

THE ARTICULATION OF PUBLIC VALUES IN HEALTH TECHNOLOGY ASSESSMENT:
THE USE OF DELIBERATIVE DISCOURSE

THE ARTICULATION OF PUBLIC VALUES
IN HEALTH TECHNOLOGY ASSESSMENT:
THE USE OF
DELIBERATIVE DISCOURSE

By

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ABSTRACT

Objectives: The use of interactive public engagement methods to elicit public values is becoming routine practice in health system planning, policy and evaluation; however, little systematic attention has been given to the analysis of *how* these values are articulated. This process will be examined with the use of deliberative discourse methods in the context of health technologies.

Approach: The deliberations of a 14-person Citizens' Reference Panel on Health Technologies were audiotaped and transcribed. The panel provided input to the Ontario Health Technology Advisory Committee in developing its recommendations. Discussion transcripts were analyzed using Gee's (2005) 'building tasks' framework with a focus on identities, relationships, and politics. In depth language-context analysis was then used to study 'situated meanings' of social and ethical citizen values. Both levels of discourse analysis were then used to elicit the meso-level dynamics within the citizen panel deliberations.

Results: Panel members used the provided materials, personal experience and other sources of information to express their values toward the technologies under review. In the group, members used their occupational, personal and cultural identities and adopted in-group citizen panel roles that involved summarizing small group discussions, challenging other members, providing information, providing expertise, interpreting information and facilitating. These individual roles were similar across meetings and members began to form relationships with their fellow citizens and make connections between the values involved in similar technologies.

Conclusion: Discourse analysis methods can be used to draw in-depth insights from public engagement deliberations which contribute important new knowledge to the field of public deliberation and health policy. Further use and refinement of deliberative discourse methods will allow public values to be better understood and more adequately portrayed in the health technology assessment process.

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LIST OF ABBREVIATIONS

PE	Public Engagement
NICE	National Institute for Clinical and Health Excellence
NBAC	National Bioethics Advisory Commission
HTA	Health Technology Assessment
NHS	National Health Service
INAHTA	International Network of Agencies for Health Technology Assessment
EUnetHTA	European Network for Health Technology Assessment
OHTAC	Ontario Health Technology Advisory Committee
MAS	Medical Advisory Secretariat
CRPHT	Citizens' Reference Panel on Health Technologies
LHIN	Local Health Integration Network
CDA	Critical Discourse Analysis
DA	Discourse Analysis
CRC	Colorectal Cancer
PAVR	Percutaneous Aortic Valve Replacements
GEP	Genetic Expression Profile

CHAPTER 1: INTRODUCTION

Interactive public engagement (PE) methods are being used more routinely to solicit the opinions and values of citizens to inform health system planning, policy development and health technology evaluations (Abelson, Giacomini, Lehoux, & Gauvin, 2007; Mitton, Smith, Peacock, Evoy, & Abelson, 2009; Rowe, Horlick-Jones, Walls, Poortinga, & Pidgeon, 2008). Their use in high profile organizations such as the National Institute for Clinical and Health Excellence (NICE) in the United Kingdom (U.K.), the Romanow Commission in Canada and the National Bioethics Advisory Commission (NBAC) in the United States (U.S.), is proof of the global emergence of public engagement as a method worthy of inquiry and application (Cohen, 2005; Milewa, 2006; Romanow, 2002). These types of methods are also being subjected to more rigorous evaluation through research studies that are seeking to define “quality deliberation” (De Vries et al., 2010) as well as emphasize the importance of context in public engagement work (Abelson et al., 2007; O’Doherty & Hawkins, 2010)

The formation of a permanent citizens’ panel by the U.K.’s NICE in 2002 pioneered a formal, institutionalized approach to eliciting values and public opinion about health technologies (Davies, Barnett, & Wetherell, 2006). This Citizens Council was to provide ethical and social perspectives to supplement health technology assessments (HTA). Still, HTA reports around the world often inform policy makers on the efficacy of technologies, and only 17% of these reports discuss the ethical and social issues involved in their recommendations (DeJean, Giacomini, Schwartz, & Miller, 2009; Lehoux, Tailliez, Denis, & Hivon, 2004). Since the public has growing interest in which technologies are publicly funded, and policy makers must include ethical and societal perspectives in these value-laden decisions, researchers are investigating how to adequately include Canadian citizens in this process.

Recently, Ontario began using PE methods to integrate social and ethical values with scientific evidence to inform HTAs. Typically, highly technical scientific evidence surrounding efficacy, effectiveness and cost is used to carry out HTAs. However, in order to obtain detailed information in the context of a technology, a disease and a target population, different evidence from public consultations, surveys, polling and qualitative research is required (Lomas, Culyer, McCutcheon, McAuley, & Law, 2005). Since value perspectives emerge from colloquial evidence, it is a worthwhile endeavour to explore this topic and establish values as context-specific evidence via the use of PE (Lomas et al., 2005).

There is ongoing research on how to evaluate the effectiveness of PE methods with emerging frameworks that require further empirical study in different policy contexts (Abelson & Gauvin, 2006). However, despite the growing body of research about deliberative public engagement methods, remarkably little attention has been given to the in-depth analysis of the discourse that occurs during these deliberative processes. Closely looking at the politics, identities, and relationships that develop during citizen deliberation will provide a different and much needed perspective on how deliberation plays out in the real world and the challenges and benefits that can be learned therein.

1.1 Research Objectives

This study aims to uncover how values are articulated during the deliberative process in the context of discussing health technologies in Ontario by tackling three main objectives. First, this work will ascertain what type of citizen identities result in the elicitation of certain values and the relationships that could emerge during this process. Second, the use of discourse analysis methods will establish the importance of language analysis in examining PE methods. Lastly, approaching the corpus of data from a micro and macro level analysis will bring out key connections between these levels that will give health policy makers and users of public engagement methods a better idea of how individuals make sense of the deliberative process.

1.2 Overview of Manuscript

The subsequent chapter outlines the background literature surrounding public engagement including origins and perspectives in the field. It also discusses current public engagement methods with a focus on citizens' juries and deliberative discourse, and the context of the health technology assessment process. Chapter 3 presents the discourse analysis method used in this particular study and supplementary methodological components from grounded theory, Bourdieu's views on capital and power and one-on-one interviews with each panel member. The qualitative findings are provided in Chapter 4 and are discussed in the context of previous work in Chapter 5. Finally, this manuscript concludes by describing future research objectives for the field of public engagement as well as the implications of the resulting insights for HTA agencies looking to incorporate social and ethical values into their evaluations.

CHAPTER 2: BACKGROUND

2.1 The Importance of the Lay Perspective

Lay perspectives may be obtained from patients, consumer advocates and the general public to provide insights beyond those available from health care professionals, policy makers and government decision makers. Not only has lay involvement begun to be mandated politically in order to reinforce ideas of democracy where the public “owns” publicly funded research and should thus be allowed to contribute their opinions, but public opinion is also viewed as having legitimacy and value that can enhance health research and strengthen decisions (Entwistle, Renfrew, Yearley, Forrester, & Lamont, 1998). Further, the public has grown to be more reflective and less confident in leaders and government; no longer willing to accept tokenistic roles in health care planning and decision making (Davies et al., 2006).

However, acceptance of public perspectives challenges experts’ scientific knowledge and institutional power where some view consumer knowledge as “soft evidence” that is subjective and labile (Litva et al., 2002; Ong, 1996). Thus, many attempts to gain public opinion require the dual expectations of those involved to be knowledgeable about health care, while maintaining an ordinary perspective that brings forth the voice of a local community (Learmonth, Martin, & Warwick, 2009). This contradicts the objective of bringing forth racial, ethnic and cultural diversity to allow for broad and representative public participation (Davies et al., 2006; Learmonth et al., 2009). Nevertheless, public participation is on the rise and deciding on an effective method for engaging citizens is a prevailing challenge (Abelson et al., 2003b; Davies et al., 2006).

2.1.1 The Professional Perspective

The health professional and decision maker perspective on PE appears to be one of cautious curiosity. Although some politicians are unwilling to give up their decision making power and looking for a method to legitimize their decisions (Irvin & Stansbury, 2004), many health policy makers and researchers have incorporated citizen and patient perspectives into service delivery development efforts (Forbat, 2009; Gold, Abelson, & Charles, 2005). Some decision makers are confident that PE methods will allow for decisions to gain legitimacy and improve the transparency and accountability of the policy process (Irvin & Stansbury, 2004). Others still believe that deliberative dialogue leads to trouble when group polarization, ignoring

low-status members and other flaws of group deliberation are too often encountered during PE attempts (Sunstein, 2000). Lastly, gathering citizens to participate in decisions can be costly, taking away from implementation funds, and may breed more uncertainty and complacency in the public once they become privy to information on a policy process that involves PE (Irvin & Stansbury, 2004).

2.1.2 The Public Perspective

Whether it be increased activism in one's own community or the creation of a better health service, the public and patients seem to benefit from PE efforts (Forbat, 2009; Gold et al., 2005; Irvin & Stansbury, 2004). However, engaging with fellow citizens and patients takes time and may not be interesting for all members which can lead to drop outs. Further, PE activities may be rendered wasteful if the opinions or decisions reached by the public are ignored (Irvin & Stansbury, 2004). In fact, members of the public appear to be more comfortable weighing in on system- level decisions but allowing the professionals to have final say and what is done (Litva et al., 2002). Further, in split focus groups of 57 public and professional informants most felt the public should participate in system level decision (68%), just over half agreed PE can be used in programme level (51%) decisions and even less (21%) thought the public should be involved at a patient level (Litva et al., 2002).

Overall, it would seem that both citizens and professionals can learn from each other and use the trust and skills gained during public participation to pursue different routes to reaching more effective decisions (Irvin & Stansbury, 2004).

2.2. The Use of Deliberative Public Engagement Methods

One specific branch of PE methodology is public deliberation which typically includes 1) the provision of topic specific information to participants; 2) interactive, values-based discussions and 3) an explicit method for collecting input from individuals and/or a group of participants in order to inform a decision-making process (De Vries et al., 2010). These key elements can be carried out in a variety of ways including citizens' juries, consensus conferences, deliberative polling and citizens' panels, which are often combined with other methods in order to facilitate application in different health contexts (Abelson, 2010a).

Deliberative participation is grounded in democratic deliberation theory which aims to integrate citizens' democratic power with the opportunity to think about how to exercise that power through deliberation and reasoning with fellow citizens and government representatives (Fishkin, 1991; Gutmann & Thompson, 1996). The term deliberation is defined as a discussion where individuals with different ethnic, cultural and socioeconomic backgrounds, interests and values come together to listen, understand and possibly persuade each other in order to reach a more informed, reasoned and public-spirited decision (Abelson et al., 2003). The use of deliberative methods, deliberative and democratic ideals, and the empirical evaluations and endeavours to measure public deliberation are elaborated on below.

2.2.1. Deliberative Public Engagement Methods in Health

The establishment of deliberation as an approach to guide decision making processes began in the late 1980s in the U.S., Sweden, the Netherlands and New Zealand (Abelson et al., 2003b). Although deliberative methods had been used in different sectors for decades, it was not until the early 1990s that the National Health Service (NHS) began experimenting with these processes in obtaining citizen input on healthcare priorities in the U.K. (Department of Health, 1992). Despite the initial use of surveys (Heginbotham, 1993), only marginally improved by interviewer-administered surveys (Donovan & Coast, 1996); the need for public understanding and debate around complex issues in healthcare called for deliberative methods to be introduced into the health sector.

By the mid-1990s, citizens' juries were being held in New Zealand and the U.K. to tackle issues of resource allocation and the privilege and act of setting priorities in particular health programs (Bostwick, 1999; Lenaghan, 1999). The U.K. was the first nation to mandate a permanent Citizens Council to inform NICE's decision making around health technologies in 2001 (Davies et al., 2006). More recently, public engagement initiatives in health have also been carried out in Canada and the US with the use of public forums, deliberative polling and citizens' panels (Abelson, Lomas, Eyles, Birch, & Veenstra, 1995; Bombard, Abelson, Simeonov, & Gauvin, 2011; Grogan & Gusmano, 2005; National Forum on Health, 1997). Published work in this area has been concerned with using public deliberation in different contexts as well as closely examining its elements (Abelson, Forest, Eyles, Casebeer, E. Martin, et al., 2007; O'Doherty &

Hawkins, 2010). Deliberative methods have been used in policy development, research ethics, regulatory processes, health planning and priority setting, and national health reform processes in a wide range of content areas that continues to grow (De Vries et al., 2010).

2.2.2. The Goals and Theory of Deliberation

Deliberation and the more active inclusion of citizens both play a major role in the contemporary political scene that is seeking to renew democracy through participatory politics (Davies et al., 2006). This appealing option, some hope, would lead to a more direct democracy where preferences are transformed through in-depth discussion regarding complex issues as opposed to forming a position on pre-established opinions (Saward, 2000). The deliberative ideal of a diverse group of citizens coming together to discuss, reflect and problem-solve on a complex or controversial issue after being exposed to fact and opinion (Davies et al., 2006; Dryzek, 2000; Fishkin, 1991; Gutmann & Thompson, 1996) is complementary to the democratic ideals of legitimacy, transparency and accountability (Abelson et al., 2002; Rowe & Frewer, 2000). These ideals serve to motivate the proponents of deliberative participation who believe that engaging citizens in decision making processes will allow for decision maker actions to be easily accepted by the public. More pragmatic reasons for carrying out deliberative activities come from a need for updated methods to correspond with the changes in the decision making process itself as well as the increasingly educated and less complaisant public body (Inglehart, Nevitte, & Basáñez, 1996; O'Hara, 1998).

Overall, the ambitious goals of deliberation have lead to its widespread use in policy, politics, public relations and research where it is used as a method to inform healthcare decision making processes or is studied as a process in its own right. Despite its increasing application, researchers are still unclear on the ideal conditions under which deliberation is appropriate (Abelson et al., 2003). Many agree, however, that using deliberative methods early on in a decision making process is helpful in preventing interest group mobilization surrounding controversial issues (Epstein, Wray, & Harding, 2006; Kathlene & Martin, 1991; Klijn & Koppenjan, 2000). Deliberation users are cautioned away from discussing difficult decisions, or “crisis” issues, where the input of citizens may be acknowledged to a lesser degree. Yet, others

still press on that these scenarios are ripe for deliberation in order to unearth the value-based opinions involved in making difficult decisions (O'Hara, 1998).

2.2.3 Evaluating and Analysing Deliberative Discourse

Empirical work in the field of deliberation in the last decade has advanced considerably beyond the initial descriptive case studies of the late 1990s and early 2000s (Einsiedel, 2002; Einsiedel & Eastlick, 2000; Litva et al., 2002). While some have used the deliberative democracy models of the past to examine the processes and outcome of deliberations (Goold, Biddle, Klipp, Hall, & Danis, 2005), others have become increasingly interested in comparing different public deliberation methods and their effectiveness as inputs into decision making (Abelson et al., 2003a; C. B. Cohen, 2005; Lezaun & Soneryd, 2007; Parkinson, 2004; Timotijevic & Raats, 2007). Much work has also been undertaken in developing evaluation and ethics frameworks and models via the use of public deliberations that inform policy development (Bracci, 2001; Grogan & Gusmano, 2005; Parkinson, 2004; Timotijevic & Raats, 2007). For example, the work of NICE in developing a social values judgement framework involved a literature review, workshops, surveys as well as input from the Citizens Council and key stakeholders. Deliberations were summarized in Citizen Council reports and NICE was able to put forth eight principles to abide by when formulating their guidance on health technologies (National Institute for Health and Clinical Excellence, 2008).

Lastly, De Vries and colleagues (2010) have recently begun using a case study deliberation method to develop and test measures of “quality deliberation” in order to inform clinical research and ethics policies. They considered four aspects of quality deliberation including 1) equal participation by members, 2) respect for others' opinions, 3) a willingness to adopt a societal perspective as opposed to an individual one and 4) reasoned explanations of one's opinions (De Vries et al., 2010).

Overall, a wide range of approaches are currently being applied to explore the field of public deliberation from different vantage points. However, deliberation has seldom been viewed as a socio-political process in the context of health. This requires the examination of power relations between participants and the type of information they use to justify their positions (Abelson, 2010a). The method of discourse analysis, which involves detailed language analysis,

is equipped to take on this challenging objective but has only recently entered the arena as a tool to explore the process and outcomes of deliberative dialogues (Walmsley, 2010). Further application of discourse analysis is required to establish this method's value in the deliberative discourse literature.

2.3 Incorporating Social Values and Ethics in Health Technology Assessments

In recent years, the field of health technology assessment (HTA) has begun to work on incorporating public values into its decision making frameworks, via the use of citizen engagement methods. Healthcare systems have been grappling with emerging technologies and their accompanied rising costs since the 1980s, and the development of HTA organizations has flourished in North American, Europe and Australia as part of the solution (Lehoux, 2006). However, the entrenched perspective of health technologies (defined as including screening, diagnostic and monitoring tests, surgeries, drugs and other technical devices) as neutral tools that only have ethical implications after they are implemented poses a challenge to including public views into HTA (Lehoux, 2006). While proponents of new technology dismiss ethical concerns as society's stubbornness towards technological change, ethicists believe that ill-considered and hasty implementation of these devices can result in serious concerns (Giacomini, Cook, Streiner, & Anand, 2000). Further, ethical and social values and issues are seen as being relevant to society and not the technologies themselves or the design and assessment process (Morgall & Traulsen, 1993). Nevertheless, Lehoux (2006, 115) believes that in order to end this superficial debate and include citizen input to foster legitimacy and accountability in HTA, health technologies must be defined as "socially constructed, multidimensional and subject to constant change". The beginning frameworks and stages of incorporating social and ethical values into HTA, using public deliberation methods, are outlined below.

2.3.1 Established Frameworks for Incorporating Social Values and Ethics

As mentioned previously, U.K.'s HTA organization, NICE, created a Citizens Council of thirty members who were recruited to reflect the diverse populations of England and Wales based on criteria of age, education, ethnicity, gender, employment status and place of residence (Davies et al., 2006). The council meets twice per year for three days during which members

listen to key experts on relevant topics and participate in deliberations that inform NICE's guidelines. The Citizens Council operate under a Social Value Judgements framework that they developed in their initial meetings (National Institute for Health and Clinical Excellence, 2008). This framework includes eight principal statements that must be considered when evaluating technologies and has underlying values that have been distilled from early Citizen Council reports.

In Switzerland, citizens' panels in combination with consensus conferences dubbed Publiforums are also being held by a health technology agency to explore broad social and ethical issues (Skorupinski, Baranzke, Ingensiep, & Meinhardt, 2007). On a larger scale, the International Network of Agencies for Health Technology Assessment (INAHTA) has established an ethics working group where they recognize Hoffman's (2005) morally relevant questions (See Appendix A) and recommend that an author is designated to perform ethical analysis, conduct a primary and secondary literature review and make the findings relevant to the HTA that is being undertaken at the time by the agency (INAHTA Ethics Working Group, 2005). The European Network for Health Technology Assessment (EUnetHTA) Working Group took this one step further and narrowed Hoffman's 33 questions (Hoffman, 2005) to 16 slightly altered questions (EUnetHTA, 2008). Further, EUnetHTA suggested that the person in charge of the ethical analysis can use further informational sources including expert opinion and stakeholder hearings as well as their choice of the recommended ethical analysis methods (Saarni et al., 2008).

In general, it is clear that efforts are underway towards establishing social and ethical frameworks and exploring proper ethical analysis methods that will allow public values to be incorporated into the HTA process. While considerable attention has been paid to *which* values are elicited from this process and the aforementioned value framework, little systematic attention has been given to *how* these values are articulated through deliberative reasoning, and in the specific context of health technology evaluations.

In Canada, the Ontario Health Technology Advisory Committee (OHTAC) Social Values and Ethics Evaluation Subcommittee is also working towards exploring the current value frameworks being used (Giacomini, 2010) in order to supplement its HTA decision determinants framework (Perera et al., 2009). The following section describes the results of

a pilot project where OHTAC employed a citizens' panel to inform the specific decision determinant criteria of "consistency with societal and ethical values" (Abelson, 2010b; Perera et al., 2009)

2.3.2 Citizens' Reference Panel on Health Technologies

In 2008, the Ministry of Health and Long Term Care funded a pilot project in collaboration with the Medical Advisory Secretariat (MAS), the OHTAC and Dr. Julia Abelson from McMaster University. The project involved the creation of a 14-member Citizens' Reference Panel on Health Technologies (CRPHT) to provide input to OHTAC's health technology review process (Abelson, 2010b). Members were randomly selected from phonebooks (stratified by Local Health Integration Network (LHIN)) and respondents to the invitation letter were further stratified by age and gender. Five full-day meetings were held between February 2009 and May 2010 involving public deliberation on various health technologies under review with the aid of a workbook, a few evidence based articles and an abbreviated version of Hoffman's framework (See Appendix B). All meetings were audio recorded and transcribed.

Currently, this analysis has revealed a set of core social values identified by panel members - *universal access, choice and quality care* – at stake in evaluating health technologies and in forming recommendations for their use in the health system (Bombard et al., 2011). Further content analysis by the research team has shown that these values are shaped by materials provided to panel members, expert speakers, previous knowledge and experience and information accessed via the Internet and other communication mediums (Simeonov & Abelson, 2010). These findings are consistent with previous work on how values are shaped, where Canadians relied on their experiences with the healthcare system and their physician to form their opinions on the value of trust (Abelson, Miller, & Giacomini, 2009).

Although we are developing a preliminary understanding of citizens' values toward health technologies and how they should be evaluated in Ontario, how these values emerge through the deliberative process and their underlying rationales remains unclear. Further, despite the widely available research on public participation, little systematic attention has been given to

the topic of values and how they are articulated in the empirical public deliberation literature (Giacomini, Hurley, Gold, Smith, & Abelson, 2004; Mitton et al., 2009).

