

Multidisciplinary Roundtable Discussion on Lyme Disease Session Report

Tuesday, June 19, 2018

Lord Elgin Hotel, Ottawa

Prepared by: Consultants ConversArt Consulting
on behalf of the Public Health Agency of Canada

July 5, 2018

Table of Contents

1.	Introduction.....	3
2.	Opening Dialogue.....	3
3.	Patient Perspective.....	4
4.	Update on the Federal Framework on Lyme Disease	5
5.	Priority Topic Selection.....	5
	5.1 Diagnosis.....	6
	5.1.1 Defining the Problem.....	6
	5.1.2 Aspirational Reframing of the Problem.....	7
	5.1.3 Proposed Actions and Potential Contributors.....	8
	5.2 Maternal-Child Transmission.....	9
	5.2.1 Defining the Problem.....	9
	5.2.2 Aspirational Reframing of the Problem.....	9
	5.2.3 Proposed Actions and Potential Contributors.....	9
	5.3 Treatment.....	10
	5.3.1 Defining the Problem.....	10
	5.3.2 Proposed Actions and Potential Contributors.....	10
	5.4 Aboriginal Health	11
6.	Final Round.....	11
	Appendix 1 – Agenda.....	12
	Appendix 2 – List of Participants.....	14

1. Introduction

This report summarizes the proceedings of a Multidisciplinary Roundtable Discussion on Lyme Disease hosted by the Public Health Agency of Canada (PHAC) on Tuesday, June 19, 2018 at the Lord Elgin Hotel in Ottawa.

The objectives of the roundtable were to:

- Bring together a diverse group of partners to have an open dialogue on Lyme disease.
- Foster new partnerships amongst participants.
- Identify opportunities for collaboration to continue to advance work on Lyme disease in Canada.
- Propose concrete actions and identify roles and responsibilities.

Participants included representatives from patient groups, health professionals, researchers, and representatives from provincial and federal governments. A meeting agenda and list of participants are attached.

2. Opening Dialogue

Kim Elmslie, Vice-President of the Infectious Disease Prevention and Control Branch at PHAC, opened the meeting by welcoming participants and sharing a few thoughts on the context and purpose for the roundtable. She apologized on behalf of Dr. Siddika Mithani, President of PHAC, who had to cancel her participation at the last minute due to unexpected circumstances. Kim Elmslie noted the increasing profile of Lyme disease in Canada, and encouraged participants to work through their different perspectives so that we can move forward together. She acknowledged the desire of patient groups to engage more with PHAC on this issue, and to ensure that we take a patient-centered approach to the work.

The facilitator, Lise Hebabi, then reviewed the agenda and approach for the day, and invited participants to share their definition of success for the day. The intent of the exercise was to hear people's positive aspirations for the day, not to reach consensus on a common definition of success.

The points that were raised are listed below, in no particular order and similar elements are combined:

- That we end the day with a recommended plan containing immediate, tangible actions and a clear idea of next steps.
- That we have significantly increased respect for diverse viewpoints.
- That we are focused on helping Canadians.

- That we take a One Health approach that recognizes the wealth of knowledge in disciplines like animal health.
- That we recognize the importance of education.
- That we recognize that Lyme can be chronic.
- That we will have discussed topics such as diagnosis and treatment, Aboriginal issues, and maternal-child transmission.
- That we recognize evidence-based medicine as drawing from research, patient experiences, and clinical practice.
- That we have commitment by PHAC for financial support.
- That we have a process that allows for increased connectivity between the silos.
- That we are united in seeking more consistency across the provinces.
- That we are excited to actually meet again.

3. Patient Perspective

Three of the roundtable participants from patient groups spoke in turn to frame the day in terms of the patient perspective.

Jennifer Kravis from LymeHope spoke first, presenting Lyme disease in Canada as a human rights issue. She stated that people in Canada suffering from Lyme disease are being denied proper medical attention, and are being discriminated against by medical professionals.

