

**“IT’S NOT PROBABILITIES, IT’S POSSIBILITIES”:
LAY VIEWS OF DISCLOSURE REGARDING EMERGING HEALTH ISSUES**

**“IT’S NOT PROBABILITIES, IT’S POSSIBILITIES”:
LAY VIEWS OF DISCLOSURE REGARDING EMERGING HEALTH ISSUES**

By

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ABSTRACT

Products and technologies provide us with significant lifestyle benefits but they can also evolve into hazards and bring about concern for human health. A history of poor regulatory performances has resulted in a public displeased with and skeptical of the actors responsible for protecting the public against the unintended effects of progress. It is within this historical and social context that the study explores the following objectives: to understand people's responses to emerging health issues, of which there is considerable knowledge uncertainty and little public awareness; to identify the information needs regarding these issues, and to explore the role of government disclosure for personal decision-making around these issues. Seven focus groups were conducted in Hamilton, Ontario with community members from a range of backgrounds: youth, faith, allophone immigrants, environmental, health, recreational, and mixed. Two scenarios about potential hazards, i.e. a persistent pollutant and extreme heatwaves from climate change, were used to generate discussion about people's experiences with risk and knowledge. Results indicate that emerging health issues are framed by lay individuals as a chronic societal phenomenon. Their concerns about health and well-being, resiliency, and issue comprehension point to an overarching preoccupation about social vulnerability, irrespective of the presence of confirmed hazards. The analysis further revealed several roles for disclosure which would allow for more capacity in personal decision-making; more transparent and accountable regulatory processes, and which could lead to more trustworthy relations between citizens and government.

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Knowledge comes by taking things apart: analysis. But wisdom comes by putting things together. – John A. Morrison

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CHAPTER ONE

INTRODUCTION

1.1 Research Context

In the risk society, products and technologies once thought of as harmless turn out to be dangerous. Health controversies and crises compound to create a pattern of risk that has impacted many dimensions of life. Risk becomes political as hazards have social and economic consequences for which actors must take responsibility. A lay dependency is created in risk experts, and when risks cannot be clearly defined or agreed upon and when regulatory systems fail to protect health, citizens become increasingly skeptical and reflexively turn inwards to make independent and personal risk judgments (Beck, 1992).

Social science risk research has developed in parallel. Interpretive approaches capable of exploring the broader social and historical dynamics of health hazards have developed. They examine how lay individuals develop their own risk expertise in everyday life as well as their understanding of other types of knowledge constructions such as scientific knowledge and policy knowledge (e.g. Wynne, 1996). This type of research has so far shown that people consider the political and economic causality of risk; factoring in social relationships, and accounting for their own personal beliefs. These are contextual attributes that play a significant role in how lay individuals respond to potentially hazardous agents. In this research, the term *emerging health issue* will be used to refer to context and agent combined, including epidemiological and biological features of the hazard (e.g. source, exposure path, and toxicity) and the organizational,

economic, social, and ethical contingencies that affect its impact. Giacomini et al. (2002) echo the use of a broader conception of risk arguing that risk management programs focused on proximate causes of harm are too narrow to be adequate.

While it is analytical risk expertise that typically supports regulatory decisions, it is the citizen who later searches for information and knowledgeable sources relating to the products and technologies they utilize to negotiate risk. Where analytical risk is still undefined, considerable uncertainty about hazardousness and exposure can be found both in terms of scientific knowledge and complexity. This lack of knowledge about potential and theoretical hazards creates an information void or an arena for multiple and often conflicting views. Under these conditions, how does the public make sense of the safety of products and technologies? There is a body of work conducted in experimental settings that explores the types of information people desire about potential and theoretical hazards (see section 2.3.1). However, studies that explore people's information needs through their own framings are relatively recent and few (see section 2.3.2). These studies can explore the contextual dimensions of potential and theoretical hazards, which can be themselves objects of concern.

Currently, Health Canada is focusing aspects of policy research on disclosure of potential and theoretical hazards. It is hoped that providing information early on in the course of knowledge development can better assist the public in their decision-making regarding health risks. From a policy perspective, it is also hoped that disclosure of potential and theoretical hazards can improve transparency and public accountability mechanisms and result in more harmonious government-citizen relations, thereby

improving public trust (Health Canada, 2002). This study was developed out of this federal health policy research initiative. It explores the types of information people desire about consumer goods, risk, uncertainty, and their management. It attempts to understand governmental disclosure from the citizen's perspective.

1.2 Research Problem

Subscribing to the notion that lay understandings and experiences of risk are constructed and negotiated according to the relationships individuals hold with various actors in the social and historical contexts of their lives, we come to understand that certain current conceptualizations of risk are inadequate. Analytical and psychometric characterizations of risk, irrespective of the professional or lay perspective they assume, focus on assessing risk resulting from hazard and exposure. However for its part, analytical risk assessment has been at times unable to foresee key uncertainties and has led to public alienation and distrust of scientists and policy makers (e.g. UK BSE and Canadian tainted blood scandals). Alternatively, in the area of risk communication, psychometric findings can be used to persuade the public of justifiable risk management policies and best practices (Covello et al. 2001). To appreciate the integrative nature of people's understandings, a more democratic framework is needed to assess issue risk; not only the assessment of the likelihood of adverse effects as influenced by hazard and exposure characteristics but also as influenced by the contextual factors present such as the quality of knowledge sharing, the value stakes, the regulatory controls, and the antecedents of both hazard producer and regulator.

This thesis provides an interpretation of the complex relationships that help define how people conceive of emerging health issues, with particular attention to the objects of people's concerns and their information needs. It specifically explores the nature and state of government-citizen relationships surrounding emerging health issues as government acts in roles that can both accentuate and minimize risk: as an information provider, regulator, protector of the public's health, and facilitator of progress. The following research objectives are addressed:

1. To understand people's responses to emerging health issues;
2. To identify the information needs regarding these issues, and
3. To explore the role of government disclosure for personal decision-making around these issues.

1.3 Contributions

This research will contribute substantively to the risk perception and health policy literatures wherein investigations of the contextual relationships shaping lay-defined responses to emerging health issues are relatively recent (circa 2000), few, and still absent from the Canadian perspective. Specifically, this research contributes to our understanding of people's objects of concern, of the power dynamics at play, the scales at which concern occurs, and the knowledge needed for personal decision-making.

Methodologically, this research brings a novel approach to studying information needs through the combined use of factual scenarios depicting unfamiliar and uncertain health issues and a useful but underused method in risk perception research: focus

groups. Data collection through focus groups is particularly insightful when there are power differences between the participants and other stakeholders, when the everyday use of language and culture of particular groups is of interest, and when one wants to explore the degree of consensus on a given topic (Morgan and Kreuger, 1993).

Theoretically, the key findings from this research have informed the development of a conceptual framework for understanding people's sense of vulnerability. The framework contributes a template suitable for the identification of health risk-specific concerns yet inclusive of the other types of concerns within the larger systemic character of emerging health issues. The framework helps identify three main areas of concern that shape people's sense of vulnerability towards emerging health issues: health and well-being, resilience, and comprehension.

People's information needs within these areas of concern, particularly those related to government expectations; were formulated into eleven roles for disclosure and consequently numerous key response opportunities for decision-makers. The policy contributions of this research involve informing policy-makers that people's sense of vulnerability is explicitly linked, not only to potential hazards, but also to the actions and behaviours of government and industry that contribute to the problematic societal trend of emerging health issues. This research suggests that accountable and trustworthy disclosure should be transparent and comprehensive enough to allow people to evaluate government as an actor influencing their sense of vulnerability; that disclosure should be considered not so much a risk communication tool as a window onto risk analysis, decision-making, and regulatory processes, and that because peripheral concerns about

government and industry behaviours and actions persist and are carried over to the next series of health issues, disclosure should be a continuous undertaking and not just used during times of controversy or crises.

1.4 Chapter Outline

Following this introduction there are four additional chapters. **Chapter 2** reviews the risk literature relating to lay responses to hazards from three different research perspectives: geography, psychology, and sociology. The chapter then reviews the information needs literature with an emphasis on risk uncertainty. The thesis is then situated within the small base of public perception literature on risk uncertainty and emergent technologies. Lastly, Healy's (2004a) 'risk in relational terms' is identified and discussed as the theoretical framework informing the research.

Chapter 3 describes the research design and methodology used in this research as well as an outline of the analytical techniques employed.

In **Chapter 4**, the study results are presented. The survey and focus group results are the outcome of seven focus group discussions conducted in Hamilton, Ontario detailing participants' views of emergent health issues and their information needs. The discussion contents are organized within categories representing people's framings, the objects of concern, and their information needs. Views of science, governance, industry, information provision, and disclosure categories reflecting broader dialogues of various emergent health issues are discussed. This chapter also compares the roles of disclosure as expressed in the focus groups with disclosure recommendations expressed by Health

Canada's Public Advisory Committee in documented meeting minutes. The results of this document analysis helped create a convergent validity by reinforcing the accuracy of the interpretation of focus group respondents' views.

Lastly, **Chapter 5** offers a discussion of the implications and applications of the findings. These are contextualized through a conceptual framework for understanding people's sense of vulnerability (Figure 5.1); making explicit connections between health and well-being, personal and societal resilience, and issue comprehension. The framework also suggests that public perception in conditions of significant risk uncertainty is influenced by an assessment of vulnerabilities present at multiple scales. The thesis ends with a discussion of the policy implications of the findings and suggests directions for further research.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This research employs an inductive approach to explore people's views of health issues emerging within the public sphere. Using focus groups of residents of Hamilton Ontario, the research addresses three core objectives:

1. To understand people's responses to emerging health issues;
2. To identify the information needs regarding these issues, and
3. To explore the role of government disclosure for personal decision-making around these issues.

Within the wide range of intellectual perspectives on risk, this chapter opens with a review of the research traditions dealing with environmental health hazards and risk from the lay perspective. The second section reviews the literature on people's information needs for conceptualizing risk. The third and final section discusses the theoretical perspective informing the analysis.

2.2 Research Traditions

In the last thirty years of research into people's perception of hazards and risk, the work of geographers, sociologists and psychologists has intersected as fields have corroborated, making disciplinary boundaries difficult to define (Cutter, 2001). Over time, research on natural and technological hazards has also become less segregated

(Short and Rosa, 1998). Yet, in terms of intellectual history, there are distinctions between *hazard research* in geography and *risk research* within sociology and psychology. Different disciplinary and theoretical concepts and approaches to risk have been developed within each tradition, providing unique perspectives on risk causation and experience. Conversely, the heterogeneity of perspectives and methodologies has delayed the development of an integrated analysis of hazards, risk, and social causes, and their linkages with environments, historical contexts, and social settings (Kasperson, 1992).

The early work on natural hazards led by geographers Gilbert White, Robert Kates, and Ian Burton (circa 1967) envisioned hazards as the outcome of the interaction between natural processes and human activities. In order to improve on hazard mitigation policies, one of the early research problems of hazard researchers was to understand what people thought of natural hazards and how these views influenced their actionable responses to the threats. A series of international field studies led to the development of a natural hazards paradigm linking natural events to societal processes that recognizes that each type of hazard requires of individuals particular sets of protective adjustments or actions. Combined, the studies provided a general understanding of how people felt about extreme events, suggesting that people living in hazard-prone areas tend to underestimate the risk of low-frequency, high-consequence events and were not likely to respond to preventative measures until some kind of tolerance threshold was reached (White, 1974). Research in environmental behaviour has since consistently shown that the link between

knowledge and behaviour is complex and that information is insufficient to change most people's behaviours (Röling and Maarleveld, 1999).

The body of geographical work led by Gilbert White was central in sensitizing psychologists and sociologists to the problems in hazard research relevant to understanding people's attitudes, coping strategies, and limitations (Kunreuther and Slovic, 1986). In the 1980s, research groups developed models that focused on the cognitive processes underlying people's attitudes towards risk (mainly from technological hazards) to identify the variables that have an impact on risk perception. Douglas and Wildavsky (1982) first described a cultural theory of risk whereby group- and culture-level variables can affect the perception of risk. In contrast, the psychometric paradigm developed by Paul Slovic (1987) holds that it is the characteristics of risk itself (as opposed to the characteristics of the perceiver) that affect perception. The psychometric paradigm provided a quantifiable approach for understanding why some risks are acceptable to individuals, while others are not. Psychometric studies found recurrent patterns in the social and psychological contexts of risk: perceived risk is influenced by mental images of a hazard; expert and laypeople tend to have different risk perceptions of hazards, and scientific evidence does not necessarily reduce perceived risk (Fischhoff et al. 1978; Slovic, 1987, 2000; Covello and Merkhofer, 1994). The most significant outcome from this body of work is the discovery of dozens of risk attributes modulating risk perception by heightening or decreasing concern. A series of cross-cultural risk perception studies have identified the following risk attributes as particularly relevant regardless of social or cultural background: familiarity with the risk source;

voluntary acceptance of the risk; ability to personally control the degree of risk; whether the risk source is capable of causing a disaster (catastrophic potential); certainty of fatal impact should the risk occur (dread); undesired impact on future generations; sensory perception of danger; impression of fair distribution of benefits and risks; impression of reversibility of the risk impact; congruence between benefactors and risk bearers; trust in state-operated risk control and risk management; experience (collective and individual) with technology and nature; reliability of information sources, and clarity of information on risk (Renn and Rohrman, 2000).

If the socio-cultural contexts encompassing risk were critical elements of study for hazards researchers (e.g. Whyte, 1986; White, 1988), they are largely neglected within the areas of analytical risk assessment and risk perception. However, sociology has always maintained an interest in situating people's responses towards technological hazards, specifically localized technological disasters, in a cultural, social, and historical context-dependent manner (e.g. Erikson, 1976 and Levine, 1982). Erikson's study in particular signaled the beginnings of qualitative environmental health research, which explores how individuals and communities develop narratives or construct beliefs related to hazards and risk (Brown, 2003). A renewed interest from human geographers later ensued relating to the impacts of technological hazards on psychosocial health (e.g. Taylor et al., 1991; Baxter et al., 1992; Elliott et al., 1993, Crichton et al., 2003). Qualitative findings in environmental health have so far shown that people employ broad viewpoints of risk-related issues by considering political and economic causality,

factoring in social relationships, and accounting for their own personal beliefs to make sense of the influence and impacts of hazards and risk.

In the last decade, research on lay views towards hazards has broadened to include the perception of new products and technologies and emerging environmental health issues, of which hazardousness and risk have yet to be defined by scientific findings, e.g. genetically modified foods (Grove-White et al., 2000; CSEC, 2001; Shaw, 2002), nanotechnology (BMRB, 2004), hydrogen energy (Flynn et al., 2005), and carbon storage and sequestration (Shackley, 2004). Common to these emerging health issues is considerable scientific uncertainty and the public's relative unfamiliarity. It has been suggested that the steady rate of crisis events and controversies appearing in the public sphere have been responsible for stimulating lay people's interest in potential and theoretical hazards and their indeterminate risk. Smith and McCloskey (1998) outline the reasons behind this phenomenon: a lack of knowledge of rapidly evolving scientific and technical processes, a lack of confidence in expert opinions about hazardous operations and processes, and public skepticism in the certainty and capability of scientific theories or technical solutions to mitigate complex environment and health problems.

Public concerns over these types of risk determinants has led researchers interested in studying public perception not to presume *a priori* what the object of a person's perception is in any given issue without first exploring through qualitative research methods how an issue is perceived. In fact, risk may not be the primary or the only focus of an issue; particularly when hazardousness is unknown or uncertain (Grove-White et al., 2000). Thus, public perception studies can help clarify the nature of people's

concerns about emerging health issues and ensure that public debates are accurately framed.

The study of people's views about issues involving potential hazards is not solely a matter of perceptions of risk facts and probabilities and of asking lay people "How safe is safe enough?" as experts would (see Starr, 1969 and Fischhoff et al., 1978). Instead, it is about asking "How safe is fair enough?"; "How safe is voluntary enough?" and "How safe is informed enough?" (Shrader-Frechette, 1997), questions that probe people's views of risk but also of trust, power, and knowledge. Hence, research on public perceptions of risk has identified the object of public responses as any or all of the following: risk magnitudes (e.g. death frequencies), risk attributes (e.g. psychometric qualifiers), mismanagement of risk, dominant institutional framings that neglect aspects of importance to publics or that disrespect public views, and technological progress (Krimsky and Golding, 1992; Marris, 2001). Observably, people's information needs and their framings of emerging health issues may be interchangeable since framings are subject to change as people's experiences of emerging health issues evolve.

2.3 Information Needs

2.3.1 Experimental Models

While it is risk expertise that mainly drives regulatory processes, the public must also negotiate risk. Research into people's information needs about risk has been conducted with aims to shape the contents of disclosure to people's understandings of risk (Kahlor et al., 2003); to understand social differences in risk behaviours (Lindbladh

and Lyttkens, 2003); to give support to the concept of right-to-know (Beierle, 2004), and to explore people's acceptance of new technologies (Frewer, 2003). At the most elemental level of information, Lion et al.'s (2002) study explored what people want to know about specific unfamiliar hazards, namely hazard and exposure characteristics, e.g. what the risks are; what the consequences are; whether the effects are controllable; and when, where, and how people might be exposed. Their results identify the personal relevance of a hazard as the most important determinant of how laypeople might respond. However, the research design falls short of exploring people's information needs about risk uncertainty, message credibility, and the reasons underlying people's inquiries.

Other studies, most noteworthy those of Lynn Frewer and colleagues, have explored not the inquiries about hazards *per se* but rather how people consider risk information. They offer alternative insights into the types of information people desire. For instance, knowledge about the social context of risk messages is likely to be as important as the information being conveyed to the extent to which the source of the risk message is trusted or credible (Frewer and Shepherd, 1994). Moreover, information about the benefits of products and technologies (Frewer et al., 2003) and about ethical considerations are also important (Miles and Frewer, 2001).

Research findings relevant to products and technologies embedded with high uncertainty are of particular relevance to this thesis. Frewer (1999) and Frewer et al. (2002) found that information-seeking behaviours increase under conditions where the hazard is perceived as unknown, uncontrolled, or where knowledge of the hazard is only emerging. Uncertainty about emerging hazards results in heightened concern than for

older hazards, where the message receiver has already formulated perceptions regarding risk. In a review of public attitudes towards novel technologies Frewer (2003) notes that responses can change as an individual receives progressively more information. The author suggests that the focus of communication should be on what is being done to reduce the uncertainty. People seem to want transparency in risk management to be able to make informed choices about hazard exposures. The author concludes that all information about uncertainty should be available in the public domain, together with guidance for consumer decision-making.

It is important to point out that many studies of information needs have considered risk communication as a one-way flow of information, to the extent that their experimental settings compel respondents to react to strategically formulated messages about risk (e.g. Frewer and Shepherd, 1999; Kahlor et al., 2003; Lion and Meertens, 2005). Bates (2005) considers these studies to be using a “transmission model of communication” which assumes that people are interested in information about the risk aspects deemed important by the experimenter prescribing to various risk perception paradigms. Indeed with surveys or polls, there is little room in the methodology for respondents to argue about the information and call for alternative interpretations. Paradoxically, the model contrasts to the widely acknowledged definition of risk communication as “an interactive process of exchange of information and opinion among individuals, groups, and institutions” (National Research Council, 1989).

