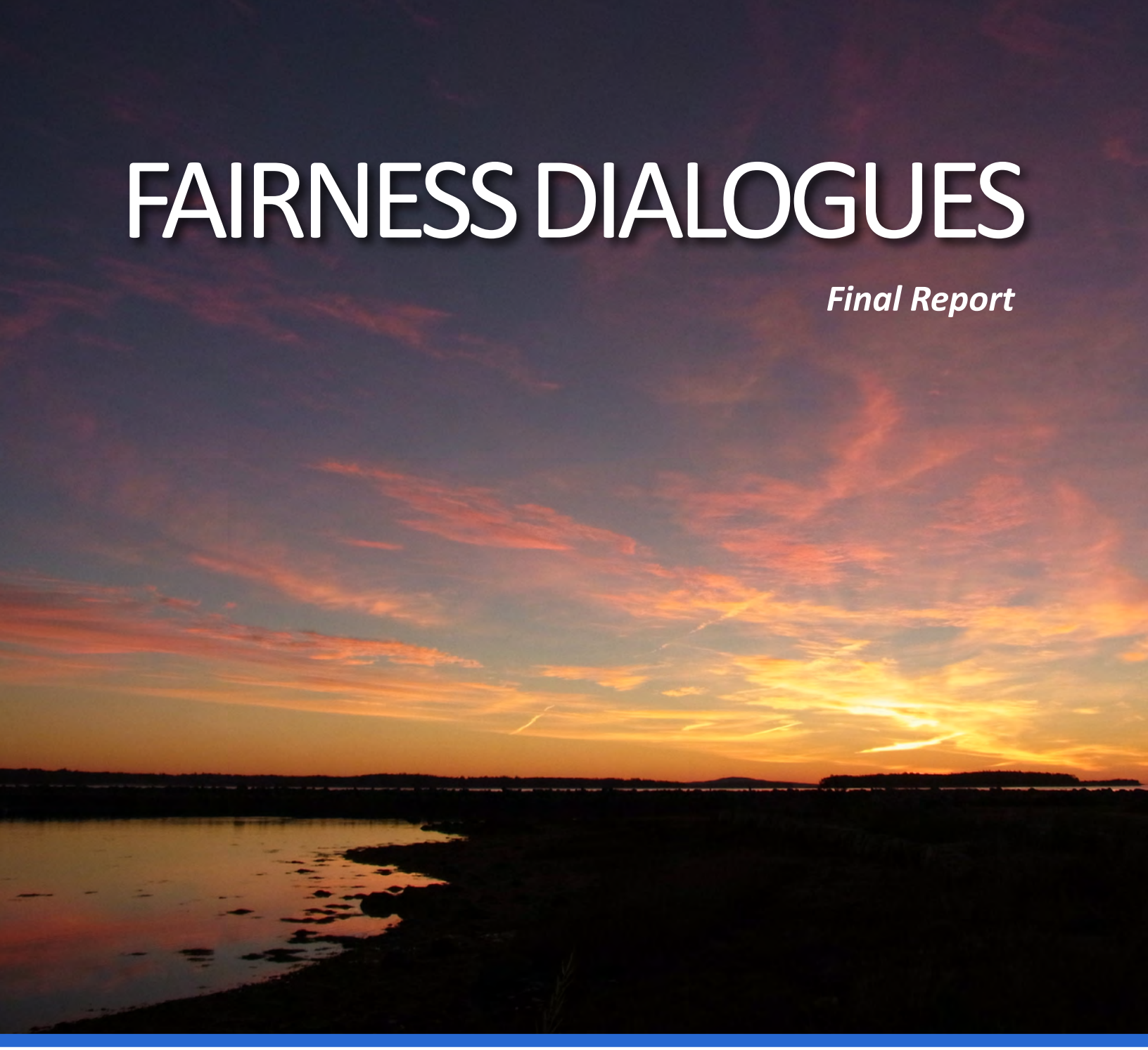

FAIRNESS DIALOGUES

Final Report

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

Stratégie de recherche axée sur le patient
SRAP
Le patient d'abord

MSSU - USSM
MARITIME SPOR SUPPORT UNIT
UNITÉ DE SOUTIEN SRAP DES MARITIMES

Town of Troutville, Nova Scotia
Where people discuss fairness issues

PROJECT INFO

PROJECT TITLE
STRENGTHENING THE FOUNDATIONS FOR FAIRNESS DIALOGUES

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KEY MESSAGES

The public plays a pivotal role in health research, health policy, and the delivery of health care. The simple question of "What do people think?" drives many public engagement efforts, particularly when asked about values such as fairness or equity.

Fairness Dialogues, under development by a group of researchers at Dalhousie University, is a guided, scenario-based discussion forum to obtain values of the public on health care issues. Fairness Dialogues is designed to be:

- an ongoing listening forum, through which researchers and policy-makers can regularly seek the public's views;
- a methodological laboratory, where researchers explore different methods of public engagement; and
- conversations between the public, policy makers, and researchers that inform health policy decisions through a collective and dynamic reflective process.

A phase 1 pilot study in 2016 demonstrated the feasibility of eliciting the public's views on fairness through a guided, scenario-based discussion format. Participants were asked to imagine they lived in the fictional town of Troutville.

The phase 2 pilot study, described in this report, demonstrated the usefulness of the Troutville discussion format with a policy-relevant question related to equity in primary health care. Specifically, the topic for this phase 2 pilot study related to "accountability of citizens and the health system for health and health status" in the 2016-19 strategic plan of the Nova Scotia Health Authority (NSHA).

The findings of this study suggest:

- the public is eager to engage in discussion about "easy to understand but difficult to answer" questions of equity in primary health care; and
- the public has diverse and nuanced views on the concept of personal choice, and even those who believe individuals have a personal responsibility for health strongly support the principle of equal health care for equal health care need.

In addition, the results of this study suggest that Fairness Dialogues is a promising method to elicit people's views on fairness and enhance their capacity to contribute to complex value-laden health care issues.

EXECUTIVE SUMMARY

CONTEXT

The public plays a pivotal role in health research, health policy, and the delivery of health care. The simple question of "What do people think?" drives many public engagement efforts, particularly when asked about values such as fairness or equity. Our research team from Dalhousie University is developing and testing Fairness Dialogues, a guided, scenario-based discussion forum to obtain values of the public on health care issues. Objectives of this study were to: demonstrate the usefulness of the Troutville discussion format with a policy-relevant question related to equity in primary health care; and expand Nova Scotia's capacity for public engagement regarding equity issues in primary health care.

IMPLICATIONS

The findings of this study have implications for health policy makers, especially in relation to "accountability of citizens and the health system for health and health status" in the 2016-19 strategic plan of the Nova Scotia Health Authority (NSHA). The findings of this study suggest:

- the public is eager to engage in discussion about "easy to understand but difficult to answer" questions of equity in primary health care; and
- the public has diverse and nuanced views on the concept of personal choice, and even those who believe individuals have a personal responsibility for health strongly support the principle of equal health care for equal health care need.

In addition, the results of this study suggest that Fairness Dialogues is a promising method to elicit people's views on fairness and enhance their capacity to contribute to complex value-laden health care issues.

APPROACH

This study consisted of focus groups and telephone interviews. Specifically, we conducted two 1.5-2-hour focus groups with 7-8 persons per focus group who were purposefully sampled. We conducted one focus group in a rural setting in Nova Scotia and another in an urban setting in Nova Scotia. About one week after each focus group, we conducted a half-an-hour telephone interview with each participant to ask about further reflection on the content and process of the focus group.

We used a facilitated group discussion format, employing a scenario in a fictional town called Troutville. The scenario described four hypothetical inequality cases in Troutville: inequality in healthy life expectancy between criminals and non-criminals, between extreme sport lovers and non-extreme sport lovers, between firefighters and non-firefighters, and between veterans and non-veterans. The facilitated discussions were centred around judgments on fairness and unfairness regarding these inequality cases, personal and societal responsibility for these inequality cases, and the allocation of a limited health care resource to potentially address these inequality cases. We conducted a thematic analysis of the focus group and interview data.

FINDINGS

Overall, the 15 participants in both focus groups were diverse in terms of their demographic, socioeconomic, health, and health behavioural characteristics. The participants in the two focus groups voiced five arguments regarding fairness and unfairness of the four inequality cases: personal responsibility (the person made a choice and is responsible for the consequence); societal responsibility (society failed to help the person); fulfillment (the person had his/her own aspiration and pursued it); agency (the person should have the choice to live his/her life how he/she wants to live it); and irrelevancy (the person made the choice, and only that person can make the judgment of fairness).

