

MINUTES

BC SUPPORT Unit Advisory Council

June 5, 2023

Attendees:	Martha MacLeod (chair), Lin Chen, Courtney Defriend, Linda Dempster, Gregory Haljan, Alison Hoens, Sherri Mytopher, Lisa Ridgway, Swapnil Shah, Anni Rychtera
Ex-officio:	Stirling Bryan, Michelle Duffy, Monica Mamut, Waqar Mughal, Gayle Scarrow, Victoria Schuckel
Regrets:	Ellen Chesney, Terri Fleming, Stephanie Irlbacher-Fox, Alison Orth, Martin Wright
Tentative:	
Guests:	Ross Duncan, Laura Harvey, Maria Torrejon, Shirley Wong (<i>for Martin Wright</i>)
Secretariat:	Sara Lima Branco

1. Call the Meeting to Order

M. MacLeod welcomed all members to this meeting of the BC SUPPORT Unit Advisory Council and brought the meeting to order at 2:33 pm.

M. MacLeod spoke to the plans of the day: (1) to learn from and with each other (2) to discuss the two issues of sustainability and legacy (3) and to consider how the council may advise the BC SUPPORT Unit.

2. Territorial Acknowledgement

S. Bryan acknowledged that this meeting is being hosted from within the ancestral, traditional, and unceded territory of the x^wməθk^wəyəm (Musqueam), Skwxwú7mesh (Squamish), and səliłwətaʔł (Tseil-Waututh) Nations.

S. Bryan spoke to the “Seven Generations” Indigenous principle; consideration of the three generations of the past, the current generation, and the three generations in the future. It recognizes learnings from past generations, and that it’s important to consider the current and future generations. This ties into this meeting, as we are looking forward to the future and how we judge what it looks like for the Unit and as a patient-oriented research community in BC.

3. Introductory thoughts

S. Bryan notified the assembled group that for the first time, all three Advisory Councils are meeting (Clinical Trials BC, Research Ethics BC, and the BC SUPPORT Unit), and then coming together afterwards for a celebratory dinner.

These three groups are part of the completely consolidated organization: Health Research BC, BC’s Health Research Agency.

4. Introductions

Round table group introductions took place.

5. Approval of Minutes

The minutes from the April 3, 2023, meeting were presented to the group and approved as written.

6. Goals for the Day

- a. To build a shared understanding of the terms '**sustainability**' and '**legacy**'.
- b. To seek advice on approach/criteria for determining sustainability and/or legacy for Unit's work.

This is looking both to four years from now (when Phase II ends) but also what we can be done now to enhance the likelihood of sustainability and legacy for the work being done now.

7. BC SUPPORT Unit spotlight

To help inform our discussions, three short presentations will take place, regarding some of the work the Unit is doing. The purpose of these presentations is to help council members in group discussions take place later in the meeting to think about what should be sustained and how that takes place.

Council members are encouraged to consider the following as presentations are taking place:

- how do we make judgements about what should be sustained?
- how do we ensure we have legacy from the work?
- how do we think about sustainability?

S. Bryan reviewed the component areas from Phase I and those from Phase II, as well as definitions for 'sustainability' and 'legacy'.

Sustainability: "...the continuation of programme or programme components, or the continuation of outcomes, after initial implementation efforts, staff training or funding has ended."¹

Legacy: "An amount of money or property left to someone in a will." "The long-lasting impact of particular events, actions, etc. that took place in the past".

Three presentations followed: (1) the Citizen Science platform (which started in the Phase I Methods Clusters) (2) the Putting Patients First conference and (3) Health Data Platform BC (HDPBC). Slide decks of these presentations will be circulated with the minutes from this meeting.

Meeting attendees moved into breakout rooms to consider the following discussion questions:

- What criteria should we consider when determining what should and could be sustained?
- How should we determine which organization(s) (including Health Research BC) should be involved in supporting sustainability?

