Patients Engaging Government

A guide for patient partners to advance patient safety

Developed by Patients for Patient Safety Canada July 2021



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About us

Patients for Patient Safety Canada (PFPSC) is a patient-led program of Healthcare Excellence Canada (HEC); formerly the Canadian Patient Safety Institute (CPSI), and is the Canadian arm of World Health Organization's (WHO) Patients for Patient Safety global network.

Beginning in 2006, a small group of patients and family members in Canada began to share their experiences of harm in healthcare settings and their ideas about how to make care safer, offering their vital yet often-forgotten perspective. Growing in numbers and areas of influence, these dedicated volunteers have contributed the patient voice in hundreds of patient safety improvements both across Canada and internationally.

PFPSC members believe that patient experiences and perspectives are essential elements of safer care. As patients, we know that our experiences and the way we view the healthcare system as users are unique. Our insight and perspectives are as valuable and important as those of care providers, health leaders, policymakers, and managers of healthcare organizations. We believe that a partnership approach that brings together these perspectives is the best way to ensure that care is safe for all and is provided in a patient- and people-centred manner.

Our vision remains "Every Patient Safe."

About Healthcare Excellence Canada

In 2002, the National Steering Committee on Patient Safety published *Building a Safer System*. The report outlined a national integrated strategy for improving patient safety in the Canadian healthcare system, and its number-one recommendation was to establish CPSI. As a result of this work, in 2003, Health Canada supported the creation and funding of the CPSI, and since then the organization has worked with governments, health organizations, leaders, and healthcare providers to inspire extraordinary improvement in patient safety and quality healthcare.

In March 2021, the Canadian Patient Safety Institute and the Canadian Foundation for Healthcare Improvement teamed up to form a new organization. Together, as the new Healthcare Excellence Canada (HEC), we have greater capacity to support Canadians to turn proven innovations into widespread and lasting improvement in patient safety and all the dimensions of healthcare excellence. Healthcare Excellence Canada is an organization with a relentless focus on improving healthcare, with – and for – everyone in Canada.

Purpose of this guide

As patients, we are important advocates for safer care because we have first-hand experiences in the healthcare system.

We are compelling spokespeople when we share our experiences and respectfully point out gaps, holes, concerns, or flaws that others might not see and may cause harm to patients. *Patients Engaging Government* was developed as a resource to assist PFPSC members and the public in their efforts to advocate for safer healthcare in Canada.

Through our understanding of best practices, our ideas and insight, and our suggestions for improvements, we can effectively engage with governments to make healthcare safer.

This guide provides detailed information on how to communicate effectively with elected and government officials. It includes strategies, resources, and tools so our patient voice can be heard, our calls to action can be understood, and partnerships with patients can be formed. Together, we can take appropriate steps to improve safety in healthcare.



Patients

Patients, clients, residents, customers, and family members (as defined by patients). See the <u>PFPSC website</u> and the <u>Engaging Patients in</u> <u>Patient Safety guide</u>.



Elected official

A person elected to serve as a politician, including, federal Members of Parliament (MP), and members of a provincial or territorial parliament or legislative assembly (MLA).



Government official

Includes elected officials and a staff member of an institution of government (such as Health Canada, or a provincial or territorial health ministry) or may include a civil servant involved in the work of government. Senators are not elected; however, they serve in Parliament like elected Members of Parliament.

How the guide was developed

This guide was developed by PFPSC members of the Government Relations Group HEC staff provided advice and support throughout the process.

How to use this guide

This guide is designed to serve as a starting point for patients who want to engage with governments to make healthcare safer. *Patients Engaging Government* and the tools and resources it links to should be referenced using citations.

Fundamentals of engaging government

The Canadian healthcare system

Canada's health system is made up of 13 single-payer, publicly funded provincial/territorial health coverage programs that guarantee access to select healthcare services to its citizens and permanent residents.

Each province, and territory has a government portfolio responsible for health, often called the Ministry of Health, led by an elected official appointed as Minister of Health. Healthcare delivery and policy-making protocols are outlined in provincial and territorial legislation.

