RESEARCH

Am I attached? A patient-partnered approach to creating infographics about attachment to primary care in Ontario, Canada

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Abstract

Background Having a primary care provider is associated with better care experiences and lower care costs. In 2021, INSPIRE-PHC released Primary Care Data Reports - publicly available summaries of administrative billing data about how populations in each of Ontario's 60 health teams use primary care services. Given the characterization of Canadian primary care systems as 'in crisis', publicly available data about primary care at the regional level presented a significant opportunity for knowledge mobilization. An understandable resource could ground the public conversation about primary care access in data. Recognizing the role that lived experience plays in ensuring the public understands research findings, a partnership between patient advisors, Ontario Health Team representatives, researchers, and trainees was established to co-produce public-facing infographics based on primary care data.

Methods Evidence-based guidelines for public health infographic creation and elements of transformative action research guided a six-meeting process to engage up to 14 patient advisors, three Ontario Health Team staff and two primary care trainees. Patient advisors were affiliated with a provincial patient-oriented primary health care research group or a Hamilton-based Ontario Health Team. Ninety-minute meetings were conducted virtually, and notes were shared with attendees to ensure they accurately reflected the conversation. Two consultations with Ontario Health Team-affiliated primary care providers provided direction and ensured project outputs aligned with local priorities.

Results Project partners shared feedback on draft infographics, audience identification, priority elements from Primary Care Data Reports to include in the infographics, and aesthetic features (e.g., headings, colour scheme, charts). Project partners felt the most important metrics to convey to the public were those that simultaneously reinforced the benefits of primary care on individual health outcomes and health system costs.

Conclusions Patient engagement in research is becoming widespread, but co-developing knowledge products with patient and health system partners is less common. Our approach to engaging patients prevented both oversimplification and unnecessary complexity in a public-facing visual about attachment to primary care.

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Plain English summary

Primary care is the first point of contact for patients accessing the health care system. Primary care providers (i.e., family doctors and nurse practitioners – working individually or in teams of nurses, dieticians, pharmacists, social workers and others) – help patients and families manage health concerns over time by working to prevent, diagnose, and treat illnesses and link patients with specialist care when needed. Having a primary care provider is associated with better healthcare experiences and lower costs of care. In 2021, the Primary Care Data Reports were released to the public. The reports contain administrative data about how patients engage with primary care in each of the 58 Ontario Health Teams. Patient advisors, Ontario Health Team representatives, researchers, and trainees created an infographic to share this data in a way that can be understood by everyone. Infographics use images to help people process information faster, which can make health-related topics easier to understand. By understanding the value of primary care, people can participate in conversations about how to ensure primary care is accessible to everyone. Engaging patients is becoming common in research, but collaborating with patient advisors and health system partners to create visual summaries is less common. We had six virtual meetings that were 90 min each with up to 14 patient advisors, Ontario Health Team representatives, researchers and trainees. Patient advisors helped decide who the audience would be, which information from the Primary Care Data Reports to include, and how the infographic would look. Patient advisors felt it was most important to highlight the benefits patients can get from primary care, and the impact primary care can have to reduce health system costs. We consulted with primary care clinicians to ensure the infographic reflected local priorities. Working with patient advisors and Ontario Health Team representatives helped to create an infographic about Primary Care Data Reports data that is easy to understand by the public.

Keywords Patient engagement, Patient and public involvement, Patient partner, Community-based participatory research, Primary care research, Primary health care, Health services research, Health communication, Big data

Background

Health research that engages patients as partners in research teams is an increasingly widespread practice. Partnering with people with lived expertise can bring value to health research, ensuring that research priorities, questions, and approaches are relevant and have the potential to improve patient outcomes [1]. Patient partners are motivated to become involved in health research by their desire to improve health systems; many continue their involvement when they see the impact their contributions have made [2, 3]. They are most frequently engaged during knowledge mobilization, often supporting the uptake of research findings among diverse knowledge user audiences, including practice, policy, and importantly, the public [4, 5].

As the foundation and entry point to health care in Canada, primary care can benefit from engaging patient and community partners in research. In Ontario, a province of 14 million people, primary care providers receive nearly one million visits per week, and two-thirds of all daily physician visits are to primary care [6, 28]. This suggests that primary care may be the sector of the health system where contributions from patient partners to health services research and health system decision making stand to have the greatest impact. Previous authors have shown the impact of patient partners in creating lay resources specific to primary care. For example, Archibald and colleagues describe codesigning video resources with patients to increase understanding and reduce shame around the concept of frailty [7]. Patients have also partnered with researchers to design infographics that present patient-reported outcomes data from a community health survey back to the individuals who participated in the survey to support comprehensibility and action [8], as well as promoting healthy behaviors for community members with varying levels of health literacy via infographics [9].

Given the demonstrated impacts of patient partners on creating materials for lay audiences, and the growing consensus around the need for better integration of patient expertise in primary care research [10–14], this study aimed to partner with primary care patients/caregivers, providers, and local health system representatives to create lay-friendly visualizations of regional and provincial primary care administrative data.

What is primary care and why is it important?

