The Laurel Foundation Grant Final Report

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Name of Project: New technologies to support mental health and wellbeing in bipolar disorder: Using online co-design methods to develop a mobile phone app

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Goals and Objectives

The overarching goal of this grant was to support the development of a mobile phone app that facilitates access to evidence-based wellness strategies for people living with bipolar disorder (BD) in Canada and beyond. The proposed one-year project aimed to: a) develop understanding of the perspectives of diverse potential users with BD regarding apps used to support health and wellbeing, and b) refine a prototype app designed to support mental health and wellbeing through field testing with potential real-world users with BD.

While timelines were disrupted due to a) release of funds in March 2021 (rather than November 2020 as expected), and b) ongoing impacts of the COVID-19 global pandemic, we are pleased to report that a number of project goals have been met, including:

1. Analysis of a large-scale online survey of people with bipolar disorder regarding attitudes towards mental health apps
2. Development of a beta-version of a self-management and quality of life app for BD using user-centred design and co-creation approaches, including:
   a. A series of focus groups discussing attitudes towards specific features for integration with a proposed app to support self-management and quality of life
   b. Co-design of app content and messages with people with lived experience
   c. Online usability testing of an app prototype, informing the final beta version of a self-management and quality of life app for BD.
3. A series of nationally disseminated knowledge translation outputs, including journal articles, blog posts, and social media outputs.

Outcomes

Three key outcomes have been completed or are in progress as a part of this project and have resulted in a variety of traditional academic (journal publications, conference presentations) and plain-language (blog posts) knowledge translation outputs.

1. **Analysis and Reporting of Survey Findings**

Analysis of a large-scale, international, web-based survey was proposed as a foundational step for the Bipolar Bridges app development project, including identifying potential features for in-depth discussion in qualitative focus groups, and supporting the development of knowledge translation outputs. We are pleased to report that analysis of this data has been completed, and a number of knowledge translation outputs have been released. In addition, further funding ($15,000) has been obtained via a Michael Smith Foundation for Health Research REACH grant to develop educational materials to address knowledge gaps identified in this survey.

A total of 919 people with BD completed the survey. 97.5% of people with BD reported using smartphone apps. Despite high rates of smartphone use, only 42% of respondents with BD reported

using a self-management app to support mood or sleep. Limited uptake of digital tools may be attributable to difficulties navigating the increasing number of apps: respondents who did not use self-management apps had significantly lower levels of digital health literacy (the ability to identify, evaluate, and use health information in an online context). Apps used by people with BD were largely created by commercial developers and designed for the general population, highlighting a gap in the development and dissemination of evidence-informed apps for this population. Half of reviewed apps had published peer-reviewed evidence to support their claims of efficacy, but little was specific to BD. This finding is concerning, given that there may be risks in using generic health apps for BD self-management. For example, sleep restriction is a technique that can be used to address insomnia in the general population, however this should be used with caution in BD due to the potential for triggering mania. Apps designed for the general public or unipolar depression may offer suggestions to increase activity in response to low mood; people with BD should be warned that such strategies, while helpful, can trigger or exacerbate manic symptoms. Together, these findings affirm the importance of continued research efforts to develop and evaluate evidence-based apps for BD.

To inform the design of the proposed CREST.BD self-management app, survey respondents were asked to indicate their preferences for characteristics and features of mental health apps specifically. People with BD commonly prioritised content quality/accuracy, ease and flexibility of use, cost, and data security. The ability to share data with others, rewards for use, inter-app connectivity, and peer support were endorsed as important by fewer than half of respondents. Responses to free-text items suggested that sustained app use could be supported by novel and positive content, customisation, meaningful use of data, interactivity, and perceived real-world benefits. Importantly, some features that have previously been suggested as clinically beneficial or likely to support engagement were perceived ambivalently, emphasising the need for in-depth consultation with potential end users during app development.

Eighty healthcare providers completed an analogous survey. Approximately half of the respondents reported discussing or recommending apps in clinical practice with BD populations. Barriers to discussing apps included a lack of healthcare provider knowledge/confidence, concerns about patients' ability to access apps, and beliefs that patients lacked interest in apps. These findings emphasise the importance of considering the information needs of healthcare providers when planning knowledge translation outputs and dissemination strategies for app-based interventions for BD.

