

## BCC3 Provincial Community Advisory Board (CAB) TERMS OF REFERENCE<sup>1</sup> (Nov 24, 2020)

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### BACKGROUND & PURPOSE

#### Project Overview

The British Columbia CARMA-CHIWOS Collaboration (BCC3) is an interdisciplinary partnership between two established cohorts studies of women living with HIV (WLWH). CARMA (Children and Women: AntiRetroviral therapy and Markers of Aging) is a pan-Canadian cohort of >1000 WLWH and their children, with socio-demographically matched HIV-negative women. It was established to study the effects of HIV and cART on biochemical markers of aging. CHIWOS (Canadian HIV WOMen's Sexual and Reproductive Health Cohort Study) is a pan-Canadian community-based research study examining women-centred HIV care and the sexual, reproductive, and mental health outcomes of 1,422 women living with HIV across British Columbia, Ontario, and Quebec.

Using a “cell-to-society” approach, this study aims to understand healthy aging in women living with HIV in British Columbia by considering cellular markers of aging, hormonal influences, and psychosocial and structural factors, and interactions between these factors.

BCC3 is driven by community-based research methodology, and the principles of the Greater Involvement of People Living with HIV/AIDS (GIPA), the Meaningful Involvement of Women Living with HIV/AIDS (MIWA), and Ownership, Control, Access, and Possession (OCAP).

The BCC3 study will be advised by a provincial Community Advisory Board (CAB). **The purpose of this document is to provide an overview of the BCC3 study and the Terms of Reference for the BCC3 CAB.**

#### BCC3 Survey and Biospecimen Collection protocol

The BCC3 study aims to enroll n=350 women living with HIV and n=350 women not living with HIV with similar socio-demographic characteristics. Among participants, we estimate that 400/700 will be pre-menopausal women, while 300/700 will be menopausal. Participants will be preferentially recruited from the BC cohort of CHIWOS (n=356 women living with HIV) and CARMA (n=275 women living with HIV and n=291 women not living with HIV, as controls). Data collection will occur in a two-part visit, one in clinic and one in the community. The clinic visit is comprised of a short survey

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<sup>1</sup> **Acknowledgment:** The BCC3 team adapted these TORs from the document originally created by the CHIWOS team.

covering clinical history, administered by a research coordinator or research assistant at Oak Tree Clinic, and will be asked to provide anthropomorphic and biospecimen data (approximately 3-3.5 hours). Within one month of the clinic visit, all participants will be asked to complete a community survey, administered by a Peer Research Associate (approximately 1-1.5 hours).

Recruitment was launched on December 1<sup>st</sup> 2020, with a larger recruitment launch planned for March 2021.

### **Project Funding**

The BCC3 study is supported by a 5-year (2019-2024) Canadian Institutes of Health Research (CIHR) Project Grant (grant # BCA-408242), a 3-year CIHR HIV/AIDS Community-Based Research Grant (grant # 170103), a 1-year University of British Columbia Partnership Fund, and a 1-year Simon Fraser University 2020 Community Engagement Initiative Grant.

### **Purpose of the Community Advisory Board (CAB)**

“Community” will be broadly and inclusively defined in an effort to seek consultation from the many stakeholders on this issue. We prioritize the diverse voices and lived and living experiences of self-identified women living with HIV (including cisgender, transgender, and gender non-binary).

We are also including academics, researchers, policy makers, clinicians, community workers, activists, and others in the field of HIV, women’s health, and healthy aging.

Bringing together diverse voices from various backgrounds and areas of knowledge, the CAB will provide essential consultative input into participant recruitment and retention, survey topics, study implementation efforts, and knowledge translation activities. The CAB will ensure that the study’s design, documents, and roll-out plans are appropriate and acceptable to women living with HIV and other community members. The CAB will also provide a regional voice, to ensure that the study is tailored to distinct provincial realities.

### **CAB ACTIVITIES**

The BCC3 Community Advisory Board will:

- Attend and actively participate in annual meetings
- Provide expert advice to the BCC3 research team on relevant study processes, and provide input and perspectives on matters that impact women living with HIV and healthy aging
- Review and advise on the relevance and comprehensibility of study documents including consent forms, recruitment flyers, and survey instruments
- Assist with recruitment strategies to engage women living with HIV in the study
- Bring up any concerns or hesitations about the study to the research team leadership
- Provide direction and participate in knowledge translation activities
- Disseminate BCC3 study information and findings
- Use research findings to advocate for policy and programming change

## **COMMITTEE COMPOSITION**

The BCC3 CAB will have two Co-Chairs, comprised of a community lead and an academic lead. One designated BCC3 research coordinator will be responsible for organizing the CAB logistics, with support and guidance from the Co-Chairs and the BCC3 Core research team.

