



ADVISORY COUNCIL MEETING MINUTES

Monday January 11th
9.00am – 12.00pm

Attendees:	Angie Bain Eugenie Lam Holly Longstaff Jim Mann Jude Kornelsen Julie Hadden Karin Maiwald Laurel Evans	Mark Barnes Namaste Marsden Nicolette McGuire Sara O' Shaughnessy Sarah Bennett Sunny Loo Victoria Schuckel
Ex-Officio:	Alison Orth, Aoife Kelly, Gillian Corless, Jean Ruiz, Paola Pinto Vidal, Terri Fleming	
Regrets:	Minnie Downey	
Recording Secretary:	Aoife Kelly	
Guest:	Syexwaliya Ann Whonnock, Stirling Bryan	

1. Welcome & Opening

- 1.1. Elder and Knowledge Keeper Syexwaliya Ann Whonnock opened the meeting with a Traditional Welcome, song and prayer.
- 1.2. Sarah Bennett welcomed the Advisory Council and guests.

2. Update from Stirling Bryan, CEO of BC AHSN

- 2.1. Stirling Bryan thanked the Advisory Council for their work and provided background and answered questions on the upcoming consolidation of BCAHSN with MSFHR. **CONFIDENTIAL:** This information is confidential and not to be shared outside of the Advisory Council. Public announcements are expected within the next few weeks.

3. Membership updates and changes

- 3.1. Victoria Schuckel will be stepping down from the Council and will be replaced by Nicolette McGuire. Victoria stated that she is happy to continue to participate and support wherever is helpful. Sarah welcomed Nicolette to the Advisory Council.
- 3.2. Sarah Bennett will be stepping down from her role as chair and will be replaced by Namaste Marsden and Jude Kornelsen as Co-Chairs of the Advisory Council.

3.3. Namaste thanked the Advisory Council for their support and provided her background.

Namaste stated that her goals as Co-Chair are ensuring broad perspectives, including those of research participants, patients, communities, elders and knowledge keepers, and stated hopes that at the end of her term with Jude, the Council would be transitioning to a Co-Chair from the community and patient sectors.

3.4. Jude Kornelsen also thanked the Advisory Council and provided her background. Jude noted that she is excited to facilitate provincial discussions on the conduct of ethical research and creating a supportive context for researchers.

4. Approval of minutes

4.1. Sarah Bennett reviewed the outstanding items from the minutes.

4.1.1.Terms of Reference

- The draft terms of reference have been reviewed by Co-Chairs.
- Updated draft will go to Council for approval.

4.1.2.Client/Researcher Satisfaction Survey

- To be part of Priority Setting discussion

4.1.3.Revision of Reciprocity Agreement

- Revision is underway.
- Has been with UBC Legal, is now with Interior Health for their initial input as a non-UBC-affiliated REB and a Health Authority.

4.2. The minutes were approved.

5. Priority Discussion

5.1 Sarah Bennett and Terri Fleming presented background on Priority Setting, including a Budget and Operations Timeline. These slides were included in the agenda in the meeting package.

5.2 There was a discussion about differentiating where REBC has a mandate (directive) role vs a support (advocacy) role.

- Laurel Evans stated there is a need to be wary of mission creep.
- Laurel suggested that Indigenous research ethics & privacy are areas where REBC should hold a more supportive role.
- Laurel stated that in her opinion returning results to participants should be a more directive role.
 - REBC has been working with CTBC's working group on this issue and progress on this will be presented at CTBC Conference.
 - Terri will be bringing this up with REBA Meeting group.
- Laurel also brought up another directive role - that it would be beneficial for REBC to be involved in BC guidance for SOPs for Clinical REB review and Behavioural REB review and to dedicate resources for province-wide SOPs.
- Sunny Loo asked what influences where we should be in support role vs. mandate role. In some areas we should be in a support role because of lack of expertise e.g. privacy, whereas in Indigenous research ethics it is because it is not REBC's place to dictate what is needed in this area.
- Victoria suggested organizing these priorities based on the key audience that are impacted.
 - Research participants

- Institutions
- System level
- Jude Kornelsen suggested discussing what may be missing from the diagram (slides, page 5) and making some adjustments to the framework.
- Jude also noted that ethics of engagement is wider than just Indigenous research ethics.

5.3 Privacy

- Terri provided background that during the COVID-19 pandemic the duplication of effort between institutions on privacy reviews caused some difficulties with research studies being moved forward.
- Terri, Holly and Laurel were involved in drafting some advice and recommendations with regards to privacy reviews.
- This became a briefing note that has been supplied by the COR-TF to Ministry representatives and has been directed to a department that has links to privacy departments in Health Authorities.
- As Research Ethics is the first port of call for researchers, these issues often get brought to Research Ethics when their study has not progressed for reasons to do with institutional approval.
- Terri stated that her perspective in providing these recommendations is that Research Ethics has already worked through some of this process of improving and streamlining, so some of the lessons that were learned during that process could be applied to help to refine and streamline other processes such as privacy.
- Sara O' Shaughnessy suggested that we need a consistent approach to REB review & privacy so that we're not causing unnecessary barriers.
- Holly brought up that based on Section 35 requirements, what the REBs do is already covered by FIPPA, so extra privacy reviews are unnecessary.
- Terri suggested that herself, Laurel and Holly are part of the COR-TF meeting, and will ask for feedback on briefing note, stating that there is a call from the REBC Advisory Council to find consistency of approach between the institutions with regards to ethics and privacy, whether they are separate or they are integral.
- Terri is creating a report of studies that were stalled due to privacy issues.
- Victoria will discuss the Briefing Note at meeting later today with Mary Ackenhusen to find out its status. Victoria will follow up with Terri regarding this.

