CLEARING UP THE 2022 PREVALENCE DATA CONFUSION

This article is intended to clear up the confusion that was created in May and June 2024 surrounding Statistics Canada’s 2022 prevalence data for Chronic Chemical Injury, also known as Multiple Chemical Sensitivity (MCS).

On this web site, we prefer to use the names Chronic Chemical Injury, Chemical Injury and Chemical Intolerance for this health condition because we believe that these names help to clarify the facts that the people have been injured by their exposures to toxic chemicals, and that the reactions experienced by these individuals are toxic reactions, not allergic reactions.

However, Statistics Canada uses the more common name of Multiple Chemical Sensitivity (MCS). Since this article is all about our correspondence with Statistics Canada, we will also use the name Multiple Chemical Sensitivity (MCS) throughout this article.

The Statistics Canada 2022 MCS prevalence data revealed that the number of people in Canada with medically diagnosed MCS declined by over 50% since 2020. Since we are so used to the prevalence increasing, it was hard to believe that the prevalence had actually decreased.

Then, on top of that, some Canadian MCS advocates began publicly stating that this 2022 MCS prevalence data was inaccurate, unreliable and undependable. Then they shared information that appeared to back up their claims. Consequently, on June 4th, 2024, we removed the 2022 MCS prevalence data from our web site until we could get the facts checked and verified with Statistics Canada.

Over the next 5 months, we exchanged many emails with Statistics Canada. They educated us on how their Canadian Community Health Survey (CCHS) worked and we educated them on MCS. There was a mutual working together to try to understand the “why” behind the huge prevalence drop of MCS in 2022. We examined many possible causes. However, none of the suggested possible causes were plausible, and we came full circle to concluding that the Statistics Canada's 2022 prevalence data for MCS was indeed accurate, dependable and reliable.

Below we will share how we arrived at that conclusion. Before we do, it is important to know that these prevalence numbers do not reflect everyone in Canada who is Chemically Sensitive. Statistics Canada was only monitoring those who have been diagnosed by a health care professional. It is very difficult to get diagnosed by a health care professional in Canada, because there are currently only three main clinics in the entire country where one can go for a diagnosis – one in Nova Scotia, one in Ontario and one in British Columbia. There are huge waiting lists to get an appointment in these clinics and many people become too ill to travel long distances for an appointment.

Therefore, in Canada, as in the global community, many Chemically Sensitive individuals are self diagnosed by various methods. For those doing self-diagnosing, medical researchers at the University of Texas Health Science Center at San Antonio have created a Self-Assessment Questionnaire for people globally, who don't have access to a doctor. The questionnaire is called Quick Environmental Exposure and Sensitivity Inventory (QEESI). It can be used for personal use by people who suspect

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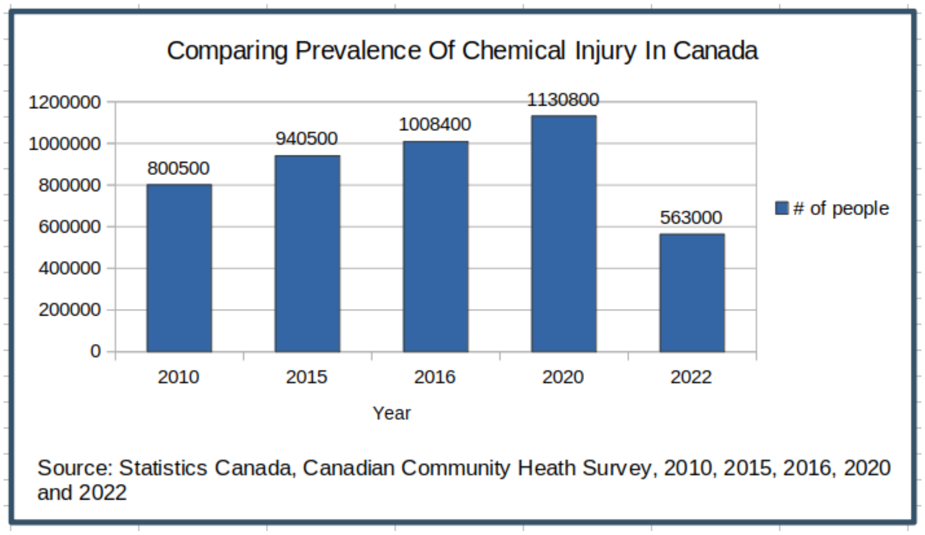
that they might have MCS. It is also sometimes used internationally as a screening tool by doctors and medical researchers. Here is a link to it: https://tiltresearch.org/self-assessment/

