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EMPOWERING COMMUNITY AND REMOVAL OF BARRIERS (ECRoB) PROJECT INTERIM REPORT: ASEQ-EHAQ NOVEMBER 2022 - JULY 2023

EMPOWERING
COMMUNITY
AND REMOVAL
OF BARRIERS

Empowering Community and Removal of Barriers (ECroB) Project
Interim Report: Progress and Results Achieved

Phase I

November 2022 - July 2023

ASEQ-EHAQ

July 28, 2023

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Acknowledgement and broad results of ECRoB project for people experiencing the disability of Multiple Chemical Sensitivity (MCS)

We would like to acknowledge keen leadership in addressing accessibility and disability concerns, and equally, convey sincere thanks to the Employment and Social Development Canada, disability, for entrusting ASEQ-EHAQ with the formidable task of paving the way for equity, inclusion, diversity and accessibility for the 3.5% of the population of Canadians diagnosed with Multiple Chemical Sensitivity (MCS) (CCHS, 2020), and the many more without a diagnosis. This community numbers over 1.1 million and presently has no infrastructure in place for accessibility in the workplace, to health care and services, for education and worship, and generally to the community.

We feel privileged to be given this important task to educate, create awareness, uplift, include, support, recognize, and work for the disability of MCS and other disabilities.

Given our starting point, with limited resources, we are incredibly proud of the progress we have made in such a short time span! We are dedicated to achieving sustainability in all our endeavors. The magnitude of the challenges we face necessitates our continuous efforts to scale up to improve accessibility on a larger scale, and address crucial areas that require attention in order to effectively support the community we serve.

The community we serve has long experienced a distressing absence of access to vital services, community, work, healthcare, education, and more, acknowledging that they have been overlooked and underserved by existing systems designed to provide assistance, support, and protection. Their daily lives are often characterized by mere survival - with accessibility concerns being a distant consideration. It has been reported to us that for many, survival is from day to day and even hour to hour..

It was reaffirmed that the MCS community by and large have resigned themselves to their fate of being unemployed often though they are educated and highly educated at the same level as the general population (CCHS, 2015-2016), to the lack of access to essential services and they acknowledge that they have fallen through the cracks of systems in place to help, support and protect. Accessibility is nowhere on their radar.

In response, we are diligently constructing a robust support infrastructure from the ground up, aimed at dismantling barriers not only for this community but also for individuals with similar needs, including those affected by coexisting conditions and various other disabilities.

Social media has yielded some positive results such as the measured increased awareness of MCS, as the benefits to education. Adopting accommodation measures as a form of accommodation for MCS is the response for equity, inclusion and accessibility which is understood and agreed upon after learning about MCS.

The MCS community has responded in a positive manner to the ECRoB Project.This project gives hope and we have already started to see the positive effects on our community and the public at large. It has brought our community together. There has been hope generated because of the scope of the work and the inclusion of lived experience not only through the Disability Advisory Committee, but also through membership input. People have reported feeling validated, acknowledged and they see this as a start for the change that we need to see happen to allow for equity, inclusion and accessibility for people with MCS and other disabilities. This project has allowed for others to step up and join our voice in calling for accommodations for accessibility for people with MCS. This response not only from the MCS community but also everyone else, is heartening for us at ASEQ-EHAQ, to know that the work done though the ECRoB project is making a difference outside of the MCS community. This is what we needed to see in order to make lasting, sustainable change.

Summary

The ECroB project has been advancing well, demonstrating significant positive progress towards its goals. Adjustments to the schedule have been necessary since we have had to adjust to the effects of COVID-19 on society and systems that are in place, that affect participation due to increased workload and difficulty finding staff, this has been witnessed across Canada. We have therefore had to put in place necessary adjustments to the schedule, driven by our commitment to delivering accurate and up-to-date information. We undertook additional research to ensure the highest quality in our existing work, strengthening its reliability.

Furthermore, the project has adjusted and expanded based on valuable feedback received from the disability community. This input has been crucial in shaping the project's direction and enhancing its effectiveness and inclusivity. While these adjustments have impacted the timeline, they are essential for maintaining the project's integrity and sustainability, by having removed barriers to access and increased inclusion.

Our workshops developed from this research are on track, as well as the planned events. To better serve our community, we have made the decision to shift from an online "train the trainer" workshop series to accessible self-paced training modules that are more appropriate and applicable for our audience and project goals to remove barriers of inclusion.

Measuring Outcomes Against Schedule A: Summary

Demonstrated Results and Project Updates

Through the Empowering Community and Removal of Barriers (ECRoB) project, we have made significant strides in promoting understanding, equity, inclusion, accessibility, education, and awareness of the disability of Multiple Chemical Sensitivity (MCS). The ongoing feedback received from participants and people with the lived experience of MCS has been instrumental in shaping our work, and leading to improvements and expansions of our content and materials. Creating long term sustainable content is at the heart of our mission - such as creating video resources and leveraging online platforms. In doing this, we have increased the accessibility and reach of our project, centering the needs of this community who have been historically underserved.

Moving forward, we remain committed to fostering an inclusive environment and developing tools that empower individuals with MCS in their day-to-day lives, ensuring they are easily accessible, giving equitable access to information in order to better facilitate access to community. Additionally, various tools have been developed for the community to understand and learn how to provide accessibility for this community.

We have made significant progress in enhancing capacity within the disability community by reducing barriers to inclusion and fostering inclusivity. We have had considerable participation by diverse groups from disability legal organizations, other disability advocacy and support groups, environmental groups, etc. This engagement, collaboration, and partnership with these organizations has also enriched our learning experience. Pre and post workshop surveys including polls during workshops have helped shape our messaging and resulted in productive workshops where we can measure understanding and commitments towards accommodation for MCS.

For more information on the outcomes we are measuring against, please see our original Schedule A document in Annex 1: Schedule A.

The way it is being done:

Expected Results and Outputs:

1. Educational tools (powerpoints, website, tip-sheet and pamphlets) on the disability covering the biological, social and legal aspects of ES/MCS;
2. Creation of a steering committee, national disability advisory committee and a national legal advisory committee;

3. 4 ‘train the trainer’ sessions (two in English, two in French) provided to partners;
4. 15 individuals trained as trainers;
5. 95 online workshops conducted in English or in French;
6. 2,000 people reached directly through workshops;
7. 6,000 surveys administered;
8. 2000 polls to measure the changes made for accessibility;
9. 500 pamphlets to be posted via mail;
10. Website updated with disability information, tip-sheets, newsletters;
11. One million people received disability information through website;
12. A 1-800 helpline to assist individuals with accessibility;
13. 8,000 calls for assistance answered;
14. 10,000 emails for support answered;
15. A final report on project activities; and
16. A final scale-up and sustainability plan.
17. A final report to ESDC on project activities

<u>Current Results and Outputs as of June 30, 2023:</u>

1. Educational tools on the disability covering the biological, social, and legal aspects of MCS were created for people experiencing the disability, and for those providing accommodation.
    - Powerpoints
    - Training guide (covering biological, social, and legal aspects of MCS)
    - Website updates
    - Legal disclaimer for our website
    - Legal Tools
        - Document overviewing the Accessible Canada Act
        - Letters to the Human Rights Commissions
        - Document outlining the global landscape of MCS
        - Document outlining the duty to accommodate and undue hardship
        - Document outlining examples of appropriate accommodations and accommodation sample letters
        - Information on the social model vs medical model of disability
        - Alternative dispute resolution methods
        - Legal database
    - Fragrance-free policy
    - Fragrance-free terminology document
    - Pan-Canadian fragrance-free policy compilation

- Workshops
- Videos
    - Lived experience story on MCS
    - What is MCS
    - The Cost of Smelling Good
    - Le Coût de Sentir Bon
    - What to do when you come down with MCS (series for good management)
- Tipsheets and Information Sheets:
    - Tipsheet: What to Do When You Come Down With MCS
    - MCS Misconceptions Fact Sheet
    - MCS Best Management Practices Tipsheet
    - Activity and Symptom Tracking
    - Symptoms of MCS Fact Sheet
    - Creating a Safe Bedroom for People with MCS
    - Checklist for Managing Your Health
    - Sample Disability Accommodations for MCS
    - Designing, Implementing, and Monitoring Scent-Free Policies
    - Perfluoroalkyl and Polyfluoroalkyl Substances (PFAS) Factsheets
    - Cleaning When You Have MCS, Home Owner Seasonal Cleaning Schedule
    - Cleaning When You Have MCS, Tenant (Rental) Seasonal Cleaning Schedule
    - General Food Preparation Tipsheet for MCS
    - Eating Organic on a Budget
    - Home Renovations: Creating a Healthy Low Exposure Environment
    - 10 Tips for Exercising when you have MCS
    - Tips for Cleaning Mould in Your Home
    - The Importance of Being Fragrance-Free
    - How to be Fragrance-Free
    - Best Practices Tipsheet for Managing MCS
    - Inclusive Laundry Notice
    - Attention: Laundry Facility Users
    - MCS-friendly Emergency First Aid Kit
    - Tips on fragrance-free policies
    - Fragrance-free educational poster

2. Committees: There are three main committees for the ECRoB project. The Steering Committee (SC) is made up of our partners, who actively attend monthly meetings which are set for the last Thursday of every month from 2:30 to 3:30 pm. The Terms of Reference for our Steering Committee include oversight of the project, troubleshooting and identifying sustainable solutions among other important points. The national Disability Advisory Committee (DAC) has been created with people with lived experience of Multiple Chemical Sensitivities, who actively participate in viewing content and attending focused meetings to guide the project. We have also created a national Legal Advisory Committee (LAC). This is being organized so that the LAC remains a sustainable activity that will go on due to active participation from interested legal participants. At present Human Rights is being researched and will be taught across provinces for people with MCS, lawyers and other legal communities.This legal outreach will upscale to other identified neglected areas such as workman’s compensation and tenancy issues. At these events, invitations will be extended to join the LAC. The SC decided that building the LAC in this manner would create a more sustainable LAC. Hence, though building the LAC in this manner is a slower process than inviting known individuals to donate their time to a cause, in the long run, it will yield better results.
3. We held 4 ‘train the trainer’ sessions (two in English, two in French) provided to partners in December 2022, and January 2023. We trained staff, volunteers, partners, and 8 organizations from various fields including: indigenous, legal, disability, health, industry, and environmental organizations.
4. Our initial goal was to have 15 individuals trained as trainers in their organizations and they could teach others. We reached out to 55 organizations across Canada in order to request their interest in signing up to receive training on MCS. We understood from communications that most organizations had difficulty staffing and meeting their own needs.We took this opportunity to inform that 1 in 34 people diagnosed in Canada with MCS meant that someone with this disability could very likely be part of these organizations including the community they serve. In response to valuable community feedback, we made the decision to transition from a "training the trainer" model to a more inclusive and accessible online self-paced training module series. This modification aims to create a lasting tool for the future while eliminating barriers to inclusion, allowing a greater number of individuals to participate at their own convenience.
5. As of June 30, 2023 we have hosted 30 online workshops conducted in English or in French, with either ASL or LSQ interpretation options. We also have options to use translation services via Zoom, and have hired a language interpretation company to do live translations in English and French when required. We have scheduled 65

workshops up until August 31, 2024, which will bring us to our goal of hosting 95 workshops.

6. As of June 19, 2023 we have reached 1903 people directly through our workshops.
7. As of June 19, 2023 we created 32 surveys, administered by 305 participants during events. Total surveys administered are 305; In July 2023, surveys will be hosted on the website, reaching out to people with lived experience of MCS and to people without MCS. This will help us identify barriers to access, including barriers created through lack of knowledge and attitudinal barriers. This will help us provide specialized targeting of social media, and teaching tools to address these gaps. Another set of surveys will help us identify ease of understanding of content on the website, help to guide new content development, and to evaluate the ECRoB project..
8. As of June 19, 2023, we created polls that would inform us on accessibility issues. Here is the breakdown of the polls: 6 polls, completed by 111 participants during events.For paid social media, we created 36 polls, completed by 9635 participants. For organic social media, we created 3 polls completed by 196 participants. Total polls administered are 9942.;
9. The pamphlets will be completed and printed once the final content is placed on the website.
10. We have been continually updating our membership through newsletters, and as of June 30, 2023 we have updated our website with disability information on MCS, including tipsheets, how to's, Q&As, and plan on releasing more throughout the next month as final copies of materials are finalized.
11. As of June 20, 2023, we have reached 327,382 people through our websites, providing disability information to the community.
12. As part of our initiatives, we have accomplished the establishment of a dedicated 1-800 helpline aimed at providing assistance and support to individuals with accessibility needs.
13. As of June 30, 2023, we have answered 2550 number of calls. Despite encountering logistical delays in the initial setup of infrastructure, we have successfully established the helpline as planned. Although this caused some delays in our timeline, we are pleased to announce that the helpline is now operational and we received calls to provide assistance and support.
14. Thus far, we have responded to just over 3000 emails, receiving between 20 to 30 per day, and providing assistance and addressing inquiries for support, information and resources, or inquiring about events. These include emails of appreciation.
15. A final report on project activities; and
16. A final scale-up and sustainability plan.

17. A final report to ESDC on project activities

Deliverables/Actuals (Schedule A) and Upscaling

The deliverables versus Actuals (Schedule A) are below. Also mentioned in this table are upscaled performance metrics.

Table: Deliverables / Actuals (Schedule A)

Deliverable		Actual	
Item	Number (Deliverable)	Actual	Comparison
Educational tools (powerpoints, website, tip-sheet and pamphlets) on the disability covering the biological, social and legal aspects of ES/MCS	None specified in Schedule A	Powerpoints 32 Website 35 updates Tip-sheet 25 Pamphlet pending 5 videos 8 different legal tools including Powerpoints, website updates, tipsheets, and other tools have been developed, including information on duty to accommodate, the Accessible Canada Act, letters to the Human Rights Commissions, alternate dispute resolutions methods, a legal database, a Pan-Canadian fragrance-free as well as fragrance-free policy and terminology documents.	Work is presently ongoing to get ready to load content on the website.Once this has been done, we have another set of tools and information that will be prepared and loaded on the website.
Powerpoints	None specified in Schedule A	32 powerpoints were developed to educate on the biological, medical,	As part of the sustainability plan, we are planning on

		social and legal aspects of MCS. They were tweaked for subsequent presentations, and new content was developed for new areas of education. All powerpoints were translated to French.	converting the powerpoints into voice-over video presentations in English and French, with accessibility features.
Tipsheets	None specified in Schedule A	25 tipsheets and information sheets have been created from the biological, social, and legal content from the ECRoB project..	Additional topics for expansion have been identified and additional tipsheets and information sheets are in development.
Pamphlets	500	Pending	Being developed. Plan is to release pamphlets after the ECRoB content is fully on the website.
Creation of a steering committee, national disability advisory committee and a national legal advisory committee	3/3	All three committees were created.	These committees are being run efficiently, and function well.
Steering Committee	8	Steering Committee created.	Made up of partners, and include oversight of the project, troubleshooting and identifying sustainable solutions among other important points
Legal Advisory Committee	4	Legal Advisory Committee created.	The Legal Advisory Committee (LAC) is being organized so that it remains a sustainable activity that will go on due to active

			participation from interested legal participants
Disability Advisory Committee	English: 12 French: 6	Disability Advisory Committee created.	The national Disability Advisory Committee (DAC) has been created with people with lived experience of Multiple Chemical Sensitivities, who actively participate in viewing content and attending focused meetings to guide the project.
4 'train the trainer' sessions (two in English, two in French) provided to partners	English: 2 French: 2	We held 2 English sessions and 2 French sessions.	Switching to online self paced accessible format to exceed this metric and make more longer lasting sustainable accessible format and delivery.
15 individuals trained as trainers	15 people committed*	We trained 5 staff members, 6 volunteers, 4 committee members, and 8 organizations from various fields.	Switching to online self paced accessible format to exceed this metric and make more longer lasting sustainable accessible format and delivery.
95 online workshops conducted in English or in French	95	29	Workshops are being planned that are province specific, there will be 3 to 4 workshops per province to cover the legal, medical, social and province-specific

			human rights. Communications have been prepared to reach different disciplines in order to give workshops.
2,000 people reached directly through workshops	2000	1903	It is estimated that the final number of people reached through workshops would exceed the deliverable.
6,000 surveys administered	6000	305	Executing plan for surveys in July 2023. Expected to catch up and surpass.
2000 polls to measure the changes made for accessibility	2000	9942	We will continue with the plan and upscale to meet our requirements to inform on accessibility in order to best serve the MCS community.
500 pamphlets to be posted via mail	500	In progress	This will be completed by the fall 2023.
One million people received disability information through website	1,000,000	327,382 reach on the websites.	It is estimated that we will reach this deliverable, especially after the ECRoB content is published.
A 1-800 helpline to assist individuals with accessibility	1/1	A 1-800 helpline implemented to assist individuals with accessibility.	This helpline is answered at the ASEQ-EHAQ physical office.
8,000 calls for assistance answered	8000	2550 calls answered.	This aspect will continue, and as the 1 800 number is advertised more

			broadly, we expect the number of calls to increase.
10,000 emails for support answered	10,000	Responded to just over 3000 emails, receiving between 20 to 30 per day.	This is an ongoing activity and is expected to increase after the content goes up on the website, and workshops start in the autumn.
A final report on project activities		In progress	
A final scale-up and sustainability plan		In progress	
A final report to ESDC on project activities		In progress	
Additional Outcomes (Not specified in Schedule A)			
Website updates	None specified in Schedule A	The website was updated 35 times to reflect the need for advertising events, content, and the ECRoB project.	Within a month the ECRoB part of the website will be developed with content, tools, tip-sheets, videos and it will be accessible.
Newsletters	Not specified in Annex A	From November 2022 to June 30, 2023, a total of 63 news and newsletter emails were sent out to the membership, partners, and community groups that included disability, environment, health, and the community at large. These emails were viewed 32,966 times, and were	This is an ongoing activity and we will work on an increased outreach, by combining newsletters with surveys and linked to social media.

		engaged 2,823 times through forwarding	
Outreach through Social Media	None specified in Schedule A	1,610,467 total impressions across all platforms (reach)	Social Media is carefully monitored for impact and outreach. It is expected that this number will increase exponentially.
	None specified in Schedule A	Needs assessment	Needs and barriers to inclusion for the MCS community were identified and included in this report.
	None specified in Schedule A	Accessibility Best Practices document	Accessibility best practices have been identified throughout the course of this project and written into a document to share with other employees.

