HAN Survey Report

2025

Roadblocks to Diagnosis:

Symptoms of a Crisis & Priorities for Improvement

A call to action for employers,
patient groups and policymakers

A unique collective representing Canada’s top 20 health charities, HealthPartners empowers Canadian workplaces to host fundraising campaigns to advance research, deliver programs, and lead advocacy efforts around health conditions affecting 9 in 10 Canadians.

The HealthPartners Health Advisory Network (HAN) is an online community that empowers people with health conditions and caregivers to share their lived experiences through surveys and consultations with the objectives of producing valuable insights that can help shape more inclusive workplaces and improve Canada’s healthcare ecosystem. Learn more about how you can join the Network and share your story today: https://healthpartners.ca/network/.

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Executive Summary

Obtaining a diagnosis should bring clarity, relief and a path forward through a complex health system. Yet for many in Canada the journey to diagnosis is long, painful and marked with obstacles, setbacks, and disappointment.

Patients and caregivers describe the toll of this experience as profound - worsening of existing symptoms and conditions, deepening anxiety and uncertainty, and eroding mental health, financial stability, and overall quality of life.

HealthPartners' national survey of patients and caregivers within the Health Advisory Network (HAN) reveals that most experienced:

- **Unreasonably long wait times** for tests and appointments with specialists: **60%** waited more than a year to receive a diagnosis, and **1 in 3 waited over 3 years**;
- **Missed, delayed or inaccurate diagnoses: 1 in 2** were misdiagnosed at some point;
- **Bias and inequity: more than 1 in 3** felt their gender negatively influenced their care; and
- **Systems not built for complex needs: over 3 in 4** live with multiple conditions, yet pathways remain designed for single diseases.

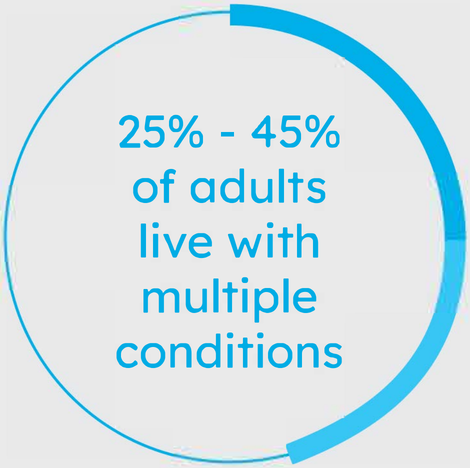
As Canada's population ages and multimorbidity becomes the norm, these cracks in the diagnostic system are widening. **With 72% of respondents feeling dismissed or not taken seriously, and 68% seeking second opinions without support, the message is clear: Canada's diagnostic system is at a breaking point.**

Yet solutions are within reach. Patients and caregivers are showing us the path forward - one grounded in listening, coordination and compassion. This report calls for a transformation of Canada's diagnostic system – to address the root causes of delay and inequity, and rebuild trust through timely, empathetic, and patient-centered care.

The Diagnosis Crisis in Canada

Across the country, people are struggling to get timely, accurate diagnoses. Long wait times, rushed appointments, and fragmented care are leaving patients in prolonged uncertainty — delaying treatment, worsening conditions, and increasing emotional and financial strain. This growing combination of delays, misdiagnosis, and lack of coordinated support is creating a diagnosis crisis that affects people's health, quality of life, and economic stability.

Prompt and accurate diagnosis is widely understood to be essential for effective treatment and care. The 2024 Fraser Institute report warns that prolonged wait times cause "increased pain, suffering, and mental anguish. In certain instances, they can also result in poorer medical outcomes—transforming potentially reversible illnesses or injuries into chronic, irreversible conditions, or even permanent disabilities. In many instances, patients may also have to forgo their wages while they wait for treatment, resulting in an economic cost to the individuals themselves and the economy in general."



At the same time, multimorbidity – living with multiple health conditions – is now common. Statistics Canada estimates that between 25% to 45% of adults, and more than half of those over 65, live with multiple conditions.

Patients and caregivers echo these realities: a national survey of 166 people who self-identified as patients or caregivers living in Canada reveals that diagnosis in Canada too often becomes a complex, emotionally draining ordeal rather than a clarifying step toward care.

