If it takes my whole life, I won't break, I won't bend
It will all be worth it, worth it in the end
Cause I can only tell you what I know, that I need you in my life
When the stars have all gone out, you'll still be burning so bright

"Answer" by Sarah McLachlan

University of Alberta

Effect of Equivocal Science on Public Participation: A Chlorinated Disinfection By-product Case Study

by

Merry Turtiak 

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Master of Science

Centre of Health Promotion

Edmonton, Alberta
Fall 2008

Library and
Archives Canada

Published Heritage
Branch

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque et
Archives Canada

Direction du
Patrimoine de l'édition

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence
ISBN: 978-0-494-47429-7
Our file Notre référence
ISBN: 978-0-494-47429-7

For my mom,
for your endless love, support and strength;

For John,
whose strength keeps things together

For Kevin,
the sparkle in my eye;

For Michael,
I miss you every day.

Countless thanks to my committee members – Dr. C.G. Jardine, Dr. S. M. Driedger, Dr. L. Reynolds, Dr. J. Church, S. Muhfled, C. McBride and Ms. H. Madill for your countless hours of reading, editing and reading once again.

To family and friends whose immeasurable support encouraged, badgered and pushed me towards completion - Kevin Webster, Tara Yanda, Melanie Repstock, Karina Thomas, Debra Hopkins, Mike Zemanek, Alex MacKenzie, Chris Gentile and Danny Regan.

Abstract

When science is equivocal, decision makers tend to diminish the role of the public as technical or scientific discussions dominate the risk management process. The objective of this research was to determine the roles and responsibilities the public wishes to undertake in these circumstances. Using a case study based on chlorinated disinfection by-products, 15 drinking water experts and 92 public participants (selected either randomly or as representatives of community based organizations in Winnipeg, Manitoba and Edmonton, Alberta) were used to define the public's roles and responsibilities when scientific uncertain exists. The findings revealed that scientific uncertainty should not minimize the role of the public. Results reinforced the need for a clarified public participation process which creates meaningful opportunities that value public opinion as an input into the decision-making process. Additionally, resources need to be targeted towards identifying those personally affected and in improving access by creating multiple avenues for involvement.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

AFHE-REB	Agriculture, Food and Human Ecology - Research Ethics Board
BDCM	Bromodichloromethane
CDBP	Chlorinated Disinfection By-products
DBP	Disinfection By-products
EI	Edmonton Informed (type of focus group)
ER	Edmonton Random (type of focus group)
HAA	Haloacetic Acids
MLA	Member of the Legislative Assembly
THM	Trihalomethanes
UV	Ultraviolet
WI	Winnipeg Informed (type of focus group)
WR	Winnipeg Random (type of focus group)

1.0 Introduction

1.1 Overview

As human society has evolved and moved forward, science has played a larger and larger role in improving our understanding of not only ourselves but the world around us. This is one of the goals of science, to improve knowledge and insight. However with every positive, there can be negatives. As we delve deeper into understanding, we pose new questions and identify issues which were previously unknown to use, but may have unforeseen impacts on our health or the environment. As a result, a decision maker may utilize science to protect the health of the public, while at the same time exposing them to be unforeseen consequences. Understanding what these consequences are, can be complicated and hampered by the inability of science to offer a clear explanation. This can introduce uncertainty into policy decision-making that is intended to protect the public's health.

The assessment of hazards and associated risks posed to human health is based on varying levels of direct evidence and thereby reflects varying levels of certainty. For example, we have good knowledge of the health effects of smoking tobacco. This knowledge is based on having a large population directly and measurably exposed to high enough doses for a sufficient length of time to ascertain actual toxicity to humans. On the other hand, our information on the human health effects of some contaminants in drinking water is much less conclusive. Knowledge of the toxicity of these compounds is

primarily based on animal studies done at very high doses. Using this information to extrapolate the possible effects on humans who are exposed to much smaller doses is very difficult (Graves el al, 2001).

Epidemiological studies of actual human populations at realistic doses often show inconclusive or contradictory results that fail to confirm association (Graves et al, 2001). In addition, health risk assessments are intentionally biased to err on the side of caution by seeking the most sensitive endpoints from the available toxicological literature. These assessments also include the application of uncertainty factors so as to limit the possibility of adverse health effects and limit exposure to acceptable levels. As a result, risks based on emerging and equivocal scientific knowledge are associated with uncertainty. This uncertainty creates a distinct challenge when formulating appropriate policy directives for effective risk management.

Decision makers are being asked to regulate a growing number of activities that involve increasingly complex environmental and health issues. As science cannot always provide the required information in resolving these issues, other factors must be considered in managing these risks. These other factors include but are not limited to economic, legal, social and cultural considerations (U.S. Presidential Congressional Commission, 1997). Members of the public have perceptions, opinions and beliefs about each factor. As decision makers must consider these factors in risk management, it follows they must also take into account the convictions and principles of the public. Thus learning how the

public should be engaged and what role they are expected to fulfill in such decision-making processes is becoming increasingly important.

1.2 Research Goals

The importance of public participation is a well explored area in social science literature (Buchy and Hoverman, 2000; Rowe and Frewer, 2000, 2004; Abelson et al, 2007; Church et al, 2001). Despite this understanding, attempts to formalize a participatory risk management process, while well intentioned, remain controversial and unclear. This is further complicated when scientific uncertainty exists and the risks, benefits and impacts of an issue may be technically challenging or unavailable. Thus the present research attempts to explore and characterize the role, responsibilities and processes of involving the public under these circumstances. To investigate the potential roles and identify suitable processes, the case study of chlorinated disinfection by-products (CDBPs) was used to provide context for research participants.

As their name implies, CDBPs are a byproduct produced during the chlorination of drinking water. Chlorination of drinking water has prevented the death of millions from diseases like typhoid and cholera. But CDBPs have been epidemiologically associated with an increased risk of cancer and adverse reproductive outcomes. However, confirming these health impacts is hampered by the difficulty in effectively measuring the exposure an individual receives. Therefore, there is a dichotomy of benefit and risk with a caveat of uncertainty as to what the risk may actually be. On one hand science has

provided us with a method of ensuring our drinking water is free from microbes but on the other, the addition of chlorine to water can create chemical by-products which may impact our health in the long term. The case study of CDBPs thereby serves as a realistic example which can be used to explore how scientific uncertainty can affect the role of the public in decision-making.

The research presented here is a portion of a larger research project which involved eliciting information and opinion from over 100 public and relevant agency decision makers who answered a wide range of questions related to scientific uncertainty, public participation and risk management strategy development. The key areas investigated in this master's level research are outlined below.

1.3 Research Questions

The focus of this research was to clarify the role and responsibilities of the public in the risk management of issues where the scientific knowledge is emerging and characterized by uncertainty. For the purpose of this research 'roles' are defined as active tasks undertaken by individuals as part of a formalized process, while 'responsibilities' account for an individual's conduct or obligation in fulfilling their designated duties. To provide context, this research also uses a case study on chlorinated disinfection by-products (CDBPs) in drinking water. The research questions are:

1) What role and responsibilities *does* the public currently play in decision-making?
2) What role and responsibilities *should* the public play in the risk management of emerging or uncertain scientific knowledge?

Addressing the first question will provide a baseline of what role the public currently plays from both the viewpoint of decision makers and members of the general public. The second question seeks to identify an appropriate role for the public when scientific uncertainty exists. It is here where the case study was employed to facilitate discussion(s) to identify opportunities for public involvement. While decision makers may perceive that there are opportunities for members of the public to participate, clarifying how and when these will occur may contribute to more meaningful interactions with the tax payers.

1.4 Chapter Overview

A review of the history of chlorination and water treatment is provided in Chapter 2. This history starts with the discovery of the need to treat water to prevent disease and the basics of water treatment. It describes how by-products are formed from the chlorination process. This chapter also offers a review of scientific uncertainty and the results of previous research on the effect on public participation. Finally, research into how uncertainty may be communicated and the risks and benefits of doing so are described.

In Chapter 3, the potential health effects and uncertainties associated with CDBPs are outlined in a case study format. Finally, a review of the water treatment processes for the two community sites, Edmonton, Alberta and Winnipeg, Manitoba is provided. This discussion outlines the differences in water treatment and levels of CDBPs between the two communities.

In Chapter 4, the methods used in this research are reviewed. Interviews were conducted with two distinct groups of participants: stakeholders or decision makers in the regulation, production and distribution of drinking water, and focus groups were conducted with members of the general public. The participants of the public focus group were subdivided into two types of participants: (1) members of relevant community organizations in each research site and (2) people randomly selected from the general population of each city. The rationale of using separate groups is provided.

In Chapter 5, the demographics of the participants and overall research results are presented. For each question, the responses are categorized, and described by using examples of responses from the participants.

Chapter 6 provides a discussion of the results. The discussion focuses on the similarities and differences between participants groups and the relevance of these comments. Factors such as location and type of focus groups were also evaluated to determine their impact on the participant's comments. The researcher also identifies what components or considerations were missing during discussions and possible biases that may have been present.

In the final chapter, Chapter 7, the conclusions of the research are presented along with recommendations for decision makers, best practice and future research implications.

2.0 Literature Review

2.1 Chlorination

2.1.1 History of Water Treatment

Having access to a safe, fresh water supply is not only a basic necessity of human life but essential for the development and growth of a civilization. For millennia people have built towns or cities near lakes or rivers as their source of water to drink, to wash in, and for transportation purposes. However, despite our basic need for water, it has only been within the last 250 years that we have understood the need to have effective water treatment to prevent disease.

Historically, water was considered clean and safe if it was clear or had no odor. Humans made this determination by using our five senses, as any analytical or microbiological techniques had yet to be developed. Even ancient Egyptians from 15th Century BC realized that water could be "cleaner" if basic water treatment steps such as sedimentation and coagulation with alum were utilized (Symons, 2006). Romans in the 3rd Century BC also utilized these water treatment techniques to provide safe water to population in their growing cities (White, 1999). Moreover up until the early 1600s there was no change or improvement in water treatment methods or techniques (Symons, 2006).

The first tentative connections between disease and water supplies occurred in 1680 when the discovery of "wee animacules", now known as microorganisms was made by the father of microbiology Anton van Leeuwenhoek (Symons, 2006; Brock and Madigan, 1988). Yet the connection between these water borne organisms and disease was not confirmed until 1870 when Drs. Robert Koch and Joseph Lister were furthering the work of Louis Pasteur[1] (Schoenen, 2002; Brock and Madigan, 1988). This confirmation was further support to Dr. John Snow's earlier suspicions about the relationship between cholera and water during the infamous Broad Street Pump Affair in 1854[2].

2.1.2 Chlorine and Chlorination

Chlorine was discovered in 1774 by the Swedish chemist Karl Wilhelm Scheele and confirmed to be an element in 1810 by Sir Humphry Davy (Wigle, 1998). Chlorine does not exist alone in nature and is most commonly found as sodium chloride or simple table salt (White, 1999). In 1774, chlorine's powers to destroy colors (bleach) and its ability to

[1] Louis Pasteur demonstrated between 1860 and 1864 that fermentation and the growth of microorganisms in nutrient broths did not occur by spontaneous generation. He exposed freshly boiled broths to air in vessels that contained a filter to stop all particles passing through to the growth medium: and even with no filter at all, with air being admitted via a long tortuous tube that would not pass dust particles. Nothing grew in the broths, determining that living organisms that grew in such broths came from outside, as spores on dust, rather than being generated within the broth (Brock and Madigan, 1988).

[2] During a cholera outbreak in 1854 the local physician and notable anesthetist Dr John Snow noted the addresses of the sick, and found that all cases of illnesses occurred in the homes which obtained their water from the Broad Street pump. He famously persuaded the parish council to remove the handle of the pump, thus preventing any more use of the infected water. The spring below the pump was later found to be contaminated with sewage (White, 1999).

disinfect have been known. But it was not until the germ theory of disease[3] was accepted that disinfection by chlorine became truly established (Wigle, 1998).

Initially, chlorine's capability as a disinfectant was utilized in medical and hospital settings. The first recorded usage was at the Vienna General Hospital in 1846 to clean the hands of medical staff and prevent puerperal fever (Symons, 2006; White, 1999). Dr. John Snow attempted to temporarily disinfect a water supply in London as early as 1850 (White, 1999). Yet it was not until 1881, that a student of Dr. Robert Koch demonstrated chlorine's ability to kill bacteria (Schoenen, 2002).

In 1902, chlorine gas, as opposed to hydrated lime, was first used to disinfect drinking water in Middlekerke, Belgium (Schoenen, 2002; White, 1999). This was the first permanent chlorine water disinfection system and similar systems soon followed in Lincoln, England in 1905 and Jersey City, New Jersey in 1908 (Symons, 2006;White, 1999; Schoenen, 2002). In Canada, the earliest confirmed usage of chlorination was in Peterborough, Ontario in 1916 (Wigle, 1998; PUC, 2007). From that time, the application of chlorine has spread throughout the world and for over a hundred years, chlorine has remained the most popular method of disinfecting water (Wigle, 1999; White, 1999).

[3] Robert Koch was the first scientist to devise a series of proofs used to verify the Pasteur's hypotheses now known as the Germ Theory of Disease. Koch's Postulates were first used in 1875 to demonstrate anthrax was caused by the bacterium *Bacillus anthrasis*. These postulates are still used today to help determine if a newly discovered disease is caused by a microorganism (Brock and Madigan, 1988).

The reason for chlorine's continued usage is multi-faceted. Chlorine itself is an inexpensive product that can either be easily purchased or generated in large scale water treatment facilities (White, 1999). Also, it has an ability to form a residual and be effective at low amounts or concentrations. This ability to form a residual is important as regrowth of bacteria needs to be prevented as water travels from the treatment plant to an individual's home (Koren and Bisesi, 1996). Water may travel through many kilometers of piping, which could allow regrowth or recontamination if distribution lines become damaged. Having a residual level of chlorine in water thereby ensures that the water remains safe for drinking after it leaves the water treatment plant (White, 1999).

Finally, chlorine is a strong oxidizing agent, meaning it is very effective at destroying a variety of microorganisms especially bacteria and viruses. Due to this, chlorine earned a reputation for being a broad spectrum disinfectant which can kill organisms such as *E.coli* 0157:H7 in less than one minute or Hepatitis A in approximately sixteen (16) minutes of contact time (CDC, 2007). While its usefulness against organisms such as *Cryptosporidium* and *Guardia* is lower; with sufficient contact time, a low pH level (7.0 – 7.2) and the type of chlorine being used, chlorine still offers limited protection against these organisms and their associated diseases (White, 1999; Koren and Bisesi, 1996).

Chloramines, which were discovered in the early 1900s (White, 1999), have many of the same benefits of chlorination. Chloramines are themselves strong disinfectants and are more stable in water then chlorine (White, 1999). Some water treatment plants will utilize chlorine and then add ammonia to generate chloramines. Chlorine acts as the

primary disinfectant, with chloramines providing a stable chlorine residual in the distribution system.

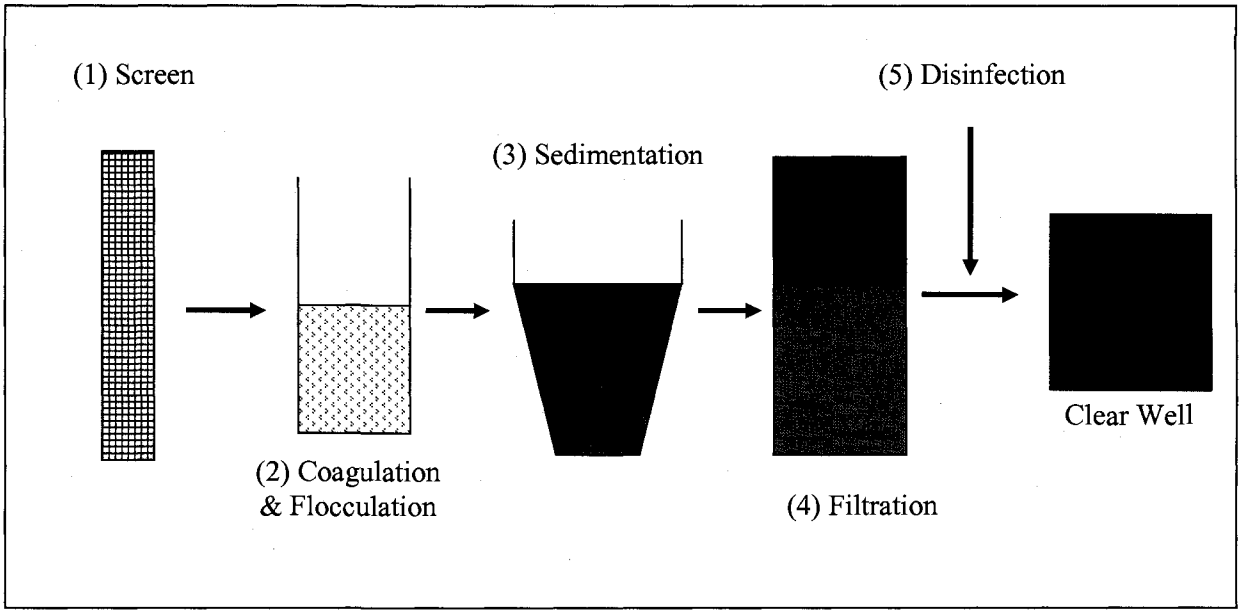
2.1.3 Chlorination and Water Treatment

Water treatment is the process that is used to make water more acceptable for a desired end use (Koren and Bisesi, 1996). These end uses include drinking, industrial processes, and medical or pharmacological uses. Water purification is the removal of contaminants from untreated water to produce water that is pure enough for its intended purpose, most commonly human consumption (Koren and Bisesi, 1996). These contaminants include microorganisms (bacteria and viruses, algae, and fungi) as well as minerals such as sulphur, iron or calcium.

The water purification practices needed to produce safe drinking water is very dependent on the source. Ground water is usually a less expensive to treat since it is pre-filtered by the aquifer of origin. Surface water such as that from rivers, lakes or streams is more locally abundant but it is subject to more inputs from human and animal activities (White, 1999). These activities can include industrial operations, farm run off containing pesticides, animal operations, sewage outfalls, and contamination by wild animals. For large communities, such as Edmonton or Winnipeg with growing populations and high demands for water, surface water sources are often utilized but with an awareness of the issues present for water treatment.

Figure 1 provides a visual summary of a basic water treatment process. It should be noted that these are the typical base practices followed by water treatment plants but facilities may have additional treatment processes in place to address local concerns.

Figure 1: Basic water treatment plant processes



Koren and Bisesi (1996) described the five basic treatment steps that are shows in Figure 1: (1) *Screening:* where large debris such as sticks, leaves and garbage are removed to prevent interference with further processing; (2) *Coagulation and flocculation:* clarification methods that utilize chemicals such as alum to draw together small suspended particles to encourage them to settle out of the water or be trapped by the filters; (3) *Sedimentation:* after the water leaves the flocculation basin, it moves into another basin which allows the large particles to settle to the bottom; (4) *Filtration:* water is drawn vertically through sand or charcoal filters to remove suspended particles as well

as some microorganisms especially protozoans like *Giardia* and *Cryptosporidium*; and (5) *Disinfection*: where the water is disinfected to kill any pathogens such as bacteria and viruses which may have passed through the filters. It is here that chlorine, the most popular disinfectant, is added into the clear well to allow for sufficient contact time to destroy microorganisms present.

2.1.4 By-products of Chlorination

Disinfection of drinking water is widely recognized for its significant role in reducing human illness from water borne pathogens (White, 1999; Symons 2006, AWWA, 2007). The process has been recognized as the biggest step ever undertaken in public health and has virtually eliminated diseases like typhoid, cholera and dysentery (Mills et al, 1998; Health Canada, 2006c). Although disinfection is necessary, it can also lead to the generation of a variety of chemicals known as chlorinated disinfection by-products (CDBPs).

These by-products were discovered in the early 1970s, when it was determined that chlorine combined with natural organic matter (NOM) in water to produce halogenated organic compounds (Rook, 1974). These by-products include compounds such as trihalomethane, haloacetic acids, haloketones and chloroform (Rook, 1974). Of particular importance was identifying chloroform as one of these by-products. Chloroform was and is still considered a possible human carcinogen (Health Canada, 2006a). A subsequent survey conducted in the United States determined that CDBPs

were a major contaminant of chlorinated drinking water (Morris et al, 1992). Similar findings were found in 1993 when Health Canada conducted a survey all major water treatment plant operations in the country (Health Canada, 1995).

2.1.5 Formation of Chlorinated Disinfection By-products

As CDBPs form when NOM is present in the water, a major driver of their formation is the amount of organic matter in the water source. Examples of this organic matter are humic and fulvic acids which are produced from decomposing plant matter (Oliver and Lawrence, 1979; Chang et al, 2001a, 2001b). To understand the formation mechanics of chlorinated DBPs, it is important to understand something of the chemistry of chlorine and chloramine. Chlorine quickly dissolves when added to water and establishes a series of equilibrium reactions with hypochlorous acid (HOCl) and hypochlorite ion (OCl-). The NOM in the water reacts with hypochlorous acid to form the CDBP. The general equations for these reactions can be shown as follows (White, 1999; Zwiener et al, 2007):

$$Cl_2 + H_20 \leftrightarrow HOCl + H^+ + Cl^-$$

$$HOCl + NOM \rightarrow \text{halogenated CDBPs}$$

To stabilize the chlorine oxidation reaction and decrease the amount of chlorine required for a residual, ammonia is sometimes added to chlorinated water to form chloramines.

The reactions of chlorine and ammonia to form chloramines are as follows:

$$NH_3 + HOCl \rightarrow NH_2Cl + H_20 \text{ (monochloramine)}$$

$$NH_2Cl + HOCl \rightarrow NHCl_2 + H_20 \text{ (dichloramine)}$$

$$NHCl_2 + HOCl \rightarrow NCl_3 + H_20 \text{ (trichloramine)}$$

Over time research has determined which factors influence the formation of disinfection by-products. These factors are summarized below in Table 1. While this table describes the factors which derive the production of CDBPs, it also provides information on how water treatment operators can reduce or prevent their formation. This information is critical in understanding the different levels of CDBPs in the community sites used in this research.

Table 1: Factors influencing chlorinated disinfection by-product formation

Factor	Effect
Type of disinfectant	A variety of disinfectants can be utilized in water treatment. It is important to know the properties of the disinfectant to control CDBP formation (Koren & Bisesi, 1996; White, 1999).
Amount of Natural Organic Matter (NOM) in the Water	NOM acts as the precursor for CDBPs. The level of organic matter is usually registered as the total organic carbon concentration or the dissolved organic carbon concentration. Seasonality and weather conditions which increase run off or agitate surface waters can affect the level of NOM in water sources. (Nikolaou et al, 2004a, 2000b; Oliver & Lawrence, 1979; Chang et al 2001a, 2001b)
Water Treatment Process	The processes within the water treatment plant can reduce or minimize the amount of NOM present in the water prior to the final step of chlorination (Koren & Bisesi, 1996).
Amount of Disinfectant	Otherwise known as the dose, if high amounts of the disinfectant are being added to the water, there is an increase in the number of reactions which can occur (Koren & Bisesi, 1996; White, 1999).

Residual Properties of the Disinfectant	Some types of disinfectants have the capability to remain in "free" forms which increases the ability of them to have continued reactions over time (Koren & Bisesi, 1996; White 1999).
pH of the water	Different pH levels can favor the formation of different types of CDBPs (Koren & Bisesi, 1996; White, 1999).
Temperature of the Water	Warmer water temperature can influence DBP formation in two ways: (1) it causes reactions to take place faster and (2) depending on the type of disinfectant being used, more of the disinfectant agent may need to be added because it is depleted faster (White, 1999).
Water Source	Water facilities that utilize surface water (lakes, rivers, reservoirs) produce drinking water with higher levels of by-products than facilities that draw from ground water sources. This difference is due to higher levels of NOM in surface waters. (Koren & Bisesi, 1996; Arora et al, 1997).

2.1.6 Classification of Chlorinated Disinfection By-products

Hundreds of halogenated and non-halogenated disinfection by-products have been identified in chlorinated drinking water (Krasner, 1999, Richardson, 1998). The most abundant groups of CDBP are the trihalomethanes (THMs) which are volatile, followed by the haloacetic acids (HAAs) which are semi-volatile. Volatility indicates the speed at which a chemical agent evaporates. As THMs have a high volatility, they have higher rates of evaporation than HAAs. This factor is important in determining rates of individual exposure to CDBPs.

While other CDBPs occur at low levels (Krasner et al, 1989), more than 250 CDBPs can be identified or measured in treated drinking water (Williams et al, 1997; Richardson, 1998; Rodriguez et al, 2003). It should be noted that there are several alternative disinfectants used in drinking water today, such as chlorine dioxide, chloramine and

ozone. Each type of disinfectant can produce its own suite of CDBPs, but all of them are not relevant to this research. A sample list of several well known chlorination and chloramination by-products are found in Table 2 (Kasner et al, 1989; Health Canada, 2006a).

Table 2: Categories of chlorinated disinfection by-products

Disinfection By-Product Family*	Examples
Trihalomethanes (THMs)	Chloroform (tricholoromethane, TCM) Bromodichloromethane (BDCM)
Haloacetic Acids (HAAs)	Monochloroacetic acid (MCAA) Dichloroacetic acid (DCAA)
Haloacetonitiriles (HANs)	Dichloroacetonitrile (DCAN) Trichloroacetonitrile (TCAN)
Haloketones (HKs)	1, 1 – dichloro – 2 – propanone 1, 1, 1 – trichloro-2- propanone
Aldehydes	Formaldehyde Acetaldehyde
Other	Chloral hydrate (Ch, also trichloroacetaldehye) Chloropicirin (trichloronitromethane)

Source: Health Canada (2006b); Kasner et al (1989)

As stated previously, THMs and HAAs are the two major groups of CDBPs found in high levels in drinking water. Together, THMs and HAAs can be used as indicators for the presence of all CDBPs in drinking water. Also by implementing measures to control THMs and HAAs it is expected that the level of other CDBPs will be reduced (Health Canada, 2006a).

2.1.7 Guideline Development

Despite the uncertainty about the impact of exposure to CDBPs, Canadian decision makers have been recommending a guideline level for THMs in drinking water since 1978 (Health Canada, 2006a) and in 1979 in the United States (AWWA, 2007). Over time this guideline level has decreased as scientific measurement has improved. New guidelines have since been created for bidichloromethane (BDCM) and haloacetic acids (HAA) (Health Canada, 2006 a, b). Table 3 provides the current guideline or regulatory levels for both Canada and the United States. In Canada, while the enforcement of these standards rests with the provinces or territories whose government can choose to adopt all or part of the *Guidelines for Canadian Drinking Water Quality* (Health Canada, 2006a,b,c). In the United States, the following levels are part of the National Safe Drinking Water Act, and were enforceable within three years after adoption of by either a state or national authorities (US EPA, 2006, 2001).

Table 3: Concentration of chlorinated disinfection by-product by country, μg/L

Country	Chlorinated Disinfection By-Product		
	Total Trihalomethanes	Bromodichloromethane	Total Haloacetic Acids
Canada	100[a]	16[a]	80[b]
United States	80[c]	6[c]	60[c]

a: Health Canada (2006a)
b: Proposed Guideline for Haloacetic Acid (Health Canada, 2006b)
C: U.S. EPA (2001)

The reader may also notice that the United States has lower guideline levels than Canada. While the best scientific evidence was utilized in both countries to determine an acceptable level for each of these CDBPS, agencies may also consider other factors. When reviewing the guideline in 2006, Health Canada considered not only the available science but also the potential economic or financial burdens which may be placed on a water utility to reach this standard. Therefore while Health Canada (2006a) also calculated an 80 μg/L guideline level, they recognized the cost of achieving this standard was not realistic. Also, scientists agreed that the difference in risk between exposure at 80 and 100 μg/L is minimal and as such the THM limit for Canada was set at 100 μg/L. The other CDBPs listed in Table 3 were determined in a similar manner.

2.2 Uncertainty and Risk Communication

2.2.1 Uncertainty in Science

Science and its methods are used to explore and produce knowledge about things we do not understand. Increasingly though, science faces a paradox. Previously science was used as a tool to achieve greater certainty in our knowledge and control of the natural world; now it is seen as having to cope with increasing unknowns (Friedman et al, 1999). Chlorination is an example of this situation. It has taken over 250 years to understand how and why chlorination of our drinking water is important. And yet there are aspects of CDBPs that we still do not understand particularly in relation to the impacts on our health.

Uncertainty is more than simply an absence of information (Rowe, 1994). Brashers (2001) offered a more encompassing definition:

> *"Uncertainty exists when details of situations are ambiguous, complex, unpredictable or probabilistic, when information is unavailable or inconsistent and when people feel insecure in their own state of knowledge in general."*

Understanding various types of uncertainty can enhance our ability to describe its influences on our behavior (Brashers, 2001). To this end, a variety of researchers have investigated and categorized uncertainty. Rowe (1994) categorized uncertainty in this way: (1) temporal – uncertainty in what occurred in the past or will occur in the future; (2) structural – uncertainty due to the complexity of the issue; (3) metrical – uncertainty in the ability to measure the effect of occurrence and (4) translational – uncertainty in explaining uncertain results. While structural uncertainty is applicable, it is translational uncertainty that is the focus of this research. Translational uncertainty refers to the variety of perspectives, goals and values along with different capabilities and levels of training that must be taken into consideration (Rowe, 1994). Understanding this diversity is important to communication of uncertainty.

