



Determining social values for resource allocation decision-making in cancer care: a Canadian experiment



Tania Stafinski^a, Christopher McCabe^b, Devidas Menon^{a,*}

^a School of Public Health, University of Alberta, 3021 Research Transition Facility, 8308 114 Street, Edmonton, Alberta, Canada T6G 2V2

^b Faculty of Medicine & Dentistry, University of Alberta, 736C University Terrace, Edmonton, Alberta, Canada T6G 2T4

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ABSTRACT

Aim of the study: To determine the content values that 2 separate juries of individuals consider to be important in making decisions about resource allocation in cancer care.

Methods: Two citizens' juries were established through random and stratified sampling of the population of Northern and Southern Alberta respectively. Four deliberative sessions were run identically in both juries. Juries participated in exercises, in small groups as well as in plenary. In an exercise in which they had to select 5 out of 10 cancer technologies for funding, the juries separately identified the factors they considered to be important for resource allocation decision-making.

Results: Socioeconomic measures between the 2 juries of 16 individuals did not differ significantly. The juries independently arrived at an identical list of content values that they deemed important to them to have included in decision-making processes. These were: number of patients who could benefit, current health state, prognosis without the technology, health outcome with the technology, age, and dependents. They also identified "levels" of these values, 2 for number of patients (many, few), 3 for current health state (severely, mildly and moderately ill), 3 for prognosis without technology (a few weeks, 2 years and 5 years for survival), 3 for health outcome with the technology (full functioning, sufficient functioning, insufficient functioning), 2 for age (old, young) and 2 for dependents (yes, no).

Conclusion: Given appropriate design and delivery, Citizens' Juries can deliberate on complex health issues and reach similar conclusions.

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Introduction

Over the past 2 decades, resource allocation decision-making in developed countries has moved from a consideration of primarily technical factors to the recognition that various other factors need to be incorporated into the decision process. While the technical factors usually relate to aspects of the competing demands for resources (e.g., details of the specific health programs being considered), it has become clear that decision-making in specific contexts requires the consideration of values as well [1–3]. This is particularly accentuated in cancer care. For example, cost containment in cancer care has been referred to as a "moral issue", and there are calls for a more open and participatory process for making choices [4]. It is also recognized that an acceptable definition of the value of cancer treatments does not exist [5]. Finally, the conclusion has been reached in Great Britain (based on criteria used

by NICE to make decisions on oncology drugs) that not using actual social values while making decisions may have significant health and financial implications [6].

"Values" have been defined and categorized in various ways. Kenny and Joffres [7] group them into *terminal values* (the goals that the decision is to achieve), *procedural values* (related to the decision-making process itself), and *content values* (the criteria and principles employed). Clark and Weale [8] focus on *process values* (similar to procedural values above) and *content values* (which relate to factors considered in the decision-making process). These authors also propose that values that are incorporated into resource allocation decision-making ought to be "...the same values as those held by the population served by the healthcare system in question". This begs the question, how are these values to be determined?

What do we know?

Since the late 1970s, a number of empirical studies have reported on eliciting content values (i.e., factors considered

* Corresponding author. Tel.: +1 780 492 908.

E-mail addresses: tania@ualberta.ca (T. Stafinski), mccabe1@ualberta.ca (C. McCabe), menon@ualberta.ca (D. Menon).

important for decision-making) from individuals and groups of individuals. They have varied widely, in the methods of elicitation, the specific populations involved, and the exact questions addressed. The approaches used to try and obtain an idea of the values that people consider to be important in making resource decisions have included self-administered questionnaires [9–20], web-based surveys [21], in-person interviews [22–29], and in an early study, a citizens' jury approach [30]. These studies have been described and compared in a 2011 review by Stafinski et al. [31]. More recently, a participatory approach was used with a standing technology advisory committee in the province of Ontario in Canada [32], a mixed-methods approach in South Korea [33] and a survey in Great Britain [6], all intended to elicit values held by groups of people.

