

Panel Summary

Achieving Greater Impact from Investments in Medicine in Canada

16 August 2019



HEALTH FORUM

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McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 14-16 citizens from all walks of life. Panellists share their ideas and experiences on an issue, and learn from research evidence and from the views of others. A citizen panel can be used to elicit the values that citizens feel should inform future decisions about an issue, as well as to reveal new understandings about an issue and spark insights about how it should be addressed.

About this summary

On the 16th of August 2019, the McMaster Health Forum convened a citizen panel on how to achieve greater impact from investments in medicine in Canada. This summary highlights the views and experiences of panellists about:

- the underlying problem;
- three possible elements of an approach to addressing the problem; and
- potential barriers and facilitators to implement these elements.

The citizen panel did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among panellists and (where possible) identifies the values underlying different positions.

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Summary of the panel

During the deliberation about the problem, panellists were asked to share what they perceived to be the main challenges to achieving greater impact from investments in medicine in Canada. They focused on five challenges: 1) patients have unmet informational needs; 2) patients have limited opportunities to have meaningful conversations with their providers about their treatments; 3) providers are not supported with an interoperable information system; 4) many patients cannot afford and access the medicines they need; and 5) bringing cohesive and sustainable changes across the country will be difficult.

After discussing the challenges, panellists reflected on three elements of a potentially comprehensive approach for achieving greater impact from investments in medicine. A key values-related theme was the need for greater collaboration to support patients and providers to appropriately use medicines (element 1) and to make sure patients can access and afford appropriate medicines (element 2). Panellists emphasized the need to improve the relationship between patients and providers, thus engaging patients as part of a cohesive care team. They supported greater collaboration among Canadian jurisdictions to combine their negotiation power to bring down the costs of prescription medicines. They voiced their support for the idea that health systems should commit to making small and rapid improvements to the way in which medicines are prescribed, paid for and provided (element 3). In discussing this approach, participants emphasized that these rapid changes should be evidence-based, and that an arm's-length organization could be best positioned to steward these changes.

Panellists pointed out the lack of public communication and awareness about this topic as being a key barrier to moving forward. They also emphasized the political nature of these issues, which makes it difficult to achieve a cohesive vision about the problem and its solutions. When turning to potential facilitators to moving forward, some panellists envisioned that the 2019 federal election was an opportunity to better understand where the major parties stand regarding a national pharmacare program, while at the same time raising public awareness. They also pointed out the need to leverage new and emerging information and communication technologies, which could help patients and providers to appropriately use medicines.



“To make a huge national shift, it’s going to be hard without a cultural shift.”

Discussing the problem:

Why is it challenging to achieve greater impact from investments in medicine?

During the deliberation about the problem, panellists were asked to share what they perceived to be the main challenges to achieving greater impact from investments in medicine in Canada. They were also asked to identify any challenges that either they encountered personally, or that a member of their family had encountered with respect to: determining whether medicines were right for them (e.g., having discussions about other treatment options, and receiving clear explanations about why they were prescribed the medicines); affording – or being unable to afford – the medicines they needed; and physically accessing the medicines they needed.

They individually and collectively focused on five challenges in particular:

- 1) patients have unmet informational needs;
- 2) patients have limited opportunities to have meaningful conversations with their providers about their treatments;
- 3) providers are not supported with an interoperable information system;
- 4) many patients cannot afford and access the medicines they need; and
- 5) bringing cohesive and sustainable changes across the country will be difficult.

We review each of these challenges in turn below.

Patients have unmet informational needs

When asked whether they are usually provided with enough information to determine whether medicines are right for them, panellists indicated that:

- their experiences ranged from not being provided with enough information, to being provided with too much information or with conflicting information;
- there is a lack of access to trusted information sources; and
- many patients and caregivers have limited capacity to use health information.

Most panellists indicated that they did not receive enough information about their conditions and the various treatment options. In some cases, they were provided with instructions that their providers were not fully able to explain (for example, restricting their consumption of grapefruit or grapefruit juice when taking certain medication). As one panellist said: “No one has been able to explain why, so I am unnecessarily cutting it from my diet with no one being able to explain it to me.”

