BEST
MEDICINES COALITION
COALITION POUR DE
MEILLEURS MÉDICAMENTS

July 18, 2025

Positions and considerations regarding an Essential Medicines List

The following points were developed in response to Canada's Drug Agency (CDA-AMC) consultation on a proposed Essential Medicines List.

Overview considerations:

The important work of the Advisory Panel and the inherent challenge in developing a reasoned approach to the development of a proposed essential medicines lists is acknowledged.

The Best Medicines Coalition, with its 32 patient organization members, seeks timely access to a comprehensive range of medically necessary, safe, and effective drugs and related treatments, informed by patient-driven evidence and values, and delivered equitably and affordably to all patients.

Evaluation of all elements of Canada's framework for providing pharmaceutical care to patients, including new or proposed initiatives or reforms, is viewed through the lens of the above mission. As such, regarding an essential medicines list, we request that the CDA-AMC, through the Advisory Panel or otherwise, conduct appropriate analysis and consider whether its application has potential to meaningfully improve timely and comprehensive access to medically necessary drugs and related treatments.

Related to the above, it is recommended that clarity be provided on the intended role and function of the essential medicines list as it has been presented. Material provided by the CDA-AMC states that the list is a starting point in a dialogue about a potential national formulary and that it is not intended to replace coverage in public or private drug plans. However, some confusion and potential for misinterpretation remains. Further explanation is needed and should be highlighted to all stakeholders through targeted communications to enable full clarity on the role and application of the list to enable more meaningful evaluation.

List development considerations:

While it is understood that essential medicines lists have a range of objectives and roles, including, as stated, ensuring that Canadians can access prescription drugs and informing the potential development of a national formulary, their limitations must also be fully recognized. Relying on a fixed list can unintentionally create barriers, particularly for individuals or patient communities whose needs fall outside standard definitions of "essential". Developing such a list is inherently difficult and carries the risk of omitting therapies that are necessary to some patients.

To help address this challenge, instead of beginning with the question *"What drugs should be on the list?"*, we would encourage asking a more inclusive one: *"What supports do people need to stay well — and how can we remove the barriers they face in accessing them?"* This shift in perspective encourages systems that reflect the diversity of patient lived experiences, not just clinical or economic criteria, opening the door to more responsive, person-centered models of care which uphold values like equity, dignity, and shared decision-making. By integrating flexibility, community input, and mechanisms for addressing unmet needs, approaches can be adopted that are both sustainable and truly equitable.

The list development process must look at how the right therapies can drive broader cost savings and contribute to avoiding hospitalizations, reducing complications, and enabling people to remain active in their communities. True value emerges only when drug coverage is seamlessly integrated with prevention, care coordination, and social support to amplify its positive impact on people's lives.

The Advisory Panel's is comprised of respected health care professionals and leaders who diligently applied their expertise and varied backgrounds to inform the panel's deliberations. It is important, however, to reflect on how this panel, or subsequent panels, could be strengthened by including participants who bring diverse perspectives from lived experience as patients to inform processes and shape decisions. While it's common to see a single patient representative on advisory panels, this approach often falls short of the meaningful engagement that patient organizations, including the Best Medicines Coalition, are calling for and which would bring value. True involvement means creating space for diverse voices, shared decision-making, and real influence over the policies that affect their lives.

To ensure inclusion going forward, the processes for adding or removing drugs should be co-designed with patient groups, individuals with lived experience, healthcare professionals, and researchers. This process should also include a mechanism for ongoing updates as new treatments become available without the need to reconvene an advisory panel each time. For example, clear criteria could allow promising new therapies to be provisionally included, with the full list reviewed frequently, such as on a quarterly basis, to ensure it remains current and responsive to evolving evidence.

Ways to ensure that the process for including and excluding products is informed by patient perspectives should be explored in a comprehensive manner. Some initial suggestions for consideration include the following:

- **Transparent criteria:** Co-design with patient groups to identify factors like affordability and access.
- **Learning from lived experience:** Patients should help define "value" — not just clinical efficacy, but impacts on quality of life, independence, and daily routines.
- **Equity lens:** Leverage patient input to ensure medicines for marginalized or Indigenous communities are fairly represented.

List updating considerations:

Updating an essential medicines list only every two years is not sufficient to meet the evolving needs of patients. New diagnoses, changes in treatment response and evidence, or emerging therapies can and do happen on an ongoing and continual basis. A rigid, one-size-fits-all approach leaves too many people waiting for access to medications that could improve their quality of life or prevent serious decline.

The Advisory Panel appropriately notes that any list should undergo reevaluation to ensure it continues to be informed by current evidence and to ensure that drugs continue to offer value. The Panel's stated perspective that the process for this review should be efficient, timely, and able to meet the quality standards and be responsive to updated treatment pathways while integrating patients, clinicians, and health systems partners perspectives and real-world evidence into the process, also has merit. To truly support equitable care, more responsive, timely, and flexible systems that reflect the realities of patients are needed.

