ODPRN ONTARIO
DRUG POLICY
RESEARCH NETWORK

Cognitive Enhancers for Alzheimer's Disease

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 of cognitive enhancers for dementia management.

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 cognitive enhancers for the management of dementia took place on Monday, July 20th, 2015. Six members were in attendance during the meeting. Five members completed the pre-meeting survey 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 of each option, pre- and post-meeting, on a scale of 1 (most acceptable) to 5 (least acceptable)
- There was not much variation in overall ranking options from pre-meeting to post-meeting.
- The most preferred choice pre- and post-meeting was option D:Limited use (LU) for cholinesterase inhibitors and Exceptional Access Program (EAP) for rivastigmine patch).
- The least favorable choice for pre- and post-meeting was option A.

Table 1. Overall option ranking

	Mean Ranking (1 = Most acceptable, 5 = Least acceptable)	
	Pre-meeting	Post-meeting
Option A: LU for cholinesterase inhibitors (status quo)	4.2	4.6
Option B: LU for cholinesterase inhibitors and EAP for rivastigmine patch (mild to moderate severity)	3.2	3.0
Option C: LU for cholinesterase inhibitors (all severities)	2.4	3.0
Option D: LU for cholinesterase inhibitors and EAP for rivastigmine patch	1.4	1.4
Option E: General Benefit (GB) for donepezil and LU for rivastigmine and galantamine	3.2	3.0

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).

- Options A, B, and C were mostly rated higher pre-panel than post-panel, especially in the aspects of considering safety and efficacy, benefitting those who require the drugs, and being an acceptable option.
- Option D was looked on more favourably after the meeting, and members strongly agreed that the option allows for equitable access, that it benefits those who require the drugs, and that it is the most acceptable option.
- Option E was rated favourably as well, as members also agreed that it would allow for the greatest equitability and also be affordable.

Table 2. Overall aspect ratings for each option

	Mean score (SD) 1 = Strongly disagree to 7 = Strongly agree									
	Option A		Option B		Option C		Option D		Option E	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
The policy helps those who need the drugs to access them easily.	3.4 (1.6)	3 (1.4)	3.6 (1.4)	4.2 (1.0)	5 (0.6)	3.4 (1.6)	5.6 (1.0)	5.8 (1.0)	5.6 (1.5)	4.8 (2.1)
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 (1.4)	3 (1.1)	3.2 (1.5)	4.4 (1.0)	5 (0.9)	4.6 (1.0)	5.4 (0.8)	6 (1.1)	5 (0.9)	6.2 (1.0)
The policy adequately provides coverage for the appropriate types/quantity/doses.	3.4 (1.4)	2.6 (1.5)	4.2 (1.5)	4.6 (1.2)	4.8 (0.7)	3.2 (1.5)	5.4 (0.5)	5.8 (1.0)	5 (1.4)	4.8 (2.0)
The policy is a good option to make the drugs more affordable.	4.2 (1.8)	3.2 (1.3)	3.8 (0.7)	3.4 (1.6)	4.8 (1.2)	4.6 (1.0)	4.8 (1.2)	5.6 (1.0)	5.4 (1.0)	5.6 (1.5)
The policy is a good option to limit the burden of cost on the healthcare system.	4 (1.7)	3.6 (1.6)	3.6 (1.0)	2.6 (0.8)	4.2 (1.3)	4.8 (1.2)	4.8 (1.0)	5.6 (1.0)	4.8 (1.2)	5.8 (1.0)
The policy adequately considers the safety and effectiveness of	4 (1.9)	2.4 (1.5)	5.4 (0.8)	4.4 (1.2)	4.6 (1.2)	3.4 (1.7)	5.4 (0.8)	5.6 (1.0)	5 (0.9)	4.2 (2.1)

the drugs.										
I think this policy will benefit those who require the drugs.	3.8 (1.7)	2.4 (1.2)	4.8 (0.4)	4.6 (1.2)	5 (0.9)	3.8 (1.6)	5.6 (0.8)	6.2 (0.7)	4.6 (1.4)	4.6 (1.9)
I think this policy is an acceptable option.	3.4 (1.7)	2.2 (1.2)	4 (1.4)	3.6 (1.2)	4.6 (1.4)	3.2 (1.7)	5 (1.4)	6.4 (0.8)	4.4 (1.5)	4 (2.5)

Comments and key points from meeting discussion

Option A: LU for cholinesterase inhibitors for patients with mild to moderate Alzheimer's disease (status quo).

- This option was not looked upon favourably by the panel.
- Participants felt it restricted accessibility to individuals with severe dementia.
- Perceived that patients who would benefit from the use of rivastigmine patch because of GI side effects would become more of a burden on the system for the need of additional treatment, and their well-being would be hindered.

"*Status quo does not improve access to any helpful treatments. Patients suffer the most with this plan.*"

Option B: LU for cholinesterase inhibitors and EAP for rivastigmine patch for patients with mild to moderate Alzheimer's disease.

- The panel had similar concerns to option A in terms of restricting access to those with severe dementia, but they were glad that the patch is listed for those that need it.
- There were also concerns regarding the wide range in potential cost increase to the system.

"*While greater access is helped with this option at the end of the day the high cost of the patch makes this option not viable*"

"*Better than status quo but not as good as other options*"

Option C: LU for cholinesterase inhibitors for patients with all severities of Alzheimer's disease

- Members still thought the patch should be available and listed.
- Expanding access for all severities was perceived to be reasonable given the benefits of the drugs.
- They agreed that there was no need to increase access to memantine if it is not as effective.

"*Although there are a limited number of studies that show that donepezil improved cognition in patients with severe Alzheimer's disease, this is a promising policy that shows equitable coverage*

for patients at all stages of disease."

"*Excludes the patch, which is concerning if patients will not want to take the medication due to side effects. This could lead to faster deterioration of Alzheimer's disease burdening institutions. Use of medications as directed is important factor to consider to keep ALZ patients home as long as possible and lessen $$ to system.*"

Option D: LU for cholinesterase inhibitors and EAP for rivastigmine patch.

•   Perceived as the most favourable option as it covered all severities and included the patch.

•   There were some concerns regarding the cost and how much it would increase for this option.

"*With EAP used for the patch, and it being the least cost efficient option but still effective to ease discomfort for patients, I find this policy to be the most favourable.*"

Option E: GB for donepezil and LU for rivastigmine and galantamine.

•   Some participants liked that Donepezil was on GB, but other had concerns that that the GB listing may allow for misuse.

•   Others still had concerns that Rivastigmine was not covered.

•   Members wanted more information about how many patients experienced GI side effect (i.e. how many would benefit from the patch).

•   One individual wanted to include an additional "option F":

"*General Benefit Donepezil. LU for others. EAP for Patch. The savings on GB could offset Patch cost. Doctors could initially prescribe donepezil (cost savings). For the 10 to 20% who have side effects, could switch to patch. Through EAP there would be financial accountability for those patients who need it. This would hopefully help patients to continue to take their medication and prolong time for admission to institutional care. Another cost savings.*"

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 review on cognitive enhancers. These findings will be used to help frame

the final options in the consolidated reports. The consolidated reports will be posted at
www.odprn.ca.

References

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