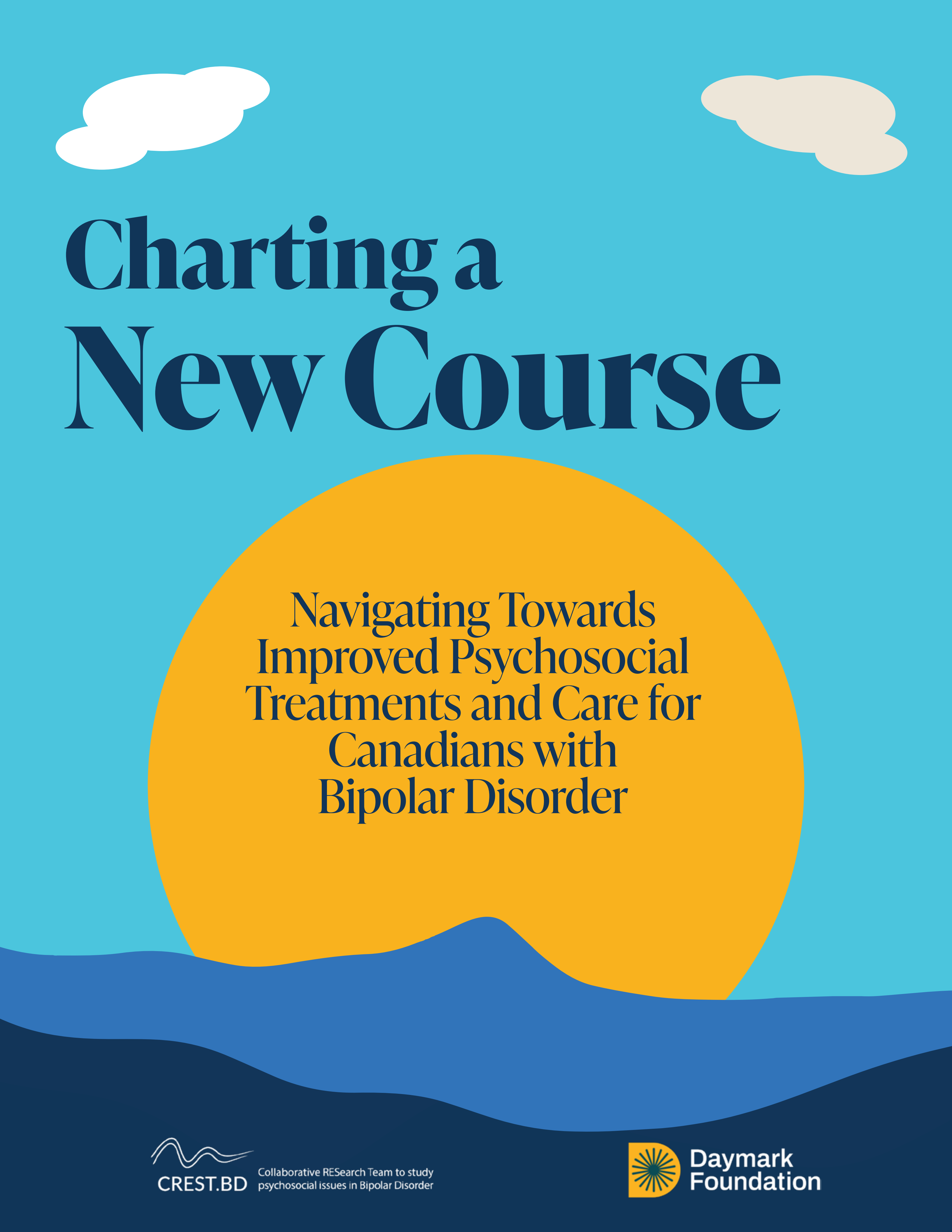

Charting a New Course

Navigating Towards Improved Psychosocial Treatments and Care for Canadians with Bipolar Disorder

CREST.BD Collaborative RESearch Team to study psychosocial issues in Bipolar Disorder

Daymark Foundation

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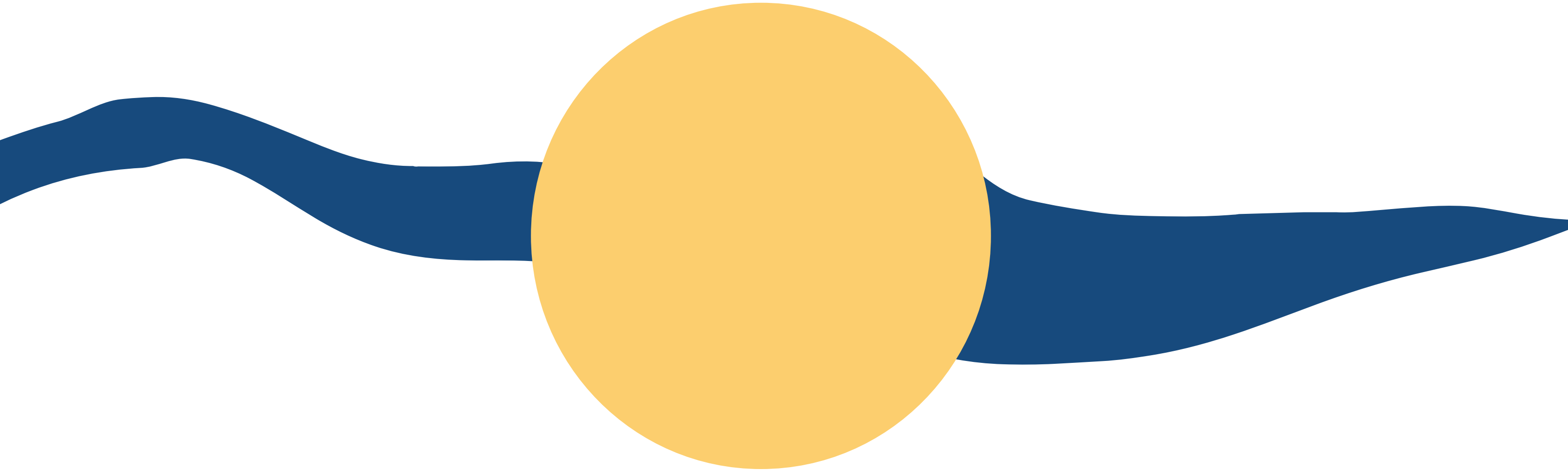
Executive Summary



This report is a collaboration between the Collaborative RESearch Team to study psychosocial issues in Bipolar Disorder (CREST.BD) and the Daymark Foundation to prioritize ways to improve psychosocial treatment and care for people living with bipolar disorder (BD) in Canada. It was informed by a diverse range of people with direct experience with BD, specifically: people living with BD; their family members, supporters, and loved ones; healthcare providers; mental health policy makers; and, representatives from community mental health organizations.