Marnie Lepage from Manitoba Lyme Disease then described the approach in her province, illustrating the success that can be achieved when all stakeholders work together in a respectful, mutual partnership that incorporates the patient perspective. She talked about successful communications efforts such as joint messages to educate Canadians and health professionals, joint media interviews, and leveraging of patient group networks to get the message out. Other successes include progress on testing of dog ticks, and a multi-disciplinary clinic on tick-borne diseases.

Sue Faber, from LymeHope, stressed the important role that nurses play in helping ensure that patient voices are heard, both in their day-to-day work and through the efforts of organizations like the Registered Nurses Association of Ontario, which recently passed a resolution to advocate for Lyme disease prevention programs and patient-centred care. She cited research providing evidence for transplacental transmission, and reminded participants of the human impacts of the disease by reading aloud two letters from patient families describing their struggles in obtaining health care for their loved ones.

4. Update on the Federal Framework on Lyme Disease

Kim Elmslie then provided the group with an update on the progress made by PHAC on Lyme disease since the 2016 conference. She stressed the importance of data collection, and described initiatives in human health surveillance, in surveillance of ticks, and in collaboration with provincial Ministries of Health. She noted that the number of human cases of Lyme disease being reported is increasing each year, and that tick surveillance indicates that the disease is not confined, with new geographic areas continuously being identified. She then talked about education campaigns on Lyme disease, and efforts being made to continuously improve outreach. She also discussed PHAC work on research, highlighting the collaboration between PHAC and the Canadian Institutes of Health Research (CIHR) to establish a Lyme Disease Research Network. She closed by reminding participants that while PHAC does important work, it cannot do everything, and is committed to supporting further collaboration on this important topic.

A participant questioned the fact that there was nothing in the update on the clinical aspects, such as the development of guidelines. Kim Elmslie indicated this type of multi-stakeholder dialogue will help create collaborations to advance Lyme disease tools and guidance.

There was some discussion about the approach of funding a single research network on Lyme disease, and concerns were raised that this type of approach often means exclusion for the least powerful voices, and a loss of diversity. The HIV network experience was cited as an example where diverse perspectives were successfully integrated into a network.

The last intervention in this portion of the agenda was a request that PHAC more clearly communicate that the surveillance data it publishes does not include data from cases diagnosed through out-of-country testing.

5. Priority Topic Selection

After the morning break, participants individually selected two to four topics that they felt should be discussed during the rest of the day. They were instructed to select topics based on what they felt the group could successfully address, rather than necessarily the ones about which they are most passionate.

Individual choices were then collected and organized into the following broad themes:

- Clinical and lab diagnosis
- Maternal-child transmission
- Aboriginal health
- Treatment
- Education

- Prevention
- Risk communication
- De-stigmatization of patients and doctors who treat them
- Surveillance, especially on those with persistent symptoms
- Engagement (although the group agreed that this could be included in all the topics)

Based on the number of times each theme was identified, the top four topics were selected for discussion. The group then agreed to apply the Aboriginal perspective to the other topics rather than dealing with it separately.

The general questions that the group had been invited to address for each topic were:

1. Where are we now in this area?
2. What needs to happen to make progress?
3. What can we build on or leverage?

In the actual conversation, participants first defined the problem, then reframed it as aspirational statements, and finally identified actions that could be taken to address it.

**The statements and ideas summarized in the following sections are not intended to indicate a consensus of opinion or agreement among participants on these topics.*

5.1 Diagnosis

5.1.1 Defining the Problem*

The following problem statements were put forward during the discussion:

- Co-infection: jurisdictional boundaries, physician knowledge, Manitoba is currently the only province testing for anaplasmosis
- Finding the right balance of sensitivity and specificity for tests and other diagnostic assessments; this is compounded by political issues and the multiple types of tests available
- Canada does not have enough patient cohorts to validate the tests
- Tests discussed included:
 - Tier 1 tests specific to Lyme, for example C6 Elisa
 - Tier 2 tests, for example serology with bands, national western blot
 - PCR testing (highly specific but not highly sensitive)
 - Urinary antigen – Nano testing
 - T-cell: Elispot
 - Culture

