

Prescription for Ontario

Doctors' 5-Point Plan for Better Health Care

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Broad consultation informs plan

Diverse voices help shape plan that resulted in more than 85 recommendations to help resuscitate Ontario's health-care system.

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Backlog of
20 million
health-care services

Doctors' visits, surgeries, diagnostic tests

The problems plaguing Ontario

Chronic underfunding and a backlog of services have done more than weakened a system, they've weakened lives, and livelihoods

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Finding hope in a hopeless situation

One family shares its struggle to secure adequate home care.

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Photo illustration/Bryan Davidson

Full economic recovery depends on full health-care recovery

As Ontario emerges from the pandemic, the province's health-care workers will continue to work well over capacity to clear the backlog of almost 20 million health-care services the public health crisis has created. They must also work to address the looming mental health tsunami and treat the undiagnosed

patients who did not seek care.

The Ontario Medical Association, representing 43,000 physicians, offers solutions in *Prescription for Ontario: Doctors' 5-Point Plan for Better Health Care*, focused on:

- Reducing the backlog of services and wait times
- Expanding mental health and addiction services in the community
- Improving and expanding home care and other community care
- Strengthening public health and pandemic preparedness
- Giving every patient a team of health-care providers and linking them digitally.

OMA's plan addresses the unique health-care challenges in northern Ontario and calls for action on climate change to mitigate its consequences on human health. It recognizes that a full economic recovery depends on a strong health-care system and healthy population. **See full story on page 3.**



Diverse voices help shape OMA’s plan

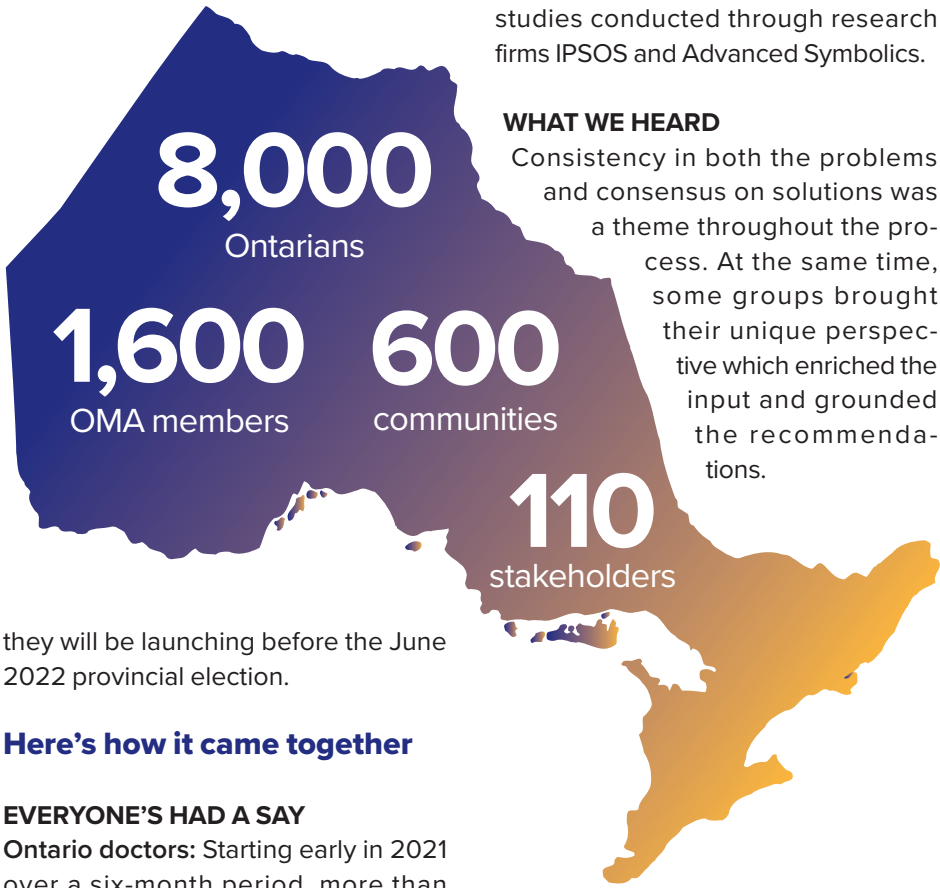
Provincewide consultation the most comprehensive in association’s history

The Ontario Medical Association’s new health-care recommendations are informed by months of consultations with thousands of people representing Ontario doctors, health-care stakeholders, community leaders and the public. The result: powerful policy recommendations that reflect Ontarians’ concerns.

The largest consultation in its 140-year history aimed to ensure the OMA plan captured system issues, health-care worker needs and patient concerns in communities across the province. With its partners, the OMA engaged thousands of patients, physicians, and other health-care workers, industry leaders, and others across the province in in-depth surveys, interviews, and group consultations, covering an exceptionally broad spectrum of open-ended and guided questions.

The feedback from those consulted is consistent, with five key priorities emerging to create the OMA’s new *Prescription for Ontario: Doctors’ 5-Point Plan for Better Health Care*: addressing wait times and the backlog created by the pandemic, putting more resources into addressing mental health and addictions, taking better care of our elderly and offering increased and improved care options, pandemic preparedness, and access to integrated care including fixing the doctor shortage. The plan offers solutions to the most pressing problems in Ontario’s health-care system today.

The OMA’s objective is to encourage all parties to incorporate some, and ideally all, of the recommendations into the health-care platforms



they will be launching before the June 2022 provincial election.

Here’s how it came together

EVERYONE’S HAD A SAY
Ontario doctors: Starting early in 2021 over a six-month period, more than 1,600 members shared their views through regional member roundtables, one-on-one meetings with physician leaders, a survey of OMA members, Ontario’s physicians, along with a member prioritization session.

Health and community leaders: More than 110 health-care stakeholders and community leaders participated in virtual roundtable discussions.

The public: Close to 8,000 Ontarians from more than 600 communities have completed a public survey, validated by

studies conducted through research firms IPSOS and Advanced Symbolics.

WHAT WE HEARD
Consistency in both the problems and consensus on solutions was a theme throughout the process. At the same time, some groups brought their unique perspective which enriched the input and grounded the recommendations.

From the public
Through surveys with the public, we learned that:

- Perceptions of the health-care system have deteriorated during the pandemic for most Ontarians. About 59 per cent of respondents said their view of the way health care is delivered in their community had worsened, while 31.7 per cent said their impression hadn’t changed and only 9.4 per cent said their perception had improved.
- Most respondents assigned our

health-care system a mediocre to failing grade; 49 per cent gave it a C and 23 per cent an F. Just 25 per cent of respondents gave the health-care system a B and only four per cent an A.