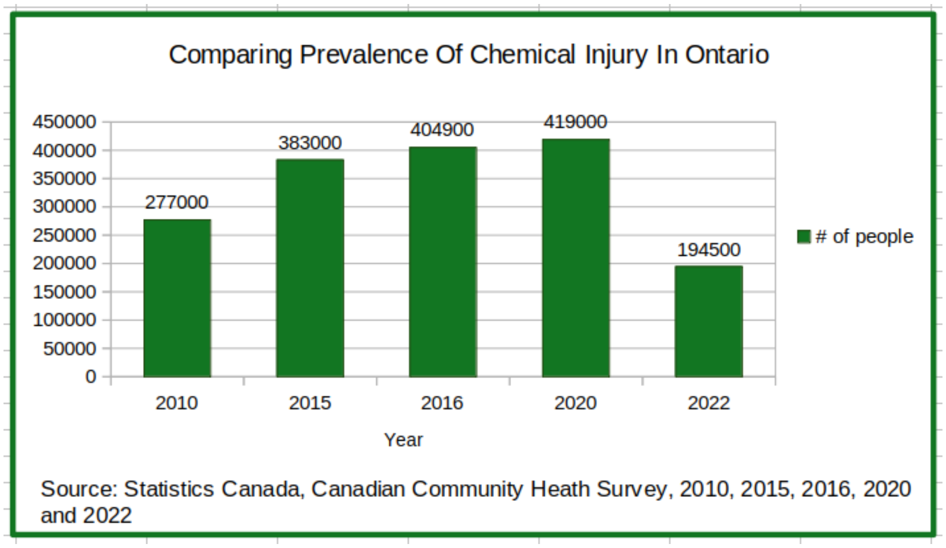
Unfortunately in Canada, as of 2024, there is no way to know how many self diagnosed Chemically Sensitive people there are. Statistics Canada does not include them in the prevalence data, as they only monitor those who have been diagnosed by a health care professional.

Below is a graph showing the 2022 huge drop in prevalence in Canada of people with MCS, who have been diagnosed by a health care professional.



Source: Statistics Canada, Canadian Community Heath Survey, 2010, 2015, 2016, 2020 and 2022

This drop of prevalence was evident in every province. Below we show this drop for the province of Ontario.



Source: Statistics Canada, Canadian Community Heath Survey, 2010, 2015, 2016, 2020 and 2022

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For those of you who want to understand how we came to the conclusion that the Statistics Canada's 2022 prevalence data for MCS was indeed accurate, dependable and reliable, we share that process with you below. This explanation makes for a very long article, as I walk you through the process chronologically.

HRNI Dependability Analysis Of The 2022 MCS Prevalence Data

On March 6th, 2024, we received the 2022 prevalence data for Multiple Chemical Sensitivity (MCS), Chronic Fatigue Syndrome (CFS) and Fibromyalgia (FM) from Statistics Canada. We immediately noticed a huge drop in the prevalence data for MCS. The data for CFS and FM was lower than the previous years, but still relatively similar to other years. However the MCS data concerned us as the dramatic drop in numbers seemed completely unbelievable. So on March 7th, we asked Statistics Canada if the methodology of collecting data was different in 2022 than previous years.

