Youth Engagement and Community-Based Participatory Research: The Bipolar Youth Action Project

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Abstract

Bipolar disorder is a mood disorder characterized by changes in mood (ranging between mania and depression), thinking, and behaviors. It is often first diagnosed in young adulthood, emphasizing the importance of early intervention. The Bipolar Youth Action Project took place in Victoria, BC, over 2 years. It was a *community-based participatory research* project co-led by a team of youth researchers who live with bipolar disorder, an academic researcher, and the lead of a community mental health organization. The Bipolar Youth Action Project explored (1) what wellness, or *self-management*, strategies youth with bipolar disorder use to stay well, and (2) how youth chose to share those strategies with the wider community. Over two research and community-engagement events, called Youth Forum I and Youth Forum II, the research team recruited 29 youth with bipolar disorder from British Columbia to discuss these research questions, gathering knowledge via a range of diverse research methods, including qualitative (focus group), quantitative, consultation (World Café), and arts-based approaches (graphic facilitation). Forum I findings included description of four approaches to self-management strategies used by youth with bipolar disorder. In Forum II, youth participants talked about how they would want knowledge about these self-management strategies shared with the wider community. Based on findings from Forum II, the research team produced three videos as one form of *knowledge translation* output from the Bipolar Youth Action Project. The videos share (1) mindfulness strategies used by youth participants in the Bipolar Youth Action Project (http://ow.ly/y5iN300xW0L), (2) key messages that participants wanted to share with other youth who live with bipolar disorder (http://ow.ly/EZqP300xVYs), and (3) the process of the Bipolar Youth Action Project study itself (http://ow.ly/FUOx300xVVJ).

Learning Outcomes

By the end of this case, students should be able to

- Identify the importance of, and key takeaways for, effectively engaging youth as equal partners in research studies
- Learn about community-based participatory research as an orientation to mental health research
- Understand what knowledge translation is and why it is an essential element of the cycle of health research
- Recognize the importance of including diverse expertise from academic and lived experience perspectives in academic research

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Project Overview and Context

This case study describes the Bipolar Youth Action Project (BYAP). The BYAP is a study co-led by youth who live with bipolar disorder (BD), academic researchers, and a community partner, performed under the umbrella of the Collaborative RESearch Team to study psychosocial issues in Bipolar Disorder (CREST.BD), an international research network that is physically located in the Department of Psychiatry at the University of British Columbia (UBC), Vancouver, Canada.

BD is a mood disorder characterized by changes in mood (ranging from severe depression to mania), thinking, and behaviors (Goodwin & Jamison, 2006). People are often first diagnosed with the condition in young adulthood. About 4% of the general population lives with some form of BD, and, according to the World Health Organization, BD is the sixth leading cause of disability among people aged 18-44 (Kessler et al., 2005; Murray & Lopez, 1997). People who live with BD often experience high rates of hospitalization, relapse, and risk of suicide (Gitlin, Swendsen, Heller, & Hammen, 1995; Nordentoft, Mortensen, & Pedersen, 2011). The condition can be associated with poor functioning, for example, in employment and relationships, and a low *quality of life* (QoL), as described by Michalak, Yatham, Kolesar, and Lam (2006). Recent research, however, shows that QoL can be relatively high in people newly diagnosed with BD (Michalak et al., 2013), stressing the importance of early intervention and support.

Previous research into BD has mostly focused on the biological causes of the condition and medication treatments to help reduce symptoms. More recently, however, research has shifted focus to examine the psychological and social (*psychosocial*) factors in BD that can impact how well people manage with the condition (Miklowitz, 2008).

CREST.BD is a research network dedicated to collaborative research and knowledge exchange in BD, with a special focus on psychosocial factors. The network prioritizes four main areas of research: Self-Management Strategies, Psychosocial Interventions, QoL, and Stigma. We view the contributions of empirical studies, the personal experience of people who live with BD, and healthcare provider expertise as equally valuable. Thus, our network is composed of both academic researchers and *peer researchers* who live with BD from diverse backgrounds, in order to share expertise and encourage inclusivity, partnerships, and authentic collaboration (Michalak et al., 2016).