Our interest in investigating the use of public deliberation in this context is to contrast the deliberative and democratic ideals with an in-depth description and analysis of a real-world application of this method. The results will provide useful guidance to both researchers and policy makers interested in incorporating these methods into their practice. Also, this study aims to further the knowledge base on how to best apply deliberative methods and explore a new way of examining the outcomes of deliberative processes through the use of discourse analysis.

This Master's thesis will answer the following research questions in order to contribute to social values and ethics literature in HTA:

2.4 Thesis Questions

Primary Research Question

How are values articulated during the deliberation process of Ontario citizens' panel members in the context of discussing health technologies?

1. Whose values are heard and validated during the deliberative process?
2. Why are certain values articulated over others? How, if at all, are member roles and power relations involved?

Secondary Research Questions

- 1a. How are identities being enacted through the citizen panel's deliberative process?
- 1b. What social relationships are established among citizen panel members and how do they influence deliberations?
- 2a. What perspective on social goods are citizen panel members' deliberations seeking to achieve? Social goods in this study include equal access to quality health care and health technologies, patient autonomy and, publicly available and accurate health information.

CHAPTER 3: METHODS

This study uses discourse analysis, an in-depth text analysis approach, to investigate how values are articulated in the HTA context during citizen deliberations. The following chapter briefly outlines the overarching study design and rationale for using this method. Discourse analysis, as envisioned by Gee (2005), is then introduced along with grounded theory coding methods. Alternative methods to analysis are also presented in order to explicate the rationale for employing discourse analysis. Finally, the implementation of the design and the study context are described.

3.1 Research Design

Using discourse analysis methods, transcripts from all five CRPHT meetings were analyzed using the qualitative software QSR NVivo 8. First, initial coding methods, adapted from grounded theory, were applied in order to describe citizen politics, identities, and relationships, and the situated meanings used in their discussions (e.g., how citizens define societal and ethical values) (Charmaz, 2006). This will aid in formulating a deliberative ‘discourse model’ which will produce a holistic understanding of the connections between politics, identities, and relationships used by panel members in the context of HTA (Gee, 2005, 2010). To carry out this work, we draw on Gee’s (2005, 61) concept of ‘discourse model’, which is defined as ‘the “theories” (storylines, images, explanatory frameworks) that people hold, often unconsciously, and use to make sense of the world and their experiences in it.’

In the second phase, the outlined ‘discourse model’ allowed for a more in-depth analysis of how values are articulated and given significance within group discussions. Here, a more detailed look at the data, with a focus on line-by-line language-context analysis, was carried out where the setting, individuals present and their beliefs, as well as the language used, were studied iteratively (Gee, 2005). Lastly, results from these two phases were triangulated with qualitative one-on-one interview data, in which each panel member was asked about their perceived roles, representation and relationships in group discussions in order to ensure trustworthiness of the resulting discourse analysis.

Overall, this method allowed for textual microanalysis which complements the thematic macroanalysis in aims to formulate a ‘discourse model’, both of which will elicit the discourse dynamics within the citizen panel deliberations.

3.1.1 Rationale for Using Discourse Analysis

This is a novel application of discourse analysis in the field of social values and ethics relating to HTA, which will serve to outline the importance of language analysis to the growing field of PE methods. Language serves a significant role in creating and shaping social and institutional practices and deliberations. Fairclough (1993) states that since it is a form of social practice, language requires more than text analysis but also an investigation into how it is created and received. The literature on values and ethics in HTA, as well as public engagement, has not addressed language analysis as a method of elucidating the meanings and interactions between citizens involved in discourse. This in-depth research is required in order to fully understand how social and ethical values are articulated in this context.

The results of the presented discourse analysis will serve as a description of how deliberative processes work and what they entail in a real world context. Further, this study will advance our understanding of how the field of post modern linguistic anthropology and PE intersect, by examining how people perform their identities during deliberations. The outcome of this work will influence how researchers and health policy makers incorporate deliberative methods into their practice, and how they choose to analyse their outputs.

3.2 Introduction to Discourse Analysis

Discourse analysis is the study and examination of how language is used and, as a method, can be broken down into three broad categories. First, formal linguistic discourse analysis involves close analysis of grammar, structure and semantics, and how they are used to evoke meanings in text (Hodges, Kuper, & Reeves, 2008). Second, empirical discourse analysis, such as genre and conversation analysis, investigates broad themes and functions of language in order to demonstrate how it is used to create meaning and action in social processes (Hodges et al., 2008; Shaw, 2009). The third type is critical discourse analysis (CDA), which uses a macro-level constructivist approach to examine how language and texts formulate institutions and individual roles, as well as the power dynamics therein (McHoul & Grace, 1995; Smith, 2010). CDA addresses macro and micro levels of discourse equally (Smith, 2010), and views the nature of discourse as ‘an instrument in the social construction of reality’ (Jaworski & Coupland, 1999)

where it functions as both formed of and formed by social practices (Blommaert & Bulcaen, 2000; Jørgensen & Phillips, 2002).

This study will be adopting James Paul Gee's critical discourse analysis (Gee, 2004), where he categorizes discourse into two groups: *discourse* with a small "d" is defined as language-in-use; and *Discourse* with a capital "D" is language plus the gestures, tools, interactions, values, beliefs, emotions etc., that accompany language in order to formulate a full picture of the 'discourse model' (Alvesson & Kärreman, 2000; Gee, 2005). Similarly, Moje and colleagues (2001, 470) describe Discourses as "ways of knowing, talking reading, and writing" (Moje, Collazo, Carrillo, & Marx, 2001).

3.2.1 Gee's Framework

Gee's (2005) method of discourse analysis involves seven building tasks that construct seven areas of "reality" through the use of language. These building tasks include: (1) significance which is achieved through word emphasis and positioning, (2) activities such as informal conversation within a group, (3) identities established by the participating individuals, (4) relationships built between group members as well as groups not present, (5) politics surrounding social goods and norms, (6) connections created between building tasks and interactions and (7) sign systems (e.g. graphs) and knowledge such as using technical language versus everyday language (Gee, 2005). From this framework of tasks, I focused on politics, identities, and relationships because they were most suitable for addressing the research questions outlined for this study. However, other parts of the framework are inextricably linked to those chosen and were thus also employed in some areas of the analysis.

First, examining the construct of politics will provide a perspective on how social goods are distributed (Gee, 2005). Gee (2010, 118) defines politics in a special way that is not associated with government or political parties, but is described as "any situation where the distribution of social goods is at stake". Social goods are anything that a group or society considers as a good worth having. In the context of our study, the main social good that is discussed is health care and more specifically health technologies where equal access, quality care, patient autonomy, and publicly available and accurate health information are considered important. Closely looking at distribution of this social good involves the concept of 'haves' and

‘have nots,’ which is defined by different types of capital: economic capital includes financial resources, social capital is one’s membership to particular social networks, and cultural capital is one’s credentials and knowledge (Bourdieu, 1997). Differences in capital are said to result in differences in power linking politics and relationships (Bourdieu, 1997). Further, different individuals hold unique combinations and quantities of various capitals that influence how they are perceived in society. Second, identities are framed from a constructionist perspective, where identity is one’s self conception that is shaped by multiple discourses and requires continuous justification to maintain a self-narrative (Kuhn, 2006). Here, I will form hypotheses based on the communicative language and how it is used to constitute socially situated identities in the study context (Gee, 2004). Individuals participate in Discourse under different social models, where they assume slightly different identities based on the context they are operating in – this changes the stable, internal view of identity into one that is more flexible and socially constructed. Finally, relationship development will be ascertained by looking at how language is used to indicate what types of relationships participants have, want to have, or are trying to have with individuals in the group, the group as a whole, members of the research team, and broader institutions. Since relationships are inherent in social practices, issues of solidarity, status and power will also be examined to uncover how relationships are built, and whether this impacts which values are articulated during deliberations.

Along with this broad structural framework, many of Gee’s (2010) analytical tools were employed in developing the textual analysis through line-by-line readings. These included ‘The Fill In Tool’ which was used to ensure clarity of context, ‘The Making Strange Tool’ which was used to explore unclear or assumed parts of the text that may have been taken for granted by panel members because they are insiders and ‘The Frame Problem Tool’ which challenges the researcher to expand the context of the text. ‘The Doing and Not Just Saying Tool’ which looks at how panel members are trying to achieve certain actions through their use of language, and ‘The Why This Way and Not That Way Tool’ which examines why panel members say things in a particular way and what this means in terms of their goals, were also employed.

Finally, ‘The Intertextuality Tool’ analysed references to other “texts” or spoken word and the ‘The Situated Meaning Tool’ looked at how members established meaning around particular words in this study context.

3.2.2 Grounded Theory, Social Constructivism and Reflexivity

Using a social constructivist paradigm, initial coding adapted from Kathy Charmaz's (2006) grounded theory was employed (Charmaz, 2006; Creswell, 2007a). Social constructivism is a specific worldview in which meanings are subjective and multiple views are considered in order to assess the complexity of how these meanings are negotiated (Charmaz, 2006; Creswell, 2007a). Thus, meanings are formed through interactions with others, and the process of these interactions is the basis of my analysis. This paradigm is appropriate for the present study because it emphasizes locating the data in a context, which in this case is the field of HTA and PE in Ontario (Charmaz, 2006). Within this worldview, I adapted the coding methods for developing a grounded theory in order to develop a 'discourse model'. This involves an initial open coding of the data, and a second stage of focused coding based on the three elements of identities, relationships and politics as well as the social capital and power dynamics embedded within (Charmaz, 2006). The final stage of language-context analysis is an adapted version of line-by-line coding, with attention to the context defined by Gee (2005, 57) as 'material setting, the people present, the language that comes before and after a given utterance, the social relationships of the people involved, and their ethnic, gender, and sexual identities, as well as cultural, historical, and institutional factors'. This part of the analysis will reveal situated meanings and the relationships between words and context through the use of Gee's (2010) analytical tools

Finally, as a social constructivist researcher, I recognize that I may hold certain preconceptions that may impact how I analyse and interpret the transcripts and one-on-one interview data (Charmaz, 2006). Thus, I kept a reflexive journal where I outlined any biases or assumptions I noticed during data collection, and also annotated the transcripts with any hunches or ideas I wanted to explore further. Being self-aware in my role as a participant observer (i.e. engaging in overt observation of the deliberations that took place with mutual awareness of the research by all present) (Mays & Pope, 1995) and practicing reflexivity, assure the trustworthiness of the results (Finlay, 2002). Not only did I describe my social locations through my reflexive journal, I also reflected on how they influence each stage of analysis (Harper, 2006). Finally, maintaining a consistent methodological approach, where I analyse each

participant's contributions in the same manner while acknowledging personal biases, allowed for a thorough and consistent discourse analysis process (Smith, 2010).

3.2.3 Bourdieu's Forms of Capital

Pierre Bourdieu believed that in order to be able to consider the structure of the social world and how it functions, the concept of capital has to be recognized from a broader perspective than simply from that of economic theory (Bourdieu, 1997). He described capital as being able to take on three fundamental guises: economic, cultural and social. First, economic capital has the capability of being turned into money and can be institutionalized in the form of property rights.

Second, cultural capital can take on three forms including the embodied, objectified and institutionalized states. In the embodied state, cultural capital takes the form of "long-lasting dispositions of the mind and body" which are acquired through work on oneself and can be converted into habitus, an integral part of the individual (Bourdieu, 1997, 47). Unlike economic capital, the transmission and acquisition of cultural capital are better disguised and can function as symbolic capital where they can be recognized as "legitimate competence" as opposed to cultural capital (Bourdieu, 1997). The objectified state of cultural capital comes in the form of cultural goods such as paintings, books, and machines, which can be possessed materially through economic capital and symbolically through embodied cultural capital in order for them to be used as they were intended. For example, one with economic capital can easily purchase a machine, but still requires the embodied cultural capital to make use of it. The final institutionalized state of cultural capital involves academic qualifications which are legally recognized and formalize individual competence in the social world.

Third, social capital includes one's social connections to other individuals and groups and can also be converted to economic capital (e.g. in the form of job opportunities) and institutionalized (e.g. in the form of official titles). This form of capital involves the possession of a reliable network of institutionalized relationships through membership to specific groups or societies. Thus, the level of social capital one has depends upon the network of connections which the individual can effectively access and mobilize when required.

Finally, the idea of habitus is that individual ways of acting, feeling, and thinking are created through social processes and can shift depending on the context. This process of creation involves the interplay of free will and social structure over time where both shape and can be shaped by one's identity (Bourdieu, 1991). Generally, the broad categories of economic, cultural and social capital were employed during initial coding and were later examined more closely to bring forth the underlying differences in capital and power.

The use of Bourdieu's different forms of capital in this analysis allows for a more in-depth and focused examination of the underlying power dynamics that exist between members as well as between the panel and those not present at the meetings such physicians and manufacturers. This additional component supplements Gee's framework by providing a theoretical basis for how power is gained, transferred and negotiated which will allow for the data to be viewed through another lens of analysis. Being able to characterize capital in the three forms outlined by Bourdieu provides a more refined way of approaching this portion of the study.

3.2.4 Advantages and Disadvantages of Discourse Analysis

Proponents of discourse analysis (DA) believe that the method's strengths far outweigh its limitations (Harper, 2006; Morgan, 2010). The key advantages of DA are similar to those of other qualitative methods, where validity or trustworthiness can be attained in ways that do not involve replicating analysis or examining reliability. Internal coherence is the goal and mark of a properly executed DA, where the story is outlined in a clear and concise manner. Another strength of DA is its ability to provide new theoretical insights that generate future questions for investigation (Harper, 2006). DA can be used in a variety of contexts, regardless of time, place and individuals involved. This method is ideal for revealing hidden or dominant discourses that enforce marginalized positions in society, and can even be used to aid in constructing more empowering social positions. Further, DA challenges traditional theory, policy and practice in different contexts via a deeper understanding of how language and discourse interact to promote individual and social change (Morgan, 2010).

Finally, the use of the social constructivist paradigm strengthens this method by allowing meanings to be fluid in order to analyse how concepts emerge and are shaped by culture, context

and history. Potter (1998, 139) states that this method provides a ‘rigorous way of directly studying human practices’. Also, viewing the researcher as an active interpreter, where no analysis is presented as the only ‘true’ reading but as one possible interpretation of many, requires the researcher to be reflexive which strengthens the rigour of DA (Harper, 2006).

Nevertheless, DA does have several limitations. First, the process of analysis can lead to several procedural issues including under-analysis through summary, and over-quotation as well as circularity in discourse identification, false application of findings and spotting patterns without interpretation (Antaki, Billig, Edwards, & Potter, 2003; Stevenson, 2004). Summarizing data does not add anything to the analysis and can lead to losing the nuances of the original discourse. Using many quotations results in a failure to go beyond the text and present a worked analysis of how discourses were used. Circularity or finding what you were looking for based on previous assumptions is also an analytical trap that can be avoided by looking for negative examples (Stevenson, 2004).

Second, the strength of socially constructed and flexible meanings can also be a significant challenge, since analysis with one set of data can be ongoing and each new interpretation provides further avenues for more thorough analysis. Thus, to avoid what seems like a never ending analysis, clear explanations of concepts and justification for their use throughout the analysis process can help to focus the output of this method (Morgan, 2010). Further, DA can be a complex technique, and does not have a strict set of mechanistic steps to follow (e.g. grounded theory (Corbin & Strauss, 2008)). Researchers must be exposed to a wide variety of literature, maintain an open but clear method, and be willing to invest time into their analysis (Harper, 2006). Finally, different types of discourse analysis have more specific limitations in terms of depth and breadth. For example, Foucauldian discourse analysis is criticized as being too broad, which is why Gee’s framework was used to focus the course of this analysis (Morgan, 2010). Despite these limitations, the open acknowledgement of the pitfalls inherent in DA provides testament to its rigour. Still, there are alternative qualitative methods that can be used to if these limitations cannot be resolved in the researcher’s specific study context.

3.2.5 Alternate Methods

Two alternative approaches that aid in the understanding of discourses and meaning in health research are phenomenology and grounded theory. The goal of phenomenology is to describe the subjective meanings of a lived experience of a phenomenon, whereas grounded theory aims to develop an explanatory theory of a social process (Creswell, 2007b; Dukes, 1984; Starks & Trinidad, 2007; Walker & Myrick, 2006). Neither of these aims address the study's overarching goal which is to understand how individuals create and enact their identities in the same way that DA does. Phenomenology asks 'what' and grounded theory asks 'how', which is closer to the aims of the discourse analysis method employed. However, the 'how' is used differently. DA asks, "How do discourses shape identities, politics and relationships?", whereas grounded theory asks, "How does a particular social process occur in a given context?" (Corbin & Strauss, 2008; Gee, 2005). Thus, only initial and focused coding procedures were directly drawn from grounded theory in this thesis, with Gee's DA conceptual framework used to guide the research questions and analysis.

One main similarity between these two approaches and DA is the use of bracketing, where researchers recognize and document their previous assumptions and biases – which is the equivalent of examining one's position in a Discourse while employing DA. Further, the overarching process of separating the data from its original context, by assigning meaning and then re-contextualizing themes in order to draw conclusions, is similar in all three approaches (Starks & Trinidad, 2007).

Nevertheless, the final products of phenomenology and grounded theory do not necessarily set out to elucidate how language is used to shape, negotiate and produce identities, relationships and social goods. In DA, theory and results are generated within the existing building blocks outlined by Gee (2005). Phenomenology results in a thick thematic description intended for clinicians, practitioners and anyone interested in understanding the lived experience of a specific phenomenon. Similarly, grounded theory is useful for researchers and practitioners, who require an explanatory theory to help them design interventions. The audience for DA generally includes policy makers, clinicians and program evaluators interested in understanding why a certain practice is headed a certain way, or to gain support for a particular policy (Starks & Trinidad, 2007). One of the goals of this study is to inform researchers and policy makers of

the opportunities DA presents as a method to understand how framing and language are used by citizens to accomplish their objectives.

Overall, although phenomenology and grounded theory have somewhat similar analytic methods to DA, their goals, audiences and products differ, making DA the most suitable approach for answering the outlined research questions and objectives.

3.3 Implementing Discourse Analysis

Discourse analysis is an iterative process that involves going back to the data, checking assumptions and conducting the analysis as a reflexive researcher. After obtaining ethics approval (see section 3.3.1), a citizen lottery sampling strategy was employed, resulting in a 14 member citizen panel. Five meetings were held between February 2009 and March 2010, each lasting a full day, and involving a discussion of one of the five different technologies examined through the course of the study (See Appendix C). During each meeting, panel members engaged in informed, facilitated discussion and values elicitation through structured deliberation on the following topics (Abelson, 2010b):

1. Incorporating ethical and societal values into the evaluation of health technologies (how should this be done? what are the core social values that should guide OHTAC evaluations of health technologies?);
2. Review of selected health technologies at various stages in the MAS-OHTAC review process (i.e., vignette stage, draft recommendation stage and public comment stage).

All meetings were audio-recorded and transcribed. One-on-one telephone interviews were also conducted with each panel member, after the completion of the five meetings, to gain further insight into how members perceived their experience in the panel. Interviews were also recorded and notes were taken for each member's responses. All transcript data was coded using qualitative research software, QSR NVIVO 8, and was then worked into memos for interpretation. Interview data was then incorporated into the final interpretation of the discourse analysis.

Using Gee's (2005) framework, adapted grounded theory coding methods (Charmaz, 2006) and Bourdieu's forms of capital (Bourdieu, 1997) provides a tailored approach to implementing DA in this study. The context of the analysis originates from a pilot project

described in section 2.3.2, discussing the Citizens' Reference Panel on Health Technologies (CRPHT). In order to delve deeper into the data set and reveal not only *what* type of values are important to Ontario citizens, but also *how* they arrive at these values, a 'discourse model' will be created by examining the politics, identities, relationships, and dynamics involved therein.

3.3.1 Ethics Approval

Study approval was obtained from the Hamilton Health Sciences/McMaster University Research Ethics Board as part of the CRPHT pilot project. Confidentiality of the data was maintained by password protecting all transcripts and documents containing identifying citizen information. All members of the research team, who had access to the data set, signed a confidentiality agreement and electronic documents were kept on a password protected laptop and hard drive, which were locked safely in a cabinet. Participants are identified by their gender and were assigned an anonymous name.

3.3.2 Study Population

During the creation of the 14-person panel, demographic and geographic balance was achieved by using a 'civic lottery system' (Dowlen, 2008). Using a stratified, random sampling approach, 3500 Ontario residents were mailed an invitation letter, information sheet, and postage-paid response form. From this initial sample, 163 expressed interest and 14 were blindly selected to reflect stratification by Local Health Integration Networks (LHINs), gender and age categories. The final panel was comprised of 5 women and 9 men, one member from each LHIN, and included two members between ages 18-24, four between 25-39, four between 40-54, two between 55-70, and one aged over 71 (See Table 1) (Bombard et al., 2011).

3.3.3 Data Collection and Analysis

Meeting deliberations were transcribed verbatim, and transcripts were managed and coded using QSR NVivo 8. Initially, themes and 'intuitive hunches' were open coded before employing Gee's framework for further analysis. Then, a second focused code was applied using the themes of politics, identities, and relationships and politics as well as the dynamics that emerged through disagreements or alliances. Examples of these codes include: "choice", "occupational identity", "respectful relationship" and "cultural capital" respectively. This

comprised the macroscopic analysis piece of DA. Close textual examination of the transcripts using Gee's (2005) language-context microanalysis allowed for situated meanings regarding social and ethical values, as well as the politics, identities, and relationships to be studied.

In order to enhance rigour, the results of this discourse analysis were triangulated with one-on-one interviews in which each panel member was prompted to answer the following statement: "This next question is about group process, and how you personally contributed to group discussions. Some roles that panel members had were, for instance, a facilitator or an information-provider. What types of roles did you feel you played in group discussions?" (See Appendix D for full questionnaire) Further, reflexivity and microanalysis allowed for testing initial hunches and the confirmation of a 'discourse model' surrounding articulating ethical and social values in the Ontario HTA context.

