

Participating in a CIHI Project

Patient Toolkit

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Canadian Institute
for Health Information

Institut canadien
d'information sur la santé

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Introduction

Whether you're thinking about participating in a patient engagement initiative with the Canadian Institute for Health Information (CIHI) or have already agreed to, this patient toolkit will

- Tell you a bit about CIHI;
- Explain the roles patients play in our engagements;
- Help you prepare for and participate in a patient engagement;
- Answer frequently asked questions; and
- Suggest some additional resources.

Our CIHI teams have engaged with patients using patient interviews, committees, surveys and public consultations. We try to make every engagement meaningful, purposeful and authentic.

And we're still learning about and evolving our patient engagement work. This toolkit reflects the best practices we've learned from patients and patient network organizations across the country, as well as what we've learned from our own experiences.

Thank you for your interest in this work. If you have any questions, please feel free to email us at patientengagement@cihi.ca.

A little bit about CIHI!

You may not have heard much about us before.

CIHI is an independent, not-for-profit organization. For the last 25+ years, we've been dedicated to providing essential health information to all Canadians.

We work closely with federal, provincial and territorial partners and stakeholders across Canada to gather, package and disseminate information that can inform policy, management, care and research. The goal is to support better and more equitable health outcomes for all Canadians or, as our vision says, *Better data. Better decisions. Healthier Canadians.*

CIHI's strategic goals are to

- **Be a trusted source of standards and quality data** by delivering more timely, comparable and accessible data across the health continuum;
- **Expand analytical tools to support measurement of health systems** by delivering reporting tools, methods and information that enable improvements in health system performance and population health; and
- **Produce actionable analysis and accelerate its adoption** by collaborating with stakeholders to increase their ability to use data and analysis to accelerate improvements in health systems and the health of populations.

You can read more in [CIHI's Strategic Plan, 2016 to 2021](#).

Our strategic plan highlights 4 key health system performance themes (patient experience; quality and safety; outcomes; and value for money) and 4 priority populations (seniors and aging; mental health and addictions; First Nations, Inuit and Métis; and children and youth).

CIHI data holdings

We gather and analyze data from a wide variety of sources and sectors:



Types of care

- Hospital and emergency
- Mental health
- Home care
- Long-term care
- Rehabilitation
- Pharmaceuticals
- Clinical registries: organ transplant/renal, hip and knee replacements; trauma
- More



Patient-reported data

- Patient-reported outcome measures (PROMs)
- Patient-reported experience measures (PREMs)



Health spending

- Patient costing data
- Hospital and regional health authority financial accounts
- Physician billing
- System-wide health expenditures



Health workforce

- Physicians
- Nurses
- Occupational therapists
- Pharmacists
- Physiotherapists
- Allied health professionals
- More

Including the patient perspective in CIHI's work

Patients are becoming increasingly involved in decisions about their health care. Many are working with institutions and providers to change the way care is delivered. And research is showing that this shared ownership can result in better patient outcomes.

There's also growing evidence that patient involvement helps with health research. Patients' experiences can help identify priorities and guide research questions. They can provide important contextual information about findings. And patients can help research teams communicate their results to the public in a meaningful way.

At CIHI, we want to bring the patient perspective to more of our work. Already, patients' experiences are helping us

- Highlight key issues in health care;
- Illustrate the “why” behind our data; and
- Make our work accessible to the Canadian public.

“Patients have a unique perspective that none of the other players can fully represent in an unbiased way. Patients have unique, legitimate interests in how services are designed and delivered. Patients have ideas and suggestions. Patients have a lot to say. All the players in the health care system need to hear the patient voice, not as represented by other players, but directly. For that to happen, patients need their own seat at the table . . . and, from time to time, [their] own megaphone.”


— Michael Decter, Board Chair, Patients Canada, February 2016

The term “patient” includes clients, residents, and family members and caregivers with lived and living experiences of health systems.

Patient roles

This table shows the various roles patients can play in our engagements. You'll see us use these role names in our communications with you. Whatever role you play, we want your engagement to be meaningful, purposeful and authentic.

