Making fair and sustainable decisions about funding for cancer drugs in Canada

Julia Abelson
Colene Bentley
Michael M Burgess
Stuart Peacock
Olivier DPayette
John N Lavis
Michael G Wilson
Deliberative Public Engagement

I have no disclosures
Pan-Canadian Public Engagement

- Initial Public Engagement Event: BC, September 2014
- CPAC RFP: “development of a pan-Canadian framework of public values and priorities for integration into cancer drug funding decision-making”
- 2-day deliberative public engagement events in four provinces (SK, ON, QC, NS) (Apr – June 2016)
- Pan-Canadian event (Oct 2016)
- Analysis, reporting and dissemination (Nov 2016 – May 2017)
- ARCC, McMaster Health Forum collaboration
Pan-Canadian Public Engagement

- Objectives:
  - to generate guidance and recommendations from deliberative public engagement to inform cancer drug funding decisions within different provincial jurisdictions
  - to identify common guidance across provinces
  - to explicitly address trade-offs (costs, interests) to determine what trade-offs are publicly acceptable
Design principles

• 2-day off-the-record dialogues where participants:
  – bring their own views and experiences to bear on an issue;
  – learn from the evidence about the issue and from others’ views and experiences; and
  – share their newly informed views about the issue and how to address it

• Combined the strengths of two complementary and well-established models:
  – the McMaster Health Forum’s Citizen Panels; and,
  – the Deliberative Public Engagement approach developed by Burgess and O’Doherty
Deliberation structure & outputs

24-26 demographically stratified participants (online recruitment via AskingCanadians™)

Pre-circulated material (Citizen Brief)

INFORMATION
- Discussion of the brief
- Expert & Stakeholder Q&A
- Identify hopes and concerns

DELIBERATION
- Small & large-group discussion & recommendations
- Noting areas of consensus and persistent disagreement

INFORMATION
- Discussion of the brief
- Expert & Stakeholder Q&A
- Identify hopes and concerns

Policy Uptake
- Reports, articles & online materials
- Media and Public Uptake

Adapted from Burgess et al. 2015
Participant resources

• Pre-circulated document that covers:
  – the features of the problem
  – elements of an approach for addressing it
  – implementation considerations

• Video documentary with experts in the field

• Local expert for Q&A

• Patient perspective
Deliberation topics and questions

Provincial Panels

1) What should guide policy decisions about whether to fund new cancer drugs, or change the funding provided for existing cancer drugs?

2) What would make cancer drug funding decisions trustworthy?

3) How can we improve existing approaches to decision making about cancer drug funding?
Data collection and analysis

Data collection

Each event was audio recorded and transcribed verbatim

Recommendations

Detailed comparative review of the recommendations within their provincial or pan-Canadian context

Themes

Initial review led to the thematic of categories aligned with our deliberative topics

Themes

Within each thematic category - looked for convergence or high-level agreement within recommendations as well as diversity of viewpoints
1. Cancer drug funding decision processes should be adequately supported through range of inputs and evidence

2. Increases in cancer drug spending must be justified using clear and consistent principles

3. Processes for re-reviewing data and making disinvestments should be developed, and should be based on clear and consistent principles

4. Ensuring fairness and equity are important principles when considering the funding of cancer drugs

5. Decision-making processes, decisions, and their rationales should be transparent and made available to the public

6. There should be a pan-Canadian approach to cancer drug funding decisions

7. Citizens can provide informed, relevant guidance on funding decisions for cancer drugs
3. Processes for re-reviewing data and making disinvestments should be developed, and should be based on clear and consistent principles

- Participants accepted the principle of disinvestment - to stop or scale back funding for some currently funded drugs
- Strong support across all panels for comparing the cost-effectiveness of currently funded cancer drugs with new cancer drugs, and for the principle that the health system should be funding drugs that are more cost-effective and more clinically effective relative to other cancer drugs
- Participants endorsed reviewing approved drugs on a regular basis to assess real-world effectiveness and cost-effectiveness to obtain better value for money
Scenario c.