The research method we used to build consensus around priorities is called “**deliberative dialogue**,” where diverse groups of people exchange and weigh ideas and opinions about a particular issue in which they share an interest. Over several months, we held a series of deliberative dialogue groups as well as an online survey in which we:

- Examined the current international evidence base for psychosocial treatments and care for BD
- Reflected on whether this evidence was being put into action in Canada and, if not, what barriers prevented its implementation
- Generated ideas for improvement in psychosocial treatment and care for BD
- Prioritized the top ideas generated through the deliberative dialogue process.

Our key questions:

1. What are the **main priorities** for advancing psychosocial treatments and supports for people with BD in Canada?
2. What are some **promising directions** for meeting these priorities?

Our key insights from this research are...

1

There is a mismatch between current research and treatment priorities and the interests of people with BD

- Psychosocial care is important to people with BD but is not reflected as a research priority
- Current treatments for BD are overly focused on medication management and acute care with not enough attention to psychosocial factors

2

Psychosocial care is important but needs improvement

- There is limited integration of quality of life (QoL), functioning, and self-monitoring into psychosocial care
- There is a lack of access for most Canadians with BD because of multiple intersecting barriers
- Certain communities are especially underserved, such as low-income, rural and remote, Indigenous, racialized, and 2SLGBTQIA+ communities

3

System investments and improvements are critical

- BD-specific funding must be increased to expand and enhance services
- Improvements to and additional capacity in primary care should be priorities

4

Family members—in their broadest possible definition—are critical to the psychosocial health of people with BD but

- Family members of people with BD need their own support—both the expansion of existing evidence-based interventions and the creation of new services
- Liaison between family members and healthcare providers needs to be improved
- Family members in rural or remote areas of Canada face particular challenges in accessing supports

Navigating this document:

This report summarizes what we learned from the deliberative dialogue and consensus-building process and outlines ways to chart a new course towards improved health and quality of life for Canadians living with BD. Details about the current evidence base for psychosocial treatments and supports, the methods we used in this project, the research team, and the results of the ranking of participants' priorities are available in the appendices, and a glossary is available at the end of this document.

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Appendices

Introduction

About bipolar disorder

Bipolar disorder (BD) is a mood disorder characterized by pronounced variability in mood, activity, and energy levels. The condition is relatively common: the lifetime prevalence of BD is estimated to be 2.4% globally,[1] with approximately half a million people living with the condition in Canada alone.[2] Only an estimated 50% of people with BD in high-income countries such as Canada receive any treatment for their condition during their lifetime.[1]

BD can be a highly disabling, and sometimes lethal, condition. The World Health Organization lists BD as the fifth-leading cause of disease burden among mental disorders.[3] Years lost to disability from BD are similar to very common diseases like asthma and Alzheimer's. Beyond the direct experience of symptoms of depression, hypomania or mania, and psychosis, as well as the side effects of medications and hospitalizations, people with BD can experience difficulties with interpersonal relationships, memory and cognition, and work and social life.[4–6] People with BD also experience other distressing impacts, including loss of hope for the future, loss of secure sense of self, and stigmatization and discrimination.[7] Most disturbingly, 6–10% of people with BD will die by suicide.[8]

Misery statistics about BD abound. But some people with lived experience of BD describe a rich array of positive aspects associated with the condition. These include, for example, higher levels of empathy, spirituality, creativity, resilience, personal growth, and enhanced abilities.[9–10] And, importantly, people with BD can experience good health and quality of life (QoL), and wellness and QoL outcomes are prioritized by people living with BD. Although there are evidence-based methods for measuring QoL specifically in people with BD, regular assessment of QoL does not occur widely in clinical care settings. Further, people with BD are not yet fully supported to assess their QoL in their daily lives and implement tailored self-management strategies or psychosocial treatments based on their QoL concerns.

> *"Misery statistics about BD abound. But some people with lived experience of BD describe a rich array of positive aspects associated with the condition."*

Evidence to support psychosocial care for BD

For many people with BD, medications are the foundation of treatment.[11] But many patients who take mood-stabilizing medications as prescribed will still experience relapse into mood episodes, as well as poor functioning and QoL between mood episodes. In addition to medications, evidence-informed psychological and social ("psychosocial") treatments and supports can help people with BD improve outcomes and well-being. The psychosocial interventions for BD with the **strongest evidence** are:

1. Psychoeducation
2. Cognitive-behavioural therapy (CBT)
3. Family-focused therapy (FFT)
4. Interpersonal and social rhythm therapy (IPSRT)

There are several emerging treatments being explored as well—see Appendix A for a complete summary of the evidence base and emerging areas of research on psychosocial interventions for BD.

Despite the strong evidence for psychosocial care for BD, these interventions are not readily available, accessible, or acceptable to people with BD. However, only 50% of people with BD in high income countries such as Canada receive any treatment for their condition during their lifetime.[1] Further, only 54% of people receiving treatment from their psychiatrist had engaged with psychosocial services during the last three months.[12] Accessing the right care at the right time can be even more challenging for members of equity-deserving communities, including Indigenous people, those living in rural and remote areas, and racialized people. Psychosocial supports can also help family members and loved ones of people with BD, but there are enormous barriers to access and availability for them, as well.

> *"Only 50% of people with BD in high income countries such as Canada receive any treatment for their BD"*

Project Overview

Key questions

This project explored two key questions:

1. What are the main priorities for advancing psychosocial treatments and supports for people with BD in Canada?
2. What are some promising directions for meeting these priorities?

We summarize the method we used in this project below, and full details are available in Appendix B.

Our team

This project was conducted in partnership between CREST.BD, a Canadian network that advances psychosocial research, care, and knowledge exchange in BD, and the Daymark Foundation, a Canadian philanthropic organization funding BD research as one of two key priorities. The inherent complexities of the BD field, the **lack of agreement on priorities** and strategies for system-level advancements, and the underemphasis on psychosocial supports and functioning was the motivation for the current project to **build consensus on future directions** for BD psychosocial treatment and care in Canada. Our project team consisted of long-standing members of CREST.BD, representatives from the Daymark Foundation, and new researcher and clinician-scientist collaborators with specific expertise in consensus-building research methods and family medicine. Full team details are available in Appendix C.

CREST.BD

First established as a provincially focused team in British Columbia, CREST.BD secured Canadian Institutes of Health Research (CIHR) funding to create a national network in 2010. Under the umbrella of advancing psychosocial research and care, CREST.BD specializes in including lived experience in research, exploring self-management interventions, measuring quality of life, reducing stigma, and developing digital mental health interventions. All of CREST.BD's research and knowledge exchange is done hand-in-hand with people with lived experience of BD.

