Canadian Task Force on Preventive Health Care

Tobacco and Smoking Cessation Community Jury: Final Report

Prepared for the Canadian Task Force on Preventive Health Care

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Executive Summary

Integrating patient priorities and perspectives into clinical practice guidelines (CPG) advances patient-centered care. The Canadian Task Force for Preventive Health Care (Task Force) continues to engage the support of the Knowledge Translation (KT) team at St. Michael's Hospital to explore ways to meaningfully involve patients and members of the public in its guideline development process.

The KT team leveraged the Task Force Public Advisors Network (TF-PAN), consisting of patients, caregivers, and the members of the public (defined in this context as individuals who are not in clinical practice or former primary care professionals) to provide input on key message statements for the Tobacco and Smoking Cessation Clinical Practice Guideline.

A community jury was selected to provide insight on the key messages for the Tobacco and Smoking Cessation guideline. A cohort of 8 TF-PAN members were selected to participate in the jury. The two-phased Community Jury commenced with a two-hour educational Phase 1 (November 2nd, 2023), where Working Group chairs presented core concepts on Tobacco and Smoking Cessation, including health impacts of smoking and current evidence on smoking and smoking cessation encompassing interventions, outcomes, benefits, and potential harms. Participants had the opportunity to ask clarifying questions to the Working Group chairs during this session. During Phase 2, the Deliberation stage (November 9th, 2023), a facilitated discussion with participants was held in order to ascertain their thoughts and feedback on the Working Group's CPG key message statements.

In summary, participants proposed that the key messages should be reframed to offer hope and encouragement while acknowledging the challenges of quitting smoking. They cautioned against making absolute claims about quitting success and recommended using language that provides actionable information. Specifically, they emphasized the need for clear recommendations regarding both medication and non-medication options for quitting, as well as clearer messaging around e-cigarettes. Participants stressed the importance of providing specific details rather than general statements to support individuals in their quit attempts. Participants completed three iterations of edits to the key messages which were reviewed by the Working Group members. The final proposed key messages are presented in this report.

Background and Objectives

Involving patients in the development of clinical practice guidelines (CPGs) can yield recommendations that are more likely to be patient-centered, practical, and can provide opportunities for shared decision-making.[1-6] For guideline developers, patient involvement may enhance the credibility, transparency, and applicability of CPGs. Numerous international organizations that appraise the quality of CPGs explicitly call for patient involvement in the guideline development process.[3-5] Similarly, findings from a literature review conducted by The National Institute for Health and Care Excellence[6] suggested that involving patients early in the guideline development process and asking how they would like to be engaged can improve the effectiveness of participants' contributions, as well as influence guideline scope and improve inclusion of patient-relevant topics.[6-12] Despite the benefits of involving patients in the guideline development process, adequate training and support are commonly cited as barriers to patient involvement.[6-12]

The Canadian Task Force on Preventive Health Care's (Task Force) 'Task Force Public Advisors Network' (TF-PAN) is an initiative to encourage early and meaningful engagement of members of the public with the Task Force by seeking their input throughout the development and dissemination of Task Force guidelines. Participants are trained in key concepts on preventive health and screening and are meant to be engaged routinely for various Task Force guidelines. Participants are asked to provide population-perspective insights to inform clinical practice guidelines. TF-PAN activities are facilitated by the St. Michael's Hospital Knowledge Translation (KT) Program in partnership with the Task Force.

Objective: The objective of this community jury was to provide insights and feedback on the Tobacco and Smoking Cessation guideline key message statements.

