Troutville: Where People Discuss Fairness Issues

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Résumé de l'article

Contexte. Les efforts d’engagement du public en politique de santé ont posé de nombreuses questions chargées de valeur, mais celles qui tiennent compte de la complexité et de la diversité du concept d’équité en matière de santé sont rares. Nous présentons les Fairness Dialogues, une nouvelle méthode pour débattre de l’équité en matière de santé auprès du grand public. Nous en fournissons les fondements théoriques et en présentons l’illustration empirique et l’évaluation qualitative. Méthodes. Principalement inspirés par l’érudition de la délibération, nous avons conçu les Fairness Dialogues, caractérisés par une délibération de groupe objective et inclusive utilisant un scénario hypothétique (la ville de Troutville) qui présente des cas soigneusement conçus, simples, ouverts et axés sur une question d’équité et de justice. Pour évaluer si les Fairness Dialogues encouragent la réflexion, nous avons mené une enquête qualitative en nous concentrant sur l’équité et l’iniquité des inégalités en matière d’espérance de vie. Résultats. Nos résultats ont révélé les intuitions complexes des gens et leur curiosité, leur patience et leur volonté de les examiner en profondeur dans le cadre d’un dialogue en petit groupe. Les intuitions partagées par les participants à notre étude sont similaires à celles présentées dans la littérature philosophique académique. Conclusions. Les Fairness Dialogues sont une méthode prometteuse pour intégrer les points de vue du public dans l’élaboration de politiques impliquant un jugement de valeur et pour développer la capacité du public à discuter de questions chargées de valeurs de manière réfléchie et inclusive.
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Abstract

Context. Public engagement efforts in health policy have posed many value-laden questions, yet those that appreciate the complexity and diversity of the concept of health equity are rare. We introduce the Fairness Dialogues, a new method for deliberating health equity among the general public. We provide its theoretical underpinning and present its empirical illustration and qualitative assessment. Methods. Primarily informed by the scholarship of deliberation, we designed the Fairness Dialogues, featured by reason-giving and inclusive group deliberation using a hypothetical scenario (the town of Troutville) that presents carefully designed, simple, open-ended cases focusing on a chosen equity and fairness issue. To assess whether the Fairness Dialogues encourages reflective views, we conducted a qualitative investigation by focusing on fairness and unfairness of inequalities in life expectancy. Findings. Our results revealed the complex intuitions that people have and their curiosity, patience, and willingness to scrutinize them in-depth through a small group dialogue. Intuitions shared by our study participants are similar to those presented in the scholarly philosophical literature. Conclusions. The Fairness Dialogues is a promising method to incorporate the public’s views into policy-making involving value judgment and to develop the capacity of the public to discuss value-laden questions in a reflective and inclusive manner.

Keywords

health inequality, health equity, deliberation, public engagement, values

Introduction

The public increasingly plays an important role in health policy (1). The simple question “What do people think?” drives many public engagement efforts. Posing this question is particularly meaningful when issues relate to values, such as equity or fairness, where the “right” answers cannot be found easily or at all. Public value elicitation is important because a well-functioning health system is not only effective and efficient but is also an embodiment of social values. While public engagement efforts have posed many value-laden questions in the past, those that appreciate the complexity and diversity of the concept of health equity are rare. The consideration of equity is prominent when making policy decisions regarding priority setting, which often engages various stakeholders including the public (2). However, in priority setting discussions, equity is often a “black box” and elaboration on what equity means in a given context is relatively new (3).

A related but distinctly separate line of work explores distributional principles that people employ in allocating limited health care resources (4,5). As a classic example, in a series of questionnaires using stylized, hypothetical resource allocation scenarios, Nord (1999) uncovered the importance of concerns for severity of disease – little discussed in the scholarly literature – when the public makes resource allocation decisions (6). Largely situated within the discipline of economics, this subfield of value elicitation regarding resource allocation employs careful empirical examination of values underlying distributional principles through ongoing methodological development as to how best to elicit such values (7–10). Equity concerns in health policy go beyond the context of resource allocation, and these concerns await a similar, rich exploration. For example, what are society’s responsibilities for, and its limits to, promoting healthy behaviours? How should we operationalize a well-accepted equity principle, such as “equal access for equal need” (11), across a large and diverse geographic area? For these types of equity questions, the focus has often been on people’s experiences (e.g., accessing care) and not their judgment (e.g., what constitutes equitable access) (12,13).

Equity is a complex concept, which is evident from the fact that even experts working in the field have been unable to reach a single, agreed-upon definition of health inequality (14–17). Arguably, the most widely cited definition is by Whitehead, for whom health inequities are “differences in health which are not only unnecessary and avoidable but, in addition, are considered unfair and unjust” (18). This all-encompassing definition, however, is circular as it does not clarify what unfair and unjust mean (19). Despite the absence of a single, agreed-upon definition, equity is a key health policy goal endorsed by many jurisdictions (20).
Ongoing debate as to what constitutes equity or fairness might indeed be what we would expect for a complex concept upon which many health system decisions pivot. Public engagement squarely focusing on equity can add a new dimension to health policy by enriching our understanding of equity and fairness, working towards health systems that are informed by societal values, and developing capacity among the public to engage in value-related questions.

Myriad methods are available for public value elicitation on a range of topics and are applicable to the topic of equity. Primarily informed by the scholarship of deliberation (21,22), we designed the Fairness Dialogues, a method that encourages collective, thoughtful reflection about health equity among the general public. In this paper, we first situate our conceptualization of the Fairness Dialogues within the rich literature on public value elicitation on health and health care issues in order to present its theoretical underpinning. We then provide an empirical illustration of the Fairness Dialogues and its qualitative assessment.