First Possible Reason For Prevalence Drop

On March 18, Statistics Canada informed us that the wording of the question had changed. The question was changed from "Do you suffer from multiple chemical sensitivity?" to "Do you have multiple chemical sensitivity?" They also informed us of the fact that the year 2022 was the first time survey respondents could now also choose to do the CCHS via an electronic questionnaire on-line, instead of by a telephone interview. At the time, neither of these caused us concern. We concluded that changing the wording of the question did not alter the meaning of the question and wouldn't have negatively affected the numbers. We also concluded at that time that the electronic questionnaire would likewise not negatively affect the numbers.

So instead, we turned our attention to analyzing the reason for the drop in numbers, based on what we know of MCS.

> MCS is an acquired health condition that is caused by the body becoming overloaded with toxic chemicals being stored in the tissues and organs of their body from constant exposures to them. This has led to their body crossing it's toxic threshold and producing toxic reactions to further exposures of toxic chemicals. There is a wide variation in the degree people are affected. Some are still able to work and just require some modifications to their home and work space; some become disabled, but their disability is invisible (not obvious to others); some become physically disabled requiring a walker or wheelchair (In our 2019 housing survey, 20% of MCS respondents required a walker/wheelchair accessible home); and some, who become disabled, are completely bedridden. Sadly, MCS can also be fatal.
>
> However, recovery of health or some degree of recovery of health is also possible, if adequate medical intervention occurs in time. The key treatment of MCS is avoidance of further exposures to toxic chemicals. To recover, good indoor and out door air quality is required. The degree of this requirement depends on the degree their health has been negatively affected. Avoidance of further exposures to toxic chemicals is very hard to achieve and is typically done

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> by people moving into a safe low-toxicity home (Clean-air home) in a low-toxicity locality.
>
> Although governments have known about this need for many decades, there is still no specialized housing in Canada built for those suffering from MCS. Many are disabled, and live on provincial disability pensions and are dependent on governments to meet their housing needs. Yet governments refuse to do so. Therefore, the reality for so many people is that their health continues to decline instead of recovering.
>
> However, the restrictions that were put in place during the Covid 19 pandemic brought about good outdoor air quality. This was due to polluting-generating industries being shut down and there being a huge reduction in traffic as people were ordered to work from home.
>
> Consequently, we drew the conclusion that the good outside air quality caused by the pandemic restrictions granted some people with MCS the opportunity to recover their health. These would probably be ones, who had MCS mildly and were not yet disabled with it. Therefore we concluded that the deep drop in prevalence numbers for MCS for 2022 were due to some people actually recovering their health.

Other Facts Made Us Doubt Our Conclusion

Then in May and early June, an MCS support group informed us that the Statistics Canada 2022 MCS prevalence data was unreliable and strongly urged us and everyone else not to use the data. They shared a statement from Statistics Canada, which read:

> “Among people who completed the survey online by themselves, the prevalence of MCS was 0.7% compared to 2.4% for those contacted by an interviewer through telephone."

Initially this statement caused us concern and convinced us that there must be something unreliable in the way the online survey was formatted. Therefore we took down the 2022 prevalence data from our web site until we could get facts checked and explained by Statistics Canada.

Second Possible Reason For Prevalence Drop

So the next reason given for the decrease in prevalence numbers is that the "Help" text defining MCS was not visible in the electronic version of the survey. The respondents had to click the "Help" button in order to learn Statistics Canada explanation of MCS. The "Help" text wasn't visible for other health conditions either, and people with other health conditions also had to hit the "Help" button in order to read the text.

We informed Statistics Canada:

> Since it is currently very difficult in Canada to get diagnosed with MCS by a health care professional, it is absurd to think that someone who succeeded in jumping the hurdles to

> actually get diagnosed with MCS needs an explanation of what MCS is in order to answer yes or no to the question "Do you have multiple chemical sensitivity?".
>
> Many people with MCS have university degrees or other post-secondary education and some are medical doctors and lawyers. People with MCS are more than capable of understanding the need to click the "Help" button if they actually need help to learn what MCS is. To state otherwise, would be an insult to the intelligence of people with MCS. The vast majority of people diagnosed with MCS know what MCS is and what it is called.
>
> A tiny handful of people that might need the "Help" button would be people who have been diagnosed with this health condition, but their doctor used a different name for it, such as Toxin Induced Loss of Tolerance (TILT). However, MCS is currently the most common name used, and most people that are diagnosed with it by a different name, know it is also called Multiple Chemical Sensitivity.
>
> We strongly suspected that the majority of people who needed to use the "Help" button would be the general public who don't have MCS and are completely unfamiliar with it, yet have to answer the question: "Do you have multiple chemical sensitivity?".