- It was also revealed that while health care is a high priority for Ontarians, 80 per cent of respondents said that health-care issues were not being discussed or debated at all in their community.
- Access to health care ranks as the most critical issue aside from COVID.
- About 30 per cent of respondents identified wait times as their top choice for what should be prioritized in health care
- Next to COVID-19, 18.8 per cent of respondents ranked the need for more doctors as the most pressing health-care priority.

From health-care stakeholders
Our partners served as a conduit of insight on issues important to patients and caregivers, including caregiver access, backlogs, inequities and other long-standing problems that have only heightened through the pandemic.

THE RESULT
Deep research and broad consensus enabled the OMA’s plan to reflect the needs of everyday Ontarians, and the priorities of medical professionals tasked with delivering Ontario’s health care. OMA President Dr. Adam Kassam is optimistic that the recommendations will become platform planks in next year’s election.

“We heard loud and clear from our members and health-care partners, we need a plan that reflects the needs of those working together to make health care better for all, and we need a plan that encourages even greater collaboration and partnership. We believe this plan, based on the input of doctors, nurses and other health-care workers, patients and community leaders, provides a very clear path forward.”

—Dr. Adam Kassam, OMA president

“This process gave us the opportunity to really bring the patient perspective together with the physician perspective. For instance, our own research has shown that caregivers’ anxiety was higher even than that of cancer patients themselves during the pandemic. That was really insightful because it quantified what so many people understand instinctively: the foundational importance of caregivers to quality of care.”

—Stephen Piazza, Canadian Cancer Society, participant in OMA consultation

Recovering from the COVID-19 pandemic

Strong health-care system key to strong economy

Physicians and health-care partners have been speaking out for decades about the worrying state of health care in Ontario. Unacceptable wait times for patients. Inadequate long-term care, home care and mental health and addiction programs. Inequities in the north and in low-income and racialized communities.

Those problems, and many more, have been magnified by the COVID-19 pandemic, pushing the health-care system into an unprecedented crisis, with a staggering backlog of almost 20 million delayed health-care services. The pandemic has also proved that Ontario cannot have a strong and sustained economy without a robust, resilient and reliable health-care system that reduces the need for lockdowns and other measures in a public health emergency.

Practical solutions to long-standing problems

The Ontario Medical Association, representing the province’s 43,000 doctors, has released a new plan to tackle these problems and transform the health-care system over the next four years.

“The urgent need to focus on solutions to improve patient care is a top priority for the profession,” said OMA President Dr. Adam Kassam. “Physicians have a prescription for the future of health care and a roadmap to transformation for Ontario.”

The OMA’s plan, *Prescription for Ontario: Doctors’ 5-Point Plan for Better Health Care*, is the result of the broadest consultation in the organization’s 140-year history. More than 110 health-care organizations, social service agencies and community leaders provided input. Almost 8,000 Ontarians from 600 communities shared their views last spring and summer through an online survey. More than 1,600 physicians representing a wide range of specialties and regions gave their expert advice.

Prescription for Ontario: Doctors’ 5-Point Plan for Better Health Care has 75 recommendations to strengthen the system and improve patient care provincewide in five priorities areas:

- Reduce the backlog of services and wait times
 - Expand mental health and addiction services in the community
 - Improve and expand home care and other community care
 - Strengthen public health and pandemic preparedness
 - Give every patient a team of health-care providers, and link them digitally.
- The plan also includes 12 specific recommendations to deal with the unique health-care challenges faced in northern Ontario.

It starts by reducing the backlog

The most immediate crisis facing Ontario’s health-care system is the backlog of almost 20 million delayed services, including visits to doctors, diagnostic tests, cancer screening, rou-



tine immunizations, treatments and surgeries.

Doctors are seeing patients sicker than they ought to be because of serious conditions left undetected or untreated during the pandemic. However, focusing on the pandemic backlog alone ignores the bigger problem – an inefficient health-care system

doctors per 1,000 patients (2.3) and has one of the lowest doctor-to-population rankings among OECD countries (28 out of 33). *Prescription for Ontario: Doctors’ 5-Point Plan for Better Health Care* also points out that many doctors are retiring or leaving the profession because of burnout exacerbated by the COVID pandemic.

to keep pace with demand in other years. Ontario’s per capita health-care spending is about eight per cent lower than the average of other provinces, according to CIHI.

More investment, more collaboration, broader thinking
The Ontario government can’t fix the ailing health-care system on its own, said OMA CEO Allan O’Dette.

“It requires collaboration among health providers, support from the public and political will. This requires significant investment from the federal government, including increased spending through the Canada Health Transfer to the provinces to cover 35 per cent of all health-care costs, up from the current 22 per cent,” O’Dette said.

And investing dollars in the health-care system is not enough, the OMA report said. Planning a better system must remove regional disparities and recognize that social determinants of health – income, education, food security, housing and early childhood development – are key factors in health outcomes, as is the need for action on climate change to mitigate its severe consequences on human health.

“During the pandemic, routine cancer screening, diagnostic procedures and surgeries have been delayed or cancelled. Cancer isn’t waiting for the pandemic to be over, and unfortunately we are seeing more cases of advanced disease.”

Dr. Timothy Asmis, chair, OMA Section on Hematology and Medical Oncology, Ottawa

with too few doctors, who are not linked digitally.

To clear the backlog of services and procedures, the OMA says doctors, nurses and other health-care workers would have to work considerably more hours than they already are over many months and years:

- 30 months to catch up on knee replacements
- 25 months for cataract surgeries
- 19 months for hip replacements
- 14 months for heart bypass surgeries
- 11 months for MRIs.

Even before the pandemic, there were long wait times to see specialists and access critical diagnostic tests, treatment and surgeries.

Fixing the doctor shortage

There are serious shortages of doctors and other health-care professionals in many regions, especially in the North and rural communities. One million Ontarians don’t have a family doctor. We know that access to care starts with the family doctor.