3.3.4 Ensuring Scientific Rigour

Gee's (2005) method of achieving trustworthiness involves four main elements: (1) *convergence* is achieved when different parts of the analysis are compatible and convincing; (2) *agreement* results when participants in the Discourse and other DA researchers agree on the results of the analysis on how language is used in the particular study context; (3) *coverage* is attained when that analysis can explain previous situations and text related to those analysed, as well as being able to predict what may happen in future; and (4) the use of *linguistic details* where the analysis is more credible when communicative functions are used according to the participants' and linguists' view of the Discourse. Although Gee (2005) suggests that trustworthiness of his discourse analysis method is achieved through a full application of his framework, which answers the questions corresponding to each building task, other methods for maintaining rigour were also applied in this study.

Potter (1996) addresses the issue of credibility by using his own four factors that require consideration: deviant case analysis; participants' understanding; coherence; and readers' evaluation. The first factor is similar to convergence where deviant cases are sought out to confirm an established pattern in the analysis or to negate it (Potter, 1996). The second element is similar to agreement, where the researcher seeks out the opinion of the participants to confirm the meaning of the analysis. The last two elements are akin to the concept of coverage for they

require looking to other DA studies to ensure coherence, as well as allowing the reader to judge themselves whether the analysis is sound, based on their experiences as part of society (Potter, 1996; Stevenson, 2004).

CHAPTER 4: RESULTS

4.1 Study Participants, Data and Setting

The participants used for this analysis included mostly male individuals (64%) aged 40 to 54 (29%) who had some college or university education and were employed (See Table 1). All five citizens' panel meetings were analyzed to get a complete understanding of the deliberative process. These five meetings involved in-depth, recorded and transcribed discussions regarding colorectal cancer (CRC) screening, percutaneous aortic valve replacements (PAVR), breast cancer screening, personalized medicine with a focus on genetic expression profile (GEP) testing, and celiac disease testing. Each meeting began at 8:30 am and was structured around a morning session devoted to introductions, follow-up from previous meetings, and general discussion about how to incorporate ethical and social values into HTA. Morning discussions generally took place in a large group format, complemented by some small group discussions when initially introducing Hoffman's societal and ethical questions which lasted about one hour. Members were given a short morning break and a full hour for lunch. In the afternoon, a new technology topic was introduced; members were given an opportunity to ask questions, and were then split up into two smaller groups to answer discussion questions posed by the research team. This lasted about seventy-five minutes, and, following the afternoon break, members reported back from their small groups for about one hour. Finally, each meeting included a thirty- to forty-five minute wrap-up session where members provided their input on how the panel was functioning and recommendations for future meetings (See Appendix C). The research team played an informing and facilitating role during these meetings. The Principal Investigator (PI), acted as the lead facilitator. Her role was to introduce discussion topics; summarize key information relevant to the discussion that was provided in reading materials; lead large group discussions and facilitate interactions between group members and experts. Other members of the research team, including myself, acted as facilitators of small group discussions in the later meetings. If panel members missed two or more meetings in the course of the study, they were not included in the focused line-by-line textual analysis. All facilitator remarks were also excluded from the analysis.

4.2 Politics and the Social Good of Health Care

Gee's concept of politics aims to examine how language is used to build what constitutes a social good and how these type of goods are viewed, based on societal and ethical values and beliefs. Here, the term "politics" does not relate to government in the traditional definition of the word but is more about social goods that are deemed important and worth having by society and how they are viewed and distributed (Gee, 2010). Panel members identified health care as a social good, and then went on to discuss how it should be distributed, administered and accessed in the context of the aforementioned health technologies. Participants were concerned with four main categories surrounding the social good of healthcare: universal access, quality, choice and cost. However, members also held opposing views on which values were more important in the context of certain technologies.

4.2.1 Healthcare as a Social Good

Panel members viewed healthcare as a social good that would be accessed by all members at one point in their lives, and that maintaining a good health status was something that all citizens 'should' aim for:

"I think if we just kind of simplify it that way and say, 'You know what, we value, whether it's a yearly or biyearly physical, however often we do a physical.' Now there [are] other things that we *should* be doing for ourselves that have staffs to support them that they can be picked up early on when they hit us." (Benjamin)

In this quotation, the word 'should' implies that not only are regular physicals necessary for preventing disease, but screening procedures are also an important technology that requires regular access. This suggests that panel members view health technologies as part of their holistic access to health care.

Further, the obligation that some panel members felt towards representing those that likely need health care services, but do not have access, is also indicative of their views on health care as a social good:

"But we know that there are people out there who should be seeking medical advice and aren't going and maybe we're all very privileged that we have a family doctor that is looking out for our best health interests. So that's where I see the societal [values as] very, very important and that we have a huge contribution to make on behalf of those." (Nancy)

This statement not only emphasizes the panel’s understanding of health care as an important social good but also confirms health care as part of the Canadian citizen identity and accompanying social values. Being privileged suggests having the social capital of being connected to a family physician is something that not all Canadians possess, creating a power imbalance in terms of being able to access health care services. This quotation serves to establish this social capital within the group and to ensure that it is exercised positively in their discussions.

4.2.2 Core Social and Ethical Values

In addition to establishing health care as an important and valuable good, panel members also identified what they perceived to be the core values of the healthcare system:

“I’m just hearing some of the things that you’re saying as far as the option of consent, the choice piece, those are the three fundamental, core values of our healthcare system. It is: universal access, quality care, and choice of options.” (Paula)

These results are presented in detail elsewhere but, in brief, they describe the values of universal access, quality care and choice of options, which were expressed by panel members throughout the five meetings analyzed, regardless of the technology being assessed (Bombard et al., 2011).

4.2.3 The Fourth Core Concern

Although members of the panel were instructed to focus on societal and ethical values, they also believed that cost was an important factor to take into consideration. One member discussed this in the context of CRC screening and how statistics and cost information is helpful to further understand the topic:

“Again, I always believe in statistics and as a user you need to have statistics. I know we’re trying to get away from the information, that’s not part of what we’re trying to do. But I like, for instance, the part about, what is it, that CRC is the third [most common cancer]..., so that’s important because you want to know for one thing, cost is always in an issue, I know we’re getting away from that. But as a user you want to know.” (Kurt).

Here, Kurt employs the word ‘user’ in order to emphasize the significance of numerical information in the forms of statistics and cost. The patient or ‘user’ perspective seems to be employed in order to give more weight to his argument in the sense that if ‘users’ require this

type of information to make treatment decisions, then panel members should also have access to it when deliberating about health technologies.

Members often used the concept of weighing the costs versus the benefits to both support their arguments and work through assessing technologies:

“We talked about the *cost* of implementing [GEP testing] versus the people that we are losing to cancer in terms of the women that are dying of breast cancer... Yea. So we’re just doing a balancing there of you know the cost of implementing it versus the *value* of it to the families that are facing breast cancer. (Frank)

This quotation shows that the word ‘cost’ can mean monetary resources needed to implement a technology, like GEP testing, as well as social ‘cost’, where families are losing their loved ones to cancer. ‘Value’, in this case, means the social benefit to families who are using this technology to make better treatment decisions when diagnosed with breast cancer. There were other times when members interpreted the word ‘value’ as meaning the monetary cost of things. These dual situated meanings of the words ‘value’ and ‘cost’ led to confusion among panel members resulting in a need for more transparency and explicit definition of these concepts, which was sometimes accomplished by facilitators and other panel members.

Citizens also distinguished between individual and system-wide definitions of cost when talking about GEP, a technology that was not at the time covered by the provincial health insurance plan:

“I guess everyone’s definition of *expensive* would be different right and what is someone willing to pay for it for better quality of life right. So to me \$5000 is a pretty penny as a student but if I had income I think I’d be ready to pay that like right off the bat right. So in terms of expensive like what do we define that as?” (Keith)

In this example, the word ‘expensive’ is shown to have different meanings depending on the individual’s financial situation. This suggests that if one holds a certain amount of economic capital, they can have better access to technologies which are not covered by provincial health insurance thus giving the power to exercise that choice. The technology, in this case, is only being considered from an individual’s perspective, but when facilitators used the word, ‘expensive’, they were referring to the cost of the test as well as the infrastructure to implement it provincially. This shows how some citizens are concerned with individual availability of resources, while other members take into consideration the large scale distribution of resources.

Once this infrastructure cost issue was articulated, another member became very vocal in her concern about large scale impact to the health system and how this would determine access and quality of care. This concern over how a technology is implemented solidifies the theme of health care and health technologies as important social goods within the politics portion of Gee's framework and also indicates a discourse of careful consideration around how these social goods are financed and distributed.

The importance of cost as the fourth core value was confirmed by a member's one-on-one interview, where she stated that "the financial piece was missing from discussions" and that this was where she felt the panel could have been most useful. This indicated an inability of citizens to bracket cost from their deliberations, despite the research team's guidance to focus on societal and ethical values, which suggests a strong taxpayer identity that is integral to their roles within the panel. Another example of this is one member's assertion that physicians are "working because of us." This moral responsibility to take on the role of decision makers who deal with cost, as well as societal and ethical values, will further be explored in section 4.3 on identities and representativeness (Section 4.3.4.1).

4.2.4 Competing Values

Although members agreed on their top values and concerns, many of them believed some were more important than others, especially in the context of specific technologies. These values conflicts emerged between different panel members as seen in the following exchange where two individuals, who had both battled cancer, revealed the conflict between allowing patient choice and providing quality care:

Bernard: If the odds are heavily against you, I do not believe that we should be sending people to surgery.

Benjamin: And what decides what is heavily against, is 50/50?

Bernard: Less than 50/50 for you. A lot less, 50/50 yeah, I think you could take the chance.

Benjamin: Okay, I'm going to jump in then, because I just set you up. Because I had cancer, and if I didn't go into treatment, I would have died. I was given a 50/50% chance that if I had the aggressive treatment that they gave me of surviving or 50% of dying. They didn't know, I was on the fence and I said hammer me. And, I'm here 2 years later... They said, 'The only thing that we can tell you right now that will increase your odds are adding chemotherapy

to the radical radiation treatment that we're going to give you, which is only going to increase the percentage of success up by 2 to 3 percentage points.' I said, 'I'll take it.'

Bernard: I didn't take the chemo, I took the radical radiation.

Benjamin: I took it both, and then surgery.

This interaction illustrates that even though two citizens can have similar health-related experiences, they use them to articulate different values. Bernard was articulating the value of providing quality care in terms of foregoing surgery if an individual's chances of survival are low, whereas Benjamin was expressing the value of choice. This speaks to the competing values between health care professionals and patients, where physicians try to provide quality care to the individual as well as the community, and alternatively patients want to be given choice and access to all information and options.

Lastly, availability of resources also appeared to be in conflict with the social value of access as indicated when one member discussed breast cancer screening for younger women. Members were asked in what circumstances prevailing public attitudes should be accounted for and Keith, viewing things from the perspective of the government, stated:

"...there should be sort of like a threshold. So if there are enough resources available to consider public views or *prevailing public attitudes* then they should be considered because we have the resources available. But if we don't and like let's say the public is suggesting mammogram at the age of 30 but we don't have the resources that would be a circumstance where we can't take them into consideration. But if we do have the resources that's when we should open it up and say ok we are now going to take the public into consideration because we have the resources for it." (Keith)

Here, Keith's use of the term 'prevailing public attitudes' is taken from information given to the panel to aid them in grappling with how to consider vocal public beliefs when they conflict with scientific information. This member believes that the availability of resources is the deciding factor, which reinforces the importance of cost in the politics portion of Gee's framework.

These statements reveal that when members are not directly involved as users of the technology, it is easier for them to be pragmatic in their understanding of the finite resources associated in the healthcare system. However, on the other side of this spectrum, some panel members believe that there shouldn't be limitations on accessing technologies and that patients should have a choice regardless of cost. This is part of a broader theme of wanting the newest and most effective screening or treatment technology regardless of significant cost constraints,

and scientific evidence that suggests there are no benefits.

Overall, under the politics components of Gee’s framework, panel members emphasize health care as a social good by voicing their concerns about the availability of resources to fund technologies, universal access to treatments and screening procedures, quality care by physicians and choice of options. Members were concerned about the cost of procedures, considered resource use when stating their arguments and sometimes gave resource availability higher importance than social values such as increasing access to screening technologies. Societal and ethical values also sometimes conflicted with each other depending on the worldview of opposing panel members and the context of the discussion. Panel members articulate these values by enacting a variety of identities and in-group functional roles which were examined as part of the identities component of Gee’s framework.

4.3 Identities and In-Group Roles

Gee defines identities as being built by how individuals speak and act in different contexts. Thus, an individual can act out different and multiple identities depending on his or her environment and further, these identities can influence each other when one is being performed. Notably, Gee also describes how we are all capable of acting as an “everyday person” without expertise in certain contexts. This, of course, is dependent on one’s culture and language dialect and is what Gee calls our “life world identity” where the life world is the many contexts in which individuals act as everyday people (Gee, 2010, 106). This is especially important in this study’s context since panel members often identified as “laypersons” and “novices.”

Throughout the deliberative process, panel members make use of identities that have been established prior to participating in this study, roles that are established during panel meetings or a combination of both. Panel members also co-created a group identity by clarifying the goals of the panel and re-evaluating the scope of their representativeness at each meeting. These identities and roles were not always in agreement and conflicts occurred between and within panel members when it came to adopting their roles. Ultimately, individual identities and group roles were used to directly articulate their top three core values of universal access, quality care and choice of options as well as the concern of how resources are used and distributed.

Further, members indirectly communicated the importance of these four themes by asking questions and assigning meanings to societal and ethical values and resource concerns.

4.3.1 Previously Established Identities

Panel members bring identities constructed through past **health-related experiences**, their occupational knowledge and less prominently, their cultural background to help them tackle the novel topic of health technologies. Members also used their religious views, socio-economic class, age, residential area, family roles and citizenship status to construct their opinions and enact their in-group functional roles during their deliberations.

When panel members were asked to introduce themselves at the first panel meeting, most identified themselves in relation to their occupation and/or a significant health care experience. Members consisted of a university student, a retired veterinarian, a counsellor-consultant, an airline worker, a train conductor, a financial planner, a business manager, a retired vice principal and members who did not specify their occupational identities. Members often used their **occupational** identities and knowledge to grapple with the information they were provided. One member used his knowledge of economics to discuss breast cancer screening:

“...and I mean, I don’t know if there’s statistics for if there is a *demand* or what the *supply* is but that’s definitely something you should figure out. Because right now we want to stimulate demand so that we can or the governing body can work out how much supply is needed, how many doctors are needed, how many clinics are needed to do that because we can talk hypothetical situations all we want and that’s great to stimulate thoughts but I mean, we need to worry about creating demand, because to be honest before the last meeting, I never knew anything about this right.” (Keith)

The words ‘demand’ and ‘supply’ are economics terms used by Keith who studies these concepts in his **occupational** identity as a student. Those working in health-related services also exhibited their occupational identities and were especially instrumental in providing further information on specific medical terms and conditions:

“Anaesthesia is in effect the poisoning of the nerves that causes pain. It doesn’t do anybody any good at any time. And I have seen in practice, where anaesthesia has killed animals with a dose less than normal even. So *these people* are not even that good a subject for anaesthesia. And prolonged anaesthesia isn’t quite any better than the short-term.” (Bernard)

The phrase ‘these people’ refers to individuals with aortic stenosis who are in the later stages of their lives. Bernard’s **occupational** knowledge informs his opinion on the use of PAVR, a trial

technology, on this vulnerable population.

Since panel members were asked to discuss various health technologies, much of their discourse stemmed from how they or their friends and families have interacted with the healthcare system. Two panel members identified as being cancer survivors, several had helped an elderly family member navigate through the system, and three identified going to their physician for regular care (e.g. check up). One member articulated his **health-related experience** in his introduction to the group for he had missed the inaugural meeting of the panel:

“And I’m glad to be here today I was unfortunately just had a double surgery last time and couldn’t make it. That was all related to the cancer treatment.” (Benjamin)

Another member described her personal experience during a breast cancer scare and how quality of care and choice of options were both achieved by her family physician:

“I was just going to share my personal story, like 3 weeks ago I found a lump and I was just saying how, we were talking about how your health care provider can make such a huge difference. I saw him on a Tuesday, the following Monday I was in for my mammogram and ultrasound, I saw the surgeon the next day... Any way and I had the results by the end of that week from the mammogram but they don’t feel that it’s anything. I’m still having the tumour out. But so my point was just even the way the perceptions of the doctors has changed. I mean my doctor was on it. Now not everybody’s as lucky to have a physician who is on top of the situation but I think that they have changed their tune also.” (Marissa)

This sharing of very personal information suggests that Marissa may be trying to establish her own sense of social capital to relate to the cancer survivors in the panel, who have already instituted themselves as part of this sub-group. The attempt at conveying some authority on the topic of breast cancer is met with approval from both cancer survivors, who commend her for being vigilant and advocating for herself, further reaffirming her newly attained social capital.

Overall, health-related experiences and identities were used to relate to the technologies discussed by the panel and as a mechanism for articulating core values that were entrenched through these experiences.

Finally, two members shared their **religious and cultural backgrounds** openly with the group. However, neither of them based their opinions solely on these identities. One member specifically articulated this as follows:

“I’m a devout Roman Catholic myself, I’ll admit that, but I live with abortion in our communities, I live with euthanasia, I live with our legal system and its abolishment of

capital punishment - one day in Canada it was not illegal. So I'm *challenged* every day and we're all challenged every day with things in our healthcare system and our legal system, we're facing these religious, social and cultural convictions and challenges every day and I'm not sure that's a bad thing I don't think we'd be able to live our lives in the society we have if we weren't challenged... could be something that is maybe good for us to be challenged in, that's what brings us to discussions like this." (Frank)

This panel member uses the word 'challenged' to describe how his religious views are in opposition to how society currently functions, but he frames this as a positive thing that will not interfere with his contributions within the group. Frank is suggesting that he can keep his religious and cultural conviction in a personal realm and tolerate, in the context of this society-oriented panel, convictions that he may not agree with. Perhaps, the subtext here is a recommendation for the other members to consider setting aside personal values, since he is capable of doing so, despite being quite "challenged" with this task. This disclosure of religious values may have been prompted by the list of societal and ethical questions, adapted from Hoffman, which the panel was given to aid their discussions. The question in this case asked "Does the technology contest religious, social, or cultural convictions" and is used here to illustrate that this is an important component of considering societal and ethical values but not a consequential one. The previously established identities that members developed prior to joining the citizens' panel were invoked in the panel's deliberations as points of reference from which members made their contributions. The multiple occupational, health-related, cultural and other identities that panel members revealed during group discussions contributed to establishing in-group roles that functioned to shape the deliberative process.

4.3.2 In-group Functional Roles

During group deliberations, members also adopted functional roles unique to the study's context. In-group roles were identified during the initial coding phase where I used verbatim text from the meeting transcripts to assign codes that were grounded in the data. These codes were refined through the second phase where I used focused coding analysis and composed the resulting five in-group roles including: **challenging, providing information, summarizing, providing expertise, and interpreting**. After reviewing the one-on-one interview data, a sixth role, initially coded as 'encouraging' in the meeting transcripts, emerged. The importance given to this sixth role by panel members warranted its inclusion with the other five in-group roles and

was labelled using the panel's classification - **facilitating**.

Most panel members adopted the **challenging** role over the course of all five panel meetings. Members actively disagreed with each other and posed counter examples to each others' statements. When discussing whether to incorporate minority religious, social or cultural opinions in assessing health technologies, two members exhibited this role:

Larry: Well you may not like this. 'Does the technology test religious, social or cultural convictions?' I'm sure there's no yes or no answer to that but if yes you shouldn't we care? I think of the line from Spock 'the needs of the many far outweigh the needs of one.'

Paula: I'm going to disagree with you on that one.

Larry: Sure. (the panel laughs)

Paula: It's an example and it's maybe a historical example but it's about women's reproductive health and what's happened as far as the mainstream social perception was so anti women's health and women's choice that we ended up in a mess. Thirty years later thanks to Morgentaler and a lot of other people a lot of this has shifted, my biases are coming through very strongly... It's more about being mindful of the social structures that are in place that, looking at some of our conditioned responses that may have implications for the choice of the constituents. That's the best example I can come up with around that.

There is a difference in the type of examples these panel members used which may relate to the **occupational** identities they are using to articulate their points. Larry makes a popular culture reference to the Star Trek character Spock, whereas Paula makes a more academic, historical reference to the women's rights movement. These examples illustrate the different levels of cultural capital that are held by each member, where Paula likely has academic credentials through which she learned about her example, and Larry obtained his example from entertainment. This difference allows Paula to yield more power in this disagreement, which is reaffirmed by other members subsequently siding with her view and further critiquing Larry's statement. Moreover, Larry uses a direct quotation which employs a more authoritarian type of language as compared to his typically conversational vernacular. Conversely, Paula uses her usual vernacular which tends to be quite academic and really explains her example making her point arguably stronger.