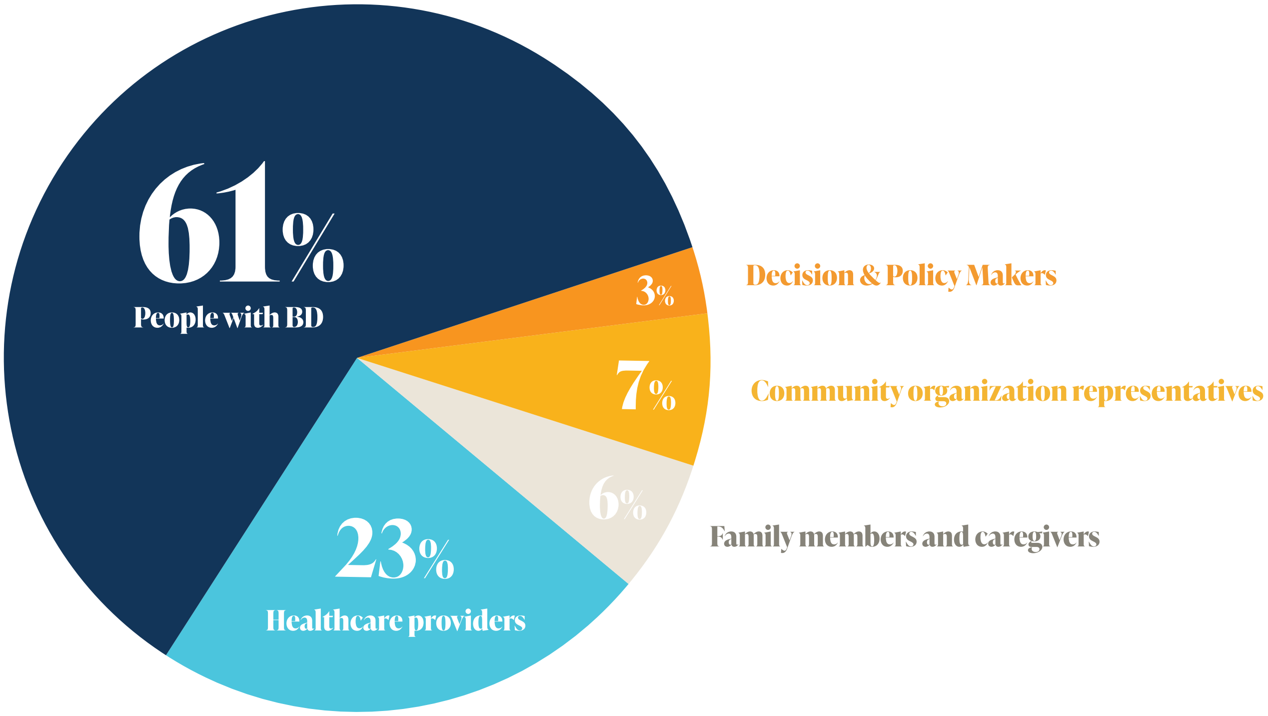
Daymark Foundation

Founded by the Michael H. McCain family in 2020, Daymark entered the BD space knowing that the condition is complex and challenging to diagnose, treat, and manage. Daymark recognizes the value of breakthrough basic science and clinical research on BD and, at the same time, acknowledges that there is good evidence for psychosocial interventions and self-management techniques that is not being put into practice. Prioritizing access to and uptake of a more holistic set of evidence-based supports for BD is one of the Daymark Foundation's key objectives.

Participants

To learn about priorities and promising directions for advancing psychosocial supports for BD in Canada, participants were recruited through CREST.BD and the personal networks of the research team. 61 people from one or more of the groups listed below participated. When participants identified with more than one group, they were asked to pick one primary identifier:

1. Person with lived experience of BD
2. Family member or supporter of someone with BD
3. Healthcare provider working with patients with BD (for example, psychiatrists, family doctors)
4. Community organization representative
5. Mental health policy maker



Deliberative dialogue sessions

This project used a consultation approach called deliberative dialogue. Deliberative dialogue is an approach designed to help build consensus, where groups of diverse people exchange and weigh ideas and opinions about a particular issue in which they share an interest.[13–14] Deliberative dialogue approaches are different from qualitative methods for generating data, such as interviews or focus groups: the multi-directional, facilitated conversations characteristic of deliberative dialogue yield data that speak to collective interpretations and decisions.[15]

Five online deliberative dialogue sessions were conducted between June and October 2023, each co-facilitated by an outside expert in deliberative dialogue and a peer researcher with lived experience of BD trained in deliberative dialogue methods.

The deliberative dialogue sessions focused on a variety of discussion topics, including the following:

- What do ideal psychosocial services look like for people with BD, and how might these needs vary between communities?
- What kinds of support would be useful for family members or supporters of people with BD?
- What actions are needed from primary care providers for better access to psychosocial services for people with BD?
- At the end, a prioritization exercise was conducted using Mentimeter polling software, followed by a final “blue-sky thinking” dialogue centred on questions such as “What are the goals for the future of psychosocial services for BD in Canada?”

Consensus-building survey

After all of the deliberative dialogue sessions, all participants were invited to complete an online survey to prioritize actions in the following areas:

1. Values related to psychosocial supports in Canada’s healthcare system
2. General improvements needed in Canada’s mental healthcare system
3. Ways psychosocial supports in Canada could be improved to support people with BD
4. Improvements to Canada’s mental healthcare system for family members of people with BD
5. Resources that could be created for family members of people with BD
6. Strategies for improving psychosocial supports for people with BD in Canada

Results

Reflections on current issues

Research and evidence

The deliberative dialogue and consensus-building survey yielded these key themes related to the available research on psychosocial treatments and care for BD:

1. The current research landscape does not match the needs of people with BD
2. Current research feels inadequate compared with the richness of lived experience expertise
3. QoL, functioning, and self-monitoring should be more integrated into research

> “I’m just waiting for the research to catch up to my reality.”

Awareness and availability of psychosocial supports and care

Some participants voiced surprise at how many evidence-based psychosocial treatments there are for BD, saying that this was the first time they had ever heard of these options because they had never been brought up or offered as treatments.

> “As I went through this evidence summary, I found myself confused. It was the first time I’d heard of some of them, despite the fact that I’ve had quite a bit of psychoeducation. I have not been exposed to a number of these types of therapies.”

Even those who were aware of various psychosocial treatments described barriers to access such as:

- Resource strain within the healthcare system (e.g., time, physicians, and funding)
- Patient-level financial barriers
- Geographical barriers
- Language barriers
- Lack of culturally appropriate treatment options
- Stigma relating to BD within healthcare, research, and community settings

Current treatments for BD were also seen as overly focused on medication management, with sub-optimal integration of psychosocial treatments. Participants viewed treatments as being heavily focused on acute care, with not enough attention paid to psychoeducation, early recognition, relapse prevention and planning, suicide risk and prevention, social determinants of health, trauma-informed care, comorbidities (additional mental or physical health concerns), and patient priorities.

Access to psychosocial supports and care

Participants highlighted that current services are not adequately serving members of the following communities effectively: Indigenous communities, 2SLGBTQIA+ communities, racialized communities, rural and remote communities, pregnant and postpartum communities, and people with BD across the age span, particularly for youth transitioning to adult care.

At a system level, participants called for increased investment in several areas:

- Funding for non-profit and peer support organizations who provide support and care to people with BD
- Direct funding for people with BD in need of psychosocial care including travel and accommodations for those living in remote and rural areas
- Funding for BD research that prioritizes the needs of those living with BD
- Specialized training on BD for healthcare providers

Quotes from deliberative dialogue participants:

> “In the 40 years I have been navigating the healthcare system, not one clinician has asked me about trauma.”