A few panellists discussed the challenges of handling the vast amount of information for any single medicine, noting that “[there are] so many side effects listed that there comes a point where you ignore them,” which gets exacerbated when you need several medicines.

Some panellists emphasized that they often receive conflicting information about their medicines from the prescriber, the pharmacist, the handouts provided by the pharmacists, and the labels on packages. As one panellist said: “The pharmacist said to take it and then eat right after, while the pamphlet said to take one hour prior to any meal, and finally the prescription said two hours after food.”

Some panellists mentioned that research evidence on medicines is constantly evolving and it’s hard to keep up. As one panellist indicated: “[I have been] taking a medicine for years and all of a sudden there is a warning on it that was never there before. Is this new or has this always been the case? If the latter, why now?” A second panellist went further:

“[Pharmacists] do explain the stuff to me, but long-term medication, they assume you already understand, but it needs to be discussed again.”

The deliberations then turned to the lack of trusted information sources. Many times, patients and caregivers have to do their own research to obtain information about their medications. For example, one panellist described being explicitly told by his physician to use Google to get information. Several panellists expressed frustration about having to do their own research, and concern about the quality of information they could find online. As one panellist stated: “Do you ever believe everything you see online?” Other panellists consulted the websites of disease-specific organizations, provider organizations (for example, the Mayo Clinic), and the drug manufacturer to find additional information. One panellist indicated that he ran online searches to learn what other patients had to say about specific medicines.

Lastly, the deliberations focused on the limited capacity of some individuals to understand and use complex health information, and its impact on medication adherence. Several panellists pointed out that many Canadians have a low level of health

Box 1: Key features of the citizen panel

The citizen panel about achieving greater impact from investments in medicine in Canada had the following 11 features:

1. it addressed a high-priority issue in Canada;
2. it provided an opportunity to discuss different features of the problem;
3. it provided an opportunity to discuss three elements of a potentially comprehensive approach for addressing the problem;
4. it provided an opportunity to discuss key implementation considerations (e.g., barriers);
5. it provided an opportunity to talk about who might do what differently;
6. it was informed by a pre-circulated, plain-language brief;
7. it involved a facilitator to assist with the discussions;
8. it brought together citizens affected by the problem or by future decisions related to the problem;
9. it aimed for fair representation among the diversity of citizens involved in or affected by the problem;
10. it aimed for open and frank discussions that preserve the anonymity of participants; and
11. it aimed to find both common ground and differences of opinions.

literacy, which may limit their capacity to appropriately use their medication. Yet, some panellists indicated that the lack of adherence goes beyond the level of health literacy, and that their level of motivation and their complex daily routines may have a further impact. For example, one panellist said: “I am fairly well educated, but I get busy and just don’t take my medication. I think it’s more laziness over knowledge.”

Patients have limited opportunities to have meaningful conversations with their providers about their treatments

Most panellists emphasized that medical appointments are not conducive to meaningful conversations about their health, the care they receive, or the appropriate use of medicines. These appointments often last a short period of time (estimated by many panellists to be about 10 minutes) and do not allow them to discuss all of their health issues. As one panellist said: “We have seven to eight minutes to talk for a year of problems.” A second panellist went further: “The time a doctor spends with a patient is very short. The doctor tries to figure out and prescribe the drug all within one visit, with no follow-up or time to explain how the prescription works.” The limited opportunities to discuss with providers have also been identified as

Box 2: Profile of panel participants

The citizen panel aimed for fair representation among the diversity of citizens likely to be affected by the problem. We provide below a brief profile of panel participants:

- How many participants?
14
- Where were they from?
British Columbia (1), Alberta (1), Saskatchewan (1), Ontario (7), Quebec (2), New Brunswick (1), and Nova Scotia (1)
- How old were they?
18-24 (3), 25-44 (5), 45-64 (4), 65 and older (2)
- Were they men, or women?
men (7) and women (7)
- What was the educational level of participants?
21% completed community college, 21% completed technical school and 57% completed a bachelor’s degree/post-graduate training or professional degree
- What was the work status of participants?
14% self-employed, 57% working full-time, 7% unemployed, 7% retired, and 14% students
- What was the income level of participants?
14% earned less than \$20,000, 7% between \$20,000 and \$40,000, 7% between \$40,000 and \$60,000, 29% between \$60,000 and \$80,000, 21% more than \$80,000 and 22% preferred not to answer
- How were they recruited? Selected based on explicit criteria from the AskingCanadians™ panel

an underlying reason that can exacerbate the inappropriate use of medicines: “[It’s the] physician time and availability that leads to the misuse of medication.”