These studies have collectively concluded that there appears to be a set of criteria that different groups believe to be important in considering resource allocation in health care. However, typically, the individual studies have focussed on a limited number of criteria when considering the views of groups of people. As well, the clear rationale for who “the public” comprised is not always explicated. In this paper we report research into the content values that should be used to inform resource allocation specifically in cancer care. In designing the study we explicitly sought to recruit respondents who were representative of the population affected by the decisions which the values would inform.

The objectives of this study

1. To determine the content values that citizens of a Canadian province (Alberta) would consider important for consideration in resource allocation in cancer care
2. To compare these values in two different samples of Alberta's population
3. To obtain, through deliberative discussions with citizens, what they consider to be meaningful different levels of each value

Building on the existing literature, the study was designed with the following stipulations:

- The group of citizens selected for the study must be socio-demographically representative of the general population of Alberta; this reflects the requirement that the values decision-makers incorporate into decisions must reflect those of the population they serve [8].
- The process of engagement by which citizens' views are elicited must be deliberative in nature; this is elaborated on later in this paper.
- The process of engagement must include an educational/informational component, so that the participants can engage in informed deliberations.
- Participants must have to make choices between programs, and must be able to defend their choices.
- The study must be conducted in two different regions of the province, under identical conditions, to study consistency of views across the province.

Reporting of the study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [34].

Materials and methods

Choice of method of engagement

There are numerous deliberative methods that have been applied in health care, and the appropriate method will depend

on the purpose of the deliberation. For example, Abelson et al. [35] have concluded that “the design of procedurally fair and legitimate processes that provide opportunities for meaningful involvement, shared learning and the consideration of a range of views – the pillars of deliberative methods” requires a small group of citizens. This is one rationale for the choice of the Citizens' Jury as the approach to the elicitation of content values and resource allocation in this study. The citizens' jury has attracted considerable interest from healthcare decision-makers [36–38]. Citizens' juries, like legal juries, are based on the idea that “once a small sample of the population has heard the evidence, its subsequent deliberations can fairly represent the conscience and intelligence of the general public” [39]. They typically involve 12–16 individuals who are selected to be broadly representative of their community. Charged with addressing 1 or more complex questions, they meet over a 2–4 day period, during which they hear from expert ‘witnesses’ who represent a broad range of perspectives, engage in deliberations among themselves, and come up with a common ground answer [36]. Therefore, in contrast to traditional opinion polls, surveys, focus groups, and interviews (where information flow is one way), citizens' juries attempt to seek ‘more informed’ public views (through a multidirectional flow of information among jurors and witnesses). Findings from external evaluations of citizens' juries are sparse, but positive. Regarding fairness and competence, juror deliberations have been shown to demonstrate rational, logical flows of thought that build upon previous arguments. They also reveal a shifting of views from primarily self-interested to more socially aware ones [40–43]. It has also been demonstrated that individuals who were involved in a citizens' jury retained the conclusions they reached as a result of the deliberations, i.e., their positions on the topic are not transient [44].

Selection of the juries

Two juries of 16 individuals each were selected to broadly represent the population of Northern Alberta and Southern Alberta (totalling approximately 1.8 million people), respectively as follows.

For each jury, fourteen hundred individuals were selected randomly (using a random number generator) from a commercially prepared database of registered telephone numbers (Survey Sampling International®). In addition, 100 randomly selected cellular phone numbers from each area were selected to ensure adequate sampling of individuals in the 18–34 year old range. This sample size was calculated from response rates for previously published citizens' juries, which ranged from 2 to 40% [37]. A letter informing individuals of the study, and eliciting expressions of interest in participating was sent to each address. Information letters and consent forms were then mailed to those who responded positively. To reduce volunteer bias, an honorarium of \$400 was offered to jurors, as well as reimbursement of all jury-related expenses; this is considered standard practice in citizens' juries [45].

