ODPRN ONTARIO DRUG POLICY RESEARCH NETWORK

DRUGS USED IN THE MANAGEMENT OF ATTENTION DEFICIT HYPERACTIVITY DISORDER IN ADULTS

Citizens' Panel Report

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Background

The ODPRN Citizens' Panel, a stakeholder group comprised of members of the general public, provides feedback on drug reimbursement policy options for each ODPRN drug class review. The purpose of this exercise is to understand perceptions of the general public about the feasibility and social acceptability of the draft policy options developed at the end of each drug class review, and to rank the most preferred policy options from the perspective of the Citizens' Panel for the Ontario Public Drug Programs' consideration. This report is a high level overview of the methods and results of the ODPRN Citizens' Panel engagement process for the drug class review on the treatment of Attention Deficit Hyperactivity Disorder (ADHD) in adults.

Methods

Citizens' Panel Recruitment

Members of the general public were invited to join the Citizens' Panel by posting advertisements on public websites, the ODPRN website, and social media (e.g. Charity Village, getinvolved.ca, Kijiji, Craig's list, Twitter, Facebook). Citizens' Panel members were also recruited from the Ontario Citizen's Council (OCC). We aimed to recruit 10 to 15 individuals 18 years of age or older who reside in Ontario, with varied education levels and work experience. Members of the general public who expressed interested in joining the panel were asked to fill out an application form. Follow up interviews were conducted with potential panel members over the phone to make final selections. We assessed each potential panel member on their level of knowledge of the healthcare system and drug policy making in Ontario, with the goal of including diversity of knowledge, experiences, and opinions. A total of 15 panel members were ultimately selected and comprised a panel that we engaged for each of the ODPRN's drug class reviews.

Data collection

All panel members were asked to read the draft report and recommendations from the drug class review to familiarize themselves with the research findings. The report was re-written in lay language to enhance its readability and accessibility. Feedback from panel members was obtained in two surveys and a webinar using a modified RAND Appropriateness Method (also known as The Delphi Method) (Fitch, 2001). First, an online pre-meeting survey was distributed to Citizens' Panel members to collect their input on the policy options rated on domains of social acceptability and pharmaceutical policy acceptability analysis: general access, equitable access, appropriateness, affordability, cost to the system, safety, and overall benefit (Morgan, 2009). Panel members were also asked to rate the general acceptability of each option, as well as to rank the policy options relative to one another in terms of their preferred option. Open –ended responses were provided to enable panel members to contribute thoughts, questions, or justifications for their ratings/rankings. Next, Citizens' Panel members attended a webinar meeting, at which we presented key issues, findings and policy implications, and engaged in deliberative group discussion on the recommendations. Any questions, issues or themes that arose from the first round of surveys were addressed in the meeting. Citizens' Panel members completed a second survey after the meeting, enabling them to provide additional feedback and giving them the opportunity to re-rank the policy options. This approach allowed each person to express their idea(s); each person's opinion was taken into account (compared to traditional voting where only the largest group is considered). The findings from the Citizens' Panel surveys and discussion were used by the team to make any necessary revisions to the reports and draft reimbursement options.

Data analysis

Survey responses were analyzed using descriptive statistics and content analysis for open-ended questions. Extensive field notes were taken during meetings and key themes were summarized.

Findings

The ODPRN Citizens' Panel meeting on adult ADHD took place on Tuesday, November 10th, 2015. There were nine members in attendance during the meeting. Seven members completed the pre-meeting and the post-meeting survey. Below is a summary of the findings from the discussion and the subsequent survey.

Overall ranking of options

- Table 1 shows the mean ranking and standard deviation (SD) of each option, pre and post Citizens' Panel meeting.
- Overall, there was a general favorability towards option B, list atomoxetine as limited use (LU) (for adults), with the panel choosing it as their most acceptable choice in both surveys.
- The least favorable choice both times was option A, all stimulant products on general benefit (GB) and atomoxetine on the exceptional access program (EAP) (status quo).

Table 1. Overall option ranking

	Mean Ranking (SD) (1 = Most Acceptable, 3 = Least Acceptable)	
	Pre-meeting	Post-meeting
Option A: All stimulant products on GB and atomoxetine on EAP (status quo).	2.5 (0.8)	2.9 (0.4)
Option B: List atomoxetine as LU (for adults).	1.3 (0.5)	1.1 (0.4)
Option C: No age restriction should be applied to stimulants or atomoxetine.	2.2 (0.8)	2 (0.6)

Ratings of policy options on acceptability domains

- Table 2 shows the mean score and standard deviation (SD) of the specific aspects of each option. Each member of the Citizens' Panel was asked to rate the extent to which they agreed with each statement on a scale of 1 (strongly disagree) to 7 (strongly agree).
- Option A scored low overall, with members disagreeing with every aspect.
- Panelists were in high agreement with nearly all of the aspects for option B, with scores being slightly higher post panel.
- Option C was also rated favourably with members in strong agreement that it would increase equity, and allow for easy accessibility.