Focus Group on MCS

The Heart of Inclusion: Honoring Lived Experiences

Key Points from the Focus Group

The Environmental Health Association of Quebec (EHAQ) represents people who have become disabled by chemical exposures, through sensitization, and experience Multiple Chemical Sensitivity (MCS), a medical condition which is increasing in prevalence in Canada. (CCHS, 2000-2020) Due to the profoundly life altering nature of this condition, it has been classified as a medical disability by the Human Rights Commission of Canada. Over 1.1 million people have a diagnosis, and 72% diagnosed are women. (CCHS, 2020) Common triggers include, and as reported by membership and participants of the focus groups:

- fragrances, perfumes, colognes, essential oils
- petrochemicals
- volatile organic compounds (VOCs) (from products. and those emanating from new items such as clothes, books, and others)
- mould
- pesticides
- smoke
- plastics

Without immediate government intervention, improperly and inadequately regulated industry will continue to pollute our environments, and the prevalence of MCS, comorbid conditions, and ecological devastation to the environment flora and fauna in Canada will continue to increase - placing a higher burden on the healthcare system, increasing unemployment, increasing disability and putting further strain on the Canadian economy. This already leads to incalculable pain, and suffering, increased poverty and homelessness, especially for this already marginalized group of people experiencing the disability of MCS.

Disability and Legal Justice in Canada

Disability and legal justice in Canada are critical areas of focus in the pursuit of creating an inclusive and accessible society. The Accessible Canada Act aims to make Canada accessible by 2040. Currently there is no infrastructure in place for people with MCS.

There is a need for clear, easy-to-understand information on adequate product choices that would allow for accessibility through scent-free spaces in employment, health care, services including essential services. Additionally, there is also a need to improve understanding from the wider community, as this presents significant barriers to the full inclusion and participation in society from conditions or disabilities that depend on accessible air quality to work, study, pray, play and live. These conditions can include MCS, asthma, autism, COPD, migraines, and dermatitis, that make up a significant part of our population.

To truly achieve an accessible Canada, it is essential to recognize the distinct challenges faced by individuals with MCS and other disabilities and take proactive measures to accommodate their needs.

MCS as Leaders in Environmental Health Reform in Canada

"I feel attacked, assaulted, when I have an exposure and the first thing that happens for me is my… my voice. I start to lose my voice. That's how it all started when I had a big exposure. And the doctor told me I had lumps in my throat so the first thing that goes is my throat and at the same time I get other symptoms. My eyes hurt, my head hurts, I experience confusion, lose my balance depending on the strength of the chemical and the length of the exposure. Yeah, I too was recently told by a friend after I had an exposure to her perfume, and all of a sudden she blurted out, it's all about you. It's all about you. She said everything she had to say. And later because it took me time to heal from this friend that I trusted and I give her least-toxic detergent and give her products to help her be unscented. And then she comes back with this. And a few days later, I replied to her, it's not all about me. It's about the chemicals, and it's about the companies who make them, and the people who use them. And some people don't know that these chemicals are toxic, but I do my best to inform them nicely. Gently, I inform people and some take it well, some don't. But I'm not going to let this discourage me. I'm going to keep on telling people that I'm suffering or, and others suffer and it's not acceptable. They're harming themselves and others. So I will persevere and keep informing people, and not let them shut me down. We are the canaries in the coal mine. And we have a right to stay here. She said to me, I have a right to wear perfume. If I want to wear perfume. I replied in my email, you have a right to wear your perfume. And I can't stop you from doing it. But I have a right to express myself and tell people when I'm suffering."

People with MCS possess a unique perspective as their condition is developed by sensitization through and triggered by exposure to chemicals and pollutants prevalent in everyday environments. By courageously sharing their stories and experiences, the MCS community in Canada has been able to draw attention to the pervasive impact of chemical exposure on public health. This advocacy has encouraged policymakers and public health officials to reassess existing regulations. More stringent measures are needed to be implemented to safeguard both individuals with MCS and the general population. The lived experiences of the MCS community serve as compelling evidence of the urgent need for improved environmental health policies.

People with MCS are instrumental in fostering a shift towards sustainable and eco-friendly practices. Their demand for fragrance-free, lowest-emission and least-toxic environments motivates healthy green sustainable businesses to develop products to cater to this population and the countless other Canadians who are interested in least toxic products free of known or unknown harmful ingredients. As these healthy products appear on our shelves, regulations need to protect us from greenwashing, and it should be acknowledged that the power of the dollar is driving change as seen by the number of new least-toxic alternatives. Tax breaks for responsible manufacturing should be encouraged, instead of to the polluters.

Adapting accessibility measures for MCS means removing barriers for other disabilities and health conditions. Adapting a universal design approach to our public shared built environments is crucial in order to remove barriers to access for people of all abilities and disabilities.

The trailblazing efforts of individuals with MCS are a central element in environmental health policy reform. Their dedication and resilience continue to inspire meaningful change and propel society towards a more sustainable and health-conscious future for all Canadians. As advocates for a healthier and inclusive world, people with MCS have demonstrated the power of lived experiences in shaping transformative environmental policies that benefit not only their community but also the well-being of the entire population.

The Importance of the Empowering Community and Removal of Barriers (ECroB) project

“I'm quite happy that this project is going to be born because it's extremely difficult to change mindsets. We were talking about essential services, and the two things that mattered most to me were health services.”

Through administered surveys a significant number of groups reported a high interest in supporting the ECRoB project. After learning about MCS, post workshop, everyone agreed to the importance of accommodating this disability through change in product use to remove barriers for inclusion and promote accessibility.

Several individuals who have taken part in the project have subsequently engaged in other accessibility initiatives or research endeavors, showcasing the project's positive impact in inspiring and empowering individuals to contribute further to creating inclusive environments.

Medical students working on a Canadian national scale, proactively reached out to ASEQ-EHAQ, as they have expressed interest in the ECRoB project, to learn about MCS, and to request that this disability and environmental health (the connection between our environmental and health) be part of the teaching curriculum in medical schools.

The ECRoB project, through education and awareness (focusing on the biological, social and legal considerations of this disability) will help to build infrastructure in Canadian society and reverse the lack of accessibility as shown below:\

- The participants were provided with a list of potential experiences and were asked to choose as many as they felt fit their personal experiences. 13.2% expressed that they had difficulty shopping, and 11.3% had difficulty finding healthy housing, banking, and accessing places of worship. 9.4% of the responses showed difficulty accessing hospitals and places of learning. 7.5% experienced stigma, stigma from a health provider and discrimination from a health provider. Finally, 5.7% expressed difficulties asking for accommodations and accessing transportation

After conducting workshops with various groups, we found that they were eager to share the ECRoB project within their networks, both internally and publicly. This network comprises organizations and individuals associated with:

- Academia
- Private Sector
- Public Sector
- Scientists
- Media
- Environmental Health Organizations
- Health Professionals
- People with Intellectual Disabilities
- Legal Professionals
- Community Groups

Lived Experience - Stories, Feedback and Needs Assessment

We were able to do a general needs assessment based on accessible informal interviews, focus groups, and meetings with people with lived experience of MCS. From this we compiled the list below to develop key themes that were emerging.

Barriers to Inclusion and Needs of the MCS Community

*Please note: *'Scent-free or a Scent-free policy' is defined as 'Fragrance/cologne/perfume/essential oil-free, lowest-emission and least-toxic product use'*

Barriers to Inclusion:

- lack of awareness and understanding of MCS
- inaccessible public spaces
- widespread fragrance and toxic chemical use
- inadequate chemical regulation in Canada
- lack of workplace accommodations
- limited medical understanding of MCS.
- social isolation
- financial barriers (inability to work according to education, and earn appropriately)
- lack of healthy housing
- lack of legal protections
- insufficient public and government advocacy and policy gaps
- stigma, prejudice, and discrimination
- inadequate support services and programs
- air quality issues
- lack of healthy and appropriate long term care facilities for seniors with MCS

Accessibility Needs:

- scent-free policies* in public spaces
- medical support (accessibility with ambulances, hospitals & clinics, trained medical staff and professionals)
- accessible and safe housing
- workplace accommodations
- least toxic and scent-free transportation
- MCS education
- social and recreational Inclusion
- non-toxic building materials
- supportive social services
- public policy and advocacy
- legal support and education
- improved regulations in Canada
- financial support (MCS is a costly condition: need for organic, least-toxic, purifiers, special masks, etc)
- lack of protection from law enforcement, as they themselves use colognes and perfumes, and often side with the party deliberately causing harm, making the situation even worse. Therefore education and awareness is required.
- lack of understanding of the disability in the courts

Chart Summarizing Barriers and Needs for MCS Community (Focus Group)

Barriers to Inclusion and Access:	**Accessibility Needs:**
Lack of awareness and understanding of MCS	Public policy and advocacy MCS education
Inadequate chemical regulation in Canada Industry synthesizing new chemicals before regulation	Reduced chemical exposure Indoor air policies including scent-free policies
Industry greenwashing and marketing harmful products (use of masking agents)	Adequate legislation Clear and transparent labelling Incentives to manufacture ‘healthy’ products
Inaccessible public spaces	Fragrance-free & least-toxic solutions for all applications Policies in public spaces
Inaccessible transportation	Least toxic solutions for all applications and scent-free transportation
Widespread fragrance and chemical use	Scent-free, least Toxic products
Lack of workplace accommodations and workplace discrimination	Workplace accommodations, scent-free policies
Limited medical understanding of MCS	Medical education and support
Limited legal understanding of MCS	Legal education and support
Social isolation	Programs and accessible community centers
Financial barriers	Financial support to live with the disability
Inadequate support services and programs	Create infrastructure through product-choice

	policies (scent-free policies)
Housing challenges	Accessible, appropriate, healthy housing
Lack of legal protections	Education to legal community, the courts, and law enforcement
Insufficient government advocacy and policy gaps	Improved regulations in Canada public policy
Stigma, prejudice, and discrimination	Education and awareness Social and recreational inclusion
Air quality (indoor and outdoor)	Education and awareness on appropriate product choices
Inadequate support services and programs:	Education and awareness Supportive social services
Inadequate domestic manufacturing of least toxic eco-friendly sustainable circular economy products	Incentives through tax breaks for non-toxic building Materials (and not to polluting industries).

Explanation of Barriers to Inclusion and Needs of MCS Community:

MCS Barriers to Inclusion:

In order to best remove barriers to inclusion, we needed to better determine the needs of the MCS community. In order to accomplish this we did a needs assessment to determine barriers they faced.

In addition to our quantitative data collection, including surveys, polls, and questionnaires that people with lived experience of MCS took part in, we also took a qualitative approach to interpreting and understanding the lived experience of MCS. We identified key barriers faced by this community from interviews, workshops, written feedback, oral feedback, research, and meetings.

Barriers to Inclusion Experienced by the MCS Community Include:

Lack of awareness and understanding of MCS: Limited knowledge and misconceptions about MCS among the general public, employers, professionals, and service providers can lead to skepticism and stigma.

Inaccessible public spaces: Many public spaces, including healthcare facilities, workplaces, and recreational areas, may have chemical pollutants or fragrances that trigger MCS symptoms, making them inaccessible.

"I mean, in my environment ever since COVID hit, even going for a walk now is becoming extremely difficult to get out of the house because of all the laundry products in the neighborhood. So I physically am not able to breathe, which means that I cannot go to stores, I cannot access healthcare, I cannot go to the hospital."

Inaccessible healthcare facilities: There is a need to immediately enact, monitor, and enforce strict fragrance-free policies in hospitals and other healthcare facilities in Canada in order to make these spaces accessible to those with MCS and other conditions that are excluded due to the use of these products.

Widespread fragrance and chemical Use: Widespread use of fragrances and chemicals in personal care products, cleaning agents, and building materials pose significant challenges for individuals with MCS and other disabilities.

"I cannot go anywhere. No public space, no doctor's office, no hospital - nothing. This could have been solved with two words from Health Canada, fragrance free hand sanitizer, we would all be feeling so much better. I don't know why that was not in the guidance. What the hell? This is a problem for so many groups of people, not just MCS."

Inadequate chemical regulation in Canada: The need for better chemical regulation in Canada is imperative to safeguard public health and the environment. Strengthening regulations and oversight will ensure that harmful chemicals are properly assessed, managed, and restricted, reducing potential risks and promoting a safer and more sustainable future for all Canadians.

Workplace accommodations: Employers may not understand MCS and may not provide necessary accommodations, leading to difficulties in obtaining and maintaining employment. Lack or loss of employment often spirals into poverty, increased stigmatization, lack of appropriate housing and food insecurity, and isolation.

Limited medical understanding of MCS: Many healthcare professionals lack proper education or even awareness of MCS leading to misdiagnosis, and impacting appropriate and timely diagnosis and treatment. This results in lack of accessibility and increases stigma.

Social isolation: Living with MCS may lead to social isolation, as individuals may be excluded from gatherings, events, and social activities they love due to their disability. Lack of understanding the disability often leads to loss of friendships and family.

“I had to sometimes I had to be isolated from the choir because you know, instead of removing the person that had scent I was the one that have had to be removed because I wasn't able to be be near my fellow choristers that have scent so you know, before COVID I was isolated now I'm even more isolated.”

Financial barriers: Accessing medical care, including appropriate healthy housing, purifiers, special masks, organic food, and least-toxic products can be costly, creating financial barriers for individuals with MCS and increasing chances of poverty and homelessness.

*“I'm literally going crazy. I don't have enough to qualify for EI. If I get sick benefits and disability, it's only $800 a month. I can't work more than $6,400 a year. My rent is 1450 -I don't like - Do you want me to just apply to die? Would that be a convenience for you that I end my life? I don't understand. I don't I don't understand. This is f***** up. It's f***** up. I don't know how* (or what) *more to say.”*

Housing challenges: Housing insecurity affects all Canadians, but people with MCS disproportionately. Finding appropriate, healthy, affordable, exposure-free housing is extremely difficult as many buildings and accommodations have unsafe materials or environmental factors that trigger symptoms.When combined with financial insecurity, these challenges significantly accumulate. When living accommodations are shared such as in buildings or condos, it becomes unbearable as exposures are constant and the disability worsens with no appropriate medical help. People are forced to live in their cars, tents or with their windows open even in winter. Lack of protection and accommodations for tenants is also proving difficult for many. In some cases landlords or neighbours harass tenants through known exposures, like fragrances or certain laundry products, or increasing the use of chemicals, etc., and there is little to no recourse for the victim of harassment or abuse.

“I would say one of my biggest needs right now is healthy housing. Where I live right now I'm very ill, I get almost daily exposures to laundry, off gassing coming into my unit. And basically, when I've asked for accommodation, all I've gotten is abuse and harassment and more discrimination. You've tried to take, you know, my human rights on an individual basis, one at a time, but it's exhausting, period, but especially for people who are already ill. And I find when you try to do that you encounter barrier after barrier systems that are in place to help you oftentimes end up letting you down.”

“I would really like to advocate for safe housing because I think there's a lot of us that need it. I can't stand hearing some of our people living in cars in winter. [...] trying to find a place to stay for the winter, trying to figure out where to camp and stuff. I'm not in the safest housing myself, but it's probably better than trying to take a chance on something else, and finding myself in a worse situation. So I just sort of stay where I am.”

“[...] the issues around accessible housing, I live in a water damaged building, and have been trying to find something that's more accessible, or that would be healthier, and have I think I could write a book on how bad every single place that I visited, has been in Montreal, everything from mold to, you know, off gassing (of chemicals)*, due to building materials to chemicals, and just badly designed buildings.”*

“I was so sick in my home that I had to move out. It took me over a year to find a place and it was impossible to find an apartment or to find housing where the apartment units are separated. Whether it's a twelve hundred dollar a month apartment, that I can't afford anyway, or an affordable apartment, the units were not separated. I had my balcony, I had all the dryer outlets not far away and it came in through my windows, through my patio door where I can't open the windows, it came in through the kitchen order, it came in through the bathroom vent. I went through hell, I didn't eat much because I was nauseous. At some point a cannabis user moved two dwellings above mine so the fumes came in. I was so sick, I fought for a year to try to fix the problem, I just made enemies, it was extremely difficult. I paid three thousand dollars for lawyers and I got help from ASEQ to provide information.

Lack of safe healthy scent-free long term care facilities for seniors: The lack of safe, healthy, and scent-free long-term care facilities for seniors poses significant challenges to the well-being and comfort of vulnerable elderly populations.

Air quality: Outdoor air pollution from cars, smoking, etc. as well as indoor air quality issues in housing and shared spaces. The recent pollution from smoke due to the fires, left people with

MCS in a very bad state. Many have reactive respiratory systems, and being indoors with the doors and windows closed did not keep the smoke out. There were many calls saying ‘I can't breathe’.

Insufficient public and government advocacy and policy gaps: There is a need for more advocacy and improved policies co-created and centering on those with a lived experience of MCS in order to create inclusive environments and services.

Stigma, prejudice, and discrimination: Some individuals with MCS may face disbelief or dismissal of their condition, making it challenging to access the support and accommodations they need.

Disrespectful attitudes, harassment, and violence:
*“The janitor has called me “you f******* crazy b*****”. It's in your head. My mother and father have this rental where I am now* (living) *in their name and they refuse to say anything. So I'm essentially paying rent and living in a place where I'm being poisoned purposely to drive me out. I don't know where to go. I lost my second job with the school board as a teacher that I got here.”*

Lack of legal protections: There are currently inadequate legal protections and accommodations for individuals with MCS, making it challenging to assert their legal human rights in various settings. This includes law enforcement protections.

