ME/FM/Lyme/Long COVID Patient Healthcare Experiences and Priorities in BC

A Patient Survey, 2025

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Common abbreviations used in this report

ME = Myalgic Encephalomyelitis, sometimes referred to as ME/CFS or chronic fatigue syndrome

FM = Fibromyalgia

LC = Long COVID, also referred to as Post-COVID Condition, long-haul COVID, Post Viral COVID, and post-acute sequelae of COVID-19 (PASC)

Lyme = Lyme Disease or Chronic Lyme Disease

PEM = Post Exertional Malaise, or a worsening of symptoms, often hours or days following even minor physical, mental or emotional exertion.

Executive Summary

Context and Purpose

Over 347,000 British Columbians live with ME, FM, Long COVID, or Lyme disease[1] - conditions that collectively incur a direct healthcare cost of $1.2-$3.1 billion annually.[2] These patients endure significant pain, fatigue, brain fog and impairment. Many become functionally disabled and unable to work for months, years, or permanently: over 40% of FM and Lyme patients cannot work for significant periods[3], 53% of Long COVID patients report "moderately severe" functional impairment[4], 75% of ME patients cannot work[5], and 25% of ME patients are bed- or homebound[6]. Studies show that these patients have lower quality of life measures than people with diabetes, multiple sclerosis, heart disease[7], cancer[8], and other pain disorders[9].

[1] The ME|FM Society of BC estimates 347,000 BC residents have ME, FM, and Long COVID (lasting over a year): https://www.mefm.bc.ca/. No specific statistics were available on current patients, but BC reported 6 to 39 Lyme disease cases annually from 2013-2022: http://www.bccdc.ca/health-info/diseases-conditions/tick-borne-diseases/lyme-disease-borrelia-burgdorferi-infection.

[2] "Estimated Costs of ME/CFS, Fibromyalgia, and Long COVID in British Columbia," 2025. https://drive.google.com/file/d/1V0FEtkT-LT7sdbiOlvYQAUcyBvRFwhrN/view

[3] For FM patients: Mukhida, W., Carroll, R., & Arseneault, A. "Does Work Have to Be So Painful? A Review of the Literature Examining the Effects of Fibromyalgia on the Working Experience from the Patient Perspective." *Canadian Journal of Pain*, vol. 4, no. 1, 2020, pp. 268–286. *PMC*, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7951172/. For Lyme patients: Johnson, Lorraine. "LYMEPOLICYWONK: Chronic Lyme Disease Patients Suffer High Unemployment and Disability." *LymeDisease.org*, 8 May 2014, https://www.lymedisease.org/lymepolicywonk-chronic-lyme-disease-patients-suffer-high-unemployment-and-disability-2/.

[4] Van Beusekom, Mary. "Fatigue Can Lower Long-COVID Patients' Quality of Life More Than Some Cancers." *CIDRAP*, University of Minnesota, June 8, 2023, https://www.cidrap.umn.edu/covid-19/fatigue-can-lower-long-covid-patients-quality-life-more-some-cancers

[5] Podell, Richard, Mary E. Dimmock, and Barbara B. Comerford. "Documenting Disability in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)." *Work*, vol. 66, no. 2, 2020, pp. 339–352. *doi:10.3233/WOR-203178* (https://journals.sagepub.com/doi/full/10.3233/WOR-203178)

[6] Park, Jae-Woong, et al. "Systematic Review of Fatigue Severity in ME/CFS Patients: Insights from Randomized Controlled Trials." *Journal of Translational Medicine*, vol. 22, no. 1, June 2024, https://doi.org/10.1186/s12967-024-05349-7.

[7] ME patients: Hvidberg, Michael Falk, et al. "The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)." *PLOS ONE*, vol. 10, no. 7, 2015, e0132421. https://doi.org/10.1371/journal.pone.0132421

[8] ME (see ft nt 3) and Long COVID patients: Van Beusekom, Mary. "Fatigue Can Lower Long-COVID Patients' Quality of Life More Than Some Cancers." *CIDRAP*, University of Minnesota, June 8, 2023, https://www.cidrap.umn.edu/covid-19/fatigue-can-lower-long-covid-patients-quality-life-more-some-cancers

[9] FM patients show significant disability overall and poorer health-related quality of life than those with refractory angina, a potentially life threatening pain disorder: **Andréll, Paulin, et al.** "Health-Related Quality of Life in Fibromyalgia and Refractory Angina Pectoris: A Comparison Between Two Chronic Non-Malignant Pain Disorders." *Journal of Rehabilitation Medicine*, vol. 46, no. 4, 2014, pp. 341–347. DOI:10.2340/16501977-1279 (https://www.medicaljournals.se/jrm/content/html/10.2340/16501977-1279?utm_source=chatgpt.com).

Anecdotal reports and previous studies[10] demonstrate that these patient populations have been consistently underserved by BC's medical system, experiencing poor care, stigma, and worsening symptoms due to ineffective or harmful treatment approaches.

The patient survey upon which this report is based was initiated in late 2024 in response to continuing and mounting evidence of persistent and significant systemic failures within existing BC healthcare models. Evidence of patient healthcare experiences, needs, and priorities must be the cornerstone of health service design, reform and delivery across the province.

The objective of this report is to articulate patient perspectives of strengths and weaknesses in existing healthcare delivery models and practices, and to identify gaps and opportunities for improvement. The intended purpose is to inform policy reform; funding allocation; healthcare provider education; and the development of safe, effective, appropriate healthcare delivery models for patients with these complex and debilitating illnesses in BC.

The research lead, data analyst and author of this report, Kelly Lautt, is a member of the Board of Directors of the ME|FM Society of BC. She has extensive experience in the social sciences, research, statistical analysis, and healthcare advocacy, with graduate degrees in Political Science from UBC and UCLA.

Summary

This survey captured the experiences of **1,045 BC respondents**[11], representing the largest systematic examination of healthcare experiences for these patient populations in the province. This survey was structured in 4 main sections: **Demographic** information; **positive** healthcare experiences; **negative** healthcare experiences; and patient **priorities** for healthcare. There were several opportunities for survey respondents to add optional additional write-in comments.

Respondents were distributed 60/40 between the Lower Mainland/Fraser Valley and other BC regions. 81.2% have ME, 54.4% FM, 30.4% Long COVID and 5.1% Lyme. About two thirds reported having more than one of the listed conditions, with one third experiencing additional comorbidities. Interestingly, about a third reported an illness duration of over 19 years, demonstrating the often long-term nature of the disease.[12]

[10] An example is the report on unmet needs of British Columbians living with ME at: https://mefm.bc.ca/our-research#unmet-needs

[11] There were also about 100 respondents from elsewhere in Canada whose data will be analyzed in separate future work.

[12] Excluding patients whose first illness onset was from COVID, as their earliest onset would be 2020.

Themes

The main themes highlighted by this survey were:

- An alarming overall **lack of accessible, respectful, one-on-one healthcare.**
- A **lack of awareness and knowledge** of these illnesses among healthcare providers.
- Active and passive **harm** from existing healthcare services, arising from: a paucity of knowledgeable one-on-one care; no or incorrect diagnoses; potentially harmful treatments and advice; refusal of safe, appropriate tests; and dismissal, disbelief and disrespect from providers.
- **Loss and hardship** across financial, personal, and overall quality of life domains, often unsupported or dismissed by healthcare providers.
- Many individual **positive experiences with specific providers**, demonstrating that appropriate treatment is possible when accessibility, knowledge and respect converge.

Key Findings

1. The **healthcare system in BC is failing patients** living with ME, FM, Long COVID and Lyme disease, with widespread dismissal, ineffective and unsafe care, and often worsening symptoms defining their experience.

SYSTEM FAILURE
UNMET NEEDS
KNOWLEDGE GAPS
FINANCIAL BARRIERS

2. Existing **healthcare service models fail to meet fundamental patient needs**: ongoing, accessible, one-on-one care (in-person and virtual) from knowledgeable providers across all care settings.
3. Healthcare providers across disciplines critically **lack current, science-based education on these conditions**, covering: the nature of these illnesses, diagnostic criteria, safe care practices, current research on causes and biomarkers, illness severity and patient impact, and effective treatment options.
4. **Patients face significant financial barriers due to both systemic gaps and provider failures**. Limited MSP coverage for treatments and medications, restrictive BC Disability Assistance criteria, and inadequate benefit amounts create substantial hardship, while healthcare providers often refuse to support disability applications, lack experience with the application process, are unaware that many patients with these illnesses meet program eligibility criteria, or fail to inform patients about available financial programs.

Contents

Study Overview

Survey Design

This report is based on an online survey developed on the QuestionPro platform by the ME|FM Society of BC, conducted between December 6, 2024 and April 17, 2025. The survey employed a mixed-methods design combining structured and unstructured data collection across four main sections: **demographic** information (geography, illness type, and illness duration); **positive** healthcare experiences (by provider type and experience type); **negative** healthcare experiences (by provider type and experience type); and patient **priorities** for healthcare. The full survey text can be obtained from the ME|FM Society of BC upon request.

Analysis

Analysis employed multiple methodological approaches: traditional statistical analysis of structured question responses; computational data mining and analysis (including word count, theme, and sentiment analysis) using ChatGPT-4.o, and Claude 4 and 5; with additional manual thematic analysis of unstructured write-in comments. All analysis was completed by the report author/lead analyst.

Demographics of Respondents

The survey upon which this report is based was open to participants from any location.

A total of 1045 British Columbian respondents completed the survey.[13]

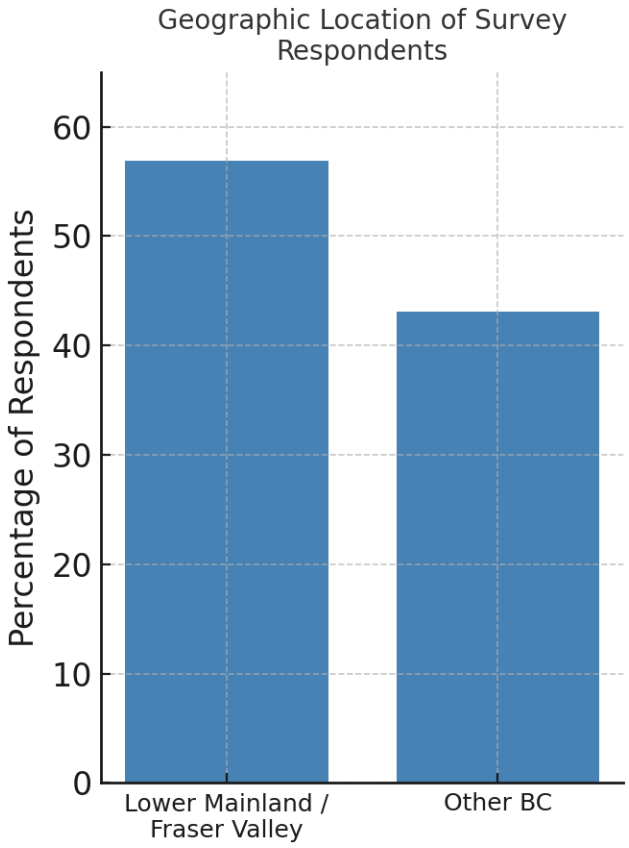
Note: This paper reports on patient healthcare experiences and priorities in BC. Therefore, only BC respondent data are included in this analysis. However, there are plans for future analysis and publication based on the just over 100 responses from across Canada (outside of BC).[14]

[13] Note that "completed" means entering valid data in at least one of the questions past the demographic questions (Q1). Respondents were allowed to answer as many or as few questions as they wanted to/were able. Nearly 90% of respondents completed all answers. However, where appropriate, statistical analysis was done on numbers of respondents completing a specific question and not on the total respondent population.
[14] There was only one verified international respondent.

Geography

BC survey respondents were distributed 57% to 43% between the Lower Mainland/Fraser Valley (LM/FV) and other BC regions.[15] This closely mirrors the provincial population distribution of approximately 60% to 40%,[16] indicating the survey sample is geographically representative of BC. However, as will be noted in sections below, this has low analytical relevance as there are no significant response differences between respondents from the LM/FV region and other BC regions.

Figure 1: Geographic Location of Survey Respondents.



[15] The original, raw data does delineate more specifically around region, but there were minor data issues with certain regions and the impact of region on respondent answers was insignificant. Therefore, the data used for analysis coded for two regions: Lower Mainland/Fraser Valley and Other BC.