Theoretical underpinning of the Fairness Dialogues

Why ask people?

Value-related questions are difficult, and those in the context of health and health care, such as equity or fairness, are no exception. Addressing them seriously requires going beyond gut feelings and intuitions; it demands a reflective thought process. Careful examinations do not often spontaneously take place, and even when they happen, they rarely point to the “right” answer. Answers are most often multiple, not because there is no right or wrong answer but because there are likely many right or partially right answers. Balancing these right answers is often challenging but is necessary to make policy decisions on health and health care. There are many professionals who are trained to examine these value-related issues, such as academics and policy makers. It is thus important to articulate why we should ask the public to engage in such a taxing process. The literature suggests four purposes: foundational, instrumental, process-oriented, and educational (10,23,24).

Foundational purposes. Public engagement can serve a foundational purpose, that is, enhancing our understanding of value-related issues. Precisely because value-related issues are complicated, by asking the public we might arrive at a more nuanced, layered understanding of the issues. Trained professionals who study and work in related fields often have shared assumptions and approaches, and the public’s views can provide a counterforce to offset these positions, or even highlight overlooked viewpoints in the professional discourse (10). For example, in asking people about distributional principles, Hurley and colleagues discovered a view that “everybody must get something, nobody should get nothing,” a concept not well discussed in the academic literature (4,25).

Instrumental purposes. Purposes of public engagement can be instrumental, that is, acting upon the values revealed through public engagement. When assessing many plausible values in the context of health and health care, it is not clear nor consistent whose values should take priority. The values of trained professionals are presumably well informed and cohesive, but that does not make their values more correct than those from others. Value-laden questions in health and health care can affect people profoundly through personal experiences situated within social policies and norms. It is thus important to take public values seriously and act upon them (23).

Depending on the way that one decides to act upon the public’s values, the instrumental purposes can be either direct or indirect. With direct instrumental purposes, public engagement can be designed to inform specific policy decisions, such as decisions related to planning, priority setting, and coverage of health services and health technologies (26–28). With indirect instrumental purposes, public engagement can be designed to develop a set of guiding principles related to social values to inform multiple policy decisions, such as the public dialogue sessions organized to explore a shared health care contract to inform health reform and the Citizens’ Reference Panel on Health Technologies to derive core values for health technology assessments (29,30). Arguably, the most notable example of public engagement for the indirect instrumental purpose is the Citizens’ Council in the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom (31). With the premise that advice on best care must be based both on scientific and social value judgments, the NICE formed the Citizens’ Council in 2002 to inform social value judgement principles that guide the NICE’s decisions on health and health care. There are many professionals who are trained to examine these value-related questions.

Process-oriented and educational purposes. Interests in public engagement can be focused on process rather than outcomes. Daniels and Sabin argue, for example, that reasonable people can disagree about value-related questions, and, rather than trying to identify the right answer, society might make greater progress by focusing on the process through which these value-related questions are examined (24). In addition, public engagement can be considered as a means of showing respect to the public, and in so doing, can improve the legitimacy of decision-making (23,24). Thus the third purpose of public engagement is process-oriented. In a similar manner, the process of public engagement can be considered as an educational opportunity. The fourth purpose of public engagement is then educational, increasing the knowledge and capacity of the public involved in the engagement (23,24).
Public engagement on value-related questions can be designed with one or any combination of these four reasons in mind. Whatever the purpose may be, an important commonality among public value elicitation efforts is the pursuit of reflective values derived from a careful thought process.

How to ask?

The relevant literature offers a variety of methods for public engagement that aim to obtain reflective values through a careful thought process. This literature is multidisciplinary, ranging from health sciences (e.g., public health and health services research) to social sciences (e.g., sociology, political science, and economics). The methods proposed include, but are not limited to, surveys (35,36), experiments (4,37–40), focus groups (41–43), and deliberation (30,31,44,45), each of which comes with a wide range of variation (e.g., Citizens’ jury, Citizens’ panel/council, Deliberative Poll, and Town halls) (22,27,46). The choice of the method is often driven by the disciplinary orientation of the investigators. For example, the use of questionnaire-based experiments, focus groups, and some form of deliberation are well-accepted traditions among health economists, health researchers, and political scientists, respectively. This multidisciplinary literature with distinct disciplinary orientations hinders comparison of methods across disciplines. Yet, only through such comparison can we distinguish the available methods and identify advantages and disadvantages of using one method over another to obtain reflective values from people through a careful thought process.

Schneiderhan and Khan offer a useful framework to assist in the comparison of diverse value elicitation methods (47). These authors are interested in deliberation, more specifically, what features distinguish deliberation from other similar methods to obtain people’s views. Central features of deliberation are much debated (48), yet they build on the premise of reasons and inclusion as central features. By reasons, deliberative dialogues ask participants not just to talk and offer opinions, but to provide reasons for their views. By inclusion, deliberative dialogues ask participants to listen to each other and remain open to new proposals.

