

Necessary Medicines:

Recommendations of the
Citizens' Reference Panel on
Pharmacare in Canada

“We are a group of 35
volunteers randomly selected
from across the provinces
and territories of Canada.
We came together to learn
about how prescription
medications are covered in
Canada, and to recommend
changes that will benefit
all Canadians...”



Publication information

Published by the Pharmaceutical Policy Research Collaboration
University of British Columbia
2206 East Mall, Vancouver BC V6T 1Z3

You can download this publication at www.circle.ubc.ca

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How to cite this report:

Citizens' Reference Panel on Pharmacare in Canada. (2016) "Necessary Medicines: Recommendations of the Citizens' Reference Panel on Pharmacare in Canada." Vancouver, Pharmaceutical Policy Research Collaboration, University of British Columbia.

Library and Archives Canada Cataloguing in Publication

Necessary Medicines: Recommendations of the Citizens' Reference Panel on Pharmacare in Canada.
Citizens' Reference Panel on Pharmacare in Canada.
ISBN: 978-0-9948427-1-8

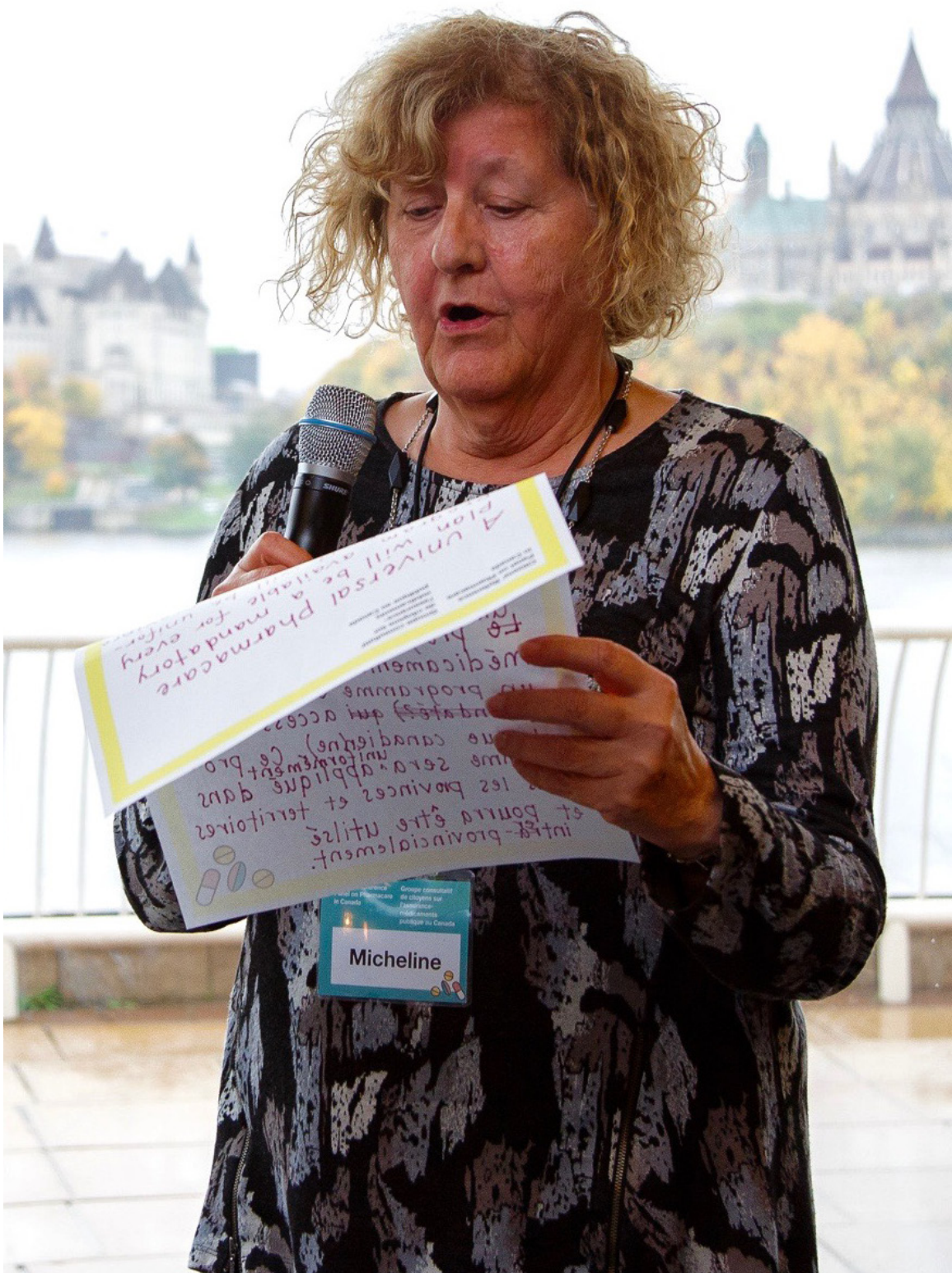
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The members of the Citizens' Reference Panel on Pharmacare in the Grand Hall at the Canadian Museum of History





Micheline Allard (Mont St-Hilaire, QC) reads her working group's definition of one of the panel's guiding principles.

Letter from the Chair

The Canada Health Act ensures that all Canadians are able to visit their doctor, free of charge. Yet when that doctor writes a prescription, only some Canadians have the means to pay for it. Now more than ever, prescription medicines are used to save lives, prevent and cure diseases, and improve the quality of life of Canadians. But a growing number are struggling to pay for the medicines they need.

Polls show that Canadians want their governments to improve access to prescription medicines, yet it is far from clear what policy solutions Canadians would be willing to explore and ultimately endorse. Is there a national model of prescription coverage that is well aligned with values and well suited to the needs of Canadians?

The Citizens' Reference Panel on Pharmacare in Canada — only the second national process of its kind — convened 35 randomly selected people from across the country to learn from experts, deliberate on behalf of Canadians, examine options, and together offer policy makers clear and considered recommendations.

As the Chair of the panel, I encourage you to read not only the members' recommendations, but also their biographies. The 35 panelists truly represent Canada. They come from every province and territory, cover a range of ages and stages of life, and proportionately represent the population's different levels of pharmaceutical insurance. They were selected through a made-in-Canada process called the Civic Lottery, in which 10,000 letters were mailed to randomly selected Canadian households, inviting residents to volunteer for the panel as an act of public service. The 35 members were selected at random from among the 387 Canadians who stepped forward. Their costs were covered, but they volunteered their time, travelling to Ottawa for five days to work together to produce this remarkable report.

Over the course of their time together, the panel members, working in both official languages, learned from twenty experts, ranging from doctors and pharmacists, to pharmaceutical and insurance industry representatives, to academics and patient representatives. They spent many hours asking questions and probing speakers, deliberating and debating amongst themselves, and formulating and refining their recommendations.

These 35 people put everything else on hold for five days, without remuneration, in order to serve their fellow Canadians and provide government with their best advice. The question of drug coverage affects each panelist differently, and although they did not always agree with one another, they found a way to tackle this challenge with enthusiasm and grace.

Their time with experts and with each other no doubt shaped their views on this complex issue — a unique experience their fellow Canadians will not have the opportunity to share. But this is exactly why their report is so instructive: the panelists outline a rationale for action that, if explained effectively, is likely to be convincing to many of their fellow Canadians.

As an informed cross-section of Canadians, they can reasonably claim to speak with authority on behalf of their country. They do not expect that each of their recommendations will be heeded, but they believe their work deserves notice and careful consideration.

As Chair and with a unique vantage point on the process, I believe several factors helped shape the panel's recommendations.

First, in their discussions, panelists routinely spoke of health care as a fundamental right and Canada's health system as a source of national pride. That access to medically-necessary drugs outside of hospital would be subject to a person's ability to pay offended — especially in the case of chronic and rare diseases — their sense of fairness and their confidence in medicare.

Second, they expressed concern for the existing patchwork of public drug coverage which varies between provinces and territories and concluded that the cost and availability of pharmaceuticals should be consistent across Canada.

Third, panelists noted that many pharmaceuticals cost significantly more in Canada than they do in comparable countries with comprehensive forms of public insurance.

In the pages that follow, you will find a summary featuring highlights from the process and the panel's recommendations, and then a more detailed explanation of the process. The official report of the panel — written in their own words — is shaded light blue.

I would also like to acknowledge the careful work of the panel's Oversight and Advisory Committee. This group comprising ten of Canada's leading health policy experts worked with my team to ensure the impartiality of the curriculum and our proceedings. Their generosity, thoughtfulness, and confidence in the capacity of all Canadians to play a constructive role in shaping public policy contributed immeasurably to the quality of the panel's deliberations.

I urge readers to make the most of what this report represents — a call to considered and careful action on one of the defining health care issues of our time.

Respectfully,

Peter MacLeod
Chair, Citizens' Reference Panel on Pharmacare in Canada

Letter from the Research Lead

Scientific studies have documented the advantages and disadvantages of different approaches to prescription drug coverage, and public opinion polls have found that Canadians support the general idea of universal “Pharmacare.” But existing research and polling data provide limited insight about Canadians’ values, goals, and willingness to accept trade-offs when considering different approaches to drug coverage.

The Citizens’ Reference Panel on Pharmacare in Canada was convened as a citizen-centred process that could provide an unprecedented opportunity for informed and extended dialogue between experts, stakeholders, and citizens. Working together, members of the panel offer essential and timely guidance to policy makers working to strike the right balance.

This was a thorough civic engagement activity funded by the Canadian Institutes of Health Research and other partners. A Civic Lottery involving 10,000 Canadian households was used to select a diverse panel of 35 citizens from across the country. These citizens heard from twenty speakers over the course of five days of professionally facilitated, bilingual deliberations in the nation’s capital. They then spent several weeks refining their final recommendations, which are contained in this report.

This distinctive approach to public engagement helps to illuminate an often neglected civic perspective. The carefully considered recommendations of the panel reflect not only the individual knowledge, experience, and values of the participants — which one can gather via opinion polls — but also the consensus that emerges from citizens sharing and balancing their perspectives with one another and in view of evidence and stakeholder opinions — which one can only get through deliberative dialogue.