The terms primary care and primary health care, while often treated as synonymous, refer to different concepts [15, 16]. Primary care is one component of primary health care and refers to first point-of-contact services provided to individuals and families to sustain and promote their health and well-being across the lifespan [15–17]. Primary care services are delivered by providers (e.g., family physicians, nurse practitioners) working together or separately, and occasionally in conjunction with teams of interdisciplinary providers [15, 16]. Primary care has been associated with better patient outcomes, lower rates of hospitalizations, and reduced Emergency Department

visits, resulting in lower healthcare costs [18–20]. People who regularly receive primary care are healthier, have longer life expectancies, and have lower mortality rates associated with heart disease, cancer, or stroke [19]. Furthermore, patients who receive primary care from a consistent provider over time are happier with their care and more likely to follow medical advice [19].

Many Canadians access primary care services like preventive care and care and management of chronic conditions [18, 19]. However, as of September 2022, over 2 million people in Ontario do not have a regular primary care provider. This number is expected to continue to rise due to population growth and reductions in the supply of primary care providers [21]. Additionally, the COVID-19 pandemic exacerbated preexisting stressors in primary care [22], increasing the demand for primary care services (e.g., increased complexity of patients post-infection, backlogs created from forgone care during the pandemic [23]) while simultaneously decreasing the supply of primary care providers (e.g., further reduction of interest in primary care as a speciality among medical graduates [24], accelerated retirements of primary care practitioners in response to administrative burdens of managing their practice during a pandemic [25], health care providers transitioning away from roles providing direct care to patients [26]). In Canada, this situation is widely acknowledged as a health human resource crisis in primary care [27, 28].

Primary care in Ontario
Ontario's healthcare system has undergone several reforms to create a high-performing system and support the health of residents [29]. In 2019 Ontario Health Teams were introduced, bringing together self-organized groups of regionally-based hospitals, primary care organizations, and community services providers as well as representatives from long-term care, mental health, and paramedicine to integrate care across sectors, improve patient experience and reduce costs, using a population-based approach [30–33]. Modelled after accountable care organizations in the United States, each Ontario Health Team aims to demonstrate eight "building blocks" that serve to improve patient and provider experiences of care, population health, and reduce costs [31, 33–35]. More recently, the Ontario Health Team implementation process has an added emphasis on equity and accessibility of care [36].

Ontario Health Teams are responsible for delivering care to a defined group of patients based on their specific needs. They require health and demographic data to understand both who their patients are and the needs of the populations they serve. Ontario Health Teams receive provincial data and support (e.g., advice on implementation) to understand their population and its' health

service use at a high level. Supplementing this high-level data with a more nuanced understanding of how the population in each Ontario Health Team engages with and utilizes primary care specifically is necessary, given that the majority of healthcare is provided in primary care [6].

Data and patient engagement in primary healthcare
INSPIRE-PHC (Innovations Strengthening Primary Health Care through Research- Primary Health Care) is a provincial research and policy partnership that produces primary care research, data support and expertise for health policy in Ontario. Their Primary Care Data Reports address gaps in freely accessible, region-specific primary care data [37]. Primary Care Data Reports are composed of Billing Data from primary care providers which contains data that can help regional health systems in Ontario better understand the people they care for including their: age, sex, income, health status (including diabetes, frailty, congestive heart failure, mental health condition), health care use (e.g., Emergency Department visits, hospitalizations), visits with primary care providers (number of visits, follow-ups after hospitalization) [38–40]. First produced for the 2018–2020 period, these reports represent a 2-year retrospective synthesis [41]. Some allow for primary care data metrics to be viewed publicly across other geographies of interest (e.g., reported by census tract and public health unit). This accessible, region-specific, publicly available data is foundational to plan health systems that advance the Quintuple Aim: better care outcomes and experiences for patients and caregivers, more resource-efficient health care systems, improved provider experience, and health equity [42–44].

The concept of attachment enhances understanding of population health by grouping populations according to whether and how they receive primary care services. Each Ontario Health Team can access a spreadsheet outlining their population profile, organized by type of attachment to primary care ('attached', 'uncertainly attached'), prepared by INSPIRE-PHC researchers. The Primary Care Data Report attachment algorithm considers patients to be attached in one of four ways (see Table 1) [38, 41].

Recognizing the importance of patient partnership in achieving the Quintuple Aim, Patient Expertise in Research Collaboration (PERC), a patient-oriented research centre within INSPIRE-PHC, was established to enable authentic partnerships with patient and public partners [45]. PERC aims to promote and support meaningful and appropriate engagement of patients in primary health care research in Ontario and beyond. PERC is funded by the Ontario Strategy for Patient-Oriented Research Support Unit, one of eleven Canadian Support Units that support Canada's Strategy for Patient Oriented

Table 1 Defining Attachment in Primary Care Data Reports [38, 41]

Attached patients	Uncertainly attached patients
1. Receive care from a family doctor	1. Only sought health care by vising the emergency department
2. Receive care from a Community Health Centre	2. Received primary care from an inconsistent source
3. Repeatedly see the same pediatrician (children)	
4. Repeatedly visit a walk-in style provider	

Research, which is led by the Canadian Institutes of Health Research [46, 47]. In alignment with this strategy, PERC engages researchers, people with lived experience, and health system representatives in active partnerships to improve health outcomes and enhance health service delivery [48]. It has an Advisory Board composed of primary care patients with personal experience living with chronic illness or life-limiting conditions, family and friend caregivers, and researchers. PERC meaningfully engages Advisory Board members as strategic partners in research across all stages of the research process and patient-oriented research capacity development activities [47, 48]. PERC Advisors are diverse in age, gender, ethnicity, and geography (from urban, rural, and suburban areas in Ontario, Canada). Throughout the paper, we use the terms 'patient advisor' and 'patient partner' interchangeably to reflect how each group (PERC and Greater Hamilton Health Network [herein, GHHN]) use different labels.