2.3.2 Qualitative Research Models

An optimal approach to understanding people's information needs requires the combination of different methodologies. Qualitative research designs allow members of the public to articulate their own ideas using their own vocabulary. These studies offer more refinement, i.e. more detailed information needs, and more insight, i.e. knowing the rationales behind information needs, in the investigation of the types of information people want in unfamiliar and uncertain circumstances.

Results of the Public Acceptance of Agricultural Biotechnologies (PABE) project (see CSEC, 2001) as reported by Marris (2001) describe the following 'lessons learned' on BSE and other issues from PABE's 14 European focus groups: it is impossible to anticipate all risks – especially in the long-term; uncertainty is not admitted and not taken into account in the decision-making process; preventive action is delayed even when risks become apparent; even when rules are established, they are not strictly adhered to; there is no transparency in decision-making, and important decisions which influence our lives are made by unaccountable 'alien' institutions over which we have no control. The PABE findings also indicate that public concerns with respect to the handling of health controversies can persist and accumulate as previous health issues help shape people's understandings of future health issues – a phenomenon akin to that described by the social amplification of risk framework. Specifically, study participants used their experiences of scientific innovation, regulation, commercial pressures, and the complexities of social and ecological systems to construct their opinions about biotechnology. The authors of the study suggest that it is perhaps the history of

institutional behaviour (e.g. denial of scientific uncertainties) that may be responsible for the lack of trust contemporary societies perceive and not the risk communication strategies (e.g. the quality of disclosure). If this is the case, institutions like Health Canada, which hope to rebuild trust by improving on their risk communications, may face poor results.

Smith and McCloskey (1998) have recognized this shift or escalation of public concern from a focus on hazard to that of trustworthy expert and lay relations. They raise key trust issues within risk communication: What is the role of expert judgments in the lay conceptualization of risk when there is a lack of trust? How publicly credible is the public sector as a regulatory interface between risk generating organizations and the public if it may choose to selectively disclose or withhold risk information? Because governments are responsible for both human and environmental safety as well as for encouraging and promoting technological progress, they create conditions, as with the BSE crisis, where vested interests can become key variables in decision-making processes to the neglect of consumer safety.

Taking into account our history with hazards is important. Figuratively, society has asked itself: "How could such a thing come to happen?" many times. In other words, if trust can only be built up gradually over time, the increasing number of emerging threats to the environment and our health is preventing reserves of trust from being replenished or worse, it is diminishing them. Perceived risks to the social fabric render vulnerable the relationship of interdependence between the public and decision-makers (Turner and Pidgeon, 1997). Moreover, when our problem-solving expectations of

science and expertise are not met or when their performances have shortcomings or fail, trust is diminished along with our sense of security (Short and Rosa, 1998).

Wilsdon and Willis (2004, p.28) stress that with regards to new products and technologies entering the market, that is before any hazard is perceived, citizens are likely to be reticent and insist on asking: “Why this technology? Why not another? Who needs it? Who is controlling it? Who benefits from it? Can they be trusted? What will it mean for me and my family? Will it improve the environment?” Answers to such questions would enable people to scrutinize the underlying assumptions and values that underpin technological innovations, in effect potential hazards. Thus, it may be important to provide the earliest disclosure before new products and technologies are even put to use (Macnaghten et al. 2004).

In an age of information, people are exposed to multiple sources of information. Consequently, understanding the process by which people retrieve and receive information has relevance for understanding people’s information needs. Bates (2005) explored through focus groups how people made use of cultural messages from news, sci-fi, and documentaries to understand genetics research. The findings showed that media information and public understanding do not exist in a one-on-one relationship. Instead, people utilize a variety of information sources to critically and complexly integrate and re-organize information to produce ideas and meanings. The author argues that although it is useful to understand how people respond to message content, it is also necessary to examine how people use that content, how their response is influenced by the source of the message, and what messages people choose as important ones and why.

Logar and Pollock (2005) have noted that non-disclosure by regulatory agencies of information on novel technologies (i.e. transgenic fish) forces the public to rely on “speculative rhetoric” from interest groups and media. Their argument assumes that people will take at face value any information they receive without first interpreting it. It reflects, what Horlick-Jones et al. (2004) believe is a failure of regulatory bodies to appreciate that personal decision-making on risk and risk management is neither wholly technical, social, or political, but combines all of these dimensions. People have also come to understand that science does not have the monopoly on truth. In a study by Lindbladh and Lyttkens (2003), interview respondents identified a fundamental property of scientific risk information: what is valid one day could be invalid the next. Risk information is inconsistent and ever evolving.

2.4 Theoretical Context

This research considers that emerging health issues are not solely about harm and its likelihood, but that these issues are rooted in social and historical context, institutional performance, and trust. Thus, its thesis is founded on the theoretical and methodological understanding that the objects of people’s responses are multidimensional and that in order to grasp the nature of these responses, these must be explored within people’s own contextual framings and in their own words.

The theoretical context in which this research is situated is what Healy (2004a) coins *risk in relational terms*. The subscribed approach has two components: Actor-Network Theory, where risk is seen as shaped by social, material, and conceptual

relationships, and Epistemological Pluralism, where the observational viewpoint on emerging health issues recognizes multiple knowledge constructions and is unclouded by a particular epistemological stance. Hence, Healy proposes an alternative approach to the study of risk in health issues that both transcends and complements the dominant intellectual traditions in hazard and risk research.

2.4.1 Epistemological Pluralism

The emergence of an ever-increasing number of hazards from scientific and technological progress coupled with frequent accounts of managerial dysfunction and neglect have contributed to an increasingly disbelieving public (Powell and Leiss, 1997). Beck (1992) and Giddens (1991)'s analysis of the erosion of authority in the late modernity center on risk and the limits of scientific expertise. The alternatives they describe (i.e. Giddens's *humanization of technology* and *multi-layered democratic participation*, and Beck's *sub-politics* and *reflexive scientization*) involve decentralized democracy through decision-making. These social theorists see an important role for public participation in risk decision-making but as theorists they fall short of explicitly formulating how a democratization of knowledge is possible and by what means.

Alternatively, at the center of Funtowicz and Ravetz's interest is not democracy but science. Through their exploration of the ethics of uncertainty in their work on risk management, Funtowicz and Ravetz (1992, 1993, and 1999) have conceived of a *post-normal science*. It contrasts to Kuhn's (1962) 'normal' science and its traditional methods of investigation as well as the 'normal' policy environment where traditional methods of

risk analysis are adequate to justify policy decisions (De Marchi and Ravetz, 1999). Their concept of managing complex and uncertain issues proposes an adjustment of the role of science for policy making when ‘hard’ decisions have to be made on the basis of ‘soft’ information. The standard phrase referring to post-normal science is that in some policy processes facts are uncertain, values are in dispute, stakes are high, and decisions are urgent (Funtowicz and Ravetz, 1992).

When risk cannot be quantified or when possible damage is irreversible, we are out of the range of the traditional expertise and problem-solving strategies. The authors distinguish between the knowledge realms of applied and normal science, professional consultancy, and post-normal science using two analysis criteria: system uncertainties and decision stakes (Figure 2.1) By ‘decision stakes’ Ravetz (2004) means the investments and commitments, personal, commercial, and institutional that are at stake in the inquiry.

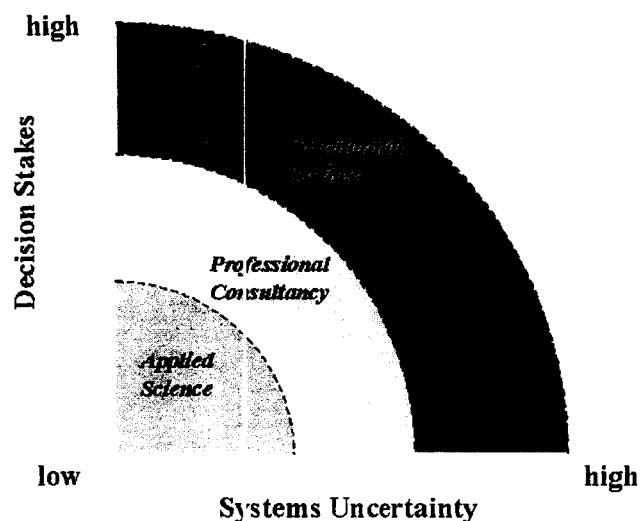


Figure 2.1 Analysis Criteria Diagram (Funtowicz and Ravetz, 1992)

Emerging health issues are post-normal issues: data are often insufficient to make them fully comprehensible (e.g. biotechnology, persistent pollutants, nanotechnology, and climate change), they are often global and long-term in their impacts or have ill-defined boundaries in space and time. Thus, normal science knowledge is incapable of or unreliable in considering important non-quantifiable elements such as uncertainties and unknowns, and fails to foresee many of the emerging risks (Wynne, 1996). In Funtowicz and Ravetz's theoretical construct of post-normal problems, it is not so important whether risks 'really' exist and how they 'really' are, but rather how they are constructed and managed by people (Pellizzoni, 1999). To understand this, Funtowicz and Ravetz (1999) propose the use of *extended peer communities* (e.g. focus groups, public hearings, and town hall meetings); in essence participatory methods that integrate the public's participation in decision-making by contributing social knowledge; setting context; conveying alternative perspectives and values, and legitimizing policy.

However, Healy (2003) argues that there is more to dealing with post-normal problems than simply adding the public's perspectives and interests to the discussion, so long as these problems continue to be discussed using a dominant construction of knowledge, e.g. science. In effect, 'extended peer communities' is a process that offers to 'democratize' knowledge by providing public input to current political practices based on scientific knowledge. Current usage of the precautionary principle in society reflects this whereby the production and use of products and technologies are negotiated within democratically chosen constraints (e.g. public pressure to GM potatoes) to avoid adverse outcomes. This maneuvering implies that there are different forms of knowledge and a

power dynamic between them; social interests may influence science and policy but they still remain subordinate to the prevailing culture of expertise – and there lies the tension. Alternatively, Healy (2003, 2004a) suggests that knowledge should be viewed in terms of *shaping* our reality through the interactions of its various forms (epistemic plurality), instead of *reflecting* reality through a dominant body of knowledge (epistemic sovereignty). Brown's (2001) concept of 'nested knowledges' builds on this idea of respect for multiple and integrated forms of knowledge. Figure 2.2 illustrates the relationship between the different forms of knowledge as nested knowledges, each drawing on the other.

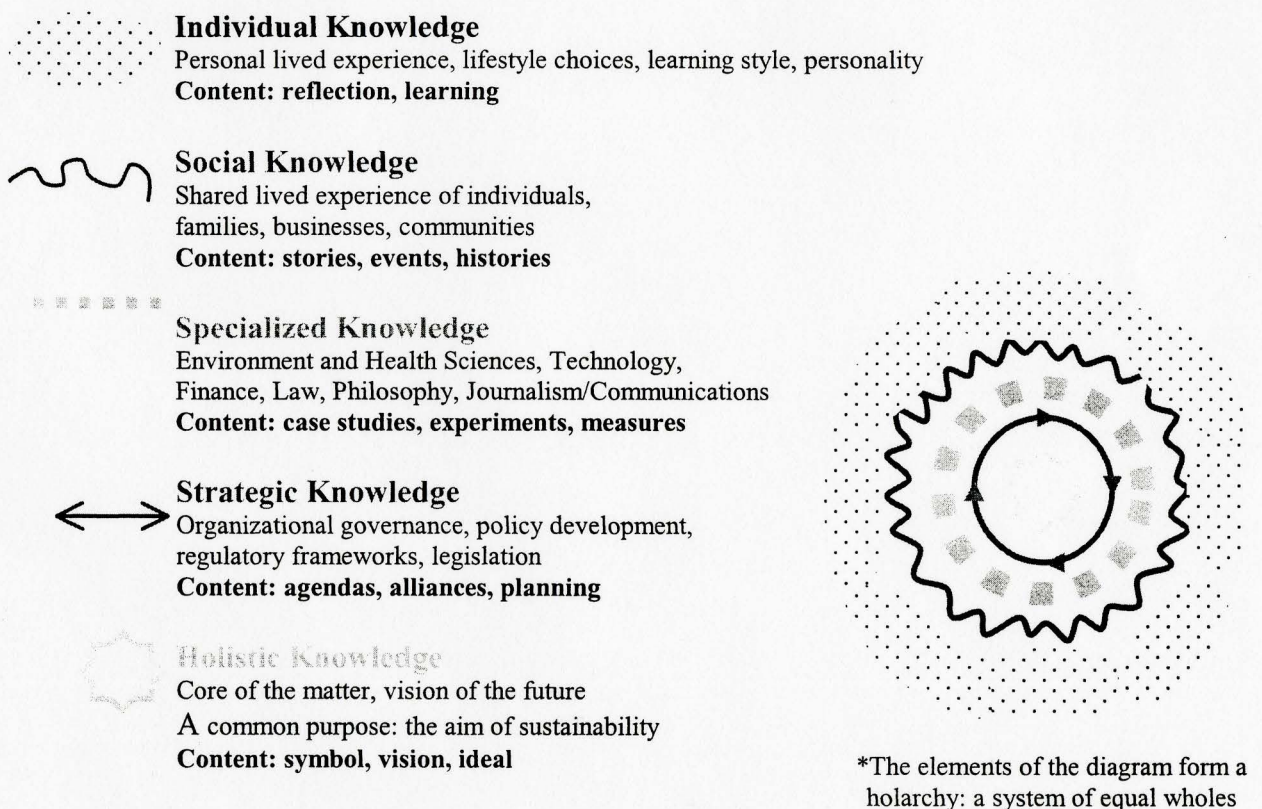


Figure 2.2 Knowledge cultures within Western decision-making systems (adapted from Brown, 2001)

Effectively, each form of knowledge depends on the other, so that there is also a cumulative information synthesis: a holarchy, as well as specific modes of information synthesis. As such, knowledge is initially constructed by individuals. Local communities draw on shared individual lived experience. Specialized knowledge is built from data collected from biophysical observations and the experiences of individuals and communities. Strategic knowledge uses specialized and community knowledge in establishing the feasibility of reaching the set goals. Holistic knowledge provides the essence or core of the shared enterprise. The result is a holarchy – a set of interdependent wholes; not the more familiar hierarchy made up of parts ranked in order of importance (Brown, 2001).

The policy question then becomes how do we, as a society, account for and reconcile all forms of knowledge to create informed involvement, choice, and consent in the generation, dissemination, and utilization of knowledge? Healy suggests that is the role of governance. Using two case study examples in his 2003 paper: drinking water contamination in Sydney, Australia and the International Panel on Climate Change's third assessment report, he underlines how institutions self-reflecting and open to focusing their efforts on the processes and practices of knowledge making, knowledge dissemination and knowledge use, create outcomes reflecting epidemiological pluralism through actions such as internal changes to governing institutional structures, assessment procedures, accountability mechanisms, reporting conventions, regulations, and personnel.

2.4.2 The Actor-Network Theory

Actor-Network Theory (ANT) has been adopted by researchers in sociology, geography, and social psychology interested in the processes of interactions. ANT is more of a broad-based perspective than a body of theory. As a research approach, it does not draw a distinction between humans and objects. Instead it describes the social world in terms of the relations between entities (actors) of all forms: social, material, and conceptual, i.e. as networks composed of people, objects and concepts. The argument holds that the hierarchical structures, exchanges, and symbolisms in society would not exist if it weren't for the heterogeneous networks of entities in our lives. Hence, the study of entities, e.g. the study of products, hazards, "the public", regulatory frameworks, trust, and risk, may be conducted through a characterization of the patterns of networks (Law, 1992).

ANT has two major features: *relational materiality*, which is the notion that entities are maintained through their relations with other entities, and *performativity*, which refers to how entities define those relations (Law, 1999). Thus, an ANT reality is constituted by the performances of the relationships, which are also maintaining or reinforcing the entities. Consequently, it is the relationships that demand an intellectual focus, not the entities *per se*. For instance, our views of automobiles (a material entity) are shaped by the relationships which they are a part of (means of transportation, status symbol, source of pollution, expense, source of accident, etc...). These relationships, perceived as beneficial, detrimental, dangerous, etc..., are the focus of our preoccupations. Bruno Latour (1993) argues that intellectual perspectives, such as science

and policy, engage only partially with reality by focusing on certain entities (e.g. harm from hazards) and downplaying or ignoring other aspects of reality (e.g. social norms, value stakes, and socio-economic limitations). Applied to the post-normal domain (high uncertainty, high stakes issues), he notes that problems such as Ozone Depletion and BSE persist, proliferate, and compound today because the complex interplay between entities that constitute these issues is not being addressed. A more tangible example of this is Donaldson et al.'s (2002) study of the effects of the 2001 UK foot-and-mouth disease (FMD) epidemic – not on the livestock industry, but on wider rural economies. He used an ANT framework to follow the chains of associations that led from virus to disease, from disease to a collection of crises, and on to institutional change. The study highlights the lack of attention during the crisis to the complexities and interconnectedness of rural economies (which also comprise tourism and agriculture within the same landscape) and the subsequent alteration of the policy context in rural areas from one of crisis management to post-FMD rural governance. The ANT perspective showed that although mismanagement had a role to play in this contextual translation, fundamentally its cause was the misidentification of the actors involved. Explicitly, the initial problematization was partial (industry-focused) and excluded the majority of actors involved (communities).

2.4.3 Merging the Theories: Risk in Relational Terms

In this thesis, risk is defined as the possibility of an adverse outcome, and uncertainty over the occurrence, timing, or magnitude of that adverse outcome (Covello

and Merkhofer, 1994). The adopted notion of risk is subjective to the extent that risk does not exist independent of our minds and cultures. It is a concept we construct to facilitate our understanding of threats and uncertainties in life (Krimsky and Golding, 1992).

Conceptually, Healy (2004a, p. 285) suggests that,

“A condition of risk exists when the performance of an ensemble [network] varies or deviates from that intended so as to result in unwanted, deleterious consequences. A key concern here is to provide an account of these dynamics and to explain how conditions of risk arise and might be ameliorated.”

This statement illuminates how risk when conceived as dependent upon the interrelationships between entities highlights their scale and complexity. These parameters are largely ignored or ill-controlled in traditional representations of risk but they are critical to understanding how emerging health issues can eventually develop into crises and controversies. The findings of this research provide an exemplar application of conceiving of risk in relational terms using actor-network theory and epistemological pluralism.

Specifically, this thesis adopts the perspective that there exist multiple forms of knowledge and as a result a lay individual will consider an assortment of knowledge types. Adopting a perspective of epistemological pluralism to the study of emerging health issues also enables us to consider the value of people’s knowledge on par with that of scientific knowledge. It ignores the perception/fact differentiation, which is largely made irrelevant by scientific uncertainties and unknowns. Adopting a perspective of actor-network theory allows us to focus on the social and power relations that subsist between the actors involved in these issues. This is particularly useful for exploring lay-

expert, public-government, and public-industry relationships where information sharing is contentious but required for publics to aptly evaluate risk.

Risk: the likelihood of adverse effects, is considered here as a dynamic conceptual entity; its evaluation results from the interactions of complex and multi-scale ensembles of social, material, and conceptual entities. In this respect, this relational perspective on risk facilitates the holistic description of the social (e.g. lay-expert relationships), material (e.g. lay-hazard relationships), and conceptual (e.g. vulnerability and resiliency) framing processes of emerging health issues. Whereas contemporary attempts to solve risk related-issues have tended to emphasize one conceptual risk perspective over another, i.e. objectivist or subjectivist, risk in relational terms is incompatible with epistemological sovereignty. Rather, it transcends the familiar dichotomous representation of risk by remaining open to all knowledge perspectives. Without explicit referencing, some of these principles have been used by researchers studying public perceptions of emergent technologies (e.g. Grove-White, 2000), to the extent that they have remained open to public framings of novel technologies thereby uncovering more refined constitutive relations like 'institutional behaviour' and 'past controversies', which influence how laypersons perceive risk.