Panellists suggested that another reason why patients and providers do not have meaningful conversations about their treatments may be that many patients share a culture of deference to their providers. While some panellists hoped that patients would be more proactive regarding their own health and their own care (for example, by asking questions about their conditions and treatment options, and challenging their provider whenever necessary), others highlighted that many patients share a culture of complete deference (and sometimes blind trust) towards their providers. One panellist wondered if this was a generational issue, referring to her grandmother: “Older people won’t ask a question, there is absolute trust in the doctor... [My grandmother] doesn’t even want to know the name of the medication. She is from an era where you trust the doctor.” A second panellist agreed: “I’m finding it confusing sometimes, but he’s the doctor so we trust them if they prescribe it.”

Providers are not supported with an interoperable information system

Panellists expressed frustration about the absence of an interoperable information system allowing for the timely sharing of patient information across all providers and settings. They didn’t understand why health systems in Canada were so slow in taking up information and communication technologies that could improve access, affordability and appropriate use of medicines (for example, patient portals, electronic medical records, and computerized decision aids).

Many patients cannot afford and access the medicines they need

Panellists expressed concerns about the 1.7 million Canadians facing cost-related barriers to using medicines, and many highlighted the high costs of private health insurance. Some self-employed panellists indicated that they cannot afford private health-insurance plans, so they do not purchase them and then pay out-of-pocket when necessary.

Some panellists pointed out that when patients face cost-related barriers, they sometimes try to stretch their medications by not taking it as prescribed, which can cause additional health problems.

Panellists highlighted that it is not just the cost of the medicines that constitutes a problem. It is also the dispensing fees, the costs of travelling to obtain the medicines, and other costs (for example, \$50 to transfer paperwork from one provider to another).

Some panellists expressed serious concerns about their providers explicitly asking about their coverage before prescribing medicines. They worried that it may have an impact on the treatment options considered by the provider. As one panellist said: “What is your insurance or coverage is always the first question. I’m worried that could affect the quality of medication I’m receiving.”

From a systems perspective, panellists were surprised to learn that prescription medicines in Canada are among the most expensive in the world (particularly that Canadians pay about 30% more for the medicines they use compared to other OECD countries). They were not aware of the magnitude of the financial challenges currently being confronted in Canada. On a related note, one panellist also emphasized that, as patients, it is not just the cost of medicines at the individual level that they worry about. It is also the cost to the system, which could contribute to a lack of resources for other programs and services, and lead to instances of not having timely access to providers, and not enough providers being able to have meaningful conversations with their patients. The participant noted that this, in turn, could exacerbate the inappropriate use of medicines and the broader costs to health systems.

In addition to the impact of affordability on access to needed medicines, panellists also pointed out the challenges of accessing providers who can prescribe the medicines they need. The lack of timely access to a primary-care provider (mostly a family physician) was identified as a critical factor influencing the lack of access to the medicines they need: “The trouble is getting a doctor, so you stick with them even if you don’t agree with their opinion.”

Panellists indicated that they were not familiar with the scope of practice of the different providers (beyond physicians), and who could write prescriptions for what conditions, limiting their ability to access medicines through different avenues.

Bringing cohesive and sustainable change to medicines across the country will be difficult

Panellists indicated that they had limited knowledge about how provinces and territories outside of their own are covering medicines: “We don’t necessarily know what’s happening in other provinces.” As a result, they had difficulty comparing their situation to other Canadians.

Many indicated that the absence of a national pharmacare program (or the absence of similar coverage policies and decisions across jurisdictions) was a source of concern and created inequities across the country. “We need to be under one umbrella.”

But having more than one health system in Canada (13 provincial and territorial health systems, and a federal government with jurisdiction over decision-making for some components of these health systems), politics often gets in the way. Panellists indicated that it would be hard to achieve consensus on how to move forward and to make changes. Many panellists indicated that they believed a cultural shift appeared to be the key to any national pharmacare program, because at every level, in every jurisdiction, everyone has an agenda. “To make a huge national shift, it’s going to be hard without a cultural shift.”



