experience in

1	TITLE
2	Eleven top research questions asked by people with lived depression
3	Alberta: A survey.
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CONTRIBUTOR'S STATEMENT

- 40 LB, KR, KH, RBW, CdB, YJ, EA, SP, AM, GS, SRU, LVW, BN, KK, EM & PML made
- 41 substantial contributions to the conception, design, acquisition of data, analysis and
- 42 interpretation of data
- EM, PML, LB, KR and KK were involved in drafting the manuscript and revising it
- 44 critically for intellectual content.

45 ACKNOWLEDGEMENTS

- The authors wish to acknowledge the partnership with the Addictions and Mental Health
- 47 (AMH) Strategic Clinical Network (SCN) of Alberta Health Services, and the Alberta
- 48 Hub of the Canadian Depression Research and Intervention Network (CDRIN). The
- 49 authors also wish to acknowledge the support of Heidi Chorzempa from Performance
- Management and Evaluation, Alberta Innovates (AI), Athabasca University, Research
- Services staff, for her contributions on the survey design, building and implementation.
- 52 The authors are grateful for the in-kind contributions and support from Alberta Health
- 53 Services, Alberta Innovates, and the Knowledge Translation and Data Platforms of
- 54 AbSPORU.
- 55 The authors acknowledge the critical contributions of time and energy by individuals
- 56 (people with lived experience, clinicians, and health care professionals) who participated
- 57 in the final priority setting workshop in June 2017: Anne Clifford, Bryan Meetsma
- 58 Glenda Maru, Janet Bodnar, Kristina Devoulyte, Laurie Sutherland, Lynne Kaluzniak,
- 59 Ofelia Leon-Featherstone, and Steve Gaspar.
- The authors also wish to thank the following facilitators for supporting the June 2017
- 61 priority setting workshop: Levi Borejko, Lisa Petermann (PE Platform), Sarah Prescott
- and the meeting recorders Robyn Laczy (PE Platform) and Sennait Yohannes (PE
- 63 Platform). Acknowledgement to Lona Leiren, Carr Leiren & Associates Ltd for
- evaluation support of the depression research priority setting project.
- The authors further acknowledge and thank the AbSPORU Patient Engagement Platform
- 66 Lead, Dr. Virginia Vandall-Walker for her strategic direction, endorsement and support –
- both financial and in-kind of this project.

FUNDING DETAILS

- The PE Platform of AbSPORU gratefully acknowledges the funding received from the
- 70 Canadian Institutes of Health Research (CIHR)—Strategy for Patient-Oriented Research
- 71 (SPOR) and Alberta Innovates (AI).

72 DECLARATION OF AUTHORS COMPETING INTERESTS

73 The authors have no competing interests to declare.

ABSTRACT

Background: To support patient-oriented depression research priority setting in Alberta, Canada, the Patient Engagement Platform of the Alberta Strategy for Patient Oriented Research SUPPORT Unit and the Addiction and Mental Health Strategic Clinical Network of Alberta Health Services, along with partners in addictions and mental health, designed a depression research priority setting project. The research question guiding this project was "What are the patient and clinician priorities for depression research in Alberta?" The aim of the Alberta depression research priority setting project (the Project) was to survey patients, caregivers and clinicians/researchers in Alberta about what they considered were the most important unanswered questions about depression. **Methods:** The Project adapted the UK's James Lind Alliance method into a six-step survey to gather and prioritize questions about depression posed by people with lived depression experience, which included patients, caregivers, clinicians and health care practitioners. **Results**: A total of 445 Albertans with lived experience of depression participated in ultimately identifying the 11 priority depression research questions, spanning the health continuum, life stages, and both treatment and prevention opportunities. **Interpretation:** This Project is a fundamental step that has 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 the patient-engagement in research enterprise overall.

