

**A PATIENT VISION FOR PHARMACARE IN CANADA  
REPORT from the ONCOLOGY ROUNDTABLE MEETING**

**June 1<sup>st</sup>, 2016  
Toronto Ontario**

**INTRODUCTION**

In its capacity as an oncology patient community health policy leader, the Canadian Cancer Survivor Network (CCSN) convened a roundtable in partnership with allied mental health groups to formulate a common patient position and perspective on Pharmacare at a daylong event at the Vaughn Estate located on the grounds of Sunnybrook Health Sciences Centre on June 1<sup>st</sup>, 2016. CCSN was supported in this effort by a Steering Committee including representatives from Save Your Skin Foundation, Lung Cancer Canada, The Schizophrenia Society of Ontario, The Carcinoid Neuroendocrine Tumour Society and The Colorectal Cancer Society of Canada. CCSN gathered representatives from the oncology community and allied partners in the mental health community to come together to develop a patient centred statement of purpose – **A PATIENT VISION FOR PHARMACARE IN CANADA** – a vision supported by values and principles that could serve as a lens or filter through which proposed health and health system policies related to Pharmacare in Canada could be analyzed and critiqued. Jackie Manthorne, CEO of CCSN, welcomed the participants to the day.

**SETTING THE TABLE**

The establishment of our current system of nationalized public healthcare has its roots in the Saskatchewan government of Tommy Douglas in 1947. Subsequent efforts to expand the definition of healthcare beyond coverage of hospital and doctor-related services (as found in the Canada Health Act of 1984) have largely failed. The Romanow and Kirby Commissions are two examples of such attempts to include universal access to medically necessary therapies as an integral part of the healthcare system. As a result, the present system of provincial and territorial determination of drug coverage remains in place, contributing to unequal coverage across the country.

More recently, the stars appear to be aligning for a renewed pan-Canadian initiative to fill the gaps in the current patchwork of public and private drug reimbursement programs in an effort to achieve truly universal access to the current and innovative therapies that are required for all Canadian residents.

**AGENDA AND RATIONALE FOR THE DAY**

The agenda for the day (Appendix C) was provided by Louise Binder, Health Policy Consultant for CCSN, who provided the history and rationale for the need to develop a patient-centred vision for the future of Pharmacare. Louise explained that despite a number of failed attempts initiated at the federal level, the political will, particularly among the Premiers, has never been stronger. Now is the moment for patient groups to weigh in with a clear and well-articulated vision of what matters to those who need access to safe, effective and affordable treatments now or in the future.

She reminded the audience that in determining a solution, one must clearly define the problem one is trying to solve, and whether there is already in place a policy mechanism for doing so within our existing systems. If not, then a true policy gap exists. At the moment, the only problem for which no solution

exists is that there are a number of people in Canada who have no health coverage whatsoever or are underinsured for medically necessary drugs.

Importantly, as there is no clear definition of what Pharmacare means to different people, let alone a consensus on the best formula to achieve it, the goal for the day is therefore to develop a consensus on an aspirational vision for Pharmacare that can be agreed upon by additional patient groups and then shared broadly in meetings with politicians and policy makers in a combined effort to produce the best program and policy outcome for all people in Canada. It forms the lens through which any proposed plan will be analyzed.

A draft version of the Vision, Values and Principles was presented to the participants to gather initial feedback. The group discussed the importance of rooting the vision in the context of barriers to access posed by the social determinants of health. The social determinants of health (see link in statement) refer to “equity” in the health system or fairness in terms of social justice, whereas “equal” refers to access regardless of where people reside. It was generally agreed that health and Pharmacare should therefore be viewed within a broader framework of social and economic drivers.

Rather than talking about “drugs”, it was felt that the statement should refer more broadly to “therapies” – a term that is meant to be inclusive of treatments and medications. Questions arose regarding the values of importance to patients and rather than focusing on “evidence based”, simpler terms such as “safe and effective” were preferred.