Lack of access to significant federal government services: This includes, but is not limited to: Service Canada, Justice Canada, Supreme Court of Canada, CRA, Elections Canada, Emergency and Public Safety, etc:

Inadequate support services and programs: This lack of support creates barriers for individuals facing various accessibility challenges hindering their access to essential resources and opportunities for growth and empowerment. Addressing these gaps and investing in comprehensive support systems is crucial to fostering inclusive and resilient communities where everyone can thrive.

<u>Removal of Barriers - Understanding The Needs of the MCS Community:</u>
The care infrastructure for individuals with MCS faces substantial gaps that have resulted in incalculable pain to the community. These gaps span medical services, legal justice, and various other areas. There is a complete absence of adequate protection and support, coupled

with the stigma and discrimination that has been caused, compounding and exacerbating the challenges faced by this community.

To address these deeply concerning and pressing issues, our project has been created centering the lived experience of those with MCS and designed to extend beyond a three-year duration. Through this extended timeline, we aim to provide sustained support to the community and continue to proactively build the necessary infrastructure to enhance their overall well-being and ensure they receive the comprehensive assistance they rightfully deserve.

By implementing the following strategies into Canadian policy and infrastructure, we can take an inclusive universal design approach which reduces barriers to minimize the need for accommodation in the future and in this case, development of the health condition that can develop without these in place.

In order to remove barriers of inclusion for this population, the following needs of the MCS community need to be addressed:

1. **Fragrance-free, lowest-emission, least toxic products:** The availability of clearly and transparently labeled fragrance-free least toxic personal care products, cleaning agents, laundry and household items to avoid triggering symptoms.
2. **Fragrance-free policies in public spaces:** Implementation of fragrance-free policies that are monitored and enforced in places like educational institutions, hospitals, the workplace, places of worship, transportation, and other public settings to ensure inclusive environments for people with MCS and other disabilities that are triggered by chemical exposures.
3. **Medical support:** Access to healthcare professionals knowledgeable about MCS, who can provide accurate and timely diagnosis, provide letters for accommodation needs, and effective treatment plans.
4. **Accessible and safe healthy housing:** Housing that is free from toxic building materials, pesticides, moulds with monitored scent-free policies in place providing a safe and healthy living space for individuals with MCS. Also, housing that is affordable to all Canadians regardless of income, but especially on the lower end of the income scale.
5. **Workplace accommodations:** Supportive workplace environments with proper ventilation, monitored fragrance-free policies, and reduced exposure to chemicals to accommodate individuals with MCS.
6. **Least toxic and scent-free transportation:** Access to public transportation or transportation options free from fragrances and other pollutants.

7. **Education:** Increased awareness and understanding among the general public, employers, and healthcare providers about MCS to ensure accessibility, appropriate medical treatment and disability accommodations.
8. **Social and recreational inclusion:** Opportunities for individuals with MCS to participate in social and recreational activities that prioritize their health and well-being by using least toxic products and implementing and monitoring a scent-free policy.
9. **Non-toxic building materials:** Availability of building materials free from harmful chemicals and VOCs for those constructing or renovating living spaces.
10. **Supportive social services:** Access to specialized community and medical support groups, social workers, programs and services that are educated on the medical condition in order to offer best practices to manage the challenges of living with MCS and enhance overall well-being.
11. **Public policy and advocacy:** Advocacy for MCS recognition and accommodations in public spaces, workplace settings, and housing regulations.
12. **Legal support and education:** To better advocate for themselves in legal situations, especially related to disability accommodations, housing, etc.
13. **Improved regulations in Canada:** Improved regulation of private industries profiting from environmental pollution and degradation and contributing to ill-health from their products - all while the products are consciously marketed to consumers, and new chemicals are being synthesized and released into the environment.
14. **Financial support:** Funding from the government, increased and specialized disability funding to support people with MCS.
15. **Comprehensive warning labels on consumer products**: Products should be labeled clearly, in simple language, and be accessible for all disabilities - for instance, colour coding included. Regulations must be strict with labeling rules, closing loopholes to protect consumers. Even very low percentages of a product's content must be disclosed. All harmful products such as sensitizers, carcinogens, endocrine disruptors, mutagens, etc, must be mentioned on the label. Healthy labels must ensure the contents are safe to protect people experiencing disability. If contents of a product are not known due to a lack of supply chain transparency the manufacturer must test the product and declare 100% of its content.

For additional information on our needs assessment and report from focus groups on MCS, please see Annex 11: Lived Experience Report.

Project Development and Governance

The development of this project has allowed us to further develop our strong structures for smooth implementation.

Employee Disability Training

In order to promote an inclusive and supportive work environment, it is essential for employees to receive training on the disability of Multiple Chemical Sensitivity (MCS) as they are the member base of our organization, and the community we work for whether they are members or not. The aim of our training is to equip employees with the knowledge and understanding of the disability of Multiple Chemical Sensitivity (MCS), in order to foster a culture of empathy, respect, and inclusivity.

Employee disability training encompasses a self-paced model to explore various mixed media resources in order to understand and learn more about those with a lived experience of MCS. Some materials include:

- videos
- journal articles
- one-on -one meetings and team meetings
- presentations
- news articles
- workshop

Committee Development and Meetings (LAC, DAC, SC)

Legal Advisory Committee

The ECRoB project's Legal Advisory Committee (LAC) is composed of ASEQ-EHAQ team leaders, doctors and lawyers. For the time being, the project will focus on Human Rights. This was decided as a sustainable action to make sure that the workload is manageable, doable, and to keep interest in the LAC. The reasoning also included that as issues were identified, research could be done within the legal and other teams, to inform on the legal needs, barriers experienced and gaps in access, for this disability, and to address them going forward in an accessible manner.

Disability Advisory Committee

The ECRoB project's Disability Advisory Committee (DAC) is composed of 18 members. Everyone on the DAC is active and committed to their role in guiding the project forward. In the spirit of ‘Nothing Without Us’, we acknowledge that lived experiences guide the needs of the community and the ECRoB project. The DAC has also participated in surveys and focus groups.

The key takeaways from surveys on those with lived experience of MCS can be viewed at Focus Groups on MCS which shared lived experience stories and feedback which allowed us to develop our needs assessment.

Steering Committee

The Steering Committee (SC) is made up of groups who have had a good relationship with ASEQ-EHAQ, who know about and understand the needs of the MCS community, who are aware of the work that ASEQ-EHAQ has been doing over the past 20 years, and who are committed to making a change for the community of people with MCS and other disabilities.

A date to meet every month was agreed upon at the first meeting and the last Thursday of the month was unanimously accepted. The Terms of Reference were presented and signed by all.

Besides being very supportive and helpful, the SC provides oversight of the project, reviewing documents, troubleshooting and identifying sustainable solutions among other important points

The ECRoB project’s Steering Committee is composed of 10 individuals from various organizations including:

- ASEQ-EHAQ
- Women’s College Hospital: Environmental Health Clinic
- ARCH Disability Law Centre
- NB Lung
- Environmental Doctor specialist in MCS
- La Confédération des organismes de personnes handicapées du Québec (COPHAN)
- Spinal Cord Injury Canada
- Medical Student (McGill)
- British Columbia Aboriginal Network on Disability Society (BCANDS)
- Associate professor. — Health Sciences, Ontario Tech U

Partnership Development and Stakeholder Engagement

Summary:
Increased partnerships have been formed with multiple stakeholders including:

- the MCS community
- the disability community
- legal professionals
- physicians
- law societies
- medical professionals including physicians, medical students, and other healthcare practitioners
- individuals within civil society
- individuals and organizations from the social sector - not for profits, charities, etc.
- federal government
- provincial government
- municipalities

Some of the partners we would like to thank for their collaborative work include:

- ARCH Disability Law Centre
- La Confédération des organismes de personnes handicapées du Québec (COPHAN)
- NB Lung
- Spinal Cord Injury Canada
- British Columbia Aboriginal Network on Disability Society (BCANDS)
- Canadian Network for Human Health and the Environment
- New Brunswick Lung Association
- Well Earth Collaborative Affiliate
- Santé Mobile A-1

MCS Community:
One of our strongest ties is with the MCS population itself. Our last public education sessions go back to a few years back, during our project accomplished in partnership with the University of Québec in Montreal (UQAM) and UQAM's online teaching university, TELUQ, and they solely focused on Québec, where we gave workshops in over 10 regions of Québec. This time, our workshops focus across Canada. Although we tailor our workshops so that it applies to all of Canada, we have created and will be disseminating province-specific content, especially regarding human rights.

We had many individuals from the MCS community attend our workshops. We targeted them through our communication channels, including our social media, newsletters, emails, and website.

We take pride in centering the voices and experiences of individuals who have firsthand experience with the challenges we address. We believe that their lived experiences are invaluable in shaping our work and creating meaningful change. To ensure their active involvement, we extend a warm invitation to individuals with lived experience to join our workshops and events. These gatherings serve as platforms for education, where we aim to provide valuable insights, knowledge, and resources. Moreover, these events foster a sense of community, enabling individuals to connect with others who share similar experiences. By building a strong community of individuals with lived experience, we strive to create a supportive and empowering environment that amplifies their voices and enables collective action toward positive outcomes.

These workshops have allowed the MCS population to learn about their human rights. We are laying the groundwork to cover a great need for legal education for other areas of the law, such as worker's compensation and tenancy law.

Legal Partnerships:

Long-term innovative solutions and activities were undertaken for the MCS community by ASEQ-EHAQ in partnership with legal professionals. These include legal workshops designed for legal professionals, the MCS community, and civil society organizations, and the development of a comprehensive legal database.

The Legal Advisory Committee has been created in collaboration with ARCH Disability Law Center. ARCH participates with us in Legal Advisory Committee legal meetings, monthly Steering Committee meetings, and have been vital contributors and collaborators to our work. They have generously made themselves available to consult with and disseminate information in regards to the disability of MCS.

Over 1000 individuals from the legal profession registered for our workshop held in collaboration with the Law Society of Ontario. Future clientele will likely be dealing with MCS, legal issues, potentially encompassing human rights, and disability law.

These professionals were reached via our website, social media, newsletters, emails, ARCH Disability Law Center's website, and the Law Society of Ontario's platform.

Medical Partnerships:

Some of our more medical content has included presentations and workshops that include collaborations with the following physicians:

- Dr. John Molot, environmental health medicine.
- Dr. Ellie Stein, psychiatrist and environmental medicine
- Dr. Domenica Tambasco, environmental health medicine.

We had medical students, community members, and other professionals and civil society members attend our Medical Student workshop, a workshop developed in collaboration with International Federation of Medical Student's Associations – Division Québec (IFMSA-Québec). As future physicians, these medical students will inevitably encounter patients with health issues including disabilities such as MCS. The majority of these students hailed from Quebec universities, with a substantial attendance from McGill University. McGill's Project Green Healthcare (CFMS HEART) and McGill's Medical Student Society were instrumental in promoting the event among their student population. Our own promotion channels, including our social media, newsletter, emails, and website, also contributed to attracting these students. We had members from our own organization attend, in the spirit of 'Nothing About Us, Without Us'.

These partnerships in the medical field will continue to help us advocate for better support and treatment of MCS. ASEQ-EHAQ intends to continue training certified and future health professionals about medico-legal considerations when dealing with the MCS disability.

In the long run, and hopefully near future, the ECRoB project will result in MCS being taught in medical school, with up to date science.

Civil Society Engagement:

Civil society groups have partaken in our workshops. We targeted these groups through our channels, including our social media, newsletter, emails, and website. We have undertaken numerous actions to empower and foster active participation within diverse groups in the disability community, specifically concerning initiatives related to the implementation of the Accessible Canada Act and its regulations. We have used email communications to identify groups and invite them to our upcoming training sessions. These initiatives include:

- The creation of a training guide focused on MCS and human rights, designed for delivery in upcoming workshops for various civil society organizations.

- The organization and delivery of multiple workshops aimed at informing the MCS community about their rights and protections under human rights law, be it at provincial, territorial, or federal levels.
- The tenure of several meetings with civil society organizations, legal professionals, and the MCS community.
- The development of several educational tools aimed at the MCS community, including a fragrance-free poster, sample accommodation letters, examples of MCS-appropriate accommodations that should not result in undue hardship, a compilation of fragrance terminology, our Pan-Canadian fragrance-free policy, and information pages dedicated to the Accessible Canada Act.

Legal Advocacy

Summary:

Phase 1 of our project has included the following legal advocacy measures:

- Civil society legal workshops on MCS
- Public legal education for those with MCS
- Legal professionals education
- Medical professional education

In keeping with the principle of 'Nothing About Us Without Us,' we have conducted several meetings with the MCS community to ensure that our efforts are aligned with their needs.

The attendance of our legal workshops varied greatly, from a few individuals to over 1000 registrants for the event with the Law Society of Ontario. Through these workshops, we strengthen our legal partnerships with ARCH Disability Law, one of our main legal partners in the ECRoB project, by working closely with them to verify the veracity of our legal content for each of our presentations, and directly working with us to build and deliver the Continuous Legal Education (CLE) event on May 31st. In this vein, we also strengthen ties with the Law Society of Ontario by working directly with them to deliver a successful event. If we were to ask them to permit us to deliver another workshop within their mandate, we feel confident that it would again be a success, due to this very successful first interaction with them. We also created ties with two Ontario lawyers during the event, who respectively are a disability law lawyer and a federal prosecutor. These ties will help us build a list of lawyers to whom we can refer individuals with MCS who experience legal issues such as finding a lawyer that understands how to navigate the procedural challenges of a client with MCS as well as their medical needs, such as a scent-free environment or alternative proper accommodations.

Despite our numerous achievements, a significant amount of additional legal needs have been identified within the MCS community. Hence, we conscientiously plan out sustainability and upscaling into our work to maximize our long-term impact to support this community to the highest degree.

Legal Workshops

Workshops are aimed at educating civil society about MCS, and providing a general presentation suitable for civil society organizations that operate nationwide. These workshops have the potential to reach many disciplines, but we cannot cover all of them during Phase 1. However, we have laid the groundwork to widen the scope of the outreach in a sustainable manner to reach many more disciplines that directly impact the daily lives of Canadians, who need to learn about accessibility, equity, and inclusion for the disability of MCS.

Included are:
Public legal education workshops intended to inform the MCS community about their accommodation needs, how to request them, and their rights and legal protections. These workshops will be customized for each territory and province to account for the unique laws, institutions, and procedures related to human rights and disability law in each jurisdiction. What applies in one province, such as Québec, may not apply in another province like Nova Scotia. Part of this training is to share knowledge about the accommodations required for accessibility, to teach the MCS community best practices for requesting accommodations, steps to take to ensure that their human rights are respected, and that accessibility is provided to them.

Continuous legal education workshops targeted at the legal community, focusing on educating legal professionals about MCS and its intersection with human rights law. Currently, these workshops have been conducted only in Ontario. However, we have communicated with our community, indicating that the Maritime provinces will be the next focus. We are actively reaching out to relevant organizations and legal professionals to facilitate this process. It is in the plan to reach every province, and this could be a sustainable practice to repeat it alongside legal professionals in each province, and to complete training in the remaining provinces that could not be covered in Phase 1.

There is interest from medical professionals to learn the up-to-date science on the disability of MCS, including patient needs for disability accommodation for accessibility, and how to provide a medico-legal to support patients. Through our partner NB Lung, we have access to 3000 health professionals in the Maritimes who would be interested in workshops or training. An effort will be made to have Continuing Medical Education points for health professionals. Discussions have started to do the same for Ontario. It is estimated that this upscaling of the project may not be completed for all provinces, and would need another Phase to complete this from coast to coast. Accessibility measures can be easily supported through health professionals, and we view this ability to upscale as being vital towards equity, inclusion and accessibility.

This work has resulted in the creation of a document that compares the social and medical models of disability. We are in the process of completing a document that elaborates on a range of alternative dispute resolution methods we have identified.

For more information on our legal advocacy and content, please see Annex 3: Legal Report.

Content Development

Summary

The biological, social, and legal content development for the ECRoB project focused on building capacity and inclusion by educating people with the disability of MCS on their rights and increasing their access to legal support and other information to effectively manage their disabilities.

Methodological approach: Participatory action community-based research with an intersectional feminist disability justice lens.

The methodological approach adopted in this work is rooted in intersectional feminist disability justice, taking a participatory action community-based approach to this work in order to best adapt and cater to the needs of the community we serve.

The biological, social, and legal themed tools and resources developed from the project include:
- Tipsheets
- Videos
- Powerpoint
- Public poster notices
- Pamphlets
- Legal tools including:
    - Document overviewing the Accessible Canada Act
    - Letters to the Human Rights Commissions
    - Document outlining the global landscape of MCS
    - Document outlining the duty to accommodate and undue hardship
    - Document outlining examples of appropriate accommodations and accommodation sample letters
    - Information on the social model vs medical model of disability
    - Alternative dispute resolution methods
    - Legal database
- Policy papers: Perfluoroalkyl and Polyfluoroalkyl Substances (PFAS), flame retardants

Biological section

The main focus of the biological section is to give a comprehensive review of the current literature surrounding MCS, updating the previous literature and expanding on it. This section focused on the final content outline for the biological section which included:

- What is Multiple Chemical Sensitivities (MCS)?
- How Common is MCS? Prevalence of MCS and Disability in Canada
- Symptoms
- Diagnosis
- Comorbidities
- A Review of Current Theories and Emerging Research on the Development of MCS
- Pollution & Air Quality
- Illness Management: How to Adapt and Optimize Your Health When You Have MCS
- Call to Action for Canada: A Path to a Better Future
- Glossary
- Bibliography

Biological Tools:

- Tipsheet: What to Do When You Come Down With MCS
- Best Practices Tipsheet for Managing MCS
- 10 Tips for Exercising when you have MCS
- MCS Misconceptions Fact Sheet
- MCS Best Management Practices Tipsheet
- Activity and Symptom Tracking
- Symptoms of MCS Fact Sheet
- Checklist for Managing Your Health
- General Food Preparation Tipsheet for MCS
- Perfluoroalkyl and Polyfluoroalkyl Substances (PFAS) Factsheets

To see the expanded content outline for the biological section created in collaboration with the Disability Advisory Committee and the membership of ASEQ-EHAQ with lived experience with MCS, please see Annex 9: Expanded ECRoB Content Outlines.