The participants considered personal choice to be the central concept. They had a subtle understanding of whether the choice is free or not quite free. They

considered societal influences on: a person making the choice to become a criminal, extreme sport lover, firefighter, and veteran (and, for criminals, engaging in risky activities); preventing poor health consequences that are result of such choice; and alleviating seriousness of the poor health consequences if they happen.

The participants also understood a choice a person makes with regard to whether the choice relates to societal debt. Society owes people who made the choice to become a firefighter or veteran because they are responding to societal need. On the other hand, society does not owe people who make the choice to become a criminal or extreme sport lover because the choice in this case does not respond to societal need. Even when participants argued for personal responsibility for health, they supported that Troutville is responsible for everybody's health and should not punish anyone for their choices with health care.

The general consensus regarding Troutville as a method to elicit the public's values was that the Troutville scenario was "easy to understand but difficult to answer" and that the facilitator-guided group discussion was an engaging format. Common challenges voiced by the participants included difficulty remaining focused on the hypothetical town of Troutville during the discussion and difficulty grasping how the Troutville discussion could inform policy.

FURTHER RESEARCH

This phase 2 pilot study provides the following three important lessons for the further development of Fairness Dialogues:

- explain more clearly to participants the goals of the Fairness Dialogues, reasons why the Fairness Dialogues uses the Troutville scenario, and how their discussion relates to health policy;
- formalize the procedure to encourage reflective discussion by clarifying the facilitator's role and establishing ground rules for the discussion; and
- devise a recruitment mechanism to ensure diversity among the participants for rich discussion.

ADDITIONAL RESOURCES

This work was inspired by previous or existing work that aims to elicit the public's values on health care issues to inform principles that guide specific policy decisions, such as:

National Institute for Health and Care Excellence. Citizens Council. [cited 2018 May 16]. Available from: https://www.nice.org.uk/get-involved/citizens-council

Shah KK, Cookson R, Culyer AJ, Litteljohns P. NICE's social value judgments about equity in health and health care. Health Econ Policy Law. 2013 Apr;8(2):145-65.

Public Engagement of Subcommittee, Ontario Health Technology Advisory Committee (OHTAC), Health Quality Ontario (HQO). [cited 2018 May 21]. Available from: https://participedia.net/en/cases/citizens-reference-panel-health-technologies-ontario-canada

Abelson J, Wagner F, DeJean D, Boesveld S, Gauvin FP, Bean S, et al. Public and patient involvement in health technology assessment: a framework for action. Int J Technol Assess Health Care. 2016 Jan;32(4):256-264.

Abelson J, Giacomini M, Lehoux P, Guvin FP. Bringing "the public" into health technology assessment and coverage policy decisions: from principles to practice. Health Policy. 2007 Jun;82(1):37-50.

CONTEXT

The public plays a pivotal role in health research, health policy, and the delivery of health care.[1] The simple question of "What do people think?" drives many public engagement efforts, particularly when asked about values, such as fairness or equity.[2,3] Our research team from Dalhousie University is developing and testing Fairness Dialogues, a discussion forum to obtain values of the public on health care issues.

The inception of the Fairness Dialogues project dates back to 2013, when we organized the first of the two workshops on public value elicitation. We invited some of the leading scholars across the globe to Western Shore, Nova Scotia, to examine the questions: why ask, what to ask, and how to ask people. Encouraged by this workshop experience, we formed the Fairness Dialogues research team as a cluster project for Dalhousie University's Collaborative Research in Primary Health Care (CoR-PHC). During 2013-2014, we articulated the vision for Fairness Dialogues (see Box 1) and searched for funding for pilot projects to move us toward this vision.

With support from the Nova Scotia Health Research Foundation (NSHRF) in 2015-2016, we laid the foundation for Fairness Dialogues. We completed the phase 1 pilot study to demonstrate the feasibility of eliciting the public's views on fairness through a guided, scenario-based discussion format. Participants were asked to imagine they and their family lived in the fictional town of Troutville. They were presented with cases describing inequalities in life expectancy between men and women, rich persons and poor persons, those who love extreme sports and those who do not. They were asked if they thought these differences were unfair, and if so, why. The graphics and verbal explanations of the inequality cases in the Troutville scenario were based on our reviews of the literature on how our brains perceive graphs and process numerical information.[4]

In the phase 1 pilot study, we examined, among a small sample of Nova Scotians, how the public conceptualizes health inequity, and how these views may differ from those of researchers and policy

Box 1. What is Fairness Dialogues?

- An ongoing listening forum, through which researchers and policy-makers can regularly seek the public's views;
- A methodological laboratory, where researchers explore different methods of public engagement; and
- Conversations between the public, policy makers, and researchers that inform health policy decisions through a collective and dynamic reflective process.

The study presented in this report is the phase 2 pilot study.

Box 2. What is health equity?

Health equity is a complex concept. Experts working in the field have not been able to come up with a single definition that they agree.

For example, the following definition of health inequity by Margaret Whitehead is one of the most widely cited definitions: "health inequities are differences in health which are not only necessary and avoidable but, in addition, are considered unfair and unjust."[11]

But this definition begs further questions: What are unnecessary and avoidable differences? What do unfair and unjust mean? Different answers to these questions lead to different definitions of health equity.

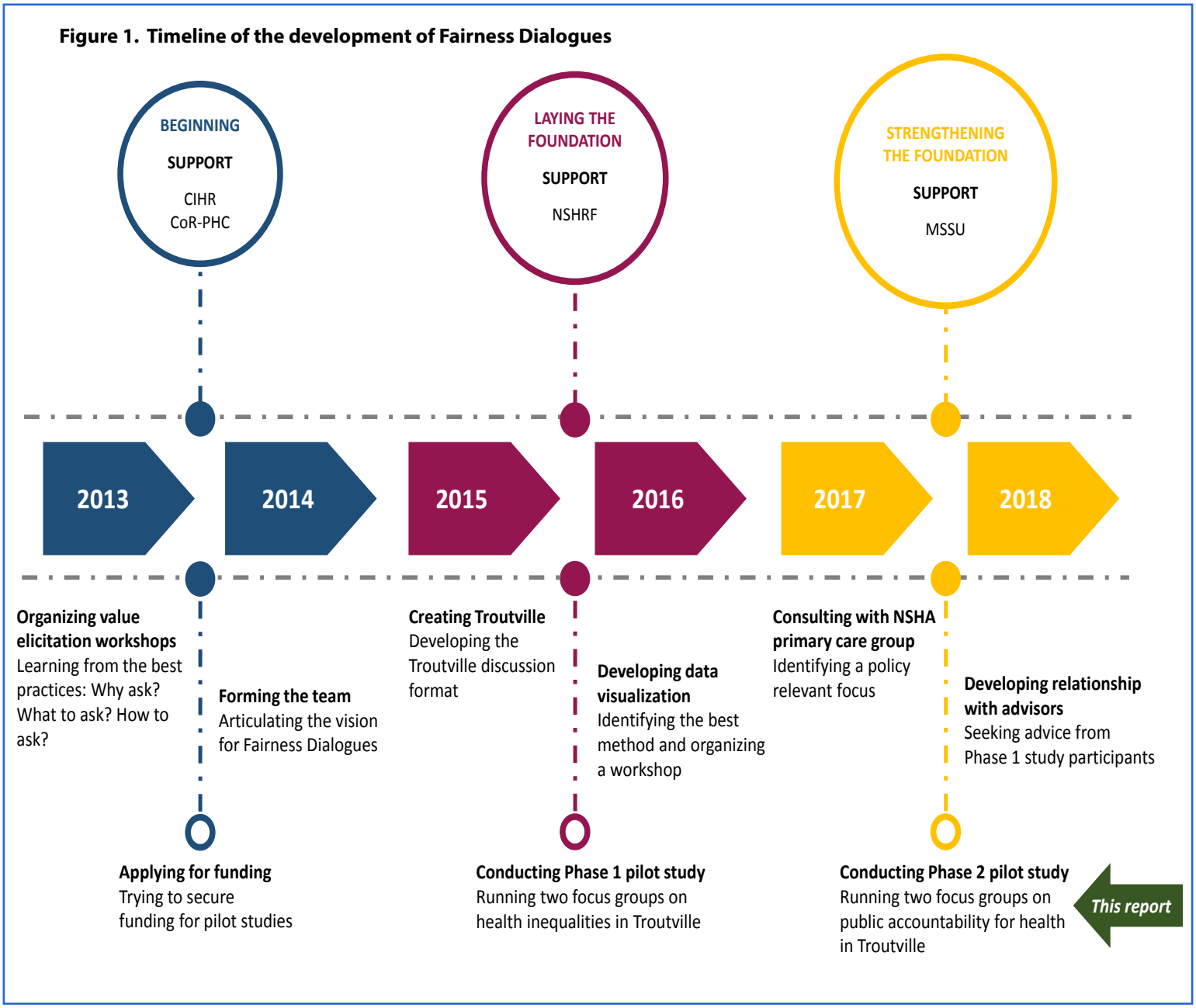
makers. The study also shed light on how people approach and make sense of a complex issue with ample opportunity for reflection. The results showed that the Troutville format is a promising means to facilitate and engage members of the public in discussion on complex value-related issues.

