Collaborating with Individuals with Lived Experience to Adapt CANMAT Clinical Depression Guidelines into a Patient Treatment Guide:

The CHOICE-D Co-Design Process

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ABSTRACT

Effective treatment of depression involves collaboration with informed patients and families and appropriate knowledge-sharing. We describe here our experience, as a case example, of a collaboration to “translate” a clinical guideline designed for practitioners into an accessible, plain language version that patients and families can use during the care process, both to provide basic educational information and to foster “informed discussions” with their treatment providers. Content experts in knowledge translation, patient advocacy, patient-oriented research, and psychiatry guided overall project design. Our first step was to identify lived experience writers to join in the co-design and co-writing of the “CHOICE-D Patient and Family Guide to Depression Treatment”. A national call for writers attracted 62 applicants, from whom 8 individuals with lived experience of depression and writing experience were selected. Individuals subsequently attended a welcoming teleconference, followed by a one-day workshop designed to provide (1) a detailed overview of the clinician guideline, (2) an opportunity to select what should be included in the Guide, and (3) key principles of knowledge translation/lay writing. Both from the workshop and subsequently through the co-design process, lived experience writers recommended that the Guide address symptoms, effects of illness course on treatment, first-line treatments, safety/side effects, and treatment misconceptions. To promote patient autonomy, question scripts (how and what to ask your treatment provider), self-triaging resources, and treatment selection aids were suggested. Stylistic considerations included use of simple yet hopeful language, brevity, white space, key terms glossary, and graphics. Several strategies were particularly useful to optimize writer engagement in the co-design process: a pre-workshop conference call and circulation of project resources, an in-person workshop to increase content knowledge, structured discussion with co-writers and project leads to develop ideas, and practical training exercises with the provision of feedback. Both during and at the end of the project, writers provided additional recommendations for improving the process, including more in-person meetings, distribution of step-by-step instructions on the writing task, and a key terms glossary of technical terms to support their role. In conclusion, we describe a process with practical tips and reflective feedback on important considerations for engaging persons with lived experience as leaders in the co-design and writing process of lay treatment guidelines. These methods may serve as a model for similar projects in other areas of healthcare.

Keywords: depression, treatment, lay guidelines, lived experience, patient engagement, CHOICE-D

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1. Introduction

Effective treatment of Major Depressive Disorder (MDD) ideally involves the collaboration of patients and practitioners in patient-centred care, using best practice as identified by evidence-based treatment guidelines. In 2016, the Canadian Network for Mood and Anxiety Treatments (CANMAT) developed a third iteration of updated guidelines for the clinical management of MDD, with new content on burden and principles of care[1], psychotherapy[2], pharmacotherapy[3], neurostimulation[4], complementary and alternative medicine[5], and special patient populations[6]. Designed for clinicians, these guidelines were generated using evidence review, expert opinion, and clinician (end-user) feedback. The 2016 CANMAT MDD guidelines evaluated evidence published since the 2009 edition, with a focus on meta-analyses, systematic reviews, and randomized control trials. Using level of evidence criteria, recommendations reflected both the quality of the data and expert consensus. The expert consensus process involved content experts in psychiatry, pharmacy, and psychology who graded evidence and balanced side effect and other considerations to generate treatment recommendation levels (e.g. first-line treatment, etc.). Finally, external clinicians reviewed draft recommendations to provide end-user feedback, but patients were not incorporated into this process.

Similar to the CANMAT MDD guidelines, most other clinical guidelines have been produced under the medical model[7], where clinicians are considered to possess knowledge and expertise over what is best for the patient. Consequently, the information presented within treatment guidelines is often made inaccessible to patients, such as through use of medical jargon that creates barriers in respect to language and education. This has a negative effect on mental health literacy, which refers to a patient's capacity to access, understand, evaluate, and communicate basic health information to effectively inform healthcare decision-making[8]. In fact, limited health literacy is a common phenomenon affecting 60% of Canadian adults, with outcomes varying according to factors such as age, sex, level of education, geographic location, and immigration status[9,10]. Within mental health, there is an inadequate understanding of common symptoms, prevalence rates, risk factors, treatment options and their effectiveness, and crisis response protocols, which can have secondary effects on negative and stigmatizing perceptions of mental illness, including treatment and recovery[11,12]. Other potential consequences include negative health outcomes, reduced use of screening and preventative health services and health-promoting behaviours, increased hospitalizations, poor treatment compliance, patient safety and mortality concerns, and higher healthcare costs[9]. In contrast, improvements in mental health literacy have been shown to increase a patient's likelihood of sharing decisions with their physician, verifying information credibility, and exploring options beyond those presented by their healthcare team[13]. Patient involvement in healthcare decision-making is an important aspect of optimizing the quality of mental healthcare being delivered, and is a predictor of improved clinical outcomes[14] and increased patient satisfaction[15]. Moreover, how healthcare professionals support patient autonomy in healthcare decision-making has been shown to influence overall patient engagement, specifically their participation and health-information seeking behaviours, which can subsequently affect treatment adherence[16].

Consequently, there is an urgent need for patient education to improve. In support, the recovery model for mental health[7] has challenged more paternalistic approaches to treatment by placing patient agency within healthcare decision-making at the centre of recovery and healing. Under this model, patients are viewed as the experts of their own circumstances and should be empowered to harness their strengths and abilities to support their own recovery. This premise can extend beyond increasing patient involvement in healthcare decision-making to also include a direct role in the development and delivery of mental health information and services. This stems from the concept that persons with lived experience of mental illness have unique perspectives and ideas on the impact of mental illness and the navigation of mental health services that are informed by their own recovery journey. The integration of these ideas with evidence-based data can be used to identify topics that are clinically impactful for patients, and can improve health satisfaction and optimize health outcomes in the long-term[17]. The Mental Health Commission of Canada (MHCC) has recognized these benefits, and thus developed a mental health strategy that identifies the lived experience voice as an asset to recovery[18]. Within this strategy, the MHCC recommends that patients with mental illness, in addition to their families, assume leadership roles in the planning, delivery and evaluation of mental health services to contribute to the meaningful transformation of the mental healthcare system. Under this framework, clinical guidelines can best support patient recovery when they are made available in an accessible format using simplified language, coupled with the involvement of persons with lived experience in the development and dissemination process.

Many organizations have started to recognize the importance of including person with lived experience within guideline development, such as the Guidelines International Network[19], the AGREE (Appraisal of Guidelines, Research and Evaluation) Collaboration[20], and the National Institute for Health and Care Excellence (NICE)[21]. NICE, for example, has incorporated patient input into developing clinical guidelines for various acute and chronic clinical conditions such as cancer, mental health, and women and child health[22]. The World Health Organization (WHO) is also incorporating patient feedback into revising the diagnostic guidelines for the Mental, Behavioural and Neurodevelopmental Disorders section of the International Classification of Diseases (ICD)-11 after finding that current content inadequately reflects the lived experience perspective and uses language that is poorly understood and even objectionable to patients[23].

Despite the growing inclusion of patient feedback into guideline development, there is a paucity of lay language depression treatment guides that present comprehensive, evidence-based information for patients using persons with lived experience as leaders in the writing and dissemination process. This gap was identified in 2017 by the Canadian Biomarker Integration

Network in Depression (CAN-BIND) and the Mood Disorders Association of Ontario (MDAO), a patient and family advocacy group. In response, a knowledge translation project was initiated to adapt the CANMAT clinician guidelines into an accessible, plain-language version that incorporated the expertise of individuals with lived experience. Termed the CHOICE-D (CANMAT Health Options for Integrated Care and Empowerment in Depression) Guide, this patient and family guide to depression treatment was written by patients (and families) with lived experience of MDD to enhance patient-centred care. The current report describes the protocol employed during Phase I of the CHOICE-D project: the co-design of the CHOICE-D Guide with a Writing Committee comprised of persons with lived experience of mental illness (see Figure 1). The co-design process refers to content selection for the Guide, in addition to graphic design, formatting, and layout considerations.

2. Approach to Project Design and Participant Training

Expert Consultations: Informal consultations with ten content experts in knowledge translation, patient advocacy, patient-oriented research, and psychiatry were completed (see Table 1). The purpose of the consultations was two-fold: (1) to define the composition and scope of the Writing Committee; and (2) to design an in-person workshop to provide training to members of the Writing Committee on their project roles and responsibilities, and engage them in the co-design process for the CHOICE-D Guide (see Figure 2). Consultations were completed either in person or via teleconference. Experts provided insights and ideas for project development, and recommended knowledge translation literature for review to identify optimal methods for patient education and engagement.

Writing Committee: MDAO released a national call inviting individuals with lived experience, either direct or indirect, of mood disorders and mental health service navigation from across Canada to join the Writing Committee. Stringent selection criteria were not imposed during the process to increase the breadth of applicants who were eligible to apply. For those with direct lived experience, there were no specific eligibility criteria involving the type of mood disorder, symptom length and severity, or treatments used, but applicants needed to confirm a level of current symptom stabilization that would allow them to manage the workload of the project. Project leads received 62 applications and invited 13 to interview; of these, eight applicants were selected but one writer withdrew their participation for personal reasons prior to project onset (see Figure 3). Based on the applicant pool, and as advised by our expert consultants, applicants were primarily selected based on skills and experiences in areas such as writing, editing, communications, graphic design, marketing, healthcare/health research, and work with the vulnerable sector to more directly support project objectives. The focus on member expertise was to permit engagement at all stages of Guide development, where possible, to ensure relevance to end-users and enhance quality. Demographic diversity was a secondary consideration to increase the range of experiences and insights offered. To see the demographic composition of the CHOICE-D Writing Committee, refer to Table 2. All Writing Committee members confirmed their comfort in articulating ideas verbally in a group setting and in written format. Writing Committee members were financially compensated for their involvement in the project. Project leads were transparent about project goals, anticipated workload, and the projected timeline for deliverables at outset.

Writer Workshop: A full day workshop was delivered to provide training to members of the Writing Committee before onset of the translation and writing phases. There were four main goals for the workshop: (1) to provide an opportunity for the team to meet each other in person; (2) to provide writers with a common foundation of knowledge on the CANMAT guidelines, the writing process, and other writing considerations; (3) to discuss content priorities for inclusion (or exclusion) in the CHOICE-D Guide based on the lived experience perspective; and (4) to determine writing sub-groups. To ensure all Writing Committee members understood the content of the original guidelines, a copy of the CANMAT Guidelines and lay summary notes on each section were distributed prior to the workshop to allow sufficient time for review. Writing Committee members were encouraged to familiarize themselves with the content, while noting any areas of uncertainty and questions on the material for clarification and group discussion. A conference call was also held in advance of the workshop to provide opportunity for Writing Committee members (and project leads) to introduce themselves, receive an overview of the workshop including key objectives and goals, ask questions, and facilitate discussion.