As per the needs of our community, we will be expanding on the sections that have been identified by community members as needing updates, additional resources or tools, or more information.

Social section:

The purpose of this section is to educate people on this disability, in order to do that, we felt it was necessary to situate the context these people are operating within and consider the intersections of their identity and their experiences. These intersections include the effects of environmental racism, classism, and ableism in considering the impacts of climate change and pollution.

To foster inclusivity and respect, the content also emphasizes the significance of using appropriate terminology and employing an intersectional lens. Additionally, an understanding of Canada's economic history is crucial in comprehending the present circumstances. By tracing the country's economic development, we can gain insights into the contextual factors that shape the experiences and barriers faced by individuals with this disability in Canada.

The final content outline for the social section included:

- Background - Environmental Health in Canada: Understanding the Intersection of Policy, Industry, and Community
- Power of Words How the Naming of MCS Shapes Our Perception of Disability and Health
- Etymological Development of MCS: The History of the Word "Multiple Chemical Sensitivities"
- Multiple Chemical Sensitivity and Disability: Lived Experiences
- Living with Multiple Chemical Sensitivities
    - Product Choice
    - Ecological Logos and Certifications
    - Accessing Transportation
    - Accessing Community
    - Workplace
    - Home Cleaning
    - Emergency Preparations for MCS
    - Disability Accommodations
    - Home Renovations
- Community Exposure Reduction: Healthy Air is Good for Everyone
- The Impact of Fragrances on Multiple Chemical Sensitivities (MCS)
- The Importance of Being Fragrance-Free for People with Disabilities
- The Intersections of Climate Change and Pollution: Environmental Racism, Classism, and Ableism
- Environmental Violence: Inequity & Systemic Injustice

- Marketing & Advertising in a Consumerist Society
- Looking Forward - Accessibility for All: Advocating for Change on an Individual and Community Level

Social Tools and Resources

- Sample Disability Accommodations for MCS
- Cleaning When You Have MCS, Home Owner Seasonal Cleaning Schedule
- Cleaning When You Have MCS, Tenant (Rental) Seasonal Cleaning Schedule
- Creating a Safe Bedroom for People with MCS
- Tips for Cleaning Mould in Your Home
- MCS-friendly Emergency First Aid Kit
- Home Renovations: Creating a Healthy Low Exposure Environment
- Eating Organic on a Budget
- Designing, Implementing, and Monitoring Scent-Free Policies
- The Importance of Being Fragrance-Free
- How to be Fragrance-Free
- Inclusive Laundry Notice
- Attention: Laundry Facility Users

For additional information on the biological and social content development, please check out Annex 2: Biological and Social Content Report.

Legal section

The main focus of the legal section of our content is to empower those with MCS to advocate for themselves and others with their disability in order to remove barriers to inclusion. The general outline for this section included:

- General Introduction to Legal issues faced by MCS community
- Legal principles
- Alternative Dispute Resolution (ADR)
- Federal legal disputes
- Provincial and territorial legal disputes
- Specific legal context
- Legal toolkit
- Conclusion
- References and further readings

Legal Tools:

Pan-Canadian fragrance-free policy compilation: A comprehensive compilation of all scent-free and fragrance-free policies throughout Canada.

- In this detailed document spanning over 60 pages, we have exhaustively catalogued the multitude of organizations, businesses, health institutions, and other diverse built environments across Canada that have instituted scent-free policies. These policies either (a) impose a ban or restrictions on the use of fragrances, or (b) advocate for the avoidance of such products. We've made sure to distinguish between these two fundamentally different approaches. Furthermore, the document is thoughtfully organized by policy type, built environment category, and the jurisdiction it falls under, be it federal, provincial, or territorial.
- This comprehensive directory offers an extensive selection of locations where individuals can anticipate a fragrance-free environment, eliminating the need for preparatory measures or concerns about encountering fragranced spaces. It encompasses a diverse range of built environments including hospitals, clinics, dental offices, psychological practices, and government buildings, with each category neatly segregated for convenience.
- This compilation also provides a vast repository of policy templates and language usage examples, which have been instrumental in drafting a comprehensive fragrance-free policy template. This boilerplate can act as a guide for individuals and organizations looking to implement or revise their fragrance-free policies.

Global MCS Landscape document: This document provides a detailed account of the awareness, advocacy, and research efforts related to Multiple Chemical Sensitivity (MCS) undertaken globally. Every group and article we have discovered on MCS worldwide is cataloged in this document. The document is organized by country, focusing on regions where pertinent material is available. Each country's section is divided into four categories:

1. Support Groups
2. Scientific/Opinion Articles
3. Governmental/University/Agency Recognition
4. Policy Guidelines/Legal Aspects

Legal Database: This extensive Excel-based database offers a comprehensive review of all jurisprudence related to Multiple Chemical Sensitivity (MCS) across Canadian jurisdictions.

A comprehensive training guide that includes:

- Federal legal disputes
- Applicable context

- Applicable laws
- Canadian Human Rights Act
- Policy on Environmental Sensitivities
- Canada Transportation Act
- Accessible Canada Act
- Applicable commissions and tribunals
- Applicable jurisprudence
- Provincial and territorial legal disputes
- Applicable context
- Applicable commissions, tribunals, laws, and prescriptions per jurisdiction
- Applicable jurisprudence
- Specific legal context
- Employment
- Unionized-work
- Non-unionized work
- Legal toolkit
- Conclusion
- References and further readings

This document will be repurposed into several electronic booklets tailored for attendees of our forthcoming training sessions. They will include:

- Letters to the Human Rights Commission
    - Should we receive a response or if a policy is drafted as a consequence, we will share it with all our partners and make it readily accessible on our website.
- Fragrance-free educational poster
    - Upon requests from our members for specific-purpose posters, such as those addressing laundry products for use in shared laundry spaces, we plan to create and distribute these additional educational materials shortly.
- Accommodation sample letters
    - At present, we only have one template, but our plan is to create a variety of samples tailored to a broader range of situations, thereby providing more specific guidance for different scenarios.
- Legal intro and disclaimer for website
    - As we continue to expand and enrich the content of the ECRoB legal page, we will ensure the introduction is updated correspondingly.

- Fragrance-free Policy
    - We plan to offer more context-specific samples, such as for workplaces, clinics and hospitals, businesses, housing, and so on, rather than a general one.

Outreach

In order to best share our content, outreach efforts have been multifaceted and diverse - including community engagement and partnership development primarily focused on building connections with the following communities:

- medical
- legal
- disability

Our goals in all of our outreach include:

1. Building awareness and understanding about MCS.
2. Promoting inclusivity, removal of barriers to inclusion, and advocating for the rights of people with MCS.
3. Connecting with relevant organizations to establish partnerships and collaborations to build supportive networks of community power.
4. Engaging our target audiences to encourage their active participation.
5. Providing educational resources and support to both individuals with MCS and the public.

Our methods of outreach included:

- Building of a comprehensive list of organizations to target for outreach efforts.
- Utilizing social media platforms to connect with and reach out to organizations, leveraging the power of online networks for engagement.
- Actively participating in meetings with other organizations to foster discussions, share insights, and explore potential collaborations.
- Individualized emails and phone calls to organizations president, executive director, or executive assistant.
- Paid and organic advertisements and outreach to administer surveys and polls.

One of our volunteers made a call for participation - calling for Canadians with MCS to participate in the ECRoB project. She posted in the following 6 Facebook pages:

- MCS/EI Ontario Issues
- MCS Canadian sources
- Multiple Chemical Sensitivity & Multiple Food Intolerance Support Group.
- MCS/TILT Survivors
- MCS Van Life and Car Camping

These approaches allowed us to effectively expand our reach, establish meaningful connections, and facilitate productive dialogue with relevant organizations.

Additionally, in our social media outreach efforts we reached out to the following organizations to develop partnerships, collect data, and make posts.The primary groups from which data was collected include the following:

Group Name	Number of members	Link	Platform	Actions taken
Disability Without Poverty	1,425 followers	https://www.instagram.com/disabilitywithoutpoverty/	Instagram	Liked our post
Center for Environmental Health	67,000 followers	https://www.instagram.com/centerforenvironmentalhealth/	Instagram	-
Accessibility Innovators	8,470 Members.	https://www.linkedin.com/groups/4512178/	LinkedIn	Post shared successfully – Liked by members
Global Network for Entrepreneurs with Disabilities	500 Members	https://www.linkedin.com/groups/2932107/	LinkedIn	Post under review by group Admin2
Lime Connect	1,000 members	https://www.linkedin.com/groups/3671515/	LinkedIn	Post shared successfully
Web Accessibility	11,900 members	https://www.linkedin.com/groups/41800/	LinkedIn	Post shared successfully
Web accessibility education	706 members	https://www.linkedin.com/groups/1796098/	LinkedIn	Post shared successfully
Online Auction for Accessibility Project	388 members	https://www.facebook.com/groups/webaccessibilityeducation/	Facebook	Post under review by group Admin
Accessibility Ontario	120 members	https://www.facebook.com/groups/1230227237885130/	Facebook	Post shared successfully
The World is Accessible	13,800 members	https://www.facebook.com/groups/1230227237885130/	Facebook	Post shared successfully
Environmental Awareness	36,700 members	https://www.facebook.com/groups/138936256805458	Facebook	Post shared successfully – Liked by members
Environmental Humanities Research Forum		https://www.facebook.com/groups/102138850392400	Facebook	Post under review by group Admin
	5,600 members	https://www.facebook.com/groups/696601870518614/	Facebook	Post under review by group Admin

Disability Awareness and Advocacy	13,600 members	https://www.facebook.com/groups/272906196111225	Facebook	Post shared successfully
The World is Accessible	22,600 members	https://www.facebook.com/groups/theworldisaccessible	Facebook	Post shared successfully

Overview of Outreach from Month 1 to 8

Workshops					
Event	**Outreach**	**Type of communication(s)**	**# of communication(s)**	**Total emails (approx.)**	**Total phone calls**
Train the Trainer	55 groups	4 emails & 1 phone	5	115	53
disABILITY	72 groups	4 emails & 1 phone	5	178	58
TOTAL	**127 groups**			**293**	**111**

Lists for Outreach		
Lists		**Contacts**
Healthcare groups	General healthcare groups	20
	Nurses Associations	17
	Medical students	14
	Provincial medical associations	25
	Services	7
	Hospitals	73
Alternative medicine	Alternative medicine & healing	30

Lists for Outreach		
Lists		**Contacts**
HRCC Database	Human Rights Commission of Canada	14
Unions	National Affiliates & Independent	31
Ministries	Government & ministries	51
CAPE	Canadian Association of Physicians for the Environment executive contacts	8
Train the Trainer	Disability & environmental groups	55
disABILITY	Disability Groups	72
Mailing list	Organizatons EN & FR	120
Committees & Groups	ASEQ committees	27
Total		**564**

For more information on our outreach strategy, please see Annex 7: Outreach Report.

Newsletters

For our newsletters, we sent emails out through an email platform, which we use to keep records of the number of people an email reaches, and the number of times people engage with the email.

For a period covering approximately eight months, from November 10, 2023, to June 30, 2023, a total of 63 news and newsletter emails were sent out to the membership, partners, and community groups that included disability, environment, health, and the community at large. These emails were viewed 32,966 times, and were engaged 2,823 times through forwarding. See details at Annex 8: Newsletter Report.

Marketing and Social Media

Objective and Strategy

The objective of our social media strategy is to raise awareness about the medical disability of MCS so that people with this condition experience equity, inclusion and accessibility for all spheres of life including employment, health care and the community. The social media strategy therefore reflects this objective and focuses on sharing educational content about Multiple Chemical Sensitivity (MCS) from our website, gathers feedback from surveys, promotes upcoming workshops to organizations, institutions, and the general public through our websites, social media, partners, and by word of mouth. We used paid ads and organic growth to achieve these goals.

We used the following social media platforms:

- Facebook
- LinkedIn
- Instagram
- TikTok
- Youtube

Our comprehensive social media strategy includes a digital engagement series, which is an integral part of our comprehensive strategy aimed at enriching public understanding and fostering active participation in crucial environmental health, disability, inclusion and accessibility issues.

This series adopts a balanced and sustainable approach to content delivery, merging information with engagement and entertainment to keep our audience informed and stimulate valuable discussions. We focused on marketing initiatives that:

- promote awareness about environmental health issues such as MCS
- advocate for fragrance or scent-free, lowest-emission, and least toxic product choices
- highlight relevant news
- share powerful lived experience stories and narratives
- spotlight relevant films
- engage in community outreach
- uplift our community by acknowledging their deep loss, strength, courage, and how their healthy product choices benefit everyone including our environment, and help with climate change, as the chemicals they avoid, are also implicated in climate change.

Surveys and questionnaires were collaborated on by team members to better understand community needs and measure and track the public's understanding of MCS, including the accommodations required for accessibility for MCS, and for health and the environment. Part of the social media upscaling plan is to then measure the willingness to provide accessibility for this disability through product choices.

For additional information on our social media strategy, please see Annex 6: Social Media Strategy Report.

Summary of Results:

A key component of our project's data collection and outreach strategy revolves around utilizing both paid ads and organic ads. These engagement methods play a crucial role in spreading awareness about MCS and engaging the public in our efforts. The overarching objective is to educate and inform individuals about MCS, thereby enhancing their knowledge and comprehension over time, which we measure through our paid and organic polls.

By utilizing paid ads, we can strategically target specific demographics and reach a wider audience, ensuring maximum visibility. They allow us to reach out to a diverse range of individuals within a targeted community, such as the medical, legal, or disability community. Additionally, through these ads, we convey our commitment to supporting and assisting individuals with MCS, encouraging them to participate in workshops and educational programs specifically designed to empower them and raise awareness of their rights within the community.

Another crucial aspect of our data collection is measuring and evaluating comprehension levels of MCS over designated periods of time. By employing surveys, questionnaires, and feedback mechanisms, we can measure the impact of our awareness campaigns on individuals' understanding of this disability. This data serves as a vital tool in evaluating the effectiveness of our outreach strategies, enabling us to make informed decisions for future initiatives. Additionally, tracking the growth in knowledge and comprehension allows us to identify areas that require further attention or improvement, ensuring that our outreach efforts are continually tailored to meet the evolving needs of our project.

Our data collection and assessment efforts have allowed us to continuously refine our strategies to ensure maximum impact and effectiveness in our efforts to create a more informed and inclusive society.

Key Takeaways:

- Paid surveys: Though people don't identify themselves as being diagnosed with or having MCS, a significant number of people responded to our surveys that they experience symptoms after being exposed to fragrances. Fragrances are a major accessibility barrier for people with MCS. General public might benefit from the installation of fragrance-free policies, and the removal of barriers for people with MCS will benefit the general population, some of whom are reacting to fragrances, yet not seeking medical attention or accommodations for it.
    - Note: This is verified by reporting to our phone line. A fair number of people have 'realized' they have MCS through our work. They cannot tolerate perfumes and other products, but had no idea that the condition had a name. Also reported, is that these individuals chose fragrance-free and least-toxic products, since that was all they could tolerate.
- The paid surveys have gathered 9,774 answers.
- The non-paid surveys gathered 196 answers.
- Websites: 327,382 new visitors across all websites
- Since the start of the ECROB project, there has been a 413.7% increase in reach when compared with the previous 8-month period, which spans from February 21st until the end of October 2022.

Goals vs Results of Social Media and Google

Our key performance metrics we tracked over our social media channels included:

- impressions (the number of times the ad was shown)
- clicks

Social Media and Google Ads

We exceeded our impression goals by reaching over 1,610,467

Social Media & Google Ads Breakdown

Platform	Impression Goals	Impression Results	Click Goals	Click Results
Facebook/Instagram	205,314	419,809	9,511	16,149
TikTok	66,253	419,991	3,068	5,660
Google	756,600	542,000	48,600	44,500
YouTube	120,000	132,400	6,000	604
LinkedIn	11,102	59,085	200	66
Total	1,159,269	**1,573,285**	67,379	**66,979**

**Facebook and Instagram ad statistics shown combined as Meta owns both platforms and combines the statistics for ads on 1 platform*

Social Media Content (Excluding ads)

Platform	Posts	Impression Results
Facebook	289	30,063
Instagram	142	770
TikTok	16	6,349
YouTube	27	11,095
LinkedIn	264	4,932
Total	738	**53,209**

Social Media & Google Total Statistics

Platform	Posts	Ads	Impression Results	Click Results
Facebook/Instagram	431	25	450,642	16,149
TikTok	142	12	426,340	5,660
Google	N/A	40	542,000	44,500
YouTube	27	12	132,400	604
LinkedIn	264	1	59,085	66
Total	**738**	**90**	**1,610,467**	**66,979**

Paid Ads Campaign Report:
The purpose of our paid ads campaign is to administer surveys to better understand the awareness of MCS, and the number of people who react to fragrances. Surveys were created to measure and monitor community education, needs, and engagement.

Total Ad Cost Year-To-Date: $3,235.58

The paid surveys have gathered 9,774 answers across Facebook, Instagram and TikTok, which was a significant increase of participation compared to our non-paid surveys which gathered 196 answers. However, non-paid surveys have just been started around one month ago. Organic ads were not in the original plan. We saw it as an opportunity to run organic and paid ads together, and in a few months, to compare the results.

We maintain a vigilant approach in monitoring the effectiveness of our strategies and adapt accordingly to the ever-changing landscape of various platforms. It is essential for us to stay updated with the latest trends and shifts in order to optimize our outreach efforts. By closely tracking these developments, we can identify what is working well and what needs adjustment. This proactive approach allows us to stay agile and make informed decisions that align with the evolving needs of our target audience. For more specific information on the trends and shifts we have observed, please refer to the details provided in Annex 5: Marketing and Social Media (Survey/Poll Reporting) Report.