INTRODUCTION

Depression is a major public health issue in Canada (1). Approximately 8% of adults aged 25-64 years projected to experience major depression at some time in their lives, (2) and estimated to account for at least \$32.3 billion of direct and indirect costs to this nation annually. (3) Continued investment in research which explores prevention and treatment is needed (4, 5) and in particular through engaging patients in this endeavor (i.e., people living with depression, family members and informal caretakers) 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) Unfortunately, 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 (the Project) was to have patients and clinicians in Alberta, Canada, identify the most important unanswered questions about depression by answering the Project research question, "What are the patient and clinician priorities for depression research in Alberta?" The Project was codesigned and co-implemented by the Patient Engagement Platform of the Alberta Strategy for Patient Oriented Research (SPOR) Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit, the Addictions and Mental Health (AMH)

Strategic Clinical Network (SCN) of Alberta Health Services, and the Alberta Hub of the Canadian Depression Research and Intervention Network (CDRIN). In this paper, we describe the process used to survey patients and clinicians on what they believe are unanswered questions about depression. We report our findings taking into account the GRIPP2 (Guidance for Reporting Involvement of Patients and Public) checklist criteria for patient and public involvement (9) and the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (10). A separate paper discussing the patient engagement components of the Project is published elsewhere (11). Manuscripts on the knowledge synthesis and literature search strategies, including the identification of knowledge gaps, are in process.

METHODS

Setting and Recruitment of Persons with Lived Experience

The study, conducted in Alberta, Canada, focused on recruiting people who live within the geographic boundaries of this province. The previously-identified partner organizations recruited 14 members from their communities to form a Project Steering Committee consisting of six people living with depression, one caregiver, four clinicians, five researchers and two members of the project planning committee. As evidenced by the total number of committee numbers, several members represented more than one category (i.e., a person living with depression who is also a clinician). A convenience sampling strategy was predominantly used to recruit people living with depression, people who care for those with depression, and health care professionals who treat depression.

Digital recruitment collateral for participants was advertised via social media platforms (Twitter and Facebook), through websites of partner organizations, and through network connections of Steering Committee members. To facilitate data collection, participants were asked to participate by giving them a specific URL to access the questionnaire. For specific populations, including Métis and homeless populations, a purposive sampling technique was used, through engagement with established partnerships working with members of the population. A sampling frame was developed to address the study objectives by including people with lived experience with representation from a broad demographic spectrum (e.g., age, ethnicity, immigration status) who are justifiably considered 'experts' with depression (12). Paper copies of the questionnaire were disseminated to these populations who may have more limited online access. Participants were informed that their participation will 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. The survey required 10-20 minutes for completion and all responses would be kept confidential and for the purpose of the study. Participants were not required to provide their name or contact information.

Study Methods and Design

The UK's James Lind Alliance (JLA) Priority Setting Partnership method brings patient and clinician groups together on an "equal footing" to produce a jointly agreed list of research priorities that are recorded and made available to researchers and funders. (13) A "funnel approach" is used: a larger sample of people with lived experience first

identifies research questions about a health issue, with a smaller sample ranking the questions, and a still smaller sample prioritizing the final questions. (12)

The Patient Engagement Platform adapted the four-step JLA method into a six-step process to ensure that the voices of people with lived experience of depression were included throughout the Project. The Project used an egalitarian, consensus-building process, combining the perspectives of people with lived depression experience and clinicians. It is, therefore, classified on the "Collaborate" level of Patient and Researcher Engagement in Health Research Schematic. (14). A complete description of the methods used is given below. The implementation of the Project, from initial data collection to final priority setting, took 10 months. The Project was reviewed and received approval by Research Ethics Boards (REBs) at two universities, the University of Alberta and Athabasca University.

Step 1: Data gathering (Online and paper survey)

The Steering Committee co-designed the survey by consensus, with the goal of ensuring that people with lived experience of depression to identify their concerns and unanswered questions about depression. A copy of the survey can be found in Appendix 1. The two REBs identified above approved "implied consent"; that is, consent was implied by the positive act of completing the survey. The ISO 27001 compliant Snap Survey online platform was used and hosted by Alberta Innovates: Health Solutions, with data stored on secured internal systems. Access to the application was limited by site licenses, and only accessible from onsite/internal systems only. In addition, the web host function was password protected. No incentives were provided to complete the survey.

In an effort to engage populations that have traditionally been voiceless in health research, a purposive sampling technique was used, utilizing established connections and relationships through partner organizations (e.g., leveraging positive connections at the Bissell Centre in Edmonton, AB). One hundred paper surveys were taken to a Métis settlement in Buffalo Lake (nine were returned), and 25 paper surveys were distributed to homeless individuals at the Bissell Centre in Edmonton (13 were returned, response rate of 52%). Survey responses were accepted for a four-month period.

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 three months; 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 two or more steering committee members agreed did not meet the purpose of the project. The remaining questions were reviewed by the entire committee to ensure that they were easy to understand, 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 using a patient lens. (15) 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., one person

with lived experience and one clinician) to re-develop research the questions using a PICO (Population, Intervention, Comparator, Outcome) format, where possible.