We specialize in *community-based participatory research* (CBPR), an approach to research that involves partnering with members of the community who live with a particular health condition and/or other stakeholders. CBPR can include community members in each stage of the research process—from the development of research questions and methods, to actually performing the research, and then sharing the results. CBPR approaches aim to adapt to the needs of community members and engage them as active participants, rather than as objects, of research (Evans, Hole, Berg, Hutchinson, & Sookraj, 2009). As such, CBPR is especially valuable for engaging with marginalized and at-risk populations (Minkler & Wallerstein, 2011).

Although CBPR approaches have been used successfully in various areas of youth mental health research (Lincoln, Borg, & Delman, 2014; Soleimanpour, Brindis, Geierstanger, Kandawalla, & Kurlaender, 2008), we knew there was a gap in the application of CBPR approaches in research with youth with BD. We secured funding from the Vancouver Foundation for a 2-year CBPR study to build knowledge on effective wellness or *self-management strategies* in youth living with BD. This study was called the BYAP.

Our team defines self-management strategies as the things that individuals do for themselves to cope or live better with a health condition (Michalak et al., 2016). These strategies may be developed through trial and error or be suggested by healthcare providers or support networks, but it is typically the person with BD who chooses and enacts their own self-management strategies. Examples of common strategies include keeping healthy sleep routines, exercising regularly, monitoring and responding to early warning signs of the illness, or practicing stress-reduction techniques such as mindfulness or exercise.

The BYAP was designed to explore (1) what self-management strategies are effective for youth living with BD on Vancouver Island, BC, and (2) what the best methods are for sharing these strategies with other youth, families, and the wider community (e.g., healthcare providers, schools).

Research Practicalities

Research Participant Groups

The BYAP involved two related, but distinct, groups of youth: Youth Action Group (YAG) members and Youth Research Forum participants.

YAG members collaborated throughout the study as peer researchers. An initial group of 12 members aged 19-25 was hired for the duration of the project. At the end of the 2-year project, 7 of the original 12 members remained engaged (see “Challenges and Lessons Learned” section for more discussion on retention rates). YAG members were expected to attend monthly meetings over approximately an 18-month period, as well as do occasional project-based work from home (e.g., writing blog posts, producing presentations). YAG members also co-designed two research, information-gathering, and community-building events, called the Youth Research Forums.

Youth Research Forum participants were youth who live with BD, aged 16 to 25, who attended either of the two Forums but did not participate in the YAG. Over the two forums, a total of 29 Forum participants were involved in the study (see demographic details for both Forums in Tables 1 and 2).

Table 1. Forum I demographics.

Total N	21
Gender N (%)	
Male	6 (28.6%)
Female	14 (66.7%)
Other	1 (4.8%)
Ethnicity N (%)	
Caucasian	14 (66.7%)
Other[a]	5 (24.0%)
Missing	2 (9.5%)
Age M (SD)	21.2 (3.1)
Age of diagnosis M (SD)	17.3 (3.8)
Diagnosis N (%)	
BDI	5 (23.8%)
BDII	6 (28.6%)
BD NOS	7 (33.3%)
Unsure	3 (14.3%)

Employment N (%)	
Student	12(57.1%)
Employed	4 (19.0%)
Long-term Disability	1 (4.8%)
Unemployed	3 (14.2%)
Other	1 (4.8%)

[a] Ethiopian-Canadian, Polish-Canadian, Portuguese-Canadian, Canadian

Table 2. Forum II demographics.