Individuals who were willing and able to participate were interviewed by 2 researchers (experienced in qualitative research methods) using a pre-tested interview script. Survey questions were designed to collect information on socio-demographic data (age, gender, ethnicity, education, household income and employment status) as well as information on potential affiliations with health-related special interest/patient advocacy groups and/or employment as a healthcare professional in a healthcare delivery organization or government. The latter were used as exclusion criteria for the study, as the intent was to elicit the views of the general public or ‘ordinary citizens’ (i.e., individuals with no particular axe to grind or whose voices might otherwise not be heard). Purposive and stratified sampling was then used to select the 16 jurors as follows: eligible respondents were first grouped according to

gender and age; then stratified by level of education and household income (before taxes); then purposively selected to match the age, gender and socioeconomic distribution of the Alberta population, based on census data from Statistics Canada. Ethnic backgrounds (including First Nations) were also taken into account. This sampling was used because it is well known that such socio demographic factors influence health, and so differences in them between the juries had to be minimized in order to generate data that might otherwise be biased [46]. When several respondents with the same characteristics were identified, random sampling (using a random numbers table) was used to choose among them. In the following, the Northern Alberta (Southern Alberta) jury is referred to as NA (SA) jury.

Organization of the juries

As is standard procedure for citizens' juries, an advisory committee was created, comprised in this case of 2 senior health executives with experience in healthcare resource allocation in Alberta (in cancer and in health services generally), a practising oncologist and a senior researcher. Based on previous experience and published evaluations of citizens' juries, a 2½ day jury session was planned [44,47]. The advisory committee also helped to select 'expert witnesses' representing various stakeholder perspectives: an oncologist, a senior cancer service delivery decision maker, a senior health service delivery decision maker, an ex-senior government decision maker responsible for funding policies and a cancer patient advocate (3 male, 2 female). These expert witnesses were the same for both juries. Cancer technologies were chosen as the 'case study' for presentations and jury deliberations for 3 main reasons: (1) the public has a general familiarity with cancer and its implications; (2) cancer technologies span the entire care pathway (including prevention, screening, curative treatments, and palliative interventions) and, thus, encourage trade-off discussions around the range of benefits or effects various types of health services may have on different patient populations; and (3) much of the recent public criticism over access to quality health care has been related to cancer technologies (mainly high-cost pharmaceuticals) [5,48,49].

Conduct of the juries

The 2 juries were run in exactly the same way. Eight sessions were conducted over the entire period of each jury. The sessions were organized such that at the end of the fourth session, the jurors were to be able to identify the values that they considered important for them to consider during resource allocation decision making. This paper reports on the outcomes of these first 4 sessions.

Session 1

A facilitator conducted an "ice-breaker" session for the jurors and witnesses. Introductory presentations were made by the expert witnesses on the need for priority-setting in healthcare and decision-making challenges in cancer care. The use of citizens' juries as a means of obtaining public views was described to the jurors by the principal investigator of the project, who is an experienced health services/policy researcher.

Session 2

"A day in the life" presentations by the 5 'expert witnesses'. This was followed by a simulated decision making exercise by these witnesses, who were presented with 5 cancer technologies: (1) bevacizumab for glioblastoma multiforme, a common and fatal type of primary brain tumor, (2) brachytherapy for breast cancer, (3) robotic surgery for localized prostate cancer, (4) faecal immunochemical tests for colorectal cancer screening, and (5) implantable

Table 1

List of technologies used in decision simulation exercise.

Technology	Indication
Endobronchial ultrasound-guided transbronchial fine needle biopsy	Determining the spread of lung cancer to areas between the lungs
Bortezomib (proteasome inhibitor treatment)	Recurrent multiple myeloma
Laser therapy	Removal of fetal tumours
Brachytherapy (localized internal radiation)	Unresectable liver cancer
BRCA 1 and 2 genetic test	Screening for presence of genes linked to hereditary breast cancer
Cementoplasty (injection of acrylic bone cement)	Relief from pain and stabilization of bone with malignant cavities
Cryotherapy (use of liquid nitrogen to freeze and destroy cells)	Localized kidney cancer
Human papillomavirus vaccine	Protect boys and men from catching and spreading genital HPV to female sexual partners
Chemotherapy wafer	Delivery of anticancer drugs directly into sites of removed glioma (type of brain tumour)
Gemtuzumab (monoclonal antibody treatment)	Relapsed acute myeloid leukemia in children