Cracks in the System:
3 Roadblocks to Diagnosis

With **78%** of respondents experiencing difficulty in obtaining a diagnosis, and only **35%** rating their overall diagnosis experience as positive – the reality is unmistakable: **the diagnostic journey adds another layer of uncertainty and hardship to already difficult circumstances.** This survey identified 3 roadblocks in the journey to diagnosis.

78% experience difficulty getting a diagnosis | **35% have a positive experience**

1. Delays

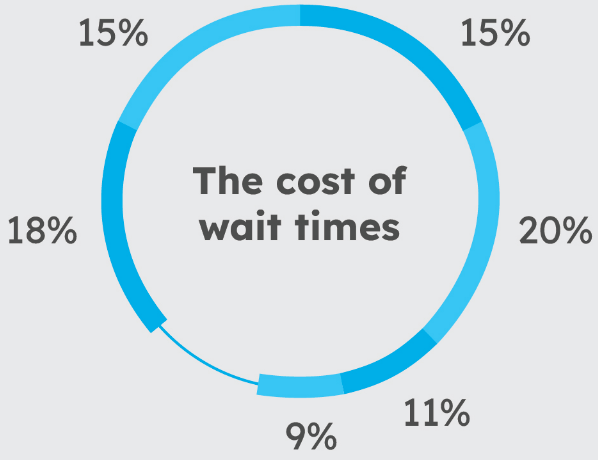
1/3 received diagnosis within 1 year	1/3 waited 2-3 years for their diagnosis	1/3 waited 3+ years for their diagnosis

Not unsurprisingly, the single most common barrier to obtaining a diagnosis was long wait times, primarily for medical tests and appointments with specialists.

Nearly 60% of respondents waited over a year for a diagnosis, and 1 in 3 waited more than 3 years. These findings mirror a 2023 report from the Canadian Organization for Rare Disorders, Experiences of Rare Disease Patients, which found similarly prolonged delays.

> ***"…the delayed access to diagnostic tools…as well as wait times to see a specialist after referral - none are in line with clinical practice guidelines or what the evidence informs as best practice."***

These wait times come at a cost: respondents reported emotional distress (20%), worsening of existing medical conditions (18%), strain on personal relationships and quality of life (15%), challenges in managing work and family responsibilities (15%), and financial hardship (9%). Many missed work or school (11%) due to repeated medical visits and uncertainty.



“The lag time between referrals... the cycle started again.”

2. Misdiagnosis

Half of respondents were misdiagnosed at least once, and another **15% remain unsure if their diagnosis was correct.** Nearly three-quarters (72%) saw three or more healthcare providers before receiving an accurate diagnosis, and one in ten saw more than ten providers.

“Doctors did not take the time to be thorough or listen to me - they blamed stress right away.”

These numbers clearly show that misdiagnosis isn’t a matter of luck or accident - they reflect systemic challenges in coordination, communication, and continuity of care.

Misdiagnosis:

- Delays effective treatment
- Worsens conditions
- Inflicts emotional harm
- Causes undue stress
- Drives unnecessary testing and procedures.

All of which places additional pressure on an already burdened healthcare system, causing further delays and undermining trust between patients and providers.

3. Bias & Stigma

Inequity, bias and stigma remain pervasive in Canada’s healthcare system.

Over one third of respondents said their gender negatively influenced their diagnostic experience, and many others described being dismissed because of age, race or mental health status.

“Young adults cannot be dismissed and invalidated because we are ‘too young’ for cancer. Delays reduce our chances of survival and quality of life.”

“Believe women. Believe patients.”

“If he stopped yelling at her and started listening to her. If he wasn’t prejudiced against her because of her mental illness.”

72%
felt unheard by their healthcare provider

Half
turned to holistic care

68%
sought out second opinions

The intersection of these three roadblocks leave many patients and caregivers feeling abandoned by the very systems meant to care for them. **72%** felt dismissed or not taken seriously by their healthcare provider, **68%** sought second opinions, often without support, and **half** turned to holistic care in search of relief or answers.

"The Emergency department sent me home since they were busy and had no room in the ward. If I had gone home when that nurse dismissed me, I would have died."

"There was no interest or even curiosity… perfunctory tests were done within whatever specialty, and when results were 'normal', she was dismissed."

"Listening to your patients more! We know our symptoms the best."

