CADTH Management Response
To
CADTH Patient Input Process Review
Findings and Recommendations

Prepared by SECOR for CADTH
September 2012

Background

No standard (national or international) for patient involvement in health technology assessment was available at the time that the Canadian Agency for Drugs and Technologies in Health (CADTH) launched its patient involvement initiative, and thus, CADTH did so with the knowledge that the initiative would require evaluation and change. As part of Phase I of the 2011 CADTH evaluation, SECOR reviewed the Common Drug Review (CDR) patient input process at a high level. SECOR did identify some strengths and shortcomings during this part of the review, including that the value-add of the newly created patient submission process is unclear internally and to patient groups. The resulting recommendation was that CADTH develop a common understanding of how patient input will be used in reviews both internally and externally.

In April 2012, CADTH engaged SECOR to conduct a more thorough evaluation of the patient input process in order to identify a clear set of recommendations for enhancing the program. SECOR was asked to analyze the stakeholder surveys (patient groups, CDR reviewers, Canadian Expert Drug Advisory Committee (CEDAC) members, and industry) that CADTH had undertaken in the fall of 2011. Additionally, SECOR was asked to develop actionable recommendations, based on the synthesis of insights from the stakeholder survey results and external analysis of national and international patient involvement processes. Findings and recommendations from this evaluation support CADTH's objective of continuous improvement of the patient input process.

SECOR concluded that CADTH's patient input process is on par with or more developed than most of its peers, but that the National Institute for Health and Clinical Excellence (NICE) and the pan-Canadian Oncology Drug Review (pCODR) have significantly more evolved programs. (It should be noted that at the time of evaluation, pCODR had just recently been implemented and thus its experience with its patient input process was still limited.) SECOR also concluded that many best practices from national and international peers can be implemented by CADTH to address several patient input process design and execution gaps identified by stakeholders. SECOR made 19 recommendations that range from strategic to tactical; however, the alignment of stakeholders on purpose, value, and credibility of soliciting patient input is a priority.

The list of SECOR recommendations (numbered in the same manner as done in the full SECOR report posted on the CADTH website) and actions being taken by CADTH to address them are noted in the following table. Since the release of the SECOR report, CADTH has developed an action plan and is moving forward to implement changes, recognizing limited resources. Some of the recommendations are already being addressed or implemented.

List of SECOR Recommendations and CADTH's Responses

EVALUATION RECOMMENDATION	CADTH'S RESPONSE
1. Philosophy and Goals	
G1. Clearly define the objective of patient input and align internal and external stakeholders accordingly.	CADTH recognizes the importance of ensuring that internal and external stakeholders are clear and aligned on the objectives of the patient input process (i.e., this is a priority) and thus will: • review posted (e.g., template) and internal documents to ensure that the objectives are clearly articulated and consistent from document to document • include reference to the objectives of patient input and the process in information sessions with stakeholders and staff.
G2. Increase transparency by communicating how patient information is used in decision-making processes — during and after the review is published.	CADTH now incorporates the patient input that was received into the posted Canadian Drug Expert Committee (CDEC) *Recommendation and Reasons for Recommendation* document. If the patient input received contributes to the reason for the recommendation, this is reflected in the document. CADTH will provide greater clarity on how patient input is used by: • describing the use of patient input in the CDEC deliberative process (as part of the work by CDR on the CDEC recommendation options and deliberative process) • posting a sample CDEC public member discussant report (based on what is considered a "good" submission) • considering the posting of the full patient group submissions.
G3. Further increase awareness of program among patient groups and the broader patient community to broaden reach of intake.	• CADTH will continue to work with patient umbrella organizations to assist in increasing awareness of its patient input program. • CADTH will review the list of drugs for which no patient submission was received to determine if a lack of awareness was a reason, and if not, what the reason may have been to determine what can be done to increase the rate of input.
G4. For further consideration: Reduce the duplication of the patient input process in British Columbia and Ontario, and continue to forward the patient input information to jurisdictions.	CADTH will continue to make patient input submissions and summaries available to jurisdictions. • CADTH will follow up with British Columbia and Ontario regarding opportunities to reduce duplication.