To operationalize these two features in an empirically observable manner, the Schneiderhan-Khan framework considers rules of communication (“unspecified” or “reason-giving and inclusive ethic”) and interactive context of communication (“communication with oneself” or “with others”) (47). These considerations create four modes of public value elicitation as shown in Table 1. Schneiderhan and Khan consider Mode 4 to be a deliberation, where a person communicates with others in a group and is encouraged to provide reasons, as opposed to only opinions, in an inclusive manner. In contrast to deliberation is a discussion or “just talk” (Mode 2), where a person still communicates with others in a group, but the rules of communication are unspecified (47). When the rules of communication are unspecified and a person communicates with oneself, Schneiderhan and Khan call it a spontaneous essay (Mode 1) (47). They are ambivalent about Mode 3, as inclusive communication arguably cannot occur when a person communicates with oneself. Emphasizing the reason-giving, however, they consider Mode 3 as legitimate, an internal reflective mode.

Table 1. Modes of public value elicitation

| Rules of communication | Interactive context of communication |
|------------------------|-------------------------------------|
|                        | Communicate with oneself | Communicate with others |
| Unspecified             | 1                       | 2                        |
| Reason-giving, inclusive ethic | 3            | 4                        |

Source: Schneiderhan & Khan (47)

This classification can map onto some existing public value elicitation efforts in health and health care. Opinion surveys, such as one conducted by Rigby et al. (35), which asked about public support for government interventions to address income-, education- and race-related health inequalities, would be an example of the spontaneous essay (Mode 1). The aforementioned, common method among health economists to obtain people’s values regarding resource allocation using questionnaire-based experiments can be considered as an internal reflective mode (Mode 3). Focus groups, common in the health sciences literature at large, are primarily structured around people’s experiences and are an example of the discussion (Mode 2). Some group dialogues that emphasized reason-giving and inclusive ethic are examples of deliberation (Mode 4) (see (30,31,43)). Mapping out the diverse methods available in the literature in this way, we can begin to discuss which methods may be more suited for the purpose of eliciting values related to health and health care from the public. Because public engagement in this context seeks reflective values derived from a careful thought process, the reason-giving and inclusive ethic rules of communication are critical features. This points to the methods of either the internal reflective mode (Mode 1) or deliberation (Mode 4) rather than spontaneous essay (Mode 1) and discussion (Mode 2).

Reason-giving and inclusive dialogue (in a group or alone) rarely occurs naturally, and existing public engagement efforts employ a variety of strategies for that to take place. These strategies attempt to address potential factors that prevent reason-giving and inclusive dialogue from happening. For example, people may have a hard time thinking beyond personal experiences and circumstance. Personal anecdotes can help assist reflective thoughts, but too many anecdotes can be distracting. People may also be uninformed about the topic or informed in a particular manner without the appreciation for other perspectives. To understand the strategies to encourage reason-giving and inclusive dialogue used in the literature, it is helpful to ask: 1) Who are the participants — oneself or not oneself?; and 2) Within which context are the questions posed — hypothetical or real world? Answers to these questions classify four strategies as shown in Table 2.
Table 2. Strategies to encourage reason-giving, inclusive dialogue

| Who the participants are asked to be | Context within which questions are posed |
|-------------------------------------|------------------------------------------|
| Oneself                            | Stylized / hypothetical                  |
|                                     | Real world                               |
| Non-self                            |                                          |

Strategy 3 in Table 2 is rooted in the work of philosopher John Rawls (1971) and has served as a foundation for the scholarship of deliberation (47,49,50). To derive fundamental principles of justice for institutional arrangements, Rawls’s thought experiment, “the veil of ignorance” asks us to imagine being deprived of personal characteristics and social and historical contexts but having a knowledge of basic facts and functions of the society (50). Strategy 4 is a social scientist’s empirical operationalization of Rawls’s philosophical thought experiment. Some social scientists have operationalized the idea of the veil of ignorance with the “bracketing” of personal identities. Participants of the group dialogues are prompted to put aside their identities (such as race/ethnicity) in order to discuss real-world issues in group dialogues (51).

Strategy 1 is used by health economists when they elicit values from the public on resource allocation (4,7). Contrary to Strategies 3 and 4, participants are not asked to be someone else or bracket their identities, but they are asked to answer questions in highly stylized, hypothetical scenarios. The use of these scenarios can be considered as an attempt to reduce the “noise” brought by the participants that could hamper reason-giving and inclusive dialogue (with oneself, in this case). Strategy 2 is the most unrestricted among the four strategies as it instructs the participants to be themselves and discuss real-world issues. The strategy to encourage reason-giving and inclusive dialogue here is to prepare participants with sufficient, well-rounded information for the topic to be discussed. The spirit is, as often discussed in the deliberation literature, to imagine how a dialogue of ideal citizens would look. This strategy is used extensively in deliberations on value-related questions in health and health care, so much so that the provision of sufficient, well-rounded information is sometimes considered as a defining characteristic of deliberation (48).

The Fairness Dialogues, a deliberative group dialogue using the Troutville scenario

Informed by the literature discussed in the previous section, we designed a public value elicitation method, the Fairness Dialogues, to obtain the public’s values on equity and fairness issues in health and health care. The primary purposes of the Fairness Dialogues are foundational and educational, that is, to enhance our understanding of equity and fairness issues and to increase the capacity of the public to engage in collective, thoughtful reflection about these issues. The Fairness Dialogues has the following three features:

- The mode of public value elicitation is deliberation, where a person communicates with others in a group, and is encouraged to provide reasons in an inclusive manner (Mode 4 in Table 1).
- The strategy to encourage reason-giving, i.e., inclusive dialogue, is the use of a hypothetical scenario (Strategy 1 in Table 2), specifically, a fictional town of Troutville, a typical mid-sized town in the region where the group dialogue takes place.
- The Troutville scenario presents carefully designed, simple, open-ended cases focusing on a chosen equity and fairness issue.

