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Making Decisions about Funding for Cancer Drugs:

A Deliberative Public Engagement
Summary Report 2015

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Summary report

In September 2014 a public deliberation was held in Vancouver, British Columbia (BC), to obtain public input on the topic of setting funding priorities for cancer drugs. The event was titled *Making Decisions about Funding for Cancer Drugs: a Deliberative Public Engagement*. This summary report describes the approach to public deliberation taken for the event, including the level of stakeholder involvement, the development of the deliberative questions, recruitment methods, and preliminary results. This report has been prepared for stakeholders in advance of transcription analysis to provide timely feedback on what the public values with respect to pressing policy initiatives. In the interest of transparency, the report is also available to the event participants and to the public via the CanEngage.ca website. The hope is that the information presented here will lead to the best possible cancer control decisions for the people of BC.



Expert speaker
Dr. Nadine Caron with
event participants

Executive summary

In September 2014 a public deliberation was held in Vancouver, British Columbia (BC), to obtain public input on setting priorities for cancer drug funding. Titled *Making Decisions about Funding for Cancer Drugs: a Deliberative Public Engagement*, the event brought together 24 British Columbians to discuss how best to allocate resources for costly cancer treatments. The purpose of the event was to elicit the values or principles British Columbians feel ought to underpin cancer drug funding decisions in their province, thereby generating values-based evidence to help inform health policy decisions.

Over the course of four days, participants discussed quality of life, disinvestment, and decision governance around cancer drug funding and provided collectively reached policy advice—in the form of 30 recommendations—to decision makers. The topic for deliberation was developed in collaboration with health researchers and senior decision makers at the BC Cancer Agency, the pan-Canadian Oncology Drug Review, the Canadian Cancer Society, and the BC Ministry of Health. Several decision makers from these agencies observed the event. Participants were recruited to reflect the diversity of the people of BC. On the final day of the deliberation, participants presented their recommendations to a panel of senior health policy leaders.

The deliberation was audio recorded and transcribed. Detailed analysis of the transcribed proceedings is forthcoming.

The deliberation event was sponsored through research grants from the Canadian Institutes of Health Research Partnership in Health Systems Integration (CIHR-PHSI Grant #114107), the Michael Smith Foundation for Health Research and the Canadian Centre for Applied Research in Cancer Control (ARCC). ARCC is funded by the Canadian Cancer Society Research Institute (Grant #019789). The research project was led by Stuart Peacock. The deliberation event was conducted by researchers at the University of British Columbia, the BC Cancer Agency and ARCC, and by the CanEngage team.

Key findings from the deliberation:

- Participants accepted the principle of setting limits: Participants supported the principle that it is necessary to utilize thresholds when deciding acceptable levels of funding for new drugs, including the need to rule out some benefits as too costly.
- Strong buy-in from policy makers: Senior decision makers in BC and at pan-Canadian cancer organizations worked closely with the deliberative engagement team to identify key policy topics on which public direction is desired.
- Collective statements for policy: Participants' recommendations represent collectively reached statements for current policy challenges. The statements are the explicit result of informed deliberation over four days.
- Key recommendation to guide disinvestment decisions: There is an obligation to continue to fund a cancer drug if discontinued funding would have a negative impact on populations in rural communities and others with limited access.
- Key recommendation on trustworthy governance of drug funding decisions: There is a need for an independent body that would oversee and review drug funding decisions and involve a variety of people without political motivations.
- Key recommendation on the trade-off between cost and length of life: To justify doubling the cost of a treatment, participants recommended there needs to be a minimum of 12 months of additional duration of life.
- Successful recruitment: Innovative recruitment methods were developed specifically for the deliberation to select participants who represent the variety of social perspectives of British Columbians.
- Confidence in the public deliberation process: Stakeholders and observers remarked on how well participants grasped the issues of cancer drug funding and how seriously they took their task. In addition, participants expressed their readiness to trust the recommendations reached by other publics having undergone similar processes.

Introduction

Statistics tell us about 2 in 5 Canadians will develop some form of cancer in their lifetime, and about 1 in 4 Canadians will die of cancer.[1] In BC, the total number of cancers is projected to increase by more than 45%, from 23,829 new cases in 2011 to 34,666 in 2027.[2] The price of promising new cancer drugs is also on the rise. In 2010-2011 alone, the annual growth in BC's cancer drug budget increased 15% over the previous year. Experts agree these trends are likely to continue. These circumstances present ethical and social challenges for citizens and governments alike. Leaders in health care are tasked with finding evidence-informed and publically acceptable policy solutions to these challenges.