drug delivery systems for cancer pain. These technologies represented funding requests in the province at the time and had been recommended by the advisory committee. The information provided to the witnesses was similar in content and type as is frequently contained in ministerial briefing documents. It had previously been pilot-tested for readability with a convenience sample of the public who had agreed to the initial survey, but had not been selected for the juries. The expert witnesses were asked to describe the characteristics of the patient populations (which are content values) for each technology that they considered during the deliberations.

Session 3

In 3 small groups (roughly balanced on age, gender and education), the jury acted as a provincial coverage committee and undertook a decision simulation exercise, to select 5 out of 10 technologies (see Table 1). The cost of each technology was assumed to be the same. Each group was facilitated by a researcher (with master's degree level preparation in health research) who offered clarification on the choice task and ensured active participation from all group members. The groups then reconvened in plenary to compare choices and discuss characteristics they had considered. They then compiled a list of these ranked in order of importance. In addition, through further deliberative discussions, they identified distinct categories or levels within characteristics which they felt shaped their choices (e.g., age: young versus old).

Session 4

In order to illustrate the implications of "no" decisions, including public and patient responses to them, and to test the robustness of the juries' choices of the 5 technologies in Session 3, scenarios were developed on 3 technologies that were not unanimously selected by the juries for funding: (1) a newspaper article about a child denied 'last chance' therapy for leukemia; (2) a letter to the Board Chair of the provincial health services delivery organization from a nurse with unresectable liver cancer, caused by hepatitis C contracted through work, whose only option other than "gruelling" systemic alternatives, was brachytherapy, a treatment available in neighboring provinces; and (3) a letter to the Premier from a prominent neurosurgeon condemning the province's decision not to fund the chemotherapy wafer for high grade glioma, a particularly "aggressive and deadly form of cancer with few treatment options". These "appeals" to "do not fund" decisions were presented to the jury

by 3 of the expert witnesses. At the end of the discussion, jurors were given the opportunity to change their minds (i.e., revisit and revise the list of 5 technologies they selected to fund), in light of the arguments presented.

Analysis of data

All jury sessions were digitally recorded and transcribed. Transcripts were analyzed using content analytic and constant comparison techniques to assess the flow of arguments, assess the extent to which all of the jurors' views had been captured, and to systematically organize data into a structured format [34]. To accomplish this, data (chunks of information) were sorted, arranged, and coded using dedicated qualitative research software (NVivo® 8). To minimize observer bias, 2 researchers trained in qualitative methods independently reviewed all of the transcripts, and then met to compare findings and reconcile differences [50].

In addition to these qualitative analyses, quantitative methods were used to compare the two juries. Differences in response rates to invitations to participate between the two juries were assessed using Pearson's Chi-Square Test [51,52]. Given the small sample sizes of the actual juries, Fisher's Exact Tests were used to detect statistically significant differences in age, gender, ethnicity, education level, household income (before taxes), employment status, and geographic location of residence (all categorical variables) between the two juries [50].

Results

Jury composition

A total of 684 replies accompanied by completed consent forms were received within 2 weeks of the mail-out in Northern Alberta, and 701 in Southern Alberta. The difference was not statistically significant (p -value = 0.56). All respondents completed the telephone screening survey. Approximately 60% of the non-respondents had not received the original invitation (letters were returned by the post office, marked as 'no known address', 'change of address' or 'no forwarding address'). Socio-demographic characteristics of the 16 individuals selected for each of the 2 juries are presented in Table 2. Slight variations in the distribution of age, education and household income between juries were evident, but none reached statistical significance at the 95% level.

