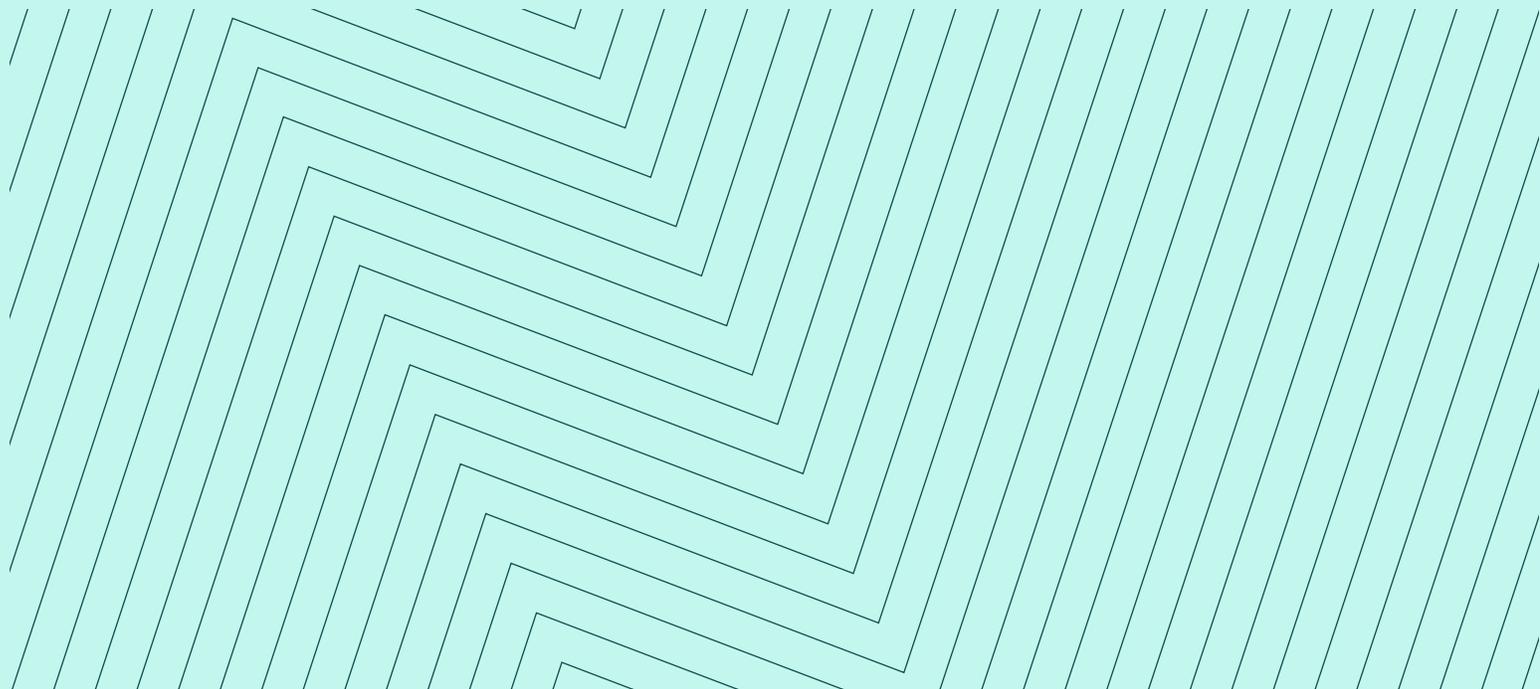# The AI-informed patient has arrived. Are rare disease brands ready?

New Canadian data on how AI is shaping decisions and behaviours in people living with a rare disease.
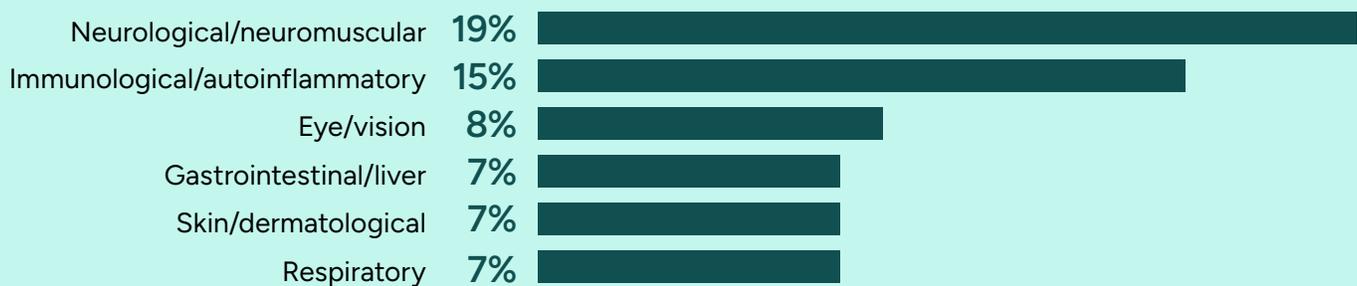
✳ ChangeMakers
Health

Leger

AI use is everywhere.
Rare disease is no exception.