This report describes our effort to strengthen the foundation for Fairness Dialogues in 2017-2018, with support from the Maritime SPOR SUPPORT Unit (MSSU). The phase 1 pilot study aimed to test the feasibility of the Troutville discussion format and used fictionalized questions without considering policy relevance. In the phase 2 pilot study, we were interested in developing questions related to equity issues that are of current importance and priority in the Nova Scotian health care system.

Objectives of this study were to:

- demonstrate the usefulness of the Troutville discussion format with a policy-relevant question related to equity in primary health care; and
- expand Nova Scotia's capacity for public engagement regarding equity issues in primary health care.

Figure 1. Timeline of the development of Fairness Dialogues



Box 3. Why is it important to consider equity in the health system?

The absence of the single, agreed-upon definition does not mean that equity is unimportant. In fact, many jurisdictions, including Nova Scotia, endorse health equity as a key health policy goal. They recognize a well-functioning health care system is not only effective and efficient but also equitable or fair.

Questions related to equity or fairness in the health system are many, for example:

- In what way, and how much, should the health system help vulnerable populations?
- What are society's responsibilities for, and its limits to, promoting healthy behaviours?
- What does "equal access to equal need" mean across urban, rural, and remote areas in Nova Scotia and Canada?

Box 4. Why do we ask people about health equity?

If even experts have challenges thinking about health inequity, why do we want to ask people? There are at least four possible reasons:

- People may point out something experts overlooked.[12] Thus, by asking people, we can enhance our understanding of what equity means.
- Equity questions matter to everyone individually and as a society.[13] It is thus important to listen to the public's views and act upon them.
- Asking people sincerely means showing respect to the public.[13] By doing so, we can improve the legitimacy of policy decision-making.
- Engaging people in discussing health equity serves as an educational opportunity.[13] By doing so, we can enhance the capacity of the public to contribute to discussing health system issues.

IMPLICATIONS

Although this study is a pilot study, our findings have implications for health policy makers, especially in Nova Scotia. The focus of this study was inspired by the 2016-19 strategic plan of the Nova Scotia Health Authority (NSHA), specifically, its emphasis on "accountability of citizens and the health system for health and health status."[5]

A key policy-relevant message that can be drawn from the results of our study is that the public is eager to engage in discussions about "easy to understand but difficult to answer" questions of equity in primary health care. The questions need to be clear and understandable, but they do not need to be simple. Our study participants were keenly engaged in discussing complex social influences before, during, and after a person makes a choice and how the choice leads to a certain consequence.

Another key policy-relevant message from this study is that the public has diverse and nuanced views on the concept of personal choice, and even those who believe individuals have a personal responsibility for health strongly support the principle of equal health care for equal health care need. A clear division between the acknowledgment of personal responsibility for health and the endorsement of equal care for equal need observed in this study may call for a separate development of policy on the accountability of citizens for health and health status from the development of policy on priority setting and allocation of health care resources.

Our findings also provide insight into how to engage the public in value-laden health care issues. Patients, families, and communities are increasingly encouraged to take part in the delivery and organization of health care, and it is critical to identify effective means to understand and incorporate their values in health care. Results of our study suggest that Fairness Dialogues is a promising method to elicit people's values and enhance their capacity to contribute to complex value-laden health care issues.

Box 5. Honorary citizens of Troutville

Some participants from the initial Fairness Dialogues pilot study (phase 1, conducted in 2016) played an advisory role for this second phase pilot study. We consulted with them on the attributes used for the inequality cases, the presentation of these inequality cases, and recruitment strategies. They were ideal advisors because they were familiar with the Troutville discussion format, had a developing relationship with the research team, and shared the visions of Fairness Dialogues.

With these advisors, there is a potential to develop an ongoing advisor group, "honorary citizens of Troutville," among some of the participants of Fairness Dialogues as it proceeds with a growing number of focus groups in future. The honorary citizens of Troutville will serve as a vehicle to expand Nova Scotia's capacity for public engagement regarding equity issues in primary health care.

APPROACH

STUDY DESIGN

This study consisted of focus groups and telephone interviews. Specifically, we conducted two 1.5-2-hour focus groups with 7-8 persons per focus group who were purposefully sampled. We conducted one focus group in a rural setting in Nova Scotia and another in an urban setting in Nova Scotia. About one week after each focus group, we conducted a half-an-hour telephone interview with each participant to ask about further reflection on the content and process of the focus group.

In this study, we were interested in *what* people think as well as *how* they think. To encourage a reflective thought process, we opted for a facilitated group discussion among several persons with as diverse background as possible, as opposed to a survey, where the study participant is asked to provide his or her opinion alone. Furthermore, we opted to use a hypothetical scenario for the facilitated group discussion. Specifically, we asked the participants to imagine they and their families lived in Troutville, a fictional, mid-sized town in Nova Scotia. Situating Troutville between total abstraction and personally attached real world, we hoped to encourage safe exploration and imagination that can assist reflective thoughts.

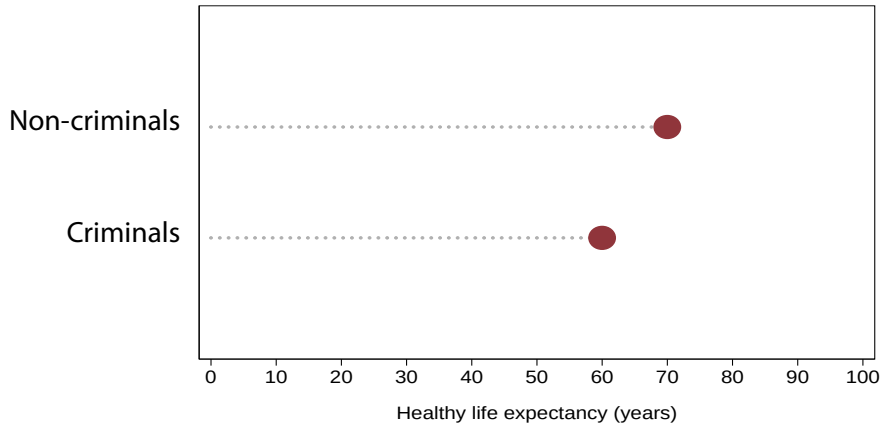
To select a policy-relevant equity topic for the focus group discussions, we looked to the 2016-19 strategic plan of the Nova Scotia Health Authority.[5] In particular, we paid attention to its emphasis on "accountability of citizens and the health system for health and health status." After informal consultations with the Primary Health Care branch of the Nova Scotia Health Authority and considerations for the academic literature on personal responsibility and accountability for health,[6,7]

Figure 2. An example of the Troutville scenario, the criminal case

In Troutville, criminals are expected to live for 60 healthy years, and non-criminals are expected to live for 70 healthy years.

This means criminals will live 10 healthy years shorter than non criminals, and non-criminals will live 10 healthy years longer than criminals. There is a 10-year difference in healhty life expectancy between them.

To put it differently, criminals' healthy lives will be 86% of non-criminals' healthy lives, or criminals' healthy lives will be 14% shorter than non-criminals' healthy lives. This means that for every 100 healthy days that non-criminals will live, criminals will live 86 healthy days or 14 fewer healthy days.



Is this difference or inequality in healthy life expectancy between criminals and non-criminals unfair? Why and why not?

we determined personal responsibility and accountability for health to be a good topic for the focus group discussion. Personal and societal responsibility for health was also one of the strong themes that emerged in the phase 1 pilot study of Fairness Dialogues in 2016.

To encourage a reflective thought process for this topic, we presented four hypothetical inequality cases in Troutville: inequality in healthy life expectancy between criminals and non-criminals, between extreme sport lovers and non-extreme sport lovers, between firefighters and non-firefighters, and between veterans and non-veterans (Figure 2 and Appendix 1). These inequalities were exactly the same, with 60 healthy years for the unhealthy group and 70 healthy years for the healthy group. The data were hypothetical but designed to be similar to what participants might observe in their real lives. The question that opened the focus group discussion was, "Is this difference or inequality in healthy life expectancy between [the unhealthy group] and [the healthy group] unfair? Why and why not?"

