

KINGSTON, FRONTENAC AND LENNOX & ADDINGTON PUBLIC HEALTH

*CIHR LD Research Network*

**MINUTES**

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| **Date: March 19th, 2018** | **Location: Teleconference** | **Start Time: 1:00 PM (EST)** |
| **Chair: Kieran Moore** | **Recorder: Sophie Felleiter** | **End Time: 2:00 PM** |

**PRESENT:** *Kieran Moore, Sophie Felleiter,**Cecile Aenishaenslin, Samir Patel, Todd Hatchette, Kirk Leifso, Patrick Leighton, Tara Moriarty, John Frampton, Rylan Egan, Muhammad Morshed, George Chaconas, Kristina Areseneau*

**REGRETS:** *Beate Sander, Manisha Kulkarni, Ravi Prakash, Anna Majury, Gerald Evans, Prameet Sheth, Claire Jardine, Scott Weese, Janet Parsons, Ian Lewis, Pierre Sullivan, Seth Chitayat, Shelly McNeil, Lisa Barrett, Caroline Cameron, Francois Milord, Alex Carrigan*

CIHR Registration, Webinar and Strengthening Workshop

* Our registration application was deemed relevant and therefore we have been invited to participate in a strengthening workshop
  + NB: We were the sole applicants for the grant
* March 21st from 1:00-2:00 PM is the Webinar which will focus on the upcoming strengthening workshop
  + You should receive an email from CIHR with an Agenda, webinar and teleconference details if you wish to participate
* April 19th is the CIHR Strengthening workshop in Ottawa:
  + We can bring a max. of 7 people to this (this will include Kieran and Tara)
  + We should include at least one person from each pillar, at least one early career investigator and one patient
  + If you are available to and would like to attend, please let Sophie know.

Lyme Website

* We are making a few last changes with the website. We will send out the link this week. Much of the site will be open to the public. There will an option for Network researchers to request an account and this will allow access to secure documents.
* If you have any issues or feedback regarding the site, please get in contact with Sophie. If you have any resources, papers, etc. that you wanted added to the site, send to Sophie
* We would like feedback on what information should be publicly available and what should be password protected

Patient Engagement

* We will establish a working group for patient engagement strategy
* Sophie will arrange for a teleconference to cover patient engagement next week
* Tara has been talking to experienced patient advisors in other networks, and they have commented on how this role can be difficult for patients or citizens. Often, they are intimidated, and/or they have a lot to catch up on, we will make sure to address this in our plan
* We need some people dedicated to supporting patients on our network. Some of the logistics of this can be handled by a network manager, like arranging for travel etc. but we should have someone experienced with patient engagement as well. May require at the minimum a part-time individual
* Todd was talking to Lisa Barrett about this and she had some suggestions. One of them being that patient advisor is not the best terminology to use. **Community based researchers** may be a better alternative, and it will also encompass those who are not patients (i.e. interested citizens in or near emerging zones)
  + We would have to be careful how we identify this term within the proposal so as not to appear too ambiguous
* We need to make sure we are including patients who have been alternatively diagnosed outside of the Canadian Healthcare system
* CIHR has also indicated that we can include patient advisors etc. on the grant that are international
* Kieran has engaged the Kingston Health Sciences Centre patient group. They can provide non-biased feedback on our patient strategy
* Tara has indicated that she has been contacted by a number of patients who would like to participate in our Network but remain anonymous, we will have to check with CIHR if this is allowed.
* It would also be a good idea to have physicians (i.e. family doctors and infectious disease) involved in patient/advisory committees. Especially those in emerging areas on the frontline, but who are not necessarily researchers
  + We are partnering with the Canadian College of Family Physicians, they could help us recruit physicians for this purpose and we can detail this in a letter of support
  + On this note, it is important that we continue to seek out doctors in Manitoba we can work with to establish a biobank/cohort site in the 3rd/4th year of the Network

Updated Timelines

* It has been indicated by a number of people, that writing their pillars in isolation can be quite difficult. Need overall objectives and strategies to help with this
* The currently used organizational structure is not really working for the proposal and needs to be changed up:
  + For instance, more space should be dedicated to the pillars and less to introductory and surrounding material.
  + Ideally, each pillar could be 4 pages and the foundational resources can be 2-3 pages.
* Sophie will share a google doc with the group that has the original skeleton, so everyone can edit and provide their input on how it can be changed
* We would like to have a face-to face meeting in Toronto at PHO to go over the entire grant at that point:
  + April 23rd/24th
  + Kieran, Tara and Sophie will be in attendance. Samir, Todd, Patrick and Cecile also indicated they could probably attend.
  + If anyone else is available to and would like to attend, please let Sophie know
  + If unable to attend in person we will set up a webinar and teleconference
  + We would have very limited funds to support travel

Other

* At our next teleconference, we will discuss a communication strategy going forwards
* We will also discuss at the next teleconference establishing a working group that will seek out network funding. This can be supported by some staff at Queen’s. Very important for the piece about long-term sustainability of the network
* There were some questions on whether the ability for PHAC to support this grant has changed give we are the sole applicants.
  + We could ask CIHR, but the general thought is that this will not change

Next Steps

* We have a teleconference to discuss clinical science on March 20th
* We will set up a meeting regarding patient engagement for next week, keep your eye out for a doodle poll
* We will invite everyone to edit a google doc that contains the original grant skeleton. Please provide your input by end of day March 27th before our next meeting, this will be an agenda item
* Next Bi-weekly meeting is March 28th, 11:00-12:00 PM (EST)