Emerging health issues certainly include emergent technologies. Moreover, they encompass the multitude of health-related problems society potentially faces in time or in space or both from products, technologies, and vectors. Albeit wide-ranging, they are certainly a discernable notion in our risk society. This area of environmental health research is in need of alternative approaches that can bring insight into unifying

conflicting forms of knowledge to resolve multi-actor, multi-scale, and multi-sector problems. The current research can contribute to building ‘knowledge-unifying policies’ through a citizen-centered perspective on emerging health issues. By adopting Healy’s (2004a) conception of risk in relational terms, this research will explore people’s framings of emerging health issues; explicitly, understanding their views and the objects of concern to inductively identify people’s disclosure needs within post-normal arenas.

2.5 Summary

This chapter began by providing an overview of how the disciplines of geography, psychology, and sociology have investigated lay responses to hazards and risk. The review of their disciplinary contributions revealed that the relative input of apparently universal risk attributes to a person’s views of and attitudes towards risk ultimately depends on a combination of intrinsic values and a range of contextual factors. The focus then shifted to the contributions of public perception research, the research approach guiding this thesis, outlining the particular value of this relatively recent body of work for exploring in-depth people’s framings of issues that present both unfamiliarity and uncertainty. Subsequently, research into people’s information needs was reviewed. While much of this area of research has utilized experimental modes of inquiry, qualitative research models are now gaining in popularity. These allow more refinement and complexity in the investigation of the types of information people want in unfamiliar and uncertain circumstances. The chapter closed with the thesis’ theoretical context informed by epistemological pluralism and an actor-network theory perspective on risk.

A review of both concepts identified that this research required a framework that could draw upon their combined and compatible perspectives. Epistemological pluralism contrasts to epistemological sovereignty, where a dominant form of knowledge (e.g. science) underlines policy actions. Epistemological pluralism on the other hand, considers all forms of knowledge equality. While it is a particularly useful way to conceive of problem-solving knowledge in situations of high uncertainty, it does not provide means of understanding where power relationships lie – an important component of public framings of emerging health issues particularly as it relates to trust. The actor-network theory perspective seeks to investigate the relationships between entities, which in turn define those entities. These two perspectives help conceive of risk in relational terms (Healy, 2004) and provide a basis from which to conceptualize people’s risk-related framings of emerging health issues, particularly in the context of lay-expert, public-government, and public-industry relationships where information sharing is contentious but required for publics to aptly evaluate risk, and where high uncertainty lessens the merit of epistemic sovereignty: science-for-policy practices, which create tensions between publics, industry, and government. Chapter three provides an explanation of the research design and methodology which permitted the exploration of people’s risk-related framings of emerging health issues.

CHAPTER THREE

RESEARCH DESIGN

3.1 Introduction

This chapter outlines the research design and methodology used to address the research objectives.

1. To understand people's responses to emerging health issues;
2. To identify the information needs regarding these issues, and
3. To explore the role of government disclosure for personal decision-making around these issues.

The chapter begins by introducing the Health Canada policy research project which instigated this thesis. The methods used in this study are subsequently described, including the data collection methods, i.e. sampling strategy, focus groups, survey, and scenarios. The chapter concludes with a description of the analytical techniques employed.

3.2 Health Policy Research Project

The research reported in this thesis forms the pilot component of a policy study conducted by the McMaster Institute of Environment and Health (MIEH) titled "Using scenarios to explore disclosure needs about potential health hazards". Both pilot and main study were reviewed and approved by the McMaster Research Ethics Board. The MIEH project led by John Eyles and Susan Elliott is an independently-conducted research

project funded by Health Canada's Applied Research and Analysis Directorate within the Health Policy Research Program on public disclosure of potential and theoretical health risks. The program's objective is to support the development of tools and methodologies that complement Health Canada's Decision Making Framework (2000) and improve health policy and regulatory initiatives for better public accountability. In addition, it is hoped that research stemming from this program can point to ways by which Health Canada can enable publics to make informed choices about their personal health risk management. By funding the MIEH study, Health Canada seeks to improve the ways it communicates with the public about potential and theoretical risks to health. From an academic perspective, the MIEH study seeks to understand how potential and theoretical risks are seen as having adverse impacts; how risks are compared to other concerns in life; what trade-offs, if any, are made in assessing and responding to risks, and what information or disclosure is needed to help deal with these issues.

3.3 Study Design and Methodology

To address the research objectives, this study used focus groups. Qualitative research is concerned with developing explanations of social phenomena. Given the exploratory nature of emerging health issues as a research topic, focus groups were chosen as a qualitative methodology for discovering how such issues are constructed and expressed (Miles and Huberman, 1994). That is, how and in what ways do people know what emerging health issues are? Waterton and Wynne (1999) point out that a qualitative

approach can also access the more subtle aspects of people's attitudes about risks that have been theorized and experimentally investigated in risk perception research.

Focus groups are group discussions exploring a specific set of issues. The group is focused in an activity – such as examining a scenario and discussing a related set of questions. A facilitator encourages participants to share and interact: expressing attitudes; exchanging experiences; and commenting on each other's viewpoints. Focus groups are thus appropriate for investigating people's experiences, opinions, wishes, and concerns within a social network, and for allowing participants to generate their own questions, frames, and concepts and for pursuing their own priorities on their own terms, and in their own words within a given cultural context. Focus groups offer advantages over other qualitative methods in that numerous perspectives can be gathered efficiently. Furthermore, group interactions help characterize the nuances in responses and help identify social norms (Kitzinger and Barbour, 1999, p.4-5). In contrast to market research, where ideal participant numbers are between eight and twelve, many social science researchers prefer to work with groups of five or six participants, or even as few as three (p.8).

3.4 Data Collection Tools

The focus groups were conducted in the following manner: participants were asked to complete a brief survey on arrival, after which the focus group began with an introduction by the facilitator and a warm-up question. Subsequently, a scenario was presented in either handouts or through a projector and was read out loud by the

facilitator; participants were asked for their impressions, and a discussion ensued guided by a related set of questions. The process was repeated with a second scenario. The order in which the scenarios were presented alternated with each following focus group.

The scenarios used illustrated two real emerging health issues: 'A persistent pollutant' and 'Extreme heatwaves from climate change' (see Appendix A). These scripts were developed from peer-reviewed literature. The scenarios portrayed the unfamiliarity and the uncertainty that characterize emerging health issues. They conveyed information on the nature of the hazard, its uncertainty, exposure parameters, and susceptibility components.

Although the focus group process outlined above had a defined structure, the topic guide used to facilitate discussions was designed to create a relatively unstructured and open-ended discussion for a broad exploration of participants' thoughts and experiences related to the scenarios and beyond (see Appendix B). Its questions linked to the study's research objectives thereby covering a range of questions relating to people's views of hazards, uncertainty, risk, information-seeking behaviours, information sources, and roles of disclosure. The topic guide enabled both scenarios to be covered with all groups and was flexible enough to allow participants the freedom to discuss other health issues of importance to them.

The survey instrument administered at the beginning of each focus group explored people's concerns about various environmental hazards and their management and collected demographic data on participants (see Appendix C). The survey instrument also proved useful in providing a context for the subsequent focus group discussion.

Both topic guide and survey questions were tested prior to their use. These were examined for clarity of construction and meaning bias by people familiar with the study and the methods. The revised instruments were then tested with a pilot group composed mainly of graduate students and revisions were subsequently made. Despite this, the survey questions were unpopular with many of the participants as questions were deemed to inadequately reflect their views. The focus group discussions provided a subsequent opportunity for participants to fully express their views.

3.5 Sampling and Recruitment

Hamilton, Ontario was chosen as the study's sampling area. Individuals living within this urban landscape were presumed to have some common frames of reference of the living environments they share, which in turn facilitates social interactions and understandings. Flyers, postings, and email announcements were used to advertise the study locally. In some cases, contacts were made with 'gatekeepers' (Hammersley and Atkinson, 1995), i.e. resource persons within organizations, which in turn informed their members of the study's need for participants. Recruitment efforts were directed towards organizations that fit specific lines of interests (Table 3.1).

Table 3.1

Recruitment Strategy

Focus groups	Number of Participants	Mode/Place of Recruitment
Culture	8	A Franco-African immigrant community
Recreational	10	A sailing club
Faith	3	An inter-faith group
Environmental	3	Local environmental groups
Youth	13	A local youth drop-in center
Health	6	Public health organizations and a nursing school
Non-affiliated/mixed	9	Public advertisements (unsuccessful); via other focus groups recruitment efforts

For the non-affiliated/mixed focus group, recruitment from advertisements posted in libraries and community notice boards was unsuccessful. Consequently, this group was composed of both individuals unable to attend other scheduled focus group and individuals identified by others having participated in previous focus groups (snowball sampling).

The seven focus groups were conducted between October 15 and 29, 2004. Each lasted between sixty to ninety minutes. Fifty-two participants were distributed in groups according to the common interest they shared in either culture (N=8), a recreational activity (N=10), faith (N=3), environmental issues (N=3), youth activities (N=13), or an interest in the public health sector (N=6). Another group of individuals ('non-affiliated/mixed') were recruited under no particular criteria (N=9). The socio-demographic composition of the sample is summarized in Chapter 4. Appendix D details the socio-demographic characteristics of each focus group.

The purpose of categorizing the focus groups was two-fold. First, to explore potentially influential value-commitments regarding health risks, whereby identifying potential inter-group differences in people's framings of emerging health issues in relation to their different lines of interests. From a qualitative methodological perspective, this categorization may allow confirming and disconfirming accounts to emerge and reveal new insights (Gilchrist, 1992). And second, shared interests may provide a commonality to further facilitate group interactions. In contrast to market research, where strangers are preferred to avoid the 'group effect' from existing relations and shared values, many social science researchers prefer participants who are already acquainted through living, working, or socializing together or at the very least fraternizing in the same milieus. Of this, Kitzinger and Babour (1999, p.8-9) point out:

“These are after all, the networks in which people might normally discuss the sorts of issues likely to be raised in the research session and the ‘naturally-occurring’ group is one of the most important context in which ideas are formed and decisions made.”

3.6 Data Analysis

The focus groups discussions were tape-recorded for verbatim transcription. Data were entered into NVivo, a software program that facilitates the organization and management of qualitative data. The data analysis drew on techniques derived from the principles of grounded theory (see Glaser and Strauss, 1967 and Strauss and Corbin, 1998). It drew specifically on open coding and the 'constant comparison' method to generate core thematic categories from the data. The analysis also focused on the use of

'sensitizing concepts': key theoretical and empirical ideas in the literature used to create the beginnings of the coding scheme (Charmaz, 2002).

The process of coding the transcripts began where segments of text representing ideas, concepts, opinions, and exchanges were identified. This process is iterative and inductive, requiring re-reading and re-coding of transcripts as codes are progressively refined and broadened with a deepening of understanding of the discussions. The coding scheme is progressively transformed into a reflection of the participants' own framings of emerging health issues and their objects of concern. When no new categories emerged from the transcripts, the coding scheme was considered complete. Appendix E presents the final coding scheme.

The evaluation of reliability, i.e. the degree to which the findings are consistent and independent of accidental circumstances of the research (Kirk and Miller, 1986, p.20), was not evaluated through inter-coder agreement because of the absence of multiple investigators in this study. Albeit, this is a useful method for verifying that respondent's discourses are accurately represented in the analysis, Janet Ward-Schofield (1993, p.202) suggests that multiple interpretations does not necessarily lead to representation:

...at the heart of the qualitative approach is the assumption that a piece of qualitative research is very much influenced by the researcher's individual attributes and perspectives. The goal is not to produce a standardized set of results that any other careful researcher in the same situation or studying the same issues would have produced. Rather it is to produce a coherent and illuminating description of and perspective on a situation that is based on and consistent with detailed study of the situation.

Alternatively, the evaluation of reliability was performed through consistency and comparability assessments via the combined methods of intra-analyst reliability and synchronic reliability. The former establishes consistency and refers to the extent to which the same person analyzing the data comes to the same coding conclusions (Goodwin and Goodwin, 1984). Repeating the coding procedure for a sample of each of the transcripts yielded near consistent results with the final coding scheme. The method of synchronic reliability refers to the similarity of observations within the same time frame. It concerns itself with particularities of interest to the research (Kirk and Miller, 1986). For this, a convergence assessment was performed, whereby document analysis results from a public advisory committee were compared against focus group results pertaining to disclosure (see Section 5.4 and Table 5.3). This exercise yielded comparable findings.

The interpretation of the focus group data was based on an examination of the variations of responses within categories, the nature of the associations between the categories, and inter- and intra-group converging and diverging views. The coding categories were compiled in tables according to total frequency and number of group mentions. Frequencies provide some additional support for the analyst's choice of thematic categories (Silverman, 1985). Chapter four provides these tabular results accompanied by respondent quotations chosen for their explanatory power as well as by interpretive descriptions relating each of the thematic categories.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the results of the analysis of the survey instrument and focus group discussions completed in Hamilton, Ontario with individuals from a range of backgrounds (i.e. recreational, allophone immigrants, environmental, faith-based, health, youth, and non-affiliated/mixed). These results specifically address the following research objectives:

1. To understand people's responses to emerging health issues;
2. To identify the information needs regarding these issues, and
3. To explore the role of government disclosure for personal decision-making around these issues.

4.2 Survey Results

4.2.1 Socio-Demographics

On arrival focus group participants were asked to complete a brief survey on various environmental health issues. This was done to gather complementary opinions that could contribute to understanding subsequent views. The survey was also beneficial in setting the context of the group discussions. Eight demographic variables were also recorded: sex, age, marital status, number of occupants per household, level of education, occupation status, household income, and health status. Details of the socio-demographic data for each focus group are presented in Appendix D.

The modal age range of the sample was 26-44 years of age. Most described their health as being good or excellent (79%). Of 52 participants, women outnumbered men 2:1. Many participants were single (63%). Recruitment was performed through college and university channels. Hence, many had completed or were in the process of completing a post-secondary diploma or degree (79%) and a number of individuals identified themselves as full time students (46%). The sample is not a representation of the Hamilton population, nor is it intended to be. Nevertheless, socio-demographic information may support interpretations of people's framings of emerging health issues.

4.2.2 Concerns about Environmental Health Issues

In the survey, participants were asked to select the reason that most reflected their concern about several environmental health issues. Table 4.1 presents results in terms of the frequency of participant mentions for each health issue. Inter-group comparisons were not possible considering the small sample size. For most issues, most people indicated that health effects and a lack of trust in regulators are the main reasons to be concerned about these issues. However for GMOs, scientific uncertainty was cited as the most important reason for concern. For extreme events from climate change and outdoor air quality, participants expressed heightened concern about a lack of personal control over the hazards.

Table 4.1
Reasons for Concern about Environmental Health Issues

Environmental Health Issues	Health effects	Lack of trust	Little control	Scientific uncertainty	Not concerned	Did not know	Total (N)
Pesticide use	8 (17%)	14 (29%)	5 (10%)	9 (19%)	5 (10%)	7 (15%)	48
Extreme events from climate change	11 (24%)	4 (9%)	14 (31%)	9 (20%)	6 (13%)	1 (2%)	45
GMOs	6 (13%)	12 (27%)	3 (7%)	19 (42%)	5 (11%)	0	45
Outdoor air quality	19 (40%)	7 (15%)	15 (31%)	3 (6%)	2 (4%)	2 (4%)	48
Indoor air quality	14 (29%)	8 (16%)	8 (16%)	6 (12%)	7 (14%)	6 (12%)	49
Food and water contamination	19 (40%)	13 (28%)	6 (13%)	3 (6%)	3 (6%)	3 (6%)	47
Infectious diseases	21 (45%)	9 (19%)	6 (13%)	5 (11%)	4 (9%)	2 (4%)	47
Blood transfusions	13 (37%)	16 (33%)	2 (4%)	2 (4%)	9 (18%)	2 (4%)	49

4.2.3 Opinions on the Evolution of Hazards

Participants were surveyed on how certain environment health effects, environmental quality, and regulated areas had evolved over the past twenty years. Most believed that compared to 20 years ago, cancer rates, allergy cases, and fertility problems had increased. Participants appeared to be more familiar with trends in cancer rates and allergies than with trends in fertility problems and learning disabilities (Table 4.2).

Table 4.2
Perception of Trends in Health Effects

Environmental Health Effects	Increased	Stayed the same	Decreased	Did not know	Total (N)
Cancer rates	41 (83%)	3 (6%)	3 (6%)	2 (4%)	49
Allergies	37 (74%)	7 (14%)	1 (2%)	5 (10%)	50
Fertility problems	27 (55%)	3 (6%)	2 (4%)	17 (35%)	49
Learning disabilities	17 (35%)	11 (22%)	2 (4%)	19 (39%)	49

Most participants viewed urban air quality, ground litter, water quality, and noise as worse than 20 years ago (Table 4.3).

Table 4.3
Perception of Trends in Environmental Quality

Environmental Quality	Improved	Stayed the same	Worsened	Did not know	Total (N)
Urban air quality	8 (16%)	6 (12%)	35 (69%)	2 (4%)	51
Ground litter	8 (17%)	6 (13%)	27 (56%)	7 (15%)	48
Water quality	14 (29%)	5 (10%)	28 (58%)	1 (2%)	48
Noise	3 (6%)	7 (15%)	33 (69%)	5 (10%)	48

In contrast to health effects and environmental quality, participants were more divided on their views of regulated areas (Table 4.4). Half of participants believed mechanisms controlling car emissions, waste disposal, food inspection, and drinking water treatment had improved in the last twenty years. The other half had somewhat mixed views as to whether these regulated areas had stayed the same or had worsened.

Table 4.4

Perception of Trends in Regulated Areas

Regulated areas	Improved	Stayed the same	Worsened	Did not know	Total (N)
Car emissions	25 (51%)	8 (16%)	13 (27%)	3 (6%)	49
Waste disposal	21 (44%)	12 (25%)	11 (23%)	4 (8%)	48
Food inspection	31 (65%)	3 (6%)	11 (23%)	3 (6%)	48
Drinking water treatment	18 (38%)	13 (27%)	9 (18%)	8 (17%)	48

4.2.4 Opinions on Risk and Information

Participants were asked for their level of agreement on various statements about risk and information (Table 4.5). Most participants (68%) agreed that suspected health threats were as worrisome as proven health threats; more than half (58%) agreed that unless their health is immediately threatened, they are not too concerned about health threats, and most participants (68%) did not think that society accepts too many health risks in exchange for social progress and technological advancements. On information about environmental health risks, opinions were split on whether they were usually informed in a timely manner about potential threats to their health, and on whether they were satisfied with the amount of information they received about health risks.