The workshop, designed by integrating evidence-based research and recommendations from expert feedback, was divided into two parts. The first part offered training sessions to support the Writing Committee in their project role. The Writing Committee was also provided with the resources and information they would need to develop the Guide. The second part focused on content selection for the Guide since only certain sections were translated from the original CANMAT guidelines to ensure brevity and accessibility (see Figure 2). Members of the Writing Committee were also given opportunity to get to know one another and share their experiences to facilitate bonding and mitigate any social anxieties. All writers were provided with hard copies of the workshop material, in addition to paper and pens for them to document any ideas or suggestions in the absence of an immediate opportunity to share them. Evaluations were provided at the end of the workshop to collect writer feedback on the co-design process.

Writer Training: The workshop provided didactic instruction interspersed with individual and interactive activities that allowed members of the Writing Committee to practice newly learned skills, provide their perspectives and opinions, and facilitate feelings of engagement and cohesion. Three training sessions (and related activities) on writing stylistics, clear language and design, and editing were provided. Individual training sessions were limited to 20 minutes to minimize burnout and fatigue. Writing Committee members also completed a lay translation exercise that resembled the translation task they would be assigned for the CHOICE-D Guide, which necessitated application of all the skills learned during the workshop. This exercise required the Writing Committee to translate an excerpt from the original CANMAT Guidelines into plain language text using the ‘Think (individual) - Pair (small group, in pairs) - Share (larger group discussion)’ method[24]. Feedback from the activity was immediately provided during a group discussion, where translation challenges and potential strategies were also reviewed.

Content Selection: The latter half of the workshop was spent distilling tangible points of information for translation such as content, structure, and order of presentation. Content selection was facilitated through discussions about ‘must-haves’ for the CHOICE-D Guide, and use of a content prioritization scoring activity. Scoring was completed for sections on ‘Disease Burden and Principles of Care’, ‘Psychotherapy’, ‘Pharmacotherapy’, and ‘Complementary and Alternative Medicines’; the ‘Neurostimulation’ section was discussed but not scored due to a primary focus on first-line treatments. During this activity, the Writing Committee provided feedback on which sub-sections of the original CANMAT guidelines should be included (or excluded) in the translated version based on a lived experience perspective of topic relevancy for mental health service navigation and engagement in mental healthcare decision-making. To facilitate prioritization, members provided a score of *‘yes’*, *‘maybe’*, or *‘no’* for each sub-section. The group erred on the side of over-inclusion where, if the number of combined votes for ‘*yes’* and ‘*maybe*’ exceeded the number of votes for ‘*no*’, then the sub-section would be included in some capacity. The activity was accompanied by active group discussion to share personal insights for score assignment, and to ensure that all members of the Writing Committee were agreeable with final decisions. Use of this format allowed member feedback to be weighed equally, with the majority consensus dictating final outcomes. To ensure that potential Writing Committee biases or conflicts did not influence content translation, a moderator was appointed to put ideas in context and balance different points of view. Feedback was also collected on the order of presentation, graphic design considerations, and development of clinical tools that can be used by patients to facilitate discussions with their mental health practitioner(s) and support healthcare decision-making. Regardless of the sections selected for translation in the CHOICE-D Guide, all original content is still available to lay audiences through the CANMAT guidelines. The translated Guide does not aim to remove any content per se, but only to highlight aspects that are deemed to be particularly interesting and relevant to patients (and their families) for mental health treatment, as based on the lived experience perspective of the Writing Committee.

3. Implementation Steps in Project and Reflective Feedback

3.1. Guide Scope

The Writing Committee identified the main purpose of the translated Guide as "*to facilitate conversations with healthcare providers and to help build a sense of agency*". The Writing Committee believed that the Guide should be written with the following end-users in mind: individuals with depression, caregivers (e.g. parents, children, siblings, friends), healthcare providers, and staff at various resource centres. The Writing Committee further believed that these end-users may be facing potential challenges that include: fear of stigma including cultural- and faith-related stigma, English literacy barriers, limited access to comprehensive care, family changes (e.g. divorce, death, pregnancy), environmental changes (e.g. starting school or a new job), and financial difficulties. To reach these end-users, the Writing Committee believed the Guide should be distributed at drop-in clinics, emergency rooms, learning institutions (e.g. high schools, universities, colleges), community centres, homeless shelters, faith centres, and senior centres. These concepts influenced how the Writing Committee chose to shape the Guide.

3.2.Translation Exercise

After completing the lay translation exercise, the Writing Committee identified challenges with extracting essential information, understanding the material, and feeling overwhelmed or anxious with the translation task. Group discussion generated the following strategies to address these challenges: using ‘*Who? What? Where? When? Why? and How?*’ questions to condense the message, cutting out extraneous or irrelevant information, considering the audience, identifying which sections could be supplementary, isolating the take home message, and consulting with others.

3.3. Content Selection and Development

The Writing Committee elected to retain the majority of sub-sections from the original CANMAT guidelines, with the exception of 11 which they believed would be unhelpful for end-users (see Table 3). Of these sections, writers prioritized content on psychotherapeutic options over pharmacotherapy. There were also several content areas that the Writing Committee felt were pertinent to address (see Table 4).

In addition to section prioritization, other considerations were noted: *Disease Burden and Principles of Care*: There were recommendations to include symptom summaries that support end-users in recognizing the signs of both depression and suicidality. When transitioning into treatment overviews, the effects of illness stage (e.g. initial diagnosis, a few treatments tried, multiple treatment ‘failures’) and severity on treatment outcomes should be included. *Psychotherapy:* The Writing Committee recommended providing tools on selecting the best type of therapy, including tips on what to look for in a therapist and how to select between group, individual or online formats. *Pharmacotherapy:* Reference to terms such as 'treatment-resistant depression' was deemed to have a discouraging connotation, and thus alternate language should be used. Including a section on new treatments under development may offer hope to those struggling to find effective medications. *Neurostimulation:* Coverage should review electroconvulsive therapy and repetitive transcranial magnetic stimulation over other treatments. Across sections, first-line treatments and their effectiveness should be conveyed, in addition to a review of common and readily available options. Treatments should also be reviewed in respect to safety and side effect considerations, and treatment misconceptions or myths should be dispelled. Writers also opted to include crisis line information at outset, and quick reference summary sections for the entire Guide.

One overarching principle endorsed by the Writing Committee was to support patient autonomy, particularly by developing supplemental resources. The Writing Committee recommended developing a tool that can enhance end-user involvement in healthcare decision-making, particularly by informing how to ask a healthcare provider '*the right questions*'. A self-triaging tool that helps end-users evaluate illness severity to determine when to visit a doctor or hospital or access other resources was recommended. Finally, inclusion of a decision-tree flow chart that assists end-users with selecting suitable treatment was also suggested.

A guiding principle was to "*keep it simple*" but also to "*keep it informative*". The amount of included information should be limited to prevent end-users from feeling overwhelmed. However, since some readers may want more information, content could be organized into a "top-line" section which will be most visible, and a "more information" section which end-users can access for additional details. The Writing Committee agreed that providing access to the full CANMAT guidelines is important for this sub-section. The text should ideally be presented in point form, and graphics should be included whenever possible. The Writing Committee further recommended inclusion of a glossary of key terms and treatments to simplify usability. The Guide could also include an “additional wisdom” section, written from the lived experience perspective of the Writing Committee, to provide real-world advice on managing depression treatment that is clearly distinguishable from research. Finally, since there are specific considerations for special patient populations, separate documents or different adaptations may be needed to capture this information.

3.4. Workshop Feedback

Overall, the Writing Committee evaluated the workshop positively (see Figure 4A). In assessing learning outcomes, 86% of attendees felt that they gained knowledge of the CANMAT guidelines, and 71% felt more informed about the writing process. All Writing Committee members thought the workshop was easy to understand, and 67% believed that the information they received would support their role as a writer. Consequently, the Writing Committee expressed high levels of confidence to serve as a writer for the CHOICE-D Guide (see Figure 4G). Half of the Writing Committee also expressed interest in being involved in other stages of Guide development beyond writing, including editing, graphic design, and dissemination.

In providing a more detailed assessment of workshop structure, the Writing Committee was particularly pleased with the inclusion of a pre-workshop conference call, coupled with the opportunity to receive introduction to other writers. In respect to content, attendees found the translation exercise, group content review of the CANMAT guidelines, and content prioritization activity to be most valuable. However, 29% of attendees still requested that project leads provide additional resources to support their role as a writer. More specifically, Writing Committee members requested step-by-step instructions on how to translate clinical text, more concrete examples of lay translations, a translation toolkit including more resources for plain language writing, and a glossary defining technical terms found in the original CANMAT guidelines. There was also recommendation to include more wellness breaks throughout the workshop.

4. Discussion

Improving healthcare involves integration of multiple perspectives and different types of evidence. Two leading components of efforts to improve healthcare involve enhancing patient involvement and increasing use of evidence-based care. For enhanced patient involvement, key attributes include involving patient stakeholders in all aspects of healthcare design and implementation, and use of shared decision-making (by patient and provider) at the point of clinical contact. For increasing evidence-based medicine, attention to clinical guidelines may provide an optimal summary of relevant treatments. In this article, we have described a unique process where we used principles of knowledge translation, patient engagement, and evidence-based medicine to develop a co-design team that was predominantly comprised of individuals with lived experience of mood disorders. Our team subsequently evaluated, re-wrote, and extended a traditional CANMAT clinical treatment guideline for MDD into the plain-language

"CHOICE-D Patient and Family Guide to Depression Treatment". Our report provides details of our approach, based on feedback from professionals and lay members of the team, on how to optimize efforts to create other patient and family guides. To the authors' knowledge, inclusion of lived experience writers has yet to be done in the translation of clinical depression treatment guidelines into a lay language patient guide. In fact, the involvement of patients in any capacity within guideline development has been shown to be quite infrequent, occurring less than 25% of the time, despite the documented benefits[25]. As demonstrated within this report, the involvement of patients within the co-design process has the potential to optimize the final Guide, such as by identifying target populations and end-user considerations, prioritizing content selection, outlining graphic design considerations, suggesting real-world tools to increase effectiveness, incorporating the lived experience perspective to more directly support patient needs, and suggesting suitable dissemination strategies to increase uptake.

The methods used in this project provide unique insights on how to effectively engage a patient Writing Committee throughout the co-design process. For one, the Writing Committee noted the benefits of a pre-workshop call to informally meet the other writers and projects leads, become acquainted with the material and process, and ask questions. This was coupled with the circulation of project materials and resources with sufficient time for the Writing Committee to review prior to the in-person workshop. The inclusion of a phone meeting provided writers with the opportunity to prepare for the workshop and start generating ideas, opinions, and further questions. Increasing content knowledge allowed the writers to improve their confidence on the topic and feel more comfortable actively contributing to the group discussion. The opportunity to receive introductions to fellow co-writers also visibly helped to mitigate social anxieties, which permitted increased collaboration among writers during the workshop. These findings are supported by data suggesting that insufficient content knowledge and poor group dynamics are barriers to successful patient participation in guideline development[26]. Moreover, the call further improved the writers' level of comfort with project leads and helped to reduce any perceived power differentials, which can negatively affect participation due to increased intimidation[26].