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2. Design	
D1. Establish a framework to more objectively and systematically incorporate patient input into the decision-making process.	CADTH has described a framework in its presentations to patient groups and other audiences. Also it has: • incorporated the deliberative framework into its existing documents posted on the CADTH website • described the CDEC deliberative process, which includes a presentation of patient input by CDEC public members during the CDEC meeting • implemented the use of the deliberative process at CDEC meetings.
D2. Establish strategic relationships with research agencies, such as Canadian Foundation for Healthcare Improvement (CFHI), and academia to diversify sources of patient-based evidence.	CADTH currently participates in a local network of research agencies (e.g., Canadian Institutes of Health Research, CFHI, Health Canada, etc.) that engage patients and public to share initiatives and use of patient evidence. CADTH will take steps to ensure that relevant research is captured in CDR literature searches.
D3. Create opportunities for individual patients / caregivers to be engaged in the process without necessarily accepting individual patient submissions (e.g., have patient experts at the decision-making table, provide links to patient groups should an individual patient want to make a submission, patient preference ranking of outcomes of importance online).	CADTH engages with patient groups. It currently directs individual patients or caregivers to contact the patient group that aligns with their medical condition and have that group include their input in the submission for CDR. CADTH will: • include a statement on the patient input website indicating that CADTH can help direct individual patients, who want to make a submission, to the appropriate patient group • direct individual patients to the Canadian Health Technologies Expert Patient Network, if and when it is established, or umbrella patient group organizations • consider providing patient groups that have filed a submission for a particular drug with the opportunity to rank the importance of the outcomes identified in the submissions for CDR review • consider options to enhance patient engagement in the patient input process.
D4. Continue to share and exchange patient group email lists with Ontario and British Columbia, include patient groups currently not subscribed to the mailing list.	CADTH exchanges information with Ontario and British Columbia and will continue to do so.

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D5. For further consideration: Sign a non-disclosure agreement with manufacturers so draft reports can be released to the public for comments.	CADTH will publish full CDR reports in the fall of 2013.
3. Submission Process	
P1. Encourage industry to give even more advance notice to CADTH when possible.	Industry agreed to give greater advance notice of pending submissions, with up to 20 business days to be given. (Note: advance notification is voluntary.)
P2. Increase flexibility of input by removing or increasing the page limit; ask patient groups to submit a summary if the information is > 10 pages.	CADTH will pursue changes to the template to streamline patient input submissions by reducing the amount of information required.
P3. Send disease-specific alerts.	CADTH will not be sending disease-specific alerts. CADTH is sending e-alerts to all subscribers.
P4. Send patient groups an email receipt when submission has been received.	CADTH will explore sending a computer-generated, tailored email receipt.
4. Data Inputs	
I1. Schedule periodic formal communication opportunities with patient groups to understand their needs and incorporate their feedback into improvements for the overall process.	CADTH is committed to enhancing communications with patient groups. CADTH attends meetings with patient groups and will continue to do so.
I2. Devote a half-time / full-time employee to patient engagement initiatives to support patient groups on making submissions (e.g., provide advice and feedback to patient groups).	CADTH has dedicated a 0.5 full-time employee to support CADTH patient / public involvement processes.
I3. Demonstrate what a "good" submission is by posting examples online.	CADTH will work with reviewers and CDEC to develop a "good" submission and post examples online.
I4. Allow patient groups to review draft summaries of patient input before CDEC discussions.	• CADTH will establish a process for patient groups to provide feedback on the summary of patient input. • CADTH will consider posting full patient group submissions.
I5. Organize and deliver quarterly training sessions to public members on CDEC.	CADTH holds training / information sessions for its public and science-oriented members as needed to support the committee work, in addition to orientation.
I6. Organize and deliver quarterly training sessions to patient groups.	CADTH has held training / information sessions for patient groups and will explore additional training opportunities.

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5. Outputs (note: these are duplicate recommendations)	
O1. Establish a framework to systematically and objectively incorporate patient input as evidence for decision-making (same as D1 under Design).	CADTH has described a framework in presentations to patient groups and other audiences and its website. Also it has: • incorporated the deliberative framework into its existing documents posted on the CADTH website • described the CDEC deliberative process, which includes a presentation of patient input by CDEC public members during the CDEC meeting • implemented the use of the deliberative process at CDEC meetings.
O2. Increase transparency by communicating how patient information is used in decision-making processes (e.g., distribute verbatim comments; explicitly summarize how data received contributed to decision-making [same as G3 under Philosophy and Goals]).	• CADTH will continue to work with patient umbrella organizations to assist in increasing awareness about its patient input program. • CADTH will review the list of drugs for which no patient submission was received to determine if a lack of awareness was a reason, and if not, what the reason may have been to determine what can be done to increase the rate of input.