Laurel funding was instrumental in granting the postdoctoral research fellow adequate time to conduct the in-depth analysis and reporting of survey findings. Importantly, this also supported capacity-building for a new generation of researchers and clinicians. Multiple CREST.BD volunteers, research assistants, and psychiatry residents were involved in the project, and trained by the postdoctoral research fellow to conduct qualitative/quantitative analyses, evaluate mental health apps according to a standardized framework, and write academic and plain-language research

summaries. Further, two patient-partners were involved as co-applicants with the postdoctoral fellow and Dr. Michalak on the REACH grant application, and will be working with Dr. Morton to co-develop a series of educational resources supporting people with BD to identify and use appropriate, safe and secure mental health apps.

Journal articles

Morton, E, Torous, J, Murray, G, & Michalak, EE. (In press). Using apps for bipolar disorder – An online survey of healthcare provider perspectives and practices. *J Psychiatr Research.*

Morton, E., Ho., K., Barnes, S. J., & Michalak, E. E. *Digital health literacy in bipolar disorder: An international web-based survey.* Manuscript in submission.

Morton, E., Nicholas, J., Lapadat, L., O'Brien, H., Barnes, S. J., Poh, C., & Michalak, E. E. *Use of smartphone apps in bipolar disorder: A web-based survey of feature preferences and privacy concerns.* Manuscript in submission.

Morton, E., Nicholas, J., Yang, L., Lapadat, L., Barnes, S. J., Provencher, M. D., Depp, C., Chan, M., Kulur, R., & Michalak, E. E. *Evaluating the quality, safety, and functionality of commonly used self-management apps for bipolar disorder.* Manuscript in submission.

Conference presentations

Use of smartphone apps in bipolar disorder: A web-based survey of feature preferences and privacy concerns. International Society for Bipolar Disorders Conference, May 13-15, online. Awarded Best Poster.

Blog posts

https://www.crestbd.ca/2021/10/05/risks-benefits-headspace-and-other-mhealth-apps/

https://www.crestbd.ca/2021/06/02/bipolar-bridges-6-health-apps-poster/

https://www.crestbd.ca/2021/03/23/prescribing-apps-bipolar/

https://www.crestbd.ca/2021/06/02/bipolar-bridges-6-health-apps-poster/

https://www.crestbd.ca/2020/08/18/mhealth-med-student/

2. User-centered design of app features and content

We proposed a series of online or telephone-based qualitative interviews with people with bipolar disorder to solicit in-depth perspectives regarding their needs, preferences and concerns for the in-development QoL-focused app. Given delays to the project timelines and first-hand experience of the rapid pace of app development, it was determined that a series of individual interviews may not be

optimal. Instead, a series of focus groups were conducted with existing CREST.BD community advisory groups. This leveraged two key strengths:

- First, an existing collegial atmosphere, founded on a long history of collaboration and empowered decision-making on behalf of community members. This encouraged open brainstorming of ideas.
- Second, the existence of diverse perspectives within CREST.BD networks. It can take time to develop trusting relationships with underrepresented or marginalized communities, especially in regards to discussing stigmatized topics like mental health. CREST.BD has specifically recruited and encouraged the contributions of diverse genders, ages, sexualities, and ethnic/cultural backgrounds. Further, we encourage the participation of people who may be experiencing, or recently recovering, from mood symptoms. By reaching out to advisory groups with a history of working with CREST, we may have been more likely to receive input from diverse perspectives. We were able to include the perspectives of people with and without experience of using mental health apps, by consulting both with a group specifically established to provide feedback on app design and functionality, as well as with a group established to provide input into broader CREST.BD studies and activities.

Two focus groups were held between April and May, 2021 to specifically discuss user preferences for engagement features for the beta app. Participants were predominantly people with lived experience of BD, however some clinicians and researchers were also present. Both groups were briefed on the core functionality of the PolarUs app, and asked to consider specific engagement features as they may be applied to this system. Engagement features were identified through analysis of the web-based survey (above). Features selected for discussion included broad characteristics such as 'flexibility' (in order to brainstorm specific ways this could be achieved within the PolarUs app) or had mixed levels of endorsement in the survey and prior literature (for example, the ability to share results with family or a healthcare provider was endorsed as important less than 50% of the time in the web based survey, however prior work has suggested this may be a clinically beneficial feature).

