

Partnering with People: making lived experience key to innovation strategy

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 @HINSouthLondon

 healthinnovationnetwork.com

Today we'll discuss:



Understanding the **benefits of involving people** with lived experience within health and care systems, including at strategic levels.



Learning about an **innovative approach** of employing Lived Experience Partners in the NHS.



Exploring **practicalities**, such as inclusive recruitment, to support applicants from **diverse communities**, and how to **support individuals to influence change**.

Welcome to our fireside chat

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Health Innovation Network South London

We are the **innovation** arm of the **NHS**.

For **over 10 years** we have helped change services and health outcomes for the better through:

- **Piloting**
- **Evaluating**
- **Supporting** the spread of the most promising health and care innovations.



How the HIN works



**Improving
outcomes**



**Driving down
costs**



**Stimulating
economic growth**

Our mission

*Speeding up the
best in health and
care, together*

Involvement at the HIN

At the HIN, we believe that, by **sharing their insights** and **knowledge**, people with lived experience can help us to **improve and innovate** health and social care.

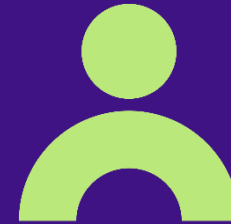


Always improving:

The HIN has a history of **involvement and co-design** activity which we wanted to **build on and embed.**

In 2022, the HIN co-developed an **Involvement Strategy** and **action plan.**

HIN Involvement Strategy and action plan co-developed with **over 65 people:**



HIN colleagues



People with lived experience



Other partners and stakeholders

Lived Experience Partners

A key action within the action plan was to:

“recruit **Lived Experience Partners who are connected to the local community**, to work across the organisation to **support culture change** needed to make the **strategy a reality**.”

In February 2023, Faith and Aurora joined us.



Lived Experience Partner role includes:

- Championing involvement work
- Connecting
- Listening
- Project delivery
- Providing advice
- Reviewing communication
- Signposting
- Supporting and facilitating workshops
- Supporting inclusion
- Supporting others
- Supporting recruitment
- Understanding impact of involvement



Our Involvement Principles

1

Ensure that involving people is embedded in all our work.

2

Embed our belief in equality, diversity and inclusion in our approach to involving people.

3

Extend the profile and influence of people's voices in the decisions we make as an organisation.

4

Build on our local connections and inspire more organisations and people to partner with us in our work.

5

Demonstrate where involving people has made a positive difference.

At the HIN, the type of involvement required will vary.

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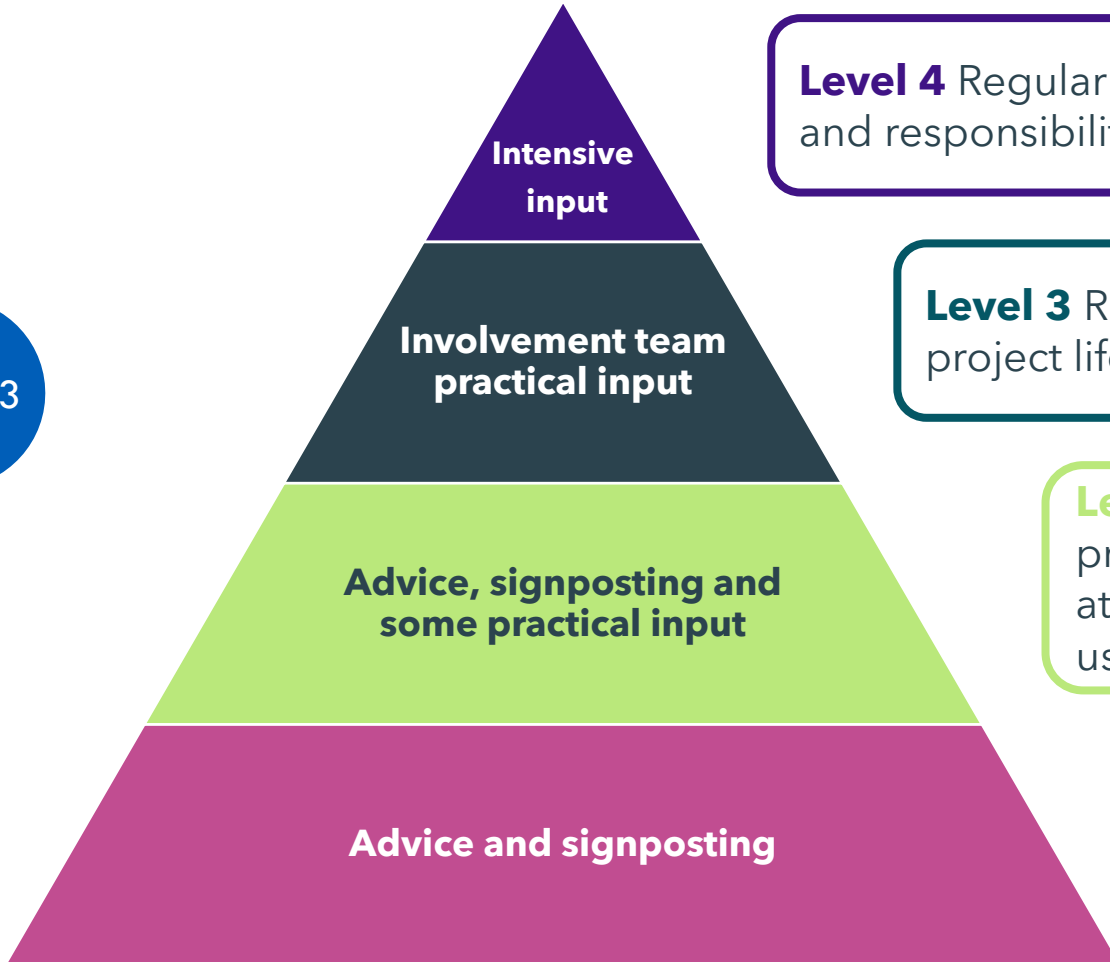
The most important thing to consider is that involvement is **meaningful.**





HIN levels of involvement support

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Level 4 Regularly attend meetings and active project delivery with similar roles and responsibilities to other team members (delivering workshops).

