

Are we in an “infodemic”?

“The coronavirus is at some point ... going to sort of just disappear.”

Over the past five months, Canadians have shared their stories and concerns about their experience watching television, listening to talk radio or on social media platforms reading posts calling COVID-19 a “political hoax” or that the virus has been created in a government laboratory with no consumer warning or label on these reports. The International Fact-checking Network has called COVID-19 “**the biggest challenge fact-checkers have ever faced.**” In July 2020, the World Health Organization (WHO) hosted the first “infodemiology” conference to study the infodemic of misinformation and disinformation around the coronavirus.

In this issue of JointHealthTM insight, Arthritis Consumer Experts (ACE) covers what you need to know about the ‘infodemic’, how we got here and what it means for arthritis patients and researchers. As an additional bonus section, we also provide some fun and helpful lifestyle tips shared by experts on our Arthritis At Home program. After all, even during a pandemic, people living with arthritis want to make the most of their summer and keep their joints as happy and healthy as possible!



According to WHO, in the context of the COVID-19 pandemic, the phenomenon of an “infodemic” has escalated to a level that requires a coordinated response. WHO defines an infodemic as “an overabundance of information, some accurate and some not – that makes it hard for people to find trustworthy sources and reliable guidance when they need it.” Even when people have access to high-quality information, misinformation continues to spread further and faster and adds complexity to a public health emergency response.



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How did we get here?

What we have learned over the past five months is that the traditional media and, even more importantly, high-powered social media have accelerated the spread of lies and the political polarization that motivates people to believe misinformation. Experts are concerned that unless the public health sphere can effectively counter misinformation, not even an effective vaccine may be enough to end the pandemic.

While fake news is anything but new, the difference is the infodemic can make people sick and even kill them if they don't understand what precautions to take.

Beyond its effect on individuals, the infodemic erodes trust in science and government leadership at the moment when that trust is most needed. A **study by the Reuters Institute** found 39% of English-language misinformation assessed between January and March included false claims about the actions or policies of authorities.

The infodemic has spread nearly as widely as the pandemic itself in North America. Based on an **online survey** by Ryerson University researchers, misinformation about the **COVID-19 pandemic** is reaching a majority of Canadians who use social media and popular apps. Nearly 7 in 10 Canadians who responded to the survey said they had personally encountered misinformation about the global health crisis on social media platforms or on popular aggregator websites like Reddit.

In the US, 38% of Americans **surveyed by Pew** in June said that compared to the first couple of weeks of the pandemic, they found it harder to identify what was true and what was false about the virus.

An evolving outbreak: Misinformation and disinformation have always been a destabilizing feature of infectious disease outbreaks. But several factors have made the situation worse with COVID-19.

COVID-19 is new, and as scientists have learned more about the virus, they've had to change recommendations based on new evidence and science. That's how science works but for people who are distrustful of health authorities, an expert

changing a guideline or recommendation in a matter of days or weeks just confirms their bias and unfounded suspicions about public health recommendations.

The use of masks is an excellent example. Back in February, North American health authorities were not recommending wearing masks; by May, based on real-world evidence from countries who effectively flattened the curve, our authorities began recommending the use of masks in public places where physical distancing was difficult to maintain. Today, people are still arguing about wearing masks -- a tiny infringement of personal freedoms that represents one of the few hopes of easing the spread of the virus. It's becoming increasingly clear that wearing a mask is one of the most effective ways to prevent the spread of COVID-19. But whether or not people are willing to wear one has less to do with the risk of the pandemic than their political affiliation and their inherent belief or distrust in science.

Social media: Social media is an indispensable lifeline for people to connect to friends, families, classmates, and co-workers. This is also a potential problem; false claims or narratives about COVID-19 appealing to people's bias or denial of science, have gone global and are spreading almost as fast as the virus itself.

While experts give some credit to companies like Facebook and Twitter for their efforts to stem the spread of coronavirus misinformation, the reality is that platforms built on engagement will often end up as platforms to spread conspiracy content, which tends to be the online information most influential and most shared. A **review** by the Reuters Institute of 225 pieces of COVID-19 misinformation spread by political figures and celebrities made up only 20% of the sample but accounted for 69% of engagement.

The "infodemic" seems to be most acute on Facebook, where 80 per cent of Canadian users responded in the Ryerson University survey that they encounter COVID-19 misinformation "sometimes" or more frequently. But while Facebook users were more likely to encounter misinformation, Ryerson researcher Anatoliy Gruzd said misinformation is platform-agnostic: "Misinformation can start as a post on Facebook, morph into an image on Instagram, and then become a part of a YouTube video."



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Respecting and promoting science: what it means for the Canadian arthritis community

Underlying the “infodemic” is a distrust and denial of science. In Canada, we have followed the science and evidence more effectively than our neighbours in the US and have made heroes of Dr. Bonnie Henry and Dr. Theresa Tam unlike the US experience where Dr. Anthony Fauci requires 24-hour personal security from law enforcement. However, that doesn’t mean that we are immune to science denial or distrust. Science research funding from the federal government has ebbed and flowed the past 20 years often reflecting the government of the day’s trust and promotion of science.

