Pillar 4 Update

Rylan Egan, Tamara Rader, Cécile Aenishaenslin, Natasha Nofal,
Janet Parsons, Clara Juando-Prats, Claire Hiscock, Lisa Dias

CLyDRN AGM, November 10th 2021

Dr. Rylan Egan,
Assistant Professor,
Pillar IV Co-Lead

Queen’s University

Rylan Egan and team

Publications in 2021

- Coderre-Ball, A. M., Robertson, M., Matzinger, E., Durando, P., & Egan, R. (2021). Training initiatives that enhance knowledge, attitudes, and practices regarding the prevention, diagnosis and treatment of Lyme disease: a systematic review. *International Journal of Health Promotion and Education*, 1-24.
- Coderre-Ball, A. M., Sahi, S., Anthonio, V., Roberston, M., & Egan, R. (2021). Lyme Disease Training and Knowledge Translation Resources Available to Canadian Healthcare Professionals: A Gray Literature Review. *Journal of Primary Care & Community Health*, *12*, 21501327211050744.

National HCP Interviews

Purpose

1. Establish HCPs approaches and criteria for diagnosing LD across different stages
2. Consider difference across disciplines, geographic area, gender, and the extent of LD in region
3. Contrast perspectives and approaches across and within these demographics
4. Generalize findings from these interviews via survey methods – potentially funded by a recently applied for a New Frontiers in Research Fund - Exploration 2021

Current Progress

- Completed 23 interviews with an additional 4 interviews scheduled for the next two weeks.
- Continuing to recruit participants for the study.
- Participants have been across Canada including Ontario (7), Quebec (6), Nova Scotia (3), Alberta (3), Newfoundland and Labrador (2), British Columbia (1) and Manitoba (1)
- Sampling frame has included 17 family physicians, 4 nurse practitioners, and 2 specialists

Knowledge Translation Porthole

- Provide accessible, comprehensive and well-rounded depiction of all literature associated with controversial areas of LD (e.g. Chronic/Post Treatment)
- Committee currently being established
- Designing porthole in collaboration with PCAC
- Will include stakeholders from across CLyDRN
- Integrate approach with Brokered Dialogue

Université de Montréal

Cécile Aenishaenslin & Natasha Nofal

Our working group

Cécile Aenishaenslin,
Assistant professor

Catherine Bouchard,
epidemiologist at PHAC,
Adjunct professor

Patrick Leighton,
Associate professor
and pillar 2 co-leader

Natasha Nofal Bowser,
Doctoral student

Valerie Hongoh,
Epidemiologist at
PHAC

Lucie Richard,
Full professor

Rylan Egan and
Madison Robertson
(Queen's University)

Université de Montréal

Our objectives

Enhance knowledge on factors that affect the adoption of healthly preventive behaviors toward tick bites and LD to inform the development of more effective preventive strategies

Objective 1: Identify barriers and facilitators to LD prevention

Objective 2: Measure current levels of knowledge, attitudes and behaviors towards ticks and LD

Objective 3: To design, implement and evaluate new preventive tools for tick bites and LD in high risk Canadian regions
- Web-based interactive platform
- Scheduled for 2023-2024

Brief overview of two projects

1. *Understanding the drivers of healthy preventive behaviours against Lyme disease of the Canadian population*
    - *Identify barriers and facilitators to adopting healthy preventive behaviours*
    - *Explore the impacts of living in a tick endemic region*

Online focus groups with members of the general public in BC, ON, QC, and NS

High risk groups: outdoor enthusiasts, outdoor workers, parents and care-givers of young children, pet owners
October/November 2021 → 17 focus groups

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2. Measuring the adaption of the Canadian population to ticks, using a 'One Health' approach.