Focus groups clarified several design elements that were identified as of interest based on survey findings, which resulted in the selection of key features for inclusion in the beta-app:

- Flexibility was endorsed by 80% of survey respondents – on the basis of focus group discussion, this was operationalized as:
    - Personalised colour schemes (including dark mode)
    - Notifications tailored based on user-chosen self-management plan
    - The ability to complete additional daily and weekly check-ins as desired
    - Daily check-in items adapted to allow reporting of mixed states (i.e., symptoms of both depression and mania)

- Notifications were highly endorsed in survey free-text responses, with an emphasis on warm, friendly, conversational tone. Focus group respondents were clear that notifications should not risk disclosing bipolar diagnosis. On the basis of these findings, a writing group was established to generate positive daily 'affirmations' related to the user's chosen self-management plan (discussed below).
- Peer support was highly endorsed in survey free-text responses – focus group respondents suggested that notifications emphasize the role of people with lived experience in designing the app by including initials. The involvement of peers in designing the app was also incorporated into the app name (PolarUs), branding strategy, and onboarding materials.
- The ability to share data with family/friends was endorsed by only 22% of respondents. Similarly, sharing with clinicians was endorsed as important by less than half (47%) of respondents. Focus group participants discussed barriers to data sharing in more detail, including the need for nuanced and dynamic control over data sharing (i.e., the user controls who gets what data, and can turn that on and off at will, rather than static permission for sharing all data). Users wanted to be in control of when and if data is shared. Users were enthusiastic about the idea of sharing app content (not just personal data) by including the option to send a PDF summary of chosen quality of life domains and self-management strategies to a nominated supporter.
- Although "rewards for use" was rarely (29%) endorsed as important in the survey, features such as streaks, badges, and leaderboards were mentioned frequently in free-text responses. Focus group respondents were keen on the idea of streaks to log daily check-ins with the app, but noted that resetting a streak to zero could be highly demoralizing. They suggested the inclusion of multiple counters (continuous streak of daily check-ins and a cumulative total of daily check-ins completed).

Some advisory group members made suggestions for ways to incorporate features into the app that were positively received, but not feasible for inclusion at this stage in the development process. For example, a number of attendees suggested that notifications and recommendations for self-management strategies could be automatically generated on the basis of self-monitoring data. However, this suggestion requires the collection and analysis of data from the evaluation of the efficacy of the beta-app, in order to meaningfully and appropriately tailor app content to the user. This, and several other suggestions (e.g., peer feedback on strategies, coach support), were selected as goals for the next iteration of the app.

In addition to the focus groups described above, one advisory group in particular was regularly consulted (at least once per month since the establishment of the group in March 2020) on topics related to the development, delivery and evaluation of the Bipolar Bridges project. The Bipolar Bridges Advisory Group (BBAG) has played a key role, through collaborative input, in making decisions regarding the naming of the bipolar bridges app (PolarUs), the iterative process of designing the app's

logo and icons, selecting color schemes, interface design and navigation. Users were shown wire-frames of the PolarUs app using the clickable online prototyping software 'Figma' at various stages in the development process. This process was instrumental in helping us identify, from a user perspective, the intuitiveness and utility of various features, and generate suggestions for features to address unmet needs. For example, meeting with the BBAG resulted in the design decision to allow users to review data collected for research purposes via a 'daily check-in', as members suggested that this would support their interest in using the app long term, and benefit them by facilitating self-reflection.

Blog Post

https://www.crestbd.ca/2020/12/09/bipolar-bridges-5-bbag/

Building on a qualitative finding from the survey data (the importance of which was reinforced through focus group discussions), the team decided to incorporate the voices of people with lived experience of bipolar disorder into the app content itself. A team of writers with BD (including members of the BBAG, volunteers and members of the extended CREST.BD network) and content experts were recruited to co-develop affirmations for the app. Affirmations are positive statements that help create a sense of being "good enough", and research shows that using affirmations can improve our resilience to stress, enhance wellbeing, and help support changing behaviour. For the PolarUs app, our goal in including affirmations is to encourage users to keep checking in with themselves by using the app, while also giving little boosts of encouragement related to the self-management strategies they have chosen to work on. This aligns with the survey finding that people with BD valued mental health apps that had a positive tone, sent warm and inviting notifications to encourage app-use, and included the support of people with lived experience.