Participants discussed how best to describe and incorporate what “excellence” means for health systems and health policy. Discussion resulted in the articulation of “informed decision making” as a value that recognizes the importance of integrating best practices and all available evidence, both qualitative and quantitative, in deciding which therapies should be made available, including at a systems and policy level.

Louise gave a brief history of attempts to develop a pharmacare model, including the National Pharmaceutical Strategy outlined in the 2006 Health Accord and then presented a proposed solution from the Canadian Treatment Action Council (CTAC) model, developed in 2009.

The overarching goal for the day was to provide relevant background and to stimulate the ongoing discussion of the Values statement, which was further revised at the end of the day based on what was heard during the following presentations and discussions.

## **HIGHLIGHTS OF THE PANEL PRESENTATIONS: WHAT WE HEARD**

### **First Panel Discussion**

#### ***“Discussion on Existing Models/Proposals for Canadian Pharmacare and Implications for New Drug Access on Canadian Pharmacare”***

In addition to Louise, we heard from:

- Glen Doucet, Vice President, Public & Professional Affairs, Canadian Pharmacists Association, presenting CPA’s Pharmacare 2.0 Initiative
  - The status quo is not acceptable as Canadians are failing to fill their prescriptions, often due to cost.

- Pharmacists have an important role to play in healthcare and that should be valued and factored into system costs.
- Evolution of the system, not revolution.
- Agnostic on models but all have benefits and drawbacks.
- No system is “perfect”.
- Marc-André Gagnon, PhD, School of Public Policy and Administration, Carleton University, presenting Pharmacare 2020
  - “Pharmacare is not an open bar”.
  - The system must be matched to finite resources.
  - Out of pocket expenditures have been on the rise since 1997.
  - **Access:** all Canadians should have equitable access to medically necessary prescription drugs without financial or other barriers.
  - **Value:** Prescription drugs should be competitively priced and represent value for money within Canada’s universal healthcare system.
  - **Safety:** Prescription drugs should be licensed only when proven to offer benefits that outweigh harms for the patients that use them.
  - **Appropriateness:** Medications should always be prescribed and used in accordance with best evidence concerning risks and benefits.
  - Favours eliminating fragmentation but with a National Formulary.
  - Favours bulk purchasing and use of HTA.
  - Favours prescribing guidelines/”rational use of medicines”.
  - Questions the collective cost of private insurance.
  - A universal pharmacare program would generate savings of 10% to 41% on prescription drugs.

## Second Panel Discussion

### *“Panel Discussion on Cost/Savings of these Proposals to Health Systems and Access Implications”*

- Don Husereau, Senior Associate, Institute of Health Economics, presenting Reflections on impact of proposed Pharmacare Models
  - We need to be mindful of direct and indirect costs, e.g., time lost from work and usual activities and non-medical costs, such as travel, suffering, cost of caregivers and devices.
  - Costs to whom: governments, companies, public insurance programs, and households.
  - Build incrementally: Cover costs first for drugs with known value, generics via tendering.
  - Overall savings predicted to be 12% to 42% on prescription drugs.
  - Savings could be \$1.5-10B on drugs, \$1.5B on administration.
  - This could make Canada a lower priority for innovative drug product launches.
  - The goal of pharmacare should be a program that produces better health at lower total cost than we currently spend while providing a good experience for patients.
  - There could be legislative challenges, especially if responsibility is transferred back to the federal government.
  - Public insurance programs have the benefit of maintaining lower transaction costs.
  - The creation of separate insurance programs in some provinces for rare diseases, while an expedient political solution, will likely be associated with significant future expenditure growth.