> “No one [health care provider] ever asked me what I needed.”

> “I can go to a doctor a number of times for sniffles but I can’t get any psychological help without paying. This needs to change. Physical health and mental health go hand in hand, but they don’t have equal priority in our system. The system is broken, and we just simply need to change it. It needs to be driven by mental health, not have mental health fall behind.”

Did you know?

Mental healthcare funding in high-income countries corresponds to 5.1% of all spending, despite mental health and substance use disorders comprising 10.7% of total burden. The United States spends more than $195 billion annually for people living with BD—about 25% is due to medical costs, and about 76% is related to costs from unemployment and time off from work for people with lived experience and caregivers.[16] The United Kingdom spends £20 billion annually on BD with £114 million due to hospital admissions, £1.6 million for outpatient appointments, and £890,000 on accident and emergency services. Although the financial impact of BD in Canada is likely similar, there is a problematic lack of data on the annual costs related to people living with BD in this country. There is comparatively little financial support in the area of BD in Canada compared with other conditions of equivalent impact and prevalence. There is a need for fairer funding to enhance our knowledge, policies, and care available to people living in Canada with BD.

Issues in primary care

Participants highlighted the need for primary care as a central resource for people with BD, to help them navigate the healthcare system and receive continuity of care, and, at the same time, noted that primary care providers are short on time and resources. Many providers have 10-minute appointments per patient, which is not enough to address the needs of the whole person, particularly because BD would frequently be only one of many issues to address within that short visit.

Team-based care—a model of collaboration between different types of providers, such as family doctor, psychiatrist, and mental health provider—and improved screening for BD were suggested as ways to improve BD primary care. Some participants spoke to a perceived lack of knowledge about BD among primary care providers, particularly with regards to medication management, suggesting that additional training and information on BD be streamlined, such as through commonly used medical websites or apps.

To truly reduce the burden on primary care, we heard that resources in other parts of the system needed to be made more readily available. Currently, there are long wait times to see a psychiatrist or specialized psychotherapist, and limited access to psychoeducation. Availability of peer support was also mentioned, but participants recognized that relying on peer support might not be appropriate in times of crisis or shortly after diagnosis.

> “If we really want to fix mental illness, at its core, it comes down to budget.”

> “I think I provide sub-optimal care all of the time.” – Primary care provider

> “Frontline providers cannot do it all.”

Supporting family members of people with BD

Discussions relating to supporting family members, supporters, and loved ones of people with BD occurred in all of the deliberative dialogue sessions. Although the term “family member” was most commonly used in the dialogues, participants pointed out that this can represent an array of relationships and support people, including found family. At a general level, family members were seen as a critical component of psychosocial support for people with BD but are currently underserved and undervalued in treatment and care systems.

Two specific themes were identified. The first was the desire for specific policies for family members’ involvement in the care of people with BD—for example, engaging family members in care conversations, keeping them informed, and inviting their input in crisis planning. The second related to a lack of family-specific BD supports, such as Family Focused Treatment (FFT), which provides people with BD and their family members with psychoeducation about the condition, communication and problem-solving skills training, and relapse-prevention strategies. Participants also expressed that family members and loved ones of people with BD deserved specialized psychosocial support, because supporting people with mental health conditions can come with an emotional and physical toll or burnout.

Top Priorities

Consensus-building survey results

Of the original 61 participants, 44 completed the consensus-building survey to prioritize needs, issues, and solutions. Complete details about the ranking of these priorities are available in Appendix D.

Values related to psychosocial supports in Canada's healthcare system

1. Reduce stigma and discrimination
2. Empower people
3. Take a holistic view of wellness
4. Embrace lived experience as expertise
5. Promote shared decision making

General improvements needed in Canada's mental healthcare system

1. Better access to psychiatrists
2. Better access to counselling and/or therapy
3. Greater capacity in the Canadian mental healthcare system
4. Greater attention to addressing the social determinants of health
5. Better access to family doctors

Ways psychosocial supports in Canada could be improved to support people with BD

1. Psychoeducation on self-management and relapse prevention is regularly provided to everyone with BD
2. New evidence-based treatments for BD are made available more rapidly and effectively
3. Mental health services are more responsive to people with BD at different life stages
4. Psychosocial supports are more responsive to people with BD during different phases of the condition
5. QoL in people with BD is measured and prioritized in mental healthcare

> “When I hear the term ‘client-centred’ or ‘patient empowerment,’ I want it to move further than that. I want it to be the expertise—I want to be seen as an expert in my own condition. To be seen as a source of authority on myself.”

Improvements to Canada’s mental healthcare system for family members of people with BD

1. Improved systems for liaison between family members and healthcare providers
2. Increased capacity for providing family-focused therapy
3. Increased capacity for support groups for family members and supporters of people with BD
4. Improved support for family members and supporters in rural or remote areas of Canada

Resources that could be created specifically for family members

1. Introductory educational resources about BD
2. Resources for family members on how to find services available to them
3. Resources about how to create a plan for crisis (e.g., when to seek emergency help)
4. Resources focused on maintaining healthy relationships between family members and people with BD
5. Resources focused on health and wellness of family members of people with BD

Strategies for improving psychosocial supports for people with BD in Canada

1. Create a guidebook for people newly diagnosed with BD to help with system navigation and recovery
2. Create a tool to help patients find healthcare providers specializing in BD
3. Create a central online repository for people with BD and their supporters to access existing resources
4. Create a pan-Canadian organization dedicated to specifically supporting people with BD and their loved ones and supporters
5. Create new educational resources for diverse knowledge users to increase understanding of BD

Discussion

Key insights

There is a mismatch between current research and treatment priorities and the interests of people with BD

- Psychosocial care is important to people with BD but is not reflected as a research priority
- Current treatments for BD are overly focused on medication management and acute care with not enough attention to psychosocial factors

Psychosocial care is important but needs improvement

- There is limited integration of QoL, functioning, and self-monitoring into psychosocial care
- There is a lack of access for most Canadians with BD because of multiple intersecting barriers
- Certain communities are especially underserved, such as low-income, rural and remote, Indigenous, racialized, and 2SLGBTQIA+ communities

System investments and improvements are critical

- BD-specific funding must be increased to expand and enhance services
- Improvements to and additional capacity in primary care should be priorities

Family members—in their broadest possible definition—are critical to the psychosocial health of people with BD but are underserved and undervalued

- Family members of people with BD need their own support—both the expansion of existing evidence-based interventions and the creation of new services
- Liaison between family members and healthcare providers needs to be improved
- Family members in rural or remote areas of Canada face particular challenges in accessing supports

Promising directions for change

This project identified and prioritized several concrete solutions for improving psychosocial care for people with BD in Canada. Both CREST.BD and the Daymark Foundation commit to further exploring these ideas:

