

REBC Advisory Committee and Council Meeting Minutes

February 11, 2020 – 10:30am – 1:30pm

LOCATION: BC AHSN Office, Suite 420, 1367 West Broadway, Vancouver, BC



British Columbia Academic Health Science Network

ATTENDEES:

Bain, Angie – Union of BC Indian Chiefs	Hadden, Julie – Providence Health Care	Maiwald, Karin – Interior Health	Orth, Alison – CTBC (ex-officio)
Barnes, Mark - UNBC	Kornelson, Jude – UBC	Marsden, Namaste – FNHA	Pinto Vidal, Paola – REBC (ex-officio)
Bennett, Sarah – Island Health (Chair)	Lam, Eugenie - UVic	Mann, Jim – Public/Patient Partner	Ruiz, Jean – REBC (ex-officio)
Corless, Gillian – REBC (ex-officio)	Longstaff, Holly – PHSA	O’Shaughnessy, Sara – Fraser Health	Schuckel, Victoria – Ministry of Health
Fleming, Terri – REBC (ex-officio)	Loo, Sunny – Public/Patient Partner		

GUESTS: Stirling Bryan, President, BC AHSN

APOLOGIES: Evans, Laurel - UBC

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

Topic	Discussion	Decision or Action	By Whom
Welcome and Review and Approval of agenda Review of minutes from previous meeting	Round of introductions at the table. Motion to approve the agenda. Motion to accept minutes from previous meeting. No changes to the meeting minutes were requested.	Agenda accepted Minutes accepted	Motion: Holly Longstaff Second: Julie Hadden Motion: Holly Longstaff Second: Sara O’Shaughnessy
Guest: Update from Stirling Bryan, President of BC AHSN	Stirling introduced himself and his new role as President of BC AHSN. The BC AHSN is working towards supporting a <i>Learning Health Systems</i> (LHS) model and REBC will play an integral role with the other units in supporting a LHS that aims to improve delivery of quality health care.	For information only	
Update to Terms of Reference	Update from Terri regarding development of a short one-page confidentiality agreement that establishes more of the relationship between the Council and expectation of confidentiality, as opposed to ownership of any intellectual property created from the meetings. Will be brought to the Advisory Council when ready.	For information only	Terri

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Development and Training for the Advisory Council members	<p>Sarah initiated a discussion around what research ethics resources and training would best help support members in their role on the Advisory Council.</p> <p>- BC AHSN has an organizational subscription to the CITI Program training (Collaborative Institutional Training Initiative) and as members of the Council, they also have access.</p>	<p>Action: Anyone who wishes to take CITI courses needs to contact Terri for registration</p>	<p>Contact Terri if interested</p>
	<p>- A list of available training resources was provided last year and will be recirculated through email. They will also be added to the resource section of the REBC Advisory Council ECoP (Electronic Community of Practice).</p>	<p>Action: Send out list of training resources to Advisory Council members</p> <p>Action: Add to the Resource section of the REBC AC ECoP</p>	<p>Ex-officio</p>
	<p>- A handbook would be appreciated, including key policies, Terms of Reference, and training resources.</p>	<p>Action: Create handbook for new members</p>	<p>Ex-officio</p>
	<p>NOTED: Face to face meeting last year in Kelowna was greatly appreciated.</p> <p>- A suggestion was made to have a mentor for new council members who receive/have questions specific to research ethics.</p>		<p>Ex-officio</p>
	<p>- There was a discussion about the distinction between research and evaluation, and the implications in supporting a learning health systems model. There was general agreement that it should be a key priority for REBC to work on a consistent approach for determining if projects are QA/QI/evaluation/research.</p> <p>-PHSA has launched a sorter tool that is available through REDCap and sorts projects into “buckets” of research/QI/evaluation. Holly agreed to share the questions used in the tool.</p>	<p>Action: Questions used in ‘sorter tool’ from PHSA to be shared with REBC</p> <p>Action: Send out link to PHSA sorter tool</p>	<p>Holly Longstaff</p> <p>Ex-officio</p>
	<p>- Glossary of acronyms is required.</p>	<p>Action: Develop glossary of terms and acronyms</p>	<p>Ex-officio</p>