Total N	8
Gender N (%)	
Male	0 (0.0%)
Female	7 (87.5%)
Other	1 (12.5%)
Ethnicity N (%)	
Caucasian	4 (50.0%)
Other[a]	2 (25.0%)
Missing	2 (25.0%)
Age M (SD)	19.9 (1.9)
Age of diagnosis M (SD)	16.6 (1.5)
Diagnosis N (%)	

BDI	0 (0.0%)
BDII	4 (50.0%)
BD NOS	3 (37.5%)
Unsure	1 (12.5%)
Employment N (%)	
Student	5 (62.5%)
Employed	0 (0.0%)
Long-term Disability	1 (12.5%)
Unemployed	1 (12.5%)
Other	1 (12.5%)

[a] Filipino-Canadian

Ethics

Ethics approval was granted by the UBC Behavioral Research Ethics Board and the Island Health Research Ethics Board. For this study, we defined “youth” as ranging from age 16 to age 25. YAG members were required to be between the ages of 19 and 25, while Forum participants were aged 16 to 25. A certain level of work experience and maturity were required for the long-term commitment of YAG membership. However, for the Forums, it was important to include a high-school-aged perspective on self-management, hence the differing age requirements for the two types of participant.

Consent packages were written in plain language to a Flesch–Kincaid reading level of Grade 8; importantly for youth, consent forms contained discussion around the permanency of media (i.e., photos and video) produced as products of the study. It was required that participants consented to being audio-recorded as part of Forum I and II research methods (i.e., focus groups and World Café discussions), but not essential that they consent to being photographed or videotaped. Youth aged 19 or over provided their written consent to participate; youth aged between 16 and 18 provided both their written assent and the written consent of a parent or guardian.

Two psychiatrist collaborators were involved in the project to consult on safety. At each forum, one male and one female identified healthcare provider was available to provide crisis support if required.

Method in Action

The nuts and bolts of this project started with assembling the right kind of team. The work of the 12 YAG members was guided by two study leads—one academic researcher who specializes in CBPR approaches (Michalak) and the lead of a local community organization, the Bipolar Disorder Society of British Columbia (BDSBC, Paquette). In addition, there were two psychiatrists on the team, someone who specializes in youth engagement (Canas) and a research coordinator (Balram Elliott). Supporting the project (especially during the Forums) were additional CREST.BD members and student volunteers. However, while this wider group of supporters played an important role, they did not join the core team at regular meetings. The rationale for this was that we aimed to create a trusting environment and culture of consistency for the youth involved and believed it was important to maintain a smaller, trusted core team of co-researchers.

CBPR is not a discrete research method per se; more correctly, it is considered an “orientation to research” (Schneider, 2010). As such, it can adopt a variety of different research methods: for example, quantitative, qualitative, and arts-based approaches. In other words, CBPR can be adapted to suit the particular study in question. Below, we describe how we applied a CBPR approach in this project, across a series of study phases.

Pre-Funding Phase

As noted, this project was funded by a BC funding agency—the Vancouver Foundation (http://www.vancouverfoundation.ca)—which specializes in supporting research embedded in communities. We involved community members in the development of the application for funding in three primary ways: (1) by partnering and writing the grant application with Paquette, director of BDSBC; (2) by collecting pilot data to support the application; and (3) by involving two youth with BD as co-applicants in the funding application.

As the first step in grant development, Paquette and Michalak convened a group of five young people living with BD, all participants associated with BDSBC programming. Paquette and

Michalak met with this group to discuss the self-management strategies they identified as core to their health and QoL. They discussed their interest in exploring how to share information about BD with other youth. Finally, the youth in this group were keen to make a difference in their community, educate others, and share their personal stories. Two of the youth from this process became co-applicants on the Vancouver Foundation grant; two others, although not co-applicants on the grant, became members of the YAG. Although the two youth grant co-applicants were not able to be involved in the project after it was funded, they were instrumental in ensuring that there was a youth perspective in the development of the research methods and project framework from the outset.

After funding was secured, youth were also integral to the delivery of the project's four distinct research phases.