Affirmations are based on research findings; the team of writers moved through each quality of life domain to write affirmations corresponding to the findings. This process required reading through research results and finding ways to transform them into notes of encouragement. The content writing team has reached the project goal of writing at least 90 affirmations per quality of life domain, for a total of over *1,400* affirmations.
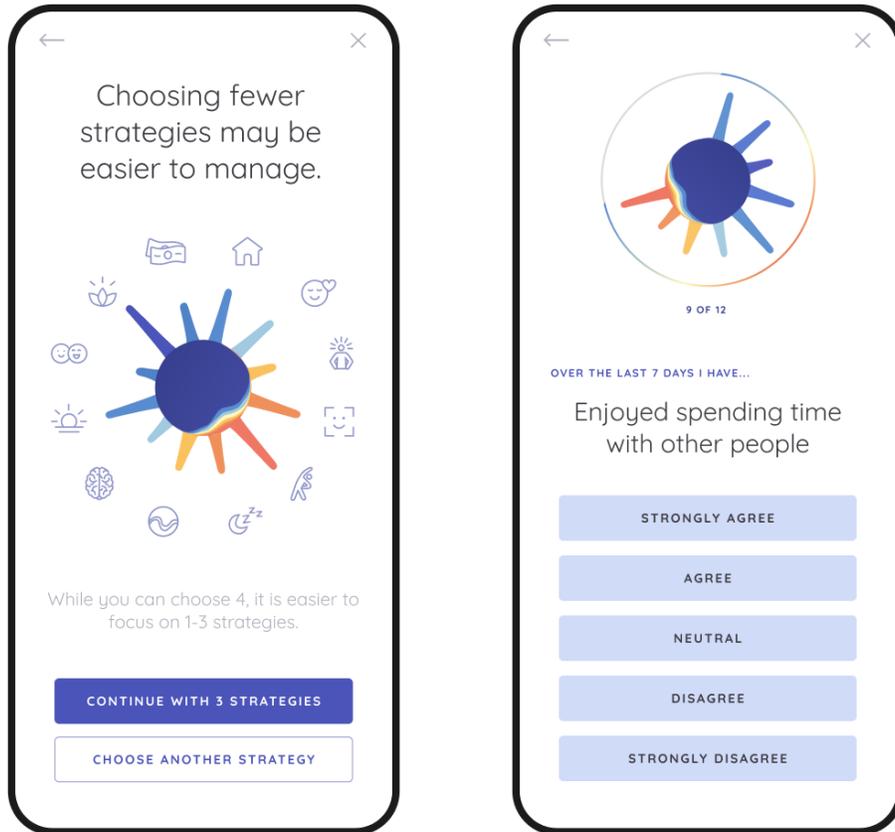
Work on the next phase of content development has commenced, with researchers and people with lived experience working together to identify tools and resources for inclusion in the app, as well as co-develop in-app videos. This phase of content development is expected to conclude November, 2021.

Laurel funding provided the research assistant sufficient time to lead the affirmations and strategies co-writing process. It was also instrumental in funding graphic designer time for the multiple iterations of consultation and iteration of app logos, app interface, and in-app icons.

Blog Post

Figure 1. PolarUs app interface: icons/logo co-designed by people with bipolar disorder.

3. Online usability testing of app prototype

The final phase of activities supported by this Laurel grant will be pilot user testing. This phase will be used to gain preliminary feedback on the usability (e.g., ease of navigation), functionality, and critical issues (e.g., bugs, compatibility across various devices) in the beta app prototype. Such issues may be more difficult to detect for developers, researchers, and the patient advisory committees who have contributed to the design of the beta-app. As such, naïve participants (~n = __ psychology undergraduate students) will be asked to download a clickable app prototype to their phone or computer and complete several tasks (e.g., navigating the app, or entering data), before completing surveys on their experiences. The beta app will also be pilot tested by members of the BBAG and

other members of the extended CREST.BD network, who will give feedback from the perspective of users living with bipolar disorder.