Other researchers have focused on the single categorizations as described by Rowe. Bradshaw and Brochers (2000) argued that uncertainty can be described as a lack of confidence in scientific procedures or methods. Uncertainty about evidence can be the result of procedural errors. Similarly, there could be technical restrictions such as equipment that is not sufficiently sensitive to detect a contaminant. Uncertainty is also compounded by questionable methodology and procedures. This has occurred in areas like climate change, where experts disagree both within and outside of their disciplines;

there are limitations in the amount of available data to make calculations and over conservative exposure estimates on mortality and morbidity calculations (Haimes et al, 1994; Woodward and Bishop, 1997; Brashers, 2001; Peterman and Anderson, 1999).

Frewer et al (2002) has also described uncertainty as an absence of understanding. This differs from absence of information, as like a puzzle piece the knowledge gained does not appear to fit the tested theory yet cannot be discarded as speculative. This lack of understanding can be common to both scientists and members of the general public (Bradshaw and Brochers, 2000).

Bradshaw and Brochers (2000) argued that uncertainty can be valuable in that it adds to the knowledge base. They assert that "*environmental policy is most effective if scientific uncertainty is incorporated into a rigorous decision theoretic framework as knowledge, not ignorance.*" Kriebel et al (2001) also notes that uncertainty is a positive aspect of knowledge development because it clarifies what is known and unknown and thus stimulates further investigation.

2.2.2 Impacts of Uncertain Science

Understanding the impacts of uncertainty is becoming increasingly important as the rate of technological advancement create unknown risks to humans and the environment (Weiss, 2003). It is important to distinguish between uncertainty and ignorance as

ignorance does not know what we do not know whereas uncertainty arises from gaps in knowledge (Gee, 2006). At times scientific evidence falls short the reasons may include:

(1) Exposure to the contaminant often requires a significant long period of time to determine a health effect (Dowie, 2004);

(2) At best mathematical models and simulations can be achieved but are not testable in humans (Dowie, 2004; Gee, 2006);

(3) Variances in sampling and monitoring, parameter variability and other attempts to approximate reality (Gee, 2006); and

(4) Difficulty in measuring small exposures over time (Wynne, 2006).

Moreover, pure science does not consider morality, politics and economics, all of which further complicate the decision-making process (Dowie, 2004; Pellizzoni, 2003b). The field of uncertainty management is growing as an understanding of uncertainty enhances our ability to describe and explain the impact on behaviour and to develop strategies for improving health and safety (Brashers, 2001).

Confusion occurs when scientific research produces uncertain results. This confusion can impact three distinct groups or audiences: (1) other scientists and researchers; (2) decision or policy makers, and (3) members of as the general public or society at large (Miller, 2001). As a result, each group has a responsibility to try and minimize uncertainty as much as possible. Scientists, for example, need to do a better job of presenting and identifying the uncertainties created by the results of their work (Dowie, 2004). They also need to be aware of how the public may view uncertainty and be prepared to respond to their inquiries (Wynne, 2006; Miller, 2001).

Decision and policy makers need to become more aware of how scientific uncertainties are constructed and in turn how they can be managed (Wynne, 2006). Policy makers want straight forward information as the basis for their decision-making. In other words, they want numbers that provide certainty and safety (Johnson and Slovic, 1998). However, many of the current issues facing decision makers involve uncertainty, social, and ethical aspects that are inextricably linked which makes trying to determine safe limits a challenge. Ravetz (1999) recognized this dilemma and suggested that the concept of "safe" is often fraught with difficulties. However in terms of policy, "safe" is what counts.

Uncertainty can arise when decision makers disagree about the interpretations of research findings. These disagreements are often based on how serious the health risk may be and what actions should be taken to address them. As noted in Powell et al (2007) it is the media that typically reflects these controversies, as occurred in the 2008 health risk advisory for Bisphenol A issued by Health Canada . As there was a lack of clear instruction and impact of the risk to individuals especially children, this was what was discussed in mainstream media, and it is this uncertainty which impact the third audience, the public (Doble, 1994).

Research has shown what when institutions take responsibility for risk management they do not deny the existence of scientific uncertainty (Miles and Frewer, 2003). Johnson and Slovic (1998) determined that attention to uncertainty can be critical to deciding which action to take and that the public must be included in such discussions. Despite

these assertions, some researchers have concerns about how uncertainty may impact how the members of the public views science. Exposing the public to information about uncertainty may further compromise the publics beliefs about science, the scientific processes and regulatory agencies (Miles and Frewer, 2003; Frewer et al, 2003).

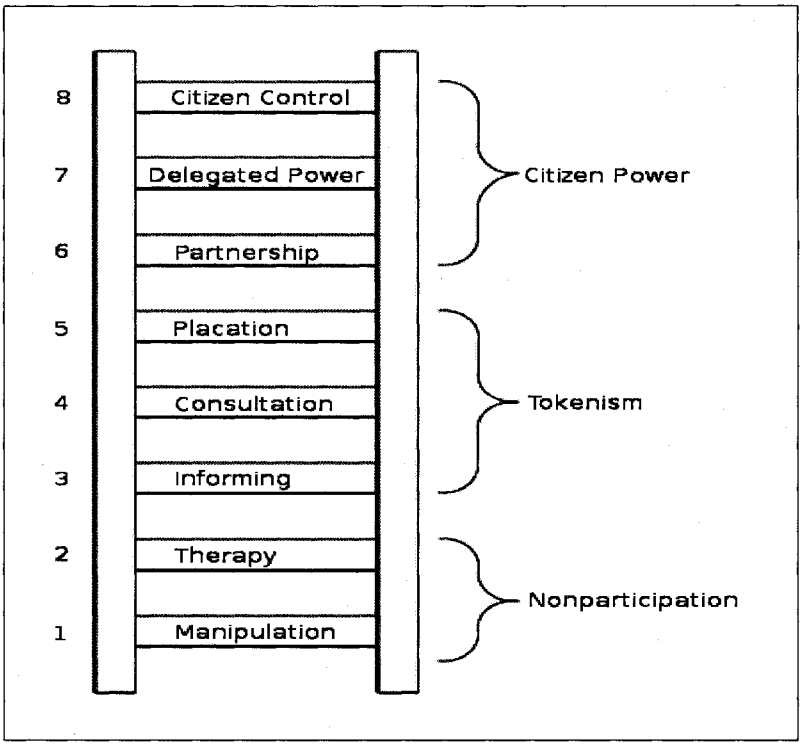
But Wynne (2006) considered that it was futile to attempt to ensure public trust in science whether it is achieved by public engagement, dialogue or other means. It is a contradiction to instrumentalize a relationship where the assumed objective is to manage and control the response of others. Instead, decision makers need to take responsibility for their own trustworthiness and not have expectations of the response (Wynne, 2006). Powell et al (2007) also attempted to understand how lay people perceive uncertainties about health and environmental risks. They found perceived uncertainty was strongly associated with negative emotions such as worry and anger.

2.2.3 Public Participation

Public participation has been likened to eating spinach; everyone agrees that it is good for you in theory but everyone does not want to participate or see it served at their dinner table. Consequently, there continues to be a gap between the theoretical and applied aspects of public participation (MacKean and Thurston, 1999; Jardine et al, 2007). Arnstein (1969) stated that there is a *"critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process"*. Arnstein (1969) also developed a "ladder of citizen participation" that

identifies what roles the public has played in the past and what they should play in the future. Illustrated in Figure 2, there are three major areas: nonparticipation, tokenism, citizen power, and a total of nine "rungs". Yet despite the creation of this participation ladder close to 40 years ago, many agencies are still struggling to satisfy the demand for consultation (Lomas and Veenstra, 1995).

Figure 2: Arnstein's ladder of citizen participation (1969)



Appropriate mechanisms for facilitating meaningful public participation have been well documented in the social science literature (Fiorino, 1990; Buchy and Hoverman, 2000; Rowe and Frewer, 2000, 2004; Abelson et al, 2007; Charles and DeMalo, 1993). For the purposes of this research, the following review of research into public participation is restricted to areas where scientific uncertainty is a factor in this process. The theoretical

basis of and justification for public participation in environmental and public health decision-making has been well described (Beierle and Konisky, 2000; Bierle and Cayford, 2002; Renn et al, 1995; Charles and DeMalo, 1993). However, other evidence points to some of complications when involving members of the public in the decision-making process.

First, McDaniels et al (1999) noted that risk professionals and decision makers remain skeptical about public participation, as this process and scientific rigour are viewed as being mutually exclusive. Second, members of the public may exaggerate real risks because they do not understand science (Frewer and Hunt, 2003; Wynne, 2006). Wynne (2006) and Kriebel and Tickner (2001) noted that the public's expectations of science are different from those of decision makers. Instead, members of the public are often skeptical about the scientific knowledge that is presented to them and any claims of uncertainty (Miller, 2001). Also, non-experts (i.e., the public) are not as bound by disciplinary constraints as experts may be and tend to think more broadly (Kriebel and Tickner, 2001). Furthermore, as people experience uncertainty about scientific evidence and risk in the form of relationships, interactions; scientific knowledge is defined and judged as part of this whole social package (Wynne, 1992).

While the public's attitude can not change scientific facts or natural laws; they can change how information is interpreted and used in decision-making processes. Some researchers have suggested public participation functions as a "social peer review" process that complements the scientific review process (Lipworth, 2007; Beierle and

Konisky 2000; Yosie and Herbst, 1998; Pellizzoni, 2003a,b). This has been demonstrated in studies on genetically modified food where it was concluded that *"more inclusive styles of decision-making are not only more democratic but also more scientifically robust"* (Scott, 2001, p. 129). Beierle (2002) reviewed 239 published case studies of stakeholder involvement in environmental decision-making and revealed that intensive stakeholder processes were more likely to result in higher quality decisions. Public participation processes that have clearly defined goals, early involvement of stakeholders, flexible and innovative mechanisms, and a means of evaluating efforts were usually the most effective (Beierle and Konisky, 2000; Chess and Purcell, 1999; McDaniels et al, 1999, Rowe and Frewer, 2004).

Nonetheless, many regulatory processes continue to be dominated by those who conduct the technical risk assessments not public engagement (Fiorino, 1990). Snary (2002) and Petts (2004) support this by noting that opportunities for interested parties to participate fairly and competently in the decision-making process are limited. As was noted in *Understanding Risk: Informed Decisions in a Democratic Society* (1996, p. 87):

> *"behavior based on this assumption* (that risk assessment is for experts only) *may lead some of the interested and affected parties to feel disenfranchised from the regulatory process and either withdraw from the policy arena or seek unconventional means to interfere with the process".*

Pellizzoni (2003a), Fiorino (1990), Kraft (1988) and many others argue that in situations when scientific knowledge of a risk is equivocal, involving the public in formulating decisions becomes particularly critical. However, many aspects of public participation remain unclear. This includes the interest of the public in participating and the role they

should play to optimize the process (Church et al, 2001; Pellizzoni, 2003a; Aronson, 1993; Jardine, 2003), as current thinking has been formulated on the assumption that interested and affected parties would welcome a stronger and more interactive involvement (Abelson et al, 1995). The role of decision makers and their associated institutions in determining an approach to public participation in circumstances of uncertainty is also uncertain. This approach could be either:

(a) *precautionary*, based on the precautionary principle which advocates for increased public involvement especially when scientific uncertainty exists to respond in advance to clear evidence of a public health risk (Kriebel and Tickner, 2001); or

(b) *reactionary*, which occurs when there is a more definitive public health risk and there is a need to manage a potential or perceived risk in a short time frame, often without public input (Kriebel and Tickner, 2001; Fiorino, 1990).

2.2.4 Uncertainty and Risk Communication

The goal of risk communication is to establish a two-way dialogue with people about a risk issue (U.S. Presidential Congressional Commission, 1997). This dialogue allows people to make an informed decision about whether a potential hazard is within acceptable limits or if they need to undertaken action to mitigate the risk (Viscusi et al, 1991; Miles and Frewer, 2003; Brashers, 2001). While this sounds easy, in practice determining how best to convey risk information from scientists and officials to citizens is rarely simple (Johnson and Slovic, 1995). As such, risk communication in its

traditional form has tended to be driven by expert conceptualization of public information needs versus what the public wants or requires (Frewer et al, 2002).

When a decision maker has complete knowledge about the potential effects or outcomes of a risk, communicators need to identify the most effective way to share that information. However, certainty in science is rare and such a perfect scenario rarely exists. Instead, uncertainty abounds in science and confuses not only the public but the scientists and decision makers involved. This confusion compromises typical methods of public participation as the message the decision maker wishes to send is conflicting and indecisive.

The research evidence presents varying viewpoints about the importance and effects of communicating uncertainty. There are positive and negative views. On the positive side, telling the truth should be an inherent part of any risk communication practice. If organizations such as government agencies are truthful and demonstrate honesty in the face of uncertainty, credibility and trustworthiness may be enhanced (Johnson and Slovic, 1998; Beierle and Konisky, 2000; Zussman, (1997). Simply acknowledging the uncertainty associated with different hazards may improve public confidence in the quality of scientific output (Doble, 1995). In addition, it has been argued that presenting uncertainty information will allow members of the public to make more informed decisions where such a choice is possible (Frewer, 2004; Johnson and Slovic, 1995). Effective communication may also change lay beliefs about science or a particular technology if it is: presented in a balanced fashion; has come from a credible source; and

is honest about the particular limitations of the technology (Frewer et al, 2002; Frewer et al, 1998).

Not all researchers agree that explaining uncertainty will increase trust and public confidence. Johnson and Slovic (1995) point out that uncertainty may disturb people when they may want assurances of their safety. They may prefer being told that a situation is safe or unsafe instead of receiving formal risk estimates which may undercut the illusion of safety (Johnson, 2003; Johnson and Slovic, 1995). This may inadvertently give people an excuse not to under take precautionary measures or increase people's concern about a particular hazard inappropriately (Johnson, 2003; Slovic, 1986).

Second, technical risk information may cause confusion or even outrage (Ravetz, 1999; Johnson and Slovic, 1995). In other words, presenting uncertainty in risk estimates may create so much confusion that members of the public become disinterested in the conflicting data (Johnson, 2003). Outrage may result as the agency presenting the uncertain information may be viewed as failing in their duty to advise on safe levels or protect the public (Ravetz, 1999).

Finally, as people expect regulatory action to mitigate the risk of potential hazards raising the topic of uncertainty may cause suspicion that it is being used to cause inaction on an issue (Johnson and Slovic, 1998). While this is not likely the case, even the most experienced advisors may find it difficult to convey an accurate reflection of the uncertainty and how it is calculated. As such, this may result in the public feeling there is

a lack of transparency in the participation process; or provide them with an excuse for not taking the necessary precautions.

Regardless of arguments for or against, communicating about uncertainty an essential task of decision makers. If they wish to encourage meaningful public participation, identifying effective ways to present and explain uncertain scientific knowledge must be determined. At the same time, they must be aware of the effects that communicating uncertainty (as described above) may have and the barriers to gaining the public's participation and views. Exploring and identifying new methods of considering uncertainty is an anticipated outcome of this research.

3.0 Case Study – Chlorinated Disinfection By-products (CDBPs)

Chlorine disinfection of drinking water supplies has been hailed as the single largest advancement in public health history (Mills et al, 1998). Chlorination has ensured a safe drinking water supply for many and when properly maintained has controlled and prevented the return of major waterborne diseases like cholera, dysentery and typhoid (Driedger and Eyles, 2003; Driedger et al, 2002). Yet despite these obvious benefits there have been growing concerns about the potential health risks posed from CDBPs which are produced during the water treatment process.

3.1 Health Risks Associated with Chlorinated Disinfection By-products

Since their discovery in the early 1970s, a variety of adverse health effects have been associated with chlorinated disinfection by-products (CDBPs). Animal studies with rodents first indicated that after exposure to CDBPs tumors were found in the liver, kidney and intestines (Dunnick et al, 1993). Studies with human subjects have also suggested that CDBPs may be associated with an elevated risk of cancer, particularly cancers of the bladder, pancreas and colo-rectum (Minh et al, 2005, Cantor et al, 1987; Wilkins and Comstock, 1981; Doyle et al, 1997). Of these cancers, cancer of the bladder was found to have the most consistent association (Villanueva et al, 2004, Mills et al, 1998; Cantor et al, 1987; Freedman et al, 1997; King and Marrett, 1996; McGeehin et al, 1993; Zierler et al, 1988; Gottleib et al, 1982; Young et al, 1981; Wilkins and Comstock, 1981; Brenniman et al, 1980; Alvanja et al, 1978). In particular exposure to the

trihalomethane (THM) family of compounds which includes compounds such as chloroform or dibromochloromethane (BDCM), appear to increase the risk for bladder cancer (King and Marrett, 1996; Koivusalo et al, 1997, Doyle et al, 1997; Cantor et al, 1998; King et al, 2000b).

Cancer is not the only health outcome that exposure to these agents may generate. The linkage of CDBPs was first identified in a Californian study that investigated a suspected cluster of adverse pregnancy outcomes in relation to water chlorination (Deane et al, 1989). Results were inconclusive with respect to a relationship between the suspected agent (trichloroethane) and birth outcomes; however a higher than average rate of adverse pregnancy outcomes in women consuming large quantities of water was observed. These outcomes included stillbirth, miscarriage or birth defects (Dodds et al, 2004, King et al, 2005, Chad et al, 2007; Sarvitz et al, 2006; Shaw et al, 2003).

Many studies have investigated a possible link between specific CDBPs and adverse reproductive effects with inconsistent results (Chad et al, 2007, Savitz et al, 2006, Lewis et al, 2006, Waller et al, 1998; Dodds et al, 1999; Klotz and Pyrch, 1999; King et al, 2000a,b). Graves et al (2001) reviewed the evidence of all toxicology and epidemiology studies which investigated the possible association between CDBPs and adverse reproductive or developmental effects. This literature review resulted in three conclusions about CDBP exposure and health outcomes: (1) for some CDBPs there was no good scientific evidence of association; (2) available scientific evidence is weak or inconsistent; and (3) the available evidence is suggestive of positive outcomes in terms of

disease relation. Therefore despite all these associations, the evidence remains equivocal about the causative effect of CDBPs on human health. As Shaw et al (2003) and others noted the difficulty for researchers trying to link health effects to CDBPs continues to be an inability to adequately describe an individual's exposure (Reif et al, 1996; Arbuckle et al, 2002; Nieuwenhuijsen et al, 2000a; Graves et al, 2001).

3.2 Exposure and Uncertainty

Trying to calculate a realistic exposure level to CDBPs from drinking water is very complex. First, CDBPs are measured in μg/L units, a very low measurement which may be challenging to measure in some drinking water supplies. Second, similar to smoking, cancer development requires long term chronic exposure. Finally, while the obvious route of exposure to these agents is by ingestion, the calculated guideline levels for CDBPs must also need to consider inhalation and dermal routes (Health Canada, 2006a). In 2005, Jo et al suggested that THM exposures from ingesting drinking water are equivalent to those from showering. As such calculating exposure may need to be multiplied two fold for some CDBPs.

Exposure to each type of CDBP is also dependent upon a variety of other factors. One factor is the chemical characteristics of the contaminant such as its volatility and or evaporation rates in hot water (Jo et al, 2005). Secondly, the method of water treatment used by a community will influence what CDBPs are formed (Lynberg et al, 2001) Next, is where an individual's home is located in a distribution system, as homes close to the

water treatment plant or to chlorine boosting stations may be exposed to higher levels of CDBPs Lynberg et al, 2001).

Finally, an individual's drinking water usage and consumption pattern must be considered (Jo et al, 2005; Nuckols et al, 2005). For example, the most significant exposure to these compounds occurs during large household water uses, such as showering, bathing and clothes washing activities. The length of time spent showering or the effectiveness of mechanical ventilation in washrooms and laundry can affect the level of CDBPs in indoor air, which can prolong exposure and effect the dose an individual receives (Nuckols et al, 2005).

As a result, multiple factors which vary from individual to individual and from community to community cause difficulty in determining a reliable measure of an individual's exposure.

3.3 Community Sites

3.3.1 Edmonton, Alberta

Edmonton's two water treatment plants are owned and operated by EPCOR, a private company that purchased the plants from the City of Edmonton in 1996 (EPCOR, 2003b) Each treatment plant draws water from the North Saskatchewan River which travels through the community of Edmonton. The first plant, Rossdale, opened in 1903 and is

located in Edmonton's downtown core whereas the second plant, E.L. Smith, which opened in 1976, is 18 kilometers upstream (EPCOR, 2003b). These facilities provide drinking water to approximately one million people including Alberta's capital city, Edmonton, and 40 other communities.

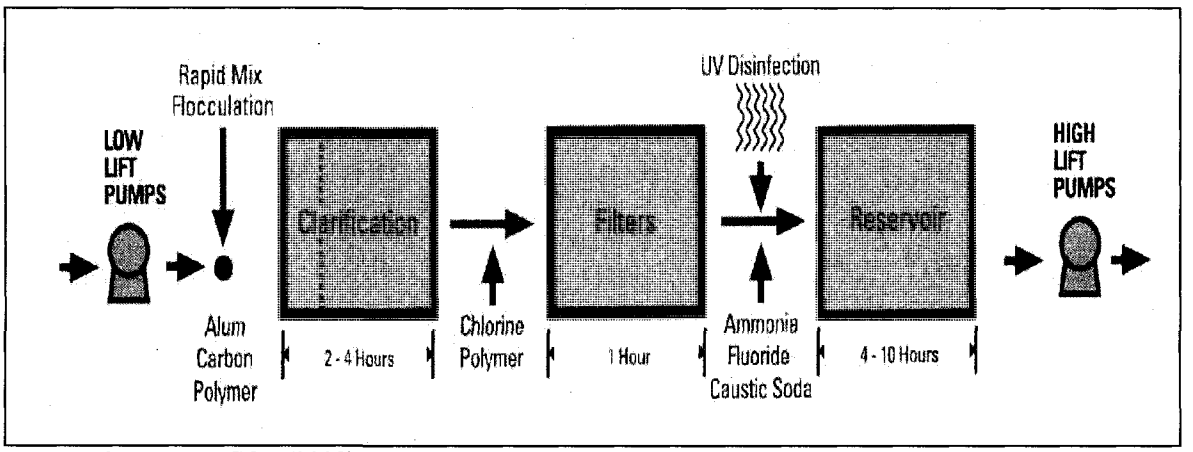
As noted in the overview of water treatment (Chapter 2), depending on the water source, the processes used to make drinking water safe can vary significantly. The North Saskatchewan River which Edmonton uses as its raw water supply is considered to be a contaminated water source for a variety of reasons. First, as a surface water source it is subject to natural and adverse weather conditions which can increase the level of turbidity and debris present. High levels of debris or turbidity provide additional precursors or natural organic matter (NOM) needed for chlorine to interact with to form CDBPs. Second, it is utilized by wildlife (e.g. deer, moose, and beaver) which contaminate the water with their droppings or feces. Feces from all animals including humans often contains pathogenic or disease causing microorganism such as *Giardia, E. coli* or *Hepatitis A* (Koren and Bisesi, 1996). Finally, upstream of Edmonton there are a variety of other water users, such as municipalities, industries or agricultural operations. These users may be adding contaminants to the river from sewage outfall from wastewater treatment plants, manure and/or pesticide runoff from agriculture lands or dumping of waste water by industries. Therefore, as a result of all these upstream impacts EPCOR has expanded upon the basic water treatment practices described earlier, to ensure Edmontonians have a safe drinking water supply.

Edmonton's Treatment Process

Water is collected by two intakes at two separate strategic positions in the river bed. The water is first screened to remove large debris such as trees, roots, garbage and wildlife. The water then moves through the treatment process described in Figure 3. After clarification, a single dose of a chlorine polymer is added to kill susceptible microbes. This chlorine polymer is a combination of chlorine and ammonia, or a chloramine, which is still a disinfectant, however not as reactive as chlorine.

The water is then filtered which removes fine particles, microbes as well as some CDBPs. Due to concerns of *Cryptosporidium* and *Giardia*, protozoans resistant to chlorination and regularly found in all surface waters, EPCOR has added a secondary disinfection step by using ultraviolet (UV) lights. The UV lights effectively kill any remaining pathogenic microorganisms, especially protozoans. The water then leaves the water treatment plant and enters into the distribution system, where an additional dose of chloramines is added to act as a residual and protect against regrowth or recontamination of bacteria.

Figure 3: Basic water treatment processes for City of Edmonton, Alberta



Source: EPCOR (2008)

3.3.2 Winnipeg, Manitoba

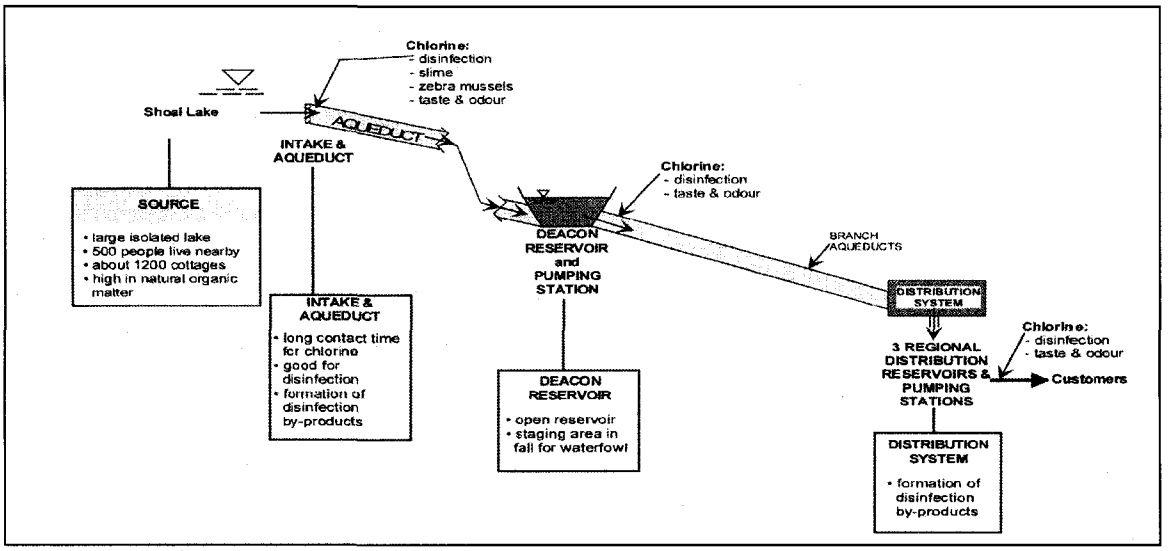
The City of Winnipeg is similar to Edmonton in that it has used a surface water source, Shoal Lake, since 1919 for its drinking water supply (City of Winnipeg, 2002a). Shoal Lake, located in Ontario, is located 137 kilometers east of Winnipeg and provides water to approximately 300,000 households and businesses every day (City of Winnipeg, 2002a). This lake was chosen due to its abundance of water and its isolation which prevents it from being heavily utilized or contaminated. Although subject to adverse or natural weather conditions and wildlife contamination like the North Saskatchewan River, there are no industrial or agricultural operations in the area and no major communities along its shores.

Winnipeg's Treatment Process

Currently Winnipeg does not have a water treatment plant in the conventional sense. While a new water treatment plant is expected to be put into operation in the spring of 2009 and will include ultra-violet radiation, the current water treatment is very simplistic. As shown in Figure 4, water travels to Winnipeg via an aqueduct to be processed through the two step treatment process (City of Winnipeg, 2002a). Screening is the first step and it occurs at the intake pipe at the lake. This involves the removal of large pieces of debris, zebra mussels and other particles by a large metal screen.

The second treatment step also begins at the intake location. This second step is chlorination of the water. From there the water then travels towards the City of Winnipeg to a variety of reservoirs and boosting stations. At each of these stations, the water receives additional chlorine as it moves toward the consumer's tap. As such, due to the lack of coagulation, sedimentation and filtration, the NOM precursors which are needed to form CDBPs are not removed. This combined with the continual dosing of chlorine, results in Winnipeg being subject to higher levels of CDBP formation.

Figure 4: Basic water treatment processes for City of Winnipeg, Manitoba



**Source: City of Winnipeg (2002a)*

3.4 Level of Chlorinated Disinfection Products by Community

Tables 4 and 5 show the annual median level of the two major CDBP groups, trihalomethanes (THMs) and haloacetic acids (HAAs), in each community since 2001. For THMs, Winnipeg residents are exposed to a ten fold higher level than Edmonton residents. In the case of HAAs, a five fold higher level is found in Winnipeg. When compared to the *Canadian Drinking Water Guidelines*, Edmonton has regularly been lower than the level of 100 µg/L for THMs and 80 µg/L for HAAs. In contrast with the exception of the 2004 THM level, Winnipeg routinely exceeds Health Canada's guidelines.

