



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



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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

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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

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