The particular equity issue we chose for the first Fairness Dialogues sessions, reported in this paper, is fairness and unfairness of inequalities in life expectancy. The Troutville scenario presents inequalities in life expectancy between men and women, between poor and rich people, and between extreme sport lovers and non-extreme sport lovers (Table 3 and Appendix 1). Regardless of the comparison, life expectancy is 70 years for the unhealthy group and 80 years for the healthy group. The data are hypothetical but designed to be close to what the participants might observe in their real lives. The dialogue opened with the following question: “Is this difference or inequality in health between [the group with lower life expectancy] and [the group with higher life expectancy] unfair? Why and why not?” After the discussion on fairness judgments about these health inequalities, the question of whether Troutville should address these health inequalities follows (Table 3). The Troutville scenario further includes questions regarding health inequalities over generations, with a specific aim to obtain insights about the measurement of health inequalities (Appendix 1).

Table 3. Questions in the Troutville scenario on fairness and unfairness of health inequalities

| Fairness judgments                                                                 |
|-------------------------------------------------------------------------------------|
| In Troutville, [the unhealthy group] are expected to live for 70 years, and [the healthy group] are expected to live for 80 years.† |
| • Is this difference or inequality in health between men and women unfair? Why and why not?   |
| • Is this difference or inequality in health between poor people and rich people unfair? Why and why not? |
| • Is this difference or inequality in health between extreme sport lovers and non-extreme sport lovers unfair? Why and why not? |

| Roles and responsibility                  |
|------------------------------------------|
| Should your town, Troutville, address these inequalities? Why? If so, which ones, Why? |
| Which inequality should Troutville address first, second, and last? Why? |
| Whose responsibility is it to address these inequalities? Why? |

† For each inequality, the participants also received verbal and graphic explanations of the inequality (see Appendix 1 and Figure 1 for the exact explanation of the inequality).
The Troutville scenario presents the inequalities verbally, including numeric expressions, and graphically as the literature shows that different presentation modes may influence participants’ thought processes and answers (Figure 1 and Appendix 1) (52). The verbal expression is informed by the risk communication literature (53,54). Verbal explanation of an inequality is particularly difficult as the same difference can be expressed absolutely (e.g., 10-year difference) and relatively (e.g., 12% less), and there are multiple ways to express relative terms (52). Our choice of words balances the cognitive burden and the importance of explicitly communicating different ways to express inequality. The use of dot charts, a particular type of graph, is informed by the literature on graph perception (55,56). Dot charts are easier to understand and more accurate than bar charts, a more common type of graph used to communicate health inequality (52).

We pilot tested the Fairness Dialogues as described here — i.e., a group dialogue using the Troutville scenario on fairness and unfairness of inequalities in life expectancy — with students at Dalhousie University, in the province of Nova Scotia (Canada). We subsequently conducted a qualitative investigation to ascertain whether the Fairness Dialogues is engaging for participants and encourages reflective views. Two specific questions were asked in the qualitative investigation: How does a small sample of Nova Scotians who participated in the group dialogues consider the fairness and unfairness of health inequalities presented in the Troutville scenario? And what do the participants think of the Fairness Dialogues as a method to engage and incite reflective views?

**Methods**

The empirical illustration and qualitative investigation consisted of group dialogues and telephone interviews. Specifically, we conducted two 1.5 to 2-hour group dialogues in community facilities in the fall of 2016, one in an urban setting (n = 8) and another in a rural setting (n = 6) in Nova Scotia, Canada. About one week after each group dialogue, we conducted half hour individual telephone interviews with the participants (n = 12). The group dialogues were the empirical illustration of the Fairness Dialogues, and the telephone interviews were primarily to aid the assessment of the Fairness Dialogues from participants’ perspectives.

We recruited the general public in the study areas using purposeful and snowball sampling recruitment strategies. For this study, we defined the general public as persons without training and/or expertise in health and excluded persons who were currently or formerly health care professionals; academics and/or government employees whose primary focus area is/was health; or students whose primary focus area is/was health. For logistic reasons, we also excluded persons who were not residents of Nova Scotia; were younger than 19 years old; or could not read and converse effectively in English. To select
participants with as diverse personal attributes as possible for a rich group dialogue, during the screening process a research assistant asked the interested potential participants three brief questions regarding their education, home ownership, and recreational activities. This study was approved by the Dalhousie Research Ethics Board. Each participant gave written informed consent, including permission for audio-recording and anonymized quotes, and received a modest stipend for participating.

Before the start of the group dialogue, participants answered a brief sociodemographic survey. The participants were generally healthy and socio-demographically diverse (Table 4). While they mostly identified as female (n = 11) and never smoked (n = 10), on other aspects they came from diverse sociodemographic backgrounds. Most participants were either in their 20s or 30s (n = 7) or 60s or 70s (n = 6). About half had some post-secondary education or less, and another half had above that level. Household income varied greatly, spanning household income of less than $20,000 for a family of 3 persons to that of over $100,000 for a family of two persons. One participant rated their physical and mental health as fair, and all others rated as good, very good, or excellent.