- Imagine you are decision-makers, responsible for the cancer budget. The decision you make will affect the people in your province only. A fixed budget has been set aside to fund 1 treatment. The budget is not large enough to fund both of the treatments. The total cost of the treatment includes all costs that are relevant to the decision.

- The third scenario will ask you, the decision-maker, to consider trade-offs regarding the appropriateness of continuing to fund a drug when the drug is not as good as originally thought and a new drug is almost as good but less expensive.
<table>
<thead>
<tr>
<th></th>
<th>CURRENT DRUG</th>
<th>DRUG A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life after treatment</td>
<td>63 out of 100</td>
<td>60 out of 100</td>
</tr>
<tr>
<td>Duration of life without treatment</td>
<td>2 years</td>
<td>2 years</td>
</tr>
<tr>
<td>Additional duration of life from treatment</td>
<td>Additional 3.5 months (original evidence determined 6 additional months)</td>
<td>Additional 3 months</td>
</tr>
<tr>
<td>Number of patients treated</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Access to treatment (week long treatment, 3 times year)</td>
<td>Short distance (30 mins), cost incurred by patient</td>
<td>Short distance (30 mins), cost incurred by patient</td>
</tr>
<tr>
<td>Total cost to the budget of the treatment per year</td>
<td>$1.5 million budget cost ($30,000 per patient)</td>
<td>$___ million budget cost</td>
</tr>
</tbody>
</table>

At what cost to the total budget should we discontinue funding the current drug? (Please check only one box)

- A. [ ] $1.25 million ($25,000 per patient)
- B. [X] $1 million ($20,000 per patient)
- C. [ ] $0.75 million ($15,000 per patient)
Scenario c.

- Generated the most discussion from participants on the qualifications and criteria needed to guide disinvestment and re-review decisions.
- Most participants felt that “any amount” of savings justified delisting a drug so long as the replacement drug was comparable.
- Out of a concern for fairness, participants stipulated that a drug could not be delisted without an alternative drug available for patients (the so-called “grandfather clause”).
Participants expressed concern about the current drug’s under-performance in real-world conditions:

• there was “skepticism” and distrust about data supplied by industry and participants wanted greater certainty around the evidence (e.g., more trial evidence, specific criteria met, etc)

• they felt decision makers assumed considerable “risk” when paying large sums for drugs that ended up under-performing in real-world conditions and thus wanted to see better ROI for assuming that risk

• saw monitoring real-world effectiveness as engendering public trust in decision processes for cancer drugs
Processes for re-reviewing data and making disinvestments should be developed, and should be based on clear and consistent principles

- Participants accepted the principle of disinvestment - to stop or scale back funding for some currently funded drugs
- Strong support across all panels for comparing the cost-effectiveness of currently funded cancer drugs with new cancer drugs, and for the principle that the health system should be funding drugs that are more cost-effective and more clinically effective relative to other cancer drugs
- Participants endorsed reviewing approved drugs on a regular basis to assess real-world effectiveness and cost-effectiveness to obtain better value for money
Participants at all panels expressed surprise that drugs weren’t being re-evaluate on a regular basis (ON, SK, QC, NS, pan-Can)

- “From a funding point of view, I think, when -- if you're looking at funding, and we're looking at a stressed healthcare system, if you can buy, you know, Tide at $9 and you can buy Cheer at $5, and Cheer works just as good as Tide, why would you give somebody the Tide? Give them the Cheer.” (NS)

- “And another thing we talked about was re-reviewing a lot of the drugs that are on there and, like, things that were decided -- we decided to fund them 20, 30, 40 years ago. Do they stand up to the same standards that we hold a brand new drug to today? If not, why are we funding it?” (NS)
Need to re-review in-use drugs

- “I think that there should be a process to re-evaluate the drugs that are already on the market to see if they are as effective as they were when they first came out. And if not, if we can re-allocate the funds to different drugs.” (SK)

- “But in any case, there should be a system in place where we kind of – if [the drug has] become obsolete, take it off the list instead of -- we keep on adding, adding, adding drugs to the list.” (SK)
Need to re-review in-use drugs