More broadly, members also challenged the healthcare system, physicians, manufacturers and the maintenance of the core societal and ethical values that they held. When discussing PAVR one member expressed this scepticism by **challenging** the lack of information regarding

how individuals gain access to this technology:

“Is that the cardiologist’s great aunt that’s having that surgery... I have a great problem with, in these experimentations, whatever you want to call them, do we have readily available guinea pigs and do we have readily available experimenters? I know that that’s ultimately what we have to go through in order for medical advancement.” (Nancy)

Here, Nancy is challenging the information she is being given to understand PAVR and trying to get more in-depth details regarding the process of using this technology, as opposed to just taking the provided material as fact. Similarly, Larry adopted the role of **challenging** another member, who stated that the Canadian healthcare system operates under the principle of universality. He used the example of the H1N1 vaccine and how it was distributed to the public:

“I think all throughout history and it’s not going to stop now it’s always the affluent and educated who are getting or not, who are getting the greater consideration its always the uneducated and the poor who are not getting the greater consideration and that cuts across all things in society. A perfect example of that right now is the uneducated masses are not up in arms about this H1N1, the Toronto Maple Leafs and the Calgary Flames get their shots before all other groups because they are of greater consideration, because they are rich and powerful, they’re educated and they’re big.” (Larry)

Both of these quotations illustrate how the **challenging** role is used by panel members to disagree with one another and to establish cultural capital in the eyes of other group members, in the way of being informed about current events and aware of the issues within the health care system.

Finally, Larry’s one-on-one interview confirmed that he purposely acted as a sceptic devil’s advocate, by using sarcasm in his articulation, in order to “get to the underlying story”. Although this was sometimes ineffective, it did produce healthy disagreement between members, as shown between him and Paula, which allowed them to further flesh out their ideas. Another member also stated that **challenging** other members was the “only way to get good answers” in his one-on-one interview, while a third member stated that his awareness of others’ emotions led him to refrain from adopting this role.

All panel members adopted the **providing information** role. They used their personal and often health-related experiences, information obtained on the Internet, and newspapers to discuss health technologies. One member discussed the polarization of how technologies are portrayed on the Internet:

“So what I feel is, because when I was trying to find out because about PAVR I went on Google because that’s the best place I can get information, there’s like completely negative or completely positive. There is not something which actually says it is good. Some say it’s absolutely bad some say it’s absolutely good.” (Jagad)

Jagad openly shares how he sought out additional information, but had difficulty using it to take a clear stance on the technology. Perhaps this perceived need to acquire more information is indicative of seeking out more cultural capital from which to base his contributions. Further, as seen in previous statements, some members actively read and keep up with the news creating common dialogue around collective knowledge such as the H1N1 crisis which serves as another source of information.

About half of the panel members adopted the third role of **summarizing** previous meetings to absent members and serving as representatives for their small group discussions. In the following example, a panel member summarizes the large group discussion on PAVR that occurred at the previous meeting:

“Yea and looking at PAVR specifically I recall, [we were referring to] an elderly population over the age of 75 that this technology was going to be offered to and we weren’t privy of course as to how that selection process would take place. So that had significant, we come in with our filters around age and costly procedures and also that this was a testing process. So we’ve got a number of factors coming into play. (Paula)

Paula often serves to summarize previous meetings by providing the context for the technology as the reasons for why certain values were of more importance to the group. She was also called upon often by her small group to act as a representative to summarize the discussion, suggesting that other members find her summaries useful and accurate, further institutionalizing this role. When reporting back to the large group one member would often incorporate his opinions into the final group summary:

“So a lot of interesting topics came up in our group which made it nice and lively and interesting. So I tried to capture a summary of all those things. We talked about...Not so much doctor training on that level but the pathology training in the laboratory. Like I said the physical infrastructure of just getting the laboratory set up. Again that just being a separate topic that would need to be addressed.” (Frank)

This member would often stay fairly quiet during small group discussions and then use his **summarizing** role as an opportunity to insert his views into the deliberative process. This member’s summaries were so detailed and complete that one member exclaimed “I don’t think I

am going to have to present anything after this,” and another said “He's covered it all off.” These types of statements are further indication of the utility of the **summarizing** role.

Although members were chosen to represent a lay perspective, two members took the role of **providing health-related expertise** to further group discussions and to inform, and expand the perspectives of the group as a whole. This was already illustrated in the challenging role where Paula referenced Morgentaler, an activist for women's reproductive health care options. As mentioned, this member often uses a more academically inclined vernacular, which is indicative of her expertise. The other member with a health-related profession takes a slightly different approach to his **providing expertise** role where he helps panel members understand health technologies and diseases by defining and describing them. When discussing breast cancer screening and diagnostic options this member outlined them as follows:

“First an x-ray, x-rays’ are relatively cheap. We have lots of people can do them and quite a few people that can read them. Of course we have the people reading them that can't but that's, we can't get into that. Then next thing you go for a CAT scan. CAT scans show certain things well, certain things they don't. So before you go for the CAT scan let's find out if what we suspect actually a CAT scan could find. or it can't? Ok well then we're going to have to have an MRI, it's the newest thing or practically so. It may not show what this is either and to follow up with what [Benjamin] said we may have to go to a, I was going to say autopsy, biopsy. An autopsy usually shows that the doctor was right.” (Bernard)

Interestingly, Bernard identified as an **information provider** in his one-on-one interview and gave similar examples of how he provided this type of **expert** information. He believed that the topic area was “up his alley” suggesting that he is aware of the expertise he holds, but perhaps does not want to identify in this way since the group as a whole preferred to identify as laypeople (See Section 4.2.4.1 Representativeness). Nevertheless, other members often commented that this type of information was useful to the group stating “that was helpful” after Bernard's remarks, and encouraging him to share his small group insights during large group discussions. This also reveals that the roles of providing information and providing expertise are not mutually exclusive and one member can take on multiple roles as was seen when Paula acted as a challenger and expert.

The fifth role, adopted by all panel members, is that of **interpreting**. Most members would ask questions to help clarify new material on health technologies and some, particularly,

used examples to work through ethical and societal concepts. In the following example, a member interprets the value of having options and information in order to make informed choices, by comparing it to choosing to drive a vehicle:

“The thing is everybody knows driving can cause accidents, the choice is still yours but if you’re not aware that there’s an option to drive you will never drive, let’s put it that way. So the whole idea about giving that information is ‘this is what you can do so that we can help you prevent this thing’. Now if you don’t want to do it it’s your choice. That choice is not taken away that choice still remains with you.” (Jagad)

Members also used extreme examples such as needing to amputate or the decision to not be resuscitated, to work through concepts of end of life care and choice, and milder examples such as the flu to discuss access. Members often interpreted numbers to give them a sense of the percentage of the total population that technologies were applicable to:

Facilitator: 30% of people who have aortic stenosis are not getting the open heart [surgery] heart valve, would be the people who would be eligible for this procedure.

Jagad: It’s actually 1.6

Facilitator: It’s 30% of 4.6

Jagad: Yes, so it’s pretty much around 1.6% of that 75+, so it’s not a very big number considering the whole population.

This role shows a willingness to learn by panel members not simply in a didactic format but in a more interactive and involved way. This was facilitated by the workbook that they were provided with prior to each meeting.

When asked “What types of roles did you feel you played in group discussions?” during their one-on-one interviews at the end of the study, members revealed a sixth role - that of **facilitating** - which confirmed a similar interpretation that emerged from the initial code analysis where the role of ‘encouraging’ was detected. Members in this role would serve to systematically answer questions posed by the research team, redirecting the conversation away from some of the tangents and broader healthcare issues that other group members had begun exploring. Members also facilitated discussion by encouraging others to speak and being conscious around “over-imposing.” Less than half of the panel exhibited this role in the transcripts and most of those who were facilitating were also adopting the summarizing role, suggesting that the two are related in their aim to keep the group on task and advance the process of deliberation.

Nevertheless, two members felt that some were “perhaps monopolizing time and answers,” and

while some indicated that small group discussions allowed them to “hold the floor longer,” they still felt that members of the research team were necessary in these groups to provide guidance and prevent off-topic discussions.

These six in-group functional roles were, for the most part, consistently held by individual members with some renegotiation and new role adoption occurring in later meetings. During the third meeting, one member attempted to provide the opportunity for adopting the role of **summarizing** to others:

Larry: Paula’s our summer [summarizer].
Paula: No way! I’ve done it every time it’s somebody else’s turn.
Benjamin: You’ve got the paper, you’ve got the pad.
Paula: It’s someone else’s turn. You’re summing the next one then.

This unsuccessful attempt at getting out of summarizing suggests that once in-group functional roles are established, it was difficult to renegotiate them because of the expectations of other group members. The role of summarizing was likely the most intensive because it required the member to listen, take notes and provide a representative summary. Thankfully, Frank, who first adopted the role of summarizing for the other small group at the third meeting, was in a group with Paula at the fourth meeting and this renegotiation was achieved. This new role for Frank may have been adopted out of need, or perhaps a growing comfort between himself and the rest of the panel members. Moreover, this exchange indicates that some roles have more cachet and are more enjoyable than others, because of the level of effort they entail. For example, challenging another member based on personal opinion is a lot less difficult than constructing a well formulated summary of a small group’s lengthy discussion.

Lastly, there is some convergence between the identities citizens brought to their deliberations and the roles they adopted during the group process. For example, citizens who served in providing expertise on certain topics often had occupational knowledge in that area. Those who were providing information and challenging often spoke from both personal health-related experiences as well as occupational knowledge. Overall, previously established identities and health-related experiences served as hooks upon which members hung their deliberations and tried to relate to the task. These identities and experiences worked to shape in-group functional roles, which were sometimes negotiated and generally confirmed by the one-on-one

interview responses. As mentioned, members also took on multiple roles depending on the technology and their comfort level with the group, with roles of providing and interpreting information being more prominent than facilitating and providing expertise. In the later meetings, members tended to adopt more roles and were more confident in enacting them.

4.3.3 Competing Identities and Roles

Throughout the panel deliberations, members exhibited competing identities and roles not only in the form of discussions and opposing opinions between each other but also within their individual roles. In Section 4.3.2, we described the former situation where members were challenging each other, using different types of information to support their arguments. Where Paula used a historical example and reframed the issue as being aware of “mainstream cultural convictions”, Larry did this in a much more abrupt way by qualifying his statement with “you may not like this” and dismissing the minority perspective by referencing a movie. These differences result in different alliances between members. For example, another member used his **occupational** identity to voice another reason for disagreeing with Larry’s statement:

“Just to address Larry’s point about Spock saying you know [how the needs of the many outweigh the needs of the one]; what is the many? Like in Canada the trends are showing that there’s an increase in immigration and there’s an increase of new people coming into the country so when you say whatever you were saying was what is the many? There isn’t like a predominant, oh there might be a predominant society or religion or whatever it is but I feel like there isn’t. We’re all going to be mixed in.” (Keith)

This statement illustrates how different worldviews result in different functional roles that compete with each other during the deliberative process. Further, both Paula and Keith exhibited their cultural capital by presenting historical and factual counterexamples which introduced more powerful arguments to the discourse.

Another member contested the capacity of the **providing information** role and believed that extensive information seeking behaviour was beyond the scope of her role:

“I think that’s the crux of the matter is, I think all of us are maybe too preoccupied about pre prep and homework or whatever. It seems to be more that people come in here and think, ‘Oh my God, I’ve got this big responsibility’, instead of what we’re really mandated to do is to come without experience and our thoughts and we’re given permission to give them. I think it’s not appropriate to do too much pre prep and be inquiring of our friends and family really. You can have their experiences, you can

mention it, but I think that that can colour your response in here, and I don't think that that's really what we were asked to do. I think it should be solely of our own experience.”
(Nancy)

This quotation illustrates that while some members may like to seek out multiple sources of information, others believe that using their experiences, and the information provided to them by the research team, is what they are asked to do in order to formulate their contributions. The contrast in how this role is perceived by panel members indicates that, although individuals may adopt the same role, the way they enact it may differ.

One member, who discussed the conflict between his religious identity and his husband/father identity, verbalized the latter dynamic of within individual member identity competition. This occurred when he had to make a difficult decision:

“According to our religion, I'm somebody from a Hindu ethnic culture right, according to our religion C section is not actually something [that is allowed], the only reason is what they say when the baby is born they have to go through the pain because they will be actually purified. I don't know why they think that. But my daughter was born with a C section and at that time when my, when the doctor told me that she's not going to come out in the normal procedure and [we] are actually risking the mother's life for the kid's life suddenly my religious belief went out [the window]. It was thrown out. I didn't even think about it. I said let's put her in, cut her open and take it out; simple as that. So what I'm trying to say is that was a choice that I made. I could have said that no, no it's against my religion I'm not going to do that but it's a choice that I made.” (Jagad)

This member's struggle to balance his religious identity with his responsibility to care for his wife and child divulges the sometime contradictory nature of identity. Depending on the circumstance, an individual may act differently and view the situation from a different set of values making these perspectives difficult to capture.

In general, panel members are used to adopting different and multiple identities in the many contexts they encounter in their lives, as outlined by the identities component of Gee's framework. Thus, it is not surprising that, during their deliberations, members used these previously established identities to inform their in-group functional roles. Moreover, these roles sometimes conflicted not only between how members enacted them but also within members. These diverse identities and roles are used in conjunction in the creation of a collective group identity over the course of the study.

4.3.4 Establishing Group Identity

Many members placed a great deal of meaning in the act of being asked to participate, which shaped their yearning to make a difference and signified their role as important. Motivations behind attending the panel ranged from interest and excitement, to being frustrated with certain issues in the healthcare system. Overall, members felt privileged to be part of the group and considered it an enriching and exciting experience. When discussing their group identity and purpose, members were initially unclear on the group's objectives and the degree of their responsibilities to their respective Local Health Integration Network (LHIN), their representativeness as well as the level of impact their deliberations were going to have on OHTAC and society as a whole. This confusion is introduced in the following example where a member tried to describe the panel's role:

“It's interesting because you know as we talk about this I think, the whole purpose of this is to make technologies easily available to people without the intervention of a doctor. That's really what our goal is, to find out here isn't it? To know that there are things that we don't always have to go to a doctor to administer.” (Nancy)

The phrase “that's really what our goal is, to find out here isn't it?” clearly demonstrates a lack of clear understanding of the panel's objectives which were to provide societal and ethical value perspectives, as opposed to act as informants to make technology more available. Perhaps the excitement and ambition towards the task, combined with the particular worldviews of each panel member, led them to view their objectives in a different way. For example, Nancy is from a small town and is likely interested in technologies that bypass the physician due to a lack of physicians in her community. Moreover, the use of the word ‘we’ in the quotation above refers to patients and consumers of healthcare, whereas in previous statements it has referred to government, the panel or citizens. This speaks further to the panel's shifting group identity.

Other misconceptions about their task included wondering if they should consult their communities on the topics to be discussed at each meeting, and asking how they can increase awareness around technologies and provide information to the broader public. The research team tried to reduce confusion by stating and re-stating the panel's overall purpose and the explicit objectives of each meeting. Further, a senior member of Medical Advisory Secretariat explained the panel's role at the first meeting and two other OHTAC members were present at the fourth meeting serving as a much needed reminder of what the panel is being asked to do. After this

reassuring interaction, one member stated, “I think now we know who we are and where we’re going.”

4.3. 4.1 Representativeness

Throughout their deliberations, citizens wrestled with the idea of who they represent on the panel. Opinions ranged from a pervasive theme of acting as laypersons or “Joe Citizen” to the ambitious proposition that members should solicit opinions from their communities so that they can bring a more representative view. This dimension of representativeness was overlaid with a sense of responsibility to their communities, and especially vulnerable populations (e.g. lower socioeconomic class, rural communities, and senior citizens) and the diversity of the Canadian population.

Ultimately, the group did not want to be identified as representing the full diversity of their geographic region but to be seen as an anonymous “Subcategory of OHTAC”. Along with this, members identified themselves as “lay people,” a “novice group” and “not experts” consistently throughout the five meetings. One member said he found it “mind boggling” to try to incorporate cost, scientific information and societal and ethical values, yet some wanted these multiple sources of information. This suggests that members, in a way, viewed themselves as decision makers as well, albeit novice ones, making information of utmost importance to some of them. Members, thus, came to terms with allowing themselves to believe that their perspectives are unique and valuable because of their intuitive nature. One member stated:

“I decided that my input is important and I’m willing to share it so yes, I think that verifies that what we’re doing here has significance” (Nancy)

When members discussed who they were representing on the panel, concerns were raised that the group was not truly reflective of all segments of society. More specifically the perception that the group was of a particular socio-economic class emerged as a concern:

“One of the things I’m concerned about is that I look around here and I think, ‘Are we ever examples of middle class society sitting here’ and I know that we were picked at random but still. So I feel like I’m imposing my values, my background, my education, my work, and who is speaking for those people who aren’t as well off as us in many ways.” (Nancy)

This concern stems from a sense of responsibility to represent those who are not present at the

panel meetings. Members often discussed “orphan patients” and individuals “living under a rock” as segments of the population that are difficult to reach when implementing technologies. The comment is also another way of saying “we are just your average citizen” which supports the lay people discourse that permeates throughout the panel’s deliberations. In terms of capital, this member perceives the group as having more economic, cultural and social capital than those seen as “living under a rock” which is indicated by her reference to the middle class, her education and her connections with two particular social groups formed around her background and work. In this case, this difference in capital is not used to yield power against those with less capital, but as a call to arms to use this perceived power to represent them.

Further, because of how the panel was created (randomly selecting individuals from each LHIN in Ontario), some members explored the idea of going out and talking to friends and family to get support for their views on a particular technology in order to be more representative of the different views in their area:

“maybe I can talk to a couple of my friends, people who are in my society, and bring that topic up and maybe get 10 people behind me to bring that idea over here.” (Jagad)

This notion was beyond the scope of the panel’s purpose but illustrates a moral sense of duty to “represent” more than themselves. They talked about “strength in numbers” and often hinged onto expert and facilitator opinions. For example one member would often state “Yes, exactly, that’s exactly what I was trying to say,” after the facilitator would talk and, as already mentioned, another became very concerned about the infrastructure costs of GEP testing once this was uttered by two of the facilitators. Further, members wanted input from an expert ethicist to increase the credibility and possibly the impact of their discussions. This relates to not being sure that they have the adequate social and cultural capital to effectively cover all the societal and ethical value concerns around technologies. Using expertise could be a way in which they are trying to legitimize their discussions and increase the group’s cultural capital via the expert’s credentials and the group’s social capital via the expert’s likely stronger or more valued connections to decision makers.

Finally, panel member deliberations around representation were reinforced by one-on-one interview results where members primarily identified themselves as representing the perspectives of Ontario citizens, secondly as individuals in a particular age, social position and socio-

economic bracket and thirdly as residents of a particular region in Ontario. One member felt the first two perspectives were what the panel was explicitly asked to do. Few members identified their roles as representing the perspectives of a patient or client of the health system, or an Ontario taxpayer. This notion of representing a taxpayer tries to re-establish some of the economic capital that citizens hold as contributors to the healthcare system. Other groups that members felt they represented included rural communities, women, baby boomers, senior citizens, and health professionals, which were consistent with their deliberations.

4.3.5 Three Approaches to Articulating Values

There are three main ways in which panel members articulate their values of universal access, choice, and quality care, and the concern of proper resource allocation. The first, and most direct way, is through employing the aforementioned **previously established identities** and/or **in-group roles** as well as their **group identity**. The second and third approaches are indirect where members either **ask a question** leading to the articulation of a value, or **assign meaning** to information they are presented with.

During the course of the panels' deliberations two members on the panel identified as cancer survivors but only one of them used this **health-related experience** to articulate the value of choice:

"I used my example because they couldn't tell me how I got throat cancer when I didn't smoke and I didn't drink. So it was like well if you could give me a little bit of *hope*, if you could give 1 or 2 percentage points of hope that chemo is going to add to my success then I wanted that hope." (Benjamin)

Here, we can see that the value of choice is closely related to patients' need for 'hope', when getting treatment, and information, in order to be able to make a decision.

One example of a member using his **in-group functional role** of **providing expertise** to articulate the values of providing choice and quality care was articulated as follows:

"Well, it's not going against his Hippocratic oath I'll say, if he doesn't tell you that this might be available but you're not eligible, that's where we got into it here. If you're not eligible for it, he's not bound to tell you or to send you on to somebody else to prove you can't do it. That's what the doctor does, he evaluates as well, so I don't think that's a big issue." (Bernard)

Here, the member explained the Hippocratic Oath and what it means for choice and access to

particular options for citizens. Bernard relates the idea of choice to the physician's consideration of system costs when offering technologies to patients, by using his expert knowledge in this area.

The following example shows the use of both a previously established **occupational** identity in a health-related field as well as the in-group functional role of **summarizing** to express the values of choice and quality care. The individual was summarizing the discussion about CRC screening from a previous meeting, after a member had asked what had transpired:

“the public really wasn't receiving sufficient amount of information that would help them to be able to decide the type of procedure that they would like to engage in. So it was more about if people had information could they decline, because there's this huge push from a medical educational perspective to engage in a screening process that really isn't very successful. And so if people had information, what dynamic was that going to setup with their primary caregiver who of course is the gatekeeper to all of the other technology.” (Paula)

You can see how this panel member uses academic language words such as “gatekeeper” and “primary caregiver” as opposed to “doctor,” the term used by the rest of the panel members. This choice of words reveals her occupational knowledge of being employed in a health-related field.

Finally, some members used collective identities to articulate their values ranging from the panel's **group identity** to a more broad societal identity. In the following example, one member expresses his primary concern surrounding resource use and his secondary value of patient choice:

“I think for such a statistics run society nowadays and it's so easy to gather that information and we all run a household on a budget. ...So, I mean why don't we just use those statistics and they'll all have dollar values associated with them. So I mean if there's four common cancers that can be picked up in a very, very early stage by some technology, then lets [give] those to our patients, or from the doctors to patients, and the risks involved with each one of those, and it's always up to the patients who say yay or nay.” (Benjamin)

Although Benjamin uses the term “we” to depict his view of running households and the healthcare system on a budget as one that is shared amongst the group, this is really a way of including his own worldview as one of the collective group. As seen, there are multiple ways in which identities and roles can be used to articulate the societal and ethical values of citizens.