- Developing a guide for people newly diagnosed with BD to help with system navigation and recovery
- Creating a central online information repository for people with BD and their supporters to access existing resources
- Supporting patients to find healthcare providers specializing in BD
- Developing educational resources for diverse knowledge users
- Creating a pan-Canadian, non-partisan, BD-focused organization for people with BD, family members, and healthcare providers

APPENDICES

Appendix A:

Current evidence base for psychosocial treatments and supports

To chart a new way forward, we needed to first understand the current evidence base for psychosocial treatments and supports for BD. To begin this process, the research team drafted a brief "evidence summary" document. We then held a two-hour online focus group with 20 participants specializing in BD treatment, research, or support (12 healthcare providers, 4 researchers, 3 representatives from community organizations, 1 person with BD, and 1 policy maker). Focus group participants examined the draft evidence summary in detail and identified highlights or gaps. We incorporated feedback from the focus group into the evidence summary, which we then provided as pre-reading material to participants in the first deliberative dialogue session. The evidence summary was not a static document across the five deliberative dialogue sessions—rather, we adjusted and added to it after each session based on what participants highlighted and wanted more information about. For example, evidence about trauma-informed approaches to treatment was added after the second session, in keeping with participant comments and a literature search on the topic by the peer researcher.

The evidence summary first defined psychosocial treatments and supports. The document stated that current evidence-based psychosocial treatments for BD include[17]:

1. Cognitive-behavioural therapy (CBT)
2. Family-focused therapy (FFT)
3. Interpersonal and social rhythm therapy (IPSRT)
4. Psychoeducation

Common treatment components in these psychosocial treatments include psychoeducation about BD, self-management, self-monitoring, and problem solving. Current evidence[17] suggests that:

- psychoeducation with guided skills training helps decrease risk of mood episodes
- CBT, IPSRT, and FFT are associated with reduction in symptoms of depression
- CBT, psychoeducation, and FFT are likely to stabilize residual manic symptoms

But there is no current evidence that any of these treatments help people with BD during acute mania. CBT, FFT, and family psychoeducation may help youth with BD manage symptoms and prevent relapse.

There are also several emerging treatments and areas of research being explored that relate to psychosocial treatments and supports in BD, including:

1. Advancements in delivery models and systems (e.g., peer support delivery, digital mental health delivery, trauma-informed care models, culturally informed care models)
2. Third-wave treatments (i.e., mindfulness-based interventions, acceptance and commitment therapy (ACT), dialectical behaviour therapy (DBT), and compassion-focused therapies (CFT))
3. Novel treatments (e.g., psychedelics, MDMA, ketamine)
4. Early intervention and first-episode mania interventions
5. Lifestyle interventions (e.g., nutrition/diet interventions, exercise-based interventions)
6. Cognition-focused interventions
7. CBT for insomnia
8. Comorbidities (e.g., anxiety, ADHD)
9. Suicide risk and prevention strategies

But even treatments currently supported by evidence are not readily available, accessible, or acceptable to people with BD. 54% of people with BD receive the psychological components of best-practice care.[12] Digital mental health solutions offer one route to increasing access to psychosocial care and support but are not a panacea. Getting access to the right care at the right time is even harder for low-income, rural and remote, and equity-deserving populations.

Finally, the evidence summary noted that many people with BD prioritize wellness and QoL outcomes and that there is an existing evidence-informed method for measuring QoL specifically in people with BD. But regular assessment of QoL does not occur widely in clinical care settings. Further, people with BD are not yet fully supported to assess their QoL in their daily lives and implement tailored self-management strategies or psychosocial treatments based on their QoL concerns.

Did you know?

Broadband internet is accessible to 90.9% of the general Canadian population, but only 59.5% of Canadians in rural communities and 42.9% of First Nations have adequate broadband access.[18] Lack of access to devices to support virtual mental health care represents another barrier.

QoL areas impacted by BD, as assessed by the Quality of Life in Bipolar Disorders (QoL.BD) scale[19]

Appendix B: Methods

Recruitment

We recruited participants through CREST.BD and the research team's personal networks. We also promoted the study via newsletters, social media posts, and blog posts on the CREST.BD and Daymark Foundation platforms. Prospective participants received an overview of the project and information on the deliberative dialogue process and what involvement would entail.

Many of the participants had existing relationships with CREST.BD or the Daymark Foundation. Participants with BD who did not have a prior relationship were screened for eligibility during an interview with one of the research leads or the project peer researcher. The interviewers asked questions about how disclosed the participants were about their diagnosis, and whether they would be comfortable sharing their experiences in a group setting that would include various interest groups (e.g., doctors, mental health policy makers). Participants with lived experience of BD were not eligible for the study if they were in apparent distress or crisis at the time of the interview, or if they were currently hospitalized for a mood episode. If participants were eligible and remained interested in participating, they then provided informed consent. Ethics approval for the project was secured from the University of British Columbia, and participants were compensated for their time.

Participant profiles

61 people participated in the deliberative dialogues. Participants were asked to select the category they identified with the most for the purpose of the dialogues, although many participants identified with more than one category. 61% of the sample identified as a person living with BD and 23% as a healthcare provider specializing in BD treatment.

The average age of participants was 47 years. 70% identified as women, 28% as men, and 2% as non-binary. 80% of participants identified their ethnicity as white/European, 10% as East Asian, 7% Latin, Central, or South American, 5% Middle Eastern, 5% South Asian, and 2% South East Asian. Over 80% of participants resided in British Columbia or Ontario (62% and 26%, respectively), with the remaining participants being in Alberta (5%), Yukon (3%), and Quebec (3%).

Of the participants living with BD, 73% were diagnosed with BD type I, 22% with type II, and 5% with BD Not Otherwise Specified. 84% of the sample of people with lived experience reported being in treatment, and, of that group, 89% were taking medication, 43% were in counselling or psychotherapy, 22% had access to peer supports, and 24% reported that they had access to "other" treatments.

Project Phases

Preparation

- Scoping review of prior consensus methods on BD
- Development of the evidence synthesis document
- Think Tank - BD experts to determine most germane evidence
- Formation of diverse International Advisory Board

Deliberative Dialogue

- Assemble team of BD partners & experts in consensus methods
- Recruit DD group members - diverse Canadian BD partners
- Promote significance & impact of this project through social media
- Run 5-6 DD group sessions