Similarly, the provision of an in-person workshop, which has been shown to enhance patient engagement in guideline development[27,28], further supported the Writing Committee in obtaining knowledge on how to complete their role as a writer for the Guide. The Writing Committee shared that receipt of information within training sessions and practical exercises allowed them to feel better prepared to participate in the project and increased their interest in expanding their involvement to other project tasks beyond writing. The lay translation activity was particularly useful in improving writer confidence by providing them with an opportunity for direct practical exposure to and feedback on their upcoming translation task. Writers further expressed that the Think-Pair-Share format was preferable because it gave them an opportunity to develop their own ideas and work through areas of uncertainty with someone in a safe space with ample opportunity for equal discussion. In particular, being able to share ideas with another person helped writers determine if they were approaching lay language translation correctly without being intimidated or embarrassed within a larger group. However, the large group discussion towards the end was deemed to be a beneficial learning opportunity to hear about other challenges to potentially expect and more translation strategies to consider. The benefits of the full group discussion were also acknowledged during the content prioritization and development activities, which helped writers process and refine ideas and suggestions for the Guide. This aligns with other data that have shown that group discussion can assist participants with generating ideas by building on shared experiences and perspectives, and posing questions to one another[29]. Moreover, having a moderator allowed all writer preferences to be weighed equally to ensure no one was excluded from the process and that the final product would best represent the lived experience perspective.

Nevertheless, the workshop on its own was insufficient to meet the needs of the writers, who requested more step-by-step instructions and translation tool kits that could be referenced while completing the writing task. This suggests that although writers need training opportunities and resources to improve their content knowledge, it is essential to present this information in a simplified manner that can be translated into discrete steps for how to approach the assigned task. Presenting too much information and complex concepts or using unfamiliar technical terms make it difficult for writers to extract what is needed to complete their project responsibilities[28, 30]. Instead, project leads should provide writers with easy-to-use instructions on the translation process (and other writer tasks) that would be a useful aid during the writing process.

During the co-design process, the writers recommended that the Guide contain content that addresses symptoms, effects of illness stage and severity on treatment outcomes, first-line treatments and their effectiveness, safety/side effects, and treatment misconceptions. This selection was based on the lived experience perspective regarding which information would be most interesting to patients (and their families) and relevant to increasing patient understanding of their mental health treatment, as informed by the writers' own experiences navigating the mental healthcare system. Similarly, the Writing Committee requested the addition of question scripts, self-triaging resources, and treatment selection aids to improve patient autonomy, and increase the uptake of the Guide in real-world patient settings. In fact, the inclusion of tools that encourage question-asking, particularly questions that address the main medical concern, next steps, relevant treatment options, and all the '*whys?*' have been shown to improve patient engagement[31,32]. In respect to stylistic considerations, writers opted for the use of simple, yet hopeful language, brevity, short content sections surrounded by ample white space and graphics to make the Guide less overwhelming, and the addition of a key terms glossary for quick reference. Overall, the recommendations generated by the Writing Committee are highly aligned with the information extracted from the knowledge translation literature on how to best improve health literacy rates[31,33]. The literature suggests that use of patient-based interventions that adhere to these formats have the potential to improve patient engagement and satisfaction[34].

Despite the strengths of the applied co-design methodology, the recruitment process for the Writing Committee had some limitations. Since a major consideration was to ensure writer engagement throughout all stages of project development to maximize the lived experience perspective, project leads emphasized skills and experiences as the primary basis for Writing Committee selection. This decision was not only based on feedback received from our expert consultants, but it also aligns with criteria used in other patient guideline development groups[26]. In doing this, demographic characteristics were secondary considerations. Use of this approach limited the diversity of our Writing Committee, particularly in regard to gender, ethnicity, and geographic location of residence (see Table 2). Moreover, project leads were also restricted to the pool of applicants that applied to be part of the Writing Committee, as multiple applicant calls or recruitment of specific individuals known to project leads to fulfill demographic quotas were not performed. However, future patient groups should be diverse in as many aspects as possible to ensure the final Guide resonates with various readers[30]. Geographic diversity is important to gain insights into mental health resource limitations and accessibility concerns, such as those affecting patients in rural areas. Applicants with varied educational backgrounds, occupational/employment statuses, and socioeconomic statuses should be considered, as they may inform how untreated mental illness can create barriers for work or school and even for securing treatment. Age considerations should be addressed by including at least one youth and older patient representative to inform content and language. Patient writing groups should also be balanced in respect to sex, which can provide insights into both biological and social differences that can affect treatment options, such as treatment changes in the event of pregnancy and breastfeeding[6], for example. Representation from various ethnic and cultural groups informs treatment perspectives beyond Western medicine and is especially important considering the multicultural landscape of the Canadian context in which the Guide will be offered. To address these limitations for the CHOICE-D Guide, diversity profiles will be expanded during the editing process, as the Guide will be distributed to anyone who is interested in reviewing it, and their feedback will be integrated into the final version. Culturally diverse groups will also be included in other aspects of Guide development, such as dissemination, delivery of educational workshops on Guide use, and content translation into additional languages or culturally-informed versions.

Use of this process will ensure that any missed content, perspectives or considerations that are integral to the overall quality of the Guide be identified and added.

In terms of next steps, members of the Writing Committee were organized into writing sub-groups and randomly assigned content from the CANMAT guidelines to translate at the end of the in-person workshop; these sub-groups have since moved into the writing phase of the project. During the writing process, project leads will be available to support writers as needed to reduce burden. Moreover, attention to writer mental wellness is an important consideration, and development of good rapport and an open dialogue with writers will facilitate disclosure if more supports are needed. Although project deadlines are an important consideration, it is imperative to place writer wellness as a priority and to clearly articulate this to the Writing Committee. Consequently, deadlines will need to be flexible and this should be communicated to all involved stakeholders at outset. The Writing Committee will remain involved during the editing phase to ensure the final document is aligned with their original vision and retains the lived experience perspective. Several iterations of editing will be included in the development process and will involve additional persons with lived experience of depression and other stakeholder groups to broaden the scope of the feedback received. Upon Guide completion, writers will be invited to support dissemination to the extent that they are advocating for people with depression, with potential utility as community presenters or promoters via social media. There may also be opportunity to create accessible videos on how to use the Guide to increase uptake.

The creation of patient-developed depression guidelines is a novel initiative with ground-breaking clinical implications for patients (and families), which include improved understanding of treatment options, greater involvement in healthcare decision-making, and increased satisfaction in primary and secondary healthcare. This report adds to the literature by addressing important considerations for actively engaging persons with lived experience of depression as leaders in the co-design and writing process of lay treatment guidelines. This methodology provides a model that can be used to inform the creation and engagement of other patient groups within guideline development, particularly the co-design process, to ultimately produce a product that has real-world utility for patients and their families.

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Conflicts of Interest

SVP has received honoraria for consulting from Assurex and Takeda, honoraria for speaking from CANMAT, research grants from Assurex, Takeda, the Ontario Brain Institute, the Canadian Institutes for Health Research, the Ethel and James Flinn Foundation, and has shares in Mensante. **SHK** has received research funding or honoraria from the following sources: Abbott, Allergan, AstraZeneca, Boehringer-Ingelheim, BMS, Brain Canada, CIHR, Eli Lilly, Janssen, Lundbeck, Lundbeck Institute, Ontario Brain Institute, Otsuka, Pfizer, Servier, St. Jude Medical, Sunovion and Xian-Janssen. **AK**, **JTP**, and **TMF** have no conflicts to disclose.

Contributors

All authors had full access to the data presented in this report and take responsibility for the integrity of the data and the accuracy of the data interpretation. Study concept and design: TMF, JTP, AK, SHK, SVP. Acquisition of data: TMF, JTP, AK, SVP. Interpretation of data: TMF, JTP, AK, SHK, SVP. Drafting of the manuscript: TMF. Critical revision of the manuscript for important intellectual content: TMF, JTP, AK, SHK, SVP. Study supervision: SVP. All authors have given approval for the final version of the article to be published.