Step 3: Question rating (Online survey)

An online rating survey was initiated and the URL shared on Twitter and through contact networks of the Steering Committee to rate the short-list of questions. Over a one-week period, survey respondents identified which questions were most important using a 5-point Likert scale: Not a priority, Low priority, Medium priority, High priority, Undecided. Data were collected and managed using REDCap electronic data capture tools (16), a secure and user friendly application, hosted at the University of Alberta. Similar to the Step 1 questionnaire, access to the application was limited by site licenses, is accessible from onsite/internal systems only and is password protected. Questions that were most frequently identified by 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 by those surveyed. No incentives were provided to complete the survey.

Step 4: Question prioritization (In-person workshop)

, Finally, participants attended a full day workshop to identify the top 10 questions submitted by Albertans. This was supported by, three facilitators, three Patient Engagement Platform members and two observers (one student and one evaluator) attended and supported the workshop, but did not participate in ranking. This sample fits within the JLA recommendation that prioritization workshops not exceed 30 participants (12). Prior to the workshop, participants were given a ranking tool listing the top-ranked

25 questions from the rating survey, and asked to prioritize the questions from most important to least important. At the workshop, a Nominal Group Technique was used, where participants were divided into three groups to compare their personal rankings. Each group had a facilitator and recorder to manage the dialogue and guide the process towards group consensus. After two 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 (versus the JLA suggestion of 10 questions as two questions had equal rating).

Step 5: Knowledge Synthesis

The Knowledge Translation Platform of the Alberta SPOR SUPPORT 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).

Step 6: Knowledge Translation

The Patient Engagement Platform developed a final report in conjunction with the Steering Committee and planned, implemented and hosted a media launch that resulted in TV, radio, and print news coverage, as well as attendance by researchers. The Platform is currently working with the identified partner organizations to facilitate dissemination and knowledge translation opportunities by developing a knowledge mobilization plan.

RESULTS

A total of 445 Albertans with lived depression experience participated in identifying depression research questions. Forty-nine Albertans rated the research questions to

inform the 25 medium to high priority questions. During a full day workshop, 20 people (11 steering committee members and nine public members, including clinicians, health care professionals, and people with lived experience) attended an in-person workshop to identify the top 10 questions submitted by Albertans. A description of the participant sample is included in Table 1.

The Project was successful in gaining representation from people with lived experience at every step. In Step 1 (data gathering), more than three quarters of respondents identified as people living with depression or as family members or caregivers of a person with depression (80.2%, n = 357). Within this population, 37.9% (n = 159) had more than five years' experience with depression, and a further 28.3% (n = 119) identified a lifetime of experience with depression. Nearly all participants in Step 3 (question rating) identified as having some experience with depression (n = 44, 90%), as did more than half of participants (n = 12, 60%) in Step 4 (question prioritization).

- The summary of outputs of the Project across each of the six 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. To our knowledge, this is the first time in Alberta that 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 (17). This strategy presents many advantages for patients, clinicians and researchers, and the patient-engagement in research enterprise itself. First, as suggested by the IAP2 spectrum, the higher the degree of participation within research priority setting activities, the more accurately the results reflect the community. (18) In this study, more than three quarters of the initial respondents identified as persons with 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 impacts the well-being of those affected. Second, this 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. (17, 19) It recognizes patient contributions as valuable, acknowledging the expertise brought forward from patients' own experience (20, 21).Third, while the JLA method incorporates a simultaneous review of the literature to validate research uncertainties, the Project 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. The patient engagement literature suggests several benefits from such meaningful representation, including improved quality of research design, increased participant enrolment and decreased attrition in research studies, wider application of research findings, and overall improved research effectiveness. (20, 22, 23) Therefore, we believe that employing the results from this study can assist in closing the knowledge-to-action gap (24) by mobilizing timely and relevant data to inform clinical care and research.

Finally, 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 (25) This study helps illustrate outcomes of meaningful patient and researcher engagement, building on other such work in Canada. (19, 26-34) It also contributes to the growth of evidence that people with lived experience are valuable research partners.