Ontario ranks seventh among Canadian provinces in number of family

Backlog of

20 million

health-care services

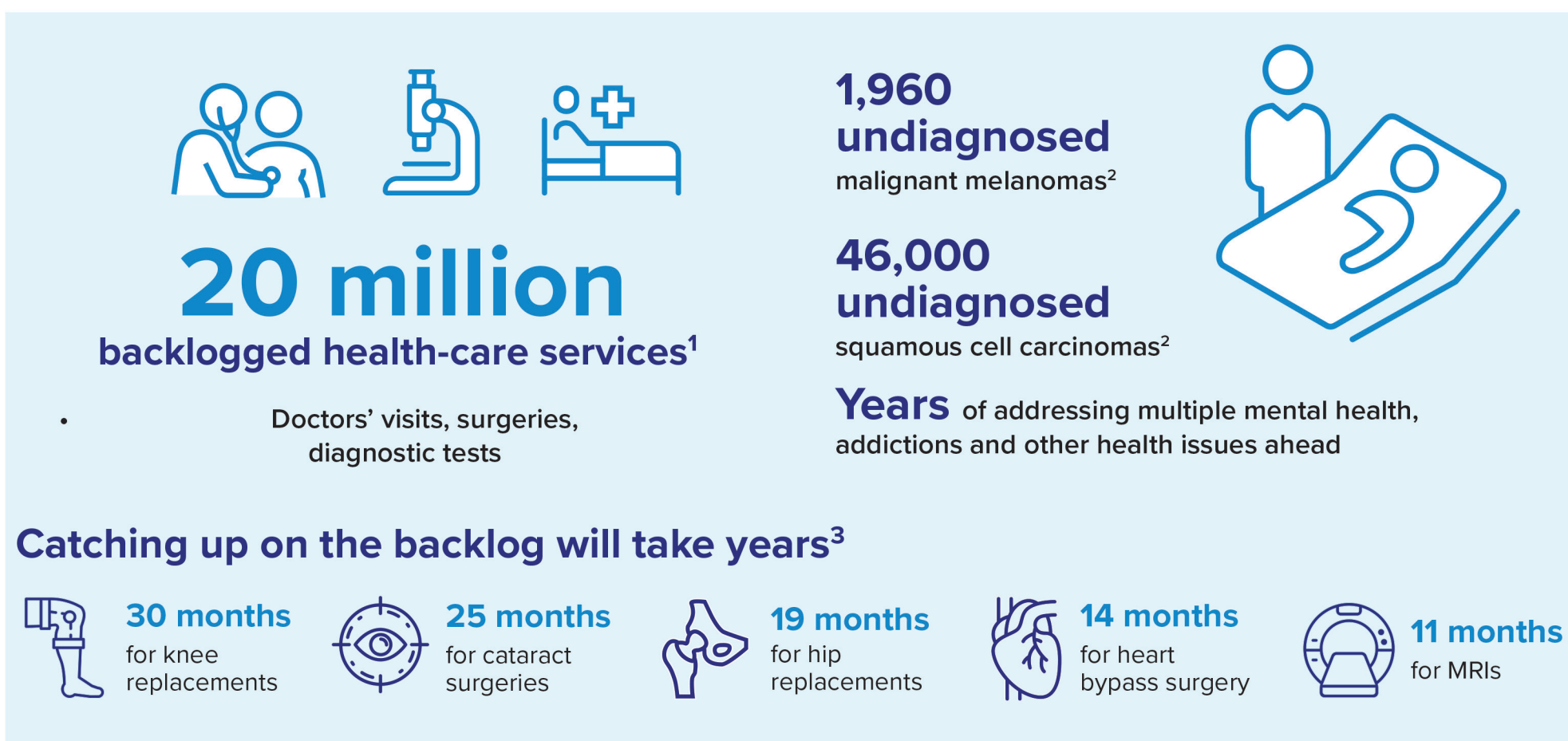
Doctors’ visits, surgeries, diagnostic tests

Details on page 4

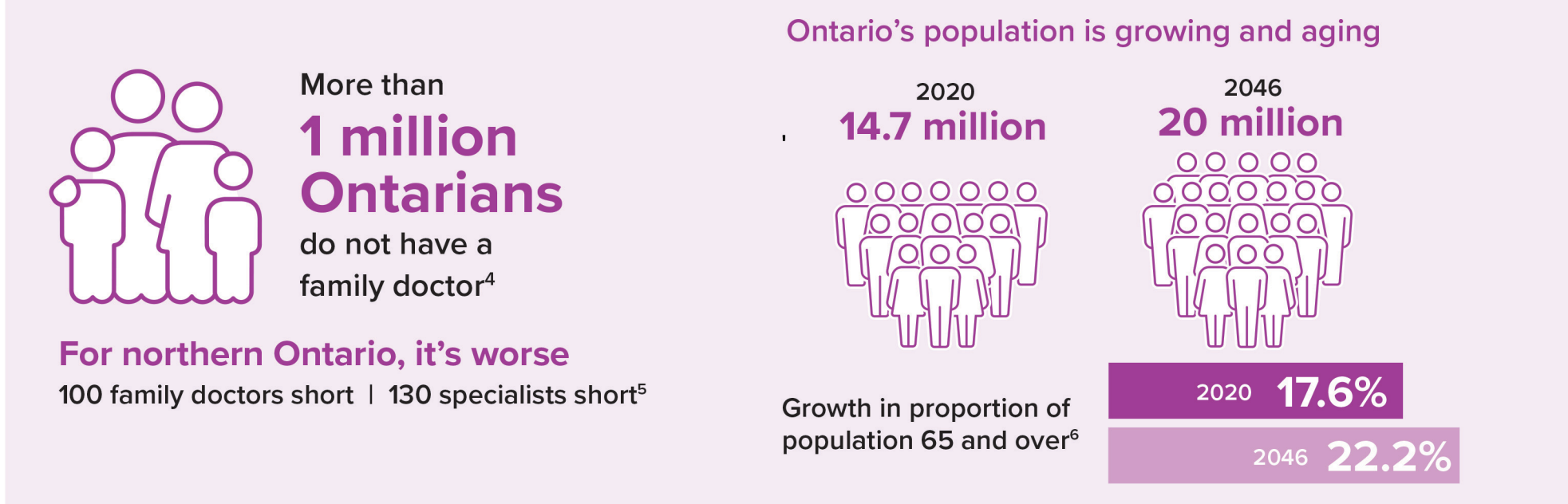
Source: OMA Analysis of OHIP Data

Ontario's Health-Care Challenges

The pandemic has created a significant backlog of health-care services in Ontario