As a result of the rigour and integrity of the process, the vision and recommendations of the Citizens’ Reference Panel on Pharmacare in Canada — for “a system that Canadians could be proud of” — is an important guide for policy analysis, planning, implementation, and evaluation. There is much work to be done, but this diverse group of Canadians has recommended, for the sake of their country, that we begin that work right away.

Respectfully,

Dr. Steven G. Morgan
School of Population and Public Health, University of British Columbia

On behalf of the researchers, professionals, and organizations that supported the Citizens’ Reference Panel on Pharmacare in Canada.



Nabil Gbian (Saint-Laurent, QC) reacts to a fellow panelist's comment during a plenary discussion.

What policy makers should know

Advances in pharmaceuticals mean Canadians are spending more on prescription medicines than ever before, and the cost of prescriptions is becoming prohibitive for many of those uninsured and under-insured. Some end up taking their medications less often than they should, or they forego them altogether. Others deplete savings and accumulate debt to pay for the medicines they need. Decision makers are increasingly aware of the gaps in drug coverage that leave many Canadians unable to afford the medications they are prescribed. At the provincial, territorial, and federal levels, policy makers are assessing options and searching for policy solutions that suit Canada's circumstances — solutions that would ultimately make prescription drugs more accessible, affordable, and appropriately prescribed for all Canadians.

The Citizens' Reference Panel on Pharmacare in Canada was assembled to provide Canadian policy makers with an informed and impartial citizens' perspective on whether a national drug coverage system is desired, and if so, how that system could be designed to best reflect the values and priorities of Canadians.

The Reference Panel was made up of 35 Canadian residents, who were randomly selected in such a way as to be demographically representative of the Canadian population. They were brought together in Ottawa for five days, where they learned from twenty experts of diverse viewpoints, and then deliberated amongst themselves, assessing options and ultimately agreeing on a set of policy recommendations. The Reference Panel was funded primarily by a grant from the Canadian Institutes of Health Research, which seeks to advance medical research and health policy.

THE PROCESS IN BRIEF

The first two days of the panel represented a crash course on how medications are prescribed, used, and paid for in Canada and around the world. Twenty experts spoke to the panelists in a series of fast-paced presentations and discussion panels. The choice of speakers was guided by an Advisory and Oversight Committee made up of academics, physicians, and policy leaders from across Canada, and representing a range of opinions about what kind of national drug coverage system is right for Canada — if any. The speakers ranged from clinicians and professors, to representatives of the pharmaceutical and insurance industries, to pharmacists and patient representatives.

The learning curriculum started with the fundamentals: the evolution of the Canadian health care system and how the use of prescription drugs has changed in past decades. The panel then learned how Canadians

currently pay for medications in different provinces and territories, through a mix of public and private insurance and out-of-pocket payments. Then, they looked abroad for examples of the different approaches to coverage that exist in comparable jurisdictions. During three discussion panels, they heard from speakers representing different professions and industries — and who did not always agree with one another — about what the impact of different mixes of coverage might be in Canada.

Identifying principles and issues

Panelists worked together through a series of facilitated small-group activities to draft the recommendations contained in this report. They began by agreeing on the principles they believed should guide policy efforts. The panel decided that coverage should be universal, ensuring basic care to every Canadian, and patient-centred, providing flexibility for individual needs and priorities and giving patients an active role in their own care. The system of coverage should also be accountable to the public — transparently run and clearly effective in the eyes of Canadians. Decisions about which drugs are covered must be evidence-based and rooted in careful consideration of safety, effectiveness, and costs. And in order to ensure a system that continues to serve the needs of Canadians for many generations, panelists agreed that a drug coverage program must be financially sustainable and independent from political pressure.

Panelists then identified the priority issues that a national drug coverage program should seek to address. They agreed that a central gap was that some Canadians have insufficient prescription coverage, which leads to poor health outcomes. The panel felt there should be greater public awareness about this issue — several panelists themselves were unaware of the depth of the problem before convening in Ottawa, and felt Canadians need to know about the personal and social consequences of this state of affairs. Another major issue the panel identified was regional variability in service, in access to drugs, and in the price of medications. These variations mean that Canadians have uneven access to prescription drugs, ultimately leading to differences in patient outcomes. The panel felt that a national drug coverage program should also address the high price of drugs in Canada, as compared to many similar jurisdictions. Panelists attributed these higher costs in part to Canada's fractured buying power and insufficient oversight of pharmaceutical manufacturers, and also to the inconsistent use of generics over more costly brand-name medications. Finally, panelists agreed that a national drug coverage system should address over-prescription, abuse, and misuse of medications.

Developing a vision for a national drug coverage program

After examining options, learning about the approaches in other jurisdictions, and engaging in many hours of deliberation, the panel agreed upon a vision for a national prescription coverage system that best reflected the principles and issues described above — one that they believed “Canadians could be proud of.”

The panel's report calls for a universal, mandatory, public national drug coverage program. This system would cover prescription medications included on a formulary through public insurance. The report recommends an extensive but selective public formulary — extensive enough

to provide the flexibility for prescribers to accommodate the full range of individual patient needs and circumstances, including rare diseases, yet also selective, with drugs undergoing a rigorous evaluation process to ensure that they are the most effective treatments available for the price. The panel's report also calls for a national system where individuals and employers maintain the option to purchase complementary private drug insurance, which would be restricted to covering medications not on the publicly-covered formulary.

THE RECOMMENDATIONS IN BRIEF

A universal, mandatory public drug insurance system that provides necessary coverage to all Canadians

After careful consideration, the panel recommended that provincial, territorial, and federal policy makers work together to implement a universal, mandatory public drug insurance system that provides coverage to all Canadians for necessary medicines no matter their province or territory of residence. Such a system should be funded by equitable revenue tools that reflect the variable means of Canadians.

Rigorous cost-effectiveness evaluation and supplemental private drug insurance

The panel recommended that the public drug insurance program provide every Canadian access to all medicines necessary to treat the full range of individual patient needs and circumstances, including rare diseases. However, the panel recommended that only the most effective treatments available for the price be covered by this program, with drugs undergoing a rigorous, evidence-based evaluation of their clinical value and their cost-effectiveness before being added to a national public formulary. The panel recommended that private drug insurance continue to play a role in Canada, but that private insurance providers be restricted to covering medications not included on the national public formulary.

Increased negotiating power leading to lower drug costs

The panel recommended such a system because they believed it has the greatest likelihood of being universally accessible, responsive to patient needs, grounded in the best evidence available, accountable to the public, and financially sustainable. Panelists agreed that since governments would become the main purchasers of medicines in the country under the recommended system, they would have the buying power to negotiate lower drug prices, helping to reduce the overall cost of medicines in Canada. They also believed that their proposal would create new opportunities to put in place systems that would reduce the over-prescription, abuse, and misuse of medications.

Coverage of an essential medicines list as an urgent first step

In addition to the core recommendations above, the panel urged governments to act quickly to fill some of the largest gaps in prescription drug coverage in Canada. They recommended that coverage be extended to all Canadians for prescriptions of a carefully selected, minimal list of essential medications, including the relatively small number of drugs that

address major health needs in Canada. Panelists also recommended that provinces and territories maintain or extend existing public drug plans that cover the most vulnerable, and that the federal government develop a plan for covering the often prohibitively expensive medications prescribed to those with rare diseases. The panel emphasized that these urgent first steps represented a stop-gap measure.

Fiscal considerations

The panel considered in broad strokes the basic approach to funding their vision for a national drug coverage program. They recommended revenue tools whereby Canadians contribute to the system in a manner proportionate to their means: primarily through dedicated income and corporate taxes. The panel also recognized the potential of a model where patients pay a portion of the cost of their prescriptions, and they urged the government to study the possible consequences of co-payments — but underlined that under no circumstances must the equity of the system be compromised.

Additional recommendations and supporting policies

The panel recommended that governments work together to take some urgent first steps, filling some of the most pressing gaps in the current patchwork prescription coverage system without delaying the speed with which a comprehensive system is implemented. They advised that governments quickly provide all Canadians with a modest, evidence-based list of medications that together would address a large portion of Canadians' health needs. They also recommended that governments strengthen existing means-tested and catastrophic public insurance programs while a comprehensive universal system is being put in place.

The panel urged governments to develop two information-sharing systems. First, they called for a national medicines data repository, available electronically to prescribers, containing clinical information about all medicines approved for use in Canada as well as their costs. Second, they recommended that uniform standards be developed to share patient prescription and drug fulfillment data, so that information related to patient care would be available when necessary to all prescribers.

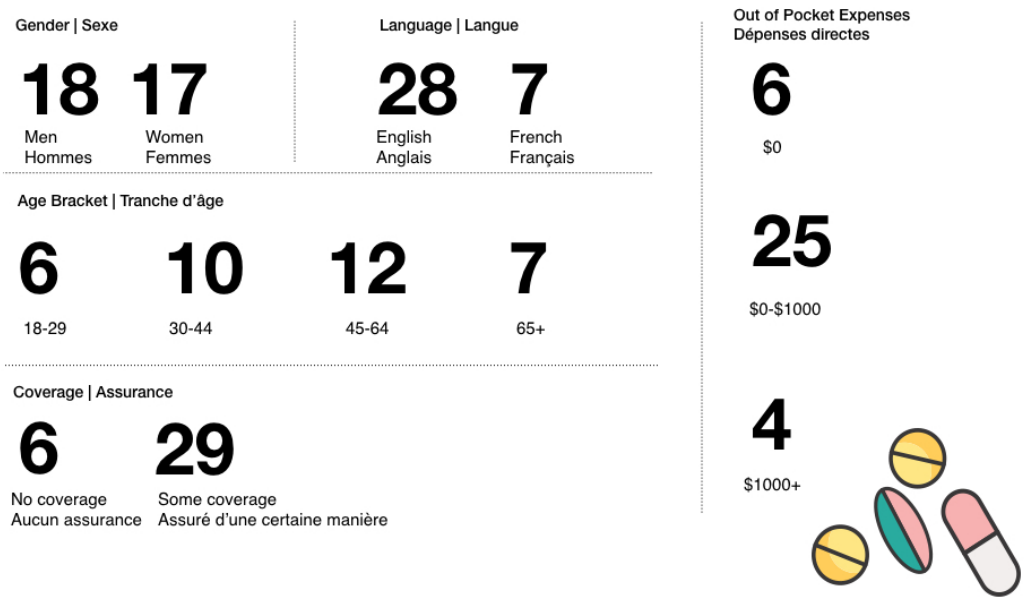
Panelists also called for several national policies to be put in place to further address gaps in access to prescription medications. First, they recommended that governments develop a national plan for providing Canadians with orphan drugs — medications used to treat very rare conditions. Second, they supported expanding mandatory generic substitution policies, which require pharmacists to substitute brand name drugs with lower-cost generics. Third, the panel urged governments to broaden the role in prescribing for nurse practitioners and pharmacists consistently across Canada.