To enhance our social media presence, we will implement a comprehensive strategy that includes both paid and organic surveys. These surveys will be tailored to target specific provinces as we expand our legal content to cater to province-specific regulations and requirements. Additionally, we will focus on reaching out to various audiences, such as medical professionals, legal practitioners, and other disability organizations, ensuring that our content is relevant and valuable to these specific groups. By leveraging paid and organic surveys, we aim to maximize our reach, gather valuable insights, and foster engagement with our target audiences, ultimately driving greater awareness and impact in our efforts.

Impact of ECRoB Project

Data from polls show that there has been an increase in awareness of MCS by 9%.It is expected that when content has been loaded on the website and workshops have recommenced, social media will also direct traffic to this information, increasing education and awareness of MCS.

Paid Polls

Polls	Question	Yes Change %	No Change %
1	Have you ever experienced symptoms after using a cosmetic product?	+9%	-9%
2	Would you prefer to use eco products instead of regular products?	-1%	+1%
3	Have you heard of Multiple Chemical Sensitivities (MCS) ?	0%	0%
4	Have you ever experienced symptoms after using perfumes ?	+1%	-1%

5	Do you know anyone that has Multiple Chemical Sensitivities (MCS) ?	N/A	N/A
6	Exposure to chemicals leads to symptoms of MCS. Do you experience MCS?	N/A	N/A

Interpretation

Poll 1: This shows that there has been an increase in awareness of symptoms of MCS by 9%.
Poll 2: The percentages are relatively the same, indicating that the preference for eco products is about the same.
Poll 3: There has been no change in awareness for this poll.
Poll 4: This shows that there has been an increase in awareness of symptoms of MCS by 1%.
Poll 5: This poll has no data for March 22nd to May 12th 2023, no comparison can be made.
Poll 6: This poll has no data for March 22nd to May 12th 2023, no comparison can be made.

Events & Workshops

Purpose

The primary purpose of our events and workshops is to foster empowerment within individuals with MCS, as well as providing education to the broader public. By doing so, we aim to dismantle the barriers that impede access to healthcare, community spaces, transportation, and other shared spaces and provide education on the subject. These workshops were designed with three primary objectives in mind:

1. Empowering the MCS population by educating them about their legal rights.
2. Educating civil society about MCS and fostering greater awareness and understanding to remove barriers of inclusion.
3. Conducting public education workshops to inform the MCS community about their legal rights and the latest information on their condition.

Additionally, these workshops align with the broader objectives of the ECRoB project, which include fostering collaborations and partnerships with legal, medical, disability, environmental, and community stakeholders.

Our workshops include the biological, medical, social and legal aspects of MCS. Developed to cater to specific audiences of intersecting identities, the workshops are tailored to meet specific needs. For example, workshops for people with MCS, are tailored to teach about all aspects of the disability, and additionally, accommodation measures will also include the process, and best practices for requesting accommodation. For the medical and legal community, often doctors and lawyers will give these workshops to their peers; for the disability community, accommodation needs will be explained in relation to removing barriers for accessibility, as also the overlap and intersections of different disabilities and medical conditions. There is a greater impact on the person with MCS when they are also experiencing other disabilities. For future workshops as we reach out to unions, nurses, lawyers, etc., these workshops will be tailored to address these different disciplines.

Through these workshops, we aim to achieve comprehensive education, empowering individuals with MCS, and promote a more inclusive and supportive environment for the community.

Summary

- 30 online workshops conducted in English or in French, with either ASL or LSQ interpretation options.

- 65 additional workshops scheduled up until August 31, 2024, which will bring us to our goal of hosting 95 workshops.
- 32 surveys administered during events
- 6 polls given throughout the events
- 305 survey responses
- 111 poll responses

Key Points:

- The project's success has sparked community empowerment, as evidenced by the positive feedback received during and after events. Participants have taken the initiative to get involved in other projects, actively sharing the knowledge and information gained during our initiatives to promote accessibility and inclusivity for people with MCS beyond our immediate scope. This ripple effect underscores the project's lasting impact and the potential for creating a more inclusive society.
- There is a desire especially from civil society and government for additional events and workshops, especially ones tailored to specific communities.
- Based on pre- and post event surveys, there has been a demonstrated increase in understanding around the disability of MCS.
- According to our post event questionnaire, attendees felt it important to provide accessibility to people with MCS. 24.2% responded with a 4, rating it important, and the remaining 75.8% rated a 5, extreme importance to provide people with MCS accessibility. These results are very encouraging and drive our determination to create the change we need to see happen for equity, inclusion, and accessibility.

Accessibility considerations

In order to enhance the accessibility and effectiveness of our events, we have implemented a comprehensive inclusive framework.

As part of this framework, we have enlisted the services of American Sign Language (ASL) interpreters and translators proficient in both French and English for each of our events. By leveraging the translation feature provided by the Zoom platform, we have further bolstered our accessibility measures, improving communication and collaboration among participants.

List of Workshops:

#	Date	Workshop	Number of

			people
1.	2022 Nov 24	Workshop, lived experience in English *This first workshop introduced the ECRoB project, and the workshop was viewed by participants through the lens of disability, suggestions were made for improvement.*	28
2.	2022 Nov 25	Workshop, lived experience in French. *The same as above was done for the initial workshop in French.*	26
3.	2022 Dec 16	Disability training English. *This workshop was given to partners, staff, volunteers, other groups, and members in English.*	67
4.	2023 Jan 12	Disability training French. *A similar workshop was given, as the one on December 16, 2022, in French.*	32
5.	2023 Jan 17	Disability training English. *The workshop was updated and given to participants who could not be present for the first workshop.*	29
6.	2023 Jan 24	Disability training French. *The workshop was updated and given to participants who could not be present for the first workshop in*	47

		French.	
7.	2023 Jan 31	Given to Medical Students. *This workshop was given to medical students to teach about the scope of the medical content, that could be evaluated and used for another workshop in April.*	8
8.	2023 Feb 14	Disability advisory committee English. *Workshop given to the Disability Advisory Committee to inform on the latest science on MCS, in English.*	15
9.	2023 Feb 14	Disability advisory committee French *Workshop given to the Disability Advisory Committee to inform on the latest science on MCS, in French.*	9
10.	2023 Feb 16	Workshop to groups to become trainers EN *Workshop given to civil society groups, with an invitation to become a 'trainer' or, to collaborate with ECRoB*	18
11.	2023 Feb 20	Workshops to groups to become trainers FR *Workshop given to civil society groups, with an invitation to become a 'trainer' or, to collaborate with ECRoB*	5
12.	2023 Feb 21	Workshop to groups to become trainers EN *Workshop given to civil society groups, with an invitation to become a 'trainer' or, to collaborate with*	6

		ECRoB	
13.	2023 Feb 24	Workshop to groups to become trainers EN *Workshop given to civil society groups, with an invitation to become a 'trainer' or, to collaborate with ECRoB*	12
14.	2023 March 20	Workshop for Accommodation measures *Workshop with a focus on accommodation measures for people with MCS*	44
15.	2023 March 23	Workshop Accommodation housing *Workshop with a focus on accessibility to the built environment, with healthy building materials, given by experts on air quality, and medical expertise on MCS.*	222
16.	2023 March 25	Legal aspect of MCS *Workshop on the legal aspects of MCS, for people with MCS, and also to inform people without the disability.*	51
17.	2023 April 3	Medical Students *Workshop on the medical, biological, social and legal aspects of MCS, given to medical students.*	76

18.	2023 May 31	National AccessAbility Week Program *As part of the National AccessAbility Week, a workshop in collaboration with ARCH Disability Center, the Law Society of Ontario, the Environmental Health Association of Canada. The workshop was for the legal community and presentations included a medico-legal, lawyers who have worked with MCS clients, accommodations for MCS, lived experience, and ASEQ-EHAQ presenting on what we hear from the community, and particularly related to the legal aspect.*	1000
19.	2023 May 10	Disability French *In May workshops were held to educate and create awareness among the disability community. MCS is diagnosed in communities across Canada, and is also experienced with other disabilities, and health conditions. Since one in 34 have a diagnosis, it is important for groups to understand and know appropriate accommodation measures for MCS..*	13
20.	2023 May 10	Disability English *As mentioned at #19.*	28
21.	2023 May 17	Disability French *As mentioned at #19.*	10

22.	2023 May 17	Disability English *As mentioned at #19.*	23
23.	2023 May 24	Disability French *As mentioned at #19.*	15
24.	2023 May 24	Disability English *As mentioned at #19.*	27
25.	2023 May 12	MCS Prevalence Workshop *Workshop, which included the prevalence of MCS*	38
26.	2023 May 18	Workshop – air quality and accessibility *A workshop presented to teach on accommodations and accessibility to the built environment, for MCS.*	15
27.	2023, June 2	Workshop members, disability English *Workshop for people with MCS, disability issues, in English*	8
28.	2023, June 6	Workshop members, disability, French *Workshop for people with MCS, disability issues, in French*	2
29.	2023. June 7	Inclusion Canada	9

		A workshop given at a Lunch and Learn to Inclusion Canada	
30.	2023 June 12	*Workshop on ECRoB to universal accessibility committees* *A presentation of the ECRoB project and MCS to accessibility committees.*	20
Total participants until June 2023			**1903**

Key Takeaways about Events

These events have also helped us strengthen our ties to our membership and to the MCS community. Our last public education sessions go back to a few years back, during our project accomplished in partnership with the University of Québec in Montreal (UQAM) and UQAM's online teaching university, TELUQ, and they solely focused on Québec. With the ECRoB project, we are able to update all this information and expand on it, including it in our workshops that are expanded to focus across Canada. In order to teach province-specific human rights, we have created and will be presenting province-specific content, as this has been identified as a need in the community.

These workshops have empowered the MCS population to learn about their health condition, accessibility needs, and their human rights. We are laying the groundwork to cover a great need that has been identified for legal education for other areas of the law, such as worker's compensation and tenancy law.

To ensure high quality medical information, we collaborated with some physicians for some of these workshops. These collaborations included medical doctors: Dr. John Molot, Dr. Ellie Stein, and Dr. Domenica Tambasco.

Breakdown of Events

Train the Trainer: February 2023

- This event was to promote our project to organizations and invite them to become 'trainers'.

We held a set of workshops in order to appeal to other groups about becoming advocates for Multiple Chemical Sensitivity (MCS). Our initial plan was to train other groups to be trainers on the topic. However, the more productive decision was made to open communication with groups and offer future, individualized training and workshops with them.

Key Points:

- For this event, we reached out to 55 groups/organizations across all Canadian provinces and territories. We initially had 12 organizations confirming attendance (21%), but the remainder were unable to attend.
- Through our polls we learned that our attendees work with many different stakeholder groups, including academia, the private sector, public sector, community groups, scientists, media, environmental health organizations, people with intellectual disabilities, public sector, health professionals, and legal professionals.
- Our pre and post surveys also showed us that there was a range of understanding of Multiple Chemical Sensitivity (MCS) before the event. After our presentation, survey results showed an increase in understanding of the condition.
- Participants showed interest in supporting the ECRoB project moving forward, we had 36.4% who showed a high interest in supporting this work and 27.3% were moderately interested. These responses inform how to move forward with training on MCS and educational workshops. During our discussion at the end of the event, participants gave great feedback. This feedback inspired us to alter our project into an accessible online training module format to increase accessibility and interest in supporting the project moving forward.

Air Quality Event: March 2023

- 222 attendees

We held an air quality event in order to discuss the importance of accessible air quality in the built environment, the necessary measures that must be taken for accessibility, the most important of which is product choice. This event was mainly informative so it was closed out with the request to fill out a short survey that also allowed for attendees to input their contact information for future newsletters and events.

Medical Student Workshop: April 3, 2023

- The significance of this collaboration lies in its focus on education and awareness of MCS, ensuring that future doctors are equipped with up-to-date scientific knowledge about this disability. Also, as a sustainability feature, there is an understanding that the medical students will advocate for teaching MCS as part of the syllabus.

On April 3rd, 2023, the Environmental Health Association of Québec hosted a workshop with medical students across the provinces to give some perspective to the ECRoB project in a medical setting. Because medical students are proponents of our future, they were an important group to build a relationship with and, in consequence, very receptive to our discussion. This meeting was open to some members as well, however, the content was geared toward the medical students.

Key Points:

- When asked what they would like to see in future events, we had the feedback that 68% wanted more scientific research, 61% wanted to see advice for the management of MCS and 39% wanted to hear lived experiences from people with this condition.

May disABILITY Workshops: (3 English, 3 French)

- a total of 116 attendees (groups & individuals) across the 3 weeks in both languages
- 18 groups attended

In May, the Environmental Health Association of Québec hosted a series of workshops titled ‘disABILITY’ in English, and ‘disABILITÉ’ in French. There were 3 English and 3 French workshops, with the purpose of educating groups that represent other disabilities on the condition of MCS. The aim of the workshops were to educate for awareness but also so that disability groups knew how to provide accessibility for people with MCS within their own organizations or membership, and also to have inclusive environments to allow accessibility for the disability of MCS..

These workshops during the month of May were offered to disabled persons and organizations that represent them. We have aimed to make these as accessible as possible as a result by shortening them, offering sign language interpretation and providing different dates to promote attendance.

Key Points:

- Through social media, we reached out to many groups to spread the message about the workshops to their memberships.This increased the visibility of the disability of MCS.

Workshop including prevalence of MCS: May 12, 2023

- 38 attendees

For the month of May, as Multiple Chemical Sensitivity Awareness Month, the Environmental Health Association of Québec hosted an event on prevalence to bring awareness to the topic. This workshop took place on May 12, 2023, as it was MCS Awareness Day and made for the perfect opportunity to discuss with people from our community, as well as introduce the topic to people who are not already informed about the condition.

Workshop on MCS to the Legal Community: May 31, 2023

- 1000 attendees

On May 31st, 2023, a workshop on MCS was hosted with hundreds of lawyers and members across Canada. The goal of this event was to provide lawyers and people within the legal profession education and awareness on MCS, and how to provide appropriate accessible help to this community, helping to recognize barriers to care and how to eliminate them, and working to create an inclusive environment. They were presented with the up-to-date science of MCS, and a medico-legal presentation, which would be very useful in the courts, and the presentation included the legal aspects of the condition from lawyers who work with clients who have MCS. Lived experience of MCS was also presented via a video to keep the presenter anonymous, and ASEQ-EHAQ shared stories of people of MCS to show the dire need for immediate change. Participants were provided with a short survey to gauge their knowledge on the condition and their motive for joining the workshop.

Inclusion Canada Workshop:June 3, 2023

- 9 attendees

On June 7, 2023, a workshop, by way of lunch-and-learn was presented to Inclusion Canada. This was an educational workshop on MCS and ways to integrate best practices into personal and public spaces (i.e. the workplace). The goal of this was to bring attention to the condition so that Inclusion Canada could be made aware of its potential within their membership and team, The workshop was attended by key staff and decision makers within the organization.

Movie Nights and Open Houses:

The community experiencing MCS experiences great loss and one of these losses is social inclusion, such as developing friendships and community. For this reason, we have started a 'Movie Night' to get together and watch films of interest. To date we have had two movie nights and this has been warmly received by the community. In August we will commence Movie Night.

In addition to Movie Night, we also have ‘One hour of self-care’ which provides chair yoga for people with mobility issues common to MCS, and ‘Open House’ on the last Friday of every month. Community members join in for a chat, with no agenda, except to have friendly conversations. Sometimes these get serious and great ideas flow out of them.

Key Points:

- It is important to think about the people we work for not just as numbers and issues, but as people with needs that are presently unmet due to inaccessibility. We try to create safe spaces where they can freely express themselves without judgment.
- Interest in additional movie nights is growing, and especially with fun or comedy themes.

Surveys, Questionnaires, and Polls Report

We have created data collection tools to monitor and analyze data related to different aspects of our project including - accessibility, barriers to inclusion, and the experiences of individuals with lived experience of MCS. This data will be used to inform, track and monitor progress, and identify areas that require further attention and action.

Demographic data was collected on participants who joined our workshops. Tools have been built to centralize data collection for reporting and sharing in the future in an accessible manner with the public and our partners.

Team members created and administered 17 unique surveys and polls sent out in English and French to community members and participants of workshops in order to gather qualitative and quantitative data for project evaluation. Some surveys were also developed to gather information on our committees, including the Disability Advisory Committee and Steering Committee.

Event Surveys and Questionnaires

The following surveys, polls, and questionnaires were used during events and workshops:

1. ASEQ-EHAQ Demographic Survey (English)
2. Sondage démographique (Français)
3. Stigma Reporting Form (English)
4. Stigma Reporting (Français)
5. ASEQ-EHAQ Feedback Survey (English)
6. Housing Survey (English)
7. Sondage de logement (Français)
8. MCS Lived Experience Team Survey
9. L'expérience vécue de SCM sondage (Français)
10. Sondage sur l'impact du rapport de l'INSPQ sur la SCM/MCS (Français)
11. INSPQ Questionnaire (English)
12. Impact of MCS Survey (English)
13. Social Event Learning Survey Form (English)
14. Sondage sur les événements d'apprentissage social (Français)
15. Sondage d'opinion de l'ASEQ-EHAQ (Français)
16. Questionnaire sur l'événement du 3 avril 2023 avant l'événement (Français)
17. Pre-Event Survey: Medical Students Workshop on April 3, 2023 (English)

Polls on Website:

1. ASEQ-EHAQ website front page #1 (experiencing MCS)

2. ASEQ-EHAQ website front page #2 (not experiencing MCS)
3. Eco Living Guide: (MCS and no MCS, combined)
4. ECrOB Page: (For our community members with MCS and no MCS, combined)

Surveys were initially sent out pre-event, though it became evident participation was low, which caused us to alter our practice to sharing pre-surveys at the start of the workshop, and the post-survey at the end of presentations, but before Q & A. This approach yielded much higher responses. Polls were presented during the workshops to keep interest and engagement with participants. The pre and post surveys measure knowledge, understanding and commitments. These responses helped shape the work of ECRoB and either validated the work being done, or identified areas for improvement.