Patients as representatives	Patients as advisors	Patients as partners	Patients as leaders
<ul style="list-style-type: none"> • Patients and/or their families, caregivers, loved ones are engaged to reflect on their own health care experience, history • Via focus groups, one-on-one interviews for patient stories or input on a particular topic 	<ul style="list-style-type: none"> • Patients provide advice to inform program/project directions • Input taken into consideration for final decision-making • Brings the patient perspective/lens via representation on expert advisory/working groups 	<ul style="list-style-type: none"> • Patients develop content alongside team/organization (co-design) • Brings patient perspective/lens to a particular topic 	<ul style="list-style-type: none"> • Patients take the project lead/manager role for managing projects, content development



Time, commitment and expertise

The amount of time you'll need to commit depends on your role and the type of engagement we're conducting. Here's an overview:

Type of engagement	Time commitment
Focus group or one-on-one interview	2 hours or less
One-time presentation to staff or sharing of a personal story	Variable
One-time consultation	3 to 4 hours, including advance prep time
Consultations	Several 1-hour meetings over 3 to 6 months
Quarterly advisory group	2- to 3-hour meetings, plus advance prep time
Weekly/biweekly advisory group	1- to 2-hour meetings, plus advance prep time
Full-day meeting	7.5 hours, plus advance prep time

“It has been an honour and a pleasure to work with CIHI as one of their patient partners. They demonstrate a sincere commitment to authentic engagement, and are open to feedback and continuously evolving their engagement practice. I look forward to sharing the next steps of their journey.”

— Susan Dunn, Patient Partner, December 2020

Want to get involved? Here's what to expect!

If you have any questions, please contact us at patientengagement@cihi.ca.

Setting you up for success!

CIHI's project team will provide you with the following information:

- A short project backgrounder with the project's goals and a glossary of terms
- Our expectations for your role and the duration of your commitment
- A list of meeting dates, times and durations, as well as any travel dates and technology requirements
- Contact information for the team
- Information about coping and self-care

We recognize that talking about your health care experience or the experience of a patient you represent may be emotional and cause anxiety, stress or fatigue. In this toolkit, we've included information to help you cope with your feelings and to highlight how to get additional help.

- A list of the out-of-pocket travel expenses CIHI will reimburse (e.g., taxi or bus fare, parking fees), if applicable
- Information about any compensation available for your project participation
- The [Terms of Participation and Consent Form](#) for you to sign (*one-on-one interviews only*)
These documents outline how CIHI will use and protect your information. We've included them in this toolkit.
- The Advisory Committee Member Agreement form for you to sign (*committees or expert advisory groups only*)

We'll offer to meet with you ahead of time to help familiarize you with the content of the work and answer any questions.

- Information about any potential media release requirements, if applicable

Creating a safe space

In all our interactions with you, we want to make sure you feel safe sharing your personal experiences with us.

Before the meeting or one-on-one interview, we'll

- Ask if there are any barriers to your participation (e.g., technology, accessibility considerations)
- Review and share a coping and self-care resource with you
- Acknowledge that sharing personal experiences about your health or illness or about receiving care — or the experiences of a patient you represent — may be an emotional experience and cause anxiety, stress or fatigue
- Confirm that you have support from friends, family or other groups, or have access to resources, to help you cope with any difficult reactions these discussions may trigger

During the meeting or one-on-one interview, we'll

- Confirm that you're comfortable with us recording the meeting and/or interview
- Confirm that you can pause or opt out of the meeting or interview at any time, even after it's started

After the meeting or one-on-one interview, we'll

- Check in with you to evaluate your engagement experience and ask what went well and how we can do better
- Share information about the project completion or release and give you feedback on the impact of your contribution

“I felt respected and supported participating in a session where I was new to the group. The CIHI staff don't just tick boxes, they are genuinely committed to patient engagement and providing a patient voice at the table.”

— Donna Rubenstein, Patient Partner, December 2020

Tips for coping and self-care

CIHI has adapted this from content provided by the [BC Crisis Centre](#).

During your patient engagement with CIHI, you'll be asked to reflect on and speak about a time when you, or a patient you represent, was ill or receiving care. Some of those experiences may have been difficult.

While you and CIHI may gain important insights from the stories you share, you may find that sharing them makes you feel vulnerable or filled with difficult emotions, fatigue or stress. As a result, you may show symptoms of anxiety, worry or withdrawal.

The best way to cope with these feelings is to communicate with a safe person, someone you trust. This might be a family member, a friend or some other support person. CIHI's staff are also here to listen, so please don't hesitate to share any of your feelings with one of our team members. We'll treat these discussions as private and confidential.

There are other things you can do to help reduce your feelings of stress, fatigue and emotional discomfort. Here's some information on coping strategies and how you can deal with these challenges:

Am I stressed?