"I educated myself entirely. They just give you a diagnosis and send you packing."

Though these findings speak to symptoms of healthcare systems that are under enormous pressure, they also point to opportunities for improvement.

The Way Forward

This survey reveals deep, systemic barriers in Canada's diagnostic processes, but also points to a roadmap for improvement. Patients and caregivers are not asking for perfection; they are asking to be seen, believed, and supported by a system designed to meet today's realities.

1. Build for Multimorbidity

Multimorbidity is the norm, not the exception, with **77%** of respondents reporting living with multiple health conditions. This highlights an opportunity to design diagnostic pathways that reflect how people actually live - with multiple, overlapping conditions. **Interdisciplinary diagnostic teams, holistic assessments, and provider training on multimorbidity** can improve accuracy and reduce wait times.

2. Tackle Wait Times Head-On

It is widely understood that reducing wait times can contribute to better outcomes. Setting **national time-to-diagnosis targets** and expanding **rapid diagnostic clinics** for priority conditions can help relieve the pressure on the system, improve coordination and ensure patients receive timely, effective care. **Measuring success** not only by speed but also by quality of life and mental health outcomes.

3. Reduce Misdiagnosis

Adopt **diagnostic checklists, structured review processes** and **decision support tools** and strengthen communication between **primary and specialty care**. Implement feedback loops to learn from diagnostic errors and foster a culture of continuous improvement.

4. Consider Payment Models

Payment models influence how much time, continuity, and relationship-based care patients receive during the diagnostic process. A recent report from the Canadian Medical Association and other studies, highlight that fee-for-service structures often lead to short appointments; **making it harder to address complex diagnostic needs**. As provinces modernize physician payment models, an opportunity arises to **strengthen diagnostic quality and support more thorough assessments**.

5. Address Bias

Addressing inequities, bias and stigma - whether based on gender, age, race, or the nature of a condition - is essential to building a diagnostic system rooted in respect and inclusion. Implementing mandatory **bias-awareness and equity training for healthcare providers**, and **funding culturally appropriate navigation programs** for racialized and Indigenous communities will shape how patients are heard, believed, and treated.

> *"Non-stigmatizing care. Trauma informed. Basic empathy and human decency."*

6. Support Patients Seeking Answers

Empower and enable patients and caregivers by developing **clear guidance for second opinions** and funding **navigation services** that connect patients and caregivers to accurate information, mental health resources and peer support.

7. Help Support Persons in Their Caregiving Role

Recognize caregivers – who make up nearly 1 in 4 of the surveyed population - as integral to the diagnostic process. Offer **tailored resources, education, and respite supports** to their role.

8. Empower Patient and Caregiver Communities

Health charities play a vital role – offering information, connection, and advocacy for patients and caregivers across Canada. They fund medical research, deliver programs, provide community, and raise awareness. **Support for health charities** supports the communities they serve.

Survey respondents shared the following advice to those seeking a diagnosis:

- Advocate strongly for yourself
- Keep detailed medical records
- Build a strong support network
- Do your own research
- Trust your instincts about symptoms
- Understand the impact on mental health

> *"It would have been helpful to receive information from other patients and survivors with the same diagnosis."*

A Cry for More Caring Healthcare

Across Canada, patients and caregivers are asking for the same thing: a healthcare system that listens, believes, and acts with compassion.

Delays, misdiagnosis, and bias are not inevitable - they are symptoms of systems under strain. By reimagining the diagnostic experience around empathy, coordination, and equity, we can restore trust and deliver better outcomes for all.

This report is both a warning and a call to action: to build a more compassionate, efficient, and inclusive diagnostic system - one that ensures every person in Canada is seen, heard, and cared for when it matters most.

Did you know?

HealthPartners 20 national member organizations are vital allies for patients and caregivers. Please visit Healthpartners.ca to learn more or connect with others navigating a similar journey.