Study purpose

This project aimed to create visualizations of primary care data by partnering with primary care patients/caregivers, providers, and local health system representatives. It was funded through a provincial Applied Health Research Question granting stream designed to provide research evidence to support health system decision-making by linking provincially funded health researchers with representatives from health organizations [49]. In projects funded by this grant stream, health system representatives identify a priority topic or question that would benefit from research evidence, and how the findings will inform planning, service delivery, policies, or programs [49]. The GHHN worked with PERC's leads and Advisory Board to propose a project about patient partnership and primary care data infographic creation within this OHT to inform regional planning.

The GHHN is responsible for integrating the care of approximately 600,000 people. Its strategic plan explicitly prioritizes addressing health inequities amongst this population and emphasizes providing equitable and continuous care that actively improves population health and meets the individual needs of its community [50]. Importantly, primary care is one of their strategic plan's five core priorities, and patient/community engagement is one of its three overarching guiding principles [50]. At the time the project was initiated, the GHHN was aware of the release of Primary Care Data Reports and wanted to understand how to use these data to support the delivery of integrated primary health care to their attributed population. They were also interested in how Primary Care Data Reports could help them communicate with the public about their decision-making processes, and how working in partnership with patients to ensure these conversations were centred around the needs of patients and families.

PERC researchers partnered with the GHHN to facilitate understanding: (i) what elements of primary care data were most important to patients and the public, (ii) how patients and Ontario Health Teams can co-produce visualizations of primary care data using patient-identified priorities, (iii) how visuals can inform the work of Ontario Health Teams, and (iv) how the visuals can be shared with the public. The GHHN felt that project outputs could support communication with the public about the accessibility of primary care within their Ontario Health Team and provincially. They also wanted to contribute to a broader, national conversation about the primary care system. Presenting understandable information to the public about attachment to primary care would raise awareness about the health human resources crisis in primary care and could support initiatives to improve its accessibility in Canada.

Methods

With the GHHN as knowledge users, PERC and its Advisory Board partnered with primary care patients/caregivers, providers, Ontario Health Team representatives, and a graphic designer in virtual meetings to create lay-friendly visualizations of local/provincial primary care data [51]. This project combined aspects of participatory design with evidence-based guidance for developing public health infographics. Participatory design is a method that empowers end-users to make design decisions and includes three stages: initial exploration of work; discovery processes; and prototyping [9, 51]. Stones and Gent [59] outline seven principles of public health infographic design were used to ensure audience, color, alignment, prioritization, highlighting, imagery, and charts were considered. Our approach to engagement was best aligned with Transformative Action Research, where the researcher becomes a facilitator, taking direction from community members to plan research projects, generate questions, gather and analyze data, and return data to the community for reflection and action [52, 53]. Transformative Action Research's emphasis on doing research
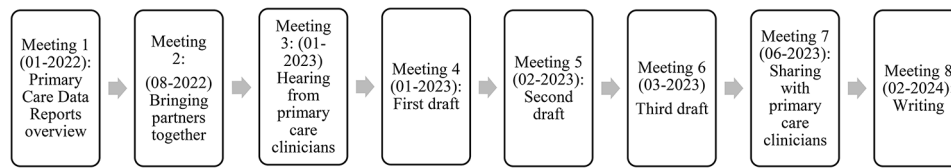
Fig. 1 Engagement Timeline. Eight text boxes appear horizontally across the page with an arrow pointing to the right between each box. Each box indicates the meeting number, the date, and the topic discussed