Jury sessions

Session 1

The 'ice breaker' session, and dinner with the expert witnesses and researchers resulted in the jurors reaching a level of comfort with them and each other. The jurors took advantage of the opportunity to question presenters in this session, who described the need for priority-setting in health care, the conflicting challenges in cancer care, and the use of the citizens' jury as a means of eliciting the views of the public. This session resulted in a better understanding on the part of the jurors (based on their verbal feedback) of how provincial funding decisions are made, and of the trade-offs inherent in this, both within health care and across all public sectors.

Session 2

Each expert witness described his/her roles in the provincial health system and the types of decisions they faced. The pressures they confronted in making resource allocation decisions (between patient populations with different characteristics) were described and discussed with the jurors. In this way, the jury acquired a better

understanding of the complexities of resource allocation decision-making, particularly in an area such as cancer care, which impacts almost every individual at some time or other. Then as a panel, and facilitated by the principal investigator, the expert witnesses discussed the 5 technologies presented to them. The objective of this exercise was not to select a single technology, but to deliberate around what they would consider while making a choice. The witnesses came up with characteristics of the particular patient populations that would use the technology, e.g., the number of people who might benefit and severity of the condition being managed by the technology, and of the potential impact of the technology, e.g., on survival, quality of life and costs. It was also suggested that there should be an attempt made to ensure a range of services (e.g., preventive and palliative) be made available through such processes. The jurors actively engaged in discussion with the witnesses on what the relevant considerations ought to be. The deliberations served as an example of how the jurors could subsequently engage in simulated decision-making exercises.

Session 3

(a) Selection of technologies: Four of the five cancer technologies selected for funding were identical between juries: endobronchial ultrasound-guided transbronchial fine needle biopsy; a genetic test for hereditary breast cancer; cryotherapy for localized kidney cancer; and cementoplasty for bone pain. The rationale for choices was similar across juries, with both expressing a desire to fund technologies that represented a wide range of types of interventions (e.g., screening or prevention, diagnosis, treatment, and supportive care). (Please see Appendix A row 1 for quotations from individual members (identified by a number) of the two Juries).

Both juries spent considerable time deliberating over their fifth choices. Though their deliberations covered similar issues and arguments, the juries arrived at different decisions. For example, both juries felt that the HPV vaccine could benefit a large number of individuals. Please see Appendix A row 2 for comments.

They also raised points related to 'lifestyle' choices as risk factors for certain cancers, such as liver cancer. In both juries, this topic led to an active, lengthy debate among jurors. Some argued that funding priorities should focus on patient populations whose "unhealthy behaviours" had not contributed to their health state. Please see Appendix A row 3.

Others presented the 'slippery slope' argument, consistently raising the example of obesity. Please see Appendix A row 4.

Both juries also discussed the issue of entitlement to healthcare as taxpayers. Please see Appendix A row 5.

In the end, the NA jury chose to fund the HPV vaccine for boys, reiterating the importance of funding technologies that they felt benefitted the greatest number of individuals. In contrast, the SA jury selected brachytherapy for unresectable liver cancer, citing severity of illness and the lack of "good" alternative treatments as the main reasons.

(b) Identification of important factors: Both juries compiled similar lists of factors or characteristics of patient populations they thought influenced their choices. The list comprised the following factors. Appendix B provides quotations from both Juries on each factor.

- (1) Number of patients who could benefit (Appendix B, row 1).
- (2) Current health state (severity of illness) (Appendix B, row 2).
- (3) Prognosis without treatment (Appendix B, row 3).
- (4) Health outcomes – quality of life (Appendix B, row 4).
- (5) Age (Appendix B, row 5).
- (6) Dependents (care-giving responsibilities) (Appendix B, row 6).
- (7) Personal responsibility for illness (Appendix B, row 7).
- (8) Health outcomes – length of life (Appendix B, row 8).

Table 2
Comparison of socio-demographic profiles of the 2 juries.

