

KINGSTON, FRONTENAC AND LENNOX & ADDINGTON PUBLIC HEALTH

*CIHR Lyme Disease Network*

**MINUTES**

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| **Date: March 1st, 2018** | **Location: Teleconference** | **Start Time: 2:00 PM (EST)**  |
| **Chair: Kieran Moore** | **Recorder: Sophie Felleiter**  | **End Time: 3:00 PM**  |

**PRESENT:** *Kieran Moore, Sophie Felleiter, Kristina Arseneau, Tara Moriarty, Ravi Prakash, Manisha Kulkarni, Samir Patel, Shelly McNeil, George Chaconas, John Frampton, Caroline Cameron, Francois Milord, Patrick Leighton, Anna Majury, Cecile Aenishaenslin, Pierre Sullivan, Scott Weese*

**REGRETS:** *Todd Hatchette, Beate Sander, Rylan Egan, Muhmmad Morshed, Ian Lewis, Gerald Evans, Kirk Leifso, Prameet Sheth, Janet Parsons, Seth Chitayat, Lisa Barrett, Claire Jardine*

CIHR Registration

* Sophie created the one-page summary and shared via google docs on Monday. Thank-you for everyone that has already contributed their edits and comments. If you would like to make further edits, please do so by end of day Friday (March 2nd, 2018)
* 15 Key participants: If you haven’t already, please send Sophie your CIHR PIN and Registration CCV ASAP
* We will be allowed to bring 7 people to the strengthening workshop in April (Date TBD).
	+ It is **suggested** that we bring at least one Early Career Investigator, Health Care Professional, Clinician Researcher, and Patient Representative
	+ We will nominate people to go at a later date based on their availability as well as their ability to put substantial work into the writing of the proposal

3-page Summary Document

* This was also sent by Sophie Monday morning. Thank-you to those who commented and returned. Comments were anonymized and sent back prior to this meeting
* Can the Biobank be made broader to include *Borrelia* isolated from ticks and animals as well?
	+ This would be very interesting but not an immediate priority. We are not sure we would have the funds to support and must focus on collecting human samples first
	+ We are expecting to recruit at least 50 patients/year/site (550 total after 4 years). However, we expect we can recruit many more based on the number of cases we are seeing annually from southeastern ON and NS alone. We will recruit as much as possible by engaging with our local ER departments as well as having our health unit nurses personally calling all reported cases of LD in our region. These estimates also don’t include those that could self-register through a web portal.
	+ We also plan to get upfront consent to follow a patient’s clinical course through ICES and CPCSSN, so we can still follow them longitudinally even if they drop out and don’t attend follow ups at 3, 6, and 12 months
	+ We also need to decide if we are studying the natural history of LD or are we interested in post-Lyme syndrome
* Have we explored other options for the Biobank besides the Canadian Cancer Trails Group? Cancer research usually has a lot of funding- may not be the most cost-effective option
	+ We have chosen the CCTG for a number of reasons: (1) It is close to a region where we are expecting the most samples to come from and they already have a good relationship with the Kingston Health Sciences Centre, (2) They are internationally renowned and have other sites across Canada we can potentially link up with, (3) They are giving us a really good price, $5,000/yr to store up to 10,000 samples, (4) We can also piggyback on their expertise, TOR’s, governance models, etc.
	+ We had looked at some other options, for instance PHO. It would be possible to store samples here, but we don’t want to deal with the level of bureaucracy that would come with releasing samples etc.
	+ Important to note that their will be one ethics form regarding initial collection and storage of patient samples in the biobank but that we will need individual ethics forms developed for usage of samples in individual research projects
* It might be more important to get a Manitoba Biobank up and running sooner than later. This region may have significant strain diversity compared to the rest of the country, and some strains may be similar to the US
	+ This can certainly be done. We had initially planned to have the QC biobank up first because we had already identified individuals from Quebec who will assist with this and have not identified those from Manitoba yet. Todd is looking into this
* Regarding Pillar 4, should we separate the foundational resources from clinical science?
	+ Many people seem to agree with this as long as it is something we can afford
	+ Kieran doesn’t think it will be too expensive with KFLA supporting (i.e. epidemiologists here to support clinical science). We would need for those with expertise to help guide us especially when the cohort is initially being set up (what questions we should be asking, what data to collect etc.)
	+ KFLA would also build and host the platform that would allow access to the cohort. This would be accessible through an online secure portal so that RA’s from each of the sentinel sites can enter data
* Could we consider the evaluation of other aspects of *B. burgdorferi* strains (i.e. regional variation, relation to animals and tick isolates).
	+ This can be done as that data is available to public health
* All issues with Pillar 2 regarding surveillance activities:
	+ Pillar 2 needs to be reworked to focus on research questions rather than focusing on surveillance networks that either already exist or should be government mandates
	+ What we are currently missing and should be focused on is a way to assess the affect of exposure and link people with different risk profiles
	+ We can certainly scale back the number of sentinel surveillance sites and match them up with the biobank sites instead. However, one thing missing with these sites will be control: we have a cohort of patients but no info on epi. profiles/exposure leading to acquiring disease or not
	+ Need to do a proper case-control study with the funds that would have been initially used for surveillance
	+ If were not doing surveillance this also means we would have to drop the Canadian Risk Repository and then we couldn’t make the national risk maps we had initially wanted to. We would essentially retain the modelling and risk reduction sections which should be higher priorities anyways given the research areas in the call
	+ Instead of setting up sentinel surveillance sites across the country we could partner with local public health units and then do in house testing of ticks. This is what Manisha has been doing at U of Ottawa. However, this will be resource intensive and not necessarily the best use of funds
	+ We could do pilot projects of new ways to assess risk than what already exists. I.e. mobile apps, animal testing, IDEXX databases. They could be developed and shown to work at a local scale and then maybe the government would want to roll it out on a national scale
	+ Keep in mind the PHAC Infectious Disease Climate Change Funds will be announced soon, our group has submitted a few different projects for this that if funded could take off some of the burden from Pillar 2 and other activities
* Do we need as many as 2500 participants for the public survey? Seems very large
	+ We would like to do some multivariable analysis to compare the changes in KAP within regions and different subgroups of the general population (ex. gender, age groups, risk profile, etc.) and in order to have enough statistical power, this number of participants is not high. This sample size is based on a previous study that we did in 2014

Other

* We are currently developing a website for the network that will be up soon. This will be a central place for document sharing, updates, resources, etc.
* Sophie is also developing Terms of Reference for a strategic advisory committee. We will share this with you for input on terms, membership etc.
* Our next meeting will be March 20th, time TBD