Table 4. Participant characteristics

| Range | Most frequent category (n) |
|-------|---------------------------|
| Sex   | Male – female Female (11) |
| Age   | 20s – 70s 20s (5) |
| Marital status | Single, married or common-law, divorces, widowed Single (8) |
| Self-reported physical health | Fair – excellent Very good (8.5*) |
| Self-reported mental health | Fair – excellent Very good (5.3*) |
| Smoking | No – yes, currently No (10) |
| Education | Less than high school – university graduate University graduate (6) |
| Household income | < $20,000 for family of 3 to $100,000+ for family of 2 < $20,000 for family of 1 (7) |
| Employment | Not employed – full time Full time (4) / retired (4) |

Full sample (n = 14)

*When a participant responded to two of the five response categories, 0.5 was given to each of the two categories. Similarly, when a participant responded to three of the five response categories, 0.3 was given to each of the three categories.

A research team member facilitated each group dialogue (MB or RU). The facilitator’s role included an implicit emphasis on inclusivity, by paying attention to the speaking time used by individuals, and on reason-giving dialogue, through using language that encouraged dialogue and probed for meaning. The group dialogues followed the Troutville scenario as described in the previous section. This scenario was provided to each participant in the form of a booklet (Appendix 1) and projected on a screen. Both group dialogues lasted for approximately 100 minutes. In addition to the facilitator, 3-4 research team members were present at the group dialogues, including 1-2 note taker(s) (MB, EM, or RU), one content expert (YA), and one logistic support assistant (the research assistant). All but one participant from each group dialogue took part in follow-up individual telephone interviews about one week after the group dialogue the participant attended. The interviewer was a member of the research team who was not the facilitator of the group dialogue the participant attended (MB or RU). The interviewer followed an interview guide, consisting of questions regarding the participant’s reflections on the content and process of the group dialogue (Table 5). Each interview lasted for about 20-30 minutes. The group dialogues and interviews were audio recorded and later transcribed. The transcripts were not returned to the participants for comments or correction.

Table 5. Interview questions

Understanding of the scenario

(1) Tell me if you found the scenario easy to understand.
   - [If yes] tell me how you understood it. [If no] tell me what you found difficult.
   - Tell me about any ideas you have to make the scenario easier to understand.

(2) We explained life expectancies in different ways. For example, between men and women, we said [read out the script for the inequality between men and women].
   - Did you find different explanations helpful? Which one was most helpful for you? Why?
   - Tell me about any ideas for explaining the scenario that may have helped you to better understand.

(3) We showed you several graphs. Were graphs helpful for you to understand the scenario?
   - [If yes] tell me how you understood it. [If no] tell me what you found difficult.

(4) When we presented inequalities in life expectancy between the poor and the rich at different times – we talked about now, your grandparents’ time, and a long time ago – we presented two different graphs.
   - Did you find them helpful?
   - Tell me which one was most helpful.

The degree of engagement of the scenario

(5) Did you find the scenario interesting?
   - [Either yes or no] in what way?
   - What ideas do you have to make it more interesting to people?

(6) Tell me how you found the focus group discussion.
   - Was it helpful? [If yes] in what way? [If no] why?
   - Did the focus group discussion change your view? [If yes] in what way? [If no] why?
   - Tell me if there was anything you wish you had discussed in the focus group discussion but did not.
   - Tell me if there was anything that you found difficult during the discussion. [If yes] what was it?
Reflective thoughts on fairness

(7) When we were talking about the Troutville scenario during the focus group, did you think of your own experiences or real-world issues?
- [Either yes or no] can you tell me what you were thinking about?
- How did your thoughts impact what you said during the focus group?
(8) Tell me what you thought about the Troutville scenario after you left the focus group.
- Can you give me an example of when you thought about the focus group and what you thought about?

Format of the session

(9) If we were to do this kind of project again and wanted to learn about people's views on health inequalities, what would be your preferred way of doing it?
- Would you be willing to attend a focus group?
- What are your thoughts on using surveys (online or paper-based) to do this kind of project?

Do you have anything else you would like to talk about?
Do you have any final questions for me before we hang up?

We analyzed data from the group dialogues and interviews using thematic analysis. One research team member (YA) initially coded the transcripts. The development of these codes was primarily inductive, but also informed by the literature on concepts on health inequalities and inequities and social determinants of health. In an iterative process through discussion, team members (YA, RU, and MB) revised the codes and reached consensus on coding decisions. In a similar iterative manner, the research team collectively identified the most prominent themes relating both to the content (i.e., how the study participants considered fairness and unfairness of health inequalities) and the methods (i.e., whether the Fairness Dialogues was engaging and inviting reflective views). Whenever possible, we relied on field notes and our own reflections. We managed data and coding with word-processing software and NVivo (57).

Results

We describe the findings in accordance with the two specific questions we posed for the qualitative investigation. First, we report how the study participants considered fairness and unfairness of health inequalities presented in the Troutville scenario. Specifically, we explain: 1) whether, and if so, in what way, participants considered unfair inequalities between men and women, between poor and rich people, and between extreme sport lovers and non-extreme sport lovers; 2) who participants felt was responsible for addressing these inequalities; and 3) what strategies participants used to contemplate the questions related to fairness. Second, we describe findings pertaining to the Fairness Dialogues — a deliberative group dialogue using the Troutville scenario — as a method to engage and invite reflective views.

Considerations for fairness and unfairness of health inequalities presented in the Troutville scenario

Fairness judgments regarding health inequalities

For each of the three inequalities (i.e., men vs. women, poor vs. rich people, and extreme sport lovers vs. non-extreme sport lovers) participants presented and examined arguments considering them as unfair or fair. Below we describe key arguments discussed in the group dialogues.