[16] "Table 98-10-0002-02 Population and dwelling counts: Canada, provinces and territories, and census subdivisions (municipalities)". *Statistics Canada*. 9 February 2022.

Illnesses and Comorbidities

Overview of Illness Distribution

The majority of respondents (81.2%) have ME, over half (54.4%) have FM, and approximately one-third (30.4%) have Long COVID. Fifty-three respondents (5%) reported having Lyme disease, split roughly equally between the Lower Mainland/Fraser Valley and other BC regions.[17] Of those, 56.6% also reported having ME, 41.5% FM, and 11.3% Long COVID. Lyme patients' responses largely mirrored those of other participants, with notable differences highlighted later in this report.

About two-thirds of respondents have more than one of these illnesses, as detailed below.

About a quarter of BC respondents reported they also had one or more other post-viral or dysautonomic illnesses: 55% of those reporting such other illnesses mentioned POTS[18], 16% mentioned MCAS[19], and 4% mentioned EDS[20].[21]

[17] Of Lyme respondents, 47.2% were from the LM/FV region and 52.8% were from other regions in BC.

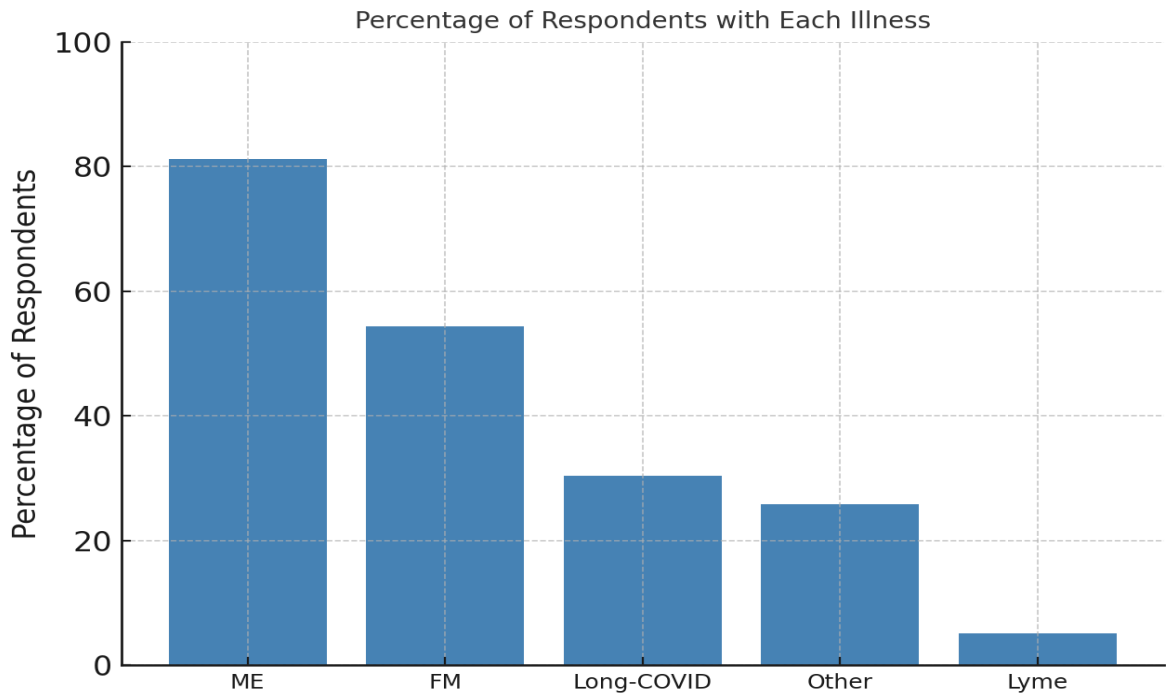
[18] Postural Orthostatic Tachycardia Syndrome - A condition that affects blood flow and heart rate, leading to symptoms like light-headedness, palpitations, and fainting when standing up. Chronic fatigue and other autonomic symptoms are also reported.

[19] Mast Cell Activation Syndrome - A disorder where mast cells (an immune cell) release mediators inappropriately, causing allergy-like symptoms such as flushing, hives, or anaphylaxis, often with no clear allergen trigger.

[20] Ehlers-Danlos Syndrome – While there are 13 types of EDS, the most common as a comorbidity with other post-viral illness is Hypermobile EDS – A syndrome characterized by joint hypermobility, chronic pain, fatigue, and often gastrointestinal or autonomic symptoms.

[21] Other illnesses were mentioned at ≤2% and 11.5% of people with these "other" illnesses (or 31 out of 270 people) left what their other illness is blank.

Figure 2: Percentage of Respondents with Each Illness



Multiple Illnesses and Comorbidities

About two thirds of respondents (65.7%) reported having more than one of the listed illnesses (ME, FM, Long COVID, Lyme): 46.0% reported having both ME and FM (known common comorbidities) and 22.5% reported having both ME and Long COVID.[22]

Additionally, despite there not being a specific question asking to list these, 34.2% of BC respondents mentioned having other *non*-post viral or dysautonomic comorbidities including:

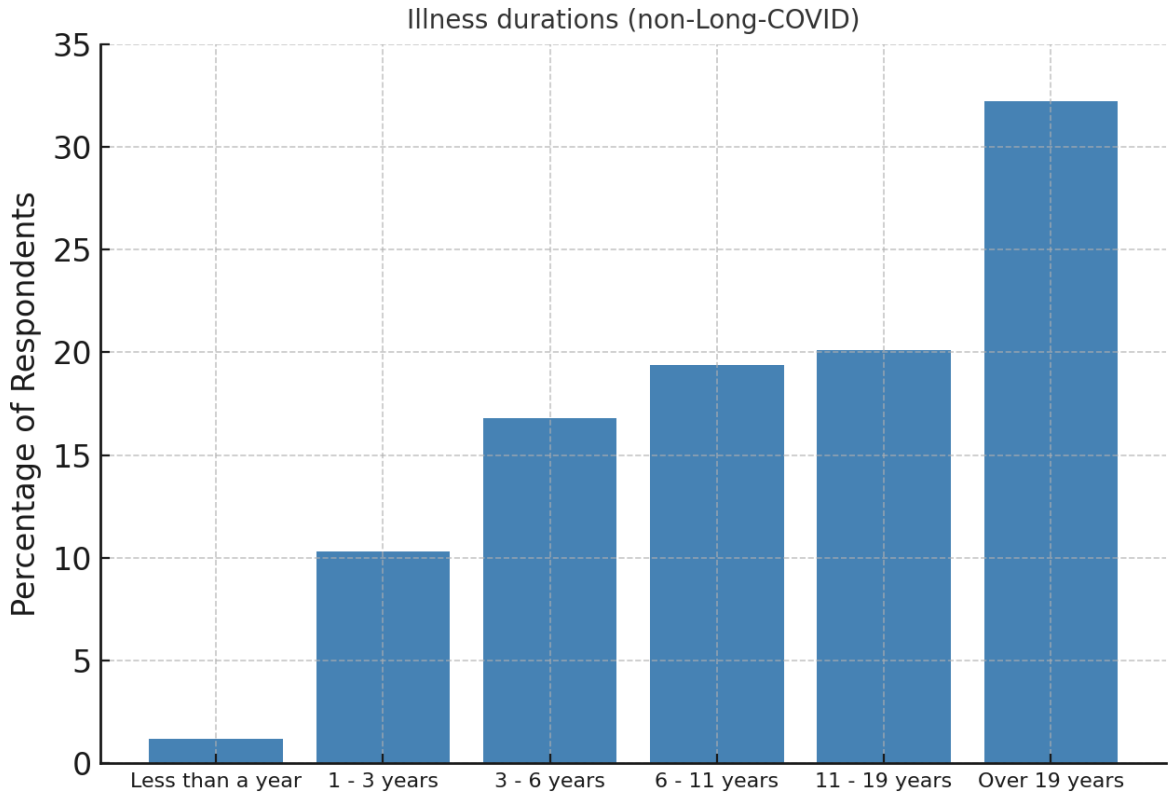
- Chronic conditions like diabetes, heart disease, and arthritis
- Autoimmune/inflammatory conditions such as thyroid disease, lupus, and interstitial cystitis
- Neurological and gastrointestinal disorders including epilepsy, migraines, IBS, and GERD
- Mental health conditions including anxiety, depression, Post Traumatic Stress Disorder (PTSD), and bipolar disorder

[22] There is strong symptom/diagnosis overlap between these two illnesses and labelling of Long COVID that meets the diagnostic criteria of ME remains somewhat inconsistent in BC, with some practitioners assigning both diagnoses.

Duration of illness [23]

Long COVID was reported by 30.4% of respondents, with 43.2% of this group experiencing symptoms for 1-3 years. Given that the pandemic began in 2020, Long COVID patients are inherently limited to a maximum illness duration of five years. To provide meaningful comparison of illness duration patterns, the following table excludes Long COVID respondents.

Figure 3: Illness duration distribution for all non-Long COVID respondents (who answered the question on illness duration)



About one third of respondents have been ill for 20 years or more, 20% for 11-19 years, just over a third have been ill for between 3 and 19 years, and only around 11% have been ill for 3 or fewer years.

[23] Note that the duration of illness did not have any significant impact on survey answers and so will not be referenced again in this report. Regression on illness duration against frequency of (positive and negative) experiences as well as against priority were run, with almost no relationship (slope close to zero) and R-squared values in all cases under 0.01.

Limitations of Study

Technical/Demographic Limitations

The survey was built in QuestionPro with six questions, some quite extensive.[24] Pre-publication testing with five ME patients - including two with self-reported medium technology comfort - confirmed the survey was easy to understand and complete for our target audience. Two test participants used the save-and-continue feature to complete the survey across multiple sessions, and one reported a longer completion time of 20 minutes. With these test results and about 90% of BC respondents completing all questions of the published survey, its delivery and structure were deemed accessible for the target audience.

The survey remained open for 4.5 months and was distributed through social media and patient email lists by BC advocacy groups and patient activists, as well as directly to patients through physician contacts and clinics.

Despite instructions allowing caregivers to complete the survey on behalf of patients, severely ill individuals were likely heavily underrepresented. These patients are less likely to monitor email, social media, or patient communications and face barriers to completing a multipart survey.

Topic parameters

This survey explicitly focused on patient experiences with and priorities *for healthcare services and providers*. Consequently, several themes central to the illness experience—many of which emerged in write-in comments—were not explored in depth within this report, including:

- personal loss (basic functioning, career, identity, relationships, hobbies, quality of life);
- the extent of the physical and cognitive disability caused by these illnesses; and
- the emotional struggles associated with living with such debilitating illnesses (including sorrow, confusion, anger, anxiety and fear).

[24] Questions included multiple sub-questions (the one demographic question (Q1)); multiple options (the one priorities question (Q6)); and/or opportunities to add write-in comments (the four questions regarding positive and negative experiences, and the priorities question (Qs 2 through 6)).

Healthcare experiences

Overview

Over 90% of respondents reported at least one negative experience.[25] Of all respondent-reported experiences of seeking diagnosis, testing, and safe, effective ongoing healthcare in BC, over 60% were negative.[26] Over 88% of write-in comments contained negative sentiments.[27] Many reported significant healthcare-related trauma, mental or physical harm, and/or long-term worsening of their symptoms, health and quality of life. Interestingly, the location of respondents (Lower Mainland/Fraser valley versus other parts of BC) and length of illness had no significant impact on responses.

For detailed **statistics** on healthcare experiences, see Appendix A.

For commentary on experiences with different **types of healthcare providers**, see Appendix B.

For additional **write-in comments** regarding healthcare experiences see appendix D.

For the just under 40% of structured responses[28] regarding healthcare experiences that were positive, almost all reported being believed, getting a correct diagnosis (though often after years or decades), being helped with prescriptions, being helped with financial applications, and/or being provided with helpful, practical information. The majority of people recording positive experiences also reported related negative experiences[29] and made comments such as "finally finding one person in this sea of horror who believed me and would help was such a relief" and "I was so lucky to finally get in to see someone who could help me. I know so many others have still not found this."

Experiences by Provider Type/Healthcare Context

While respondents reported both positive and negative healthcare experiences across all provider types, the patterns varied significantly by care setting.[30]

[25] 92.5% of respondents who completed the survey reported one or more negative experiences. Note that 93.2% reported one or more positive experiences.