Table 2 Our Process: Transformative Action Research

1. Planning and Preparation	
Identify members of the team	Meeting 1: INSPIRE-PHC representatives gave overview of Primary Care Data Reports at PERC Advisory Board Meeting, discussed opportunities for knowledge translation. Patient partners noted that Primary Care Data Report information could bring public attention to the shortage of family doctors and support efforts to increase provider supply. Patient partners noted expertise needed to synthesize complex information in the Primary Care Data Report spreadsheets. Partnered with knowledge user partners (GHHN) to complete grant application. GHHN leads suggest consulting primary care clinicians (via a GHHN Advisory Group) in project scoping. Secured graphic design support.
Outline a conceptual framework using participatory principles	Laying out the research plan (e.g., refining aims and processes of project plan with PERC patient advisors, providing additional orientation to Primary Care Data Report project, understanding advisors' interest/availability for project.
Define parameters for the process	PERC research staff met individually with 5 GHHN patient partners to provide orientation, understand engagement preferences (e.g., communication, honoraria, any required support) [56]. Meeting 2 topics: similarities between GHHN and PERC engagement approaches, timelines, deliverables.
Negotiate the purpose, objectives of the project, and transformative action approach	Meeting 2 topics: each partner's connection to the topic, GHHN primary care priorities/how Primary Care Data Reports could support them
Assess enabling and inhibiting factors	Meeting 2 topics: background, context, limitations of Primary Care Data Reports, defining terms.
2. Generating questions	
Collectively identify focus of project	Meeting 3 topics: PERC researchers present/discuss project, aims, sharing preliminary findings (GHHN/Ontario comparison) with primary care clinicians from GHHN Advisory Group. Meeting 4 topic: discuss audience(s) for visuals and how to frame messages for audience(s).
3. Data gathering, and analysis	
Provide feedback on the quality of data gathered Analyze data collectively	Meeting 4 topics: discuss first draft of visual (comparing GHHN and Ontario attachment data) Meeting 5 topics: discuss second draft of visual (GHHN/Ontario comparison with additional background information/definitions) Meeting 6 topics: discuss third draft of visual (1 background infographic, 1 to share Primary Care Data Reports results)
4. Returning data to community, reflection, and action	
Return data to communities for: interpretation, reflection, dissemination, and decision making	Meeting 5, 6 topics: determine aesthetics and design features, co-create key messages, and dissemination strategies Meeting 7 topics: future of publicly available primary care attachment data, limitations of working with administrative data (e.g., can quickly become out of date) Meeting 8 topics: developing plan for co-authored peer-reviewed manuscript

with (as opposed to for) community members aligned well with PERC's and the GHHN's approaches to engaging patient partners [54].

A series of meetings with patient/caregiver advisors, Ontario Health Team representatives, trainees and researchers were held to provide orientation to Primary Care Data Reports, share early findings about primary care locally and provincially, facilitate small-group infographic design discussions, and iteratively refine prototypes (Fig. 1). These meetings were informed by a co-developed engagement and dissemination strategy with patient partners that specified how (i) this project was prepared for and focused, (ii) data was collected and

analyzed, and (iii) results (including this manuscript) were constructed and disseminated (Table 2).

Meeting agendas with specific discussion questions were shared a few days before meetings. Summary notes were recorded by a PERC project coordinator and shared with project partners after sessions to ensure an accurate reflection of the conversation. Those unable to attend a meeting were encouraged to share feedback on draft infographics for incorporation into meeting notes. Between meetings, PERC researchers analyzed these notes to identify aspects of the visuals to revise and communicate them to a graphic designer, who had experience iteratively incorporating feedback from patient research

partners into their designs. Analyzing meeting notes served as a form of process tracing, an evaluation method that has been used to identify the impacts of involving patients and the public in research [55, 56]. A final draft was presented to project partners by email. Project partners were invited to provide additional feedback on this draft by email or telephone with PERC researchers. Recommendations received were subsequently integrated into the infographics, which were presented for discussion with primary care clinicians.

All patient partners were provided with honorariums to acknowledge their lived expertise ($25 per hour for time spent preparing for and contributing to meeting discussions and document review) and, given their significant contributions across all stages of this project, were invited to be co-authors of the infographics and this manuscript [55]. This research project was approved by the Hamilton Integrated Research Ethics Board at McMaster University in Ontario, Canada under Project #13,199.

Results

Up to 14 patient/caregiver partners, four researchers, one GHHN staff and two primary care trainees were involved in six 90-minute meetings, conducted virtually between January 2022 and February 2024. Virtual meetings took place between 11:30am and 4:30pm. Two other GHHN staff were unavailable to attend meetings but reviewed and provided feedback on iterations of the infographics by email. All (of the nine invited) patient/caregiver partners from PERC and five (of the sixteen invited) patient/caregiver partners from the GHHN chose to be research partners on this project. On average, 9 of 14 patient/caregiver advisors attended per meeting. None of the six meetings were attended by fewer than 7 patient/caregiver partners. Two Ontario-based primary health care Graduate Student Trainees were also involved in all project activities as part of PERC's yearly Patient Engagement Training Fellowship, which supports trainees via presentation opportunities and advice from PERC Patient partners on incorporating patient perspectives into their graduate research. Figure 1 depicts how project partners came together across meetings to contribute to draft final the infographics (Figs. 2, 3, 4 and 5). Table 3 summarizes strategic input received from primary care clinicians in two additional meetings that PERC researchers attended with primary care clinicians. Table 4 describes patient/project partner feedback as it relates to principles of infographic design.

As seen in Table 4, under 'Prioritize Parts', we heard from patient/project partners about how important it would be to let readers know how valuable primary care is to patient outcomes, and how higher rates of attachment lead to better value for the system. To this end, our infographic drafts highlighted variables where the

region differed significantly (5–10% or more) from provincial-level rates of attachment. Given that 'uncertainly attached' patients who only receive care by visiting an Emergency Department, are often referred to as 'healthy non-users' [41], our analyses excluded this group (65% of 'uncertainly attached' patients). We instead focused on the 35% of 'uncertainly attached' patients who demonstrated need, but were not able to access a consistent primary care provider [41]. To emphasize the importance of attachment, metrics about income, newcomers, minorities, and housing instability were added, to demonstrate how these characteristics differed between attached and patients with need, but not access to primary care.

