

ORGANIZATIONAL FACTORS THAT FOSTER ENGAGEMENT-CAPABLE ENVIRONMENTS: A STUDY OF HEALTH RESEARCH NETWORKS

CREST.BD ACTION REPORT

JANUARY 2023



ACKNOWLEDGEMENTS

Our Team

We are an interdisciplinary team of researchers, knowledge users, and patients with an interest in patient engagement in research.

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The Canadian Institutes of Health Research

Thank you
To all of our participants



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DELIBERATIVE DIALOGUE

In November 2022, we began our process of priority setting. At our deliberative dialogue meeting on November 23rd, 2022, we discussed the findings of our work so far and worked as a group to discuss the barriers and facilitators to patient engagement, as well as ways to improve it.



THE DELIBERATIVE DIALOGUE PROCESS

Deliberative dialogue meetings can include a variety of activities, including guided discussion, consensus methods, and voting. During the meeting, we invited all participants to contribute, creating an inclusive space to discuss issues and potential actions.

BEFORE THE MEETING

As well as receiving an evidence brief, participants were asked to review the participant information sheet provided and contact us with any questions. Written and/or verbal consent was also obtained from all participants. Additionally, we provided a brief summary of findings.

DURING THE MEETING

Plain language was used throughout. During the meeting, members of our team aided meeting facilitation, technological support, support for participants, and note-taking. Participants were invited to reach out at any time if additional support was needed. Our meeting began with some introductions, followed by a review of the process and findings to date. We then discussed each theme as a group and determined strategies to achieve our priorities.

WHAT HAPPENS NOW?

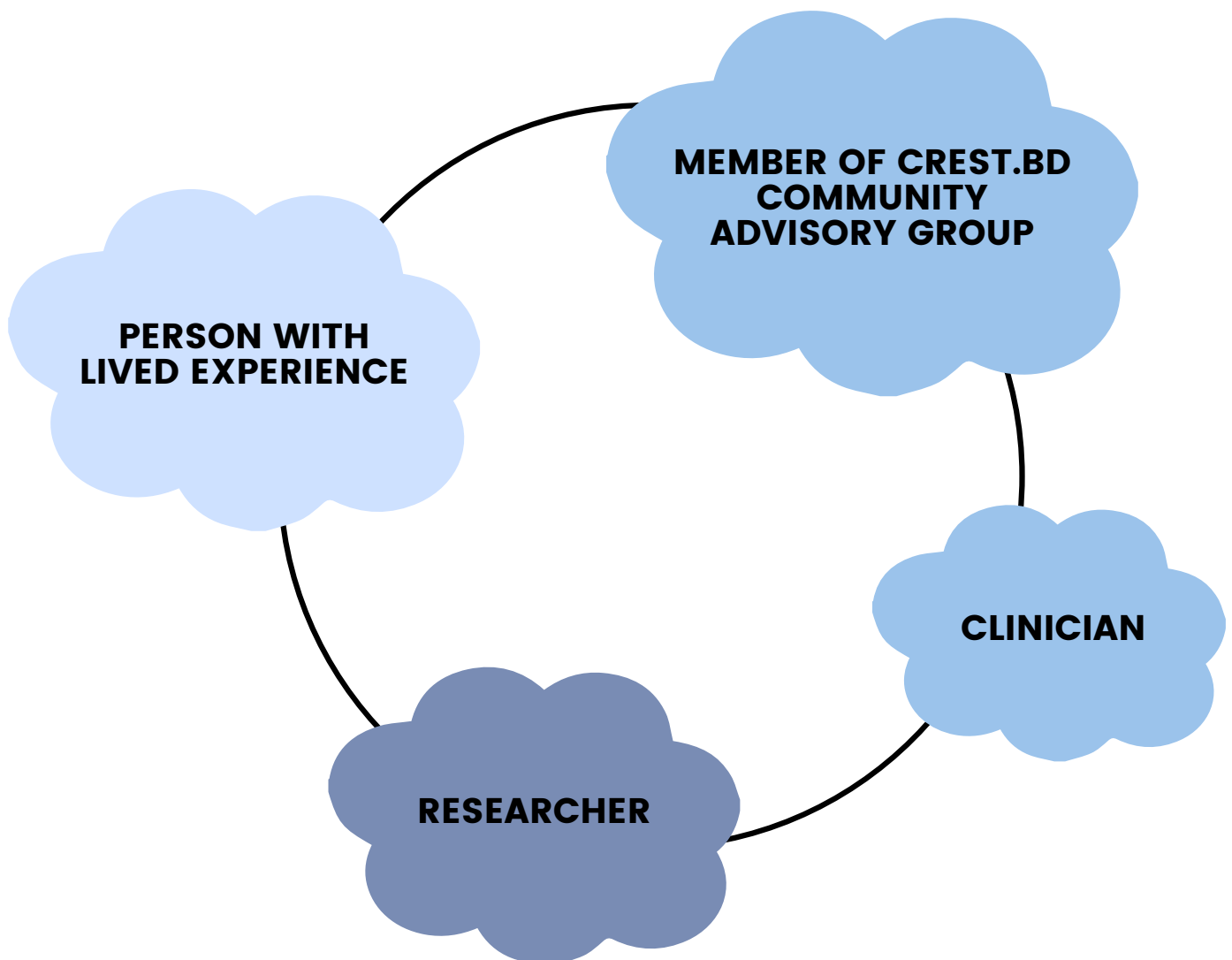
Our team has summarized these discussions and priorities and are looking forward to reviews and feedback from participants. Once we have a finalized document, we will complete our report and share it with the wider community of health research networks.

