

# Examining the Unmet Needs of British Columbians living with Myalgic Encephalomyelitis: Clinician Perspective

Lana LeBlanc<sup>1</sup>, MPH; Hilary Robertson<sup>1</sup>, MScHA, PhD; Kati Debelic<sup>1</sup>, RN, BScN; Luis Nacul<sup>2</sup>, MD, PhD; E. N. Prestley<sup>3</sup>, BA; T. Boulter<sup>2</sup>, BA  
<sup>1</sup>ME/FM Society of BC (BC, Canada) <sup>2</sup>Complex Chronic Diseases Program (BC, Canada) <sup>3</sup>Women's Health Research Institute (BC, Canada)

## Background

Understanding the explicit needs of British Columbians living with ME is critical to informing research that improves patient outcomes.

Community led project designed as a catalyst for larger provincial needs assessment through key stakeholders the identification and piloting methods.

There is a known knowledge and education gap of ME content in current medical curricula and in medical practice.

## Objectives

1. Test feasibility of conducting a provincial needs assessment
2. Identify and engage health sector stakeholders critical to mobilization of research outputs
3. Collect preliminary data regarding barriers and facilitators to health service provision and access.

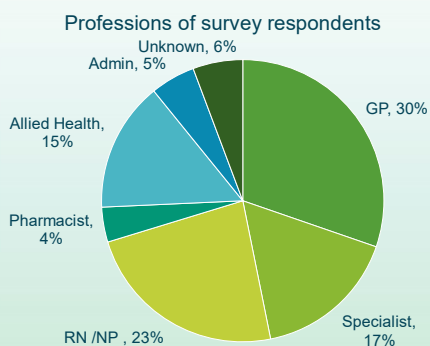
The project period was from February 3, 2020 – September 30th, 2020; The survey was distributed in July 2020.

## Methods

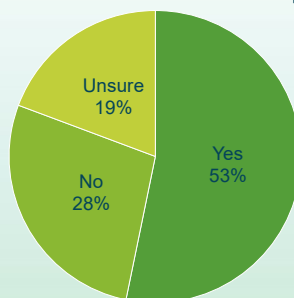
- BC Clinicians recruited via social media and communication support from BC clinician related agencies.
- Invited to complete a short, online, anonymous, 12 question, survey.
- Close-ended questions: knowledge, confidence and experience in treating ME.
- Open-ended questions: how best to address needs of ME patients.

## Results

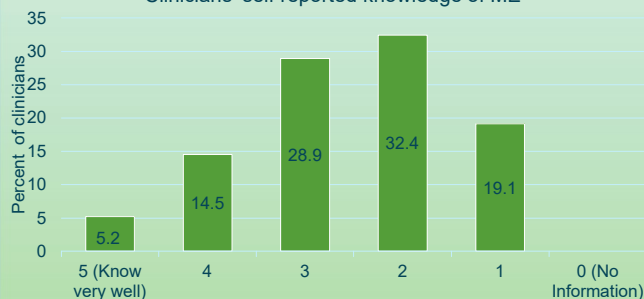
- The survey enlisted 173 clinician responses, with representation from all regional BC health authorities.
- Approximately half of the survey respondents provided open ended comments.



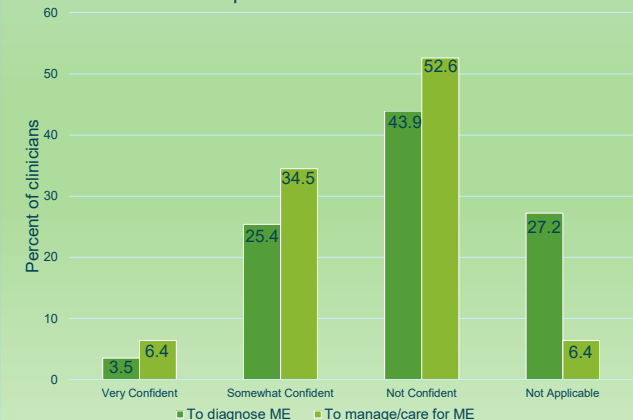
Have clinicians interacted with an ME patient?



Clinicians' self reported knowledge of ME



Clinicians' self reported confidence of ME interactions



- Short, electronic survey distribution was effective in recruiting range (type, location) of BC clinicians.
- Social media advertising supported survey recruitment.
- Interacting with ME patients ranged from half (52.0%) clinicians indicating they had and 33 (19.1%) unsure if they had or not.
- Majority of respondents (80.4%) indicating moderate to no knowledge of ME ( $\leq 3$  on Likert scale)
- Confidence in diagnosing and treating ME was low, with 43.9% clinicians indicating no confidence to diagnose and 52.6% of clinicians not confident to treat ME patients.
- In open ended responses, clinicians offered common recommendations for improving clinical care for ME patients to include:
  - 1) practitioner education
  - 2) diagnosis/clinical guidelines
  - 3) referral resources
- Somewhat common was concern that there is not a specialist "home" for ME, thus contributes to the stigmatization of patients

## Conclusion



The clinician survey parallel challenges to patient portion of project, noting the need for:

- 1) Increased awareness of ME within the clinical community
- 2) Improved clinical resources (e.g. diagnosis pathways, clinical guidelines)
- 3) Improved community referral resources
- 4) Improved empathy for the patient experience/ lack of options for patients.

Considering known challenges to engage clinicians in surveys online methodology was deemed successful and satisfactory for this pilot.

This initial inquiry has the potential to guide the development of larger studies and medical ME education efforts.

## Limitations

- Survey responses are a fraction of the province wide professional population and are a small representation of each demographic. Thus, findings are limited to this group and cannot be extrapolated across all health professionals in the province of BC.
- A larger, more expansive project would allow for greater depth of inquiry, broader participation and clarity of conclusions.

## Partnerships & Funding



Partial summary of a larger project  
 Full report is available at  
[www.mefm.bc.ca](http://www.mefm.bc.ca)