Pilot user testing is scheduled to commence November 2021, and expected to run through December. Feedback from pilot testers will be iteratively implemented in the app to ensure the final product is ready for the evaluation phase in Spring 2021.

Future directions

Beta app evaluation and qualitative interviews

The project goal of developing understanding of features preferred by people with BD will be informed by qualitative interviews conducted during the forthcoming evaluation of the beta app. This will further refine understanding of how app features influence intervention engagement, addressing an important gap in the literature: self-reported preferences for various app features may not align with real-world use behaviours. For example, a comparison of various mHealth tools to support symptom monitoring in BD found higher levels of engagement with an app (in which self-reported symptom data was actively input by users) versus passive data collection, despite the fact that participants reported the latter method to be less burdensome (Van Til et al., 2020). It may be that aspects of the app promoted engagement (e.g., push notifications), or potentially, active monitoring was better aligned with participants' motivations for self-monitoring (i.e., to develop awareness of symptoms).

A sample of 150 adult research participants with a confirmed diagnosis of BD will be recruited to use the app for a three-month period. A mixed-methods design will be adopted; the interpretation of quantitative data will be informed by a series of semi-structured qualitative interviews with a subsample (~n=30) participants. App usage statistics (number and frequency of pages accessed; time spent on the app per session and overall; time spent on specific pages; number and length of unique sessions; length of time between unique sessions) will be used to quantitatively explore engagement with specific features. The qualitative interviews will deepen understanding of what factors influence engagement with the app-based intervention, including specific app features.

Following completion of the three month intervention, participants will be invited to an interview (~1 hour) discussing experiences of the intervention (including attitudes towards specific features and content), patterns of engagement with the app (including use of app content in everyday life), facilitators and barriers to app use, and subjective impacts on QoL and self-efficacy. Participants who demonstrated diverse patterns of engagement with the app (i.e., from low levels of engagement to consistent, daily use) will be invited to participate in the qualitative interviews to ensure findings are representative of the spectrum of users.

Ethics approval is currently being sought for the beta app evaluation (including qualitative interviews), and a protocol paper describing the evaluation methodology is in development (with intended submission in an open-access journal).

Digital health literacy training

Funding for additional knowledge translation outputs has been obtained; Professor Erin Michalak, BBAG members Natalie Dee and Rosemary Hu, and postdoctoral researcher Dr. Emma Morton have successfully applied for a Michael Smith Foundation for Health Research REACH grant ($15,000). The grant aims to address challenges that people with BD and clinicians face in selecting appropriate mental health apps from the increasing number of publicly available findings. The proposed activities build survey findings which identified sub-optimal awareness of evidence-based self-management apps for BD in patients and providers. Respondents in our survey rarely relied on government/health organisation resources for information on apps, preferring to seek recommendations from others with BD, app store reviews, or family/friends. Providers commonly obtained information on apps from co-workers or patients. Taken together, this suggests that BD-specific guidance for navigating app store offerings is likely to be beneficial, and dissemination strategies are necessary to support the visibility of these materials. At present, there is a risk that patients will use unsafe apps, and a missed opportunity for patient-provider collaboration. The project goal is to broaden the reach of existing knowledge to enhance digital health literacy in these groups. To achieve this, community-based participatory research methods will be used to co-create a suite of multimedia patient and clinician-facing informational resources, disseminated through online and in-person events. Project goals are expected to increase the uptake of safe and credible apps for BD, thereby improving care and health outcomes for people with BD in British Columbia. Patients and providers will be empowered to make health decisions using the best available evidence. Further, the project will build capacity for knowledge translation across diverse stakeholders including trainees, clinician-scientists, and people with lived experience.

Conclusions

Thanks to contributions from the Laurel Foundation, the CREST.BD team has completed important foundational work to inform the design of a beta app to support self-management for people living with BD. The perspective of people with lived experience, obtained through international surveys, focus groups, and co-design activities will help ensure the eventual app is useful, acceptable and engaging in the eyes of people living with the condition.

Planned next steps will iterate from the findings of the beta app evaluation. Features identified as engaging in the survey and focus groups that were not feasible for integration in the beta-app will be revisited in future user-centered design activities. Additional features to support accessibility (e.g., translation into French, Canada's other national language) will also be addressed.