

REBC Advisory Committee and Council Meeting

Minutes for June 19 2019 – 10:30am – 12:20pm

Location: Four Points Sheraton, Kelowna, BC

Room: Meritage D



British Columbia Academic Health Science Network

INVITEES:

Bain, Angie – Union of BC Indian Chiefs	Ganz, Pia – UBC	Longstaff, Holly – PHSA	Pinto Vidal, Paola – REBC (ex-officio)
Barnes, Mark - UNBC	Hadden, Julie – Providence Health Care	Loo, Sunny – Public/Patient Partner	Prasad, Jennie – Children’s & Women’s
Bennett, Sarah – Island Health (Chair)	Hartley, Isobel – UNBC	Maiwald, Karin – Interior Health	Ruiz, Jean – REBC (ex officio)
Evans, Laurel - UBC	Herbert, Dorothy – Interior Health	Marsden, Namaste - FNHA	Russell, John – Langara College
Flann, Sarah – Fraser Health	Kornelson, Jude – UBC	Mann, Jim – Public/Patient Partner	Westerlaken, Kristie – BC Cancer
Fleming, Terri – REBC (ex officio)	Lam, Eugenie - UVic	O’Shaughnessy, Sara – Fraser Health	Wong, Shirley - Ministry of Health

APOLOGIES: Jude Kornelson, Jim Mann, John Russell

CHAIR: Sarah Bennett **RECORD KEEPING:** Paola Pinto Vidal

Topic	Discussion	Decision or Action	By Whom
Acceptance of minutes from previous meeting	Motion to accept minutes from previous meeting. No changes to the meeting minutes were requested.	Minutes accepted	First: Sara O’Shaughnessy Second: Isobel Hartley
Approval of agenda and round table of introductions	-Round of introductions at the table, introducing committee members with incoming council members, what background (if any) they have with research ethics, and their current work role.		
Other business	-Acknowledgment and thanks to our REBC committee members for all their hard work and dedication -The group was asked if they are comfortable sharing contact information amongst the council members. There were no objections expressed amongst members.	Council member contact information will be circulated	Paola

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<p>1. Update report on REBC and AHSN and REBC Governance Structure</p>	<p>Terri Fleming, one of the two Unit Directors presented the REBC strategies and new governance structure.</p> <p>-A brief summary of the new structure: REBC is moving from an Advisory Committee to an Advisory Council structure for two reasons: First, to be consistent with the other BC AHSN units of Clinical Trials BC and the BC SUPPORT Unit. The second being the goals of the original BCEHI (ethics harmonization initiative) have been achieved. The next phase for the group requires the broader expertise of an advisory group.</p> <p>- Working groups will be created as needed to address specific themes or issues e.g. Pediatric trials, jurisdictional requirements</p> <p>- Working groups will be supported by REBC ex-officio: Jean Ruiz, Terri Fleming, and Paola Pinto Vidal.</p> <p>-Working groups will report to the Advisory Council, and the Advisory Council and REBC staff are responsible to the BC AHSN Board of Directors through Tom Noseworthy, CEO.</p>		<p>REBC Staff</p>