- Universal coverage will not:
  - Eliminate concerns about affordability and access.
  - Eliminate the need for private insurance, including drugs.
  - Guarantee sustainable costs.
- Neil Palmer, President and Principal Consultant of PDCI Market Access Inc., presenting Access Implications of proposed Pharmacare Models
  - In an ideal world, there would be no co-pays or deductibles.
  - Patients would have a clear voice in decision-making.
  - Evidence based; pCODR is designed specifically for cancer drugs, but there is uncertainty that this cancer-specific plan would continue under 20/20.
  - National formulary: The 20/20 model would integrate 13+ health plans into a single national formulary; this fails to account for provincial healthcare priorities.
  - Under the 20/20 proposed model, there is no priority for disease severity, the burden of illness or life expectancy.
  - Public-only drug programs generally result in fewer drugs being available.
  - Multiple sources of funding are necessary.

### Third Panel Discussion

#### ***“Panel Discussion on International Practices, including Best Practices in Universal Drug Coverage”***

- Marc-Andre Gagnon:
  - In 2013, Canada fared poorly in the percentage of the population covered by a public drug plan compared to OECD countries.
  - Our total *per capita* expenditure is second only to the United States among OECD countries.
  - Canada is the highest among OECD countries for growth of per capita spending on drugs.
  - There are drawbacks to every system in place, for example, Netherlands, Germany, the United Kingdom or New Zealand.
  - Costs may be reduced, but so is access.
  - Public provision of pharmaceuticals must be organized based on a normative framework focused on clinical evidence at every stage (approval of drugs, willingness-to-pay, prescribing habits, and monitoring appropriate use).
  - Consulting patients in designing the reimbursement criteria is central, but societal values of fairness and equity should underpin design. Every dollar spent should maximize therapeutic gain.
  - Mechanics and decisions for reimbursement should be clear and transparent. Decision-making should be accountable but depoliticized.
- Neil Palmer:
  - United Kingdom: Value is determined by success of the treatment. If treatment is ineffective, the company must reimburse the cost of the drug. In general, the United Kingdom’s discrete Cancer Drug Fund has performed badly in terms of access.
  - Germany: price controls have led to companies leaving the market.

- France: provides interesting lesson on value calculation based on assessment of clinical improvement.
- Most countries have a mix of public and private coverage to some degree.
- Cost sharing (co-payments) is common in most countries (for all health services).
- All countries conduct some form of health technology assessment.
- Some provide immediate access to new cancer drugs (Germany).
- Drug budgets (national, regional or local) limit access to newer drugs in the UK, New Zealand for example.
- Most new cancer drugs are not cost effective using traditional health economics.
- Risk sharing agreements are necessary to facilitate access.
- Patient advocacy is essential for securing funding for cancer drugs.
- Limited drug budget – government cannot fund all drugs.

Please visit the CCSN website at [www.survivornet.ca](http://www.survivornet.ca) for links to the above presentations.

## **REVIEW AND FINALIZATION OF VISION STATEMENT**

Louise Binder presented a series of questions or “takeaways” based on the stimulating and varied points of view presented in the panel discussions. It was noted that to date no one person or group has done a detailed analysis of various models in order to develop a detailed picture of the potential costs and savings. Moreover, any decision to adopt a single public payer system vs. building on the existing framework of public/private reimbursement has yet to be fully debated.

That said, a plan for the introduction of Pharmacare in Canada would garner patient support if:

1. The plan continues to provide what people are currently receiving for medically necessary care (or improves on what is currently available).
2. The plan provides access for the approximately 10% uninsured and underinsured notwithstanding ability to pay.
3. The plan ensures access to innovative drugs as required.
4. The plan recognizes varying severity of disease including life-threatening illnesses, diseases and conditions that are debilitating and end of life situations.
5. The plan can find a way to recognize and value qualitative and quantitative real world evidence.
6. All savings are returned to the drug budget in order to increase access to therapies.
7. The plan strives to work within existing mechanisms and programs to deliver the vision where possible and to assure cost effectiveness and efficiencies.
8. The plan is able to ensure access to medically necessary drugs – leaving no gaps unfilled.
9. HTA bodies are able to analyze the value of a drug in broader terms of overall cost to the healthcare system and society as a whole.
10. The plan has a patient centred notion of values – with patients playing a role in HTA processes and in defining values.
11. A plan wherein 6-16% of healthcare budget is set aside for drugs.
12. The plan demonstrates a framework that has metrics attached to all aspects of the system.
13. The plan puts appropriate data systems and data sharing in place.