Table 4: Median levels of trihalomethanes by community from 2001 – 2006, μg/L

	2006	2005	2004	2003	2002	2001
Edmonton	13[a]	15[b]	11.4[c]	7.1[d]	8.8[e]	11[f]
Winnipeg	N/A	115[g]	83[h]	118[i]	116[j]	119[k]

a: EPCOR, 2007 b: EPCOR, 2006, c: EPCOR, 2005 d: EPCOR, 2004 e: EPCOR, 2003, f: EPCOR, 2002 g: City of Winnipeg, 2006 h: City of Winnipeg, 2005 i: City of Winnipeg, 2004 j: City of Winnipeg, 2003 k: City of Winnipeg, 2002

Table 5: Median levels of haloacetic acids by community from 2001 – 2006, μg/L

	2006	2005	2004	2003	2002	2001
Edmonton	19.4[a]	N/A	16.2[c]	13.8[d]	9.0[e]	11.0[f]
Winnipeg	N/A	120[g]	93[h]	108[i]	95.9[j]	100[k]

a: EPCOR, 2007 b: EPCOR, 2006, c: EPCOR, 2005 d: EPCOR, 2004 e: EPCOR, 2003, f: EPCOR, 2002 g: City of Winnipeg, 2006 h: City of Winnipeg, 2005 i: City of Winnipeg, 2004 j: City of Winnipeg, 2003 k: City of Winnipeg, 2002b

Although they both access surface water sources these values reflect the difference in water treatment practices that each community uses. In Winnipeg, NOM is not adequately removed due to poorer pre-screening or coagulation/sedimentation practices. A high level of NOM favors CDBP production. The likelihood of formation of CDBPs is also further aggravated by the type of chlorine used (free chlorine) and the continual dosing throughout the water treatment/distribution system. These practices result in Winnipeg producing drinking water which regularly exceeds the health exposure guidance levels set by the *Canadian Drinking Water Guidelines* and the Province of Manitoba.

Finally, these values also demonstrate why these two communities were chosen as the research sites for this study. The higher THM and HAA values in Winnipeg result in their residents having both a higher exposure and potential consciousness of the issue. For Edmonton residents, EPCOR's water treatment process minimizes exposure to CDBPs. This difference combined with the uncertainty around the health effects of CDBPs sets the stage for investigating the public's role in decision-making that involves scientific uncertainty.

4.0 Methods

Before describing the methodology, the reader is reminded that the data being presented is part of a larger study. What follows describes this researcher's portion of that study as it forms the basis of a master's thesis.

4.1 Research Sites

As described in the case study background, each of two communities, Edmonton and Winnipeg use different water treatment practices which produce differing levels of chlorinated disinfection by-products (CDBPs). In particular as Winnipeg does not presently utilize good prescreening and coagulation/sedimentation practices prior to chlorination, the natural organic matter (NOM) is not adequately removed favoring high levels of CDBP formation. Edmonton is at the opposite end of this spectrum, where due to its more complex and sophisticated water treatment practices, much lower levels of CDBPs are produced. Therefore, Edmonton residents are exposed to lower levels of CDBPs in their drinking water when compared to Winnipeg residents.

By utilizing two communities with different levels of CDBP concentrations, the researcher was able to explore the differences in responses based not only on geographical location but also on measuring exposure levels. This comparison provided a method of determining whether the results can be generalized and potentially useful to other location and or issues.

4.2 Phase I – Stakeholder Informant Interviews

4.2.1 Overview

The first phase of this research involved conducting semi-structured interviews with a variety of key informants or stakeholders. A stakeholder was defined as any representative of an organization who is actively involved in supplying, regulating or monitoring drinking water supplies. Prior to commencing the interviews, an ethics review was conducted and the interview questions were pretested. The qualitative data was analyzed using a coding scheme developed by the researcher and validated by an independent coder.

4.2.2 Ethics Review

For each phase of this research study, application was made to the University of Alberta's Faculty of Agriculture, Food and Human Ecology (AFHE) Research Ethics Board (REB). The mandate of REB is to rule on the ethical acceptability of proposed research (AFHE-REB, 2005). This ethical acceptability is based on two essential components: (1) the selection and achievement of morally acceptable ends and (2) the morally acceptable means to those ends (PWGSC, 2005). The first component is directed at defining acceptable ends in terms of benefits of research for participants and for the advancement of knowledge. The second component is directed at ethically appropriate means of conducting research.

To ensure these components are thoughtful and based on morally acceptable foundations, the Tri–Council of the major Canadian research councils or organizations developed eight guiding principles in their policy statement (PWGSC, 2005) which have been subsequently adopted in a variety of research disciplines. Three of these principles are of highest importance or applicability to this research: (1) respect for free and informed consent of a participant; (2) respect for vulnerable persons and (3) respect for privacy and confidentiality (PWGSC, 2005). The first two principles were especially important in Phase I, as those interviewed were in decision-making capacity and at times were requested to speak to their personal beliefs not just their agencies mandate or agenda.

To ensure this research study meets these guiding principles, an application was submitted to the AFHE REB. In the application, the researcher was required to provide details about the investigator(s)/researchers(s), funding sources, sites of data collection, the purpose, objective and rationale behind the research as well as methodology proposed to collect the data (AFHE-REB, 2005). In addition, the researchers had to describe the benefits, expected outcomes and identify any risk to a participant involved in this research.

The primary benefit of conducting this research is the development of effective methods and recommendations which can be utilized by decisions makers, on how to involve the public in complex scientific issues. The stakeholders being interviewed predominantly represented government organizations and to answer the proposed research questions,

frank discussion needed to occur. As this may result in a stakeholder being critical of their agencies or their practices, this was viewed as a potential risk by AFHE REB. The risk being they could be vulnerable to reprisal from their employer. To counter this, the researcher was directed to add a statement by AFHE REB which advised a stakeholder of the potential risk. The statement was as follows:

> *The closing questions are directed towards your expertise and knowledge obtained throughout your career. Therefore your responses may be based on your personal opinion or experiences outside of the current practices of the agency you represent. As these questions may place you in conflict with your agencies practices, please be aware you are under no obligation to respond to the following questions.*

Also, to protect the confidentiality of stakeholders all their responses will be presented in a manner which protects their anonymity. Additional ethical requirements are addressed throughout the methods section. In Appendix A is a copy of this certificate.

4.2.3 Stakeholder Selection

Interviews were conducted with individuals determined to be "stakeholders" within the case study topic of this research. A stakeholder was defined as any representative of an organization who is actively involved in supplying, regulating or monitoring drinking water supplies and routinely interacts with the public. The researcher recognizes that the public as well is a stakeholder in issues such as these, therefore the term stakeholder is not meant to exclude or diminish their purpose or role. Instead this term was used for convenience and to delineate between the two participant groups involved in this research study.

While some stakeholders were well known to the researcher, others were selected by "snowball sampling." This type of sampling is well known in social science research for developing a research sample where participants recruit future subjects amongst their acquaintances (Bernard, 2000; Frank and Snijders, 1994). Snowball sampling is often used to access hidden populations which are difficult for researchers to access (i.e., drug users, homeless persons) (Welch, 1975; Faugier and Sargeant, 1997). Similarly, this technique is used to identify stakeholders who would not have been easily reached in large government or non-government organizations. This technique has also proven useful if a stakeholder is a reluctant to speak to a researcher without a recommendation from a colleague (Bernard, 2000).

However, a limitation to snowball sampling is that potential participants may have similar political, technical or scientific viewpoints that could be a source of bias (Bernard, 2000). To off set this limitation, if the technique identifies all possible participants the likelihood of including all views is enhanced. In this study interviews were conducted until the stakeholders were identifying individuals already interviewed and subject saturation was reached. Subject saturation is the point when no new information is being received (Sarantakos, 1998). Upon completion of the interviews, the researcher was able to determine that no major stakeholder organizations or individuals had been overlooked.

In total, fifteen interviews were conducted between August 2005 and January 2006. These informants included:

(1) Alberta and Manitoba representatives of the Federal-Provincial-Territorial Committee on Health and Environment (n=2) which oversees the Committee on Drinking Water responsible for the development of CDBP guidelines in Canada;

(2) Representatives from the Committee on Drinking Water noted above (n=3);

(3) Representatives of the Water Quality Issues Subgroup of the CDBP Task Group for the Committee of Drinking Water (n=1);

(4) Regional and provincial health representatives who are involved in regulating or monitoring drinking water supplies within the communities of Edmonton and Winnipeg (n=7);

(5) Water utility representatives who share common interests and work with federal and interprovincial bodies with respect to policies, programs and legislation for drinking water (n=2) and

6) Water utility associations (n=1).

Many of the stakeholders held multiple roles. For coding purposes, individuals were categorized by their primary role. In Chapters 5 and 6, when discussing the results of this research, stakeholders were categorized into regulatory, health, industry, and national agencies. This was done to protect the anonymity and confidentiality of the participants in the small sample.

4.2.4 Question Design

Semi-structured interviews are conducted with a fairly open framework which allows for focused, conversational, two-way communication (FAO, 1999). Unlike questionnaire or survey frameworks, where detailed questions are formulated ahead of time, semi-structured interviewing begins with more general questions or topics (Bernard, 2000; Kitzinger and Barbour, 1999). These general questions set the tone of the initial discussion but still allow for the opportunity to ask more specific questions or have open dialogue. For this research the questions prepared were in five primary areas: 1) uncertain science; 2) disinfection by products and use of chlorine; 3) organizational practices; 4) role of the public and 5) regulatory involvement and approaches. Additional time was also structured into the interview process for the researcher to clarify responses or probe further into a unique comment.

Before commencing the stakeholder interviews, the questions were pretested on a stakeholder of similar educational, technical background and regulatory responsibility as that of the target groups. Pretesting serves as a trial run that allows the researchers to identify potential problems in the proposed interviews and the larger study (Bernard 2000; Varkevisser et al 2003). Although this practice involves additional planning and effort at the beginning of a research study, the pretest allows for the revision of the questions and an insight into data collection and analysis implications (Kitzinger and Barbour, 1999). After pretesting, the questions and process were reviewed using three criteria: 1) reaction of the participants to the questions in terms of clarity, understanding,

sequence and willingness to respond; 2) an assessment to determine if the questions being asked would collect the information needed to answer the research questions of the study; and (3) an overall determination of the amount of time needed to conduct an interview. Pretesting also allowed the researcher/interviewer an opportunity to practice their interviewing technique (Oskenberg et al, 1999; Schaffer and Presser, 2003). Based on the evaluation of these aspects, modifications of the core questions occurred and a list of the finalized list of the semi-structured interview questions was developed (Appendix B).

4.2.5 Interview Process

At the beginning of each interview, the researcher each participant with an information sheet about the research study. The information sheet was reviewed with each participant and sufficient time was given for them to review the document independently. The potential interviewee was encouraged to ask any questions they had at this time or at anytime during the interview. The interviewee was then asked to complete and sign the informed consent form (see Appendix C).

To ensure accuracy and consistency, the interviews were digitally recorded with the consent of the stakeholder (Bernard, 2000; Barnball, 1994). Barnball (1994) stated recording interviews reduces potential interviewer error, increases the understanding of the nuances of the interactions between participant and interviewer (i.e., intonations, pauses), and improves the overall completeness of the information collected. Two digital recorders were used per interview in the event an error or battery failure occurred during

the interview process. In addition, as recommended by Bernard (2000), an observer was also present who took notes about key messages and categories which may be missed by the researcher who was conducting the interviews. The observer also noted if the interviewee was nervous, any distractions, if the order of questioning was changed or amended due to time or flow of conversation.

The recordings were transcribed verbatim by a contracted third party (transcriptionist) who as part of the conditions of the ethical approval had signed a confidentially agreement. As suggested by McLellan et al (2003) the recording was transcribed in its entirety and included mispronunciations, nonverbal sounds (i.e., laughter) and whether background noise was present. With the exception of two interviews, all were conducted by the researcher in Edmonton, Winnipeg or Ottawa. In regards to the other two interviews, one was conducted solely by the researcher by telephone as this stakeholder was not available during the researcher's visit to Winnipeg. The second was contacted solely by the researcher upon a visit to Ottawa.

Overall, this approach allowed for a consistent application of the process of ensuring informed consent (Presser, 1994) as well as the style of questioning and probing (Schaeffer and Presser, 2003). As the success of the semi-structured interview method is dependent upon the skill of each interviewer (Barnball, 1994), it should be noted that the researcher had extensive experience in conducting interviews through previous research studies, participation in focus group sessions and related career experiences.

The interview process can be summarized as followed:

(1) Introduction of the researcher and observer including professional background, roles and responsibilities in the research study;

(2) Review and explanation of the information sheet with the stakeholder.

(3) Completion and collection of the consent form;

(4) Commencement of the interview process based on the developed questions. (Each interview was expected to take one (1) to one and a half (1.5) hours);

(5) Opportunity for the interviewee to ask further questions about the research topic or to modify any previous responses was given at the end of the interview;

(6) Identification of other stakeholders (i.e. application of snowballing technique) to identify other potential interviewees.

4.2.6 Data Organization

While Kvale (1996) recommended that two transcriptionists independently transcribe an audio recorded interview to allow for accurate comparison, budgetary conditions did not allow for this. To ensure accuracy and precision however, a professional transcriber was used. For ease of readability, transcripts were formatted identically and included all mispronunciations, slang and grammatical errors (McLellan et al, 2003). McLellan et al (2003) also recommended that the transcripts be reviewed by an individual with a high level of familiarity with the research topic, research questions, vocabulary and

transcription processes. This was completed by the researcher and any errors were corrected. As a result, a high degree of data quality control was achieved.

4.2.7 Data Analysis

Miller and Crabtree (1999a) described qualitative analysis as an interpretative process consisting of five phases: (1) describing, (2) organizing, (3) connecting, (4) corroborating/legitimating and (5) representing the account or research study. Describing is a reflective phase in which the researcher steps back from the field and reviews what has happened, how what has occurred may influence the interpretation of the data and what should happen next. The second step, organizing, helps prioritize and form of the interdependent texts (Miller and Crabtree, 1999a). It is here that the coding scheme was applied to the transcripts.

Coding refers to naming segments of data with a label that simultaneously categorizes and accounts for each idea or unit of data (Charmaz, 2006; Miller and Crabtree, 1999b). Bernard (2000) stressed that when coding text, all themes or categories should be identified even if they were only found once in the material being analyzed. This ensures that all ideas and concepts are captured in the interpretation of the results. Provided coding is consistently applied, it is considered an accepted and recognized practice to analyze qualitative data (Bernard, 2000).

In this research, two common coding methods were utilized. First was initial open coding, where the researcher formed initial categories of information about the phenomenon being studied by segmenting or unitizing (Miller and Crabtree, 1996b). This researcher used hand colour coding[4] as the initial coding step to identify responses made by each stakeholder. A colour was assigned to each part of the following coding scheme:

(1) Identification of prescribed, pre-designated questions (green);

(2) Direct responses to these prescribed questions (pink);

(3) Identification of secondary or "probing" questions to the prescribed questions (blue);

(4) Responses to the secondary questions (purple);

(5) Additional questions (i.e. extras) asked by the researcher (orange); and

(6) Interesting comments which may lead to a unique perspective (yellow).

To reduce problems in coding, Lombard et al (2002) suggested having a second coder use the same process to determine whether the coding scheme is appropriate. An alternative coder reviewed two transcripts as part of the process to establish the validity of the data collected. The second coder had no relationship to this research study thereby providing an objective application of the coding scheme. This objectivity is important to improve content validity of the data collected (Bernard, 2000). It should be noted here that the researcher chooses to use the terminology of validity and reliability when describing the quality control methods applied to this research. While the researcher appreciates the

[4] Hand color coding is the practice of using pens or highlighters to manually identify different passages in a document (Bernard, 2000).

academic debate as to whether this terminology applies to qualitative research, it was felt that these concepts are applicable when used as a representation of trustworthiness, rigour and quality (as described by Golafshani, 2003).

After the initial coding was completed, responses from each participant were amalgamated into a Microsoft Excel 2003 spreadsheet by question to allow for comparison of responses. The spreadsheet was organized by the pre-designed core questions as well as other common questions asked during the interview. This provided an easy method of viewing all the data in similar format for application of the secondary coding technique. Particular care and attention was paid to identifying responses which a stakeholder may have provided in earlier or latter parts of the interview. To ensure the accuracy of the transfer of the data, 15% of the transcript material was randomly selected and reviewed by a third party; a practice recommended by Lapadat and Lindsay (1999).

A second stage of coding was conducted known as axial coding. This involves a second pass through the data but with a focus on the initially coded categories and the primary task of reviewing and examining those initial codes. Additional codes or new ideas may emerge, and they are noted, however the researcher focuses on causes and consequences, conditions and interactions, strategies and processes and looks for categories or concepts that cluster together (Charmaz, 2006).

Connecting is the third phase of data analysis as described by Miller and Crabtree (1999a), this involves critical reflection of the content of the transcripts, notes taken

during interviews, discussions of finding with colleagues or supervisors and investigation into the literature. Through this reflection, categories and patterns are discovered, linkages are made between codes and categories, and answers to the research questions are identified. These connections must then be corroborated or legitimized to determine if examples of the "truths" identified were actually found in the texts. In this fourth phase, alternative explanations must be discussed, cross-referenced to other literature and categories evaluated to determine if they have been consistently identified and accurately reflect the participant's statement.

In the fourth phase the researcher must decide how to handle the emergence of single responses of ideas or issues raised by participants. Krueger (2000) and Bernard (2000) both stress that presenting only the responses of the majority of participants can devalue the findings of the data collected. It follows that categories with low numbers of responses should also be connected to other literature and categories that emerge from the data similar to categories where the majority of participants may have focused their responses (Miller and Crabtree, 200b). This is particularly important in the second phase of this research which involved focus group discussions.

The final phase of the interpretative process is to find a method of demonstrating and sharing the findings of the research. The researcher needs to ensure the data collected from the participants is honestly represented, the process of collecting the data well described and any limitations of proposed conclusions are adequately explained. It is here that future research recommendations can be made for further testing the findings of

research especially unique ideas or solutions that emerged (Kreuger, 2000). Finally, while one of the primary purposes of this research will be to submit articles to applicable social science journals and provide recommendations to decision makers, a portion was completed in partial fulfillment of a Master's of Science in Health Promotion Studies.

4.3 Phase II – Public Focus Group Sessions

4.3.1 Overview

The second phase of this research study involved conducting focus groups with three different publicly based participant samples. As in Phase I, ethical approval was applied for and received for the public based focus groups sessions. Questions were created by the researcher, pretested and modified as needed. The data collected was also transcribed and hand-coded using a similar coding scheme developed in Phase I.

4.3.2 Ethics Review

As required for all research and as stipulated in Phase I, an application for ethics review was submitted to AFHE REB. Appendix D contains a copy of the ethics certificate for this phase of the research.

Unlike the stakeholder participants, honorariums were paid to each participant in the nine (9) focus groups conducted in June and July of 2006. Offering an honorarium is

sometimes considered controversial as participants may be become simply involved in research due to the "carrot" of being paid (Bernard, 2000; Krueger, 2000). However, the researcher felt it was necessary to offer an honorarium to ensure attendance. This was especially true where focus groups were held in the City of Winnipeg and the Edmonton based researcher needed to travel to conduct the sessions. Also, as stakeholders participated in this project as part of their professional duties, it is only fair that public stakeholders be compensated for their time. The bias that may be presented by this inducement is a noted limitation of this research and is addressed as necessary in the discussion of the results.

4.3.3 Utilizing Focus Groups

Developed after World War II to evaluate audience response to radio programs (Stewart and Shamdasani, 1990), social scientists and program evaluators have found focus groups to be useful in understanding how or why people hold certain beliefs about a topic or program of interest. A focus group is typically comprised of 7 – 10 individuals who are unfamiliar with each other, but have some common interest or characteristics (Bernard, 2000). They are brought together by a researcher, who uses this group of interacting individuals to gain information about a specific issue or topic (Kitzinger, 1995). This method allows researchers to study people in a more natural setting than a one-on-one interview (Morgan 1996), in an environment which encourage different perceptions and points of view, yet without pressuring participants to vote, plan, or reach consensus (Krueger, 2000).

Morgan (1996) noted that focus groups can: (1) provide insights into how groups of people think or feel about a particular topic; (2) reveal why certain opinions are held; (3) improve the design of a new program; (4) provide a means of evaluating existing programs and (5) develop strategies for outreach programs. As the idea of a focus group is to take advantage of group interactions, it is important to use the information at the group level, not the individual level (Bernard, 2000). Also, because focus groups are usually made up of a very small number of people who voluntarily participate, one cannot assume that the views and perceptions necessarily represent those of other groups that might have slightly different characteristics (Bertrand et al, 1992).

Focus groups are very useful as they are low in cost and results can be received quickly (Bernard, 2000). However, there are also disadvantages, in that the researcher can have less control over a group than in a one-on-one interview and data can be difficult to analyze because comments are made in relation to comments by other group members (Bernard, 2000; Kitzinger, 1995). The design and operation of the focus group procedures must therefore be carefully constructed in order to reduce this effect.

4.3.4 Public Sample Selection

Informed Public

Two separate samples of a concerned informed public group were used which evolved indirectly from results of the interviews conducted during Phase I of the research. During those discussions, stakeholders from each of the research sites, identified community groups which they utilized to discuss various decisions made by their respective organizations. In Edmonton, the water utility operator, EPCOR, operates the Home Water Sniffing Program which consists of 133 volunteers who provide feedback about the aesthetic (i.e., taste and odor) qualities of the municipal drinking water (EPCOR, 2007).

In Winnipeg, the regional health authority has six Community Health Advocacy Councils (CHACs) which are defined by geographical areas of the city. These councils are appointed by the Board of the Winnipeg Regional Health Authority (WHRA) to provide an on-going opportunity for community members to have input into the planning of health services in their communities. The CHACs complete this task by utilizing a population health framework and consist of 11–15 members from a variety of backgrounds who have a keen interest in exploring how health services are delivered in their community (WRHA, 2007).

The participants in each of these two groups were designated by the researcher as "informed' as they are comprised of individuals who have actively volunteered and become a part of the decision-making process. Members of the Edmonton group are directing how water services can be improved and delivered to the community. Whereas the Winnipeg group identifies and provides community input into health related issues. The benefits of these groups is that they have experience in the participation process and understand the current processes decision makers utilize to involve the public. In addition, while each group has a different focus, their individual uniqueness can offer a wider perspective than that available from a single group.

Members of these two informed public groups were invited to attend a focus group session by their respective program facilitator or coordinator. This indirect method was necessary as the community organizations, due to ethical and privacy legislation, were not able to provide a contact list of their members directly to the researcher. A letter of invitation was provided to each participant by their program coordinator either by direct or electronic mail. The invitation (see Appendix E) outlined the research study, the role of the participant as well as the offer of an honorarium of fifty ($50) dollars. A total of five informed public focus groups were held, two in Winnipeg and three in Edmonton. An additional focus group was held in Edmonton due to the enthusiastic response to the invitation by members of this community group. A recognized limitation of these two informed groups is the self-selected nature of the participants.

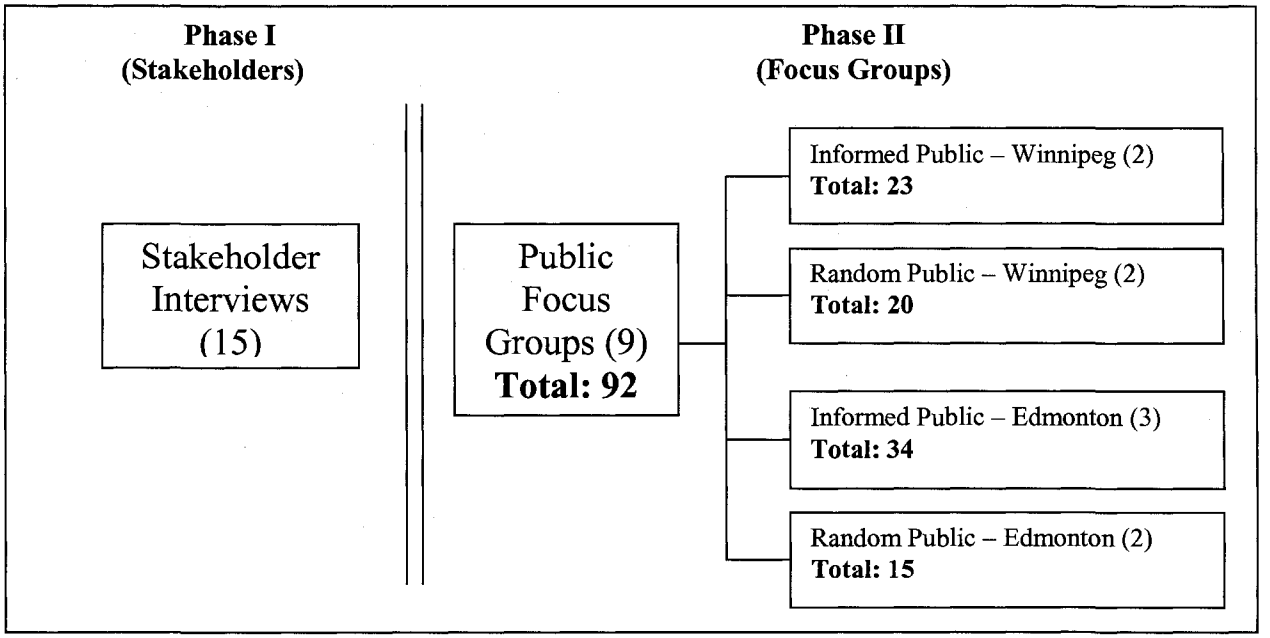
Random Public

In the second category, focus groups participants were randomly selected from the cities of Edmonton and Winnipeg. Individuals were contacted by a private market research company, (NEXUS), who has specialized experience in coordinating and selecting members of the general public to be part of public focus groups. The researcher provided the company with a sampling plan for the participants to be selected in each community. It was requested the groups be age-gender stratified with equal percentages of women and men (i.e. 50%) and two individuals from each of the five age categories: 18-24; 25-34; 35-44; 45-64; and 65 years and older. Also, the participants should have a variety of educational and employment backgrounds. Two focus groups of the "random public" were conducted in each city.

A possible limitation of using a private company was revealed after the sessions were conducted in that many of the randomly selected participants had previously been involved in focus group research. This is a potential bias as these participants may not be as open or frank in their responses as they have preconceived ideas of what the researcher may be asking (Morgan, 1996). Also, the researcher became aware of some volunteers belonging to the same household. Again, participants may not be as open in their responses, or limit their responses if they expect their partner or spouse to have contrary opinions to their own (Morgan, 1996). Therefore, this sample of the public was not as random as initially expected. Any potential effects of this bias are discussed during the presentation of the results.

Figure 5 provides a pictorial summary of the participant groups involved in this research.

Figure 5: Summary of participant groups



4.3.5 Question Design

As in Phase I, a list of prescribed or core questions were developed and pretested prior to utilizing them in a focus group session. Questions for focus groups should be carefully prepared, in a logical sequence and open ended to allow a participants to easily respond (Morgan 1996). The interviewer should also ensure there is a sufficient amount of time available for unanticipated questions, or exploration of comments made by the participants (Bernard, 2000).

Pretesting was conducted with two separate groups composed of environmental health professionals who work extensively with members of the public and possible impacts to their health. They are also experienced in working with legislation and consulting the public in regards to policy and procedures. As in Phase I, the questions were amended as necessary to ensure that they were clear, on topic and applicable to the research questions. Although two separate categories of public participants were used, the same questions were asked in each focus group session. Appendix F contains the focus group question.

4.3.6 Interview Process

The interview process was similar to that described in Phase I. Three documents were provided to participants at the beginning of the focus group sessions: an information sheet, a demographic information form and an informed consent sheet (see Appendix G). The information sheet was reviewed with all the participants, and they were encouraged to ask any questions if the information or process was unclear.

The participants were asked to complete the demographic information form, however this was optional. The goal of this form was to collect some basic information about the participants in terms of age, gender, education level, marital status and employment status[5]. The participants were not asked to provide any information which could identify them individually such as name or address. The demographic data was used to assess the

[5] It should be noted that for the random public participants the researcher received this information from the private marking firm, NEXUS. This information was collected again at the beginning of focus group to ensure accuracy.

generalizability of the sample to the each of the community populations (Bernard, 2000). It also aided in describing the transferability and application of the information collected from these sessions (Bernard, 2000; Morgan, 1996).

The role of the moderator or interviewer in a focus group session is essential to the success of a focus group. The interviewer must be experienced in keeping discussion flowing and on track, be able to make easy transitions to other questions and be sensitive to the mood of the group (Bernard, 2000). The moderator must also enforce the ground rules of participation which include: minimizing or eliminating side conversations, encouraging only one person to speak at a time, not allowing participants to criticize what others have to say and treating everyone's ideas with respect.

The researcher conducted all nine sessions which aided in maintaining consistency of approach. Two observers were also present at each session who took more comprehensive notes, collected consent and demographic collection forms, ensured operation of tape recorders, and responded to unexpected interruptions (e.g. latecomers).

In summary, the focus group sessions were conducted as follows:

(1) Greeting and registration of each participant upon arrival.

(2) Introduction of the researcher and observers including professional background, roles and responsibilities in the research study;

(3) Providing each participant with a copy of the information sheet about the project which was also verbally explained. Emphasis was placed on

confidentiality of the responses, and projected use of the data. Permission was requested to record the interview;

(4) Completion and collection of the consent and demographic collection forms;

(5) Review of the basic ground rules of a focus group.

(6) Commencement of the focus group based on the developed questions. (Each session took one (1) to one and a half (1.5) hours);

(7) Opportunity for the participants to ask further questions about the research topic or modify any previous responses was given at the end of the interview. It was also common for the participants to have questions about the case study topic of water treatment and quality;

(8) Collection and signing for participant honoraria.

4.3.7 Data Organization and Analysis

As in Phase I, the focus group sessions were digitally recorded in duplicate and electronically downloaded and transferred to a contracted transcriptionist. Each session was transcribed, verified and then analyzed using the same coding methodology described in Phase I. Responses to each question were organized by spreadsheet and then compared not only individually but within and between each of the four types of focus group sessions: Edmonton Informed, Edmonton Random, Winnipeg Informed, and Winnipeg Random. As with the responses gathered in Phase I, all responses were considered in the analysis regardless of the number of participants who vocalized the idea or issue.