5.4 Data

- Jude brought up the subject of streamlining data access – where is REBC positioned? Is this in an advocacy/support role? To actualize the mandate of learning health system.
- Victoria noted that there needs to be provincial work related to the health data platform, which needs to include each of the health authorities having similar interpretations of privacy and access.
- This platform has to deliver to researchers, so there may be some connections here.
- Jude asked whether there is a statement about timely access to data in BC? Suggestion to have a conversation with Shirley Wong to ask about commitment to data access, what will be done in 2021 to advance this, and how we can work with you.

- Terri mentioned SPOR Phase 2: Overlap & alignment – REBC & CTBC working with Support Unit

5.5 Non-research ethical oversight

- Terri provided some background on non-research ethical oversight as an area where people have relied on research ethics boards to tell them if their study requires research ethics review, if it is quality improvement (QI), or if it is research under the TCPS2 definitions.
- QI oversight is based at institutional in the province.
- Jean Ruiz said the different interpretations on the line between what is or isn't research could be streamlined/standardized across institutions.
- Terri brought up a resource from Alberta called the ARECCI Ethics Screening Tool, which assists in determining whether a project requires research ethics review or not, and also provides tools to develop skills when looking for the ethical implications of a project, even if it doesn't require formal REB review.
- This project is being revised and they will collaborate with BC on a future tool.
- Sara O' Shaughnessy brought up the issue of capacity, especially in health authorities: even if QA/QI projects do not fall under the purview of REBs, these issues are still being brought to REBs.
- Jean agreed with this, as QA/QI projects can potentially double submissions coming to REBs. A province-wide unifying mandate that attempts to define this could be helpful.
- Holly agreed and noted that multidisciplinary QI teams have specific expertise that REBs do not have (and vice-versa).
- Laurel highlighted the nuances between when it's a health authority quality assurance improvement vs a behavioral quality improvement project that's being done e.g., within the Faculty of business at UBC. Laurel said she had doubts that a checklist tool would work without context and input from a person with experience.
- Holly brought up the PHSA sorter tool that acts as a conversation starter that can point researchers in the right direction. Holly is currently doing an evaluation of the tool and can share this date with the Council.
- Eugenie brought the fact that many grad students are health professionals, and they look to the REB for the determination.
- Namaste told the Council that FNHA developed a screening tool and did a literature review. They found that REBS were looking at projects as QI but there was a clear new intervention, data collection and intent to publish. Standardization is needed especially as it relates to consent.
- Sarah summarized that there is an appetite for creating consensus across the province on this issue and that it would fall under the mandate of REBC and should be considered a priority for 2021.

5.6 Clinical trials review model

- Terri said that a pilot model for a harmonized clinical trials review using the PREP/RISe system is in place and needs to be reviewed to determine its effectiveness and if improvements can be made to the process.
- Sara O mentioned issue around education on how to use PREP for these sites and ensuring it is being done in a way that supports sites to be as compliant as possible.

- Terri noted that this is something that is already being managed via the Clinical Research Community of Practice group and that it will be a priority for 2021 to examine the pilot.
- Alison Orth mentioned that industry clinical trials tend to have concerns about the research ethics institutional review in BC versus being able to use a central or a private IRB.

5.7 Indigenous Research Ethics

- Angie said that communities have their own access processes and protocols and that it is challenging for communities to benefit from studies. Privacy and data access needs to be a priority.
- Terri explained REBC's role as lifting together with external partners i.e., BC NIEHR and IRSI, and working in a support/advocacy role. Three bodies can work together to see what each is doing, in order not to be duplicate effort. REBC has a network of REBAs to offer to the groups e.g., could ensure REBs have cultural safety training.
- Laurel said that REBC's role must be one that assists, advocates, and provides links to networks but leadership needs to come from indigenous communities.
- Gillian Corless said that we need to look to the capacity of Indigenous communities. This group should be looking for a way to bring that community voice forward.
- Namaste brought up jurisdiction at operational level. Decolonizing ethics review is in the hands of the institution. VIHA for example have taken steps to tackle fundamental institutional control with shift to indigenous leadership. We need to keep in mind the principle of "Nothing about us without us". This comes in the context of OCAP which is about data sovereignty and intersects with issues already discussed. There is still quite a bit of work to do in Implementing UNDRIP – how will this implement work of province in data and beyond. TCPS2 is a light standard, there was a policy document by CIHR which was an indigenous community fundamental standard which was shelved so ethics boards are determining ethics review standards and interpreting TCPS2, based on the assertion of researcher. Communities are still being bombarded by requests from researchers working in own interest and not what communities need.
- Gillian noted that cultural safety is the bare minimum standard – REBC can lift that through REBs then deepen over time.
- Laurel suggested that REBC have an educational/informational role among REBs in province, raising issues back to broader REB community.
- Namaste said that they had been working with REBC & Angie on engagement, which has been paused due to COVID.
- Angie said that in terms of research in 2021 with Indigenous communities, UNDRIP must be priority. REBC can advance this work as a priority in 2021, and consider what it means in terms of relationships, engagement, and data sovereignty.

6 Closing

6.1 Syexwaliya Ann Whonnock closed the meeting with a prayer and song.

7 Meeting adjourned

7.1 The meeting was adjourned at 12.07pm.