Phase I

In Phase I, our team formed the YAG (again, "YAG" stands for "Youth Action Group"). The YAG members were co-researchers on the BYAP study, and all of them lived with BD. YAG members approached us through a traditional job application process. We were looking for potential YAG members' abilities to commit to a 2-year project, as well as their passion for the work of the project itself. Initially, 12 YAG members were engaged, with 2 appointed as Co-Leads. These Co-Leads were responsible for taking a lead at meetings and helping other YAG members with their research tasks if necessary. We took care to consider how the group would fit and interact in our selection of the YAG members and Co-Leads.

The plan for meetings throughout the project was also solidified in Phase I. Monthly meetings between the YAG and at least one, if not all three, of the members of the adult research team were conducted. Regular meetings helped the research team provide mentorship and support to the YAG and helped YAG members to be accountable for their projects. Some of these meetings took place via teleconference or webinar, but the majority of meetings were face-to-face. The YAG members communicated that this was what they preferred. Listening to, and acting on, this feedback was vital to keeping the YAG members engaged with the project. The success of this model was apparent by the end of the project: our team had anticipated that we would experience about a 75% drop-out rate (also called *attrition*) over the 2-year project and had a fallback plan to recruit an entirely new YAG if needed. However, the 2-year project was completed with 42% attrition (7 of 12 original members remained fully engaged throughout), and it was not necessary to recruit new members.

Training for the YAG was our main Phase I goal. This was to prepare the YAG for their roles as co-researchers and to provide them with concrete training in research methods (see Table 1) for the rest of the study. All of our training events incorporated team-building elements—it was important for the team to develop cohesion and trust (and simply to have fun). We included arts-based activities as often as possible. It was also important to have meals available. Not only did healthy meals provide for individuals for whom income was a challenge, but sharing meals supported relationship-building.

The trainings provided during Phase I involved the following, and are summarized in Table 3:

- One full-day event focused on team-building, CBPR, and education about concrete qualitative research methods like focus groups and qualitative interviews;
- A second full-day event with a combined focus on learning about self-management strategies and arts-based research methods by sharing CREST.BD's program of research on adult self-management strategies using an arts-based method called graphic facilitation;
- A refresher presentation at the end of Phase I on CBPR and qualitative research methods, which set the stage for Phase II of the study;
- The Tri-Council Policy Statement Tutorial Course in Research Ethics (TCPS2 CORE), an online research ethics course for researchers and research staff (Government of Canada Panel on Research Ethics, 2016).

Table 3. Phase I research trainings.

Research training day (full day)	Graphic facilitation day (full day)	CBPR Webinar	TCPS2 CORE course
Team-building day	What is graphic facilitation?	What is CBPR?	All YAG members to complete online
What is CBPR? What is qualitative research?	CREST.BD's research on self-management	What are some qualitative research methods?	

CBPR: community-based participatory research; YAG: Youth Action Group; CREST.BD: Collaborative RESearch Team to study psychosocial issues in Bipolar Disorder.

Phase II

The main task in Phase II was the planning and hosting of the project's first research event: Forum I. The purpose of the first Forum was to consult with youth with BD from the community on their strategies for wellness, as well as to create a venue for mutual learning and knowledge exchange. The YAG and adult research team worked together to choose the methods for Forum I, to recruit participants, and to co-deliver the event.

Forum I was held in July 2015 in Victoria, BC, and asked the question, "*what self-management strategies are effective for youth on Vancouver Island who live with BD?*" The chosen venue was critical to the success of the Forums and was an important consideration for our team. The YAG agreed that a youth-friendly space was a key consideration—a space that was fun to be in, was close to public transportation, and didn't feel institutional. We selected an event space in downtown Victoria called the Victoria Event Centre, that is often used for concerts and arts events and that many of the YAG members had visited before. The YAG members also noted the importance of this venue including not only formal space (i.e., desks or tables and chairs) but also an inviting, casual space with couches and a low table where youth could relax on breaks.