[26] From survey questions 3 and 5, which asked about parallel positive and negative experiences.

[27] Sentiment and keyword analysis were conducted using an iterative combination of manual analysis and Natural Language Processing (ChatGPT-4.0 and Claude).

[28] To questions 3 and 5, which asked about parallel positive and negative experiences.

[29] In both the structured and unstructured data fields.

[30] Whether the respondent lives in the Lower Mainland/Fraser Valley or elsewhere in BC made no significant difference in these responses.

Primary Care and Specialists

Over 65% of respondents who reported on experiences with primary care providers and specialists[31] reported negative experiences, while about 54% (Primary Care) and 61% (Specialists) reported positive experiences.[32] When the experience was positive, respondents valued being believed and receiving helpful referrals, but less often reported receiving reliable, knowledgeable care or treatment for their actual illness.

Alternative Healthcare Practitioners

77% of respondents who reported on care from alternative practitioners (such as occupational therapists, physiotherapists, naturopaths, and mental health professionals) reported a positive experience, though 51% also reported a negative experience. Despite being described as often lacking illness-specific knowledge and rarely being MSP-covered, respondents reported that these practitioners often offer: belief, respect, time for discussion (illness, symptoms, general health), and a willingness to prescribe potentially helpful treatments.

Emergency, Walk-in and Acute Care

Respondents reported the most challenges in emergency and urgent care settings: 92.8% who reported on these services noted negative experiences versus only 14% positive. Write-in comments described unsafe treatments, lack of illness accommodations, dismissal and misdiagnosis, often resulting in patient trauma and future care avoidance.

See mini report Topic 1: **Experiences with Emergency Care** (in Appendix F) for detail and respondent quotes.

ME/FM/Long COVID/Lyme-Focussed Clinics and Practitioners

88.4% of respondents who reported on experiences with illness-focussed practitioners, in-person Long COVID clinics or the CCDP noted positive experiences. Respondents reported being believed, gaining access to helpful illness information, receiving accurate diagnoses (often after years or decades), and getting help with financial applications. However, over 80% faced significant access barriers including lengthy wait times, travel requirements, limited program availability (such as limited time in program and few if any one-on-one physician appointments), referral difficulties, and program eligibility restrictions. Additionally, many noted that while group sessions/appointments and online resources (the main services offered

[31] Specialist refers to formal medical specialists such as cardiologists, gastroenterologist, and rheumatologists. The term "specialist" does not refer to general practitioners who focus their practice on ME/FM/Long COVID or Lyme.
[32] There were separate questions asking about positive and negative experiences by provider type. Therefore, respondents were able to report both positive and negative experiences with the same provider type.

by these clinics/programs) were positive and helpful, they still need ongoing individualized medical care that these programs can't fully provide.

"…these [group sessions and appointments] are good but not ideal"

"I love the group meetings and I have met people there, but I need a doctor"

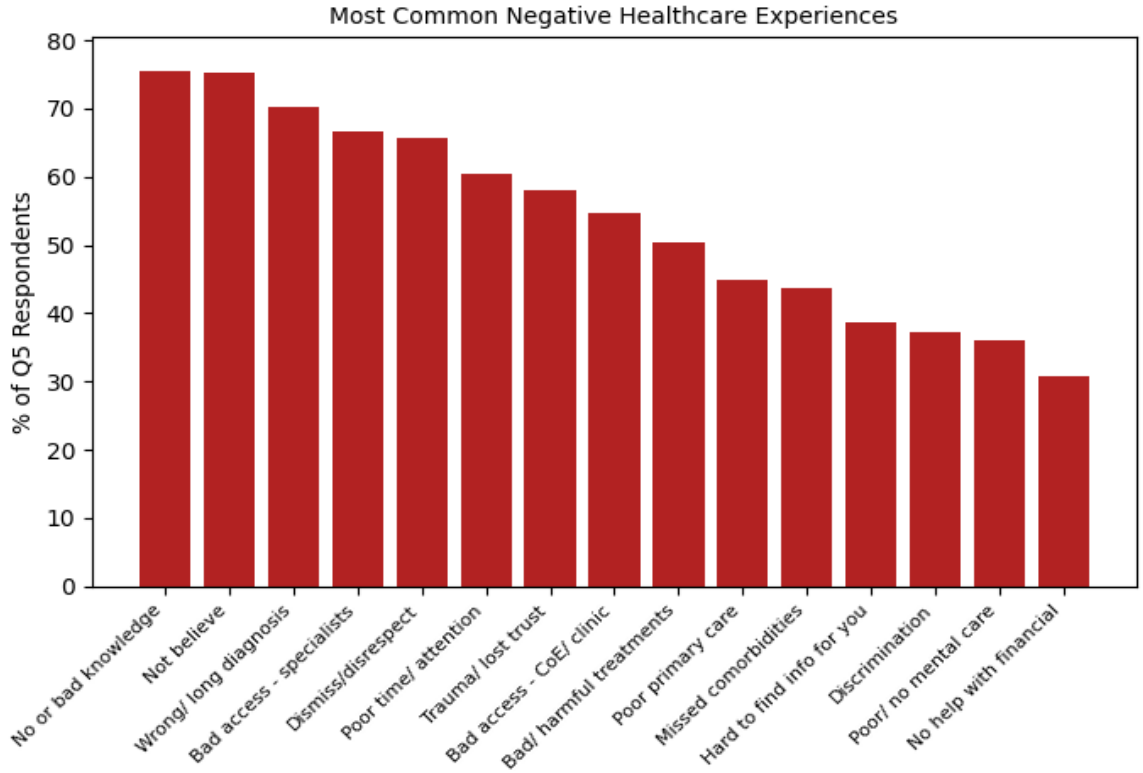
"Getting my prescriptions decided and renewed in a big group works great for me. It's the only way to get some of this stuff here [in BC]. But what about people who don't know anything medical? How can the doctor know if they don't have something else [a different illness]. Are people even getting the right thing [prescription]?"

"[A BC clinic focussed on these illnesses] provides essential access to medication and information but NO real personalized treatment. There is no confidentiality -- ie. the way to get your health concerns addressed is to bring it up in a group medical visit."

Negative Healthcare Experiences - Detail

Survey respondents reported negative experiences with healthcare through a combination of structured responses (choosing from supplied options) and unstructured write-in comments. This section reports the structured responses in the following chart, followed by a detailed breakdown reflecting both the structured and unstructured data throughout the survey.

Figure 4: Negative healthcare experiences noted by at least 30% of respondents to question 5



Full text of survey question 5 and mapping to labels in Figure 4 are in Append. E

Lack of knowledgeable one-on-one care

Respondent answers (structured data, as seen above in Figure 4) and comments (unstructured data) revealed recurring themes around healthcare providers' **lack of awareness and knowledge** of these illnesses, as well as patients' **need for more time** with providers:

- Lack of **Awareness**
  Healthcare providers often have never heard of these illnesses or hold significant misconceptions about them:
  - ME – Many providers have never heard of it, believe it's psychological, or dismiss it entirely, often accusing patients of being out of shape, lazy, or having school/work/exercise aversion.
  - Long COVID – Limited understanding of the various ways COVID effects can persist (organ damage, viral persistence, chronic post-viral syndrome), and that the post-viral syndrome that can occur after COVID overlaps with ME, with similarly debilitating and long-term symptoms.
  - FM – Weak understanding of how difficult and painful it can be, with a bias that sufferers are exaggerating symptoms or are lazy, out of shape or drug-seeking.
  - Lyme – Lack of knowledge about symptoms and/or disbelief that it exists in BC.
- Lack of **Education** and **Knowledge**
  Healthcare providers demonstrate critical knowledge gaps regarding:
  - the physiological (rather than psychological) nature of these illnesses,
  - acceptable diagnosis approach and criteria,
  - the often debilitating effect these illnesses have on patients,
  - available evidence-based treatments,
  - outdated, harmful assumptions and treatments that should be avoided, and
  - the complexity of illnesses and their common comorbidities.
- Lack of **Time and Attention**
  Respondents reported that there are several barriers to the time and attention of healthcare providers they feel is required for proper assessment, care and management of these illnesses, including:
  - Extended wait times for GPs, specialists, and clinics, with difficulty accessing urgent or emergency care,
  - Service model limitations to provider time with patient, including:
    - MSP coverage models restricting appointment time (15-minute limits),
    - Models restricting conversation to single topics/symptoms per visit, and
    - Restrictions on home-based and virtual appointments, and
  - Provider ignorance around complexity and impact of illnesses lead to patients not being given time and attention for proper care and illness management.

Weaknesses in Current Specialized Programs and Clinics contributing to a lack of knowledgeable one-on-one care were reported throughout the structured and unstructured (write-in comment) data. These included issues with accessibility and the healthcare service models for people with these illnesses in BC:

- **Accessibility**
    - Wait times: Reported to be currently 1.5-4 years or more (historically as low as 6 months).
    - Geographic barriers: Respondents reported that travel requirements limit their access to quality care and/or add to their existing burden of fatigue and disability.
- **Service Model** Weaknesses
    - Respondents reported several formal restrictions on access:
        - Age restrictions excluding patients based on demographics rather than medical need.
        - Time-limited program participation despite the chronic, often life-long nature of these conditions.
        - Prohibition on re-enrollment for previous participants, regardless of symptom changes, severity progression, or changed circumstances.
    - Structural limitations in current service models were also discussed:
        - Restricted access to one-on-one doctor appointments.
            - The Complex Chronic Disease Program (CCDP)—the province's officially designated clinic for these conditions—has a reported 2.5 to 4-year wait list and provides only 564 intakes annually, representing less than 0.2% of patients with these illnesses in BC.[33] Of these intakes, the CCDP reports that only 120 meet with a CCDP doctor, while the remainder see Allied Health Professionals for previously confirmed diagnoses.[34]

[33] The CCDP Program Manager confirmed to the CCDP's Community Advisory Committee that the CCDP provided 47 intakes per month in 2025, up from a previous 23. This is 564 intakes annually.
[34] See previous foot note.

- Dr. Ric Arseneau's clinic, the largest private practice BC clinic focusing on ME, FM, Long COVID and related illnesses[35], typically provides one initial one-on-one consultation, with all subsequent care delivered through group-based models including medical care, prescription initiation and renewal, lecture series, and patient groups.[36]

> Drs. Arseneau and McKay:
>
> "Patient[s] who need ongoing 1:1 follow up are not well suited for our practice model"
>
> June 27, 2025[37]

- Inadequate services for patients with severe illness.
- Minimal support for educating primary care workers or expanding services and knowledge more widely among healthcare workers across the province.
- A few respondents mentioned "unfair" informal prioritization criteria (ex: prioritizing newer cases over established patients[38], potentially disadvantaging equally ill long-term sufferers within lengthy waitlists).

Perceived Harm from Healthcare Services

Respondents mentioned several perceived **harms experienced** within the healthcare system**:**

- Disbelief and dismissal – Practitioners denying the physiological nature of illnesses, minimizing severity and impact, or questioning whether patients actually have these conditions.
- Inability or unwillingness to diagnose – Sometimes including practitioners refusing to requisition necessary tests, provide referrals, or pursue proper diagnostic processes.
- Discrimination – Practitioners dismissing patient experience due to weight, age, gender, activity levels, perceived non-compliance or other demographics.
- Shaming/anger/accusation from practitioners.

[35] "Scope of care includes ME/CFS, FM, Long COVID, POTS, MCAS, hEDS, HSD, cPTSD, central sensitivity syndromes, and associated psychiatric disorders."
[36] Arseneau, Ric and McKay, Jane, "Innovative Multidisciplinary Chronic Disease Care Cost Effective and Efficiency of Group Visits," (white paper) June 27, 2025.
[37] Arseneau, Ric and McKay, Jane, "Innovative Multidisciplinary Chronic Disease Care Cost Effective and Efficiency of Group Visits," (white paper) June 27, 2025, p. 14.
[38] Anecdotally, the rationale is that more recent onset patients have a higher chance of being cured or stabilized and are therefore prioritized over longer-term patients.