Characteristic	Number of jurors (%) ^a		p Value [*]
	Southern Alberta Jury	Northern Alberta Jury	
Gender			
Male	8 (50%)	8 (50%)	0.64
Female	8 (50%)	8 (50%)	
Age			
18–24	2 (13%)	2 (13%)	1.00
25–34	2 (13%)	2 (13%)	
35–44	2 (13%)	2 (13%)	
45–54	4 (26%)	3 (19%)	
55–64	3 (19%)	3 (19%)	
65–74	2 (13%)	2 (13%)	
>74	1 (6%)	2 (13%)	
Education (highest level)			
<High school	1 (6%)	1 (6%)	1.00
High school	4 (25%)	5 (31%)	
Post-secondary diploma	4 (25%)	4 (25%)	
Undergraduate degree	4 (25%)	4 (25%)	
Graduate degree	3 (19%)	2 (13%)	
Annual household income (\$ Cdn, before taxes)			
<\$25,000	2 (13%)	3 (19%)	1.00
\$25,000–\$45,000	4 (25%)	4 (25%)	
\$46,000–\$70,000	3 (19%)	3 (19%)	
\$71,000–\$100,000	4 (25%)	3 (19%)	
>\$100,000	3 (19%)	3 (19%)	
Employment status			
Employed	12 (75%)	12 (75%)	1.00
Unemployed	2 (13%)	2 (13%)	
Retired	2 (13%)	2 (13%)	
Ethnicity			
Asian	2 (13%)	1 (6%)	0.60
Caucasian	13 (81%)	13 (81%)	
First Nations (Aboriginal)	1 (6%)	2 (13%)	
Geographic location			
Urban	12 (75%)	12 (75%)	0.66
Rural	4 (25%)	4 (25%)	

On further discussion in plenary, the jurors agreed that “personal responsibility for the illness” should not be a consideration in resource allocations, and “health outcomes” were already covered by “prognosis without treatment” and “health outcome (with technology)”. This reduced the list to 6 factors. Juries ranked these 6 factors from most important to least important, producing two lists which were almost identical (see Table 3).

On further deliberation in the jury as a whole, agreement was reached on the levels that each of these factors could be divided into. The results are presented in Table 4.

Session 4

Importantly, when jurors were “interrogated” by ‘witnesses’ on their selection of technologies for funding, they stood their ground, choosing not to revise their decisions. They explained that “it is

not that we don’t value what those other technologies could do for people, we do . . . it is just that we think these ones are more worthwhile”; “we would have loved to fund them all, but there wasn’t enough money and some difficult decisions had to be made . . . we thought we would be giving up the least by not funding these ones”; and “2 months of life is not a helluva lot over something that could ease pain for many cancer patients, I don’t think so, not on my watch”.

Discussion

This study was conducted with three main objectives. The first objective was to understand what Albertans considered to be the important “content values” to be included while making decisions on resource allocations in health care. These values have been determined and documented above, focussing on cancer care. Further, the study was repeated in two separate parts of the province, using identical approaches, and this yielded essentially the same results. This addresses the second objective. Finally, through their deliberations, the juries were able to come to agreement about the “levels” of each of the factors that might weigh differently in choice decisions; this was the third objective of this study.

The other stipulations of the study, presented in the section “The Objectives of This Study” have also been met. In order to understand the views of the population of the province of Alberta, the participants for the study were sampled from this population and can be seen as representative of Albertans generally. Recent research points to the need for healthcare decisions made in a system to

Table 3
Comparison of rankings of factors/patient characteristics between juries.

Factor/patient characteristic	Rank (from most to least important)	
	Southern Alberta Jury	Northern Alberta Jury
1. Number of patients who could benefit	1	1
2. Current health state	2	2
3. Prognosis without treatment	4	3
4. Health outcome (with technology)	3	4
5. Age	5	5
6. Dependents	6	6

Table 4
Summary of factors/patient characteristics and categories/levels around which distributive preferences were elicited.