As a whole, Canada's healthcare system is guided by federal legislation, The Canada Health Act (CHA or the Act), which establishes criteria and conditions related to insured and extended healthcare services that the provinces and territories must fulfil to receive the full federal cash contribution under the Canada Health Transfer (CHT). Federal transfers through the CHT account for a portion (less than a quarter) of overall provincial and territorial healthcare spending.

Under this system, all Canadian citizens and permanent residents should have reasonable access to medically necessary hospital, medical, and diagnostic services without having to pay out of pocket. Roles and responsibilities for the funding and provision of healthcare services are shared between the federal, provincial, and territorial governments.

The federal government is also responsible for:

- Where applicable, setting and administering national standards for the healthcare system;
- Supporting the delivery of healthcare services to specific groups, including eligible Indigenous Peoples living on reserves, the military, and inmates of federal prisons;
- Leading health protection and regulation (e.g., regulation of pharmaceuticals, food, and medical devices), and consumer safety;
- Public health functions including disease surveillance and prevention, and health promotion;
- Enabling health research capacity; and
- Providing health-related tax relief and income support, including tax credits for medical expenses, disability, caregivers, and infirm dependants; tax rebates to public institutions for healthcare services; and deductions for private health insurance premiums.

The provincial and territorial governments are responsible for:

- The organization and provision of healthcare services, including healthcare and public health programs and services for their residents;
- Creating policy and standards around the quality and safety of healthcare services, and
- Allocating funds and other resources to regional or arm's-length provincial/territorial health authorities.



What is advocacy?

In the context of this guide, we define advocacy as actions taken by us as patients to help educate and inform elected and government officials about the current state of patient safety in healthcare, and the potential impacts and consequences of making changes or maintaining the status quo concerning public policy, legislation, regulations, programs, and services (i.e., the delivery of care).

In our work, we believe that advocacy should be non-partisan and focus on raising awareness and promoting best practices for safer patient care.

When we engage government, we learn that the political environment can be greatly influenced by different organizations and bodies. Governments must consider requests from advocates in terms of available funding, governmental goals and promises, and public opinion. Many successful advocates follow the strategy and process we have captured in this guide. Engagement should focus on building positive relationships with elected and government officials and identifying windows of opportunities to advocate specific patient safety issues.



Advocating for change

Patient safety policy affects every part of our healthcare system, including programs, services, the type of care provided, where, how and to whom care is provided, and how we as patients are engaged in our care. We can extend our engagement to become co-designers of, and equal partners in policymaking, respecting the expertise and perspective each party has to share. Patient partners can be thought leaders, advisors, reviewers, evaluators, teachers, educators, mentors, and coaches.

Health policy as it impacts safe patient care

Health policy impacts the safety of our care at many levels.

At the federal level, policy:

- Determines the allocation of federal contributions to provincial and territorial healthcare funding;
- Supports national 'safe care' policies; and
- Supports standards for patient safety data collection, reporting and surveillance.

At the provincial and territorial level, policy:

- Determines the allocation and management of resources for ensuring that safe care is a part of all healthcare services, program designs, and operations;
- Establishes priorities and ensures continuous efforts to review, monitor, and evaluate the safety of care and efforts for improvement;
- Informs training, education, and maintenance of patient-safety-related competencies;
- Allocates and enables the deployment of healthcare providers—physicians, staff, and teams—so they can work safely, provide safe care, and engage patients in their care; and
- Enables the design, implementation, and monitoring of care standards, regulations and processes that provide system oversight for safe patient care.

We are determined to make care safer by bringing our voice to the table as necessary partners with healthcare policymakers. We can improve policy by ensuring policymakers have a full understanding of safety implications for patients.

A patient's role as an advocate

Patients are essential stakeholders in our healthcare system.

We are an invaluable source of information, lived experiences, insight, and perspectives, and we must contribute our voice and work as partners in federal, provincial, and territorial policymaking. Patients provide important context in the design and development of new healthcare policies and practices. We can serve as advisors, experts, and educators and act as a sounding board for governments.