Adding to stress on health care is a doctor shortage and growing population

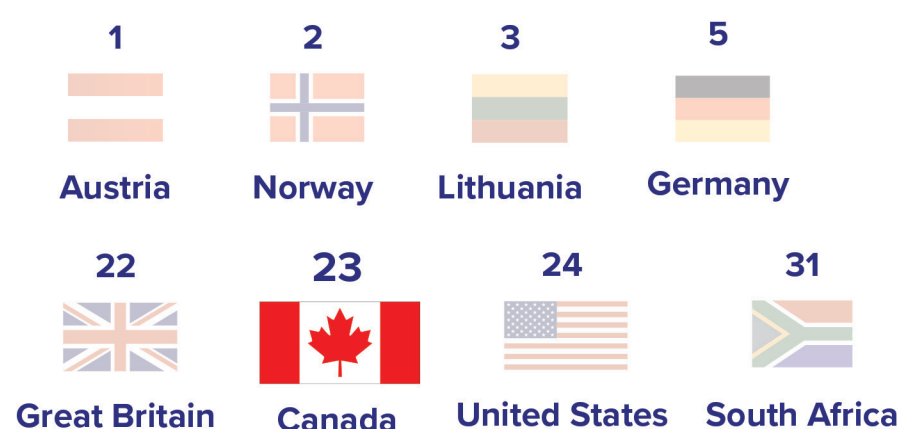


Compared globally and nationally, Ontario is lagging

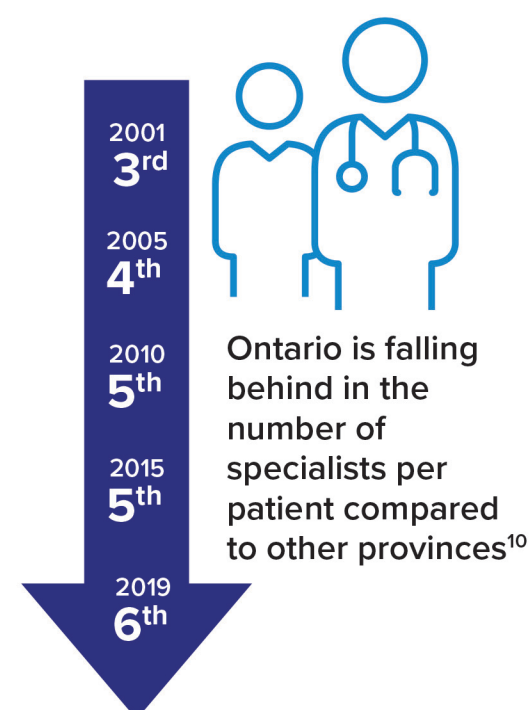
Compared to other countries, Canada ranks 23rd out of 32 Organization for Economic Co-operation and Development countries in doctor-to-population ratio

2.78 physicians for every 1,000 people⁷

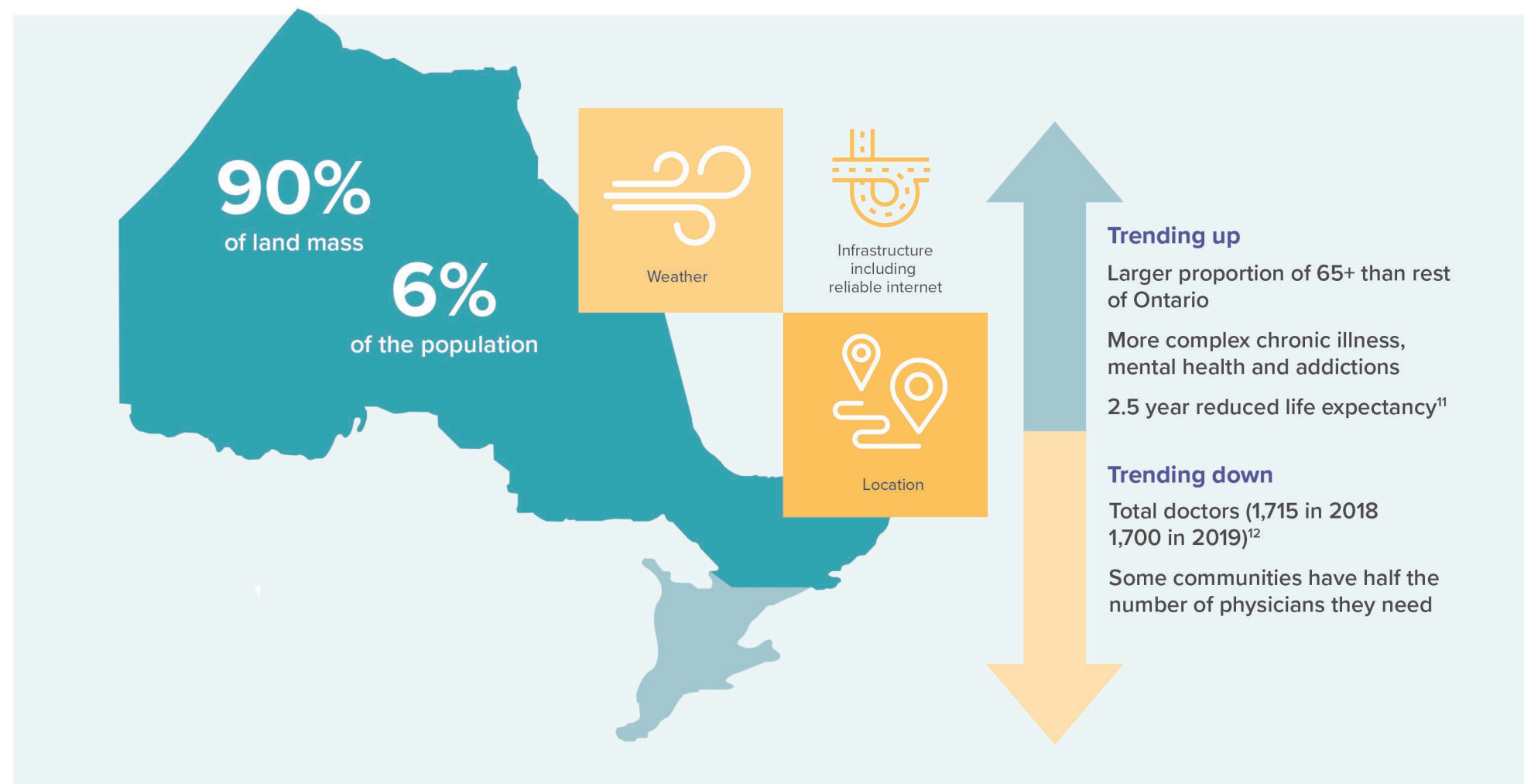
If Ontario were an OECD country – we'd be 28th out of 33 regions (2.32 physicians per 1,000 people)⁸