Quantitative pan-Canadian survey Summer 2022

Impacts of living in tick endemic regions

Psychological

- Frustration, anxiety, concern, resentment, sadness, inevitability, helplessness, defeated, petrified, hypersensitivity, overwhelmed.
- Monitoring tick dates, responsibility to self-diagnose, no sense of freedom for children and pets
- Some positive: shared experiences and bonding, feeling of preparedness, “learning to live with it”

Activities

- Avoidance of high-risk areas and activities
- Altered interaction with nature
- Impacts on children’s relationship with the nature

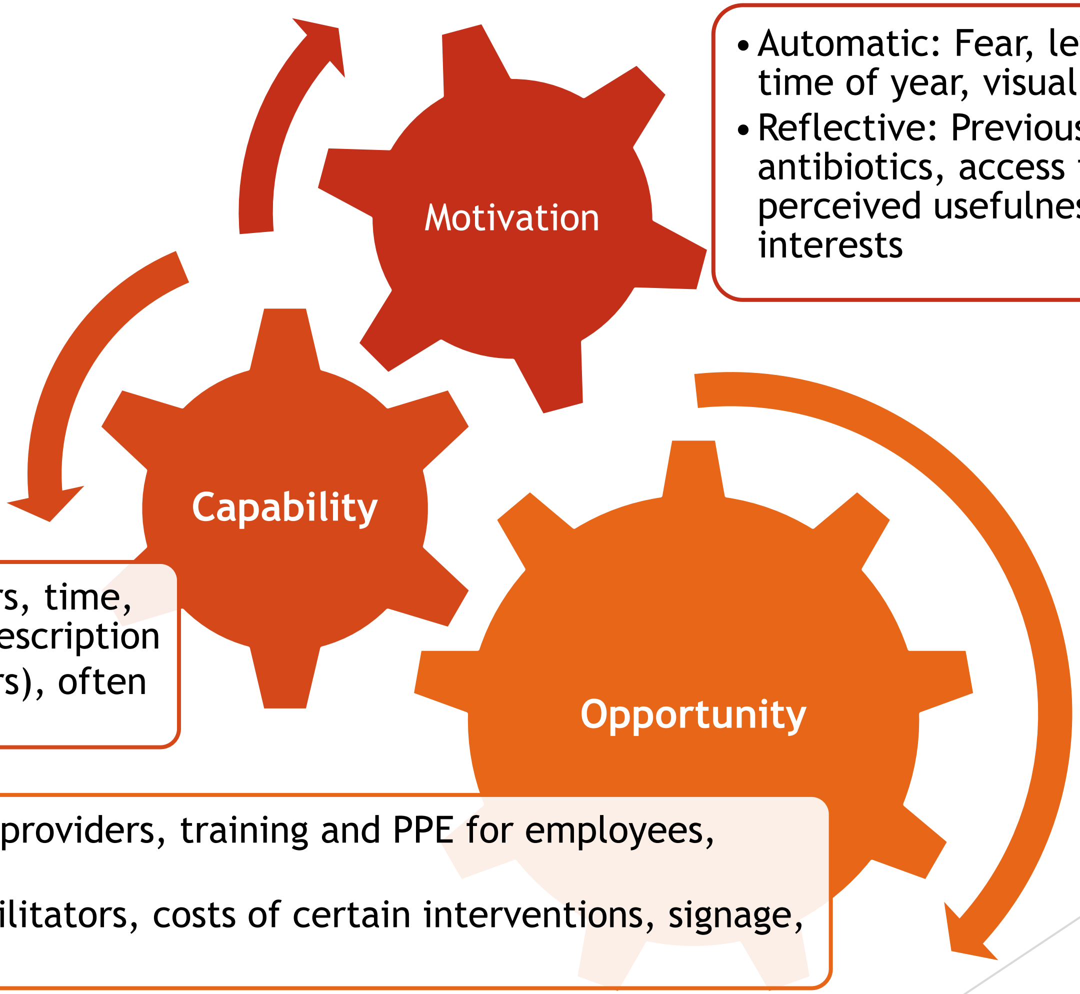
Family life

- Perception of pets and consequences
- Decision of family moving closer
- Perceived potential to be a burden to family

Economic

- Preventive behaviours (carpets, clothing, landscaping)
- Preventive treatments in pets
- Turning down work opportunities

Understanding the drivers of healthy preventive behaviours against Lyme disease of the Canadian population



- Automatic: Fear, level of confidence, time of year, visual appearance, effort
- Reflective: Previous disease, concern of antibiotics, access to healthcare, perceived usefulness, conflicting interests

- <u>Physical</u>: living with someone, mirrors, time, ability/health, shaving, antibiotic prescription
- <u>Psychological</u>: knowledge (pet owners), often contradictory, looking to the US

- <u>Social:</u> Availability of healthcare providers, training and PPE for employees, word-of-mouth.
- <u>Physical</u>: Access to perceived facilitators, costs of certain interventions, signage, pet ownership, vaccine

Special situations:
- Outdoor workers
- Newcomers to an endemic region

Michie, S., van Stralen, M.M., West, R., 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. Implementation Science 6, 42

Conclusion

Data collection for qualitative study will soon be completed.