Clinicians felt that attachment for all patients should be the policy goal, compared to focusing on the subset of 'uncertainly attached' patients with need, but not access to primary care (Table 3). Clinicians emphasized the role that regular primary care plays in preventing disease and maintaining health, and the implication of 'healthy non-users' missing out on preventative care could lead to avoidable decline and disease. Clinicians felt that co-developing the infographic with patients would bring attention to attachment issues and by focusing on health equity in choosing the variables highlighted in the infographics, raise awareness about the disproportionately higher rates of uncertain attachment among people who are racialized or living with low incomes.

Patient and project partners gave us the most substantive feedback on the audience for the infographics, (see 'Get to know your Audience' in Table 4). The early drafts of the infographics were found to be too brief by patient and project partners, who suggested defining terms (e.g., uncertain attachment, morbidity, chronic conditions, and primary care provider) before displaying local and provincial results from the Primary Care Data Reports. Subsequent drafts defined terms, but in a much longer document. Patient/project partners felt splitting the material into two shorter (2-page) documents might be better than one 4-page version. Many group members also stated that the text had become too complex to be easily understood by the public. A communications advisor from the university was consulted to reduce the complexity of the text to a Grade 8 Reading Level; text on previous iterations had been higher than a grade 12 level. As part of the ongoing discussions about defining terms, patient/project partners highlighted how administrative data can simplify complex experiences of care and differed from their perceptions of these terms- which were generally broader. For example, the administrative data we used captured sex (as opposed to gender), and mental health issues were only captured by care encounters where a mental health diagnosis was present.

Additional comments from project partners about the audience focused on accessibility and nuanced

Fig. 2 Infographic 1: Who is my first point of contact with the healthcare system

messaging, noting that patients without internet access could not use the website resources included in this iteration to support finding a PC provider. It was recommended that phone numbers for these resources be added. Project partners emphasized that messaging be neutral and avoid any sense of blame on individual patients for not having a PC provider.

Aligned with the transformative action research approach (see 'Returning data to community for reflection and action' in Table 2), we asked patient and project partners to reflect on the data and process. Meeting notes from the last session indicated that patient advisors saw that the aim of engagement was to ensure conversations about primary care attachment included those with

Is there a shortage of primary care doctors?

Many Canadian provinces, including Ontario, are experiencing a shortage of family doctors that is expected to increase as more retire (5,7). Changes to the supply of family physicians may impact each region in different ways (8). Good data can help each region with health workforce planning for the future, to ensure all Ontarians can access a family doctor when they need care.

The recently released Primary Care Data Reports (PCDR) contain data that can help regional health systems in Ontario better understand the people they care for, including their:

age, sex, income

health status (including diabetes, frailty, congestive heart failure, mental health condition)

health care use (emergency department visits, hospitalizations)

visits with the family doctor (number of visits, follow ups after hospitalization)

How can someone without a doctor get health care?

In Ontario, anyone can get health care advice from a registered nurse by dialing 811. This is a free, confidential service which is staffed 24 hours a day. It is designed for non-urgent health issues. Health811 operates a similar service which can be accessed online anonymously by live chat. People without a primary care provider can register online or by phone (1-800-445-1822) for the Health Care Connect program to be connected to a primary care provider accepting new patients in their area.

To learn more and see our references, please visit: https://perc-phc.mcmaster.ca/

Fig. 3 Infographic 1: Who is my first point of contact with the healthcare system

lived experience, in addition to expertise from policy, research and practice. The advisors felt that the engagement approach was inclusive, which was exemplified by the partners feeling comfortable enough to share their personal experiences of attachment during the discussions. Patient advisors emphasized the value associated with having been involved early in the process and throughout the project. They felt that their lived experiences as patients and caregivers 'brought life to the stats', enhanced the final product, and helped to 'put the word out' about a resource that they hoped will be helpful to others.

The group described the engagement process as iterative, where their suggestions were heard and integrated

People with family doctors in the Greater Hamilton Health Network and Ontario

Differences between most and least attached patients

Primary Care Data Reports (PCDR) consider a patient 'attached' if they received most of their care from a family doctor or nurse practitioner.

In both Greater Hamilton Health Network (GHHN) and Ontario:

- Attached patients are slightly younger, more likely to be female with lower rates of mental health illness than those receiving Primary Health Care with no consistent provider.

- Those receiving Primary Health Care with no consistent provider are more likely to live with: low incomes, housing instability and a mental health diagnosis than attached patients. People in this group are more likely to be a visible minority or new to Ontario than attached patients.

	Greater Hamilton Health Network		Ontario	
	Attached to primary care provider	Inconsistent primary care provider	Attached to primary care provider	Inconsistent primary care provider
Number	565,480 people	25,433 people	12,854,553 people	631,553 people
Average age	41 years old	45 years old	41 years old	45 years old
Sex	49% male	53% male	48% male	53% male
Low income[a]	21%	27%	19%	26%
New to Ontario[b]	6%	14%	8%	18%
Visible minority[c]	13%	20%	29%	33%
Housing instability[d]	18%	27%	21%	30%
Mental health diagnosis	20%	27%	20%	26%