Many respondents described **clinical interventions they see as inappropriate or harmful**:

- Advice patients feel is misguided or harmful – Healthcare providers told respondents to: "Just lose weight," "exercise more," "get back to your regular life,"
- Incorrect diagnoses - respondents reported practitioners saying “it’s just anxiety,” “it’s school aversion,” “it’s just a trauma response… you need to see a psychiatrist,” ”…you’re tired and getting stress headaches.” One patient reported: “they [healthcare workers] say it’s central sensitization… I can work through this… it’s based on my experiences and it’s my fault how I’m responding to them.” Respondents reported that proper diagnosis often required multiple practitioners and years or decades.
- Prescriptions patients feel are inappropriate or harmful - Several respondents reported being given Ativan or SSRIs (most often by primary care providers or in emergency care) when they did not have comorbid anxiety or depression; and being prescribed medications they feel worsened their symptoms (such as stimulants or advice to drink coffee or energy drinks).
- Potentially dangerous treatments – respondents reported practitioners recommending contraindicated therapies[39] such as Graded Exercise Therapy (GET) for patients with Post-Exertional Malaise; Cognitive Behavioral Therapy promoted as a cure rather than a supportive tool.

“My doctor told me to exercise more every day. I’m not even a doctor and I can find all the places online where it says not to do that with my sickness [ME]. I know a lady that listened to that advice and got way worse.”

One patient was told to *"work on how you think about this—your mind is keeping you sick"*

- Denial of care – Respondents reported accusations of “non-compliance” and refusal of continued care: one patient reported being refused future care when they refused an

[39] Most reputable sources now advise against the use of GET all together and have downgraded CBT from a treatment to a supportive therapy only. As an example, the current NICE guidelines state that CBT "is not a cure for ME/CFS and should not be offered as such. Instead, it aims to improve wellbeing and quality of life and may be useful in supporting people who live with ME/CFS to manage their symptoms and reduce the distress associated with having a chronic illness” [NICE, NG206,Box 5]. NICE also advises: "Do not offer people with ME/CFS: any therapy based on physical activity or exercise as a cure for ME/CFS · generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses · any programme that uses fixed incremental increases in physical activity or exercise, for example, graded exercise therapy (GET)" [NICE NG206, 1.11.14]. From: National Institute for Health and Care Excellence. Myalgic Encephalomyelitis (or Encephalopathy)/Chronic Fatigue Syndrome: Diagnosis and Management. NICE Guideline [NG206]. 29 Oct. 2021. National Institute for Health and Care Excellence, https://www.nice.org.uk/guidance/ng206.

exercise-based stress-test due to PEM. Respondents also reported being refused tests/treatments, such as LDN prescriptions or Lyme tests, sometimes for fear of losing their license:

"Not a single doctor here in any hospital would even recognize my Lyme disease diagnosis or treat it despite the severity of Neurological and cardiac symptoms. It is one thing to be refused care as an adult woman, it is an entirely different experience when the care of your children is also refused and they are suffering. I was told by a GP to take my daughter out of country if I wanted treatment for her suffering; he stated he wasn't risking his medical license by treating her."

Many respondents noted significant **negative psychological and social impacts** of poor or harmful care**:**

- Trauma and PTSD (Post Traumatic Stress Disorder) from repeated dismissive or harmful healthcare encounters.
- Care avoidance - Patients avoiding essential medical care (primary, specialist, emergency) due to repeated trauma or inappropriate/unhelpful care.

Financial Hardship: Provider Barriers and Inadequate Support Systems

Because this survey focused on *healthcare* experiences in BC, the structured questions on positive (Q3) and negative experiences (Q5) only asked whether respondents had received successful support for financial program applications from their providers. While only 30% of respondents to question 5 reported not receiving this help, financial hardships, challenges accessing funds and benefits, and inadequate funding levels emerged as the most common themes in write-in comments.

According to respondents, many **healthcare providers fail or refuse to help patients** access financial supports. They:

- fail to inform patients about relevant options, programs and rights;
- refuse to provide required testing or documentation;
- charge significant fees for related services;
- provide insufficient or no guidance regarding limitations, risks, and common rejection factors for various programs; and
- submit unsuccessful applications due to inexperience and discomfort describing these illnesses and their true impact on patients.

Respondents facing challenges getting healthcare provider support in seeking access to financial programs described the experience as financially and emotionally "devastating," "frustrating," "angering," "unfair," "shameful," "embarrassing," and "traumatic."

It was also reported that rejections of assistance frequently involved shaming, "gaslighting," denial of patient experience, accusations of trying to cheat the system, or outright dismissal of the illness.

Respondents frequently reported **insufficient access to financial support and resources**[40] to cope with these debilitating illnesses, which commonly eliminate or drastically reduce patients' long-term ability to work. This included:

- Absence of MSP coverage for critical healthcare provider types (e.g., physiotherapists, occupational therapists, massage therapists) and necessary treatments (e.g., low-dose naltrexone or LDN).
- Difficulty locating healthcare providers willing to support financially-related applications such as for disability benefits, parking permits, tax credits, and housing assistance.
- Complex, lengthy application processes inappropriate for illnesses featuring crippling fatigue and brain fog as core symptoms.
- Rejection of financial support applications, attributable both to restrictive eligibility criteria and inadequate application completion by healthcare practitioners
- Denial of coverage for essential medical and living supports (such as in-home healthcare, in-home living assistance, medical devices, etc.), typically due to a lack of recognition of the severity and impact of these illnesses
- Overall insufficient financial supports even when all applicable programs are accessed, for patients often unable to work for months or years at a time and who may require expensive treatments, supplements, medical devices, and in-home care

Many respondents listed their continued and increasing financial burdens (due mainly to inability to work, plus high uncovered medical costs) as untenable and crushing.

Several respondents listed financial factors for family breakdown, rapidly and severely worsening physical health and symptoms, and serious considerations of Medical Assistance in Dying (MAID).

Positive Healthcare Experiences - Detail

Belief, Empathy, Knowledge and One-On-One Care

Just under 40% of responses regarding types of healthcare experiences were positive.[41] Most people who identified having had specific types of positive experiences[42] added additional write-in comments.

[40] While this survey was explicitly about *healthcare* experiences and priorities, the often devastating financial impact of living with these illnesses (as described by respondents) was one of the most strongly and most emotionally discussed items in write-in comments, hence this bullet's inclusion in this section and the report's key findings.

[41] Percentage of all responses from questions 3 and 5 on types of healthcare experiences.

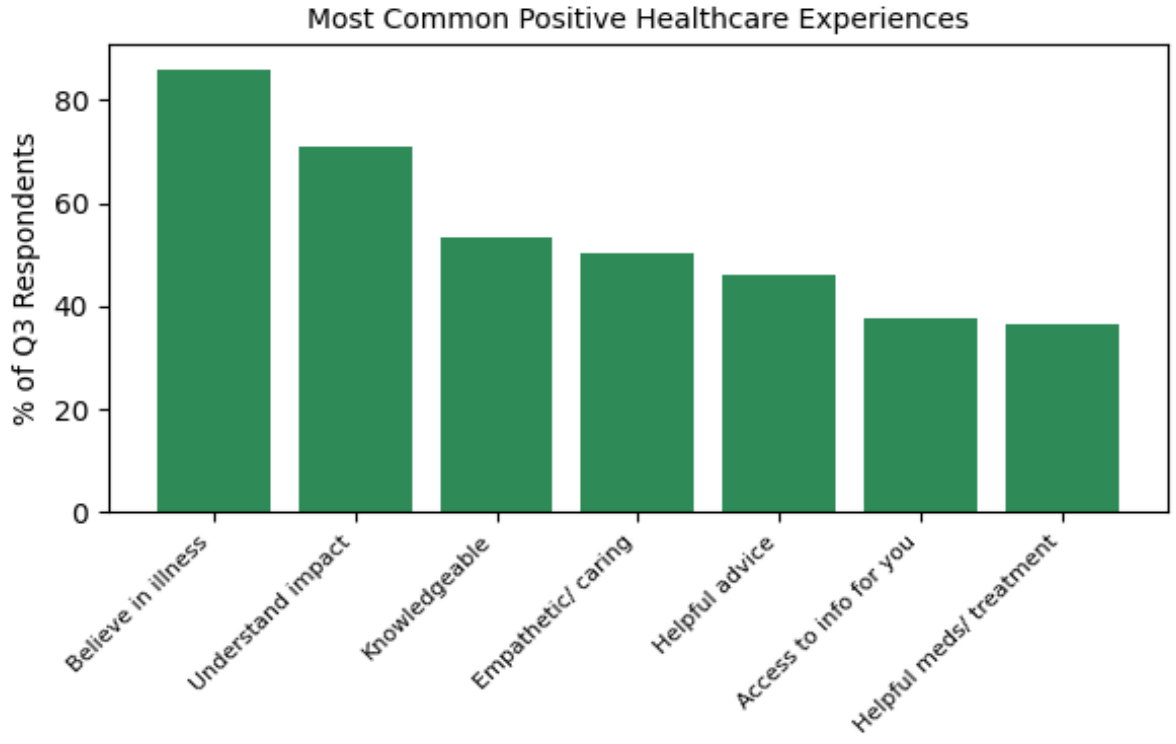
[42] From questions 2 and 4 regarding experiences with various healthcare provider types (primary care, specialists, urgent/emergency, alternative medicine, etc.) and questions 3 and 5 on types of healthcare experiences.

Reflecting respondents' top priorities for care (see section below), positive experiences[43] most often centered on:

- Belief and empathy → included in over 95% of reported positive experiences[44];
- Practitioners with correct, current knowledge → included in over 85% of reported positive experiences; and
- Sufficient one-on-one time and attention to diagnose; understand patients' experiences, symptoms and comorbidities; and provide safe, effective treatments and illness management support → included in over 80% of reported positive experiences.

Many respondents also expressed relief at receiving information or help with financial assistance programs, some of which require healthcare practitioner input.

Figure 5: Positive Healthcare experiences noted by at least 30% of respondents to question 3



[43] In both the structured and unstructured data.

[44] The percentages in this section's bullets are the percentage of respondents who reported a positive experience of some type who noted each topic (such as "belief and empathy") in one or more of their structured answers and write-in comments. Because these include analysis of unstructured data, they must be taken as estimates as they are partially based on the author's tagging of theme/meaning in respondents' write-in comments.

Caveats on Reported Positive Healthcare Experiences

The many reports of specific positive experiences provide examples of the powerful impact on patients (reported as “a relief,” “lifechanging,” and “profound”) of supportive, safe, effective care. However, most respondents reporting positive experiences (usually from only one or two instances or practitioners) included write-in comments that revealed the broader "desert of care" they generally encounter.

“Finally one person (one!) who believed me, who even knew what I had. I barely even cared if they could actually make my health better. I just wanted someone to validate me! Isn’t it sad that THIS is my so-called positive experience?!”

Positive experiences were often described in some form as “a light in the darkness of hellish experiences,” “lucky,” “rare,” and a “relief.” Many also reported their positive experiences as having been in the past, temporary, or from one specific group or practitioner:

“When I got into the CCDP, it was so great. Finally someone to help. I got diagnosed and got some prescriptions. But then that was it. I could never see a doctor, my GP didn’t believe the diagnosis, my referrals fell through and now I can’t get back into the CCDP because I was already in the program. That was years ago.”

“When the Long covid clinic at St. Pauls was first open, it was good. I could see doctors and get help. No one knew what they call a post virus sickness was. But these guys seemed to. They were the ones who told me how to cope and gave me some drugs that seemed to help my dizziness and tiredness – it was that drug for alcoholics [LDN]. Then they shut down. Like, what, we’re all good now? Now my doctor doesn’t even know about it.” and *“Sadly the current provincial post covid clinic is not a helpful model.”*

“I finally found a GP who was pretty good [after 10 years of illness]. Listened, helped with prescriptions. Then they retired and I have had nothing after that but insults and not listening.”

“I know someone who saw Dr. Hyams. He helped. But now he’s retired. I finally got in to see Dr. Arseneau. He was so helpful and so nice. But now I mostly just get to use his online stuff and maybe can do group things online. But these are nice but not what I need… I just wish there were other people nice and who know stuff like Dr. A. but who had time to keep helping me. I have so many symptoms and they change all the time and I think I have other problems too. I think I’m getting worse and don’t know what to do. I really really just want a doctor that can help me.”