Each of these four hypothetical inequality cases highlights a particular "attribute": a profession and/or activity that a person does or has done in the past. To select these four attributes – criminals, extreme sport lovers, firefighters, and veterans – we first examined what considerations we typically have when we attempt to judge consequences of a choice as fair or unfair (R. Cookson, email communication, January 2016). One consideration is whether the choice is made free and voluntary or not. Another consideration is whether the choice is "noble" or "selfish." These two considerations create the "choice grid" as shown in Figure 3 with four combinations: not quite freely made "selfish" choice (southwest); freely made "selfish" choice (northwest); freely made "noble" choice (northeast); and not quite freely made "noble" choice (southeast). We then selected the four attributes that are often considered, appropriately or inappropriately, to represent each of these four combinations.

We did not show the choice grid to the study participants, and we did not prompt them to consider whether the choice is free or not free or the choice is "noble" or "selfish." We did not even suggest if a choice was involved in judging fairness and unfairness in relation to the inequality cases with the four attributes. The participants were only presented with the inequality cases highlighting these attributes and asked about their views on fairness and unfairness regarding

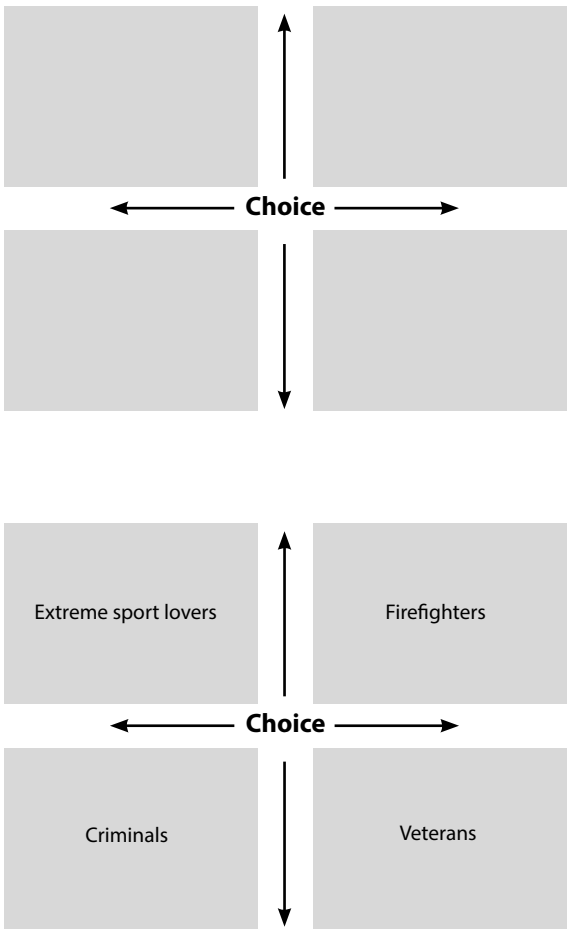


Figure 3. The choice grid and the four cases used in the Troutville scenario

these inequalities. We acknowledge that the four selected attributes were simplified and that our placement of these attributes in the choice grid can present tension. Indeed, we hoped these four attributes conveyed some tension in order to encourage engaging and thoughtful focus group discussions.

After the discussion on fairness judgments regarding inequalities pertaining to these four attributes, we asked the participants about their views on the personal responsibility of the criminals, extreme sport lovers, firefighters, and veterans and the societal responsibility of Troutville for their shorter healthy life expectancy. We then asked about the allocation of a limited health care resource (i.e., one spot available for a primary care doctor) to meet their health care needs. The Troutville scenario concluded with a brief

reflection on gender - whether the participants assumed the criminals, extreme sport lovers, firefighters, and veterans were male or female, and if such gender assumptions potentially influenced their views. Table 1 lists the questions asked in the Troutville scenario (see also Appendix 1 for the full scenario).

Table 1. Questions in Troutville focus group

Fairness judgments	• In Troutville, [the unhealthy group] are expected to live for 60 healthy years, and [the healthy group] are expected to live for 70 healthy years.* o Is this difference or *inequality* in healthy life expectancy between criminals and non-criminals unfair? Why and why not? o Is this difference or *inequality* in healthy life expectancy between extreme sport lovers and non-extreme sport lovers unfair? Why and why not? o Is this difference or *inequality* in healthy life expectancy between firefighters and non-firefighters unfair? Why and why not? o Is this difference or *inequality* in healthy life expectancy between veterans and non-veterans unfair? Why and why not?
Personal and societal responsibility	• Are they [criminals, extreme sport lovers, firefighters, and veterans] responsible for their shorter healthy life expectancy? Why and why not? • Is Troutville responsible for their shorter healthy life expectancy? Why and why not?
Health care priority	• Imagine a criminal, an extreme sport lover, a firefighter, and a veteran all have serious mental health problems. They need regular visits to a primary care doctor. But, unfortunately, there is currently only one spot available in Troutville. o Who should get the spot? Why? Who should not get the spot? Why?
Gender	• Did you think about criminals, extreme sport lovers, firefighters, and veterans as male or female? • Do you think about inequality, responsibility, and the treatment of health care system differently if they were male or female? Why and why not?

* For each of the four cases, the participants also received verbal and graphic explanations of the inequality (see Appendix 1 and Figure 2 for the exact explanation of the inequality).

STUDY PARTICIPANTS

We recruited participants from the general public in two study areas (one rural and one urban) in Nova Scotia. For the purpose of this study, we defined the general public as persons without training and/or expertise in health. Accordingly, we 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 recruit potential participants, we used purposeful and snowball sampling recruitment strategies. We placed posters in key popular public places, such as libraries, grocery stores, bus terminals, and university campuses in and around the two focus group areas. We also distributed the recruitment posting electronically, such as on the MSSU social media platforms, Kijiji, and Halifaxnoise. We screened interested potential participants, either by telephone or email, to determine their eligibility for the study. To select participants with as diverse personal attributes as possible for a rich focus group discussion, we asked the interested potential participants about three brief questions regarding their education, home ownership, and recreational activities. After considerations for the eligibility criteria, participant characteristics, and scheduling, we recruited ten participants for each focus group. Seven participants attended the focus group in the urban setting, and eight participants attended the focus group in the rural setting. One participant in each area did not take part in the follow-up individual telephone interview.

DATA COLLECTION

Sociodemographic suvey

Before the start of the focus group discussion, the participants answered a survey to provide basic sociodemographic and health status information. The questions referred to: gender, age, marital status, self-rated physical health, self-rated mental health, smoking, education, household income, and employment.

Focus groups

The focus group in the urban setting took place in a public library on a weekday evening in January 2018. The focus group in the rural setting took place in the community room of a local grocery store on a weekday evening in March 2018. Four research team members were present: one facilitator, one note taker, one content expert, and one assistant for logistic support. The facilitator moderated the focus group discussion following the Troutville booklet (Appendix 1). This booklet was also provided to each participant and projected on the screen. Both focus group discussions lasted for approximately 100 minutes. The discussions were audio recorded and later transcribed verbatim. The transcripts were not returned to the participants for comments or correction.

Individual interviews

A member of the research team conducted a follow-up telephone interview with each participant about one week after the focus group she or he attended. The interviewer followed an interview guide, consisting of questions regarding the participant's reflection on the content and process of the focus group discussion. Each interview lasted for about 20-30 minutes. With the participants' permission, the interviews were audio recorded and later transcribed verbatim. The transcripts were not returned to the participants for comments or correction.

ANALYSIS

We used data from the sociodemographic survey to learn about the participant characteristics. We used data from the focus group discussions to analyze thoughts and thought processes of the participants. We used data from the telephone interviews to examine Troutville as a method to elicit the public's values. We analyzed our data at the group level, except when differences were noteworthy. We analyzed the data from the focus group discussions and telephone interviews using thematic analysis.

FINDINGS

THE PARTICIPANTS

Overall, the 15 participants were diverse in terms of their demographic, socioeconomic, health, and health behavioural characteristics, as summarized in Table 2. The participants in the urban setting were diverse in terms of age, health status, and education level, more so than the participants in the rural setting, who tended to be older, healthier, and more educated.

THOUGHTS AND THOUGHT PROCESSES OF THE PARTICIPANTS

Five themes emerged from the focus groups: arguments regarding fairness and unfairness of the four inequality cases; examinations regarding fairness; examinations regarding responsibility; examinations regarding health care priority; and strategies to think of fairness judgments on health inequality, societal responsibility, and health care priority (Table 3). Below we contextualize these themes.

Five arguments regarding fairness and unfairness of the four inequality cases

When considering the four inequality cases, the participants thought of personal choice as the central concept. Despite the same origin, this key concept led to the five different arguments regarding fairness and unfairness of the four inequality cases (Figure 4):

- personal responsibility;
- societal responsibility;
- fulfillment;
- agency; and
- irrelevancy.

