

Alberta Depression Research Priority Setting Project





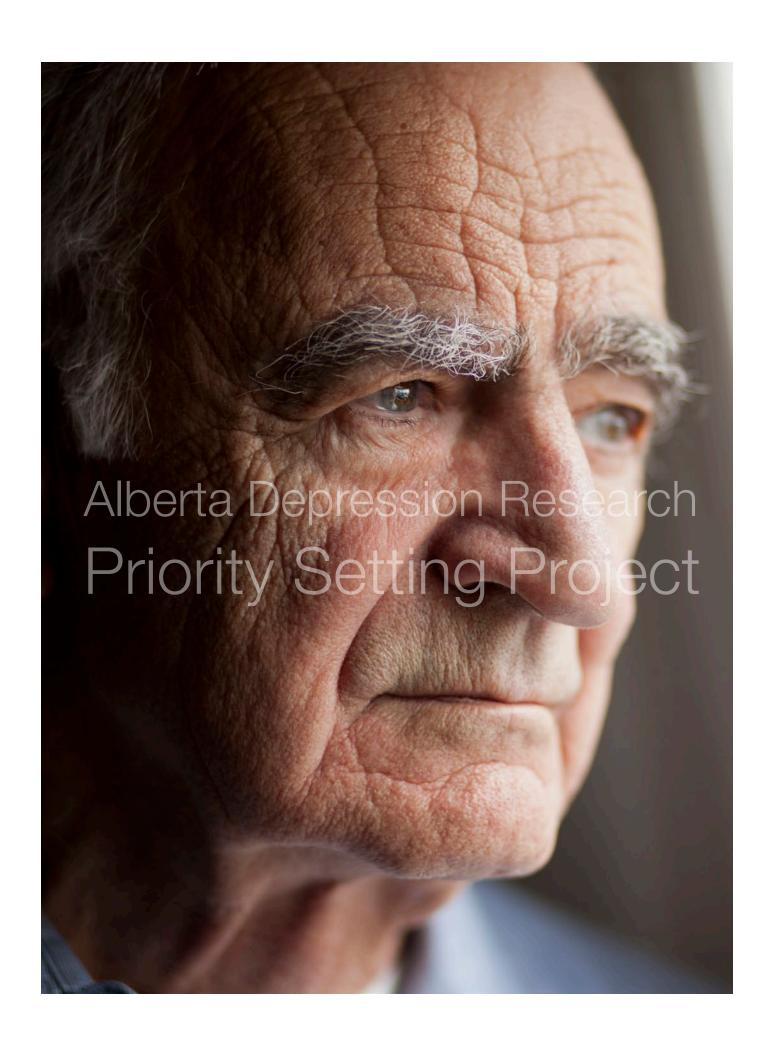






"As a person with lived experience this project allowed me to get my voice back. It gave me the opportunity to advocate for myself and impact research that could affect care I might need in the future. It also allowed me to engage with front line clinicians on an even level which gave me insight into some of the struggles they encounter when providing care to people, such as myself, who are dealing with depression."

Catherine deBeaudrap, Steering Committee Member



Contents

Why a research priority setting project matters to Albertans 2
Why research into depression is a priority for Albertans 2
Who was engaged in the project 4
Who drove the process 4
How engagement turned unlimited questions into 11 research prioritie

es 6

- The process
- Survey respondents
- Alberta's top 11 research priorities determined by those with lived experience

What was learned 11

- Summary of learnings
- Participant perspectives

What next steps are needed to move from knowledge to action 15

17 Appendices

- Timelines
- Shortlist of 25 priorities
- Communication samples

Contact 21

WHY a research priority setting project matters to Albertans

Alberta has highly trained researchers who collaborate globally and contribute to advancing our knowledge every day.

The questions Alberta researchers and researchers worldwide seek to answer are largely determined by matching their interests to grant opportunities. Yet evidence shows that research has greater and more immediate impact if research priorities are determined by the end users of the knowledge generated: patients, caregivers, and clinicians.

