

How do you know and who do you trust? Health information & SLE

What's the problem?

Mis/Disinformation

The terms misinformation and disinformation have increased in popularity since the COVID-19 pandemic, but what do they mean and why does it matter? **Misinformation** is false information not created with the intent to deceive but is either incorrect or misleading. **Disinformation** is false information created to deliberately deceive and is either fabricated or misleading. The spread of health-related mis/disinformation in the news or on social media can have real impacts on health and wellbeing. Although social media has become a popular space for health information sharing, the spread of mis/disinformation can lead to fear and anxiety for the reader, impact how we trust how public health information is communicated, and influence how patients make important decisions about their health.

The spread of mis/disinformation has increased during the COVID-19 pandemic. This **'infodemic'** emphasizes the need for accessible and trustworthy health information for all.

SLE and COVID-19

While the COVID-19 pandemic has been challenging for everyone, individuals with SLE have faced unique challenges. Some people experienced increased levels of stress and anxiety, and the spread of mis/disinformation heightened these feelings for many. For individuals with SLE, stress and anxiety can impact overall wellbeing and even trigger a flare. Infectious diseases can also present a higher risk to health and wellbeing for people with SLE compared with others, and those with SLE may be at higher risk of severe illness from COVID-19.

The tipping point

Remember when the media reported that President Trump announced hydroxychloroquine could be a potential treatment for COVID-19? This media coverage led to reports of panic buying, concern about medication shortages, and warnings from advocacy organizations. Early research results indicated this led to significant impacts on the wellbeing of individuals with SLE.

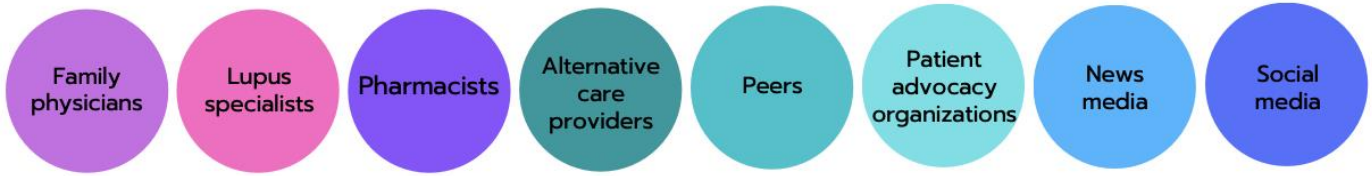
What did we do?

During the COVID-19 pandemic, we surveyed individuals with SLE from 6 Canadian regions:

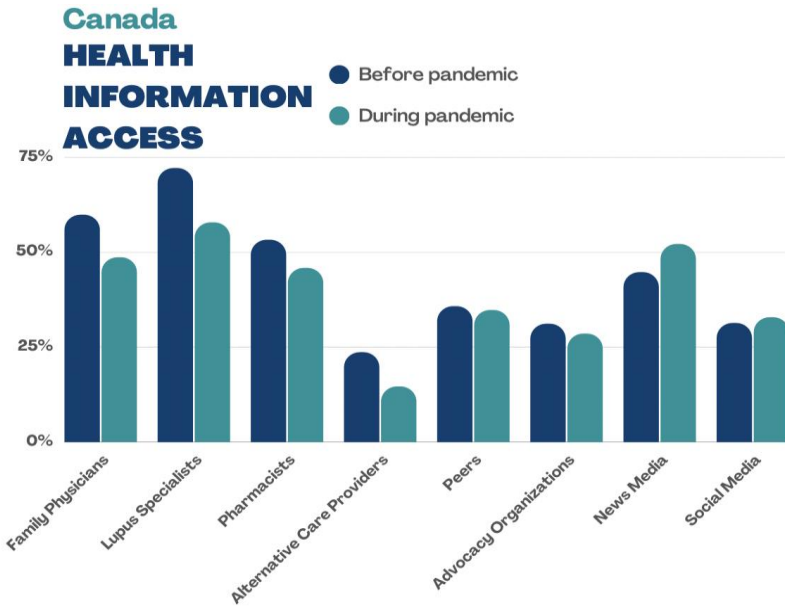
Calgary, AB; Winnipeg, MB; Toronto, ON; Montreal, QC; Quebec City, QC; Halifax, NS



We asked them about where they get their health information and who they trust, before and during the pandemic.