The BCC3 CAB will be composed of:

- Women living with HIV including, but not limited to
  - Indigenous women
  - Women from African, Caribbean, and Black communities
  - Women from countries with a high prevalence of HIV
  - Women with current or past experience of injection drug use
  - Women with current or past experience of incarceration
  - Women living in rural and/or remote areas
  - Women who identify as being part of the LGBTQ2S+ community
  - Women who identify as trans women, or gender non-binary women
  - Women with current or past experience of sex work
  - Women who are unstably housed
  - Young women
  - Older women
- The partners, children, and families of women living with HIV
- Physicians, nurses, and other healthcare professionals caring for women living with HIV
- Academic researchers, including research from all four pillars of health sciences research ( 1) Biomedical research; 2) Clinical research, 3) Health services research; and 4) Social, cultural, environmental, and population health research.
- Representatives of Community Service Organizations, AIDS Service Organizations, and Health Centers
- Policymakers and representatives from the relevant governmental bodies
- Members of the BCC3 Core Research Team, including Coordinators, Principal Investigators, and Peer Research Associates (PRAs)
- National stakeholders interested or working to support healthy aging among women living with HIV

The BCC3 Core Research Team will also maintain a general listserv of people who are interested in healthy aging and health equity among women living with HIV. This listserv will include anyone who is interested in healthy aging among women living with HIV and will receive study updates as appropriate.

The contributions of CAB members will be recognized on the BCC3 Website.

## **DETAILS**

### **Term**

The duration of the project will run for ten years (February 2021 – January 2031) with the possibility for extension, pending future funding. Membership will be reviewed every two years and members are welcome to join or leave at any time.

The Co-Chair roles may change over time. The BCC3 Team is committed to capacity building and will support the appointment of new academic and community Co-Chairs as discussed and identified within the BCC3 leadership team and the larger CAB.

### **Frequency of Meetings**

The CAB will meet once per year; any subcommittees or working groups will set their own frequency of meetings, as required. Frequency of the CAB meeting may vary as the study progresses. Meetings will last between two to three hours, and will be held in person when possible. The option to join remotely via Zoom will always be available. When held in person, refreshments and lunch will be provided. **BCC3 is not able to provide reimbursements for travel costs at this time. Childcare to support in-person attendance will be available on an ad hoc basis.**

### **Accountability and Engagement**

CAB members will be accountable to the BCC3 PIs who are in turn accountable to their Institutions and Funders. CAB members are also accountable to their own Institutions and the communities they serve. CAB members should also see themselves accountable to women living with HIV in British Columbia.

The CAB meeting agenda will be developed by the co-Chairs, with input from the larger BCC3 Core research team. The agenda will be circulated one week prior to the CAB meeting, and CAB members will have the opportunity to add agenda items where appropriate. Presentation slides and minutes of the CAB meetings will be finalized and circulated by the BCC3 Coordinator within 10 working days of each meeting to facilitate reporting, if required. Any communication to the CAB and the BCC mailing listserv will be via email, and will use the blind carbon copy ('BCC') function.

### **Decision Making**

Decisions will be made by consensus as much as possible. In some circumstances, the PIs may be required to make final decisions.

### **Grievance Process**

Sometimes, differences of opinion or disagreements happen. BCC3 prefers the mechanism of handling such differences directly with the person that the disagreement occurred with. If still not resolved, please see a provincial coordinator to help resolve the disagreement. If still not resolved, the person and coordinator will involve one of the PIs. However, please understand that if anyone is uncomfortable speaking directly to another about a matter, you can go directly to one of the PIs or the nominated PI.

### **MAINTENANCE**

The Terms of Reference will be reviewed every two years along with the membership list. All CAB members will be encouraged to reach out to the BCC3 research team with any suggestions, frustrations, acknowledgments, or concerns, and to ensure that their voices are accurately represented.

## **Appendix A: Roles & Responsibilities**

### **Co-Chair Responsibilities**

1. Provide leadership to the BCC3 research team in areas such as participation and communication, and creation of effective community and academic partnerships.
2. Co-lead Community Advisory Board meetings, held annually.
3. Elicit agenda items from both community and study priorities to establish the meeting agenda at least two weeks before the scheduled meeting date.
4. Ensure that all CAB-related meetings start and end at agreed-upon times.
5. Assign key responsibilities and action items to all team members to ensure that the meeting runs smoothly, and project objectives move forward accordingly. This includes bringing meetings to a conclusion with a summary of key issues decided on and any further follow-up that may be needed.
6. Make recommendations for the CAB budget.
7. Guide the evaluation process of study-related neighborhood activities and the CAB.
8. Assist with the coordination of the CAB's community activities as guided by the study.

*Source: Adapted from the Sister-to-Sister Advisory Board Manual, 2008.*

### **Coordinator Responsibilities**

1. Organize food, technical support, meeting rooms, supplies, remote logins, and other related logistics required.
2. Distribute invitations and 'Save the Dates' on behalf of the Co-Chairs to the CAB mailing list.
3. Monitor, develop, and reconcile the CAB budget.
4. Circulate all relevant meeting information (including meeting agenda, call in details, and other relevant meeting materials) to the CAB list at least one week prior to the meeting.
5. Assist with note-taking during the CAB meeting, and circulating meeting minutes after the meeting.