Without the involvement of those with lived experience¹, research agendas may vary significantly from what patients and clinicians need, meaning the research knowledge generated has limited practical value.²

The Alberta Depression Research Priority Setting Project, officially launched in April of 2016, was established to demonstrate that patients, families and clinicians can be meaningfully involved in determining a research agenda aligned to the needs of Albertans in an area of research that mattered greatly to them.

The project was modeled after a process developed in the UK by the James Lind Alliance and adapted to fit the Alberta context.

- 1 For the purposes of this project, those with lived experience include those diagnosed with a disease, the loved ones who care for them, and frontline community health care professionals.
- 2 Tallon, D. et al. (2000) 'Relation between agendas of the research community and the research consumer', The Lancet, Vol. 355. Pp. 2037 40





WHY research on depression is a priority for Albertans

Project partners chose to focus on depression for this demonstration project, because it is a significant health problem and health risk in the province. More than 301,000 Albertans are currently affected by a mood disorder and one in 10 Albertans will experience depression in their lifetime.¹

Depression can affect anyone, but particularly targets vulnerable populations, our young, the elderly, and those with physical illnesses.

- The highest rate of depression is among teens and adults under 20 years of age.
- Forty-five percent of seniors in residential care homes suffer from depression.
- Forty per cent of people with physical illness also have depression.

Depression steals futures. Suicide is the second leading cause of death among Canada's youth.

Depression steals livelihoods. Seventy per cent of people with serious mental illnesses are unemployed.

Depression steals productivity. Half a million Canadians miss work every day due to stress-related symptoms of depression. ²

- 1. Statistics Canada 2014
- 2. Presentation of statistics is adapted from the Canadian Depression Research and Intervention Network website Depression Facts.

"The passionate and very well-informed participation from the wide spectrum of stakeholders within the committee and among the generous respondents to the priority-setting survey, was truly unique and inspiring. The successful articulation and prioritization of under-studied areas of depression research provides clear support for the use of this method to direct future health-research priority setting of greatest relevance to the community we serve."

Scot Purdon, Steering Committee member

WHO was engaged

AbSPORU and Alberta Innovates provided in-kind support for survey design, development, implementation, and a web presence for communications and promotion. The AbSPORU Knowledge Translation Platform provided assistance with literature reviews and search strategies. The AbSPORU Patient Engagement Platform provided all financial and human resources to the project including project management, facilitation, administrative support, hosting, and patient reimbursement. Significant support developing graphs was provided by the AbSPORU Data Platform and the final infographic of the Top 11 priorities was developed by AHS.

3 Planning organizations

- Alberta SPOR SUPPORT Unit AbSPORU Patient Engagement (PE) Platform
- AHS Addictions and Mental Health Strategic Clinical Network (SCN)
- Canadian Depression Research and Intervention Network (CDRIN)

5 Partner organizations

- Canadian Institutes of Health Research (CIHR)
- Alberta Innovates (formerly Alberta Innovates Health Solutions)
- Alberta Health
- Alberta Health Services
- Athabasca University
- 14 Steering committee members representing those with lived experience of depression, carers and clinicians
- Respondents to an in-depth survey to identify research priorities (445 surveys respondents came from Alberta)
- University of Alberta medical students who spent the summer of 2016 conducting literature searches for systematic reviews of effective treatments for depression, knowledge gaps about the effectiveness of treatments and questions raised in the research.

WHO drove the process

The research process was led by the **Alberta Depression Research Priority Setting Steering Committee**, balanced to have equal numbers of those with lived experience and those who treat persons with depression.

Steering Committee members leveraged their broad networks to engage Albertans in the project.