<p>2. Review and Approval of Terms of Reference</p>	<p>Terri presented the key highlights of the draft “Terms of Reference” which includes the reporting relationships discussed earlier.</p> <p>-The purpose of the Council is a source of expert advice to the unit by providing input, advice, and recommendations to support the successful achievement on the REBC strategic priorities.</p> <p>-Membership is a balance between stakeholder categories including investigators, public, patients, participants, research organizations, professions and industry, as well as a balance representation from across the regional areas of BC.</p> <p>-Membership is capped at 15 members, not including the ex-officio of Terri, Jean, and Paola</p> <p>-Appointment term is for 2 years with an option for renewal of 2 years after that. Resignation from the Council is by notification to the Chair.</p> <p>-The REBC Unit Director (interim part time shared position between Terri and Jean) nominated the inaugural Chair. It was important that the first Chair have the connection to the past structure and history of ethics harmonization.</p> <p>-After one year the Chair will be determined by the Advisory Council members</p> <p>-It was asked if the sessions will be recorded. After discussion, agreement was reached to record the session but these unlike minutes will not be publically available.</p> <p>-Clarification around the difference between the committee and council: the Advisory Committee was a working committee that REBA worked “off the side of their desks” for years, whereas the Council’s role is advising, and not necessarily considered a working committee. The hope is that everyone who was previously on the Committee can stay equally involved, participating in working groups, and REBC staff will be there to support them.</p> <p>-A concern was raised that we do not want to lose the connection REBC has with the REB administrators “on the</p>	<p>Audio recording of the meetings will be done for meeting minute purposes and will only be available to the Advisory Council members</p>	<p>Advisory Council members</p>
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	<p>ground”and if something can be added in the ToR to clarify that connection and legacy.</p> <p>-Clarification on section 2 was requested. What is meant by “industry” and Terri clarified it is not meant to denote only pharma, but for our unit that it encompasses “industry” like the Ministry of Health for example.</p> <p>-Under the section on Membership, Isobel suggested that it should be made clear that if you are joining REBC that the partner institution will be expected to provide support to the working groups and identify new needs as new partners join.</p> <p>-It was raised that the responsibilities of the Council need to be better fleshed out.</p> <p>-A question on confidentiality led to the discussion that the Chair’s responsibilities also need to be developed. The issue of confidentiality is not foreseen to be an issue.</p> <p>-Suggestions and clarifications will be incorporated in the new version of the draft of Terms of Reference which will be circulated to the group.</p>	<p>An additional sentence or two to clarify the connection with REB Administrators</p> <p>Clarification on how industry is defined to be added in the ToR; suggestion that it be plural to industries</p> <p>Add a new section on the <i>Responsibilities of the Advisory Council</i>, greater detail on the process of onboarding new partners, and flesh out the Chair’s Responsibilities</p> <p>The latest iteration of the ToR will be distributed electronically and made available on the eCoP to all Council Members for review and approval</p>	<p>REBC staff</p> <p>REBC staff</p> <p>REBC Staff</p> <p>REBC Staff</p>

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<p>3. Presentation of AHSN Strategic Plan and REBC's Role</p>	<p>Terri presented the work that has been done thus far with the AHSN Strategic Plan and REBC's role in it. The Strategy is expected to be approved by the BC AHSN Board of Directors by end of June, and an REBC operational plan should be developed around October of this year</p> <p>-The Directors of each of the units have been meeting on a weekly basis to work on the Strategic Plan. The first at the top is BC AHSN's mission: To better connect and catalyze BC's collective expertise and resources to obtain substantive measurable improvement in health and health care.</p> <p>-There are a variety of institutions that are trying to achieve a similar goal as BC AHSN, like the Ministry, universities, the BC Patient Safety & Quality Council, PHSA, Michael Smith Foundation, so what the goal was to determine how we can bring value to this mission which is a similar mission others have in the province</p> <p>- Please refer to slides for detail</p> <p>- Terri requested that the Council reflect on these goals and think on where they can see REBC's role in achieving these goals.</p> <p>-Dorothy suggested that to foster patient-oriented research we could reach out to the SUPPORT units. Terri responded that perhaps a tactic we could use is to provide education to research ethics boards and administrators on new technologies that are coming and how to handle that, for example, patient partners that are both directing the research project and participating in the project, and how to evaluate the ethics around some of these issues.</p> <p>-Sara O. wanted to note that we need to be careful with recognizing what our scope and what falls within research ethics and what is a part of a greater scope in research integrity.</p> <p>-We were approached by Privacy Research Advisory Group (PRAG) to give a presentation as they are interested in harmonization of privacy reviews.</p>	<p>We will send out the latest version of the plan and the group will discuss further.</p>	

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4. Discussion on REBC areas of focus	<p>Council discussed areas where REBC could add value to research ethics in BC. The following area of focus were proposed:</p> <ul style="list-style-type: none"> -Education and advocacy for patient engagement in research. This goes beyond being included on the research team but true input into the design and analysis. Research Ethics boards could facilitate this during reviews. -Comprehensibility of consent forms and the consent process in research is a problem in research, particularly in clinical trials. -Community based research ethics and indigenous research ethics (land-based holistic approach) are different than the historical biomedical models used to evaluate ethics in research. There is already a lot of work being done in this area and REBC could further help facilitate and catalyze this work. -Raising the precedent around returning research results to participants and reporting negative trial results. -Work with communities to navigate research institutions. -Sponsored (For Profit) Clinical Trial models for harmonized ethical review. -Privacy and access to data for research purposes. There are so many barriers to data access in the healthcare setting and it is difficult to respond to emergencies or issues without data and an informed approach. -REBC needs to have a clear evaluation and assessment strategy. -Given the new regulations around cannabis, REBC may be able to help partner institutions with resources about conducting research with cannabis. 	REBC Staff will compile the feedback, categorize and suggest next steps for developing working groups around prominent areas of interest.	REBC Staff
Adjourn and next meeting proposed date	Motion to conclude the meeting. The next meeting time is proposed for October.	Adjourned	First: Laurel Evans Second: Eugenie Lam