

KINGSTON, FRONTENAC AND LENNOX & ADDINGTON PUBLIC HEALTH

*CIHR LD Network- Pillar Leads*

**MINUTES**

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| **Date: March 28th, 2018** | **Location: Teleconference** | **Start Time: 11:00 AM (EST)** |
| **Chair: Kieran Moore** | **Recorder: Sophie Felleiter** | **End Time: 12:00 PM** |

**PRESENT:** *Kieran Moore, Sophie Felleiter, Ravi Prakash, Kristina Arseneau, Cecile Aenishaenslin, Patrick Leighton, Tara Moriarty, Janet Parsons, George Chaconas, Anna Majury*

**REGRETS:** *Beate Sander, Manisha Kulkarni, Muhammad Morshed, Rylan Egan, Samir Patel, Seth Chitayat, Todd Hatchette, Ian Lewis, Pierre Sullivan, John Frampton, Caroline Cameron, Claire Jardine, Gerald Evans, Kirk Leifso, Prameet Sheth, Shelly McNeil, Lisa Barrett, Francois Milord, Scott Weese, David Patrick*

CIHR Webinar and Strengthening Workshop

* Thank-you to everyone who participated in the webinar last week and put forward their questions and concerns directly to CIHR. If you were not able to participate, Sophie has circulated notes from the meeting which will also be available on the Lyme website
* At our request, CIHR has indicated they will focus on patient engagement for the workshop
  + They are looking into inviting additional patients to participate from the linkage tool
* For the strengthening workshop we have selected the seven participants: Kieran, Tara, Patrick, Rylan, Samir, Heather Wise (Patient Representative and Pharmacist) and Kate Kehoe (Patient Representative and Lawyer)
  + Should one of these participants find out they are unable to participate in the next week or so, we also have a few people who may be able to make time in their schedules if given reasonable notice (ie. Cecile and Ravi)
* Sophie will also attend to provide admin. support

Lyme Website

* If you haven’t already, please take a look and register for an account so you have full access to secure documents
* The site is apart of the KFL&A platform for now, but we will migrate it to its own unique domain
* Apparently, there have been some issues in trying to select the drop-down menus (moves across to fast to click on). We will address this
* Patrick suggested we should change the homepage picture to something more realistic. Catherine Bouchard for instance has some really nice photos of ticks we could ask to use
  + We could also pose an open call to the Network for any images they would like to see on the site. This would give us a whole library to choose from. May give us an option for “photo of the week”. Would be a good way in the future for student photos to be seen as well, nice feature for our full website when/if the Network is funded
* Suggested that we eliminate the timeline with the “Apply Now” button on the homepage. May be confusing for those outside of the Network that there is something they should be applying for. We can take this off the homepage and put elsewhere in the secure portion of the site
* Kristina suggested that it may be better if those outside of the Network are given the option to register for an account. We might find ourselves in a situation where researchers or members of the public are trying to register for an account and we must explain its for Network members only at this point in time.
  + Sophie can address by removing any links to a registration page and only giving that link to Network members. Alternatively, could setup accounts for people and provide them with temporary passwords

Contacting Researchers in Linkage Tool

* Tara has contacted all the patients from the Linkage tool and waiting for a few more to follow up
* She can follow up with a few more researchers (Fiona Hunter, Kateryn Rochon, Kirk Hillier), that can perhaps be brought into Pillar 2 given their interest in ticks. The first two are Manitoban researchers which we are severely lacking at the moment, they might be able to help us connect with Manitoban physicians as well for the biobank and cohort. Kirk is from Acadia, so good to have more researchers out east
* Patrick already knows Kateryn and Fiona and agrees they should be brought in. However, this will depend on the redefinition of Pillar 2, may mean keeping these researchers in mind for right now until the project comes together more and then figuring out how to involve them
* There is also a new researcher (Maarten Voordouw) current at U. Neuchatel in Switzerland who has recently been recruited as a new faculty member at the University of Saskatchewan starting in September and will continue research on LD in the Canadian Context. We could bring him in now as more of an international advisor, but could also wait until the Network is established and he could probably take on more of a role
* Tara will follow up with the researchers in the linkage tool, Patrick with Maarten and anyone else he knows that should be included but hasn’t been recruited yet