Province	Doctors to 1,000 people ⁹
Nova Scotia	2.69
Newfoundland	2.60
Alberta	2.54
Quebec	2.52
British Columbia	2.50
New Brunswick	2.47
Ontario	2.32
Manitoba	2.16
Saskatchewan	2.12
Prince Edward Island	2.04

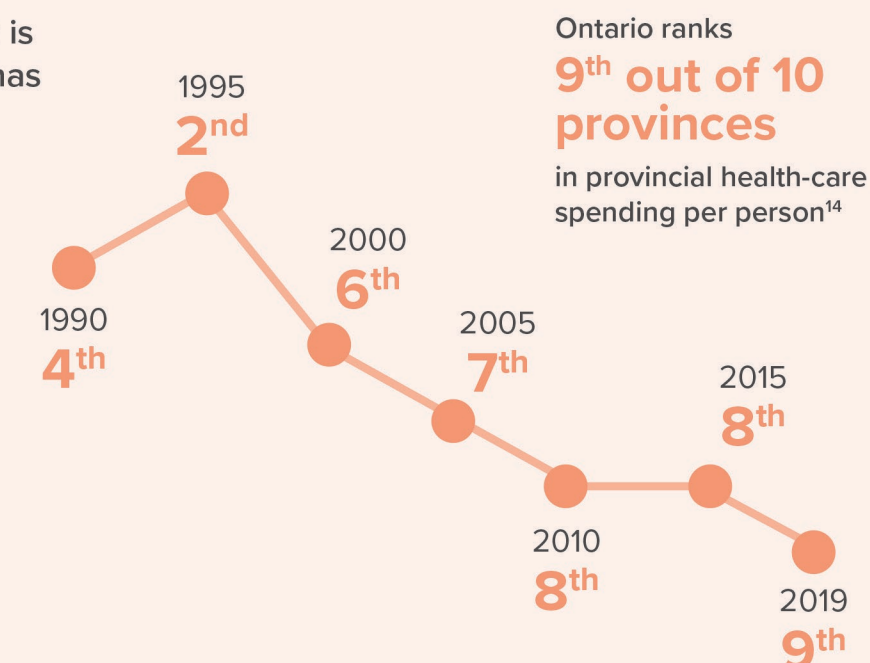
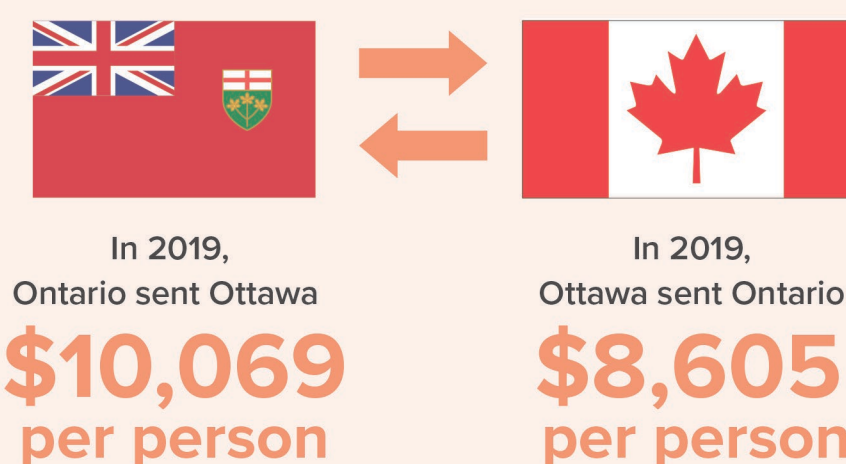


Northern Ontario has unique needs

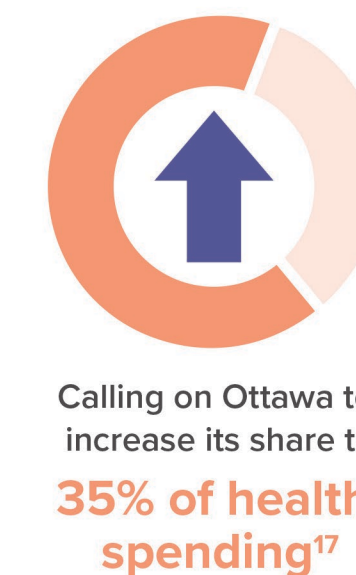


Health-care funding isn't keeping pace with demand

Per person, the amount of money Ontario receives from Ottawa is less than the amount Ontario sends to Ottawa. This difference has been increasing over time¹³



The Canada Health Transfer — intended to share the cost of health care with the provinces — has not been keeping pace with patient need



¹³OMA Analysis of OHIP Data

¹⁴National Society of Cutaneous Medicine, January 2021

¹⁵Ontario Ministry of Health, Health Care Experience Survey, 2019

¹⁶Ontario Physician Human Resources Data Centre

¹⁷Ontario Ministry of Finance Population Projections, Reference Scenario

¹⁸OECD.org Doctors Total Per 1,000 Inhabitants 2019

¹⁹OECD.org. Doctors Total per 1,000 Inhabitants 2019; Scott's Medical Database, Supply Distribution and Migration of Physicians, CIHI 2019

²⁰Scott's Medical Database; Supply Distribution and Migration of Physicians, CIHI 2019

²¹Health in the North, Health Quality Ontario

²²Ontario Physician Human Resources Data Centre

²³Statistics Canada, Table 17-10-0005-01; Table 36-10-0450-01

²⁴CIHI National Health Expenditure Trends, 2020

²⁵Canada.ca

²⁶Canadaspremiers.ca

Prescription for Ontario:

Doctors' 5-Point Plan for Better Health Care

Since early 2021, the Ontario Medical Association has been consulting widely with physician leaders and members, representing different specialties and regions, as well as health-care stakeholders, community leaders and the public to develop recommendations for better health care. The result is a solutions-based plan that focuses on five key themes plus specific actions to address the unique needs of northern Ontario. The OMA is offering more than 85 recommendations informed by our consultation. From now to the June 2022 provincial election, the OMA will be advocating for all major political parties to adopt as many of these recommendations as possible in their own election platforms. Regardless of who wins the election, all Ontarians should win better health care. The recommendations focus on fixing the health-care system, and acknowledge the importance of addressing equity, access, and climate change challenges as they also affect health outcomes.