As patients, we are more able to influence government decisions when we have a strong understanding of how issues move through the decision-making process of government. With this knowledge, we can use windows of opportunities as they arise to influence policy outcomes.

Typically, efforts to engage government officials are directed at one level of government—federal, provincial, or territorial—but sometimes, it is appropriate to engage multiple levels simultaneously. Advocates aim to deliver messages and critical information to elected officials, political advisors, members of the public service, and senior health leaders.

How to engage government

When communicating with elected and government officials such as political advisors, government staff, and health leaders, your message must resonate with those you are meeting with—your audience. Some tips and strategies are outlined below to help make your message more easily understood and acted upon.





Begin the process early

Advocacy should start early and ideally well before any policy measure you are concerned about appears in the legislature or is talked about by government leaders. Aim to be ahead of the decision-making process on the issue. A good time to start the process of engagement is between legislative sessions when elected officials are in their home ridings and able to meet with their local constituents.

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Do your homework

To be an effective voice for patients and safer healthcare, you do not need to be a health policy expert; however, it helps if you know where different policymakers and elected officials stand on specific health issues and bills. Any background information you can find about their ideas, priorities, opinions, on specific healthcare issues can be helpful. Some useful resources on locating this information are included in this guide.

Before setting up a meeting or sending a letter to an elected or government official, you should feel prepared and have access to facts and information on your topic. You may want to review these sheets in preparation and have them on hand during your communications and meetings.



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Know your key messages and your "ask"

As you seek opportunities to speak to governments or elected officials, remember that you will have a limited time in which to make your case. It is beneficial to work through your most important and impactful messages ahead of time. Practice these statements in advance and adjust them, as necessary.

You should also equip yourself with a defined "ask." Your ask is what you would like the person to do on your behalf. In discussions with elected and government officials, ideally, your ask will be policy-related. It will require the official to present and propose a change to their colleagues in government.

Think local

As patient safety advocates, our greatest opportunity to impact policy may be with our local elected officials, rather than with leaders or those in other ridings. Elected officials are keenly interested in hearing from their constituents and want to better understand the issues that are important to those in their riding.

Each province, and territory has a directory to help you find the name and contact information for your member of provincial parliament. The federal government also has a directory that lists all members of parliament (MPs) by province and riding.

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Establish relationships

Staff in an elected official's office are a vital part of your elected official's team. They advise the official on issues to consider, so you should build a good relationship with these staff members. You will often be required to work with, and through these team members as they perform their roles. As they have influence with your elected official, legislative staff can be key allies and supporters in helping you make your case.

Arranging a meeting with your elected official

Meeting with your elected official is one of the best ways to make progress on a public-policy issue.

The following guidelines are aimed at helping you connect with federal, provincial, and territorial elected officials.





Find out who your elected official is

Elected officials generally prefer to deal with concerns raised by their constituents. If you are not sure who your member of parliament (MP) or member of provincial legislature (MLA) is, visit the House of Commons website or your provincial or territorial legislature's website.

Schedule a meeting

The preferred way to set up a meeting with an elected official is to call or email. When setting up a meeting, provide your name and the name of the community where you live (riding, city, town, or region). You may also be asked to provide your postal code. You will be asked to provide the reason you would like to meet with your elected official.

If the official cannot meet you, you can request a meeting with a member of their staff. Staff usually have more time to meet with you, and they can bring your message directly to the official.

In the "Tools and Resources" section of this guide, you will find a <u>sample letter</u> of introduction to help you make initial contact with your elected official.

Plan your meeting

When scheduling your meeting, be sure to ask how much time you will have. This will help you to better plan your time with the elected official and practice how you will deliver your message. You may be asked to provide a summary of the issue ahead of time so the elected official can prepare for the meeting. You should also let the official's staff know ahead of the meeting if you plan to bring anyone else with you.

Offer to post a photo of your meeting to social media

During your meeting with the elected official, ask if you can take a photo and post it on your social media platforms. Most elected officials appreciate positive social-media posts. Along with the photo in your post, thank the official and mention their support for your issue (e.g., safe patient care).