It was recommended and decided that the draft Vision statement be amended and circulated as follows:

## **A PATIENT VISION FOR PHARMACARE IN CANADA**

### **OUR VISION**

- All people residing in Canada have timely, consistent, equal and equitable access to safe and effective therapies, including treatments and medications, as well as the information, diagnostics, care and support that they need, without conditions.
- This is part of a broader vision for every person to have equal opportunity to access therapies regardless **of barriers related to the social determinants of health.**<sup>1</sup>

### **OUR VALUES**

- **Respect** for people who access the health system including their support team.
- **Meaningful and ethical engagement** of people who access the health system, including engagement in health systems planning, decision making, implementation, knowledge transfer and exchange, monitoring and evaluation, and systems redesign.
- **Accountability** as the framework for all health systems processes and health policy.
- **Transparency** in sharing **information** about all health systems processes and health policy decisions.
- **Timely access** to health innovations.
- **Informed decision making** that integrates best practice and available evidence into health systems and health policy.
- **Capacity building and mentorship** for all who engage with the healthcare system.
- **Social Justice** as a principle to uphold equal opportunity to access and benefit from all social determinants of health.

### **OUR PRINCIPLES**

**The plan for Pharmacare in Canada must:**

- **Protect** or **improve** existing individual access to therapies at or above their current level.
- **Ensure universality and equality** that recognizes diversity in all its forms and accommodation for disability.

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<sup>1</sup> Public Health Agency of Canada; <http://cbpp-pcpe.phac-aspc.gc.ca/public-health-topics/social-determinants-of-health/>

- **Safeguard access** to medically necessary therapies for uninsured and underinsured residents of Canada regardless of ability to pay or place of residency.
- **Recognize** the discrete needs of people with life threatening and serious debilitating illnesses that significantly impact quality of life.
- **Accept, assess and value** real world evidence in determining therapeutic value.
- **Reinvest** pharmaceutical system savings back into the Pharmacare budget in order to provide increased access to therapies.
- **Build** on the foundation of healthcare mechanisms and systems already in place.
- **Develop** value-based drug pricing contracts, including systems for sharing data and other relevant information.
- **Analyze** the value of a drug or treatment for a Pharmacare system to include savings in other parts of the healthcare budget and broader socio-economic impact.
- **Expand** health technology assessment processes to measure the value of all components of the healthcare budget.

## NEXT STEPS

Following a discussion among the participants, it was decided to disseminate the DRAFT Vision, Values and Principles statement broadly among patient groups for their feedback. The agreed upon **PATIENT VISION FOR PHARMACARE IN CANADA** will be shared with other stakeholders for discussion. It will then form the lens through which future discussions and proposals will be analyzed and critiqued.

## Appendix A

### Original DRAFT Vision Statement (distributed prior to start of day)

#### OUR VISION:

**All people residing in Canada have timely, consistent, equal and equitable access to the safe and effective drugs, treatments and medications, as well as the information, diagnostics, care and support that they need, without conditions. This is part of a broader vision for every person to have equal opportunity to access all social determinants of health.**

#### OUR VALUES:

**Respect** for people who access the health system and their support team

**Meaningful and ethical engagement** of people who access the health system including engagement in health systems planning, decision making, implementation, knowledge transfer and exchange, monitoring and evaluation, systems redesign.

**Universality and equality** recognizing diversity and accommodation.

**Accountability framework** for all health systems processes and health policy.

**Transparency and information sharing** in all health systems processes and health policy decisions.

**Support** for health innovations.

**Excellence** in health systems and health policy including recognition of the importance of integrating best practices in evidence based qualitative and quantitative medicine.