Level 3 Regularly attend meetings and touchpoints throughout the project lifecycle.

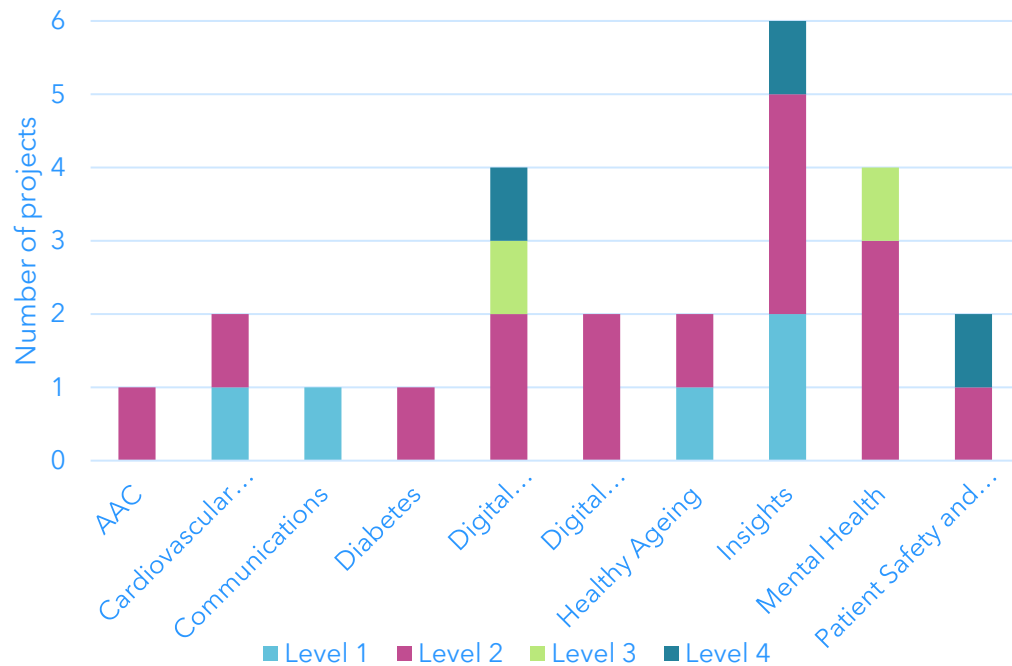
Level 2 One-off meetings and advice; review of bids and proposals; review of comprehensive patient facing materials; attending workshops or events to represent the patient/service user/public voice.

Level 1 Ad hoc requests: Involvement Champions Club; reviewing simple patient facing material; disseminating information to contacts.

HIN Lived Experience Partners: projects supported in first 8 months

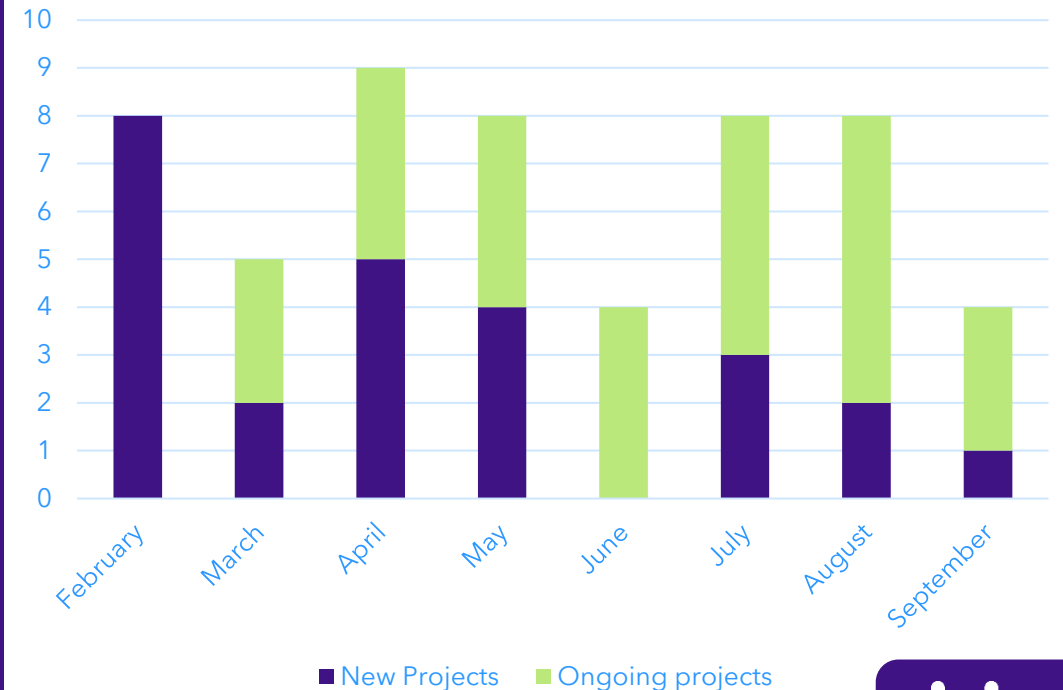
25 HIN projects supported
across all **10 HIN teams.**

Number of projects supported per HIN team split
by 'level' of involvement



Over time, the Lived Experience Partners have supported between **4 and 9 projects each month.** With the number of 'new' projects generally decreasing each month as capacity is reached.