Table 2. Comparison of each aspect rating

	Mean score (SD) 1 = Strongly disagree to 7 = Strongly agree					
	Option A		Option B		Option C	
	Pre	Post	Pre	Post	Pre	Post
The policy helps those who need the drugs to access them easily.	2.9 (1.3)	3.6 (1.7)	5.1 (1.3)	5.9 (1.1)	5.7 (0.8)	6.1 (0.7)
The policy will allow those who need the drugs to access them equitably (in other words, regardless of age, income, health status, gender, etc.).	3.4 (2.2)	3.7 (1.6)	5.3 (1.5)	5.4 (1.1)	6.1 (0.7)	6.6 (0.8)
The policy adequately provides coverage for the appropriate types/quantity/doses.	3.0 (0.8)	3.6 (1.7)	5.3 (1.1)	5.7 (1)	5.9 (0.9)	5.7 (1.1)
The policy is a good option to make the drugs more affordable.	2.4 (1.1)	3.6 (1.8)	5.4 (1.5)	5.7 (1.1)	5.4 (1.1)	5.3 (0.8)
The policy is a good option to limit the burden of cost on the healthcare system.	1.9 (0.7)	2.6 (1)	5.0 (1.5)	5.6 (1.3)	5.3 (1.1)	5.3 (0.8)
The policy adequately considers the safety and effectiveness of the drugs.	3.7 (1.8)	3.6 (1.4)	5.0 (1.0)	5.4 (1.0)	4.9 (1.1)	4.6 (1.0)
I think this policy will benefit those who require the drugs.	2.7 (1.0)	3.3 (1.1)	5.3 (1.5)	5.7 (1.1)	5.3 (1.5)	5.4 (0.5)
I think this policy is an acceptable option.	1.2 (1.1)	2.9 (1.2)	5.4 (1.5)	6 (1.2)	5.0 (1.3)	5.1 (0.7)

Reactions and comments from meeting discussion

Option A: All stimulant products on GB and atomoxetine on EAP (status quo).

Reactions:

- The entire panel was in agreement that the listing should not remain at the status quo.
- They felt that EAP is too restrictive for those who are in need of a non-stimulant drug option.
- They also mentioned that EAP is burdensome from a cost-efficacy standpoint, and should therefore not be used for a drug that is in need.

Comments:

"Burdensome process for any patients who require Atomoxetine. Limits access to non-stimulant option, and does not address the economic benefit that can be obtained from adding this drug to the formulary."

Option B: List atomoxetine as LU (for adults).

Reactions:

- Panelists' were in agreement that this was the best option to free up access to those who require a non-stimulant and also to potentially lower the cost through generic pricing.
- Some individual's questioned why atomoxetine would not be listed under GB instead of LU to maximize access.

- However, many agreed that there should still be some oversight in prescribing because of the limited research available for the broader population.
- There were also concerns as to whether or not children would be able to access atomoxetine.

Comments:

"This option provides greater access to non-stimulant treatment. Also, due to its removal from EAP non-stimulant medications will be eligible for generic pricing thereby making treatment more affordable."

"Support adding atomoxetine to the Limited Use category as if allows for more oversight especially for the population for which little testing/no real studies have been undertaken."

Option C: No age restrictions should be applied to stimulants or atomoxetine.

Reactions:

- The panel had mixed feelings regarding Option C.
- Some participants were hesitant to completely remove age restrictions due to the lack of research for older age groups.
- Others felt that it was important to remove age restrictions, due to the growing adult population in need of these drugs.

"It would be beneficial to have more studies on the safety of stimulants and non-stimulants in older adults and to ensure that this information is provided to prescribers in order that any additional monitoring (i.e. cardiovascular adverse effects) be performed as the user age increases."

Recommendation 1: Monitor the cardiovascular safety of stimulants and atomoxetine, especially in older adults with related medical conditions.

- The panel was in full agreement with this recommendation, and concluded that it is a necessity.
- There were questions as to how the monitoring would take place (e.g.,, through a therapeutic note).

"*This will be necessary as more [and more] older adults with co-morbidities take ADHD medications"*

Recommendation 2: Health care practitioners should remain vigilant about the potential for misuse/abuse/diversion of stimulant medications.

- Panel members were also very much in agreement with this recommendation.
- Similarly, there were many questions on how this can be better enforced.

"Education of prescribers and some type of control mechanism need to be put into place to prevent drug diversion."

"This is very important, regardless of the option ultimately recommended."

Limitations

Since the sample for this this Citizens' Panel was small the results in this report may not be representative of the general public in Ontario. However, the literature on public engagement methods,

such as the Delphi, states that group dynamics and diversity play a more important role than sample size (Bruni, 2008; Okoli, 2004). The Delphi method is separate from traditional survey methods and is considered a type of virtual meeting or a group decision technique (Okoli, 2004). The panel members who participated in this exercise provided a range of diverse and valuable insights from the perspective of Ontario tax payers who do live with ADHD. This information, in combination with additional feedback from various stakeholders (e.g., qualitative interviews, in-person forums, and online submissions) and quantitative research evidence, will aid in the development of the final policy options for this review.

Conclusion

The Citizens' Panel provided important feedback on the feasibility and social acceptability of the draft policy options for the adult ADHD review. These findings will be used to help frame the final options in the consolidated report. The consolidated report will be posted at www.odprn.ca.

References

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