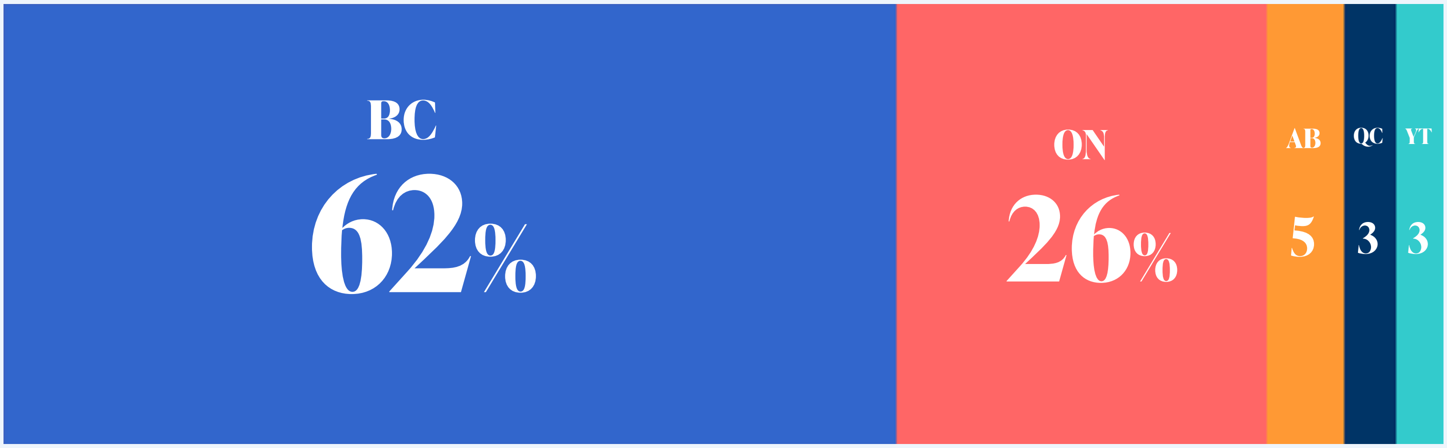
Data Analysis

- Conduct iterative data analysis
- Identify key messages/themes from DD sessions

Share the Roadmap

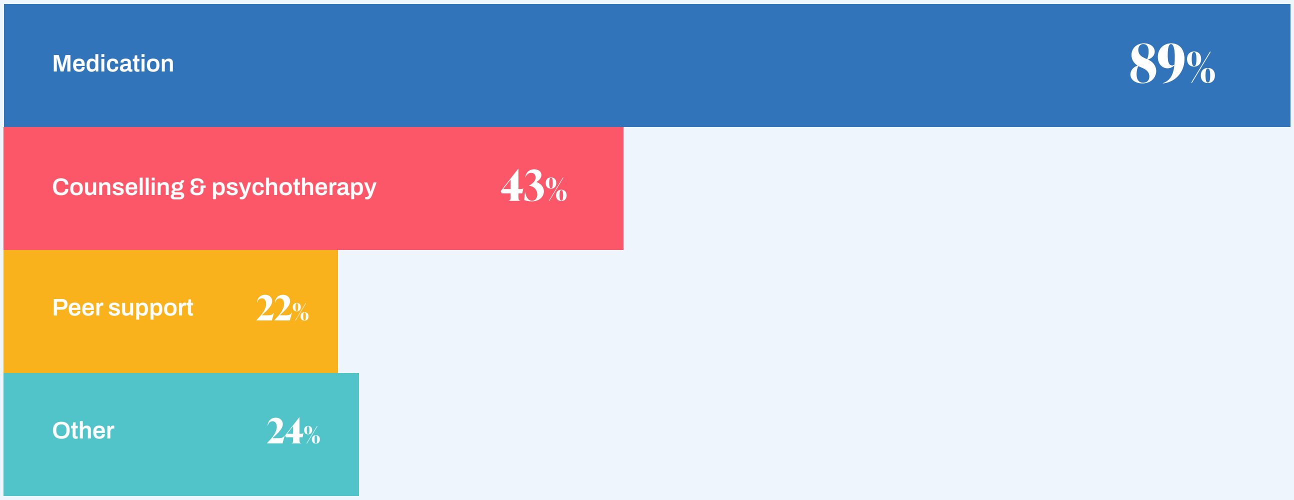
- Produce Canadian Roadmap for BD Psychosocial Research & Care
- Share the Roadmap via peer-reviewed publications & conference/online presentations

Participant Province/Territory of Residence



Participants living with BD (n=37)

Currently in treatment



Deliberative dialogue sessions

This project used a research method called deliberative dialogue (DD). DD is an approach designed to help build consensus, where groups of diverse people exchange and weigh ideas and opinions about a particular issue in which they share an interest.[13–14] DD approaches are different from qualitative methods for generating data, such as interviews or focus groups. The multi-directional, facilitated conversations characteristic of DD yield co-created data that speak to collective interpretations and decisions.[1]

We conducted five online DD sessions between June and October 2023. Each session was co-facilitated by an outside expert in DD and a peer researcher with lived experience of BD trained in DD methods. All five sessions included representatives from the five participant groups described above. The sessions involved two roundtable discussions and one small group discussion. The first roundtable discussion of each session built consensus on the evidence summary.

We asked these questions:

- What are your reflections on the evidence summary?
- What are some highlights?
- What's missing?

The small group discussion topics varied across DD sessions. They focused on topics including the following:

- What do ideal psychosocial services look like for people with BD, and how might these needs vary between communities?
- What kinds of support would be useful for family members or supporters of people with BD?

One of the five DD sessions focused specifically on primary care as a key context for BD care. In that session, we asked questions such as:

- What actions are needed from primary care providers for better access to psychosocial services for people with BD?
- What partnerships are needed to implement these strategies?
- After the small group discussions identified possible actions, participants in that dialogue session prioritized those actions using Mentimeter polling software.

Finally, the last roundtable discussion of each dialogue focused on "blue-sky thinking." We asked: What are the goals for the future of psychosocial services for BD in Canada? The dialogue sessions were audio-recorded and a detailed notes document for each session was produced. The research team shared this notes document with the participants of each session to check for accuracy or omissions.

DDs are designed to iteratively build knowledge across individual dialogue sessions. To support this, after each dialogue we updated a plain language "knowledge gathered" document, which was then shared with the participants of the next dialogue. For example, participants in the fourth session received a document summarizing the knowledge gathered in the first, second, and third dialogues before participating, which they reviewed as a group at the start of their session, along with the evidence summary.

Consensus-building survey

After all of the DD groups were conducted, all participants were invited to an online survey to prioritize the various actions identified in the voting polls conducted in each of the individual DD sessions.

Survey key topic areas

1. Values related to psychosocial supports in Canada's healthcare system
2. General improvements needed in Canada's mental healthcare system
3. Ways psychosocial supports in Canada could be improved to support people with BD
4. Improvements to Canada's mental healthcare system for family members of people with BD
5. Resources that could be created for family members of people with BD
6. Strategies for improving psychosocial supports for people with BD in Canada

Analysis

After the DD sessions, the research team held a series of in-person meetings to identify the key themes, actions, and strategies from the data from the DD sessions and the consensus-building survey. Data analysis for the project used an integrated analytical framework.[16] A full description of methods and findings from this analysis will be presented in a research publication. For this report, we focus on sharing key outcomes from this analysis.