The Steering Committee:

- Collaborated to design the survey and leverage their networks to develop communication and distribution.
- Submitted an abstract and presented a poster at the 2016 Alberta Primary Care Conference and at the 2017 Canadian Association of Health Services, Policy and Research Conference.
- Sorted and categorized survey question responses into relevant themes, both as a collective and in pairs of one person with lived experience and one clinician.
- Identified 70 questions to begin the literature review process.
- Narrowed the 70 questions to 25 priorities.
- Achieved consensus on the top 11 priorities for depression research in Alberta through a workshop process involving additional public participants.



BACK ROW L-R: Lorraine Breault, Catherine deBeaudrap, Ping Mason-Lai, Brad Necyk, Emily Ardell, Katherine (Kay) Rittenbach, Sharon Unger, Scot Purdon, Kelly Hartle KNEELING L-R: Ashton Michael, Yamile Jasaui MISSING: Lorin Vandall-Walker, Ginger Sullivan, Robbie Babins-Wagner

Steering Committee Members

Emily Ardell, The Alex Community Health Centre
Robbie Babins-Wagner, Calgary Counselling Centre
Emily Lorraine Breault, University of Alberta
Catherine deBeaudrap, Lived experience
Kelly Hartle, University of Alberta
Yamile Jassaui, University of Calgary
Ping Mason-Lai, University of Lethbridge
Ashton Michael, Lived experience
Brad Necyk, Lived Experience
Sharon Unger, Lived experience
Scot Purdon, University of Alberta
Katherine (Kay) Rittenbach, AHS
Ginger Sullivan, University of Alberta
Lorin Vandall-Walker, Lived experience

Final Workshop participants Steering Committee Members

Kay Rittenbach
Kelly Hartle
Lorraine Breault
Robbie Babins-Wagner
Catherine deBeaudrap
Yamile Jasaui
Emily Ardell
Scot Purdon
Ginger Sullivan
Lorin Vandall-Walker
Ping Mason-Lai

Additional Public Members

Anne Clifford
Kristina Devoulyte
Bryan Meetsma
Steve Gaspar
Janet Bodnar
Lynne Kaluzniak
Laurie Sutherland
Glenda Maru
Ofelia Leon-Featherstone

Facilitators

Lisa Petermann Levi Borejko Sarah Prescott

Patient Engagement Platform Memnbers

Kiara Krawec Robyn Laczy Sennait Yohannes

Guest

Alex Su - student

HOW the project turned unlimited questions into 11 research priorities

Process

Identify the focus and assemble the team

- Identify area of research for priority setting project in this case, depression.
- Form collaborative partnership (AbSPORU, Addictions and Mental Health SCN and CDRIN)
- Recruit leadership group of persons with lived experience, carers and clinicians to serve on the steering committee.

Generate research questions the public wants answered about depression

- Co-design and launch public online and paper survey.
- Conduct literature review for published research uncertainties. (This was a parallel process to inform next steps and did not influence the identification of priorities.)

Identify common themes and priorities

- Engage Steering Committee members in reviewing 1,200 possible questions from survey responses and combining similar questions and ideas into themes.
- Design and launch a second public survey to ask Albertans to rank the 75 themed questions identified by the Steering Committee.
- Engage Steering Committee members in reviewing the rankings from the second public survey to identify the 25 most commonly asked questions.
- Engage the Steering Committee and additional persons with lived experience, carers, family members, health care professionals and clinicians in a priority setting workshop to identify the top 11 research priorities. The final workshop had 22 participants with lived experience, three recorders, two observers and one event organizer.



1200 questions

Surveys answered by 664 individuals generated 1200 questions, gaps in knowledge or uncertainties regarding prevention and treatment of depression.



75 themes

The 1200 questions were shortlisted after a process of verification and grouping into themes: patient or population, intervention, comparator or control, and outcome (PICO).



25 most commonly asked questions

A second public survey asked Albertans to rank the 75 questions identified in themes. The Steering Committee reviewed these responses to identify the most frequently asked questions.