4.4 Bias and Limitations

In the methodology, there were bias and limitations identified with these procedures. As no research study is perfect, it therefore becomes the responsibility of the researcher to outline issues, which may bias the findings of the research. Biases can arise from a perception of unacknowledged favoritism on behalf of the researcher or an error in the methodology, which may favor a particular outcome (Bernard, 2000). To ensure the reader was aware of any bias, it was felt that a section be added to this work which summarized any of these limitations.

Selection Bias

Participant selection bias is a potential concern for both stakeholder and focus group participants. Commencing with the stakeholders, it was the researcher who invited their participation. This causes an inherent selection bias however it is unavoidable as there are limited experts in the area of drinking water within Canada. Therefore, random selection was not achievable and this method was necessary to have a successful level of participation. .

Secondly, each stakeholder was asked to identify other potential individuals who may be able to contribute to this research. This type of selection bias may also be known as referral bias. This may be a concern, as stakeholders may not recommend certain individuals because of their own bias or even limit the access of the researcher to

colleagues. Upon analysis of the transcripts, these situations were not detected. There were neither derogatory comments made about viewpoints expressed by other individuals or agencies nor any reluctance to share names of individuals whose opinion should be sought. Finally, as there are a limited number of drinking water experts it was highly unlikely that any individual or organization was not included.

Finally, the stakeholders identified the community groups which were eventually used to form the two informed focus groups. This may also present a form of selection or referral bias as the stakeholders facilitated the researcher's efforts to contact these individuals. However, stakeholders only suggested potential community groups and provided the researcher with contact information as to who should receive the research proposal. The proposal was submitted to the coordinator of the community group who circulated the invitation to participate to its membership. Based on these reasons, this potential bias was minimized and did not impact the research.

For the informed public participants, those who comprise the informed focus group sessions, selection bias may also occur. While all participants received the invitation to the session from their organization's project coordinator, they did self-select themselves for inclusion. Also, the researcher did select participants on a first come, first serve basis which may have resulted in an over selection of some individuals in a demographic category.

For the randomly selected public participants, a third party company was utilized. The company, NEXUS, contacted individuals who have self-selected themselves to participate in focus groups. Due to their self-selection, there is a possibility they may not be as open or frank in their responses as they have preconceived ideas of what the researcher may be asking. In an effort to minimize this effect, a sampling frame for selecting participants was created and implemented by NEXUS. An unexpected complication arose when it was noted that some participants who participated in the first Edmonton focus group had the same address. This created an unpredictable bias into the research where an individual may not be as open with a response if they are concerned their partner, spouse or house mate has a contrary opinion to their own. While this was prevented from occurring in the second focus group session, overall the participants for the Edmonton random focus groups were not as randomly selected as initially expected by the researcher. The effect of this occurring will have to be evaluated once the data analysis is completed.

Another factor which may have induced selection bias in the focus group participants was the offering of an honorarium. This may have been why individuals chose to be apart of this research instead of a true interest in the study. While honorariums compensated individuals for their time, they are also aided in ensuring participants attend the organized sessions. As the researcher had to travel to Winnipeg to conduct part of this research, offering alternative sessions was not an option due to budgetary constraints.

Information Bias

The researcher may have introduced bias into the study during the description of the case study of chlorinated disinfection by-products (CDBPs). The potential bias may be the researcher favored a particular scientific viewpoint or downplayed the associated health risk of CDBPs due to their own beliefs. To counter this effect both the benefits and risks with CDBPs were explained. Care was also taken to limit the use of technical or scientific language about CDBPs and water treatment to ensure all participants had a good basis of understanding.

There is also the potential that some participants would not feel comfortable asking questions about the information to clarify their understanding. The result may be that the participant comments were based on a less than complete understanding of the issue. To minimize this bias, participants were encouraged to question the information given as well as being offered supplementary information if they had further questions. This was achieved during the sessions as the participant responses were frank, full of humor and curiosity.

This type of bias was not identified as being an issue in regards to the stakeholders. As these individuals are considered experts on this topic, they have a well-founded understanding and knowledge of the scientific uncertainty associated with this issue.

Participant Influence

In focus group discussions, it is always possible that one or more participants could both dominate and influence the comments in response to a particular question. To limit this, particular care was taken to ensure all participants had an equal opportunity to speak and encouraged everyone to express their opinion. Also, individuals who were more expressive of their opinions were tempered and "cut off" by the researcher as necessary.

While some stakeholders vocalized an interest in the responses of other interviewees, the occurrence of participant influence for the stakeholders is low. None of the responses from the stakeholders appeared to be restricted or abbreviated due to a potential conflict with their agencies mandate or policy. Reassurance by the researcher to keep confidential and anonymous may have assisted in this openness, but there was also a feeling that their views did not differ from their employer.

5.0 Results

5.1 Demographics of Research Participants

Demographics refer to the characteristics of individuals who are involved in a research study. For this research study, only the focus group participants were asked to complete a short survey which captured their age, gender, education; marital status and employment status (see Appendix G). The demographics of the stakeholders were not collected as they were selected due to their roles and responsibilities. These variables were collected as they were the most important characteristics which may bias the results of this research. To control or moderate these biases the researcher collected this information to determine what impact it may have on the data collected. The relationship between the demographics of the participants and the results will be presented in the discussion section of this document.

Sample Size

Basic demographic information was collected for all public participants. This information included: age, gender, marital status, employment status and last level of education completed. Table 6 shows the demographics for participants in each of the public participant groups. The total number of participants was 92, which was greater than the originally targeted 80 participants. This higher number resulted from a high level of interest from members of the informed public group based in Edmonton.

Unfortunately, due to lower attendance at one focus group session held for randomly selected public in Edmonton, an even distribution of participants was not achieved.

Table 6: Number of participants by sampling group

	Edmonton		**Winnipeg**	
	Informed	Random	Informed	Random
Males	12	7	7	10
Females	22	8	16	10
Total	**34**	**15**	**23**	**20**

Age and Gender

Tables 7 and 8 show the age and gender of the public focus group participants by community. The informed public samples in both communities did have significantly higher proportions of female participants. This is a common event according to Bernard (2000) who has found females are more likely to volunteer to be a part of research studies or programs.

In terms of age, the majority of the participants from the two informed public samples were 45 years of age or older (Tables 7 and 8). As convenience sampling was utilized to select the informed participants, a result such as this was expected. This age range is more likely to be involved in community-based organizations such as health councils and water quality programs (Bernard 2000).

For the participants recruited by the private market research company, a prescribed sampling frame was followed as discussed in the methodology. Generally, the sampling frame was followed and a good degree of variability was achieved in both community sites. There is a higher representation of 45-64 in the Edmonton sample, however again due to an error on the part of the marketing company some of participants could not attend one session. This resulted in higher proportion of participants of this age group being involved in this research.

Table 7: Age and gender of public participants – Edmonton

Age	Informed Public Sample (%)		Random Public Sample (%)	
	N = 12	N = 22	N = 7	N = 8
	Male	Female	Male	Female
20 - 24	0	4.6	14.3	12.5
25 - 44	8.3	18.2	14.3	25.0
45 - 64	16.7	54.6	42.9	50.0
65 - 74	75.0	22.7	28.6	12.5

Table 8: Age and gender of public participants – Winnipeg

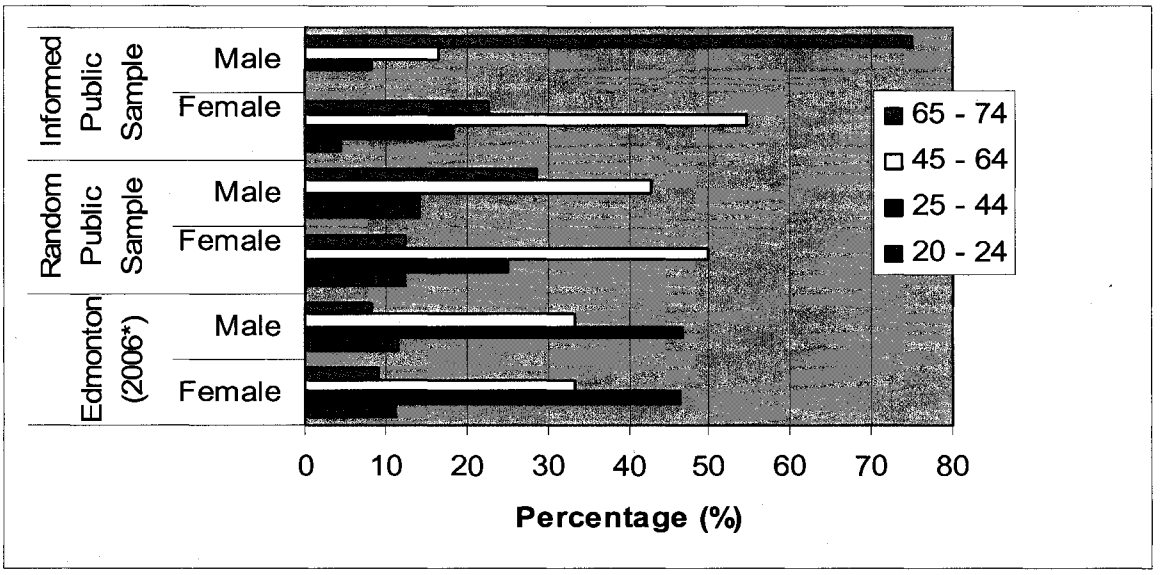
Age	Informed Public Sample (%)		Random Public Sample (%)	
	N = 7	N = 16	N = 10	N = 10
	Male	Female	Male	Female
20 - 24	0	6.3	0.0	30.0
25 - 44	28.6	31.3	40.0	30.0
45 - 64	42.9	50.0	30.0	30.0
65 - 74	28.6	12.5	30.0	10.0

Figures 6 and 7 graphically depict the age and gender distribution patterns of the two community samples. In addition, data from the 2006 Canadian Census was retrieved to determine if the distribution of the informed and randomly selected participants and

consistent with the population distribution for each community. In the Edmonton samples (Figure 6), while the randomly selected sample shows acceptable alignment with the population of Edmonton, the informed public sample does contain high numbers of participants over the age of 65 and insufficient number of participants below the age of 44. This bias is the result of the individuals involved in EPCOR's home water-sniffing program. EPCOR's program targets individuals who are available throughout the day to "sniff" the water as such many of the program members include retired individuals.

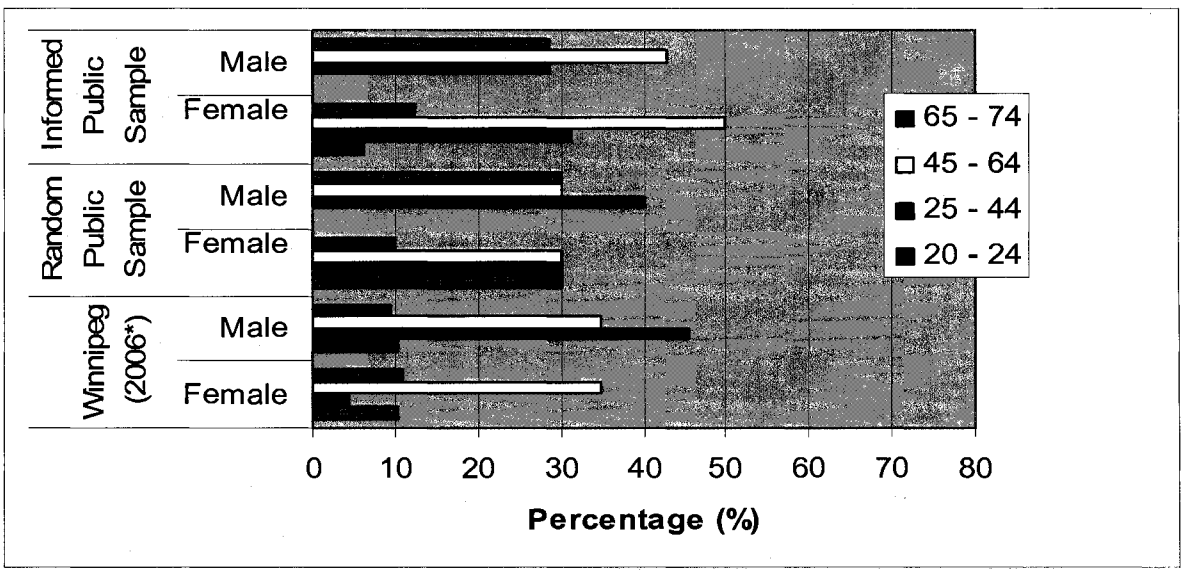
In the Winnipeg samples (Figure 7), the randomly selected public participants did follow a similar distribution pattern to that of the population of Winnipeg except for the absence of male participants under the age of 25. For the informed public samples, a higher number of participants were between the ages of 45 – 64 in the community distribution. In both the Edmonton and Winnipeg samples, there was a general lack of participants who were under the age of 25, particularly males.

Figure 6: Age and gender of public participants – Edmonton



Source: Statistics Canada - Census 2006, 2007a

Figure 7: Age and gender of public participants – Winnipeg

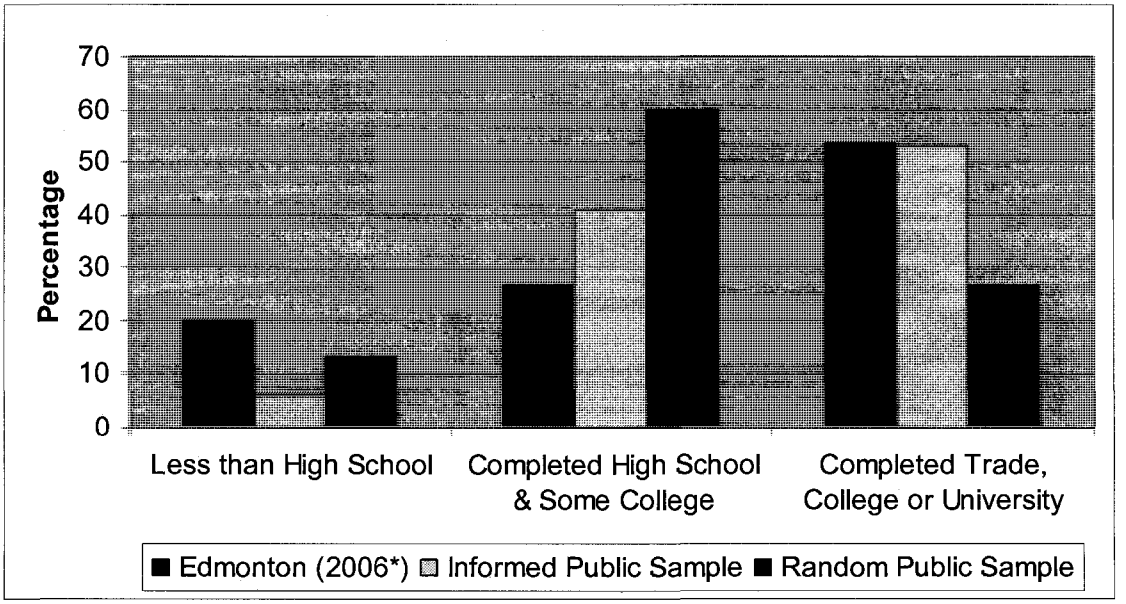


Source: Statistics Canada - Census 2006, 2007b

Education

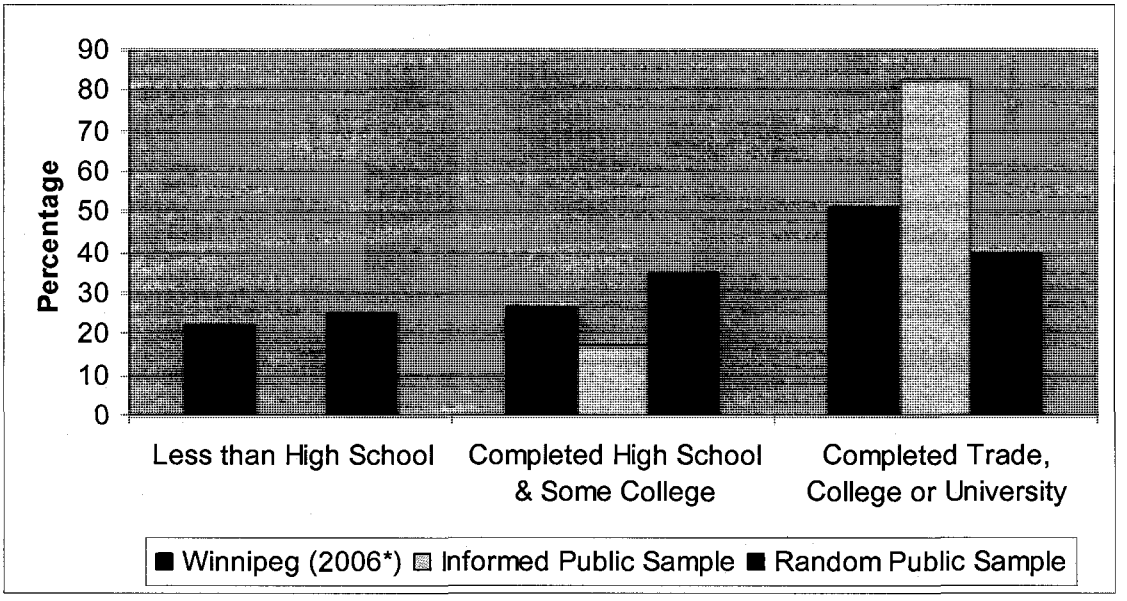
Figures 8 and 9 compare the level of education of each category of public participant to the population living in either the Metropolitan areas of Edmonton or Winnipeg at the time of the 2006 Census (Statistics Canada, 2007a, b). A higher proportion of Edmonton participants from the informed public groups had completed high school or college/university than found in the overall population. Whereas the majority of the randomly selected public had completed high school, a lower proportion of them had completed college or university. For the Winnipeg samples, all participants in the informed public sample had at a minimum completed high school. The randomly selected public followed the general distribution pattern for the population of Winnipeg.

Figure 8: Education levels of public focus groups – Edmonton



Source: Statistics Canada - Census 2006, 2007a

Figure 9: Education levels of public focus groups – Winnipeg

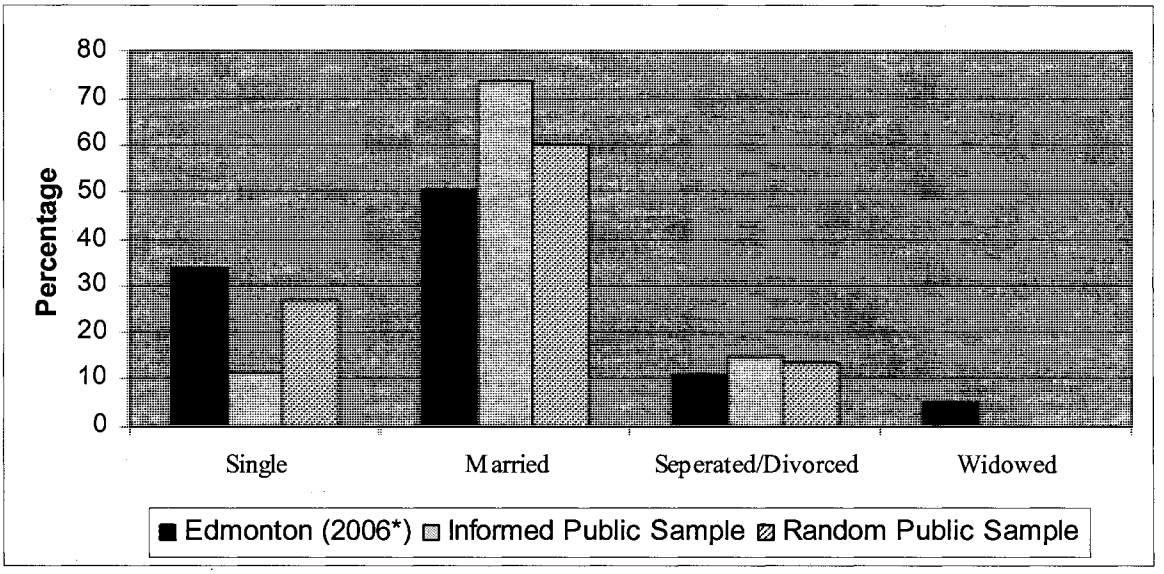


Source: Statistics Canada - Census 2006, 2007b

Marital Status

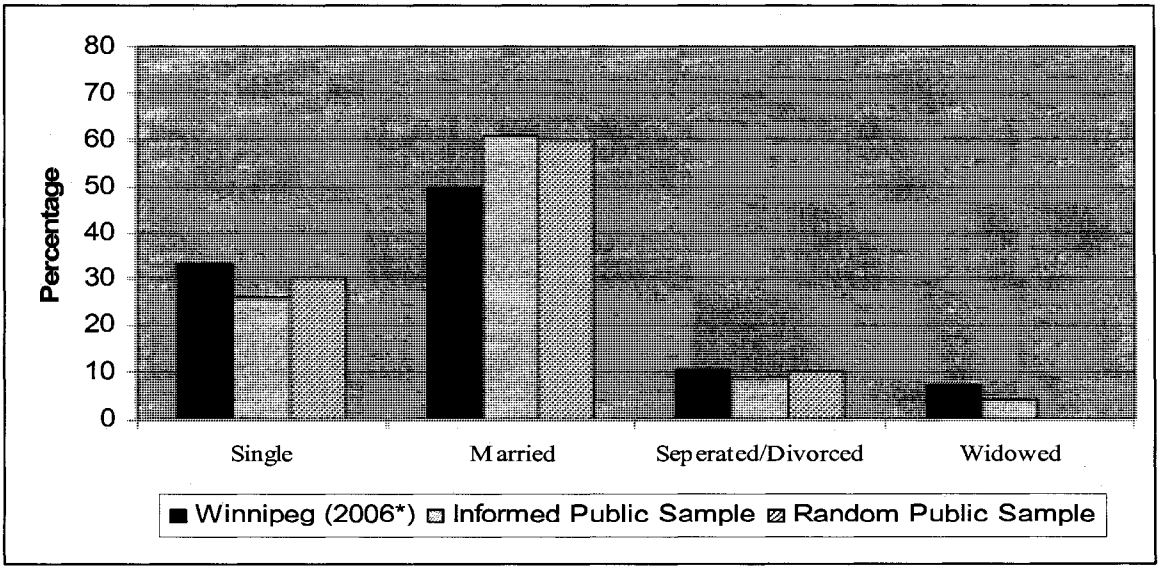
A high proportion of the participants in the Edmonton informed public sample (see Figure 10) were married. In the randomly selected public from Edmonton, the participants generally followed the martial distribution pattern of the population with one exception; no participant indicated they were widowed. For the Winnipeg participants (Figure 11), both the informed public sample and randomly selected public generally followed the proportions of the population of Winnipeg.

Figure 10: Marital status of public participants – Edmonton



Source: Statistics Canada - Census 2006, 2007a

Figure 11: Marital status of public participants – Winnipeg



Source: Statistics Canada - Census 2006, 2007b

Employment Status

The employment status of the public samples by community is presented in Figures 12 and 13. Unfortunately, the categories used to collect this demographic were not comparable to Statistics Canada's information about employment status due to the categories chosen to classify participants. Therefore the figures that follow simply describe the differences between the informed and randomly selected samples.

Figure 12 shows that the majority of the Edmonton informed group was comprised of retired participants. As mentioned earlier this is a reflection of the community group used in this convenience sample. For the randomly selected Edmonton public, employment status was not specified in the sampling frame given to the private marketing company. Overall, the majority of the sample was employed full-time. Their employment status is a reflection of the age of these participants.

Figure 13 shows the distribution of the employment status of the public samples taken from Winnipeg. The random and informed samples have similar distribution patterns for each category of employment. Overall the majority of the participants from Winnipeg were employed full-time.

Figure 12: Employment status of public participants – Edmonton

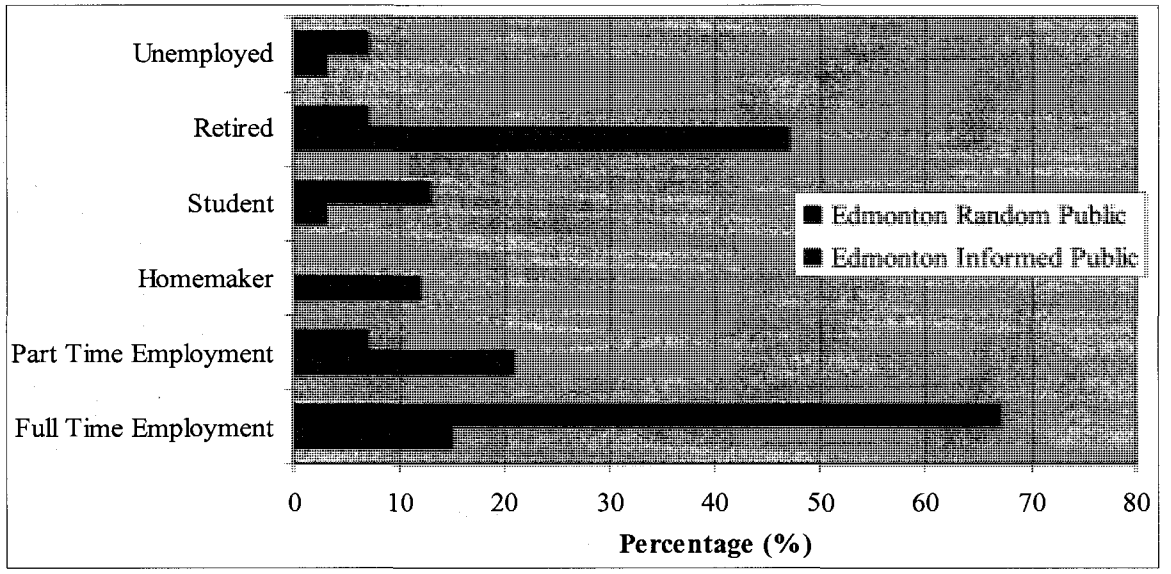
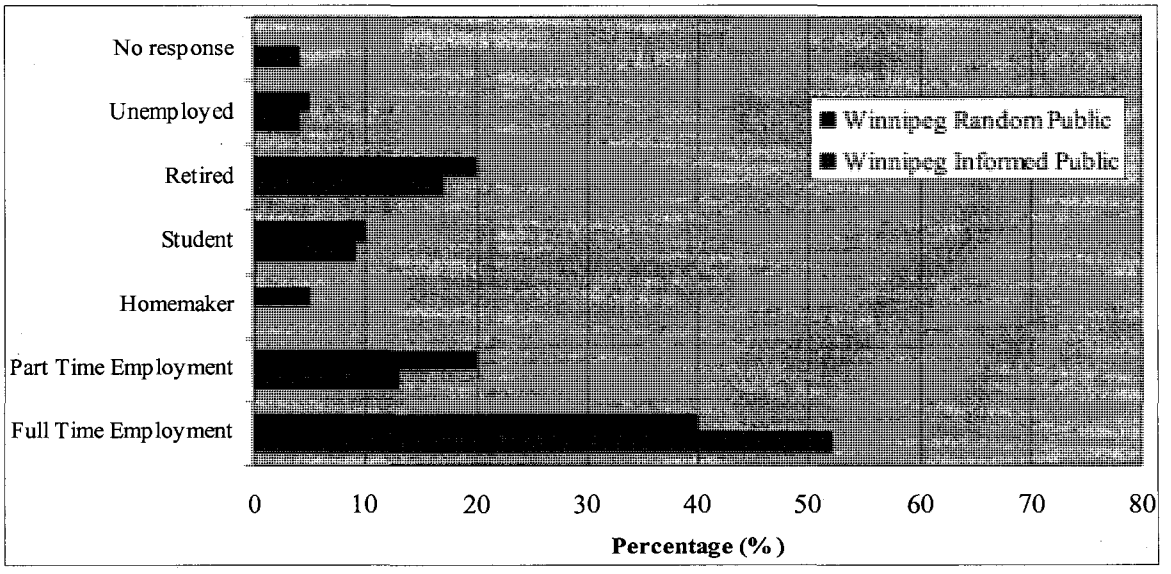


Figure 13: Employment status of public participants – Winnipeg



5.2 Results and the Research Questions

The two research questions are used to divide the results into two main areas. This layout style is being utilized to facilitate the presentation of both the results and the discussion sections. It is hoped that this design will aid the reader in their understanding of the qualitative research being presented. This same layout will be utilized in the discussion chapter of this work (Chapter 6). An overview of each of the sections is provided below.

Part A: Current Role of the Public in Risk Management

This first section is a discussion of the first research question, which is: *What role does the public currently play in decision-making*? Here, utilizing both the stakeholder and public responses the researcher will attempt to establish a baseline level of public participation. To organize the presentation of the responses from the two groups, this section is further divided into three parts. These three parts are as follows: (1) expectations and responsibilities of the public in decision-making, (2) sufficient opportunities to participate and (3) value of the opinion. Under each of these sections, as show in Table 9, the applicable questions from each participant group are arranged. In some cases a very similar question is asked to each group. This similarity was deliberate in order to allow comparison between responses and provide a well-rounded representation of the current status of the public's role.

Table 9: Participant questions for research question #1

A: Expectations and responsibilities of the public in decision-making	
Stakeholder	Public
	P-1: What role do you expect the public to play in creating public policy
	P-2: Do you think the public has a responsibility to participate?
B: Sufficient opportunities to participate	
S-1: Do you think there are sufficient opportunities for the public to be involved in setting policy/regulations?	P-3: Do you currently think you have sufficient opportunities to be involved in decision-making?
C: Value of the public's opinion	
S-2: In your experience, do you feel the public's opinion is valued?	P-4: Do you think the public's opinion is valued?