Finally, the panel recommended that governments put in place arm's-length oversight bodies to ensure that the national drug coverage system is fair, evidence-based, and accountable to Canadians.

Panelist place of residence



Panel profile



Meet the members

The 35 members of the Citizens' Reference Panel on Pharmacare in Canada were randomly selected using a Civic Lottery process to broadly represent the demographics of the country. Here, they introduce themselves in their own words.

Alain Tardif, Edmonton, AB | I am originally from Repentigny, Quebec, and moved away in 1983. I am now retired, after a long career at Imperial Oil. I volunteered for this panel because I think pharmacare is an important issue for Canadians, and I wanted to help ensure all Canadians are covered for their prescription medication needs. In my spare time I enjoy gardening, hunting, and cooking.

Claude Dubé, Québec, QC | I was born in Québec City. I studied pharmacy at the Université de Montréal and worked in the pharmaceutical industry for 12 years, which brought me to live in Gatineau, Montréal, and Toronto. I'm currently living in Québec, where I work as a director for a construction and apartment renting firm. I volunteered for this panel to bring my experience to the table.

Emily Dukeshire, Calgary, AB | I am from Calgary, Alberta, where I was born and raised. Most days, I am a full-time mom to my two young daughters. One day a week, I work as a recreation therapist in long term care and mental health. I volunteered to participate in the panel to make my country better for my children and in honour of my great-great-grandparents who made many sacrifices to leave their homelands and come to Canada. When I am not busy working or volunteering, I enjoy racing in triathlons and Spartan races.

Harland Coles, Burnaby, BC | I grew up in the lower mainland of British Columbia, became a skateboarder, and then moved on to a B.Sc. in physics at the University of British Columbia. I am Metis, and bear the blood, knowledge, and spirit of my forbearers, as I learn about my Metis heritage and the history of an interlacing and foundational people of Canada. I am a co-founder and director of Energy X Systems Ltd., providing engineering services as an electrical engineer. And I try to walk humbly with my Lord and Saviour and keep His Word. I volunteered for the panel for many reasons, but the foremost are: I liked the chance to travel to Ottawa and share my views on an important Canadian subject; I wanted to see how this citizen-first process of policy making could work, and help to see it succeed; I have a deep interest in determining my own health and that of my family's; and, I wanted a chance to influence Canadian policy, not to be aimed at consumers of for-profit goods, but to be determined by and for the wellbeing of a citizen, a living soul, and a Canadian.

Heather Greene, Middleton, NS | I am from beautiful Nova Scotia, and I am excited to have a say in how our health care can be better

for everyone. I have six grown children, and now grandchildren, so I care about their future in our health care system. My interests include gardening and rug-hooking.

Jean-Pierre St-Onge, Dieppe, NB | I grew up in Edmunston, NB and for the past 30 years I have lived in Dieppe, NB. Since the age of 25, I have worked in the financial services sector as a representative, team leader, and instructor. I am currently semi-retired while continuing my work as an advisor to those who can benefit from my experience. In my free time, I volunteer with people who require palliative home care. I decided to join the Citizens' Reference Panel because over the course of my career I have observed how many Canadians become very vulnerable when their health status changes. No one in Canada should have to choose between feeding their family and taking the medications they need to survive. My social conscience is highly developed in light of my Christian convictions. I feel the need to speak for those who don't have the opportunity or the education to speak for themselves. If I can humbly propose some avenues for reflection during this process, I will have contributed to the greater good.

Jocelyn Thomas, Chilliwack, BC | I was born in Comox, BC, moved to Abbotsford as a young child, and grew up in the Fraser Valley. I now live in scenic Chilliwack with my husband and our three children. I enjoy golfing, travelling, and camping with my family. I have been part owner/full-time employee at a major Canadian airline for the past ten years. I am also studying child and youth care at the University of the Fraser Valley. I wanted to be on this panel to learn more about pharmacare, to collaborate with the other panelists from across Canada, and to use my voice to try to make a positive change for Canadians.

Julia Cann, Winnipeg, MB | I am from Winnipeg, Manitoba. I have lived there for 13 years. I work as a laboratory technician within the agricultural field. I joined the panel to help make changes to the pharmacare system to improve accessibility to medication within Canada.

Kate Glover, Englehart, ON | I was born in southern Ontario, but now call northeastern Ontario home, where I am a professor at a local community college. I have my feet firmly planted in both the world of the arts, where I am a theatre actor whenever possible, and that of the sciences, which are used at times in my work world. I live in a very rural setting, where health care is something of a luxury for those who can access it. Doctor shortages are plenty, health care specialists are at a distance, and many members of the population in my "immediate" township live below the poverty line and cannot afford pharmaceuticals. I joined the panel because I believe that just because we have always done something one way, doesn't mean it's the best way. I thought it would be an excellent opportunity to participate in our country's great decisions and evoke a positive change.

Larisa Gulenco, Hamilton, ON | I was born in Moldova and lived in the Netherlands and the USA before moving to Canada in 2008. I live in Hamilton. I'm a professional musician, classical pianist, and piano teacher. I joined the panel because I believe that prescription drugs should be more accessible and affordable in our country.

Laura Sargent, Smiths Falls, ON | I have lived in Smiths Falls for five

years, after moving here from Uxbridge, ON. I am a wife and have a long list of hobbies including computers, animals, crafting, colouring, sewing, gardening, and reading. I volunteered for the panel because pharmacare is something I have had to deal with on many fronts. I have been in the position of having to forego medication due to affordability concerns. I want to help move this issue forward in Canada.

Lester Balsillie, Whitehorse, YK | I am from Whitehorse where I have lived for 27 years with my family. I have an 18-year-old son attending Queen's University and a 14-year-old daughter in high school. I enjoy golfing, hiking, mountain biking, and other outdoor adventures. I work for Yukon Housing Corporation as manager of capital projects. I volunteered for the panel because opportunities to be involved in positive change of this magnitude do not come along very often.

Lianne Parent, New Liskeard, ON | I am a professional transition and empowerment coach from Temiskaming Shores, a small community in northern Ontario. I joined the panel as I am interested in assisting in the discussions of pharmaceutical issues that affect myself and others across Canada daily.

Lindsay Ohrling, Yellowknife, NWT | I am a registered nurse living and working in Yellowknife. Having lived in the Northwest Territories for most of my life, I have a unique view of the challenges presented by service delivery in such rural and remote locations. A national pharmacare strategy would have a direct impact on the clients that I work with on a daily basis, and so I felt it was only fitting that I volunteer to draft such a strategy when the opportunity arose. When I'm not working, or spending time with family and friends, I like to travel. The best places to visit are those rich in history, culture, and architecture.

Mark Hiltz, Gibsons, BC | I grew up in Surrey and I have lived in Vancouver and Toronto, and have worked in or visited every province and territory except Labrador. I have been living on the Sunshine Coast of BC for the last 25 years in a rural setting, working for local governments and volunteering with community groups. The Reference Panel happened when I had time available, and I'm ready to see how I can contribute to Canada's health care system.

Marly Babich, Saskatoon, SK | I grew up in Saskatoon but have only recently moved back to complete my bachelor's degree in Anthropology and pursue a master's in sustainable environmental management. Over the past ten years I have lived in Victoria, St Louis, Aspen, Montreal and Angers, France, and I believe my travels have helped me to understand different perspectives and experiences. I joined the panel because I am interested in making health care more accessible to all Canadians.

Martin Fraser, Timberlea, NS | I live and grew up in Halifax. I served six years in the Canadian Armed Forces, and upon leaving, started working at Dalhousie University, where I have worked for the last 27 years. I joined the panel because I am curious about health care in Canada and would like a voice in making it better for all Canadians.

Michael Krause, Mississauga, ON | I have lived in Mississauga for one year, after moving here from Cambridge. I am a father of two and a truck driver. When I'm not spending my free time with my kids, I like to ski. I

volunteered for this panel because I thought it was a very unique and interesting opportunity.

Michael Siska, Thunder Bay, ON | I grew up in Hearst, a small town in Northern Ontario, but now call Thunder Bay home since moving there for university 33 years ago. I am married with three children. In my work as a mental health worker, I see and hear about the challenges many Canadians face when they do not have access to necessary medications. I excitedly volunteered for this panel because I view it as a great opportunity to serve and to help make positive change in Canada. In my free time, I like to paddle outrigger canoes on Lake Superior.

Micheline Allard, Mont St-Hilaire, QC | I have always lived in Quebec and am retired from teaching, where I worked in special education becoming more aware of the issues and challenges that people with differences face. I have travelled extensively. I agreed to participate in this Reference Panel because I have always been careful about my lifestyle and diet with the goal of taking the least medication possible. I worry that too many people are often over-medicated, but I also know it's important that people who need medicine can obtain it.

Mike Otto, St. Albert, AB | I have lived near Edmonton, Alberta, for most of my life, but have worked in many different positions and places, including a summer at a boy scout camp in southern California, two years at a well-to-do girls' camp in Pennsylvania, and three summers in mountain national parks in BC. Right now I am teaching first aid and CPR for St. John Ambulance, and having fun working with different students. I enjoy new adventures and life-long learning.