11 priorities

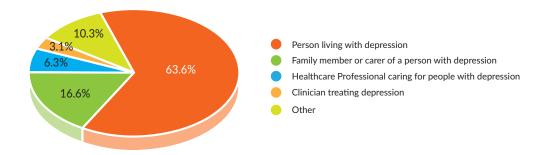
The Steering Committee and additional participants with lived experienced worked through a facilitated session to identify the top 10 priorities, but determined 11 were essential areas of research focus.



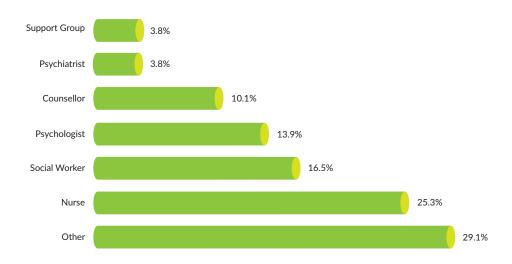
"Just want to let you know how much I appreciated being part of the workshop. Everything was so well organized and implemented. The facilitators were pretty amazing in leading all of us to a successful end of the day! It sure encourages me to continue to be part of research and clinical studies and I know that many of my friends will be more motivated to become involved as well. You all deserve a round of applause!"

Janet Bodnar Workshop participant

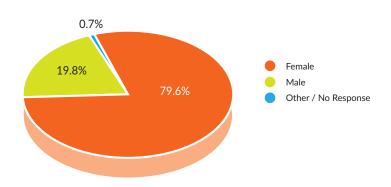
Survey Respondents



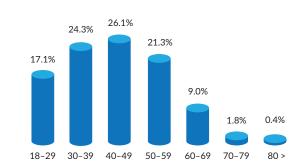
Breakdown of Healthcare Professional / Clinician Type



Survey Responder Gender

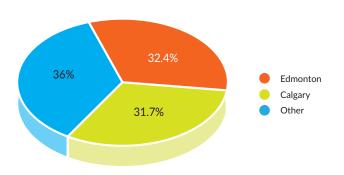


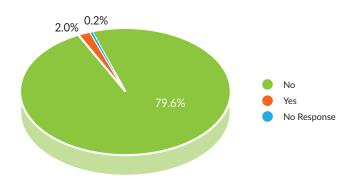
Survey Responder Age



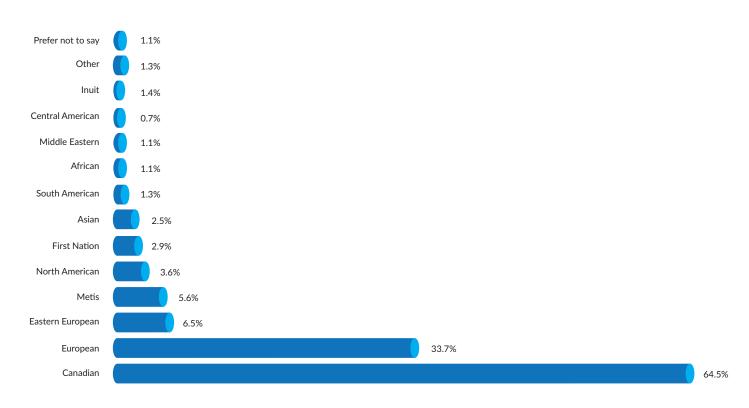
Survey Responder Primary Residence

Survey Responder Immigrant or Refugee (2011–16)

