Cancer Clinician Advocacy Forum (CCAF)

Submission to CDA-AMC's Consultation on Clinician Group Input into Drug Reimbursement Review Process

Submitted to the online written feedback form

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1. Input for the Deliberative Framework

In this section, we are interested in exploring WHAT information is provided from the clinician perspective and how to focus on what is needed to support reimbursement review deliberations.

1.1 What suggestions do you have for evolving the clinician input process to focus on what is needed to support deliberations on the deliberative framework domains?

Guidance and structure

Clinicians should be given clear instructions on how to participate in the input process, including guidance on forming or joining groups and clarification of the specific type of input required. The CDA-AMC template form should continue to be used to ensure consistency and ease of use in collecting input. Additionally, the input process should be streamlined by aligning questions directly with each domain of the deliberative framework, focusing on concise and structured feedback that addresses the most important values, trade-offs, and uncertainties necessary for informed decision-making.

Content of clinician input

Encourage clinicians to focus on providing high-level insights and perspectives rather than restating detailed clinical trial data, with particular emphasis on assessing clinical value, unmet needs, and ethical considerations such as disparities in care and implications for underserved populations. For rare diseases or molecular subtypes of cancers, it is important to seek input from experts who actively treat these conditions, ensuring that the significance and impact of specific treatments on the patient journey are adequately highlighted.

Additional input and flexibility

It is recommended to include an additional section, such as a comment box, to capture supplementary insights or considerations that may not align with structured domains.

- For instance, a new oral therapy with CNS activity (that may treat CNS metastases or prevent CNS disease) is considered, together with impact on quality of life and CNS morbidity.

Expert involvement and accessibility

Medical oncologists, including hematology-oncology and gynecology-oncology experts, should always be core members of expert committees to ensure comprehensive and relevant clinical expertise. To facilitate their participation, virtual attendance at meetings should be implemented, thereby minimizing travel requirements and time away from clinical responsibilities. The busiest and most experienced clinicians may have the least time to attend. Additionally, clinicians should be encouraged to contribute input to analyses conducted by industry or clinical groups, as such involvement can enhance the evaluation process and provide valuable insights to inform committee deliberations.

2. Input Collection and Submission Methods

In this section we are interested in exploring HOW clinician input is collected and submitted.

2.1 What are your ideas and suggestions for methods you think work well to collect clinician perspectives (e.g., surveys, interviews, focus groups, videos, or other)? Please explain why.

Proactive outreach and engagement

Requests for input should be directed to the appropriate group of oncologists through professional associations, such as the Canadian Association of Medical Oncologists (CAMO), utilizing their email distribution lists to ensure targeted engagement of clinicians most relevant to the topic. Additionally, it is important to actively recruit input from community oncologists, who administer over half of systemic therapies in Ontario and may be unaware of the input process. Their perspectives are vital as they reflect diverse patient populations and care settings, including those not typically represented by academic groups, such as older patients, those facing greater travel distances, and members of Indigenous communities.

Methods of collecting perspectives

To streamline the submission process and avoid delays caused by having too many contributors, it would be effective to coordinate with dedicated groups of expert clinicians to draft the submission, supported by a broader group who can endorse it, while partnering with patient advocacy groups (such as Breast Cancer Canada, Lung Cancer Canada, and Colorectal Cancer Canada) to coordinate the submission process (e.g., collection of conflict of interest declarations,

version, control, etc.). Utilizing surveys enables efficient collection of standardized, quantitative and qualitative input from large groups, whereas interviews are suited for in-depth exploration of individual reasoning, especially for rare diseases or specialized topics. Perspectives should be gleaned from both subject matter experts and patients with lived experience. Focus groups would be valuable for understanding collective dynamics and regional differences, with small regional groups offering particular insight into inter-provincial or regional distinctions. Incorporating short video or slide submissions can enhance authenticity and emotional resonance, especially in value-driven discussions. Virtual platforms like ZOOM or TEAMS should be used for interviews and focus groups, ensuring scheduling accommodates all regions. Ultimately, a mixed-methods approach that combines surveys, interviews, focus groups, and flexible input formats, would provide a balance of breadth and depth, allowing for comprehensive and nuanced perspectives.

2.2 What formats do you find most efficient and effective for submitting your clinician group input (e.g., structured template, verbal input, a letter, a combination of these and/or other formats)? Please explain why.

Structured templates

A structured template allows for greater consistency and completeness in clinician input. It ensures that all required information is addressed, as long as there is the opportunity to add comments and references as needed for nuance and depth. This format also streamlines the review process for CDA-AMC, expediting feedback and ensuring submissions meet their specific requirements.

Combination of formats

A combination approach of structured templates, verbal input, and unstructured input will maximize engagement, as it accommodates diverse communication preferences and enable clinicians to express their perspectives in various synergistic formats, ensuring that all relevant points are systematically addressed while allowing narrative explanation.

3. Input Submission Communication and Guidance

In this section, we are interested in learning about the support tools, resources, and communication that can support clinician group input submissions.

3.1 What guidance, communication, or tools would make the input process easier for you (e.g., video guide[s], learning sessions, guidance document, tool kit, or other)?

