

# Provincial Pilot Study using virtual and online mixed methods to access a marginalized group: An exploration of unmet needs of British Columbians living with Myalgic Encephalomyelitis (ME)

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## Introduction

Myalgic Encephalomyelitis (ME) is a complex, chronic multi system illness that is under researched and unserved in the medical system (1). ME patients report living highly disabled, and low quality of life (2). Currently, there is no cure and little medical treatment available (3). ME patients are driven to support research and improve health care provider knowledge.

Pilot study designed to initiate access in an under reported, underserved patient community. The project aimed to test data collection methods and begin to learn about the unmet needs of ME patients in BC (4).

This project may be of interest to those involved in patient-oriented research, health researchers, health care providers and health system decision makers.

## Methods

A mixed methods approach was designed to recruit from two stakeholder groups across BC.

### 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.

### BC Patients:

- People living with ME were recruited from the ME/FM Society of BC to participate in individual interviews and focus groups.
- Semi-structured interview and focus group guides were developed, and thematic analysis of content was conducted.
- Community members trained in qualitative research methods led the data collection and analysis.

Graphic illustrator worked with the research team to develop patient themes into graphics for visual dissemination of results.

## Graphic Reporting of Project



## Acknowledgements

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## Discussion & Implications

Electronic and virtual participation was successful in both stakeholder groups. Virtual interviews supported more severe patients by reducing exertion requirements of travel and in-person visits. Electronic survey engagement exceeded target expectations. Broad geographic representation occurred in both groups.

Full and partial illustrations have been used in a variety of KT and awareness building efforts. Full presentations were offered to patient participants to validate information.

Patient-led and disease-informed conduct allowed for methods and administration decisions to increase recruitment and participation of a patient group typically not represented in research. The project team's composition of having patients with lived experience of specific illness and research skills supported methodology choices, participant recruitment, rapport development, as well as graphic KT creativity.

While a successful pilot project, more robust evidence is required to impact significant change in the patient population. There is a dire need to prioritize equitable access to health services and more comprehensive research funding. ME patient care requires system-wide change. The current symptom overlap between long COVID and ME (5) necessitates research and clinical attention to post-viral populations.

## References

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