Large variation in how risk of tick bite and infection is perceived, and how an individual reacts to their perceived risk.

Invitation to PCAC to contribute to analysis and interpretation of results.

Quantitative survey be able to measure predictors of the knowledge, attitudes and practices related to tick bite prevention and how Canadians are adapting to the presence ticks and Lyme disease.

Our working group:
St. Michael’s Hospital & University of Toronto

Janet Parsons,
Research Scientist &
Associate Professor

Clara Juando-Prats,
Research Scientist &
Assistant Professor,
PCAC Co-Chair

Lisa Dias,
Clinical Research
Specialist

Claire Hiscock,
Doctoral student

UNIVERSITY OF TORONTO

ST. MICHAEL'S
UNITY HEALTH TORONTO

Caring hearts. Leading minds.

Perspectives of Patients, Families and Other Stakeholders on Lyme Disease in Canada

A Brokered Dialogue Study in Two Phases

Brokered Dialogue Working Group

Members

- Janet Parsons, Clara Juando-Prats, Tamara Rader, Twylla Bird-Gayson, Ariane Quintal, Emily Rack, Billie-Jo Hardy, Lisa Dias

First Principles: Study Design

- Designed in partnership with patient members of Working Group
- Met with PCAC in October
- Patient and family perspectives will be front and centre
- Experiences of persons living with chronic LD emphasized
- Diversity of perspectives welcomed

Study Purpose/Objectives

1) To elicit the perspectives and experiences of persons living with LD (PWLD), in particular those living with chronic sequelae of LD, and their family members.
2) To explore the varying perspectives of a range of stakeholders who engage in LD ‘practices ’ (people living with LD, patient advocates, health care practitioners, researchers, decision-makers) related to the diagnosis and management of LD in Canada, in order to understand the sources of contention and to identify opportunities for enhanced collaboration across/between stakeholder groups.

Proposed Study Design

- **Phase I: Foundational interviews**
  - To lay groundwork and develop focus for Phase II
  - *Emphasis on patient and family experiences, including living w chronic LD*

  - *Individual audio recorded interviews:*
    - *Patients and family members (n = 21)*
    - *Other stakeholders (clinicians, researchers, decision-makers, others) (n = 9 - 10)*

- **Phase II: Brokered dialogue**
  - *Filmed interactive interviews (series over time)*
  - *Patients, families, clinicians, researchers, decision-makers (total n = 6-10)*
  - *3 rounds of interviews*

Doctoral Project

Claire Hiscock

Indigenous Health and Lyme Disease

- Gap in knowledge about Lyme Disease and Indigenous people in Canada
- Barriers to health services and time spent on land may put Indigenous people at risk of LD
- Climate change is exacerbating the issue

PhD Journey

- Literature Review
- Community Engagement
- Research Proposal

Community Engagement

Lisa Dias

Community Engagement

- Stakeholder Mapping
  - Input from PCAC and Pillar Leads.
  - Identified key stakeholders to engage.

- Results of the Stakeholder Mapping are informing Outreach efforts
  - Outreach to organizations and associations both at provincial and national level.
  - Examples: horticultural associations; conservation and park areas; nature schools and youth education programs.

Community Engagement Outreach

- Goals
  - Increase awareness about CLyDRN
  - Connect with new community members
  - Establish a Community Engagement Advisory Committee

- Initial Phase
  - Email outreach
  - Network member supported outreach

CANADIAN LYME DISEASE
RESEARCH NETWORK

Who we are: a national network consisting of researchers, patients, public health professionals, healthcare providers, and community stakeholders.

Our aim: to improve the prevention, diagnosis and treatment of Lyme disease in Canada.

Are you concerned about ticks or Lyme disease? Would you like to join a group of like-minded people?

What you can do: Learn about the latest research, design strategies, advise research, share your experience, and spread knowledge.

Join Us!

There are many ways to collaborate and support research in the Network. To become involved contact:
engage.lyme@unityhealth.to

Visit our website: www.clydrn.ca

Patient and Community Engagement

Clara Juando-Prats & Tamara Rader