A rare disease is one that affects fewer than 1 in 2,000 individuals. It is estimated that 1 in 12 people in Canada are living with a rare disease or condition, which, extrapolated to the Canadian population equates to over 3 million people.[1]

Important strides have been made to support Canadians living with rare disease. Through the National Strategy for Drugs for Rare Diseases[2], the federal government has committed $1.5 billion to improve access to new and existing rare disease drugs, while national recognition of World Rare Disease Day reflects growing awareness of the community's needs. But more needs to be done to understand and support rare disease care needs. It is vital that we understand the evolving landscape and the work that still lies ahead.

With artificial intelligence (AI) growing and having a significant impact on health and health misinformation; we wanted to understand how AI was being used by Canadians living with, and impacted by, rare diseases. To better understand their experiences, ChangeMakers Health partnered with Leger and fielded a national survey, between January 20th and February 5th, 2026, with Canadians living with rare disease or caring for a person with a rare disease.

Most common type of rare disease/ disorder (% of respondents)

Neurological/neuromuscular	19%
Immunological/autoinflammatory	15%
Eye/vision	8%
Gastrointestinal/liver	7%
Skin/dermatological	7%
Respiratory	7%

Online survey with 254 Canadians, 18 and over
• 142 individuals with a rare disease
• 112 individuals caring for a person with a rare disease

An information gap in an era of information overload.

Living with a rare disease can leave those impacted feeling lost, confused or even alone. They don't know where or who to turn to and accessing much-needed, accurate and timely information can be a struggle.

According to findings from a 2023 survey of 528 respondents living with a rare disease or condition conducted by the Canadian Organization for Rare Disorders (CORD) and Ipsos, less than six in ten of those surveyed indicated that they had access to the appropriate information they need to help them with their condition.[3] When information is needed but not readily available, it creates space for alternative sources – including AI.

AI is becoming a first stop for health information.

The utilization of AI has increased exponentially and has expanded to all facets of life, healthcare included. According to the Canadian Medical Association's 2026 Health and Media Tracking Survey that included over 5,000 Canadians, 52% of respondents stated that they have used an AI platform to search for health information.[4]

Turns out, people living with rare disease or their caregivers are too, in similar proportions. Findings from the Leger/ChangeMakers Health survey found that 52% of the respondents indicated that they have used AI tools for information about their condition. Not only are they using AI tools, but they are doing so frequently. Of those that have used AI tools for information, almost six in ten indicated that they are using them frequently (daily/ weekly). The use of AI for healthcare-related information or support is no longer an experimental edge-case, it's becoming an integrated behaviour.

When people living with a rare disease or their caregivers search for information about their condition or its potential treatments, what information will AI-generate about your product and the disease it is intended to treat?

52%
of Canadians living with rare disease have used AI for health information

Although Canadians living with a rare condition are looking to AI, many are skeptical.

AI use is high – but trust is still low.

AI tools synthesize large volumes of internet-based information, and the quality of the output depends on the quality of the available sources. This can impact the trust people place in the information they acquire through AI tools.

Approximately one in five AI users in our survey feel that AI-generated treatment and medication information is not trustworthy. These results are in line with the findings from the CMA 2026 Health and Media Tracking Survey, where 34% of the respondents indicated that they had no trust in medical advice or treatment recommendations provided by an AI tool.[4]

How can your organization help ensure that AI-generated health information is credible and can be trusted?

That skepticism is driving responsible behaviour.

Fortunately, this skepticism seems to be driving positive behaviours. Almost 60% of AI users indicated that they regularly (always/often) verify AI-generated information, with 47% using official sources (i.e., Health Canada) and 44% using other trusted websites or medical journals.

58%

of AI users regularly verify AI-generated content

When advice becomes action, risk emerges.

There are many constraints on the healthcare system in Canada making accessing care difficult and, often, a lengthy process. This could lead some to take matters into their own hands.

36% of AI users in our survey have acted on AI-generated health information without consulting a healthcare professional first, potentially putting themselves at risk. Findings from the CMA 2026 Health and Media Tracking Survey suggest that patients who followed AI health advice were five times more likely to experience harm compared to those who did not.[4]

Acting without consulting a healthcare professional was more common among those living with a rare condition vs. caregivers (48% vs. 21%); frequent AI users vs. non-frequent AI users (55% vs. 10%), and men vs. women (47% vs. 26%).

