MINUTES
BC SUPPORT Unit Advisory Council
November 21, 2022

Attendees: Anne-Marie Visockas (chair), Courtney Defriend, Linda Dempster, Martha MacLeod, Alison Mclean, Anni Rychtera, Swapnil Shah, Martin Wright

Ex-officio: Stirling Bryan, Michelle Duffy, Terri Fleming, Waqar Mughal, Alison Orth

Regrets: Ellen Chesney, Gregory Haljan, Alison Hoens, Stephanie Irlbacher-Fox, Monica Mamut, Megan O’Reilly, Victoria Schuckel

Tentative:

Guests:

Secretariat: Sara Lima Branco

1. Call the Meeting to Order
A.-M. Visockas welcomed all members to this meeting of the BC SUPPORT Unit Advisory Council and brought the meeting to order at 11:02 am.

2. Territorial Acknowledgement
A.-M. Visockas acknowledged that this meeting is being hosted from within the ancestral, traditional, and unceded territory of the Syilx people in the Okanagan Valley. Meeting attendees were welcomed to share their respective territory in the chat or during discussions.

3. Thank you to outgoing members and welcome new member
A.-M. Visockas led a thank you to A. Mclean for her work and perspective on the Advisory Council.

A.-M. Visockas also provided an introduction and welcome for L. Dempster to the group as the newest member. L. Dempster introduced herself to the group.

4. Action items from last meeting.
Action Item: Discussions regarding the Terms of Reference will be deferred to the next meeting, with a presentation of the draft Terms for review and approval. COMPLETE – this item is on today’s agenda.

5. Approval of Minutes
The minutes from the August 22nd meeting were presented to the group and approved as written.

6. Terms of Reference
   a. Discussion of revisions based on member provided feedback.
A.-M. Visockas thanked M. Mamut and S. Lima Branco for their assistance in crafting this version, and special thanks to all members that provided their feedback.
A.-M. Visockas led the group through a review of the latest draft of the Terms of Reference. Both the original Terms of Reference and this new draft were circulated in advance of this meeting.

Changes include:

- Increase in patient partner members from 4 to 5.
- Introduction of a vice-chair model.
- Clarified that this is a consensus-based group, based on providing the best advice based on consensus (and re-convening for further discussion, if that’s not achieved).
- Addition of a conflict-of-interest section. Request that members connect with A.-M. Visockas, S. Bryan or S. Lima Branco with concerns pertained to conflict of interest.

Discussion / comments:

- Request to confirm what number of members is needed for quorum.
- The previous ToR outlined that meeting minutes would be provided on our website. That is no longer addressed in this ToR. Going forward, there will be opportunities to report up to the Board of Directors of Michael Smith Health Research BC.

ACTION ITEM: Will remove “of the former BC AHSN” from Section 2 (Membership).

ACTION ITEM: “Representation from Indigenous and community-based research interests” will be changed to reflect them as two separate groups.

b. Next steps

DECISION: The changes identified in this meeting will be made, and the Terms of Reference will be circulated to the group to request their signature (approval).

7. Updates

a. BC SUPPORT Unit Update.

S. Bryan provided the assembled group with a BC SUPPORT Unit update, including component areas of Capacity Development, Data, Learning Health Systems, and Patient Engagement.

Discussion:

- The response to the Data component area and its progress was extremely positive.
- One example of how the Health Data Platform (HDP) projects tie into POR:
  - Long-Term Care Quality Improvement Initiative (LTC-QI). Patient Oriented nature of that project is ascertained by centering analysis on the patient voice provided from data from the Office of the Senior’s Advocate survey, 2016/2017. The next version of this survey is being administered now.
  - Exploratory analysis is taking place to connect the experience of the resident with the measures of the administrative data environment. This is being connected to a list that identifies facility characteristics such as bed size, owner type, location, and soon it will be possible to identify those in rural areas, as well (Statistic Canada Rurality Codes).
- M. Wright provided the group with some additional background regarding HDP, some of its current and upcoming features (including that researchers will be able to bring their own data in to link to the larger data set), and the importance of collaboration (individuals adding their own data and other researchers being able to use it).
Patient-centred data is coming via 2 avenues. Firstly, from researchers themselves that are collecting that data, linking it to the data, and allowing others to use it. The second is the PREMS/PROMS data which has been collected over the years and is available on HDP.

A request was made for future updates regarding the progress of the Data component area.

b. Tri-council meeting, June 2023
Planning is underway for an in-person meeting in June. Advisory councils for the BC SUPPORT Unit, Clinical Trials BC, and Research Ethics BC will each meet for a meeting, then the group will come together for a meet and greet and an early dinner.

B. Holmes joined the meeting and S. Bryan provided the assembled group background and a high-level review of the strategy circulated in preparation for this meeting. The strategy was circulated in advance of this meeting.

Discussion:

- How can we make POR and patient experience of care part of the culture, how things are done, and how can patients and public be engaged in more parts of health research?
- An ongoing discussion has been regarding sustainability; what do we want to sustain? How can we move from considering SPOR as a Phase I or Phase II project to POR being a standard?
- It may be helpful to consider ‘legacy’ versus ‘sustainability’, while still working towards sustainability of principles, practices, culture, and protecting progress made regarding the integration of POR.
- An inquiry was posed regarding more details on how partnerships could be formed (organizations, health authorities, communities). Senior leadership engage with a variety of groups, a partnership strategy that also addresses how the organization connects with other groups/organizations, and Health Research BC has also taken on secretariat duties with the Heath Research Council of BC.
- The BC SUPPORT Unit, as well as Health Research BC, welcome recommendations on potential partners or groups to partner with. Please connect with either a specific Region or connect with us directly.
- A question was raised about ‘intersectionality’ as a priority for the strategy. It was noted that although the strategy doesn’t use the word ‘intersectionality’, reflections on Equity, Diversity, and Inclusion (EDI) and engagement with indigenous communities are part of the work. However, it was agreed that this could be communicated more effectively.

9. Summary & Next steps
An email with the Doodle poll for the advisory councils of the BC SUPPORT Unit, Clinical Trials BC, and Research Ethics BC to hold meetings in June 2023 will be shared with the group, and the revised ToR will be shared with the group for their approval (signature and return).

10. Group adjourned at 12:29pm.