Figure 1: CHOICE-D Project Stages

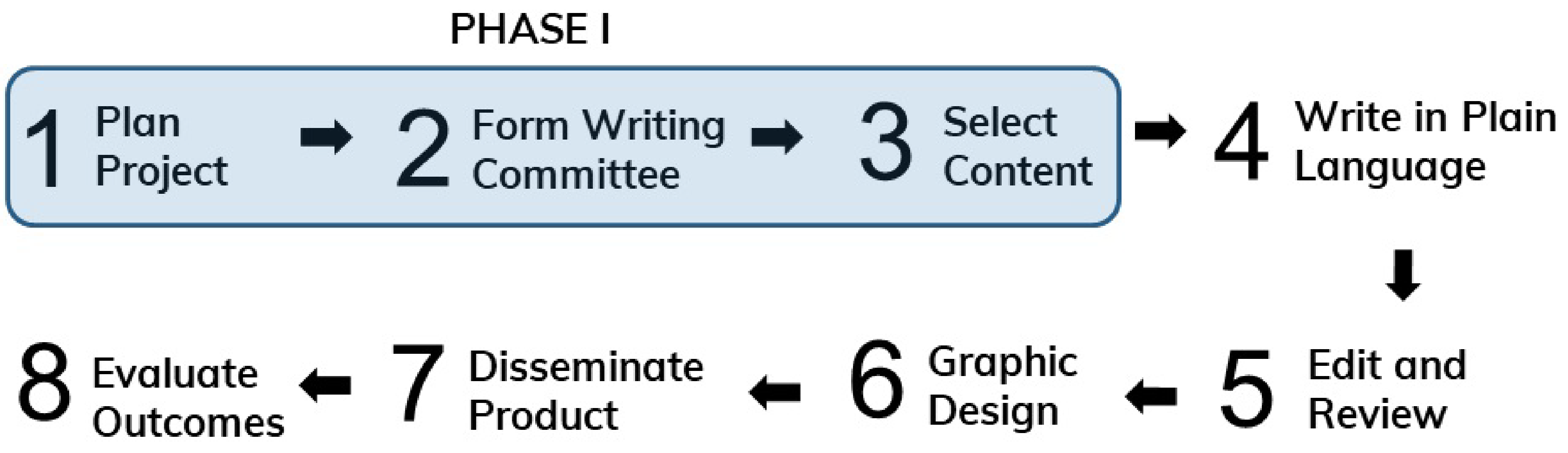


Figure 2: The Use of Expert Consultations to Inform CHOICE-D Project Methods

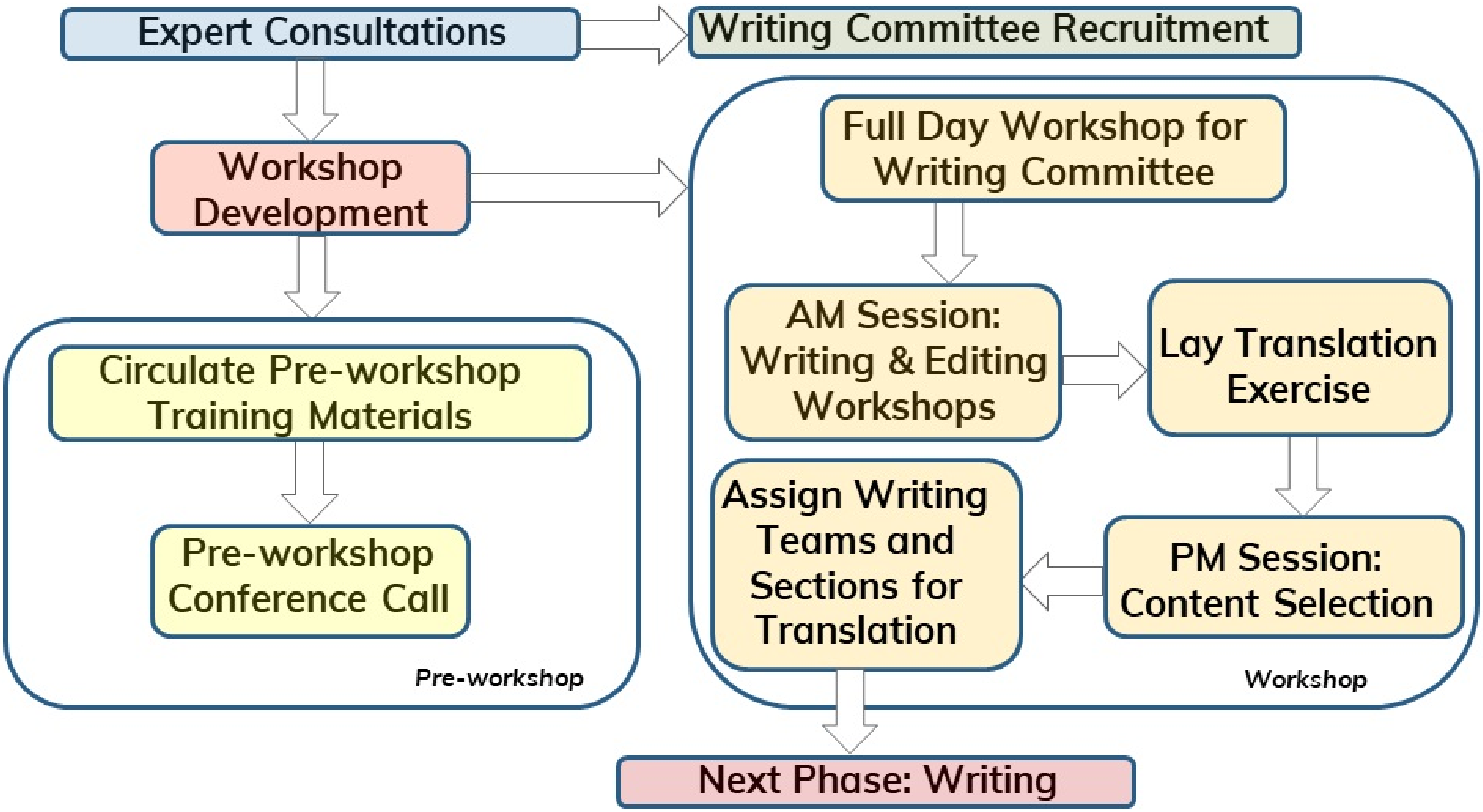
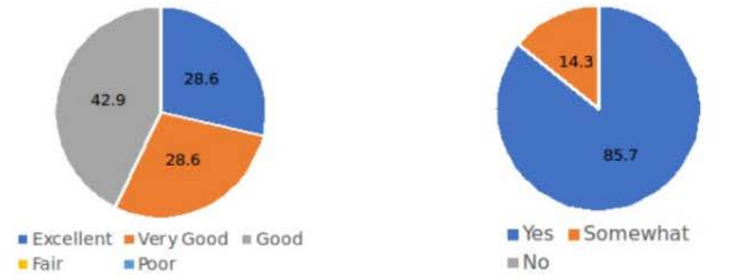


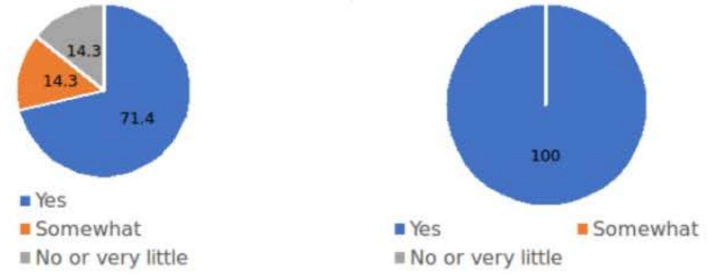
Figure 3: CHOICE-D Recruitment Process

Figure 4: Writing Commitee Feedback on Workshop*

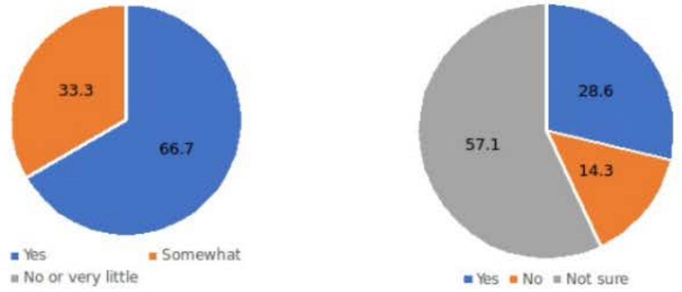
4A. Overall workshop rating.	4B. Did you learn something about the CANMAT Guidelines?



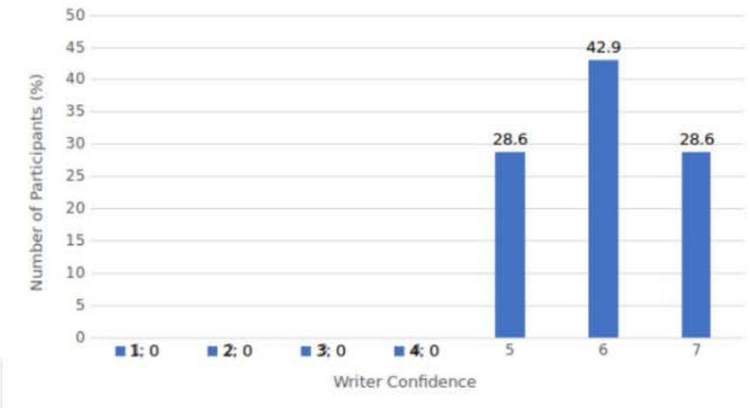
4C. Did you learn something about the writing process?	4D. Were the talks easy for you to understand?



4E. Will this workshop be helpful to you in your role as a writer?	4F. Are there any additional resources you need to support your role?



4G. How confident are you in your ability to serve as a writer, using a scale of 1 = not at all confident to 7 = extremely confident?



*Based on 7 completed responses

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Collaborating with Individuals with Lived Experience to Adapt CANMAT Clinical Depression Guidelines into a Patient Treatment Guide: The CHOICE-D Co-Design Process

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ABSTRACT

Effective treatment of depression involves collaboration with informed patients and families and appropriate knowledge-sharing. We describe here our experience, as a case example, of a collaboration to “translate” a clinical guideline designed for practitioners into an accessible, plain language version that patients and families can use during the care process, both to provide basic educational information and to foster “informed discussions” with their treatment providers. Content experts in knowledge translation, patient advocacy, patient-oriented research, and psychiatry guided overall project design. Our first step was to identify lived experience writers to join in the co-design and co-writing of the “CHOICE-D Patient and Family Guide to Depression Treatment”. A national call for writers attracted 62 applicants, from whom 8 individuals with lived experience of depression and writing experience were selected. Individuals subsequently attended a welcoming teleconference, followed by a one-day workshop designed to provide (1) a detailed overview of the clinician guideline, (2) an opportunity to select what should be included in the Guide, and (3) key principles of knowledge translation/lay writing. Both from the workshop and subsequently through the co-design process, lived experience writers recommended that the Guide address symptoms, effects of illness course on treatment, first-line treatments, safety/side effects, and treatment misconceptions. To promote patient autonomy, question scripts (how and what to ask your treatment provider), self-triaging resources, and treatment selection aids were suggested. Stylistic considerations included use of simple yet hopeful language, brevity, white space, key terms glossary, and graphics. Several strategies were particularly useful to optimize writer engagement in the co-design process: a pre-workshop conference call and circulation of project resources, an in-person workshop to increase content knowledge, structured discussion with co-writers and project leads to develop ideas, and practical training exercises with the provision of feedback. Both during and at the end of the project, writers provided additional recommendations for improving the process, including more in-person meetings, distribution of step-by-step instructions on the writing task, and a key terms glossary of technical terms to support their role. In conclusion, we describe a process with practical tips and reflective feedback on important considerations for engaging persons with lived experience as leaders in the co-design and writing process of lay treatment guidelines. These methods may serve as a model for similar projects in other areas of healthcare.

Keywords: depression, treatment, lay guidelines, lived experience, patient engagement, CHOICE-D

Word count Text: 5262 Abstract: 300

1. Introduction

Effective treatment of Major Depressive Disorder (MDD) ideally involves the collaboration of patients and practitioners in patient-centred care, using best practice as identified by evidence-based treatment guidelines. In 2016, the Canadian Network for Mood and Anxiety Treatments (CANMAT) developed a third iteration of updated guidelines for the clinical management of MDD, with new content on burden and principles of care[1], psychotherapy[2], pharmacotherapy[3], neurostimulation[4], complementary and alternative medicine[5], and special patient populations[6]. Designed for clinicians, these guidelines were generated using evidence review, expert opinion, and clinician (end-user) feedback. The 2016 CANMAT MDD guidelines evaluated evidence published since the 2009 edition, with a focus on meta-analyses, systematic reviews, and randomized control trials. Using level of evidence criteria, recommendations reflected both the quality of the data and expert consensus. The expert consensus process involved content experts in psychiatry, pharmacy, and psychology who graded evidence and balanced side effect and other considerations to generate treatment recommendation levels (e.g. first-line treatment, etc.). Finally, external clinicians reviewed draft recommendations to provide end-user feedback, but patients were not incorporated into this process.