Reduce wait times and the backlog of services

- To reduce the pandemic backlog and shorten wait times, Ontario's doctors recommend:**
- Providing adequate funding to address the backlog of services in hospitals and community clinics
 - Evolving the model of surgical care delivery to include a greater portion of services delivered in community-based specialty settings outside of hospitals
 - Ensuring enough nurses and technologists to expand MRI and CT machine hours, and for ultrasound and mammography
 - Greater efforts to educate young people about healthy lifestyles and disease prevention, including an adequately funded anti-tobacco



Source: Canadian Institutes of Health Research

- strategy, which will lead to better long-term health and reduce future stress on the system
- Expanding the use of home remote monitoring programs to streamline pre- and post-surgical delivery
 - Ensuring sufficient health human resources to meet Ontario's needs
 - Enhancing data collection and timely data sharing to support planning, measurement and evaluation
 - Better integration of health-care service provision with public health and other services, including but not limited to palliative care, long-term care, home care and community care

- To address the unequal supply and distribution of doctors, Ontario's doctors recommend:**
- Creating a detailed analysis, based on high-quality data, that accounts for the types and distribution of doctors to meet population needs
 - Establishing a set of best practices around physician supports to help ensure Ontario has the right doctors in the right places at the right times
 - Using best evidence regarding forecasted population need, increasing the number of medical student and residency positions
 - Supporting students from remote, rural and racialized communities to go to medical school aligned with populations in need
 - "Letting doctors be doctors" whereby they spend more time with patients doing the things that only doctors can do and less time on paperwork or other tasks
 - Helping doctors trained in other jurisdictions become qualified to practise in Ontario
 - Investing in more training and educational supports for practising doctors

Expand mental health and addiction services in the community

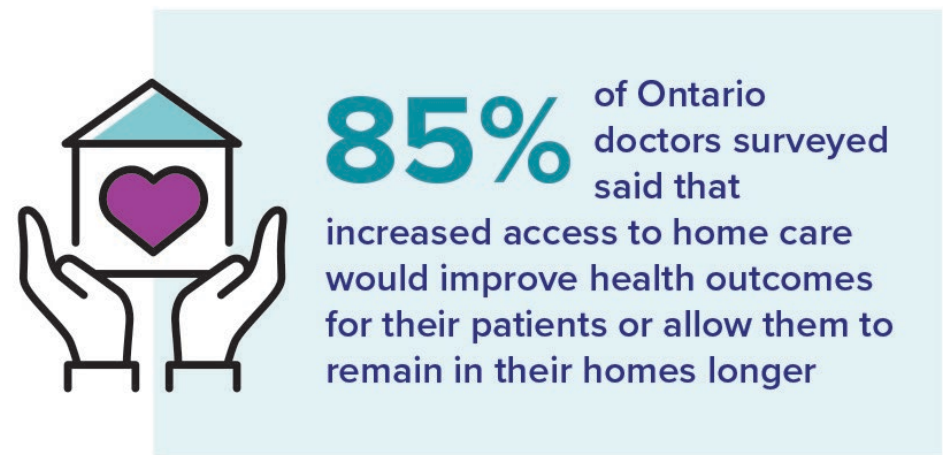
- To improve access to mental health and addiction care, Ontario's doctors recommend:**
- Province-wide standards for equitable, connected, timely and high-quality mental health and addiction services to improve the consistency of care
 - Expanding access to mental health and addiction resources in primary care
 - Specific mental health supports for front-line health-care providers
 - Ensuring that appropriate resources are in place to provide virtual men-

- tal health services where clinically appropriate
- Increased funding for community-based mental health and addiction teams where psychiatrists, addiction medicine specialists, family doctors, nurses, psychologists, psychotherapists and social workers work together
 - More mental health and substance awareness initiatives in schools and in communities
 - Make access to care easier by defining pathways to care, navigation and enable smoother transitions with the system

- Build service capacity for young patients moving into the adult system
- Reducing the stigma around mental health and addiction through public education
- More resources to fight the opioid crisis, particularly in northern Ontario where the crisis is having a significant impact and resources are limited
- Increasing the number of supervised consumption sites

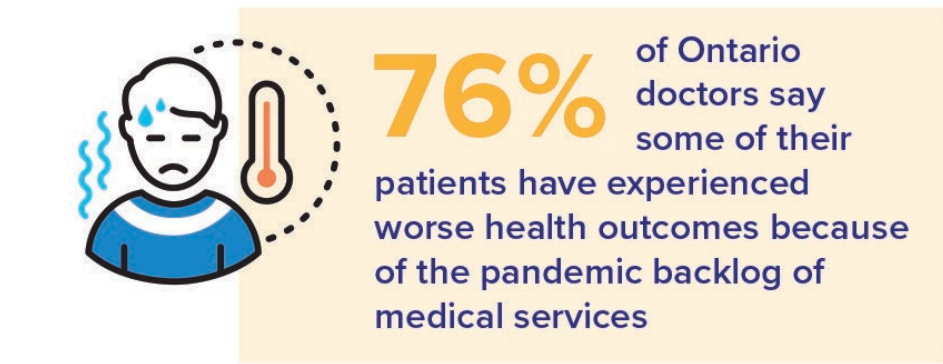
Improve home care and other community care

- To ensure equitable and timely access to high-quality home care, Ontario's doctors recommend:**
- Developing provincewide standards for timely, adequate and high-quality



Source: 2021 OMA member survey

- home-care services
- Increasing funding for home care and recruiting and retaining enough skilled staff to provide this care
 - Embedding home care and care co-ordinators in primary care so patients have a single access point through their family doctor
 - Ensuring people without a family doctor can still access home care seamlessly
 - Enabling electronic sharing of information between doctors, care co-ordinators and home-care providers
 - Expanding a direct funding model so patients can customize their home care according to need
 - Reducing needless administrative paperwork so more time can be spent on actual patient care
 - Providing tax relief for families who employ a full-time caregiver for a family member