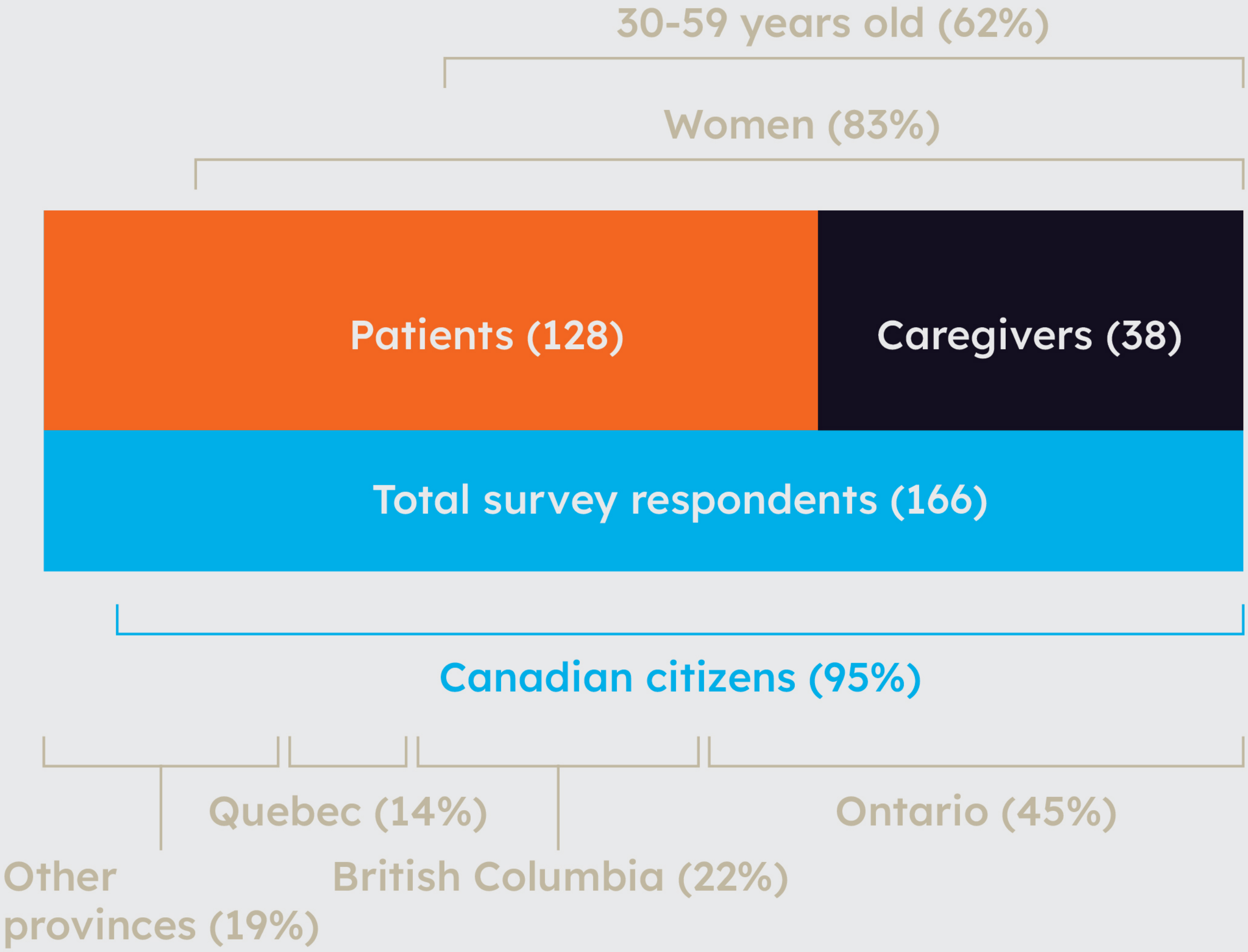
Respondent Profile

Of the 166 survey respondents, 128 were patients with lived experiences and 38 were support persons or caregivers.