Similar to the CANMAT MDD guidelines, most other clinical guidelines have been produced under the medical model[7], where clinicians are considered to possess knowledge and expertise over what is best for the patient. Consequently, the information presented within treatment guidelines is often made inaccessible to patients, such as through use of medical jargon that creates barriers in respect to language and education. This has a negative effect on mental health literacy, which refers to a patient’s capacity to access, understand, evaluate, and communicate basic health information to effectively inform healthcare decision-making[8]. In fact, limited health literacy is a common phenomenon affecting 60% of Canadian adults, with outcomes varying according to factors such as age, sex, level of education, geographic location, and immigration status[9,10]. Within mental health, there is an inadequate understanding of common symptoms, prevalence rates, risk factors, treatment options and their effectiveness, and crisis response protocols, which can have secondary effects on negative and stigmatizing perceptions of mental illness, including treatment and recovery[11,12]. Other potential consequences include negative health outcomes, reduced use of screening and preventative health services and health-promoting behaviours, increased hospitalizations, poor treatment compliance, patient safety and mortality concerns, and higher healthcare costs[9]. In contrast, improvements in mental health literacy have been shown to increase a patient's likelihood of sharing decisions with their physician, verifying information credibility, and exploring options beyond those presented by their healthcare team[13]. Patient involvement in healthcare decision-making is an important aspect of optimizing the quality of mental healthcare being delivered, and is a predictor of improved clinical outcomes[14] and increased patient satisfaction[15]. Moreover, how healthcare professionals support patient autonomy in healthcare decision-making has been shown to influence overall patient engagement, specifically their participation and health-information seeking behaviours, which can subsequently affect treatment adherence[16].

Consequently, there is an urgent need for patient education to improve. In support, the recovery model for mental health[7] has challenged more paternalistic approaches to treatment by placing patient agency within healthcare decision-making at the centre of recovery and healing. Under this model, patients are viewed as the experts of their own circumstances and should be empowered to harness their strengths and abilities to support their own recovery. This premise can extend beyond increasing patient involvement in healthcare decision-making to also include a direct role in the development and delivery of mental health information and services. This stems from the concept that persons with lived experience of mental illness have unique perspectives and ideas on the impact of mental illness and the navigation of mental health services that are informed by their own recovery journey. The integration of these ideas with evidence-based data can be used to identify topics that are clinically impactful for patients, and can improve health satisfaction and optimize health outcomes in the long-term[17]. The Mental Health Commission of Canada (MHCC) has recognized these benefits, and thus developed a mental health strategy that identifies the lived experience voice as an asset to recovery[18]. Within this strategy, the MHCC recommends that patients with mental illness, in addition to their families, assume leadership roles in the planning, delivery and evaluation of mental health services to contribute to the meaningful transformation of the mental healthcare system. Under this framework, clinical guidelines can best support patient recovery when they are made available in an accessible format using simplified language, coupled with the involvement of persons with lived experience in the development and dissemination process.

Many organizations have started to recognize the importance of including person with lived experience within guideline development, such as the Guidelines International Network[19], the AGREE (Appraisal of Guidelines, Research and Evaluation) Collaboration[20], and the National Institute for Health and Care Excellence (NICE)[21]. NICE, for example, has incorporated patient input into developing clinical guidelines for various acute and chronic clinical conditions such as cancer, mental health, and women and child health[22]. The World Health Organization (WHO) is also incorporating patient feedback into revising the diagnostic guidelines for the Mental, Behavioural and Neurodevelopmental Disorders section of the International Classification of Diseases (ICD)-11 after finding that current content inadequately reflects the lived experience perspective and uses language that is poorly understood and even objectionable to patients[23].

Despite the growing inclusion of patient feedback into guideline development, there is a paucity of lay language depression treatment guides that present comprehensive, evidence-based information for patients using persons with lived experience as leaders in the writing and dissemination process. This gap was identified in 2017 by the Canadian Biomarker Integration Network in Depression (CAN-BIND) and the Mood Disorders Association of Ontario (MDAO), a patient and family advocacy group. In response, a knowledge translation project was initiated to adapt the CANMAT clinician guidelines into an accessible, plain-language version that incorporated the expertise of individuals with lived experience. Termed the CHOICE-D (CANMAT Health Options for Integrated Care and Empowerment in Depression) Guide, this patient and family guide to depression treatment was written by patients (and families) with lived experience of MDD to enhance patient-centred care. The current report describes the protocol employed during Phase I of the CHOICE-D project: the co-design of the CHOICE-D Guide with a Writing Committee comprised of persons with lived experience of mental illness (see Figure 1). The co-design process refers to content selection for the Guide, in addition to graphic design, formatting, and layout considerations.

2. Approach to Project Design and Participant Training

Expert Consultations: Informal consultations with ten content experts in knowledge translation, patient advocacy, patient-oriented research, and psychiatry were completed (see Table 1). The purpose of the consultations was two-fold: (1) to define the composition and scope of the Writing Committee; and (2) to design an in-person workshop to provide training to members of the Writing Committee on their project roles and responsibilities, and engage them in the co-design process for the CHOICE-D Guide (see Figure 2). Consultations were completed either in person or via teleconference. Experts provided insights and ideas for project development, and recommended knowledge translation literature for review to identify optimal methods for patient education and engagement.

Writing Committee: MDAO released a national call inviting individuals with lived experience, either direct or indirect, of mood disorders and mental health service navigation from across Canada to join the Writing Committee. Stringent selection criteria were not imposed during the process to increase the breadth of applicants who were eligible to apply. For those with direct lived experience, there were no specific eligibility criteria involving the type of mood disorder, symptom length and severity, or treatments used, but applicants needed to confirm a level of current symptom stabilization that would allow them to manage the workload of the project. Project leads received 62 applications and invited 13 to interview; of these, eight applicants were selected but one writer withdrew their participation for personal reasons prior to project onset (see Figure 3). Based on the applicant pool, and as advised by our expert consultants, applicants were primarily selected based on skills and experiences in areas such as writing, editing, communications, graphic design, marketing, healthcare/health research, and work with the vulnerable sector to more directly support project objectives. The focus on member expertise was to permit engagement at all stages of Guide development, where possible, to ensure relevance to end-users and enhance quality. Demographic diversity was a secondary consideration to increase the range of experiences and insights offered. To see the demographic composition of the CHOICE-D Writing Committee, refer to Table 2. All Writing Committee members confirmed their comfort in articulating ideas verbally in a group setting and in written format. Writing Committee members were financially compensated for their involvement in the project. Project leads were transparent about project goals, anticipated workload, and the projected timeline for deliverables at outset.

Writer Workshop: A full day workshop was delivered to provide training to members of the Writing Committee before onset of the translation and writing phases. There were four main goals for the workshop: (1) to provide an opportunity for the team to meet each other in person; (2) to provide writers with a common foundation of knowledge on the CANMAT guidelines, the writing process, and other writing considerations; (3) to discuss content priorities for inclusion (or exclusion) in the CHOICE-D Guide based on the lived experience perspective; and (4) to determine writing sub-groups. To ensure all Writing Committee members understood the content of the original guidelines, a copy of the CANMAT Guidelines and lay summary notes on each section were distributed prior to the workshop to allow sufficient time for review. Writing Committee members were encouraged to familiarize themselves with the content, while noting any areas of uncertainty and questions on the material for clarification and group discussion. A conference call was also held in advance of the workshop to provide opportunity for Writing Committee members (and project leads) to introduce themselves, receive an overview of the workshop including key objectives and goals, ask questions, and facilitate discussion.

The workshop, designed by integrating evidence-based research and recommendations from expert feedback, was divided into two parts. The first part offered training sessions to support the Writing Committee in their project role. The Writing Committee was also provided with the resources and information they would need to develop the Guide. The second part focused on content selection for the Guide since only certain sections were translated from the original CANMAT guidelines to ensure brevity and accessibility (see Figure 2). Members of the Writing Committee were also given opportunity to get to know one another and share their experiences to facilitate bonding and mitigate any social anxieties. All writers were provided with hard copies of the workshop material, in addition to paper and pens for them to document any ideas or suggestions in the absence of an immediate opportunity to share them. Evaluations were provided at the end of the workshop to collect writer feedback on the co-design process.

Writer Training: The workshop provided didactic instruction interspersed with individual and interactive activities that allowed members of the Writing Committee to practice newly learned skills, provide their perspectives and opinions, and facilitate feelings of engagement and cohesion. Three training sessions (and related activities) on writing stylistics, clear language and design, and editing were provided. Individual training sessions were limited to 20 minutes to minimize burnout and fatigue. Writing Committee members also completed a lay translation exercise that resembled the translation task they would be assigned for the CHOICE-D Guide, which necessitated application of all the skills learned during the workshop. This exercise required the Writing Committee to translate an excerpt from the original CANMAT Guidelines into plain language text using the ‘Think (individual) - Pair (small group, in pairs) - Share (larger group discussion)’ method[24]. Feedback from the activity was immediately provided during a group discussion, where translation challenges and potential strategies were also reviewed.

Content Selection: The latter half of the workshop was spent distilling tangible points of information for translation such as content, structure, and order of presentation. Content selection was facilitated through discussions about ‘must-haves’ for the CHOICE-D Guide, and use of a content prioritization scoring activity. Scoring was completed for sections on ‘Disease Burden and Principles of Care’, ‘Psychotherapy’, ‘Pharmacotherapy’, and ‘Complementary and Alternative Medicines’; the ‘Neurostimulation’ section was discussed but not scored due to a primary focus on first-line treatments. During this activity, the Writing Committee provided feedback on which sub-sections of the original CANMAT guidelines should be included (or excluded) in the translated version based on a lived experience perspective of topic relevancy for mental health service navigation and engagement in mental healthcare decision-making. To facilitate prioritization, members provided a score of *'yes'*, *'maybe'*, or *'no'* for each sub-section. The group erred on the side of over-inclusion where, if the number of combined votes for '*yes*' and '*maybe*' exceeded the number of votes for '*no*', then the sub-section would be included in some capacity. The activity was accompanied by active group discussion to share personal insights for score assignment, and to ensure that all members of the Writing Committee were agreeable with final decisions. Use of this format allowed member feedback to be weighed equally, with the majority consensus dictating final outcomes. To ensure that potential Writing Committee biases or conflicts did not influence content translation, a moderator was appointed to put ideas in context and balance different points of view. Feedback was also collected on the order of presentation, graphic design considerations, and development of clinical tools that can be used by patients to facilitate discussions with their mental health practitioner(s) and support healthcare decision-making. Regardless of the sections selected for translation in the CHOICE-D Guide, all original content is still available to lay audiences through the CANMAT guidelines. The translated Guide does not aim to remove any content per se, but only to highlight aspects that are deemed to be particularly interesting and relevant to patients (and their families) for mental health treatment, as based on the lived experience perspective of the Writing Committee.