a   percent of population among the lowest provincial income quintile
b   percent of population registering a new provincial health card
c   percent of population living in areas with highest rates of recent immigrants and visible minorities
d   percent of population living with the highest rates of residential instability (measure of family/dwelling characteristics, neighborhood quality and cohesiveness
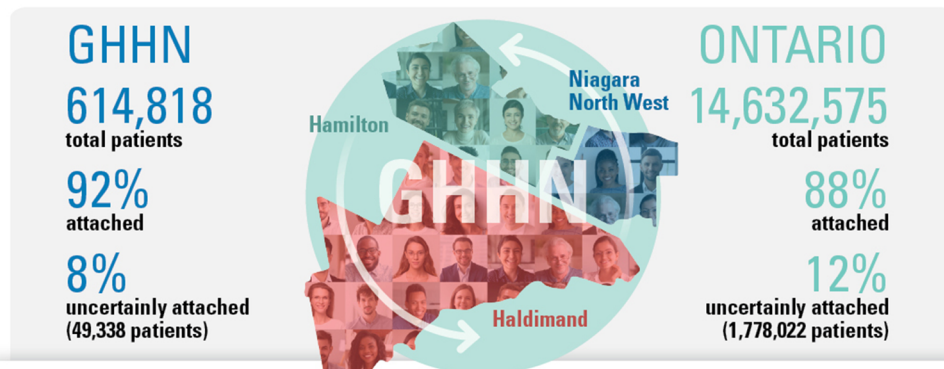
Fig. 4 Infographic 2: People with family doctors in the Greater Hamilton Health Network and Ontario

into subsequent infographic drafts. One advisor noted that the project was successful because people were asked "How can we make things better" and their suggestions were heard and implemented. Another identified how the team approach to engagement led to interesting results. When asked how their contributions impacted the infographics, advisors said their emphasis on equity and diversity, along with their suggestions about simplifying language and adding definitions made the infographics more inclusive, so that anyone would be able to understand the final product. They felt that a project to share primary care data with the public 'should not be done in a vacuum' and that including patient partners helped researchers better understand how attachment

Fig. 5 Infographic 2: People with family doctors in the Greater Hamilton Health Network and Ontario

to a primary care provider (or lack thereof) impacted the health and well-being of patients. The partners reviewed and approved the final versions of the infographics and supported their dissemination. Partners also provided valuable suggestions regarding earlier drafts of this manuscript, recommending more context in the background section, and the inclusion of quotes to describe their comments during Meeting 8.

At the end of the study, project partners also described how their involvement with this project impacted them. A partner working in the health system said the project offered valuable learning about how to communicate with the public about primary care. A patient advisor

Table 3 Feedback received from clinicians and decisionmakers

Clinician & decision-maker perspectives

• Emphasized that good quality primary care data to guide local decision-making is valued and welcomed.

• Expressed interest in support to better understand Primary Care Data Reports data. Having PERC's support to examine the data in greater detail was a value-add to the project.

• Advised against losing sight of the goal of 'Attachment for all' by focusing too narrowly on those with primary care needs but not access.

• Discussed the consideration of using Primary Care Data Reports as a public-facing measure of attachment and expressed caution that primary care access may worsen before it improves.

• Identified the role that Primary Care Data Reports could play in guiding public-facing, educational and/or awareness-raising campaigns about primary care locally and generating public interest in advocacy.

• Acknowledged the value of patient advisor perspectives on attachment issues (e.g., people who are racialized or those living with low incomes disproportionately experience uncertain attachment, even exclusion from the primary health care system).

Table 4 Feedback received from patient, project partners

Principles of Infographic Design (G.R.A.P.H.I.C. [49])

G - Get to know your Audience

• Acknowledge and be open about data limitations in Primary Care Data Reports (e.g., health equity data).

• Define words/concepts (e.g., attachment, continuity), reduce technical words, and aim for a grade 8 reading level.

• Use consistent language (e.g., "inconsistent primary care provider" vs. "uncertainly attached").

• Use "mental health issues", instead of "illness".

• Consider where the infographic will be shared when creating it.

• Create an accessible, engaging, and educational infographic for the public.

• Raise awareness and encourage engagement among the public.

• Prioritize the needs/interests of the public when choosing which data to include. Use bullet points, not full sentences.

• Create two shorter documents (vs. one long document) to make the content more digestible.

• Clarify that primary care providers can be team-based and use broader language when referring to them (e.g., use "healthcare providers" vs. "doctor").

• Include resources for finding primary care providers.

• Consider accessibility for people without phones or internet access.

• Consider multiple delivery formats (e.g., video, bookmarks, flyers, shorter versions of the infographics).

• Use brochure format for printed materials (e.g., paper folded in three).

• Add a QR code to link to INSPIRE-PHC and Primary Care Data Reports

R- Restrict Colour

• Keep the GHHN colour scheme, as it is welcoming, and non-abrasive.

• Ensure the content "pops" when printed in grayscale.

A- Align Elements

• Increase font size/decrease margin size for accessibility.

• Create white space at the bottom of the page.

P- Prioritize Parts

• Prioritize definitions and background over visuals comparing attachment rates.

• Highlight the benefits, risks, and importance of primary care/attachment, without implying blame on those without PC providers.

• Frame the concept of attachment as "value-added" (e.g., attached patients have lower costs).

• Highlight actions the public (including 'uncertainly attached' patients) can take.

• Condense, or move the data about attachment types to the end of the draft.

H- Highlight the Heading

• Consider using a question format for the title and subtitles to engage the audience.