Number of projects supported per month



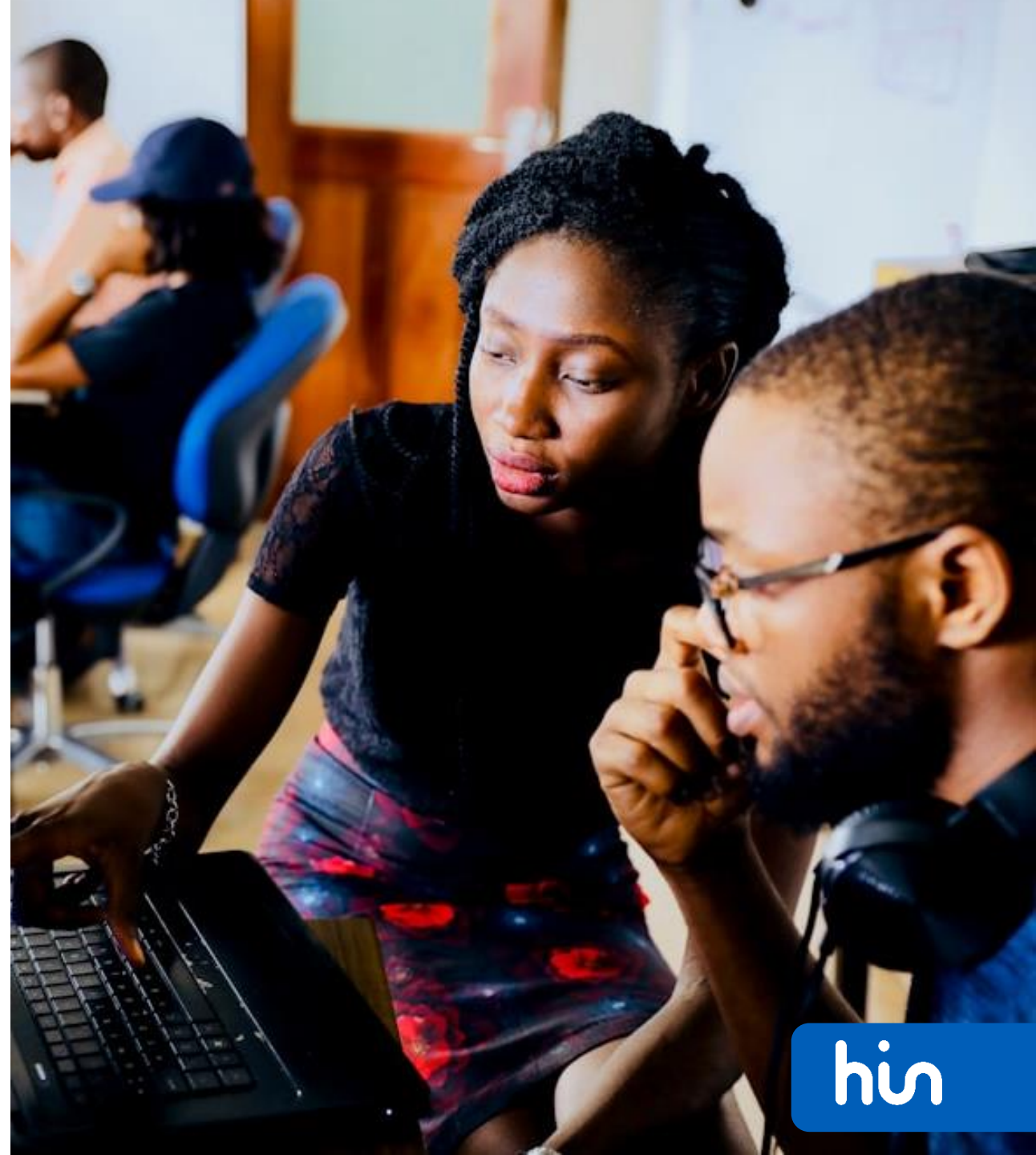


Digital Transformation and Technology - Physical Health Checks in Serious Mental Illness (SMI)

“

*Lived Experience Partner **advised** on **involvement approaches** for the project and **supported the codesign** of materials, including content for a GP staff education session to highlight the importance of physical health checks.*

”





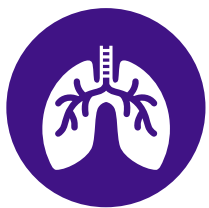
Digital Transformation and Technology - Physical Health Checks in Serious Mental Illness (SMI)

“

*Faith's **experience and knowledge** on patients with serious mental illness has ensured that we always keep the patients at the forefront of the project.*

*Faith has provided us with **insights that we as a project team would not have thought of**, she has allowed us to **continuously learn** and ensure that the project will have the **most positive impact on patients**.*

”



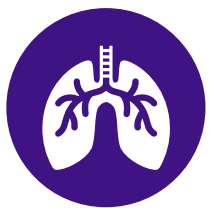
Accelerated Access Collaborative - Respiratory

Lived Experience Partner
advised on involvement plan
and supported further project
developments.