Nabil Gbian, Saint-Laurent, QC | I left Benin and immigrated to Canada in December 2002. As a graduate of Montreal's Polytechnique and having completing postgraduate studies in IT governance and security at Sherbrooke University, I am now a specialized software engineer working in computer security. I have lived in Montreal since 2002. I am my own boss and am looking for contracts relating to the computer security sector.

Nequila Horne, Kamloops, BC | I am 25 and have worked almost six years as a pharmacy technician, and I am in my third year of nursing school. I have a passion for people and I certainly think with my experience in health care that there are many areas with room for improvement as far as accessibility and coverage of prescription drugs. I have agreed to participate in this panel because I would love to collaborate with other Canadians to improve our health care, both provincially and nationally.

Robert Carrière, St-Hubert, QC | I am a young retiree, father of four children, married to the same woman for the past 42 years, and am happy in my life. I am the former owner of a business which produced interior displays and signage for financial institutions. Today, I am a Caisse Populaire administrator, a very active cooperative. I want to give back and leave my mark for my grandchildren. The first condition for success is communication. Can I bring my viewpoint on the various topics of great magnitude in the health field? What the Reference Panel aims to do is the secret to success: listen, communicate, and find solutions. I am excited to begin.

Robert Doull, Saint-Majorique, QC | I am from Drummondville, Qc., which is one hour east of Montreal, and one and a half hours west of Quebec City. As

much as I am interested in health care, I'm also interested to see how this exercise will be executed and the final results. I speak both English and French and call myself a Canadian Quebec-er. I love music and play some drums.

Ryan Heney, Stouffville, ON | I am a proud father of two.

Shanti Ram Mainali, Regina, SK | I am from Regina, Saskatchewan, where I live with my wife and two sons. I have been in Canada for a year. I am originally from Bhutan, and came to Canada as a refugee from Nepal, where I was a high school teacher. I am now a student of the LINC program at SaskPolytechnic in Regina. I like to make new friends. I enjoy volunteering and social work, and I was looking for a volunteer opportunity when I got the chance to participate in the Citizens' Reference Panel. I am looking forward to learning and sharing my ideas on this panel.

Sharon Debler, Yellowknife, NWT | I have lived in Yellowknife for 45 years, after moving from Quebec. I am now retired after living a life wearing many hats. In my free time, I enjoy gardening, camping, and spending time with family and friends. I volunteered for this panel because I have seen many people — including my immediate family and friends — struggle to pay the cost of prescription medications when they have to pay out of pocket. I would like to see people all across Canada get coverage for prescription medication so that these costs no longer hang a heavy burden on individuals.

Sidney Burdett, Sorrento, BC | I am from Sorrento, BC, a very small town in the Shuswap. I joined the panel because prescription medication is a vital part of modern health care and we should make sure that it is accessible to everyone.

Soh Ouafu, Calgary, AB | I have lived in Calgary for two years after moving to Canada from Italy. I moved here to learn English and am now pursuing a job in my field of civil engineering. I volunteered for the panel because I wanted the opportunity to share my opinions on prescription drug coverage in Canada, and to help improve the health care system. In my spare time, I like to watch and play various sports, especially basketball.

Susan Goold, St. John's, NFLD | I was born in Ireland but grew up in St. John's. Then I moved to Toronto, where I got married, raised a family of four children, and worked for the Toronto District School Board. We retired to Costa Rica but returned to St. John's for family reasons. I am on very expensive drugs (about \$120K a year), and had I had these conditions before returning to St. John's, I would not be covered for them. My autistic daughter is on social assistance and she can't always get her drugs covered. It really concerns me that we don't have a federal pharmacare program to help people with their drugs.

Syed Hussain, Toronto, ON | I have lived in Toronto for over 40 years. I am a professional photographer and have worked at numerous studios in the city, including two of my own in the 1980s. I volunteered for the Citizens' Reference Panel for two reasons. First, I am a Canadian citizen, and if there is any way in which I can help my fellow citizens and government, I believe it is my duty to do so. Second, pharmacare is a very important issue for all Canadians, and an issue I care about personally;

the importance and impact of this topic encouraged me to volunteer for the panel. I am incredibly thankful for the opportunity to serve my country and community by being a member of this Citizens' Reference Panel on Pharmacare in Canada.

Teresa Yeung, Burlington, ON | I grew up in Burlington and lived on University of Toronto campus for a couple of years. I am a finance operations manager at a community health centre. I enjoy working with nurse practitioners, dieticians, mental health and addiction outreach social workers, and youth mentorship program elders to empower patients with holistic health awareness. My hobbies include travelling, nature photography, canoeing, and birdwatching in Northern Ontario. I also enjoy going to movies, museums, and cultural festivals. At the panel, I enjoyed sharing ideas on how to build a cost effective and accessible drug plan with quality service to patients.

Virginia Winter, Murray River, PEI | I am from Prince Edward Island, Canada. I am an artist, having spent a lifetime in cultural affairs, arts, and performance — working in radio and television media as well as with non-profit arts and cultural organizations. I studied and majored in fine arts and broadcast journalism, worked in radio, television, and film media, served in education, and in 2002, founded the Centre for Performing Arts in PEI. I was most pleased to serve on this panel, as I believe my contribution to this very important Citizens' Reference Panel will someday make a positive difference in the lives of not only my family, but for all Canadians, whom I was privileged to serve. It is my hope that our work will serve to enhance our health care system and increase our quality of life universally.

Vivian Chabot, Winnipeg, MB | I grew up in a very small town of approximately 500 people (Elie, MB) and moved to Winnipeg upon graduating from high school. I retired two years ago from a very fulfilling career as a disability case manager for a group insurer. I have been very fortunate to have always enjoyed good health, but have had family members with chronic and terminal illnesses. This exposure, coupled with my career, has allowed me to be empathetic and understanding of others' hardships and challenges.



Emily Dukeshire (Calgary, AB) and Robert Carrière (Saint-Hubert, QC) discuss guiding principles.

Understanding the Reference Panel process

A call to participate and serve

In July 2016, 10,000 bilingual letters were mailed to randomly selected Canadian households inviting any resident to volunteer to become a member of the Citizens' Reference Panel on Pharmacare in Canada. Their task as panelists, if selected, would be to learn about the use of prescription medicines and existing public and private drug coverage models in Canada and in other countries, deliberate about the different mixes of coverage that could respond to the needs and priorities of Canadians, and develop recommendations for provincial, territorial, and federal policy makers.

From among the over 400 people from across the country who volunteered to serve on the Reference Panel, 36 were selected through the made-in-Canada Civic Lottery process. This stratified sampling methodology ensures that panelists are selected at random, but in a way that broadly represents the demographics of Canada — balancing for self-defined gender, age, and identification as an Indigenous person or as a member of a visible minority.

To ensure the group's recommendations were not skewed by panelists' levels of coverage, members of the Reference Panel were also selected to approximately represent the proportion of Canadians who are covered by any form of public or private prescription drug insurance, and for the amount spent out of pocket for prescription drugs in a year.

Panelists were not remunerated, but great lengths were taken to ensure that there were no financial or accessibility-related barriers to any panelist's participation. All travel-related costs were reimbursed, participants were offered all meals and accommodation while in Ottawa, and reimbursements for childcare or eldercare were offered to any who had to make these arrangements in order to participate. As well, simultaneous translation was provided during the presentations and plenary sessions, all materials were provided in both official languages, and several bilingual facilitators were on hand to ensure that panelists could participate fully in the language of their choice.

One of the 36 selected panelists was forced to withdraw for family reasons before the panel began. Because this was a last-minute emergency, it was not possible to select another volunteer to replace her, and so only 35 members joined the Reference Panel in Ottawa.

Working together

The 35 members of the Reference Panel came from all parts of the country to the Panorama Room of the Canadian Museum of History, in Gatineau, Que. — a room which fittingly has a view overlooking the Ottawa River to Parliament Hill. For roughly a third of the participants, this was their first time visiting the nation's capital.

Panelists came from as close as Smiths Falls, an hour drive from the museum, and as far as Whitehorse, some 4,150 km away. The panel members brought diverse backgrounds — they included a pharmacy technician and a truck driver, an engineer and a classical pianist, a retired teacher and a professional photographer. In addition to the 35 adult participants, one fifteen-month-old baby and one service puppy-in-training joined the daily sessions in the Panorama Lounge, which started promptly at 9:00 a.m. every morning and often extended past the end of planned programming at 8:00 p.m.

Expertise and contrasting perspectives

Over the course of just two days, panelists heard from twenty experts. These guest speakers were selected under the guidance of the panel's Advisory and Oversight Committee, a group of health policy leaders that was tasked with ensuring that the curriculum was substantive and impartial.

Panelists were not expected to have any prior knowledge about drug coverage programs, or indeed about the health care system in general. The curriculum was designed to provide panelists with the foundation needed to make informed recommendations — in terms of knowledge and exposure to different points of view — while still remaining accessible.

To achieve this, the curriculum started from core concepts — such as how the health care system works in Canada — and then focused gradually in on the specific issues of prescription drug coverage. After each presentation or panel discussion, speakers engaged in a lengthy question-and-answer session, moderated in such a way as to create a collegial atmosphere and to spark discussion.

The learning program began during the first evening's welcome dinner with a keynote presentation by Greg Marchildon from the University of Toronto, one of Canada's leading experts on health policy. Dr. Marchildon provided an overview of the origins and evolution of the Canadian medicare system. The following morning, Bill Tholl, president and CEO of HealthCareCAN, picked up on several of the themes from Dr. Marchildon's keynote in his overview of health care policy in Canada. His presentation was wide-ranging, touching on topics such as the principles enshrined in the Canada Health Act, to variations in how the health care system is implemented in different parts of the country, and how health spending has changed in recent decades.