• Consider changing "Understanding primary care in Ontario" to "Who is my first point of contact with the healthcare system?"

I- Invest in Imagery (wisely)

• Include visual representations of the content/definitions.

• "Humanize" the infographic with patient-provider images.

• Add a graphic to indicate the GHHN's location.

• Remove binary gender icon.

• Differentiate hyperlinks with colour or font size.

C- Choose Charts Carefully

• Add definitions for some of the variables in the chart

said the topic of attachment resonated with them, that it was valuable to engage in research that felt relevant, and validating to know that their 'experience is valid to the big picture'. Another patient advisor noted that their positive experience being engaged in this project motivated them to return to Meeting 8 (11 months later), and contribute to developing this manuscript. Several project partners (including nine patient advisors) welcomed the opportunity to contribute as co-authors on the manuscript.

Discussion

A partnership between patient advisors, regional health system representatives, researchers, and trainees was established to co-produce public-facing visualizations of primary care data. Using a transformative action research approach, we worked together to decide who would be involved, how the group would work together, and what the aims, timelines and constraints of the project would be. Over six meetings, project partners shared feedback on draft infographics, audience delineation (including how they conceived of health care and primary care), priority element identification from a primary care data resource, and advising on aesthetic features (e.g., headings, colour scheme and charts). Advice from project partners led to two 2-page infographics aimed at the public being created. The first defined relevant terms and promoted a shared understanding of the roles and impacts of primary care. The second infographic presented priority metrics (age, sex, income, new-to-Ontario, visible minority, housing instability and mental health diagnosis) from Primary Care Data Reports, comparing the population-level data for the GHHN and Ontario. The group co-designed the colour scheme, brainstormed multiple headings and emphasized the importance of imagery in the infographics.

Implications of findings

This research responds to calls in the literature for increased patient engagement in knowledge translation and research using administrative data [57, 58]. Previous authors have described the utility of using infographics and videos to increase health literacy and promote self-management for individuals [7–9]. To our knowledge, this is the first example of working with patient advisors to co-create a visual depiction of population-level data on attachment to primary care. Our process to engage patients and visualize data corresponds with a recent review outlining strategies to enhance public health data literacy for the general population, and especially equity-deserving groups, in Canada [59].

Previous authors have identified the importance of visuals in enhancing understanding of health-related topics. By reducing the mental load of interpreting information, visuals help people process complex information faster [9, 60]. However, infographics developed without input from their intended audience can contain details which distract from the main point or become so oversimplified that they either lose meaning or become detached from patients' lived experience [7, 9]. Throughout this project, patients told us both when we had too much detail, linguistic complexity, or jargon, and where more detail was needed. Each group meeting offered tangible improvements in infographic readability through our partnership with patients and health system representatives. Notably, we were not consistently complex or simplistic; at times, we missed the mark in both directions.

This project aligns with previous authors' identification of the importance of patient engagement in primary care to ensure that patients are supported in both individual-level care decisions and in system-level planning of primary care services [9, 61–63]. Patient engagement, and policy directions which are anchored in public values, needs and preferences, are structural features characteristic of a high-performing primary care system. Recent work, however, suggests that patient engagement is an undeveloped component of most Canadian primary care reforms between 2012 and 2021, and requires significant improvement [30]. How we developed public-facing infographics translating data about primary care provides an example of how to meet this call for improvement. This project also responds to calls for using primary care data to make policy decisions (as the infographic results helped the GHHN use Primary Care Data Reports to address a local need), while explicitly assisting local decision-makers (supported by Ontario Health Team-affiliated patient advisors) in public communication.

This project occurred as Ontario is moving towards operating as a Learning Health System [44]. A Learning Health System 'brings together information from practice and research and feeds it back to teams in ways that are meaningful and useable to them. This in turn leads to practice change that improves care.' [64]. A Learning Health System utilizes an iterative process and blurs the distinctions between research, care delivery, and quality improvement to accelerate the ongoing incorporation of feedback and uptake of evidence [44]. In Learning Health Systems, patient engagement is crucial to identify areas where health system change, or learning should occur [44, 65]. In Ontario, provincial supports (resources, access to expertise) exist to promote Learning Health System principles among Ontario Health Teams.

Though Learning Health System frameworks position patients and caregivers as drivers of health system change [44], patients report difficulties knowing how they fit into a Learning Health System, or what roles they can play to contribute [66]. Relatedly, a recent review of 81 articles about Learning Health System highlighted the absence of patient engagement in this literature and called for future work in this area [65]. The results of Arcia and colleagues [9], which parallel ours, indicated that their work to co-develop infographics of patient health information aligned with the original vision for Learning Health System, as articulated by the Institute of Medicine, which indicates that patients should be involved in developing data processes for their health information [63]. The results from this project confirm that patients can make important contributions to learning within

health systems in both knowledge translation (e.g., the infographics developed) and by developing new knowledge (e.g., the learnings about co-producing infographics documented herein). This project, as such, offers a tangible example of how patients can contribute to a Learning Health System. To this end, we recommend other Ontario Health Teams engage their patient advisors in interpreting Primary Care Data Reports, to identify areas where health system learning or change is warranted.