17



hin



Accelerated Access Collaborative - Respiratory

“

*Aurora was brilliant at **helping us navigate** quite a complex landscape of **considerations, tools and real-world challenges**.*

*She has been **invaluable as a sounding board for ideas**, whether it be distribution of surveys or giving us insight into the way in which primary care engages with its population.*

*The fact that HIN employs Lived Experience Partners has given us **leverage and credibility to successfully ring-fence funding for engagement activities**.*

”

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Mental Health Learning Resource Development

Lived Experience Partner contributed to two projects (one from bid stage) on the best way to involve people with lived experience as well as being a key project team member - advising on involvement approaches and connecting with key contacts.





Mental Health Learning Resource Development

“

*Faith's involvement in helping think about what is developed from **a service user's perspective** has been invaluable in **shaping what is produced**, so that it is **understood and digestible**.*

”



Chronic Pain Experience Based Co-Design

Lived Experience Partner member of steering and delivery group for project, which involved advising on involvement approach as well as co-facilitating workshops and codesign sessions.





Chronic Pain Experience Based Co-Design

“

*Working with Aurora was **invaluable**.*

*She **supported** with ensuring the supporting documentation for patients was **accessible and the language was simple and clear**.*

*Aurora was also able to **share a wealth of resources** that guaranteed we were able to **support patients effectively during the project**.*

”



Diabetes Book & Learn

Lived Experience Partner attended diabetes book and learn website refresh workshop to provide an alternative perspective.

Both have also contributed to reviewing the redesigned website for usability.





Diabetes Book & Learn

“

*It was **really valuable** having Faith attend a service pathway mapping meeting as she was able to **view and critically appraise the process from a user viewpoint**, in a meeting structure that required an **existing level of knowledge and experience** of providing input, that is made possible by a role like this.*

”

Lived Experience Partners: reflections on the role

“

*Our **personal and professional networks helped the HIN to broader connections**, from supporting the meaningful involvement of people with relevant lived experience to link with key decision makers at strategic level.*

*Our ability to advise on involvement approaches creates **a culture of partnership** with new and existing external and internal stakeholders.*

”



Lived Experience Partners: reflections on the HIN

“

HIN staff are generally **enthusiastic about involvement and understand the importance of it**, demonstrating the culture change as one of the results of our employment.

Within the HIN, there is still some occasional uncertainty / hesitancy about who should lead on involvement / outreach.

”



Lived Experience Partners: reflections on the role

“

Sometimes we need to clearly explain that we are not here to share our personal experiences of health and care, unless this is appropriate and we wish to.

*We are having to explore **new ways to demonstrate impact**, as the direct impact of the role is not always tangible or quantifiable and fits in KPIs.*

”



Lived Experience Partners: reflections on the HIN

“

It's not always easy to come across in the correct way while working with partner organisations who don't have a similar approach to involvement as the HIN.

*There are a lot of projects going on at the HIN. It is **not possible to have a constant oversight of / input into everything** as we are not always fully embedded within project teams.*

”



Lived Experience Partners: reflections on the role

“

We have had the opportunity to be exposed to a number of projects / teams (and therefore an overall view of what projects are going on at the HIN).

*It has been possible for us to **transfer professional background knowledge and learning from our other roles,** and vice versa (from advising on involvement activities at all project stages, including the associated project plans and budgets).*

”





Top Tips

Pay people fairly

Go to people

Understand what
you mean by
partner

Take risks

Focus on the
experience

CELEBRATE

focus on the
detail

seek to
understand your
communities

Some additional background on the HIN and to subscribe to our newsletter:



<https://healthinnovationnetwork.com/report/hin-involvement-strategy/>



Our vision

We want a future where health and care innovation spreads fast. We're building it by connecting people with great ideas, inspiring people to think differently and giving them practical support to do something new.

hin



Ensuring south London benefits from national innovation priorities which address health inequalities.



Supporting innovators and the health and care workforce to achieve faster adoption of innovations and drive economic growth.



Evaluating the effectiveness of innovations in real-world settings and generating evidence to identify which innovations should be adopted in health and care.



Building an organisation that is sustainable, resilient, diverse and joyful.



Delivering health and care change programmes with a focus on long-term conditions and mental health.

The south London innovation ecosystem

Universities / Academic Research:



ARCs/evaluation partners:



Health innovation networks:



Entrepreneurial ecosystem (examples)



Incubators / Start-up Programmes



HIN Values and Involvement Values

Brave

We encourage and support our colleagues to be open and willing to change as a result of involving people.

Kind

We care about our communities and want people to have a positive experience when they work with us.

Together

Our core belief is that we can close the health inequalities gap by including diverse communities in the design and development of innovations.

Different

We find strength in our differences and are committed to involving people with a multitude of perspectives so that we can identify areas to improve and try new things.

Open

We're open about what we do, and we continuously share what we learn with those who have been involved and helped us to make a difference.