A complete report on the surveys and polls taken pre and post workshops, can be found in Annex 4: Surveys, Questionnaires, and Polls Report.

Lessons Learned: Success and Challenges

The ECroB project underscores the importance of involving people with lived experience with Multiple Chemical Sensitivity (MCS) in the planning, design, and implementing phases. Their input was invaluable in identifying barriers to inclusion, highlighting areas for improvement, and suggesting innovative solutions by pooling community wisdom. By including them in decision-making processes, we ensured that our efforts were relevant, appropriate, and effective.

Another lesson we learned was the need to prioritize accessibility in all aspects of our project. People with disabilities face specific challenges when it comes to accessing information, services, and opportunities. By actively involving individuals with lived experience of MCS we gained firsthand knowledge of the unique accessibility issues and identified ways to address them. Whether it was incorporating assistive technologies, ASL/LSQ, providing alternative formats for materials, we realized that accessibility should be a core consideration from the project's inception.

By centering people with lived experience of MCS, we were reminded of the importance of diversity and representation. Disabilities encompass a wide range of experiences, and it was crucial for us to ensure that our project reflected this diversity. By including individuals from various backgrounds we were able to gain a comprehensive understanding of their needs and develop solutions that were relevant to a broader spectrum of people.

- Need for more expanded and specifically tailored content. Identified interest in additional workshops and content development.

Successes:

- From our medical student workshop, the attendees were asked if they believed that policies should mandate fragrance-free and least-toxic policies, to which the question was unanimously answered yes.
- When asked what they would like to see in future events, we had the feedback that 68% wanted more scientific research, 61% wanted to see advice for the management of MCS and 39% wanted to hear lived experiences from people with this condition.
- The medical student collaboration was very important for this project. Through education and awareness, future doctors are being taught about MCS with up-to-date science. An understanding was developed that the medical students will advocate for teaching MCS as part of the syllabus, as they had proactively reached out to us to collaborate on this workshop.

- Post-survey workshops showed that after learning about MCS - the biological, social and legal aspects, which included up-to-date science and best practices for accommodation, including resources to make the appropriate changes for accessibility for MCS, people reported that they would make the product change required to accommodate and provide accessible spaces for people with MCS.
- ASEQ-EHAQ partnered with ARCH Disability Law Center and the Law Society of Ontario to promote the ECRoB project. The responses following the event in Ontario on May 31 was very positive. In addition, the audience for that workshop which were lawyers and officers of the court including Judges, and this knowledge exchange from professionals to the audience, helped to meet the objective of the project regarding MCS, which is: *Build capacity and inclusion by educating people with ES/MCS disabilities on their rights and increasing their access to legal support and other information to effectively manage their disabilities*.
- We have seen an increase in active participation from the MCS community, including increased validation and hope for the future
- We created a new very strong partnership with La Confédération des organismes de personnes handicapées du Québec (COPHAN), and COPHAN has taken a resolution to support MCS at all levels of government. Through COPHAN we have met lawyers, and well established scientific bodies who would work on MCS. All this is being done with the ECRoB project.
- We are very cognizant of the work that has gone into social media and the outreach that has been achieved.

Best Practices

- Accessibility Best Practices Document (social media, website, internal, etc.)
    - For more information on this document, please see Annex 10: Accessibility Best Practices.
- Centering the disability needs of MCS community and removal of barriers that are also other barriers of access for people with other disabilities and health conditions.

Successes:

- Adapting into a more accessible longer lasting more sustainable format with online accessible self-paced training modules and videos.
- Updated content from a biological, social, and legal perspective for people with MCS. Tipsheets, videos, pamphlets and other materials were created and shared.
- Positive feedback from the MCS community, and their desire for more.

Challenges:

- One obstacle identified was the need for updated information and expansion on the project's content on MCS. The initial research and data collected for the project required to be updated as it proved to be insufficient for meeting the current status of MCS, and project's objectives. This necessitated extensive additional research and the acquisition of more recent and reliable sources, resulting in a considerable increase in the project's timeline. The search for accurate and up-to-date information demanded significant time and effort, involving thorough analysis, cross-referencing of data, and verification of sources. However, this meticulous approach was essential to ensure the project's accuracy and relevance, despite the additional time investment required.
- Another challenge that emerged during the project was the need for adjustments to the project's deadlines. As the project scope expanded due to the need for updated information and expanded content, it became evident that the initially set deadlines were no longer feasible. The inclusion of more comprehensive research, data analysis, and content development called for additional time to ensure the project's high quality and thorough completion.
- Due to present challenges post-COVID, or during this period of COVID, which has led to hiring issues, and that fact that though online communication has its advantages, it has led to an increased workload for many. These and other difficulties that groups commonly face these days, have been reflected in the responses from other groups when they were offered training as ‘trainers’ for the ECRoB project. We have had to re-think and regroup to change strategy to include civil society in the conversation of MCS. The lunch and learn approach could work going forward, as it did with Inclusion Canada, and we will be trying this approach with other groups, including offering training to HR. Offers of this nature have been sent out and we are waiting for responses.

Additional Comments / Outstanding Issues

Additional comments/Outstanding Issues

As was mentioned at the beginning of this report, the support received to launch the ECRoB project is historic and needs to be acknowledged. This will help to pave the way for sustainable change towards equity, inclusion, and accessibility for a disability that has been neglected, stigmatized, labelled, and ignored. The work we are doing will help people with MCS return to life, to society, and become contributing members on the social and economic scenes, instead of drawing from this pool for survival.,

The above coupled with the fact that we now can offer sustainable and some meaningful help to the community, is also good for our own morale. It has not been easy to watch this population suffer.

Therefore in this section, we would like to affirm our dedication to this project and especially because of the human health and environment benefit for people with MCS and everyone else.

During the analysis of our focus groups, we realized that without input from our community, we would not know all the issues that this community faces that need addressing. As with other disabilities, this community experiences high unemployment and poverty. The experiences and results of this are varied, and we need to do more to get the entire picture. Going forward, we will increase the number of focus groups with very specific questions, to fill the gaps.

This report is an in-house evaluation, and is reported in the Annexes.

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July 2023 - February 2024

The ECroB project has identified the need to reach a larger audience and broaden our content based on feedback from researchers, membership, and the Disability Advisory Committee (DAC). To achieve this, we plan to expand our content in the areas of biological, social, and legal aspects of this disability. Additionally, we aim to adapt our content to cater to different disability contexts, considering the intersecting needs of diverse communities that are impacted by this issue and or have similar needs to the MCS community.

In order to extend our reach and impact, we recognize the importance of engaging with other communities beyond our current scope. This includes reaching out to health systems, legal and medical institutions, unions, the service industry, and various community groups. By fostering collaboration and partnerships, we can enhance our project's effectiveness and ensure that it resonates with a wider range of stakeholders.

Through this scale-up process, our goal is to provide comprehensive and inclusive resources that address the multifaceted aspects of disability. By expanding our content and adapting it to different contexts, we can better serve marginalized communities and meet their intersecting needs. Moreover, by engaging with other sectors such as health and legal systems, we aim to create a more holistic approach to disability advocacy and support.

Overall, our project aims to amplify its impact by scaling up, diversifying content, and collaborating with other relevant communities. By doing so, we hope to foster greater inclusivity, understanding, and support for individuals with disabilities across various intersecting contexts.

The data collection for the sustainability plan has been started and will be submitted at the 16 month report.

Partnerships

a. Scope and diversity of partnerships

Partners:

Partner	**Location**	**Type of Organization**	**Skills**	**Collaborations**	**Long Term Plans**
Arch Disability Law	Ontario	Disability law not for profit	Legal Expertise, lawyers specialized in disability law	Legal Advisory Committee	MCS and Housing Law
British Columbia Aboriginal Network on Disability Society	British Columbia (BC)	indigenous disability society	Disability advocacy, indigenous network and advocacy	Steering Committee	BCANDS will support the workshops in BC and help reach Indigenous networks.
Canadian Network for Human Health and the Environment	Canada	National Canadian not for profit network that works on environmental health	Environment and Health	Steering Committee	Works to support healthy spaces through least-toxic chemical use.
New Brunswick Lung	New Brunswick (NB)	Environmental health and disability organization - lung health	Environment and Health	Steering Committee	Links with medical, legal and other disciplines. Work together to give workshops in the Maritimes to the medical, legal, and to civil society groups.
Spinal Cord Injury Canada	Canada	disability	Disability issues	Steering Committee	Experience on disability issues, promoting the

					workshops and the ECRoB. project
Well Earth Collaborative		Medical and environmental health charity	Medical	Steering Committee	Expertise on Environmental Health
Santé Mobile A1	Québec	Industry	Medical	Steering Committee	Help and support in meeting place in Montreal, introductions to groups, promoting newsletters
Confédération des organismes de personnes handicapées du Québec (COPHAN)	Canada and Québec	disability	All disability issues in Québec and at the federal level	Steering Committee	Supporting all actions of the ECRoB project. Partnering on workshops to the legal, medical and to civil society.
Environmental Health Association of Canada	national	Disability and environmental health charity	MCS support and help	Steering Committee	Work together on all issues. Collaborating on a podcast to spread the word on MCS, workshops, and the ECRoB project
Autism Alliance Canada	Canadian national	Disability - autism not for profit	Lived experience, expertise in shared disability barriers/needs	Workshops to the autism community	MCS and autism: People with autism also need scent-free and least-toxic spaces. We will work together on these issues.
The International	Canadian,	Medical	Medical,	Workshops to	To have

Federation of Medical Students Association (Québec), IFMSA	but we work with the Québec chapter	students	concerned about environmental health	medical students	workshops online, but across Canada

We have been working on developing our partnerships. By expanding our scope and diversity of partnerships, we are actively seeking collaborations with a wide range of organizations representing various sectors and structures. These include legal, medical, and environmental organizations, as well as entities such as, charities, unions, and more.

Maintaining and expanding our partnerships is a key aspect of our long-term strategy to create lasting impact and foster a more inclusive society. We are committed to nurturing and strengthening our existing collaborations while actively seeking new opportunities for partnership and engagement.

Our goal in diversifying our partnerships is to amplify the voices and contributions of diverse groups within the disability community, ensuring that their perspectives and needs are fully represented and integrated into our initiatives.

b. Relevance of project partnerships

The selection of partnerships is of utmost importance in achieving the goal of building infrastructure for a disability that currently lacks adequate support. Choosing the right partners ensures that the collaboration is built on a solid foundation of shared values, expertise, and commitment to the cause. Each partner should bring unique strengths and resources to complement one another, creating a synergistic effect that maximizes the impact of their combined efforts. Moreover, selecting partners who are dedicated to long-term sustainability and continuous improvement will ensure that the infrastructure developed remains robust and effective over time. By carefully evaluating potential partners and fostering relationships based on trust, mutual respect, and a common vision, we can pave the way for a truly inclusive society where individuals with disabilities are supported, empowered, and valued as equal members of the community.

Project partnerships that are involved in our committees will continue to help us build on our shared vision of reduced barriers to inclusion for people with MCS - which also reduces barriers for other disabilities. We aim to expand on other comorbid conditions that have the same needs as those with MCS in order to reduce barriers to inclusion for more people.

Partners also help us to collectively advocate for the project's goals and raise awareness about MCS disability issues. Through social media and event collaborations, with our partnership we are able to engage with the broader community and stakeholders to increase awareness of MCS, build infrastructure to support those with the disability, and sustain the project for the long term.

In the long run, and hopefully near future, the ECRoB project will result in MCS being taught in medical school, with up to date science.

c. Developing, maintaining, and meaningfully engaging partnerships

To ensure the continued expansion of our partnerships, we will continue to collaborate with our Legal Advisory Committee, Disability Advisory Committee, and Steering Committee.

We are currently engaging new stakeholders in the upcoming years, particularly in the following areas:

- Legal professionals
- Medical professionals
- Housing/building and other indoor air quality professionals

Our partners attend Steering Committee meetings and show great interest in the unfolding of the project. Every member provides input, advice and resources. Documents that are shared with them before meetings are commented on, and they will soon receive drafts of the content created before we finalize the content.

In particular, ARCH Disability Law Center, attends all Steering Committee meetings, and has helped with the collaboration with the Ontario Law Society and helped to organize the online event for lawyers in Ontario. They remain a very active and strong partner. The intention is that they will continue to work with us past this project and most definitely in Phase 2, to develop and deliver legal workshops that cover tenancy and workman's compensation. ARCH Disability Law Center has already co-signed letters to provincial human rights commissions, informing them of the ECRoB project, the need for uniformization of rights for MCS across Provinces, and to have accommodation measures on their respective websites. In addition, we also jointly wrote (along with other Steering Committee members), requesting the Human Rights Commissions to participate in the delivery of workshops to the legal community.

British Columbia Aboriginal Network on Disability Society (BCANDS) attends Steering Committee meetings and supports the project through advice. They will support workshops in British Columbia and sign letters to the BC Human Rights Commission. Their support has been important due to the reach of our messages through them. They were aware of MCS before we met them and have signage on their stationary and in their office space regarding ‘Scent-Free’ policies in place in their office building. We see them supporting this project since it addresses an unmet need in our communities.

NB Lung and the Canadian Network for Human Health and the Environment regularly attend Steering Committee meetings, and have similarly signed letters to the human rights commission in New Brunswick. They will collaborate and promote workshops across the Maritimes. They also have networks across Canada, and have been advertising the ECRoB project through different development stages, and will continue to do so. Since our work aligns, i.e, the need for healthy spaces, we see this as a long term partnership going forward.

Spinal Cord Injury Canada, is also represented at our monthly Steering Committee meetings. They support the project through advice and directing our emails and messages to their community. We see a long term partnership since they are convinced about the disability of MCS and the work that we do

Well Earth Collaborative attends some monthly Steering Committee meetings. The work done on Environmental Health by this collaborative helps to strengthen our project through outreach to the other groups. We see this group remaining with us as partners since we work on similar issues.

Santé Mobile A1 attends Steering Committee meetings and supports the group and the project by providing office space for meetings in Montreal, by forwarding the newsletters and messages on the project and by introducing us to other groups. The long term relationship with Santé Mobile A1 is strong as the person representing this group is a long standing board member of ASEQ-EHAQ.

New Partnerships

Confédération des organismes de personnes handicapées du Québec (COPHAN) is a new partner, and a very strong one. They attend Steering Committee meetings and have expressed the desire to do much more than what is in the scope of the project, and that is, to work on the disability of MCS being recognized as a physical medical condition in Québec. They have introduced us to lawyers and other organizations, and will partner with us for workshops in Québec, taking this even further, and being present at the National Assembly of Québec with workshops. We see a long term relationship with them as we are both disability groups, with similar missions.

Autism Alliance Canada has expressed interest in promoting our workshops. A letter has been distributed to other autism groups, in order to spread the word in the community. This relationship has to be developed, but so far there is conversation and an acknowledgement that we work on the same issues related to accessible indoor air quality.

Environmental Health Association of Canada is a new disability national group, working on MCS. Besides attending Steering Committee meetings, the group works closely with the ASEQ-EHAQ to serve the same community. A long term relationship is therefore seen with this group.

The International Federation of Medical Students Association (Québec), IFMSA, is being developed over time, hoping to create a strong bond that would fill the gap on education for MCS in medical schools, and also bring this condition which is growing in prevalence to future doctors.

Intersectionality

a. Intersectional lens

Adopting an intersectional lens has ensured that our work and our partnerships reflect the diverse needs and experiences of the disability community. One of the key strategies we have implemented is centering the lived experience of MCS in all our work. Embodying “Nothing about us, without us.

For our project, we have established a culture that encourages ongoing learning and discussion around intersectionality. We prioritize discussions involving developing best practices for applying an intersectional lens to our work. These sessions provide opportunities for knowledge sharing, brainstorming, and critical reflection. By consistently considering the intersectional dimensions of our programs, initiatives, and policies, we aim to address the unique needs and challenges faced by individuals with intersecting identities.

b. Benefits to diverse and underrepresented communities

Our project helps improve the health of all Canadians, particularly those with MCS. We all need healthy clean air to breathe and those experiencing this disability are often facing additional barriers due to systemic injustice.

This disability can affect anyone, including diverse and underrepresented communities who because of different systems of oppression frequently face additional barriers to inclusion in society.

Our ongoing development includes creating additional tools and educational resources that aim to empower individuals to advocate for themselves and others effectively. By ensuring enhanced relevance and improved effectiveness, these resources cater to the specific needs of diverse and underrepresented communities. Our approach incorporates universal design principles, taking into account diverse perspectives and identities during the creation process to ensure inclusivity and accessibility for all.

To minimize unintended negative impacts on individuals with intersecting identities over the long-term, the project places a strong emphasis on open dialogue, continuous learning, and growth. By fostering an environment of active communication, we can identify potential challenges and address them proactively. Additionally, our commitment to learning and growth ensures that we stay informed about emerging issues and best practices, enabling us to adapt our approaches to be more inclusive and responsive.

Furthermore, capacity building within our organization is a vital component. By investing in the development of our team members' awareness and understanding of intersecting identities, we can better navigate the complexities of diversity and inclusion.

In addition to these measures, continuing our current process of continual and regular feedback and engagement with the affected communities play a crucial role. By seeking input and insights from individuals with intersecting identities, we can gain valuable perspectives and adjust our strategies to be more supportive and accommodating to the people affected by this disability.

We recognize that an intersectional approach is fundamental in addressing the unique challenges faced by individuals with multiple identities. By acknowledging and valuing the complex ways in which identities intersect, we can develop interventions and resources that are truly equitable and considerate of all individuals involved.

We are committed to enhancing the accessibility of our project materials by translating them into even more inclusive formats. This could include engaging a specialized company to produce braille materials, ensuring that individuals with visual impairments can access our content. Furthermore, we remain dedicated to keeping our resources free and readily available to all, regardless of income level. By continuously striving for greater accessibility, we aim to create an inclusive environment where everyone can benefit from the valuable information and resources we provide.