Table 4.5

Opinions on Risk and Information

Opinions	Agreed	Disagreed	No opinion	Did not know	Total (N)
Suspected just as concerning as proven	34 (68%)	7 (14%)	4 (8%)	5 (10%)	50
Not concerned unless immediately threatened	13 (26%)	29 (58%)	4 (8%)	4 (8%)	50
Society accepts too many health risks	34 (68%)	8 (16%)	3 (6%)	5 (10%)	50
Timely informed	24 (47%)	15 (29%)	7 (14%)	5 (10%)	51
Satisfied with amount of information received	25 (49%)	20 (39%)	2 (4%)	4 (8%)	51

4.3 Focus Group Results

The results of focus group discussions relate to how participants' frame emerging health issues and the objects of their concern. The section begins by detailing the findings as they were discussed within each health issue scenario. It subsequently explains participants' views of informants, information, and disclosure. These results are grouped and indexed within distinct categories. The categories are presented within frequency tables and interpretive summaries supported by quotes subsequently illustrate the categories.

4.3.1 Persistent Pollutant Scenario

Scotchguard and PFOS, the product and the potential hazard in this scenario, were the intended subjects of discussion. However in all focus groups this emerging health issue became a conduit for discussions about many known 'product-potential hazards' presenting similar characteristics. Consequently, Scotchguard-PFOS and other product-potential hazards were discussed interchangeably within all focus groups: foremost, in the

context of negotiating hazard risk and product benefits but also in the exemplification of a problem trend related to a range of consumer products and technologies that are later found to be potentially hazardous.

4.3.1.1 Product/Potential Hazard

The unintended characteristics (e.g. the persistence, bioaccumulation, and toxicity of PFOS) and the purposeful traits of a product or technology were two important types of information respondents considered in their views of product-potential hazards.

Table 4.6

Product/Potential Hazard

Descriptors of Product/Potential Hazard	Total number of mentions	Number of focus groups mentioning (N=7)
Benefits Paradox	25*	7
Hazard Characteristics	13	6

*Number of mentions of the category as defined by segments of discussion involving one or more participants.

Respondents discussed the paradox of wanting the benefits of products and technologies despite the potential of incurring adverse health outcomes:

Well you see we voluntarily use things that we know are hazardous because we want the results... I hate to say it but it's the price we pay for things we want as a society. So when does the price become too high? • **Female, Non-affiliated/mixed**

On the other hand you might have a miracle occur for something like cancer and you say that we can't bring this on the market for 20 years because

that's going to be how long it takes to test it? So there's a trade off here as well. • **Female, Recreational**

Is Scotchguard really all that important? • **Female, Non-affiliated/mixed**

When discussing the scenario specifically, the benefits of Scotchguard were valued and widely recognized:

I couldn't imagine buying a couch and not having it Scotchguarded with the kids around. ...it's one of the things I insisted on. It had to be Scotchguarded because we had children around and a dog. It was terrific stuff. • **Male, Non-affiliated/mixed**

Yet, respondents had clear concerns about the environmental persistence and the bio-accumulation of PFOS, the stain-repellant chemical in Scotchguard. The likelihood that this substance was in their blood was particularly disconcerting:

Any chemical that's going in and not coming out in 20 years, I've got a concern with this. • **Female, Non-affiliated/mixed**

Female: So chances are like all of us have some of this stuff in us right now?

Male: That's kind of creepy. • **Youth**

The possibility of the substance being carcinogenic was also considered, albeit this seemed less stirring than its bio-accumulative property:

As soon as I read that at first I'm saying ok, it causes cancer in mice and I'm not too worried about that. I'm not a mouse. ...but as soon as I noted that it was in my blood, I'm saying...somebody missed that in the testing. • **Male, Faith**

...I also agree that there are many things out there that are risks to health and if it's been out there for 30 years well I've been alive for those 30 years. What is the impact on my life? Is it in all of us now? In some ways it is truly shocking to think that we all now have a component of this in us. • **Female, Recreational**

4.3.1.2 Emerging Health Issues

This category describes the theme of ‘emerging health issues’ as a phenomenon.

Table 4.7

Emerging Health Issues

Emerging Health Issues	Total number of mentions	Number of focus group mentions (N=7)
Description of the problem	19	7
Societal concerns		
• Direction of progress	13	6
• Lack of precaution	12	6
Unconcerned	9	4
Causes of emerging health issues		
• Assessment limitations	28	5
• Benefit trade-offs	20	6
• Lack of long-term monitoring	12	3
• Lack of regulatory control	5	4
• Hasty product release	3	2

General descriptions of emerging health issues relate to chemicals, including pharmaceuticals causing previously unknown adverse health effects. This was described as an unsurprising or all-too-frequently experienced problem:

...les médicaments aussi y a souvent des risques comme ça, plus tard quand tu vient pour le prendre:«non y a pas d'effet secondaires», et apres tu va trouver qu'il y en a. C'est reguliers, ca arrive souvent. • **Female, Culture**

So things like this, at first when I read it, I went yeah, yeah these kinds of things happen all the time. • **Female, Environment**

...I have been on Vioxx for 5 years and now they are taking a look at those drugs, so that's been a great concern this week. • **Female, Recreational**

The problem of products evolving into hazards was often described using time increments ranging from 10 to 30 years, after which adverse effects were discovered. These periods were perceived to correspond to either the time required for science to develop methods of detection or to the latency period after which health effects appear:

...it took about 20 years to find that DDT was a problem. So this is 30 years almost to find that this agent [PFOS] was an issue. But that's the problem right. • **Male, Faith**

There was a sense among all groups that societal pressures influence people's decisions to accept consumer products and technologies for their benefits and despite their risks; and that this promotes the potential emergence of hazards. Concerns were expressed over the incapacity or unwillingness to apply discipline and precaution in order to curtail the disquieting trend:

...as consumers we grew up and we were told that we need to Scotchguard everything and your sheets and your socks should be bright white. So in a way we have done this type of thing to ourselves. We've allowed ourselves to be exposed and we buy into that thing...for heaven sakes you wouldn't want stains on your carpet because people next door might see them, so we all buy these products and the more we buy them the more you know... • **Female, Recreational**

Despite clear concerns over the societal problem of emerging health issues, for some, receiving information about specific potential hazards produced indifference about their actual threat, particularly when information about them was not reinforced or substantiated:

I think it all gets to a blur too...“Oh another thing”...and blow dryers cause cancer too! • **Female, Health**

I think to some extent it's a current issue. I think in 5 years time like many of these other health concerns, there'll be something else that is in the spotlight and grabs your attention. • **Male, Recreational**

...I think you can take almost any of many products and you will find some correlation [of adverse effects] somewhere. The bottom line now is in the Western hemisphere, the projected lifespan of human beings has increased significantly over the last number of years. How does this all tie in with this? Has it really improved or not and how is it related to this? • **Male, Faith**

Emerging health issues were viewed as resulting from one or more causes. For instance, respondents pointed to the limitations of assessment methodologies in uncovering adverse health effects, particularly the power of detection methods and the ever-evolving state of knowledge:

Well you have to look at life expectancy too and when the actual exposure is going to happen because the latency period is going to depend on the product. Animal studies can tell you a lot but not necessarily that. • **Female, Health**

Another thing is, has the testing equipment improved over the years? Maybe when they were doing it originally they didn't know how to properly test for PFOS so that it didn't show up. • **Female, Recreational**

The benefits of progress have been previously discussed as a highly valued trade-off to the potential for harm, both at a personal and societal level. Consequently, individuals rely on regulatory processes for protection. Under these circumstances, the lack of long-term monitoring was considered another important factor limiting the identification of hazards:

Someone has to take that longer amount of time to find what the risks are. • **Health, Non-affiliated/mixed**

Respondents had other concerns over the efficacy of regulatory frameworks that permitted PFOS and other hazards to emerge. All but one individual, who had worked for a pharmaceutical company, had no in-depth knowledge of how such regulatory

frameworks work. However, most did postulate various causes for the faultiness of regulations protecting the public's health. In particular, they questioned the work of government regulators; the quality of regulatory procedures and controls; the disclosure practices of industry transmitting information to government; and the extent of testing performed or commissioned by government:

When someone is offering a convenience for modern society and it's not tested then, that's when I wonder who regulates that? Like this thing they decided to replace PFOS with, who was it that decided they could put that on the market? Was it just because they have a big company that they can do that? Are there any regulations on that? • **Female, Recreational**

Who's working on this? Who's doing the research [on PFOS]? Do they have any kind of testing to check food and stuff? • **Male, Youth**

Lastly, respondents deplored the hastiness by which chemical and pharmaceutical companies often release new products:

Well it's been kind of a practice with the chemical industry for decades to release chemicals until they're proven dangerous. This is a perfect example of the thousands and thousands of chemicals released per year for use in household products... And it just seems like the cart before the horse. Let's put it out there. 'Dangerous DDT' and remove them and that's been the common practice... That's the problem with a lot of chemicals and a lot of drugs. • **Male, Health**

To summarize, knowledge was seen as ever evolving. The process of identifying and defining hazards was seen as difficult and limited by irreducible uncertainty, i.e. the knowledge we presently are incapable of knowing. Alternatively, other causes of hazard emergence were perceived as manageable; where uncertainty could be reduced using current means. For such instances, respondents suggested improvements to pre- and post-

market regulations to minimize negative outcomes that may still be undefined but which are likely to occur if past experiences are any indication of future events:

We have the abilities and the technology to create and we won't know the effects of everything we create. So we have to put reasonable safeguards in place, reasonable testing and then cross our fingers and see what happens. • **Male, Faith**

And we seem to be much more comfortable minimizing time to release than we are to react when there's a problem. So we need more studies at the back end when we see the trending of the problem than we do at the front end when we release the product when we don't really know.

- Female, Health

4.3.1.3 Risk Relevance

How “risky-ness” was framed was explored early on in the focus groups when participants were asked “what’s risky to you?” as a warm-up question. The question was largely interpreted by respondents as asking for issues that are particularly worrisome. Mentioned were issues that were concerning for personal and familial health (e.g. air pollution, driving, and stress) as well as for the health of others, i.e. vulnerable populations and for society as a whole (e.g. poor nutrition, infectious diseases, and water quality). The risk relevance expressed about the persistent pollutant scenario was also framed at these various scales.

Table 4.8

Risk Relevance

PFOS risk relevance	Total number of mentions	Number of focus group mentions (N=7)
Personal relevance	22	5
Global relevance	6	2
Publics at-risk	5	4

Learning of a personally relevant exposure pathway such as Scotchguard-treated household furniture and carpets generated concern about PFOS:

But the thing that struck me was that I started looking at the dates. I started looking at Scotchguard and I went: my couch, 1999. And that for me is what did it. I have a Scotchguarded couch that was done in 1999.

• **Female, Environment**

Culture group respondents were particularly concerned about the potential danger of exposure to their children through contact with household furnishings:

Female # 1: C'est dangereux pour les enfants. Tu mets ca sur les sofas. Ya des enfants ils mangent meme des sofas et des choses comme ca, c'est dangereux.

Female #2 : C'est ca. Mon garcon, il aiment surtout manger qu'est ce qui est parterre. • **Culture**

Yet, a few respondents mentioned that the lack of evidence of PFOS' toxicity did matter in their views of personal risk relevance:

...I'd think about it a little bit but I wouldn't go out and change my lifestyle now. You know that I'm not going to [avoid] sit[ting] in my [Scotchguarded] car or whatever because I've read this piece of information because there still isn't enough information out there to tell you exactly and if you're worried about every article that came out such as this than you would be worried about everything.

• **Female, Recreational**

Alternatively, respondents considered the risk from PFOS as globally relevant. Its persistence in ecosystems and human populations around the world was concerning:

This one is only one of tens of thousands, tens of thousands of chemicals out there and who knows what else they're doing. These are floating out in the environment... Like you say PFOS is in Arctic wildlife so it's also obviously in Africa, so this one [is] definitely [a concern]. • **Male, Health**

Finally, the risk posed by PFOS was viewed as particularly relevant to the uninformed: people ignorant of the issue were a public perceived to be particularly at-risk since they lacked the knowledge, and thus the opportunity, to make lifestyle modifications:

Male #1: ...there's nothing we can really do [about PFOS].

Male #2: Or you could just not use Scotchguard on your carpets.

Male #3: Well, what about the people who don't know this information? •

Youth

So what about those who don't necessarily have access to the academic world; who don't necessarily know to look up a journal online or an article, they're going to be waiting for it in their local paper. So if it's not going to be accessible right away then the majority of the public won't know about it and so won't necessarily know of the risks. • **Female, Health**

4.3.1.4 Personal Control

Participants discussed the personal control strategies they have to minimize risk:

Table 4.9

Personal Control

Personal Control	Total number of mentions	Number of focus group mentions (N=7)
Avoidance	15	6
Limitations		
• Personal financial	11	3
• Place	4	3
• Lay knowledge	2	2

Avoidance was the main mechanism for controlling exposures to hazards. People could choose not to purchase Scotchguard or remove existing PFOS sources from their homes:

Les produits d'ailleurs, moi je n'achete plus les produits. Mais ca [climate change], je ne peut pas eviter ca. • **Female, Culture**

Respondents were satisfied knowing that PFOS had been removed from Scotchguard once its persistence became known. Still, many respondents were concerned to know that even if they could avoid point sources of exposure, they still could not avoid contamination:

Once it's there, what are you going to do it's not going anywhere.

• **Male, Recreational**

Control over risk was said to be largely limited by socio-economic status, where you live, and knowledge. For example, risk was discussed among the women of the Culture group in the context of living in Canada as compared to their countries of origin in the Third World. The high cost of food in Canada was an important limiting factor in maintaining good health. Still, they used their knowledge of food preparation as a coping strategy:

Female #1: C'est parce que manger naturelle ca coute cher. On peut pas manger ca tout le temps. Ici, c'est pas a la porter de tout le monde

...

Female #4: Peut etre par mesure de prevention de sante, on va encourager les gens a cuire les aliments. • **Culture**

Employment and workplace were other limiting factors in controlling risk for two steel sector workers in the Non-affiliated/mixed group. Earning a living came at the price of being exposed to multiple chemical and physical hazards:

...you don't always have a choice. ...you can work there or you can become unemployed, which of course is quite detrimental to your life, and I worked in a building where there was an asbestos wall, I was working with lead solder and their big issue was to wear safety glasses. That was their big push because that's what the customer would see. So those are the things you deal with in the real world.

• **Female, Non-affiliated/mixed.**

Many participants recognized that knowledge was invaluable in exercising control over hazards. A lack of information barred choice and caused involuntary exposure:

If a carpet is pre-treated then it's pre-treated. There's nothing you can do about that. You don't even necessarily want to purchase that product, you're just purchasing it. • **Female, Recreational**

...one of the things I am quite concerned about in general is our food supply...genetically modified foods and how they are present in our food and not being labeled, and we don't know the impacts of that
• **Female, Recreational**

Further, one respondent noted that as a lay person, her understanding of complex scientific information was limited. Consequently, relying on experts, irrespective of their affiliation, was deemed necessary to minimize risk:

...when a drug is regulated it's like the only thing we can do is trust the higher powers. And the higher powers in these cases are the drug companies and the doctors who are prescribing them for you because we can't possibly get as much information and knowledge about all of these complex chemicals to make those decisions on our own. So there are some decisions where we just have to trust. And who do you trust? I mean I can't go out and get a pharmacy degree just to make sure that the drugs I'm taking are not going to harm me in some way. I just have to trust that somebody is doing something that will help me. Can't do anything more than that. • **Female, Environment**

4.3.2 Extreme Heatwaves from Climate Change Scenario

4.3.2.1 Event/Potential Hazard

Extreme heatwaves from climate change was the intended subject of discussion in this scenario. Yet, respondents felt it was important to focus on establishing the knowledge certainties and uncertainties of climate change prior to discussing extreme heatwaves as its potential outcome.

Table 4.10

Event/Potential Hazard

Event/Potential Hazard	Total number of mentions	Number of focus group mentions (N=7)
Debatable	17	4
Origin	14	5
Benefit trade-offs	10	4

Respondents were aware of conflicting opinions among climate change experts. These debates were linked in part to political considerations but also to different scientific interpretations of climate change evidence:

But what have we done compared to 500 years ago and 1500 years ago because there are cycles that have to do with sunspots and that have far more to do with it than how much we drive cars. There is a whole different side to it. At the moment this is the big issue that's got David Suzuki and the like making careers out of this, and there are government and UN bodies and those who believe we should do something about it. They have got the upper hand at the moment. • **Male, Recreational**

...journalists are reporting now that the oil industry has funded the other side of it, the side that: it's just a natural cycle. ...there is a lot of inaccuracy portrayed out there and scientific facts that are not [facts].
• **Female, Non-affiliated/mixed**

Many respondents were unfamiliar with the origin of climate change and attempted to clarify certain assumptions amongst themselves. While the majority of respondents perceived climate change as already existing or as a likely future event, determining whether climate change was a natural or man-made phenomenon was a preoccupation for many:

I look at that and I'm still not sure, I'm kind of a believer in that we have climate change and that is warming. I'm still not too sure of how much of it is natural and how much of it isn't. And then there are the conflicting reports that come out about what's causing it. So nobody's consistent and

the science behind it does not seem to be coming out to explain to you that this is what's going to happen. I think we are experiencing severe weather changes but again I don't know if that's a natural occurrence or not. •

Female, Environment

Compounding causal uncertainty, respondents questioned whether a future of extreme heatwaves could really be predicted with confidence. Individuals understood the existence of complexities and uncertainty in forecasting weather systems and considered their own experience of the past summer which stayed particularly cool throughout:

Female: So how do we know for sure that climate change is happening?

Male: You don't... Well they can't be any more precise in fact it may not affect us. Heat waves, you're only looking at the short term weather forecast to see how uncertain they are. So the planet's warming but it doesn't necessarily mean there'll be heat waves here.

Female: But that's what it says.

Male: I know that's what it says but that's not particularly true

• **Environment**

Male: Are you dead certain that it's going to get hotter?

Female: Judging by last summer...

Male: ... You can see where it could get hotter. I can believe it. But then we have the moderating effects from the lake and you know is it getting hotter here or not? I don't know. • **Non-affiliated/mixed**

Personal behaviors involving transportation and the use of fossil fuels were recognized as benefits of technologies which lead to climate change. Respondents were concerned about the cumulative impacts of their lifestyles on the global environment:

I think we are in a trend. I think we need to reverse the trend. I'm concerned about it. I'm concerned about my own car driving heat production. • **Male, Faith**

We're all in trouble. Ten people driving down the street in cars, while they could all be on the bus. • **Male, Youth**

Interestingly, only two respondents pointed to larger stakeholders, such as industry and government, as important carbon producers. Concerns revolved around the sense that these producers shift blame and burden onto publics:

...the spin is to put power shortages and problems back on to the public, back on the corporations, back on to the hospitals and everybody else. “If you guys cut down your power consumption...”, yet across the province of Ontario the majority of our hydro is generated by burning fossil fuels which creates global warming. ...[they] put it back on us. • **Male, Health**

4.3.2.2 Risk Characteristics

Table 4.11

Risk Characteristics

Risk Characteristics	Total number of mentions	Number of focus group mentions (N=7)
Risk Relevance		
• Publics at-risk	22	7
• Social risk relevance	22	4
• Personal risk relevance	6	2
Non-hazard risk determinants	17	6

Respondents of the Culture group were particularly concerned about a future with extreme heatwaves, pointing to the hazard affecting their children and grandchildren; the compounding influence of living in poorly ventilated urban buildings and their lack of transportation and financial means to visit green spaces. They shunned air conditioning and fans, preferring wind and air, which were natural and free.

Female #1: C’est nos enfants.

Female #2: Ici, ya les buildings! Ici. Tu est condamné a rester la dans l’immeuble. Des fois on ne veux meme pas sortir, on veut rester a la maison mais il fait chaud. Mais tu n’as pas d’autobus ou de voiture pour aller dans les parcs. Tu va rester dans la maison.