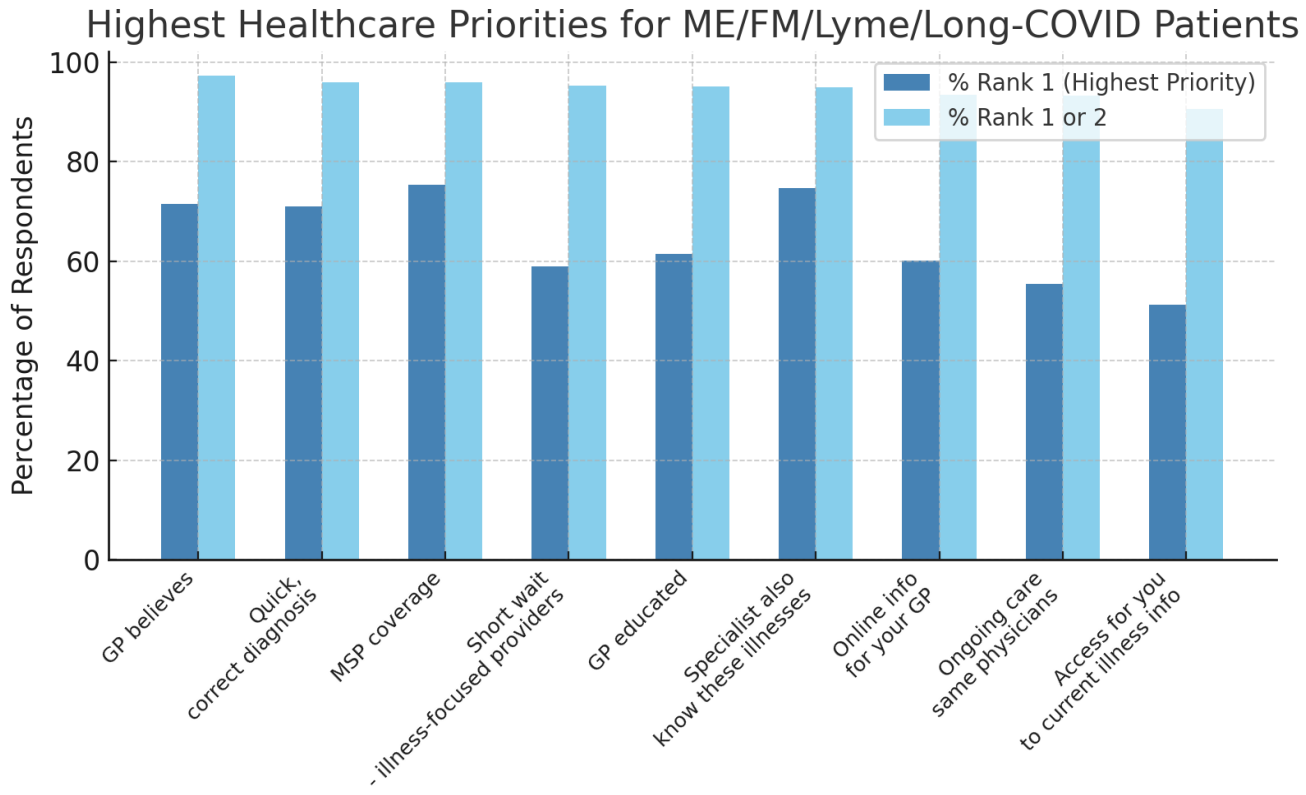
Healthcare Needs and Priorities

Following the questions regarding positive and negative experiences within the BC healthcare system discussed above, the final major question of the survey covered patient healthcare priorities. The question included structured sections (respondents ranked healthcare priorities) and several opportunities to enter write-in comments (providing unstructured data).

Top Priorities

Figure 6 shows the top priorities that emerged from the (structured) question in which respondents ranked healthcare priorities.

Figure 6: Highest healthcare priorities (Q6, structured data)



Further, manual tagging by theme and a "mentions" analysis of the write-in comments[45] was completed and added to the structured data results. In summary, the top priorities reflected in both the structured replies (figure 6 above) and write-in comments[46] included:

- Quick, **one-on-one** access to knowledgeable, helpful healthcare providers:
  - Quick, correct **diagnosis**
  - **Continuity of care** (consistent, ongoing care by same one or group of doctors)
  - **Safe, effective treatment** for specific high-impact symptoms
- Healthcare providers who **believe** the patient, believe in the physiological (rather than psychological) nature of the illnesses, and **understand** the severity of the disability and overall impact of these illnesses. Respectful treatment.
- (Correct, current) **education and information** for primary caregivers and specialists
- **Financial** coverage for tests, drugs and treatments. **Help with (successful) applications to financial and assistance programs** such as disability benefits, insurance, tax credits, education/work support, and housing
- Evidence-based **information for patients** (online, print, etc.) that complements (rather than replaces) medical care
- **Online/virtual one-on-one** appointments (not just information or group sessions)

"There's no one. Was diagnosed by Doctor Arsonolt[sp.]. But my [primary care] doctor can't help with anything. Says I'm not as unfunctioning as I am. Still stuck. Come get us off the ground!"

"They don't believe me. Say I'm crazy and lazy. Just hear what I say."

"I got good doctors. even PT at the start. Can't go to Snt Paul hospital [in-person Long COVID clinic] anymore. And can't pay. I mean, I can't work now. I need that stuff like meds and help."

"Love things ME society [ME|FM Society of BC] puts out. Helps my doctor know what I have."

"There are, like, 2 people who know about this [Long COVID] here [in BC]. And they aren't great. I mean, good they are there, but crappy."

"Without Dr. Ric Arseneau and his team, we would basically have nothing."

"I help my family doctor understand. She kind of gets it now that covid has been around. But zero help. Knows zero. Does zero. Nice lady…"

[45] See Appendix C for a "mentions" analysis of top priorities from the unstructured data, and Appendix D for samples of the thousands of write-in comments, organized by theme.

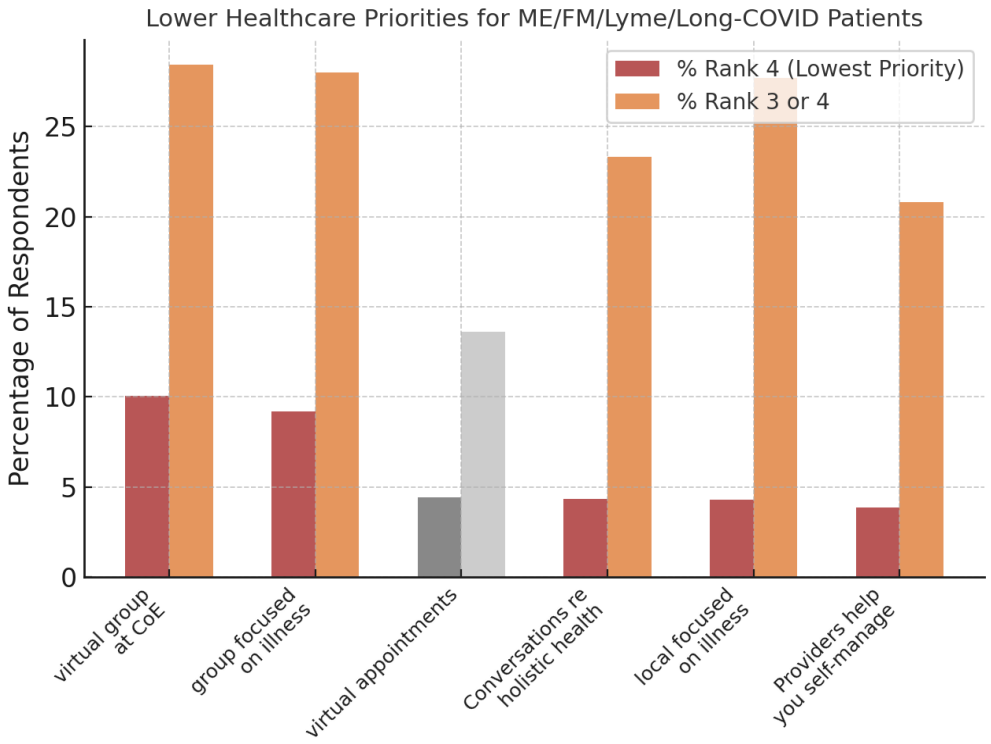
[46] Note that there was no significant difference in priorities expressed by respondents based on geography (Lower Mainland/Fraser Valley versus other regions of BC), duration of illness, or type of illness (though those with Lyme added write-in comments about lack of available testing in BC at higher rates than other respondents).

Lower Priorities

The priorities marked as less important by respondents (see figure 7), along with their write-in comments, further supports and explains the top priorities.

In the healthcare priority ranking question, respondents assigned lower priority to group sessions of any sort; conversations with practitioners regarding holistic health (such as including mental health, diet and lifestyle); having *local* practitioners who *focus* their practice on these illnesses; and receiving general illness management information *from providers* (in lieu of ongoing care and assistance with illness management).[47]

Figure 7: Lower healthcare priorities (Q6, structured data)[48]



[47] Virtual appointments were also listed as lower priority, but these were greyed out in Figure 7 for two reasons: 1) respondents often had related write-in comments that *they* did not see it as highest priority but recognized that people with more severe illness may see it as one of the higher priorities; and 2) it is likely that survey respondent demographics were skewed away from severe patients who were probably less likely to have seen survey-related social media posts, have heard of the survey, or have completed the survey.

[48] The exact text of the items chosen as lower priority, in order as appears in Figure 4, were: "Access to virtual group sessions from a centralized specialty clinic/centre of excellence in BC."; "Access to group healthcare/information sessions with healthcare workers who focus on ME/FM/Lyme/Post COVID."; "Online/virtual appointments." (in grey in chart, see previous footnote for explanation); "Conversations with healthcare workers about holistic health, including mental/emotional, symptoms, diet, lifestyle, etc."; "Local, close to where you live, in-person and online access to healthcare workers who focus on ME/FM/Lyme/Post COVID."; and "General support/information from healthcare workers for illness self-management."

Related write-in comments highlighted several interesting points:

- Group sessions[49] are "a life preserver in a healthcare desert" and "have been a godsend when I can't get any help otherwise." However, respondents prioritized primary, specialist and other provider education/knowledge around these illnesses; provider and public awareness of the severity, complexity and impact of these illnesses; and ongoing, one-on-one healthcare (in-person and virtual).
- Group sessions and online information for patients are felt to be generally (often very) helpful, but mostly within the context of the reported existing paucity of effective healthcare for these illnesses.

> *"Don't get me wrong. Group meetings… connected me with other patients and things I got sent from the ME and FM Society [ME|FM Society of BC] helped talk to my doctor about how bad it is and how I can't exercise. But I really want my family doctor to know about this stuff and listen and help me. Like actual for real help from an in my face doctor."*

- Respondents who had but lost quality one-on-one care - due to retirements; programs that historically had shorter wait lists and more one-on-one care; or clinics closing, moving to, or focussing on group and/or online information - value group work and online information less than other respondents.

> *"I have Longhaul Covid. I got doctor and physio and I think even psych help at the start. I think all under medical plan [MSP]. Then it was shut down. Now I can't afford half the stuff I got and they think giving us papers and videos on the internet is going to replace that. No. Just no. And other options sound like a bunch of groups. Like, I don't need AA with group hugs. I need a doctor to give me drugs and help me."*

> *"A lo[n]g time ago I saw Dr. A [Arseneau] at the CCDP. I'm pretty sure. And I think I saw a few other people there, too. Way helpful back then. Helped with lots of issues. But now Dr. A is all online and team [group] stuff. I don't like that."*

- Reflecting several respondents, one person noted that holistic healthcare conversations are desired, but are "so far away from what I am getting now, that I don't even see it as something I will ever get." A second respondent summarized: "It's so bad right now that I feel like I don't even deserve care for my whole self. Like wishing for 'conversations' of any sort, forget about my overall health and feelings, is just crazy. It's so unfair we are at

[49] By centres of excellence or clinics/providers focussed on these illnesses

a point where hoping for holistic care is so out of reach we don't even try to think about it."

- Local illness-focused practitioners are viewed as less important than ensuring all providers have basic knowledge:

> *"Wouldn't it be lovely to have local people focussed on the way I am sick? Oh, lovely. But not realistic. I just need my doc to get with it and believe what I am telling him. Like, listen and help me. You're a doctor!"*

> *"Just make specialists and regular doctors know anything about what I have and what I am going through. I don't need some* special[ist] *guy or gal right next door."*

- Several respondents noted that, while good (especially on-line) information for both practitioners and patients is critical, it is less important that practitioners *provide* patients with general information on self-management.