Note: S-1 refers to stakeholder question #1; P-1 refers to public question #1

Part B: Potential Role of the Public in Risk Management

The second section discusses what the role of the public should be in risk management in circumstances of uncertainty (research question #2). It is here the case study, chlorinated disinfection by-products (CDBPs) is utilized to explore what the role of the public should be in context of uncertain science. To answer this research question, this section is divided into two parts. The first part explores how science is valued and what role it should play in the eyes of the public participants. In the second part, the participants were asked if they felt their role had changed when science provided conflicting information. These questions were asked after the case study topic of CDBPs was explained to the participant. The researcher explained the controversy in the scientific literature, the expected exposures and believed health outcomes associated with CDBPs.

The participant's were also provided with information on the benefits of chlorination, how CDBPs are formed and how formation can be prevented or reduced in the water treatment process. Table 10 shows the relevant participant questions for this research question.

Table 10: Participant questions for research question #2

A: Public's View of Science	
Stakeholder	Public
	P-5: What role do you think science should play in decision-making?
B: Effects of Uncertainty on the Role of the Public	
S-3: Does the role of the public change when the science is uncertain?	P-6: When scientific studies come to different conclusions, do you think there is a different role for the public to play?
	P-7: What role do you think the public should play in a case like this when science is uncertain but policy decisions must still be made?

It should be noted that questions P-6 and P-7 are very similar. This was intentional as it provides two opportunities for the participants to provide input into the key question of this research. Rewording the question also ensures that the participant has a clear understanding of the question being asked. Plus this duplication, improves the validity of responses especially in the event of similar responses.

5.3 Presentation of the Results

To simplify and minimize the length of the results chapters, a few common rules or guidelines were developed and followed. These rules were laid out below:

1) Only when a category is specific to a particular location or focus group will it be recorded. Otherwise, it can be assumed the categories arose from a combination of focus groups. Appendix H provides the quantity of responses per category and can be consulted for further reference. This appendix is specific for the public focus group sessions only.

2) To protect the confidentiality and anonymity of the stakeholder participants, the researcher did not provide the distribution of the responses as shown in Appendix H for the public focus groups. More detail was included in the presentation of results about the quantity of responses associated to each category to compensate.

3) Every category is considered to have equal importance regardless of the quantity of the responses coded to it.

4) All participants were encouraged by the researcher to respond to questions. However, this did not always occur. Every effort was taken to capture the responses of participants who only nodded their head in agreement. This was

done by asking them directly or by recording this action in the researcher's notes of the discussion. Therefore at times this maybe noted in the results.

5) To simplify which focus group was the source of quotations, a label was created for each. They are as follows:

WI = Winnipeg – Informed **WR = Winnipeg – Random**

EI = Edmonton – Informed **ER = Edmonton – Random**

Further, a number is assigned to the group to indicate which focus group session the quote came from. For example, WI#1 represents Winnipeg – Informed Focus Group #1.

5.4 Research Question #1: Current Role of the Public in Risk Management

5.4.1 Expectations and Responsibilities of the Public in Decision-Making

5.4.1.1 Public Question #1 (P-1)

The opening question for each focus group was designed to determine what the public currently views as their role in creating public policy. Roles are defined as active tasks undertaken by individuals as part of a formalized process. The following question was asked to all focus groups involved in this research: *What role do you expect the public to play in creating public policy?*

In total there were five categories which emerged. Two of those categories were very dominant and consisted of a variety of aspects. These separate yet linked components

were labeled sub-categories. The remaining three categories were less complex and had a lower frequency of responses.

Category #1 – Roles of the Public

The first category encompasses both direct and indirect responses from the focus group participants to the posed question. Here the participants described what role they expected to play in public policy development. Generally, many of the participants indicated or implied that the public has *"a very important role to play"* (WI#1). However, four more specific roles were identified from their responses.

1) **Involvement.** Many participants expected to be involved in policy development and decision-making. Often participants described their involvement in terms of size. Phrases like *"large amount"* (WI#1), *"big input"* (WR#2) or even *"huge role"* (ER#1) were commonly found in the transcripts.

   Other participants indicated that *"the public should be consulted about issues"* (WI#1). Alternatively, some participants felt the public's role should be a more active one. An Edmonton participant indicated the public did not have to *"wait to be asked* [for their] *opinion of something"* (EI#3). Instead of waiting for a decision maker to come to them, they should be out there expressing their views. The public needs to *"be active about it"* and whether this is in *"small ways like*

neighborhood watch program or in big ways like making noises when our premier's or our prime minister's do things we don't like" (EI#2)

Various participants also noted that their involvement should be throughout the entire process of decision-making and policy development. A participant from Winnipeg summarized this as follows:

> *"I think the public should be involved at the preliminary stages of the discussion in regards to policy decisions, affecting any public health issue. Not only the preliminary, but I think during all initial phases because I know that, sometimes when they address the public, it's always at the end of the phase when the decision's already been made"* (WI#1).

2) **Self educate.** Some participant's felt that the public *"owes it to themselves to become informed"* (EI#3). While this could be categorized as becoming involved, it is a more specific activity. Instead of passively waiting for decision makers to act, participants reflected *"the primary role of the public is to educate itself"* (WR#1). This would allow the public *"to play an informative role"* (EI#3). By doing so, one participant noted they may become more aware of *"political agendas attached to certain decisions"* (WI#1). And while this may cause people to become *"more cynical"* (WI#1), the public may be able to participate in a more knowledgeable way.

3) **Ensure decision makers are acting responsibly.** In this final role, some participants felt they needed to act as checks and balances for decision makers. Some participants expressed uncertainty as to whether or not decision makers

were making the right decisions. This view using water as an example was captured by the following Edmonton participant:

> *"I'm very concerned that the people that are controlling water and so on are doing their job. Like the big fiasco they had down east, not putting in the right chemicals and so on. How does the public know this is being done and being done properly?"* (EI#1)

To manage this uncertainty, participants felt they needed to exercise their voting power during elections. They described this as their *"basic role in terms of public policy"* (WI#2). An Edmonton participant noted *"we have to vote people in who we think are going to carry out what we want"* (EI#2). If decision makers fail to do so, the reaction should be *"en mass we change the guys that make those decisions"* (WI#2).

4) **Trust elected or appointed officials.** Some participants believed that they "*have to trust the people who are working in that, they have the knowledge, they are the professional"* (EI#1). A second participant noted that the politicians *"should be empowered to hire people that are qualified"* (EI#2). This indirect response was found only in the Edmonton Informed focus group session and provides valuable insight into a potentially limited role for the public.

Category #2 – Role of the Decision Maker

As the coding for this question was conducted, it became apparent that not only did the participants identify roles for themselves but also for decision makers. As the second

major category, these responses reveal what the participants felt the decision makers should be doing to encourage and engage the public. Three roles were identified with two common to all focus groups. The third was only identified in the final focus group held with randomly selected public in Edmonton.

1) **Identify the process of participation**. It became apparent very quickly that existing participation was a *"chaotic attempt at input"* (WI#1). The public was also having to *"muddle through"* (EI#1) the process. One participant noted that *"there's the role of the decision maker and until that role is clear to the decision maker"* (WI#1) the public's role will remain the same. This lack of a clear process causes the public to become frustrated as something *"may have been in the works for a year"* and *"we don't know about it"* (EI#3). To reduce the public's frustration they need to be *"made more aware of where they can go and how they can get the answers"* (EI#1). In other words, a clearly understood participation process should be created by decision makers and shared with the public.

2) **Provide balanced and complete information.** Participants expressed concern about whether they were *"actually receiving all of the facts to be able to make decisions"* (WR#1). As without all the information, *"the public can't have an opinion unless they know what it is they have to make an opinion about"* (EI#2). It is from these and similar comments that the second role for decision makers is outlined. This second role is to provide sufficient well rounded information which

will allow the public to be capable of participating in decision-making. By doing so, there would be an "*opportunity to have full information on whatever was being looked at. Open, honest.*" (ER#2).

3) **Opportunity to share their opinion(s).** In the previous role, participants wanted information from decision maker that was balanced, open and honest. This final role describes a different kind of openness. The participants wanted to impress upon the decision makers that they, meaning the public, want to have the freedom to express their opinion. A participant from Edmonton shared that they wanted *"a place where you can like verbally say your opinion, rather that just say yes or no*" (ER#1). A second participant echoed this statement by stating they wanted an *"opportunity to express their concern and how, whatever is being looked at or studied, how it will impact them"* (ER#2). It is therefore the role of the decision maker to provide such an opportunity which allows the public to express and explain their viewpoint. This role should be considered during the defining of the participation process and will be further discussed in Chapter 6.

Category #3 – Difficulty of Getting Public Input

This category was an indirect answer to the question posed to the focus groups. While many agreed that the public should be involved, six participants recognized the challenge of trying to communicate with the general public. A participant from Winnipeg summarized this viewpoint as follows: *"I think we should be involved, but I think the*

public as general as [it] *is, it's hard to inform the public properly"* (WR#2). A second participant agreed and questioned *"how do you go about getting the input from all these people?"*(WR#2) There was no solution offered by any of the participants.

Category #4 – Identifying the Public

This category speaks to what is meant by the word the "public". It is a very general term which provides little definition as to who is included or who is excluded. Two participants, one from each community site spoke about this issue. One participant questioned who answers media surveys except that person who has *"a specific issue with that particular item*" (WI#2). They felt this created *"quite a bias"* (WI#2). The second participant from ER#2 was also concerned about bias and who was *"going to be determined as the public"*. They were concerned that the *"uneducated won't be informed"* and it *"could be skewed towards the middle class"*. It would be the middle class *"who are deciding"* or providing input into surveys which may influence decision makers. Despite the low number of responses coded to this category, this may be a very important factor to consider for a decision maker. They need to know just who of the public they are trying to target or have included in the process of decision-making.

Category #5 – Apathy

As the researcher listened to the recordings of the transcripts, apathy became apparent in the tone and inflections used by the participants and some participants also verbalized

this feeling during the discussions. By definition, apathy means a lack of interest or concern over an issue. Or, it can be thought of as the need for individuals to be personally affected about an issue before they will become involved. Citizens of Edmonton were described as not *"giving a hoot"* as long *"as the buses run on time and you turn on your tap and* [there is] *water"* (EI#1). In both communities the public were described as *"very lazy"* (EI#2) and *"don't care"* (EI#2). The only thing that changes that attitude is *"when something happens* [then] *you see everybody wake-up"* (EI#2).

If apathy is present, gaining public involvement in any issue may be difficult. If someone is not personally affected, there is no "buy-in" for them to participate. This category may also provide insight into the third category which described the difficulty of getting input from the public. This may also be an important factor for decision makers to recognize when trying to get public input.

5.4.1.2 Public Question #2 (P-2)

The second question - *Do you think the public has a responsibility to participate?* - was asked to determine the level and type of responsibility the public perceived they currently have. For the purposes of this research, responsibilities were defined as individual's conduct or obligation in fulfilling their designated duties. The structure of this question tends to prompt a participant to give a yes/no response. While 42% (39/92) of the participants gave clear "yes" responses, the remaining proportion responded indirectly.

These indirect responses were still supportive of the public having a responsibility to participate. After coding the transcripts four categories emerged and are outlined below.

Category #1 – Responsibilities of the Public

This first category encompasses more than responsibilities of the public. It also describes the limitations of their responsibilities and the outcomes of not participating. As a result, there are five sub-categories coded to this category. The first two sub-categories are two responsibilities the participants indicated the public should be undertaking. These two action based responsibilities are:

1) **Sharing their opinion with decision makers.** Participants indicated it was the responsibility of the public to express their opinion. This opinion should be expressed to an elected official or decision makers within government organization. However, while *"a lot of people maybe talk or complain they don't take any initiative"* (EI#3) to have their concerns addressed. If the public fail to do so, it was felt that *"elected representatives are going to go off in a direction that may not be to their liking or anyone else's"* (WI#2).

   To share an opinion, it was also recognized that it may not be easily done or accomplished in one contact. This was predicted by an Edmonton participant who noted that respectful persistence may be needed. Their comment is shared below:

> *"I think we have to take responsibility* [or] *onus that if we have a concern with any particular issue however it comes through the media, that you don't just make a phone call. If it's not working that you write a letter and you send a fax, you send an email and just contact them. And let them know what your concerns are or ask your questions and you keep on* [going] *in a respectful way if you're not getting* [the] *proper response"* (EI #3).

2) **Self educate**. These participants felt that if you were going to participate in discussions, you take on the responsibility of ensuring you are knowledgeable enough about the issue. It was described as a responsibility since people *"shouldn't complain without educating themselves"* (WR#1). A second participant also stated *"there are a lot of people that don't care and don't know enough about the issue"* (EI#3).

In the next two sub-categories associated with this category, the first describes a limitation of the public's responsibility. The second highlights the responsibility the public has to accept if they fail to participate.

3) **Responsible to participate, not to make the decision.** While most participants agreed the public has a responsibility to participate in decision-making, some also shared that it did not mean they had the task of actually making the decision. One participant noted the public is *"responsible to a point"* (ER#1). This limitation of responsibility alludes to the attitude that they have the right to be heard but *"not to make the policy"* (WR#1). Part of this attitude was based on the thought *"the public doesn't always know what's*

best" (WI#2). These comments lead to an understanding that the public's participation and opinion may be only part of the decision-making process.

4) **Accepting decisions.** This final sub-category is very distinctive from the previous three coded to this category. Some participants contributed insight into what should occur if the public fails to fulfill their responsibility to participate. This viewpoint was best articulated by one participant who noted: *"if they don't participate then they don't have a right to complain about it afterwards"* (ER#1). Two other participants from Edmonton agreed with this statement. These participants brought forth the idea that if an individual fails to act or respond when they are engaged, that they have to accept the decision once it is made. While this may be a simplified viewpoint, it is an important belief held by some which needs to be recognized.

5) **Right and responsibility.** In this last category, some participants felt not only did they have a responsibility to participate but also a right. An Edmonton participant stated *'the public has a right and responsibility to be informed and involved"* (EI#3). A Winnipeg participant also supported this by stating: *"I think it's more of a right to participate. We have a right to express our opinions, it's not an obligation, we have the right to do it"* (WI#1). As to why it was perceived a right, one participant offered this explanation: *"if it's paid publicly, if it's publicly funded then the public has a right to play a role in the decision-making process"* (EI#1).

Category #2 – Responsibilities of the Decision Maker

The participants identified four responsibilities for the decision makers. These four are active steps a decision maker should be taking to ensure the public is appropriately engaged. These responsibilities are described as follows:

1) **Determine process of participation**. This sub-category was previously noted in response to the first question (P-1) and is duplicated here. A participant pointed out it is *"more a responsibility of those in charge to give us the opportunity to participate"* (WR#2). Participants shared that when *"the process isn't there for it"* (WR#2) or if decision maker has not ensured that the right *"factors"* (WI#1) are in place, the process of participation will fail. Therefore, decision makers need to define the process of when and how the public would fulfill their responsibility.

2) **Ensure transparency**. Some participants indicated that the process and the decisions that are being made are failing to be transparent. If decision makers do not ensure transparency, then *"people don't participate"* (WI#2) and *"there's no accountability"* (EI#1) for the decision being made. This responsibility needs to occur as with *"transparency people are able to access the information"* (WI#2). From these comments, it appears transparency is not occurring in the participation or decision-making process. This sub-category will need to be built into the participation process in order for decision makers to fulfill this responsibility.

3) **Provide an opportunity for involvement.** This third sub-category speaks to the decision maker having a responsibility to ensure the public is consulted. The participants indicated that they simply wanted an *"option"* (WR#2) or *"a chance"* (WR#2) to respond to an issue. One participant indicated he was not *"convinced that we get the opportunity"* (EI#3). Another put forth the question of *"where were we when these decisions were made?"* (WI #1). These comments by the participants suggest that decision makers are not currently fulfilling this responsibility. Like the second sub-category, addressing this responsibility could be fulfilled by a better definition of the participation process.

4) **Listen.** Participants reflected that they did not feel that decision makers were willing to listen to their concerns or viewpoints. One participant expressed this by saying decision makers *"have to be willing to listen"* (WR#1) while a second noted: *"we have a right to complain about something and have somebody hear about it"* (EI#1). This left people feeling *"cynical"* (WI#2) and having no *"guarantee that those people actually are listening"* (WI#1). These participants want the decision maker to recognize this responsibility and address it appropriately.

Category #3 – Barriers to Participation

Within the discussion about responsibilities, participants provided comments about what factors influenced the level of participation. The focus group participants identified four

factors which may limit or prohibit people from fulfilling their responsibilities. Recognizing these barriers provides insight into the current status of public involvement in decision-making. These four factors are as follows:

1) **Ensuring representative participation.** Having *"accurate representation of Canadians"* (WR#2) and ensuring a *"larger segment of the general population"* (EI#3) involved was also noted by participants. This was seen to be a barrier as currently some individuals may be marginalized from participating and the participants want to ensure all the public is provided with an opportunity in the future.

2) **Inadequate education about the decision-making process.** A few participants indicated that not enough of the public understood the process of participation. This becomes a barrier as *"we aren't aware of the appropriate channels that we're supposed to go through"* (EI#3). So in affect people are prevented from getting involved because they do not know where to start. The solution to overcoming this barrier was education to improve public awareness of the participatory process.

3) **Too busy.** This factor was only mentioned by two participants in one of the focus group sessions, Edmonton Informed #2. These participants noted that people were *"just too busy"* (EI#2) and that this was a *"big part of the problem"* (EI#2) of getting participation in consultations. The second

participant agreed *"that's what happens"* but perceived it as being *"a cop-out"* (EI#2). The day to day demands everyone faces must be appreciated and understood by decision makers. These pressures need to be included in the design which will encourage the participation of the public.

4) **Need to be personally affected.** This final factor may explain why some members of the public do not become engaged in discussions about issues. In total eight participants similarly noted *"you only really focus on the issues that are relevant and important to yourself"* (EI#3). Or put another way, *"most people pay attention to things that affect them. I find that individuals will focus most on issues that impact their lives"* (WI#2). Being conscious of this final factor may be the key to overcoming the three previous barriers presented. If the decision makers can identify those who are personally affected, they may be able to improve participation.

5.4.2: Sufficient Opportunities for Participation

5.4.2.1 Public Question #3 (P-3)

Having opportunities to participate is obviously important if decision makers wish to have public involvement. The researcher wanted to determine if participants felt they currently had sufficient opportunities to participate. Participants were asked: *Do you currently think you have sufficient opportunities to be involved in decision-making?* This

question was also asked of the stakeholders and those responses can be found under Question S-1. Having both viewpoints may aid in determining how to improve public engagement and or involvement.

The first focus group, Winnipeg Informed #1, was not asked this question because of time limitation and difficulty keeping this group on track during the discussion. The responses from the remaining eight groups were grouped into two categories - yes (positive) or no (negative).

Category #1 – Negative Responses

Within this group there were two categories of responses. The first category consisted of very simplistic and straightforward negative responses about there being sufficient opportunities to participate. These responses consisted of statements such as: *"I don't think there's any opportunity for us to be involved"* (WR#2) or *"I don't think there's really lots of ways to tell your opinion anyways"* (EI#3). In total 26 or 32% of the participants provided an overall negative response with little or no explanation as to why they held this attitude.

The second category is more complex and arose only in one of the randomly selected public focus group session in Winnipeg. While the participants acknowledged that opportunities existed, they believed these events did not promote active participation by the public. Instead, these occasions were venues for the decision maker to share *"what is*

actually going on" (WR#1) or share the *"decisions* [which] *have already been made"* (WR#1). Other participants described these occasions as *"opportunities after the fact"* (WR#1). To counter this, a participant suggested that they *"should be involved prior to them having these open houses"* (WR#1).

Category #2 – Positive Responses or are they?

The second group represents those participants who responded positively to having opportunities to participate. Yet upon closer examination, these responses revealed restrictions some limitations. The participants identified five restrictions:

1) **Process of participation is unclear.** Once again, this issue of no clear process or course of action occurred. An Edmonton participant described this difficulty as *"sometimes it's not easy to get at them"* (EI#2). A second participant noted opportunities are *"there, but you have to work too hard to get most things through"* (WI#2).

2) **Barriers.** During the discussion, a number of obstacles were revealed which might be inhibiting participation by members of the public. The participants described three such barriers in their comments:

    I. First, we need to be reminded *"there's a whole segment of society, who isn't involved because of the daily grind of their life, just trying to survive"*

(WI#2). If a person is too busy trying to survive, it is not likely they will consider participating in the public consultation processes which takes additional time out of their day.

II. Second, a participant pointed out to participate, you may *"have to submit a resume"* (WI#2). Not everyone has a prepared resume and the need to prove their educational level maybe *"a barrier for many people, who maybe don't have the skill to do that"* (WI#2). This likely result in the person not participating.

III. The final barrier refers to where and how many public consultation events are planned. One participant questioned: *"Are they going through every area of the city? Are they offering multiple nights?"* (WR#1) This comment highlights that attending a session may be difficult if it is not in a residents local community or at convenient times.

3) **Do not take advantage of opportunities.** The focus group participants also pointed out a failing of the public. Eleven participants identified that the public does not participate in opportunities which currently exist. A Winnipeg member participant described this by stating *"we* [the public] *often, don't do it"* (WR#2). A second participant expanded upon this idea by noting "*there are a lot of cases when they do hold forums* [but] *not that many people show up"* (ER#1). Another participant questioned if *"there* [was] *sufficient interest from the broader public*

to take action" (EI#3). This final comment is reminiscent of apathetic responses identified as a category in an earlier question.

4) **Unknown opportunities.** Here, the participants pointed out a failure of the decision maker to communicate effectively about what opportunities there may be to participate. Participants commented *"we're not informed"* (EI#1) or they had to *"seek them out"* (EI#2). Opportunities were also deemed to be *"stumbled upon"* (ER#2) and *"a lot of them are unnoticed"* (ER#1). So while decision makers may feel they have provided opportunities, these are not sufficient as the awareness level was high.

5) **No influence.** The participants commented that their opinions were not going to *"hold water"* (ER#1) or if the public has *"enough means to have a significant influence"* (EI#3). The participants determined that they had limited influence as *"we've been given surveys and nothing gets done after we fill it out"* (EI#3). As *"it doesn't seem like things change"* (EI#3); if the public does not see any outcome following their participation, further participation from their viewpoint seems to be useless.

5.4.2.2 Stakeholder Question #1 (S-1)

Stakeholders were asked if they believed the public had enough opportunities to participate in decision-making: *Do you think there are sufficient opportunities for the*

public to be involved in setting policy or regulations? This question was also asked in the public focus groups and the results are presented under Question P-3 in section 5.4.2.1.

A variety of responses were identified from the 14 of the 15 participants who were asked this question. Some stakeholders gave multiple reasons in their responses, which could be coded as either positive or negative. Therefore, it may appear to be that there are more responses than stakeholders.

The responses collected could be divided into three categories. Five stakeholders responded positively; they believed there were sufficient opportunities to participate. Four stakeholders indicated that there were insufficient opportunities and five participants indicated that they have "tried" to that ensure sufficient opportunities exist.

Category 1 - Positive or "Yes" Responses

Five of the stakeholders interviewed believed there were sufficient opportunities for the public to participate. Three of the five participants they perceived that there were sufficient opportunities because of activities they have observed within their own organizations. An industry participant noted their organization *"offered ample opportunity for the public to be involved"* (Winnipeg – Industry participant). And a regulatory stakeholder in Edmonton observed, *"people are going to it* [hearings, consultations] (Edmonton - Regulatory participant). A third participant felt that there

must be sufficient opportunities present since *"public input is almost a mandatory thing for us to do"* (Winnipeg – Regulatory participant).

The remaining two stakeholders while believing sufficient opportunities were provided recognized two limitations associated with these opportunities. These include one stakeholder who noted: *"for those people who are articulate and well educated"* (Edmonton – Health participant) opportunities certainly exist. The second limitation is a familiar concern about whether the public takes *"the opportunity to be involved or not"* (Edmonton – Health participant). Both of these limitations have been raised in public focus group responses to this same question.

Category 2 - Negative or "No" Responses

Seven responses from four stakeholders were coded as being negative. The seven responses were divided into four sub-categories. First, three stakeholders brought forward the difficulty in identifying and engaging the public directly. A health participant from Winnipeg stated: *"It's not easy to know how to engage them, but even then you have a hard time, deciding who the public is."* A second health participant from Winnipeg stated: *"I don't think we get enough input from the public. We get lots of input of newspaper stories* [when reporters] *have talked to Joe Smith on the street".* Similar views were also found in the responses from public focus group participants.

The second sub-category reflects the costs of conducting effective consultation. Due to the potential high cost of doing public consultation, two stakeholders questioned if sufficient opportunities existed. A health participant from Winnipeg summarized it most effectively by saying *"one always thinks of it being a road show"* or a *"bit of a community hall thing that you can do around the province"*. But such things are *"expensive"* which often results in this level of consultation not being conducted.

The remaining two sub-categories are two single responses from different stakeholders. In one sub-category, the stakeholder indicated that having access to opportunities may be *"harder* [with] *people who don't have the same resources"* (Edmonton – Health participant). This comment refers to access and the educational level of some segments of the population. The public focus group participants identified a similar concern in their responses.

The final sub-category was in direct response to the lack of opportunities for the public to be consulted about drinking water issues. An Edmonton based health participant commented, *"There aren't opportunities for the public to be involved in drinking water issues the way they are for air quality issues"*. This stakeholder is referring to a consensus based organization created by the Alberta provincial government which uses a multi-stakeholder approach to address air quality issues. This organization, known as the Clean Air Strategic Alliance (CASA), could be a possible model to consider when attempting engagement of the public on other public health issues such as drinking water.

Category 3 - We "try" Responses

Five stakeholders clearly indicated that they believed that they have tried to provide a sufficient number of opportunities. A Winnipeg Health participant stated: *"on the whole many organizations, and I hope ours, generally tries to provide adequate and appropriate opportunities for public participation".* An Edmonton regulatory: *"we advertise, and we made sure that the general public was aware there's something, there's a new change in the regulations".* Yet despite these efforts, there is a feeling that these stakeholders were not satisfied with the attempts to engage the public.

A reason for this discontent may be the realization that if a member of the public is not vested or personally affected by an issue, they are not likely to respond. A stakeholder who did reside in either of the community sites captured this best by noting: *"taking up the opportunity is largely not done".* Opportunities were not exploited due to *"lack of interest"* and a belief that some *"issues do not affect me".* The "me" in the previous quotation referring to the public. Similar sentiments were vocalized by an Edmonton regulatory participant who stated: *"if they're not directly impacted you know, they don't get too involved. They must have a vested interest."* These comments mirror ones from the public focus group sessions and highlight a factor that needs to be considered during public consultation.

5.4.3 Value of the Public's Opinion

5.4.3.1 Public Question #4 (P-4)

It was necessary to determine whether the focus group participants felt that decision makers value public opinion. To do this the focus groups were asked to respond to the following question: *Do you think the public's opinion is valued?* All of the participants responded negatively to this question.

While twenty-one of the participants responded with direct "no" responses, the majority of responses were negative but qualified in some way. The responses were coded into three categories based on the following questions designed by the researcher during the data analysis. Under each category, a variety of categories are then described.

(1) Why is the public's opinion not valued?

(2) What is needed for public opinion to have value?

(3) When is public opinion not valued?

It should be noted that while this question was asked of all focus groups, for the first informed group held in Winnipeg, there were no responses coded to this question. The participants ignored this question as the previous one still dominated the discussion and the question could not be re-raised again due to limitations on time.

Category #1 – Why is the Public's Opinion Not Valued?

This first category describes why the participants believed that their opinions were not valued. In total four reasons were identified:

1) **Collected public opinion is not utilized.** Participants were very clear in expressing that when decision makers do solicit the public's opinion it is not often used or heeded. A participant from Edmonton summarized this perception by stating *"I don't know what they do with the answer they get from us because I don't think they use them"* (EI#1). One participant described decision makers listening with a *"deaf ear"* (ER#1). As a result, the belief that their opinion *"doesn't mean anything"* (ER#1) since *"they won't apply it"* (WI#2) exists and becomes validated. This results in *"people hav*[ing] *reached the point that they don't want to be bothered even coming because nobody listens"* (EI#1). This perception could explain why public participation is low.

2) **Public relations exercise.** Some participants reflected that collecting the public's viewpoint was done *"just to make it look good"* (WR#2). Or even when asked, the public is supposed to say *"Oh well, they asked me and its ok"* (EI#1). Furthermore some participants labeled consultations as an exercise as the *"government decide*[d] *what they're going to do long before* [politician X gives] *it to the public"* (ER#1). An opinion collected under these circumstances is an attempt to fulfill the decision maker's responsibility to consult. Members of the

public perceive that this is the case therefore they question the value of their opinions.

3) **No influence.** Participants pointed out that there were limitations to the influence of the general public's opinion. As one participant described: *"it depends on the attitude of whose giving the opinion"* (EI#3). The level of influence is also dependent on two other factors (1) *"people that have the money behind them"* (ER#1) and (2) *"what political party you belong to"* (WI#2). Again, if the public perceives that their opinions have no influence the value of the whole process is called into question.