Follow up with a thank you

Elected officials have many responsibilities and obligations. A critical part of the relationshipbuilding process is to thank them for their time and interest in patient safety. A <u>sample thank-</u> you note is included in the "Tools and Resources" section of this guide.

Attend a town hall meeting

As well as meeting privately with their constituents, most elected officials hold regular public meetings, known as town halls. Elected officials decide when, where, and how local town halls are held. For MPs, town halls are usually held during House of Commons break weeks, or on weekends when the MP has returned to their home ridings from Ottawa. Call your elected official's constituency office to find out about any upcoming public meetings.

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Attend a community or social gathering

Many elected officials invite their constituents to community and social events as meet-andgreet opportunities. Officials and their staff may also use these occasions to gather input on issues and hear directly from voters about topics of interest in their riding. Community and social events might include picnics, barbecues, and breakfasts.

Some communities invite their elected officials to their social events so community members can mingle with the officials. These events are normally posted on community calendars or in community newsletters. If an elected official plans to attend a community event, it is often noted on the official's calendar and posted on their website. You can also get information about events your official plans to attend by contacting their riding office.

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Tell PFPSC about your meeting

PFPSC is keen to know how you are using this guide and connecting with policymakers. Please reach out to us if you plan to meet with your elected official about a patient safety issue; and contact us after the meeting to let us know how it went. We can be reached at patients@hec-esc.ca

Preparing to deliver your message



Ensuring that your message is clear, relevant, and motivating is fundamental in achieving your advocacy goals. Remember that the right message needs to reach the right person at the right time.

The following section outlines an approach you can use to help identify opportunities to advocate for safer patient care.

Wherever possible, back up your message with key facts and evidence, and have the sources of your facts and evidence on hand. This improves your credibility and can increase the interest of the person you are meeting with.

Your message should tell the listener what the problem is, explain the impact of the problem, and provide ideas from your perspective and experience of what a solution might look like. While an argument is strongest when backed up with supporting facts and evidence, you also strengthen your message by:

- Sharing examples of how widespread the problem is or might be;
- Elaborating on others' experiences and stories; and
- Referencing others (including recognized organizations) who may have influential voices.

Be sure to back up these statements with facts and published reports.

Championing your message

Expressing your personal experiences is a key part of public policy advocacy.

When you share a lived experience, you are more likely to engage elected officials, their staff, and the public at a deeper level. While telling a story of your personal experience in the healthcare system can be helpful, you do not have to share anything that makes you feel uncomfortable.

Sharing your personal experiences can be emotional and can take a lot of time. You should develop a strategy and key speaking points before you meet with your elected official.

Your strategy might include writing out the story of what you experienced. Some patient advocates have found that this helps them reflect on what the key issues are. You can bring a copy of your story to your meeting, or send it to the elected official in advance so you can spend more of the meeting focused on what needs to be done and the next steps to be taken. You can also include these key messages in your written story.

Others find it helpful to make a list of the most important points about your experiences and how you want to address them during the meeting. Consider the tips below as you develop your strategy for sharing your experience and delivering your message.



Be concise

You may only have a few minutes to tell your story. Practice telling your story in advance; it should take less than two minutes.

Be relevant

Your personal story needs to relate to why you are meeting with your elected official, including the issues you asked to talk about and the solutions you want to propose.

Be proactive

You may get only one opportunity to make your case for change. Don't forget to ask the elected official for support for the policy measure.

Be positive

Choose how you want to express yourself the words you want to use, and the passion and emotion you want to convey during the meeting. A positive and thoughtful approach to the conversation usually leads to greater success and helps to forge long-lasting relationships with elected officials.

Be action-oriented

Think about the actions that will lead to change and improvement, especially ones linked to policy changes that the elected official you are meeting with has some influence over. These are the specific "asks" that you should state clearly and leave with the official to consider.