Statistics Canada responded with the acknowledgment that people diagnosed with MCS by a health care professional would know enough to click the "Help" button if needed. They simply stated that they knew their data was accurate and they were trying to find reasons for the statistically significant drop in prevalence. The need to click the "Help" button was the only thing they could find. So they thought that must be the reason, but now acknowledged that that could not have been the reason.

Third Possible Reason For Prevalence Drop

We took time to examine Statistics Canada's Canadian Community Health Survey (CCHS) for the years 2016, 2020, 2021, 2022, 2023, and 2024. We discovered that in 2022 there was a distinct difference in how the survey was formatted from all previous years. In 2022, both Chronic Fatigue Syndrome (CFS) and Multiple Chemical Sensitivity (MCS) were removed from the Chronic conditions (CCC) module and put into the Chronic conditions (CC1) module. To us, it appeared that Chronic conditions (CC1) was classified as those with anxiety disorder, post-traumatic stress disorder and forms of dementia. (Please see the screenshots below that show the survey's information on Chronic Conditions (CCC) and Chronic Conditions (CC1).)

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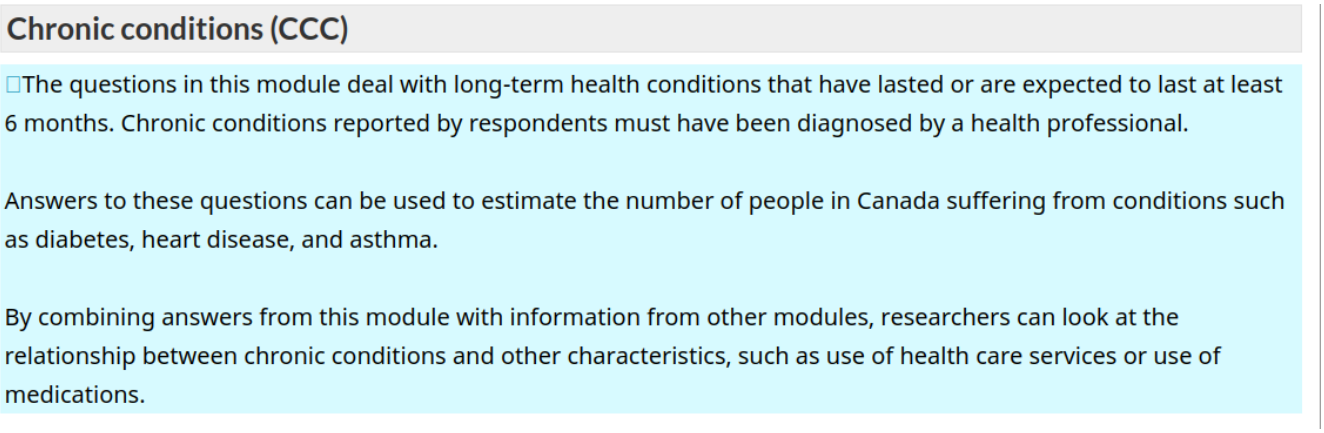
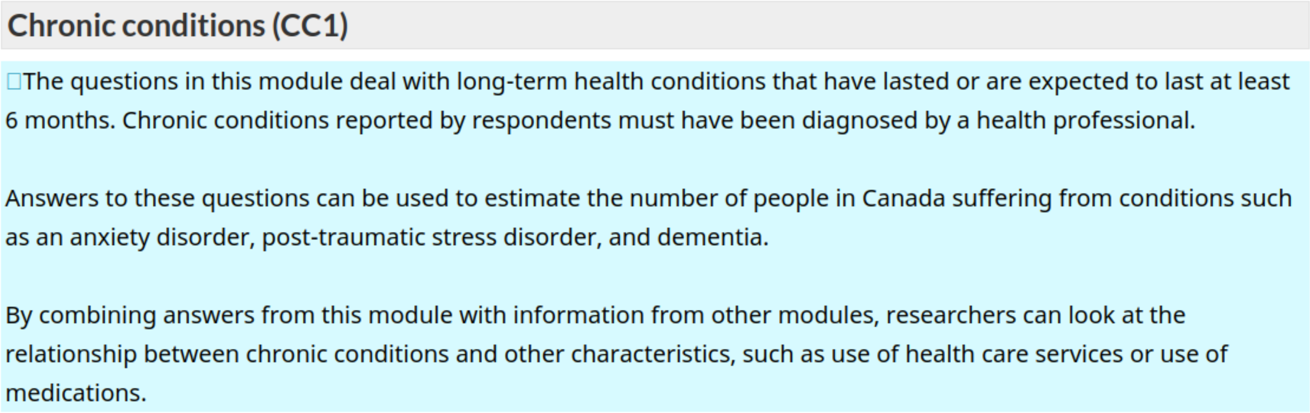