Increasingly, decision makers are turning to the public for guidance in addressing ethically charged policies [3, 4]. In September 2014 a public deliberation event, titled *Making Decisions about Funding for Cancer Drugs: a Deliberative Public Engagement*, was held in Vancouver, BC, to obtain public direction on setting priorities for cancer drug funding. A public deliberation is a specific form of civic engagement that seeks values-based collective solutions to challenging social problems [4, 5]. It involves participants in a process of learning and exchanging views explicitly directed towards collective problem-solving [6], thus making deliberative public engagement distinct from other discussion-based consultation forums, like focus groups. The Vancouver deliberation took place over two weekends. It provided an opportunity for participants to learn about cancer drug funding, to share their perspectives on it, and give meaningful advice to health leaders on a course of action. Participants made recommendations on priority setting and quality of life, disinvestment, and decision governance for funding cancer drugs in BC.

Deliberative forms of public engagement are becoming part of health policy practice in Canada and across the globe [3]. This is because involving citizens meaningfully in creating the policies and programs that shape their lives has moral and practical purchase: it furthers the democratic ideal of self governance and helps establish trust between citizens and

Expert panel (L to R:
Dr. Stuart Peacock,
Ms Mona Sabharwal,
Ms Lindsay Kislock)



government in the decisions reached as a result of this rigorous process [7, 8]. In Canada, deliberative engagements have been set up periodically to advise provincial Ministries of Health on technology assessment [9-12], health services [13, 14] and policies for biobanks [15, 16]. To our knowledge, this is the first deliberative engagement event on funding for cancer drugs in BC.

The Vancouver deliberation brought together 24 members of the BC general public to discuss cancer drug funding. The purpose of the event was to elicit the values or principles British Columbians feel ought to underpin cancer drug funding decisions in their province, including what the acceptable trade-offs are between costs and benefits, fairness and compassion. Participants were asked to make policy recommendations based on their own values or principles, of which they are experts. They were not asked to operationalize the recommendations nor make medical assessments, as these are beyond the remit of ordinary citizens.



Participants at the public deliberation event

Innovative recruitment methods were developed specifically for the deliberation. The goal of recruitment was to select participants who represent the distinct life experiences of British Columbians [17]. Participants received a per diem and their travel and accommodation costs were paid through research funds. The event was sponsored by research grants from the Canadian Institutes of Health Research Partnership in Health Systems Integration (CIHR-PHSI Grant #114107), the Michael Smith Foundation for Health Research and the Canadian Centre for Applied Research in Cancer Control (ARCC). ARCC is funded by the Canadian Cancer Society Research Institute (Grant #019789). The event was conducted by researchers at the University of British Columbia, the BC Cancer Agency and ARCC, and led by Stuart Peacock.

Under the rubric of cancer drug funding, specific policy topics were selected for deliberation. They were identified through in-depth consultation with those responsible for setting policy and practice standards at the BC Cancer Agency, the pan-Canadian Oncology Drug Review, the Canadian Cancer Society, and the BC Ministry of Health. Stakeholders and senior policy makers attended the event as observers and speakers, and to receive the group's recommendations on the final day of the event.

Developing the questions for deliberation

In preparation for the event, the research team consulted Canadian decision makers in cancer control on the policy issues they felt would benefit most from informed public input. Two paths of consultation were pursued: i) a pan-Canadian survey of decision makers in cancer control [18] and ii) face-to-face consultations with health leaders at the BC Ministry of Health, the Canadian Partnership Against Cancer, the BC Cancer Agency, and the pan-Canadian Oncology Drug Review. The pan-Canadian survey was conducted in 2012 by the deliberative engagement research team. Among other things, it asked cancer control decision makers to identify via write-in response which topics they felt would benefit from the degree of public consultation suggested by a deliberative public engagement. Treatment options for cancer drugs was the most frequently cited topic. The face-to-face consultations with senior decision makers revealed a need for public direction on upcoming drug funding decisions, like disinvestment, the trade-offs between quality of life and quantity of life for expensive new therapies, and how best to pursue a policy shift from intravenous to oral chemotherapy treatment delivery.

