

---

# M.E. IN BC: HOW THE HEALTHCARE SYSTEM FOR M.E. IMPACTS CLINICIANS AND PATIENTS

---

## A preliminary project examining the unmet needs of British Columbians living with Myalgic Encephalomyelitis (ME)

*"ME took away every single thing. Every single construct that I was as a human being". – BC Patient*

*"I feel extremely sorry for them because BC has almost nothing for them."  
– BC Clinician*

---

### SHORT REPORT

---

Report released: February 2021

Full report available from: [www.mefm.bc.ca](http://www.mefm.bc.ca)

Prepared by:

ME/FM Society of BC

Hilary Robertson, MScHA, PhD, ME/FM Society Co-Chair, Lead Researcher

Lana LeBlanc, MPH, Research Coordinator

Kati Debelic, BScN, ME/FM Society Board Member

*In partnership with: BC Women's Hospital + Health Centre*

Luis Nacul, MD, PhD, Medical and Research Director, CCDP, Lead Researcher

Nicole Prestley, Research + Knowledge Translation Manager, Women's Health Research Institute

Travis Boulter, Research Assistant, Women's Health Research Institute

The ME/FM Society of BC partnered with the WHRI (BC Women's) to receive a Convene Grant from the Vancouver Foundation to complete this work. Vancouver Foundation is dedicated to creating healthy, vibrant and livable communities across BC. Since 1943, our donors have created 1,800 endowment funds and together we have distributed more than \$1 billion to charities. From arts and culture to the environment, health and social development, education, medical research and more, we exist to make meaningful and lasting improvements to communities in BC.



## Summary

This patient led community inquiry project was conducted through a partnership between the ME/FM Society of BC, the Complex Chronic Diseases Program at BC Women's Hospital + Health Centre, and the Women's Health Research Institute. The project was funded by the Vancouver Foundation through the Convene competition.

Understanding the explicit needs of British Columbians living with Myalgic Encephalomyelitis (ME) is critical to informing research that improves patient health outcomes. Robust evidence ensures health and social services are designed and delivered effectively and appropriately to the ME community, which includes patients, clinicians, and health care decision makers.

The primary focus of this project was to plan for a health needs assessment on ME/CFS in the province of British Columbia. A secondary objective was to conduct a preliminary assessment of the needs/ barriers to service provision and challenges in health service delivery to ME patients across British Columbia (BC).

In total, 25 patients (8 individual interviews and 17 participants in 4 focus groups) and 173 clinicians participated, with representation from all regional BC health authorities. The eight individual patient interviews informed the themes used to further the exploration through four thematically oriented focus groups. Survey questions were related to clinicians' knowledge, experience and assessment of service provision to ME patients in BC.

The patient interviews highlighted four key themes to the ME experience in BC:

- ❖ Social isolation, loss of identity and the need for emotional support
- ❖ Supports for disease management and how to live with ME
- ❖ Challenges to diagnosis
- ❖ Stigma in the healthcare system

The clinician survey identified parallel challenges noting the need for:

- ❖ Increased awareness of ME within the clinical community
- ❖ Improved clinical resources (e.g. diagnosis pathways and clinical guidelines)
- ❖ Improved community referral resources including more options for patients
- ❖ Improved empathy for the patient experience/lack of options for patients

Overall, key findings presented from this project have been defined:

1. Patients' experiences of living with ME is dire, alarming, and urgent
2. Patients are concerned with the medical system's poor awareness of ME
3. Both patients and clinicians acknowledge a paucity of available clinical care resources
4. Clinicians expressed a desire for improved education for ME care

Undertaking a community-based approach in building a province wide needs assessment is critical for targeted strategies to inform practitioners, policy makers, and patients and their support teams. This project report provides a clearer picture of unmet needs and future directions established by ME patients. This application of the community-based approach and working with 'patients as partners' aligns with the national viewpoint of ME research efforts and ideally, will allow others beyond BC to learn from our gained insights. Through patient focus inquiry exploring facilitators and barriers to health services, it is hoped that future research, policy and practice can be designed to serve both patients and the health system in an effective and economical manner.