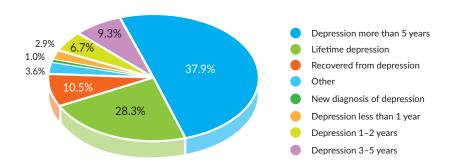




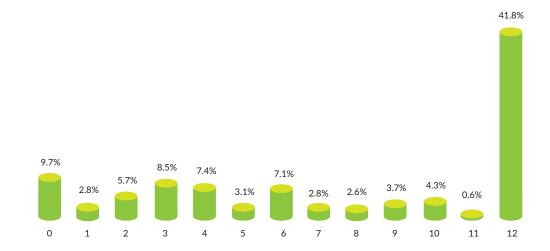
Survey Responder Ethnic Origin



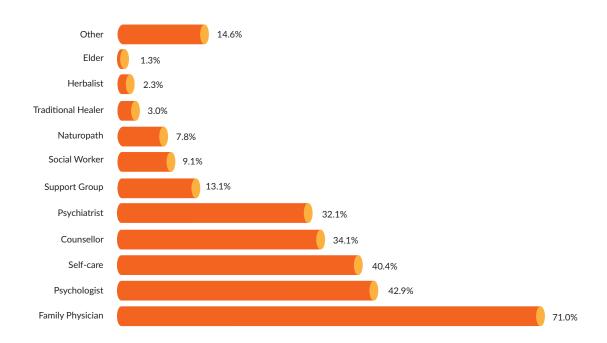
Survey Responder Depression Experience



Monthly Experience with Depression



Depression Care / Support Experience



WHAT was learned

The most important learning was the finalized top 11 list of priorities for research into depression as identified by those with lived experience. Another key outcome, however, was additional evidence to support the effectiveness of involving those with lived experience in research priority setting.

Benefits of the process

- Survey respondents identified gaps that could inform better health care delivery.
- Researchers and clinicians reported an increased understanding of the value patients bring to research and expressed an increased willingness to engage patients in future work.
- Participants with lived experience reported feeling more empowered and confident in their ability to advocate for themselves and others and to contribute to research.
- Relationships built between researchers and those with lived experience have the potential to extend to future collaborations.

Challenges and recommendations

Cost, time, and effort: Building relationships takes time and space and a commitment of financial resources that allows for face to face meetings and training and orientation for volunteers not always expert in data interpretation.

This Steering Committee met monthly and planned to have three face-to-face meetings, but held five at the request of the committee. Support in data interpretation was provided individually and virtually, but could have been more effectively managed in a face-to-face group training session.

This priority setting process may not be suitable for all types of research projects. It takes between 12 and 18 months to achieve the top priorities, but follow-up with knowledge translation, dissemination and action will require substantial investments of resources and time, not clearly articulated in the JLA UK model.

The JLA UK method recommends a full-time resource dedicated to literature reviews for a project, a resource not available to the Alberta Depression Research Priority Setting Project. Given the volume of data for the project it is also unrealistic to complete literature searches on every question submitted. Methodology on this alone could be a publication written from this Alberta experience.

Timing: The winter months, particulary over the holiday season, proved challenging in sustaining Steering Committee member attendance, while seeking ethics approval over the summer months added a delay. It is recommended there be a winter break or refresh after the holiday season and that ethics approval be sought at other times of the year.

Ethics approval: A project where those with lived experience are not the subject of research, but equal partners in the research, is unusual and required more time than usual to explore the ethical considerations.

Participation: Consideration should also be given to acknowledging the value of member participation with an honorarium. Scheduling meetings in advance for the year and seeking optimal meeting times would help participants.

The survey was primarily online, however, 225 paper surveys were delivered to special populations. The survey was delivered online and taken in paper format to Edmonton's Bissell Centre to gather opinions from a homeless population (8 responses). Consideration should be given to including an option of responding verbally. The Steering Committee also recommends purposeful planning to include more participation from rural and remote areas, primary care physicians and clinicians not connected to AHS, and under-represented populations, such as the homeless, Indigenous peoples, refugee and immigrant groups.

"The project has been helpful to develop my understanding of the patient experience in treatment of depression. I often see people in my office experiencing depression and have a better sense of what questions to answer and what information to offer. I have also greatly enjoyed working so closely with those with lived experience."

Emily Ardell Steering Committee member

Participant Perspectives

Catherine deBeaudrap

Teacher, mother and Steering Committee member



For 15 years, Catherine deBeaudrap says she's been "under a doctor's microscope" as her family physician and psychologist worked to support her through multiple periods of depression.