Source: 2021 OMA member survey

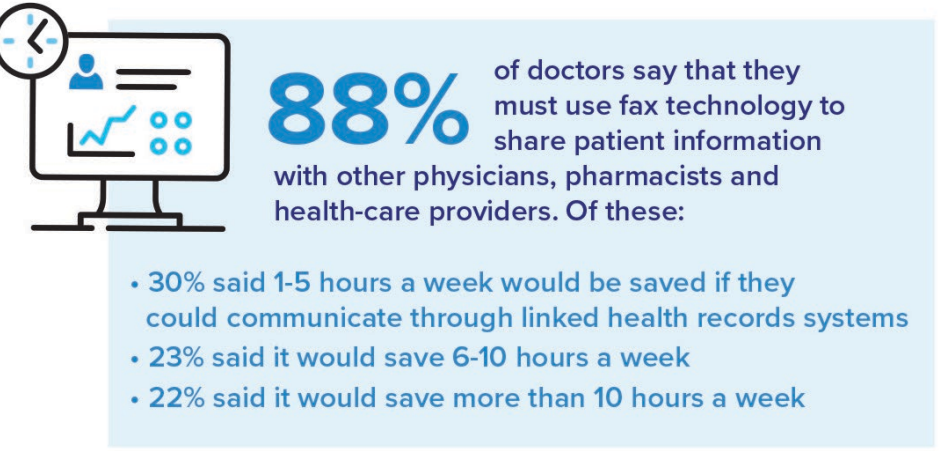


- tent operational funding to hospices so they can focus on care and not fundraising
- Greater investment in palliative infrastructure, based on geographic need
 - Ensuring there are separate plans to address pediatric and adult palliative care patients to reflect the necessary distinctions in services and needs for these patient demographics
 - Increasing the number of skilled palliative care providers, including physicians, nurses and allied providers by increasing opportunities for training
 - Making palliative care accessible 24/7, including virtually, in all regions and diverse populations including Indigenous, houseless, and others

- To better serve those living with chronic disease, Ontario's doctors recommend:**
- Increasing investment in chronic disease management to enable a larger workforce, technologies to manage these diseases, and home services

Strengthen public health and pandemic preparedness

- To build on the current strengths of our public health system overall, Ontario's doctors recommend:**
- Enhancing local public health to ensure it can be a strong local presence for health promotion and protection
 - Providing a clear, adequate and predictable funding formula for local public health units that returns to 75 per cent paid by the province and 25 per cent paid by municipalities
 - Ensuring Ontario's public health system has highly qualified public health doctors with the appropriate credentials and resources



Source: 2021 OMA member survey

- Increasing the investment in public health information systems so we can better collect, analyze, share and use information in more thorough and timely ways to improve decision-making, and asking the federal government to increase its investment in public health to provide the infrastructure to support standardized data collection and analysis across jurisdictions
- Carrying out an independent and unbiased review of Ontario's response to the pandemic including the public health system, its strengths and weaknesses during pandemic and non-pandemic times, along with its roles and responsibilities, before considering any changes
- Enhancing the ability of Public Health

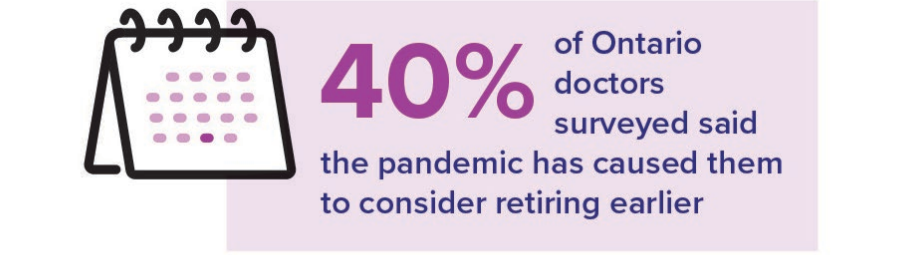
Ontario to carry out its mission/mandate which includes robust public health science and laboratory support, including providing increased funding for hiring of additional public health trained physicians

- To prepare for the next pandemic, Ontario's doctors recommend:**
- Requiring by legislation a provincial pandemic plan, including a mandatory review and update every five years to reflect changes in local public health practice, medical science and technology
 - Implementing a standardized pandemic plan across public health units that is sufficiently flexible to account for differences and inequities across this diverse province
 - Sufficiently resourcing Public Health Ontario to be the central scientific and laboratory resource during a pandemic or public health emergency, including ensuring it has the complement of public health specialist physicians needed to meet its mandate during a public health emergency
 - Strategic investments for pandemic planning for public health units so their resources aren't drained from the other important work they do every day during a crisis
 - Ensuring adequate funding to recognize additional workloads during pandemics

Give every patient a team of health-care providers, and link them digitally

- To provide patients with access to the family care model of practice that works best for them, including team-based care, interdisciplinary**

- collaboration, and increased access with fewer unnecessary visits, Ontario's doctors recommend:**
- Increasing funding and support for effective team-based and integrated care in all primary care models
 - Letting family doctors choose the type of practice model that works best for their patients and their community
 - Opening up the Family Health Organization capitation model of care to all doctors who wish to practice that way
 - Increasing the number of care co-ordinators to help patients access care more quickly and easily, and have these co-ordinators work directly in primary care settings
 - Enabling team-based and inte-



Source: 2021 OMA member survey

- grated care settings not only around primary care, but around diseases or specialties
- Optimizing the currently legislated Ontario Health Teams, including ensuring physician leadership in the process, as a way to integrate health-care services for the benefit of patients across the province

- To ensure all patients continue to benefit from virtual care, Ontario's doctors recommend:**
- Implementing permanent OHIP fee codes for virtual care services provided by phone, video, text and email, ensuring that patients can access virtual care for any insured health-care service that can be appropriately delivered through electronic means
 - That the government partner with internet providers so that Ontarians who cannot afford internet services (for example, those living in public or supportive housing, relying on Ontario Works or Ontario Disability Support Program, and seniors receiving the Guaranteed Income Supplement) can get internet services at a greatly reduced rate, to ensure all patients benefit from virtual care

- To improve sharing of a patient's medical information among their**

Improve access to care in northern Ontario

- To improve health care in northern Ontario, Ontario's doctors recommend:**
- That patients have equitable access to care in their own communities
 - Reviewing and updating incentives and supports for physicians and allied health-care workers to practise in northern Ontario, and other communities that are chronically underserved
 - Focusing on education, training, innovation and opportunities for collaborative care to address physician (health-provider) shortages in remote communities
 - Creating resourced opportunities for specialist and subspecialist trainees to undertake electives and core rotations in the North
 - Giving medical students and residents the skills and opportunities they need to be confident in choosing rural and remote practices
 - Focusing on innovative culturally sensitive education and training opportunities addressing physician and other health-provider shortages in rural and remote communities
 - Focusing on the profound and dis-

- proportionate impact of the opioid crisis and mental health issues in northern Ontario
- More social workers, mental health and addiction care providers and resources for children's mental health
 - Enhancing internet connectivity in remote areas to support virtual care, keeping in mind that virtual care will not solve health human resources problems in northern Ontario and should not replace in-person care
 - A recognition of the specific need for local access to culturally safe and linguistically appropriate health care for northern Ontario's francophone population and Indigenous Peoples
 - A collaborative partnership with Indigenous Services Canada and Health Canada to address issues of safe drinking water, and adequacy of health-care facilities and resources in Indigenous communities
 - Using a harm reduction, anti-oppressive lens, addressing the education gaps in Indigenous communities and non-Indigenous communities, as health is directly affected by education

Human cost of living without home care

One family’s story illustrates why the entire system needs increased funding

BY PATCHEN BARSS
Sharon Liff has been an electrical engineer, pianist, aerobics instructor, choral singer, personal trainer, bus driver and ham radio operator. She’s used to having a lot on the go.