# M.E. in B.C.

HOW THE HEALTHCARE SYSTEM FOR M.E. IMPACTS CLINICIANS AND PATIENTS

## PILOT PROJECT PURPOSE

BEGIN TO:

- EXPLORE M.E. CARE IN BC
- UNDERSTAND THE NEEDS OF M.E. PATIENTS IN BC

## BACKGROUND

Feb.-Aug 2020



ME/FM Society of BC

COMPLEX CHRONIC DISEASE PROGRAM - BC WOMEN'S HOSPITAL

CONVENE GRANT - VANCOUVER FOUNDATION

## METHODS

8 INTERVIEWS



4 FOCUS GROUPS  
25 PATIENTS

79 DOCTORS

42 NURSES



173 CLINICIANS/ADMIN

## FINDINGS

SOCIAL ISOLATION IS PROFOUND

STIGMA FROM THE HEALTHCARE SYSTEM

GETTING DIAGNOSED IS COMPLICATED, LENGTHY, AND CHALLENGING

"M.E. TOOK AWAY EVERY SINGLE THING, EVERY CONSTRUCT I WAS AS A HUMAN BEING."  
- PATIENT

"I FEEL EXTREMELY SORRY FOR THEM BECAUSE BC HAS ALMOST NOTHING FOR THEM."  
- CLINICIAN

CLINICIANS & PATIENTS AGREE:



We need IMPROVED COMMUNITY REFERRALS

We need BETTER DIAGNOSIS PATHWAYS & CLINICAL GUIDELINES

WE NEED MORE EDUCATION ON M.E.

THERE IS A LACK OF KNOWLEDGE & EDUCATION

## CONCLUSION

PATIENTS ARE CONCERNED WITH THE MEDICAL SYSTEM'S POOR AWARENESS OF M.E.

PATIENTS' EXPERIENCES OF LIVING WITH M.E. IS DIRE, ALARMING & URGENT

BOTH PATIENTS AND CLINICIANS ACKNOWLEDGE A PAUCITY OF AVAILABLE CLINICAL CARE RESOURCES

CLINICIANS EXPRESSED A DESIRE FOR IMPROVED EDUCATION FOR M.E. CARE



LARGE SCALE PROVINCIAL NEEDS ASSESSMENT IS NEEDED. FULL REPORT AVAILABLE AT [WWW.MEFM.BC.CA](http://WWW.MEFM.BC.CA)



## Conclusions

This preliminary project began to explore the experience of ME patients and clinicians relating to ME care in BC. The sample of patients and clinicians engaged in this topic highlight the need for further expanded research and exploration of barriers and facilitators in ME care delivery in BC. The CCDP and some individual community physicians are working to support ME patients, yet many patients included in this project, despite their own tenacity and resourcefulness, described not feeling adequately supported.

The limited care – compounded by insufficient clinical knowledge or system gaps – results in a system that does not seem to fully meet the needs of ME patients. Patients in this project expressed experiencing a high level of stigma and/or dismissal at many interfaces within the healthcare system. Clinicians engaged during the course of this project expressed a strong interest in improving clinical education, referral resources and broader support for patients with ME in BC.

The secondary aim of this project was to test the feasibility of mechanics and engagement with this particular patient and stakeholder population. The Project Team was successful in using social media to recruit patients (for interviews) and clinicians (for survey). The willingness of both patients and clinicians to participate in this project cannot be overstated. This project experienced successful adaptation of virtual research methods (e.g., online interviews, focus groups, electronic survey distribution) which could be reproduced in a larger, future project. There were unanticipated levels of engagement in both the patient invitation and the practitioner survey. The success of this project's engagement with key stakeholders serves as a strong indicator that the needs of ME patients and care in BC is important, relevant and deserving of future attention.

## Acknowledgements

We gratefully acknowledge the funding support from the Vancouver Foundation. Convene grants from the Vancouver Foundation support project teams to gather information, meet with key stakeholders to learn more about the complex issue, and to articulate the research question, methodology, and partnership. This type of support is incredibly needed in exploring and bringing forward complex patients' experiences such as those with ME in BC.

To those with ME in BC, you responded to our invitation of participation with willingness, candour and emotion. Your impressive determination to improve the patient experience in BC is much appreciated. We know that your participation was not without planning or consequence. We are grateful for your contribution.

To the clinicians and other healthcare professionals who provided time and thought, your contributions mirrored the experience of the patients. We sincerely appreciate your thoughtful contributions and reflections related to caring for ME patients in BC.

Please access the full report at: [www.mefm.bc.ca](http://www.mefm.bc.ca)