- Immuno-blotting (this is an example of an alternative test available in private labs; not all of these are recognized in Canada)
- Issues at the clinical, laboratory, and surveillance levels; in the case of clinical diagnosis: physician education is lacking for early acute cases, and it is difficult to do a clinical diagnosis for later cases
- Persistent infection and its symptoms
- Cost of T-cell tests
- Variation in the distribution of Lyme disease across Canada
- Misinformation of physicians, especially in non-endemic areas

5.1.2 Aspirational Reframing of the Problem*

Statements that were proposed by participants included: *How might we...*

- Increase early treatment
- Achieve better early diagnosis
- Help patients inform / convince their doctors
- Help physicians recognize diverse symptom presentations
- Use existing tests, for example C6, more sensitively
- Find a better test for early detection
- Improve the physicians' diagnostic practice guidelines
- Better diagnose and support Aboriginal and First Nations Peoples
- Move forward on the validation of tests
- Better test for elevated antibodies
- Use well-validated tests
- Take into account the genetic diversity of *Borrelia*
- Increase patient access to in-country tests
- Use surveillance maps more effectively (some changes in wording could make a difference)
- Allow doctors to treat without certainty in the diagnosis
- Collaborate to build solutions
- Include Aboriginal and First Nation communities in this dialogue
- Pilot a T-cell test with Aboriginal communities

5.1.3 Proposed Actions* and Potential Contributors

Ideas for action and the potential lead or contributors are listed in the table below.

PROPOSED ACTION	POTENTIAL LEAD / CONTRIBUTORS
Change the wording on test results sent to physicians (e.g., Serological tests are not useful for early diagnosis of Lyme disease. Do not rule out Lyme disease based on a negative test.); report on individual Western Blot bands (this is already done on request of physicians or public health laboratories by the National Microbiology Laboratory).	The CPHLN Working Group on Lyme Disease might be well positioned to take this on as part of their current work to harmonize messaging on lab test results. Others to include would be the Council of Chief Medical Officers of Health, also consider involving patients.
Recognize the validity of out-of-country results.	This is a provincial responsibility; provinces would have to include this in their accreditation programs. They might require studies within Canada before taking this step. A proxy could be to accept tests conducted in accordance with CDC standards and criteria.
Develop symptom checklists or diagnostic checklists for physicians and nurse practitioners.	This would require a working group involving all clinicians (One Health approach including naturopaths, veterinarians); patients; College of Physicians; First Nations; Lead = Centre for Effective Practice (PHAC funding).
Build a bio-bank of patient material to validate tests, based on culture-proven Lyme disease.	Canadian Lyme Consortium, with patient involvement.
Improve testing: broaden to more strains, using European blot IGG criteria.	Not specified.
Broaden the use of European blot in Canada.	Not specified.
Conduct research into the cost of mis-diagnoses.	Not specified.

5.2 Maternal-Child Transmission

5.2.1 Defining the Problem*

The following problem statements were put forward during the discussion:

- Women are unaware of the risk of transmission
- There is no standardized testing for Lyme disease during pregnancy
- There are no clinical practice guidelines despite a clear literature of evidence on trans-placental transmission
- Children are not being diagnosed for various reasons, including asymptomatic at birth, or multiple symptoms, or sero-negativity

5.2.2 Aspirational Reframing of the Problem

Statements that were proposed by participants included: *How might we...*

- Prevent intra-placental transmission
- Better track children's medical history
- Identify how many women are affected

5.2.3 Proposed Actions* and Potential Contributors

Ideas for action and the potential lead or contributors are listed in the table below.