4) **Ineffective process.** Having a vague public participation process had been mentioned previously in the response to other questions. It arose again in the replies of the public participants to this question. Participants commented that they *"don't know how, wouldn't know* [how] *to go about voicing* [their] *opinion"* (ER#2) or where to *"make their opinions known"* (ER#2). As a result participants felt that the decision maker *"need*[ed] *to do more through the media and stuff like that"* (ER#1) or would *"like to see an ombudsman for things"* (ER #2) to make sure their opinion is heard. If the decision maker does not attempt to utilize these methods, then it calls into question the value of public opinion.

Category #2 – What is Needed for Public Opinion to have Value?

This second category consists of reasons for what is needed to make public opinion valued. There were four categories grouped into this category. Three were distributed throughout the focus groups with one category being identified at only one location and focus group type.

1) **Self educate.** This refers to members of the public needing to be better educated if they expect their opinion to matter. This was described by participants who stated the *"public should educate themselves"* (WR#1) and *"you have to you know, do your research"* (EI#3). Self educating was also identified as a responsibility of the public in section 5.4.1.2.

2) **Timing.** The second category reflects the importance of when the public's opinion is expressed: *"sometimes* [the] *timing has to be right"* and *"the issue has to be at the right time"* (WI#2). This may be *"during elections"* (WI#2) but more generally *"depending on the situation"* (EI#3).

3) **Marketable.** Two participants identified that the public's opinion only has value when it is saleable; that is it has economic value or a monetary worth. While there were a low number of participants who shared this viewpoint, their comments were very succinct and direct:

> *"I think that if there's money to be made the public's opinion is valued"* (EI#3)

> *"I think your opinion is valuable when there's a selling tag attached to it"* (WR#2)

4) **Who is listening?** This final category was found only in the Edmonton Informed sessions. The responses coded to this category indicated that the value of the public's opinion depends upon who is receiving this opinion. In other words, for public opinion to matter it depended upon which decision maker you are trying to communicate with. As one participant noted the public needs to *"hit the right person who is willing to listen"* (EI#3).

In the discussions, participants identified specific decision makers they have attempted to share their opinion with and the outcome of those interactions. While former Premier Ralph Klein *"ignored absolutely every one of them"* (EI#1) and Stephen Harper *"never followed up"* (EI#1), others did appear to be listening. Participants indicated former Prime Minister Jean Chrétien *"used to reply"* (EI#1) and Edmonton's *"current mayor values public opinion"* (EI#2). The public realizes who is listening and this encourages them to participate.

Category #3 – When is Public Opinion Not Valued?

During the discussions held with the focus groups, some participants spoke about times when public opinion cannot be the dominant consideration. This was not to say they felt public opinion did not matter, just it could not always be the driving force behind a decision. Four participants recognized that at times the decision maker simply has to make a decision. As the decision maker is in a position of power, a participant noted *"they have to set policy that is in the best interests of the majority of the people"* (WI#2). A second participant from a Winnipeg focus group agreed and added that *"those who are in power will listen to the public, but there's a certain constraint to that. For example finances and resources"* (WR#1). This category could be considered part of the first category of "when the public opinion is not valued". However, it was felt these responses were unique and needed to be highlighted separately.

5.4.3.2 Stakeholder Question #2 (S-2)

Stakeholders were also asked the following question about the value of public opinion: *In your experience, do you think the public's opinion was valued?* Thirteen of the stakeholders responded whereas responses of two participants were missing due to a recording error or not asked. Of the thirteen participants, ten indicated a positive or "yes" response. A variety of reasons were given as to why stakeholders believed that the public's opinion is valued. The remaining three provided responses which suggested that the public's opinion was not as valuable as it should be.

Category #1 - Yes or Positive Responses

Ten stakeholders provided a total of 15 responses which indicated that the public's opinion was valued. These 15 responses can be organized into four sub-categories.

1) **Public opinion is important**. The first sub-category is comprised of the ten stakeholders who agreed that the public's opinion was important. For example:

> *"Yes I think it has to be, I guess* [valuable] *to me,* [as] *it has to be taken into account"* (Edmonton – Health participant)
>
> *"I think we value the public's opinion very highly"* (Winnipeg - Industry participant)
>
> *"I think in this office it's valued"* (Winnipeg - Health participant)

The remaining sub-categories were expansions on the first and support the public's opinion having value. It is in these three sub-categories, the stakeholders reveal why they hold this viewpoint.

2) **Responsibility of employment.** Two stakeholders articulated that considering the public's opinion is a fundamental component of their job as such they must respect the public's opinion. This was because *"they are the people we serve"* and *"protect"* (Winnipeg – Health participant). The health participant went further to state *"it would be ludicrous wouldn't it, to think that the public's opinion is not valued."* The second participant agreed by saying that they *"have*

a great respect for the public and we're here to serve and protect the public" (Winnipeg - Industry participant).

3) **Influence decisions.** The public's opinion also has value since it could influence the work of the decision maker. A health participant from Edmonton noted: *"It's been an integral component of the work we've done. The feedback that we get from those folks is valued."* This view conflicts with the public participants perceptions reported earlier.

4) **More value when**. Stakeholders highlighted two circumstances when public opinion has the highest value. The first circumstance is when they express a *"factual based concern"* (National participant). Or in other words, public opinion matters most if the concern is based on scientific knowledge that indicates a hazard may exist. A second stakeholder agreed and pointed out that when *'there is an understanding quite often they can come up with some points that are very relevant"* (National participant). In these circumstances, the stakeholder appreciated where there was a level of comprehension of the issue at hand.

The second circumstance is when the public's opinion is properly channeled. This channeling could be via the *"media"* (Edmonton - Health Participant), a *"government agency"* (Edmonton - Industry participant) or catches the attention of a *"smart politician"* (Winnipeg - Health participant). If the public does channel their opinion through one of these routes, the stakeholders believed it

"will get notice because someone has to respond to it" (Edmonton - Health participant) and increased attention when it is *"vigorously expressed"* (Winnipeg – Industry participant).

Category #2 - Constraints on the Value of Public's Opinion

Three stakeholders recognized that at times there are limitations on what value the public's opinion may have. The first limitation was *"in some circles the public's opinion is very valued and in other circles I see that it's not"* (Edmonton – Health participant). It should be pointed out that this participant did not personally agree that public opinion has no value. But as it is known to occur, the researcher coded it as a limitation.

A regulatory participant from Winnipeg noted a second constraint on the worth or importance of the public's opinion:

> *"It's been my experience, and I think there have probably been times where we've gotten public input and maybe not given them as much credence as we should have* [or] *listened to it as well as we should have."*

As the stakeholder noted, even when collected deliberately the decision makers may not consider that opinion as much as they should. This coincides with a comment made by a third participant: *"public consultation is lots of times undertaken as a PR exercise"* (Edmonton - Health participant). This participant recognized the impact that the public's opinion had on his agency yet at the same time he questioned the intent behind getting the opinion. Similar comments were also found in the public responses to this question.

5.5 Research Question #2: Potential Role of the Public in Risk Management

5.5.1 Public's View of Science

5.5.1.1 Public Question #5 (P-5)

To understand what role the public should have in emerging and or uncertain scientific knowledge, we needed to understand what value the public place's on science. Determining this value involved asking the following questions: *What role do you think science should play in decision-making?* Responses were gathered from the nine of the focus groups.

The responses to this question are categorized into three major categories. The first category speaks to what science should do. For the second category, participants identified what science needs to be. While the first two categories are somewhat positive in nature, the third category recognizes some of the limitations of science.

Category #1 – Scientific Contributions to Decision-Making

What science should do or contribute to decision-making is the premise of this category. Overall, a number of participants agreed that science has a role to play. Ten participants commented in this manner and examples follow:

> *"I think it has an important role"* (WI#1)

"I think that science plays a big role in maybe making the decisions" (WR#2)

"I think that science is important" (EI#2)

"I think a lot of it is the bottom line" (ER#1)

Some participants provided further explanation as to what role scientific evidence should play. These explanations can be divided into two sub-categories which were found throughout the focus groups.

1) **Provide information.** Participants indicated that science was there *"to learn something about the topic"* (WI#1) through *"experimentation and the research"* (WR#1). Having scientific evidence provided *"great backing"* (EI#2) to the decision-making process. Ironically, as one participant noted *"you use science to discover a problem or create a problem"* (EI#3).

2) **Making sure a decision is safe.** Some participants specified the type of information they expected science to provide. The issue of safety was raised by three participants: *"science should have a great role; to make sure whatever is done is safe"* (WR#2). While the participants did not specify what type of safety, i.e., physical, chemical or biological, the important message was *"if something's not safe for the public, if science can prove that it's not safe, then it should not be considered"* (EI#1).

Category #2 – What Science Should Be or Not Be

Responses focused on what is needed to make scientific knowledge more valuable or credible. The responses from the participants are divided into two sub-categories. The first sub-category describes comments from the participants who felt there was a lack of knowledge about what makes good science. This issue was only raised in the Winnipeg focus groups sessions and did not appear to be directed towards the decision maker. Instead in the examples provided below, this lack of understanding is directed towards everyone.

> *"Like the whole phrase evidence based, I don't think is well understood by a lot of people. Like what is evidence and* [how do] *you know what is it based on?"* (WI#2)
>
> *"I think because there are a whole lot of people out there who don't have the greatest scientific knowledge"* (WR#1)

The second sub-category refers to the need for science knowledge to be credible. As one participant pointed out *"when you do research there's different levels of research, some are much more credible than others"* (WI#2). Other participants went further and specified three criteria they felt aided the credibility of science:

1) **Source of the research**. Participants noted that *"we have to* [be] *very careful about some studies that are sponsored by the companies"* (WI#2) particularly when companies give *"a lot of funding to studies and the outcome of those studies could be influenced"* (WI#2). Or put another way, it *"depends on whose actually*

[carrying] *it out"* (WR#2). Knowing the source of scientific knowledge would aid these participants in determining its credibility.

2) **Reproducible**. The participants were quick to point out that in good science *"commonalities are very important"* (WI#2). The participants indicated they wanted to see *"similar results from many laboratories* [and] *actually in agreement"* (WI#2). Reproducibility as noted by an Edmonton participant as a *"process of science"* (EI#1). These participants have connected the credibility of science to the reproducibility of results and want to see it demonstrated that this criterion has been met when scientific knowledge is utilized.

3) **Publicly funded.** This criterion arose from one focus group session held in Winnipeg. Here the participants felt that *"research dollars have to come from another source, like a public source"* (WI#1). This was important because *"our public money has to go into research so we can trust what's happening there"* (WI#1). One participant felt that the *"army should have a garage sale for a tank and the money spent on military should go to basically support scientific ventures that are in the public interest"* (WI#1). This criterion is closely associated with knowing the source of research and funding. Indirectly by providing more public dollars for research, the results would be viewed as more credible.

Category #3 – Limitations of Science

While participants recognized the importance of scientific inquiry, they also identified the constraints that may be present and the knowledge it generates. To organize the responses related to this category, four sub-categories were formed. While there are only a few responses coded each sub-category: taken as a whole they describe the drawbacks members of the public have observed about scientific knowledge. It may be important to recognize these drawbacks when trying to design strategies for involving the public in this type of decision-making.

1) **Not the only consideration.** Participants noted that there were other factors, which may need to be considered when making decisions. These included looking at *"the values"* (WI#2) of society and *"ethics"* (WI#2). One participant also noted that you have to realize that *"the purity of science is of course modified by what you see and feel around you. You take the facts as you hear them or see them"* (EI#2). In other words, the participant noted that the public's perception of science, like ethics and values, needs to be taken into consideration when making decisions.

2) **Changes over time.** Four participants noted that *"evidence changes"* (WI#2). This was explained by one participant as *"science kind of comes up with the best knowledge or understanding"* (WR#1) to a certain stage. Science is "*always evolving, it's always changing, which is good"* (WR#1). This is seen as a

limitation as decision makers need to be aware that their decisions while made using the best scientific understanding of the day may need to be reassessed.

3) **Can make mistakes.** Three participants noted that science or scientists themselves are not perfect. In essence, *"science makes mistakes, so it would be wrong to blindly follow whatever scientists told you"* (EI#2). One source of error was described by a participant as *"find*[ing] *correlations between A and B that may not mean much"* (WI#2). If credibility and reproducibility can be assured the likelihood of science having made a mistake is reduced from the public's perspective.

4) **Can be manipulated.** In previous responses, participants indicated that science acts as both a factor to consider and a tool for the decision maker. For those reasons, scientific evidence needs to be used appropriately. This does not always occur and leads to the fourth limitation. Participants noted that "*science can actually be sort of used like statistics which could really easily be skewed either way"* (WR#1). Or as a second participant summarized, it depends upon *"what they take out of the report"* (WR#1). That science may be manipulated needs to be a concern of all the parties involved and has close ties to the issues about credibility noted earlier.

5.5.2 Effects of Uncertainty on the Role of the Public

5.5.2.1 Public Question #6 (P-6)

In the previous question (P-5), the researcher asked members of the public what they felt the role and value of science should be. Here, the researcher asked: *When scientific studies come to different conclusions, do you think there is a different role for the public to play?*

In this question, the responses could be split into three categories. Two of these categories are common to those described in questions P-1 and P-2. Those categories consisted of (1) what the public viewed as their role as and (2) what they viewed as the role of decision makers. Under each category, a variety of roles or duties were identified and tasked to each player in decision-making. The third and final category was a reaction, members in one focus group session described members of the public as being overwhelmed in these circumstances.

Category #1 – Public's role and scientific uncertainty

This category is what the participant's viewed as their role as a member of the public when faced with scientific uncertainty. There were five sub-categories coded to this category. Four of these sub-categories describe actual actions the public should be

undertaking whereas the fifth refers to a lack of understanding on what their role should be.

1) **Make own decisions.** The first sub-category had the highest number of responses. Twelve (12) participants indicated that in view of conflicting scientific knowledge they felt their role was to make their own decision about the issue. Table 11 provides a selection of responses supporting this observation.

Table 11: Selected of responses for sub-category #1

Group	Quotation
WI#1	*I think if one study says this and one study says that, then I think as an individual you need to almost form your own opinion*
WI#1	*The public has a responsibility to ask these questions and then make decisions for themselves*
WR#1	*If you're given two different answers, I think for yourself, for your own well being, I would say just look at both of them and you're going to have to just trust your own judgment and take what you can from each thing because nobody's going to give you, nobody has the right answer.*
ER#1	*You have to do what you think is best. And that's going to suit you best. I mean you choose, you chose the way, you choose the what you want to do*

2) **Self-educate.** Several participants indicated that they felt it was their responsibility to investigate the issue further. One participant from an Edmonton Random focus group session stated: "*You could actually go and do your own research on it see where they got their results from and spend a little time doing your own research*" (ER#1). Similar comments came from a Winnipeg focus group session: "*For my own end use I would ask as many questions as I could, try and get as much validated or do as much research from accredited sources*"

(WI#1). Despite the agreement that this is what the public should do, it was clearly pointed out by one participant that this does not occur: *"I think my job is, to look more into it, and look at the studies but I wouldn't do that. Like that should be what I should do"* (EI#1).

3) **Get involved.** The public needs to get involved. Participants stated that the public has *"to get involved in some aspect or some way"* (WI#2). Some participants hoped that in these circumstances that a *"bigger selection of the population would voice their opinion"* (WR#2). In the end however it was noted *"all we can do is complain about, voice our opinions with the newspaper,* [and] *write to our politicians"* (EI#3).

4) **Support and encourage further research.** Participants felt the public should *"encourage them to do more research, so they get a better focus on the problem"* (EI#3). This research *"should also look for alternative studies"* (WI#1) that can offer answers when there are conflicting results.

5) **Not sure what role should be.** In contrast to the three previous categories, four participants indicated that clarifying the discrepancies was not a duty or task that the public should have. Some participants did not know what their role was or should be. Negative perspectives included *"we don't play a role anyway"* (WR#2). But some participants made it clear that they did not know if they were qualified to play a role in the first place. A participant from Winnipeg stated:

> *"I'm sure there are people here that are qualified. I myself would never be qualified to, to give an opinion that you know, to make a decision that 2 scientists couldn't make"* (WR#2).

A representative from an Edmonton focus groups echoed similar sentiments: *"they are more qualified than me, I'm going to assume"* (ER#1). It appears that some participants felt that this was clearly beyond their areas(s) of expertise.

Category #2 – Decision Maker's Role and Scientific Uncertainty

It was clear that participants believe that decision makers had a role to fulfill. However, many participants were not willing to comment about what decision makers should be doing or define what their role should be. Five were identified:

1) **Define the issues.** Only two responses originated from the Edmonton randomly selected public wanted it noted that they *"don't want to be swamped with 350 different things you've got to sign off on"* (ER#1). Instead, a balance needs to be found between the *"many minor ones* [roles or duties]*"* (ER#1) that exist and larger ones which may need public involvement. Politicians or decision makers have to determine this balance as *"that's why we elect them"* (ER#1).

2) **Educate.** In section 5.4.1.1 participants had identified that the role of decision makers was to provide balanced information in a transparent manner. An educational role was slightly different in that *"the people who are doing the study or whoever's initiating* [the discussion] *should also carry a responsibility to*

educate the general public on why one study conflicts with another" (WI#2), especially *"if the public is going to be actively involved in making a decision"* (WI#2).

Participant's reasoning included *"if it's a major health risk or something that could pose a major health risk, then I think the public needs to be informed"* (ER#1). Therefore under circumstances of uncertainty, the decision maker's role expands from one of just providing information to that of educator.

3) **Review and identify bias**. When reviewing the scientific knowledge as the basis for policy development the decision maker should also judge the quality of the scientific information. They should review the *"methodology of the study and the data collected out of that study"* (WI#1). The decision maker should also evaluate if there was *"objectivity in the analysis"* (EI#3). Finally, the decision maker needs to be aware that *"the actual value of the scientists has depreciated because they've been bought out"* (WI#1). Again the issue of knowing the source of the research and where bias may exist is raised. Being aware of what biases exist will facilitate the public consultation process.

4) **Act safely.** When the scientific knowledge the decision makers are expected to utilize the available evidence in a manner that *"will not cause any harm, the safest possible approach"* (WI#1). Some participants wanted *"a policy or sort of a guideline"* which would ensure that decision makers would *"err on the side of*

caution" (WR#1). This role of safety was not identified previously, although safety may be part of making sure the decision maker acts responsibly.

5) **Follow the rules of majority (democracy).** The final sub-category was found only in the randomly selected focus group held in Winnipeg. Here the participants expected decision makers to abide by what the majority wishes. A participant explained it as follows:

> *"If there* [are] *two sides of an opinion and they are both valid opinions and we can't make a decision, then* [the] *majority, people's majority should be taken into a big consideration in which way we go"* (WR#1).

This may mean the decision maker may have to *"get the opinion of many people"* (WR#2) but it could provide overall direction to what action should be taken. Also, if the majority agrees, as one participant noted, *"maybe they're right"* (WR#2).

Category #3 - Overwhelmed

In an Edmonton informed focus group, two participants spoke of their frustration and described a feeling of being overwhelmed when trying to respond to this question. One participant expressed their irritation by commenting that they would not pay "*anymore attention to this nonsense"* (EI#1). This nonsense refers to this idea of conflicting science and the upheaval it can have in the decision-making process. In particular, this participant felt *"totally confused"* and they started to question "*the validity of these so called scientific results"* (EI#1)

A second participant from this same group offered the following statement which was a general reflection of the feelings of the whole group: "*we could be overwhelmed by a lot of this stuff*" (EI#1). Despite further prompting, this group did not provide any more responses to the question.

5.5.2.2 Public Question #7 (P-7)

The remaining three questions were asked after the case study topic of chlorinated disinfection by-products (CDBPs) was introduced to the focus group participants. As noted previously, the researcher provided a summary of the negative and positive effect of chlorination. As such, the case study provided context for the following question: *What role do you think the public should play in a case like this when science is uncertain but policy decisions still need to be made?*

Due to the similarity between questions P-6 and P-7, the responses were coded at separate times to minimize any potential bias. Despite this, the categories that emerged from the analysis of these two questions were comparable. One category was once again what the participants viewed as their roles or what actions they should take. The second category was what the role of the decision maker should be. While these two categories were similar, the separate sub-categories associated with them did differ. Further comparison of these two questions (P-6 and P-7) along with a similar question asked of the stakeholders follows.

Category #1 – Public's Role and Scientific Uncertainty

The first category speaks to the public's view of their roles. The participants identified three actions that should be undertaken when the scientific knowledge is contradictory:

1) **Involvement and provide new ideas**. This task had the highest number of responses. The participants noted they wanted "*to be involved in questioning*" (WI#1) especially when the scientific knowledge is uncertain. Participants viewed this as a *"major role"* (WR#2) under these circumstances. Participants understood that getting involvement from the public is *"the most difficult part"* (EI#2) but stressed that the public may be able to *"introduce something, that the scientists or whoever hasn't heard of"* (WR#2). This sub-category of involvement was also identified in question P-6.

2) **Request further research.** In question P-6, participants expressed that the public should encourage further research. Participants believed that there was a "*need to look at* [the issue] *further"* (ER#2). A second participant indicated that he *"would want further research"* (ER#2) before making a decision. This is an interesting change in the viewpoint of the need for research and will be explored further in the discussion section.

3) **Self educate.** One participant indicated that people need to *"get as much information as you can, research it, if you don't understand something, get*

somebody to explain it to you" (EI#1). In the previous question (P-6) a stronger response was seen to this sub-category.

Category #2 – Decision Maker's Role and Scientific Uncertainty

The focus group comments could be grouped into two sub-categories. The first sub-category involved decision makers providing an opportunity for the public to give their opinions. It was felt that these opportunities are *"not given"* (ER#1). Specifically, in regards to the case study, a participant indicated that we *"don't feel we're given any information on what system our water goes through"* (ER#1). The participants indicated these opportunities could consist of *"town hall type meetings"* (WR#2) or *"media"* (ER#1). Regardless, *"everyone should be strongly informed and have the option to say something"* (ER#1). This role for decision makers did not occur in response to question P-6.

The second sub-category outlined the most important role decision makers have; the responsibility to educate and explain the issue to the public. This role was mentioned in the previous question (P-6) but in the context of the case study, a stronger response was evident. Decision makers should provide a *"public education process"* (ER#1) and participants wanted to be given *"a couple of options"* (ER#2). As one participant stated *"I don't want to have the options without information on all sides, on all the choices. And the risk on all sides, the known risks and factors"* (ER#2). Therefore it appears that

decision makers need to be more direct and provide a well balanced approach in uncertain circumstances.

5.5.2.3 Stakeholder Question #3 (S-3)

Here the stakeholders were asked directly about the role of the public in situations where scientific knowledge is uncertain. The wording of the question was as follows: *Does the role of the public change when the science is uncertain?*

Of the fifteen stakeholders involved in this research, only six responded to this question. The remaining nine stakeholders were not asked this question, as it was not initially one of the predetermined questions of the researcher. While seemingly obvious it was hoped that stakeholders would have commented on what the public's role should be in their discussions with the researcher however this was not the case hence the addition of this question.

The responses provided by the stakeholders can be grouped into three categories. The first two categories were based on the role of the public and whether that changed when the scientific knowledge is uncertain. The third category was an indirect response, which speaks to how the role or duties of decision makers changes in regards to engaging the public.

Category #1 – No Change But Difficult to Reach the Public

In the first category, three stakeholders believed that the role of the public does not change. A Winnipeg Health participant stated:

> *"I think it's still reasonable to get input from the public and for them to have access to whatever knowledge and hypothesis we have. Not sure that the input should change just because science is uncertain."*

While agreeing with the concept of the public's role not changing, two of the stakeholders still expressed concern about gaining the public's involvement: "*the public health risk has to be seen to have a personal risk or a risk to somebody directly rather than generic*" (National participant). This stakeholder was referring to *"personal accountability"* and the public not participating unless an issue directly affected them. Similar sediments were expressed in response to other questions by members of both participant groups.

A second stakeholder had concerns about getting *"good representation"* or how to *"make sure you get the right people or enough spread of people that you're covering all the aspects"* (Edmonton – Industry participant). Unless you put the decision to a *"referendum"*, this same stakeholder felt there would only be representation from *"people who had some deep interest in the topic"*. Not only is this second concern closely linked to the first, it also appears to imply that issues brought to the public may need to be applicable to a broad range of people.

In summary, while the stakeholders do not believe there was a change in the public's role, they were not blinded by issues, which may hinder the public fulfilling its role. It is also interesting to note that the stakeholders located outside of the community sites, those labeled as National, lobbied indirectly for targeting people who may be affected, yet the Edmonton participant had concerns about only hearing from these people. These responses may aid in answering the final research question, which referred to how to effectively communicate with the public.

Category #2 – Surprise, the Decision Maker's Role Changes

Three stakeholders indicated that when the scientific knowledge is ambiguous and while this impacts the public's role, it is decision maker's role which changes more significantly. The increase in responsibility was due to the stakeholders' belief that engaging the public becomes more critical under these circumstances. An Edmonton Health participant summarized this best by stating when *"there's more uncertainty, then it's more important*" to connect with the public; *"if it's uncertain then you really have to work with the public"*.

The Edmonton Health participant spoke to the need to promote better understanding and to share with the public *"the degree of uncertainty"*. It is important for the public to have an opportunity *"to make* [their] *choice"*. As decision makers they can tell the public *"about this risk"* but the public is *"going to have to make* [their] *own decisions"* (Edmonton – Health participant).

The National participant offered a different reason: *"there's not enough science; the public tends to react even more furiously or feverishly"*. As a decision maker, this stakeholder suggested that good risk communication must be undertaken to ensure that the public's concerns about an issue are effectively addressed. Decision makers must be prepared to deal with the outrage in circumstances when members of the public contend that the communication has been appropriate or adequate.

In the case of the last stakeholder, the reason that the decision maker's role increases is due to his belief that under circumstances of scientific uncertainty, it then becomes a *"purely scientific question"* (Edmonton – Health participant). Decision makers must consider *"the greatest good for the greatest number of people"* (Edmonton – Health participant). This participant further points out that when a question *"can't be specifically answered by science there are other things that are brought to bear"* such as public health which does *"the best it can for the most number of people, most of the time"*. For this stakeholder, the role of the public diminished significantly and there was no role for the public to play under these circumstances.

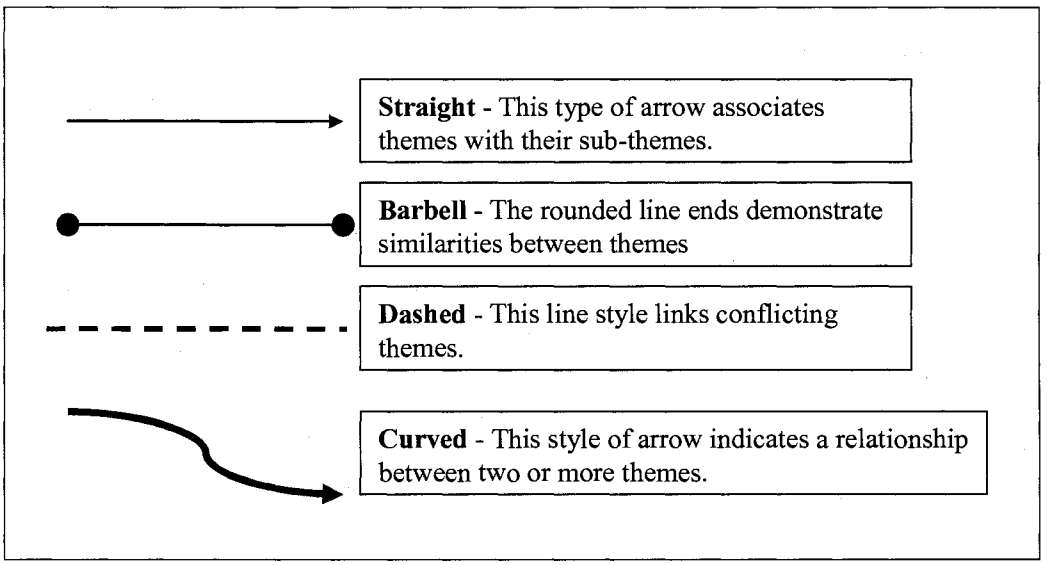
Summary

For reference purposes, Appendix I contains a summary of the categories by question for both participant groups.

6.0 Discussion

This chapter consists of two sections based on the two questions underlying this research. Assisting in answering these questions are the visual representations of the synthesis which will be used to show the relationships, disconnection and gaps. To distinguish between types of relationships, different styles of connecting lines and arrows are used to show the associations between categories. The legend in Figure 14 provides a brief explanation of each type of connecting lines. These diagrams offer a starting point for the discussion that follows.

Figure 14: Legend for discussion figures



6.1 Research Question #1

This first section of the discussion is aimed at trying to answer the first research question: *What role does the public currently play in decision-making?* Answers from four public focus groups (Questions P-1 to P-4) and stakeholders (Questions S-1 and S-2) identified the role and responsibilities the public currently plays in decision-making. Establishment of the baseline is essential to determine whether there is a difference between the public's current position and at times of scientific uncertainty, the primary focus of this research. Understanding and evaluating whether a difference exists will aid in answering the second research question.