Factor/patient characteristic	Categories/levels	Description
1. Number of patients who could benefit	Many Few	N/A
2. Current health state	Severely ill Moderately ill Mildly ill	Unable to perform daily activities; in extreme pain or discomfort; depressed Unable to perform some daily activities; in moderate pain or discomfort; mildly depressed Occasionally unable to perform a few daily activities; in mild pain; not depressed
3. Prognosis without the technology	A few weeks 2 years 5 years	Life expectancy without treatment
4. Health outcome (with technology)	Full functioning Sufficient functioning Insufficient functioning	Health returns to normal (i.e., what it was before the illness) Health does not return to normal, but patients are able to perform daily activities Health improves, but does not return to normal and patients are not able to perform most daily activities
5. Age	Young Old	Average age: 20–30 years Average age: 60–70 years
6. Dependents	Yes No	Has care-giving responsibilities Does not have care-giving responsibilities

recognize the values of people within the system [7,8], and this condition is met by our study. The choice of method of engaging members of the public was modelled after the citizens' jury, which is an intensive deliberative approach; deliberation was stipulated as a requirement of this study. The early and continued active engagement of the expert witnesses provided a good information base which enabled the jurors to discuss in a more informed manner than otherwise would have been possible. Another stipulation related to opportunity costs – by having to choose between technologies, jurors were forced to make trade-off decisions. This is an inherent part of real-world decision-making and ensures that the recommendations are expressions of preferences, in the economic sense of the word [53]. Finally, the experiment was repeated in 2 geographical regions, which was the last stipulation.

More specifically, the exercise of selecting 5 technologies for funding from 10 technologies forced sub-groups of the juries to deliberate in detail and evidently openly about the pros and cons of selecting (or not selecting) a particular technology. Through these deliberations, they were able to change their positions based on what others in the sub-group had to say. This process, which followed a similar discussion among the expert witnesses enabled jurors to articulate their views on what really mattered, and to converge on a number of factors that they considered most important.

Additionally, by being placed in the situation where they were interrogated by the expert witnesses, jurors were forced to confront their own decisions, and deal openly with the perceived negative implications of a “do not fund” decision. Although they were free to change their initial decision, in reality the process reinforced the important criteria they had considered in making their choice in the first place.

It is interesting to note that both juries arrived at the same list of 6 characteristics that they considered to be the most important. The rankings of these were almost identical between the 2 juries. Given that the juries were sampled from the two halves of the province of Alberta (so as to be representative of the population in each half), this would imply that these 6 factors could be seen as being important to Albertans in general. This could well carry a message to political and health system decision makers in the province.

Despite agreeing on the 6 specific factors, the 2 juries did not agree on which technologies they would select from a given set. This implies that the jurors were probably weighting the different content values differently, depending on the choices they faced. This suggests that merely obtaining a list of ranked priorities (in this or any other manner) and using these ranks to make priority-setting

decisions will not truly reflect what people might do, if they were in the role of deciding. It also suggests that the relative weighting of these values will change from circumstance to circumstance.

The content values identified by the Alberta juries are similar to sets of values reported in the literature, e.g. severity of illness [31,33], current health state [31], immediate need [31], age [31], lifetime health [31], pre-existing health state [31], personal responsibility for illness [31], care-giving responsibilities [31], health gain [31,33], and socioeconomic status [33]. These values are not all mutually “orthogonal” or independent, so it is not surprising to find some overlap. As well, some of the differences could be due to overriding societal values.

Two other points are worthy of mention. First, the response to the original invitations to be considered for participation in the Juries was surprisingly good. Nearly two-thirds of all individuals who received the invitation (i.e., excluding those that were returned because of address or other issues) accepted it. Clearly this reflects the fact that there is significant interest among the ordinary citizens of Alberta in being involved in health care resource allocation matters. There may be many reasons for this high response, but one plausible explanation is that this reflects a desire of ordinary citizens to have more of a say in how government decides to spend public funds.

Finally, the set of 6 content values and the levels of each (see Table 4) provide a starting point to develop an applied choice analysis, such as a discrete choice experiment. Additionally, we believe having level descriptors which describe severity, and include mental health is a strength of the study (see Table 4). This is the next step in trying to understand relative priority rankings between the combinations of factors and levels.