PROPOSED ACTION	POTENTIAL LEAD / CONTRIBUTORS
Build the evidence, conduct research, for example: <ul style="list-style-type: none">• A literature review of clinician reports of Lyme disease.• A qualitative study of families with all children diagnosed with Lyme disease.	This will be needed by the Society of Obstetricians and Gynecologists of Canada (SOGC) before they produce guidelines. Canadian Lyme Consortium, with patient involvement.
Educate clinicians – create a toolkit, checklist, or algorithm that is quick and easy to use; also create educational webinars.	The Society of Obstetricians and Gynecologists of Canada (SOGC), the Canadian Midwifery Association, the Canadian Pediatrics Society, nurses, patients – in coordination with all professional associations.
Publish an article in the SOGC Journal.	Not specified.
Testing of newborns using Elispot testing.	Not specified.

5.3 Treatment

5.3.1 Defining the Problem*

Due to time limitations this issue was discussed in less depth than the previous two. Problem dimensions that were mentioned included:

- Balancing gaps in the science with a need for immediate access to current knowledge
- Fear of treating Lyme beyond current guidelines because of the reaction of regulatory colleges; a sense of isolation in clinicians who wish to treat Lyme more aggressively
- Long-term use of antibiotics
- No access to treatment for naturopathic practitioners
- Heterogeneity of patients
- Life cycle of the bacteria, which makes it hard to treat
- Acute cases

5.3.2 Proposed Actions* and Potential Contributors

Ideas for action and the potential lead or contributors are listed in the table below.

PROPOSED ACTION	POTENTIAL LEAD / CONTRIBUTORS
Change the PHAC website reference to guidelines to make it clearer that there is more than one set of guidelines. There is a chart already in existence that compares IDSA and ILADS guidelines side by side. Move the information higher on the page. The current prophylaxis criteria are too narrow.	PHAC.
Encourage clinicians to use dual-track treatment and full-health approaches.	Not specified.
Provide tools for clinicians to navigate the complex patient discussion.	Not specified.
Increase the enrolment of patients in centres of excellence and clinical trials, with non-medical clinicians at the table.	Not specified.
Find a way to capture evidence from “N of 1 treatment trials”.	Not specified.

5.4 Aboriginal Health

Although this topic was not discussed in detail, the group referenced it periodically and returned to it at the end of the day with the recommendations outlined below.

PROPOSED ACTION	POTENTIAL LEAD / CONTRIBUTORS
Provide a national forum where Aboriginal and First Nations representatives can join the dialogue and address it from their own perspective.	PHAC could partner with Indigenous Services Canada to make this happen.
Regional and local initiatives to include Aboriginal and First Nations voices in the dialogue on Lyme disease.	Not specified.

6. Final Round

At the end of the day, all participants were given an opportunity to share a final message to the group. There was a general sense that the day had been successful based on the definitions shared in the morning. People praised the respectful and collaborative tone of the discussion, expressed cautious optimism about positive outcomes of the meetings, and shared their desire to continue to work together and to meet again in the near future.

Participants agreed to allow PHAC to share their contact information within the group, with the opportunity to opt out.

Kim Elmslie closed the meeting by echoing the participants' positive comments about the Roundtable. She stated that we are well positioned to move forward in many areas, and continued exchanges and listening to each other will be essential to tackling this complex issue. She also reminded the group that not everything requires large amounts of government funding, and we need to be creative in our approach to fully leverage existing resources. She committed to hosting a follow-up meeting next year.

Appendix 1 – Agenda

Multidisciplinary Roundtable Discussion on Lyme Disease

AGENDA

Tuesday, June 19, 2018

Lord Elgin Hotel

100 Elgin Street, Ottawa, ON

MEETING OBJECTIVES:

- Bring together a diverse group of partners to have an open dialogue on Lyme disease
- Foster new partnerships amongst participants
- Identify opportunities for collaboration to continue to advance work on Lyme disease in Canada
- Propose concrete actions and identify roles and responsibilities