Inequality between men and women: Some participants considered it fair because they saw inevitability — "It's always been like that" (Participant R5) — or they thought men's shorter life expectancy was due to choices men made. Other participants considered the primary reason for men's shorter life expectancy to be fundamentally social in nature: that is, it is not the result of men's choosing but rather of social expectations for men to be breadwinners, take risks, and not seek help, hence, the inequality is unfair. Yet, other participants thought men's shorter life expectancy is unfair simply because men do not live as long as women do and it is unfair for women to be left behind because "you've got 10 years that you've got to do everything that used to be done by two people" (Participant R2).

Inequality between poor and rich people: The primary view of most participants was that it is unfair because the inequality is socially constructed through differences in finances, resources, and connections that have compounding effects. They noted that poor people are often provided less opportunity than rich people, often from an early onset. They considered this inequality as addressable, as one participant stated, "I think it's a little bit more unfair than the...male and female thing because other people can help you...out if you're poor. Like they can help change that outcome" (Participant U8). Still, some participants contemplated opposing views. One participant argued that being rich is not the fault of rich people, who have worked hard to be rich; therefore, the inequality for rich people is deserving. Highlighting health damaging behaviour among poor people that may have contributed to their shorter life expectancy, another participant argued that engaging in such behaviour is human nature and everybody, no matter socioeconomic circumstances, should accept the resulting shorter life expectancy.

Inequality in life expectancy between extreme sport lovers and non-extreme sport lovers: The prevailing view was that it is fair because extreme sport lovers made a choice to engage in risky sports: "Because it's up to them if they want to take these sports" (Participant U7). This argument served as an anchor with which the discussion started and to which it repeatedly went back. Some participants presented counterarguments that questioned the definitive judgment. One participant stated, "Well, presumably someone engaging in extreme sports is engaging in sports and conditioning themselves to operate better...
physically. And is punished for it” (Participant U2). Participants also acknowledged that extreme sport lovers can inspire people while “non-extreme sports lovers sit on a couch and watch TV and drink pop and eat chips” (Participant U6).

Amenability: Even when the participants were mostly content with particular views presented, as a group they attempted to articulate those views further and examine them by testing with potential analogies and overlooked assumptions. For example, when discussing inequality in life expectancy between men and women, amenability emerged as a key concept to distinguish fairness and unfairness. To examine what may be and may not be amenable, the participants contrasted “natural” factors such as biology or genetics from social factors. In both group dialogues, there was a strong consensus to consider inequality in life expectancy caused by natural factors as not amenable, and thus, fair. Reflecting on changing gender roles in society over time, they further wondered about the amenability of social norms. For example, one participant argued that even social norms are amenable, stating: “We talk about sociological factors like it’s a machine that’s operating the way machines are supposed to operate. But we choose our culture collectively and imperfectly” (Participant U2).

Assumptions: Participants frequently assessed overlooked assumptions when discussing inequalities in life expectancy between poor and rich people and between extreme sport lovers and non-extreme sport lovers, cases for which they had, at least initially, easier fairness judgments than for the sex case. For example, while agreeing that inequality by income is unfair, one participant pondered whether inequality is inherently objectionable, using humour and an image: “Now, maybe all the trout in Troutville are the same. For all I know, maybe all the people in Troutville look like trouts and are all the same” (Participant U2). Some participants wondered what they were assuming when they were thinking about extreme sport lovers. By comparing to potentially analogous cases, such as smoking, illicit drug use, and obesity, some participants thought extreme sport lovers may have “addiction to risk” in much the same way as some people have “addiction to food” (Participant U1), and they were then hesitant to label addiction to risk as choice. Another participant thought that risk-taking of extreme sport lovers may be contributing to their mental health and wondered if the group made too quick a judgment to consider the shorter life expectancy of extreme sport lovers as their choice, and thus, fair.

Good health: Throughout the discussion regarding fairness and unfairness of the three types of health inequalities, participants repeatedly examined what good health actually is. They agreed that health is more than life years, as the scenario presented, and that quality of life is equally important. For example, while discussing inequality in life expectancy between men and women, one participant asked, “But also fairness, I would look at it in terms of quality. What if a man lives 70 years but has a much better life than a woman?” (Participant U6). They also underscored the importance of diversity among people and their circumstances, even when they share a common characteristic such as being male, poor or engaging in extreme sports. As one participant vividly expressed, “You see so many different shades of differences” (Participant R2). Participants also distinguished what is expected and what has actually happened (i.e., not everyone will live as long as the life expectancies presented in the scenario).

Roles and responsibilities to address health inequalities
On the question of who should be responsible for addressing the three types of health inequalities presented, the simple answer from the participants is “everyone” (Participant R1). They pointed to the responsibility of government, but at the same time, they thought everybody should be responsible because “we are the government” (Participant R2). In addition, participants wanted men, poor people, and extreme sport lovers to be responsible as well, not to blame them for what they did or did not do, but to respect their agency. One participant stated, for example, “We’re all old enough that we make our own choice” (Participant U7). Income-related health inequality was overwhelmingly supported as the priority among the three types of inequalities presented. Participants referred to it as “the base” (Participant U1) and considered it as “more direct” and its effect likely “very immediate” (Participant R3) than the other two. One group discussed as promising strategies identifying an underlying principle for all three types of inequalities that may be addressed all at once; for example, the access to certain forms of opportunity or identifying an optimal group to address all inequalities such as children.