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<p>Introduction of Gillian Corless, FNHA secondee</p> <p>Theme: Indigenous, Nation and Community Based Research Ethics</p>	<p>Gillian introduced herself and her role within FNHA and how the partnership potential arose from a conversation with Jean Ruiz last year.</p> <p>-Moving forward in this role Gillian would like to see what the broader needs are in the province and what the gaps are with respect to engaging Indigenous communities in research in a way that respects the principles of OCAP.</p> <p>-Namaste commented that they are engaged with many academic partners across the province as well as Indigenous researchers to create a space for discussion, using Indigenous values and the FNHA 7 directives framework.</p> <p>Gillian concurred that one of the major questions they would like to address is how to create <i>meaningful partnerships</i> and what that means and looks like.</p> <p>-Jude K. raised an important issue that capacity building is needed within indigenous communities to be able to move towards OCAP in a pragmatic way.</p> <p>-In this role, Gillian hopes to create some working groups that will address these gaps and provide some resources and expertise for REBs and researchers to assess if communities have been engaged and is the community behind the research project.</p> <p>-Stirling mentioned the BC Network Environments for Indigenous Health Research (NEIHR) grant and Namaste mentioned that FNHA is already involved.</p>		
<p>Working Group Updates: Jurisdiction</p>	<p>Terri provided an update on the Jurisdiction working group activities:</p> <ul style="list-style-type: none"> - BC Cancer guidance was launched designating the BC Cancer REB as a disease-specific REB for the province. (attached to minutes) - Similar discussion will be had in the near future on pediatric studies with the proposal being to recognize Children and Women’s REB as a population specific board to streamline the ethics review. 	<p>For information only.</p>	
<p>Theme: Clinical Trials Harmonized Review - no update.</p>	<p>It is too premature to evaluate the Clinical Trial pilot because it is underway. The target date for the evaluation is June 2020.</p>	<p>For information only</p>	

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Jim Mann: presentation	<p>Jim presented on ethical considerations of research involving people with dementia. Jim's presentation advocated for research which does not stereotype people living with dementia as being incapable or without the capacity to consent in research or to provide information themselves, demonstrating an overarching issue of over-protectionism.</p> <p>- Other members echoed similar issues when trying to include different cohorts of people who are also underrepresented in research.</p>	<p>Action: Send Jim's presentation to council</p> <p>Action: Link to Jim's Story video on the City of Vancouver YouTube channel: https://youtu.be/Lzd2aYpuKdk</p>	<p>Ex-officio</p> <p>Ex-officio</p>
	<p>- Suggestion made that REBC work with the SUPPORT Unit to develop video library of patient/participants speaking about their experiences and make available for REBs and researchers as education tool.</p>	<p>Action: REBC to work with SUPPORT Unit on idea of videos</p>	<p>Ex-officio</p>
Theme: Resources for Ethical Reviews, REBs and Capacity Building	<p>-Support for webinars or workshops for REBs</p> <p>- Sara O' noted she would like to see REBC working in the direction of having a strong set of province wide best practices and guidance that would be available to everyone.</p> <p>- BC Cancer and Fraser Health both have been developing new training content.</p> <p>-Consensus amongst the council that we should be tapping into the expertise from other boards and becoming more comfortable with sharing that expertise and collaborating on reviews where there may not be the expertise needed to conduct a review on a particular area.</p>	<p>Action: Create a repository of resources capturing the best examples / guidances from the REBs in the province; reach out to Fraser Health and BC Cancer</p>	<p>Ex-officio</p>
	<p>-A list of the type of research or areas of specialization for REBs would be useful.</p>	<p>Action: Create detailed list of REBs with their areas of specialization</p>	<p>Ex-officio</p>

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Working Group Updates: PREP Reports & Metrics	<p>The PREP Reports and Metrics working group has recently been formed.</p> <ul style="list-style-type: none"> - Purpose will be to define the types of reports required by institutions that are partners in using PREP, and ensuring they are available. - Institutional reports will focus on required reporting, such as delegated review listing that REB is required to see each meeting. - Provincial level aggregate data will also be available for use by REBC to demonstrate the landscape of what is happening in research ethics. - Reports will also be used for evaluation of REBC as a whole, but under a separate project. - By the Spring they are hoping to have the requirements documents submitted to UBC IT for any reports that may need to be developed, however, UBC is undergoing a system upgrade which is taking up most of the IT resources so likely by September the reports will be launched. -If anyone needs some specific reports before then, contact Jean or Paola for an institution report. 	For information only.	
Themes: Innovative Consent Processes	<ul style="list-style-type: none"> - We would like to create a working group on innovative consent, but there are a few ongoing working groups so we will have to defer this item for now. - Working group to be formed to address changes to the Clinical Informed Consent Template that is already in existence. Suggestion: national ICF form has been launched recently. Suggestion: connect with C&W hospital on work being done with e-Consent using REDCap. 	Action: obtain more information on suggestions made	Ex-officio
Privacy and Data Access	<p>-Holly was unable to provide an update on HIMA as legal counsel was unable to provide any information at the moment.</p> <p>Data Management Plans – do we have an advocacy role to ‘support’ standardized data management plans for research institutions? Can the Portage or Portage-style DMP be attached to PREP instead of answering the questions again? - for future consideration</p> <p>Update from MoH on Provincial Health Data Platform: It is underway and they are working on creating streamlined processes for health authority data to be collect and shared</p>	For information only	
AOB and Next meeting date suggestions	Next meeting to be held in Kelowna on June 24 th , 2020 ahead of the REB West conference.	Action: Meeting dates and invitations to be sent out	Ex-officio

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Meeting adjourned			Motion: Holly Longstaff Second: Julie Hadden