**Capacity building and mentoring.**



**Social Justice** to uphold equal opportunity to access all social determinants of health.

## **Appendix B**

### **Attendee List**

The following organizations were represented at the Roundtable:

- Myeloma Canada
- Life-Saving Therapies Network
- Pancreatic Cancer Canada
- Lymphoma Canada
- The Carcinoid Neuroendocrine Tumour Society
- CML Network
- CML Society
- Multiple Myeloma Patient on behalf of Myeloma Canada
- Schizophrenia Society of Ontario
- Thyroid Cancer Canada
- Sickle Cell Disease Association of Canada
- Sickle Cell Awareness Group of Ontario
- Sickle Cell Association of Ontario
- Supportive Housing in Peel (SHIP) – Peel Youth Village

**Appendix C**  
**Final Agenda for Oncology Roundtable Meeting – June 1<sup>st</sup>, 2016**

<b>Agenda Item</b>	<b>Presenter(s)</b>	<b>Time</b>
<b>Arrive and Register</b>	-	8:00am-8:30am
<b>Introduction</b>	- <b>Ron Rosenes</b> , Progressive Consulting Network	8:30am-8:45am
<b>Welcome, Review of Agenda and Lay of the Land for the Day</b>	- <b>Jackie Manthorne</b> , President & CEO, Canadian Cancer Survivor Network	8:45am-9:15am
<b>Review of Initial Feedback of draft Vision and Values</b>	- <b>Louise Binder</b> , Health Policy Consultant, Canadian Cancer Survivor Network	9:15-10:15am
<b>Break</b>	-	10:15am-10:30am
<b>Panel Discussion on Existing Models/Proposals for Canadian Pharmacare and Implications for New Drug Access on Canadian Pharmacare</b>	- <b>Louise Binder</b> , Health Policy Consultant, Canadian Cancer Survivor Network - presenting <i>National Pharmaceutical Strategy outlined in the 2006 Health Accord and CTAC Model</i> - <b>Glen Doucet</b> , Vice President, Public & Professional Affairs, Canadian Pharmacists Association - presenting CPA's Pharmacare 2.0 Initiative - <b>Marc-André Gagnon</b> , PhD, School of Public Policy and Administration, Carleton University - presenting <i>Pharmacare 2020</i>	10:30am-12:30pm
<b>Lunch</b>	-	12:30pm-1:15pm
<b>Panel Discussion on Cost/Savings of these Proposals to Health Systems and Access Implications</b>	- <b>Don Husereau</b> , Senior Associate, Institute of Health Economics - presenting <i>Reflections on impact of proposed Pharmacare Models</i> - <b>Neil Palmer</b> - President and Principal Consultant of PDCI Market Access Inc. - presenting <i>Access Implications of proposed Pharmacare Models</i>	1:15pm-2:30pm
<b>Break</b>	-	2:30pm-2:45pm
<b>Panel Discussion on International Practices including Best Practices in</b>	- <b>Marc-André Gagnon</b> , PhD, School of Public Policy and Administration, Carleton University - <b>Neil Palmer</b> , President and Principal	2:45pm-3:45pm

<b>Universal Drug Coverage</b>	Consultant of PDCI Market Access Inc.	
<b>Review and Finalization of Vision and Values/ Principles in the Context of Panel Information</b>	- <b>Louise Binder</b> , Health Policy Consultant, Canadian Cancer Survivor Network	3:45pm-4:15pm
<b>NEXT STEPS &amp; CONCLUSION</b>	- <b>Louise Binder</b> , Health Policy Consultant, Canadian Cancer Survivor Network, <i>presenting on Media Outreach, Follow-up with Bureaucrats and Politicians, and Establishing Working Groups &amp; Steering Committee</i>	4:15pm-5:00pm