YAG members prioritized two outputs from the day: (1) creating a fun and safe space for Forum participants to share knowledge and (2) generating research findings that would be publishable in a peer-reviewed journal—they wanted to get the results of their science out there. With these aims in mind, the team chose a mix of arts-based, qualitative, and quantitative methods. Specifically, arts-based methods involved the incorporation of graphic facilitation into the day (Dean-Coffey, 2013). Quantitative methods involved the administration of a demographic/clinical information form and a scale to measure self-management, the Mental Health Self-Management Questionnaire, created by Coulombe et al. (2015). We created an interactive agenda for the day that was visually engaging and could be shown on the day as well as shared prior to the event. We chose to use the online platform Smore, a free platform for designing online flyers and newsletters that was engaging for participants. The Smore agenda for Forum I can be viewed at https://www.smore.com/ta3fw.

Clinical support was also available at Forum I. Two mental healthcare providers, one male identified and one female identified, were in attendance at Forum I specifically in the role of being attentive to the group and being aware whether anybody was in need of support. Participants were informed about the support people in writing (in their consent and welcome packages on the day) and verbally by Paquette at the opening of the Forum. If they felt triggered or in need of support, Forum participants were invited to access a support person by walking up to them and introducing themselves or by handing over a small "crisis card" that each participant was given as part of their welcome package. The card was created as a non-verbal way to ask for help.

The qualitative research method chosen by the YAG for Forum I was semi-structured focus groups. Youth Forum participants were assigned to one of five focus groups (approximately five participants in each focus group). The groups were facilitated by an adult research team member with experience in facilitation; one YAG member was assigned to each group as a note-taker. Focus group questions centered on wellness/self-management strategies for BD used by Forum participants, and the full list of focus group questions can be seen in Box 1.

Box 1. BYAP Forum I focus group questions.

1. Are there self-management strategies that you have found helpful for living well with bipolar disorder?
    - 1a. Are there strategies that you have found working particularly well when you're depressed?
    - 1b. Are there strategies that you have found working particularly well when you're hypomanic or manic?
2. In your opinion/experience, are there any strategies that are particularly important or useful for younger people living with bipolar disorder?
3. How did you learn about these self-management strategies?
4. What suggestions for effective self-management would you give to a young person who has been diagnosed with bipolar disorder? *Probe: are there any messages you would want them to know?*

Focus group discussions were audio-recorded and transcribed verbatim by YAG Co-Lead Lapadat (leaving out identifying information about participants, for example, names, gender identifiers, neighborhood-level geographies) for analysis in Phase III.

Phase III

Working together in Phase III, the YAG and adult research team collated and interpreted the focus group findings from Forum I. At the same time, Forum II was also planned and executed. At this stage, our extra supporting team members, including CREST.BD members and enthusiastic volunteers, were essential to the project's success. YAG Co-Lead Lapadat was hired separately, in addition to her Co-Lead duties, to transcribe Forum I audio recordings and, in partnership with a CREST.BD researcher (Lane) who was experienced in qualitative methods, to analyze the findings using thematic analysis. Although the full YAG reviewed and approved the final drafts of the analysis, they were not all involved in the analysis itself—simply due to the time commitment involved for the analysis stage. The partnership between Lapadat and Lane was important to the CBPR framework of our research because Lapadat was able to contribute lived experience as a young person with BD to the generation of knowledge in the study while increasing her own capacity as a researcher through direct practice and through mentorship. Working together, Lapadat and Lane reviewed the focus group transcripts. Each discrete self-management strategy was given a code. Codes were created *inductively*, meaning that they were proposed based on the particular experiences and statements of the youth focus group participants and not on a pre-conceived framework. The codes were then grouped into categories of similar strategies. Lapadat independently analyzed 25% of the codes, to add her lived experience perspective and help validate the codes. The research team had regular meetings to discuss the codes and the possible resulting themes, and by repeating this process over several weeks, overarching themes of self-management strategies were identified. Once these themes were identified, Lapadat and Lane each independently analyzed half of all the findings again to check for validity (Noack et al., 2016). As seen in Table 4, four main themes emerged from the focus group findings, and each had several sub-categories.