Ontario has recently announced funding in support of team-based approaches to primary congruent with Learning Health System principles [67]. Two examples highlight how this could occur. In Ontario, The Alliance for Healthier Communities has articulated a vision for the province's Community Health Centres to act as learning health systems, using electronic health record data to guide this process [64]. Additionally, the POPLAR provincial practice-based learning and research network (which includes data from Community Health Centres and other primary care models) has integrated patient advice into their development [68]. Using new funding to embed patient partners within new team-based structures presents would ensure their expertise is included systematically, and act in the spirit of Learning Health System principles. Overlap already exists between Learning Health System principles and the Ontario Health Team Building Blocks, regarding using data to support ongoing improvements to healthcare quality, patient experience, and evaluation (Building Blocks 5 and 8). Aligning these provincial health system reform efforts (Learning Health System and Ontario Health Teams) with new primary care structures could help to address a gap in Learning Health System theory and practice, and ensure that health systems 'learn' in ways that are important to patients and caregivers.

Engagement context

The topic of access to primary care generated mainstream media attention in Ontario as this study was conducted. Many newspaper articles, radio shows, advocacy campaigns and media interviews referenced Primary Care Data Reports [69–72]. Partner's notable feelings of connection to this topic (as described in Meeting 8), and sense of the relevance of their involvement, occurred in this context. This concurs with the existing literature's identification of improving the health system and self-fulfillment as two of the most common reasons patients become partners in health services research [73, 74]. McCarron and colleagues [74] define self-fulfilment as including four components: helping others, the overall gratification received from the opportunity, meaningful connections, and a sense of purpose. These authors defined the desire to improve the health system as including both a desire to improve the culture of care, and to

speak for those who cannot speak for themselves [74]. In Meeting 8, when project partners were asked about their involvement with this project, they described their experience as meaningful and validating and felt that the output could help others. Partners' positive perceptions of their work on this project may be explained by the project's alignment with their original motivation to become patient partners. This is consistent with findings from a recent study in Ontario that interviewed patient advisors about their experiences and motivation for becoming involved with Ontario Health Teams, which emphasized self-fulfillment [32]. We therefore encourage other health system researchers to engage patients as partners on projects addressing primary care access. Doing so is ideally suited to benefitting both the patient partners and the healthcare system more generally.

Engaging project partners: process

Utilizing a transformative action research approach to partnering with patient and health system advisors [52, 53] informed by best practice recommendations for infographic creation in public health [75] allowed this project to unfold efficiently and rapidly. Spending time during Meeting 2 to highlight the alignment between documented engagement practices for the GHNN [54] and PERC could have increased buy-in among project partners and contributed to the sense of a unified approach identified by partners in Meeting 8. Though there is a legislated mandate for Ontario Health Teams like the GHNN to engage patients and communities in their development [32, 33], authors have commented on how engagement mandates can increase token forms of engagement [76] and result in a difference between the ritual of participation and the genuine power required to have an impact [77].

Previous authors have outlined how participatory forms of health research can achieve impact by breaking down 'hierarchies of knowledge' where power is retained by researchers who control access to data, through partnerships where power is shared [78, 79]. The horizontality present between PERC and GHNN representatives throughout this process presents as a demonstration of non-hierarchical collaboration in practice. This study also presents as a demonstration of genuine engagement, using the continuum from genuine to token engagement practices articulated in 2015 by members of a Clinician-Community Advisory Group of the North American Primary Care Research Group [77]. In contrast to scholarship that 'hides data from patients', this study explicitly increased the transparency of publicly available primary care data. It presents a blueprint for how data can be communicated to and with patients, levelling hierarchies between patients, researchers and health system decision-makers.

Limitations

While this project benefitted from its orientation to transformative action research principles, there are aspects of this participatory methodology we did not implement. We did not facilitate workshops in communities to share results and increase community ownership of the data. We also recognize that best practices in evaluating patient and public involvement in research include an economic assessment of engagement processes and impacts; doing so, however, was unfortunately outside the scope of this 1-year grant. We recognize the note-taking style for meetings did not attribute comments to the individual who made them, making it difficult to discern specific impacts from different types of project partners. Nevertheless, patient partners comprised the majority of project partners in every group meeting.

Conclusion

Patient engagement in research is becoming widespread, but co-developing knowledge products with patient and health system partners is less common. Co-developed infographics can prevent oversimplification and unnecessary complexity and ensure that visuals are understandable by the target population(s). Health services research benefits from the diversity of perspectives possible when knowledge users, researchers, and most importantly patient and community advisors are brought together. Addressing current health system challenges will require this diversity of input if the Quintuple Aim is to be met.

Abbreviations

GHHN	The Greater Hamilton Health Network
INSPIRE-PHC	Innovations Strengthening Primary Health Care Through Research
PERC	Patient Expertise in Research Collaboration

Supplementary Information

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> Supplementary Material 1

Data availability

The data that support the findings of this study are available from the Ontario Community Health Profiles partnership with the identifier https://www.ontariohealthprofiles.ca/ontarioHealthTeam.php.

Declarations

Ethics approval and consent to participate
This research project was approved by the Hamilton Integrated Research Ethics Board at McMaster University in Ontario, Canada under Project #13199.

Consent for publication
The authors affirm all that project partners consented to the publication of data collected during this project.

Competing interests
The authors declare no competing interests.

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