Limitations At the same time, several important limitations should be considered when applying this study's findings. First, the convenience sampling strategy may have resulted in bias due to over- and under-representation of subgroups compared to the population of interest. This inherent limitation was addressed in part by the continuous review of demographic characteristics of participants who completed the online data collection and question ranking steps. While the survey had good reach, some groups were under represented, an ongoing challenge recognized in the patient engagement literature. (35) Committed efforts were made to reach these populations; however, recruitment from these groups were not very successful. Furthermore, a response rate

cannot be calculated because the total sample number is unknown. To mitigate this in future research, a two-step process could be used where self-identified participants first agree to participate in the study; once this is documented, they are sent the questionnaire to complete, thereby allowing to calculate the response rate.

Second, the possible subjective influences of steering committee members and of patients, particularly in the smaller group that completed the final prioritization of the research questions, should be considered in establishing research priorities, to ensure that decisions are not solely informed by one type of evidence.

Third, a small sample ranked the 25 research questions (Step 3). While it is expected that the sampling frame narrows throughout the six steps, two factors may have decreased the number of persons who might have participated at this step: first, a limited time frame for completing the ranking (i.e., one week), and second, the ranking occurred during the summer months which may not have reached as wide of an available sample.

Considering these limitations, the steering committee relied on the recurrence (i.e., saturation) of themes 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 males, rural communities, immigrants, and ethnically diverse communities to ensure that priorities are representative of all Albertans living with depression. Alberta's specific demographic profile would need to be considered, with 15.8% of the population reporting an Aboriginal identity. (36)

Conclusions The authors hope that the outcomes of the Project will better align research objectives with the needs of Albertans with lived experience, 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 (20). Future studies can adapt this process to actively engage patients throughout the research cycle. It is expected that this strategy will promote greater understanding and insight into depression research, while continuously building rapport with people with lived depression experience as central to research processes. (37, 38) Ses. (5.,

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Table 1. Survey participant demographics (Step 1: Data gathering)

Variable	Result (n, (%))
Danie au Janie (n. – 4.45)	
Respondent (n=445)	292 (62 69/)
Person living with depression	283 (63.6%)
Family member or caregiver of person	74 (16.6%)
with depression Health care professional caring for	28 (6 29/)
people with depression	28 (6.3%)
Counsellor	3 (10.1%)
Nurse	7 (25.3%)
Psychiatrist	1 (3.8%)
Psychologist	4 (13.9%)
Social Group worker	1 (3.8%)
Other	12 (29.1%)
	, ,
Clinician treating depression	14 (3.1%)
Other	46 (10.3%)
Gender (n=445)	
Male	88 (19.8%)
Female	354 (79.6%)
Did not report	3 (0.7%)
Did not report	3 (0.770)
Age range (n=445)	
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 and older	2 (0.4%)
Primary place of residence (n=445)	
Edmonton	144 (32.4%)
Calgary	141 (31.7%)
Other	160 (36.0%)
<i>Immigration status (between 2011-2016)</i> (n	-445)
Yes	10 (2.0%)
No	435 (97.8%)
110	155 (77.070)
Ethnic origin (n=445) *	207 ((4.59/)
Canadian	287 (64.5%)
European	150 (33.7%)

Variable	Result (n, (%))
East European	29 (6.5%)
Metis	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 (n=420) Lifetime experience with depression More than 5 years experience with depression	119 (28.3%) 159 (37.9%)
3-5 years of experience with depression	39 (9.3%)
1 to 2 years experience with depression	28 (6.7%)
<1 year experience with depression	12 (2.9%)
New diagnosis of depression	4 (1.0%)
Other	15 (3.6%)
Recovered from depression	44 (10.5%)
Number of months in past year with depressi	on experience (n=352)
10-12	162 (46.1%)
7-9	32 (9.1%)
4-6	26 (7.5%)
0-3	64 (18.2%)

^{*} Percentage equals over 100 as participants self-identified in one or more group of ethnic origin

Table 2. Summary of process and outputs of the Alberta Depression Research Priority Setting (DRPS) Project for determining top 11 Depression research questions

DRPS Process	OUTPUTS
DITI STITUTESS	14-member steering committee formed
Step 1: Data Gathering (Participant online and paper survey) August – December 2016 (4 months)	 445 respondents (from Alberta only) 1270 questions and comments on depression received
Ston 2. Overtion	 350 questions removed that were submitted by participants residing outside of the province of Alberta from how many respondents? 724 questions removed due to duplication
Step 2: Question analysis and review (Steering Committee)	196 questions reformulated into PICO research question format and refined (e.g., removed jargon)
August – December 2016 (5 months)	• 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-week in June 2017	 49 participants rated 66 research questions (through an online survey) 25 medium to high priority questions (most commonly asked) were identified
Step 4: Question prioritization (In-person participant workshop) 1 day in June 2017	 20 participants prioritized 11 research questions (plus 4 PE staff members, 3 facilitators and 2 observers) (14 remaining questions not selected in the top 11 were deemed worthy of consideration for future depression research)