Methods

Community Jury Approach

A community jury (modified terminology regarding a citizen's jury) approach was used to engage TF-PAN members to provide input on the Task Force's Tobacco and Smoking Cessation guideline key message statements. A community jury is a form of deliberative democracy and aims to elicit an *informed* community perspective on important and potentially controversial topics.[13] Community jury participants are provided with expert presentations and opportunities to question the experts, engage in both facilitated and private deliberation, and are asked to form a consensus or majority 'verdict' on the topic in question. [14]

Community juries elicit the voices, values, and preferences of informed citizens who are presented with systematically synthesized evidence. The sessions are structured to be a two-way dialogue with a 'topic' on trial. 'Jurors' then get a chance to deliberate the evidence before formulating opinions and recommendations. The structure of a session has two phases:

1. Educating Participants
2. Deliberation

The data collection period spanned from November 9th, 2023 to January 23rd, 2024. Phase 1, Educating Participants, was 2 hours long and held on November 7th, 2023. During Phase 1, the KT team explained the objectives and processes for the community jury and the Guideline Working Group co-chairs presented core concepts on Tobacco and Smoking cessation, encompassing interventions, outcomes, benefits, and potential harms.

In Phase 2, the KT team led participants through a deliberation to review the key messages and edit the content as they saw fit, in light of the evidence presented in Phase 1 and provide insights from a patient and population perspective. Phase 2 was approximately 2 hours long, and was held one week after Phase 1 (November 9th, 2023). This allowed participants to reflect on information presented in Phase 1 and to formulate thoughtful, informed opinions or questions to bring to Phase 2.

Following Phase 2 deliberation, the KT team developed a summary document that summarized the jury's feedback and presented revised key message statements. These were shared with the Tobacco Smoking cessation Working Group members for feedback and to clarify the participants' questions/concerns. The draft was then circulated to the jury members by email for additional insights

and feedback. Participants were allotted a span of two weeks to review the revised document and provide additional feedback via email. Upon the conclusion of the review period, the KT team analyzed the collected and categorized the feedback, identifying shared concerns and additional suggestions provided by the participants. Once again, this was shared with the Working Group members to provide additional clarity on guideline content and clinical concepts. A second summary document was circulated to the jury, who were invited to share any final comments or feedback on the proposed key messages. The KT team incorporated this feedback. This final report presents the final proposed key message statements to the Working Group members, for incorporation into the clinical practice guideline.

Participants

Recruitment

Community jury participants were recruited from the core TF-PAN, comprised of individuals trained in key concepts of preventive health care and guideline development (N=18). Recruitment for the jury took place between September 18th to October 18th, 2023.

Participants were compensated $25/hr for participating in the project as per the SMH KT Program internal reimbursement policy.

From the network of 18 people, we identified 8 people who expressed interest in participating in a community jury on Tobacco Smoking cessation.

Original Key Messages Discussed

- Quitting smoking greatly improves your health and wellbeing, greatly reduces your risk of many serious illnesses, and increases how long you may live
- Task force recommendations identify several effective medication and non-medication options to help you stop smoking for good
- Your healthcare providers should discuss options with you, including the benefits and harms of different options
- There are concerns about the lack of approved e-cigarette products with verified quality standards, the lack of long-term safety data for e-cigarettes, and public impacts of encouraging vaping
- Most people should consider other effective options, but e-cigarettes may help some people stop smoking

Results

Characteristics of Included Participants

The community jury included eight participants who were 18 to 75 years of age. Five participants (63%) identified as women. Participants were diverse in race/ethnicity and represented six provinces; five

participants lived an urban area. Seven participants (88%) held a college diploma, bachelor's, or graduate degree.

Summary of Feedback (Round 1)

1st Message - "*Quitting smoking greatly improves your health and wellbeing, greatly reduces your risk of many serious illnesses, and increases how long you may live."*

- Participants suggested acknowledging the challenge of quitting smoking before presenting the benefits.
- Participants recommended including a message of hope along with an acknowledgment of the challenge. They discussed the idea of offering support and tools to individuals to help them overcome the difficulties of quitting.
- Participants highlighted the need for specific examples to accompany the key message. They suggested providing concrete data demonstrating the benefits of quitting (i.e., statistics showing improvements in health and reductions in the risk of specific serious illnesses).

2nd Message - "*Task force recommendations identify several effective medication and non-medication options to help you stop smoking for good."*

- Participants expressed the need to make this message clearer and more concise.
- They suggested to remove the term "Task force recommends" to make the recommendation more direct.
- Participants felt it was important to encourage individuals to explore their options, emphasizing that many choices they can make can have positive impact on quitting smoking.