Once she recovered her health after a difficult period a couple of years ago, she realized she had learned a great deal about the ways the system did and didn't work. "When you're going through it, you really don't have the ability to look at the larger picture," she says. "When you're healthy, however, you can reflect back on the experience and develop real insight." As a result, once well, she sought ways to become involved in impacting the system and was invited to become a member of the Alberta Depression Research Priority Setting Project Steering Committee.

It was a process she loved. "There were so many brilliant minds around the table," she says. "I started to catch on to the larger picture of how research works, how policy is impacted, to understand a research point of view."

Thanks to extraordinary facilitation and project leadership, she says that for the first time, she found herself having an equal discussion with doctors about depression without them trying to diagnose or treat her. "I found that really healing."

Through the arduous work of whittling the shortlist of 25 priorities down to the final 11, she also came to appreciate the different lenses people use to look at depression. In one discussion, she noticed carers prioritized quick access to emergency intervention, while Catherine prioritized prevention. "When I first feel like I'm going down the rabbit hole, I want to know there's a place I can go, an intervention that's proven to work, instead of my shotgun approach of trying yoga other activities in hopes it helps."

Robbie Babins-Wagner, PhD

CEO, Calgary Counselling Centre, Steering Committee member



Robbie Babins-Wagner is both a clinician and a researcher. And while her discipline, social work, tends to work collaboratively with clients, that isn't always the experience for those facing depression.

"There isn't a history of researchers and clinicians involving clients or patients," she says. Academic researchers tend to begin research projects that align with their interests and follow that line of inquiry for much of their careers. Funders are the other major influencers of the research agenda. The project's engagement with patients helps everybody look at the bigger picture, she says. "We typically look within our field and scope of work and the top down, medically- oriented model where physicians and by extension clinicians know best is still well entrenched."

"Patients know what works and what doesn't," she says. "They have tons of expertise and perspective. I think patients want to be heard and I don't think that always happens. They want the option of trying new things and aren't always supported."

Babins-Wagner describes the project's process and facilitation as "fabulous," and critical to aligning Alberta programs with patient priorities. "Local context should have an impact on how a program is offered. You can't just transplant things."

If she had one suggestion for the future, it is to provide more time for the final deliberations. "The process was inclusive and voices were heard," she says. "I support the final 11 priorities, but they would not be my priorities for my work." They are, however, what patients need us to have a focus on.

In practice, some of that focus may need to be better knowledge translation or communication to the public, rather than more research, she says. The first priority, for example—which treatment therapy or method is more successful for long term remission or recovery?—is the most researched topic out there, says Babins-Wagner. "But we know this information is not getting to the public domain. It's not expressed in practice. There are no mechanisms to do that and big Pharma and others sometimes push against it.

Through a different lens: summary reflections on the process

Person with Lived Experience of Depression	Mental Health Researcher	
Safe space to talk about concerns and questions	Got interested in public health policy	
Learned about the different experiences of depression	Became aware of the lack of depression/mental health education based on the questions received.	
Felt part of a group of people who understood the difficulties of depression with judgements	There is a great interest by the public to become involved in research and they are an excellent source of knowledge.	
Research would be more translatable if researchers listened to what we have to say. Our experiences matter.	Research is guided by curiosity and a desire to learn which shoull be coupled with what the people with lived experieneces need and want.	
I can be both a PWLE and a researcher. I know both sides and both experiences have provided me with valuable information about depression and mental health.		
It is important to also include health professionals who have experiences with depression. Both are not mutually exclusive.		

Alberta Depression Research Priority Setting Project 14

WHAT next steps are needed to turn knowledge into action

Early on, the Steering Committee articulated what success for the project would look like:

- 1. The large number of possible research questions about depression is narrowed down to 10 priorities that authentically represent what was heard from those with lived experience of depression.
- 2. Funders and policy makers know, understand and adopt the priorities.
- 3. Researchers shape their projects to address priority areas and are successful in attracting funding for these projects.
- 4. Aggregate survey results trigger discussions across Alberta's health care delivery stakeholders and catalyze significant changes to health care delivery.
- 5. Patients and clinicians use the information to improve the treatment of depression.