Chronic conditions (CCC)

□The questions in this module deal with long-term health conditions that have lasted or are expected to last at least 6 months. Chronic conditions reported by respondents must have been diagnosed by a health professional.

Answers to these questions can be used to estimate the number of people in Canada suffering from conditions such as diabetes, heart disease, and asthma.

By combining answers from this module with information from other modules, researchers can look at the relationship between chronic conditions and other characteristics, such as use of health care services or use of medications.



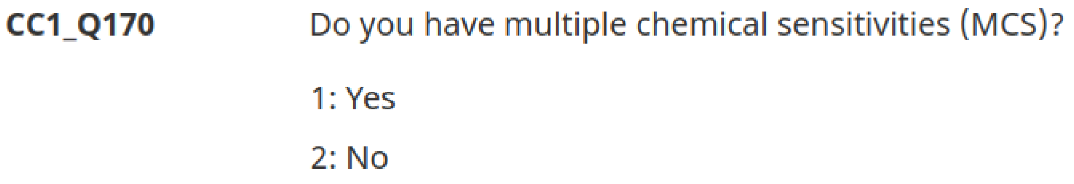
Chronic conditions (CC1)

□The questions in this module deal with long-term health conditions that have lasted or are expected to last at least 6 months. Chronic conditions reported by respondents must have been diagnosed by a health professional.

Answers to these questions can be used to estimate the number of people in Canada suffering from conditions such as an anxiety disorder, post-traumatic stress disorder, and dementia.

By combining answers from this module with information from other modules, researchers can look at the relationship between chronic conditions and other characteristics, such as use of health care services or use of medications.

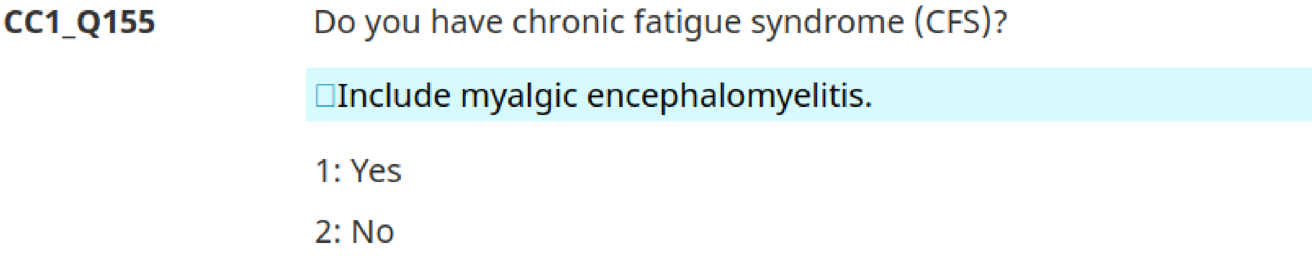
Below are screenshots of the survey showing both MCS and CFS in the CC1 module and not in the CCC module as had been the case other years.