> *"I don't need general stuff telling me to go home and take care of my own ME and POTS* [Postural Orthostatis Tachycardia Syndrom]*. I want my doctor to spend more time with me and help me get rid of [my symptoms]."*

Conclusions

- Ove 90% of patient respondents have experienced inaccessible or ineffective (and sometimes, in their view, harmful) healthcare that often dismisses, denies or disrespects them and their illness. Many no longer seek needed medical care due to traumatic or unhelpful previous encounters, creating dangerous gaps in basic healthcare access.
- The predominant experience includes physical, personal, emotional and financial loss and hardship, often worsened rather than helped by existing BC healthcare services.
- Over 90% of patient respondents reported one or a few significant positive experiences. These are marked most often by a respectful, knowledgeable provider who offers appropriate testing, proper diagnosis, helpful referrals, support for financial assistance applications and real help with illness management. However, most respondents have struggled to find consistent access to such care, creating frustration and desperation in a patient population already facing severe illness burdens.

Recommendations

BC has an opportunity to become a leader in complex chronic illness care. The following recommendations can transform patient outcomes while supporting healthcare providers with the knowledge and tools they need to deliver effective care.

1. **Comprehensive Provider Education and Support** - Develop mandatory continuing education on ME/FM/Lyme/Long COVID, clinical practice guidelines, specialist consultation access, and dedicated online resources for healthcare providers. Focus on illness recognition; the physiological nature of these illnesses; their complex, debilitating nature, including their impact on quality of life and mental health; proper diagnostic criteria and approaches; effective treatments; and awareness of potentially harmful interventions.

In a 2021 ME|FM Society of BC report on ME[50], **BC clinicians noted** 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

2. **Care Models Defined by Patient Needs and Priorities** - Design accessible, patient-centered care emphasizing one-on-one appointments with adequate time, and continuity of care. Ensure robust funding, transparent and robust patient participation in design and improvement, explicit patient tracking[51], and care pathways for severe patients that include in-home, inpatient and virtual care.
3. **Enhanced Financial Support Systems** - Ensure healthcare providers receive information and support for successful financial assistance applications. Review and revise discriminatory qualifying criteria for existing financial support programs, and increase their funding levels to ensure they functionally support eligible patients. Expand MSP coverage for essential treatments and providers.
4. **Comprehensive Patient Resources** - Provide current, evidence-based information on diagnosis, treatment, management strategies, and financial options, alongside tools for communication, symptom and treatment tracking, and peer support connections[52].

[50] https://mefm.bc.ca/our-research#unmet-needs

[51] Better tracking of these illnesses (through diagnostic codes, e.g.) would greatly help in future assessments of care, provincial funding conversations, and improvements in patient care

[52] Several respondents mentioned that interactions with other patients were helpful for overall quality of life, including social media (Facebook groups, e.g.), group sessions from clinics (CCDP, Dr. Arseneau, e.g.), facilitated online support groups (ME|FM Society of BC support groups, e.g.); and informal friendships and relationships.

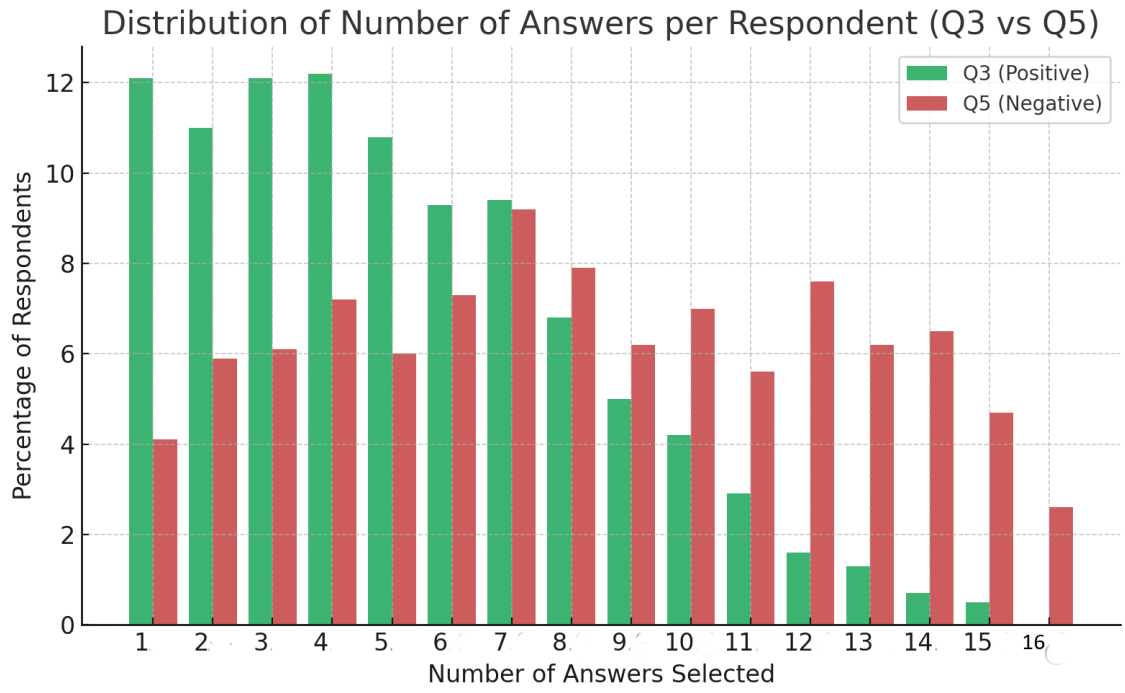
Appendix A: Overall Healthcare Experiences - Statistics

Among respondents who the relevant questions[53]: **93.2%** reported at least one **positive experience**; and **92.5%** reported at least one **negative experience**.[54]

However, the distribution of numbers of reported positive versus negative experience types shows a strong skew toward the negative overall, (despite there having been equal positive and negative options from which to choose):

- 61.1% of reported experience types were negative and 38.8% positive.
- Respondents generally had many *more* types of negative experiences than positive, as can be seen in Figures A1 and A2.

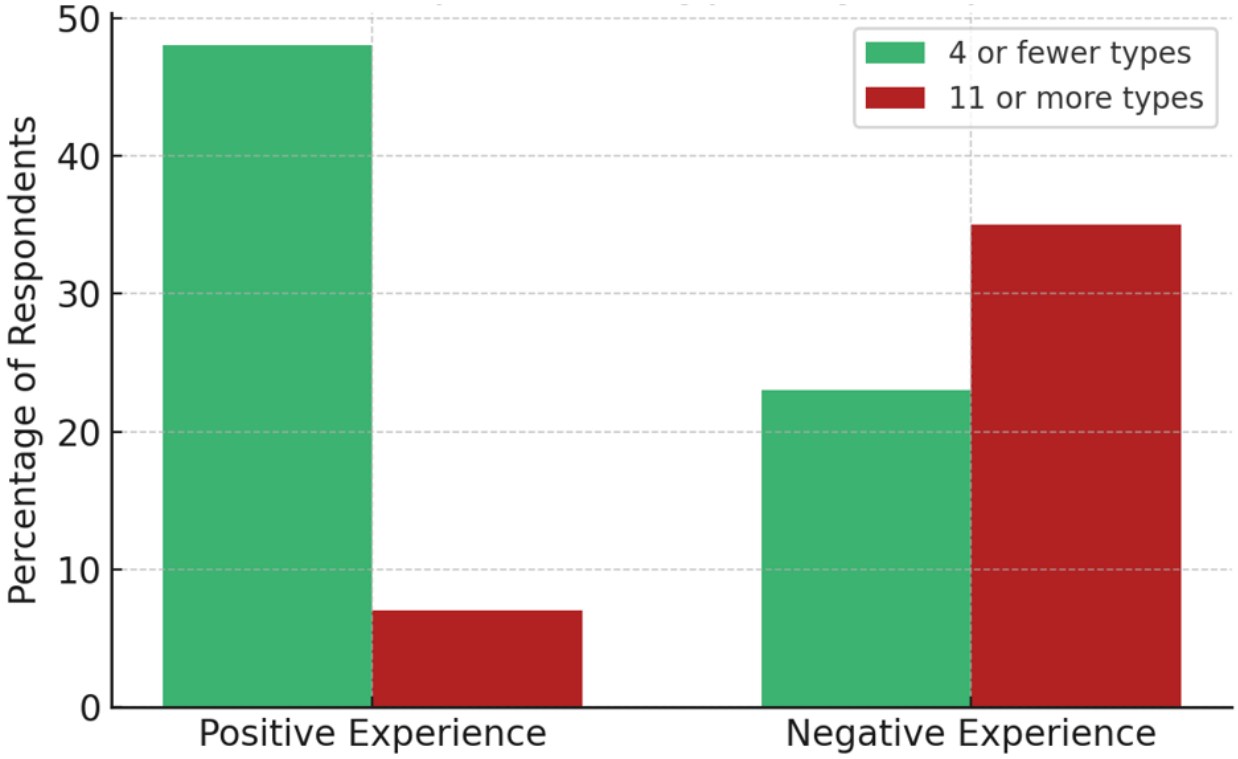
Figure A1: The percentage of respondents reporting various numbers of positive and negative experiences



[53] 124 respondents did not answer one or more of the positive and negative experience questions.

[54] This data is from questions 3 and 5 which asked parallel questions about types of positive and negative experiences.

Figure A2: The percentage of respondents recording having had 4 or fewer OR 11 or more types of positive and negative experiences.

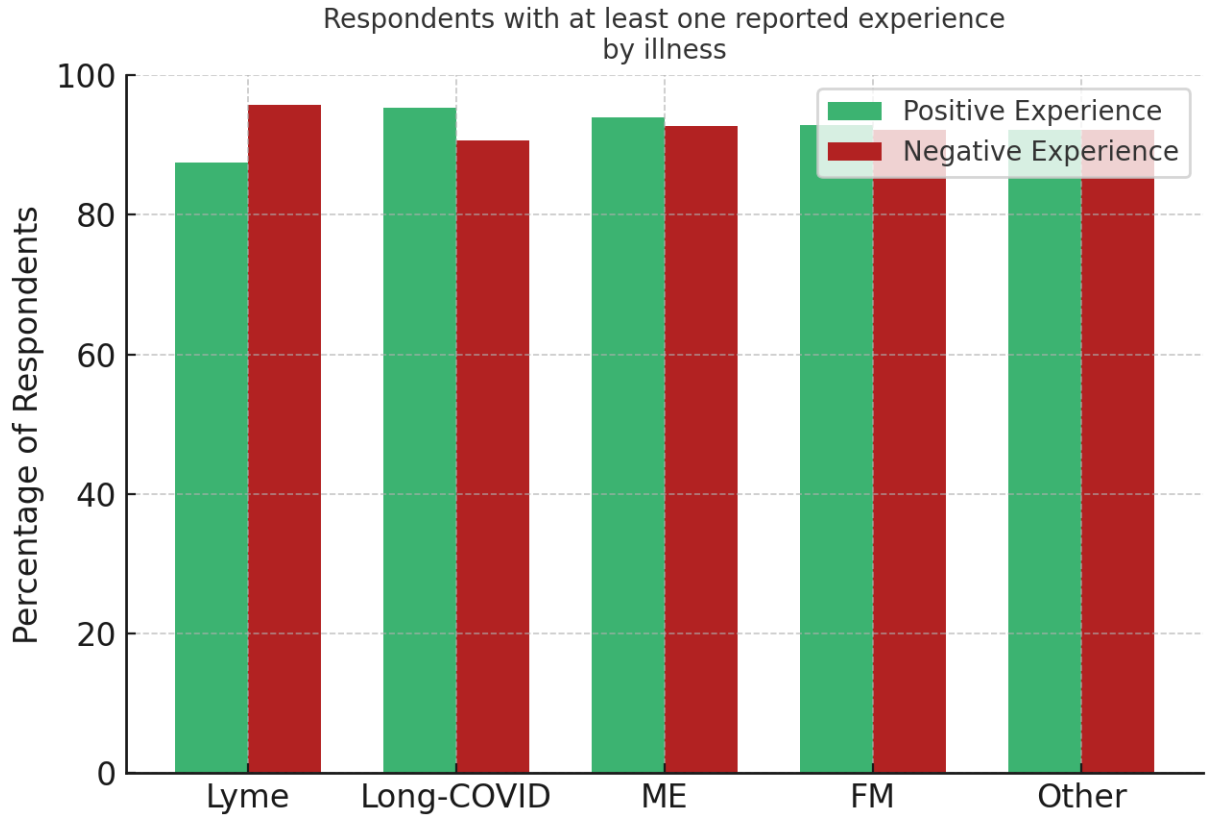


Write-in comments skew even more strongly to the negative, with over 88% of write-in comments containing negative sentiment (34% also contained some positive sentiment, 7% contained only positive sentiment).[55]

There were no significant differences by region (Lower Mainland/Fraser Valley versus other regions of BC) or by duration of illness. However, as seen in the table below, fewer respondents with Lyme reported any positive experience (87.5%) while more reported at least one negative experience (95.8%). On the other hand, more respondents with Long COVID reported at least one positive experience (95.3%) and slightly fewer reported any negative experiences (90.6%).