Indigenous communities outreach:
In order to not enable further harm to indigenous communities, we are developing a reach out plan based on Guidelines for Responsible Research (science.gc.ca)

In order to prevent harm and enable inclusivity, we are committed to enhancing our cultural sensitivity and understanding of Indigenous protocols, values, and traditional knowledge. Through ongoing knowledge sharing sessions and consultations, we aim to create a collaborative environment that respects and acknowledges Indigenous ways of knowing and being.

The long-term sustainability and success of our project rely on our commitment to minimizing unintended negative impacts on individuals with intersecting identities, particularly Indigenous communities. In line with our dedication to responsible research practices, we are developing a comprehensive reach-out plan guided by the Guidelines for Responsible Research (science.gc.ca) and in collaboration with our Steering Committee.

Recognizing the historical and ongoing impacts of research on Indigenous communities, we prioritize respectful and meaningful engagement with Indigenous stakeholders throughout the project. We are actively collaborating with Indigenous leaders, organizations, and community members to ensure their voices, perspectives, and priorities are heard and incorporated into our decision-making processes.

Human and Financial Resources

a. Skills and experience

Skills Inventory and Employee Chart:
To effectively utilize the skills and expertise of our employees, we have developed a comprehensive skills inventory list and employee chart. The skills inventory list is a repository that captures the unique skills, qualifications, and experiences of each individual within our organization. It enables us to gain insights into the diverse skill sets present among our workforce, identifying areas of expertise.

For the ECRoB project, employees have a diverse set of skills, and each employee works on areas of their expertise. A project of this size depends on volunteers for success, as the needs of the project are vast. Committed volunteering has always been important in bringing the group to this point. All together, the skill available to the project are:

- Legal expertise
- Marketing and Social media
- Community economic development
- Fundraising
- Disability and accessibility
- Equity, Diversity, and Inclusion
- Outreach and partnerships
- Strategic organizing
- Policy development
- Content development
- Financial management
- Grant writing
- Project Management
- Data analysis
- Accessibility and disability
- Customer service
- Stakeholder relations
- Research
- Medical
- Lived experience of MCS and disability

ASEQ-EHAQ skills and expertise:

- Long history and track record of helping people with MCS
- Scent-free expertise

- Lived experience of MCS
- Successful non-profit for close to 20 years
- The Mission of ASEQ-EHAQ has been funded by the Ministry of Health Québec for the past 7 years.

b. Funding sources

While hiring an individual fundraising professional seems like a logical step, we recognize that budgetary constraints and other considerations may make this option unfeasible at the moment. In light of these challenges, we are developing alternative strategies for enhancing our fundraising efforts without hiring a dedicated fundraising staff member.

In our funding development we are committed to upholding our values and principles by refraining from connecting or partnering with polluting industries or any other private entities that may have negative impacts on the environment or society. We believe in maintaining a strong ethical stance and ensuring that our fundraising efforts align with our mission of promoting sustainability and social responsibility.

A primary focus of our fundraising strategy lies in pursuing grants that support program and project-specific initiatives and capacity building. We aim to secure the necessary funding to undertake various projects or maintain programs, each contributing to our overarching mission. These programs and projects are carefully designed to have a meaningful impact on the communities and causes we serve. By allocating specific amounts of money to each project, we can maximize our resources and direct them towards initiatives that align with our organization's vision.

<u>Fundraising Objectives:</u>
The main objectives of the fundraising plan are:

- To raise funds for the various causes identified to support individuals with Multiple Chemical Sensitivities (MCS).
- To raise awareness about environmental sensitivities/multiple chemical sensitivities (MCS) and the need for proper treatment and social services.
- To engage the community and garner their support towards creating a more inclusive environment.

Website Fundraising Setup:
We will implement a user-friendly interface on our website for donations. The donation page will provide a clear description of each cause, and donors can choose which cause they want to

support. This way, we can also gather valuable data on our audience's preferences, enabling us to tailor our communication and fundraising strategy better.

Cause-Based Fundraising:
Our fundraising plan will center around the following causes:

Support for Isolated Individuals: Your donations will help us extend our reach and provide emotional support services to those feeling isolated or excluded due to Multiple Chemical Sensitivities (MCS). Your contribution will ensure that no one has to face their struggle alone.

Healthy Products Resources: By contributing to this cause, you help us create and distribute lists and resources of healthy materials/products essential for everyday life for individuals with Multiple Chemical Sensitivities (MCS).

Education and Awareness Campaigns: Support us in our mission to educate the public about Multiple Chemical Sensitivities (MCS), the risks of exposure to toxic substances, and strategies to prevent MCS. Your donation will contribute to a healthier, more aware society.

Legal Assistance Fund: Your contributions will be utilized to provide legal assistance to individuals dealing with legal issues related to MCS. With your help, we can stand up for the rights of those suffering from Multiple Chemical Sensitivities (MCS).

Target Audiences:

- Note: We respect and understand the financial constraints of our members, many of whom are living with the MCS disability and facing poverty and unemployment. We do not solicit funds from our members, and our fundraising activities are directed towards the wider community, who are in a position to offer financial support.

Primary Target Audience:

Environmentally Conscious Individuals: These are people who are aware of and concerned about environmental issues and health-related challenges. They are likely to resonate with our mission and are potential donors.

Individuals with Affected Friends or Family: People who have friends, family members, or acquaintances suffering from Multiple Chemical Sensitivities (MCS) are more likely to understand the gravity of the situation and be more inclined to donate to our cause.

Philanthropists and High Net-worth Individuals: These individuals often donate to causes that they feel are important or resonate with their personal values. We will reach out to such people through our outreach strategy and educate them about Multiple Chemical Sensitivities (MCS) and the impact of their potential contribution.

Secondary Target Audience:

Healthcare Professionals: While their primary contribution could be in the form of donations, healthcare professionals can also help us spread awareness about environmental health and MCS. Their endorsement and support could add credibility to our cause.

Young Professionals and Millennials: These individuals are increasingly becoming a crucial part of donor communities. Their familiarity with online platforms can be beneficial for our digital fundraising initiatives.

Local Community Members: Local communities often support causes that affect their fellow members. By conducting awareness campaigns locally, we can engage community members to contribute and support our initiatives.

Donor Engagement and Retention:
We will regularly update our donors on how their donations are making a difference. Success stories, updates about our projects, and improvements in the lives of the individuals we support will be shared via our website and social media platforms. By showcasing the impact of their contributions, we aim to build a long-term relationship with our donors.

Ethics and Transparency:
All funds received will be utilized strictly according to the donor's choice of cause. We pledge to maintain full transparency and regularly publish financial reports on our website. Since we have a charitable number, all our reports are on the Canada Revenue Agency website

Preparing applications to apply to the following grants:

- Community Climate Transitions Innovation Fund (tamarackcommunity.ca) (Application deadline: August 24, 2023)
- Research and apply for funding programs specific to social economy initiatives, such as CED (Community Economic Development) in Quebec. https://ccednet-rcdec.ca
- Social Innovation - McConnell Foundation

Effectiveness

a. Progress toward project outcomes

Table: Deliverables / Actuals / Future (Schedule A + Sustainable Upscaling)

Deliverable		Current and Future Plans		
Item	Schedule A Deliverable - Number	Current	In Progress Future Outcomes	Phase 2 Outcome
Educational tools (powerpoint, website, videos, tip-sheets and pamphlets) on the disability covering the biological, social and legal aspects of ES/MCS	None specified in Schedule A	Powerpoints 32 Website 35 updates Tip-sheet 25 Pamphlet pending 5 videos 8 different legal tools including Powerpoints, website updates,videos, tipsheets, and other tools have been developed, including information on duty to accommodate, the Accessible Canada Act, letters to the Human Rights Commissions, alternate dispute resolutions methods, a legal database, a Pan-Canadian fragrance-free as well as fragrance-free	Work is presently ongoing to get ready to load content on the website. Once this has been done, as part of the sustainability plan and upscaling we have another set of tools and information that will be prepared and loaded on the website.	Additional tools (powerpoints, website, tip-sheet and pamphlets) on the disability covering the biological, social and legal aspects of ES/MCS The number and type will be determined through lived experience input and unmet needs of the community.

		policy and terminology documents.		
Powerpoints	None specified in Schedule A	32 Powerpoints were developed to educate on the biological, medical, social and legal aspects of MCS. They were tweaked for subsequent presentations, and new content was developed for new areas of education. All powerpoints were translated to French.	As part of the sustainability plan, we are planning on converting the powerpoints into voice-over video presentations in English and French, with accessibility features. By the time we get to October 2024, many more powerpoints will have been created.	As a scale up for sustainability, our workshops will include a discussion period based on a pre-prepared questions relevant for each discipline (lawyers, doctors, disability, environmentalists, etc) that would inform on attitudinal and other barriers that would not allow for accessibility. Responses will help shape and improve outcomes of these workshop meetings.
Tipsheets	None specified in Schedule A	25 tipsheets and information sheets have been created from the biological, social, and legal content from the ECRoB project..	Additional topics for expansion have been identified and additional tipsheets and information sheets are in development.	Ensuring the creation and availability of these resources in an accessible format holds utmost significance. We are dedicated to exploring various intersections of disability and tailoring the content to cater to specific disability audiences, as MCS can impact anyone. Our commitment to inclusivity drives us to make these materials accessible to all individuals.
Pamphlets	500	Pending	Being developed. Plan is to release pamphlets	In an effort to reduce our environmental

			after the ECRoB content is fully on the website.	impact, we are embracing a positive change by shifting from traditional printed pamphlets to eco-friendly online versions with convenient QR codes for easy sharing. For individuals who may face limitations in accessing a computer or printing, we will gladly offer printed copies delivered directly to them, ensuring inclusivity and accessibility for all.
Creation of a steering committee, national disability advisory committee and a national legal advisory committee	3/3	All three committees were created.	These committees are being run efficiently, and function well.	The Legal Advisory Committee is expected to grow and the other Committees will guide this work going forward.
Steering Committee	8	Steering Committee created.	Made up of partners, and include oversight of the project, troubleshooting and identifying sustainable solutions among other important points	We are very fortunate to have an interactive and supportive Steering Committee.The commitment shown so far is an indication of their beliefs that this population must be supported, and that we

				need healthy environments and healthy people. With this collective determination, we are building a solid foundation for future work that prioritizes the well-being and empowerment of those with MCS.
Legal Advisory Committee	4	Legal Advisory Committee created.	The Legal Advisory Committee (LAC) is being organized so that it remains a sustainable activity that will go on due to active participation from interested legal participants.	We chose human rights at the beginning to address urgent issues. However this population experiences neglect. As a natural evolution, and through research, we have identified that workers compensation and tenancy needs will be next. This upscaling was a next step when the situation is looked at as a whole by the LAC. Similarly, LAC membership is established because they want to be part of this change and this is much stronger than asking specific lawyers to join the LAC.
Disability Advisory Committee	English: 12 French: 6	Disability Advisory Committee created.	The national Disability Advisory Committee (DAC) has been created with people with lived experience of Multiple Chemical Sensitivities,	The heart beat of our project is the DAC. We depend on their input to guide the project. Membership to the DAC is always open.

			who actively participate in viewing content and attending focused meetings to guide the project.	Inclusive practices are in place to accommodate for the disability.
4 ‘train the trainer’ sessions (two in English, two in French) provided to partners	English: 2 French: 2	We held 2 English sessions and 2 French sessions.	Switching to online self paced accessible format to exceed this metric and make more longer lasting sustainable accessible format and delivery.	Preparations are ongoing to create a minimal but effective information package that would inform on the disability, accommodations, and resources for best choices.
15 individuals trained as trainers	15 people committed*	We trained 5 staff members, 6 volunteers, 4 committee members, and 8 organizations from various fields.	Switching to online self paced accessible format to exceed this metric and make more longer lasting sustainable accessible format and delivery.	Preparations are ongoing to create a minimal but effective information package that would inform on the disability, accommodations, and resources for best choices.
95 online workshops conducted in English or in French	95	30	Workshops are being planned that are province specific, there will be 3 to 4 workshops per province to cover the legal, medical, social and province-specific human rights. Communications have been prepared to reach different disciplines in order to give workshops.	Once the workshops start, the pace will be different and the content created and placed on the website will support sustainable learning and inclusion.
2,000 people reached directly	2000	1903	It is estimated that the final number of people reached through	We have altered how we administer surveys to conduct them during

through workshops			workshops would exceed the deliverable.	workshops. We are eager to witness a significant increase in participation rates, leading to more robust data collection and analysis.
6,000 surveys administered	6000	305	Executing plan for surveys in July 2023. Expected to catch up and surpass.	Once the workshops start and the surveys on the websites are advertised, it is expected that we will reach this number.
2000 polls to measure the changes made for accessibility	2000	9942	We will continue with the plan and upscale to meet our requirements to inform on accessibility in order to best serve the MCS community.	We have exceeded the number, however, we are excited to use this platform to gather additional meaningful data that can inform our work and contribute towards policy.
One million people received disability information through website	1,000,000	327,382 reach on the websites.	It is estimated that we will reach this deliverable, especially after the ECRoB content is published.	The more people we reach, the more awareness we create, and we will focus on this outreach to help with accessibility for MCS.
A 1-800 helpline to assist individuals with accessibility	1/1	A 1-800 helpline implemented to assist individuals with accessibility.	This helpline is answered at the ASEQ-EHAQ physical office.	The 1800 helpline has been set up.
8,000 calls for assistance answered	8000	2550 calls answered.	This aspect will continue, and as the 1 800 number is advertised more broadly, we expect the	We expect a larger number of calls.

			number of calls to increase.	
10,000 emails for support answered	10,000	Responded to just over 3000 emails, receiving between 20 to 30 per day.	This is an ongoing activity and is expected to increase after the content goes up on the website, and workshops start in the autumn.	We expect a large number of emails.
A final report on project activities		In progress		
A final scale-up and sustainability plan		In progress		
A final report to ESDC on project activities		In progress		
Website updates	None specified in Schedule A	The website was updated 35 times to reflect the need for advertising events, content, and the ECRoB project.	Within a month the ECRoB part of the website will be developed with accessible content, tools, tip-sheets, and videos. Additional content has been identified by researchers, MCS focus groups, and the Steering Committee to expand on and update our website with.	We have kept the ECRoB website within the ASEQ website, for sustainability purposes and for better management outcomes. However, it will have its own identifying banner and pages. The URL will also be /ecrob.
Newsletters	Not specified in Annex A	From November 2022 to June 30, 2023, a total of 63 news and newsletter emails were sent out to the	This is an ongoing activity, and we will enhance our outreach efforts by integrating newsletters with surveys	Newsletters will be linked to social media for an increase in outreach. As the workshops to the

		membership, partners, and community groups that included disability, environment, health, and the community at large. These emails were viewed 32,966 times, and were engaged 2,823 times through forwarding	and linking them to our social media platforms.	provinces start, the number and frequency will increase.
Outreach through Social Media	None specified in Schedule A	1,610,467 total impressions across all platforms (reach)	Social Media is carefully monitored for impact and outreach. It is expected that this number will increase exponentially.	Our social media strategy will be carefully monitored and adapted according to changing platforms.
	None specified in Schedule A	Needs assessment	Needs and barriers to inclusion for the MCS community were identified and included in this report. From this report, we have identified the need for additional comprehensive disability focus groups that will allow us to better understand the diverse set of intersecting barriers and needs from the MCS community.	These groups are expected to bring light to areas we did not think of. This should be an ongoing activity.
	None specified in Schedule A	Accessibility Best Practices document	Accessibility best practices have been identified throughout the course of this project and written into a document to share with other employees. As the	

			project continues, this document will be updated to reflect the diverse needs of the communities we serve.	

b. Benefit to intended communities

Our work has had many benefits to the disability community and to Canada as a whole. As part of our upscaling plan, we will be taking significant steps to enhance our understanding of the communities we serve. This will involve increasing the number of focus groups to gain deeper insights into the unique needs, barriers, and lived experiences of the individuals we support. By actively engaging with these communities, we can ensure that our efforts are tailored to address their specific challenges and provide meaningful solutions. Through these expanded focus groups, we aim to foster a more inclusive and responsive approach to better serve those we seek to empower.

<u>Community Building and Participation</u>: Our EcroB project has allowed us to further facilitate community building by providing a platform for individuals with shared experiences of MCS to come together and engage in meaningful dialogue and design making together on our Disability Advisory Committee.

- We also encourage community participation through various activities, such as: workshops, educational presentations, and community events like yoga or movie nights, where individuals can actively contribute their ideas and perspectives, learn, or just spend time together.

<u>Empowerment through Leadership:</u> We have fostered leadership development within the community and our work by supporting individuals with disabilities who have lived experience with MCS to take on leadership roles by joining our Disability Advisory Committee.

- In the community, we have empowered individuals with the knowledge to become advocates for their health and their rights and the rights of others, promoting self-advocacy and collective action through our educational content and workshops.

<u>Educational Materials and Resources</u>: We have developed and will shortly disseminate educational materials that address the specific needs and challenges faced by those with Multiple Chemical Sensitivity (MCS) in Canada.

- Provided educational and legal resources and tools that empower individuals to access relevant information, acquire necessary skills, and navigate legal, policy, and social frameworks. This includes tipsheets, powerpoints, website and social media content, and more.

Providing information to support accessibility through product choice: One of the most important features of providing accessibility for those with MCS, is product choice. This is not always evident from labelling on products. For instance, the Canadian Centre for Occupational Health and Safety (CCOHS), advises that products labelled as ‘Scent Free’ may in fact contain masking agents to ‘mask’ the odour or perfume contained in the product. People with MCS will report that they get ill from ‘odours’ since this is what they observe - the odour, and then the symptoms. Most people are not trained to decipher each chemical they come across in an ‘odour’ such as formaldehyde, phenol, ethanol, etc. However, it is to these types of chemicals that they ‘react’ to, due to sensitization to their cells, caused from chemicals found in everyday products. Hence, they will react or have symptoms from such ‘Scent-Free’ products too, even though there is no smell.The result of this can lead to further stigma as the wearer of the ‘Scent-Free’ product has provided an accommodation. To avoid this, an EcoLivingGuide.ca has been created to propose products that can be used to accommodate people with MCS.

