

## BC SUPPORT Unit Advisory Council

### Minutes

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November 29, 2019 at 9:00am – 3:30pm

**Attendees:** Lynn Stevenson (chair), Gregory Haljan, Bev Holmes, Stephanie Irlbacher-Fox, Martha MacLeod, David Ostrow, Bernie Pauly, Beverley Claire Pomeroy, Anni Rychtera, Swapnil Shah, Anne-Marie Visockas,

**Ex-officio:** Minnie Downey, Stirling Bryan, Kelly Moran, Victoria Schuckel

**Regrets:** Ellen Chesney, Martin Wright

**Guests:** John Ward

**Secretariat:** Sara Lima Branco

## **1. Call the Meeting to Order**

L. Stevenson, BC SUPPORT Unit Advisory Council Chair, welcomed all members to the first meeting of the BC SUPPORT Unit Advisory Council and brought the meeting to order.

L. Stevenson acknowledged that the BC AHSN office is within the ancestral, traditional, and unceded territory of the Coast Salish Peoples, including the territories of the x<sup>w</sup>məθkwəy̓əm (Musqueam), Skwxwú7mesh (Squamish), Stó:lō and Səlílwətaʔ/Selilwitulh (TsleilWaututh) Nations.

## **2. Introductions**

Group introductions took place, as well as a discussion of key themes.

## **3. Setting the Scene: BC AHSN, BC SUPPORT Unit, Governance Structure, Terms of Reference, Conflict of Interest, and Non-Disclosure**

AHSN and BC SUPPORT Unit overview:

M. Downey, Executive Director, BC SUPPORT Unit, and S. Bryan, Scientific Director, BC SUPPORT Unit, reviewed a PowerPoint presentation regarding the BC AHSN and BC SUPPORT Unit. A discussion then took place regarding the PowerPoint presentation.

Governance Structure:

Feedback was provided on the org chart, including better stating the engagement and involvement of patient partners. For the purpose of consistency, this should be more clearly articulated.

Patient Partner Council:

A. Rychtera, member of the BC SUPPORT Unit Patient Partner Council, addressed the group. She provided an overview of the history of the BC SUPPORT Unit Council, and the scope of tasks the Patient Partner Council is currently undertaking. Conversation within the group confirmed that for this group of patients, patient involvement has begun to feel less tokenistic, and that more patients are involved. It was discussed that the Advisory Council may offer advice for the management team to be used in their decision processes as applicable.

Terms of reference:

A Terms of Reference was provided to the group in advance of this meeting and reviewed at this time, led by L. Stevenson.

This purpose of the council (source of expert advice for the Unit Management team) and membership (there is a limit of 15 individuals on this Council) were discussed. Part of the role of this council will be to advise looking forward to SPOR SUPPORT Unit Phase II's application, and SPOR SUPPORT Unit Phase II itself.

The group discussed the SPOR SUPPORT Unit Phase II funding opportunity, and its components as related to gender and sexual orientation. The group also discussed engaging more clinicians.

The terms of Reference don't address B. Holmes' required seat as a representative of our funding partner (MSFHR) and will be revised to clarify that MSFHR will have one seat on the Council.

**ACTION:** The ToR will be corrected and recirculated; the Council will then be able to sign and return that copy.

Feedback was also provided as pertains to removing the term 'representation'. Members will be providing perspective. (The role is 'supportive' as opposed to 'representative'.)

Conflict of Interest was discussed, and there is an agreement that members will disclose to the chair any conflict of interest, either in advance if known, or at the time of discussion if identified.

#### **4. Current state: Formative evaluation**

J. Ward, Performance Measurement Lead, BC SUPPORT Unit, reviewed a PowerPoint presentation with the group on the formative evaluation, and evaluation in general. A discussion occurred after the PowerPoint presentation:

Letters of Support (LoS), one of the services the BC SUPPORT Unit offers, were also discussed. A large percentage of projects that received a LoS were eventually funded (approximately 50%). Regional centres have allowed for the formation of new relationships with academic institutions. There has been a move away from purely academic led research into clinical research being done within the system.

An inquiry was posed regarding patient engagement frameworks; there are 68 Patient engagement frameworks currently being used. One of our projects has offered their project to us – PEIRS. Which is being used for evaluation purposes.

#### **5. Planning with the Outcomes in Mind**

K. Moran, Director, Operations, BC SUPPORT Unit, reviewed the Social Research and Demonstration Corporation (SRDC) Report as well as the BC SUPPORT Unit response with the group. These had been circulated in advance of this meeting.

After the review, a discussion then occurred regarding the SRDC Report as well as the BC SUPPORT Unit response. The response to the SRDC report was compiled by the Hub staff as well as the regional centre.

A recommendation was made that it should be better articulated that the evaluation was only a partial evaluation, and that there were already plans to implement some of these recommendation before the evaluation itself took place.

The council advised the SUPPORT Unit management that the planned response to the formative evaluation was sufficient and to look forward and plan and make decisions in the context of the current environment.

## 6. SPOR SUPPORT Unit Phase II

M. Downey and S. Bryan presented on SPOR SUPPORT Unit Phase II, as well as the SPOR SUPPORT Unit Phase II Funding Opportunity / information. Material had been circulated in advance of this meeting. A discussion of these documents then occurred.

Inquiries were posed regarding the EDI (Equity, Diversity, and Inclusion), SGBA (Sex and gender-based analysis), and OLMC sections of the Phase II application (Official languages minority communities). Clarification was requested as to what ‘consider’ means?

**ACTION:** Based on feedback provided – the SUPPORT Unit will reach out to CIHR for more clarification on this, as in some situations there may be many other languages spoken (i.e., 5).

A discussion took place as to how the Advisory Council can best aid the BC SUPPORT Unit.

Patients present in the room felt there was a tangible change in the culture of research, and a focus on POR.

## 7. Next steps / last thoughts

An inquiry was posed to group re: teleconferencing / videoconferencing. It was determined that Zoom conferencing was preferred.

## 8. Group adjourned at 3:20