CC1_Q170 Do you have multiple chemical sensitivities (MCS)?

1: Yes

2: No



CC1_Q155 Do you have chronic fatigue syndrome (CFS)?

□Include myalgic encephalomyelitis.

1: Yes

2: No

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Since MCS was moved out of the Chronic Conditions (CCC) to the Chronic Conditions (CC1) module, and since the CC1 module contained the mental health conditions of anxiety disorder, post traumatic stress disorder, and dementia, it appeared to us that Statistics Canada was classifying MCS as another mental health condition.

We became convinced that moving MCS to the Chronic Conditions (CC1) module was the reason for the prevalence numbers drop. We knew that people with MCS know that they do not have a chronic mental health condition. So since many struggle with fatigue and lack of energy, they would probably scroll past the entire module if it was possible to do so.

However, Statistics Canada informed us that their CCHS is set up in such a way that people cannot just scroll past a whole module or question and ignore it. The electronic questionnaire is set up so that people could not skip any questions. They can choose not to answer the question that is presented to them, but they cannot skip being presented with the option to answer the question.

Statistics Canada also corrected our misunderstanding of the Chronic Conditions (CC1) module. They explained that it was created specifically for the purpose of shortening the CCHS. It was not a mental health module. Instead it was a module in which health conditions could be placed as options for the provinces to choose to include or exclude in the survey.

Fourth Possible Reason For Prevalence Drop

Statistics Canada thought another possibility might be falsely elevated numbers in previous years, and maybe the 2022 prevalence data was more accurate. They presented the idea that since it is hard to get diagnosed in Canada with MCS, maybe some people were falsely stating they had been diagnosed with MCS by a health professional when they were in fact only self-diagnosed.

We informed Statistics Canada:

> Health care professionals that diagnose and treat MCS in Canada, as well as MCS support groups in Canada, all agree that the prevalence of MCS in Canada is almost identical to that of the USA.
>
> A study on the prevalence of MCS in the US was done in 2016 and published on line in 2018. The study was done by Dr. Anne Steinemann (Ph.D. in Civil and Environmental Engineering), and it is called National Prevalence and Effects of Multiple Chemical Sensitivities. It is also posted on-line at the US National Library of Medicine. Here is a link to this study: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5865484/
>
> In this study, Dr. Steinemann appears to use the term "Multiple Chemical Sensitivity" (MCS) for those who are medically diagnosed, and the term "Chemical Sensitivity" for those who are self-diagnosed, even though many people use those terms interchangeably. In the study, she states:

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> Results:
> Among the population, 12.8% report medically diagnosed MCS and 25.9% report chemical sensitivity. Of those with MCS, 86.2% experience health problems, such as migraine headaches, when exposed to fragranced consumer products; 71.0% are asthmatic; 70.3% cannot access places that use fragranced products such as air fresheners; and 60.7% lost workdays or a job in the past year due to fragranced products in the workplace.
>
> Conclusion:
> Prevalence of diagnosed MCS has increased over 300%, and self-reported chemical sensitivity over 200%, in the past decade. Reducing exposure to fragranced products could help reduce adverse health and societal effects.

Canada's 2016 prevalence of people with MCS who were medically diagnosed was only 3.3% of the population, which means that there is a huge difference in the prevalence numbers for the two countries, with the percentage of people who are medically diagnosed in the US being almost 4 times that of Canada. Therefore, we concluded that MCS individuals doing the CCHS are not false reporting. It simply reveals that it is harder to get medically diagnosed with MCS in Canada than in the US.

In both countries and globally, the number of people self-diagnosed is far greater than those who are diagnosed by a health professional. For those doing self-diagnosing, medical researchers at the University of Texas Health Science Center at San Antonio have created a Self-Assessment Questionnaire for people globally, who don't have access to a doctor. The questionnaire is called Quick Environmental Exposure and Sensitivity Inventory (QEESI). Our understanding is that it can be used for personal use by people who suspect that they might have chemical intolerance. It is also sometimes used internationally as a screening tool by doctors and medical researchers. Here is a link to QEESI: https://tiltresearch.org/self-assessment/

Unfortunately in Canada, we have no way of knowing how many people with MCS are self diagnosed. To our knowledge no medical researchers anywhere are monitoring the prevalence of MCS in Canada. The only prevalence monitoring that we are aware of is that which is being done by Statistics Canada, and it is only monitoring those who have been diagnosed by a health care professional.