“I’ve always liked to reach,” the Ottawa mother said. “That’s just my personality.”

In the past several years, though, she has had to let go of almost all these pursuits to make room for one thing: caring for her 19-year-old son Adam Liff-Neilson.

Adam has a rare genetic condition called Pelizaeus-Merzbacher Disease. It affects his brain and spinal cord, inhibiting his co-ordination, motor skills and learning abilities. He needs 24-hour caregiver assistance for everything from eating to toileting.

Before each feeding-tube meal, he needs his stomach “vented” to release the gases that would otherwise cause him pain and bloating. He’s fed by hand eight to 10 times per day, and requires a diaper change once or twice per night and up to nine more times during the day. He needs medicine each morning and throughout the day for seizure prevention, ulcer prevention, and other conditions. He gets around in a wheelchair or walker, and also uses a standing frame, all of which require lifting to get into and out of. Adam is non-verbal and requires daily assistance to exercise, learn and bathe. And he needs the company of other caring people for his emotional well-being.

While Sharon and her husband Rick Neilson are more than willing to make personal and professional sacrifices to ensure Adam has the care he needs, they can’t do it alone.

“Rick has given up his career for this. We’ve both given up a lot,” she said. “We love our son. He’s a great kid. But his care is so onerous.”

Stories of families like that of Adam and his parents were one of the driving forces behind the recommendations in *Prescription for Ontario: Doctors’ 5-Point Plan for Better Health Care*. The Ontario Medical Association is advocating for better home-care services both to improve public health, and the situation for people like Adam, Sharon and Rick.

Current gaps in home-care support not only affect the quality of life for family caregivers, but also the quality of care itself. Adam needs types of professional medical assistance that his parents never trained for, including the help of personal support workers (PSWs), developmental services workers (DSWs), and trained nurses.

Deficiencies with home care began well before COVID-19 but became more pronounced and severe because of the pandemic.

“It was getting harder and harder to find qualified people,” Sharon said. “I used to hire support workers from camps Adam attended to work part-time for us. But they’re no longer available. It happened gradually. It actually took me a while to notice because I had so much to worry about, but at some point, I just



Photo/Fred Chartrand

Sharon Liff spends some quiet time with her 19-year-old son Adam at their Ottawa home. Adam was diagnosed with Pelizaeus-Merzbacher Disease when he was a toddler, a rare genetic condition that affects his brain, spinal cord, motor skills and learning abilities, requiring 24-hour care.

thought, ‘Wow, there’s really no one out there.’ It was getting bad before the pandemic started, and then the pandemic just killed it.”

She and Rick often go weeks without being able to find help during the day. She struggled even to find time to sit down and be interviewed for this story.

In addition to general shortages, PSWs and DSWs often choose to work in care facilities rather than private homes, which can offer regular hours, benefits and higher hourly rates. Even when Sharon and Rick receive government funding to pay for home-care assistance, they can’t compete with larger facilities.

“The entire health system is struggling to find enough qualified front-line staff,” said Shirlee Sharkey, president and CEO of SE Health, a not-for-profit provider of home-care ser-

vices. “Hospitals, long-term care homes, public health units, community providers and individual families are often vying for the same talent. There’s a limited pool and it’s very competitive.”

Sharkey pointed out that a typical PSW working at a hospital earns nearly 20 per cent more than an equally qualified worker in the home-care sector. For a registered nurse the average hourly rate is \$11 higher in hospitals. Addressing these inequities, as well as prioritizing better working conditions could go a long way toward alleviating the kinds of challenges Sharon and Rick face.

Even when they can find support workers, they often cancel at the last minute because they’ve been called in for an extra shift at their main job, or because they’re just burnt out. With no give in the system, Adam’s round-the-clock care falls to his parents. They work as a team, trading off duties and giving each other breaks as best they can, but the situation is unsustainable.

“It’s killing us,” said Sharon, though the rewards of having Adam in their lives make it all worthwhile. “Adam is a very happy guy. You can see how much

required surgery on his digestive system when he was three years old and had to begin using a feeding tube as he was unable to chew and swallow safely. The family faced many more medical interventions in the years that followed. But as Adam’s needs increased, staff and funding diminished.

She would like to see the provincial government place greater emphasis on promoting programs to train DSWs. Such programs provide the exact kind of training she knows Adam needs in a home caregiver.

“They have the training to work with people in wheelchairs or who might be non-verbal. They have the knowledge to deal with developmental issues,” she said.

Sue VanderBent, CEO of Home Care Ontario, a member-based organization representing home-care service providers, agrees that increasing the number of DSWs is part of the solution, but much more is also needed to address needs across the province.

“Home-care workers look after a million people in Ontario every year. That’s massive,” she said. “More than 90 per cent of people want to live in their homes and receive care in their homes as they age. But there has been very little attention paid to the home-care system by successive governments.”

Which is what led Sharon to add one more activity to her already-packed life: advocacy, including helping to inform and support the OMA’s recommendations.

“I want to help as many people as I can by raising awareness,” she said. “I’m more connected because Adam is so profoundly disabled, and I want to do this because it’s important. If anything I say resonates, it’s because it’s the truth.”

“It was getting harder and harder to find qualified people...there’s really no one out there. It was getting bad before the pandemic started, and then the pandemic just killed it.”

Sharon Liff

he loves his father. They watch *Seinfeld* together during feeds. They are great buddies. And when I’m with him, I’m over-the-top silly because it makes him laugh.”

When he was two years old, genetic testing led to a definitive diagnosis of Pelizaeus-Merzbacher Disease. He