Panel members also indirectly articulated their three core values and their concern for resource use by **asking questions** that addressed these four concepts with regards to specific

technologies. One member questioned the outcome of a previous meeting, where members explicitly discussed not wanting to experience animosity with their physician if they refused to participate in a particular screening program:

“I know, I just wondered if somebody had had a bad experience and that’s why it was brought out because I was always under the impression that is it was your choice, I mean you reach a certain age or you have a family history, and you make your doctors aware of that, and then they would either suggest a colonoscopy, or the levels, you would start with FOBT and then depending on what that proves, then colonoscopy might be the next step.” (Benjamin)

This example obviates this member’s use of his question as a vehicle to bring forth his opinion on CRC screening and the importance of choice as an ethical value.

When interacting with members of OHTAC, one member wanted to know which technology had had the most impact and she went on to explain why by articulating her strong beliefs towards the value of equal access:

“The reason I ask is cause I’m a resident of small town Ontario near a resort area which many, many people are gravitating towards to retire, the technologies that interest me are ones that are going to preserve those people age 60+ who’ve left the you know the comfort of their good family doctor etcetera in the city and they’ve come up there and you know what might they gain in the next 20 years for survivability and how readily available are those to the proximity where they’re living?” (Nancy)

Again the use of the question is doing more than simply seeking out an answer but is also serving as a conversation starter around this panel member’s underlying concerns. Nancy here is not just saying but doing something that creates a line of questioning, where the real question she is interested is embedded in her original enquiry.

Generally, questions not only allowed panel members to get a better understanding of the technologies they were discussing, but were also used as tools for explaining their views and initiating conversations around their value concerns. Making enquiries was an indirect way in which members expressed their ideas, suggesting that members were not always confident in simply providing their views outright. Perhaps questions served as a comfortable mediator between members and openly voicing their perspectives.

Finally, the third approach in which members articulated their values was through **assigning meaning** to information they were provided with as well as questions they were asked. When given a framework of specific societal and ethical value questions to guide their

discussions, there was a lack of specific questions addressing the issue of cost and resource allocation. This led to members **assigning meanings** to these questions, which were different from those that were intended, in order to incorporate their concerns surrounding resources:

“We started out at number 1 for ethical questions. ‘What are the morally relevant consequences of the implementation of the technology?’ We wondered, is this where the dollars come into play? We didn’t see one where the dollars came into play anywhere, so *we made this one our dollar one*. Is this where they come into play and is this based on any age or health condition or ability to earn or possible problems coming to light down the road?” (Benjamin)

This quotation shows how a very ethically oriented question surrounding morals and consequences was re-interpreted to represent resource allocation issues, in order to address the absence of this concern in the framework. This relates back to the results indicating the emphasis of cost that the panel included in their deliberations.

Further, when asked to define patient autonomy, members **assigned the meaning** of choice to this core value during the fourth meeting. One member stated:

“Well I found it’s just basically the choice and finding the information like we’re talking about. The pamphlet, having the information out there to make a choice whether or not you want to proceed or not proceed with it. I thought it was straight forward. (Kurt)

Unlike the above quotation, this member provides a much clearer response and definition of this value. The meaning of patient autonomy is compatible with the concept of choice and the articulation of this is “straightforward” to this panel member.

In general, Gee’s identities building task has shown how panel members used a variety of previously established identities, individual and collective in-group functional roles as well as asking questions and assigning meaning, in order to directly and indirectly articulate their top concerns respectively. Panel members feel privileged to have the opportunity to provide their opinions, and establish a sense of worthiness and responsibility in their roles, but still wish to enhance their cultural and social capital by including experts in the process. Members felt a sense of responsibility to represent vulnerable segments of the population, but ultimately represented Ontario citizens and individuals in a particular age, social position and socio-economic bracket, as indicated in their one-on-one interviews. Through the enactment of these multiple identities and roles, members employed certain ways of speaking, using different vernaculars to create a variety of relationships with each other and those not present, such as OHTAC, physicians,

manufactures and decision makers. These relationships constitute the final component of Gee's framework that will be examined in this analysis.

4.4 Types of Relationships

Gee's relationship building task involves the use of language in order to create, sustain and break down relationships. This task is closely related to identities since individuals often define their identity, in part, by how they perceive their relationships with other individuals, groups, and institutions. Further, the individual's perception of the identities that others hold shapes how he or she will relate to other individuals (Gee, 2010). In this study, panel members generally regarded each other, as well as the process of making recommendations, as a positive experience, where friendly and respectful working relationships were being fostered. However, when discussing outside interest groups such as physicians, manufacturers and sometimes OHTAC itself, members were sceptical of the motives and intentions of these parties. Nevertheless, in discussing those who are less privileged, members invoked a more advocacy oriented position, where they felt a responsibility to speak for the under-served population.

4.4.1 Within-group Relationships

Throughout the course of the study, members became increasingly comfortable with each other. In the second meeting, where members were still getting to know one another, the group climate was easy going and members were polite and amicable. When a new member introduced himself after not having attended the inaugural meeting, another member said:

“We are glad you are here too [Benjamin].” (Nancy)

One other member acknowledged the friendly atmosphere the group had created at the second meeting saying “Again I've seen how personable everybody is” (Kurt) suggesting that members perceive each other to be open and sociable at this stage in the group's process. At the fourth meeting, after interacting with OHTAC representatives, panel members expressed the increased level of comfort that they felt with each other:

“Well I think the comfort zone now amongst the members here, I don't think I'm speaking for myself, is huge compared to certainly when we started.” (Benjamin)

This heightened level of comfort was likely brought on by the clarification of the panel's role

and how this is being perceived by OHTAC, along with the growing familiarity that comes with deliberating for four meetings. In the aforementioned quotations, the word ‘we’ clearly denotes the panel, which is not always the case as seen in previous sections.

Further members treated each other with respect indicated by using each other’s language, acknowledging expertise, allowing select members to represent smaller groups, letting members represent themselves and actively listening. Members also openly agreed with each other and had healthy disagreements during some of their deliberations.

One example of using each other’s language came about when one group shared their small group discussion. Members were deliberating the societal and ethical questions provided and after the first group stated “if [a technology] *survived the list*, then it was pretty good”, the second group’s representative reiterated this statement:

“As a group, we went through pretty much all the questions, and it’s as mentioned very comprehensive list and definitely if you survive through this list, it’s definitely good to go.” (Jagad)

Members acknowledged the information asymmetry between them and respected each other’s perspectives regardless of this difference as shown here:

“ I completely respect what you’re saying, because you have been in that profession and you do know more about it than us, but talking about a layman’s perspective and as a social or ethical value, whatever you want to put it as, if somebody tells me that in 2-5 years, you’re going to die. If you try this, chances are you might survive, but the chances are 50/50 which you were talking about. I would jump into it. I understand the medical field you are from, you would say, no, that doesn’t make sense, but if I’m talking personally as a person who doesn’t know much about the medical part it I just want to live and I don’t want to die, I would take that chance.” (Jagad)

We can see that although members respect expertise that is applicable to the context of discussing health technologies, they still feel that a layperson’s perspective is just as valuable. Here the cultural capital held by those with expertise is met with the establishing of the layperson perspective as a type of cultural capital in and of itself, creating a balance in the power dynamics.

When asked who their spokesperson was for their small group discussion, one member regularly appointed Paula, a member that often summarizes previous meetings and has occupational knowledge in the field of health. When a different member without such expertise served the role of summarizing discussion, he often referred to other members, including Paula, allowing them to represent themselves. More generally, members actively listened to each

other's comments and elaborated on them. One example of this is when Kurt expands on Paula and Nancy's comments on PAVR:

“I think again, like [Paula] pointed out, the ethical question, like [Nancy] said as well, is who are they selecting. The criteria, you never know, is it somebody's cousin, so how are they selecting these people, how many people are in this situation where they can't have the open heart surgery but can get the PAVR. This is obviously new so they only have a certain amount of people they can operate or do this procedure. So how did they do their selection, who do they pick or choose for this?” (Kurt)

This comment reiterates previous statements and shows that Kurt is paying attention to what Paula and Nancy are saying, suggesting that he is not only actively listening, but also respects their opinions. This type of connection building increases the social capital of this member as he legitimizes the concerns of others and creates alliances.

Members often openly display agreement by directly making affirmative statements after other members articulate their opinions. This is often demonstrated by saying, “I think that's a good idea”, “I think that's an excellent point” and “I agree 100% on that.” Sometimes, members will even ask each other to elaborate on statements previously made in small group so that the group as a whole can be aware of them:

“Good, this was brilliant, it really was brilliant, [Bernard] do share, because I think it's so insightful as to how decisions are made.” (Paula)

Nevertheless, members do sometimes disagree with each other. Again, members do this overtly by saying things such as “I'm going to disagree with you on that one” or more indirectly by providing an alternative opinion. This latter type of respectful opposition was seen in the last statement by Jagad and is typical of the healthy disagreement that occurred between members, which served to provide multiple perspectives on an issue. In fact, the panel enjoyed being challenged and asked that facilitators from the research team be present in the small groups, as well the large group in order to achieve this.

Finally, during the end of each meeting members often reflected on the difficulty of grappling with different topics in health technology, and how they believed the group was working hard to provide their views. One member vocalized this as follows:

“It's such a huge subject to tackle in just a few hours so I think we did really good at least to bring some things to surface and stimulating each other's ways of thinking. So we could spend a week on this you know 8 hours a day and still be hammering out things. So I think we made a really good effort on at least tackling a few things that we could in a

short time.” (Kurt)

This member recognizes that given the limited time and the novelty of the topics, the CRPHT is doing an admirable job at addressing the questions they were posed.

4.4.2 Outside Group Relationships

Members of the panel often expressed scepticism towards groups of individuals not present in their deliberations including physicians, manufacturers and even OHTAC. This scepticism sometimes related to the perception that manufacturers and physicians are more concerned with finances than societal and ethical values or the needs of patients. The following quotation illustrates the scepticisms toward manufacturers:

“Producers of the technology; what are their mandates? Is there genuine interest on a societal level or are they just trying to make a buck?” (Bob)

Similarly, members wondered if the creation of some technologies by manufacturers was “just a money making thing”, and believed that restricted access based on age for example was “all about the dollar.”

Another source of mistrust was toward physicians. When discussing PAVR, a technology only available if a patient enters a clinical trial, members were concerned about the motives for having this technology made available:

“And they have some top cardiologists there or they want to make a name for themselves, then are they going to receive money in the form of these valves to the hospital to be used in these instances?” (Nancy)

Likewise, another member felt that the short time given with his physician was possibly indicative of prioritizing income over the patient’s concerns:

“...one problem with the doctor you want to go in there and you want to have a person to person and it seems, and he’s the same like he’ll bang, slap, slap, boom you know and it’s almost like what is it a money kind of thing? You want to go see your next patient or whatever?” (Kurt)

In all of these examples, members indicated that the perceived motivation of economic capital among physicians and manufacturers is what led to their scepticism. The acquisition of this type of capital is more overt than the acquisition of cultural and social capital, which is why individuals are challenged based on their perspectives on economic capital more often. One member referred to the e-health scandal and H1N1 vaccine queue jumping as another reason for

his mistrust, not only towards physicians, but also towards the entire scientific and medical community:

“All organizations. Yea in this particular case the scientific community and the medical, the Ministry of Health, of course we don’t trust them. Somebody just walked off with a billion dollars so how can anybody trust what they’re talking about. How can they be trusted after they inoculate you know the Toronto Raptors when they haven’t got a chance of winning any way.” (Larry)

Here the misuse of economic capital is converted to lack of social capital between the public and the Ministry of Health. The decreased strength of this network poses issues for the government, especially in the realm of implementing e-health in the future. The ‘we’ in this case is referring to the broader Canadian citizenship that has grown mistrustful towards the government, in the views of this member.

Members were also very concerned about seeking a second opinion and how this would affect their relationship with their physician. Here members expressed a feeling of intimidation towards their physicians because of their expertise or cultural capital (1) and a fear of losing them if they were to ask for a second opinion (2):

(1) “...I think there’s still a lot of intimidation [from] patients no matter how long you’ve had a relationship with a doctor, family doctor, that they [the physician] know what’s best, and so when people are confronted with something like [deciding on a treatment], they’re [the patient] maybe or maybe not given information to read up before they have their next appointment. I definitely think that there’s still a hesitancy to say ‘I don’t want to have that’” (Nancy)

(2) “It’s just that whole idea of well, I’m lucky I have a doctor. What if it happens and this gentleman who has spent so much of time, acquiring all these degrees and all this education, takes it personally when I say, ‘I don’t think it’s right for me.’ And then you are stuck in another situation, where you are in a doubt that, maybe I have a cancer, and here now, because I opened my big mouth, I’m losing this doctor.” (Jagad)

These examples show the uncertainty around communicating with physicians about getting more information from them or other physicians, and the fear of denying treatment suggestions. This stems from some individuals’ lack of social capital when it comes to having access to primary physicians as well as lack of cultural capital with regards to knowing their best treatment option.

Despite evidence of scepticism towards these groups and fear specifically towards physicians, those with health-related occupational knowledge often defended physicians during these discussions. One member expressed this when discussing patients’ reliance on the Internet

to obtain health information and their need for access to the most advanced technologies:

“But it’s something that we have got in the habit of doing and we’re not going direct and we’re sort of stepping over our medical doctor to a degree and demanding things that we really don’t know about.”(Bernard)

This member clearly points out the differences in cultural capital between physicians and their patients and that this should result in respect as opposed to fear and scepticism. Further, when discussing GEP testing, one member challenged the group by questioning their expectations toward primary physicians:

“we’re losing confidence in the credibility of people who really aren’t suppose to be the carriers of this information because they’re not the specialist. Why would my family doctor know about something that shows up in the media that some journalist spent probably a year following the story? So in that type of thing I think we need a specialized area and to be able to think of this differently as far as specialized technologies and how that information is disseminated.” (Paula)

This quotation portrays primary physicians as having a certain level of cultural capital that should not be expanded to the level of a specialist physician whose job it is to hold that higher level of education. These past two statements have used the word ‘we’ to refer to patients and the Canadian public more generally, moving beyond the ‘we’ of the panel itself.

Further, members were also sceptical about their relationship with OHTAC where some individuals were concerned that they were a token panel and members were “political pawns” in a larger process:

“Cause my concern would be after doing this 3 or 4 times that all of us feel that we are making a contribution but we would hate to think that its *tokenism* you know that we’re somehow ... just a little screw in the structure you know.” (Nancy)

As mentioned, the research team addressed and re-addressed these concerns when they arose. Once given the opportunity to interact with members of OHTAC, members further wondered about their relationship to this committee. When an OHTAC representative outlined that about 85% of their recommendations were followed by the Ministry of Health and Long-Term Care, one member astutely asked:

“Can we assume then that OHTAC’s listening to 85% of what we say?” (Larry)

This question exhibits panel members’ need to be reassured that their deliberations are valued by OHTAC. Being able to interact with a few members from the Advisory Committee confirmed

for citizens that their input is wanted and being listened to, which began to quell some of the initial scepticism. One member acknowledged this by commenting:

“It certainly removed a level of scepticism on my part. First meeting I thought this is a bit of tokenism but he certainly cleared that up.” (Larry)

Another member described the relationship between OHTAC and the panel as one of validation and clarification in her one-on-one interview where she said:

“As far as OHTAC, I was grateful when they came...when he came in and said ‘these are your roles, social, ethical ... this is our role ...’; it just fell all into place for me because it gave me a framework, and so it made it very clear” (Paula)

Overall, despite an ‘us versus them’ attitude expressed by some members of the group towards physicians, manufacturers, the government and OHTAC, members believed that open communication and informed consent during a mutual decision making process between patients and physicians was something that professionals were becoming more aware of:

“the one thing I believe that physicians all over nowadays are becoming aware of that is you know what, they have got to check their egos. A lot of them are able to, some of them are still old school and may not be able to. But the thing is they are working because of all of us. *They may think that they’re here and we are here.* That’s just reality, that’s just the schooling and what they’ve gone through and where they are at and that somehow through their training, they also have to be brought to the point where you know what, they are going to be challenged. People are not going to want to do what they are being told to do by that individual for whatever reason, and that individual either needs to have an alternative to say, ‘You know what, here’s somebody you can go and speak to’, or, ‘You know what, valid question, these are the reasons why you really should do it.’

The statement “they may think that they’re here and we are here” reveals that not only does the group feel there is a divide between patients and physicians but also they perceive that physicians believe this divide exists as well. This is another way of verbalizing the difference in cultural capital (based on a physician’s schooling) and social capital (based on a physician’s ability to refer patients to other physicians), which are being increasingly questioned by patients. The exchange of economic capital was also challenged by members referring to patients as “clients” and stating that “We employ them [physicians] so they do have to relate to us not just talk down to us in a condescending manner.”

Interestingly, once members were presented with their top three values, they began to realize how difficult it is to attain them and stated that they also have a role to play in

maintaining these values, not just the physicians and health system. One member stated:

“I don’t think we can just sit back and let the system spoon feed us high life expectancy or good health... So I believe that, I agree with those 3 themes but I also feel there’s an onus on you to ... produce those 3 things the best way that we can in conjunction of a lot of things, including your healthcare in your own city, your own community. I know there’s a lot of factors but like [Benjamin’s] point of going into your doctor’s office prepared with your list of questions and taking more ownership of your own health care rather than just expecting, expecting a high life expectancy.” (Nancy)

This willingness to be an engaged patient and work collaboratively with the physician was only portrayed from this perspective at the final meeting, where ‘we’ indicates patients and citizens, suggesting that the panel’s views had developed over time. Typically, the shared decision making process was seen as something the physician had to initiate because of his cultural capital, but the emphasis on layperson involvement and restructuring of their resulting cultural capital and economic capital as tax payers has begun to introduce balance in the patient-physician exchange.

Overall, Gee’s relationships building task elucidates how language was used to build friendly and respectful working relationships between panel members and initially sceptical relations towards outside parties such as physicians, manufacturers, and OHTAC. The panel would prefer a closer relationship with OHTAC, involving better communication and feedback mechanisms that allow for validation and clarification around the task of the panel. The combination of Gee’s building tasks, where identities and roles are used to relate to others and articulate values towards the social good of health care, work together to formulate a ‘discourse model’ or ‘storyline’ of how panel members make sense of the deliberative process.

4.5 The “we matter” ‘discourse model’

The variety of previous identities, in-group functional roles, and established relationships between members and other actors result in a dynamic group process with competing roles, values and strategies in which members yield power. This is achieved by establishing alliances around worldviews and perspectives on which values are more important, as well as the effective use of occupational knowledge, accessed information and personal experiences to create rapport between members. Further, the emphasis of layperson’s knowledge to the level of holding cultural capital and yearning for impact or social capital creates somewhat antagonistic

relationships with those not present during the deliberations. Stemming from the act of asking citizens to participate in a deliberative process that feeds into healthcare decision making, members cultivated a sense of pride and worthiness towards their contributions. This “we matter” perspective was defended through challenging outside relationships and the possibility that the panel was tokenistic. All of these components create a ‘discourse model’ where citizens’ assertions that they matter are illustrated in Figure 1. Since members went through several phases of role identification, refinement and validations, this is not a linear process and depicts the circular nature of how the storyline of the CRPHT played out.

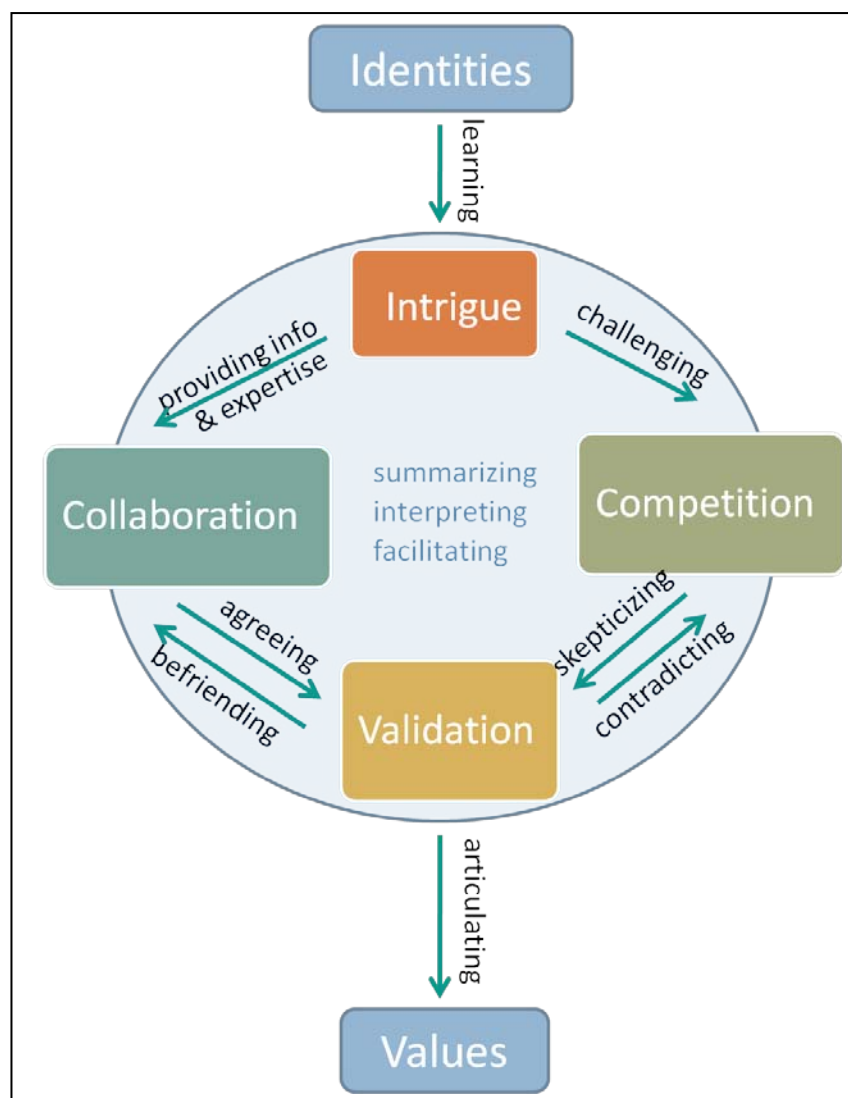


Figure 1. The “we matter” discourse model.