3rd Message - "*Your healthcare providers should discuss options with you, including the benefits and harms of different options"*

- Participants emphasized the importance of empowering patients to initiate discussions with their healthcare providers. They suggested that the message could be reframed to encourage patients to proactively ask their healthcare providers to discuss options.
  Participants suggested to use more actionable language, such as, "ask your healthcare provider to discuss options," thus making it clear that patients have the agency to bring up the topic during their appointments.
- When discussing treatment options, participants outlined that the term "harms" is perceived as strong and negative. They suggested considering alternative terms like "challenges" or "side effects" to present information in a more balanced manner.
- Participants summarized that the message should convey the idea of shared decision-making, where patients and healthcare providers work together to explore options and make informed choices.

4th Message - "*There are concerns about the lack of approved e-cigarette products with verified quality standards, the lack of long-term safety data for e-cigarettes, and public impacts of encouraging vaping."*

- Participants suggested this message was excessively long. They suggested condensing the information while maintaining the essence of the concerns related to e-cigarettes.
- Some participants expressed concerns about the perception of supporting e-cigarettes without similar support for other cessation methods.
- Participants' discussion touched on the need to include information about alternative methods for quitting smoking (i.e., not exclusively focusing on e-cigarettes).
- Participants suggested condensing the information in the 4th and 5th message into one message, while maintaining the concerns related to e-cigarettes.

5th Message - "*Most people should consider other effective options, but e-cigarettes may help some people stop smoking."*

- Participants suggested merging the 4th and 5th key messages for conciseness and clarity. They noted that both messages were related to concerns about e-cigarettes, and combining them could streamline the information.

Overall Impressions

The following themes were identified in the first round of review:

- Participants suggested framing the messages in a way that gives people hope and provides more encouragement on what they can do.
- There was consensus on the importance of acknowledging the challenges of quitting smoking and providing empathy to individuals attempting to quit.
- Caution was advised against making assumptions about the guaranteed success of quitting; participants suggested using terms like "may help" instead of absolute statements.
- Participants expressed concern about the overall vagueness of the key messages. They noted they lack actionable details and specific recommendations for medications and non-medication options for quitting.

Participants seemed to find the messaging around e-cigarettes unclear, potentially leading to mixed signals about their usage for smoking cessation.

Summary of Feedback (Round 2)

Table 1. Summary of key messages and rationale for proposed change

Original Key Message	TF-PAN feedback (Round 1)	Revised Suggestion	TF-PAN feedback (Round 2)	Revised suggestion (includes WG edits)	TF-PAN feedback (Round 3)	Proposed FINAL key message statements
Quitting smoking greatly improves your health and wellbeing, greatly reduces your risk of many serious illnesses, and increases how long you may live.	- Participants suggested highlighting acknowledging the challenges individuals face when attempting to quit smoking ,while offering hope - Participants suggested specifying examples of illnesses (e.g., stroke, cancer) to enhance clarity.	*Quitting smoking improves your health and reduces the risk of serious illnesses like heart disease, stroke and cancer. Quitting can lead to a longer, healthier life.*	- Participants suggested reordering sentences for clarity, starting with the positive outcomes of quitting smoking and then elaborating on the specific health benefits.	*Quitting smoking improves your health and can lead to a longer life. Quitting reduces the risk of serious illnesses like heart disease, stroke, and cancer.*	None	**Quitting smoking improves your health and can lead to a longer life. Quitting reduces the risk of serious illnesses like heart disease, stroke, and cancer.**
Task force recommendations identify several effective medication and non-medication options to help	- The term "Task force recommends" was removed to make the message more direct and clear.	*Although quitting smoking can be hard, there are several effective options to help you, such as medications, advice,*	- Participants suggested to replace word "hard" with "pose challenges" to clarify the difficulty of	*Quitting smoking can be challenging, but there are several effective options to help you quit including:* - *medications*	None	**Quitting smoking can be challenging, but there are several effective options to help you quit including:** - **medications**