Appendix C: Our team

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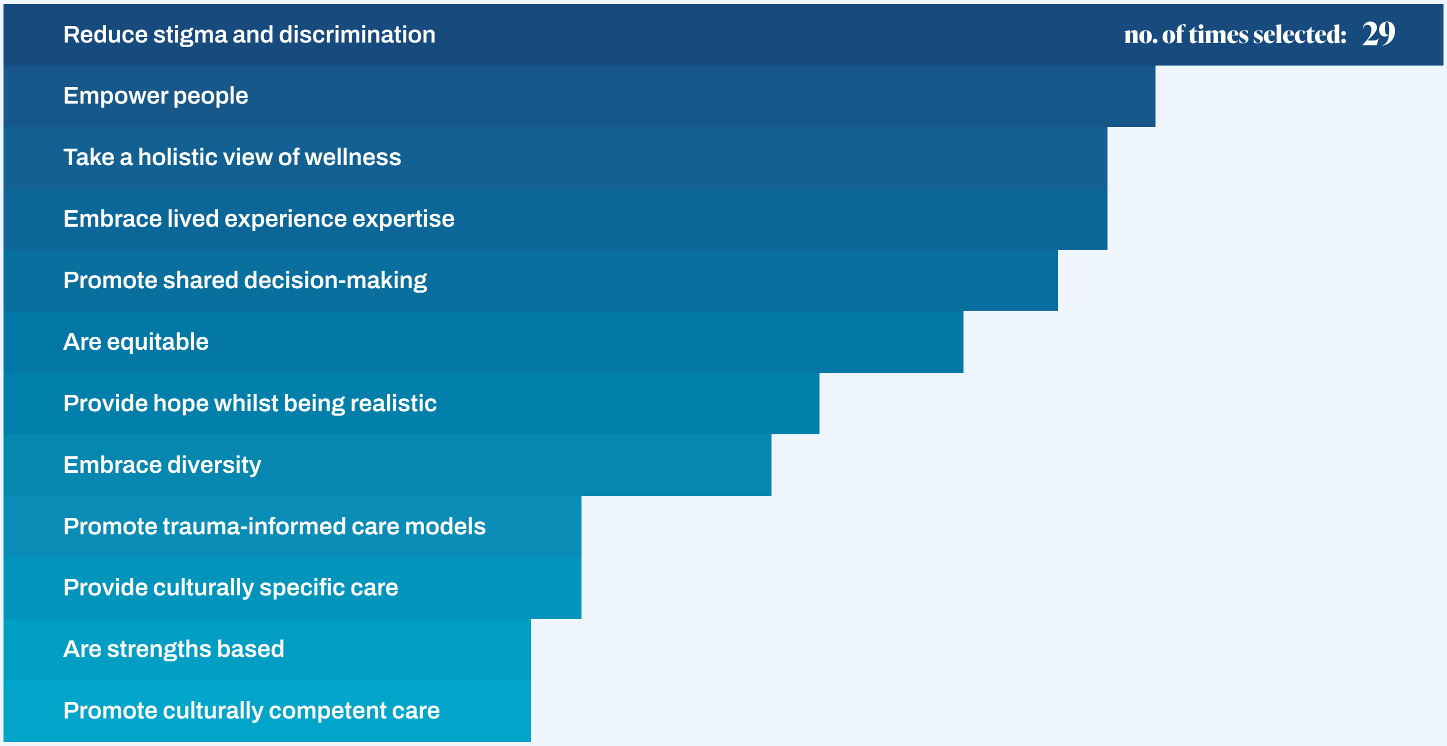
Appendix D:

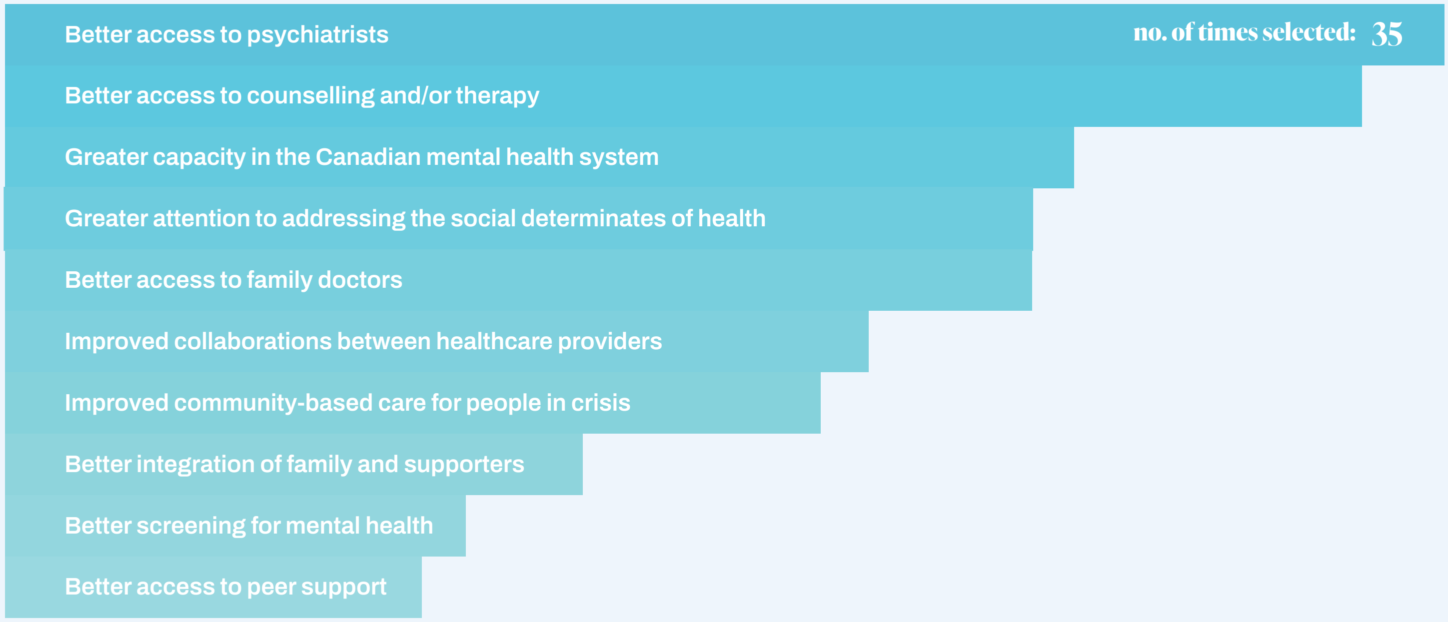
Complete ranking of priorities from the consensus-building survey

After the deliberative dialogue sessions identified priorities for psychosocial supports for people with BD, we invited participants to complete a consensus-building survey to rank those priorities. We summarize participants' top priorities in the main body of the report but present the complete rankings in each of the survey's key topic areas below.