How does this historical, fluctuating lack of government support for science and research affect the Canadian arthritis community? First, some facts. Sixty per cent of the nearly 6 million Canadians with arthritis are under the age of 65 and more Canadians are affected by arthritis than diabetes, heart disease, or cancer. As the leading cause of work disability in Canada, arthritis costs the Canadian economy approximately \$33 billion due to the direct costs (e.g., hospital care, physician visits, rehabilitation, prescription drugs) and the indirect costs (e.g., absence from work and lost potential earnings, underperformance at work).

While the prevalence and economic burden of arthritis continue to grow, arthritis research is underfunded when compared to other disease research. The Canadian Institutes of Health Research has flattened spending on arthritis-related research over the past 15 years. For comparison, diabetes research received three times as much funding per person with diabetes; cancer research received 32 times as much funding per person with cancer.

Why arthritis research is important for us

Currently, during the pandemic, researchers are gathering COVID data specific to rheumatology patients that will provide important insights on how COVID-19 impacts rheumatology patients and how autoimmune diseases and immunosuppressive medications influence the risk of infection and the outcomes of COVID-19.

On a broader scale, as arthritis patients and consumers, we still are living without a cure for arthritis. Government funding for arthritis research provides support to Canadian scientists and research teams who are working to learn more about arthritis and understand the experiences of people living with the disease. Some of the topics researchers are trying to discover and understand include:

- A cure for the more than 100 types of arthritis disease
- Effective treatments to slow or halt disease progression
- Causes of arthritis and related conditions
- Early signs of arthritis disease, and patients' awareness of these signs and symptoms
- The role of diet and exercise in arthritis prevention and treatment
- The impact of arthritis on participation in paid employment, family life, and leisure activities
- Effective self-management techniques, to help people cope with arthritis

ACE responds to the infodemic

During the current COVID-19 outbreak, patients living with arthritis and at high risk of infection and largely confined to their homes have many concerns and questions and are desperately trying to get the latest, credible information about COVID-19 and what it means for them from their peers online and from web searches.





Starting June 4th, new episodes of Arthritis At Home will be available on YouTube and Facebook channels. Never miss an episode by following hashtag #ArthritisAtHome. We hope to hear from you with your questions or ideas for future episodes. We hope



Arthritis At Home Episode 39 – A patient looks back: One year after knee replacement surgery (Part 1)

Faced with a sea of conflicting information, ACE and other patient groups, health care professional associations and public health experts have played an active role in combatting the infodemic.

ACE launched its **Arthritis at Home** program that makes it possible for people living with arthritis to watch or listen to video interviews with Canadian experts in clinical rheumatology, arthritis scientists, physio and occupational therapists, psychologists and health economists.

“ACE members have been telling us daily how stressed-out and even fearful they are about COVID-19. ACE believes COVID-19 will have a lasting effect on how patients living with arthritis will educate themselves with accurate, timely, fact-based information that is easily accessible. Written words can never be replaced to share arthritis facts and news but being able to see and hear directly from experts is more important than ever,” said Cheryl Koehn, ACE’s President.

The next challenge for science in the context of the coronavirus is whether the infodemic causes a significant portion of the North American public to opt-out of a future COVID-19 vaccine. The anti-vaccine movement is significant in Canada and the US.

Statistics Canada reported in July 2020 that even if there was a COVID-19 vaccine, 12% of Canadians wouldn’t take it, according to a recent questionnaire. In a **CNN poll** in May 2020, a third of Americans said they would not try to get vaccinated against COVID-19.

If those percentages hold or rise, public health experts warn a vaccine would be “unlikely” to provide “herd immunity,” which occurs when a sufficient proportion of a population is immune to an infectious disease, either through prior illness or vaccination, so that spread from person to person is unlikely.

While the pandemic wasn’t human-made, the infodemic surely is. But that means governments, public health authorities, patient groups, healthcare professional organizations, employers and the public itself can put a halt to it with the right strategy. And it starts with a trust not a denial in science.

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Lifestyle Tips from our Arthritis at Home Experts

Research has found that one of the most important self-management techniques for people living with arthritis is regular physical activity. Exercise helps to manage pain and inflammation and also helps improve joint strength and mobility. On our Arthritis At Home program, Dr. Jasmin Ma, Dr. Jackie Whittaker and Dr. Linda Li provide helpful exercise advice for people living with arthritis. Below are some key takeaways. Remember to talk to your physiotherapist, rheumatologist or another healthcare provider before starting a new exercise program.

