

Depression guideline written “by patients for patients” a first for Canada

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The Canadian Network for Mood and Anxiety Treatments has given its depression guideline a patient-centred makeover. Together with other mental health and brain-research organizations, the network partnered with people who have experienced depression to create a simplified version of the latest Canadian clinical guideline for patients and families. However, some experts warn that there are many unknowns about involving patients in writing guidelines.

The [new CHOICE-D patient and family guide](#) includes information on treatment options and practical resources to help patients manage their care, including a symptom chart, questions to ask physicians and self-management tools.

“We wanted to empower individuals to discuss treatment options with their health care providers and take an active role in their depression care,” said Andrew Kcomt, manager of knowledge translation and research at the Mood Disorders Association of Ontario and co-lead of the project. “Creating this guide in collaboration with people who have lived with depression is valuable, because they have a unique understanding of what people living with depression need to know.”

Clinical experts worked with a writing team of seven patients and caregivers to develop the guide, and then circulated drafts for feedback from hundreds of clinicians, patients and caregivers in the community. It’s a Canadian first, according to researchers involved in the project. “We’ve not had patient guidelines written in this detail by patients for patients,” said co-lead Dr. Sagar Parikh, a professor of psychiatry at the University of Michigan, Ann Arbor and adjunct professor at the University of Toronto.

“Historically, we’ve produced guidelines primarily for clinicians, but there’s a gap that exists between ideal practice and everyday practice,” he explained. [Low numbers of clinicians](#) actually follow guidelines, and the experiences and preferences of patients usually aren’t reflected in the documents.

Engaging patients in translating and communicating the evidence has the potential to help close these gaps, Parikh said. “Research has shown if you empower and educate an individual to take charge of their health and ask questions, that makes a powerful difference in the health outcomes.”

This goes beyond putting clinical guidelines in plain language, he said. The writing team of patients and caregivers empha-

sized certain information “in a very different way than a professional science writer or clinician alone would have done.” For example, “doctors get excited about newer treatments, including relatively rarely available ones like exotic forms of brain stimulation,” whereas patients and caregivers nixed mention of treatments that were more experimental or difficult to access. The writing team also pushed for practical resources, including scripts to simplify communication with doctors, lists of the pros and cons of different treatment options, and clear negative recommendations “when something popular was not supported by evidence.”

Weighing treatment options can be difficult at the best of times, and especially when a person has depression, said



A new treatment guide for depression developed with patients and caregivers is a Canadian first, say researchers.

Petra Dreiser, a member of the writing team. “Having all these things together in written and visual form is important because it can be a very overwhelming experience.”

Reconciling personal experience with the evidence and ensuring diverse representation remain two major challenges in involving patients in guideline development. “This is a young field that is still in search of the proper methods and ways to engage individuals with lived experience,” said Dr. France Légaré, Canada Research Chair in Shared Decision Making and

Knowledge Translation. Her [2011 review](#) of patient involvement in clinical guidelines found there was very little assessment of the impact of these projects. “As this field grows, it will learn by trying diverse strategies and documenting what works and what does not,” Légaré said.

Dreiser noted that the writing team for the patient and family guide “could probably have been more diverse in terms of gender or ethnic backgrounds.” The project co-leads agreed, although Parikh added that “the hundreds of individuals who ultimately had some input into this

document actually did a very good job of addressing issues of diversity.”

There are also plans to measure the impact of the project on patients’ help-seeking and clinical outcomes, he said. “We wouldn’t simply print it and forget about it.”

The guide was developed in partnership with the Mood Disorders Association of Ontario, the Ontario Brain Institute and the Canadian Biomarker Integration Network in Depression.

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