Female #4: Le climatiseur, mais qui va payer pour ca, you have to work. Mais c’est pas l’air naturelle non plus. • **Culture**

Respondents considered the risk associated with extreme heatwaves as affecting specific segments of the population. Except for the Culture group, most respondents did not relate the hazard to themselves. Many considered heatwaves to be a poverty issue:

I think that our social safety net for the poorest people in our society has holes all over it and I think those are the people that we need to be concerned about. Cause those are the ones that are going to be living along, lacking social contact without access to air conditioning and swimming pools. And urban areas, you know, urban poverty. • **Female, Environment**

Similarly to PFOS, globally-relevant concerns were expressed about extreme heat waves, particularly in the Faith group:

...my sense of connectedness to other countries and cultures is in someway inextricably bound with my moral values and that is why... these environmental issues are of concern even though I can tolerate the heat thank you very much, but if 800 people are dying then... • **Male, Faith**

To understand the risk and the relevance of extreme heatwaves, respondents pointed to a lack of information about the physical characteristics of the hazard; the populations to be affected, and the credibility of those predicting the hazard. These were important determinants for understanding risk:

Is *extreme* the entire summer or is it a week...it's very hard to make an educated decision that yes, this is going to be a major problem... • **Female, Health**

I'd be curious to know how that 800 breaks down. Who were they? It's hard to decide what kind of changes you are going to make if you don't know who you are targeting. • **Female, Recreational**

And I would have to look at the legitimacy of that source, I would have to find out who's credible and then look at multiple sources, for sure. • **Female, Environment**

Many respondents also concluded that multiple factors, i.e. age, health status, socio-economic status, must be involved to cause death from extreme heatwaves:

Obviously it's not people in their 40's and 50's that are dying. It's people whose health is compromised by other things that are being pushed over the edge as it were by the heat. • **Male, Faith**

It almost seems more of a social problem than a heat problem.
• **Female, Recreational**

Hypothesizing that extreme heatwaves could happen in the future, respondents focused on the need for precautionary measures. Concerns were also raised about whether our present capabilities could effectively deal with such a future:

...because it's uncertain scientifically? That's not the reason that we do nothing. We don't wait for our house to burn down before we take out fire insurance...it doesn't matter if it's happening or not, the possibility is there. It's not probabilities that determine our environment, it's possibilities. • **Male, Environment**

So I wouldn't worry about this so much if I thought there was enough research being done on these conditions already while they're here.
• **Female, Environment**

...if this is supposed to be coming, what are we doing to prepare for it? If you're worried about blackouts, are we going to have the power supply to live with that in Hamilton? • **Female, Health**

4.3.2.3 Control Mechanisms

Table 4.12

Control Mechanisms

Control Mechanisms	Total number of mentions	Number of focus group mentions (N=7)
How		
• Prepare	11	6
• Adapt	9	3
• Relocate	3	2
Limitations		
• Community	9	6
• SES	4	4
• Lay knowledge	2	1

Respondents discussed the precautionary or preventative actions they could take in case extreme heatwaves did occur. They focused on reasonably feasible low investment-high result actions like reducing energy usage; creating greenspaces, and risk awareness campaigns.

...there's a lot of things we can do as a community. Make sure there's lots of parks, lots of trees, and green spaces so that if there is a heat wave, people have an accessible place to go to where it's cooler. So there's so much we can do about this...that we should be doing it .

• **Female, Non-affiliated/mixed**

The potential for adaptation was seen as highly feasible by many:

It's not a concern to me. I better be able to adapt. It seems to be such a small thing that I can't get concerned about that, sorry to be so blunt.

• **Male, Recreational**

Male #1: I have no problem with Canada getting a whole lot warmer.

Female: Me neither....

Male #2: I'm good with heat. • **Youth**

Some participants discussed moving as a mechanism for dealing with exposure to future extreme heatwaves still others recognized that moving would not prevent exposure to this global hazard:

Female: Well, that says to me, I'm going North.

Male: That won't help you unfortunately.

Female: There's a lake that will help.

Male: The north is the most vulnerable climate change. • **Environment**

Still some felt concern as this potential hazard was perceived to be beyond their personal control and required higher level action:

...I can do so little about these issues...I find that I am often powerless...I cannot influence Stelco to move somewhere else. I cannot influence the whole industrial heartland of America to [stop] polluting and produce those days where I can hardly breathe. That sometimes makes me angry and that's why it's important to stay active because the population of the world is expanding so rapidly. There's so much going on, I worry. • **Female, Recreational**

Of the control limitations discussed, a wide range of community attributes were evoked like social behaviours and external influences preventing change, and social attachments preventing moving.

Male #1: But every house is built now in Southern Ontario with air conditioning right?

Male #2: You're right, so how do you modify peoples' behaviour? Through taxes, through legislation and education? • **Faith**

Female #1: I could move too, from Hamilton. I don't do that. It's stupid.

Female #2: That's a bigger deal right because there are other things holding you here. • **Female, Recreational**

Women of the Culture group felt particularly limited by their socio- economic status in that during a heat wave they would not be able to afford air conditioning

or transportation to cooler greenspaces. Other groups echoed these socio-economic concerns.

Female #1: Ici. Tu est condamné a rester la dans l'immeuble. Des fois on ne veux meme pas sortir, on veut rester a la maison mais il fait chaud. Mais tu n'as pas d'autobus ou de voiture pour aller dans les parcs. Tu va rester dans la maison.

Female #2: Le climatiseur, mais qui va payer pour ca.

• **Culture**

People don't have access to air conditioning and swimming pools; that's a poverty issue. • **Female, Environment**

The lack of education about hydration was also deemed limiting, particularly for an elderly population. However, the topic did not generate much interest perhaps because of the familiarity of participants with preventive measures like hydration and the lack of personal risk relevance.

Female #1: With people, especially elderly people, habits have been formed over 70 years and all of sudden we have to drink so it's very difficult. Change is a very slow process.

Female #2: I think that something as low risk like that, that telling people to drink water doesn't do any harm...

Male #1: I think it's already in the education, I think Health Canada tells you that you should drink 8 glasses of water. It's out there, it's just that people ignore it. • **Recreational**

4.3.3 Experiences with Information and Information Providers

This section combines discussions from both scenarios and describes respondents' views of information, i.e. message formats and message contents, and information providers.

4.3.3.1 Views of Science

Table 4.13

Views of Science

Views of Science	Total number of mentions	Number of focus group mentions (N=7)
Knowledge generating	35	5
Subjective	18	5

Science was generally understood as generating knowledge, whereby knowledge is in development, ever evolving, and subject to considerable uncertainty and potentially substantial unknowns:

Thirty years ago, any testing they could do and any knowledge that they had were part of the past. It was safe then. • **Female, Recreational**

Scientific information relating to hazards was considered subjective when its provider was seen as holding political or economic interests. Further, it was seen as susceptible to manipulation and spin and needing to be decoded:

It's just a cheap little comment put out by Human Resources to make everybody feel comfortable that they are really dealt with it...Just reading that and knowing that I've read so many of them. • **Female, Non-affiliated/mixed**

You look at it and think well who sponsored it. The guy that's sponsoring it is some cigarette company that's telling you it is ok to smoke cigarettes or something like that. You have to adjust the biased in it. • **Male, Recreational**

4.3.3.2 Views of Governance

In discussions on governance, respondents referred to "government" in broad terms and did not indicate a specific federal or provincial government or department.

However, most respondents did recognize the responsibility of the federal government in protecting the public's health. Health Canada was mentioned in several focus groups.

Table 4.14
Views of Governance

Views of Governance	Total number of mentions	Number of focus group mentions (N=7)
Expectation of leadership	21	5
Expectation of protection	18	4
Limitations		
• Complacency	19	7
• Political	11	5
• Competency	7	5
• Financial	7	4
• Acceptable limitations	4	2
• External pressure	4	2

Central to discussions of government was its mandate or expected role of protecting the health of citizens through regulation of industry, communications to the public, research, and the creation and funding of policies and programs aimed at protecting health:

They [government] are supposed to be there to protect us. • **Male, Environmental**

Government was also expected to take on a leadership role since inciting change at the individual-level was felt to be particularly difficult when dealing with macro-level (social and global) hazards:

I think a lot of things come on the market too soon and I think Health Canada should make their rulings much more restricted.
• **Female, Recreational**

...the government should put a super tax on eight cylinder passenger vehicles. That's where I expect the government to act and forces us all into 4 cylinder cars. This is where we expect the government to take some leadership. • **Male, Faith**

No you can't leave it to individuals. People put pesticides on their lawns and all that does is get into the water supply. • **Male, Environment**

Certain limitations concerning these expectations were raised. The majority of concerns focused on an institution that was much too passive:

...they keep delaying things until something major happens...but by that time it may be too late. • **Female, Non-affiliated/mixed**

Past or current behaviours were indicators of future behaviours. Consequently, a willingness to incite change was seen with skepticism when a history of complacency was evident. Concerns and a lack of confidence were expressed of government actions and decisions which were deemed ineffective and increased risk to the individual. Specifically, respondents were disapproving of risk minimizing strategies which placed most of the burden of risk management on individuals without providing adequate regulatory, financial or informational support.

...its how well is our government managing these problems right now and I don't have very much confidence in the future if they're not already on top of this right now. • **Female, Environment**

Decisions about health issues were perceived to be frequently made on political grounds:

That's the problem the decision isn't made because it gets politicized. If you have a standard that says: over this part per million, or if the cancer [rate] moves up, then the meeting turns into: "Is there any negative political outcome?" • **Male, Faith**

Still, there was recognition of a limit to the extent that government could protect citizens, this particularly from the Faith group. Respondents acknowledged that responsibilities also fell on the individual and that in other instances, no blame could befall:

I think in many instances the government is aware of things and doesn't take appropriate action or timely action. Having said that I think only to be fair...I'm not sure we can expect them to be on top of everything all the time. I think that's physically impossible. • **Male, Faith**

Since government was viewed as the principal organization with the means to protect the public interest, many respondents expressed skepticism and disappointment for its unwillingness to fulfill its mandate to the fullest extent:

I think if they say it's bad, it's probably true. But if you don't hear anything from them, it doesn't mean it's good.
• **Female, Non-affiliated/mixed**

Despite its unreliability, respondents had faith that government had the capacities to fulfill its role of acting on behalf of public interests:

The government is far from perfect but if the government doesn't look after our interests then who is going to look after our interest collectively? There's nobody else in society that, that's their role and that's their mandate. So I think we have to put our faith in government where we can lobby for change...but I don't think the solution is to say ok then we won't put our faith in anybody, its things have to change. • **Female, Environment**

Inversely, one respondent explained he had confidence that government could be relied on to manage hazards:

I can live with that if somebody says "I'm not even going to announce this", I think it should be, if I've heard the communication, but that's what we've got, we've got an assistant minister and it comes to his desk, he's the one that makes the call, so you live with it. • **Male, Faith**

In addition to reliability, credibility was also viewed to be a determinant of trust:

I think the general public would like to believe they can trust their government: although that's usually not the case. I would suggest that if you feel that it is credible then trust follows but you have to earn both those things. I think historically there were credible institutions where we implicitly as a community gave our trust but there have been breaches in those trusts. • **Female, Health**

Other causes limiting government's protection mandate was the allocation of funds towards risk reducing strategies:

But I think we need to go beyond information. ...if there are no resources to do anything with it well then its just information and it doesn't make any changes occur. • **Female, Non-affiliated/mixed**

Finally, another factor controlling the emergence of hazards was the pressure exerted from the corporate world onto regulatory frameworks. Skepticism and distrust were expressed about government and industry relationships:

So I guess I really don't trust the government on issues like this because they bow to the pressures of corporate profits.
• **Female, Non-affiliated/mixed**

4.3.3.3 Views of Industry

Table 4.15

Views of Industry

Views of Industry	Total number of mentions	Number of focus group mentions (N=7)
Vested interests	24	6
Self-regulation	17	4
Public accountability	11	6

Views of industry were expressed exclusively in the context of commercial products as potential hazards. The current procedure of allowing companies to self-regulate in relation to the safety testing of their own products was well known of respondents. This was considered problematic and was linked to the appearance of emerging hazards.

Should Health Canada have been finding out about the effects of PFOS before 3M? We left it up to 3M to understand their product. Yeah, that's my problem. • **Male, Faith**

Who's doing the studies? I think a lot of it too is the government's allowing industry to self-regulate. • **Female, Health**

More specifically, there were concerns over the potential for industry to delay and hide known health effects and over the lack of willingness or effort to search for the presence of adverse effects;

Because the companies do it themselves, it's very suspect and that's always the intonation when you read a lot of [journal articles]. You go ok, let's go to the back and see who gave money. It's terrible but [that's how it is]. • **Female, Health**

Concerns over the lack of accountability towards consumers were frequently mentioned. Lack of confidence in industry was associated with an absence of ethics, interest, or compassion for protecting the very people consuming their products.

Female #1 : On a pas confiance dans ce qu'on achete.

Female #2 : Il dit juste ça pour attirer le monde, après les conséquences qu'il arrive, bof, c'est pas leur problème. Juste pour avoir fait leur argent et puis le reste qui arrive et bien... • **Culture**

This is magic stuff that doesn't harm anything, it just kills the weeds. That's what they'll tell you. • **Male, Non-affiliated/mixed**

Inversely, trust was associated with confidence that a hazard-producer's actions, behaviours, and messages are made with the intent to protect or at the very least prevent harm to the public:

The carpet company's informed me of this issue [PFOS], not Health Canada. So I trusted his advice. But I've never heard anyone else mention this except carpet companies. • **Male, Faith**

Mentioned was the absence or inadequacy of a regulatory framework that holds industries publicly accountable for acting responsibly in favor of the people consuming their products:

There really is no legislation to hold companies accountable to disclose information to the public. Are these products labeled as containing genetically modified food? Well, no, of course not because then consumers would be able to make an informed decision based on their consciousness or based on their own intelligence and the companies don't want people doing that. And the government doesn't want [them] to get upset. So there's no legislation to hold companies accountable. • **Female, Non-affiliated/mixed**

Respondents also desired more accountability of industry when hazards did emerge:

There's no accountability to any of this. The guy will put the stuff on the market but he wouldn't have it in his house. And then as soon as the shit

hits the fan as it were, he's gone. He's nowhere around. • **Male, Non-affiliated/mixed**

It was commonly understood that industry has a vested interest in producing profit and that this in turn contributes to potentially premature product outputs, delayed withdrawals and cover-ups:

Well the other thing that makes me ill at ease is [whistle blowing]. That kind of thing really worries me. • **Male, Faith**

It's like are we surprised then when corporations come out with things that prove to be harmful 20 to 30 years later. They've made their money and they're not bad people, but its just that they have short term interests. • **Female, Environment**

4.3.3.4 Views of Information Provision

Table 4.16

Views of Information Provision

Information	Total number of mentions	Number of focus group mentions (N=7)
Lack of information	35	5
Triangulation	17	3
Conflicting reports	16	4
Information overload	8	4
Information spin	2	2
• Media	9	4
• Political	5	2

In general, information as presented to the public by media or by actors involved was seen by respondents as interpretations needing to be decoded to various degrees:

But you have to know how to look at that information if you're going to make an informed decision. • **Female, Non-affiliated/mixed**

I think there could be too much bad information and maybe too little good information. I think that's what's going on. • **Female, Environment**

Trust in information providers was linked to the understanding that information containing high uncertainty could be non-maliciously skewed, inaccurate, or portrayed too simplistically:

So it's really hard these days to trust any one source because they all seem to be compromised by one thing or another and sometimes it's not deliberate compromising but it's just economic or it's that the information just isn't researched properly because there isn't the time and so it's very hard. • **Female, Environment**

Scientific information about emerging health issues was seen as often being reported to the public in conflicting ways. This was seen as putting the difficult task of interpretation onto the lay individual:

...I've seen several things on TV that tell me that its going to happen [climate change] and then the next half hours somebody refutes the whole thing and I believe the first guy and then a half an hour later I believe the second guy. I mean they make a very presentable argument about what's going to happen. • **Male, Non-affiliated/mixed**

Respondents expressed feelings of being overwhelmed by the amount of information to process in their decision-making:

Too much information makes you lose sleep at night and that's another health issue. How do we filter it? Prioritize it? Sort it?
• **Female, Environment**

Nonetheless, conflicting reports were considered beneficial for personal decision-making as conflicting messages, regardless of the motives of the actors supporting them, were seen as providing information on the issue dimensions presenting high knowledge uncertainty:

There's a huge amount of rhetoric from governments and corporations and people with vested interest in continuing production and continue burning fossil fuels that will say global warming isn't happening, it's a natural phenomenon, so it's hard to grasp to say there's a heat-wave and to predict 800 deaths when there's...a huge body of science saying it's not happening...

• **Male, Health**

When prompted, respondents were often cynical and had difficulty citing credible sources of information. Albeit far from being unanimous, Health Canada, the World Health Organization, the CBC, and scientific journals were viewed by some respondents as credible sources of information. Credibility or the lack thereof was linked to past histories of risk management and vested interests:

Health Canada could have stepped in and said the risk has gone from infinitesimal to a little bit but...it was basically left for the CBC to tell us that farm salmon is bad. The journalist like we said, have an interest in breaking a story and making their careers and getting the ratings and so on, you don't necessarily trust that. The (salmon) producers on the other hand have their own agenda. You would have hoped that Health Canada would have been an impartial reference... • **Male, Recreational**

However, one respondent had confidence that in general, information sources do not intentionally go about deceiving the public:

In general I trust the information. I'm accepting of the information and hope that nobody's trying to lie to me. In general I trust the information. But do I trust it like a child trusts his parents? No. Not to that degree. Not blindly. • **Male, Faith**

The values held by the information source and how these relate to those of the individual was seen as an important determinant for considering message content:

And so you kind of wonder, you know, what sources are you going to trust? Are you going to trust the one that has a little government of Canada seal at the back or are you going to trust the one that was printed on my friend's computer 2 hours before our protest...you wonder what kinds of information you're going to be filtering through...[nonetheless]

there are other [sources] that are not necessarily as known but that you like. • **Female, Non-affiliated/mixed**

Gaining awareness of an issue through reinforcement from multiple information sources was a strategy that informed respondents on the developing state of knowledge and predominant views on an issue:

...we don't know for sure how much of an issue this will become but there seems to be trending and reinforcement from all the things we get fed through media, this has become a more substantive issue. • **Female, Health**

All we can do is [consider that] 90% of climatologists agree that this is going to happen. • **Male, Environment**

...what you read in media helps reinforce things that people have heard other places. I think that anybody who gets all of their news from one source regardless of how reputable that source is, is cutting themselves off from a lot of information which they may need to know... • **Female, Environment**

Information spin, whether at the primary (industry and government) or secondary source (media) was seen as a normal obstacle to interpreting information:

...I think many of us...don't have a great amount of confidence in what's being published. There's a political agenda and I think we all realize it's skewed in that direction. • **Female, Health**

Part of the problem, irregardless of how credible the source is, is the way the information is disseminated to the public. It's spin. • **Male, Health**

It was generally felt that some publics were not sufficiently knowledgeable about potential health issues:

...there are large segments of our society that put themselves at risk through ignorance and our society is suffering from that. • **Male, Recreational**

At the moment, [information] not adequate...there are things that to me seem very every day that I will mention to a neighbor and they look at me as if I'm from Mars. • **Male, Faith**

While it was recognized that informing on potential hazards without full knowledge certainty of the health outcomes was seen as problematic, still a lack of information was an important obstacle to personal risk management and any information was better than no information. This was particularly well explained by the recreational group:

...one of the things I am quite concerned about in general is our food supply [is] genetically modified foods and how they are present in our food and not being labeled, and we don't know the impacts of that.
• **Female, Recreational**

I think having to be informed even though they can only inform us at the time with the limited knowledge they have at the time and hopefully the information is 100% truthful and they're not whitewashing it in any way. But I think that as much information as we can get on any of the products that we purchase is bound to be helpful.
• **Female, Recreational**

...lack of information is probably what makes a thing more worrisome for me. • **Female, Recreational**

In contrast, some felt that a lack of detail prevents an adequate characterization of the risk and thus, a basis for concern:

Because there still isn't enough information out there to tell you exactly and if you're worried about every article that came out such as this than you would be worried about everything. So you have to weigh how much you're going to worry about things depending on what information you're given. • **Female, Recreational**

Understanding the process by which hazards are dealt with was viewed as an important consideration in people's comprehension of the issues:

Why has been allowed to happen if this has been known for many, many years and its got to be the regulatory standards are faulty or the

information being passed on by the companies is not what it is supposed to be? It's like, yeah who's going to protect us from that kind of thing?