The next session brought the focus from the broader health care system to the world of pharmaceutical drugs with presentations on the evolving use of prescription medications. The two speakers for this session were Michael Gaucher from the Canadian Institute for Health Information and

Tanya Potashnik from the Government of Canada's Patented Medicine Prices Review Board. Together, they illustrated recent trends in prescription drug spending in Canada, and situated them within the broader international context. Their presentations covered the rising share of overall health dollars that is spent on drugs, the relatively high cost of drugs in Canada as compared to many comparable jurisdictions, and the increasing price of specialty drugs.

Helen Stevenson then dove into an overview of the “public-private patchwork” that currently represents how Canadians receive coverage for medications, drawing on her expertise as CEO and Founder of the Reformulary Group and former assistant deputy minister of health for Ontario. She also introduced panelists to the concept of a formulary, and picked up on one of the themes from the previous session by tackling the difficult question of how to decide whether to cover extremely expensive medications under public plans.

In the afternoon, panelists heard from their first discussion panel, which addressed the question, “What drugs should all Canadians have access to?” The panel's three speakers represented different perspectives on this issue: Anne Holbrook, from the Department of Medicine at McMaster University, spoke as a clinician; Doug Coyle, professor at the University of Ottawa's School of Epidemiology, Public Health and Preventive Medicine, talked from an economic point of view; and Connie Côté, CEO of the Health Charities Coalition of Canada, represented the patient perspective. The panel explored the medical, financial, and human trade-offs involved in deciding how and whether to cover some medications and not others.

To finish off the day, Colleen Flood, professor and research chair in health law and policy at the University of Ottawa, provided a frank assessment of the political realities of creating a national prescription coverage program in Canada. Professor Flood drew on her in-depth knowledge of Canadian health law and politics as well as her knowledge of drug coverage systems in Canadian provinces and abroad.

The second day of the Reference Panel was opened by Sara Allin from the Institute for Health Policy, Management and Evaluation at the University of Toronto. Dr. Allin presented the different models for drug coverage that exist in countries with comparable health systems to Canada's, such as the UK, New Zealand, and France. She outlined how other countries pay for prescription drugs through different combinations of private insurance, social insurance, and taxes, as well as out-of-pocket payments from patients.

After lunch, panelists heard from two more discussion panels. The first brought in a range of professional perspectives: Linda Silas, president of the Canadian Federation of Nurses Unions; Glen Pearson, from the Canadian Society of Hospital Pharmacists; and Lee Donohue, representing the Canadian Medical Association. All three spoke to the trade-offs around greater and lesser forms of drug coverage, and how their professions — and their patients — might be affected by different choices.

The second panel introduced voices from industry: Glenn Monteith, from Innovative Medicines Canada, representing the perspective of branded manufacturers; Jim Keon, from the Canadian Generic Pharmaceutical Association; Mona Sabharwal, from Rexall pharmacies; and Barbara

Martinez, from The Great-West Life Assurance Company. These speakers discussed how different drug coverage systems might affect their respective industries, and the effects these choices might have on drug prices, innovation, and, ultimately, on patients.

That evening, over a casual dinner back at the hotel, three experts came in to answer questions panelists might have after spending an intense two days being exposed to a large amount of new information: Brent Fraser, from the Canadian Agency for Drugs and Technologies in Health; Lise Bjerre, a family doctor, professor at the University of Ottawa, and researcher with the Institute for Clinical Evaluative Science; and Steve Morgan, the Advisory and Oversight Committee's research lead and a professor at the School of Population and Public Health at the University of British Columbia. The discussion had become more nuanced, with panelists drawing from the different themes touched upon by the many speakers over the past two days. Among the many topics covered, the speakers recommended a focus on the clinical quality of prescribing, and they discussed the potential differences in the prices of drugs that might arise under a system of universal coverage — while urging panelists to take a conservative view of these potential savings.

Finding common ground

In between speaker sessions, panelists had several opportunities to begin processing what they were learning through a number of small-group deliberations. During the first two days of the Reference Panel, they reflected on the core principles that would guide their work and the issues they hoped to address through their recommendations. Their deliberations evolved throughout the two days as presenters seeded their conversations with new information and different points of view.

Through several facilitated small-group discussions and plenary sessions, the panel agreed upon and defined five guiding principles. They also identified a long list of gaps and challenges with existing approaches to prescription drug coverage in Canada. From this list, they settled on a primary list of priorities that they intended to address in their recommendations.

With their principles and issues decided, panelists then began deliberating upon different policy options and drafting their recommendations. This was no easy task, as the speakers who addressed the panel touched on a wide range of choices that would have to be made to design a workable prescription drug coverage program in Canada. They explored the impacts that different policy choices might have on various stakeholders — from patients, to prescribers and health care professionals, to insurers and drug manufacturers.

To assist panelists in developing their recommendations, these policy options were grouped under eight broad questions:

1. Who should be covered by a prescription drug system in Canada?

At a minimum, a national drug coverage system could expand and standardize the current approach taken by different provinces and territories, where public coverage is extended to the most vulnerable, including seniors and people with low incomes. A national system could also offer drug coverage to workers via mandatory employer-based insurance, as in Quebec. At its most expansive, a national drug coverage program could extend to every Canadian.

2. **What medications should be included for coverage?** Under a national program, Canada could choose to cover all medications or restrict itself to a formulary. This formulary could be very broad, or it could be restricted to a basic list, concentrating on a smaller number of essential medicines that account for a large proportion of prescriptions filled by Canadians. Some combination of these options could also be extended to different groups of people — for instance, a minimum list for all Canadians and a more extensive formulary for the most vulnerable.
3. **Who should provide coverage?** Coverage could be provided through a centralised public insurance program, through optional or mandatory private insurance, or through some combination of the two.
4. **Should a national system allow for regional variation?** A centralised system could provide uniform service across the country, or it could leave room for regional variations to account for differences in demographics. It could also allow for differences in how provinces and territories implement the system, while ensuring that all Canadians receive the same baseline level of care.
5. **What supporting policies should be put in place?** The experts who presented during the first two days of the panel named many gaps in the way medications are prescribed, dispensed, and paid for. Some of these gaps would best be filled through supporting actions, rather than directly through a drug coverage system. Some of these supporting policies would only be applicable under a new national system, while others could be put in place immediately.
6. **What, if any, contributions should users make under a national drug coverage system?** Those covered under a national system could be expected to contribute via co-pays or deductibles, or the system could cover the full cost of prescriptions.
7. **What level of government should be responsible for a national drug coverage system?** A national drug coverage program could be run entirely by the federal government or entirely by the provincial and territorial governments, or the responsibility could be shared.
8. **How should revenues be generated to pay for a national drug coverage system?** Although revenue considerations were not its primary mandate, the panel broadly considered how the government should pay for a national drug coverage system — for example through premiums, personal taxes, sales taxes, or corporate taxes.

To focus in on a set of recommendations, panelists first individually considered which option or options they preferred within each category and discussed their choices with one another in small groups. The panelists then grouped themselves with others who had made similar choices in each category. Each group developed the best “case” for the programmatic decisions they had made, and the groups presented back to one another in plenary.

With further deliberation in plenary, by the end of the third day, the panel had distilled its recommendations to a core set of reforms that the panel-

ists believed would achieve their vision for a drug coverage system that would truly serve the needs of all Canadians. The panel also identified a series of urgent first steps that should be undertaken immediately in order to fill the large gaps and inconsistencies in prescription coverage in Canada. They emphasized that these should be seen as a stop-gap measure only — and in no way as an acceptable endpoint for drug coverage in Canada.

On the final day of the Reference Panel, panelists split into five groups to draft their final report. The first two groups wrote up the panel's recommendations. A third group described the supporting policies that panelists had agreed upon, while a fourth laid out the principles behind revenue generation and user contributions that would be necessary to finance a drug coverage program. The final group wrote a preamble to the panel's report, describing in their own words who the panelists are, why they volunteered, and their experience of their four days together in the nation's capital.

This Citizens' Reference Panel brought together 35 Canadians chosen at random, hailing from every corner of the country, speaking different languages, and having very different points of view and life experiences. Together, through learning and respectful deliberation, they sketched out a system of prescription drug coverage that they agreed would best serve the needs and interests of all Canadians. The following pages contain their recommendations, in their own words.

Policy Options | Options de politiques

Who is covered? Qui est couvert?	For what? Pour quoi?	By whom? Par qui?	Supporting policies? Politiques de soutien?	User contribution? Contribution de l'utilisateur?	Revenues? Revenus?
Everyone Tout le monde	Everything Tout	Public insurance Assurance publique	Mandatory generic substitution Substitution générique obligatoire	Co-pay Copalements	Premiums (Social insurance) Primes (Assurance sociale)
Low income Faibles revenus	Evidence-based complete list Liste complète fondée sur les données probantes	Mandatory Private insurance Assurance privée obligatoire	Decision aids for doctors Outils aidant la prise de décision des médecins	Deductible Deductible	Personal taxes Impôts particuliers
Seniors Aînés	Minimum list Liste minimale	Optional private insurance Assurance privée optionnelle	National Formulary Formulaire national	None Aucune	Sales taxes Taxes de vente
Workers Travailleurs	Rare Diseases Maladies rares	Regional variation? Variation régionale?	Black list Liste noire	Government responsibility? Responsabilité du gouvernement?	Corporate taxes Impôts corporatifs
Children Enfants			National Medicines Data Repository Base de données nationale de référence	Federal Fédéral	
			Watch dog Chien de garde	Provincial & Territorial	
		Some Une certaine variation	...	Shared Partagée	
		None Aucune variation			

This diagram was developed to assist the panel in considering the different building blocks that could make up a national prescription drug program. Working in small groups and then as a whole, the panelists decided which options in each category would create the best system for Canada.



Guest speaker Helen Stevenson (Founder & CEO, Reformulary Group)

The Report of the Citizens' Reference Panel on Pharmacare in Canada

Preamble

We are a group of 35 volunteers randomly selected from across the provinces and territories of Canada. We represent the population, geography, and languages of Canada, and we range in age from 15 months to over 65 years. We came together to learn about how prescription medications are covered in Canada, and to recommend changes that will benefit all Canadians. After hearing from twenty experts and deliberating amongst ourselves at length, we believe that it is in the interest of all Canadians to put in place a universal pharmacare system that builds on the goals of the Canada Health Act. We are the Citizens' Reference Panel on Pharmacare in Canada, and we believe this is the way forward.