The research team translated these complex policy topics into questions oriented to a non-expert public. The questions were framed neutrally so as not to bias participants' responses or require them to be experts in medicine, law, health systems, governance or ethics in order to broach them. The deliberative questions were:

- When is it appropriate not to fund a cancer drug for a particular use?
- Under what circumstances is there an obligation to continue to fund a cancer drug when new information suggests the drug is not as desirable as previously determined?
- What would make drug funding decisions trustworthy?

Participants were also given four decision scenarios on Weekend 2. Each scenario placed participants in the role of decision makers and asked them to make explicit trade-offs between costs and various treatment and delivery options. The decision scenarios were:

- Scenario 1: Consider the trade-offs between cost and additional duration of life.
- Scenario 2: Consider the trade-offs between cost and additional quality of life.
- Scenario 3: Consider the trade-offs between cost and access to treatment.
- Scenario 4: Consider the trade-offs regarding the appropriateness of continuing to fund a drug with differences in cost, quality of life, and length of life compared to a new drug.

Recruitment

Novel recruitment methods were developed specifically for this deliberation. The primary objective of recruitment was to obtain a diversity of social perspectives representative of the BC general public. To this end, a two-pronged recruitment strategy was implemented involving i) a survey that stratified respondents based on 2006 census data for BC and ii) the administration of a Discrete Choice Experiment (DCE). Using demographic data and a DCE to inform the selection of participants meant that statistical information could be generated on the representativeness of the participant group. It also meant that the deliberation would incorporate a wide diversity of social perspectives. A market research company was engaged to implement the recruitment strategy, described below.

Sample size calculations determined that an initial pool of 80 survey respondents was needed to represent the diversity of British Columbians; from the 80 respondents, 30 would be selected to participate in the deliberation. The pool of 80 respondents was stratified by age, sex, geography (urban/rural and by health authority), parenthood, experience with chronic disease, ethnicity, and income and education levels according to the 2006 census data for BC. In addition, each respondent had to meet the following criteria. He or she:

- Was not employed by and did not have a direct financial relationship with a tobacco company.
- Did not participate in lobbying for a health advocacy group.
- Was not a health policy maker.
- Was available to attend the deliberation event on both weekends.
- Had not participated in a market research study in the previous six months.

Respondents were informed upon initial contact that they would receive \$125 per day for the deliberation.

Eighty respondents also completed a DCE. The DCE was a 16-question preference-based survey that asked respondents to imagine they had been diagnosed with a serious disease. Their health state before and after treatment, pain level, and duration of life after treatment were presented for each of the three treatment options. A one-time “tax” or cost factor was attributed to each treatment. Respondents were asked which treatment option they preferred. Based on their preferences, respondents were grouped with like-respondents into one of three categories. By combining respondents’ demographic characteristics with their preference characteristics, the research team was able to recruit participants based on their life experiences (expressed demographically) and their preferences. Respondents were given a \$25 honorarium for completing the DCE.

The next step was to select 30 participants who best represented the initial pool of 80. An algorithm was developed to achieve the optimal group of 30 individuals. The 30 individuals were invited to participate in the deliberation event. The algorithm was re-run to find replacements for those who withdrew, in order to reduce the bias of hand-picking replacements. A total of 24 people participated in the deliberation.

The recruitment strategy was successful. A series of chi-square tests revealed that the final 24 participants reflected the demographic characteristics of BC as set in the recruitment criteria.

Participants
discussing funding
for cancer drugs



Informing participants

Information materials—namely, a website, a booklet, and expert speakers—were planned specifically for the *Making Decisions about Funding for Cancer Drugs* event. The materials were important tools in helping participants broach a topic on which they might not be well informed nor have previous knowledge. The materials covered key issues relating to Canada's drug approval process, measures of treatment effectiveness in clinical trials, drug costs, and the need for trade-offs. The overall goal was to empower individuals to participate constructively in discussions, to feel comfortable expressing their views, and to be able to assess the value of others' contributions to discussion.

Booklet

A booklet was prepared to introduce participants to the complex topic of cancer drug funding, and included topics like how medications get covered by a health plan, the role of clinical trials, and getting value for money. It also included a glossary and a list of references. The content for the booklet was developed by the research team and from the academic literature. Participants and expert speakers were given a copy of the booklet prior to the deliberation. The booklet is available as a PDF on the CanEngage.ca website.