you stop smoking for good.	- Replaced "non-medication" with "other options." as per participants recommendations - Removed "for good" to avoid implying judgment	*counselling, self-help*	quitting smoking. - Participants suggested clarifying support options by providing specific examples of available assistance instead of using broad terms like "advice" and "support." - Remove the term "effective" as it may not be necessary to convey the idea. Consideration to completely remove "Quitting smoking can pose challenges.." part and	- *counselling* - *self-help information*		- **counselling** - **self-help information**

			instead acknowledge of the difficulty of quitting smoking into the preamble before introducing key messages to provide hope and context			
Your healthcare providers should discuss options with you, including the benefits and harms of different options.	- The revision uses more actionable language and encourages individuals to initiate discussions with their healthcare providers - Replaced "harms" with "potential challenges." Participants suggested to consider alternative terms like "challenges" or	*Ask your health care provider about how to stop smoking, as well as benefits and possible side effects of options that suit you*	- Participants suggested simplifying message focusing on encouraging individuals to speak with their healthcare providers rather than delving into the details of benefits and side effects. - Remove "your": the message becomes more	*Talk to a health care provider for more information on which options are best for you.*	None	**Talk to a health care provider for more information on which options are best for you.**

	"side effects" to present information in a more balanced manner.		inclusive, recognizing that not everyone may have a designated primary care provider. - Revise "suit you" phrasing: it may not resonate with everyone, as it implies a personal fit that may not always be clear.			

There are concerns about the lack of approved e-cigarette products with verified quality standards, the lack of long-term safety data for e-cigarettes, and public impacts of encouraging vaping.	- Participants suggested combining the 4th and 5th key message - The revision combines the last two messages and emphasizes the importance of consulting a healthcare professional, addressing concerns about bias and length.	*Most people should consider other options to stop smoking, but e-cigarettes may help some people.*	- One member suggested emphasizing safety concerns about e-cigarettes and the need for informed decision-making - Consider integration with the 2nd key message: one member suggested incorporating the mention of e-cigarettes into the 2nd key message, which focuses on available options for quitting smoking.	*The long-term health impacts of e-cigarette use are unknown. Most people should consider other options to stop smoking, but e-cigarettes may help some people.*	- One member still found the wording unclear and suggested revising the order of the statements in order to provide more clarity - We combine this feedback with that of the working group which emphasized the need to lead with the message against and ensure the explicit concerns around e-cigarettes are highlighted.	**E-cigarettes have been suggested as an aide to stop smoking, however, there are concerns and unknowns about the long-term health impacts of e-cigarette use. Most people should first consider other options to stop smoking, but e-cigarettes may help some people.**

Most people should consider other effective options, but e-cigarettes may help some people stop smoking.	Participants suggested to merge this message with the with the previous one	*Merged with the point above.*				

Overall Themes

The TF-PAN provided valuable insights into refining the messaging around tobacco use and smoking cessation. Participants emphasized the importance of rephrasing messages to facilitate empathy, hope and encouragement, while also acknowledging the inherent challenges of quitting smoking. They advised against making absolute claims about quitting success and urged for language that offers actionable information. Specifically, participants highlighted the necessity for clear recommendations concerning both medication and non-medication options for quitting, as well as for clearer messaging regarding e-cigarettes. Some participants expressed concerns about the perceived emphasis on e-cigarettes over other cessation methods. We made multiple revisions to this key statement and aimed to balance TF-PAN feedback with the evidence provided by the Working Group about the unknowns and potential harms of e-cigarette use. Participants underscored the significance of providing specific details rather than vague statements to better support individuals in their quit attempts.

Next Steps

We are currently in the process of conducting a process evaluation via surveys and key informant interviews with all participants involved in this community jury. The aim of this evaluation is to assess and enhance participant engagement and overall experience.

The findings gathered from this evaluation will be synthesized into a subsequent report.

Conclusion

We engaged the TF-PAN to iteratively review and revise the key messages for the Task Force's Tobacco Smoking Cessation guideline. Participants emphasized the need for tools and resources to be patient-centered, advocating for the utilization of clear and plain language to enhance accessibility and understanding. We encourage the Working Group members to incorporate these statements into the final guideline and we thank the Working Group chairs for engaging the TF-PAN on this important task.

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