As a country, Canada has unfinished business. The process of creating a comprehensive health care system started long ago. And yet, we are the only developed nation in the world with universal health care but also millions of citizens who do not have access to prescription drug coverage. Over the course of five days, the panel learned an enormous amount from experts in the field, including clinicians, pharmaceutical industry representatives, insurance providers, economists, lawyers, doctors, pharmacists, nurses, professors, and others. We learned about and drew inspiration from many other drug coverage systems that exist in the international community. We also learned from each other, sharing our unique perspectives and specific regional experiences and knowledge.

Through this process, we gained the knowledge and the vocabulary to speak about this complicated system which impacts everyone. We want to share this with our fellow Canadians, because we believe these are vital issues that matter to all, and will continue to impact future generations. We want to provide a voice for those who are not insured or are under-insured. We came together with a variety of opinions, but now we have a unified vision.

There is an urgency behind our recommendations, and action needs to be taken immediately. People are suffering and dying, as our current system does not meet their needs. Our population is aging, and new needs are emerging. We have to look out for all Canadians, young and old, regardless of socioeconomic status. The time is now — we want to join in the conversation that's starting on Parliament Hill, in provincial and territorial legislatures, and in the media.

We, as a panel, expect our federal, provincial, and territorial political representatives to listen to and review our advice.

Our principles

The Reference Panel believes that a national pharmacare system that is rooted in the following core principles will best serve the interests of Canadians. We have defined these principles as a starting point for developing a robust set of desired outcomes. The principles are listed in no particular order.

Universal

A national pharmacare system must be a universal program for every Canadian. National, uniform standards will be applied in every province and territory, ensuring that oversight and implementation are consistent across the country. We believe universality is necessary to ensure that the system is fair, equitable, and portable.

Evidence-based

Decisions regarding the inclusion of specific medications in a formulary under a national pharmacare system must be based on evidence. Each drug included on the formulary must be proven to be effective and safe. Drugs must also meet a rigorous cost-effectiveness standard. Similarly, pharmaceutical treatments used by Canadians must continue to be proven effective and safe through impartial clinical studies. The process for approving medications must always be subject to scrutiny, ensuring continued relevance and continuous improvement.

Patient-Centred

A national pharmacare system must ensure an active role for patients, placing their priorities and interests at the core of their care, regardless of their ability to pay. This requires education and open dialogue between prescribers and patients. This bottom-up approach should ensure fair, equitable, and regionally appropriate access to treatment.

Sustainable

A national pharmacare system must be long-term and durable — it must endure for future generations. Its financial sustainability relies on independently monitored fiscal responsibility. Its long-term durability rests on the system remaining independent of politics so that it cannot be terminated by a particular government for political reasons, and so that the program is managed by experts who make decisions based on evidence without political pressures.

Accountable

A national pharmacare system must be accountable to Canadians. This occurs when information about the system is shared in a transparent and accessible way, when there is a clear commitment to its stewardship, and when its fiscal management is independent and responsible. Those who manage the system demonstrate accountability if they act as negotiators, representatives, and advocates for all Canadians. Trust in the system's accountability will be built over time with robust fiscal monitoring, public engagement and feedback, and a demonstrable effect on patient outcomes.

Issues and concerns

There are many gaps that a national pharmacare system must address. We have identified the issues below as a starting point — there are many other points of concern not explicitly stated here. As a national pharmacare system is created, the issues below must be addressed in some form. They are listed in no particular order.

- The current patchwork system leaves millions of Canadians without the coverage they need. This leads to poor patient outcomes, a lack of adherence to medication, and a drain on the rest of the health care system.
- The current system is fractured, with different provinces and drug insurance providers operating independently. As a result, Canada lacks the collective bargaining power to negotiate appropriate drug prices with pharmaceutical producers.
- There is no national standard for collecting and sharing data about the costs and benefits of treatment options as well as patient medication histories. Without access to this data, patients and prescribers cannot make decisions with accuracy, nor can they take into account drug costs when selecting prescriptions. Moreover, without this data, trends cannot be tracked across the country.
- The over-prescription abuse, and misuse of prescriptions lead to poor patient outcomes as well as a financial drain on private and public insurers.
- There is a lack of awareness among Canadians about the current state of drug coverage in Canada due to a lack of communication, transparency, and accountability on the part of government.
- There is insufficient oversight of pharmaceutical manufacturers, which leads to high drug prices. Manufacturers are not forthcoming about the true cost of research and development for drugs, which creates confusion about fair prices. Manufacturers also actively seek patent extensions to prevent cost-effective generics from entering the market.
- There is no uniform standard around the use of generic drugs, and there is a lack of awareness about different drugs' efficacy and the options available to doctors and patients. Costs are increased when patients choose higher-cost brand name drugs over lower-cost generics when they are appropriate. There are also supply and inventory problems for pharmacists, with generic drugs not always available when they are needed.
- There are regional variations in the prices Canadians pay for drugs and in Canadians' ability to access certain medications. Administrative, infrastructure, and logistical costs are different in urban, rural, and remote areas. This can impact the availability of medications, the price patients pay for drugs, and the financial burden on local health systems. Markups and fees vary from pharmacy to pharmacy, also affecting the prices patients pay for drugs. These varia-

tions create financial inequities and regional differences in health outcomes for Canadians.

- Doctors, nurses, nurse practitioners, and pharmacists currently have widely divergent scopes of practice in different provinces and territories. This creates unevenness in patient services.

Our recommendations

We recommend the following reforms to create a national pharmacare system for Canada. The panel has reached consensus that this system will most effectively reflect the principles and address the issues outlined above. The following represents our vision of a system that we, as Canadians, could be proud of.

A national pharmacare system should cover all Canadians because we believe in the principle of universality. Canadians view universal health care as a right, and prescription drug coverage is an essential part of health care. Providing universal coverage to everyone will address the fact that millions of Canadians are currently uninsured or underinsured.

A national pharmacare system should provide coverage for drugs on a comprehensive, evidence-based complete list. Medicines should be selected for this list based on medical and cost effectiveness. New drugs will be evaluated using these same criteria before they are added to the formulary. In order to be patient-centred, this list should be ample enough that it provides sufficient flexibility to take into account individual patient circumstances. This list will include the drugs proven to be most suitable for all conditions, including rare and catastrophic diseases.

This national pharmacare system should be provided through public insurance. This will ensure all Canadians have the same access to pharmaceutical coverage. It will unify buying power for the country as a whole, leading to decreased costs. A public insurance system should be accountable to Canadians through an arm's-length agency free from any profit-motive.

This system must also allow individuals and employers to continue to purchase optional private drug insurance. However, all essential, medically necessary drugs will be covered for all Canadians under the public system. Private insurance will be considered a separate entity and will cover only drugs that are approved for use in Canada and not included on the evidence-based complete list. This will support a patient-centred approach that allows for individual choice.

Canada is a large and diverse country. The panel recognises that a certain amount of regional variation will exist under a national pharmacare system, as it does with the Medicare system, due to different regional demographics and needs. However, regardless of any differences in implementation at the provincial or territorial level, the system must provide comparable levels of coverage everywhere in Canada, such that patients' access to medications is equitable across the country.

Immediate actions

We propose the following actions to quickly fill some of the gaps in care that exist in Canada. What follows should not be considered final results but urgent reforms to be followed very quickly by the recommendations described above.

We urge the federal government to immediately implement universal public coverage of a minimal list of essential medications across the country. This minimal list will include a relatively small number of carefully selected drugs that effectively address major public health needs in Canada and that represent a large proportion of the prescriptions written for Canadians each year. Focusing on a minimal list will increase Canada's buying power for these drugs, potentially leading to a decrease in their cost. This will allow the medical field to offer some of the most effective medications at the lowest possible cost.

We recommend that this minimal list of medications be offered universally to all Canadians, as a measure to ensure universal access to essential medicines while addressing the high and increasing costs of prescription drugs.

We also strongly urge that the federal government to work with the provinces and territories to maintain or enhance existing public drug plans that provide comprehensive coverage to those who are the most vulnerable (such as seniors, people who are uninsured or underinsured, and those with low incomes) while the ultimate vision of comprehensive coverage for all is planned and implemented. This would maintain and possibly improve adherence with necessary medicines for these groups, leading to better health outcomes.

In addition, we recommend that the federal government cover drugs for those with rare diseases, as these can be very expensive, leading to people not taking life-saving medication. In the long run, this may save money by reducing hospital stays and improving quality of life.

In order to be effective, this strategy must be managed and financed by the federal government, taking into account health trends and demographics.

Additional actions

We propose the following policies to support the above recommendations. Many of these policies may be implemented immediately to improve the current patchwork drug coverage system.

National drug formulary

We encourage the immediate implementation of a national drug formulary. This national formulary may begin with the minimal list proposed under our immediate actions, and continue to be improved by implementing the evidence-based complete list proposed under our primary recommendations. This will begin to consolidate our buying power, thus lowering prices and costs to all Canadians. This will form the basis of an evidence-based system that selects the best and most cost-effective medicines to be accessible universally.

National medicines data repository

We recommend the creation of a national medicines information repository that improves upon and amalgamates the current databases in place. This repository must be available electronically to all primary care providers and include accurate, constantly updated information about all medications approved for use in Canada. This database must include clinical and cost information about all medicines to support health care providers' decisions when prescribing drugs. A national database that tracks information about drug inventories could also potentially aid in managing the supplies of drugs between regions. It would also provide a source of data for researchers.

National Patient Prescription and Drug Fulfillment Database

In many provinces, records of patients' prescriptions and drug fulfillments are often kept and managed only at the pharmacy level, and are therefore restricted to the pharmacy specific to the client and the attending subscribers. We strongly urge the creation of a national data standard for tracking patient medication histories, accessible to prescribers where appropriate. In this way, patients and prescribers can make appropriately informed decisions, such that over-prescription and abuse are avoided, and appropriate prescription of medications is ensured.