Expert speakers

Five individuals were invited to speak about cancer drugs from a range of expert viewpoints. The speakers included Max Coppes (Head, BC Cancer Agency), Dr. George Browman (oncologist), Jo Nanson (cancer survivor), Barbara Kaminsky (CEO, Canadian Cancer Society, BC and Yukon), and Dr. Nadine Caron (surgical oncologist from Northern BC who spoke to issues of equity and access to health services in rural and remote communities). Each speaker was given the same amount of time to address participants, and a question and answer period followed. All five speakers also took part in an informal panel and answered questions from the participants. After Day 1, expert speakers did not interact directly with participants so as not to influence the proceedings in any particular way.



Expert speaker
Jo Nanson

Website

CanEngage.ca is a dedicated website for the deliberation. It was designed to accomplish three key goals: i) to provide participants with up-to-date information on the event; ii) to give participants a mechanism by which to pose questions to event organizers; and iii) to establish the event's legitimacy.

The website is accessible by the general public; it also has a password-protected area for participants only. The protected area provides general information related to the event (e.g., transportation, event location, and meals), FAQs, and a "contact us" function. It also has a discussion forum for participants.

CanEngage.ca will be developed as a platform for future deliberations by the research team.



CanEngage website

Involving participants in deliberation

The research team designed the deliberation to encourage meaningful participation by an informed public. The event format followed deliberative public engagement methods developed by Burgess et al [19]; Burgess is also a member of the research team. The goal of the deliberations was to reach informed and collective recommendations on priorities for cancer drug funding. Dissenting perspectives were also explored and documented. The deliberation event was held in downtown Vancouver at the offices of Allwest Reporting, which is a professional court reporting company. All discussions were audio recorded and transcribed. The event took place over two non-consecutive weekends (i.e., four days) in September 2014. The purpose of the intermission between weekends was to give participants the opportunity to return home and to take a break after intensive discussions. Participants could also use the time away to explore the topic of cancer drug funding with family, friends, and neighbours.

During the event, participants met in small and large group settings. There were four small (i.e., breakout) groups of six participants each. The small group sessions were designed to: i) provide a less crowded venue so as to encourage reticent speakers to participate; ii) help participants develop the skills for successful deliberation, such as respectful listening, seeking and providing clarity on viewpoints, inclusiveness, and so forth; and iii) generate a broad range of viewpoints on the topic of discussion. The focus of the large group deliberations was to: i) ensure that participants received the same information and instructions; ii) introduce various viewpoints aired in the small group sessions to the whole group; and iii) work toward collective statements for policy.

Each weekend served a different objective. The first weekend was designed to set the foundations for successful deliberation by i) providing participants with background information on cancer drug funding (via expert speakers, the information booklet, and the CanEngage website) and ii) helping participants develop the skills required to engage in reasoned discussion focused on collective decision making. The purpose of the second weekend was to enable participants to draw on their new skills and knowledge to make policy recommendations.

The deliberative questions and decision scenarios were first discussed in the small breakout groups and then deliberated by all in the whole group sessions. All recommendations were drafted and ratified in the large group sessions only.



Transcribing participants' words into recommendations

The four decision scenarios were developed by the research team between event weekends. The scenarios asked participants to quantify acceptable limits for duration of life, quality of life, and the trade-offs between them when deciding among treatment options and additional costs. Specific recommendations were generated on these topics.

All recommendations were written in the participants' own language. They were drafted "on the spot" by a member of the research team, who transcribed participants' words verbatim using a laptop and projecting them onto a large screen so participants could confirm the

diction. Participants then ratified the recommendations using electronic clickers. Consensus was not the goal of deliberations; instead, the nature and degree of disagreement was explored and documented by the group and the research team. Selected ratified statements are presented in the following section.

All sessions were led by trained facilitators. A professional moderator led the large group discussions. The moderator was not a content expert but was informed of the issues around cancer drug funding in advance. The moderator was also well versed in deliberative democracy theory and has led several deliberative public engagements in Canada and the US. The small group facilitators had content knowledge and received practical training from the moderator.

All sessions were audio recorded and transcribed.

Participants' recommendations: preliminary results

Despite the complexity of the topic, participants were able to provide practical knowledge and values advice on setting priorities for cancer drug funding in BC. Their recommendations were composed collectively and ratified after a process of deliberation. They represent what an informed citizenry recommends as being in the interest of British Columbians. Participants were not tasked with how to implement the recommendations.

Participants produced a total of 30 recommendations. They felt that all 30 recommendations relate to one another and should be considered together. For this report, the research team has highlighted several key recommendations. The key recommendations, including any disagreements raised by participants, appear below. The list of all 30 recommendations appears in Appendix A.