Meeting with your elected official

Before your meeting

Time

Meetings between elected officials and members of the public are usually brief. Find out how much time will be you will have so that have so you can cover all your key points, including your "ask". When you are setting up the meeting, ask how much time has been allotted, and then reconfirm this at the meeting in case there has been a schedule change.

Place

Both you and your elected official have full and busy schedules. Any delay on your part may require your meeting to be postponed. Before the meeting date:

- Ensure you know exactly where you are meeting;
- Get advice on how to get there;
- Ask if you need to go through any special security procedures and approximately how long these will take; and
- Find out where public transit or parking is in relation to the building you will be meeting in.



Meeting structure

Once the meeting time and place have been established, you will want to plan how to make the most of your time with your elected official. Below is a step-by-step process to help you structure your meeting.

Start by introducing yourself.

Provide your name, where you live, how long you have lived there, and what you do for work or in the community. If appropriate, mention something that may relate to the elected official, such as an event you both attended. Then briefly state why you are meeting with the official.

Example:

- My name is Mary. I live in your riding of Saint Boniface, in Winnipeg. I am involved in (work / community / volunteer / other). We met briefly once, before a town hall meeting in September, shortly after you were elected.
- I'm here because I would like your support for new legislation being drafted regarding...
- On October 6th of last year, I was admitted to the emergency room at Winnipeg General Hospital, and I was harmed as a result of unsafe care I received.

Explain your connection/relationship to patient safety.

Talk about how your experience has shaped who you are and how it has inspired you to be an advocate for safer care.

Example:

- This incident has had a profound impact on my life and my family. (Explain what has changed and the impact it has had.)
- What concerns me most is that this incident could have been prevented, and I'm not convinced that changes are being made. I'm speaking up and sharing this with you to ask for your help. We need to ensure this doesn't happen to anyone else.

Introduce the one thing the elected official can do to help make a difference.

Introduce the legislation, policy, or action the official can support. This is the lead-in to your "ask". Provide the background the official needs to help. This information can be found in the fact sheets.

Example:

- After my incident, I was left with many questions and many unknowns: How did it happen? What could have prevented it? Is anything being done to prevent this from happening to other patients?
- Every patient affected by a patient safety incident deserves to know what happened to them. Without a policy that mandates disclosure of harm to a patient, patients may never know what happened, and the system will not learn from acts of unsafe care and improve.

Explain the specifics of the policy change or solution you are seeking.

Name the policy change, the legislation in need of support, or the specific action government should take.

Example:

• By putting patients first, this legislation will ensure that patients receive full disclosure following a patient safety incident. The legislation will provide patients with full access to information and ensure appropriate resources are available following a patient safety incident.

Make the ask. Be specific.

This is the reason you are meeting with your elected official—to ask for their support. You are asking them to take a stand, and take action.

Example:

• This legislation is important to me and many Canadians. I hope it's important to you too. Will you support this legislation so no other Canadian will be left in the dark, and so learning and improvement can take place to make care safer for all Canadians?



Outcomes

Consider some reasonable next steps your elected official can take after your meeting.

These may be key outcomes to highlight during your meeting and emphasize again at the end of it. There may also be actions you can follow up on in future correspondence and further meetings.

While it may be ambitious to expect one meeting to result in a big change, raising awareness, winning support, and effecting several small changes can lead to significant advancements toward safer patient care.

Tools and resources

This section contains tools and resources to support your efforts to engage governments as an advocate for safer patient care, as well as an overview of the structure of government in Canada.

Overview of government in Canada

Canada's system of government is divided into three levels:

- Federal
- Provincial and Territorial
- Municipal

Each level of government has a different area of responsibility. The federal government creates laws and manages programs and services that affect the whole country. The provincial and territorial governments have powers to make decisions related to areas of law that directly affect their province or territory. Municipal governments are responsible for establishing bylaws and services that are administered at the local level for a specific city, town, or village.