“We need a clear vision from leadership but there are too many agendas to make it feasible.”

Discussing the elements:

How can we address the problem?

After discussing the challenges that together constitute the problem, participants were invited to reflect on three elements (among potentially many) of an approach to achieving greater impact from investments in medicine in Canada:

- 1) supporting patients and providers to appropriately use medicines;
- 2) making sure patients can access and afford appropriate medicines; and
- 3) enabling decision-makers to make small yet rapid changes to support the appropriate use of accessible and affordable medicines.

Panellists were reminded that the three elements can be pursued together or in sequence. A description of these elements, along with a summary of the research evidence about them, was provided to participants in the citizen brief that was circulated before the event. Whenever possible, we describe areas of common ground and differences of opinions among panellists and (where possible) identify the values underlying different positions (which are summarized in Table 2).

Table 2. Summary of citizens' values and preferences related to the three elements

Element	Values expressed	Preferences for how to implement the element
Supporting patients and providers to appropriately use medicines	<ul style="list-style-type: none"> • excellent patient experience • collaboration among patients, providers and organizations within the health system • innovation • competence 	<ul style="list-style-type: none"> • provide patients with more valid and reliable information to inform decisions about the medicines that are most appropriate and support adherence • improve the relationship between patients and providers, thus engaging patients meaningfully in decision-making about their condition and how it is treated • embrace new technologies that could support timely access to care providers, as well as support the appropriate use of medicines • support mandatory professional development of all providers regarding best practices with prescription medicines
Making sure patients can access and afford appropriate medicines	<ul style="list-style-type: none"> • fairness (equity) • choice • stewardship • collaboration between Canadian jurisdictions • trust 	<ul style="list-style-type: none"> • support a publicly funded, national pharmacare program, with a list of essential medicines that would be available to all people (but have the capacity to choose additional plans that citizens could pay for to expand the list of covered medicines) • mitigate tension between a desire to have a centralized authority making decisions about public coverage for medicines, and a desire to decentralize coverage decisions so they can be tailored to unique populations • support greater collaboration among Canadian jurisdictions to combine their negotiating power in order to bring the costs of prescription medicines down • collaboration with the pharmaceutical industry in ways that prioritize the needs of patients and citizens and address mistrust of the industry
Enabling decision-makers to make small yet rapid changes to support the appropriate use of accessible and affordable medicines	<ul style="list-style-type: none"> • continuously improving (quality) • based on data and evidence (evidence-informed care and policy) • accountability • stewardship 	<ul style="list-style-type: none"> • support health systems to commit to making small yet rapid improvements to the way in which medicines are prescribed, paid for and provided • support rapid changes that are evidence-based • support the creation of an arm's-length organization that would be accountable for stewarding these changes

Element 1 – Supporting patients and providers to appropriately use medicines

The discussion about the first element focused on ensuring patients are aware of the medicines that are most appropriate for managing their conditions, on helping them adhere to them, and on supporting appropriate prescribing by choosing the right mix of provider-targeted strategies. As outlined in the citizen brief, this could include:

- ensuring patients are aware of the medicines that are most appropriate for managing their condition, and engaging them in decision-making about their condition and how it is treated;
- choosing the right mix of promising patient-targeted strategies to improve adherence to prescription medicines, including:
 - tailored ongoing support from allied health professionals,
 - education,
 - counselling (including motivational interviewing or cognitive behavioural therapy),
 - daily treatment support, and
 - support from family or peers; and
- supporting appropriate prescribing by choosing the right mix of provider-targeted strategies, such as:
 - education (materials, meetings, outreach),
 - local opinion leaders (using those individuals thought to be credible and trustworthy to share information about prescribing),
 - local consensus processes (for example, bringing together health providers to ensure they agree on guidelines and prescribing practices),
 - peer review (evaluation of one provider's prescribing habits by another),
 - audit and feedback (providing a summary of a provider's performance to them to allow them to assess their own performance),
 - reminders and prompts,
 - tailored interventions to support individual providers with their prescribing,
 - patient-mediated interventions (interventions where patients provide those prescribing medicines with more information about themselves and their medical history), and
 - multifaceted interventions.