Analysis of the transcribed proceedings is currently underway, so the recommendations presented in this report have not yet been contextualized within the discussion dynamics of the event. For this reason, they should be considered "raw" data. The descriptors "All" and "Most" indicate the measure of agreement associated with each recommendation. Disagreement was always explored during recommendation making, and could represent a rejection of the recommendation, disagreement with the wording, or an assessment that the recommendation was not necessary or redundant.

1. Deliberative question on disinvestment:

Under what circumstances is there an obligation to continue to fund a cancer drug when new information suggests the drug is not as desirable as previously determined?

- There is an obligation to continue to fund a cancer drug if discontinued funding would have a negative impact on populations in rural communities and others with limited access. (All)

- There is an obligation to continue to fund a cancer drug if it is significantly easier to use compared to other drugs or treatments (for example, oral vs. intravenous drugs). (Most)

Points of disagreement:

- Ease of use is not enough of a reason to continue to fund a drug — the drug should be beneficial.
- It doesn't specify that the new drug is more beneficial.

2. Deliberative question on governance:

What would make drug funding decisions trustworthy?

- There is a need for transparency around how drug funding decisions are made, what stakeholders are involved, and possible conflicts of interest. (All)
- There is a need for an independent body that would oversee and review drug funding decisions and involve a variety of people without political motivations (participants were concerned about patronage). (Most)

Point of disagreement:

- Some of the participants believed that this recommendation may be unnecessary because the conflict-of-interest point in a previous recommendation covers this issue.

3. Decision scenarios 1 and 2:

Consider the trade-off between cost and quality of life or length of life

For each decision scenario, participants assumed the role of decision makers and were asked to make a funding decision between the current treatment and a new treatment. The budget was limited and only one treatment could be funded. Each treatment had specific characteristics, or constraints, associated with it. Participants worked within these constraints to make cost-benefit related decisions about funding for cancer drugs. Within the context of the specific decision scenarios, participants made the following recommendations.

To justify doubling the cost of the treatment participants recommend that:

- There needs to be a minimum of 12 months of additional duration of life. (Most)

Points of disagreement:

- Participants disagreed about whether the age of the adult patient should be taken into consideration.
- Some participants recommended a minimum of 3-6 months of additional duration of life because they believe that every moment is precious.

- It is good economics to get more duration of life for more money.
- There needs to be a minimum of 20 points of improvement in quality of life (quality-of-life scale: 0=dead and 100=perfect health). (Most)

Points of disagreement:

- Being able to return to work was an important factor for some participants but not all.
- Some participants argued that 10 points on the quality-of-life scale makes a difference to the quality of life of some individuals.
- Some participants suggested that the increase in points depends on the original health status of the individual (i.e., the starting point on the scale).
- Decision makers need to consider quantity and quality of life together. (All but 1)

Point of disagreement:

- Quality and quantity are not the same things so you can't put them together.

Summary

Participants in the *Making Decisions about Funding for Cancer Drugs* event underwent a lengthy process of learning, discussing, and engaging with one another about the limits to cancer drug funding. This process resulted in 30 recommendations, which represent participants' informed, agreed-upon solutions to specific policy problems. Senior policy makers in cancer control in BC identified these policy problems as proximate and on which public direction is needed. The recommendations from this event show that participants accepted cost-benefit trade-offs as a reasonable approach to making funding decisions. They also supported the principle that it is necessary to utilize thresholds when deciding acceptable levels of funding for new drugs, including the need to rule out some benefits as too costly. As is the case with recommendations generated through any public engagement or focus group event, the recommendations identified in this report are contextualized by specific historical, social, and discursive circumstances.

It is important to emphasize that consensus was not the goal of this deliberation event; instead, points of persistent contention were explored and documented, since they, too, can inform policy action. The selected recommendations presented in this report represent the initial output of the deliberation and have not yet been situated within the discussion dynamics of the event as a whole. For this reason, they should be considered independent of academic analysis. Forthcoming academic analysis of the event transcripts will provide more detail as to the nuanced reasoning underlying the recommendations and orient them within the appropriate academic and policy contexts.



Participant at the public
deliberation event

Acknowledgments

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Appendix A

Participants' recommendations

Participants at the *Making Decisions about Funding for Cancer Drugs* event composed and ratified 30 recommendations after a process of deliberation. The recommendations represent the values or principles that British Columbians feel should underpin priority-setting decisions for funding cancer drugs in their province. Participants felt that all 30 recommendations relate to one another and should be considered together. Participants were not tasked with how to implement the recommendations or with making clinical assessments.