The main limitation to this study most likely results from what is also probably a strength – the fact that the same group of researchers and expert witnesses participated in both juries. While this reduced the possible variation in quantity and types of information presented to the jurors, it also left open the possibility that, based on the experience during the first jury, individuals might have acted in somewhat different ways to the jurors during the second jury. Attempts were made to minimize any “leading” by the team and experts by asking that presentations were scripted to the largest extent possible, and that no leading questions be asked of jurors. This also hopefully resulted in minimal “advocacy” on the part of the experts. Another limitation might be in how jurors interpreted terms, such as health “before the illness”, particularly if multiple morbidities are involved.

Conclusion

Findings from this study suggest that given appropriate design and delivery, different citizens' juries held on a common, complex healthcare topic, such as resource allocation decision-making for new health technologies, appear to yield similar results. It has been demonstrated that this approach is a reasonable and rational one to engage ordinary citizens in a meaningful way in decision-making matters of public import. However, since the jury approach is time, labour, and cost-intensive, it would be appear to be best suited to addressing high-level issues that governments may be grappling with.

Conflict of interest

The authors declare that they have no conflicts of interest.

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Appendix A.

1	"We wanted to make sure we spread the funding over many different types of technologies and people" (NAJ1) "We thought it would be a good idea to invest in a bit of everything – like, you know, prevention and treatment" (SAJ2)
2	"Of the ones left, this one [the HPV vaccine] could probably help the greatest number of individuals . . . so the money would be going the furthest" (NAJ6) "Well, the HPV vaccine has the biggest group in terms of numbers when you consider all boys in Alberta" (SAJ1)
3	"You know, if you go out drinking every night, smoke a pack a day, you should know better, and you should have to accept the consequences – like 'sorry, there are other people who got sick through no fault of their own, so they are ahead of you'" (NAJ10) "While we don't know what causes a lot of cancer, we do know what causes some, like liver cancer. When there is a shortage of funds, we need to be wise about our money, and people who live that way may not take care of themselves after we help them, so that would mean we wasted money that we could have used to help somebody else" (SAJ3)
4	"How do we know that drinking or smoking was the cause – maybe they were obese? I mean, can we really say that because you did those things you got cancer and it is your fault? The fact is, [we] really don't know – there is no magical test. Maybe it is about obesity, in which case, we wouldn't bother treating 50% of the population. I don't think we really want to go there" (NAJ1) "This opens up a whole new can of worms . . . what about obesity then? Should we be weighing people and saying to them, 'forget it, you are too fat, we aren't treating you' . . . wow, I wouldn't want to live in a society like that" (SAJ16)
5	"I pay taxes on the cigarettes I smoke and on my paycheque. . . that should more than pay for any healthcare I might need down the road" (NAJ7) "We all pay taxes, whether we smoke or don't smoke, eat right or don't eat right. . . so the healthcare system, which we pay for through our taxes, shouldn't discriminate against people either" (SAJ4)

Appendix B.

1	"What kind of numbers are we talking about – a few patients or a lot?" (NAJ1) "How many people could be helped?" (SAJ8)
2	"How sick are they now?" (NAJ2) "What is their current health like. . . are they [patients] already suffering?" (SAJ15)
3	"What happens if we don't act now?" (NAJ1) "How long do they [patients] have?" (SAJ5)
4	"How does the technology help with giving patients some quality of life – you know, some dignity?" (NAJ9) "Will patients be able to do, like, daily activities – like take care of themselves, or enjoy their families?" (SAJ2)
5	"How old are they [patients]?" (NAJ11) "Have they already had a long life?" (SAJ13)
6	"Would they [patients] probably have kids or people who they needed to take of?" (NAJ6) "Would there likely be a young family left behind?" (SAJ1)
7	"Could bad choices have contributed to them getting sick?" (NAJ10) "What about lifestyle – what role did that play?" (SAJ9)
8	"Would it extend life and for how long?" (NAJ10) "How much more time would it buy them?" (SAJ15)

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