Tips and tricks for physical activity:

- **Dr. Jackie Whittaker** reminds patients to evaluate their body before starting exercise. If your pain is 5 or lower on a scale of 10 - with 10 being the worst pain and 0 being no pain - then it is okay to start exercising. However, if your pain is over 5, you may want to consider postponing exercise for another day.
- **Dr. Linda Li** emphasizes the importance of moving often throughout the day, whether living with arthritis or not. Consider setting a soft reminder (such as a vibration) on your phone, computer or watch that reminds you to get up and walk around every hour. This feature may already be offered by your Fitbit or other types of activity trackers if you have one. 250 steps per hour is the most common recommendation provided by experts.
- During the pandemic, you may not have access to your regular gym and workout equipment. Dr. Jasmin Ma suggests using canned food as weights if you do not have your own weights at home. You can also wrap a towel around your 'modified weights' if the grip is too small and hurting your hand joints.
- If you are looking for a fun new exercise routine, check out **Dr. Jasmin Ma's 15 minute 'exercise snacks'**. There are 4 episodes in this special series, each focusing on a different set of exercises that can be done easily at home and modified to fit your level of flexibility or strength.



Modified Squats Made Easy

1.



2.



3.



Try out these **modified squats demonstrated by Dr. Jackie Whittaker** for strengthening your lower extremities (knees and hips):

1. Start standing up with arms crossed at your chest.
2. Slowly reach your bottom back while leaning your chest forward to lower yourself down onto a chair in a slow and controlled movement (do not drop onto the chair). The first part of your body to touch the chair should be your bottom, and you should be able to see your toes the entire time.
3. Once seated, lean forward putting your weight onto your feet and slowly stand.

*You may wish to adjust the height of your chair by adding books to the seat. This way you do not have to go down as far when you squat.

Staying Nourished During the Pandemic

Research has also emphasized the importance of eating a healthy and balanced diet for both inflammatory arthritis and osteoarthritis. However, eating a healthy and balanced diet can be particularly challenging during COVID-19. Luckily, **Cristina Montoya, Registered Dietitian**, has some helpful tips for keeping your body nourished while staying safe during the pandemic:

- Make your grocery list on a piece of paper (not your phone!) and throw out the list after you exit the store. This will ensure that you do not bring germs from the grocery store home with you. You can even consider leaving your phone at home or putting it in a closed pocket so that you do not inadvertently touch it while you are at the store.
- Clean foods with hard surfaces even if you do not eat the outside. For example, oranges, avocados, watermelons, etc are often foods that we don't wash because we are only eating the inside of them. However, when cutting them, our knives actually bring germs on the outer skin all the way through its insides.
- Consider buying frozen vegetables – they will last longer than fresh veggies meaning less trips to the grocery store, while still providing the same nutrients. They are also often less expensive and pre-cut which is a huge advantage for folks with pain or swelling in their hands.
- Great protein options with long shelf lives include eggs, canned tuna or salmon, beans and legumes.

Arthritis Consumer Experts (ACE)

Who we are

Arthritis Consumer Experts (ACE) operates as a non-profit and provides free research based education and information to Canadians with arthritis. We help (em)power people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, scientific and medical experts on the ACE Advisory Board. To learn more about ACE, visit www.jointhehealth.org

Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a practical necessity. Any amount remaining from our annual budget at year end remains with ACE and is used to support the following year's core programs to continue helping Canadians living with arthritis.

For its past 20 years, ACE has consistently honored a commitment to its members and subscribers, academic and healthcare professional

colleagues, collaborators, government and the public that its work is free from the influence of its funders.

To inform ACE employees and our stakeholders, members, subscribers that we will operate our organization with integrity and abide by the highest standards of lawful and ethical behaviour, ACE has adopted this strict set of guiding principles:

- ACE requests grants from private and public organizations to support its core program and plans and allocates those funds free from influence;
- ACE discloses all funding sources in all its activities;
- ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization;
- ACE identifies the source of all materials or documents used;
- ACE develops positions on health policy, products or services in collaboration with people living with arthritis, academic research community, health care providers and governments free from concern or constraint of its funders or other organizations; ACE employees do not engage in personal activities with its funders;
- Cheryl Koehn does not own stock or any financial interest in any of its private or public funders.

Thanks

ACE thanks Arthritis Research Canada (ARC) for its scientific review of all ACE and JointHealth™ materials.



Disclosures

Over the past 12 months, ACE received grants-in-aid from: Arthritis Research Canada, Amgen Canada, Canadian Institutes of Health Research, Canadian Rheumatology Association, Eli Lilly Canada, Hoffman-La Roche Canada Ltd., Knowledge Translation Canada, Merck Canada, Novartis Canada, Pfizer Canada, Sandoz Canada, Sanofi Canada, St. Paul's Hospital (Vancouver), UCB Canada, and the University of British Columbia.

ACE also received unsolicited donations from its community members (people with arthritis) across Canada.

ACE thanks funders for their support to help the nearly 6 million Canadians living with osteoarthritis, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and the many other forms of the disease.

Disclaimer

The material contained in this publication should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Please contact your physician for your own health care related questions.

ACE Arthritis
Consumer
Experts

#210 - 1529 West 6th Avenue
Vancouver BC V6J 1R1
t: 604.974.1366

feedback@jointhehealth.org
www.jointhehealth.org

ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.

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