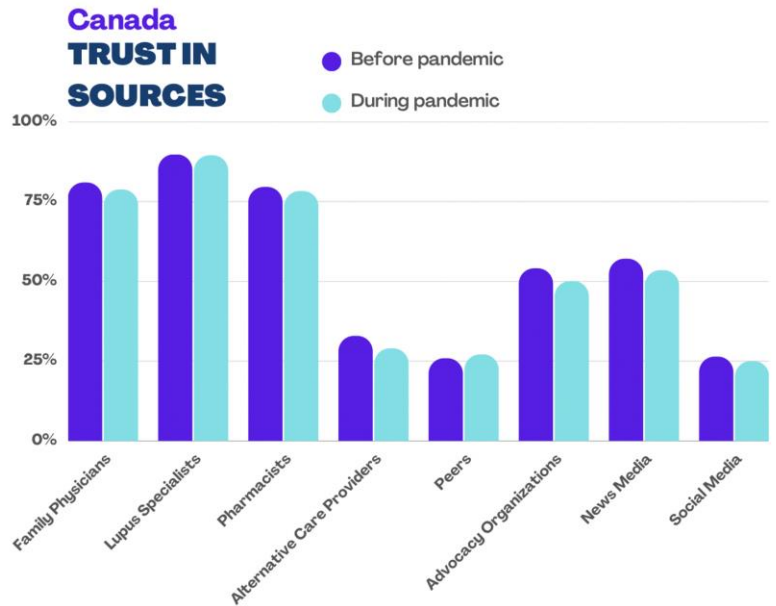


What did we find?



- Before the pandemic: the most frequently accessed sources were lupus specialists, family physicians, and pharmacists
- During the pandemic: the most frequently accessed sources were lupus specialists, news media, and family physicians
- During the pandemic: access to lupus specialists decreased by 14%, and access to news media increased by 7%
- Before and during the pandemic: advocacy organizations were less accessed than most other sources

- Before and during the pandemic: lupus specialists, family physicians, and pharmacists were the most trustworthy sources
- During the pandemic: trust in alternative care providers, advocacy organizations, and the online news media decreased
- During the pandemic: the largest decrease in trust was amongst advocacy organizations (4%)
- During the pandemic: no sources were considered more trustworthy than before the pandemic



12% of participants from **Canada** reported negative impacts to their health that they attributed to information they accessed through news or social media. Among Canadians, impacts were reported on:

Mental Health

'Health information in news media has increased my stress, anxiety and depression'

Healthcare Access

'Due to the media... I was unable to access my medication when I needed it'

Decision Making

'Somebody told me to use a cream for my rash, and I listened to them. My face is now scarred and infected'

So what?

We already know that news media and social media can circulate mis/disinformation, emphasizing the need to ensure those with SLE can continue to access their most trusted sources of health information (lupus specialists and family physicians) in times of stress and scientific uncertainty.

As a source of patient support and health information, advocacy organizations can play an important role in communicating during public health emergencies, yet our study shows that they were not as frequently accessed or trusted. Trust in many sources of health information decreased during the pandemic, but advocacy organizations saw the largest decrease in Canada. Building back this trust is essential but presents a challenge as the pandemic lingers and mis/disinformation continues to circulate.

Now what?

We need **you** to help **us** understand what's going on!

Now that we have an idea about how health information is accessed and trusted by those with SLE, we need you to help us understand how and why this is and help us develop tools to improve health information communication channels and content.

If you are looking for more information about SLE, contact your healthcare provider, visit the [Lupus Canada website](#), or one of the other advocacy organization websites listed below.

Interested in learning more? You can find the full paper with all the results here:

<https://lupus.bmj.com/content/9/1/e000755>

For more information about SLE, visit...

SLE & related organizations in Canada

Lupus Canada (www.lupuscanada.org)
Arthritis Society (www.arthritis.ca)
BC Lupus Society (www.bclupus.org)
Lupus Society of Alberta (www.lupus.ab.ca)
Lupus Saskatchewan (www.lupus.sk.com)
Lupus Manitoba (www.lupusmanitoba.com)
Lupus Ontario (www.lupusontario.org)
Lupus Newfoundland & Labrador (www.lupusnl.com)

Global SLE Organizations

Lupus Foundation of America (www.lupus.org)
Lupus Europe (www.lupus-europe.org)
World Lupus Federation (<https://worldlupusfederation.org/>)

Infodemic Resources

World Health Organization (www.who.int/health-topics/infodemic#tab=tab_1)

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