Table 2. Characteristics of study participants (total N = 15)

Characteristic	Range
Gender	Male or female (53% of the participants were female)
Age	20s to 70s, with at least one participant in every decade
Marital status	Single; married or common-law; or divorced
Self-rated physical health*	Fair to excellent
Self-rated mental health**	Poor to excellent
Smoking	No; yes, in the past, but not now; or yes, currently
Education	Less than high school to university graduate
Annual household income	Less than $20,000 to $100,000
Employment	Part-time; full-time; not employed; retired; or in school

* “In general, would you say your physical health is …?” – excellent, very good, good, fair, or poor
** “In general, would you say your mental health is …?” – excellent, very good, good, fair, or poor

For some, the examination of personal choice directly corresponded to the view of personal responsibility for health: the person made the choice and is responsible for the consequence, hence, these inequalities are fair. For others, the examination of personal choice questioned personal responsibility for health and resulted in the belief in social responsibility for health: society failed to help the person, hence, these inequalities are unfair. These two views arose in both focus groups.

For a small number of the participants in the urban setting, the acknowledgement of personal choice was connected to the fulfillment argument: the person had his/her own aspiration and pursued it, hence, these inequalities are fair. For example, a participant stated:

"They're all things that take a lot of lust for something that a person really wants to do […] But these people all probably grew up with a dream and they want to do something. And they go ahead and do it… Even some of the criminals, a lot of them wanted to be a successful criminal."

For a small number of the participants in the rural setting, the appreciation of personal choice directly led to the agency argument: the person should have the choice to live his/her life how he/she wants to live it, hence, these inequalities are fair. A participant stated:

"If you take away their ability to choose how they want to live their life, then you're unfair."

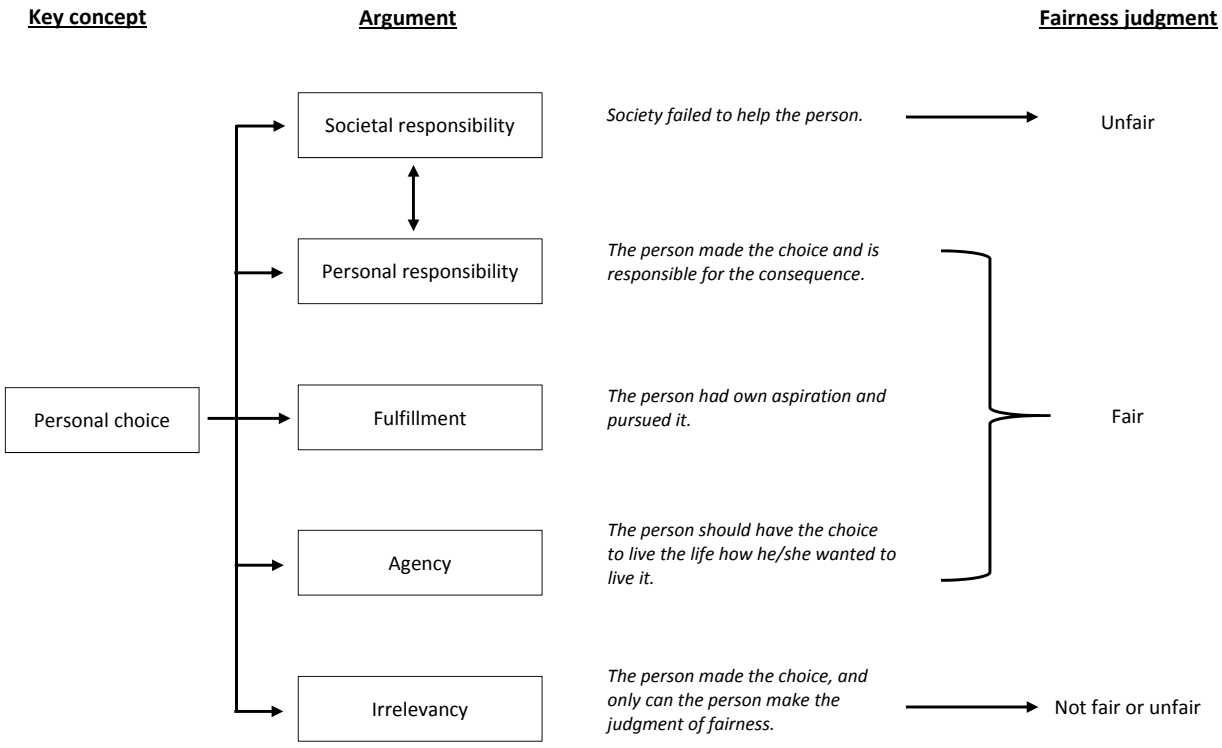
Finally, a small number of the participants in both focus groups thought it was irrelevant to ask whether these inequalities are fair or unfair: the person made the choice, and only that person can make the judgment of fairness.

Table 3. Themes emerged from Troutville focus group discussions

Arguments*	• Fair because the person made the choice and is responsible for the consequence (personal responsibility) • Unfair because society failed to help the person (societal responsibility) • Fair because the person had own aspiration and pursued it (fulfillment) • Fair because the person should have the choice to live the life how he/she wanted to live it (agency) • Fairness consideration is irrelevant because the person made the choice
Examinations (fairness)	• Value of long, healthy life • Heterogeneity within the choice (e.g., "white collar criminals" vs. "non-white collar criminals") • Personal characteristics and their intersectionality and heterogeneity (e.g., race, socioeconomic status, and genetic predisposition for risks) and resiliency and redemption • Societal influences o Societal needs for people making certain choices and the nature of the needs (e.g., degree of risks, accidental vs. intentional challenges) o Societal roles to provide opportunities, ensure safety and preventive measures, and alleviate seriousness of health consequences o Whether societal interventions are futile if not perfectly successful o Historical influences – availability of technology and knowledge • Directness and strength of relationships from the choice to health outcome
Examinations (responsibility)	• Responsibility vs. compassion • Feasibility and amenability • Reward and punishment • Community solidarity
Examinations (health care priority)	• Principles (lottery; first-come first-serve; societal debt; dependents; greatest benefit to the person vs. society; greatest need; least negative impact on society; age) • Intersectionality of personal characteristics
Strategies**	• Reflecting on experiences of one's own or family or friends • Testing with presumed analogies and overlooked assumptions • Using an imaginary, vivid "what if" cases • Referring to real world historical and current events • Contrasting to the previous questions

* Arguments regarding fairness and unfairness of the four inequality cases
** Strategies to think of fairness judgments on health inequality, societal responsibility, and health care priority

Figure 4. Key arguments emerged from the four cases of inequality in healthy life expectancy in the Troutville focus groups



The two focus groups developed these arguments differently. In the urban setting, the participants expressed all five arguments for the initial inequality case between criminals and non-criminals and largely maintained these arguments for all succeeding cases. On the other hand, in the rural setting, the central argument throughout the four inequality cases was personal responsibility. The argument regarding agency was introduced during the extreme sport lover case, and the societal responsibility argument was introduced during the veteran case.

The participants examined, revisited, and refined or reiterated these five arguments from various angles. Table 3 lists the discussion points raised under the theme of "examinations (fairness)," and Figure 5 shows at which inequality case the participants introduced these discussion points. Both focus groups introduced most points in the first criminal case. This does not mean, however, that the participants thought the four inequality cases were the same.

Rather, they considered each case presented different aspects and added increased layers of examination. These four inequality cases prepared the participants for the later responsibility questions, as discussed below.