Strategies to contemplate questions related to fairness
Participants, individually and collectively, employed various strategies to answer the questions in the scenario. Many of them often relied upon something tangible to them, for example, experiences of their own or their family and close friends or stories they have heard or read. Some used elaborate imagination to personalize the presented cases or attempt to immerse themselves in the shoes of affected people in the scenario (e.g., poor people) and think through how they would feel in Troutville. The use of real-world anecdotes and imagination went back and forth fluidly within individuals and as a group. In fact, in both groups, when real-world anecdotes predominated, there was always someone who initiated a balancing act by saying, “in Troutville, ...” In addition, participants often used their understanding of multiple determinants of health to contextualize the questions asked. They thought about the questions in the context of psychosocial determinants of health, for example, discussing complex relationships between income, occupation, geography, food security, gender, stress, and coping mechanisms and their effects on physical and mental health.

Another strategy that participants often used was to contrast with health care, i.e., they frequently compared the cases presented on inequalities in life expectancy to inequalities in access to or use of health care. For example, participants had the following exchange:
And are you saying then that the Troutville community hospital should deny treatment to the people who are smoking? (Participant U2)

No. No, it’s unfair. It’s unfair if they do that. Like it’s not…it’s dehumanizing. You know what I mean? It’s not right of Troutville to do that because they smoked or they did drugs, or they did this, or they’re rich or they’re poor, or they did rock climbing. They should treat all people alike. (Participant U7)

Furthermore, both groups implicitly identified what we might call base assessments of fairness where a clear judgment could be made, such as considerations for children and the principle of “all people should be treated with respect” (Participant U6). When discussion became difficult, the groups resorted to these base assessments to clarify their core arguments.

Fairness Dialogues as a method to engage and invite reflective views

The discussion that took place, as described in the previous section, demonstrated that the Fairness Dialogues — a deliberative dialogue among several people with diverse backgrounds using a hypothetical scenario — used a method wherein participants explored in-depth the idea of fairness pertaining to health. Views expressed during the follow-up individual telephone interviews corroborated the high level of engagement we observed during the group discussions. A general consensus among participants was that the scenario was easy to understand and verbal, numerical, and graphic expressions of inequalities were helpful to assist their understanding. For the most part, participants appreciated both absolute and relative numerical expressions of health inequality and used both to form their views. They understood the absolute expression (i.e., in life years) more clearly than the relative expression (i.e., in percentile), and while most saw the point of presenting both, a minority thought the relative expression redundant or unnecessary.

While it was common for participants to want further information about the hypothetical town of Troutville, such as its geographic location and sociodemographic composition, most found the use of a hypothetical town interesting. Some participants endorsed it wholeheartedly, for example, stating, “…it really resonated with me…it was easy to kind of try to slip into that mindset” (Interviewee R3). One participant thought the use of a hypothetical town limited the role of personal stories, and in turn, helped the discussion stay focused: “And I thought that that made the focus group much more interesting, much more thought provoking and much more really asking…trying to answer the questions that you were asking” (Interviewee U6). Many participants reported they had used personal experiences and real-world events as anchors from which to imagine Troutville.

Participants often said that they liked learning about different viewpoints and attributed that to group dialogue among a small number of people with different backgrounds — “…it was an unusual mixture. I mean I think it was a good mixture” (Interviewee R2). They thought good facilitation was also critical for the quality of discussion, corroborating our observation of the important active listener role that the facilitators played by implicitly emphasizing inclusivity and reason-giving dialogues, through reassurance, encouragement, and probes (e.g., “Why do you say so?”), yet never bringing new viewpoints not discussed by participants. While most participants thought the group dialogue was inclusive, some encouraged further consideration for allocation of speaking time. The discussion resonated with many participants, evident from some of them recalling details of the discussion and adding further thoughts during the interviews and/or reporting that they had talked to their family, friends, and co-workers about the scenario after participating in the group dialogue. Although a minority, a few reported the participation in the group dialogue changed their views. For example,

I guess it’s just like I said, even though…I’ve always been interested in social justice and fairness, I never really sat down and thought, like, what exactly is fair. You know, like how can we define it? Why do I think this is unfair and why do I think this fair? And I just kind of really had to think afterwards about that. Like I’ll be honest, I still don’t even really have it settled: I’m still kind of going back and forth (Interviewee R3).

Most participants found participation in the Fairness Dialogues worthwhile. One participant stated, for example, “Well, I wanted to keep the discussion going, and I tried to talk about it with a lot of people” (Interviewee U5).

Discussion

In this paper, we introduced the Fairness Dialogues, a method to elicit the public’s views on equity and fairness issues in health and health care, featured by reason-giving and inclusive group deliberation using a hypothetical scenario (Troutville) that presents carefully designed, simple, open-ended cases. Our qualitative investigation using questions of fairness and unfairness of health inequalities revealed complex intuitions that people have and their curiosity, patience, and willingness to scrutinize them in-depth through a small group dialogue. The simplicity of the Troutville scenario should not be confused with superficial discussion. The richness of the discussions and the high level of engagement we observed during the group dialogues are corroborated by the participants’ own reflections on the process. Taken together, this demonstrates the merits of the Fairness Dialogues as a theoretically grounded empirical method.