3. Implementation Steps in Project and Reflective Feedback

3.1. Guide Scope

The Writing Committee identified the main purpose of the translated Guide as "*to facilitate conversations with healthcare providers and to help build a sense of agency*". The Writing Committee believed that the Guide should be written with the following end-users in mind: individuals with depression, caregivers (e.g. parents, children, siblings, friends), healthcare providers, and staff at various resource centres. The Writing Committee further believed that these end-users may be facing potential challenges that include: fear of stigma including cultural- and faith-related stigma, English literacy barriers, limited access to comprehensive care, family changes (e.g. divorce, death, pregnancy), environmental changes (e.g. starting school or a new job), and financial difficulties. To reach these end-users, the Writing Committee believed the Guide should be distributed at drop-in clinics, emergency rooms, learning institutions (e.g. high schools, universities, colleges), community centres, homeless shelters, faith centres, and senior centres. These concepts influenced how the Writing Committee chose to shape the Guide.

3.2.Translation Exercise

After completing the lay translation exercise, the Writing Committee identified challenges with extracting essential information, understanding the material, and feeling overwhelmed or anxious with the translation task. Group discussion generated the following strategies to address these challenges: using '*Who? What? Where? When? Why? and How?*' questions to condense the message, cutting out extraneous or irrelevant information, considering the audience, identifying which sections could be supplementary, isolating the take home message, and consulting with others.

3.3. Content Selection and Development

The Writing Committee elected to retain the majority of sub-sections from the original CANMAT guidelines, with the exception of 11 which they believed would be unhelpful for end-users (see Table 3). Of these sections, writers prioritized content on psychotherapeutic options over pharmacotherapy. There were also several content areas that the Writing Committee felt were pertinent to address (see Table 4).

In addition to section prioritization, other considerations were noted: *Disease Burden and Principles of Care*: There were recommendations to include symptom summaries that support end-users in recognizing the signs of both depression and suicidality. When transitioning into treatment overviews, the effects of illness stage (e.g. initial diagnosis, a few treatments tried, multiple treatment 'failures') and severity on treatment outcomes should be included. *Psychotherapy:* The Writing Committee recommended providing tools on selecting the best type of therapy, including tips on what to look for in a therapist and how to select between group, individual or online formats. *Pharmacotherapy:* Reference to terms such as 'treatment-resistant depression' was deemed to have a discouraging connotation, and thus alternate language should be used. Including a section on new treatments under development may offer hope to those struggling to find effective medications. *Neurostimulation:* Coverage should review electroconvulsive therapy and repetitive transcranial magnetic stimulation over other treatments. Across sections, first-line treatments and their effectiveness should be conveyed, in addition to a review of common and readily available options. Treatments should also be reviewed in respect to safety and side effect considerations, and treatment misconceptions or myths should be dispelled. Writers also opted to include crisis line information at outset, and quick reference summary sections for the entire Guide.

One overarching principle endorsed by the Writing Committee was to support patient autonomy, particularly by developing supplemental resources. The Writing Committee recommended developing a tool that can enhance end-user involvement in healthcare decision-making, particularly by informing how to ask a healthcare provider '*the right questions*'. A self-triaging tool that helps end-users evaluate illness severity to determine when to visit a doctor or hospital or access other resources was recommended. Finally, inclusion of a decision-tree flow chart that assists end-users with selecting suitable treatment was also suggested.

A guiding principle was to "*keep it simple*" but also to "*keep it informative*". The amount of included information should be limited to prevent end-users from feeling overwhelmed. However, since some readers may want more information, content could be organized into a "top-line" section which will be most visible, and a "more information" section which end-users can access for additional details. The Writing Committee agreed that providing access to the full CANMAT guidelines is important for this sub-section. The text should ideally be presented in point form, and graphics should be included whenever possible. The Writing Committee further recommended inclusion of a glossary of key terms and treatments to simplify usability. The Guide could also include an "additional wisdom" section, written from the lived experience perspective of the Writing Committee, to provide real-world advice on managing depression treatment that is clearly distinguishable from research. Finally, since there are specific considerations for special patient populations, separate documents or different adaptations may be needed to capture this information.

3.4. Workshop Feedback

Overall, the Writing Committee evaluated the workshop positively (see Figure 4A). In assessing learning outcomes, 86% of attendees felt that they gained knowledge of the CANMAT guidelines, and 71% felt more informed about the writing process. All Writing Committee members thought the workshop was easy to understand, and 67% believed that the information they received would support their role as a writer. Consequently, the Writing Committee expressed high levels of confidence to serve as a writer for the CHOICE-D Guide (see Figure 4G). Half of the Writing Committee also expressed interest in being involved in other stages of Guide development beyond writing, including editing, graphic design, and dissemination.

In providing a more detailed assessment of workshop structure, the Writing Committee was particularly pleased with the inclusion of a pre-workshop conference call, coupled with the opportunity to receive introduction to other writers. In respect to content, attendees found the translation exercise, group content review of the CANMAT guidelines, and content prioritization activity to be most valuable. However, 29% of attendees still requested that project leads provide additional resources to support their role as a writer. More specifically, Writing Committee members requested step-by-step instructions on how to translate clinical text, more concrete examples of lay translations, a translation toolkit including more resources for plain language writing, and a glossary defining technical terms found in the original CANMAT guidelines. There was also recommendation to include more wellness breaks throughout the workshop.

4. Discussion

Improving healthcare involves integration of multiple perspectives and different types of evidence. Two leading components of efforts to improve healthcare involve enhancing patient involvement and increasing use of evidence-based care. For enhanced patient involvement, key attributes include involving patient stakeholders in all aspects of healthcare design and implementation, and use of shared decision-making (by patient and provider) at the point of clinical contact. For increasing evidence-based medicine, attention to clinical guidelines may provide an optimal summary of relevant treatments. In this article, we have described a unique process where we used principles of knowledge translation, patient engagement, and evidence-based medicine to develop a co-design team that was predominantly comprised of individuals with lived experience of mood disorders. Our team subsequently evaluated, re-wrote, and extended a traditional CANMAT clinical treatment guideline for MDD into the plain-language "CHOICE-D Patient and Family Guide to Depression Treatment". Our report provides details of our approach, based on feedback from professionals and lay members of the team, on how to optimize efforts to create other patient and family guides. To the authors' knowledge, inclusion of lived experience writers has yet to be done in the translation of clinical depression treatment guidelines into a lay language patient guide. In fact, the involvement of patients in any capacity within guideline development has been shown to be quite infrequent, occurring less than 25% of the time, despite the documented benefits[25]. As demonstrated within this report, the involvement of patients within the co-design process has the potential to optimize the final Guide, such as by identifying target populations and end-user considerations, prioritizing content selection, outlining graphic design considerations, suggesting real-world tools to increase effectiveness, incorporating the lived experience perspective to more directly support patient needs, and suggesting suitable dissemination strategies to increase uptake.

The methods used in this project provide unique insights on how to effectively engage a patient Writing Committee throughout the co-design process. For one, the Writing Committee noted the benefits of a pre-workshop call to informally meet the other writers and projects leads, become acquainted with the material and process, and ask questions. This was coupled with the circulation of project materials and resources with sufficient time for the Writing Committee to review prior to the in-person workshop. The inclusion of a phone meeting provided writers with the opportunity to prepare for the workshop and start generating ideas, opinions, and further questions. Increasing content knowledge allowed the writers to improve their confidence on the topic and feel more comfortable actively contributing to the group discussion. The opportunity to receive introductions to fellow co-writers also visibly helped to mitigate social anxieties, which permitted increased collaboration among writers during the workshop. These findings are supported by data suggesting that insufficient content knowledge and poor group dynamics are barriers to successful patient participation in guideline development[26]. Moreover, the call further improved the writers' level of comfort with project leads and helped to reduce any perceived power differentials, which can negatively affect participation due to increased intimidation[26].

Similarly, the provision of an in-person workshop, which has been shown to enhance patient engagement in guideline development[27,28], further supported the Writing Committee in obtaining knowledge on how to complete their role as a writer for the Guide. The Writing Committee shared that receipt of information within training sessions and practical exercises allowed them to feel better prepared to participate in the project and increased their interest in expanding their involvement to other project tasks beyond writing. The lay translation activity was particularly useful in improving writer confidence by providing them with an opportunity for direct practical exposure to and feedback on their upcoming translation task. Writers further expressed that the Think-Pair-Share format was preferable because it gave them an opportunity to develop their own ideas and work through areas of uncertainty with someone in a safe space with ample opportunity for equal discussion. In particular, being able to share ideas with another person helped writers determine if they were approaching lay language translation correctly without being intimidated or embarrassed within a larger group. However, the large group discussion towards the end was deemed to be a beneficial learning opportunity to hear about other challenges to potentially expect and more translation strategies to consider. The benefits of the full group discussion were also acknowledged during the content prioritization and development activities, which helped writers process and refine ideas and suggestions for the Guide. This aligns with other data that have shown that group discussion can assist participants with generating ideas by building on shared experiences and perspectives, and posing questions to one another[29]. Moreover, having a moderator allowed all writer preferences to be weighed equally to ensure no one was excluded from the process and that the final product would best represent the lived experience perspective.

Nevertheless, the workshop on its own was insufficient to meet the needs of the writers, who requested more step-by-step instructions and translation tool kits that could be referenced while completing the writing task. This suggests that although writers need training opportunities and resources to improve their content knowledge, it is essential to present this information in a simplified manner that can be translated into discrete steps for how to approach the assigned task. Presenting too much information and complex concepts or using unfamiliar technical terms make it difficult for writers to extract what is needed to complete their project responsibilities[28, 30]. Instead, project leads should provide writers with easy-to-use instructions on the translation process (and other writer tasks) that would be a useful aid during the writing process.

During the co-design process, the writers recommended that the Guide contain content that addresses symptoms, effects of illness stage and severity on treatment outcomes, first-line treatments and their effectiveness, safety/side effects, and treatment misconceptions. This selection was based on the lived experience perspective regarding which information would be most interesting to patients (and their families) and relevant to increasing patient understanding of their mental health treatment, as informed by the writers' own experiences navigating the mental healthcare system. Similarly, the Writing Committee requested the addition of question scripts, self-triaging resources, and treatment selection aids to improve patient autonomy, and increase the uptake of the Guide in real-world patient settings. In fact, the inclusion of tools that encourage question-asking, particularly questions that address the main medical concern, next steps, relevant treatment options, and all the '*whys?*' have been shown to improve patient engagement[31,32]. In respect to stylistic considerations, writers opted for the use of simple, yet hopeful language, brevity, short content sections surrounded by ample white space and graphics to make the Guide less overwhelming, and the addition of a key terms glossary for quick reference. Overall, the recommendations generated by the Writing Committee are highly aligned with the information extracted from the knowledge translation literature on how to best improve health literacy rates[31,33]. The literature suggests that use of patient-based interventions that adhere to these formats have the potential to improve patient engagement and satisfaction[34].