There were four main values-related themes that emerged during the discussion about element 1:

- 1) excellent patient experience;
- 2) collaboration among patients, providers and organizations within the health system;
- 3) innovation; and
- 4) competence.

The first values-related theme emerging from the panel focused on improving the patient experience. Panellists indicated that providing patients with more valid and reliable information was fundamental to helping them to make informed decisions about the medicines that are most appropriate for managing their conditions, and helping them adhere to them.

A second values-related theme was collaboration among patients, providers and organizations within the health system. Panellists emphasized the need to improve the relationship between patients and providers, thus engaging patients meaningfully in decision-making about their condition and how it is treated. Many indicated that patients should be part of a cohesive care team. They should be engaged in developing a holistic treatment plan, so they could have a greater investment in (and adherence to) the plan. To achieve this, panellists pointed out the need for longer medical appointments (and thus more time for conversations), and more frequent follow-ups to establish rapport with the care team (which could be facilitated by a nurse care coordinator who could do proactive follow-up, especially for the first week of any new treatment plan).

The third values-related theme was innovation. Panellists indicated that health systems should embrace new technologies that could support timely access to care providers (for example, online bookings and virtual appointments), as well as support the appropriate use of medicines (for example, innovative blister packs and specialized pill boxes to organize all the medication taken by a patient) and novel ways to ensure patients and providers can discuss medicines, side effects and interactions (for example, two-way text or phone apps

Box 3: Key messages about supporting patients and providers to appropriately use medicines (element 1)

Four values-related themes emerged during the discussion about this element.

- excellent patient experience
- collaboration among patients, providers and organizations within the health system
- innovation
- competence

prompting users to report any adverse reactions or worrying side effects, and reminding them when to take their medicines).

The fourth values-related theme was competence. Panellists called for mandatory professional development of all providers regarding best practices with prescription medicines. They also briefly discussed how we could optimally leverage the core competencies of all providers on the care team. For example, while physicians may be better equipped to provide information about diagnosis and the pros and cons of different treatment options, pharmacists may be best positioned to provide in-depth information about medicines.

Element 2 – Making sure patients can access and afford appropriate medicines

The discussion about the second element focused on determining how to expand coverage to more Canadians, and decide which medicines will be covered and what proportion of costs will be publicly covered. As outlined in the citizen brief, this could include:

- determining how to expand coverage to more Canadians,
 - for example, filling existing gaps between public and private coverage by including Canadians who aren't covered within existing plans or by a private plan, or by establishing universal access for every Canadian; and
- determining which medicines will be covered,
 - for example, covering an entire list of essential medicines or covering a sub-set of the list of essential medicines, and
 - determining what proportion of costs will be publicly covered.

Box 4: Key messages about making sure patients can access and afford appropriate medicines (element 2)

Five values-related themes emerged during the discussion about this element.

- fairness (equity)
- choice
- stewardship
- collaboration between Canadian jurisdictions
- trust

There were five main values-related themes that emerged during the discussion about element 2:

- 1) fairness (equity);
- 2) choice;
- 3) stewardship;
- 4) collaboration between Canadian jurisdictions; and
- 5) trust.

The first values-related theme that emerged was fairness (equity). This theme emerged when discussing how to expand coverage to more Canadians and which medicines should be covered. Panellists generally agreed about the need to provide public coverage for a list of essential medicines for everyone.

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The second values-related theme focused on choice. Panellists generally agreed with the idea of a publicly funded, national pharmacare program, with a list of essential medicines that would be available to all people. Yet, some panellists also wanted people to have the capacity to choose additional plans that they could pay for to expand the list of covered medicines. This discussion highlighted the inherent tensions in achieving greater fairness (equity) with a national pharmacare program, while ensuring that it would not limit patient (and physician) choice.

The third values-related theme was stewardship. This theme emerged during a discussion about the need for leadership when making coverage policies and coverage decisions. The discussions highlighted some tension among the panellists between a desire to have a central authority making decisions about coverage of drug policies, and a desire to decentralize coverage decisions. Several panellists indicated that coverage decisions regarding medicines should be managed at a more regional/local level, to get closer to priority populations while still being consistent with coverage policies established at the national level. As one panellist said: “[We need a] centralized authority combined with grassroots [actions] to remove the chaos that can occur.”