Table 4. Forum I focus group themes.

Maintaining a healthy lifestyle	In-the-moment strategies to manage mood episodes	Having a strong support network	Key messages to share with other young people with BD
Diet (e.g., eating responsibly)	Self-awareness (e.g., knowing your mood triggers)	Having positive supporters	Accepting that you have a health condition
Exercise (e.g., getting outside regularly)	Mindfulness practices	Having supporters who understand BD	Make sure to take care of yourself
Medication (e.g., taking as prescribed)	Strategies for episodes of depression	Having supporters who respect your autonomy	“You’re not alone”
Avoiding alcohol and recreational drugs	Strategies for episodes of mania/hypomania	Having diverse supporters (e.g., friends, family, healthcare providers)	

Sleep (e.g., keeping a strict sleep schedule)	Strategies that help for both mood states		

BD: bipolar disorder.

Knowledge Translation

Knowledge translation is the process of making research results accessible and understandable to the broader public—including individuals who could apply knowledge to their own health, healthcare providers and the healthcare system, and policy-makers. The goal of knowledge translation is to share, exchange, synthesize, and apply research in ways that positively affect these groups (Canadian Institutes of Health Research, 2015). CREST.BD builds knowledge translation plans into all of our research studies.

Forum II focused on knowledge translation and took place in November 2015 in the same location. Objectives for Forum II were (1) to share knowledge gathered in Forum I with participants, and (2) to exchange ideas among the group on what would be effective knowledge translation mechanisms for Forum I results. The interactive Smore agenda for Forum II can be viewed at https://www.smore.com/vm8te.

Specifically, Forum II asked, “what are the best methods for sharing information on self-management strategies with other youth, their families, and the wider community?” The first part of the day was dedicated to sharing Forum I findings about youth wellness strategies via arts-based presentations and group activities, designed and led by the YAG members. The second part of the day included a World Café activity.

According to the World Café Community Foundation (2015), a World Café invites participants to circulate among a set number of tables, each with a “host” facilitating discussion on a different topic per table. All participants visit all tables during the event, but not in set groups. This allows for cross-pollination of ideas and themes. Forum participants were given 20 min at each table, and YAG members also participated. Discussions were audio-recorded and analyzed by a YAG Co-Lead and the research coordinator in Phase IV. Each of four tables at Forum II hosted discussion on a different medium for sharing self-management information in a youth context: (1) written media, (2) in-person methods, (3) visual media, and (4) social media. The questions posed by each table’s host were as follows:

- Does this medium appeal to you?
- What is and isn’t effective about this medium?

- How would you use this medium to effectively target youth with BD?

Phase IV

In Phase IV, Co-Lead Lapadat analyzed World Café audio recordings. Specifically, she listened to recordings without transcribing them verbatim, instead making detailed notes and extracting concrete suggestions of ways to share wellness strategies, noting the frequency of mentions for each suggestion.

Visual Media

Participants in Forum II prioritized the production of short videos featuring youth, stating that outputs should be engaging, accessible, free, and easily shareable. Participants stated that it was important to them that the videos have an inspiring component and be in plain language, in the voices of young people. Less frequently mentioned were public art pieces with a collaborative youth component, art in schools (i.e., a poster contest), and photo series.

Written Word

Participants recommended the production of engaging blogs written by youth. Some youth were also interested in graphic novels and websites, including forums for youth.

In-Person Methods

These methods were mostly noted as being good ways to promote other outputs. Youth discussed presentations in schools and arts-based events (i.e., poetry slams, comedy shows, theater).

Social Media

Forum II participants focused on the best use of specific social media platforms for dissemination of specific types of output, for example, Facebook for sharing short videos, and were in agreement that they are not as engaged with Twitter.

