteristics of participants who completed the online survey and question-ranking steps. Although the survey had good reach, some groups were underrepresented, which is an ongoing challenge recognized in the patient-engagement literature.³⁶ Committed efforts were made to reach these populations; however, recruitment from these groups was not very successful. Furthermore, we could not calculate a response rate because the total sample number was unknown. To mitigate this issue in future research, a 2-step process could be used: self-identified participants first agree to participate in the study, and, once this is documented, they are sent the questionnaire to complete, thereby allowing calculation of the response rate.

Second, the possible subjective influence of Steering Committee members and patients, particularly in the smaller



Alberta Depression Research Priority Setting Project (2017, August 10). [Alberta's Top 11 Depression Research Priorities: Determined by Albertans with Lived Experience] [Infographic]. Proceedings from the final workshop with the Alberta Depression Research steering committee and workshop participants, Edmonton AB June 12, 2017.



Figure 1: Alberta's top 11 depression research priorities.

group that completed the final prioritization of the research questions, should be considered in establishing research priorities to ensure that decisions are not informed solely by 1 type of evidence.

Third, a small group ranked the 25 research questions (step 3). Although it is expected that the sampling frame narrows throughout the 6 steps,¹¹ 2 factors may have decreased the number of people who might have participated at this

step: a limited time frame (1 week) for completing the ranking and the fact that the ranking occurred during the summer, which may have decreased the available sample.

Considering these limitations, the Steering Committee relied on the recurrence of themes (i.e., saturation) as one indicator of representativeness, while continuously updating our strategies to solicit input from underrepresented populations. Future priority setting would focus on increasing representation from male participants, rural communities, immigrants and ethnically diverse communities to ensure that priorities are representative of all Albertans with depression. The specific demographic profile of Alberta would need to be considered, with 15.8% of the population reporting Aboriginal identity.³⁷

Conclusion

We hope that the outcomes of the ADRPSP will better align research objectives with the needs of Albertans with lived experience of depression and will lead to funders' identifying some or all of these top 11 research questions as qualifying for monetary resource allocation and, as a result, to research.²¹ Future studies can adapt this process to actively engage patients throughout the research cycle. It is expected that this strategy will promote greater understanding of and insight into depression research, while continuously building rapport with people with lived depression experience as central to research processes.^{38,39}

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