Some additional background on the HIN and to subscribe to our newsletter:



<https://healthinnovationnetwork.com/report/hin-involvement-strategy/>

OurCare

A Standard for the Future of Primary Care

Tara Kiran

Fidani Chair in Improvement and Innovation, University of Toronto
Scientist, MAP Centre for Urban Health Solutions
Family Physician, St. Michael's Hospital Academic Family Health Team

International Forum on Quality & Safety in Healthcare
April 11, 2024

With funding from:



Max Bell Foundation



Health Canada Santé Canada

In partnership with:

MASSLBP



ST. MICHAEL'S
UNITY HEALTH TORONTO



Family & Community Medicine
UNIVERSITY OF TORONTO

Primary Care Needs OurCare

Introducing
the OurCare
Standard

The final report of the largest
pan-Canadian conversation
about the future of primary care



Presenter Disclosure

Presenter: Dr. Tara Kiran

Relationships with financial sponsors:

- **Grants/Research Support:** Canadian Institute for Health Research, Ministry of Health and Long-Term Care, St. Michael's Hospital Foundation, St. Michael's Hospital Medical Services Association, Women's College Hospital Academic and Medical Services Group Innovation Fund, University of Toronto, Health Quality Ontario, Ontario Ministry of Health, Gilead Sciences Inc., Staples Canada, Max Bell Foundation, Health Canada, St. Michael's Hospital, University of Toronto, Health Quality Ontario
- **Speakers Bureau/Honoraria:** Ontario College of Family Physicians (OCFP), Ontario Medical Association (OMA), Doctors of BC, Nova Scotia Health Authority, Osgoode Hall Law School, Centre for Quality Improvement and Patient Safety, Vancouver Physician Staff Association, University of Ottawa, Ontario Health, Canadian Medical Association, McMaster University, Queen's University, North American Primary Care Research Group
- **Consulting:** Ontario Health

One national survey, 9000+ responses

OurCare

Survey Data Explorer

OurCare is a pan-Canadian project to gather input from the public on how to rethink the future of primary care—the type of care usually delivered by family doctors and nurse practitioners (NPs). The survey was online from September 20th to October 25th, 2022. Over 9000 people in Canada completed the full survey, sharing their perspectives and experience. You can view the data below.

[Click here to learn about how to use this tool](#)

All Questions

Those with a family doctor or NP

Those without a family doctor or NP

Those looking for a family doctor or NP

What is important when it comes to primary care

In-person and virtual walk-in clinics

Virtual care and team-based care

Access to medical information

Reimagining the future

Who responded (Weighted Data)

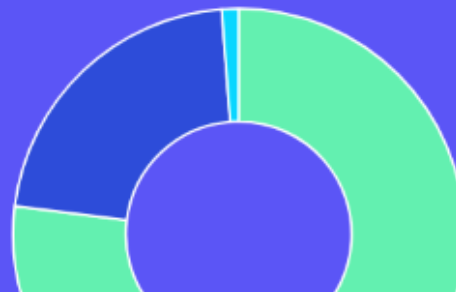
Who responded (Unweighted Data)

Select a question:

1 - Do you currently have a family doctor or nurse practitioner that you can talk to when you need care or advice about y... | v

Do you currently have a family doctor or nurse practitioner that you can talk to when you need care or advice about your health? N= 9279

Yes No Don't know



data.ourcare.ca

OurCare

The OurCare study surveyed a diverse group of more than 9,000 people across Canada (Sept–Oct 2022) about their care experiences and what's important to them when it comes to family doctor care. Learn more at [OurCare.ca](https://ourcare.ca).

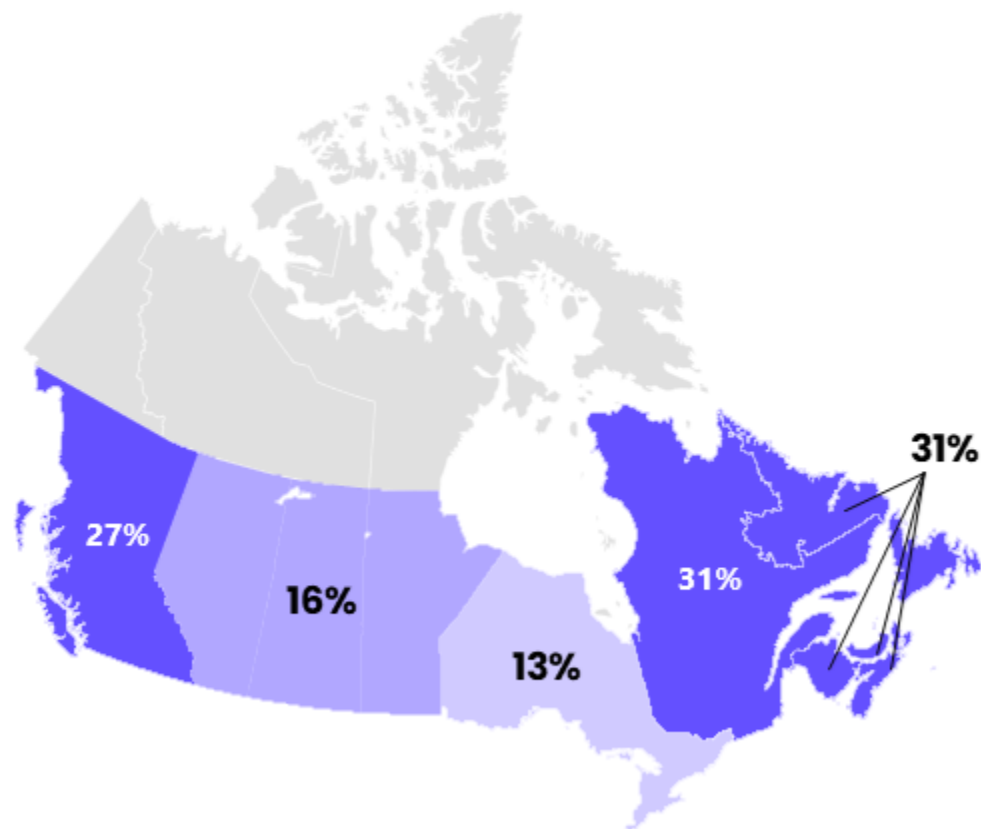
NEW NATIONAL DATA:

More than **6.5 million adults** in Canada don't have a regular family doctor or NP – that's more than **1 in 5 adults**.



