

KINGSTON, FRONTENAC AND LENNOX & ADDINGTON PUBLIC HEALTH

*CIHR LD Research Network*

**MINUTES**

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| **Date: February 20th, 2018** | **Location: Teleconference** | **Start Time: 3:00 PM (EST)** |
| **Chair: Kieran Moore** | **Recorder: Sophie Felleiter** | **End Time: 4:00 PM** |

**PRESENT:** *Kieran Moore, Sophie Felleiter, Kristina Arseneau, Beate Sander, Samir Patel, Todd Hatchette, Patrick Leighton, Tara Moriarty, John Frampton, Pierre Sullivan, François Milord, Rylan Egan, Scott Weese, Ian Lewis, George Chaconas, Anna Majury*

**REGRETS:** *Seth Chitayat, Manisha Kulkarni, Muhammad Morshed, Ravi Prakash, Claire Jardine, Cécile Aenishaenslin , Shelly McNeil, Lisa Barrett, Caroline Cameron, Janet Parsons, Colleen McGavin, Gerald Evans, Prameet Sheth, Kirk Leifso, Bonnie Henry*

**Updates to Grant call**

* Registration deadline is **March 6th, 2018**. Sophie will follow up with the 15 key participants to get their CIHR PIN and Registration CCV. We will also prepare a one-page proposal for the network to review
* There will be a strengthening workshop in April that we can bring 7 of the key participants to (including Kieran). We will discuss further in a follow up teleconference
* New application deadline is **June 6th, 2018**

**Network Communication and Transparency**

* Now that we have an extended deadline we can slow down a bit and revaluate our directions. Are we happy with the direction of the 4 pillars for instance?
* To strengthen communication within the network, we are going to set up pre-scheduled weekly calls with Kieran and Tara, and bi-weekly tele or video conferences for pillar leads (Plus others)
* We will also create a website with a secure data repository. This is where everyone in the network will have access to updates, meeting minutes, and other documents related to the proposal
* We will set up a steering committee that extends beyond pillar leads and includes senior scientists
* It has been expressed that some pillar members who are not leads would appreciate if their leads could host regular teleconferences to keep everyone up to date and give members specific tasks

**Gaps in Clinical Science**

* Currently we have plans to set up a patient cohort but no plans to do clinical science. Important that we at least do some basic studies
* We need to find a clinician scientist (preferably with an epi. background) to do a deep data dive, perform cohort studies, write up epi etc. They will need to help set up the database from the start to ensure we are starting correctly and collecting all the right information to be able to do future studies on the cohort
* They can also help us estimate the number of patients and controls needed and form a few specific questions we can realistically answer
* Todd says there is some expertise in Dalhousie that can help with this including their SPOR unit. Shelly McNeil is also very familiar with this type of work. She may be willing to help set this up in the beginning but may not have enough time to lead it for the 4 years
* Adding in this element means Pillar 4 would need more money. Some costs could be off set by in-kind support from KFL&A regarding data repository, there are also many staff who could support analysis, we just need expertise guiding us
* It is also important to consider that we already have a lot of expertise on our team that hasn’t necessarily been tapped yet. We need to be building on this before we automatically try to seek expertise outside of the current network. There are a lot of existing initiatives that can be linked using a little Network funding
* We will have a teleconference dedicated to this issue soon. We will include some front-line physicians, ID physicians and microbiologists

**Overall Direction**

* Overall, it seems that meeting all the criteria of this grant are impossible. It appears that right now it is more political than scientifically driven
* It is apparent that the review committee will include scientists (and likely international ones). However, we will also have a number of knowledge users who will review that will include patients and potentially advocacy groups
* It is important that our proposal is mainly scientific in nature
* The relevance review will be done by CIHR and PHAC staff to make sure proposal summaries meet the requirements of the call
* Do we need to look at cutting out some activities to make room for clinical science? Keep in mind we will also have to have a budget more for patient engagement (compensation for time, staff training, etc. please see Colleens edits Sophie sent the morning of Feb 20th)
* Consider we can also keep applying to other grants and seek out in-kind funding to support
* Need to step back and ask what the questions are we want to answer
* We must have the following:
  + Cohort and Biobank with at least simple clinical science studies
  + KT and training
  + Focus on capacity building and HQP
* There is no talk of surveillance in the call, this is sometimes seen as more of a Public Health mandate. We will have to have this more epi. focused if we want to include
* According to Ian who has more of an outside perspective, the most essential pieces are establishing a repository and looking more into diagnostics. Rylan believes curricula and training/KT also essential given it is an objective we must meet in the call
* Sophie will create a summary of the 4 pillars in point form (research questions being asked and methods). People can send comments back to Sophie regarding which items they think should be cut and she will anonymize them and send back a full document for discussion at the next meeting

**Patient Engagement**

* Please see the patient engagement plan with edits from Colleen that was circulated on Feb. 20th
* We would like to recruit a patient engagement expert if possible. If you know someone who isn’t yet involved in the network, please let us know
* Maybe we could also get patient help in designing a clinical cohort

**Summary**

* We will focus on science and building a body of evidence but include an important piece on patient engagement
* We will send everyone a point form document of the pillar aims and a value add of the network for review and then gather anonymized feedback. There will be discussion of this at the next teleconference
* We will discuss in more depth how to address clinical science in a follow up teleconference with the appropriate members
* We will set up prescheduled bi-weekly teleconferences