The first objective was achieved, although participants found a final 11 priorities essential. The work to implement the final objectives is underway with a target of completion in 2017.

At the same time, the project added evidence to support the science of patient engagement in having persons with lived experience be meaningfully engaged in setting research priorities. So next steps have two goals:

- 1. Spread knowledge of and use of the top 11 research priorities for depression.
- 2. Spread knowledge and practice of engaging those with lived experience in setting research priorities.

To date

Infographic (one version for funders and one for researchers), manuscript and final written report prepared for dissemination.

The Patient Engagement (PE) Platform of AbSPORU has already engaged with two other groups to provide advice, coaching and mentoring on involving those with lived experience in setting priorities for research.

The PE Platform has also completed a scoping review of priority setting methods and the impacts and/or outcomes to be submitted for publication.

In process

A knowledge translation plan is in development with stakeholders and partner organizations with the goal of having individual researchers, institutions and organizations agree to research one of the top depression research questions.

The project team also plans to work with funders and funding organizations in the area of mental health to promote funding opportunities for one or more of the top 11 questions.

Two of the top 11 depression research priorities have already been identified as not requiring additional clinical research. Dedicated strategies or research into knowledge translation to the public and clinicians are being developed for these priorities.



Alberta's Top 11 **Depression Research Priorities**

Determined by Albertans with Lived Experience

(E) (E) 1	Which treatment therapy or method is more successful for long term remission or recovery?
⊘	What are the long term physical implications of pharmacotherapy for treating depression?
3	For various treatment options (eg. psychotherapy, individual vs. group psychotherapy and psychosocial support), what are the advantages in terms of cost, effectiveness, relapse prevention and safety?
 4 4	What are the prevention strategies/tactics for reducing self-harm and suicide in children, youth and adults with depression?
5	What changes to the health care system will increase access to psychological services?
6	What changes in the health care system will result in shortened wait times for depression services?
7	Can diet or exercise affect the development of depression?
8 1/1	What are the functional, social, intellectual, physical and psychological problems experienced by children and teens living with an immediate family member who has depression?
9	What interventions are effective in preventing and treating workplace depression and reducing stigma associated with depression in the workplace?
10	Are there structural or functional changes in the brain due to antidepressant therapy during brain development?
00 NN 11	What is the role of family in the treatment and trajectory of depression?

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.

Appendices

Timelines

Aug. 2015	Formed collaborative partnership between AbSPORU PE Platform, Addictions and Mental Health SCN, and CDRIN
Sept. to Nov. 2015	Engaged partners in consultations, pre-planning, and negotiations to identify a process for identifying Albertans' depression research priorities
Dec. to Mar. 2016	Engaged partners in consultations, pre-planning, and negotiations to identify a process for identifying Albertans' depression research priorities
Oct 2015 to March 2016	Recruited Steering Committee members (a balance of people with lived experience, carers and clinicians)
April 2016	Held first Steering Committee meeting and launched the Alberta Depression Research Priority Setting Project
Aug. to Oct. 2016	Co-designed, developed and launched a public online and paper survey
Oct. 2016 to Mar. 2017	Processed and collated Albertans' survey responses as well as responses from outside Alberta.
	 Steering Committee combined similar questions and ideas to narrow the 900 of 1200 possible questions that came from Albertans to 70. (March-April 2017)
	• 70 questions ranked by importance in a second survey of those with lived experience. (AprMay 2017)
	 25 questions ranked as most important in the second survey were evaluated by the Steering Committee and additional public members in a final workshop. (June 2017)
	11 top research priorities were determined
Aug. to Nov. 2017	Report on project results and begin process of disseminating results with stakeholders and affected communities
Nov. 2017 through 2018	Call to action and knowledge to action phase

The shortlist – 25 priority research questions

The Steering Committee collated all data submitted and grouped questions into themes, honoring the intention or meaning of the original questions, and refined the data to 70 themed research questions. The 70 were then sent in a second survey to be ranked by importance by people with lived experience. Survey results identified the following 25 possible research questions as top priorities.