22% of people in Canada age 18+ do not have a family doctor or nurse practitioner (NP) who they see regularly for care.

» **More people in Québec, British Columbia, and the Atlantic region reported not having a family doctor compared with people in Ontario and the prairie region.**



Explore the data yourself: data.ourcare.ca

Five Provincial Priorities Panels, 150+ participants





OurCare | Nos Soins

Welcome
Bienvenue

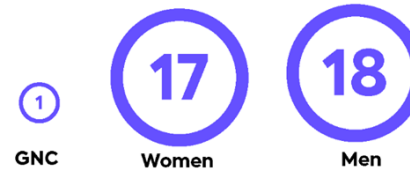


Ontario Priorities Panel

35 Ontario residents

- Randomly selected from a pool of +1,250 volunteers
- Extra representation to equity-deserving groups: ethnicity, income, time in Canada

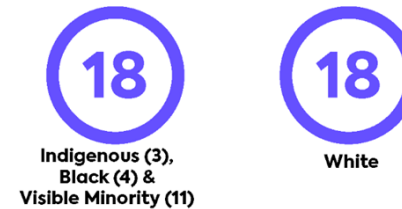
Gender



Age



Ethnicity



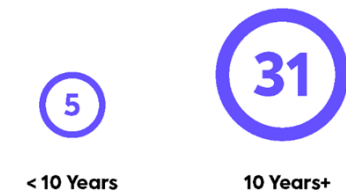
Geography



Income



Time in Canada



Primary Care Attachment



Health



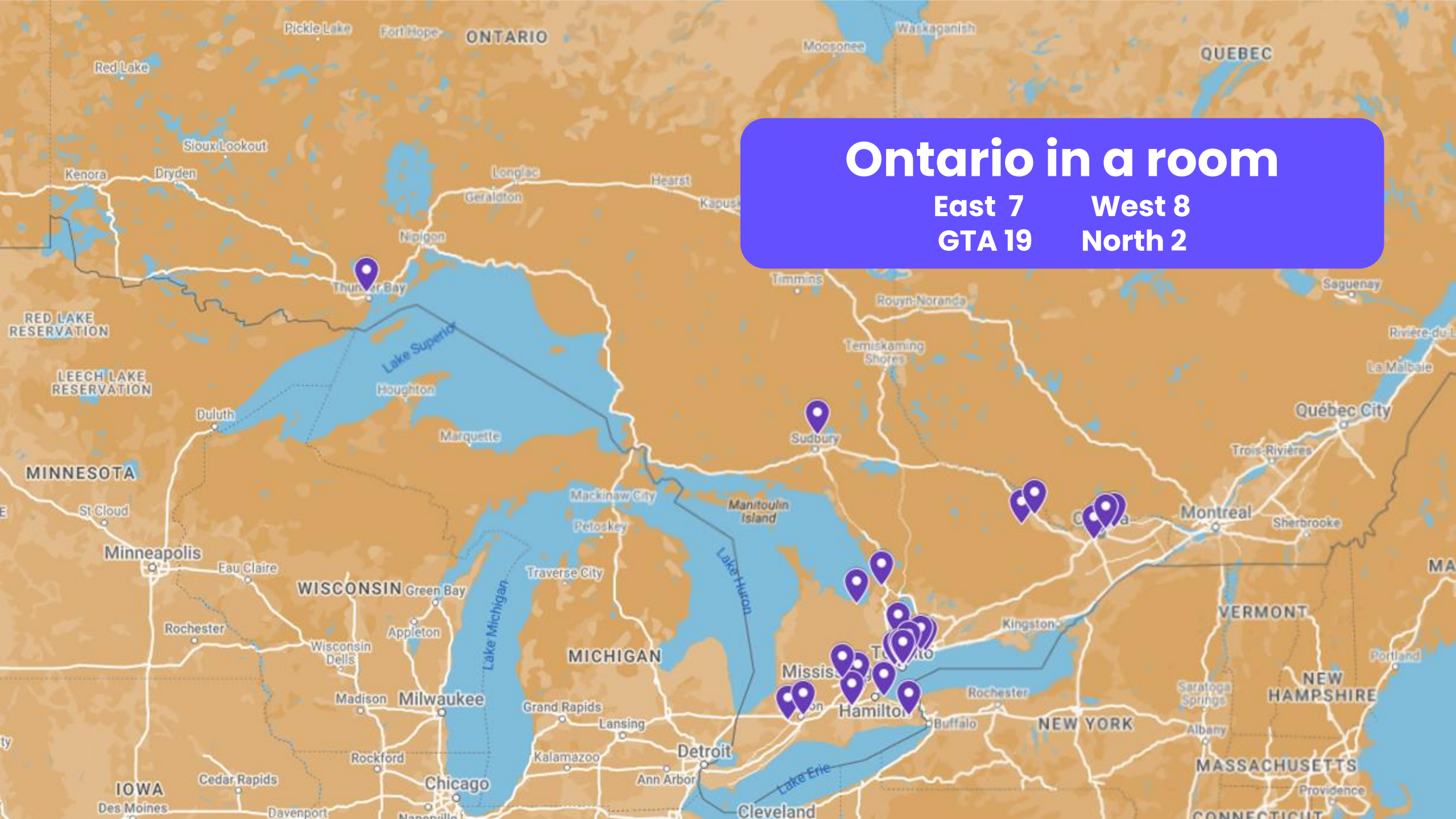
Ontario in a room

East 7

West 8

GTA 19

North 2





SIMON FRASER
UNIVERSITY
SAMUEL & FRANCES BELZBERG ATRIUM



OurCare | NosSoins

Welcome
Bienvenue



CANADIAN

NATIONAL





MANITOBA OPERA →

OurCare | Nos Soins
Welcome
Bienvenue



PROTECT
YOUR
TODAY'S
TOMORROW'S

Ten Community Roundtables, 190+ participants

British Columbia

People with Disabilities



Manitoba

Indigenous Youth



Michael Redhead Champagne

Ontario

African, Caribbean & Black Community



Quebec

Newcomers & Low-Income



Nova Scotia

Refugee Claimants



Newcomers



Newcomers



First Nations, Inuit & Métis



Well Living House

Racialized & Newcomer 2SLGBTQIA+



Black Nova Scotians [of African Descent]





We share a vision for primary care in Canada.

Learn more and join the movement. [Visit OurCare.ca](https://www.ourcare.ca)



Family & Community Medicine
UNIVERSITY OF TORONTO



OurCare



MASSLP

One thing is very clear: everyone cares about primary care

Everyone we heard from agreed that primary care should be inclusive, comprehensive, and accessible to all.

We distilled hundreds of their recommendations to create the OurCare Standard: a new way to assess primary care performance across Canada.

Read the final report at [OurCare.ca](https://ourcare.ca)



Common Values

British Columbia

- Accessible
- Prevention Focused
- Accountable
- Equitable
- Person-Centred
- Sustainable
- Universal

Manitoba

- Accessible
- Holistic
- Accountable
- Considerate Care
- Sustainable
- Understandable
- Connected
- Available

Ontario

- Accessibility
- Holistic, Intersectional, & Culturally Responsive
- Accountability
- Transparency
- Equity
- Patient-Centred
- Sustainability
- Data-Enabled
- Public & Universal
- Continuity
- Evidence-based

Quebec

- Accessibility
- Preventative and Holistic Approach
- Respect
- Equity
- Empowerment
- Effectiveness

Nova Scotia

- Accessible
- Wellness-Promoting
- Accountable
- Empathetic
- People-Centred
- Knowledge Empowering
- Affordable

Introducing the OurCare Standard

1. Everyone has a relationship with a primary care clinician who works with other health professionals in a publicly funded team.

2. Everyone receives ongoing care from their primary care team and can access them in a timely way.

4. Everyone can access their health record online and share it with their clinicians.