Advancement Working Group

* We have been having discussions with several industry and government agencies and ministries:
  + We have been in contact with Valneva and will continue to explore this relationship. We are going to have a Teleconference with their clinical team soon, and may pursue a face-to-face meeting
  + We have an in-person meeting with the DND (CIMVHR) in Ottawa on April 18th
  + Kieran and Seth met with the Dean and VP of the Faculty of Health Sciences at Queen’s. They are very supportive of this effort and will be bringing it to the attention of their advancement team
  + There was also talk about getting in touch with the Canadian Medical Association (CMA). They have been active in lobbying Lyme in parliament. We could lever their policy division and at least get a letter of support
  + We are also in discussions with OPKO who are especially interested in the detection and diagnostics pillar. They will more than likely provide a letter of support
  + The chief MOH in Ontario has been supportive in the past and they could liaise with the MOH’s in other provinces to obtain their support as well
  + Todd is leading a genome Atlantic grant, could be used to fund some of the work in the Atlantic region, but they are still trying to figure out if this is a possible. It would potentially be 750,000 over 4 years which would deficiently help with activities in Nova Scotia
* So far, this working group has really been supported by some of our Queen’s faculty including Seth and David Hyndman. If you would like to be more involved, please let us know
* On that note please let us know if other individuals, companies, agencies we should get in contact with or that you are going to reach out to:
  + See Tara’s email with the extensive list
* We will not be able to involve other CIHR institutes as indicated in Tara’s email. It would not be appropriate to ask for funding as it would present a conflict of interest. We could however ask the Institute of Aboriginal People’s Health for help in engaging that population
* Eventually want to pitch the Network as one part under a climate change and health umbrella

Clinical Science Update

* Had a teleconference last week where we talked about how to generate some reasonable questions around the cohort:
  + Tara asked patients what the top 5 questions they would like to see answered regarding LD. So far, we have established a team of advisors with 13 people spread out across the country
  + Todd is asking the AMMI working group the top 5 questions as well that we could answer with the type of cohort we are getting
* We expressed to Queen’s that we would like to find someone who is a clinical scientist with an epidemiological background, basically an LD specialist. Since there isn’t really anyone with the exact type of expertise were looking for in Canada, Queen’s may be able to look into recruiting internationally for this type of position. This wouldn’t necessarily help with the development of the proposal right now, but will be a huge value add to the Network if/when funded (it is also something that could be worked into the proposal as something were actively addressing)
* We are also meeting with John Aucott next week from the US. He is interested in being a clinical advisor for the Network and he might be able give us some names of people with this expertise
  + Will link in Tara to listen in as well and perhaps Todd or Shelly if available
* We also expressed the need to find a clinician with a Knowledge translation background as well. They also gave us some contacts for this that we will explore
* Between Todd, Shelly, Gerald, Kirk, and other clinicians in the Network we will be able to pull together and write this section for the proposal, but if funded we would really need some additional long-term expertise

Proposed Skeleton Document

* Tara believes we should consider taking another approach in writing of the grant. We are still stuck working in our own little Pillar sections
* It would be great if we could get a small group of people with experience in CIHR grant writing to draft the entire grant and then have others provide feedback (set aside a week or two to do)
* Kieran and Sophie have set up time to do this over the next week, maybe others could join by teleconferences, adobe connect etc. as we go through the grant. We had also asked if Queen’s could perhaps hire a grant writer as well
* There is some concern among members with assigning the grant to an outside grant writer, it would be a little hard for someone on the outside to give it the right context and spin, especially when it comes to coherence amongst the different pillars
* Kieran has indicated that the days he has put aside to work on the grant, maybe some other people could join us in Kingston to help. There is just concern that this is not enough time
* George indicated that it would be too hard for a number of people to try and write one grant. It should really be one person to write the first draft

Summary

* Sophie will send out meeting notes and post on the website
* Sophie will ensure that the necessary issues on the site are fixed, including a call for photos of ticks etc.
* Tara will contact the remaining researchers in the linkage tool, Patrick to contact Maarten and other Canadian researchers he knows that haven’t been included thus far
* Patient engagement meeting on March 29th, will post meeting notes on the website
* UPDATE: Tara and Patrick will be meeting with Kieran in Kingston next week to work on the grant and restructure its contents. We will then seek input on this from the Network
* We will hold our next Bi-weekly update on April 12th (Time TBD)