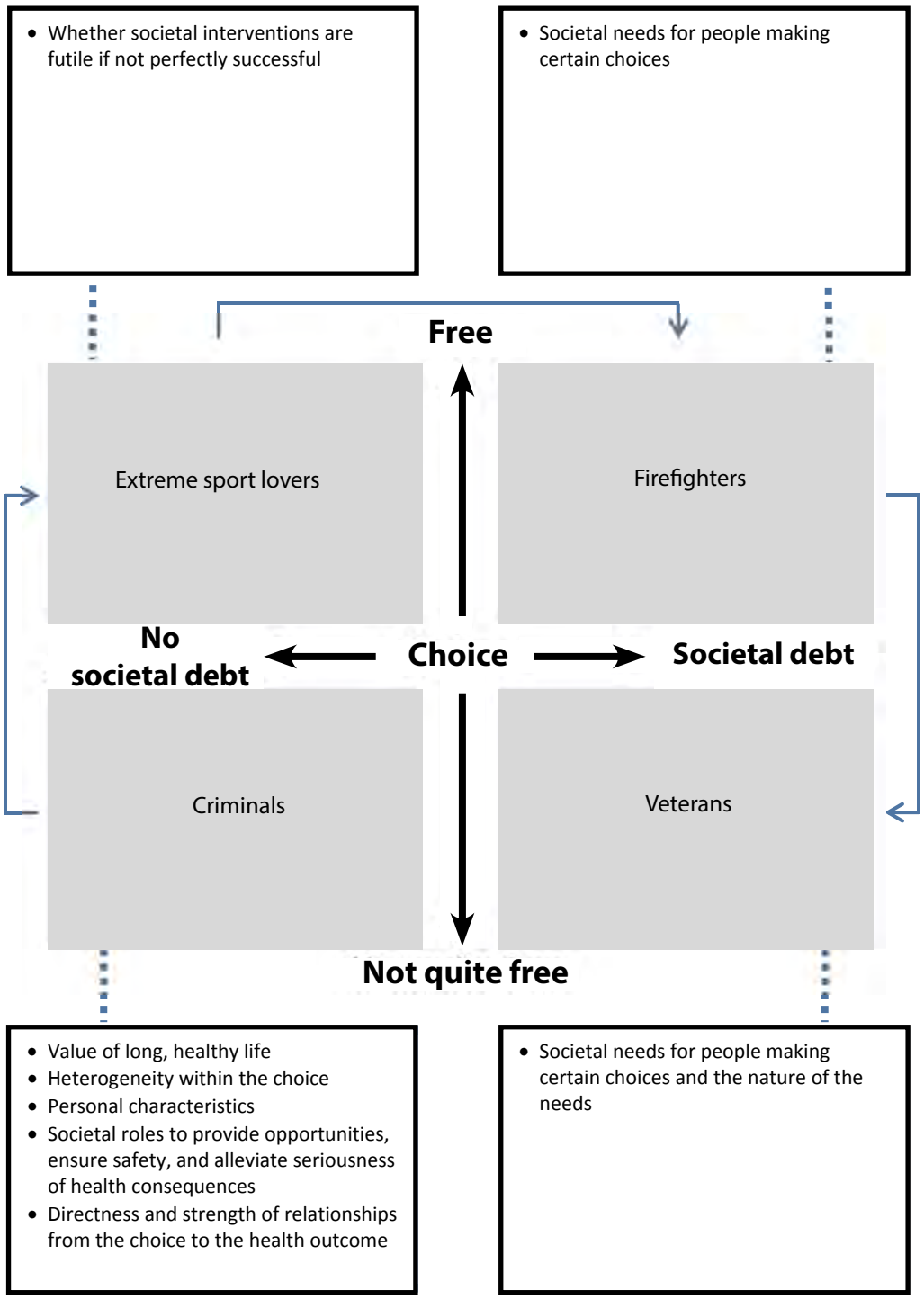
The nuanced choice grid in the participants' minds

As discussed in the study design section, the choice grid (Figure 3) informed the selection of the four attributes for the inequality cases in the Troutville scenario. The focus group discussions suggested that something similar to the choice grid existed in the participants' minds, but it was more nuanced than Figure 3.

The participants showed a subtle understanding of whether the choice is free or not quite free. Their subtle understanding appeared to stem from a clear distinction between: the choice to become a criminal, extreme sport lover, firefighter, and veteran; the choice to engage in risky activities heavily influenced by the prior choice above; and the consequence of that choice (i.e., shorter healthy life). Based on this distinction, the participants discussed societal influences on: a person making the choice to become a criminal, extreme sport lover, firefighter, and/or veteran (and, for criminals, engaging in risky activities); preventing bad health consequences happening because of that choice; and alleviating seriousness of the bad health consequences if they occur.

Another axis in the choice grid in Figure 3 is whether the choice is "selfish" or "noble." In both focus groups,

Figure 5. Layers of discussion points emerged from Troutville focus groups



the participants instead framed this axis as whether the choice was related to societal debt. Society owes people who make the choice to become a firefighter or veteran because they are responding to societal need. On the other hand, society does not owe people who make the choice to become a criminal or extreme sport lover because the choice in this case does not respond to societal need.

The participants further made distinctions regarding the nature of the societal debt. One distinction was based on the degree of risk involved in the sacrifice that the society asks people to make. The participants thought veterans have greater risk of death, injury, illness, and/or disability than firefighters, thus societal debt is greater for veterans than for firefighters. Another distinction focused on the nature of events to which the profession (e.g., firefighters or veterans) was asked to respond. Firefighters respond to fire, which the participants considered an "accidental event." On the other hand, veterans respond to war or peacekeeping mission, which the participants considered an "intentional or purposeful event." The participants viewed the "intentional or purposeful event" as man-made, unlike the "accidental event," which is caused by nature. The participants thought that societal debt is greater when the society asks a profession to respond to events caused by human conduct rather than nature. Hence, they reasoned society owes veterans more than firefighters.

Clear division between fairness judgments on health inequality, societal responsibility, and health care priority

In participants' minds, fairness judgments on inequality in healthy life expectancy, societal responsibility, and health care priority were distinct. Even when the participants argued for personal responsibility for health, they supported that Troutville is responsible for everybody's health and should not punish anyone for their choices with health care. For example, a participant stated:

> *"Of course we have a responsibility to act compassionately in all cases."*

Equal care for equal need regardless of the choices made was a principle that the participants felt strongly about. When considering the question of health care priority, the concern for societal debt was pronounced (i.e., society owes veterans and firefighters). Both focus groups discussed various ways to determine health care priority, as listed in the theme "examinations (health care priority)" in Table 3. One of the principles of health care priority that both focus groups discussed was the priority for the least negative impact on society. The participants thought that by addressing the need for health care, particularly, mental health care, among criminals, society could prevent the greatest amount of societal harm. In this view, giving priority to criminals rather than extreme-sport lovers, fire fighters, or veterans would lead to the least negative impact on society.

Underlying the discussion regarding these potential priority principles was the commitment to community solidity, expressed by the principle of equal care for equal need. For example, participants stated:

> *"I don't think our responsibility ever ends at not providing healthcare for someone who has made a poor choice."*

> *"Such is the nature of community, truly, that you caretake each other. And so by that statement, the community of Troutville is responsible for the lower healthy life expectancy of its citizens regardless of their path in life — whether they are ciminials, whether they are fire fighters, whether they are veterans. That we are, believe it or not, directly connected with each other in every way, shape, or form."*

Strategies to think of fairness judgments on health inequality, societal responsibility, and health care priority

Throughout the focus group discussions, participants used different strategies to think of fairness or unfairness regarding health inequalities, societal responsibility, and health care priority, as listed in Table 3. Without a prompt, the participants in both focus groups compared the four inequality cases and discussed similarities and differences to articulate their views. When examining the responsibility and health care priority questions, the participants referred back fluidly to earlier discussions about the four inequality cases and used them to develop their views.

Gender considerations

In both focus groups, a couple of the participants thought about criminals, extreme sport lovers, firefighters, and veterans as male. One participant in each focus group stated that no specific gender came to mind when examining the inequality cases. A general view from both focus groups was that their views did not depend on gender.

TROUTVILLE AS A METHOD TO ELICIT THE PUBLIC'S VALUES

Three themes emerged from the post-focus group telephone interviews: clarity of the scenario; discussion format; and engagement of the Troutville discussion (Table 4). These themes refer to Troutville as a method to engage the public in value-related health and health care discussions.

A general consensus regarding the clarity of the Troutville scenario is that it was easy to understand and the explanation of health inequalities verbally and graphically enhanced the understanding. The use of multiple verbal expressions of the health inequality was based on the literature that shows that the same health inequality can be expressed absolutely (e.g., 10-year difference) and relatively (e.g., criminals' healthy lives will be 86% of non-criminals' healthy lives, or criminals' healthy lives will be 14% shorter than non-criminals' healthy lives.").[8,9] The literature also shows that these expressions have important implications for the measurement and judgment of fairness.[8-10] The participants found these multiple expressions repetitive and not particularly helpful.

Most participants supported the facilitator-guided group discussion as an engaging format. They thought it promoted critical thinking by providing them with different perspectives and insights into how others think. To enhance the quality of the discussion, many participants pointed out a need for clarity the facilitator's role to intervene in the discussion, for example, when it was off-topic or some participants had a greater air time than others. Some participants suggested the need for establishing clear ground rules to encourage open-minded and inclusive discussion. Some participants suggested a multi-format approach, including interviews, small group discussions, large group discussions, and surveys.

Generally, participants perceived the facilitator-guided group discussion using the Troutville scenario engaging. Words used to describe their experience included: "interesting," "thought-provoking," "worthwhile," and "eye-opening." There was a general consensus that the discussion did not change the participants' views on fairness but encouraged the participants to challenge their views to be more nuanced for greater depth and substance. The participants found Troutville relatable. They thought Troutville evoked images of themselves or somebody they knew and prompted "what-if" imagination. At the same time, many participants found it was difficult to keep their minds focused on the hypothetical town of Troutville during the discussion. Another common view expressed was that it was difficult to grasp the reasons why they were asked to consider stylized inequality cases in a hypothetical town, and how the Troutville discussion could inform policy.