[55] Based on sentiment analysis completed by ChatGPT-4o (paid version) and verified manually by the author with a 5% check-rate. Error on the verified statements was less than 2%.

Figure A3: The percentage of survey respondents with each illness type who reported at least one type of positive healthcare experience (Q3) or one type of negative healthcare experience (Q5).



While differences between illness types are modest, two patterns stand out: Lyme patients reported fewer positive types of experiences and more negative ones, while Long COVID patients showed the opposite pattern. Write-in comments suggest distinct explanations for each. Lyme patients frequently reported being denied necessary testing that is available outside Canada. In contrast, many Long COVID patients had positive early experiences with BC's in-person Long COVID clinics until they transitioned to online-only, with no direct access to doctors, in March 2023. Most Long COVID patients reported generally negative healthcare experiences since then.

Appendix B: Experiences with Different Types of Healthcare Providers and Care Contexts

Questions 2 and 4 asked about patient experiences with different types of healthcare providers and contexts. The questions asked "Where have you had GOOD (or BAD) experiences in healthcare for these illnesses?" It is important to note that this answer represented experiences with different types of providers patients *had actually seen*. This question did not reflect issues accessing providers and many write-in comments on question 2 regarding positive experiences noted one of the following: there was only one provider with whom the respondent had had positive experiences; there had been a long wait time or resistance from a primary provider to refer; and/or the patient no longer had access to the provider with whom they had had the positive experience.

Table B1: # of respondents reporting on experiences with each care context/provider type.

Care Context/ Provider Type	# Reporting Any Experience (pos, neg or both)	# Reporting a Positive Experience	# Reporting a Negative Experience	# Reporting Both (Pos + Neg)
Emergency/acute/ walk-in	458 (43.8%)	64	425	31
Primary care	864 (82.7%)	466	566	168
Specialists	763 (73.0%)	468	503	208
Alternative/mental health	720 (68.9%)	555	367	202
ME/LC/FM/Lyme specialized	612 (58.6%)	541	136	65

Table B2: Percent of *all respondents* with at least one positive or negative experience with each provider type/care context (% of entire respondent population)

Care Context/ Provider Type	*% of All Respondents* Reporting a Positive Experience	*% of All Respondents* Reporting a Negative Experience
Emergency/acute/ walk-in	6.1	40.7
Primary care	44.6	54.2
Specialists	44.8	48.1
Alternative/mental health	53.1	35.1
ME/LC/FM/Lyme specialized	51.8	13.0

Table B3: Percent of respondents who had any type of experience with each care context/provider (see Table B1), who had positive and negative experiences (% of respondent population who entered an answer for each care context in Q2, Q4, or both)

Care Context	*% of Respondents with Any Experience* Reporting a Positive Experience	% of Respondents with Any Experience Reporting a Negative Experience
Emergency/acute/ walk-in	14.0	92.8
Primary care	53.9	65.5
Specialists	61.3	65.9
Alternative/mental health	77.1	51.0
ME/LC/FM/Lyme specialized	88.4	22.2
Other providers	76.3	42.6

There are some patterns of note.

Generally Negative Experiences with Emergency, Walk-in or Acute Care

See mini report Topic 1: Experiences with Emergency Care, in Appendix F.

Generally Positive Experiences with ME/FM/Lyme/Long COVID-Focused Providers and Clinics

Many respondents reported positive experiences once they accessed illness-focused practitioners, in-person Long COVID clinics, or the CCDP. These experiences typically included:

- Relief at finally being believed
- Receiving helpful illness information and/or prescriptions
- Finally obtaining a diagnosis (often after years or decades)
- Assistance with financial program information and applications

Unfortunately, write-in comments noted that wait times ranged from 6 months (historically) to decades, depending on primary care physicians' knowledge and referral willingness. CCDP wait times were reported as 1-4+ years (currently), with the program lasting only one year and no re-enrollment allowed.

Most respondents also noted that after initial meetings, further one-on-one care became difficult to access from the CCDP and the Arseneau clinic. Both focus primarily on online information and group sessions, which respondents appreciate and generally report on positively, but overwhelmingly value less than individual appointments.

Respondents who attended in-person Long COVID clinics all noted substantial loss of care when clinics transitioned to online information-only services. These respondents generally reported struggling to find appropriate care after in-person clinic closures.

Generally Positive Experiences with Mental Health and Alternative Practitioners

Respondents described that, while many of these practitioners lack knowledge about these illnesses and are often not accessible over the long-term due to lack of coverage by MSP, they tend to:

- Believe patients and treat them respectfully
- Take time to discuss experiences and symptoms
- Provide one-on-one appointments, often with virtual options
- Willingly prescribe or refer for helpful care

Appendix C: Top Needs and Priorities by Mention in Write-in Comments[56]

Strongly mirroring the priorities noted in the structured data, the write-in themes also focused on one-on-one care from respectful, educated providers who take the illness seriously; better help with financial supports/programs; better overall access to safe, effective care; care that recognizes the complexity and diverse nature of these illnesses, as well as their common comorbidities; and continuity and coordination of care.

Table: Priority themes – results of key-word and topic analysis of unstructured data

Theme		Mentions	What Respondents Are Saying
Appropriate Care	**1:1 care**	2,407	Urgency to fulfill the unmet need for safe, effective 1:1 care and treatment (including knowledgeable and supportive primary care, specialists, physio, mental health, occupational therapy, and other alternative care, such as naturopaths, and massage).
Appropriate Care	**Education/ Knowledge**	880	Need for educated providers with illness-specific knowledge, who keep up with research and best practices.
Appropriate Care	**Validation/ Empathy/ Respect**	671	Desire to be believed, taken seriously, respected and not dismissed or "gaslit" by healthcare professionals.
Appropriate Care	**Trauma**	177	Importance of healthcare that does not cause trauma and PTSD (Post Traumatic Stress Disorder) from negative medical encounters and disrespectful treatment.
Financial		1,378	High concern around disability supports (CPP, DTC), affordability of care and MSP coverage (including tests;

[56] Although statistical analysis of unstructured data must be conducted with caution, there were some interesting patterns in the write-in comments throughout the survey. In this table, a "mention" is any time a respondent used a word or phrase denoting a need, preference or priority regarding the listed theme. While larger numbers of mentions do not necessarily reflect a higher overall priority, the patterns seen here are interesting and reflect a similar pattern to that found in the structured data.

Theme	Mentions	What Respondents Are Saying
		alternative care such as physio, massage, OT, etc.; and drugs), income assistance, housing security, and other financial issues.
Access	1,341	Desire for shorter/reasonable wait times to see healthcare providers (especially ME/FM/LC/Lyme-focussed individuals and clinics), decreased travel barriers, better local availability of illness-aware primary caregivers, better knowledge/ability to care for chronic illnesses in general in Canada, and more virtual/online 1:1 care options.
Complexity/ Comorbidities	248	Care that recognizes and can support the complexity of these illnesses. Many also have multiple conditions/comorbidities and are poorly served by the existing fragmented and siloed care.
Continuity/ Coordination	129	Desire for long-term relationships with providers who understand their full health history, will coordinate information from multiple providers, and will help monitor and manage the illnesses with the patient over time.

Appendix D: Write-in Comments

The survey that was sent out examines ME, FM, Lyme, and Long COVID patient experiences and priorities regarding healthcare in BC. It covered multiple aspects of patient care, needs, and priorities. Throughout the survey, respondents had numerous opportunities to provide free-form, write-in comments and additional thoughts.

These write-in comments added significant depth and nuance to the structured multiple-choice responses. Examples:

- Many respondents who reported positive experiences with specific providers (such as GPs or physiotherapists) noted in their comments that these few positive encounters occurred within a "desert" of care or provided "relief" from previous care they described as poor, ineffective, or harmful—both mentally and physically.
- Most respondents who recorded a positive experience with existing illness-focused clinics added write-in comments explaining that while group sessions and online information (the core clinic offerings) were helpful, and that accessing any knowledgeable services—particularly for diagnosis, prescriptions, and assistance with disability and financial programs—was a "godsend," they emphasized their critical need for one-on-one ongoing care, access to other educated and knowledgeable providers (including GPs and emergency staff), reduced wait times for all provider types, and sustained individualized care for managing illness complexities and comorbidities.

While this report includes select representative quotes, thousands of additional comments (over 3,000) could not be captured within these pages.

The following link provides access to a supplementary document containing some of these respondent quotes, organized thematically. While not exhaustive, this compilation offers insight into the volume, tone, and substance of respondent perspectives:

https://drive.google.com/file/d/1KXk9DdSyX2Vvl07tJ5Xo1KeeCQo61SGT/view

Appendix E: Q5 wording & mapping to labels in Figure 4

The question

What NEGATIVE experiences or gaps in care/services have you had? Choose all that apply (to you or the person you are filling this out for). Add additional comments at bottom (optional).

Exact survey wording of the options, with the corresponding label used in Figure 4

Label in Figure 4	Exact survey text
Not believe	Healthcare workers who do not believe you, do not believe you are ill, think it is a mental health issue only, do not take your illness/symptoms seriously, or do not believe it is as bad as you say.
Dismiss/ disrespect	Healthcare workers who have been outright dismissive, have "gaslit" you, or have been "mean" or disrespectful.
Discrimination	Discrimination by healthcare workers due to your financial situation, race, age, gender, weight, perceived attitude, etc.
No or bad knowledge	Healthcare workers who have not heard of your illness, know little or nothing about it, or have incorrect or outdated information.
Trauma/lost trust	Loss of trust, increased hesitancy to see a doctor, or Post Traumatic experiences (PTSD) from poor/difficult medical or health care.
Wrong/long diagnosis	Incorrect diagnoses or a very long time (over a year) to get a correct diagnosis.
Poor primary care	Unhelpful, poor quality or otherwise unacceptable primary healthcare workers (such as GP/family doctor or nurse practitioner).
Poor time/ attention	Insufficient time or attention from healthcare worker(s) to discuss, understand and make care plans for your illness(es).
Bad/ harmful treatments	Unhelpful, ineffective or harmful medications, advice or treatments.
Missed comorbidities	Attributing new/additional symptoms to your main diagnosis instead of looking for possible secondary or additional health issues (possibly leading to missed comorbidities/other conditions).
Bad access - specialists	Difficulty in getting referrals to specialists or long wait times to see specialists (like rheumatologists or neurologists).
Bad access - CoE/ clinic	Difficulty in accessing clinics or centres of excellence that specialize in these illnesses.
Hard to find info for you	Challenges in finding good, trustworthy information about your illness(es) (facts, symptom details, management tools, credible online sources).
Poor/ no mental health care	Difficulty accessing or poor quality mental/emotional or other similar support services.
No help with financial	No or ineffective help getting CCP-disability benefits, employer/workplace insurance, tax benefits, parking permits (SPARC), other financial or housing assistance, and similar. What did you want but not get effective help for?

Appendix F: Topic-Specific Mini-Reports

The survey data collected contains rich and extensive information regarding BC patient experiences, needs and priorities for healthcare, not all of which can be captured at the level of detail provided in the main body of this report. In the following pages, several topic-specific mini-reports have been produced to impart some of this detail. The intent is both to bring out an additional level of detail from the survey respondents and to provide advocacy/patient groups, healthcare workers, policymakers, researchers, and healthcare service organizations and decision-makers with potentially valuable single-topic-focussed data and analysis.

Upon initial report publication, one mini-report on patient experiences with emergency care was included. Additional mini reports will be produced, published as separate documents, and added to this main report below. As mini-reports are added, the following list of topics will be updated with publication dates.