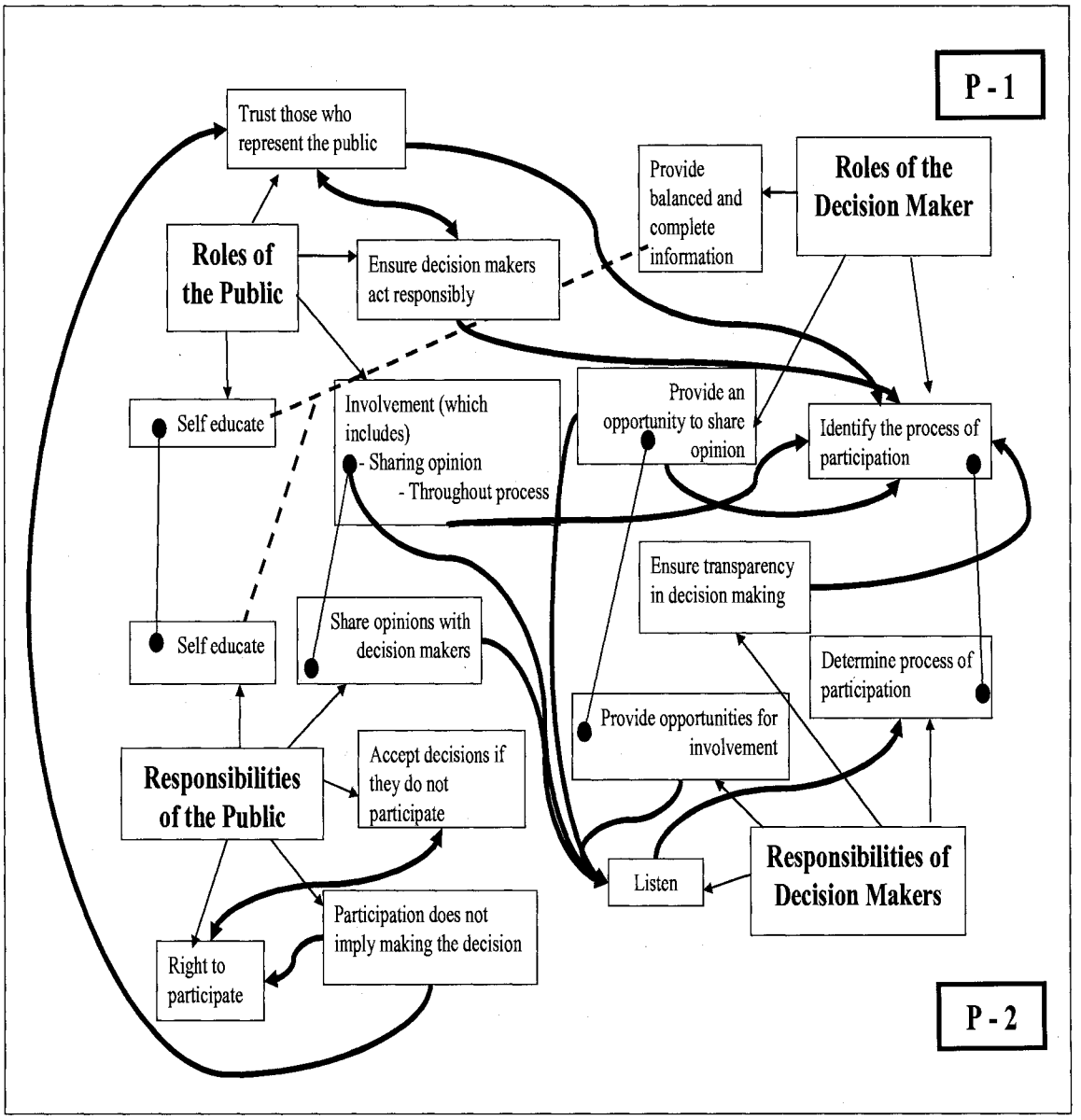
6.1.1 Roles and Responsibilities

To establish this baseline, it is first necessary to see what roles and responsibilities emerged from the public participants in their responses to questions P-1 and P-2. Again, it is important to note the differentiation between roles and responsibilities, where roles are defined as active tasks and responsibilities are defined as an individual's obligation to fulfilling assigned duties. The results are concentrated into two categories. The first category is comprised of direct responses identifying roles and responsibilities for the public as asked, whereas the second category outlines roles and responsibilities for decision makers. Figure 15 on the following page presents these first two categories. Each category is bolded and its associated sub-categories are connected by straight arrows. Responses from question P-1 are on the top of the figure, with responses from

question P-2 below. The public's or decision makers' roles or responsibilities are in each corner.

As signified by the barbell style lines, some roles and responsibilities overlap. The public focus group participants repeated the categories of self education and sharing their opinion with decision makers as both roles and responsibilities. For decision makers, the focus group participants identified determining the process of participation and providing an opportunity for the public to share their opinion as both a role and responsibility.

Figure 15: Roles and responsibilities for the public and decision makers (P-1& P-2)



There were no shared roles or responsibilities identified for the public and decision makers - instead there were clear distinctions between the duties of these groups. This was surprising as it was expected that the role and/or responsibility of educating the public would be common to both. Instead the focus group participants assigned decision

makers the role of providing balanced and complete information. Providing information is not analogous to educating, which implies developing or building capacity in regards to an issue. Instead, the decision maker's role is one of informing, which is one component of the education process. With the absence of this role and responsibility, an important element appears to be missing from the activities that have been traditionally expected of decision makers.

Figure 15 also shows where there are connections between the various categories and sub-categories. Four interconnections were identified and are represented by the curved lines in the figure. The first connection revolves around the decision maker's responsibility to listen, which was connected to four other sub-categories. These connections included sharing their opinion with decision makers but also having opportunities to have their opinion heard. However, the public cannot be heard if decision makers do not identify the process of participation. Also, the value of the opportunities is dependent upon distinguishing the process and the approach needed to effectively consult with the public.

Determining and identifying the process of participation for the public would also allow both the public and decision makers to fulfill several other roles and responsibilities pointed out by the focus group participants. These include:

- having a clear process which defines the public's role in decision-making;
- ensuring opportunities are available for the public to express their opinion;
- allowing the public to determine if decision makers are acting responsibly; and

- improving transparency in the decision-making process

By defining the routes for public participation, there could be a cascade effect which may improve relationships between decision makers and the public. In particular, as noted by Briggs and Stern (2007), defining the roles of all groups involved in consultation assists in determining the expectations of those engaged in public consultation. Additionally, the level of trust the public has in decision makers may improve (National Research Council, 2008; Zussman, 1997).

The sub-category of trusting those who make decisions on behalf of the public has other connections within Figure 15. Trusting our elected representatives also interacts with the public's role of ensuring that decision makers act responsibly. This highlights a duality in their role, as they want to have confidence in their decision makers (Zussman, 1997) but also act as a check and balance which can be exercised at election time. Finally, trust also connects to an aspect of responsibility to participate as noted by the focus group participants. The focus group participants noted their participation did not imply they, the public, had to make the decision. Instead, they just want to have input and the opportunity to be involved and consulted. As noted by Abelson et al (1995), this infers that there is a wide variation in the degree and type of control citizens would like to have about decision-making. In fact, it may be a false assumption of decision makers that communities truly wish to have the final decision on all issues.

The final connection occurs between three responsibilities assigned to the public by the focus group participants. Participants from the Edmonton random sessions shared they

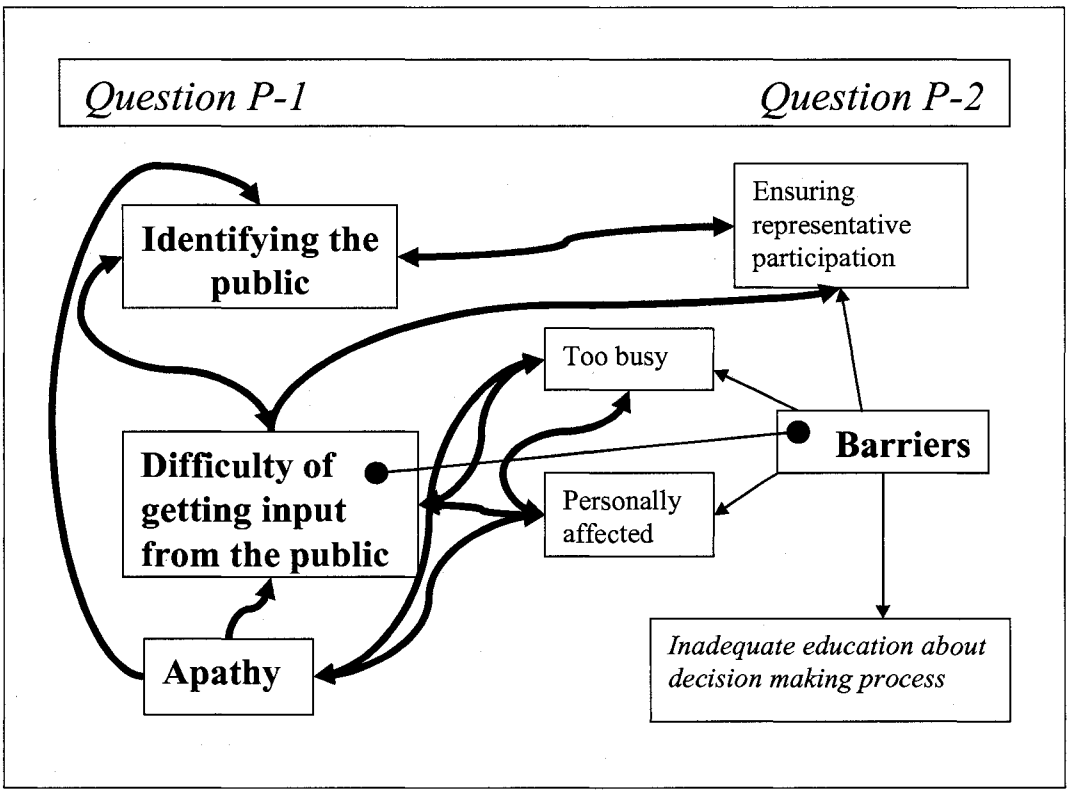
had not only the responsibility to participate but the right to participate. However, while participants sought this right, they also clarified an endpoint to the public's responsibility. In a related sub-category, participants were clear to note their participation does not imply making the decision. So while wanting an active voice, these participants did not want to be held responsible for the decision that was made. This was also seen in Abelson et al (1995) where health councils were reluctant to take on an enhanced role in decision-making. The reason they were not willing to accept the responsibility was unclear and not articulated in the focus group sessions. However, an indirect inference could be that at some level the public must trust decision makers to make the correct judgments about issues. The willingness of the public to trust decision makers was mentioned previously; however it has been reinforced here by the connection between these sub-categories.

The same participants who noted they had a right to participate were also very vocal about a second responsibility. They observed that if the public failed to participate in the decision-making process when solicited, they should not complain about the outcomes of a decision. As such, the public takes on a responsibility of accepting decisions if they do not participate. This is a consequence that the general public needs to consider when they choose not to participate.

Barriers and Limitations to Fulfilling Roles and Responsibilities

When outlining their roles and responsibilities, participants also identified and described barriers to their participation. Figure 16 diagrams the overlapping barriers between the questions.

Figure 16: Barriers to participation



With the exception of one barrier, inadequate education about the decision-making process (highlighted in italics in Figure 16), the categories identified under each question are intertwined, as indicated by the series of feedback loops. Figure 16 shows how getting public input is hampered by public apathy about the participation process and a

difficulty in identifying the general public. Even when the public is engaged in a decision-making processes, some participants expressed concern about unbalanced representation. This issue was also raised by Eyles (1993). Countering this apathy may be done by determining those who are personally affected by an issue or who have a personal reason to be involved. People are often apathetic or will not take the time to actively participate given other issues which may be more important in their lives. Eyles (1993) outlined various factors which facilitate citizen involvement, including an awareness of issues within their community. As such, these findings support decision makers selectively identifying individuals by their level of an interest in an issue.

While the barrier of an inadequate educational process does not have any connections in Figure 16, it can be linked to the roles and responsibilities of decision makers which were discussed in the previous section. An offshoot of defining the participation process would be to ensure the public is aware of how and when they play a role in this process. This has been noted by Kriebel and Tickner (2001) and Briggs and Stern (2007) as a way to increase public participation, especially when scientific uncertainty exists.

6.1.2 Sufficient Opportunities

Both the stakeholders and the focus group participants were asked to describe what they felt was the current level of public participation opportunities. The issue of opportunities was already raised in discussions about roles and responsibilities. Therefore by directly

asking each participant group about opportunities, additional understanding was gained as to the public's current role in decision-making.

A variety of categories emerged from each of the participant groups. Figure 17 demonstrates the similarities, differences and gaps found in the responses. The public responses are vertically displayed on the left and stakeholder responses to the right.

Figure 17: Current levels of opportunities

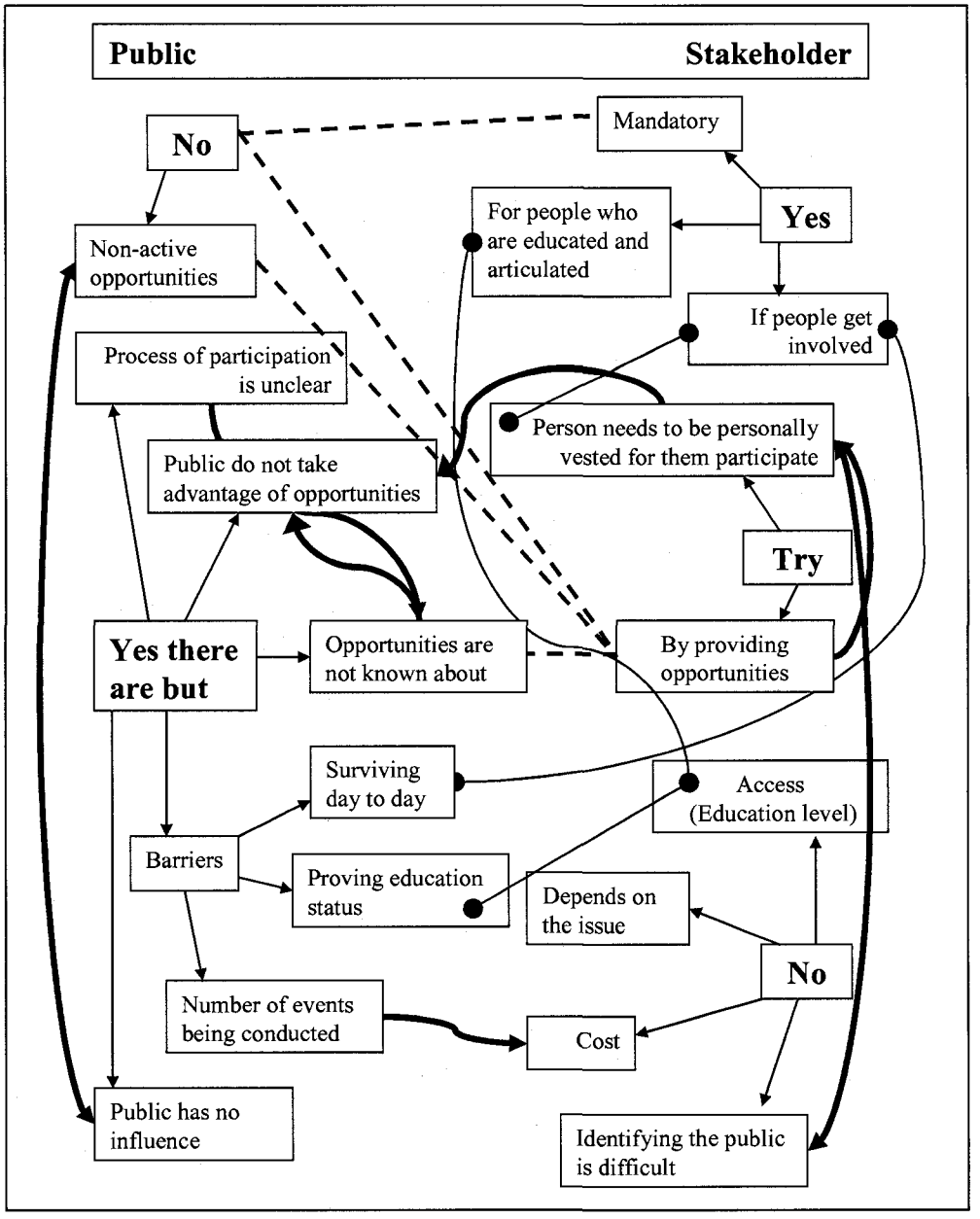


Figure 17 shows the assortment of opinions between the two groups about the current level of opportunities. The majority of the focus group participants stated there were insufficient opportunities. In support of this argument, they indicated opportunities were information sessions about decisions already made and not 'real' opportunities for the

public to aid in making the decision. Opportunities such as these are considered non-participatory or token occasions (Arnstein, 1969) and when combined with an unclear process it is unlikely the public will consider these decision-making opportunities valuable.

Stakeholders countered this view by indicating there are opportunities which they promote, advertise and are attended. In addition, for many of these stakeholders ensuring these opportunities occur is integral to the position they hold as well as being required by legislation or policy of their agency. From the conversations held with the stakeholders, however, it was felt that many of the public sessions offered would be categorized by Arnstein's ladder as non-participatory or even tokenism, as at best they can be considered "information sessions". None of the stakeholders provided examples of public participation opportunities which would be considered citizen power as described by Arnstein (1969) or Eyles (1993); this identifies a gap in the stakeholder's knowledge of what constitutes public participation. Briggs and Stern (2007) recognized this lack of knowledge was common to decision makers and advised that prior to commencing public participation activities there be an understanding developed as to what participatory methods should be used to fulfill their needs as well as those of the public.

Each participant group agreed access to these opportunities is easier achieved by those who are better educated. As was found by Pellizzoni (2003a), the participants in this research noted it is easier for some members of the public to recognize opportunities. They were also more likely to have the financial means (including transportation) and

time available to attend or contribute, and would be less likely to feel intimidated when asked to submit an application or resume prior to be involved in decision-making or consultation.

Both participant groups recognized that the public need to be personally invested or interested for them to take part in participatory sessions. They also noted that those who are personally vested in some manner will seek out opportunities to participate. A report produced by the National Research Council (2008) suggests that agencies considering public participation should define 'who' should be a part of the participatory process at the beginning of their consultation. These findings may add additional direction or definition as to which members of the public decision makers should be targeting in consultation processes.

Some stakeholders clearly indicated that they felt there were not enough opportunities for participation. In part, this was due to a difficulty in identifying the 'right' public and getting them interested enough to participate, a view also shared by Eyles (1993). But the cost of conducting consultation was also a barrier raised by stakeholders. Offering opportunities such as town hall meetings, using surveys or holding focus groups can be expensive and decision makers must recognize that there must be a commitment made which will ensure adequate funding and staff for the duration of the process (National Research Council, 2008). The cost of public consultation is also driven higher when numerous events or means are used to gather public input. However, focus group participants were insistent that having a variety of dates, times and avenues to participate

would allow for more people to contribute. Briggs and Stern (2007) supported this by advising decision makers to have both formal and information channels of risk communication.

Despite the similarities in responses from both participant groups, the impression remains that the level of existing opportunities is not sufficient. The public reflected that these limited and often inaccessible opportunities did not permit people to be in a position of influence within a decision-making process. This issue was also seen in work done by Aronson (1993) who investigated the patients in long term care attempting to have their health care needs addressed. In addition, there are too many barriers currently in place to make the current consultation process effective. The responses from stakeholders showed that they are not blind to the difficulties the public faces when they attempt to access opportunities and there is support from these stakeholder participants to address those barriers.

6.1.3 Value of the Public's Opinion

As with the level of opportunities the current value of public opinion also needs to be understood in relation to decision-making. Both participant groups were asked about the value of public opinion. Figure 18 provides a visual representation of their responses with the public comments to the left, and stakeholder comments to the right.

Figure 18: Value of public opinion compared by participant group

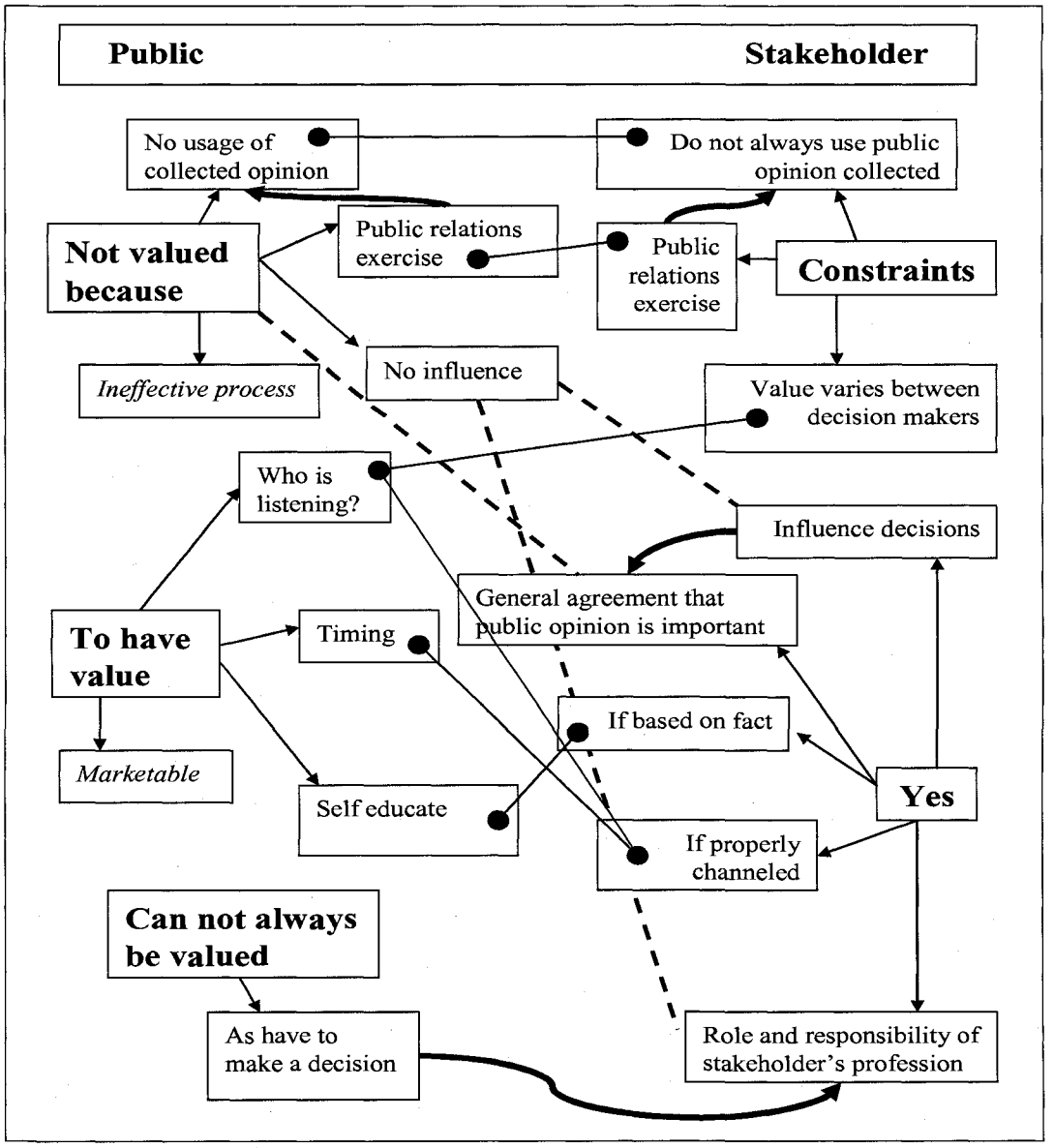


Figure 18 shows a diverse and complex range of responses to this posed question. There was general agreement amongst stakeholders that the public's opinion is valued because it is a stakeholder responsibility to ensure it matters and they believe it influences the outcome of the decision-making process. However, public participants were clear that

they did not feel their opinion was valued and some went further to state that their opinion had no influence at all. This discrepancy is shown in Figure 18 by the dashed line.

The public focus group participants also shared other reasons as to why they felt their opinions had no value. As previously discussed, the participatory process is considered ineffective. Two additional reasons, which overlapped with those raised by stakeholders, were raised. Using balled end lines to indicate similarity, the public's reasons for their opinion having no value are connected to those issues described as constraints by the stakeholder. Each group recognized that the collection of public opinion is at times a public relation (PR) exercise. The term 'PR exercise' refers to a negative activity of surveying or engaging of the public in a manner which appears to be participatory but does not actively solicit or consider public opinion. Exercises such as these would most likely belong in the area of tokenism on Arnstein's ladder (see Figure 2), meaning that citizens may be heard but not understood (Arnstein, 1969; Eyles, 1993).

When the collection of public opinion is done as a perfunctory exercise, it is often meaningless. The public participants noted that their opinions were not used because in their opinion they had no value to decision makers. This was supported by the stakeholders, who also identified this same issue. It is easy to understand that if the public opinion's are not used or considered in a decision, then an obvious conclusion is that it does not matter.

While the majority of the focus group participants felt their opinions were not valued, and some of their reasons were supported by the stakeholders, a few participants also realized that at times public opinion cannot be readily incorporated into decision-making. There are situations when a decision has to be made (i.e., guidelines for air, water or other types of media), and the public's opinion may not have as much importance as other factors such as costs, ethics or legal implications. This recognition by the public of the decision maker's role and responsibility is important. It demonstrates that the public participants appreciate that there may be other factors in addition to their viewpoint which need to be considered in decision-making. This recognition that the public's opinion is only one part of the puzzle was also voiced in Abelson et al (1995). In this research, when increasingly complex issues were introduced, participants became less willing to accept responsibility for decision-making and more willing to assign this to traditional decision makers.

Figure 18 also shows many similarities between the two participant groups as to when the public's opinion has more value. While the focus group participants alone indicated that their opinion had more value when it is marketable, both public and stakeholder respondents indicated that public opinion has more credence when it is educated or based on fact. Stakeholders felt this enhanced the credibility of the public's opinion. It also may allow decision makers to engage this fraction of the public at a different level, as they have a more in-depth understanding of an issue and may thus be considered a more affected public representative (National Research Council, 2008). This similarity also

recognizes that the public are taking on the task of educating themselves about issues, which indirectly confirms that educating is not a duty of decision makers.

Public and stakeholder respondents also agreed that the value of public opinion is dependent on how, when and to whom the public directs their opinion. Described as 'channeling' by a stakeholder, focus group participants agreed that the value of public opinion is dependent upon who is listening and when the opinion is given. The media is also included as to who may be the recipient of the public's perspectives. Yet even then the stakeholders agreed with the focus group participants that the value of the public's opinion varies according to the decision maker who receives the opinion. Therefore, the receiver of the opinion is an important factor to consider when evaluating the perceived worth or usefulness of the public's opinion.

6.2 Research Question #2

The second research question was: *What role should the public play in the risk management of emerging or uncertain scientific knowledge?* To aid in answering this question, three questions posed to the focus group participants and one to the stakeholders were utilized. In combination with the questions used to set the baseline or current level of public participation, it is possible to determine what changes need to be made in light of scientific uncertainty.

6.2.1 Role of Science

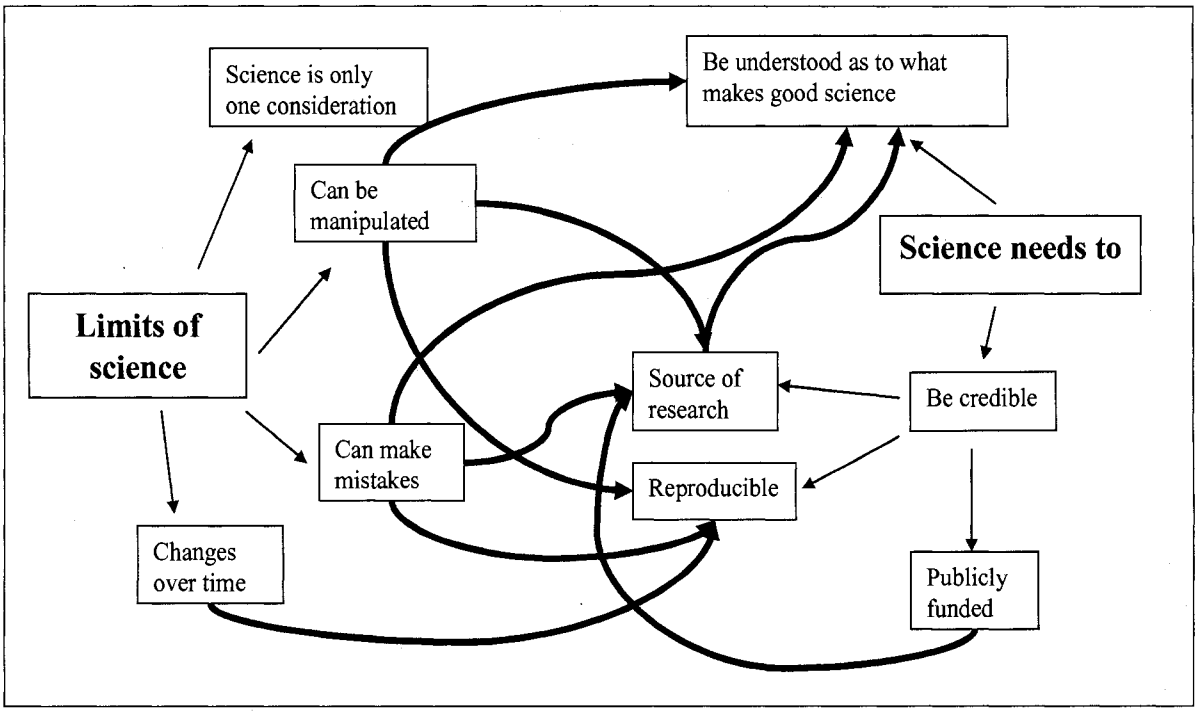
To understand how scientific uncertainty effects public participation in decision-making, it is important to evaluate what value the public places on scientific knowledge. Not only does scientific research provide valuable information, it is also highly valued by decision makers as it provides direction on the best means of protecting the health of a population. Therefore, it becomes important to understand what value the public places on science to see if the opinions of the two groups align and what science contributes to decision-making.