• “I don’t know how this is, but I'm kind of hearing through the course of the day so far that there are still drugs listed on the registries or whatnot that aren't as effective. There doesn’t seem to be any policy or procedure in place to periodical review these things and I think that needs to happen. Maybe not every year but at least every three to five years or something like that....I think the pace of government has traditionally been fairly slow and so government needs to pick up the pace and be able to make decisions faster.” (NS)
Re-review and trustworthy governance

Re-review of in-use drugs is part of trustworthy governance

- Participants felt that re-review of in-use drugs made drug-funding decisions more trustworthy (SK, ON)

- “We also thought it would be important that the mandate [of decision making committees] should include review, regular review of current drugs that are being used, that are already funded. And that the results should be communicated. We'd like to know what evidence was used in terms of indicating whether or not there was improvement, what kind of medical evidence, how much was actually used in the budget that was available.” (ON)
Support for using real-world cost effectiveness evidence

• “Well, we have this one [current drug] that we thought the researchers should say one thing and then our expectation was cut by half in real world scenarios. So the new research was being met with great skepticism...because, well, we already saw this once before, what's to say we're not going to see it happen again?” (NS)

• “Because there is -- if there were no risk, if we could depend on -- if we knew that this was in fact as effective as claimed, I would answer differently. But we don't. And I would need to see a greater benefit, financial benefit, a greater savings, to take that risk”. (SK)
Using real-world cost-effectiveness evidence in decision making is part of trustworthy governance

- Participants wanted decision making bodies to “monitor” and “track” a drug’s future real-world effectiveness to ensure the drug was delivering on the evidence provided when the drug was originally evaluated for funding. Tracking and communicating how well a drug performs under real-world conditions was something participants felt would enhance the trust people could place in decisions to fund or de-list drugs (SK, ON)

- “Re-visiting decisions and transparency [with the public] is another key part.” (SK)
“Any savings” justifies replacing an old drug with a comparable new drug

- When discussing scenario c, most participants saw little difference in performance between the current drug and the new drug (drug A). For this reason, they felt that “any savings” would justify switching from the current drug to the new drug and thus chose option a (i.e., the least savings option)

- “And then finally scenario c, this was our shortest discussion. Yeah, so we all felt that the differences between the current drug and drug A were very minimal in terms of the quality of life and the additional duration of life. So although the new drug was slightly worse in both variables, it wasn't a huge difference. And so we felt that really they're quite comparable and any savings would justify a switch.” (NS)
Other participants were not convinced that “any savings” justified delisting one drug and adopting another that would have less impact on the budget.

- “I didn't go A, I went a little bit higher. I need[]...a bit more of a savings, given the information we have here of the current drug [is] disappointing, from the outset.” (SK)

Some participants were uncomfortable with the idea of knowingly giving patients an inferior drug to save money.

- “I don't feel like penny-pinching to make somebody suffer a little bit more and live a little bit less.” (ON)
The “grandfather clause”

The necessity of having a “grandfather clause”

• There was strong support for disinvestment across all panels, so long as the “grandfather clause” regarding the availability of alternative comparable drugs was used.

• “If a patient is taking a particular drug that's about to be delisted and they don't have another option, that could be quite detrimental. So if a drug is to be delisted, there has to be another option that is, if not better, at least as good for the same or better cost.” (NS)
Some concluding thoughts ...

• Why aren’t we doing re-review and disinvestment already?
• (Some of us have been, lots have not (e.g. NICE))
• The public want value for money
• Spending by governments on ensuring value for money (evaluation, re-evaluation, priority setting, implementation) is trivial
• Health Technology Management should be an input to Priority Setting and Resource Allocation Frameworks
• Priority Setting and Resource Allocation Frameworks have long been used to address opportunity costs and disinvestment decisions
• Failure to address opportunity costs harms all patients
• Public engagement complements patient engagement, it does not replace it
For more information

www.mcmasterhealthforum.org
www.cc-arcc.ca
www.canengage.ca