Multimedia resources

A concise video guide, with 4-6 narrated slides, accessible online and featuring hyperlinks, would be highly beneficial as it enables clinicians to learn at their own pace and revisit the material as needed. This resource could also be supplemented with ad hoc learning sessions for additional support.

Guidance documents and toolkits

Providing clear online guidance documents, ideally with practical resources, templates and examples, would standardize expectations and make the input process easier by serving as a reference to help clinicians identify the most impactful sections and draft effective submissions. This would also help to ensure that inputs meet the needs of CDA and properly address the issues that need to be addressed. It is important to emphasize in all communications that clinicians are encouraged to provide "negative" recommendations when appropriate, ensuring that all relevant perspectives are captured and considered.

3.2 What type of feedback would you like to receive on your input submission?

Acknowledgement and transparency

At a minimum, the process should include confirmation of receipt of the input submission, identification of the reviewer or review group, and information about the review timeline. The final recommendations should acknowledge the group's input, discussing which issues and arguments were convincing or refuted. Additionally, concise feedback should be provided to summarize how the input was utilized, highlight key points incorporated, and explain any areas not adopted, thereby ensuring transparency and supporting ongoing learning.

Constructive feedback

Feedback should address both the strengths and weaknesses of the submission to guide improvements for future contributions, and evaluate the overall impact or shortcomings, potentially using a ranking system or similar method. Additionally, it should note any points of disagreement, including instances where lack of clarity may have led to misunderstandings or missed points.

3.3 How would you like to receive feedback on your input submission (i.e., email response, letter, or a meeting with a representative from Canada's Drug Agency)?

The most practical method for timely and accessible feedback is two-way communication via email, ensuring responses are provided directly to the submitting group or lead and creating a

written record for future reference. If the response does not fully address the needs or concerns raised, or if more in-depth discussion is necessary, a meeting with a clinician representative should be arranged. In certain cases, particularly for rare diseases, meetings with the group of clinicians who submitted the feedback may also be valuable, although coordinating such meetings for all submissions may be challenging. Feedback should consistently include both positive remarks and constructive criticism if expectations were not met.

4. Other

In this section, we are interested in learning about other considerations for evolving clinician group input into drug reimbursement reviews.

4.1 Do you have any comments or suggestions we should consider in evolving clinician group input into drug reimbursement reviews that was not captured in the previous questions?

Transparency and clarity in process

CCAF would suggest clearly defining the roles of CAPCA and CDIAC, explaining the selection process for the "3 experts" and the reasons for maintaining their anonymity after the final recommendation. CCAF also suggests that feedback is transparently provided by CDA-AMC. Additionally, there should be clear communication regarding how clinician input is considered and incorporated into the final recommendations, thereby promoting trust and accountability throughout the process. In the spirit of equitable access across Canada, reasons for disparities with INESSS decisions in Quebec should also be commented on.

Engagement in the process

Clinician group leaders should be enabled to participate more actively and earlier in the review process, whether through virtual or in-person meetings, while also fostering ongoing dialogue to refine perspectives as new evidence emerges. Additionally, the current structured template contains redundant questions, indicating a need to reassess and streamline the questions or framework used.

Other feedback

Achieving equitable access to treatments across provinces and territories is essential to prevent patients from engaging in 'province shopping' to obtain therapies. To address this, models should be considered that do not restrict access to therapies but instead support robust data collection by having every patient continuously contribute real-world information about their treatments,

such as timing, rationale, and outcomes, to inform clinical decision-making. This data collection initiative could be supported by industry, with government covering associated costs for a defined period while comprehensive data is gathered. We would encourage more conditional approvals by CDA (e.g. venetoclax in the past) similar to Health Canada NOCC (notice of compliance with conditions) for promising new therapies while further data is collected (long term outcomes, overall survival).

Further, CCAF recommends that CDA revert to its previous practice of soliciting clinician input on "Implementation Questions" through the Clinician Input Template. This approach is particularly important given the significant implementation delays experienced by many provinces, which often result from complex considerations following HTA and price negotiations. Front-line clinicians possess valuable insights that can help provinces address both clinical and logistical challenges associated with the introduction of new therapies. CCAF further suggests that the provincial drug programs, via the Provincial Advisory Group, be allowed to design these questions to collect clinician insights. Additionally, CCAF recommends that the insights gathered be promptly shared with provinces following the stakeholder input deadline, enabling them to initiate implementation efforts while the HTA and price negotiation processes are still ongoing.

4.2 If you can make 1 change, what would you do to improve or enhance the clinician group input process to reimbursement reviews?

Improved communication

CCAF recommends implementing two-way communication between CDA-AMC and the submitting groups, ensuring that dialogue is maintained and feedback is shared to inform and improve the decision-making process.

Improved access to treatment

Ensure equitable access to safe and effective therapies while systematically collecting data on all patients. Encourage provinces and territories to begin implementation planning for clinically recommended treatments immediately.

Collection of clinician input and committee representation

To enhance the reimbursement review process, CCAF recommends implementing a standardized and streamlined template that aligns directly with the deliberative framework domains, ensuring that all input is consistent, comprehensive, and easily integrated. Some CCAF members also recommend that the committee making these recommendations for CDA-AMC includes mandatory participation from systemic therapy oncologists in active practice.