Fifth Possible Reason For Prevalence Drop

There was still the statement from Statistics Canada, which caused us to take down the 2022 prevalence data from our web site. The statement read:

> “Among people who completed the survey online by themselves, the prevalence of MCS was 0.7% compared to 2.4% for those contacted by an interviewer through telephone."

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We realized that some people with MCS have also acquired a health condition called ElectroMagnetic Sensitivity (EMS). In the 2019 low-toxicity housing survey we did, 23% of people with MCS had also developed EMS. Many of these people don't own a computer any more or any other electronic communication device; and those who still own them, rarely use them. They typically communicate with others using a land line telephone or slow mail. In our survey, we did not offer the telephone survey option, but we did offer a paper version of the survey. So some of these individuals had someone else print out the survey for them, and then they filled it out and mailed us the paper version of the survey.

Consequently, we strongly suspected that, in the 2022 CCHS, the majority of MCS individuals, who have MCS severely, and MCS individuals, who also have EMS, chose to do the survey by interviewer. People with MCS, who do not have EMS and those whose health is stronger, chose to do the survey on-line.

Since over 50% of people recovered their health, the remaining numbers are made up of people who are more severely affected, some of whom have also developed EMS. Therefore, one would expect to see a greater number of respondents with MCS doing the survey by interview than doing it on-line.

No Reasons Left

Consequently, there didn't seem to be any reasons left to doubt the 2022 prevalence data. Therefore we concluded that the prevalence data numbers were accurate, reliable and dependable. We also accepted as fact that over 50% of people, who had been diagnosed with MCS by a health care professional, had been granted the opportunity to recover their health. This opportunity did not come via having a specialized low-toxicity home built for them. It came via the pandemic restrictions, which greatly reduced the outdoor air pollution and greatly increased the outdoor air quality.

We suspect that during the pandemic, the worsening of indoor air quality and the restrictions that forced people to stay indoors, caused more people to acquire MCS. However, the health clinics were also shut down and were not able to diagnose anyone. The wait list at the Toronto Ontario clinic went from a 2 year wait list to a 3 year wait list. So even though there was not an increase in the 2022 MCS prevalence data for those who had been diagnosed by a health care professional, we strongly suspect that there was an increase in those who are self-diagnosed with MCS.

In many places, especially public places, the indoor air quality went worse with the increased usage of hand sanitizers, disinfectants and strong cleansers, all of which are products that people with MCS typically react to. Many people with MCS found their intolerances and reactions worsening as a result.

However, this does not mean that that was the case for everyone. For some people, the greatly improved outdoor air quality granted them the opportunity to recover their health. These are probably ones who were not yet disabled, who were able to maintain good indoor air quality in their home, and who did not have to travel to work, but could now work from home.

Conclusion

The 2022 CCHS prevalence data for Multiple Chemical Sensitivity (MCS) is accurate, valid and dependable. It reveals that over 50% of people diagnosed by a health professional with MCS had the opportunity to fully recover their health during the pandemic restrictions, which successfully reduced the outside air pollution.

We need to remember that these are ones who were diagnosed by a health care professional, and therefore does not capture the whole MCS prevalence picture, as many are self-diagnosed and not able to get to a doctor to be medically diagnosed. During the early stages of the pandemic, even doctors offices were shut down and no one could get to a doctor to be diagnosed. So no diagnosing took place, resulting in no increase of people diagnosed with MCS, at the same time as others are recovering their health.

In Ontario, during the pandemic, the wait list for a diagnosis went from 2 years to three years. It will take a long time to get through that back log, as currently there are primarily only 3 clinics in Canada that do that diagnosing, and each clinic only has about two doctors. Our health system is failing people with MCS in every possible way.

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