#	Topic	Date Published	Lead author
1	Experiences with Emergency Care	October 9, 2025	Kelly Lautt

Mini-Report -Topic 1: Experiences with Emergency Care

Summary Statistics

About 44% of respondents from BC **recorded an experience with emergency care** (positive or negative).

Emergency care experiences were **overwhelmingly negative** across all illness types:

- **About 93%** had a **negative experience**.
- **100% of people with Lyme** reported a **negative experience** (only 4% had a positive experience).
- While not strongly significant, it is interesting that **people with Long COVID have had slightly fewer negative and slightly more positive experiences in Emergency**. This may be due to illness-recognition, but unclear.

Illness	% Positive	% Negative
ME/CFS	12.7%	92.5%
Fibromyalgia	12.1%	93.5%
Lyme Disease	4.0%	100.0%
Post COVID / Long COVID	18.3%	85.6%
Other Post-Viral / Dysautonomic	19.1%	90.4%

Themes from write-in comments

1. Lack of diagnosis/care lands people in ER
   - Waste of ER resources
   - Can lead to worse acute and/or long-term symptoms and health outcomes
2. Poor care due to general lack of knowledge among ER workers
3. Negative experiences and outcomes due to rejection or denial of patient's illness/diagnosis in ERs
   - Incorrect, often harmful treatment and recommendations.
   - Accommodations for the special needs of these illnesses ignored or denied.
   - Dismissal, shaming, misclassification as mental health issues, trauma, PTSD (Post Traumatic Stress Disorder).
   - Strong self-advocacy (often difficult/impossible due to the fatigue and brain fog of these illnesses) required for even basic illness acceptance or care.
4. Comorbidities and/or the complex nature of these illnesses posing barriers to care in emergency settings

5. Patients no longer seeking medical care, even in an emergency, due to poor, inappropriate, potentially damaging and/or traumatizing care.

There were only 3 clearly positive write-in comments, all of which were about a specific ER or a specific physician (unnamed physician in ER being kind or referring the patient to a useful specialist).

Anecdotes and Examples by Theme

1. **Lack of diagnosis/care lands people in ERs**
   People are ending up in emergency due to lack of proper diagnosis and/or care. Undiagnosed, they may experience disturbing symptoms they do not understand and go to emergency when a dark, quiet room and rest may have been the recommended treatment had they been under proper care. Not only is this wasted use of ER resources, but may significantly worsen the patients acute and/or longer-term symptoms (due to the stress and PEM that may be triggered by an ER visit).
2. **Poor care due to general lack of knowledge among ER workers**
   "Having to seek emergency care is very stressful as most ER and urgent care doctors are completely unknowledgeable about our conditions. Having educated doctors and healthcare practitioners is essential for receiving adequate care and support."
   "Emergency physicians… had no idea what else to try to help me."
   "I was cared for in emergency situations in Hospital… physicians there…didn't realize the seriousness of Myalgic Encephalomyelitis."
   "Emergency room doctors and staff [need to be] informed that chronic illness patients do not present the same as other patients and may be in great pain or other things even if they look OK."
   "Every ER should have a dr that is aware of ME/CFS, sadly trips to the ER have generally lead [sic] to crashes and bad medical care."
3. **Negative experiences and outcomes due to rejection or denial of patient's illness/diagnosis in ERs**
   - **Incorrect, often harmful treatment and recommendations**
     Several respondents mentioned having their health harmed acutely and longer-term from their experiences in ERs. Examples included being forced to stand, wait or sit upright during a crash, long waits, and difficult conversations, all leading to no effective acute treatment and often crashes or PEM over the following days/weeks.
     Respondents also mentioned being sent home with prescriptions for Ativan (in one case leading to a dangerous reaction and fainting) or advice to seek mental health care or "exercise more and lose weight."

The overarching sentiment was expressed by one person who described "Multiple emergency room experiences that were inhumane and dangerous, with advice to take medications that were irrelevant or unnecessary."

- **Accommodations for the special needs of these illnesses ignored or denied**

  Once in emergency, people are not being accommodated for the special needs of their illness (such as a need to recline, and a need for low light/noise). Mostly because their illness is not being recognized as having important accommodation requirements or because the patient is being misdiagnosed in emergency (even when telling the ER workers what illness they have).

  > "EMTs and Paramedics have been generally understanding and accommodating. However, the understanding in emergency care stops at there."
  >
  > "Currently no one in emergency understands what PEM is and that those with severe ME need to be laying flat. They do not believe patients when told that sitting up can cause permanent decline."
  >
  > "[Experiencing serious symptoms], I went back two or three times and wasn't believed that I was so sick. The bright lights and noise made everything worse and they would not call my ME doctor (Hyams) for information."

  One patient experiencing a debilitating ME crash was told in ER that they were "just experiencing a panic attack" and there was nothing else wrong with them. They were sent back to the loud emergency room, despite the patient clarifying that they required lying flat in low noise and light when their crash was this serious.

  One respondent listed several issues, and recommended fixes, including benches or cots in waiting areas to accommodate lying down, use of texting and allowing patients to leave and be called back, and better attention to the needs of immunocompromised patients:

  > "My biggest issue right now is the ER. I have some serious other health issues that require me to visit the ER many times a year. For someone with ME/CFS, the ER is already a nightmare. There are simple ways to improve the ER.
  >
  > - Firstly, allow patients to leave a cell number and get a text when it's their turn, depending on their triage level. Patients who are needing emergent care (say for a kidney infection) but are stable and at a low triage level should be allowed to leave and come back. If there needs to be a waiver of liability, so be it. I am immunocompromised and I do not need to be sitting in a room full of sick people for 8 hours.
  > - Secondly, there absolutely needs to be places to lie down. ERs seem to have purposefully bought chairs with armrests to prevent people from lying down. It's absurd. I am physically unable to sit for extended periods

of time, because it will make me crash, on top of all the stress of being sick and in a loud and bright environment. Swap out the existing chairs with benches. Add small pop-up cots. Put people in a hallway on a stretcher and send them a text when it's their turn. Convert a hallway or adjoining area into extra space for beds. There are SO many ways to fix this and seriously, how much does a bench or a cot cost? … honestly inhumane, and it doesn't just affect people with ME/CFS, but with many other disabilities and illnesses."

- **Dismissal, shaming, misclassification as mental health issues, trauma**

  Several people mentioned going into the ER with significant "debilitating and scary symptoms" and being told it was anxiety or panic. These respondents noted that they did not get the care they needed, and instead were "gaslit" into thinking they had mental health issues and often given unnecessary and/or inappropriate medication based on the misdiagnosis.

  "When my body wouldn't respond and I couldn't get out of bed, I panicked and asked my husband to take me to the emergency. After spending 6-7 hours at the hospital, I was told I had "anxiety." However, it was my symptoms that caused my anxiety, not my anxiety that caused my symptoms. I went home even more stressed because I had no idea what was wrong with me and didn't know who to turn to next."

  "Getting care in emergency is an absolute nightmare! They treat me like I'm insane or a drug addict seeking pills, when I just want care and diagnostics done. I get labeled a hypochondriac and they write these things on your file, which other doctors later see and therefore continue to dismiss my symptoms."

  "Being told your symptoms are just anxiety is not something an ER DR should tell you, unless you've done a psychological assessment."

  "Emergency visits… were traumatic"

  "poor treatment in ER (dismissive, argumentative, zero empathy, zero help from one doctor, wait times up to 8 hours)"

  "Emergency doctors who think I'm wasting their time and being very dismissive"

  One person reported that, after communicating that they were there for a bad ME crash (with shaking and severe weakness, palpitations and difficulty speaking), they were told repeatedly that they were "simply experiencing a panic attack" even when the patient assured them they knew they were not.

Many respondents reported specific discriminations across healthcare settings, including in the ER: One person described going to emergency and being dismissed and treated as a mental health case with their illness not being taken seriously due to

gender (trans), age, and weight, while others noted that their weight was often cited when being told their symptoms were likely from lack of exercise, poor self-care/general health, or laziness (not a real illness).

Some respondents mentioned being accused of attention seeking or drug seeking, when they are using emergency care because of the severity of their symptoms and the lack of other care options: “We are not drug seeking trust me I would not be there if my pain wasn't approaching critical levels and if I had not already tried all other resources. “

Several respondents noted that they have stopped mentioning they have their illness (specifically ME) because it leads to refusal of appropriate care, dismissal, accusations (such as drug-seeking, anxiety, or laziness), and worse health outcomes.

> “I rarely disclose ME, if I I'm visiting emergency for another issue for fear of being judged in a poor light.”
>
> One person described how mentioning that you have ME leads to being treated as a hypochondriac and de-prioritized in the ER, even if you are presenting with significant symptoms: “went to the Emergency for (during period where I didn't have a GP). They weren't overly concerned once I gave them a brief medical history, including telling them I had ME. They had me wait in the waiting room. Eventually the nurse came to get me for an ECG, and she said I would return to the waiting room afterward, until the tech started running the ECG, then suddenly everyone's whole attitude to me changed.... dramatically.”

- **Strong self-advocacy (often difficult/impossible due to the fatigue and brain fog of these illnesses) required for even basic illness acceptance or care**

  Several respondents mentioned that a lot of effort was expended on attempts (often failed) at self advocacy due to illness denial or lack of knowledge. It was additionally noted that self advocacy is especially challenging with the fatigue and brain fog often present with these illnesses.

  Some noted the need to carry their own detailed information about the illness into emergency care (or any new medical situation).

  > “…if I need medical help from those outside my usual network, like emergency health services, I [must have] appropriate information about my health conditions and medications available for those who need to treat me. I always have information available on my mobile device, tablet, or laptop, but I will also have information on paper.” This same person noted that they understand that they are lucky to have a supportive husband who can help advocate and manage this with her, and notes that most people are not this lucky.

4. **Comorbidities and/or the complex nature of these illnesses posing barriers to care in emergency settings**

   Many reported facing additional care challenges and barriers due to the complexity of their illness or comorbidities, including in the ER setting.

   One person expressed being sent home with dangerously high heart rate and undiagnosed secondary issues because of her primary ME diagnosis not being believed.

   One person reported that the trauma of the treatment in the ER triggered an asthma attack. But since he had already been dismissed as "simply having a panic attack," he was prescribed Ativan, from which he later had a negative reaction and serious fall. He ended up having to seek emergency care at a second location.

5. **Patients no longer seeking medical care, even in an emergency, due to poor, inappropriate, potentially damaging and/or traumatizing care**

   "The entire system is a mess and creates frustration and trauma. I no longer seek medical care even in situations that many would deem an emergency."

   "Because I had Lyme Disease one doctor in emergency ignored my acute asthma exacerbation, gave me puffers, but refused to give me appropriate nebulizers, which resulted in me having to get my respirologist to order a nebulizer machine and me refusing to go to the ER subsequent times, despite being urged to go to the ER by doctors for my acute asthma flares. This doctor created PTSD [Post Traumatic Stress Disorder] of emergency rooms for me."

   "Very negative and traumatizing ER experience after I collapsed and was unable to walk leading to extreme reluctance to engage emergency care ever again."

   "I hesitate to go to the Emergency room at my local hospital because of the treatment there that exacerbates my disease and the lack of understanding. I have arrhythmias and costochondritis. When my heart rate increases, I need to have it checked out. However, I hesitate due to the traumatic experiences I have had and my fear of being made more ill."

   "Because of my 'complex condition' I have been sent home from emergency with sustained tachycardia over 130 bpm laying down for 6 hours straight to rest at home with no follow up. The emergency room in my town… doesn't seem worth going, even if I am having severe symptoms that would normally warrant seeing a doctor."

Analysis notes

Out of the *total* BC population, only about 4.5% reported a positive experience with emergency, while about a third reported a negative experience, with no significant difference between LM (Lower mainland and Fraser Valley) and other BC regions.

Location	Negative (%)	Neither (%)	Positive (%)
BC – Lower Mainland / Fraser Valley	31.3%	63.9%	4.9%
BC – Other	29.3%	66.4%	4.2%

About 35% of respondents in BC reported an experience with emergency care (positive or negative).

> The majority (about 65%) did not record either positive or negative experiences with emergency care.

Of those who recorded an experience, about 2% reported both positive and negative experiences.

The duration of illness had no significant impact on whether a respondent reported an emergency experience of any sort OR, for those who reported an experience, whether it was positive or negative.

There were only minor differences in experience based on reported illness (Long COVID slightly less negative/more positive and Lyme less positive and slightly more negative). See table in Summary Statistics above.