- This is a useful tool for other purposes too. French media recently reported solutions for ants and for sunscreen from the EcoLivingGuide.ca

Collaborative Solutions and Engagements: We have encouraged collaboration among community members and partners to collectively identify and address issues that impact them and others. The establishment of our Disability Advisory Committee, Legal Advisory Committee, Steering Committee have facilitated an inclusive accessible sharing of knowledge, expertise, and best practices, fostering a supportive and collaborative environment for problem-solving and solution development.

We regularly seek input and feedback from our membership to ensure ongoing relevance and appropriate to their evolving needs. We actively keep open lines of communication, actively listening to feedback, and incorporating community suggestions and ideas into program development and decision-making.

Legal Tools and Resources:

- Offered legal resources to support individuals in understanding their rights and navigating legal processes in Canada.
- Advocated for inclusive policies and legislation that address the barriers faced by people with MCS, included educational materials to aid people to advocate for themselves.

By focusing on community building, leadership development, empowerment, educational resources, collaborative problem-solving, and legal support, ASEQ-EHAQ creates an environment that benefits everyone who needs clean, healthy air, especially those with MCS, other disabilities and conditions that depend on air quality for accessibility.

c. Quality of evidence

The ECRoB project has implemented various strategies to monitor its success and ensure ongoing improvement, including:

1. Surveys, Polls, and Questionnaires:

The ECroB project has created a centralized data collection system to streamline the collection, organization, and monitoring of relevant information from our questionnaires, surveys, polls, and website analytics. This system enables efficient data management, ensuring accurate and reliable information for monitoring, evaluation, and reporting purposes.

Feedback from various stakeholders, including the Disability Advisory Committee (DAC), the broader community, the Legal Advisory Committee, and the Steering Committee, is actively sought and considered. Data collected from multiple sources both quantitatively and qualitatively, such as surveys, polls, questionnaires, focus groups, and consultation sessions, are implemented to gather input on the project's effectiveness, relevance, and impact. This feedback informs ongoing improvements, program adjustments, and strategic decision-making.

2. Website and Social Media Data Analytics:

We have utilized data analytics tools to gather insights on social media and website usage and engagement. These analytics have provided valuable information on user behavior, website traffic, and content effectiveness, helping to measure the project's online impact and reach. We have also used paid ads and sent surveys through our social media, which has helped guide our efforts.

Additionally, information will be shared and collaborated on with partners to the project.

Potential for Expansion or Adaptation

a. Demand, need, relevance

There is desire for continued research and advocacy efforts created from this project. The ECRoB project has identified a strong desire for continued research and advocacy efforts resulting from its initiatives. Stakeholders and the members of the MCS community have expressed the need for ongoing support and resources to address the increasing prevalence of the condition.

According to the descriptives on a research project entitled “Impacts of COVID-19 Health Measures on People with Multiple Chemical Sensitivity”, where ethics approval was obtained from the Women's College Hospital, Research Ethics Board (2020) And this is also seen through member reporting the average time to diagnose MCS is 8 to 10 years as it is difficult to find a doctor to accurately diagnose this condition. This matches polls we have put out to the public through social media and to our community, where more people are reporting sensitivity to chemicals than are diagnosed with MCS. In some cases, participants did not realize they may have MCS until they came across our content.

Limited information is available about this condition, and individuals without medical training may struggle to comprehend its cause and effects. The lack of adequate medical support raises concerns, as these chemicals can have harmful effects on people's health. Many individuals are experiencing physical reactions to their environment due to exposure to perfumes, cleaning supplies, and chemicals, yet they lack sufficient education to fully understand these reactions. As a result, more people are reporting sensitivity to these substances rather than attributing their symptoms to a specific disease, triggered through sensitization of certain receptors on cells in the body.

New studies on MCS, comorbid conditions and other environmental health conditions and disabilities are always being released and we want to include the latest research in our work to ensure the most accurate information.

<u>Potential Impacts to Project</u>
Working online has been accessible and inclusive, but power outages and internet outages can impact meetings and work, especially if some staff are without generators. These issues have been built into our HR policy to account for what is happening in the environment - to be fair to the project and employee. These things are outside anyone’s control. We have been impacted by the project because of the fires and the floods. We are supposed to be in the Maritimes for the fall, but potential partners are not able to function because their homes and places of work

were flooded. Also because of the fires they had to previously leave their homes.

Potential changes in political parties or ministers, both federally and provincially could impact funding. Thus, we are developing a long-term plan to diversify our funding streams and build strong partnerships. Changes in provincial government, particularly Quebec, may also influence our operations.

Climate change exacerbates disabilities through higher temperatures and impacts our community significantly. Increased forest fires, hurricanes, tornadoes, power outages, flooding and other physical disasters can also impact remote working. We work around this as best we can. This also led us to identifying the need to reach out to emergency services to educate them on the needs of the MCS population experiencing climate disaster effects. There is a need for shelters that are scent-free and workplace accommodations for employees with MCS.

COVID-19 measures have improved accessibility and allow us to work remotely. Power outages and extreme weather events (e.g., sudden thunderstorms, floods, tornados, hurricanes, forest fires and smog, etc.) pose challenges as we work primarily online, but we adapt accordingly.

Employees face challenges due to the current economic and climate conditions, affecting transportation and work arrangements.

b. Scale-up and sustainability plan

Our project activities and outputs have already started to lead to some of our Phase 2 outcomes and our plans moving forward. Please click on this link to see Table: Deliverables / Actuals / Future (Schedule A + Sustainable Upscaling).

Long Term Risks:
We are looking to further diversify our funding sources to reduce dependency on certain funding streams and increase resilience to potential funding fluctuations.

Changes in political parties federally and provincially (particularly in Quebec) could affect funding, hence we are developing our long term plan that will diversify our funding streams.

Regulatory Changes: Changes in regulations and policies related to environmental health and accessibility can pose risks to the project's operations. To manage this risk, the project will stay informed about relevant regulatory developments and maintain active engagement with government agencies and policymakers. By monitoring regulatory changes and adapting its strategies and activities accordingly, the project can ensure compliance and alignment with evolving standards.

In response to this, we have also started to release policy position papers to state our position and share our calls to action - making it easier for partners to join us in collective action.

Employees: Had found hiring difficult initially, but have a well-rounded team now. Improving and adding to comprehensive documentation and training for new employees and volunteers on MCS.

Community Engagement and Retention: Sustaining community engagement, social media engagement, and retaining active participation from individuals with intersecting identities within the disability community is crucial for the project's long-term success. To address this risk, the project will prioritize ongoing community outreach, regular communication, and inclusive decision-making processes. By creating a sense of ownership and empowerment among community members, we can remove barriers together and can foster a strong and committed network of stakeholders who actively contribute to our shared goals.

The success of the project relies heavily on collaborative partnerships with various organizations and stakeholders. Challenges may arise in establishing and maintaining these partnerships, such as differences in organizational priorities, limited resources or capacity, differences of opinion, or changes in leadership. To manage this risk, the ECRoB project will focus on cultivating strong relationships, maintaining open lines of communication, and nurturing mutually beneficial collaborations that reduce barriers of inclusion. Regular meetings, clear communication channels, and collaborative decision-making processes will be implemented to adapt to potential partnership challenges and ensure their long-term sustainability.

Overcoming shared difficulties that are present for most organizations such as staff shortages and overload of ongoing work which has resulted in hesitancy to make new partnerships, has resulted in us working around that issue by providing easy to assimilate information on the disability. This information can be shared via videos, tip-sheets, social media posts and other forms of messaging.

c. Synergy

Accessible Canada Act: This federal government initiative aims to create a barrier-free Canada by developing accessibility standards, promoting inclusive employment, and improving accessibility in sectors such as transportation, information and communication technologies, and built environments.

Canada's Disability Inclusion Action Plan: The principles that underpin Canada's Disability Inclusion Action Plan are deeply rooted in the ACA, which advocates for the following:

- "Nothing Without Us": The active involvement of persons with disabilities is essential in developing and implementing government systems, policies, programs, and services.
- Human Rights-Based Approach: The development and execution of our systems, programs, and processes are guided by human rights principles, emphasizing equality, anti-discrimination, participation, and inclusion.
- Intersectionality: Government initiatives must consider how individuals interact with their environments and recognize the various intersecting forms of marginalization and discrimination faced by persons with disabilities. (Canada's Disability Inclusion Action Plan)

Disability rights organizations: There are various disability rights organizations across Canada working towards advancing the rights and inclusion of individuals with disabilities. By collaborating with and joining these organizations, we can tap into their expertise, networks, and advocacy efforts to amplify our impact of removing barriers to inclusion.

Provincial and municipal accessibility initiatives: Many Canadian provinces and municipalities have their own accessibility legislation, policies, and initiatives aimed at creating inclusive communities. We can connect with these initiatives by participating in local accessibility planning, sharing resources and expertise, and aligning our activities to support the goals and objectives of these jurisdictions.

Environmental health research initiatives: Several research initiatives and organizations in Canada focus on studying the impacts of environmental factors on human health. By establishing connections with these research initiatives, we can contribute to the existing knowledge base, share data, and collaborate on joint research projects to advance understanding of the intersection between environmental health and accessibility.

- Northern Contaminants Program (science.gc.ca)
- Home - MIREC Canada (mirec-canada.ca)
- Chemical Management Plan

Legal disability organizations and people: Those from legal backgrounds interested in learning more about environmental health and MCS.

Medical fields: There is growing interest, not only among the public, but also medical professionals like doctors, medical students, etc. who seek proper medical training on MCS.

Government interest in improving and understanding air quality: There is a growing government interest in air quality and its impact on public health. The project aligns with a research project we are doing on air quality. By establishing connections with government initiatives, policymakers, and relevant stakeholders, the project can contribute to discussions and efforts related to improving accessible air quality standards and regulations - especially in terms of removing barriers to accessing the built environment, transportation, services, etc.

Government interest in chemical management: The federal government has initiated public consultations on toxic environmental contaminants, including topics such as allergens in perfumes, cosmetic ingredients hotlist, flame retardants, consumer chemical products, and Perfluoroalkyl and Polyfluoroalkyl Substances (PFAS). These consultations signify a recognition of the importance of addressing environmental health concerns and seeking input from the public. By actively participating in these consultations and sharing insights from the project's research and community engagement, there is an opportunity for us to positively contribute to policy development and influence decision-making processes to improve the Canadian environment.

Increase in chemical regulation and the emergence of green markets: In light of the increased and enhanced chemical regulation in the EU and US, certain imports and exports will be banned to promote environmental health. Canada has a unique opportunity not only to adopt similar standards but to also lead in the green market by proactively regulating and incentivizing the use of environmentally friendly, least toxic, and scent-free products. By doing so, we can gain a competitive edge in the market and avoid financial losses associated with toxic products remaining on store shelves. Embracing this approach will not only benefit our environment but also position Canada as a pioneer in the global green market movement.

Academic institutions and research centers: Canadian universities and research centers undertake extensive research on topics related to disability, environmental health, and accessibility. By establishing partnerships with academic institutions, our project can engage with researchers, access resources, and foster knowledge exchange to inform our strategies, interventions, and policy recommendations.

By actively connecting with these related initiatives, our project can create synergies and foster a coordinated approach towards advancing environmental health and accessibility in Canada. Through partnerships, knowledge sharing, and collaborative action, we can maximize our impact and work collectively towards creating a more inclusive and accessible society for all.

Leadership by Persons with Disabilities

a. Leadership development within the project

Leadership by persons with disabilities is a core value of the ECRoB project, it’s in the name - Empowering Communities and Removal of Barriers. We are committed to ensuring meaningful involvement in all aspects of the design and delivery process. Contributions by people with MCS and other disabilities have been invaluable in shaping the project's direction and ensuring its relevance.

The project has exemplified the significance of leadership from individuals with disabilities. Through their active involvement, people with MCS have taken leadership roles, not only in driving the project's success but also in inspiring and guiding others towards greater inclusivity. Their valuable contributions and lived experiences have played a pivotal role in shaping the project's vision and impact, demonstrating the transformative potential of disability-inclusive leadership in fostering a more equitable and accessible society.

b. Leadership development within the disability community

People with disabilities, and in particular those with MCS, will continue to play a central role in our project. They will be involved in decision-making processes, project planning, and implementation, ensuring that their voices are heard and their needs are addressed. We are committed to providing ongoing support, resources, and capacity-building opportunities to enable their active participation and leadership.

We aim to celebrate, providing recognition and support for those who have contributed. We will acknowledge and celebrate the contributions who have made it possible.

The project has exemplified the significance of leadership from individuals with disabilities. Through their active involvement, people with MCS have taken leadership roles, not only in driving the project's success but also in inspiring and guiding others towards greater inclusivity. Their valuable contributions and lived experiences have played a pivotal role in shaping the project's vision and impact, demonstrating the transformative potential of disability-inclusive leadership in fostering a more equitable and accessible society.

Knowledge Mobilization

a. Knowledge sharing

Knowledge mobilization and sharing are essential components of our project. During Phase 1, we have implemented various strategies to share knowledge. These include:

- Newsletters
- Website updates
- Social media
- Word of mouth
- Workshops
- Presentations and powerpoints
- Tipsheets, information sheets
- Videos
- Events: Movie nights, Hour of Wellness, Open House
- Conferences
- Partnerships
- Media kit development - press releases

Looking ahead to the long-term, we are committed to continuing knowledge sharing to support the scale-up and expansion of activities. Some strategies we will employ include:

1. Partner Engagement: We will actively engage our partners in knowledge sharing efforts. This may involve regular meetings, knowledge exchange sessions, and collaborative projects that facilitate the sharing of expertise, resources, and lessons learned.
2. Dissemination Channels: We will leverage various channels to disseminate knowledge, such as our project website, social media platforms, newsletters, and targeted communications to reach our intended audience. These channels will ensure that our knowledge reaches a wide range of stakeholders, including policymakers, practitioners, and community members.
3. Increasing Accessibility and Improving on Accessibility Standards:
    a. Social media: Adjusting social media posts to include alt text and Accessibility Best Practices document to improve our accessibility and outreach to people with different disabilities.
    b. Bringing the website up to WCAG2.2 (Web Content Accessibility Guidelines) standards to reduce barriers to accessing our knowledge and project, expand

our reach to more communities, particularly those with disabilities. Improve marketing and reach.

Knowledge sharing, succession planning, and incorporating the wisdom gained from lived experiences of MCS into a community best practices document hold immense significance for our upscaling efforts.

By fostering a culture of open communication and knowledge exchange, we ensure that valuable insights and expertise are not lost but passed on to future generations. Succession planning enables the seamless transfer of critical knowledge and skills, ensuring continuity and sustainability in our endeavors. By capturing and sharing the wisdom gained from lived experiences, we enrich our community's collective knowledge, empowering us to make informed decisions and implement effective strategies. This community best practices document will serve as a roadmap for our long-term goals, ensuring that Canada becomes a safe and inclusive space for all, as we draw upon the depth of knowledge accumulated over time.

b. Adaptation based on learning

Our ECRoB project utilized knowledge gained from train-the-trainer sessions and community feedback to improve its approach. As a result, we have adapted by shifting to online training modules, making the learning experience more inclusive and accessible. This transition allows participants to engage at their own pace and ensures long-term availability of the training materials.

In the future, we will continue to use knowledge to refine and enhance our project. Feedback from participants, trainers, and stakeholders will guide improvements to the online modules. We will also actively seek knowledge exchange and collaboration with partners and community members to stay responsive to evolving needs.

By leveraging knowledge and maintaining a culture of continuous learning, we aim to maximize the project's impact and effectiveness over the long-term.

In order to effectively contribute to 2 and 3 above, it was necessary to upscale, research and analyze the jurisprudence on MCS across Canada. The results have revealed that we need to address workman’s compensation issues related to MCS. We know from lived experience stories reported, that tenancy is an important unaddressed issue. Since we have identified this, it is evident that a sustainable action for this community would be to include these two areas in future upscaling plans to meaningfully help this disability access necessary spaces for inclusion and to meet basic needs.

Community Context

a. Community engagement and buy-in

The project has prioritized community engagement to establish a strong connection with the communities it serves. Through active involvement and participation of ASEQ-EHAQ community members, the project has fostered a sense of commitment, ownership, and champions among the community.

To maintain this strong connection over the long-term, the project will employ various strategies. These include ongoing dialogue and collaboration with community representatives, conducting regular feedback sessions, and involving community members in decision-making processes. Additionally, the project will continue to prioritize inclusivity, diversity, and cultural responsiveness in its activities to ensure that the communities feel represented and valued.

- Community events like yoga, movie night
- Open house every last Friday of the month
    - These open house events have allowed us to build community - the idea for this entire ECRoB project came from one of these meetings. Sometimes people will come with an issue, that leads to a possible project or program, or theme.
- Member meetings to talk, safe place to meet and discuss without judgment.
- Every last Friday of the month - two hours (international interest as well, people from other countries show up)

By nurturing this ongoing relationship and demonstrating a genuine commitment to the well-being and interests of the communities, the project aims to sustain their trust and active participation throughout its duration and beyond. By addressing the unique needs and concerns of the MCS and disability communities, we will demonstrate its ongoing relevance and commitment to their well-being.

b. Relevance/compatibility

Our project has been very responsible to the needs and norms of the MCS community, including:

- DAC and Steering Committee feedback and response, in constant communication and collaboration with them.
- Developing more comprehensive and specific content for the MCS community.

Annex - Documents

ANNEX #	DOCUMENT NAME
Annex 1	Schedule A
Annex 2	Biological and Social Content Report
Annex 3	Legal Report
Annex 4	Surveys, Questionnaires, and Polls Report
Annex 5	Marketing and Social Media (Survey/Poll Reporting) Report
Annex 6	Social Media Strategy Report
Annex 7	Outreach Report
Annex 8	Newsletter Report
Annex 9	ECRoB Extended Content Outlines
Annex 10	Accessibility Best Practices
Annex 11	Lived Experience Report