Previously established **identities** formulated from occupational knowledge, health related experiences, and other characteristics enter into the process of deliberation through **learning**. Members find out about the study, read about it in the invitation letter, maybe call the office to find out more about it, and thus learn about what the study entails. During the beginning of each meeting members talked about being **intrigued** about the technology they were going to discuss and from this point they began enacting their roles. As mentioned, members acted in **providing information** and **expertise** and they also acted by **challenging** each others' statements. This led to collaboration and competition, where **collaboration** involves open communication, shared power and members all influencing each other. This also builds stronger, cohesive and positive relationships between members, which is denoted by **agreement** leading to validation.

Validation was the process of referring to other panel members' comments after they have provided information and confirming their views. On the other side, **competition** occurred when members challenged each others' views leading to the rejection of other group members' ideas. This conflict is then extended to those not present at the panel like physicians, manufacturers and OHTAC through the creation of **scepticism**. Here validation from the research team and especially OHTAC was instrumental in continuing the cycle to **befriend** other group members that may have disagreed, using the research team and OHTAC as the mediator or point of reference. Members also began having more positive outlooks towards OHTAC and physicians near the end of the study.

However, even though OHTAC validated the role of the panel, there were still cases where members felt that their validation was **contradictory** to what occurred in real life. For example, a few days after the technology of GEP testing was discussed, the government decided to include it as part of the provincial insurance coverage. At the final meeting members were disappointed at having spent a whole day discussing the topic when the decision was already so close to being made. Members were very aware there was no way for their discussions to reach a decision maker in such a short time span. In the middle, the roles of **summarizing**, **interpreting** and **facilitating** are floating in this circle which denotes the process of deliberation. The roles are in the center because they assist the entire process in moving forward. Finally, through the enactment of these identities, asking questions and assigning meaning in this process, members **articulate** their **values** which are the outcomes of their deliberations.

In conclusion, values are articulated through the complex enacting of previous identities and/or in-group functional roles where differences in knowledge and experiences and thus different forms of capital allow for some members' values to be heard and validated over others. The relationships members established with each other formed around similar identities and worldviews leading to unspoken accords that served to articulate the importance of particular values. The process of deliberation involves intrigue, collaboration, competition and validation which are the meso-level connections between the broad themes of identities, relationships and values, and the micro-level elements like the challenging role, respectful relationships, and the value of equal access respectively.

CHAPTER 5: DISCUSSION

The main objective of this study was to elucidate the process of how citizens articulate values during health technology deliberations. The discourse dynamics that drive this process were also examined by focusing on politics, identities, and relationships to determine the importance of values and in-group roles. In the politics section, health care was outlined as an important social good and equal access, choice, quality care and the allocation of resources were the values given most importance by the panel members. These values can sometimes conflict with each other when members do not agree on which value is the most salient in the context of certain technologies. Further, members bring a variety of previously established identities which they use to shape their in-group roles of **challenging, providing information, summarizing, providing expertise, interpreting, and facilitating**. These identities and in-group roles can also create conflict between and within members.

Participants also created a group identity and worked towards defining their collective role and who they represent. Finally, members developed friendly and respectful relationships amongst each other while establishing more sceptical relationships with physicians, manufacturers and sometimes OHTAC. The dynamics within and between these three components of Gee's framework were summarized through the presentation of the "we matter" 'discourse model' which is the panel's "storyline" or "explanatory framework" that members used to make sense of their experience in this study.

5.1 Describing Deliberative Discourse

The renewal of democracy through deliberative public participation is an attempt to address the problems of representative democracy, where participation hopes to give citizens more direct influence in the decision making process (van Eeten, 2001). However, the discourse involved in building deliberative democracy has seldom been studied empirically as a socio-political process in the context of health policy. Further, the outcomes of deliberative practices are rarely linked to tangible influences on formal democratic processes, resulting in the critical questioning of both by involved stakeholders. Confronted with ample variation of voices during deliberations, clear outcomes and recommendations from the discussions are difficult to process and communicate to participants as well as decision makers. Discourse analysis is effective in capturing and processing this variation by assessing the multiple voices that are articulated, and

teasing out the values which are sought out in the first place (van Eeten, 2001). This method allows for the identification of clear outcomes from deliberations and provides the connection to policy required to give deliberation meaning and impact.

Although our findings converge with previous public engagement work, there are several areas in which this project goes beyond the available literature and paves the way for future investigation into public deliberation through the use of discourse analysis. While the “we matter” discourse model and its values, identities, and relationships components exhibit some consistency with other work, it is the development of the model itself that provides a novel contribution.

The values of choice, access, quality care and resource allocation identified by the CRPHT members are consistent with the NICE ‘Social Values Judgement’ guidance which highlights respect for autonomy, individual choice, equality, timeliness and cost-effectiveness, among others, as important factors to consider when evaluating technologies (National Institute for Health and Clinical Excellence, 2008). Further, the NICE Citizens Council that helped inform this guidance often discussed value for money in their deliberations (Davies et al., 2006). These findings are also consistent with research where citizens were asked to express their values as well as support them with well reasoned and justified arguments, and consideration of multiple perspectives (Chafe, Merali, Laupacis, Levinson, & Martin, 2010; De Vries et al., 2010; Scully, Banks, & Shakespeare, 2006). Finally, these values agree generally with those found in Canadian health policy and reform documents which include individual rights, dignity and choices, equity and quality of care (Giacomini, Hurley, Gold, Smith, & Abelson, 2004). Thus, the values articulated by the citizens’ panel members and our study of the use of deliberative practices reinforce previous work (Bombard et al., 2011). Our results contribute novel insights into this body of work by describing how citizens articulate these values through the enactment of previously established identities and in-group roles, asking questions and assigning meaning.

The identity discourse analysis themes identified in this research also reinforce findings from the NICE Citizens Council where a diversity of pre-existing identities informed in-group roles and the creation of a collective group identity. Davies et al. (2006) describe a similar process where participants brought their pre-existing social identities, including age, gender, ethnicity etc., to a new setting where they were worked up as speaking positions. In both

contexts, identities are multiple and constructed as opposed to singular and assigned (Barnes & Prior, 2009). Davies et al. (2006) outline four discursive styles that map onto some of the in-group functional roles we explored. First, the ‘researcher speech style’ was exhibited when members tried to minimize the uncertainty of not knowing about the technology topics by reading external evidence from newspapers and other sources (Davies et al., 2006). The NICE Citizens Council was similar to our panel in having a member who would cut out extracts about healthcare topics that they deemed relevant and bring a file of these clippings to meetings. The “researcher speech style” is akin to the *providing information* role that was exhibited by some of the CRPHT members.

The second discursive style was ‘a barney’ which is U.K. slang for a passionate competitive argument. This style corresponds to the *challenging* role and was typically seen as an exchange between two members of the Citizens Council where resolution was difficult to achieve since only one speaker can win (Davies et al., 2006). Interestingly, these types of encounters seemed more heated in the NICE context, especially when originating in the small-group deliberations. Large group arguments were better chaired, preventing further escalation of the exchange (Davies et al., 2006). Perhaps the CRPHT’s request for having a facilitator present during small-group discussions was not only a way to stay on task, but also a safety net for preventing conflict.

The third discursive style was ‘the chair of the committee,’ or the *summarizing* role in our context, where Council members spoke on behalf of the whole group. This style was seen as a powerful position where the member has to define the views of the group, stay on task and create a positive socio-emotional tone by referencing the consensus that was reached (Davies et al., 2006). The difficulty of this role explains why one of our members tried to delegate it to someone else after several meetings of enactment.

The fourth and final discursive style involved deliberating through the exchange of stories surrounding personal experiences. This is a component of the CRPHT’s *providing information* role where we similarly concluded that these stories become negotiable points in the discussion like other pieces of evidence obtained from newspapers. Further, the act of storytelling creates a common sense or “life world position” on what is acceptable by revealing accounts of the members and their reactions to particular events (Davies et al., 2006).

Moving beyond these four discursive styles, the CRPHT also exhibited *expertise provision, interpreting* and *facilitating* roles which were instrumental in providing in-depth context around certain health technologies and staying on topic. By no means are the identities we outline or the discursive styles put forth by Davies and her team, exhaustive accounts of the possible roles that citizens adopt in deliberative discourses. However, in the group process literature, a thorough list of task, social and dysfunctional roles have been defined as contributing and sometimes disrupting the progress of a group (Benne & Sheats, 1948). These roles also differ depending on the stage of group development, where some are more suitable for certain stages than others; for example in the initial stages of group formation, Energizers and Reporters are useful roles to have (Benne & Sheats, 1948). This expansive framework can not only be used to evaluate the need for new roles, but also as a group development tool or even in the recruitment stages of future citizen engagement efforts. More specifically, this has been utilized in settings where prospective participants members are placed in mock deliberations and selected based on their ability to provide constructive input and comments (Abelson, 2010c). One example of a constructive contribution, during the deliberations of the CRPHT, was when Paula acted as a facilitator by picking up the instructions of the research team and beginning to frame the panel's discussions into statements for OHTAC.

In contrast to other studies where 'storytelling' was the pervasive role adopted by deliberation participants, CRPHT members took on multiple roles with no clear delineation of a single, 'most employed' role. Further, some of these roles and styles were more highly regarded than others, which resulted in some members becoming more influential and listened to more intently. For example, those CRPHT members who were frequently providing expertise or summarizing held more 'deliberative capital' because the ways in which they communicated became favoured and considered very helpful within the group (Davies et al., 2006). This appreciation of certain roles over others illustrates how power flows within meetings, where those who take on these roles typically hold more social and cultural capital, which are symbolically converted to deliberative capital. The interaction between and within CRPHT member roles and the analysis of these dynamics through Bourdieu's forms of capital is another major contribution of this project.

Moreover, speaking styles originating from different class positions, gender and occupations will be regarded differently (Barnes, 2002), and even though critics of deliberation suggest that power relations within deliberative groups reflect broader social divisions in society, this was not observed in the NICE Citizens Council or the CRPHT (Davies et al., 2006). In fact, the strong emphasis placed by members on the importance and worth of the layperson's perspective appears to contradict these claims. Despite the general view that deliberative processes are always nested in "background differences in power" (Cohen & Rogers, 2003) any power relations observed in the CRPHT were subtle due to the creation of a respectful and open environment for deliberation.

Complementary to the analysis of capital and power, universalism, the equal opportunity to participate in deliberation regardless of elite status - and inclusivity - the inclusion of a diverse range of citizen voices to ensure a broad range of views are incorporated - were also examined by the research team. Results indicated that it was difficult to assess whether deliberations are of good quality based on these measures. Certain members (Jagad, Paula, Benjamin and Nancy) consistently took up more airtime when talking, and also made the most comments and took up the most text volume in the transcripts (Farjou & Abelson, 2011). Although airtime and text volume were found to be useful in evaluating the deliberations of the CRPHT, comment analysis was less accurate since some members would only comment a few times but at length. Overall, there was a wide range of participation from very little input to a great deal, and members felt that they all had an opportunity to speak, which illustrates that the group process was effectively facilitated (Farjou & Abelson, 2011).

It is clear that participating in deliberative discourse involves more complex identity work than the position of citizen itself, where participants contribute their individual opinions. The idiosyncratic backgrounds of members can be difficult to navigate for the purposes of obtaining a cohesive response to questions posed at each meeting. Still, members developed a collective group identity by working through issues of representativeness and impact, similarly to the NICE Citizens Council (Davies et al., 2006). Initially, citizens in the Ontario context did not feel themselves to be representative of the geographic region to which they belonged. However, once they shared their excitement and willingness to learn, citizens set aside their individualistic preferences that were based on their pre-established identities, and participated for

the common good. In the field of social psychology, it has similarly been observed that when people come together to discuss the issues that collectively affect them, they begin envisioning themselves in terms of a broader social identity, where values are shared and the collective perspective becomes more salient than the individual one (Kreindler, 2009; Postmes, Spears, Lee, & Novak, 2005; Tenbensel, 2010). This unused capacity among citizens challenges the image of an apathetic and disinterested public, and is encouraging for the implementation of future public engagement methods (Davies et al., 2006). Additionally, studies that include the public affirm that no special qualifications are required in order for community members to develop practical and mindful contributions (Kreindler, 2009; Lightfoot & Sloper, 2003; Mooney & Blackwell, 2004).

In accordance with other findings, citizen panel members viewed their interest, and the knowledge gained from their diverse experiences, as having a certain representative role to perform, where these past experiences and skills were the source of legitimacy in and of themselves (Martin, 2008). More specifically, the panel's range of backgrounds allowed for a more nuanced and useful contribution that enabled members to speak for the wider disempowered and sometimes vulnerable population, the representation of which was uniquely of great concern to the CRPHT group. This confirms findings where diverse groups normally choose to direct resources to those in most need of them, as well as the tendency for groups to represent the community even if they are not asked to do so (Kreindler, 2009). Further, it underscores Barnes et al.'s (2003, 397) assertion that "the importance of the micro processes through which official and lay discourses of the notion of 'representation' and legitimate participation are being negotiated suggests that the analysis of official discourse alone is insufficient to understand how 'the public' is constituted for public participation."

In terms of relationships, public engagement seeks to support the creation of a connection between expert and lay understandings of issues, such as how to assess health technologies in the case of the CRPHT (Petts, 2008). This suggests a transactional process between groups with a shift away from one-way communication to a focus on relationship building between individuals with different knowledge, experiences and perspectives. Some believe that this type of relationship can enhance trust when members are faced with disagreements. This was seen in the citizens' panel when members became less sceptical of OHTAC upon interacting with them. The

process of validation outlined by the “we matter” ‘discourse model’ provides a fresh perspective on the dynamic between citizens and the organizations asking for their input.

Another significant contribution of this study is the application of discourse analysis in public engagement which has been identified as an important tool for analysing the outcomes of deliberative processes (Value Addition through Genomics and GE3LS, 2011). Discourse analysis allows for the researcher to capture the complex variation of multiple perspectives as well as process and evaluate these perspectives. This was explicated in the deliberations of the CRPHT where multiple identities, relationships and politics were captured while evaluating the process of how this occurred. In the continued application of discourse analysis, the scientific community can begin shining a light on the principled moral questions that some scholars believe are lacking in current PE processes (Weale, 2001).

5.2 Barriers and Facilitators to Group Deliberation

Lastly, as mentioned, the process of conducting a citizens’ panel was no doubt messy and involved a learning curve for the research team and the participants. One member noted that “it got easier to integrate the information after several sessions” and that the group became “more efficient.” The initial lack of clarity around the task prevented the group from reaching clear and reasoned conclusions. Some argue that discussing values as opposed to concrete problems is an ambiguous task that corralled the citizens’ voices instead of empowering them (Davies et al., 2006). Perhaps this is why panel members expressed a need for more statistical and numerical evidence, and a framework to inform their deliberations.

Our findings identified several facilitators to effective group deliberation. These include acknowledging and working with the pre-existing identities citizens bring to the panel; having a facilitator that can actively tease out the reasons behind individual opinions in order to limit naked uses of power (e.g. accepting what an elderly member of the panel says as fact because of the perception that the elderly are wise) (Jacobs, Cook, & Carpini, 2009); panel members who came prepared having read the information ahead of time; active panel members who provided direct and systematic answers to the questions the group was posed; and having a question and answer period after the introduction of a new topic. Some barriers to effective deliberation included time, the size of the large group, the lack of a clear vision and consistency between

questions across meetings, and the tendency for some members to come with their own agendas of wanting to discuss broad scale healthcare issues. Further, although members appreciated when scientific evidence was presented and summarized by experts, some tried to get more positioned views out of these discussions to no avail. This relates to the findings from the studies of the NICE Citizens Council, which demonstrated member preference for positioned expert views because they allowed citizens to better work out their own responses (Davies et al., 2006). What was surprising about the group process in the CRPHT study was the contradictory nature of identities enactment, the high level of scepticism towards physicians, manufacturers and OHTAC, and the group's acute self-awareness around off-topic conversations and the request for small group facilitation to prevent this. Overall, discourse seems to be anchored in a process that creates equal opportunities for gathering and articulating reasoned arguments from multiple competing perspectives (Jacobs et al., 2009).

The impact of the panel's contributions was another point of concern and contention that is also one of the main criticisms of deliberative practices (van Eeten, 2001). Jacobs et al. (2009) present a range of hypothesized outcomes that a deliberative discourse can have, from direct impact on policy to the indirect development of shared meaning (See Table 2). The collective outcome of the citizen panel definitely established shared meanings around societal and ethical values, and increased the motivation of members to participate in future public engagement activities, as indicated in their one-on-one interviews. This also served to increase members' political capital and likely their general engagement in political and civic participation. However, aside from some changes in one of OHTAC's recommendations, it is too early to assess whether members had any direct policy impact, and whether their engagement around specific issues increased was unclear. The exploratory nature of this study revealed the difficulty of corroborating citizen input and the array of impact that its outcomes can have.

Table 2. Possible outcomes of deliberative discourse.

Policy	Issue-specific engagement	General engagement	Political capital	Shared meanings
(1)	(2)	(3)	(4)	(5)
Impact on policy agenda and outcomes	Increase political (e.g., voting contacting) and civic (e.g., volunteering) participation around specific issue (e.g., crime)	Increased political (e.g., voting contacting) and civic (e.g., volunteering) participation in general	Increase motivation (e.g., political interest) and ability (e.g., political knowledge) to participate	Greater agreement on foundational issues (e.g., what constitutes the public interest, community, citizenship)
Direct effects				Indirect effects

5.3 Reflexivity

In the spirit of social constructivist research, I kept a reflexive journal throughout the course of the study in order to address any bias, make notes of hunches and acknowledge challenges in the process. For example, I acknowledged my age, gender, cultural background and post-secondary education as potential sources of bias that were addressed through journaling. Further, my changing perception upon looking at one-on-one interview data was also documented in this way.

Upon reading the one-on-one interviews, I was very surprised to learn that some members deliberately adopted certain roles, which at the time of the meetings and in analyzing the transcripts seemed to be more organic and emerging by virtue of the discussion. One example of this was Larry and his overt role as the devil’s advocate, always challenging other group members. Another welcomed insight from the interviews was the shared excitement panel members felt after each meeting, which confirmed my perception of the group climate and matched my own sense of what had transpired. Although I was expecting the interviews to be mostly consistent with the deliberations, one discrepancy that I found startling was Paula’s indication that cost needed to be incorporated into future panel discussions, even though she advocated for dropping this component during the fourth meeting. Thus, I learned that citizens’ perspectives can differ depending on the context they are asked to share them in, and that taking an in-depth look at the language can enhance one’s findings. For example, looking at the word “we” and all the different meanings that panel members attributed to it, from the government to

patients, shows the dynamic nature of the group's identity and the struggle to define it. Finally, I felt that members had difficulty assigning themselves in-group functional roles during the one-on-one interviews, and that ultimately the panel's lack of awareness of using language to perform different roles suggests that discourse analysis can reveal things that are unknown to the participants themselves.

5.4 Limitations

Areas that could have skewed the interpretation of our study include the use of Hoffman's questions, which may have cued the panel's deliberations in a restrictive way, resulting in the particular values of choice, access and quality care. In order to compensate for this, the full article with all 33 questions was provided to the panel members along with the opportunity to contribute additional questions, which they did by including gender as one of their considerations. Further, the author was the only reviewer of the data through a discourse analysis lens, which was offset by regular meetings with supervisors and thesis committee members, where analytical codes and themes were presented and reworked. Finally, the range of technologies discussed by the panel are not representative of the broader scope of health technologies in general, making findings around values difficult to generalize across any technology or jurisdictional differences.

5.5 Implications

In light of our findings, there are several implications for those looking to conduct and evaluate future public engagement research and methods, as well as those seeking to employ discourse analysis in their work. Given the multitude of roles adopted in the deliberative arena, future efforts should actively identify, legitimise and commend different ways of speaking and acting in order to unpack discursive reasoning. Those wishing to employ public engagement methods can examine what roles are being filled, which additional roles are required and which roles need to be removed, a task that varies depending on the group's development and purpose. When soliciting the help of experts, encouraging them to take a more positioned stance in their talk will aid citizens in developing their own views and responses. Further, caution and careful thought are required if future designers of public engagement processes are considering using an

ethical or values framework to guide deliberations. During the deliberative process, facilitators must continuously clarify the task, the reasoning behind posed questions and the role that citizens are being asked to play, and validate the contributions of citizens. Moreover, the organization sponsoring the public engagement process must establish a positive and interactive relationship founded in continuous communication around expectations and feedback on citizen input.

Researchers looking to employ Gee's discourse analysis in this area would benefit from consulting with a linguistics expert and employing more of the grammatical tools that were outlined in his Toolkit in order to further the work in this area (Gee, 2010). Moreover, the systematic tracing of themes and terminology from the public sphere through to policy outcomes is another area ripe for investigation where researchers can closely examine the barriers and facilitators around which ideas are effectively included in policy outcomes (Value Addition through Genomics and GE3LS, 2011). The development of a systematic process for converting public engagement reports into policy options that can be used by decision makers is also an avenue worthy of inquiry. Otherwise, the application of Gee's broader building tasks is a useful and effective way to tease out dominant discourses and how they are used in the creation of politics, identities and relationships. Finally, discourse analysis and the use of public engagement methods requires significant capacity and time from the research team as well as a strong facilitator, in order to quickly interpret and summarize deliberations.

5.6 Conclusion

This study is the first to explore the use of discourse analysis in interpreting citizen deliberations on health technologies in Ontario. Given that participatory democracy involves a combination of individualism and collectivism, how 'citizens' are defined is a significant consideration for the design of future work. The results of this study offer the following contributions in order to capitalise upon the promise of public engagement and citizen deliberation.

