

# Atypical Antipsychotic Use for the Behavioural and Psychological Symptoms of Dementia in the Elderly

## 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 review of atypical antipsychotics (AAP) for the behavioural and psychological symptoms of dementia in the elderly.

## 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 interest 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 AAP use for the behavioural and psychological symptoms of dementia in the elderly took place on Monday, April 20<sup>th</sup>, 2015. There were 13 members in attendance during the meeting, 11 of which completed the follow up survey. Below is a summary of the findings from the discussion and the subsequent survey.

### Overall ranking of options

- Table 1 shows the mean rank of each option, which were ranked from 1 (most acceptable) to 3 (least acceptable) after the Citizens' Panel.
- The most preferred choice was option B 'Limited Use' (mean = 1.5), but was closely followed by option C 'Exceptional Access Program' (mean = 1.9).
- Option A 'General Benefit', was chosen as the least acceptable choice (mean = 2.5).

**Table 1.** Overall ranking of options

	Mean Ranking (1 = Most acceptable, 3 = Least acceptable)
<b>Option A:</b> General Benefit (GB) listing for antipsychotics	2.5
<b>Option B:</b> Limited Use (LU) for all prescriptions in the elderly for atypical antipsychotics	1.5
<b>Option C:</b> Exceptional Access Program (EAP) for brand-name atypical antipsychotics	1.9

### 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).
- Respondents felt that Option A (GB) (mean = 6.1, SD = 0.9) would allow for the greatest access of the drugs, but would put the highest burden on the healthcare system (mean = 2.0, SD = 1.2). Option 2 (LU) and Option 3 (EAP) were well rounded overall and rated very similarly. Both options scored high on affordability and reducing the burden on the system. The largest discrepancy between the two options was in 'the policy adequately provides coverage for the appropriate types/quantity/doses' category, as respondents felt that Option B (mean = 4.6, SD = 1.4) would be more restricting than Option C (mean = 5.5., SD = 1.2).

**Table 2.** Overall rating of option aspects

Policy Options	Policy Option		
	Mean (SD) (1 = Strongly disagree, 7 = Strongly agree)		
	Option A (GB)	Option B (LU)	Option C (EAP)
The policy helps those who need the drugs to access them easily.	6.1 (0.9)	5.1 (1.3)	4.4 (1.4)
The policy will allow those who need the drugs to access them equitably (in other words, regardless of age, income, health status, gender, etc.).	6.3 (0.7)	5.0 (1.4)	4.7 (1.6)
The policy adequately provides coverage for the appropriate types/quantity/doses.	5.4 (1.4)	4.6 (1.4)	5.5 (1.2)
The policy is a good option to make the drugs more affordable.	4.9 (1.6)	5.3 (1.0)	5.4 (1.2)
The policy is a good option to limit the burden of cost on the healthcare system.	2.0 (1.2)	5.3 (1.4)	5.3 (1.4)
The policy adequately considers the safety and effectiveness of the drugs.	2.4 (1.6)	4.6 (1.4)	5.3 (1.4)
I think this policy will benefit those who require the drugs.	4.3 (1.7)	5.1 (1.4)	4.4 (1.6)
I think this policy is an acceptable option.	2.7 (2.0)	4.9 (2.0)	5.0 (1.5)

**Comments and key points from meeting discussion**

**Comments for policy Option A - General Benefit (GB) listing for antipsychotics**

- Members were troubled by the fact that the drugs are being over prescribed, and that GB might not be restrictive enough.
- In regards to the therapeutic note, there were questions regarding its efficacy and some suggestions that it should be made stronger to gain the attention of physicians.

*“From an accessibility perspective, this option provides the fewest barriers”*

*“The general benefit listing provides great access to anti-psychotics to the point where they may be over used and used for other purpose then what they were originally intended.”*

*“Ultimately given the negative health effects of anti-psychotics particularly on those over 65 with dementia this 'status quo' option provides the greatest opportunity for the most harm to be done to the patient.”*

**Comments on Option B - Limited Use (LU) for all prescriptions in the elderly for atypical antipsychotics**

- Members though that LU would help reduce a portion of unnecessary prescribing, but physicians could still add the LU code without taking the therapeutic note into account.

- Members thought that this option, and its restrictive nature, could help physicians to “push back” on front line pressures from families.
- Some members felt that this option only appears to consider cost, not efficacy.
- This was the most preferred option overall.

*“More acceptable than status quo (general benefit).”*

*“In addition to limited use for atypical anti-psychotics I would support additional measures limiting access to name brand drugs in order to reduce the burden on the health care system, until such time as relevant studies demonstrate meaningful additional value.”*

*“Although limited use may interrupt some care for some patients, it will hopefully have physicians to consider other non-pharmacological options.”*

### **Comments on Option C - Exceptional Access Program (EAP) for brand-name atypical antipsychotics**

- Members felt that the EAP was the best choice of the 3 options in terms of reducing costs and reducing inappropriate prescribing, while still allowing access to those who need the medication.
- Members wondered why Options 2 and 3 couldn't be combined.
- Some felt that this option could encourage physicians to try other therapies and discourage off label use of brand named antipsychotics.

*“The expensive brand name drugs will be part of exceptional access program which will hopefully lead to fewer prescriptions in general of these drugs.”*

*“Concerned that some MDs will not have time to fill out the paperwork for those who actually need it. Otherwise a good option as it forces MDs to spend more to justify the exact diagnosis.”*

### **Comments on other recommendations**

- General feeling that research should be happening anyway, confusion as to why it would need to be recommended at all.
- The emphasis should be on reducing the inappropriate use of these drugs through education.
- There is a need for long-term care homes to strengthen linkages in the community, or other relevant resources, to provide better care for dementia patients.

## **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 not live with dementia. 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 AAP 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](http://www.odprn.ca).

## References

Fitch, K., Bernstein, S. J., Aguilar, M. D., Burnand, B., LaCalle, J. R., & Lazaro, P. (2001). The RAND/UCLA Appropriateness Method User's Manual. Santa Monica, CA: RAND.

Morgan, S., Kennedy, J., Boothe, K., McMahon, M., Watson, D., & Roughead, E. (2009). Toward an Understanding of High Performance Pharmaceutical Policy Systems: A "Triple-A" Framework and Example Analysis. *The Open Health Services and Policy Journal TOHSPJ*, 2(1), 1-9. doi:10.2174/1874924000902010001

Bruni, R. A., Laupacis, A., & Martin, D. K. (2008). Public engagement in setting priorities in health care. *Canadian Medical Association Journal*, 179(1), 15-18. doi:10.1503/cmaj.071656

Okoli, C., & Pawlowski, S. D. (2004). The Delphi method as a research tool: An example, design considerations and applications. *Information & Management*, 42(1), 15-29. doi:10.1016/j.im.2003.11.002