THE PARTICIPANTS

We invited a diverse range of stakeholders. Our workshop had a total of **10** participants from various health-related fields, including people with lived experience.

All participants provided informed consent before data collection.

We recognize that participants hold a variety of roles, below are some of the roles that our participants attended the meeting in.

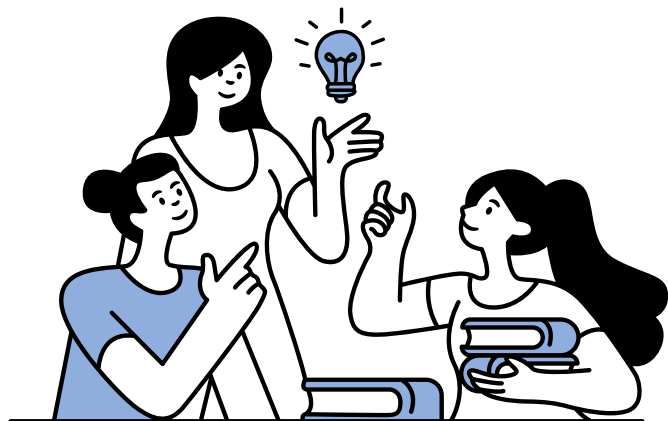


THE DISCUSSIONS

After reporting the key highlights from the documents provided (including the Evidence Report), we began with a roundtable discussion where we first asked participants to introduce themselves and their primary role (e.g., patient partner, researcher, etc.) and what institution they are affiliated with (if applicable).

We then facilitated three main discussions:

- **Facilitators** of meaningful patient engagement
- **Barriers** to meaningful patient engagement
 - **Strategies** to help mitigate these barriers
- **Blue Sky Thinking** - what meaningful patient engagement could look like in the future



FIRST DISCUSSION

FACILITATORS TO MEANINGFUL PATIENT ENGAGEMENT

Our guiding question:

- What structures, processes, and supports foster meaningful patient engagement in CREST.BD?

We heard:

- Valuing and utilizing individuals' skills increases engagement and feelings that the work is meaningful.
- Building and maintaining interpersonal relationships outside of the work setting to build feelings of trust, care, and value.
 - Importance of informal bonding activities.
- Respect for people with lived experience's time and allowing space for participation in different capacities.
- Remembering that people with lived experience are people first, not just their conditions.



SECOND DISCUSSION

BARRIERS TO MEANINGFUL PATIENT ENGAGEMENT

Our guiding questions:

- What barriers to meaningful patient engagement have you experienced or noticed?
- What strategies could be developed to mitigate these barriers?

We heard:

- Tax implications on monetary honouraria can be a barrier.
 - Need for education and resources to navigate this issue.
- Lack of diversity and power imbalances in the network are a barrier.
 - Acknowledging and naming the power imbalances that exist rather than ignoring them.
- Dual relationships for clinician researchers and people with lived experience who are also patients are difficult to navigate.
 - Need for guidelines and resources to support these relationships.
- Members being geographically dispersed is a barrier to building social relationships and trust in the network.
 - Importance of informal meetings and social events (in-person and online).
- Stigmatization of bipolar disorder can be a barrier.
 - Importance of open communication with people with lived experience regarding their comfort levels of publicity.

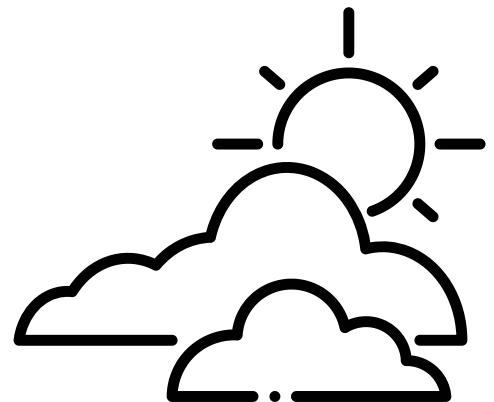
BLUE SKY THINKING

In a perfect future, what would meaningful patient engagement in CREST.BD look like?

How will we know when we get it right?

We heard:

- More diverse voices in the network
- Greater focus on the social resources of the network to help draw more people with lived experience
- More inclusive and informal events to help build comfort and trust among all members of the network
- Facilitate connections between people with lived experience in the network



NEXT STEPS

We are continuing to engage with members of the other 5 health research networks that are involved in this study. This includes one-to-one interviews and deliberative dialogue sessions with various stakeholders.

Once this phase has been completed with each of the networks, we will enter Phase 3 of the study.



Phase 3 - Engagement-Capacity Indicators

To do this we will be holding a multi-network deliberative dialogue session. If you are interested in attending this future event, please let us know. We will also reach out when we begin the planning process.



YOUR FEEDBACK MATTERS!

- *Does this report reflect the content and messaging from the workshop?*
- *What about these results resonates strongly with you?*
- *What do you think is missing?*
- *Who do you think needs to hear these results and recommendations?*
- *What do you think should happen with these results?*



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