First, the study explored societal and ethical values, which were elicited by panel members through the enactment of their identities and in-group roles. Members displayed an array of group dynamics and requested a framework from which to base their recommendations.

Thus, future efforts in this field must be careful about recruitment, rules of engagement, and the type of frameworks citizens are given up front, to limit bias and allow for organic deliberation. Attending to discourse may help facilitators of PE to be attentive of the enactment of particular roles and whether they meet the objectives of the project. To successfully engage a critical mindset, citizens should be encouraged to question, critique and even to criticize the status quo in a respectful and constructive way.

Second, the novel creation of a “we matter” ‘discourse model’ gives researchers, policy makers and users of PE a depiction of the deliberative process in the HTA context. The model provides a framework that can be modified and expanded to inform different contexts using similar methods. Serving as a foundation, this model is a testament to looking at deliberations from a language lens, which allows for the examination of underlying meaning in discourse.

Third, discourse analysis provides a mechanism for understanding how citizens construct their roles when asked to participate in the enactment of health policy. This helps users of PE to look at these functional in-group roles and move beyond the uneducated layman stereotypes in the field by re-evaluating their expectation and being clear about the aims of eliciting citizen perspectives. By understanding the language and process by which citizens elicit their concerns and values, we can learn how to better communicate to them the technical information, and goals surrounding public engagement.

Although this was a pilot study, replication of this thesis project’s methodology and the citizens’ panel design to inform health technology decision making holds the promise of informing more institutionalized methods of public engagement. Future research to fill the gaps on how these PE opportunities serve to reproduce and sustain the institution of deliberative democracy is the next challenge for discourse analysis. In the end, the CRPHT has been a useful vehicle for exploring the utility of discourse analysis and advancing the values perspectives of Ontario citizens. In the words of one of the panel members “I’d like to quote from Tennyson’s Ulysses: ‘I am a part of all that I have met; Yet all experience is an arch where through gleams that untraveled world, whose margin fades forever and forever when I move.’ We’re a part of all that we have met.”

TABLES

Table 1. Demographic characteristics of panel members.

	Total (n=14)	
	n	%
Gender		
Female	5	36%
Male	9	64%
Age		
18-25	1	7%
25-39	4	29%
40-54	4	29%
55-70	3	21%
71+	1	7%
Marital Status (n=8)		
Single/separated/divorced/widowed	2	25%
Married/common law/living with partner	6	75%
Education (n=13)		
High school & below	2	15%
Some college or university & above	11	85%
Employment Status (n=13)		
Employed	9	69%
Unemployed/Retired	3	23%
Student	1	8%
Income (n=12)		
<\$20,000	2	17%
\$20,000 - \$40,000	2	17%
\$40,000 - \$60,000	5	42%
\$60,000 - \$80,000	3	25%
>\$80,000	0	0%
Ethnic Background (n=13)		
Canadian	7	54%
European	3	23%
European Canadian	1	8%
South Asian	1	8%
Asian	1	8%
*Missing values are excluded.		

APPENDIX A

Hoffman's Moral Questions

- Q1 What are the morally relevant consequences of the implementation of the technology?
- Q2 Does the implementation or use of the technology challenge patient autonomy?
- Q3 Does the technology in any way violate or interfere with basic human rights?
- Q4 Does the technology challenge human integrity?
- Q5 Does the technology challenge human dignity?
- Q6 Will there be a moral obligation related to the implementation and use of a technology?
- Q7 Does the technology challenge social values and arrangements?
- Q8 Does the widespread use of the technology change our conception of certain persons (e.g., with certain diseases)?
- Q9 Does the technology contest religious, social, or cultural convictions?
- Q10 Can the use of the technology in any way challenge relevant law?
- Q11 How does the assessed technology relate to more general challenges of modern medicine?
- Q12 Are there any related technologies that have turned out to be morally challenging?
- Q13 Does the technology in any way challenge or change the relationship between physician and patient?
- Q14 How does the implementation of the technology affect the distribution of health care?
- Q15 How does the technology contribute to or challenge professional autonomy?
- Q16 Can the technology harm the patient?
- Q17 What patient group is the beneficiary of the technology?
- Q18 Are there third-party agents involved?
- Q19 What are the interests of the users of the technology?
- Q20 What are the interests of the producers of technology (industry, universities)?
- Q21 Are there moral challenges related to components of a technology that are relevant to the technology as such?
- Q22 What is the characteristic of the technology to be assessed?
- Q23 Is the symbolic value of the technology of any moral relevance?
- Q24 Are there morally relevant issues related to the choice of end points in the assessment?
- Q25 Are there morally relevant issues related to the selection of studies to be included in the HTA?
- Q26 Are the users of the technology in the studies representative of the users that will apply it in clinical practice?
- Q27 Are there morally relevant aspects with respect to the level of generalization?
- Q28 Are there moral issues in research ethics that are important to the HTA?
- Q29 What are the reasons that this technology is selected to be assessed?
- Q30 What are the interests of the persons participating in the technology assessment?
- Q31 At what time in the development of the technology is it assessed?
- Q32 Are there related technologies that have or have not been assessed?
- Q33 What are the moral consequences of the HTA?

APPENDIX B

Selected Hoffman Questions

Societal Questions

1. What are the interests of the users of the technology?
2. What are the interests of the producers of technology (industry, universities)?
3. Are the users of the technology in the studies representative of the users that will apply it in clinical practice?
4. How does the assessed technology relate to more general challenges of modern medicine?
5. Does the technology challenge social values and arrangements?
6. Does the technology contest religious, social, or cultural convictions?
7. Can the use of the technology in any way challenge relevant law?
8. How does the implementation of the technology affect the distribution of health care?
9. At what time in the development of the technology is it assessed?
10. Are there related technologies that have or have not been assessed?

Ethical Questions

1. What are the morally relevant consequences of the implementation of the technology?
2. Does the implementation or use of the technology challenge patient autonomy?
3. Does the technology in any way violate or interfere with basic human rights?
4. Does the technology in any way challenge or change the relationship between physician and patient?
5. Are there any related technologies that have turned out to be morally challenging?
6. Does the widespread use of the technology change our conception of certain persons (e.g., with certain diseases)?
7. Does the technology challenge human integrity?
8. Does the technology challenge human dignity?
9. Will there be a moral obligation related to the implementation and use of a technology?
10. Are there moral issues in research ethics that are important to the assessment of the technology?

APPENDIX C

CRPHT Meeting Structure

A. Summary of CRPHT Meetings

Meeting Date	Discussion Topics	Stage in MAS-OHTAC Process	Input to MAS-OHTAC
February 14, 2009	Colorectal cancer screening	Draft recommendation	CRPHT input incorporated into final OHTAC CRC screening recommendation
May 30, 2009	Percutaneous aortic valve replacement (PAVR)	Vignette	Summary report filed for future reference subject to Health Canada licensing of PAVR
November 14, 2009	Breast cancer screening for average and high risk women	Draft recommendation	Summary of meeting highlights presented at January 2010 OHTAC meeting
March 6, 2010	Personalised medicine and gene expression profile testing	Vignette	Summary report submitted to MAS lead for technology EBA
May 29, 2010	Serologic testing for celiac disease	Draft recommendation	Draft summary report prepared in July 2010

B. Discussion Questions

Meeting 1

Topic 1 - Possible Roles for Citizens in the Health Technology Assessment Process

1. How can citizens contribute to Ontario's health technology analysis process?
2. Should citizens play a role in these phases? Why or why not? If so, what role?
3. Should patients and service users be involved in the same way as citizens or should they have different roles?

1.

Topic 2 - Information and Choice in Screening Technologies for the Early Detection of Disease

1. As a potential user of a screening test, what does it mean to be informed about these screening tests?
 - Does being informed mean something different when we're talking about population-based programs or opportunistic screening?
2. As a potential user of a screening test, what does it mean to have choice about these screening tests?
 - Does having choice mean something different when we're talking about population-based programs or opportunistic screening?
3. As a potential user of a screening test, what does it mean to consent to these screening tests?
 - What is the role of consent in population-based screening programs compared to opportunistic screening?

Meeting 2

Topic 1 - Incorporating Societal and Ethical Values into MAS/OHTAC Decisions

1. What do you think of these definitions of societal and ethical values?
2. How would you add to or change them?
3. What would you add to or change the sample questions [Hoffman] listed above?
4. What are your top 3 'societal' and 'ethical' questions from the list in terms of their usefulness in guiding discussions about health technologies?

Topic 2 - Technologies for the Treatment of Advanced Heart Disease

1. What societal and ethical questions do you think are important for the Medical Advisory Secretariat and OHTAC to consider in their review of the effectiveness of this new technology?
2. What are your views regarding the current licensing of Class III and IV (i.e., high risk) devices such as PAVR?
3. Do the arrangements for providing access to unlicensed technologies through Health Canada's Special Access Programme seem reasonable to you?
4. Under what conditions, if any, should a high-risk procedure or technology such as PAVR be offered if it is unlicensed?

Meeting 3

Topic 1 - Revisiting Societal and Ethical Values

1. Are these still your top picks or would you like to adjust your responses?
2. Who needs to be asking these questions and at what point during the evaluation of health technologies?
3. What are the implications of a 'yes' or 'no' answer to any of these questions?

Topic 2a: Breast Cancer Screening for Average- and High-Risk Women

1. Reducing cancer deaths across large populations is the measure used by most cancer agencies to determine the success of their screening programs.
 - Is reducing cancer deaths the most important measure of success for a screening program?
 - Are there other measures of success that are just as important? If so, which ones?
2. How should screening programs balance their obligations *to provide information and choice to*

screening program participants and their interests in *screening as many people as possible* to reduce cancer deaths across large populations?

- Can they do both effectively?
- Should information about benefits and harms be provided by some other organization?
- What are the ethical and societal principles that should guide these decisions?

3. As new breast cancer screening approaches are introduced for average-risk and high-risk women (e.g., DM and MRI), how should they be evaluated?

- What can we learn from the current controversies about mammography screening as new screening approaches are introduced?
- Should information be shared in a different way?
- What measure of success should be used to evaluate these new approaches?

Topic 2b: Using Different Types of Information to Evaluate Screening Methods

1. Are there circumstances in which the views of some segments of the population, some patient groups or prevailing public attitudes **SHOULD** be given greater consideration than what the science of the day has to offer? If so, please describe these circumstances?

2. Are there circumstances in which the views of some segments of the population, some patient groups or prevailing public attitudes **SHOULD NOT** be given greater consideration than what the science of the day has to offer? If so, please describe these circumstances?

3. At times, scientific evidence is not consistent with prevailing attitudes or the views of a particular group. How should OHTAC approach the communication of its messages about the use of health technologies under these circumstances?

Meeting 4

Topic 1 - Incorporating Societal and Ethical Values into MAS/OHTAC Decisions

1. Pick one of the questions that is in a shaded box from the list above and think about how you might turn this question into your ‘position’ on this subject. Reflect on whether you believe this should also be *Ontario’s* position, and why (or why not).

2. What are your thoughts on how OHTAC should work to develop such values positions?

- Who should be involved in doing this?
- Would a group of citizens, like the CRPHT, play a role?
- How often should these positions be reviewed and revised?
- If there are some values that should apply to all technologies, and other values questions that are specific to certain types of technology, how does this change the process of developing values positions?

Topic 2 - Personalized medicine technologies: What values are at stake? What questions should be included in OHTAC’s analysis of these technologies?

1. What questions do you have about the value of gene expression profiling that you would like to see OHTAC include in its review?

2. What questions do you have about the area of personalized medicine, in general, that OHTAC could consider in its review of these new technologies?

3. Which of Hoffman’s questions need to be applied to: (a) gene expression profiling; and (b) personalized medicine, in general?

Meeting 5

Topic 1: Revisiting Societal and Ethical Values

1. If OHTAC were to develop a set of principles to guide their review of technologies, what would be the core ethical and societal values that should be considered for *every* technology OHTAC assesses?
2. Where in the technology assessment process should these values be considered: selecting technologies to assess, summarizing the research and current knowledge, forming recommendations, and/or in public vetting of the recommendations?
3. What are your thoughts on how OHTAC should work to develop such values positions?
 - Who should be involved in doing this?
 - Would a group of citizens, like the CRPHT, play a role?
 - How often should these positions be reviewed and revised?
 - If there are some values that should apply to all technologies, and other values questions that are specific to certain types of technology, how does this change the process of developing values positions?

Topic 2: CRPHT Evaluation

1. In general, what are the strengths and weaknesses of the CRPHT?
2. Do you believe that the CRPHT has had an impact on OHTAC's work?
3. What impact has your involvement as a panel member had on you and your life?
4. Do you think the CRPHT should continue? If it were to continue, what recommendations would you make to OHTAC for improving it?

Topic 3: Testing for Celiac Disease in Ontario

1. Does the draft OHTAC recommendation provided above make sense to you based on what you have learned about the strengths and weaknesses of the different blood tests used to help diagnose celiac disease?
2. What are the ethical and societal issues associated with OHTAC's support for the use of serologic (blood) testing for celiac disease in patients "with symptoms consistent with this disease"?
3. How should OHTAC approach the development of criteria to guide the use of this test in the Ontario population given its concerns about overuse of the test in low-risk populations (e.g., with mild gluten intolerance)?

C. Example of a Meeting Agenda

February 14th, 2009, 8:30 am – 4:00 pm

Time	Activities	Facilitator	Length
8:30	Panel members arrive/light breakfast Completion of pre-meeting surveys and consent form	J. Abelson	30 min
9:00	Welcome and introductions	J. Abelson	60 min
10 am	Introduction and orientation to MAS/OHTAC Public engagement and the health technology assessment process	L. Levin	30 min
10:30am	Break		15 min
10:45 am	TOPIC 1: Facilitated discussion of possible roles for citizens in the health technology assessment process	J. Abelson	75 min
Noon	Lunch		60 min
12:45pm	TOPIC 2: Facilitated discussion about information and choice in the context of screening programs • Introduction to the topic • Small group discussions	J. Abelson	75 min
2pm	Break		15 min.
2:15pm	TOPIC 2 (cont'd): Facilitated discussion about information and choice in the context of screening programs • Reporting back from small groups • Large group discussion	J. Abelson	60 min.
3:15pm	Meeting wrap-up and discussion of next steps • Upcoming meetings • Meeting evaluation and post-meeting survey	J. Abelson	45 min.

APPENDIX D

Interview Guide for Follow-up with Panel Members

[To be administered to consenting panel members of the CRPHT]

INTRODUCTION

- Ethical considerations, reminder of recording
- Confirmation of the estimated length of time for interview (45 min)
- Interview findings will be used as part of a recommendation report we are putting together for MAS and OHTAC
- We are genuinely interested in your thoughts on the CRPHT, and we want to learn from your experiences
- Any questions before starting

SECTION A: GENERAL REFLECTIONS ABOUT CRPHT

Section A.1: Personal Reflections

In this first section of the interview, I am going to ask you some questions about your personal thoughts on your participation in the panel. There is no right or wrong answer – we are interested in how you felt, what you saw, and any thoughts you had.

1. Thinking back to when you first received the invitation to participate on the panel, what was it about the study that interested you enough to go on and complete the form and send it in?
2. If you can recall back to the first meeting in February of 2009, what kind of feeling did you come away with from that meeting?

Was it what you expected based on what you had been told about the study?

Did the meeting in any way surprise you?

How did you feel about ongoing participation in the study? Excited, nervous, bored?

Did you have any specific concerns about your ongoing participation in the study?

Did your initial feelings change as the study progressed?

- 3a. Which perspective comes **closest** to capturing the perspective you were bringing to each CRPHT meeting:

Your perspective as a citizen of Ontario

Your perspective as an Ontario taxpayer

Your perspective as a patient or client of the health system

Your perspective as someone in a particular age, social position and socio-economic bracket

Your perspective as a resident of a particular region in Ontario
Other?

3b. Of the above-mentioned perspectives, which comes **second closest** to capturing the perspective you brought to each meeting: [*Repeat perspectives*]

Your perspective as a citizen of Ontario

Your perspective as an Ontario taxpayer

Your perspective as a patient or client of the health system

Your perspective as someone in a particular age, social position and socio-economic bracket

Your perspective as a resident of a particular region in Ontario

4. During the CRPHT meeting discussions, did you at times feel that you were speaking for others besides yourself? [*Clarification: on behalf of others*]

Yes

No

*If yes, which other groups did you feel that you were speaking for on these occasions?
I.e. members of the community, family or friends, citizens of Ontario*

5. Thinking back over the course of the meetings you attended, what stood out for you as one or two highlights. Can you explain why these were highlights?

Did you learn a lot about a topic that you didn't know beforehand?

Was it a particular topic that you found interesting to discuss?

Did you think the panel did a particularly good job discussing a specific topic?

Was it a guest speaker who attended a meeting who you found helpful?

Section A.2: Process Reflections

We are now moving into a set of questions on how you thought the CRPHT meetings went.

6. Looking back on your experience as a panel member, what would you say were the strengths of the panel? [Quebec – in general, what are the strengths of the Forum]

What made it a rewarding experience for you?

Are you satisfied with your experience as a panel member? [Quebec]

7. What were the challenges or problems that you encountered during the meetings? [Quebec – what are the challenges or problems that you have encountered during the meetings]

What was the panel's greatest weakness?

What made it a frustrating experience for you?

What could have made the panel meetings more productive?

8. During the panel meetings, which types of discussions did you find the most productive? *[Give time to provide own examples of kinds of discussions they found most helpful, then probe further to find out what it was about these discussions that they found productive: size of group, how discussion was structured, topics – see probes below]*

Large group discussions (in the morning) on the general topic of societal and ethical values?

Discussions with guest presenters?

Large group discussions about specific technologies?

Small group discussions about specific technologies?

Discussions about technologies at the recommendation stage vs. the vignette stage?

9. This next question is about group process, and how you personally contributed to group discussions. Some roles that panel members had were, for instance, a facilitator or an information-provider. What type of roles did you feel you played in group discussions?

Did you facilitate small group discussions?

Did you observe and make summaries to the large group?

Did you bring in outside information and/or personal experience?

Did you challenge members of the panel to think critically?

Was the role you played different in small vs large group discussions?

10. We realize that this may be a challenging question for you to answer but we are interested in your thoughts about whether and how the panel has influenced the work of the Medical Advisory Secretariat and OHTAC?

Do you believe the CRPHT had an impact on OHTAC?

Specific examples of influence, non-influence

SECTION B: RECOMMENDATIONS FOR FUTURE DIRECTIONS OF CRPHT

Now we'd like to ask you some questions about the future directions of the CRPHT. Once again, there is no right or wrong answer, so as we move through the questions I will be asking you for your thoughts. [Trial sequencing with first interview: overarching questions follow by probes about basic design features. May need to revise]

11. Do you think the CRPHT should continue?

[If respondent answers YES]:

12. Under what conditions and with what changes or improvements should the CRPHT carry on?

13. Are there any circumstances in which you would recommend that the CRPHT not carry on?

Should the panel be formed in the same way or differently?

Should it become a permanent structure or should it continue on as part of a research study?

How often should it meet and for how long (i.e., are 1-day meetings a good length of time or should it be extended?)

14. Do you think that there are certain individuals who would **not** be appropriate candidates for panel membership? [*Drop if short on time*]

Examples: elected members of government, healthcare professionals, employees of healthcare product companies, patient advocacy group members

15. Do you think that the relationship between the panel and OHTAC could be improved, and if so, how?

For example, do you think the CRPHT should interact directly with OHTAC? If so, approximately how often and for what purpose? How would you envision this happening? Why do you think it is important for the CRPHT to interact with OHTAC?

16. What else do you think the Medical Advisory Secretariat and OHTAC should consider as they seek to incorporate the views of the public into their work in the future?

SECTION C: IMPACT OF CRPHT ON FUTURE PUBLIC INVOLVEMENT

We're moving into the final section of the interview now, and we have just a few more questions for you, related to whether participating in the CRPHT has impacted you.

17. Have you ever participated in anything like the CRPHT before?

If yes, please describe that experience in relation to the CRPHT.

18. Do you participate in any local clubs and organizations in your community?

19. On a scale of 1-7, where 1 is not civic-minded at all and 7 extremely civic-minded, how civic-minded a person would you say you are? [*Definition of civic-minded: concerned with public interests, or active in community affairs*]

1 2 3 4 5 6 7

20. Do you think your experience with the CRPHT will make you more or less likely to get involved in other activities like it, or will it make no difference at all?

21. If you were to get involved in future activities like the CRPHT, would you be more likely to get involved in something that related to the health care system, or would you consider a wide range of activities?

22. What, if anything, will you do differently as a result of your participation on the CRPHT and in this research study?

How have you used, or how do you see yourself using, the experience or knowledge gained from being a panel member?

What is the impact of participation in the CRPHT on your own life?

CONCLUSION

That concludes the interview.

23. Is there anything you'd like to add that hasn't already been covered in the questions I asked?

Thank you very much for the time you've taken to participate in this interview, and in our study. Do we have your permission to contact you to follow up on any questions that we might have as we are analyzing the content of your interview? Also, would you like the opportunity to review your transcript to ensure that you are comfortable with the answers you have provided?