The 25 research questions went to the final facilitated workshop where participants decided on the top 11 priorities.

- 1. Does a mother having depression, or being treated with antidepressants, have measurable effects (positive or negative) on her children?
- 2. What is the relationship between the quality of the childhood environment and the likelihood of developing depression in childhood or adulthood?
- 3. What interventions are effective in preventing and treating workplace depression and reducing stigma associated with depression in the workplace?
- 4. What is the role of the family in the treatment and trajectory of depression?
- 5. What are effective public awareness strategies to inform the public about depression?
- 6. What is the relationship between hormonal changes and the risk and/or development of depression (in relation to birth control, post-partum hormonal changes, hormone therapy replacement therapy, and/or menopause in men and women)?
- 7. What are the physiological and psychological contributors to depression and how do these change over one's lifetime?
- 8. What kind of additional resources are needed to improve services for people living with depression?
- 9. What are the prevention strategies/tactics for reducing self-harm and suicide in children, youth and adults with depression?
- 10. How can schools implement depression prevention programs and address depression in schools to respond to those children and youth who are vulnerable to depression?
- 11. What changes to the health care system will increase access to psychological services?
- 12. How well are health professionals trained in evidencebased best practice guidelines for the diagnosis and treatment of depression at different life stages (e.g. childhood, young adults, seniors)?
- 13. What are the long-term physical implications of pharmacotherapy for treating depression?

- 14. What changes to the health care system will result in shortened wait times for depression services?
- 15. How well are health professionals trained in evidencebased best practice guidelines to triage patients with depression in urgent care?
- 16. What changes to services are needed to improve outcomes for people living with depression in rural and remote areas?
- 17. Are there structural or functional changes in the brain due to antidepressant therapy during brain development?
- 18. What are the functional, social, intellectual, physical and psychological problems experienced by children and teens living with an immediate family member who has depression?
- 19. Can diet or exercise affect the development of depression?
- 20. Which treatment therapy or method for depression is more successful for long term remission or recovery?
- 21. Are there measurable differences (physical, psychological or neurological) in the growth and development of children with depression?
- 22. What are the effects of depression on physical health (such as, but not limited to, migraines, high blood pressure)?
- 23. How well are health professionals trained to recognize and treat depression that is associated with another medical condition (such as, but not limited to, anxiety, head injuries, Alzheimer's, chronic pain, diabetes?
- 24. Does treating depression and addiction at the same time improve health outcomes?
- 25. For various treatment options (eg psychotherapy, individual vs group psychotherapy and psychosocial support), what are the advantages in terms of cost, effectiveness, relapse prevention and safety?

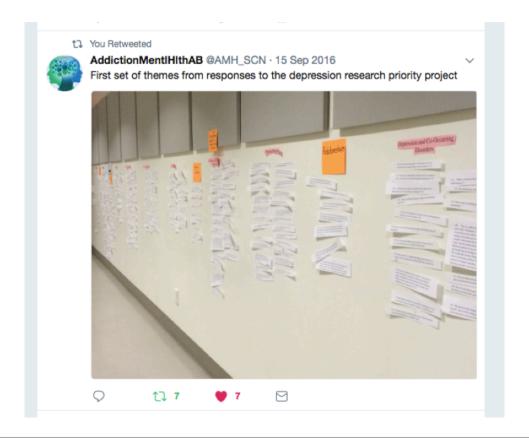
Communication samples

The project provided Steering Committee members and partners with tools to help recruit participants and keep the conversation going through social media.















Contact

For more information on this project, contact:

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Lorraine Breault

Lorraine.breault@ualberta.ca



Alberta Depression Research Priority Setting Project

QUESTIONS Albertans with first-hand experience of depression want ANSWERED.