Patient communities bring invaluable lived experience and insight into what treatments truly make a difference in people's lives. There should be a clear and transparent pathway for these communities to propose new medications for coverage — especially when those treatments address unmet needs or reflect emerging standards of care. By creating space for patient-led submissions, systems can become more responsive and grounded in real-world priorities. This could involve a structured process where patient groups, in partnership with clinicians or researchers, submit evidence of benefit, lived experience, and impact on quality of life to inform timely decisions. Including patient voices in this way strengthens the fairness, legitimacy, and relevance of medication coverage decisions. Development of processes for flagging gaps in the list and for addressing these issues would bring value.

As indicated above, it is recommended that the Advisory Panel co-develop clear criteria with patient groups, individuals with lived experience, healthcare professionals, and researchers that could allow promising new therapies to be provisionally included, and that new treatments that have received Notice of Compliance are reviewed regularly, perhaps on a quarterly basis, to be considered for addition to the list of essential medicines.

A range of processes and systems could be put in place to effectively support the updating of the list, and this should be explored in a comprehensive manner, in consultation with patients and stakeholders. The following initial suggestions are offered for consideration:

- **Structured engagement rhythm:** Hold regular patient advisory sessions to gather lived experience and emerging medication needs.
- **Real-time signals:** Create a digital feedback channel (e.g. portal or app) for clinicians and patients to flag shortages, price shifts, or adverse experiences.
- **Governance inclusion:** Ensure patient representatives have decision-making seats on the review/advisory panel, not just consultation roles — increasing their influence in real time between formal surveys.
- **Data-informed identification:** Where possible, analyze prescription volumes and public drug plan coverage to pinpoint frequently used drugs not on the list and cross-reference with patient surveys.
- **Patient-led tagging:** Invite patients to propose missing products, especially for chronic or rare conditions.

Considerations list exclusions

Conducting a comprehensive review of the list and identifying which drugs or related treatments have not been assessed or included across all conditions is important and necessary. However, not all patient organizations have the capacity to conduct this analysis, especially within the consultation period offered. Therefore, it is recommended that the CDA-AMC, separately or within the framework of the Advisory Panel, take on an initiative to conduct a comprehensive analysis of this nature, and include patients and stakeholders in this process. Furthermore, it is recommended that the focus of the analysis be shifted from commonly prescribed drugs to drugs which are medically necessary to the management of specific conditions.

Though the initial proposed list may be comprehensive for some disease areas, several Best Medicines Coalition member organizations have noted that there are many necessary drugs and related treatments which are considered essential to their patient communities but are not included in the list. By way of example, perspectives related to treatment of lung-related conditions are provided below:

> Many patients in Canada suffer from asthma and COPD yet important categories of medications useful for managing these conditions are missing from the respiratory use section:

- Triple therapy for COPD – a combination of 3 inhaled medications for patients with severe COPD who continue to experience symptoms or exacerbations despite being on a dual therapy treatment regime.
- Biologics for asthma – class of medications that target specific components of the immune system, improving symptoms and flare-ups. In addition, it is anticipated that new biologics will be developed to treat COPD and/or indications will evolve and it is necessary that there be a process for incorporation into the essential list in a timely manner.
- The section on anti-infectives for systemic use could be expanded with more commonly prescribed antibiotics as these can indirectly support respiratory care.

It is also not clear how treatments that are not yet included in the “common list” of the National Strategy for Drugs for Rare Diseases will be managed or delineated. Moreover, it is not clear what indications are included for specific molecules that are listed (e.g., adalimumab is indicated for many inflammatory conditions). How will the potential operationalization of this list take all these indications into account?

About the Best Medicines Coalition

The Best Medicines Coalition is a national alliance of 32 patient organizations. The BMC seeks timely access to a comprehensive range of medically necessary, safe, and effective drugs and related treatments, informed by patient-driven evidence and values, and delivered equitably and affordably to all patients in Canada. The BMC's areas of interest include drug approval, assessment, and reimbursement, as well as patient safety and supply issues. As an important aspect of its work, the BMC strives to ensure that Canadian patients have a voice and are meaningful participants in health policy development, specifically regarding pharmaceutical care. The BMC's core activities include issue education, consensus-based position development, and advocacy, making certain that patient-driven positions are communicated to decision makers and other stakeholders. The BMC was formed in 2002 as a grassroots alliance of patient advocates. In 2012, the BMC was registered under the federal Not-for-profit Corporations Act and operates under the direction of a Board of Directors comprised of representatives of member organizations and elected annually.

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Canadian Cancer Survivor Network
Canadian Council of the Blind
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