This universal data standard could also enable researchers, citizens, and the government to access anonymised, aggregate data about health and drugs, and see how they vary by population and region. This will allow for the assessment of regionally appropriate needs and areas of focus for prevention and education. It will also help project future needs. In short, the data standard would allow information to be collected that would help guide the decision-making process for the pharmacare system. We further strongly urge the federal government to take into careful consideration the privacy and security implications of such a data system, guarding against any possibilities of abuse.

Orphan drug strategy

We recommend that the federal government, with input from clinicians and researchers, take immediate action to develop a sustainable, equitable orphan drug plan. Orphan drugs are medications that treat very rare medical conditions — these drugs are often very expensive. The orphan drug strategy should include guiding principles regarding the coverage of medications for rare diseases. These guiding principles should inform cost-benefit decisions about which drugs to include in the national formulary. They should also include a national strategy to finance orphan drugs, in order to ease the excessive financial burden that might be placed on smaller provinces or those with a disproportionate burden of disease requiring costly treatments.

Mandatory generic substitution policy

A policy of mandatory generic substitutions that are already common in public drug plans in Canada should be expanded as the system of universal drug coverage evolves, because generics have proven to be as effective as brand name drugs, and that come at a lower price. This will create consistency across the country for providers, prescribers, and patients. It will also reduce costs, helping to create a sustainable, cost-effective program. Finally, it will support our local economy, since Canada has a robust generic manufacturing industry.

Arm's length oversight bodies

We urge the federal government to establish an impartial national oversight body to take responsibility for negotiating a fair, evidence-based, accountable system of universal coverage. We also recommend the federal government create an independent pharmacare “watchdog” mechanism to monitor and audit the delivery of the system, with sufficient authority to mediate and correct any problems that arise. This watchdog should also take steps to prevent or disincentivise financial ties between prescribers and the pharmaceutical industry, in order to ensure that treatment decisions are always based on evidence. These oversight mechanisms must be put in place prior to the establishment of other components of the pharmacare system.

More prescribers

We advise that a national pharmacare system include an expanded prescriber role for nurse practitioners and pharmacists in order to improve access to medications and to reduce the burden on physicians and hospitals for routine prescribing.

Fiscal considerations

In considering an appropriate fiscal model to fund a national pharmacare system, the panel recommends the following:

- Revenues should be raised principally through a combination of income and corporate taxes. We believe all Canadians should contribute to a national pharmacare system in a manner proportionate to their means. We also believe that some of the savings accrued to businesses that will no longer need to provide the same level of drug coverage for employees under a national pharmacare system should be captured to partially fund this system.
- These income and corporate taxes should be dedicated to pharmacare, and these charges should be clearly identified and known by Canadians. For example, taxes that are dedicated toward pharmacare are preferable to taxes that are lumped in with other sources of revenue.
- The panel recognizes the revenue potential of a co-payment model and urges the government to conduct more research into the consequences and administrative costs of different models. At the same time, the panel expresses strong reservations about the health and equity consequences of high co-payments and seeks to endorse a system that maximizes social solidarity by minimising out-of-pocket costs.



Kate Glover (Englehart, ON) introduces herself to her fellow panelists on the first day of the Reference Panel.

Appendices

Minority reports

Panelists were encouraged to share all points of view throughout the Reference Panel process. Discussion remained lively but respectful throughout the process, and while some minor differences in opinion remained, every member of the panel endorsed the recommendations in this final report. However, panelists were given the opportunity to write a minority report if they wished to highlight any points of agreement and disagreement, or to include their own commentary.

Robert Carrière: I believe that asking the provinces and territories to reach an agreement with the federal government to put in place a universal pharmacare system is almost impossible in the short, medium, and long term. It would be like trying to join the two oceans together. The provision of health care remains the preserve of each province and territory, and none of them will want to give up this power. Attempting to rally everyone around a national system runs the risk that such a system will never see the light of day. Besides this issue, I agree with the other proposals in this report.

To solve this problem, from the first days of the Reference Panel, I suggested that a cooperative could act rapidly to, first, create a national buying group for prescription medicines, and second, put in place the technical systems necessary to create a centralised information repository. Each province and territory would be a co-owner and member of this cooperative. To do this, I would be in favour of economic and political restructuring. I believe a model like this would be simple, modern, humane, and effective — and it would be a system that people could trust.

Harland R. Coles: As my first thought here, I commend the process and the people who created and made this Citizens' Reference Panel happen. It gathered from across Canada a varied group of all ages, and asked us to mold a well informed opinion into a unified Canadian perspective and recommendation. And we succeeded. Not all in absolute agreement, but through this process we bore out a set of fundamental values and the heart of many of the issues within our current system (or lack thereof). This jury of peers hashed out all aspects of 'pharmacare', and only the tiniest of stones were left unturned. I want to emphasize, while our final report may show a seemingly simple and concise way forward, it was so carved leaving much sawdust on the work floor. I am confident

this process brought forth what any group of Canadians, gathered in the same way, would ultimately recommend — showing a true Canadian value set.

While I am swayed by the consensus of the panel, there are a few points I feel I need to strengthen. I firmly believe that the primary goal of the government, and any legislative committee for a pharmacare system, should be to produce a unwavering standard and a strict set of guidelines. A kind of Constitution of Pharmacare, where every Canadian can expect the same standard of principles and practice, and that can be used as an implementation guide. This will build a confidence of expectation by patients and all providers of pharmaceuticals. And at its core, it will solidly uphold Canadian values and the citizens' power of choice and responsibility for their own health and well being. Canada sets the rule for the benefit of its people and industry cannot lobby to undermine those rules, by precedent or treaty. However, under the guidance of this rule-set, the pharmacare program should be implemented by the Canadian people and industry. And while each province should regulate and oversee the implementation, they must remain accountable to the standards and guidance, which are maintained and enforced by Canada. For example, for any system of pharmacare data exchange, Canada should determine the protocol, and then the work of the implementation should be distributed to and completed by Canadians (a useful template example is the TCP/IP internet protocol, as maintained by the IETF/IAB and implemented by industry).

Ultimately, the system to be structured should provide a health benefit, not a drug prescription. I grew up with asthma and used what was recommended by physicians to control my symptoms. With age and experience, I decided to try a different, reasoned approach and see if there was a better way. I improved and eventually resolved that my asthma could be almost nullified by a change in diet and health choices. So as a concern, I also strongly propose this Standard include the ability to choose alternative methods, and by that choice, suffer no loss of care.

A final and fundamental point I want to reinforce is one of citizen versus consumer. We as Canadians, in the eyes of the government and its subsequent law and acts, must be viewed as citizens first. That is, I want any standards or guidance influenced by this report to be grown out of a motivation that Canadians seek health and well being — and that Canadians are not labelled or targeted as consumers, of a for-profit product. This distinction is vital, and any Canadian pharmacare system developed with this in mind, will truly consider and benefit Canadians first.

Again, I thank all those instrumental and behind the scenes that made this opportunity possible, and even more, an enjoyment to participate in.

Laura Sargent: Overall, I agree with the report produced by the Citizens' Reference Panel on Pharmacare in Canada. There are two aspects of the report I wish to voice my own opinion on: funding and the co-pay system.

I believe that Canadians should not be taxed again to fund this program. Middle class and blue-collar workers already pay enough taxes. By reducing the amount of GST that is returned to Canadians, this program could be funded through existing taxes. The only additional tax that could be implemented, if need be, should be on the affluent. The average person is already paying enough.

Co-pay should not be included in the report since this already exists. So long as there is a minimum drug list that is covered, there should not be a co-pay system. Two dollars can be too much for some people to get

a prescription and not all pharmacies have \$0 co-pays (especially those located in smaller towns).

Some drugs should also be reclassified as necessary on a case-by-case basis. For example, a cancer patient who is losing their hair should have access to prescription drugs that will lessen this loss. I also believe that medical marijuana should be covered for those who have prescriptions.

Virginia Winters: Serving on the Citizens' Reference Panel on Pharmacare in Canada allowed me to recognize the strengths and weaknesses of our current health care system. While we are most fortunate to live in a country that does provide a comprehensive medicare and hospital care program for its people, there are certain weaknesses that when addressed can enhance the program for generations to come.

One such area which I believe strongly needs to receive some focus is the portability of our system inter-provincially — i.e. benefits provided equitably across our country to persons with legitimate health cards. We learned that the Canada Health Act does contain the principle of portability, which should mean that any Canadian with a valid health card should receive services without charge and without refusal anywhere in Canada. Yet, this is not always the case in reality. Some provinces "will not" accept a health card from another province and medical providers have either turned away patients and refused services or demanded payment up front with the onus on the patient to be reimbursed from their home province. If they pay for their medical services up front, they often only receive a portion in reimbursement from their home province, which determines the amount for the service it is willing to pay. This inequity renders patients unable to receive the medical attention they require, or to pay out-of-pocket for the privilege of receiving medical or hospital care, which is supposed to be covered universally.

A pharmacare program could suffer the same consequences. If the issue of portability is not addressed clearly and explicitly when creating a national pharmacare program, there is the risk that similar problems related to inter-provincial portability will exist in this system as well.

Our health ministers both federally and provincially have a very unique opportunity to strengthen our current system to perfect that which began five decades ago when universal health care was first introduced to our country. If we are to realize that potential, with the inclusion of pharmacare, I strongly believe that strengthening those weaknesses, in particular the issue of portability which is a harsh reality, is critical. A pharmacare system must, therefore, explicitly address and clearly define and include the words: inter-provincial portability.



Susan Goold (St. John's, NL) shares a light moment with a guest speaker.

Guest Presenters

Twenty experts generously gave their time and shared their knowledge with the Citizens' Reference Panel on Pharmacare in Canada. The panel extends its sincerest thanks to each of them.

Dr. Sara Allin, Assistant Professor, Institute for Health Policy, Management and Evaluation, University of Toronto; Senior Researcher, Canadian Institute for Health Information. | In her work at the University of Toronto, Sara has research underway on comparative health policy, prescribing patterns, and the public-private mix in financing and delivery of health care in high-income countries. At CIHI, she works in the population health branch, where she leads projects related to health system performance and inequalities in health.