3. Everyone's primary care team is connected to community and social services that together support their physical, mental and social well-being.

5. Everyone receives culturally safe care that meets their needs from clinicians that represent the diversity of the communities they serve.

6. Everyone receives care from a primary care system that is accountable to the communities it serves.



How can we use the OurCare Standard to move forward a patient and public-centred vision of primary care?

OurCare Partners

National Collaborating Organizations

Black Physicians of Canada
Canadian Institute for Health Research
Canadian Medical Association
College of Family Physicians of Canada
Health Canada
Healthcare Excellence Canada
Indigenous Physicians Association of Canada

National Primary Care Leaders

Canadian Association for Health Services & Policy
Research
Dalhousie University
University of Alberta
University of British Columbia
University of Saskatchewan

Ontario Advisory Group

Alliance for Healthier Communities
Association for Family Health Teams of Ontario
Black Physicians Association of Ontario
Canadian Institutes of Health Research
Carea Community Health Centre
College of Family Physicians of Canada
Health Commons Solutions Lab, Sinai Health System
Indigenous Physicians Association of Canada
Indigenous Primary Health Care Council
Department of Family Medicine, McMaster University
Department of Family Medicine, University of Ottawa
Department of Family Medicine, Queen's University
Dalla Lana School of Public Health, University of Toronto
Department of Family and Community Medicine, University of Toronto
Northern Ontario School of Medicine
Nurse Practitioners' Association of Ontario
Ontario College of Family Physicians
Ontario Health
Ontario Medical Association
Ontario Ministry of Health
Restore Medical Clinics
Upstream Lab
Women's College Hospital

OurCare Partners (Cont'd)

Quebec Advisory Group

Association québécoise des
medecins du sport et de l'exercice
(AQMSE)
Cree Board of Health and Social
Services of James Bay
Collège Québécois de Médecins de
Famille
Commissaire à la santé et au bien-
être (CSBE)
Département régional de médecine
générale (DRMG) Montréal
Direction de santé publique de
l'Estrie
Fédération des médecins
omnipraticiens du Québec
McGill University
Ministère de la Santé et des Services
sociaux (MSSS)
Ordre des infirmières et infirmiers du
Québec (OIIQ)
Ordre des pharmaciens du Québec
Universite de Montreal
Université Laval
Université de Sherbrooke

British Columbia Advisory Group

BC Association of Community Health
Centres
BC College of Family Physicians
BC Family Doctors
BC Patient Safety & Quality Council
Canadian Medical Association
Centre for Health Services and Policy
Research
Doctors of BC
First Nations Health Authority
Interior Health
Island Health
North Shore Division of Family Practice
Nurses and Nurse Practitioners of
British Columbia (NNPBC)
Providence Health Care
Rural Coordination Centre of BC
Simon Fraser University
University of British Columbia
BC Ministry of Health
Family Practice Services Committee
(FPSC)
Fraser Health
Vancouver Division of Family Practice