The intuitions that our study participants shared are similar to those presented in the scholarly philosophical literature. For example, in both group dialogues, responsibility, choice, and amenability are key concepts that emerged while examining inequalities in life expectancy between men and women, between poor and rich people, and between extreme sport lovers...
and non-extreme sport lovers. Responsibility is a key concept with which participants assessed whether the inequality in question was fair (because someone was responsible for it) or unfair (because someone was not responsible for it). The concept of responsibility was, in their minds, tightly connected to the concept of personal choice. At the same time, they were keenly aware that personal choices only apply to matters amenable to the choices, for example, if life expectancy is entirely determined biologically and genetically, then, there is nothing to make choices for men to extend life expectancy. In addition, they fully acknowledged that personal choices are conditional upon available opportunities. This line of reasoning mirrors closely the equity perspective often referred to as equal opportunity for health or luck egalitarianism (14). The struggle of our participants to articulate what is amenable (e.g., “nature” vs. social factors) and what is personal choice is in fact the core of the extensive discussion in the view of equal opportunity for health, that is, drawing the line between “legitimate” and “illegitimate” factors that distinguish responsibility (58). Furthermore, participants’ views on treating people equally in healthcare regardless of the choices they made have been discussed extensively in the scholarly literature as a harsh implication of the view of equal opportunity for health if applied literally to healthcare (14, 59). Moreover, the consideration for available opportunities within which choices were made resonates strongly with feminist ethics (60).

Participants did not develop a theory from their intuitions, and the Fairness Dialogues was not designed to encourage collective identification of a coherent view at the end of the group dialogue. What our analysis tells us is that the views expressed in this study are reflective values that came from the participants’ own exploration with minimal scholarly guidance; values explored and discussed were what the participants have sought by themselves rather than being given to them. A ground-up approach to discuss value-laden questions such as those related to fairness is of paramount importance in two ways. First, the values obtained can help us understand what the public think (10). Second, this process is in itself beneficial as a means for education and capacity development. Post-dialogue interviews of some participants indicated that the group dialogue was the beginning of a new or reinforced thought process for them, hinting that the Fairness Dialogues might not only capture “values out there” but might also contribute to participants discovering and forming values. These two aspects correspond to two of the four purposes of public engagement discussed earlier: foundational and educational. As the public is increasingly called upon for many aspects of health and health care – such as delivery, financing, organization, research, and policy – it is critical to assist them to enable the best possible participation.

The use of the Fairness Dialogues for the instrumental purpose merits further exploration. As discussed earlier, public engagement can be designed to inform either specific policy decisions (direct) or the identification of core values or principles that can inform multiple policy decisions (indirect). Given the use of a hypothetical scenario, the Fairness Dialogues is logically better suited to indirect instrumental purposes. As the first empirical application of the Fairness Dialogues idea, our focus was on whether this method of engagement can encourage reason-giving and inclusive dialogues, rather than to determine what policy context the values revealed in the group dialogues might apply. Hence, at this stage, it is unclear whether, and if so, in what way, the Fairness Dialogues can serve indirect instrumental purposes. It would be useful to determine what gains the Fairness Dialogues brings compared to existing public engagement methods. NICE Citizens’ Council, for example, asked broad questions for indirect instrumental purposes, such as: What are the societal values that need to be considered when making decisions about trade-offs between equity and efficiency? (report 17, 2014); Should NICE and its advisory bodies take into account the severity of a disease when making decisions? (report 10, 2008); and Is there a preference to save the life of people in imminent danger of dying? (report 6, 2006) (www.nice.org.uk/get-involved/citizens-council). It would be informative to examine whether the answers would be different, and if so, in what way, if the same questions were set in a hypothetical town, like Troutville. One of the critiques to the NICE Citizens’ Council was that people’s real views can only be revealed in a specific, concrete context and, by asking broad questions, the Citizens’ Council was likely unable to reveal the public’s views (61). Future work needs to examine if a similar critique applies to the use of the Troutville scenario.

With the promising results from the empirical illustration and its qualitative assessment, there is still much more work to be done to further develop the Fairness Dialogues. Specifically, in need of rigorous examination are the aspects of the Fairness Dialogues that may have contributed to value elicitation. For example, both the participants themselves and the research team took note of the potential contribution that diverse backgrounds among participants may have played to the quality of the discussion. We did not analyze participants’ views in relation to their characteristics, but in their study exploring lay persons’ values on health inequalities in the United States, Blacksher and colleagues found socioeconomic clustering of participants’ preferences regarding how to address health inequalities (62). It will be important to examine if this applies to the Fairness Dialogues and to understand in what ways diversity might contribute to the dynamics of the discussion and the exploration of new perspectives and values. In addition, both the participants and the research team identified inclusivity as an important factor for the quality of discussion. Inclusivity was an implicit emphasis in this study, for example, through the attentive facilitators and considerations for others among the participants. Furthermore, the emphasis on reason-giving dialogue relied primarily on the setup of the Troutville scenario supported by the facilitator’s implicit role. These aspects of inclusivity and reason-giving dialogue could be developed as an explicit ground rule, as some have tried (47). In sum, what is needed is the articulation of essential features of the Fairness Dialogues. To do so, further contextualization and comparison of the Fairness Dialogues to existing comparable work would be beneficial. For example, this could take the form of a randomized trial of public deliberation methods to determine whether, in fact, longer deliberative processes are more likely to result in greater knowledge acquisition and changes in perspectives among participants (45). The Fairness Dialogues uses a short deliberative process, and it would also be important to examine if a longer process would enhance the quality of the discussion we observed. With cautious optimism, the results from our qualitative investigation indicate the promise of the Fairness Dialogues as a method to incorporate the public’s views into policymaking involving value judgment.
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