- **Female, Environmental**

4.3.3.5 Views of Disclosure

Table 4.17

Views of Disclosure

Disclosure	Total number of mentions	Number of focus group mentions (N=7)
Disclosure not = Accountability	20	6
Concern over non-disclosure	11	4
Personal decision-making		
• Control over risk	30	5
• Awareness and education	35	6
• Ethical	12	6
Projected Challenges		
• Timing	6	4
• Producing Fear	13	6
• Convincing people	26	6
• Reaching people	20	6

Learning that information relevant to public health was withheld from the public was clearly concerning to individuals and seen as an indication that hazard-producers are intentionally negligent:

...look at the latest Vioxx withdrawal. I mean there was a clear point at which the liability for keeping it on the market was greater than the profits to be made by continuing to sell it. But they had to reach that point... •

- **Female, Non-affiliated/mixed**

The recent withdrawal of the medication Vioxx was mentioned as an example of delayed disclosure which increased the risk of harm but the mention of any indication of non-disclosure of publicly relevant information was grounds for concern (i.e. whistle

blowing). Respondents wanted information disclosed for several reasons, above all for the purpose of making decisions about risk (e.g. avoiding exposure, becoming aware and educated, and having a choice):

Il faut que les gens sachent...si c'est dangeureux pour les autres

• **Female, Culture**

... if we are educated to know that any kind of substance we put in our body has potential risk maybe we won't be quite so ready [to use it]. I think we can make those kinds of decisions...

• **Female, Environment**

Personally I want stickers on genetically modified foods so that I can make the choice. • **Female, Environment**

Disclosure of risk-related information was also seen as an ethical or moral obligation and a right-to-know issue:

...the ethics of it is where it bothers me: the assumption on the part of government as I understand it is that if you somehow communicate risk to the public then there will be a reaction and the management of that reaction is more important than the information itself. I call that the paternalistic principal and nothing wrangles me more than paternalism because as a health professional I have a moral obligation to communicate to my patient the risks. ...the government has an obligation too. The assumption that the public is somehow not sophisticated enough to absorb the information is I find a very paternalistic approach. ...to withhold information from the public on the basis that well, we don't want to deal with the fallout, it really smacks of paternalism to the n-th degree. • **Male, Faith**

As a consumer...don't I have the right to be informed of any potential risk to my health that may be caused by your product that you're making mass profits off? I don't have that right to make an informed consumer decision? • **Female, Non-affiliated/mixed**

Male #1: They have the right to know it's affecting their health.

Male #2: Yeah anything that harms you should be instantly told to you. • **Youth**

Disclosure was seen as one of two inter-related factors capable of minimizing risk from emerging hazards. Respondents were skeptical of disclosure, viewing it as insignificant without some sign of institutional willingness to take precautionary or remedial measures:

...Put your money where your mouth is. So they're saying this is a problem yet they're not going to do anything about it. • **Male, Youth**

...the spin is to put power shortages and problems back on to the public, back on the corporations, back on to the hospitals and everybody else. ...yet the majority of our hydro is generated by burning fossil fuels which creates global warming. But do we see a lot of initiatives, a lot of programs, looking at alternative fuels and alternative ways of creating electricity? • **Male, Health**

They're telling you it's hazardous...and that let's them off the hook. They've told you. Now, they're not going to do anything about it. They're not going to pay you a pension. They're saying that people there are going to get bladder cancer and I'll tell you, prove your cancer was caused by this Scotchguard. You have to prove that. You can't do it. • **Male, Non-affiliated/mixed**

Respondents were clear in wanting better information disclosure. Nevertheless, they pointed to several challenges in disclosing risk information heavy in uncertainties, i.e. scare-mongering and loss of credibility if additional information revealed that risks were originally overestimated and concerns over delayed disclosure when information revealed that risks were underestimated:

...if you tell people that everyday something could happen, then they'll just become immune to it. So you can't let it come out too early and then you can't let it come out and say 'we we're only kidding; no we tested and found out it's just fine'. You can't do that either because you lose credibility that way. But then you can't leave it too late either. • **Female, Environment**

You could have a bigger problem on your hands...violence, people freaking out. You don't want to do that, you want to think about it before you release something like that. • **Male, Youth**

Fear was not so much related as an outcome of personal concern as an assumption made about how the general public might react. Providing people with tangible risk minimizing strategies they could use within risk messages was seen as important to lessen the potential for high emotional outcomes:

...you want to give information but you also don't want to instill paranoia.
...you want to give information that people can actually use to be proactive. • **Female, Non-affiliated/mixed**

Respondent discussed the difficulties of getting people to consider risk messages. Overwhelmingly, they identified personal risk relevance as an important determinant of acceptance:

We select what we want to listen to what already backs up the practices we want to continue in our lives and nothing ever changes unless we are given a very compelling reason to change
• **Female, Environment**

I just don't accept the fact that I need or we need as a society to have sunscreen to protect you from the sun...I'm still not convinced it's a significant health issue that I need to be worried about. But that's what happens with information right? Some people will accept it and some people will throw it out.
• **Male, Faith**

Overall, respondents viewed the role of disclosure as informing the public of potential hazards as opposed to convincing the public of risk:

Well, you can tell them, but getting them to do it are two very different things. • **Female, Recreational**

30% of the people will say "I don't care". 30% will say "hmm maybe I should be a little bit more diligent and then there will be 1/3 of the population that will take it to the extreme and those are possibly those

people are the ones who will actually come to the hospital because they've been heat exposed. So you have to put it out there. But then people have to make the choices too right.

• **Female, Health**

Respondents viewed effective information disclosure as needing broad and diversified information channels in order to reach the uninformed - considered a public at-risk:

That information might be out there. You can go the Health Canada's website or pick up a brochure, but is that being communicated to people who don't have access to these sources? The messages can't get reinforced. • **Male, Recreational**

I more concerned about low income people. I wonder about the literacy rates. If there not reading the newspapers they're not getting the information. If they're only listening to music radio they're not getting that information if their only contact with their doctors is when something happens. • **Female, Environment**

4.4 Focus Group Summary

This section has presented the results that emerged from the focus group discussions on emerging health issues with community members from Hamilton, Ontario. First, the framings of the issues and the objects of their concerns were presented. The phenomenon of products and technologies emerging into hazards was well known and had been experienced. Community members were acutely aware of the potential presence of important risk-related uncertainties and unknowns about the products and technologies present in society. Nonetheless, they valued and desired the benefits of products and technologies and were willing to accept some indeterminacy as a trade-off. However, the regular and frequent revelation that consumer goods are in fact potential hazards has impacted people's sense of protection and control. These impacts include: a lack of

confidence in inadequate regulatory frameworks; distrust in socially irresponsible production sectors, an understanding of the limitations of a science utilized to justify safety; skepticism of subjective information or lack of information, and concern over dependency in complacent or insufficiently precautionary governance. Few inter-group differences were apparent in our respondents' views. Of these, the Culture group was found to be the most distinct. Socio-economic constraints related to protection and control were important concern topics in their discourses and cultural differences were used to highlight their concerns about the range of health hazards found in the industrialized world. The Faith group also had unique responses in that respondents' concerns focused primarily on social health inequalities and very little on personal risk relevance. To address the study's second research objective, the nature of the information people need for understanding these issues was described. Community members used their experiences with hazards to support their views. Information establishing risk relevance was important in order to understand the extent of the ramifications of the potential hazard on personal, social, societal, and global scales and the possibilities and the obstacles influencing their mitigation. Knowledge of regulatory mechanisms was important in people's understanding of the issues. Vested interests, past and current organizational behaviours, and incidences of dishonesty and non-disclosure were important types of contextual information. Respondents interpreted information by considering conflicting reports and by comparing messages from different sources. They also used their knowledge of the interrelations between various stakeholders, particularly government and industry, and of the limitations of governance in their responses to

emerging health issues. Third, the roles of governmental disclosure were determined for personal decision-making. Although, there is a considerable lack of confidence in current regulatory frameworks, community members rely on the institutions mandated to protect them for providing hazard and exposure information; for suggesting preventive measures, and for informing on risk management policies and processes, in particular raising awareness of the scientific and regulatory dimensions that can contribute to elevating health risks. However, the provision of information does not lead directly to trust without evidence that government actions are taken or planned. Other roles of disclosure as defined by respondents included clarifying government priorities, positions, and rationales in order for individuals to interpret actions and disclosure messages; enabling access to information that allows individuals to exercise choice and responsibility; and access to expertise where information is specialized or complex. Respondents did not view information as disclosed by government as truth but as one important perspective needed for a deeper comprehension of conflicting or emerging information. Disclosure was needed to re-assure individuals of government reliability to act on behalf of public interests. It was also seen as a required means to fulfill government's mandate whereby actively communicating public health information broadly to inform all citizens and specifically to inform at-risk populations. Lastly, releasing publicly-relevant information was considered a necessary ethical endeavor. There were no inter-group differences in our respondent's views of information providers and information and disclosure needs that could be linked to the groups' representative interest. Chapter five discusses the

research findings according to study objectives; it examines results from a theoretical perspective; and discusses the policy implications of disclosure needs.

CHAPTER FIVE

DISCUSSION AND CONCLUSIONS

5.1 Introduction

This last chapter provides the key findings which address the study objectives:

1. To understand people's responses to emerging health issues;
2. To identify the information needs regarding these issues, and
3. To explore the role of government disclosure for personal decision-making around these issues.

First, the ways by which participants respond to emerging health issues, i.e. how people frame these issues and the objects of their concern are discussed. Second, people's information needs about these issues are detailed. Third, the relationships that leave citizens vulnerable under conditions of unfamiliarity and uncertainty are explained using Healy's (2004a) theoretical framework for conceptualizing risk in relational terms. Fourth, the roles and rationales for government disclosure, effectively the policy implications of these findings, are discussed. This chapter ends with key policy recommendations for improving risk communication practices and suggests directions for future research.

5.2 Lay Responses to Emerging Health Issues

5.2.1 Framings

In this study, people have commonly described emerging health issues as a social trend whereby notions of familiar products and technologies are reshaped as new information emerges about their hazardousness. Emerging health issues involve hazards that science cannot currently confirm or disconfirm. These are potential and theoretical health hazards. Their conceptions can be somewhat undefined in society until new information validates their authenticity as hazards.

Principally, individuals expressed uneasiness about potential hazards within consumer goods allowed into their lives. In fact, a majority of focus group respondents (68%) felt that suspected health threats are just as concerning as proven health threats. Fifty-two percent also had concerns about non-immediate health threats. These survey results support respondents' views that concern is also directed towards potential hazards: future and undetermined.

Despite a common description of emerging health issues as counting “hundreds” and “thousands” of potentially hazardous chemicals and drugs, when asked if society accepts too many health risks in exchange for social progress and technological advancements, most (58%) did not think so. This strengthens focus group findings that the benefits of progress hold considerable weight when considering what an acceptable trade-off to living with potential hazards is. The acceptability of trading-off product benefits for precaution was often described as a choice between personal and societal values, i.e. choosing to have stain-proof furniture over discouraging the production of

chemicals, or choosing to drive over reducing global carbon emissions. Although respondents were mostly appreciative of product and technological benefits, they also expressed discomfort or embarrassment for usually favouring personal choice over social responsibility, and in so doing contributing to the creation of new potential health hazards. Indeed, much research indicates that individuals often place higher value on a near-future, more tangible reward than on a distance-future reward, even when the latter is greater (e.g. Chesson and Viscusi, 2000; Read and Loewenstein, 2000). The duality that respondents discuss between personal and social preference or immediate gratification and the idealistic greater good appears to support what Trope and Liberman (2003) call construal level theory. It posits that human preferences change depending not only on temporal distance but also on other psychological distances, i.e. whether goals are abstract (i.e. complex and uncertain), social, and future (e.g. stopping climate change) or concrete, personal, and proximate (e.g. using a car); consequently influencing their evaluations and decisions regarding an issue or event. An ideal decision-making situation would be to take into account information about both the long and short psychologically-distanced aspects of an issue. Alternatively, focusing only on abstract aspects can be desirable but overwhelming; focusing only on the concrete aspects can be easy but also unsatisfying. Trope concludes: "You need the big picture and the details, the forest and the trees."

As a chronic phenomenon, emerging health issues made respondents discuss the implications of indeterminacy as the presence of unknown and uncertain attributes due to an ever-evolving science (e.g. ignorance that PFOS could be persistent and carcinogenic)

and the complex system of interacting risk factors that produce health outcomes (e.g. the combination of carbon emissions, multi-scale climate dynamics, and poverty). Indeterminacy incited people to discuss hazardousness in terms of possibility rather than certainty (potential hazards vs. hazards). To respondents the above mentioned types of indeterminacy were inevitable and understandable. This is consistent with what other public perception studies found: that people do not expect certainty, but rather take the concept of uncertainty for granted (e.g. Levy and Derby, 2000; CSEC, 2001, and Frewer et al. 2003).

The presence of unknowns (what ifs?) and compounding risk factors adds another layer of uncertainty to expert risk assessments. It leads respondents to question the significance of scientific evidence; the efficacy of existing safeguard mechanisms, and the strength of product and technology risk assessments. Appreciably, respondents are annoyed (but not surprised) to learn that products previously considered harmless such as Scotchguard, asbestos, and Vioxx should now be considered suspect or dangerous. As a result, indeterminacy expressed as unknowns, uncertainties, and complexities was often a reason given to grant more weight to precaution than to negative health hazard assessment findings. For instance, many respondents felt a need to avoid potential hazards such as genetically modified foods, pesticides – and even Scotchguard despite knowing that it no longer contained PFOS; in effect, some respondents were suspicious about the safety of PFOS' replacement. Respondents have recognized what many intellectuals (e.g. Stirling, 2003) have written about: that health hazard assessments may indicate that there is no evidence of harm but they cannot assert that there is evidence of

no harm. Demonstrating no evidence of harm is the traditional burden of proof which respondents have recognized as causing considerable delays in hazard identification. Alternatively, demonstrating evidence of no harm (i.e. safety) is a fundamental principle of precaution that most respondents desired under conditions of indeterminacy.

In addition to emerging health issues being considered the product of natural indeterminacies in conducting progress, these health issues were also considered the product of procedural inadequacies. While respondents acknowledged the difficulty and even the impossibility of accurately predicting future outcomes with current knowledge, they were also aware that there are indeterminacies reducible through improved regulatory measures. For instance, respondents pointed to a lack of long-term monitoring of pre- and post-market consumer goods and to the self-regulation of industry as barriers to properly identifying hazards. They did not talk of conducting more research efforts as a solution. In fact, some respondents recognized that conducting more studies could also uncover even more complexity and uncertainty. Instead, they argued that if the above mentioned research inadequacies were addressed, this could reduce the number of hazards released at the source and could minimize exposures through earlier product withdrawals. In effect, in the context of the scenarios, respondents were predominantly concerned not by the knowledge uncertainties, nor by the experts' ignorance of the possible consequences, but rather by their belief that PFOS testing was not performed responsibly and that steps were not being taken to mitigate the effects of climate change, that is that risk management was not performed with indeterminacy in mind. Similarly,

Frewer et al. (2003) found that lay individuals considered scientific acknowledgements of uncertainty more credible than risk knowledge given with no details of uncertainty.

Specific findings reveal that concern is not solely about hazardousness, but also includes other preoccupations about the actors and influences which let potential hazards emerge, thrive, and impact in multiple and compounding ways. For instance, responses to the extreme heatwaves scenario point to numerous factors creating and defining concern: complexity in climatic patterns; the predictive limitations of climate models; political spin of climate change science; a lack of greener transportation alternatives; susceptibility variables such as poverty, isolation, and old age, and valued concepts at-stake such as sustainability, health equality, responsibility, and quality of life. Alternatively in the persistent pollutant scenario, the objects of people's concerns include: scientific uncertainties; dependence on a self-regulating industry; a lack of long-term product monitoring; gaining awareness; balancing product benefits with potential harm, and valued concepts at-stake such as progress, safety, and trust.

To summarize, respondents described emerging health issues as a chronic phenomenon and the product of both irreducible and reducible indeterminacy. The important framings of emerging health issues are the implications of an ever-evolving, always imperfect scientific knowledge; the unpredictable nature of complex systems producing adverse outcomes, and the perception of an under-appreciation for indeterminacy by government and industry as the sole regulatory actors.

5.2.2 Information Needs

To gain awareness of emerging health issues, respondents must necessarily be exposed to the information. The individuals perceived by respondents to be most at-risk from health hazards were the uninformed. Accordingly, respondents valued multiple information mediums to increase the likelihood of being informed. To achieve familiarity and to define the relevance of risk, respondents justifiably wanted to be briefed on hazard and exposure information: both what is known and the degree to which information is unknown within an issue. A lack of crystallized factual information and evidence of incomplete knowledge incited respondents to be critical about the information available. Information about potential hazards was perceived as subject to the interpretation of the source that transmitted the information. Respondents relayed that confusion occurs when there is debate on an issue. They recognized that different sources can use their underlying interests to subjectively 'diminish' issue uncertainties. To interpret messages, individuals considered information sources which use various epistemologies – often in combination (e.g. science-media, science-commerce, science-politics), most often in which they have no formal training. Lay individuals must also consider within the source's message, the determinants of indeterminacy. That is, uncertain information, gaps in knowledge, absent perspectives, conflicting opinions, and subjectively interpreted information. As respondents had concerns relating to both knowledge framing (e.g. capitalistic interests; limits of scientific determinations, and media sensationalism) and actor behaviours (e.g. spin, dishonesty, and complacency), they had an appreciation for multiple sources and perspectives that help them understand uncrystallized, incomplete,

complex, and unfamiliar information to distinguish fact from what remains unsubstantiated. Gibbons (1999) echoes respondents' information-seeking behaviours in a discussion on public debates. He writes,

“...knowledge, itself distributed, contextualized, and heterogeneous cannot arise at one specific site, or out of the views of one scientific discipline or group of highly respected researchers. Rather, it must emerge from bringing together the many different ‘knowledge dimensions’ involved.”