Here are some examples of the responsibilities of the different levels of government:

Federal

- national health policy
- national defence
- foreign affairs
- banking
- federal taxes
- criminal law

Provincial

- hospitals
- prisons
- education
- marriage
- property and civil rights
- rules of the road

Municipal

- building permits and zoning
- city parks
- public transportation
- garbage and recycling
- water and sewer services

Provincial and territorial governments

Provincial and territorial legislatures are made up of elected officials who are referred to as members of the provincial legislature. Provinces and territories (with the exception of Nunavut) rely on a party system to elect their premiers and the members who sit in the provincial or territorial legislature to represent each geographic constituency.





Federal government

Canada's Parliament is composed of three parts: The Monarch, the Senate, and the House of Commons. The House of Commons and Senate play an important role in the federal government by passing legislation which impacts the lives of all Canadians.

The House of Commons

Members of Parliament are elected to the House of Commons by Canadian citizens from 338 areas, called ridings.

- List of current MPs
- A Tool to find your MP
- A Tool to find out what is currently being debated in the House of Commons

The Senate

The Senate is composed of 105 senators. They are appointed to Parliament from all regions of Canada by the Governor-General, on the advice of the Prime Minister.

• List of current senators

Sample letters

Sample letter of introduction

[Name], Member of Parliament (Constituency)[Street Address][City, province] (Postal code)

(Date)

Dear (Mr./Ms./Mrs.) (Surname),

I am writing as one of your constituents to express my concerns about patient safety and to ask for your help.

(Share your personal experience in a few sentences or a paragraph. Here is an example:)

On October 6, 2016, I experienced a patient safety incident in the emergency room at the Winnipeg General Hospital. While it took just a second to occur, this incident has had a profound impact on me and will continue to affect me for the rest of my life. What concerns me most is that this incident was preventable. I believe that many other Canadians are also being impacted in the same way I was.

I am writing to you as my elected representative because I want our federal government to know and recognize the importance of (name your "ask"; in this example, it could be the disclosure of patient safety incidents).

I understand that (state the stage you think this issue is at in the policy-setting process; in this example, it could be that a proposal for new legislation is currently being drafted).

(Ask for support.) By putting patients first, this new legislation will ensure that patients receive full disclosure following a patient safety incident. It aims to provide patients with full access to information and ensures appropriate resources are available to patients after a patient safety incident occurs.

This legislation is important to me, and I hope it's important to you. I ask that you write to the Minister of Health to emphasize the importance of this issue. Please support this new legislation so no other Canadians will be left in the dark.

Thank you for your commitment to patient safety. (Ask for follow-up.) I look forward to receiving a response from you.

Sincerely,

(Your name) (Street address) (City, province) (Postal code) (Phone number or email, if applicable)

Sample thank-you note for after your meeting

(Name), Member of Parliament (Constituency) (Street address) (City, province) (Postal code)

(Date)

Dear (Mr./Ms./Mrs.) (Surname),

I am writing to thank you for taking the time to discuss with me the importance of patient safety in Canada. *(Relate it to your personal experience.)* With so many questions left unanswered after my patient safety incident, I truly believe that disclosing information about such incidents is an important step toward producing safer healthcare systems for all Canadians.

(Reinforce the request for support.) As we discussed, I hope you will write to the Minister of Health to emphasize the importance of patient safety in Canada.

I have enclosed a brief document that summarizes the main reasons the Canadian government must pay more attention to patient safety.

Sincerely,

(Your name) (Street address) (City, province) (Postal code) (Phone number or email, if applicable)

Social-media resources for patient advocates

Social media is a useful tool for advocacy, helping you connect with networks and communities with common interests in patient safety. Visit PFPSC's <u>Twitter</u> and <u>Facebook Page</u> for updates on our activities.

Key references

The Case for Investing in Patient Safety in Canada – Risk Analytica and CPSI

Economics of Patient Safety – OECD

Economics of Patient Safety in Acute Care: Technical Report - CPSI

Engaging Patients in Patient Safety: A Canadian Guide – Patient Engagement Action Team

European Patient Ambassador Program

Hospital Harm Measure – CIHI and CPSI

Shift to Safety – CPSI

Working with Partners and Stakeholders: Patients' Organization Toolkit – International Alliance of Patients' Organizations

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