Regardless of the platform, Forum participants across the World Café discussion felt that short, catchy, relatable content featuring young people that could be shared peer-to-peer, online, would be the most likely to reach a wide audience. Participants preferred a personal tone to an academic tone, as well as personal stories or information shared together with facts—but they did not want to see facts presented in a patronizing way. Importantly, they felt ways of sharing wellness strategies needed to be visceral and hold emotional weight, creative, and relatable to everybody, not only to people who live with BD.

Phase V

In the final Phase of the project, team members used learnings from Forum II to choose and inform the development of a suite of knowledge translation outputs from the BYAP. Given the prioritization of video content in Forum II, it was collectively decided to create three short videos. Specifically, these videos focused on showcasing the process of the BYAP itself (http://ow.ly/FUOx300xVVJ), mindfulness strategies mentioned by participants in Forum I (http://ow.ly/y5iN300xW0L), and a powerful Key Messages video (http://ow.ly/EZqP300xVYs). The videos were produced taking into consideration the desires of the youth from both Forums; the videos are short, in plain language, and feature the faces and voices of other young people. Videos are freely available on YouTube and continue to be shared on http://www.crestbd.ca, http://www.bipolarbabes.com, and http://www.mindyourmind.ca, as well as on social media via all of our team's Facebook pages, Twitter feeds, and Instagram accounts.

Another important priority for the YAG was the production of peer-reviewed journal articles on the study results as well as the CBPR study process. To date, there are four BYAP papers in production, all of which include YAG members as co-authors.

Challenges and Lessons Learned

Our main challenge, and thus an important learning for our team, was in youth engagement. As mentioned earlier, at the end of the 2-year project, 7 of 12 original YAG members were still engaged with the project—an *attrition* rate of 42%. First, work on the project was intensive, and although YAG members went through a thorough interview process, it was still unknown at the beginning of the project whether all members would be able to commit to the workload over time. Second, many YAG members were experiencing life situations common to young adults—educational and work changes as well as temporary housing situations—which we had expected to impact YAG member retention rate significantly. Third, it was an expectation that many of the YAG members would experience mood episodes during the course of the project.

At times, it was also a challenge to engage all the YAG members to attend and pay attention at meetings and to complete tasks assigned to them on their own time. Often, a significant amount of follow-up was required to ensure that tasks were completed, and there were, understandably, times when YAG members had other commitments or life situations that were turning their attention away from the BYAP; the YAG members' attention waxed and waned somewhat throughout the two project years, which, while to be expected, was still a challenge. These issues, however, led to concrete learnings around effective youth engagement in research:

- *Community-based recruitment through a partnership with trusted organizations with established youth relationships is essential for engagement*. Partnering with an organization that has pre-existing, authentic relationships with youth sets up better chances for long-term retention of youth participants and stronger collaboration.
- *Clear priorities and expectations from the start establish effective collaboration*. Mapping tasks and trainings onto project deliverables at the outset increases engagement, morale, and likelihood of tasks being completed.
- *All-aboard training creates common ground for values, communication, and timelines*. Considerable time in the BYAP was devoted to building capacity among the YAG, with three main goals: (1) share knowledge with the YAG about CBPR as a research framework, (2) share knowledge with the YAG on research methods, and (3) build trust as a group.
- *Youth require consistent contact and meetings in youth-appropriate spaces*. Youth felt most engaged with meeting face-to-face with the adult research team, and contact outside of meetings, via e-mail, text message, and social media channels was also a priority. An ability to build both personal and professional connections with the adult research team was important for maintaining youth engagement throughout the project. Hard timelines for tasks, with support and check-ins along the way, were required.
- *Youth participants should be compensated for their time, transportation, and childcare costs*. Meals should also be provided at meetings and events.
- *Studies directed toward or involving youth should be conducted in plain language and, if possible, incorporate creative or non-traditional aspects*. Arts-based research methods and activities, as well as youth-relevant media, proved highly engaging.
- *Research or health-focused events must be planned and executed by a core youth-adult team*. To create a safe space and culture of consistent attendance, the team needed to be moderate in size, with core research team members at every meeting and event, but with supporting members who provided expertise in the background and in person during research events and analysis stages.
- *CBPR is a self-reflexive practice*. Activities and events gained depth and impact when youth-adult teams reflected on and communicated openly about what was working and what was not. This was time well spent.