Table 4. Themes emerged from post-focus group interviews

Clarity of the scenario	• Easy to understand • Graphs helpful for visual learners • Explanation of inequality in absolute and relative terms repetitive
Discussion format	• Support for the facilitated group discussion format • Need for clarity in the facilitator role to intervene the discussion • Need for ground rules for open-minded, inclusive discussion
Engagement of the Troutville discussion	• Interesting, thought-provoking, worthwhile, and eye-opening • Relatable • No change in own views on fairness but challenged for greater depth and substance • Difficulty in staying in Troutville • Difficulty in grasping the purpose of the Troutville exercise in relation to the study purposes

ADDITIONAL RESOURCES

This work was inspired by previous or existing work that aims to elicit the public's values on health care issues to inform principles that guide specific policy decisions. The following are some of the examples.

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FURTHER RESEARCH

As the phase 2 pilot study, this study provides the following three important lessons for the further development of Fairness Dialogues:

- explain more clearly to participants the goals of the Fairness Dialogues, reasons why the Fairness Dialogues uses the Troutville scenario, and how their discussion relates to health policy;
- formalize the procedure to encourage reflective discussion by clarifying the facilitator's role and establishing ground rules for the discussion; and
- devise a recruitment mechanism to ensure diversity among the participants for rich discussion.

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APPENDIX 1

Draft 5
January 30, 2018

Fairness Dialogues

Inequalities in Healthy Life Expectancy in Troutville

Introduction

Generally, Nova Scotians are healthy. But some of them are less healthy than others.

In this study we would like to learn about your views on how much, and in what way, people are responsible for their own health. To explore your views, you will be asked to think about inequalities in health and when and why you think inequalities in health are unfair. By health inequalities, we mean differences between groups of people in terms of how healthy they are. Sometimes these differences may be fair, and sometimes they may be unfair.

Health inequalities often mean that some groups of people are not as healthy as they can be. What we learn from you today will help inform future health policies to help people be as healthy as they can be.

Thank you very much for your participation.

About healthy life expectancy and Troutville

Life expectancy is the number of years a group of people are expected to live. Life expectancy can be different across different groups of people.

People often do not just wish for a long life. What they really wish for is a long *healthy* life. Healthy life expectancy is the number of years a group of people are expected to live with good health.

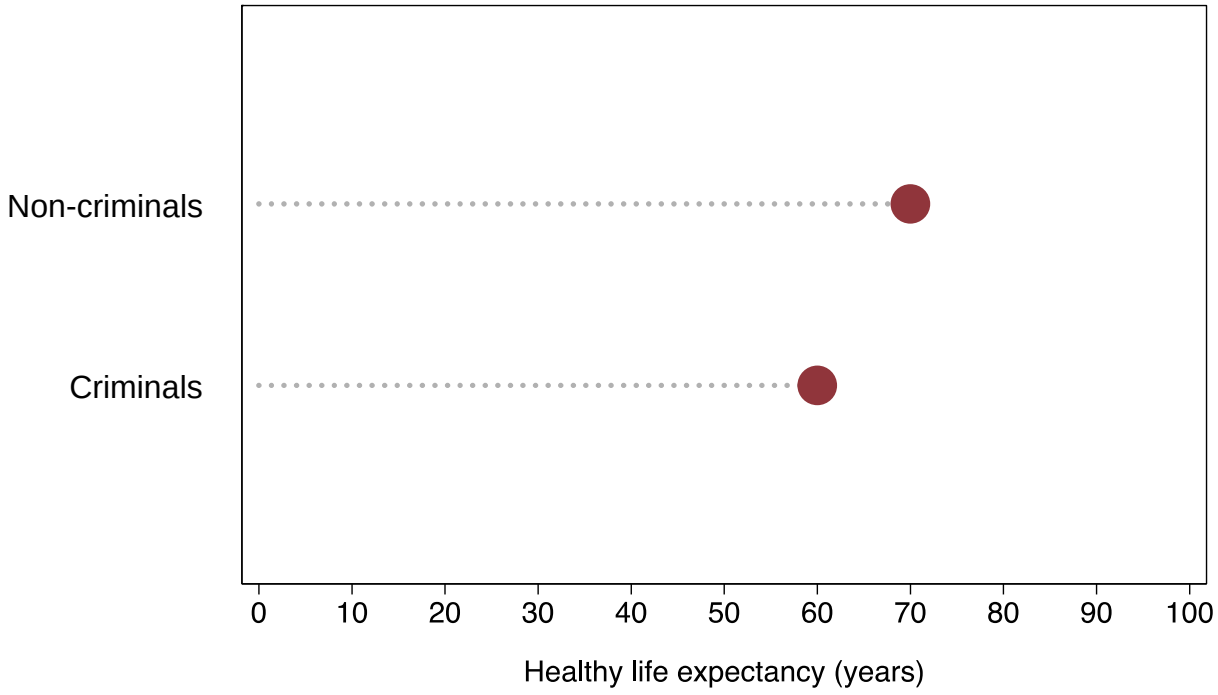
We are going to show you differences or *inequalities* in healthy life expectancy in different groups in a fictional town, Troutville. Troutville is a typical mid-sized town in Nova Scotia. Please imagine you and your family live in Troutville.

What is unfair?

In Troutville, criminals are expected to live for 60 healthy years, and non-criminals are expected to live for 70 healthy years.

This means criminals will live 10 healthy years shorter than non-criminals, and non-criminals will live 10 healthy years longer than criminals. There is a 10-year difference in healthy life expectancy between them.

To put it differently, criminals' healthy lives will be 86% of non-criminals' healthy lives, or criminals' healthy lives will be 14% shorter than non-criminals' healthy lives. This means that for every 100 healthy days that non-criminals will live, criminals will live 86 healthy days or 14 fewer healthy days.



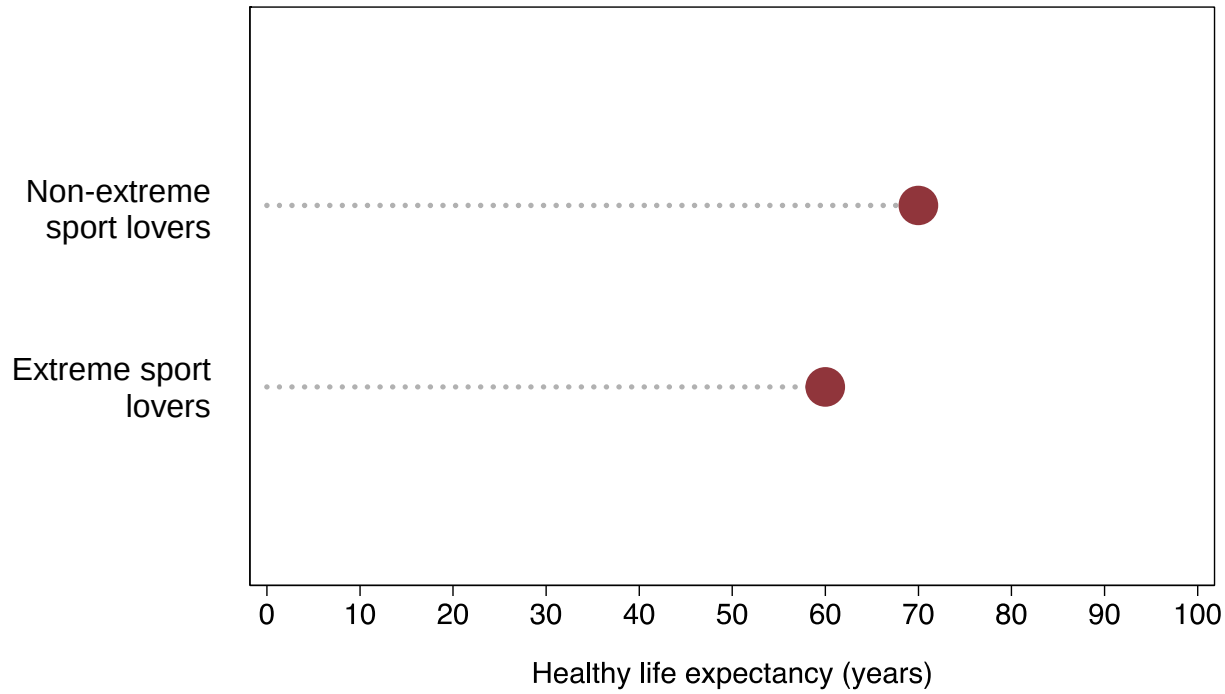
Is this difference or *inequality* in healthy life expectancy between criminals and non-criminals unfair? Why and why not?