Values related to psychosocial supports in Canada's healthcare system

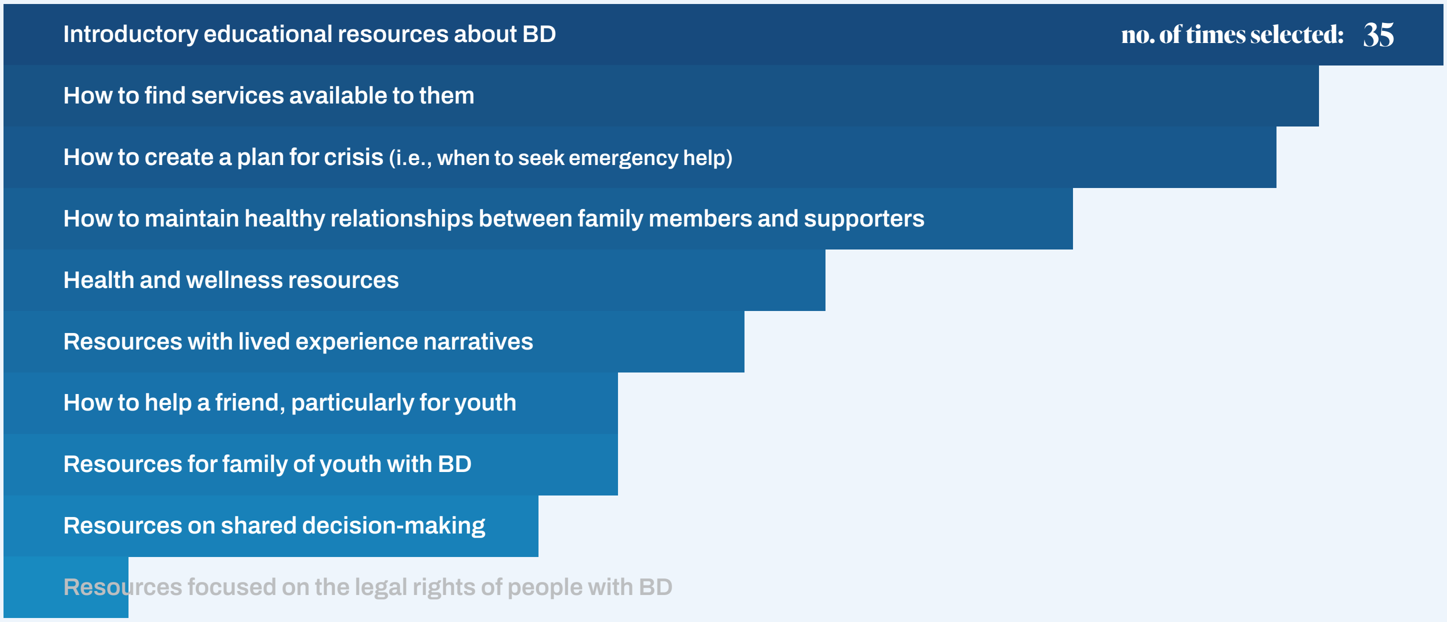


General improvements needed in Canada's mental healthcare system



Ways psychosocial supports in Canada could be improved to support people with BD

Resources that could be created for family members of people with BD



Improvements to Canada's mental healthcare system for family members of people with BD

Improved systems for liaison between family members and healthcare providers	39%
Increased capacity for provision of family-focused therapy for BD	27%
Increased capacity for support groups designed for family members and supporters of people with BD	20%
Improved support for family members and supporters in rural or remote areas of Canada	14%

Strategies for improving psychosocial supports for people with BD in Canada

Create a My Roadmap tool (online and print), a guidebook for people newly diagnosed with BD to help with system navigation and recovery	36%
Create a tool to help patients to find healthcare providers specializing in BD	26%
Create a central online repository for people with BD and their supporters to access existing resources	17%
Improved support for family members and supporters in rural or remote areas of Canada	12%
Create new educational resources for diverse knowledge users to increase understanding of BD	8%

Glossary

Acceptance and commitment therapy (ACT)
A type of psychotherapy that focuses on helping people accept the occurrence of negative thoughts, feelings, and situations and commit more to activities that line up with their values and goals.

Cognitive-behavioural therapy (CBT)
A type of psychotherapy that focuses on reducing negative thinking and increasing helpful behaviours to improve how one is feeling.

Comorbidity/comorbid disorders
The presence of two or more health conditions at the same time—for example, depression and diabetes.

Compassion-focused therapy (CFT)
A type of psychotherapy that helps people develop self-compassion and compassion towards others to promote emotional well-being.

Culturally informed care
A healthcare approach that integrates patients' cultural backgrounds, values, and practices into their treatment to ensure respectful and patient-centered care.

Dialectical behaviour therapy (DBT)
A psychotherapy for people who experience intense emotions that provides skills training in mindfulness, improving relationships, managing emotions, and tolerating intense emotions.

Equity-deserving populations
Groups of people who have experienced or are experiencing disparities, discrimination, and underrepresentation in society. Equity-deserving groups include, but are not limited to, Indigenous people, people with disabilities, racialized people, and members of the 2SLGBTQIA+ communities.

Evidence-based treatment
Treatment methods that have been proven to be helpful for a condition by scientific research. This may or may not overlap with methods that people with lived experience find helpful in managing a condition.

Family-focused therapy (FFT)
A therapy that involves family members in the treatment of mental health conditions. It is a therapeutic approach for people with bipolar disorder and family members or their caregivers that provides psychoeducation about bipolar disorder, communication and problem-solving skills training, and relapse-prevention strategies.

Interpersonal and social rhythm therapy (IPSRT)
A treatment for people with bipolar disorder that stabilizes mood and energy levels. It is focused on helping people develop (or overcome barriers to) daily routines, including sleep-wake cycles, eating habits, and social rhythms such as exercising with friends.

Mindfulness-based intervention
A type of psychotherapy that teaches people to focus on their breathing and bodily sensations while accepting one's thoughts and feelings in a non-judgmental way.

Peer researchers
People who have direct experience of the condition that is being researched and who work as members of the research team.

Peer support
Mutual support provided by people who share similar conditions that helps to improve health and resilience. It can occur individually or in groups through informal support and formalized interventions.

Primary care
Healthcare services from a family doctor, general practitioner (GP), or nurse practitioner. Nurses, dietitians, and social workers may also provide primary care.

Psychoeducation
Education for patients and family members about their mental health condition, including recognizing signs and symptoms, coping skills, treatment options, and crisis prevention.

Psychosocial care
Healthcare that supports people's emotional, social, spiritual, and cultural needs and wishes.

Quality of Life (QoL)
A person's well-being which includes many parts of their life, such as physical and mental health, relationships, sense of belonging, work, and home.

Shared decision making
Patient-centred and -informed healthcare that happens when healthcare providers and patients work together to choose tests, treatments, and care plans that are based on both clinical evidence and the patient's values and preferences.

Social determinants of health
Non-medical, societal, economic, cultural, social factors that influence the health of a person or a population. These factors include, but are not limited to, housing, access to healthy and affordable food, education, experiences of racism, employment, and income.

Stigma
A set of beliefs that society and individuals have towards a group of people. These beliefs are often negative and unfair. Stigma is often a driver of discrimination and unfair treatment.

Trauma-informed care
Health and social care that recognizes how trauma affects people and provides support in a way that respects their experiences and promotes safety and empowerment.

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