S. Bryan confirmed that the request was not to consider whether or not the topics discussed in the presentations should continue, but rather to consider how can the Unit make decisions about work that

¹ Ref: Braithwaite, J.; Ludlow, K.; Testa, L.; Herkes, J.; Augustsson, H.; Lamprell, G.; McPherson, E.; Zurynski, Y. Built to Last? The Sustainability of Healthcare System Improvements, Programmes and Interventions: A Systematic Integrative Review. *BMJ Open* 2020, 10, e036453, doi:10.1136/bmjopen-2019-036453.

should be sustained – or not? How can decisions be made regarding criteria. Emphasis is on the criteria that we can use to make decisions.

8. Discussion:

• Group 1

- Everything discussed here could be summarized under the topic of “anything that supports culture shift in POR and patient-engagement”.
- This included implementing system changes in the form of services to enhance functionality.
- Full patient engagement input – what would that look like?
 - What’s the impact for this?
 - What’s the quality of the engagement and the commitment towards engagement?

• There’s a need to leverage technology and innovate practices. Innovative solutions are needed that can leverage technology to achieve multiple outcomes.

• Group 2

- How can POR be ingrained into health authority research programs – how can there be impact here?
- Need to increase the profile of the Unit.
- Strong evaluation is needed to show impact and value to our potential partners.
- Initiatives that create strong partnerships; these assist with strong business cases.
- Strong recommendation for support of initiatives that help set the foundation for patients to continue to have their voices heard even if the Unit doesn’t exist.

• Group 3

- Significant discussion regarding the context of creating criteria. How can competing priorities and values be balanced when individuals have limited emotional and mental spaces? Two examples are social tensions (EDI) and the pandemic. How do we show our work is relevant?
- How can POR be part of funding requirements. For example, ask those requesting funding to provide evidence that POR approach was taken.
- Considering the Seven Generations indigenous principle as mentioned earlier; can we maintain the status quo for three generations, and say that’s a legacy piece?
- What are the things that assist us in understanding the lives of those individuals affected – via methods other than the conventional research methods.

9. Discussion close

The Unit is privileged to have the ability to connect and collaborate with individuals with so many different perspectives that are shared with us.

Sustainability is part of the work of the Unit. There’s an obligation to consider sustainability for all the work and engagements we’ve engaged in. Parallel roads are needed; delivering on our current work as well as working on sustainability for our work.

Strong evaluation work is needed, including dedicating more resources to this crucial area. This evaluation must address the concerns and needs of those funding partners we hope to collaborate with.

During the presentations, there were many partners identified. There are ways to engage with others, that aid in capacity building and seeds of knowledge that could be different in subsequent generations than they are now. These partnerships are needed to ensure improvements are sustainable over time, so a collaborative effort with various groups (in a collaborative way) is important.

Isolation between academic institutions and health authorities could occur as each group moves towards expanding their research departments.

Consideration that when patient/community plans/voices are meaningfully engaged, and these groups identify their needs, there are competencies built in – regardless of the researcher. The community voice informs regional and provincial plans, in areas outside of the research sphere.

10. Council experience

M. Mamut welcomed members of the council to share their reflections about their experiences as a member of the council, and that they would desire the Unit to reflect on, as well. Questions included:

- And what would you like us to think about as we go forward in planning our future meetings?
- What topics would you like us to see?
- Was there value in what we discussed previously?
- What would you like to see moving forward?
- Thoughts on how we run meetings – are there ways to improve?
- How can we just generally improve?

Discussion:

- Members spoke to the fact that the group is diverse, and welcoming to members, including patient partners. It's gratifying to feel like your feedback and voice matters.
- Members felt that reciprocity, respect, and inclusion were present in this council, and that feedback provided is being applied.
- Members appreciate when they have a point of contact that is able to provide assistance.
- Members requested if questions about the discussion topics could be circulated in advance; to allow for additional time for members to consider topics.

Council members were also asked to reflect over the coming months, leading to our next meeting. Members were asked to share any feedback and questions to S. Lima Branco for any additional inquiries or thoughts.

ACTION ITEM: A Form will be shared with members where they can provide feedback.

11. Next steps

Next meeting is Monday, September 18, from 11:00am – 12:30pm. M. MacLeod and S. Bryan thanked the council for their engagement today.

12. Group adjourned at 5:02pm.