Effectively, the integrity of the total available knowledge depends on the ways by which the different epistemic cultures are linked, i.e. who says what; who supports who; who disagrees with who, etc. – most often this is self-organizing.

To manage the messages they receive, respondents utilize such strategies as profiling information sources (e.g. their funding sources, vested interests, and past conduct) and examining the circumstances underpinning the release of information (e.g. breaking news, cover-up, whistle-blowing, and evidence of overdue disclosure) to consider the underlying motives and behaviours shaping source perspectives. Credible sources were perceived to be the sources which show evidence of objectivity or have compatible interests to those of the public. Multiple sources reinforce veracity by informing on the predominant view. One information provider is not necessarily dismissed for another more credible one. In fact, sources which may not be compatible with respondents' own interests are also seen as offering valuable information. For instance, respondents pointed out that information disproving climate change could stem from research funded by petroleum industries that do not support Kyoto initiatives and the public's interest in environmental sustainability. Such information informs the

individual on its subjectivity but more importantly it indicates that there is still sufficient uncertainty within the issue to indicate that climate change cannot be considered a truly factual phenomenon at the present time. Consequently any information, even if uncertain, conflicting, or questionable is considered useful for understanding the state of knowledge about emerging health issues. Table 5.1 summarizes the important types of information people desired for understanding emerging health issues.

Table 5.1

Respondents' Information Needs

<p>Basic hazard and exposure information</p> <p><i>Rationales:</i> Of known attributes: Determining level of control; Defining risk relevance at the personal, social, societal, environmental, and global scales. Of unknown or uncertain attributes: Evaluating information completeness</p>
<p>Manner of disclosure (e.g. evidence of partial disclosure; hesitancy, or refusal to disclose)</p> <p><i>Rationales:</i> Gaining awareness of unfamiliar potential hazards; Determining the limits, if any, of the willingness to disclose (degree of transparency); Establishing a source's reliability and compatibility with lay interests; Understanding a source's identity through its actions and behaviours</p>
<p>Nature of information source (e.g. vested interests, reputation, and history)</p> <p><i>Rationales:</i> Identifying 'spin' and interpreting biased messages; Considering source credibility; Attributing weight to various messages, Establishing compatibility with the public interest</p>

Multiple information sources*Rationales:*

Establishing strength of the information with similar/dissimilar messages and credible/less-credible sources; Identifying a trend in the dominant view; Comparing and characterizing source perspectives; Compensating for silent sources; Substantiating information through message repetition in space and in time; Identifying knowledge gaps; Increasing likelihood that relevant but overlooked information is communicated; Identifying knowledge uncertainties through conflicting messages

Multiple information mediums*Rationales:*

Increasing exposure and access to information thereby minimizing unfamiliar issues for at-risk populations

5.2.3 Components of Vulnerability

The objects of concern being drawn from the two scenarios and from other examples brought up by participants point to an overarching preoccupation with personal and societal vulnerability. Table 5.2 list specific objects of concern, including those about information providers and needs for information. Even though risk can be difficult to define under knowledge uncertainty, emerging health issues are perceived to invariably occur. If an emerging threat is highly probable, the question is: how are we vulnerable? Thus, respondents have a vested interest in striving for a resilient and adaptive society which can minimize vulnerability to adverse outcomes while maintaining and enhancing quality of life. From the viewpoint of respondents, it explains the importance of having access to products and technologies that improve our lives; of relying on an involved and respondent government, and of having opportunities to make decisions about risk. In assessing their vulnerability, respondents want to understand the social, material, and

conceptual entities involved in emerging health issues. Whereas risk is hazard-focused, i.e. the likelihood of adverse effects, vulnerability is people-focused, i.e. the susceptibility towards adverse effects. In this sense, evaluating hazard-specific risk is irrelevant as “it is not probabilities that determine our environment, it is possibilities” (Male, Environment group). Effectively, respondents expressed sentiments of vulnerability under conditions where the hazard or risk was ill-defined. This conception of vulnerability differs from the “biophysical vulnerability” usually implied in health risk literature defined as the degree or likelihood to which a system or individual is likely to experience adverse effects (i.e. physical and psycho-social) due to exposure from a hazard or event (Cutter, 1993; Health Canada, 1997, and International Panel on Climate Change, 2001). Instead, focus group participants have concerns more akin to “social vulnerability”: a state that exists within a system before it encounters a hazard event (Allen (2003) in Brooks, 2003). As mentioned, a focus on hazard exposure is irrelevant under emerging uncertain circumstances; rather it is the ability of people to cope that is of interest in emergent health issues. Attending to social vulnerability is more likely to reveal coping determinants such as economic well being, security, health and education status, and preparedness (Brooks, 2003), that may help explain the responses of citizens in specific environmental health debates and their views of societal and political impacts of health controversies and crises. The analysis revealed that respondents have objects of concern towards emerging health issues that fall into three themes, essentially the components of people’s sense of (social) vulnerability: concern about risk to health and well-being, risk to resilience, and risk to comprehension (Table 5.2).

Table 5.2

Components of People's Sense of Vulnerability

Health and Well-being

Concerns:

Maintaining and increasing quality of life through the benefits of products and technologies; Products and technologies as potential hazards; Long-term exposure to unknown hazards; Consumers as a cause perpetuating these issues; Micro- and macro-scale impacts (i.e. personal, societal and global); Limits of hazard science (undetected hazards); Industry as hazard-producer; Uncooperative industry in hazard detection; Government favouring industry interests to the detriment of public health; Lack of precaution; Protecting health & maintaining safety; Respecting public interests; Assuming responsibility; Being trustworthy; Acknowledging indeterminacy

Resilience

Concerns:

Facilitating individuals in making independent decisions; Protecting publics at-risk; Being made aware of potential hazards; Government complacency; Deficiencies in regulatory safeguards; Insufficiently precautionary; Favouring industry to the detriment of the public; Acknowledging Indeterminacy; Striving for sustainability; Exercising precaution; Maintaining progress; Protecting health & maintaining safety; Acting honestly; Acting transparently; Striving for equality; Respecting public interests; Assuming responsibility; Being trustworthy

Comprehension

Concerns:

Information spin; Dependence towards the holders of hazard information; Past histories of dishonesty or incompetence; Attributing personal and social relevance; Risk of instilling unsubstantiated fear; Risk of information overload or underload; Unfamiliar regulatory processes; Interpreting information; Acting Honestly; Acting Transparently; Acknowledging Indeterminacy

5.3 Considering Vulnerability in Relational Terms

Although physical harm is often dreaded, concern particularly in conditions of high uncertainty and unfamiliarity is not solely about the risk of adverse health effects from hazards; it is also about the risk of weaknesses in personal and societal resilience mechanisms and about the risk of being ill-informed. Consequently, examined through the lens of Healy's (2004) relational framework (refer to section 2.4.3), there is not one risk network defining vulnerability, but three. These types of risk in turn render people vulnerable in their abilities to cope with potential health hazards.

To visualize these three networks, a conceptual framework for vulnerability is conceived as a three-level network with the social, material, and conceptual entities involved in emerging health issues seen as pillars extending through all three risk networks (Figure 5.1). Such entities would most familiarly include: government, industry, media, hazards, consumer goods, and self. The nature of the relationships between entities continuously redefines the way entities are conceptualized. The framework is nested within all scales and is designed to appreciate the repercussions and interconnectedness involved in shaping people's sense of vulnerability towards emerging health issues. It can help understand the implications of people's responses. For instance in the West Nile issue, Faith group participants were particularly impressed with risk communication initiatives and this contributed to government's reputation as a responsible entity. For one participant, this in turn influenced another relationship in another network subset: any concerns about risk to comprehension and risk to health were put to rest with regards to West Nile by the recognition that government was "on

top of things”, i.e. in control (risk to resiliency). Thus, this participant did not want to know more about that particular issue. Alternatively with regards to GMOs, some respondents’ concerns about the absence of food labelling (risk to comprehension) caused concern about the public’s dependency on a government perceived to be inadequately precautionary (risk to resiliency). To reiterate Healy’s prescription: “the key concern here is to provide an account of these dynamics and to explain how conditions of risk arise and might be ameliorated” (2004a).

Scales

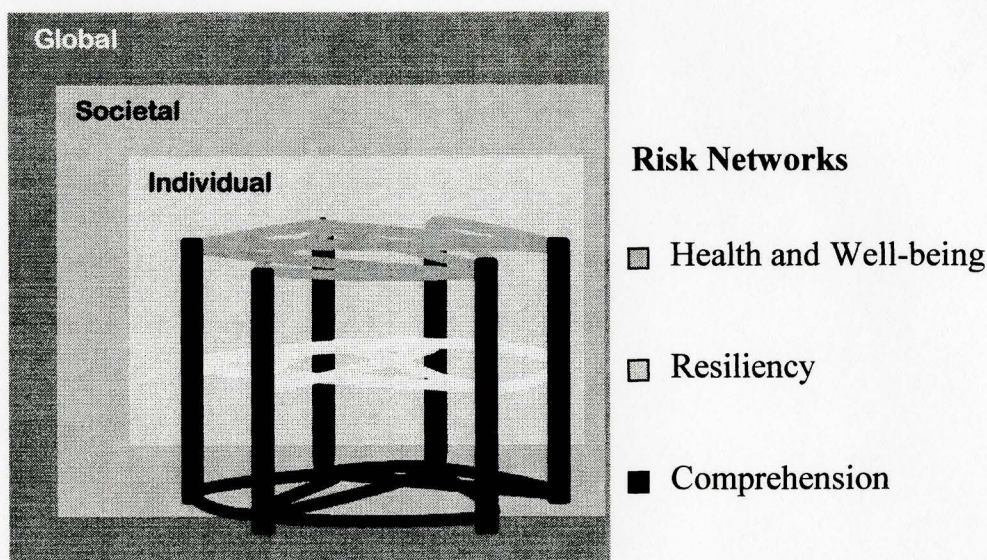


Figure 5.1 A Conceptual Framework for Understanding People’s Sense of Vulnerability towards Emerging Health Issues

5.3 Policy Implications

The focus group findings have shown that disclosure is not a tool to ease concerns, although this can certainly be an end result. Full and transparent disclosure can heighten concerns depending on the nature of the hazard, the deficiencies in regulatory frameworks, and the incompatibilities of vested interests. Further, findings show that trust relations can suffer through disclosure since early disclosure under uncertainty may lead to perceptions of scare-mongering and loss of credibility if predictions do not materialize. Such is the nature of informing transparently. Consequently, trust in government cannot be achieved solely through disclosure of hazard and exposure information, other types of information need to be communicated as well. The findings indicate that information providers are entities defined principally through their interpretations of information and their behaviours as communicators. However, government has additional functions as a protector of health, a regulator of hazards, and a facilitator for progress. This renders trustworthy relations contingent on government's multi-faceted roles, actions, and behaviours. Thus, if trustworthy relations are desired, disclosure of hazard and exposure information must also potentially be accompanied by information on those governmental actions and behaviours which are contentious in the public eye.

5.3.1 Roles for Disclosure

Eleven roles for disclosure emerged from the analysis of respondents' discourses pertaining to government and information. Although, there is a considerable lack of confidence in current regulatory frameworks, community members rely on the institutions mandated to protect them for providing hazard and exposure information (1); for suggesting personal preventive measures (2); and for informing on risk management policies and processes, in particular raising awareness of the scientific and regulatory limitations that can contribute to elevating health risks (3). However, such provision of information does not necessarily lead to trust without some evidence that government actions are taken or planned (4). Other roles of disclosure as defined by respondents included: clarifying government priorities, positions, and rationales for individuals to interpret actions and disclosure messages (5); enabling access to information that allows individuals to exercise choice and responsibility (6); and access to expertise where information is specialized or complex (7). Respondents did not view information as disclosed by government as an absolute truth but rather as one important perspective needed for a deeper comprehension of conflicting or developing information (8). Disclosure was needed to re-assure individuals of government's ability to act on behalf of public interests (9). Disclosure was also seen as a required means to fulfill government's mandate whereby actively communicating public health information broadly to inform all citizens and specifically to inform at-risk populations (10). Lastly, releasing publicly-relevant information was considered a necessary ethical or moral endeavor (11).

As a means to assess the interpretation of focus group respondents' views on disclosure, the eleven roles for disclosure were compared against disclosure-related recommendations of Health Canada's Public Advisory Committee (PAC). The PAC is composed of 17 members of the general public from across Canada, including men and women of various ages and diverse academic, cultural and linguistic backgrounds. The Committee provides advice from the consumer/public perspective on priority health issues and initiatives as requested by the Department and is part of the Health Products and Food Branch's strategy to increase transparency and public involvement (Public Advisory Committee, 2004). PAC meeting minutes from ten meetings held between January 2003 and February 2005 were examined for disclosure-related concerns and information needs. Appendix F details the document coding scheme. Together, focus group and PAC data helped create convergent validity by reinforcing the accuracy of the interpretation of focus group respondents' views (Table 5.3). The PAC recommendations were found to agree with all eleven roles for disclosure. For some disclosure roles (marked PA for partial agreement), rationales given in the PAC meeting minutes either differed, were unclear, or were unspecified; still, roles for disclosure were similar.

Table 5.3

Convergence Coding Matrix for Disclosure Roles

Focus Group Disclosure Roles (Rationales)		PAC Recommendations			
		AG	PA	S	DA
1	Inform on product/hazard characteristics and exposure pathways (unfamiliarity)	✓			
2	Suggest personal prevention measures (need for actionable advice)	✓			
3	Inform on risk management policies and processes (unfamiliarity, need for information about deficiencies and safeguards)		✓		
4	Inform on remedial actions taken and planned (need for evidence of resiliency, support, and leadership)	✓			
5	Understand government priorities, positions, and rationales (need of clarification to interpret actions and disclosure messages)		✓		
6	Access to information for allowing individuals choice and responsibility (need to establish risk relevance)	✓			
7	Access to expertise where information is specialized or complex (need for better understanding the issue)		✓		
8	Provision of a relevant perspective on health issues in conflicting and emerging contexts (need to compare information using multiple sources)		✓		
9	Reassurance of the intentions to act on behalf of public interests (need evidence of reliability)	✓			

10	Communicate health information broadly to inform publics and specifically to inform at-risk populations (need for a public health communicator)	✓			
11	Provide all information that is in the public's interest (an ethical or moral act, the 'right-to-know')		✓		

AG: Agreement with disclosure role

PA: Partial agreement, where the rationale differs, is unclear, or unspecified

S: Silence, does not mention disclosure role

DA: Disagreement with disclosure role

5.3.2 Response Opportunities

The vulnerability framework is guided by the need to provide a template suitable for the identification of health risk-specific concerns yet inclusive of other types of concern within the larger systemic character of emerging health issues. By identifying the government-specific interactions which increase vulnerability (i.e. decreases individuals' ability to cope), the roles for disclosure as perceived by respondents can be formulated into response opportunities for decision-makers, many of which are explicitly viewed by respondents as determinants of trust (e.g. inform on regulatory processes; disclose actions taken or planned, and clarify rationales). Disclosure performed as such can empower individuals through knowledge; allowing for more autonomy, responsibility, and capacity in their decision-making. At the same time, disclosure can inform on government action and behaviours whereby reshaping people's perception of government and contributing to more trustworthy relationships.

This citizen-centered perspective on emerging health issues suggests that accountable and trustworthy disclosure should be transparent and comprehensive enough to allow lay individuals to evaluate government as an actor influencing their sense of

vulnerability. More specifically, it suggests that disclosure should be considered not so much a risk communication tool as a window onto risk analysis, decision-making, and regulatory processes. This recommendation is significant; this form of disclosure requires government to clarify its understandings, assumptions, and preconceptions for all to understand and potentially contest and reshape. It creates an opportunity for epistemological pluralism to occur through the integration of different knowledges in decision-making such as public participation (Healy, 2004b). Finally, because peripheral concerns about government and industry behaviours and actions persist and are carried over to the next series of health issues, effective disclosure should be a continuous undertaking and not just used during times of controversy or crisis.

5.4 Directions for Future Research

Informed by Healy's (2004a) relational framework, this research has provided insights into how unfamiliarity and uncertainty in health issues influence people's information needs. It adds to understanding the explicit links between people's information needs and their concerns. Furthermore, this research has contributed to understanding the roles of disclosure from the perspective of the Canadian citizen stakeholder/decision-maker.

This research points to key areas in which more research is needed. First, as this research is in effect the pilot study of a federal health policy research initiative, it is important that these results be compared with those of the main study, which utilizes scenarios of more familiar and potentially less uncertain health issues (i.e. blood

transfusions, arthritis drugs, and West Nile virus). Such a comparative analysis may contribute more detailed insight into the influence of uncertainty on information needs, particularly disclosure needs. Moreover, it would be useful to conduct focus groups with policy makers to explore current professional perceptions of lay disclosure needs and the integration of different forms of knowledge in decision-making. In fact, there remains an important policy research gap regarding the need to integrate different epistemologies in decision-making, particularly the lay and the risk expert perspectives. Future research in this area should explore the capabilities of existing public involvement processes (e.g. public advisory committees and focus group policy initiatives) for their ability to address not only information needs and convey public interests, but also for their ability to influence organizational procedures and behaviours. Second, social and health geographers are particularly well suited to explore the ways by which risk and vulnerability are conceptually defined in the non-specialized context of everyday life. A deeper exploration is needed of the ways by which multiple epistemologies (e.g. science, policy, commerce, and social norms) are used by lay individuals in their understandings and decision-making regarding risk and vulnerability. Further, since information needs are also dependent on hazard characteristics, lay responses in the context of a wide range of hazards should be explored. Additionally, geographers must focus more comprehensively on all spatial (e.g. individual, social, societal, and global) and temporal scales as risk and risk perception are dependent to a large extent on a combination of contextual setting, historical background, and complex dynamics and scalar linkages that can increase the potential for adverse outcomes. Lastly, there remains an important

research gap regarding the determinants that lead to trustworthy relations between government and the publics. The research reported in this thesis has identified a conceptual framework that suggests that under conditions of unfamiliarity and uncertainty, people's concerns revolve around threats to health and well-being, but also to their capacities for resilience and their comprehension of emerging health issues. In this context, this research has identified several roles for disclosure that can assist in creating favourable conditions on which trust can be built. However, it should not be assumed that these disclosure needs are applicable to all emerging health issues, in all social settings, and at all times, as these are based on the current relationships as perceived by members of a Southern Ontario community, i.e. in a specific spatio-temporal context. Nonetheless, a survey instrument could certainly test the transferability of locally performed qualitative focus group findings to larger population groups. Such research efforts could establish if increased attention to social attitudes towards certain products and technologies is warranted particularly in the earliest stages of regulation. This would certainly be central to the execution of transparent and trustworthy governmental decision-making.

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APPENDIX A

Emerging Health Issue Scenarios

Exposure to a Persistent Pollutant

In the 1970s, 3M created Scotchguard, a stain repellent product used to protect carpets and upholstery. Testing showed the product was safe for humans to use.

In the 1990s, PFOS, the main chemical in Scotchguard was detected in U.S. and Canadian blood banks as well as in the tissues of wildlife worldwide, including the Arctic. This meant that PFOS was persisting in the environment and accumulating in living organisms.

In 2002 as a precaution, 3M began phasing-out its use of PFOS in Scotchguard.

Recent studies indicate that PFOS is not as safe as we thought it was. PFOS can cause health effects in laboratory animals and there may also be an association between PFOS exposure and incidences of bladder cancer in some 3M plant workers.