You may not always know when you're experiencing emotional fatigue and stress. So it's important to be aware of the signals. These may include changes in your emotions, body, actions and thinking. Being able to identify these changes may help you better manage how you're doing:

Changes in your emotions

- Loneliness
- Depression
- Worry or confusion
- Anger or irritability
- Sadness
- Hopelessness or suicidal thoughts

Changes in your body

- Tension
- Headache
- Stomach ache
- Disturbed sleep
- Appetite change
- Fatigue or tiredness

Changes in your actions

- Increased use of alcohol or drugs
- Withdrawal from others
- Increased smoking
- Non-stop talking
- Short-temperedness
- Fidgeting

Changes in your thinking

- Trouble concentrating
- Loss of self-confidence
- Lapses of memory
- Negative self-talk
- Negative attitude
- Poor judgment

How can I feel less stress?

Finding ways to increase our overall health helps us decrease our stress. Here are some simple ways you can do this:

- Get more sleep
- Exercise more
- Eat healthy food
- Laugh more
- Adopt positive self-talk and a positive attitude
- Talk to people you trust
- Work at managing your time
- Make an effort to relax
- Practise mindfulness

Make a stress plan

Sometimes stress can become too much. A stress plan can help you move past a difficult encounter. Here's an example of a stress plan:

1. Identify the stressors in the situation: What is upsetting you?
2. Identify your signals: How are you feeling about the situation?
3. Brainstorm your options: What can you do? For example, can you
 - Change the situation: Can I say no? Can I assert my needs?
 - Change how you react to the situation: Exercise, sleep, relax, accept support, make time to have fun, laugh.
 - Change how you look at the situation: Use positive self-talk, look for hidden opportunities in negative situations, look beyond the problem into the future.

What to avoid: Negative coping strategies

Many people knowingly or unknowingly use negative strategies to cope with stress. While these strategies may temporarily provide stress relief, in the long term they can increase the amount of stress we experience. Here are a few examples:

Avoidance

- Procrastination
- Withdrawal
- Illness
- Sleep

Distractions

- TV
- Socializing
- Shopping
- Eating

Violence

- Becoming aggressive toward others or yourself

Chemicals

- Smoking
- Sugar or caffeine
- Drugs or alcohol
- Medication

It's important to use coping strategies that will give you long-term relief from the effects of stress and help you find solutions to the problems that are causing the stress.

Successfully coping with stress

You may find that these approaches help with managing stress:

- **Be active.** Look for ways you can start to make some plans, or set some goals for yourself.
- **Write your reflections in a journal.**
- **Laugh.** Look for opportunities to laugh — laughter is great therapy.
- **Take charge.** If you notice that something isn't right, don't wait for others to notice before you take action.
- **Don't try to please everyone.** Make sure you take care of yourself and your needs.
- **Relax.** Create quiet time, meditate or listen to music.
- **Give yourself a break.** Pause and do something for yourself.
- **Reach out and talk to someone you trust, like a friend or family member.**

Please remember, **you're not alone**. If you have a difficult time connecting with a friend, family member or other support person, please contact your community and social services help line for programs and services in your community (dial 2-1-1).

Terms of Participation

If you'll be participating in a one-on-one interview or focus group, we'll share this form with you to sign.

Purpose

The Canadian Institute for Health Information (**CIHI**) is conducting a Patient Engagement Project (the "**Project**"). The purpose of the Project is to *Click to add details about the project.*

Procedures

You have shown interest in participating in the Project. By signing these Terms of Participation and Consent, you are agreeing to take part in information-gathering sessions, by way of either one-on-one interview(s) or group(s), as applicable (the "**Session(s)**"), conducted by CIHI employees. The Session(s) will be approximately; *Click to add description/information about the session(s) (e.g., length of time, when will they take place).*

Participation

Please note that participation in the Project is voluntary and you may withdraw from the Project at any time.

Information collected

During the Session(s), CIHI employees may ask about your or your loved ones' health experiences in/with *Click to add type of information/experience to be discussed*. You can decide how much detail you are comfortable providing.

Information protected

CIHI will keep all of your information collected during the Session(s) confidential, unless you consent to its disclosure (see “Review” below). To protect the information against unauthorized use or disclosure, CIHI will manage your information as follows:

- Your information will be used only by CIHI for purposes of the Project;
- Your information will be shared only with CIHI employees who have a need to know in order to complete the Project;
- Your information will be properly de-identified to ensure that you cannot be identified;
- Your information will not be linked to other data held at CIHI;
- Your information will be stored and retained separately from all other data held at CIHI and only for as long as necessary to fulfill the purposes of the Project; and
- Your information will be securely destroyed by CIHI once it is no longer needed for the purposes of the Project, or at any time upon your request.

During the Session(s) conducted in group(s), you may hear other participants' health experiences. You agree to keep all information shared during the Session(s) confidential and not to share other participants' information publicly or with any other person or entity.