Actions taken included:

31%
Tried a non-prescription treatment

29%
Changed how they monitor or manage the condition

29%
Started/stopped/changed how their prescription medication was taken

15%
Delayed or avoided booking/attending an appointment

The most serious impacts of acting without consulting a healthcare professional included:

18%
Mostly care impact (i.e., delayed care, changed care decisions, second option/trial contact)

15%
Mostly emotional impact (worry/confusion/stress)

12%
Urgent care impact (needed urgent care/emergency services)

These findings underscore the importance of human healthcare professionals always being part of the equation. They see the whole picture. AI cannot replace that.

Clinicians are cautious about AI-generated health information.

Healthcare professionals have been dealing with "Dr. Google" and health misinformation from social media, patient forums, etc. for years. This can take up a considerable amount of time in their practices. Findings from a survey fielded by ChangeMakers Health and Leger in 2025 revealed that healthcare professionals spend almost one full day per week managing the impact of inaccurate or misleading health information.[5]

It is no wonder that many may not be overly positive about dealing with AI-generated content now too.

Approximately one in three AI users in our survey indicated that they often bring AI-generated information with them to aid in their discussions with their healthcare team. Over a quarter of these respondents were met with a negative response from their healthcare professional (dismissive or it created tension or confusion); 23% had the AI-generated information corrected or their healthcare professional pointed out issues with it.

When asked how using an AI tool would change their reliance on their healthcare team, over one in three AI users said it would make them more reliant.

People living with a rare disease and/or their caregivers are doing their own research but may not know what to do with it or look to their healthcare professional to validate what they have found. It is important that HCPs are equipped and prepared to have collaborative, empathetic discussions on the AI-generated information their patients bring to them. This will help encourage and empower those living with a rare disease to take a more active role in their care.

Delayed diagnoses – could AI be an answer?

Many living with a rare disease can wait years to receive an accurate diagnosis. The not knowing can be incredibly challenging and makes it all but impossible to define the best course of action. Over one third of respondents from our survey indicated that obtaining an accurate diagnosis is one of the most challenging aspects of living with a rare disease.

34%

of those surveyed indicated that obtaining an accurate diagnosis was one of the most challenging aspects and 72% would allow their healthcare team to use AI tools to get there faster

We were curious what the interest would be in exploring AI tools to help. We were surprised by the results; when asked if they would be willing to allow their healthcare team to use AI tools to help reach a diagnosis sooner, seven in ten respondents indicated that they would.

Work is well underway in exploring AI in aiding the diagnosis of rare disease. An article published in Nature in February 2026 by Zhao et al. evaluated the performance of an AI tool developed specifically to support the differential diagnosis of rare disease. The results were very promising. This tool not only helped improve diagnostic accuracy, but it also provided evidence-based reasoning to support the diagnoses, with verifiable references.[6]

The Children's Hospital of Eastern Ontario (CHEO) is the first hospital in Canada to use AI to assist in diagnosing rare diseases. Their world-first AI algorithm called ThinkRare is helping flag some of the youngest patients who may have undiagnosed rare diseases, which can lead to important answers sooner.[7]

Those living with a rare disease and/or their caregivers can also help drive earlier diagnosis when armed with the right information. Understanding what to look for, questions to ask, and who to see may help empower them to advocate for their health and push for answers. Unbranded disease state campaigns for both patients and HCPs to drive this understanding are effective and important components of any launch strategy and beyond for a rare disease drug to help it realize its full market potential.

The strategic imperative for rare disease brands.

For many living with a rare disease, the information they need has not been readily available and as the findings from our survey show, AI-tools are increasingly being used to fill this void.

Pharmaceutical manufacturers have a very important role, even a responsibility to play. They must help ensure the integrity of the health information generated by AI tools. The quality of the output is directly dependent on the quality of the input. Pharma can and must help shape the information ecosystem that AI learns from, making sure that it consists of high-quality, up-to-date and accurate data and work with relevant patient groups to help them do the same. It is also important that Pharma helps ensure that this credible information is optimized for AI-driven search engines (like ChatGPT, Gemini, etc.) through Generative Engine Optimization (GEO), which will increase the likelihood that people living with rare disease will view it.

Is your organization ready to do what it takes and invest what it must to help ensure those living with a rare disease and their caregivers have access to the best available, highest quality, credible information?

As Dr. Margot Brunell, CMA president was recently quoted:[8]

"AI is already reshaping the delivery of health services, and it's not going away. It is critical that government, health providers and patients work together to ensure AI is a tool for reliable health information."

References

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6. Zhao, W., Wu, C., Fan, Y. et al. Nature (2026). **7.** CHEO. World-first ThinkRare algorithm helps family get early diagnosis of rare genetic disorder, accessed February 29, 2026.
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