Step 5: Knowledge	
Synthesis	
(PE and KT Platform)	• 25 rapid reviews of depression research questions conducted
July – October 2017	
(4 months)	
Step 6: Knowledge	
Translation	 Dissemination and knowledge mobilization opportunities
(PE and KT platform)	
November 2017- January	Public report launched to media, January 2018
2018 and Ongoing	



Alberta's Top 11 Depression Research Priorities

Determined by Albertans with Lived Experience

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	1	Which treatment therapy or method is more successful for long term remission or recovery?
	2	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	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?
Û	8	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?
	11	What is the role of family in the treatment and trajectory of depression?

57 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.









Appendix 1 – Data Gathering Survey (Step 1)

SF	ECTION I	
1.	Please identify which perspective you are answering or creating questions from. If more than one applies to you, please only select one and offer impressions from that perspective.	 As a person living with depression As a family member or 'carer' of a person with depression As a health care professional caring for people with depression As a clinician treating depression Other
2.	If you are a health professional or clinician, specify the type (check all that apply). If this question does not apply to you, skip to question 3.	 Family physician Psychologist Counsellor Social worker Naturopath Herbalist Elder Traditional healer Support group worker other
3.	Select your gender:	 Male Female Prefer not to say Other
4.	Select your age group	 17 and younger 18-29 30-39 40-49 50-59 60-69 70-79
5.	Where do you currently live	 Alberta First Nation Reserve Northwest Territories Outside Alberta
6.	Where is your primary residence? Only specify the option applicable to you, leave the other blank	City (specify)Rural or remove (specify)

7.	Are you a recent immigrant or refugee to	o Yes
/.	Canada (between 2011-2016)?	NT.
		o No
8.	What is your ethnic origin? Check all that	o First Nation
	apply	o Inuit
		o Métis
		o African
		o European
		o Eastern European
		o Middle Eastern
		o Asian
		 South American
		o Central American
		o Canadian
		o North American
		 Prefer not to say
		o Other
	ECTION II	
9.	Based on the perspective you chose earlier	 New diagnosis of depression
	(living with, caring and or/treat) indicate yoru experience with depression (select only one option)	Less than one years of experience with
		depression
		o 1 to 2 years of experience with depression
		 3 to 5 years of experience with depression More than 5 years experience with depression
		T 10 4 1 1 1
		D 10 1 :
		0.1
		NT (12 11
		Not applicable
10.	Indicate the <u>number of months</u> in the past	0 0
	year where you experienced symptoms of	0 1
	depression (select only one option)	0 2
		o 3
		o 4
		o 5
		0 6
		o 7
		0 8
		o 9
		o 10

	0 11
	0 12
	Not Applicable
11. Indicate your care or support experience	o Family Physician
with depression (check all that apply):	o Psychiatrist
	o Psychologist
	o Counsellor
	 Social Worker
	 Naturopath
	o Herbalist
	o Elder
	 Traditional Healer
	 Support Group
	 Self-care (please describe using the space below)
	 Other (please describe using the space below)
<u> </u>	 Not Applicable
12. If you are wiling to share, please describe	
your personal circumstances that may	
affect your experience with depression	
SECTION III	

SECTION III

The following section is your opportunity to create questions about depression that you want answered. We have included specific topic areas to help guide you, but if your question(s) do not fit within these topic areas, there is additional space at the end of this survey to submit these questions. We have included age groupings as a guide, but it is not necessary to have questions for each age group.

Here are examples of questions that some people have submitted:

- Can exercise improve symptoms of depression?
- How safe is it for my baby if I am breastfeeding and taking antidepressant medication?

13. If you have questions about the development of depression in children (0-10), youth/teens (11-18), young adults (19-29), adults (19-64) and/or mature adults (65 plus) write them in the space below	
14. If you have questions about the treatment of depression in children (0-10), youth/teens (11-18), young adults (19-29), adults (19-64) and/or mature adults (65 plus) write them in the space below	
15. If you have questions about the influence	

of depression in children (0-10), youth/teens (11-18), young adults (19- 29), adults (19-64) and/or mature adults (65 plus) write them in the space below	
16. Do you have other questions about depression that you would like researchers to know?	