Some people in Troutville love extreme sports, such as riding all-terrain vehicles (ATVs), rock climbing, and mountain biking.

In Troutville, extreme sport lovers are expected to live for 60 healthy years, and non-extreme sport lovers are expected to live for 70 healthy years.

This means extreme sport lovers will live 10 healthy years shorter than non-extreme sport lovers, and non-extreme sport lovers will live 10 healthy years longer than extreme sport lovers. There is a 10-year difference in healthy life expectancy between them.

To put it differently, extreme sport lovers' healthy lives will be 86% of non-extreme sport lovers' healthy lives, or extreme sport lovers' healthy lives will be 14% shorter than non-extreme sport lovers' healthy lives. This means that for every 100 healthy days that non-extreme sport lovers will live, extreme sport lovers will live 86 healthy days or 14 fewer healthy days.

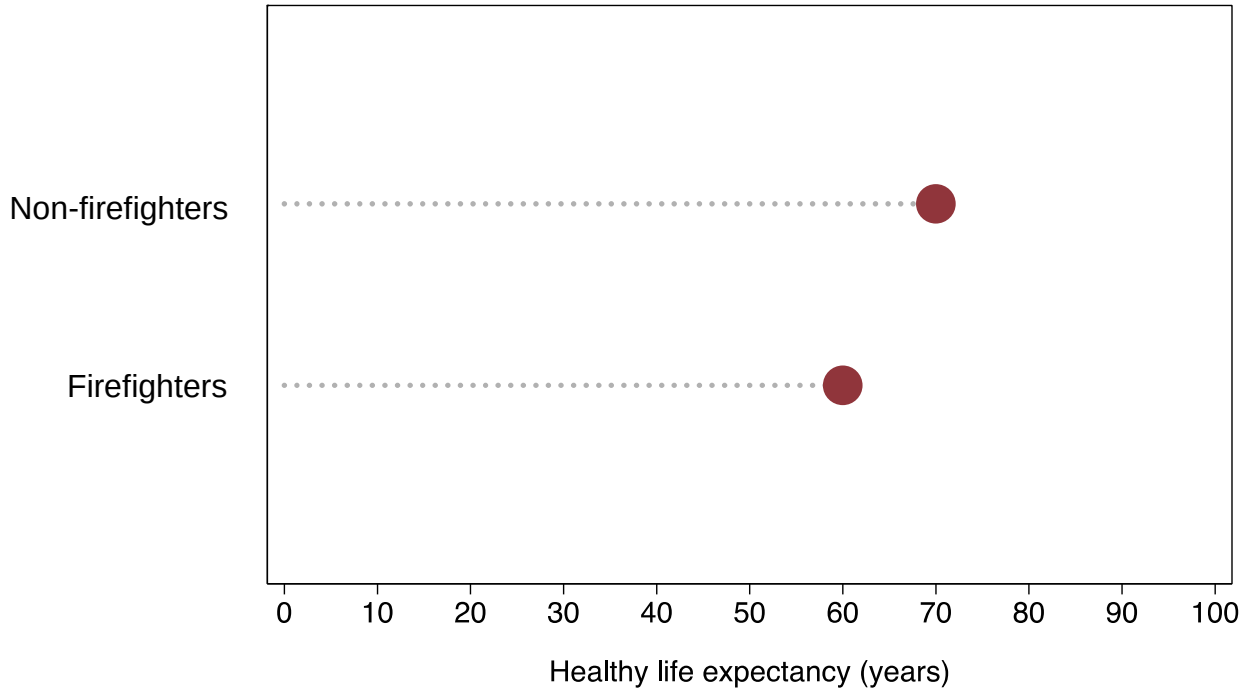


Is this difference or *inequality* in healthy life expectancy between extreme sport lovers and non-extreme sport lovers unfair? Why and why not?

In Troutville, firefighters are expected to live for 60 healthy years, and non-firefighters are expected to live for 70 healthy years. Firefighters in Troutville are volunteers.

This means firefighters will live 10 healthy years shorter than non-firefighters, and non-firefighters will live 10 healthy years longer than volunteer firefighters. There is a 10-year difference in healthy life expectancy between them.

To put it differently, firefighters' healthy lives will be 86% of non-firefighters' healthy lives, or firefighters' healthy lives will be 14% shorter than non-firefighters' healthy lives. This means that for every 100 healthy days that non-firefighters will live, firefighters will live 86 healthy days or 14 fewer healthy days.

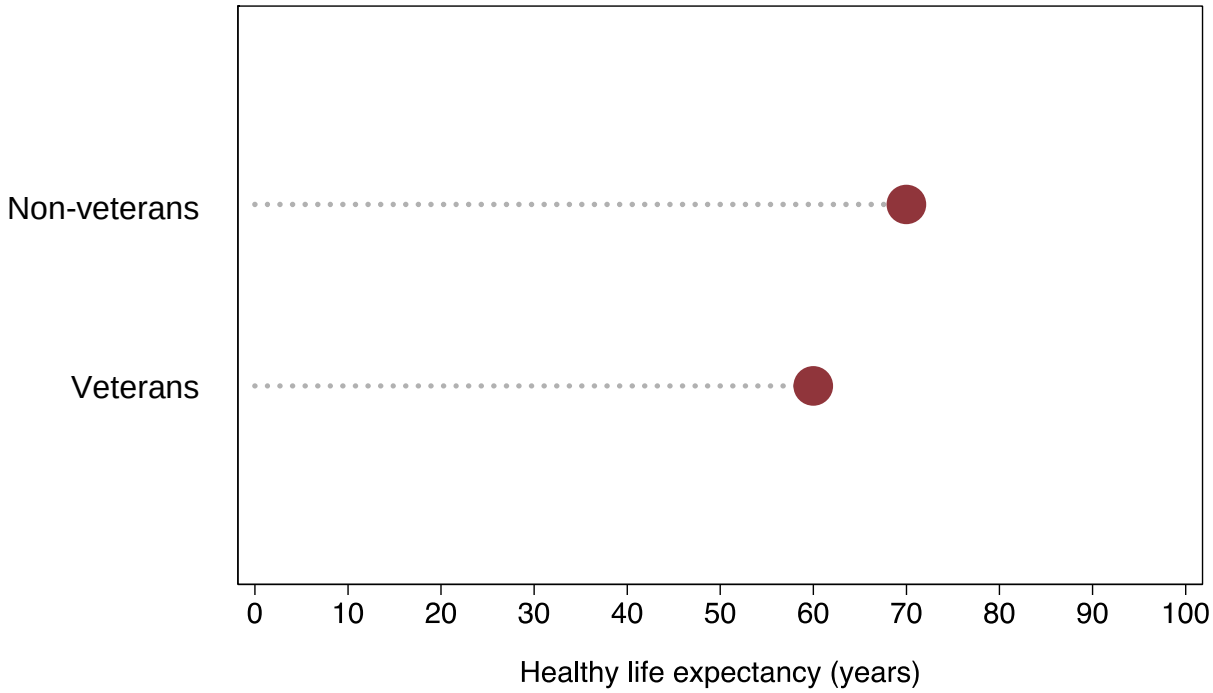


Is this difference or *inequality* in healthy life expectancy between firefighters and non-firefighters unfair? Why and why not?

In Troutville, veterans are expected to live for 60 healthy years, and non-veterans are expected to live for 70 healthy years.

This means veterans will live 10 healthy years shorter than non-veterans, and non-veterans will live 10 healthy years longer than veterans. There is a 10-year difference in healthy life expectancy between them.

To put it differently, veterans' healthy lives will be 86% of non-veterans healthy lives, or veterans' healthy lives will be 14% shorter than non-veterans' healthy lives. This means that every 100 healthy days non-veterans will live, veterans will live 86 healthy days or 14 healthy days less.



Is this difference or *inequality* in healthy life expectancy between veterans and non-veterans unfair? Why and why not?

Are they responsible for their health?

Let's go back to each of the inequalities you have seen.

In Troutville, criminals, extreme sport lovers, firefighters, and veterans have shorter healthy life expectancy than non-criminals, non-extreme sport lovers, non-firefighters, and non-veterans.

Are they responsible for their shorter healthy life expectancy? Why and why not?

Is Troutville responsible for their shorter healthy life expectancy? Why and why not?

How should the health care system treat them?

Imagine a criminal, an extreme sport lover, a firefighter, and a veteran all have serious mental health problems. They need regular visits to a primary care doctor. But, unfortunately, there is currently only one spot available in Troutville.

Who should get the spot? Why? Who should not get the spot? Why?

Did you think about criminals, extreme sport lovers, firefighters, and veterans as male or female? Do you think about inequality, responsibility, and the treatment of health care system differently if they were male or female? Why and why not?

Thank you very much for your participation!

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