9:00 – 9:05	Welcoming Remarks	Dr. Siddika Mithani
9:05 – 9:20	Review of the Meeting Objectives and Guiding Principles	Lise Hebabi
9:20 – 9:50	Opening Dialogue <ul style="list-style-type: none">• Defining success for today's roundtable: what do we hope to achieve by the end of the day?	All
9:50 – 10:10	Patient Perspective	Patient Representative
10:10 – 10:20	Update on the Federal Framework on Lyme Disease	Kim Elmslie
10:20 – 10:35	Health Break	
10:35 – 11:20	Priority Topic Selection <ul style="list-style-type: none">• What are the three to four priority topics that need our collective attention?	All
11:20 – 12:25	Discussion: Topic Area # 1 <ul style="list-style-type: none">• Where are we now in this area?• What needs to happen to make progress?• What can we build on or leverage?• Summary of discussion	All
12:25 – 12:40	Working Lunch (will be provided)	

12:40 – 1:45

Discussion: Topic Area # 2

All

- Where are we now in this area?
- What needs to happen to make progress?
- What can we build on or leverage?
- Summary of discussion

1:45 – 2:50

Discussion: Topic Area # 3

All

- Where are we now in this area?
- What needs to happen to make progress?
- What can we build on or leverage?
- Summary of discussion

2:50 – 3:00

Health Break

3:00 – 3:50

Participant's Perspective

Lise Hebabi

- Are there any gaps or considerations that need to be explored further?

3:50 – 4:00

Adjournment

Kim Elmslie

Appendix 2 – List of Participants

ORGANIZATION	PARTICIPANT
FEDERAL GOVERNMENT	
Public Health Agency of Canada	Kim Elmslie Steven Sternthal Lesley Doering Dr. Mike Drebot
Canadian Institutes of Health Research	Kelly Taylor
PROVINCIAL GOVERNMENT	
Institut national de santé publique du Québec	Dr. Alejandra Irace-Cima Dr. Karine Thivierge
Manitoba Health	Dr. Richard Rusk
New Brunswick Department of Health	Dr. Jackie Badcock
Ontario Ministry of Health and Long-Term Care	Nina Arron
Saskatchewan Ministry of Health	Dr. Denise Werker
HEALTH PROFESSIONALS	
Association of Medical Microbiology and Infectious Disease Canada	Dr. Dan Gregson Dr. Todd Hachette
Canadian Association of Naturopathic Doctors	Dr. Colleen McQuarrie Shawn O'Reilly
Canadian Association of Schools of Nursing	Janet Nevala
Canadian Veterinary Medical Association	Dr. Marilyn Keaney
Centre for Effective Practice	Lena Salach
College of Family Physicians of Canada	Dr. Marg Sanborn
Family Physician	Dr. Liz Zubek
Internal medicine specialist	Dr. Ralph Hawkins
Nature Doctors	Dr. Jason Bachewich
Nurse Practitioner Association of Canada	Teresa Chulach
Registered Nurses' Association of Ontario	Sue Faber
Society of Obstetricians and Gynecologists of Canada	Dr. Courtney Green
PATIENT GROUPS	
Association Québécoise de la maladie de Lyme	Robert Huneault
CanLyme	Janet Sperling

ORGANIZATION	PARTICIPANT
Lyme Disease Association of Alberta	Dr. Anouk Chaumont Colin Davison
LymeHope	Jennifer Kravis
LymeNB	Janet Higgins
Lyme Ontario	Ellen Hohs
Manitoba Lyme Disease	Marnie Lepage
Nova Scotia Lyme Disease Support Group	Donna Lugar
Ontario Lyme Alliance	Linda Kelso
Saskatchewan Lyme Disease Association	Triant Steuart
Voices of Canadians About Lyme (VOCAL)	Lesley Fleming
ACADEMIA / RESEARCH	
G. Magnotta Foundation	Dr. Felix Sperling
Queen's University	Dr. Kieran Moore
OTHER	
ConversArt Consulting Ltd (Facilitator)	Lise Hebabi