Summary

In the BYAP, our team included academic, community service provider, youth engagement, healthcare provider, and lived experience expertise. Our project plan included significant youth engagement, training, and support components. A team of youth co-researchers who live with BD, the YAG, were engaged in the project from start to finish. We used a CBPR framework and qualitative focus groups and other consultation methods to explore (1) "*What self-management strategies are effective for youth on Vancouver Island who live with BD?*" and (2) "*What are the best methods for sharing information on self-management strategies with other youth, their families, and the wider community?*" Concretely, we hosted two day-long research events, Forums I and II, inviting the wider community of youth with BD to consult on these questions. We utilized qualitative, arts-based and quantitative methods.

At Forum I, we found that youth who live with BD value living a healthy lifestyle; cultivating in-the-moment strategies for episodes of mania, hypomania, and depression; and having strong support networks as wellness strategies for BD. At Forum II, we found that youth with BD were most interested in having strategies shared with them by their peers, in forms that were free, creative, and featured the voices of other youth. It was also vital to them that the strategies, in whatever format they were shared in, would be made available online. Youth participants at both Forums described that the Internet was the main source they used to proactively seek out BD self-management strategies (Noack et al., 2016, Table 4). Youth forum participants were heavy Internet users and were seeking online mental health information that was credible, stigma-free, and positive. The knowledge translation outputs of our study can be found online on http://www.youtube.com/crestbd, on our website, http://www.crestbd.ca, and on our partner organizations' sites, as well as on a variety of organizations' social media channels, where youth who live with BD and their support networks can easily access and share the strategies (see "Web Resources" section).

With diagnosis of BD usually occurring in young adulthood, early intervention and evidence-based support are vital. Standing in the way of this may be mental health stigma and lack of credible mental health resources effectively targeting youth. The young people involved in the BYAP wanted to work to improve these conditions for other youth with BD and did so by engaging in the project as equal research partners and tailoring outputs for youth, sharing their knowledge about how they stay well with BD, and being open about their personal stories. The outputs of the study are as engaging as the youth themselves, and it is our hope that more young people will not only use and share the BYAP study outputs, but that these outputs will empower more youth who live with mental health conditions to lead this type of discussion and knowledge-sharing in their communities.

Exercises and Discussion Questions

1. What are some of the key elements of effectively engaging youth as co-researchers in health research studies?
2. Discuss community-based participatory research frameworks and their role in effective

health research studies.
3. What is knowledge translation? Why is it essential to the cycle of health research?
4. How is including both academic and lived experience perspectives beneficial to academic research?

Further Reading

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Schneider, B. (2010) *Hearing (our) voices: Involving services users in mental health research*. Toronto, Ontario, Canada: University of Toronto Press.

Web Resources

Bipolar Youth Action Project Key Messages Video: https://www.youtube.com/watch?v=bjfEOI5mnKc

Bipolar Youth Action Project Mindfulness Strategies Video: https://www.youtube.com/watch?v=Xh7rnZxUEww

Bipolar Youth Action Project Forum II Video: https://www.youtube.com/watch?v=5ESFHt4YIbI

CREST.BD Bipolar Wellness Centre: http://www.bdwellness.com

CREST.BD Program of Self-Management Research: http://www.crestbd.ca/research/research-areas/self-management/

Bipolar Disorder Society of British Columbia: http://www.bipolarbabes.com

mindyourmind Canada: http://www.mindyourmind.ca

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