The recommendations, including points of disagreement voiced by participants, appear below. Because the recommendations have not yet been analyzed within the dynamics of deliberative exchange, they should be considered “raw” or uncontextualized data. The descriptors “All,” “Most,” and “Some” indicate the measure of agreement associated with each recommendation. Disagreement was always explored during the deliberation and, as is documented in the recommendations, could represent a rejection of the recommendation, disagreement with the wording, or an assessment that the recommendation was not necessary or redundant.

All recommendations are written in the participants' own language.

Deliberative question 1:

When is it appropriate not to fund a cancer drug for a particular use?

1. Don't fund a drug if it does not have significant benefits over other drugs that are available. (All)
2. Don't fund a drug when results from clinical trials are not consistent and reliable. (All)

An assumption was made by the group that scientists would determine what is meant by “consistent and reliable” clinical trial data.

- 3a. Do not fund a drug without considering indirect costs. (Most)

Point of disagreement:

- There was some persistent disagreement within the group around how to define “indirect costs” but examples from the group included Environmental, Social, and Governmental issues (ESG).

- 3b. Do not fund a drug without considering direct and indirect costs, such as patient costs (e.g., lost wages, costs to caregivers, etc.). (Most)

Point of disagreement:

- Some participants felt this question was a big catch-all basket.

- 3c. Do not fund a drug without considering direct and indirect costs, such as Environmental, Social, and Governance (ESG) costs. (Some)

Point of disagreement:

- Some participants felt that patients shouldn't be denied access to treatments because a drug is manufactured by a corrupt company or in a corrupt country.

4. Don't fund a drug if it only increases quantity of life and neglects quality of life. (Most)

Points of disagreement:

- Quality of life should always be considered.
- The recommendation doesn't indicate what would happen if quality of life stayed the same.

Deliberative question 2:

Under what circumstances is there an obligation to continue to fund a cancer drug when new information suggests the drug is not as desirable as previously determined?

1. There is an obligation to continue to fund a cancer drug if it is the only drug available for that condition. (All)
2. There is an obligation to continue to fund a cancer drug if there is no better alternative drug available for that condition. (All)
3. There is an obligation to continue to fund a cancer drug if discontinued funding would have a negative impact on populations in rural communities and others with limited access. (All)
4. There is an obligation to continue to fund a cancer drug if it is significantly easier to use compared to other drugs or treatments (for example, oral vs. intravenous drugs). (Most)

Points of disagreement:

- Ease of use is not enough of a reason to continue to fund a drug—the drug should be beneficial.
 - The recommendation assumes that the drug is more beneficial.
5. There is an obligation to continue to fund a cancer drug when the new scientific information/evidence that suggests the drug is not as desirable as previously determined is not significant or conclusive. (All but 1)

Point of disagreement:

- One participant was undecided.

6. There is an obligation to continue to fund a cancer drug when new scientific information/evidence does not indicate that the drug is causing significant harm. (Most)

Points of disagreement:

- There should not be an obligation to continue to fund the drug if new information suggests it is less desirable and does not cause significant harm.
- Not causing harm is not enough of a reason to continue funding a drug – the drug should be beneficial.

7. There an obligation to continue to fund a cancer drug if withdrawing this drug from the formulary will cause serious withdrawal effects in those who use it. (Most)

Points of disagreement:

- Some participants were unsure if this recommendation should be listed: Are there cancer drugs that cause withdrawal? There are other drugs to treat withdrawal.
- If the drug is less desirable and the reason is a chemical dependence, that's not a good enough reason to continue funding a drug.

8. When considering the obligation to continue to fund cancer drugs, decision makers should consider many different kinds of costs, including direct and indirect costs to the health-care system and the patient. (All but 1)

Point of disagreement:

- This recommendation doesn't seem to fit with the deliberative question.

Deliberative question 3:

What would make drug funding decisions trustworthy?

1. There should be a multifunctional, moderated website for physicians, pharmacists, patients, and the public to visit in order to get information, educate themselves, and make comments. (All)
2. Phone support (a 1-800 free number) should complement the website where people can get their questions answered. (All)
3. People in different regions and cities should be engaged to inform drug funding decisions and the results (the information provided during these events and the opinions of these participants) should be put on the website. (All but 1)

Point of disagreement:

- A participant was concerned about the costs involved for this type of effort and if it would ultimately serve to increase trust.