Despite the strengths of the applied co-design methodology, the recruitment process for the Writing Committee had some limitations. Since a major consideration was to ensure writer engagement throughout all stages of project development to maximize the lived experience perspective, project leads emphasized skills and experiences as the primary basis for Writing Committee selection. This decision was not only based on feedback received from our expert consultants, but it also aligns with criteria used in other patient guideline development groups[26]. In doing this, demographic characteristics were secondary considerations. Use of this approach limited the diversity of our Writing Committee, particularly in regard to gender, ethnicity, and geographic location of residence (see Table 2). Moreover, project leads were also restricted to the pool of applicants that applied to be part of the Writing Committee, as multiple applicant calls or recruitment of specific individuals known to project leads to fulfill demographic quotas were not performed. However, future patient groups should be diverse in as many aspects as possible to ensure the final Guide resonates with various readers[30]. Geographic diversity is important to gain insights into mental health resource limitations and accessibility concerns, such as those affecting patients in rural areas. Applicants with varied educational backgrounds, occupational/employment statuses, and socioeconomic statuses should be considered, as they may inform how untreated mental illness can create barriers for work or school and even for securing treatment. Age considerations should be addressed by including at least one youth and older patient representative to inform content and language. Patient writing groups should also be balanced in respect to sex, which can provide insights into both biological and social differences that can affect treatment options, such as treatment changes in the event of pregnancy and breastfeeding[6], for example. Representation from various ethnic and cultural groups informs treatment perspectives beyond Western medicine and is especially important considering the multicultural landscape of the Canadian context in which the Guide will be offered. To address these limitations for the CHOICE-D Guide, diversity profiles will be expanded during the editing process, as the Guide will be distributed to anyone who is interested in reviewing it, and their feedback will be integrated into the final version. Culturally diverse groups will also be included in other aspects of Guide development, such as dissemination, delivery of educational workshops on Guide use, and content translation into additional languages or culturally-informed versions. Use of this process will ensure that any missed content, perspectives or considerations that are integral to the overall quality of the Guide be identified and added.

In terms of next steps, members of the Writing Committee were organized into writing sub-groups and randomly assigned content from the CANMAT guidelines to translate at the end of the in-person workshop; these sub-groups have since moved into the writing phase of the project. During the writing process, project leads will be available to support writers as needed to reduce burden. Moreover, attention to writer mental wellness is an important consideration, and development of good rapport and an open dialogue with writers will facilitate disclosure if more supports are needed. Although project deadlines are an important consideration, it is imperative to place writer wellness as a priority and to clearly articulate this to the Writing Committee. Consequently, deadlines will need to be flexible and this should be communicated to all involved stakeholders at outset. The Writing Committee will remain involved during the editing phase to ensure the final document is aligned with their original vision and retains the lived experience perspective. Several iterations of editing will be included in the development process and will involve additional persons with lived experience of depression and other stakeholder groups to broaden the scope of the feedback received. Upon Guide completion, writers will be invited to support dissemination to the extent that they are advocating for people with depression, with potential utility as community presenters or promoters via social media. There may also be opportunity to create accessible videos on how to use the Guide to increase uptake.

The creation of patient-developed depression guidelines is a novel initiative with ground-breaking clinical implications for patients (and families), which include improved understanding of treatment options, greater involvement in healthcare decision-making, and increased satisfaction in primary and secondary healthcare. This report adds to the literature by addressing important considerations for actively engaging persons with lived experience of depression as leaders in the co-design and writing process of lay treatment guidelines. This methodology provides a model that can be used to inform the creation and engagement of other patient groups within guideline development, particularly the co-design process, to ultimately produce a product that has real-world utility for patients and their families.

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Conflicts of Interest

SVP has received honoraria for consulting from Assurex and Takeda, honoraria for speaking from CANMAT, research grants from Assurex, Takeda, the Ontario Brain Institute, the Canadian Institutes for Health Research, the Ethel and James Flinn Foundation, and has shares in Mensante. **SHK** has received research funding or honoraria from the following sources: Abbott, Allergan, AstraZeneca, Boehringer-Ingelheim, BMS, Brain Canada, CIHR, Eli Lilly, Janssen, Lundbeck, Lundbeck Institute, Ontario Brain Institute, Otsuka, Pfizer, Servier, St. Jude Medical, Sunovion and Xian-Janssen. **AK**, **JTP**, and **TMF** have no conflicts to disclose.

Contributors

All authors had full access to the data presented in this report and take responsibility for the integrity of the data and the accuracy of the data interpretation. Study concept and design: TMF, JTP, AK, SHK, SVP. Acquisition of data: TMF, JTP, AK, SVP. Interpretation of data: TMF, JTP, AK, SHK, SVP. Drafting of the manuscript: TMF. Critical revision of the manuscript for important intellectual content: TMF, JTP, AK, SHK, SVP. Study supervision: SVP. All authors have given approval for the final version of the article to be published.

Figure 1: CHOICE-D Project Stages

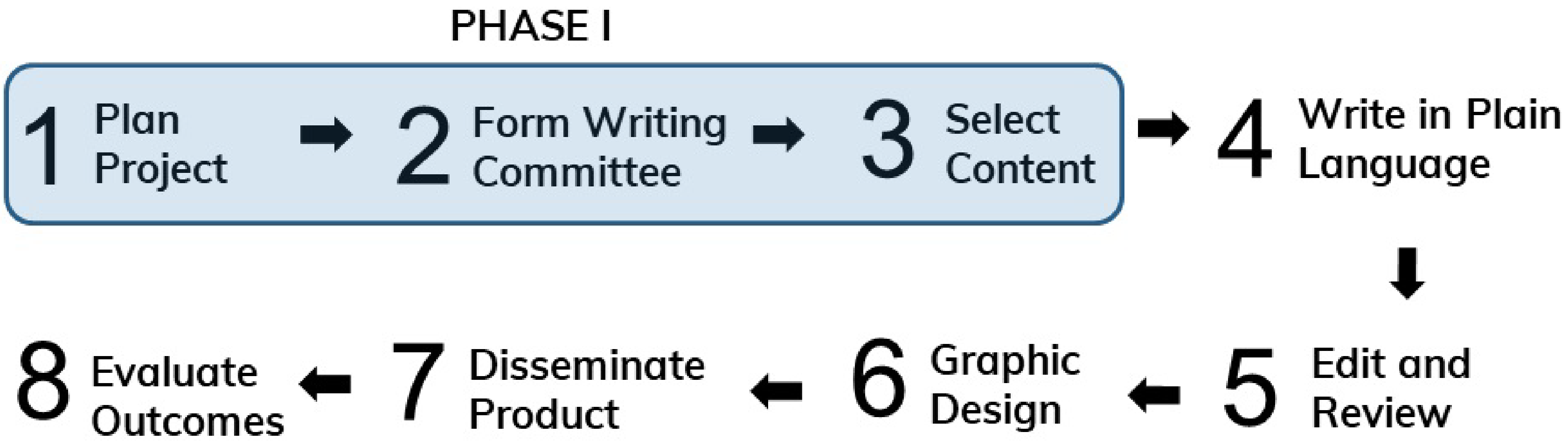

Figure 2: The Use of Expert Consultations to Inform CHOICE-D Project Methods

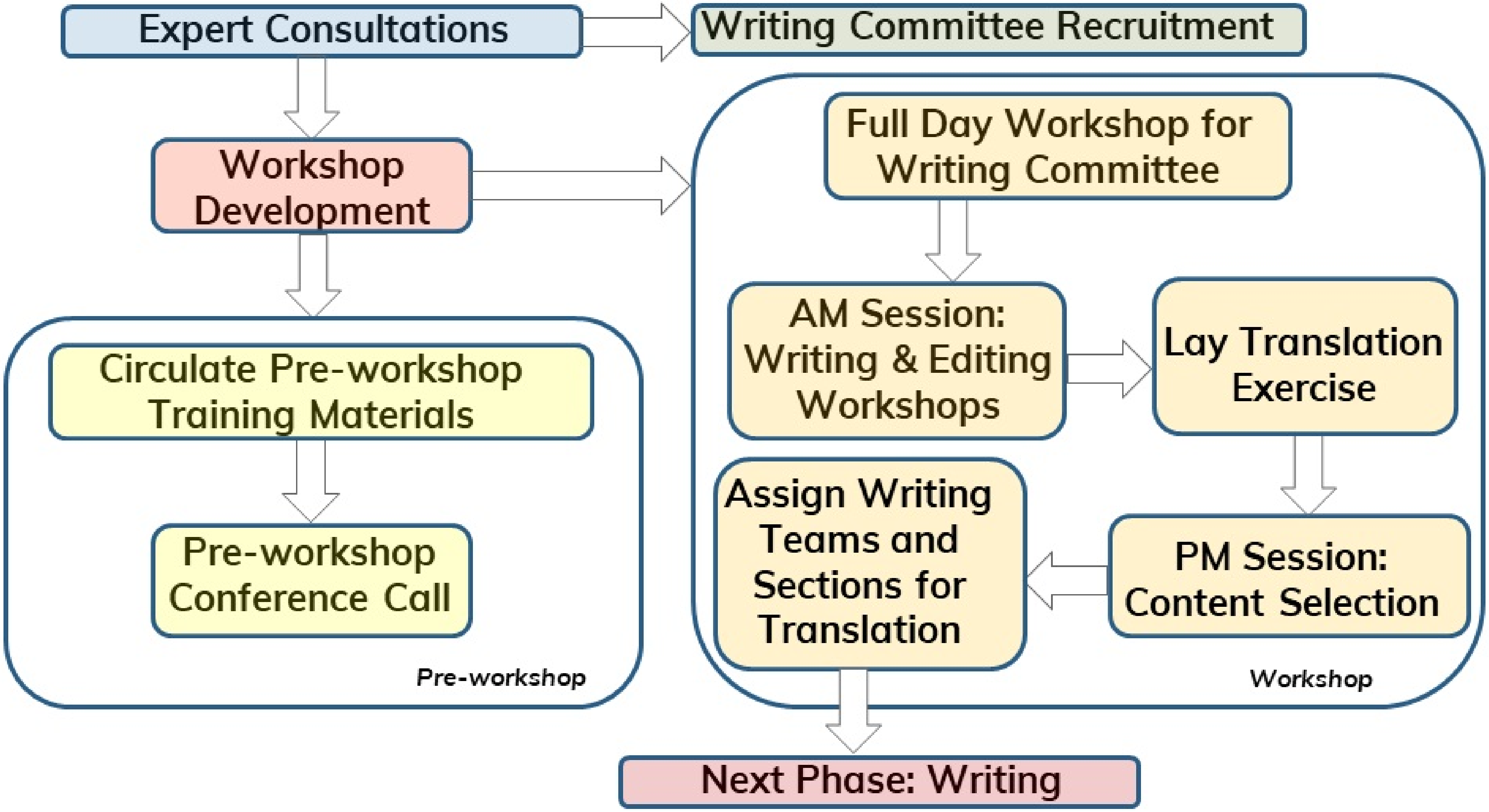

Figure 3: CHOICE-D Recruitment Process

Figure 4: Writing Commitee Feedback on Workshop*

4A. Overall workshop rating.

4B. Did you learn something about the CANMAT Guidelines?