Additionally, CIHI may share results and/or report(s) with you in advance of a public release to learn from your unique perspective and get your feedback. You agree to keep this information confidential and not to share the results and/or report(s) publicly or with any other person or entity until the scheduled public release time.

Review

Prior to publishing any Project-related publication containing your information, CIHI will share with you a copy of the proposed publication for review and approval. CIHI will not publish any of your information without your express consent and approval.

Compensation

Click to add the following if participants will be compensated:

Upon completion of the Session(s), you will be provided with a \$ stipend to compensate you in part for your time and expenses incurred by participating in the Project.

Add the following if participants will not be compensated: Intentionally deleted

Consent Form

I acknowledge that by responding to one of CIHI’s Patient Engagement Project Sessions and sharing any personal information about myself, I am indicating that I consent to the collection and use of this information by CIHI for purposes of the Project. I understand that sharing personal information about myself and my health may be an emotional experience and cause anxiety, that my participation in the Project is voluntary, and that I may provide as much or as little information as I want.

I further acknowledge that the collection of my personal information is necessary for the proper administration of the Project, and that my personal information will be used by CIHI only for purposes of the Project and will only be shared, stored, retained and securely destroyed as set out in the Terms of Participation above.

Lastly, I acknowledge that I may withdraw my consent at any time during the Project, without any consequences, by contacting the following person at CIHI: *Click to add email address in the event participant wants to opt out.*

By signing below, I acknowledge that I have read, understood and agreed to the above Terms of Participation and Consent and that I will receive a signed copy of this Consent.

Signature

Witness signature

Printed name

Witness printed name

Date

Date

Frequently asked questions

What is patient engagement?

Patient engagement is any process that involves many parties — including patients, families and caregivers, stakeholders and staff — where all contribute to decisions, influence ideas and provide input to change. “Engagement is two-way, involves the transparent exchange of information, seeks common understanding and leads to trust-based, sustainable relationships.”¹

Will I be compensated for my time? If yes, how?

We acknowledge that when you give your time to participate in CIHI’s work, you take time away from your job or otherwise busy schedule. Your experience and expertise provide contextual information that’s otherwise unavailable to us. CIHI has guidelines for providing an honorarium to patients who engage in our work. We consider the level of experience, expertise and commitment the patient role requires. We will always have this conversation with you at the start of the engagement process.

How will CIHI store or keep my personal information?

Your privacy is of the utmost importance to us. We take the collection, storage and destruction of patient interview information seriously. Please see the [Terms of Participation and Consent Form](#) in this toolkit for more details on how we protect the information we collect.

How will the project team support my involvement?

The project team helps prepare and support your engagement with us. We typically hold pre-meetings to help prepare patients for the work. We also have regular check-ins to gauge how things are going, so we can make any adjustments needed. Typically, we’ll send you some background on the project, information about the team members and contact information for your main contact on the team. We’re always learning more about the best ways to engage patients in our work, and we appreciate any feedback.

How many patients are involved at a typical meeting or working group?

We typically have at least 2 patient advisors or partners on our working groups, advisory groups or committees.

How will you keep me informed once the project has been completed?

Once the project has been completed, we'll let you know about the product release or project outcomes. If you participated in a one-on-one interview, we'll invite you to participate in a post-release follow-up call. In it, you can tell us about your experience and we'll let you know how your feedback made a difference to the product's outcome. If you participated in a group or committee, we'll ask you to fill out an evaluation form that helps us understand your experience and learn for the future.

Will I have to talk to the media?

Talking to the media is voluntary and not something we expect all patients to do. Should this be part of your role, our project team will meet with you to prepare you for media release activities.

How can I provide feedback on my engagement experience?

Our project team will ask you to fill out an evaluation form both during and after the engagement, so you can give us feedback about your experience. You can also email CIHI's Patient Engagement Office at any time to share your feedback (patientengagement@cihi.ca).

Other helpful resources

Here are some other online resources you may find helpful. You don't need to review them. We've just included them in case you want more information about patient engagement and how to share your experiences.

- Health Quality Ontario's guide for patient and caregiver advisors: [Take Your Patient Partnering to the Next Level](#)
- Institute for Patient- and Family-Centered Care: [Sharing Your Story: Tips for Patients and Families](#)
- Alberta Health Services' toolkit: [A Guidebook for Engaging Patient and Family Advisors](#)
- [Patient Advisors Network](#)
- Canadian Patient Safety Institute's patient and family resource: [Tips on ways to share your story](#)
- South West Self Management Program: [The Power of Conversation](#)

Reference

1. Nova Scotia Health Authority. [What is engagement?](#) In: Engage 4 Health FAQs. Accessed December 16, 2020.



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