The last two values-related themes that emerged during the discussion of element 2 were collaboration among Canadian jurisdictions and trust. Panellists mentioned again their astonishment and their concerns that prescription medicines in Canada are among the most expensive in the world. They supported greater collaboration among Canadian jurisdictions to combine their negotiation power in order to bring down the costs of prescription medicines. This discussion also revealed a certain level of mistrust towards the pharmaceutical industry, which many panellists perceived as resisting efforts to lower drug prices and threatening governments that it would lead to reduced research and development investments, less innovation in Canada, lowering prices and fewer jobs in our life sciences sector. As one panellist said: “We are held hostage by pharmaceutical companies.”

Element 3 – Enabling decision-makers to make small yet rapid changes to support the appropriate use of accessible and affordable medicines

The discussion around element 3 focused on how to support the health system to try new approaches and to make small yet rapid changes to the way in which medicines are prescribed, paid for and provided. Decision-makers have found these types of changes require action within seven areas:

- 1) engaging people and patients in decision-making about how best to improve programs and services delivering medicines;
- 2) capturing and sharing data related to medicines and their use;
- 3) ensuring organizations (for example, arm's-length agencies, researchers working at academic hospitals) in the system are able to produce research about medicines in a timely way;
- 4) supporting patients, providers and policymakers to use data and research to inform their decisions;
- 5) strengthening the health system in ways that enable the four actions above;
- 6) creating a culture that supports small yet rapid improvements; and
- 7) fostering the skills needed to take all of these actions.

There were four main values-related themes that emerged during this discussion:

- 1) continuously improving (quality);
- 2) based on data and evidence (evidence-informed care and policy);
- 3) accountability; and
- 4) stewardship.

The first two values-related themes that emerged were continuously improving (quality) and based on data and evidence (evidence-informed care and policy). Panellists generally agreed that health systems in Canada should commit to making small and rapid improvements to

Box 5: Key messages about enabling decision-makers to make small yet rapid changes (element 3)

Four values-related themes emerged during the discussion about this element.

- continuously improving (quality)
- based on data and evidence (evidence-informed care and policy)
- accountability
- stewardship

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the way in which medicines are prescribed, paid for and provided. Moreover, they indicated that decision-makers should commit to these rapid changes as long as there are standards around the quality of the research evidence to support such changes.

The last two values-related themes focused on accountability and stewardship. The panellists generally agreed about the need for a leadership and governance structure that would ensure accountability for and stewardship of these small, yet rapid changes.

Some panellists proposed various arm's-length organizations that could oversee these changes, for instance the 'director of change' within each province and territory, who would be accountable to a 'national director of change'. They also envisioned a national body that would oversee the costs of medicines and the list of essential medicines publicly covered for all (based on the best available statistical data, research evidence, and best practices around the world). While a leadership body was seen by many panellists as essential to embrace making these small and rapid changes, a few panellists remain skeptical about the feasibility of such an approach: "We need a clear vision from leadership but there are too many agendas to make it feasible."



“The general public is not aware of many of the issues discussed.”

Discussing implementation considerations: What are the potential barriers and facilitators to implementing these elements?

After discussing the three elements of a potentially comprehensive approach for achieving greater impact from investments in medicine in Canada, participants examined potential barriers and facilitators for moving forward.

The discussion about potential barriers generally focused on three aspects: communication, politics and cohesiveness. Several panellists pointed out the lack of public communication about the types of issues discussed during the panel: “The general public is not aware of many of the issues discussed.” Many panellists also emphasized the political nature of these issues (particularly with the wide range of lobby groups). Thus, they estimated that achieving a cohesive vision about the problem and its solutions would be difficult. As one panellist said: “What is ‘better’ is very subjective.” This resonated with a second panellist who claimed: “There will never be a solution that appeals to everyone.”

When turning to potential facilitators to moving forward, some panellists envisioned that the 2019 federal election was an opportunity to better understand where the major parties

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stand regarding a national pharmacare program, while at the same time raising public awareness. Second, a few panellists pointed out the need to leverage new and emerging information and communication technologies that could help patients and providers to appropriately use medicines.

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