Nova Scotia Advisory Group

Dalhousie Medical School,
Dalhousie University
Department of Health and
Wellness, Government of Nova
Scotia
Department of Family Medicine,
Dalhousie University
Doctors Nova Scotia
IWK Department of Family
Medicine
Mi'kmaw Native Friendship Centre
Nova Scotia Health Authority
Nova Scotia College of Family
Physicians
Pharmacy Association of Nova
Scotia
Nurse Practitioner Association of
Nova Scotia
Primary Health Care and Chronic
Disease Management Network,
Nova Scotia Health Authority
Tajikemik

Manitoba Advisory Group

Department of Family Medicine,
University of Manitoba
Doctors Manitoba
First Nations Social Secretariate of
Manitoba
Interlake-Eastern Health Authority
Manitoba Association of Senior
Communities
Manitoba College of Family
Physicians (MCFP)
Manitoba Health
Northern Health Authority
Nurse Practitioner Association of
Manitoba
Patient Network
Prairie Mountain Health
Province of Manitoba
Office of community Engagement,
University of Manitoba
Ongomiizwin Institute of Health and
Healing, University of Manitoba
Shared Health
Winnipeg Regional Health Authority
(WRH)

Policy-maker Engagement

National:

- Minister of Health's Office
- Health Canada
- Canadian Medical Association (CMA)
- College of Family Physicians of Canada (CFPC)

Ontario

- Minister of Health's Office
- Ministry of Health
- Ontario Health

Quebec

- Ministry of Health and Social Services

Nova scotia

- Minister of Health's Office
- Department of Health
- Nova Scotia Health Authority

Manitoba

- Minister of Health, Seniors & Long-Term Care's Office
- Department of Health, Seniors and Long-Term Care

British Columbia

- Ministry of Health

Potential Actions

- Design for 100% attachment
- Invest more in primary care
- Scale up community-governed teams
- Legislate interoperability
- Address equity issues

Panel

les





A major survey of what Canadians expect from their healthcare system

Feb. 28, 2024



Massive new survey finds widespread frustration with access to primary health care

Feb. 27, 2024



Reorganizing primary care could alleviate family doctor crisis

Jun. 24, 2023



What is and isn't working to fix the family doctor shortage?

Apr. 27, 2023



National survey highlights worsening primary care access

Apr. 24, 2023



Toronto residents increasingly don't have a family doctor. Here's why

Apr. 6, 2023



We need bold reform to fix family health care

Feb. 07, 2023



OurCare survey highlights lack of access to primary care

Jan. 24, 2023

TORONTO STAR

What do Canadians want for their health care?

Mar. 1, 2024

TORONTO STAR

10,000 Canadians were asked how to improve health care. Here's what they said

Feb. 27, 2024

bnp

Revolutionizing Canada's Primary Care: Expanding Teams, E-Records, and Fast-Tracking Foreign Docs

Feb. 27, 2024

CBC

Massive new survey finds widespread frustration with access to primary health care

Feb. 27, 2024

THE GLOBE AND MAIL

Primary-care teams, access to health records key fixes for family doctor crisis: report

Feb. 26, 2024

bnp

Voices for Change: The OurCare Project Unveils a New Vision for Canada's Primary Care

Feb. 26, 2024

CBC

Indigenous youth want more Indigenous-led models, support to access health care in Winnipeg, report says

Feb. 26, 2024

OTTAWA CITIZEN

System redesign, not incremental improvement, needed to erase family doctor shortage, report author says

Feb. 26, 2024



How does **your care** compare to the OurCare Standard?

Make a house call on behalf of primary care

Contact your representatives to help us make the OurCare Standard the standard of care across Canada.

Your letter will be sent to your Member of Parliament (MP) and your provincial or territorial representative (MLA, MPP, MNA, or MHA). Links to the OurCare Standard and Final Report will be automatically included.

Enter your full name and postal code to edit your message.

FIRST NAME *

LAST NAME *

EMAIL ADDRESS *

POSTAL CODE (ALL CAPS NO SPACE)*

TO:

Primary care needs OurCare

I just read the OurCare Standard and felt inspired to share it with you.

It's a fresh approach to assess and improve the delivery of primary care services. Each of the OurCare Standard's six elements was distilled from hundreds of public recommendations. Everyday people from across Canada weighed in with their experiences, ideas, and aspirations over 16 months through a national survey, panel discussions, and community roundtables.

It is a clear vision for what equitable, accessible, and sustainable primary care should encompass, as articulated by the very people it serves.

Disclaimer: Your name, email, and postal code are only used to generate your message and are not stored or shared.

SEND LETTER

OurCare



“Together we feel that the current primary health care system honours the system more than it honours and cares for the people it should serve. We truly hope this report is the vehicle through which our voices and ideas for improvement are heard, and meaningfully acted upon by decision-makers. This panel has modelled the respect, compassion, active listening, and relationship-building that needs to be reflected in the primary care system.”

[Read the Manitoba Panel Report at OurCare.ca](https://www.ourcare.ca)

Thank you!

Email: tara.kiran@utoronto.ca

Read the reports: [OurCare.ca/reports](https://ourcare.ca/reports)

Explore results from the National Survey: [Data.ourcare.ca](https://data.ourcare.ca)

Learn more: [OurCare.ca](https://ourcare.ca)