Most experts now recognize that PFOS is toxic and most people have traces of PFOS in their blood. However, how the public's health is affected, if at all, remains unknown.

Experts say more research is needed to fully understand risks to humans.

Extreme Heat Waves from Climate Change

Climate change is expected to affect the nature of our regional climate. One regional effect consists of heat waves that are predicted to be longer, hotter, and more frequent.

The densely populated region of Southern Ontario is particularly vulnerable. Experts predict that Toronto could experience 800 additional deaths every summer from the heat effect of climate change.

Extreme heat may also:

- Aggravate people's existing health conditions;
- Worsen air pollution and respiratory problems, and
- Increase stress and violent behaviours

The individuals most at-risk are:

- People living alone and lacking social contacts, and
- Those without air conditioning or swimming pools

Extreme heat waves may also cause power blackouts, water shortages, and put pressure on an already stressed health care system.

APPENDIX B

Focus Group Topic Guide

Focus Group Topic Guide

A. Broad Questions

- Introduce yourself and tell us one thing that's risky to you and why?

A persistent pollutant scenario

- What are your reactions to this issue?
- The issue of PFOS has only emerged recently in scientific and regulatory circles. So most people don't know about it. Do you think the public should be informed of this issue?

Extreme heat waves from climate change scenario

- What are your reactions to this issue?
- Heatwaves from climate change has been forecasted for 10 to 20 years away but there are things experts say we can do now to prepare. Do you think the public should be informed of this issue?

B. Probing Questions (if subject areas ill-discussed)

- What is concerning about this issue?
- What makes a certain issue more concerning than others?
- Does it matter who informs you?
- What are your views of how this issue is being handled?
- How do you decide if a source is credible or not?
- If you wanted to know more, what are some of the questions you would ask?
- When is a good time for informing the public about something like this?
- Does this issue make you think of other issues you know of?
- What are some of the health issues you're concerned about?
- What do you think of the way information is often presented to you?
- How does that influence your opinion of an issue?
- What do you consider are bad ways of informing the public?
- Which of these two issues do you find more concerning?

C. Closing Questions

- Are there any other things you would like to comment on?
- Have we covered everything with regard to health issues and people's concerns, their information needs, and the sources that deliver information?

APPENDIX C

Survey on Health Risks

SURVEY on HEALTH RISKS

PART 1

Which statement most closely represents your concern about the following issues? Tick only one statement per issue.

Pesticide use (Residential or agricultural spraying):

- The health effects are immediate and severe.
- The science is uncertain. Many facts are still unknown.
- I lack trust in the regulatory system put in place to protect me.
- I have little control over my exposure.
- Not overly concerned about this issue.
- Don't know. I need more information.
- Other (specify): _____

Extreme events from climate change (Heat waves, drought, flooding)

- The health effects are immediate and severe.
- The science is uncertain. Many facts are still unknown.
- I lack trust in the regulatory system put in place to protect me.
- I have little control over my exposure.
- Not overly concerned about this issue.
- Don't know. I need more information.
- Other (specify): _____

Genetically modified foods

- The health effects are immediate and severe.
- The science is uncertain. Many facts are still unknown.
- I lack trust in the regulatory system put in place to protect me.
- I have little control over my exposure.
- Not overly concerned about this issue.
- Don't know. I need more information.
- Other (specify): _____

Poor air quality – outdoors (from smog, car exhaust, ground level ozone)

- The health effects are immediate and severe.
- The science is uncertain. Many facts are still unknown.
- I lack trust in the regulatory system put in place to protect me.
- I have little control over my exposure.
- Not overly concerned about this issue.
- Don't know. I need more information.
- Other (specify): _____

Poor air quality - indoors (from household products, housing materials, mold)

- The health effects are immediate and severe.
- The science is uncertain. Many facts are still unknown.
- I lack trust in the regulatory system put in place to protect me.
- I have little control over my exposure.
- Not overly concerned about this issue.
- Don't know. I need more information.
- Other (specify): _____

Blood transfusion diseases (HIV, hepatitis C)

- The health effects are immediate and severe.
- The science is uncertain. Many facts are still unknown.
- I lack trust in the regulatory system put in place to protect me.
- I have little control over my exposure.
- Not overly concerned about this issue.
- Don't know. I need more information.
- Other (specify): _____

Food and water contamination (from chemicals and bacteria)

- The health effects are immediate and severe.
- The science is uncertain. Many facts are still unknown.
- I lack trust in the regulatory system put in place to protect me.
- I have little control over my exposure.
- Not overly concerned about this issue.
- Don't know. I need more information.
- Other (specify): _____

Viral and Infectious Diseases (West Nile virus, BSE, Avian flu, SARS)

- The health effects are immediate and severe.
- The science is uncertain. Many facts are still unknown.
- I lack trust in the regulatory system put in place to protect me.
- I have little control over my exposure.
- Not overly concerned about this issue.
- Don't know. I need more information.
- Other (specify): _____

PART 2

Do you think life is becoming more hazardous to your health?

Compared to 20 years ago, some health effects seem to have...				
Health effects	Increased	Stayed the same	Decreased	Don't know
Cancer				
Allergies				
Fertility Problems				
Attention and Learning Disorders				
Other (specify):				

Compared to 20 years ago, the environment seems to have...				
Aspects of the environment	Improved	Stayed the same	Worsened	Don't know
Air quality in urban areas				
Ground litter				
Water quality of rivers and lakes				
Noise				
Other (specify):				

Compared to 20 years ago, the regulatory system that protects the health of consumers seems to have...				
Regulated Areas	Improved	Stayed the same	Worsened	Don't know
Car emissions				
Disposal of domestic and industrial waste				
Food (inspection, labeling, testing)				
Treatment of drinking water				
Other (specify):				

PART 3

Do you agree or disagree with the following statements?

“Suspected health threats can be just as concerning to me as proven health threats.”

- Strongly agree**
- Mostly agree**
- No opinion either way**
- Mostly disagree**
- Strongly disagree**
- Don't know**

“Society accepts too many health risks in exchange for social progress and technological advancements.”

- Strongly agree**
- Mostly agree**
- No opinion either way**
- Mostly disagree**
- Strongly disagree**
- Don't know**

“Unless my health is immediately threatened, I'm not too concerned about threats to my health.”

- Strongly agree**
- Mostly agree**
- No opinion either way**
- Mostly disagree**
- Strongly disagree**
- Don't know**

“I'm usually informed about potential threats to my health in a timely manner.”

- Strongly agree**
- Mostly agree**
- No opinion either way**
- Mostly disagree**
- Strongly disagree**
- Don't know**

“I am satisfied with the amount of information about health risks I receive.”

- Strongly agree**
- Mostly agree**
- No opinion either way**
- Mostly disagree**
- Strongly disagree**
- Don't know**

PART 4

We would like you to provide some general background information about yourself.

- Under 18 years of age
- 18-25
- 26-44
- 45-64
- 65 and over

Male or Female

- Married or Common-law
- Widowed
- Separated
- Divorced
- Never Married

How many people live in your household?

- 1 2 3 4 5 or more

What is the highest level of education completed?

- Elementary High School College University

How do you occupy most of your time?

- Full-time work Part-time work Unemployed Retired Student

What is the income range for your total family income?

- less than \$20,000 \$21,000 - \$40,000 \$41,000 - \$80,000 \$81,000 and over

How do you rank your health compared to people of similar age?

- Excellent Good Fair Poor

Your postal code: _ _ _ _ _ _ _ _ _ _

APPENDIX D

Socio-demographic characteristics

Focus Group Socio-Demographic Characteristics

focus group * age

Focus group	age					Total
	under 18	18-25	26-44	45-64	65 and over	
health	0	1	3	2	0	6
environment	0	0	0	2	1	3
faith	0	0	0	2	1	3
culture	0	1	6	1	0	8
recreational	0	0	4	3	3	10
youth	9	4	0	0	0	13
non-affiliated	0	5	3	1	0	9
Total	9	11	16	11	5	52

focus group * sex

Focus group	sex		Total
	male	female	
health	1	5	6
environment	1	2	3
faith	3	0	3
culture	0	8	8
recreational	3	7	10
youth	9	4	13
non-affiliated	1	8	9
Total	18	34	52

focus group * marital status

Focus group	marital status				Total
	never married	divorced	separated	married or common-law	
health	1	1	0	4	6
environment	0	1	0	2	3
faith	0	0	0	3	3
culture	3	1	2	2	8
recreational	4	0	0	6	10
youth	13	0	0	0	13
non-affiliated	6	1	0	2	9
Total	27	4	2	19	52

focus group * number of people in household

Focus group	number of people in household					Total
	1	2	3	4	5+	
health	1	1	3	1	0	6
environment	0	3	0	0	0	3
faith	0	2	0	0	1	3
culture	3	0	2	0	3	8
recreational	3	6	1	0	0	10
youth	0	0	5	6	1	12
non-affiliated	1	2	0	3	3	9
Total	8	14	11	10	8	51

focus group * education

Focus group	education				Total
	elementary	high school	college	university	
health	0	1	0	5	6
environment	0	0	0	3	3
faith	0	0	0	3	3
culture	0	2	4	2	8
recreational	0	1	4	5	10
youth	11	2	0	0	13
non-affiliated	0	3	0	6	9
Total	11	9	8	24	52

focus group * occupation

Focus group	occupation						Total
	full-time	part-time	not working	student	other	retired	
health	3	1	0	2	0	0	6
environment	2	0	0	0	0	1	3
faith	2	0	0	0	0	1	3
culture	0	0	0	8	0	0	8
recreational	6	1	0	0	0	3	10
youth	1	1	0	9	1	0	12
non-affiliated	2	1	1	5	0	0	9
Total	16	4	1	24	1	5	51

APPENDIX E

Focus Group Coding Scheme

NVivo revision 2.0.163 Licensee: IBM

Project: Disclosure Focus Groups
User: Genevieve Moreau

NODE LISTING

Nodes in Set: All Nodes

Created: 4/13/2005 - 9:54:01 AM

Number of Nodes: 130

- 1 (1) /Risky issues
- 2 (1 1) /Risky issues/Driving
- 3 (1 2) /Risky issues/Poor nutrition
- 4 (1 4) /Risky issues/Stress
- 5 (1 5) /Risky issues/Medication Side-effects
- 6 (1 6) /Risky issues/Technology
- 7 (1 7) /Risky issues/Doctor shortage
- 8 (1 8) /Risky issues/Blood transfusion
- 9 (1 9) /Risky issues/Hygiene
- 10 (1 10) /Risky issues/Extreme Sports
- 11 (1 11) /Risky issues/GMOs
- 12 (1 12) /Risky issues/Water quality
- 13 (1 13) /Risky issues/Air pollution
- 14 (1 14) /Risky issues/Infectious diseases
- 15 (1 15) /Risky issues/Youth Life
- 16 (1 16) /Risky issues/Environmental issues
- 17 (1 17) /Risky issues/Tobacco
- 18 (1 18) /Risky issues/Meat industry
- 19 (1 19) /Risky issues/Chemicals in food
- 20 (2) /Emergent health issue
- 21 (2 1) /Emergent health issue/Societal concerns
- 22 (2 1 2) /Emergent health issue/Societal concerns/Lack of precaution
- 23 (2 1 4) /Emergent health issue/Societal concerns/Direction of progress
- 24 (2 2) /Emergent health issue/Unconcerned
- 25 (2 6) /Emergent health issue/Causes of hazard emergence
- 26 (2 6 3) /Emergent health issue/Causes of hazard emergence/Lack of long-term monitoring
- 27 (2 6 4) /Emergent health issue/Causes of hazard emergence/Assessment limitations
- 28 (2 6 5) /Emergent health issue/Causes of hazard emergence/Benefit trade-offs
- 29 (2 6 6) /Emergent health issue/Causes of hazard emergence/Lack of regulatory control
- 30 (2 6 7) /Emergent health issue/Causes of hazard emergence/Hasty product release
- 31 (2 8) /Emergent health issue/Emergence description

- 32 (4) /Passages
- 33 (4 2) /Passages/PFOS
- 34 (4 3) /Passages/HW
- 35 (6) /Attitudes
- 36 (6 1) /Attitudes/Needs satisfied
- 37 (6 5) /Attitudes/Needs unsatisfied
- 38 (7) /Risk
- 39 (7 1) /Risk/PFOS relevance
- 40 (7 1 3) /Risk/PFOS relevance/Personal relevance

41 (7 1 4) /Risk/PFOS relevance/Publics at-risk
 42 (7 1 5) /Risk/PFOS relevance/Global relevance
 43 (7 2) /Risk/HW
 44 (7 2 3) /Risk/HW/Personal risk relevance
 45 (7 2 4) /Risk/HW/Publics at-risk
 46 (7 2 5) /Risk/HW/Social risk relevance
 47 (7 2 18) /Risk/HW/Risk determinants
 48 (7 3) /Risk/Most concerning
 49 (10) /Governance
 50 (10 1) /Governance/Exp Protection
 51 (10 2) /Governance/Exp Leadership
 52 (10 3) /Governance/Limitations
 53 (10 3 1) /Governance/Limitations/Complacency
 54 (10 3 2) /Governance/Limitations/Political
 55 (10 3 3) /Governance/Limitations/Competency
 56 (10 3 4) /Governance/Limitations/Acceptable limitations
 57 (10 3 5) /Governance/Limitations/Financial
 58 (10 3 8) /Governance/Limitations/External pressure
 59 (10 4) /Governance/Public involvement
 60 (11) /Trust
 61 (11 1) /Trust/Compatibility
 62 (11 2) /Trust/Skewed information
 63 (11 3) /Trust/Past behaviour
 64 (11 4) /Trust/Reliability
 65 (11 5) /Trust/Honesty
 66 (11 6) /Trust/Credibility
 67 (11 7) /Trust/Reputation
 68 (13) /Potential hazard
 69 (13 2) /Potential hazard/HW
 70 (13 2 1) /Potential hazard/HW/Debatable
 71 (13 2 2) /Potential hazard/HW/It's here
 72 (13 2 6) /Potential hazard/HW/Origin
 73 (13 2 7) /Potential hazard/HW/Trade-offs
 74 (13 3) /Potential hazard/PFOS
 75 (13 3 2) /Potential hazard/PFOS/Benefits paradox
 76 (13 3 7) /Potential hazard/PFOS/PFOS characteristics
 77 (16) /Personal control
 78 (16 1) /Personal control/PFOS
 79 (16 1 1) /Personal control/PFOS/Avoid
 80 (16 1 3) /Personal control/PFOS/Limitations
 81 (16 1 3 1) /Personal control/PFOS/Limitations/Lay knowledge
 82 (16 1 3 2) /Personal control/PFOS/Limitations/Place
 83 (16 1 3 7) /Personal control/PFOS/Limitations/SES
 84 (16 2) /Personal control/HW
 85 (16 2 1) /Personal control/HW/Limitations
 86 (16 2 1 1) /Personal control/HW/Limitations/Lay Knowledge
 87 (16 2 1 2) /Personal control/HW/Limitations/Community
 88 (16 2 1 3) /Personal control/HW/Limitations/SES
 89 (16 2 2) /Personal control/HW/How
 90 (16 2 2 1) /Personal control/HW/How/Relocate
 91 (16 2 2 3) /Personal control/HW/How/Prepare
 92 (16 2 2 4) /Personal control/HW/How/Adapt
 93 (18) /Science

94 (18 1) /Science/Subjective
 95 (18 2) /Science/Knowledge generating
 96 (20) /Questions raised
 97 (20 2) /Questions raised/PFOS
 98 (20 2 1) /Questions raised/PFOS/Substance
 99 (20 2 2) /Questions raised/PFOS/Exposure
 100 (20 2 3) /Questions raised/PFOS/Informant
 101 (20 2 4) /Questions raised/PFOS/Regulation
 102 (20 5) /Questions raised/HW
 103 (20 5 1) /Questions raised/HW/Potential Hazard
 104 (20 5 2) /Questions raised/HW/Exposure
 105 (20 5 3) /Questions raised/HW/Mitigation
 106 (20 5 4) /Questions raised/HW/Informant
 107 (21) /Industry
 108 (21 1) /Industry/Self-regulation
 109 (21 2) /Industry/Accountability
 110 (21 3) /Industry/Vested interests
 111 (23) /Experiences with Information
 112 (23 2) /Experiences with Information/Conflicting reports
 113 (23 3) /Experiences with Information/Triangulation
 114 (23 4) /Experiences with Information/Information overload
 115 (23 5) /Experiences with Information/Information spin
 116 (23 5 1) /Experiences with Information/Information spin/Political
 117 (23 5 12) /Experiences with Information/Information spin/Media
 118 (23 19) /Experiences with Information/Lack of information
 119 (25) /Disclosure
 120 (25 1) /Disclosure/Projected challenges
 121 (25 1 1) /Disclosure/Projected challenges/Timing
 122 (25 1 4) /Disclosure/Projected challenges/Producing fear
 123 (25 1 9) /Disclosure/Projected challenges/Convincing people
 124 (25 1 10) /Disclosure/Projected challenges/Reaching people
 125 (25 3) /Disclosure/Concern over non-disclosure
 126 (25 9) /Disclosure/Personal decision-making
 127 (25 9 2) /Disclosure/Personal decision-making/Control over risk
 128 (25 9 6) /Disclosure/Personal decision-making/Awareness and Education
 129 (25 9 8) /Disclosure/Personal decision-making/Ethical
 130 (25 17) /Disclosure/Disclosure not = Accountability

APPENDIX F

Public Advisory Committee Coding Scheme

NVivo revision 2.0.163 License: IBM

Project: PAC documents
User: Genevieve Moreau

NODE LISTING

Nodes in Set: All Nodes
Created: 4/18/2005 - 8 20:08 PM
Number of Nodes: 34

- 1 (1) /Demographics
- 2 (3) /Purpose
- 3 (5) /Public Inv Strategy
- 4 (6) /Rebuilding trust
- 5 (8) /Concerns
- 6 (8 1) /Concerns/Regulating
- 7 (8 2) /Concerns/Ethical issues
- 8 (8 3) /Concerns/Don't allow
- 9 (8 4) /Concerns/Economic impacts
- 10 (8 5) /Concerns/Benefits
- 11 (8 6) /Concerns/Issue specific
- 12 (8 7) /Concerns/Safety
- 13 (8 8) /Concerns/Industry interests
- 14 (8 9) /Concerns/Raising public awareness
- 15 (8 10) /Concerns/Bias_Not neutral
- 16 (8 11) /Concerns/Access to products
- 17 (8 12) /Concerns/Environmental Impacts
- 18 (8 13) /Concerns/New role_drug dev
- 19 (8 14) /Concerns/Monitoring
- 20 (8 15) /Concerns/Leadership
- 21 (8 16) /Concerns/Unknown outcomes
- 22 (8 17) /Concerns/Necessity
- 23 (9) /Disclosure Needs
- 24 (9 1) /Disclosure Needs /Timely
- 25 (9 2) /Disclosure Needs /Diffusion
- 26 (9 3) /Disclosure Needs/Balanced and Neutrality
- 27 (9 5) /Disclosure Needs/HC roles
- 28 (9 6) /Disclosure Needs/Raise Awareness
- 29 (9 9) /Disclosure Needs/Clarity
- 30 (9 10) /Disclosure Needs/Suggest preventive measures
- 31 (9 13) /Disclosure Needs/Enable informed choices
- 32 (9 14) /Disclosure Needs/Consistency
- 33 (10) /Likes
- 34 (11) /Transparency