4. There is a need for transparency around how drug funding decisions are made, what stakeholders are involved, and possible conflicts of interest. (All)
5. There is a need for an independent body that would oversee and review drug funding decisions and involve a variety of people without political motivations (participants were concerned about patronage). (Most)

Point of disagreement:

- Some participants believed that this recommendation may be unnecessary because the conflict-of-interest point in the previous recommendation covers this issue.

Decision scenarios 1 and 2 - duration and quality of life

For each decision scenario, participants were placed in the role of decision makers and asked to make a funding decision between the current treatment and a new treatment. The budget was limited and only one treatment could be funded. Each treatment had specific characteristics, or constraints, associated with it. Participants worked within these constraints to make cost-benefit related decisions about funding for cancer drugs. Within the context of the decision scenarios, participants made the following recommendations.

To justify doubling the cost of the treatment we recommend that:

1. There needs to be a minimum of 12 months of additional duration of life. (Most)

Points of disagreement:

- Participants disagreed about whether the age of the adult patient should be taken into consideration.
 - Some participants recommended a minimum of 3-6 months of additional duration of life because they believe that every moment is precious.
 - It is good economics to get more duration of life for more money.
2. Decision makers need to consider quantity and quality of life together. (All but 1)

Point of disagreement:

- Quality and quantity are not the same things so you can't put them together.
3. There needs to be a minimum of 20 points improvement in quality of life (quality-of-life scale: 0=dead and 100=perfect health). (Most)

Points of disagreement:

- Being able to return to work was an important factor for some participants but not all.

- Some participants argued that 10 points on the quality-of-life scale makes a difference to the quality of life of some individuals.
 - Some participants suggested that the increase in points depends on the original health status of the individual (i.e., the starting point on the scale).
4. If the quantity of life is low, then increasing quality of life becomes more important (patients would want less quantity (length of life) if they were living with a low quality of life). (Most)

Points of disagreement:

- Participants disagreed with splitting up quantity and quality of life.
 - A few participants believed that this particular recommendation was too unclear to include.
 - A few participants were concerned that this recommendation may not be useful to policy makers.
5. If the quality of life is high, then increasing quantity of life (length of life) becomes more important (the patient would want more quantity (length of life) if they were living with a higher quality of life). (Most)

Points of disagreement:

- Some participants were concerned that this recommendation was too similar to the previous one [# 4].
 - A few participants were concerned that this recommendation may not be useful to policy makers.
6. Policy makers need to consider if quantity and/or quality of life will be lowered for certain groups of patients (participants would like for decision makers to consider the consistency of the effect of that treatment). (Some)

Points of disagreement:

- Some participants pointed out that there will always be outliers and this was something that could not be avoided. They suggested that in such cases, doctors will help manage individual patient care.
- A few participants were concerned that this recommendation may not be useful to policy makers.
- Some pointed out that quality of life is always diminished because of the toxicity associated with treatments.

- The following question was posed by some participants: If the treatment does not benefit the minority, should it not be funded for others?
- It is important to add medication choices for patients, not to take choices away because they may not be appropriate for certain groups of patients.

Decision scenarios 3 and 4 – access and disinvestment

For each decision scenario, participants were placed in the role of decision makers and asked to make a funding decision between the current treatment and a new treatment. The budget was limited and only one treatment could be funded. Each treatment had specific characteristics, or constraints, associated with it. Participants worked within these constraints to make cost-benefit related decisions about funding for cancer drugs. Within the context of the decision scenarios, participants made the following recommendations.

1. We have a responsibility to provide oral chemotherapy to those with limited access, limited mobility, who have special circumstances, or are unable to use IV chemotherapy. (All)
2. If the resources are available, everyone should have access to oral chemotherapy. (All but 1)

Point of disagreement:

- We need to consider trade-offs and the reality that money saved by restricting access to certain treatments could then be used in different ways and for other things. Participants wanted to emphasize this consideration.
3. Decision makers should consider other costs that might offset the costs of oral chemotherapy. (All)

Examples of costs included costs to the patient, the environment, or to wider society.

4. Patients who are taking an existing drug should have the option to stay on the existing drug even if it is more expensive than a similar new drug. (All)
5. Drugs should be re-evaluated when new evidence becomes available. (All)

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