



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



PATIENT LED COMMUNITY ENGAGEMENT

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

SURVEY



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



LARGE SCALE PROVINCIAL NEEDS ASSESSMENT IS NEEDED. FULL REPORT AVAILABLE AT WWW.MEFM.BC.CA

SUPPORT FOR M.E. IS NEEDED



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