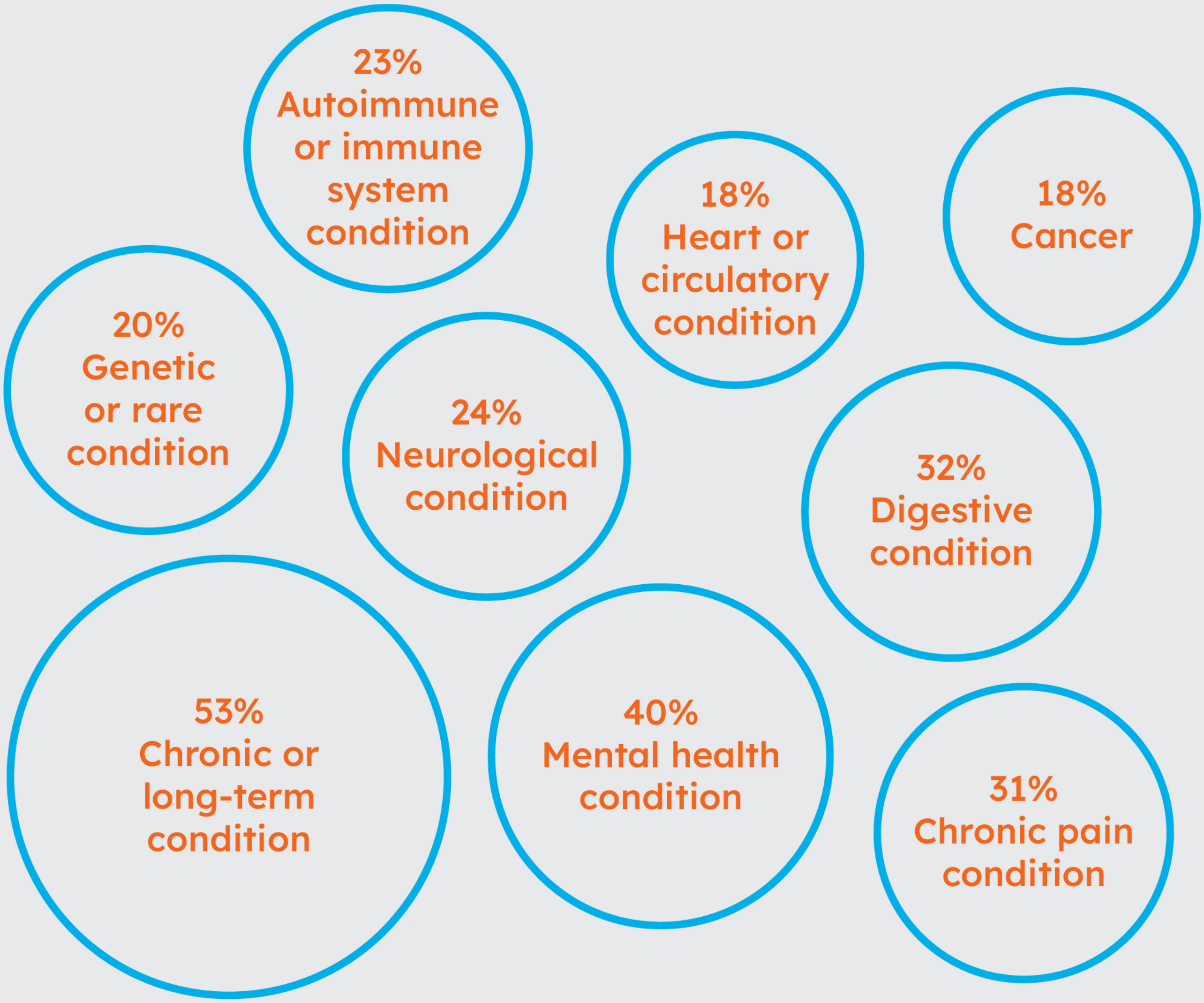
The majority of participants (83%) identified as women and 62% of respondents were between 30 and 59 years old.

A large portion of the sample was concentrated in Ontario (45%), British Columbia (22%) and Quebec (14%), with smaller numbers of respondents from other provinces and territories.

About four respondents in five lived in urban areas and 95% of respondents were Canadian citizens.



The health conditions affecting survey participants were varied. Respondents could select all conditions that applied, and many identified more than one — reflecting the complexity of their health needs.



Through the Health Advisory Network, HealthPartners will continue to amplify these voices, share actionable insights, and collaborate with stakeholders to help shape a more inclusive and compassionate healthcare ecosystem in Canada. Stay tuned for HAN's next survey report and join the Network today if you'd like to have your voice heard.

To date, HealthPartners has empowered over 600,000 employees to donate over $230 million to health charities across Canada. Adding purpose to your workplace with HealthPartners is a free way to make a proven investment in the well-being of your staff and the reputation of your organization. Your employees will be twice as happy, twice as likely to stay and twice as likely to recommend your workplace to others. Learn more about hosting your own workplace giving campaign today: https://healthpartners.ca/.