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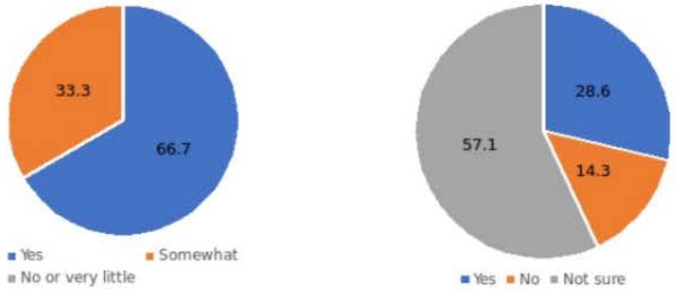
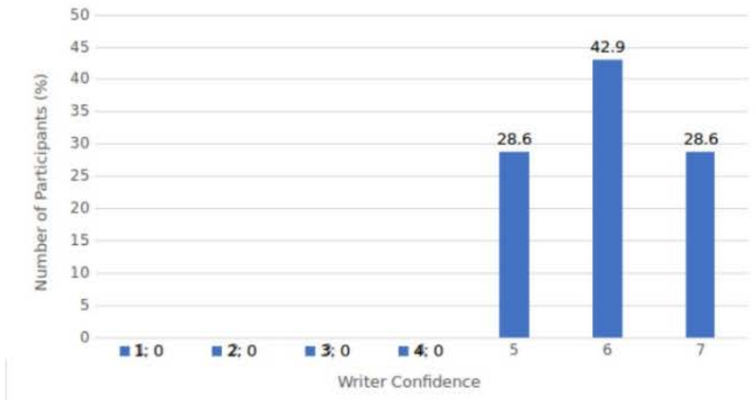
4D. Were the talks easy for you to understand?



4E. Will this workshop be helpful to you in your role as a writer?

4F. Are there any additional resources you need to support your role?



4G. How confident are you in your ability to serve as a writer, using a scale of 1 = not at all confident to 7 = extremely confident?

*Based on 7 completed responses

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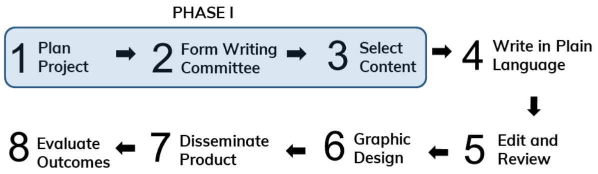
Figure 1: CHOICE-D Project Stages



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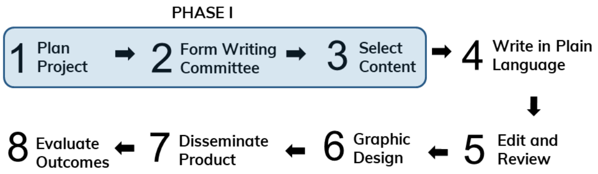

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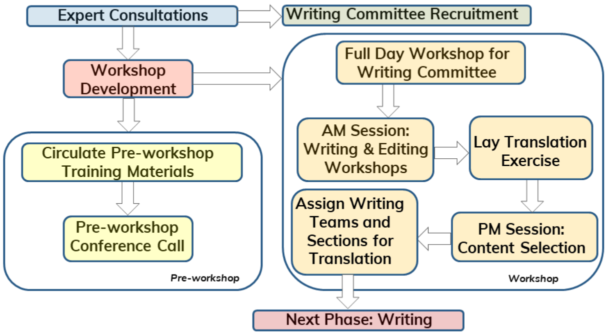
Figure 2: The Use of Expert Consultations to Inform CHOICE-D Project Methods



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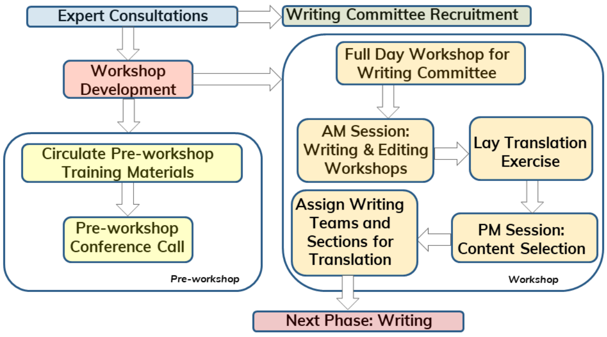

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Figure 3: CHOICE-D Recruitment Process

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Figure 3: CHOICE-D Recruitment Process

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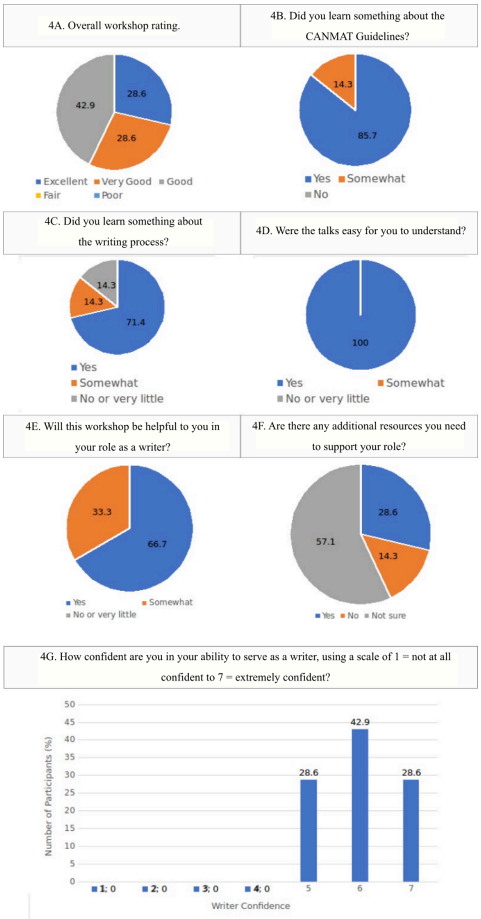
Figure 4: Writing Commitee Feedback on Workshop*



4A. Overall workshop rating.

4B. Did you learn something about the CANMAT Guidelines?

4C. Did you learn something about the writing process?

4D. Were the talks easy for you to understand?

4E. Will this workshop be helpful to you in your role as a writer?

4F. Are there any additional resources you need to support your role?

4G. How confident are you in your ability to serve as a writer, using a scale of 1 = not at all confident to 7 = extremely confident?

*Based on 7 completed responses

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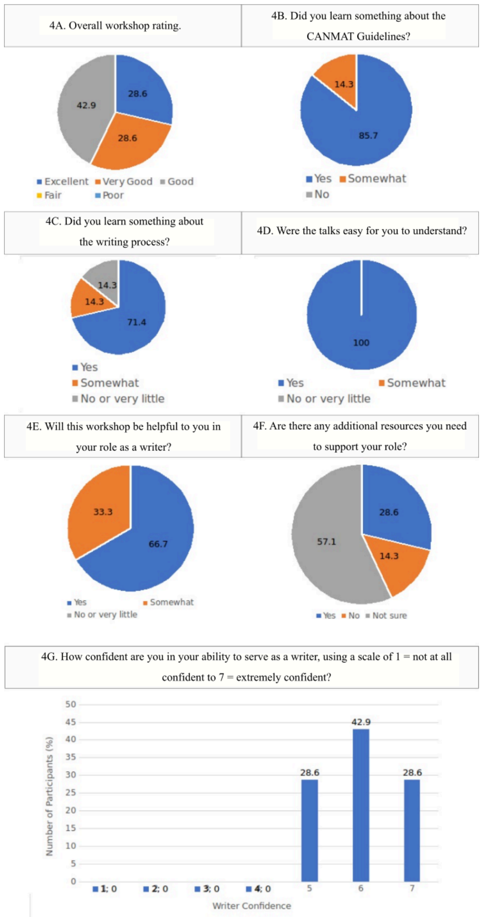

*Based on 7 completed responses

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Table 1: Content Experts Consulted for the CHOICE-D Guide

Expert Type	Number Interviewed	Area of Expertise
CHOICE-D, Project Leads[a]	4	Psychiatric practice; community mental health; patient-oriented research; knowledge translation and outreach
CANMAT 2016 Depression Guide, Section Leads[b]	4	Depression treatments particularly pharmacology, psychotherapy and neurostimulation; special patient populations
Knowledge Translation Experts	3	Knowledge translation; qualitative data collection; community education and workshop development
Patient Advocates	1	Healthcare advocacy; patient-oriented research

CANMAT = Canadian Network for Mood and Anxiety Treatments; CHOICE-D = CANMAT Health Options for Integrated Care and Empowerment in Depression; [a]Includes representatives from the partnering organizations of CANMAT, the Canadian Biomarker Integration Network in Depression, Mood Disorders Association of Ontario, and Ontario Brain Institute; [b]Two section leads are also represented under ‘CHOICE’D Project Leads’

Table 2: Writing Committee Characteristics*

Characteristic	**Frequency Count**
Gender	
Female	6 (85.7%)
Male	1 (14.3%)
Age	
20-29 years	3 (42.9%)
30-39 years	1 (14.3%)
40-49 years	2 (28.6%)
50-59 years	1 (14.3%)
Ethnicity	
Caucasian	7 (100%)
Place of Residence	
Toronto	6 (85.7%)
Kingston	1 (14.3%)

*Based on 7 completed responses

Table 3: CANMAT Sections to Exclude Based on Content Prioritization Exercise

Disease Burden and Principles of Care
Section 1.5. What is the disease burden associated with MDD? Section 1.6. What is the occupational impact of MDD? Section 1.8. What is the impact of MDD on physical health? Section 1.9. How does MDD typically present in clinical practice? Section 1.10. What are the basic principles of clinical management? Section 1.12. What is measurement-based care? Section 1.14. What are the goals of acute and maintenance treatment?
Psychotherapy
Section 2.4. How do gender and age influence the decision to use psychological treatment? Section 2.14. What is the overall level of efficacy for motivational interviewing in the acute and maintenance phases of MDD Treatment?
Pharmacotherapy
Section 3.2. What antidepressants are newly approved? Section 3.11. Are there differences in formulations of specific antidepressants?
Complementary and Alternative Medicines
None

MDD = major depressive disorder

Table 4: Summary of Guide Development Feedback

Recommendations for Content

- Provide symptom summaries for MDD and suicide
- Address effects of illness stage and severity on treatment outcomes
- Communicate first-line treatments and their effectiveness
- Address safety and side effects
- Address treatment misconceptions or myths

Recommendations to Promote Patient Autonomy

- Include question scripts on what to ask your doctor
- Include self-triaging resources
- Include decision-tree flow chart for treatment selection

Recommendations on Clear Language and Design

- Keep it simple but also informative
- Avoid negative or discouraging language; focus on messages of hope
- Be mindful of document length, and include access to supplemental information
- Use point form and graphics
- Include glossary of key terms and treatments
- Include real-world advice from persons with lived experience
- Offer guide adaptations for special patient populations