REFERENCES

- Abelson, J. (2010a). Chapter 31. Using Qualitative Research Methods to Inform Health Policy: the Case of Public Deliberation. *The SAGE Handbook of Qualitative Methods in Health Research*. London: SAGE Publications Ltd.
- Abelson, J. (2010b). *Consulting with Ontario Citizens about Health Technologies* (Final Report of the Citizens' Reference Panel on Health Technologies).
- Abelson, J. (2010c). Practicing the Theory of Public Deliberation: Case studies from the Health Sector in Ontario and Quebec. *Canadian Political Science Review*, *Accepted for Publication*.
- Abelson, J., Eyles, J., McLeod, C. B., Collins, P., McMullan, C., & Forest, P.-G. (2003). Does deliberation make a difference? Results from a citizens panel study of health goals priority setting. *Health Policy (Amsterdam, Netherlands)*, *66*(1), 95-106.
- Abelson, J., Forest, P.G., Eyles, J., Casebeer, A., Martin, E., & Mackean, G. (2007). Examining the role of context in the implementation of a deliberative public participation experiment: Results from a Canadian comparative study. *Social Science & Medicine*, *64*(10), 2115-2128. doi:10.1016/j.socscimed.2007.01.013
- Abelson, J., Forest, P.G., Eyles, J., Smith, P., Martin, E., & Gauvin, F.-P. (2002). Obtaining public input for health-systems decision-making: Past experiences and future prospects. *Canadian Public Administration/Administration publique du Canada*, *45*(1), 70-97. doi:10.1111/j.1754-7121.2002.tb01074.x
- Abelson, J., Forest, P.G., Eyles, J., Smith, P., Martin, E., & Gauvin, F.-P. (2003). Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Social Science & Medicine*, *57*(2), 239-251. doi:10.1016/S0277-9536(02)00343-X
- Abelson, J., & Gauvin, F.P. (2006). *Assessing the Impacts of Public Participation: Concepts, Evidence and Policy Implications*. Public Involvement Network. Retrieved from <http://www.chepa.org/Portals/0/pdf/CHEPA%20WP%2008-01.pdf>
- Abelson, J., Giacomini, M. K., Lehoux, P., & Gauvin, F.P. (2007). Bringing “the public” into health technology assessment and coverage policy decisions: From principles to practice. *Health Policy*, *82*(1), 37-50. doi:10.1016/j.healthpol.2006.07.009
- Abelson, J., Lomas, J., Eyles, J., Birch, S., & Veenstra, G. (1995). Does the community want devolved authority? Results of deliberative polling in Ontario. *CMAJ: Canadian Medical Association Journal*, *153*(4), 403-412.

- Abelson, J., Miller, F. A., & Giacomini, M. K. (2009). What does it mean to trust a health system?: A qualitative study of Canadian health care values. *Health Policy*, 91(1), 63-70. doi:10.1016/j.healthpol.2008.11.006
- Alvesson, M., & Kärreman, D. (2000). Varieties of Discourse: On the Study of Organizations through Discourse Analysis. *Human Relations*, 53(9), 1125 -1149. doi:10.1177/0018726700539002
- Antaki, C., Billig, M., Edwards, D., & Potter, J. A. (2003). Discourse analysis means doing analysis: a critique of six analytic shortcomings. Retrieved from <http://hdl.handle.net/2134/633>
- Barnes, M. (2002). Bringing difference into deliberation? Disabled people, survivors and local governance. *Policy & Politics*, 30, 319-331. doi:10.1332/030557302760094694
- Barnes, M., & Prior, D. (2009). *Subversive Citizens: Power, Agency and Resistance in Public Services*. Policy Press.
- Benne, K. D., & Sheats, P. (1948). Functional Roles of Group Members. *Journal of Social Issues*, 4, 41-49.
- Blommaert, J., & Bulcaen, C. (2000). Critical Discourse Analysis. *Annual Review of Anthropology*, 29, 447-466.
- Bombard, Y., Abelson, J., Simeonov, D., & Gauvin, F.P. (2011). Incorporating social values and ethics in health technology assessment: A participatory approach. *Social Science & Medicine (accepted)*.
- Bostwick, M. (1999). Twelve Angry Citizens: Can Citizens' Juries Improve Local Democracy in New Zealand? *Political Science*, 50(2), 236 -246. doi:10.1177/003231879905000208
- Bourdieu, P. (1991). *Language and Symbolic Power*. (J. B. Thompson, Ed.). Harvard University Press.
- Bourdieu, P. (1997). The Forms of Capital. *Education: Culture, Economy, Society* (pp. 46-58). Oxford: Oxford University Press.
- Bracci, S. (2001). Managing Health Care in Oregon: The Search for a Civic Bioethics. *Journal of Applied Communication Research*, 24, 29(2), 171-194.
- Chafe, R., Merali, F., Laupacis, A., Levinson, W., & Martin, D. (2010). Does the Public Think It Is Reasonable to Wait for More Evidence Before Funding Innovative Health Technologies? The Case of PET Scanning in Ontario. *International Journal of*

- Technology Assessment in Health Care*, 26(02), 192-197.
doi:10.1017/S0266462310000024
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis* (1st ed.). Sage Publications Ltd.
- Cohen, C. B. (2005). Promises and Perils of Public Deliberation: Contrasting Two National Bioethics Commissions on Embryonic Stem Cell Research. *Kennedy Institute of Ethics Journal*, 15(3), 269-288.
- Cohen, J., & Rogers, J. (2003). Power and Reasons. In A. Fung & E. Olin Wright (Eds.), *Deepening Democracy: Institutional innovations in empowered participatory governance* (p. 250). London: Verso.
- Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research: techniques and procedures for developing grounded theory*. SAGE.
- Creswell, J. W. (2007a). Chapter 2: Philosophical, Paradigm, and Interpretive Frameworks. *Qualitative Inquiry & Research Design: Choosing among five approaches* (2nd ed.). SAGE.
- Creswell, J. W. (2007b). Chapter 4: Five Qualitative Approaches to Inquiry. *Qualitative Inquiry & Research Design: Choosing among five approaches* (2nd ed.). SAGE.
- Davies, C., Barnett, E., & Wetherell, M. (2006). *Citizens at the centre: deliberative participation in healthcare decisions*. The Policy Press.
- De Vries, R., Stanczyk, A., Wall, I. F., Uhlmann, R., Damschroder, L. J., & Kim, S. Y. (2010). Assessing the quality of democratic deliberation: a case study of public deliberation on the ethics of surrogate consent for research. *Social Science & Medicine* (1982), 70(12), 1896-1903. doi:10.1016/j.socscimed.2010.02.031
- DeJean, D., Giacomini, M., Schwartz, L., & Miller, F. A. (2009). Ethics in Canadian health technology assessment: a descriptive review. *International Journal of Technology Assessment in Health Care*, 25(4), 463-469. doi:10.1017/S0266462309990390
- Department of Health. (1992). *Local Voice*. London: NHSME.
- Donovan, J., & Coast, J. (1996). Public Participation in Priority Setting: commitment or illusion? *Priority setting: The health care debate* (pp. 203-224). Chichester: Wiley & Sons.
- Dowlen, O. (2008). *Sorted: Civic Lotteries and the Future of Public Participation*. Toronto, Ontario: MASS LBP.

- Dryzek, J. S. (2000). *Deliberative democracy and beyond*. Oxford: Oxford University Press.
- Dukes, S. (1984). Phenomenological Methodology in the Human Sciences. *Journal of Religion and Health*, 23(3), 197-203.
- van Eeten, M. (2001). The challenge ahead for deliberative democracy: in reply to Weale. *Science and Public Policy*, 28, 423-426. doi:10.3152/147154301781781200
- Einsiedel, E. F. (2002). Assessing a controversial medical technology: Canadian public consultations on xenotransplantation. *Public Understanding of Science*, 11(4), 315 -331. doi:10.1088/0963-6625/11/4/301
- Einsiedel, E. F., & Eastlick, D. H. (2000). Consensus Conferences as Deliberative Democracy. *Science Communication*, 21(4), 323 -343. doi:10.1177/1075547000021004001
- Entwistle, V. A., Renfrew, M. J., Yearley, S., Forrester, J., & Lamont, T. (1998). Lay perspectives: advantages for health research. *BMJ*, 316(7129), 463 -466.
- Epstein, P., Wray, L., & Harding, C. (2006). Citizens as Partners In Performance Management. *Public Management (00333611)*, 88(10), 18-22.
- EUnetHTA. (2008). *HTA Core Model for Medical and Surgical Interventions* (Work Package 4 No. Version 1.0r). Common Core HTA. European Network for Health Technology Assessment. Retrieved from <http://www.eunethta.net/upload/WP4/Final%20Deliverables/HTA%20Core%20Model%20for%20Medical%20and%20Surgical%20Interventions%201%200r.pdf>
- Farjou, G., & Abelson, J. (2011). *The Role of Universalism and Inclusivity in Deliberative Democracy*. Unpublished manuscript, Hamilton, ON.
- Finlay, L. (2002). “Outing” the researcher: the provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12(4), 531-545.
- Fishkin, J. S. (1991). *Democracy and Deliberation*. New Haven: Yale University Press.
- Forbat, L. (2009). Engaging patients in health care: An empirical study of the role of engagement on attitudes and action. *Patient Education and Counseling*, 74(1), 84-90.
- Gee, J. P. (2004). Chapter 2: Discourse Analysis: What Makes It Critical? *An Introduction to Critical Discourse Analysis in Education*. Mahwah, New Jersey: Lawrence Erlbaum Associates, Publishers.
- Gee, J. P. (2005). *An introduction to discourse analysis: theory and method*. Routledge.

- Gee, J. P. (2010). *How to do Discourse Analysis: A Toolkit* (1st ed.). Routledge.
- Giacomini, M. (2010, April 12). *Backgrounder: Models for Ethics & Social Values Analysis in HTA*. Presented at the OHTAC Social Values and Ethics Evaluation Subcommittee.
- Giacomini, M. K., Cook, D. J., Streiner, D. L., & Anand, S. S. (2000). Using Practice Guidelines to Allocate Medical Technologies. *International Journal of Technology Assessment in Health Care*, 16(04), 987-1002. doi:10.1017/S026646230010306X
- Giacomini, M. K., Hurley, J., Gold, I., Smith, P., & Abelson, J. (2004). The policy analysis of “values talk”: lessons from Canadian health reform. *Health Policy*, 67(1), 15-24. doi:10.1016/S0168-8510(03)00100-3
- Gold, S. K. T., Abelson, J., & Charles, C. A. (2005). From rhetoric to reality: including patient voices in supportive cancer care planning. *Health Expectations*, 8(3), 195-209.
- Goold, S. D., Biddle, A. K., Klipp, G., Hall, C. N., & Danis, M. (2005). Choosing Healthplans All Together: A Deliberative Exercise for Allocating Limited Health Care Resources. *Journal of Health Politics Policy and Law*, 30(4), 563-602. doi:10.1215/03616878-30-4-563
- Grogan, C. M., & Gusmano, M. K. (2005). Deliberative Democracy in Theory and Practice: Connecticut’s Medicaid Managed Care Council. *State Politics & Policy Quarterly*, 5(2), 126-146.
- Gutmann, A., & Thompson, D. (1996). *Democracy and disagreement*. Cambridge: Harvard University Press.
- Harper, D. (2006). Discourse analysis. *Choosing methods in mental health research: mental health research from theory to practice* (pp. 47-67). Psychology Press.
- Heginbotham, C. (1993). Health care priority setting: a survey of doctors, managers and the general public. *Rationing in action*. London: BMJ Publishing.
- Hodges, B. D., Kuper, A., & Reeves, S. (2008). Discourse analysis. *BMJ*, 337(aug07_3), a879. doi:10.1136/bmj.a879
- Hoffman, B. (2005). Toward a Procedure for Integrating Moral Issues in Health Technology Assessment. *International Journal of Technology Assessment in Health Care*, 21(03), 312-318. doi:10.1017/S0266462305050415
- INAHTA Ethics Working Group. (2005). *INAHTA’s Working Group on Handling Ethical Issues* (Final Report). Stockholm: INAHTA. Retrieved from <http://www.inahta.org/HTA/Ethics/>

- Inglehart, R., Nevitte, N., & Basáñez, M. (1996). *The North American trajectory: cultural, economic, and political ties among the United States, Canada, and Mexico*. Transaction Publishers.
- Irvin, R. A., & Stansbury, J. (2004). Citizen Participation in Decision Making: Is It Worth the Effort? *Public Administration Review*, 64(1), 55-65. doi:10.1111/j.1540-6210.2004.00346.x
- Jacobs, L. R., Cook, F. L., & Carpini, M. X. D. (2009). *Talking together: public deliberation and political participation in America*. University of Chicago Press.
- Jaworski, A., & Coupland, N. (1999). Introduction: Perspectives on Discourse Analysis. *The discourse reader*. Routledge.
- Jørgensen, M., & Phillips, L. J. (2002). *Discourse analysis as theory and method*. SAGE.
- Kathlene, L., & Martin, J. A. (1991). Enhancing Citizen Participation: Panel Designs, Perspectives, and Policy Formation. *Journal of Policy Analysis and Management*, 10(1), 46. doi:10.2307/3325512
- Klijn, E. H., & Koppenjan, J. F. M. (2000). Politicians and Interactive Decision Making: Institutional Spoilsports or Playmakers. *Public Administration*, 78(2), 365-387. doi:10.1111/1467-9299.00210
- Kreindler, S. A. (2009). Patient involvement and the politics of methodology. *Canadian Public Administration*, 52, 113-124. doi:10.1111/j.1754-7121.2009.00062.x
- Kuhn, T. (2006). A “Demented Work Ethic” and a “Lifestyle Firm”: Discourse, Identity, and Workplace Time Commitments. *Organization Studies*, 27(9), 1339 -1358. doi:10.1177/0170840606067249
- Learmonth, M., Martin, G. P., & Warwick, P. (2009). Ordinary and effective: the Catch-22 in managing the public voice in health care? *Health Expectations*, 12(1), 106-115. doi:10.1111/j.1369-7625.2008.00529.x
- Lehoux, P. (2006). *The problem of health technology: policy implications for modern health care systems*. Routledge.
- Lehoux, P., Tailliez, S., Denis, J.-L., & Hivon, M. (2004). Redefining health technology assessment in Canada: diversification of products and contextualization of findings. *International Journal of Technology Assessment in Health Care*, 20(3), 325-336.
- Lenaghan, J. (1999). Involving the public in rationing decisions. The experience of citizens juries. *Health Policy (Amsterdam, Netherlands)*, 49(1-2), 45-61.

- Lezaun, J., & Soneryd, L. (2007). Consulting citizens: technologies of elicitation and the mobility of publics. *Public Understanding of Science*, 16(3), 279 -297. doi:10.1177/0963662507079371
- Lightfoot, J., & Sloper, P. (2003). Having a say in health: involving young people with a chronic illness or physical disability in local health services development. *Children & Society*, 17(4), 277-290. doi:10.1002/CHI.748
- Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchi, J., Abelson, J., et al. (2002). “The public is too subjective”: public involvement at different levels of health-care decision making. *Social Science & Medicine*, 54(12), 1825-1837. doi:10.1016/S0277-9536(01)00151-4
- Lomas, J., Culyer, T., McCutcheon, C., McAuley, L., & Law, S. (2005). *Conceptualizing and Combining Evidence for Health System Guidance*. Ottawa: Canadian Health Services Research Foundation.
- Martin, G. P. (2008). Representativeness, legitimacy and power in public involvement in health-service management. *Social Science & Medicine*, 67(11), 1757-1765. doi:10.1016/j.socscimed.2008.09.024
- Mays, N., & Pope, C. (1995). Qualitative Research: Observational methods in health care settings. *BMJ*, 311(6998), 182-184.
- McHoul, A., & Grace, W. (1995). *A Foucault Primer: Discourse, Power And The Subject*. Routledge. Retrieved from <http://www.informaworld.com/978-1-85728-553-6>
- Milewa, T. (2006). Health technology adoption and the politics of governance in the UK. *Social Science & Medicine*, 63(12), 3102-3112. doi:10.1016/j.socscimed.2006.08.009
- Mitton, C., Smith, N., Peacock, S., Evoy, B., & Abelson, J. (2009). Public participation in health care priority setting: A scoping review. *Health Policy*, 91(3), 219-228. doi:10.1016/j.healthpol.2009.01.005
- Moje, E. B., Collazo, T., Carrillo, R., & Marx, R. W. (2001). ?Maestro, what is ?quality???: Language, literacy, and discourse in project-based science. *Journal of Research in Science Teaching*, 38(4), 469-498. doi:10.1002/tea.1014
- Mooney, G. H., & Blackwell, S. H. (2004). Whose health service is it anyway? Community values in healthcare. *The Medical Journal of Australia*, 180(2), 76-78.
- Morgall, J. M., & Traulsen, J. M. (1993). *Technology assessment: a feminist perspective*. Temple University Press.

- Morgan, A. (2010). Discourse Analysis: An Overview For The Neophyte Researcher. *Journal of Health and Social Care Improvement*, 2(1). Retrieved from <https://www.wlv.ac.uk/Default.aspx?page=23747>
- National Forum on Health. (1997). *Values Working Group Synthesis Report*. Canada Health Action: Building on the Legacy. Ottawa: Health Canada.
- National Institute for Health and Clinical Excellence. (2008). *Social Value Judgements: Principles for the Development of NICE Guidance*. Second Edition. London: NICE.
- O'Doherty, K. C., & Hawkins, A. (2010). Structuring public engagement for effective input in policy development on human tissue biobanking. *Public Health Genomics*, 13(4), 197-206. doi:10.1159/000279621
- O'Hara, K. (1998). *Citizen Engagement in the Social Union*. Securing the Social Union (pp. 77-110). Ottawa: Canadian Policy Research Networks.
- Ong, B. N. (1996). The lay perspective in health technology assessment. *International Journal of Technology Assessment in Health Care*, 12(3), 511-517.
- Parkinson, J. (2004). Hearing Voices: Negotiating Representation Claims In Public Deliberation1. *The British Journal of Politics and International Relations*, 6(3), 370-388. doi:10.1111/j.1467-856X.2004.00145.x
- Perera, C., Johnson, A. P., Sikich, N. J., Evans, G., Evans, W., Giacomini, M., Glendining, M., et al. (2009). Health Technology Assessment: A Comprehensive Framework for Evidence-Based Recommendations in Ontario. *International Journal of Technology Assessment in Health Care*, 25(02), 141-150. doi:10.1017/S0266462309090199
- Petts, J. (2008). Public engagement to build trust: false hopes? *Journal of Risk Research*, 11(6), 821. doi:10.1080/13669870701715592
- Postmes, T., Spears, R., Lee, A. T., & Novak, R. J. (2005). Individuality and Social Influence in Groups: Inductive and Deductive Routes to Group Identity. *Journal of Personality and Social Psychology*, 89(5), 747-763. doi:10.1037/0022-3514.89.5.747
- Potter, J. A. (1996). Discourse analysis and constructionist approaches: theoretical background. In J. T. E. Richardson (Ed.), *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*. Leicester: BPS Books.
- Romanow, C. R. J. (2002). *Building On Values: The Future of Health Care in Canada - Final Report*. Canada: Commission on the Future of Health Care in Canada.

- Rowe, G., & Frewer, L. J. (2000). Public Participation Methods: A Framework for Evaluation. *Science, Technology, & Human Values*, 25(1), 3-29.
- Rowe, G., Horlick-Jones, T., Walls, J., Poortinga, W., & Pidgeon, N. F. (2008). Analysis of a normative framework for evaluating public engagement exercises: reliability, validity and limitations. *Public Understanding of Science*, 17(4), 419 -441.
doi:10.1177/0963662506075351
- Saarni, S. I., Hofmann, B., Lampe, K., Lühmann, D., Mäkelä, M., Velasco-Garrido, M., & Autti-Rämö, I. (2008). Ethical analysis to improve decision-making on health technologies. *Bulletin of the World Health Organization*, 86(8), 617-623.
- Saward, M. (2000). *Democratic innovation: deliberation, representation and association*. Routledge.
- Scully, J. L., Banks, S., & Shakespeare, T. W. (2006). Chance, choice and control: Lay debate on prenatal social sex selection. *Social Science & Medicine*, 63(1), 21-31.
- Shaw, S. E. (2009). Discourse analysis: what is it and why is it relevant to family practice? *Family Practice*, 26(5), 413-419.
- Simeonov, D., & Abelson, J. (2010). *Citizen' Use of Information in Public Deliberation Processes to Inform Health Technology Assessments*. Presented at the Clinical Epidemiology and Biostatistics Department Research Day.
- Skorupinski, B., Baranzke, H., Ingensiep, H. W., & Meinhardt, M. (2007). Consensus Conferences – A Case Study: Publiforum in Switzerland with Special Respect to the Role of Lay Persons and Ethics. *Journal of Agricultural and Environmental Ethics*, 20(1), 37-52. doi:10.1007/s10806-006-9016-7
- Smith, J. L. (2010). Critical discourse analysis for nursing research. *Nursing Inquiry*, 14(1), 60-70.
- Starks, H., & Trinidad, S. B. (2007). Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research*, 17(10), 1372 - 1380. doi:10.1177/1049732307307031
- Stevenson, C. (2004). Theoretical and methodological approaches in discourse analysis. *Nurse Researcher*, 12(2), 17-29.
- Sunstein, C. R. (2000). Deliberative Trouble? Why Groups Go to Extremes. *The Yale Law Journal*, 110(1), 71-119.

- Tenbensel, T. (Ed.). (2010). Public Participation in Health Policy in High Income Countries. *Social Science & Medicine*, (Virtual Special Issue).
- Timotijevic, L., & Raats, M. M. (2007). Evaluation of two methods of deliberative participation of older people in food-policy development. *Health Policy (Amsterdam, Netherlands)*, 82(3), 302-319. doi:10.1016/j.healthpol.2006.09.010
- Value Addition through Genomics and GE3LS. (2011). Discourse Analysis and the Impact of Public Engagement on Policy. *VALGEN Policy Brief*, (16).
- Walker, D., & Myrick, F. (2006). Grounded Theory: An Exploration of Process and Procedure. *Qual Health Res*, 16(4), 547-559. doi:10.1177/1049732305285972
- Walmsley, H. (2010). Biobanking, public consultation, and the discursive logics of deliberation: five lessons from British Columbia. *Public Understanding of Science (Bristol, England)*, 19(4), 452-468.
- Weale, A. (2001). Science advice, democratic responsiveness and public policy. *Science and Public Policy*, 28, 413-421. doi:10.3152/147154301781781237