Dr. Lise M. Bjerre, Assistant Professor, Department of Family Medicine, University of Ottawa; Adjunct Scientist, Institute for Clinical Evaluative Sciences. | Lise is an epidemiologist and a family physician. She is a researcher at the University of Ottawa and a staff physician at the Ottawa Hospital. Her research focuses on medication appropriateness in primary care, and particularly on potentially inappropriate prescribing (PIP) in primary care. Lise and her team on the Ottawa Rational Therapeutics and Medication Policy Research Group develop strategies and targeted interventions to reduce the number of and impact of PIP on Canadians' health.

Connie Côté, Chief Executive Officer, Health Charities Coalition of Canada. | Connie has been involved in the not-for-profit, regulatory, and charitable health sectors for over twenty years. Her current priorities include advocating on issues related to health research and health policy, working with members to identify areas of alignment and opportunity, and representing the coalition at various meetings, events, and conferences. Connie has previously worked with the Canadian Lung Association, the Federation of Medical Regulatory Authorities of Canada, and the Royal College of Physicians and Surgeons of Canada.

Dr. Doug Coyle, Professor and Interim Director, School of Epidemiology, Public Health and Preventive Medicine, University of Ottawa. | Doug's research focuses on the methods of conducting economic evaluation of health care interventions. He has an interest in the sustainability of Canada's publicly funded health care system and has advised provincial and federal governments regarding the reimbursement of health technologies. He is an expert in health economics and has authored more than 180 peer-reviewed articles.

Dr. Lee Donohue, Board Director, Ontario Medical Association. | Lee has worked as a family physician in Ottawa since 1988. She has a keen interest in advocating for reduced inequity and improving care at local, provincial, and federal levels. Lee is former Chair of the OMA Section of General and Family Practice. She is a Champlain Regional Primary Care Cancer Lead and is an OntarioMD peer leader. She has also served on several committees at the Canadian Medical Association including as a delegate to CMA General Council.

Colleen M. Flood, Director, Ottawa Centre for Health Law, Policy and Ethics; University of Ottawa Research Chair in Health Law & Policy. | Colleen's primary areas of scholarship are in comparative health care law and policy, public/private financing of health care systems, health care reform, constitutional law, administrative law, and accountability and governance issues more broadly. Previously, Colleen has held a Canada Research Chair at the Faculty of Law, University of Toronto, and served as Scientific Director of the Canadian Institute for Health Services and Policy Research.

Brent Fraser, Vice-President Pharmaceutical Reviews, Canadian Agency for Drugs and Technologies in Health. | Brent is responsible for the CADTH Common Drug Review, the pan-Canadian Oncology Drug Review, therapeutic class reviews, and optimal use projects, as well as drug-related Environmental Scans, Horizon Scans, and Rapid Response reports. Brent and his team deliver assessments of drugs using the best available tools, science, and methodologies. Brent combines a pharmacist's appreciation for the clinical and human implications of his work with strategic skills developed over many years of working in the field of drug funding decision-making.

Michael Gaucher, Director, Pharmaceuticals and Health Workforce Information Services, Canadian Institute for Health Information. | Michael is responsible for providing vision and strategic leadership at CIHI, while ensuring the production of reports in the areas of pharmaceuticals and health workforce. Michael has previously worked for over twenty years

in hospital pharmacy, including ten years as Director of Pharmacy for the Saskatoon Health Region. He also worked with the Canadian Agency for Drugs and Technologies in Health.

Dr. Anne Holbrook, Director of the Division of Clinical Pharmacology & Toxicology, Department of Medicine, McMaster University. | Anne is a Professor at McMaster University and an active medical staff member at St Joseph's Healthcare Hamilton and Hamilton Health Sciences. She trains medical students, residents, fellows, PharmD students, and practicing physicians and pharmacists in evidence-based prescribing. Anne leads multiple peer-reviewed research projects, all directed at improving the quality of medication access, prescribing, use and regulation. She is an expert advisor for drug policy at all levels of government.

Jim Keon, President, Canadian Generic Pharmaceutical Association. | Jim represents Canada's generic pharmaceutical industry. He advocates for fair and balanced patent laws and government resources for the review and timely availability of generic drugs for Canadians. He works closely with provincial governments to help them control drug costs through the listing of generic medicines on provincial drug plan formularies. Jim has previously held senior positions in the federal government, and he was a past chair and member of the International Generic and Biosimilar Medicines Association.

Dr. Gregory Marchildon, Ontario Research Chair in Health Policy and System Design, Institute of Health Policy, Management and Evaluation, University of Toronto. | Greg has written extensively on subjects such as public policy, federal-provincial relations, and Canadian history. In recent years, he has focused on health policy, comparative health systems and the policy history of Canadian Medicare. Greg currently holds an Ontario Research Chair in Health Policy and System Design with the Institute of Health Policy, Management and Evaluation at the University of Toronto. He is also a fellow of the Canadian Academy of Health Sciences; and a founding member of the Pan-Canadian Health Reform Analysis Network.

Barbara Martinez, National Practice Leader, Drug Benefits Solutions, The Great-West Life Assurance Company. | Barbara provides support to Great-West Life Group Sales Offices across Canada on prescription drug management initiatives. Barbara has in-depth knowledge of the regulatory and drug-approval process in Canada from both a government and private drug plan perspective. Barbara's experience includes thirteen years of working in the pharmaceutical industry.

Glenn Monteith, Vice President Innovation and Health Sustainability, Innovative Medicines Canada. | Glenn is an economist by training and vocation. He was previously with Alberta Health and Wellness, holding several roles including Executive Director of the Pharmaceuticals and Life Sciences Branch, Assistant Deputy Minister of the Health Workforce Division and most recently Chief Delivery Officer. Glenn also has a wealth of experience in the private sector, having worked for large multi-national pharmaceutical and life sciences companies and health management consulting firms.

Dr. Steven G. Morgan, Professor, School of Population and Public Health, University of British Columbia. | Steve is an expert in pharmaceutical policy. His research helps governments balance three goals: providing equitable access to necessary medicines, managing health care spending responsibly, and providing incentive for valued innovation. Steve has published over 100 peer-reviewed research papers on pharmaceutical policies. He has advised governments in Canada and abroad, and has produced work for the WHO and the OECD.

Dr. Glen Pearson, Professor, Faculty of Medicine & Dentistry, University of Alberta; President & External Liaison, Canadian Society of Hospital Pharmacists. | Glen is Associate Chair of the Health Research Ethics Boards at the University of Alberta, where he also lectures and supervises PharmD students in clinical rotations. He has an active interest in practice-based research and has published numerous articles on the topic. In particular, he is an avid proponent of the role of pharmacists in improving patient outcomes and the delivery of collaborative health services.

Tanya Potashnik, Director, Policy & Economic Analysis Branch, Patented Medicine Prices Review Board, Government of Canada. | A career public servant, Tanya possesses a breadth of knowledge in the areas of pharmaceutical policy, market dynamics, and pricing in Canada and internationally. At the Patented Medicine Prices Review Board, she is responsible for leading the development of strategic policy advice, economic analysis, and the management of stakeholder relations for the Board. Tanya has also held various policy and management positions in the federal government and the British Columbia Ministry of Health.

Dr. Mona Sabharwal, Vice President Industry and Regulatory Affairs, Rexall Canada. | Mona has been involved in pharmaceutical policy for over twenty years, working in drug technology assessment, formulary management, and policy development in both British Columbia and Ontario. She was the inaugural Executive Director of the pan-Canadian Oncology Drug Review, leading implementation of the national initiative and then overseeing its successful operational integration into CADTH. Mona is a registered pharmacist with experience in both community and hospital pharmacy practice.

Linda Silas, President, Canadian Federation of Nurses Union. | Linda is driven to make a difference for nurses in their working lives and advocates for nearly 200,000 member nurses of CFNU in Canada. She brings experience as a nurse leader and negotiator at the local, provincial and federal levels. Linda has also lectured domestically and internationally on nursing, women's issues, social policy, economics, and political science. Linda firmly believes health care is a human right and works to embody the CFNU motto, "where knowledge meets know-how."

Helen Stevenson, Founder & CEO, Reformulary Group. | Helen is the former Assistant Deputy Minister of Health for Ontario and CEO of the \$4 billion Ontario Public Drug Programs, leading the government to a \$1.5 billion in savings over five years. Prior to that, Helen was Executive Lead of the Drug System Secretariat in the Ontario Ministry of Health and Long-Term Care and led significant reforms to the prescription drug system under Bill 102.

Bill Tholl, President and CEO, HealthCareCAN. | Bill serves as Founding President and CEO of HealthCareCAN, the voice of Canada's health care organizations and hospitals. He has previously served as CEO and Secretary General of the Canadian Medical Association and the Heart and Stroke Foundation of Canada. Bill writes and speaks about a variety of topics including leadership in health care. He holds a graduate degree in health economics from the University of Manitoba.



Emily Dukeshire (Calgary, AB) listens to the simultaneous translation of a panelist's remarks.

The Advisory and Oversight Committee

The Citizens' Reference Panel on Pharmacare in Canada was supported by an Advisory and Oversight Committee made up of academics, physicians, and policy leaders from across Canada, all with well regarded expertise in health policy. Working with the project team throughout its mandate, this Committee ensured that the design and conduct of the Reference Panel were consistent with good democratic practices, and that the learning program was adequate, balanced and represented a range of perspectives. The Advisory and Oversight Committee remains impartial and will not comment on the recommendations made by the Reference Panel.

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Our funders

The Citizens' Reference Panel on Pharmacare in Canada was funded primarily by a grant from the Canadian Institutes of Health Research, a federally funded research agency that provides more than \$900 million in peer-reviewed grants each year to advance medical research and health policy.



Additional contributions to this project were provided by the following organisations:

Lead contributors:



Other contributors:



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Necessary Medicines:

Recommendations of the
Citizens' Reference Panel on
Pharmacare in Canada