The question posed to the focus group participants generated an overwhelmingly positive response. Participants felt science provided information which would aid in making decisions; the unspoken 'contract' alluded to by Pellizzoni (2003a). Only a few participants specified that science should provide information about safety. Surprisingly, the focus group participants did not identify or mention other roles for scientific knowledge such as providing direct information on benefits and alternatives, or indirect information on potential costs.

In many cases, the focus group participants did not speak about the role of science. Instead their comments were directed at what science needs to achieve and the limitations associated with scientific research. Participants agreed that not everyone knows what good science is, but also acknowledged that no research is perfect. As outlined in Pellizzoni (2003a), the focus group participants shared that it is important to understand

the degree of scientific credibility in order to understand its value. Figure 19 visually depicts the relationships between the limits of science and good science

Figure 19: Connections between limitations of science and good science



There are various connections between the two categories shown in Figure 19. These connections are not similarities or conflicts; instead the sub-categories of the limitations of science feed into the category of what science needs to be. The first example of this can be seen using the sub-category of the source of research. Depending on who conducted or funded the research, the focus group participants raised the issue that the results of scientific research could be manipulated to suit an individual, industry or even government purpose. This issue was also raised by Pellizzoni (2003a) and Kriebel and Tickner (2001). In addition, depending upon the researcher, the science produced could contain errors or the conclusions arising from the research could be inaccurate. A partial

solution to these concerns could be to provide additional public funding for scientific research. Not only would that improve the credibility of the science but, in the viewpoint of the focus group participants, it would improve their ability to assess if it is 'good' science. Focus group participants stressed this was particularly important for an issue which affects the general public.

Reproducibility was also a key sub-category that intersected with other issues raised by the focus group participants. In addition to improving the credibility of scientific knowledge, reproducibility reduces the possibility of mistakes and manipulation of the science (Dowie, 1994; Bernard, 2000). It also aids in determining if scientific knowledge remain true as technology and knowledge improves.

6.3 Roles and Responsibility Under Uncertainty

Using the case study of chlorinated disinfection by-products in drinking water, both participant groups were asked to explain if they felt the role of the public changes in the face of scientific uncertainty. The public focus group participants were asked this question in two different ways during the session to invoke the maximum range of responses to this important question.

The purpose of using a case study was to provide context and a framework for discussion to determine if there was a change in the roles and responsibilities of the public when the

scientific evidence was uncertain. The results are presented in Table 12, compared with the roles and responsibilities of decision makers under the two circumstances.

Table 12: Compare and contrast of perceived roles and responsibilities

Perceived Roles and Responsibilities of the Public		**Perceived Roles and Responsibilities of Decision Maker**	
Existing role	**Under conditions of uncertain science**	**Existing role**	**Under conditions of uncertain science**
Self educate	**Self educate**	**Provide opportunities for the public to share opinion**	**Provide opportunities for the public to share opinion**
Involvement	**Involvement** *and the potential to provide new ideas*	Ensure the transparency of a decision	*Follow the rules of majority (democracy)*
Ensure decision maker is acting responsibly	*Support and encourage research*	Listen	*Act safely*
Sharing their opinion with decision makers	*Make their own decision*	Identify or determine the process of participation	*Review and identify bias in the science*
To participate but not make decision	*Not sure of their role combined with a feeling of being overwhelmed*	Provide balanced and complete information	*Define issues*
Accepting decisions			*Educate and explain the issues*
Right to participate			

Note: Bolded items on each side of the table show similarities. Categories in italics are new roles or responsibilities when scientific uncertainty is a factor.

Public's Roles and Responsibilities

Only two of the seven roles or responsibilities initially identified by the public focus groups were repeated when the circumstance of scientific uncertainty was introduced. These two roles, bolded in Table 12, were self-educating and involvement in the decision-making process. When faced with scientific uncertainty, involvement was expanded to also include the possibility of the public being able to provide a different outlook or solutions to decision makers.

Three additional roles were identified when the public participants were asked to take the case study into consideration when responding. This information is presented in the second column of Table 12 and accentuated in italics. While supporting and encouraging research is self explanatory and well grounded in literature (Dowie, 1994; Benard, 2000) the remaining two roles are more ambiguous and contradictory. First, some focus group participants noted that under these circumstances the public would have to make their own decisions about an issue, while a small number of participants suggested that there may be no role for the public in decision-making under these circumstances.

These two opposing roles demonstrate that there is obvious confusion about who makes decisions in regards to these types of issues. Research by Abelson et al (1995) suggested that with increasingly complex situations the public becomes less willing to accept responsibilities and assigns the decision-making duties to decision makers such as government officials. In the light of these opposing views, the importance of defining the

public participation process when scientific knowledge is equivocal becomes more significant. A consequence of not doing so could be that decision makers continue keeping discussions such as risk management options for CDBPs in the hands of scientists and policy makers as outlined in the literature review. A clear participation process would provide direction that decision makers need to ensure public engagement is done at the appropriate times, in addition to reducing public confusion.

Second, two participants from an Edmonton informed focus group expressed feelings of being overwhelmed by conflicting scientific results and started to question the validity of the scientific information being used in decision-making. This strengthens the argument that the public must gain a good understanding of the scientific controversy when being engaged in consultation. This argument is also supported by work done by Bingham (2003) who identified five principles for making better public choices in the face of contested science. It also provides clarity into why the public changed the role of the decision maker from one of an informant to an educator. As an educator, the decision maker must dedicate more time and resources to ensure public consultation is effective, as the public may need to have a better understanding of the issue prior to their participation. The National Research Council (2008) recognized this need and indicated that decision makers need to take special efforts to ensure that the participants can understand this information.

Decision Maker's Roles and Responsibilities

As stated in the results chapter, the focus group participants not only suggested their own potential roles and responsibilities but they also identified decision maker's roles. Table 12 provides a visual presentation of these decision maker's roles and the similarities to those identified by the focus groups participants for public. The only duplication with decision makers was providing opportunities for public input.

The focus group participants identified five additional roles for decision makers, a significant enhancement of the roles and responsibilities described previously. These enhancements place higher expectations on decision makers, including taking more action on identifying and defining the conflicting the scientific evidence as well as ensuring safety is considered in each decision. These actions are well supported when scientific knowledge is uncertain (National Research Council, 2008; Bingham, 2003). Additionally, as noted when explaining the public's reaction to being overwhelmed, there was a shift in the decision maker's role from informant to educator. When information is uncertain, decision makers are expected to provide additional resources to ensure the public has knowledge and understanding of this issue. This requires a more proactive approach to public participation and engagement, as has been recommended by various researchers in this area (National Research Council, 2008; Briggs and Stern, 2007; Kriebel and Tickner, 2001).

The public participants expected decision makers to follow the rules of majority which also supports a more proactive or precautionary approach to public participation. The rules of majority refers to utilizing the democratic process (i.e., referendums, surveys) to make the decision. Whatever process is chosen, the goal is to ensure that decision makers consulted with the public in these types of situations with the caveat that there is a reluctance to take on making the final decision. When this is coupled with a decision maker's educational role, a precautionary approach will add additional transparency, provide an opportunity for the public to contribute alternative solutions and grant the public a greater role in the decision-making process.

Stakeholder's Viewpoint about the Public's Role

The stakeholder participants were asked if they felt the public's role changed when scientific information was equivocal. There was a divide in stakeholder's responses, as some felt there was no need to change the public's role while describing significant changes to decision maker's role with the presence of scientific uncertainty. The responses from the stakeholders also support an enhancement of their role. First, they agreed that there is a need to improve their efforts in educating the public about issues such as CDBPs. The stakeholders pointed out that the public needs to understand the risk (as described earlier). These comments also align with the roles and responsibilities the public participants identified for themselves under scientific uncertainty.

Secondly, it was noted that a decision maker may need to increase their role to minimize the public outrage when scientific uncertainty is present. This outrage may be related to a false expectation that science will always provide the necessary information and clarity about an issue. When the role of science is compromised and there is not good evidence to support a clear decision, it was feared that the public may act unreasonably. While the public focus group participants did not acknowledge that this reaction might occur, they did express frustration with scenarios involving uncertain science. Therefore, as recognized by the stakeholders, there are compelling reasons to work with the public more intensely to reduce the likelihood of having a negative public response.

This recognition by the stakeholders of the need to work with the public more when uncertainty exists indirectly supports and acknowledges the public's role of involvement. In essence, if decision makers have to do more to manage outrage, it shows that the public does have a role in circumstances which involve scientific uncertainty. It also reinforces the focus group arguments about the need for a clearer public participation process which provides for sufficient opportunities for them to participate. Again, if this was clarified the public may see transparency in the decision-making process along with an improved sense that their opinion is listened to, valued and incorporated into the final decision and actions taken.

One stakeholder agreed that decision makers' roles increased under conditions of uncertainty, but also countered that the public's role decreases. As shown in the results, this stakeholder argued that when science is uncertain, the decision being made must be

based on protecting the majority of the public. In their opinion, decisions being made under these circumstances should return to the hands of the scientists and the associated decision makers. as these individual are capable of evaluating the science and considering other factors which will ensure the best outcome is being achieved for the majority of the population.

This argument is disconnected from responses made by other stakeholders as well as those gathered from the focus group participants. The lone stakeholder argued that other factors must be considered, yet failed to acknowledge that the opinion of the public should be one of those factors to be included. This belief also contradicted the same stakeholder's earlier comments about the public's opinion having value particularly when the opinion was educated.

While this opinion was only expressed by one of the fifteen stakeholders interviewed, it does provide evidence that this outlook exists. Yet, as acknowledged by a panel convened by the National Research Council (2008), both public and stakeholder expertise is necessary it make good risk decisions - the public often has detailed knowledge of local context and everyday practices, plus the expertise about public values and preference whereas the scientific community holds the understanding of dynamic, complex systems and ability to assess the level of uncertainty. This opinion might have been more prevalent if additional stakeholders were interviewed, indicating there may be a gap in the understanding as to the value the public's opinion can truly bring to the table. Again, closing this gap could be partially addressed by having definition and clarity

around the roles and responsibilities of both decision makers and the public, as was well supported in the recommendations outlined in the review conducted by T. Dietz and P.C. Stern (National Research Council, 2008) about public participation in environmental assessment and decision-making.

Finally, for those stakeholders who indicated there was no change in the public's role it was apparent that they did not believe that the existence of scientific uncertainty should affect the public participation process. They argued that information and knowledge should be shared with the public regardless of what science contributes to the decision-making or policy formation process. Instead their primary concern was still trying to ensure that there was an effective mechanism to engage the public in discussion. They reaffirmed that barriers such identifying which sections of the public to engage and representativeness still hindered the public consultation process. These findings therefore reconfirm the findings of previously reported research about public participation and scientific uncertainty (National Research Council, 2008; Briggs and Stern, 2007; Church et al, 2001, Abelson et al, 1995).

The focus group participants did not explicitly identify barriers when they were questioned about their role in relation to scientific uncertainty and decision-making. However, it would be short-sighted to think the barriers previously identified will disappear under these circumstances, and they must still addressed by decision makers when defining the public participation process.

6.4 Effects of Bias

At the end of Chapter 4, a summary of the potential biases and limitations associated with this research were outlined. While a variety of biases or influences were identified, the majority of them were minimized by the efforts of the researcher. Where impact may have occurred was in two factors associated with the selection of the focus group participants

First, the participants from the informed focus group participants self-selected themselves for participation and the researcher enrolled participants in the sessions on a first come, first serve basis. In hindsight, once individuals had declared their interest, the participants should have been pre-screened before being included in the focus group sessions. This pre-screening would have ensured a more even demographic distribution of individuals. As a result, there was an over-selection of females and higher proportion of participants who were 45 years of age or older (Table 6).

This may have affected the research as the many risk research studies over the years have shown that men and women tend to judge health and environmental risks differently, with women generally exhibiting higher levels of concern than men (see, for example, Finucane et al. 2000; Flynn et al. 1994). In addition the more mature participants would may have had more public involvement experience, which could either positively or negatively prejudice their participation in this exercise (depending on the perceived suggest of their previous involvement). However, despite this possibility, the viewpoints

shared by participants were not overly pessimistic or negative. Instead participants offered constructive and helpful comments and at times solutions. Consequently, the impact of these potential biases is deemed to be minimal.

Second, the selection of the randomly based focus groups by the third party contracted company for the Edmonton sessions was not as arbitrary as expected. Many of these individuals had previously participated in research plus some resided in the same households. While this source of bias was eliminated in the second Edmonton session, it may have had an impact in the first session, when the situation was unknown to the researcher prior to conducting the focus group.

Despite these circumstances these participants maintain their uniqueness as they are not part of organization which has been actively involved in health or drinking water issues. As a more generalized public sample they provided the potential for a different viewpoint. It is in the comparison of these viewpoints from the different types of focus groups which allowed the researcher to draw valuable conclusions about public participation in uncertainty discussions.

7.0 Conclusions

When science is equivocal, it would seem that there might be a need for an enhanced public participation process, as decisions will be based more on factors besides the scientific information. However, in the past decision makers have been inclined to lessen the public's role when they design a risk management strategy to address issues of uncertainty. The objective of this research was to measure what role the public wishes to play in these circumstances. To achieve this objective, two research questions were used to first create a baseline of current involvement and then determine what role the public should be playing (in the context of a case study example).

The baseline which emerged had five clear statements which were consistent across the various types of focus groups and supported by the interviews conducted with the stakeholder participants. These statements are as follows:

1) There is a lack of clarity and definition to the existing public participation process;
2) There is confusion about the current value and usage of public opinion when it is solicited;
3) Current participation opportunities are not designed for optimum public engagement;
4) Participation is hampered by many institutional and personal barriers to involvement; and
5) The public is willing to educate themselves about issues.

Impact of Uncertainty

The identified baseline of current involvement coupled with the case study of equivocal science (CDBPs) allowed for a comparison of how public participation should change under conditions of uncertainty. The key finding was that scientific uncertainty is not a factor which should be used to reduce or minimize the involvement of the public in decision-making. Instead, the majority of researcher participants indicated that public participation in decision-making about issues such as CDBPs was even more important than when the scientific evidence is more decisive. This finding was consistently concluded across the numerous focus group types in this research.

For the public participants, this assertion was based on a need to better understand the issues which would allow them to suggest alternative solutions to addressing or managing an issue, encourage and support further research, and most importantly make their own decisions especially if there was a potential health impact. While agreeing with this finding, the stakeholders had different reasons for ensuring public involvement. With the exception of one stakeholder, there was agreement that working with the public had become essential. Public consultation needs to occur to ensure that the right information and is distributed for individual informed decision-making. It will also assist in controlling any outrage associated with the issues and in preventing people becoming overwhelmed by the information.

Where scientific uncertainty in participatory risk management has its greatest impact is in the role and responsibilities of decision makers. In the eyes of the focus group participants, they shifted from being informers to educators, and were expected to scrutinize and define the scientific conflict. Most importantly, decision makers were expected to act safely and use the democratic process. To address this enhanced role resources need to be targeted towards public education about the participatory process which will show individuals how to access opportunities as well as ensuring those personally affected by an issue have access to multiple routes to participate.

While there are strong messages for the decision makers in this research, there are also several messages for members of the general public. Just as decision makers were tasked with certain roles and responsibilities, the public research participants also identified roles and responsibilities for the public at large that must be fulfilled for an effective and meaningful participation process. The public needs to move away from an apathetic view and step forward to express their opinion with decision makers, not only about risk issues but about the participatory process in general. Barriers and gaps need to be identified and solutions offered to improve effectiveness. Despite this, it is recognized that clarifying public participation processes needs to be conducted and supported by decision makers, otherwise no change can be expected regardless of equivocal science adding an additional complexity to participatory risk management.

Future Research

There are limitations to this research which centered on the methodology used to select the individuals which comprised the focus group participants. As such, the transferability and applicability of the outcomes associated with this research to the general public may be limited. To validate these findings, future research should utilize a larger randomly selected sample size, preferably on a national scale. In addition, a variety of case study examples should be used to determine if the conclusions drawn from the present research can be replicated.

Recommendations for Best Practice

1) Public participation should be incorporated into decision-making processes where scientific uncertainty is associated with the issue.

2) Public participation should be considered an integral and valued component of the decision-making process which involves equivocal scientific knowledge, not a bureaucratic requirement to justify a policy decision.

3) Decision makers must create and supply information sources which are balanced, transparent and outline the controversy reflected in the scientific knowledge in a simplified manner. This information should be easily accessible and available through multiple avenues of inquiry.

4) Institutions and or agencies need to evaluate their current public participation approaches to determine if they contain clearly defined roles and responsibilities for the public and other groups they wish to engage. These roles and responsibilities should be transparent as well as reflect the goals and needs of both the agency and those involved in the consultation activity.

5) For each consultation activity, the roles and responsibilities need to be confirmed and understood by the individuals and or groups being consulted. There needs to be explicit understanding as to the level of decision-making power being granted to those individuals and or groups being consulted.

6) For each consultation activity, a needs assessment should be conducted to determine what barriers may be present which will hinder participation. The findings from the assessment must be incorporated and addressed in the design of participatory consultation plan in a manner which will encourage participation.

7) Agencies involved in public consultation should commit to adequate funding and resources that will provide for sufficient opportunities or means to effectively solicit the public's opinion on the issue being discussed.

Bibliography

Abelson, J., Lomas, J., Eyles, J., Birch, S., & Veentstra,G. (1995). Does the community want devolved authority? Results from deliberative polling in Ontario. Hamilton, Ontario: McMaster University, Centre for Health Economics and Policy Analysis.

Abelson J., Forest, P.G., Eyles, A., Casebeer, E. & Mackean, G. (2007). Examining the role of context in the implementation of a deliberative public participation experiment: results from a Canadian comparative study. *Social Science & Medicine, 64* (10), 2115-28.

Agriculture, Forestry and Home Economics Research Ethics Board. (2005). AFHE Research Ethics Board Application for Approval. Accessed at: http://www.afhe.ualberta.ca/Research/Ethics%20Review/Index.asp?page=Application

Alvanja, M., Godstein, I., & Susser, M. (1978). *A case-control study of gastrointestinal and urinary tract cancer mortality and drinking water chlorination in water chlorination.* Environmental Impact and Health Effects. R.L. Jolley, H. Gorchev and D. H. Hamilton. Ann Arbor (MI), Ann Arbor Science Publishers: 395-409.

American Water Works Association. (2007). Disinfection by-products (DBPs) fact sheet. Accessed at: http://www.drinktap.org/consumerdnn/default.aspx?tabid=68

Arbuckle, T.E., Hrudey, S.E., Krasner, S.W., Nuckols, J.R., Richardson, P., Singer, P., Mendola, P., Dodds, L., Weisel, C., Ashley, D.L., Froese, K.L. Pegram, R.A., Schultz, I.R., Reif, J., Bachand, A.M., Benoir, F.M., Lynberg, C & Waller, K. (2002). Assessing exposure in epidemiologic studies to disinfection by-products in drinking water: Report from an international workshop. *Environmental Health Perspectives, 110*(Suppl. 1), 53-60.

Arnstein, S.R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners, 35(4)*, 216-224.

Aronson, J. (1993). Giving consumers a say in policy development: Influencing policy or just being heard? *Canadian Public Policy, 19,* (4), 367-378.

Barnball, K.L. & While, S. (1994). Collecting data using a semi-structured interview: A discussion paper. *Journal of Advanced Nursing, 19,* 328-335.

Beierle, T.C. (2002). The quality of stakeholder-based decisions. *Risk Analysis 22(4)*, 739-749.

Beierle, T.C. & Konisky, D. M. (2000). Values, conflicts and trust in participatory environmental planning. *Journal of Policy Analysis and Management, 19(4)*, 587-602.

Beierle, T.C. & Cayford, J. (2002). *Democracy in practice: public participation in environmental decisions.* Washington, D.C.: Resources for the Future.

Bernard, H. R. (2000). Social Research Methods – Qualitative and Quantitative Approaches. Thousand Oaks, California: Sage Publications.

Bertrand, J.T., Brown, J.E. & Ward, V.M. (1992). Techniques for analyzing focus group data. *Evaluation Review, 16*(2), 198–209.

Bingham, G. (2003). When the sparks fly: Building consensus when the science is contested. Washington, D.C: Resolve.

Bradshaw, G. A. & Borchers, J.G. (2000). Uncertainty as information: narrowing the science-policy gap. *Conservation Ecology, 4(1)*, 7-10.

Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication, 51(3)*, 477-497.

Brenniman, G.R., Lagos, J., & Amsel, J. (1980). Case-control study of cancer deaths in Illinois communities served by chlorinated and non-chlorinated water In R.L. Jolley, W. A. Brungs and R. B. Cumming (Eds.), *Water chlorination: Environmental impact and health effects* (pp.1043-1057). Ann Arbor (MI): Ann Arbor Science Publishers.

Briggs, D & Stern, R. (2007). Risk response to environmental hazards to health – towards an ecological approach. *Journal of Risk Research, 10*(5), 593-622.

Brock, T. D. & Madigan, M. T. (1988). Biology of micro-organisms. Fifth Edition, Prentice Hall: New Jersey.

Buchy, M. & Hoverman, S. (2000). Understanding public participation in forest planning: a review. *Forest Policy and Economics, 1*(1), 15-25.

Cantor, K.P., Lynch, C.F., Hildesheim, M.E., Dosemici, M., Lubin, J., Alavania, M. & Craun, G. (1998). Drinking water source and chlorination by-products – Risk of bladder cancer. *Epidemiology, 9,* 21-28.

Cantor, K.P., Hoover, R., Harge, P., Mason, T.J., Silverman, D.T. & Altman, R. (1987). Bladder cancer, drinking water source and tap water consumption: a case-control study. *Journal of the National Cancer Institute, 79,* 1269-1279.

Center for Disease Control. (2007). Chlorine Disinfection Time Table. Accessed at: http://www.cdc.gov/healthyswimming/chlorine_timetable.htm

Chang, E. E., Chiang, P.C., Ko, Y.W., & Lan, W.H. (2001a). Characteristics of organic precursors and their relationship with disinfection by-products. *Chemosphere, 44*, 1231-1236.

Chang, E.E., Lin, Y.P., & P.C. Chiang. (2001b). Effects of bromide on the formation of THMs and HAAs. *Chemosphere, 43,* 1029-1034.

Charles, C. & DeMalo, S. (1993). Lay participation in health care decision making: a conceptual framework. *Journal of Health Politics, 18*(4), 881-904.

Charmaz, K. (2006). Constructing grounded theory: A practical guide through qualitative analysis. Thousand Oaks, CA: Sage Publications.

Chess, C. & Purcell, K. (1999). Public participation and the environment: Do we know what works? *Environmental Science and Technology, 33*, 16, 2685-2692.

Church, W.J.B., Wanke, M.I., Saunders, L.D., Pong, R., Spooner, C., & Dorgan, M. (2001). Citizen participation in health (care) decision making: What we know and where we might go. Edmonton, Alberta: University of Alberta, Centre for Health Promotion.

City of Winnipeg. (2002a). Winnipeg's water our most essential resource. Retrieved November 10, 2006 from http://www.winnipeg.ca/waterandwaste/pdfs/water/essentialResource.pdf

City of Winnipeg. (2002b). 2001 Drinking water quality test results. Retrieved November 10, 2006 from http://www.winnipeg.ca/waterandwaste/pdfs/water/2001_water/winnipeg.pdf

City of Winnipeg. (2003). 2002 Drinking water quality test results. Retrieved November 10, 2006 from http://www.winnipeg.ca/waterandwaste/pdfs/water/2002_water/winnipeg.pdf.

City of Winnipeg. (2004). 2003 Winnipeg drinking water quality test results – Winnipeg Distribution System Results. Retrieved from November 10, 2006 from http://www.winnipeg.ca/waterandwaste/water/testResults/Winnipeg2003.stm.

City of Winnipeg. (2005). 2004 Winnipeg Drinking water Quality Test Results – Winnipeg Distribution System Results. Retrieved from November 10, 2006 from http://www.winnipeg.ca/waterandwaste/water/testResults/Winnipeg2004.stm

City of Winnipeg. (2006). 2005 Winnipeg Drinking Water Quality Test Results – Winnipeg Distribution System Results. Retrieved from November 10, 2006 from http://www.winnipeg.ca/waterandwaste/water/testResults/Winnipeg.stm

Deane, M., Swan, S.H., Harris, J.A., Epstein, D.M. & Neutra, R.R. (1989). Adverse pregnancy outcomes in relation to water contamination, Santa Clara County, California, 1980 – 1981. *American Journal of Epidemiology, 129*(5), 894-904.

Do, M.T., Birkett, N.J., Johnson, K.C. Krewski, D. & Villeneuve, P. (2005). Chlorination disinfection by-products and pancreatic cancer risk. *Environmental Health Perspectives, 113*(4), 418-424.

Doble, J. (1995). Public opinion about issues characterized by technological complexity and scientific uncertainty. *Public Understanding of Science, 4,* 95-118.

Dodds, L., King, W. Allen, A.C., Armson, B.A., Fell, D.B., & Nimrod, C. (2004). Trihalomethanes in public water supplies and risk of stillbirth. *Epidemiology, 15*(2), 179–186.

Dodds, L. & King, W. (2001). Relation between trihalomethane compounds and birth defects. *Occupational and Environmental Medicine, 58,* 443-446.

Dodds, L., King, W., Woolcott, C., & Pole, J. (1999). Trihalomethanes in public water supplies and adverse birth outcomes. *Epidemiology, 10*(3), 233-237.

Dowie, J. (2004). Research implications of science-informed, value-based decision-making. *International Journal of Occupational Medicine and Environmental Health, 17*(1), 83 – 90.

Doyle, T., Zheng, J. W., Cerhan, J.R., Hong, C.P., Sellers, T.A., Kushi, L.H. & Folsom, A.R. (1997). The association of drinking water source and chlorination by-products with cancer incidence among postmenopausal women in Iowa: A prospective cohort study. *American Journal of Public Health, 87,* 1168-1176.

Driedger, S.M. & Eyles, J. (2003). Drawing the battle lines: Tracing the "science war" in the construction of the chloroform and human health risks debate. *Environmental Management, 31*(4), 476-488.

Driedger, S.M., Eyles, J., Elliott, S.J. & Cole, D.C. (2002). Constructing scientific authorities: Issue framing of chlorinated disinfection by-products in public health. *Risk Analysis, 22*(4), 789-802.

Dunnick, J.K, & Melnick, R.L. (1993). Assessment of the carcinogenic potential of chlorinated water: experimental studies of chlorine, chloramine, and trihalomethanes. *Journal of National Cancer Institute, 85,* 817-822.

EPCOR. (2002). 2001 EPCOR Water Quality Report for Edmonton. Retrieved on November 10, 2006 from http://www.epcor.ca/NR/rdonlyres/82AA4046-CE77-4ADE-ADA8-F183EAEBCDF4/0/EWQA_2001.pdf

EPCOR. (2003a). 2002 Edmonton Water Quality Report. Retrieved on November 10, 2006 from http://www.epcor.ca/NR/rdonlyres/A5752760-D9D7-47BA-8C8A-3C8D934EAC97/0/2002_Annual_Water_Quality_Report.pdf

EPCOR. (2003b). A Proud Century of Water Services: 1903 – 2003.

EPCOR. (2004). EPCOR Quality Assurance Section – 2003 Water Quality Data Summary. Retrieved on November 10, 2006 from http://www.epcor.ca/NR/rdonlyres/A18E4791-FB22-414C-961E-CC0F7BA71FD8/0/2003QualityAssuranceSection.pdf

EPCOR. (2005). 2004 Edmonton Water Works Annual Report – Quality Assurance Report. Retrieved on November 10, 2006 from http://www.epcor.ca/NR/rdonlyres/8E1AC410-A5B5-4152-BCAA-8CB5A4DD2C7F/0/2004AENVQualityrpt.pdf

EPCOR. (2005). News Release – EPCOR seeks volunteers for annual home water "sniffer" program. Retrieved on November 10, 2006 from http://www.epcor.ca/About/Media+Room/News+Releases/Recent+News+Releases/Feb0807.htm

EPCOR. (2006). Water Quality 2005 – Summary of Major Chemical, Microbiological and Physical Parameters of Edmonton Drinking Water. Retrieved on November 10, 2006 from http://www.epcor.ca/NR/rdonlyres/9401E068-B125-44E5-A673-830153A10D63/0/122005_211.pdf

EPCOR. (2007). 2006 Edmonton Waterworks Annual Report. Accessible at: Retrieved on March 10, 2007 from http://www.epcor.ca/NR/rdonlyres/874BA259-F138-45D2-BD26-24A93E4F1152/0/2006OpsReport.pdf

EPCOR. (2008). 2007 Edmonton Water Performance Report. Retrieved on September 24, 2008 from: http://www.epcor.ca/NR/rdonlyres/6652D409-D143-45D7-9493-5C3ECEFBE1FC/0/2007Edmontonwaterperformancereport2.pdf.

Eyles, J. (1993). The role of the citizen in health-care decision making (Policy Commentary C93-1). Hamilton, Ontario: McMaster University, Centre for Health Economics and Policy Analysis.

FAO. (1990). The community's toolbox: The idea, methods and tools for participatory assessment, monitoring and evaluation in community forestry. Retrieved on October 15, 2006 from http://www.fao.org/docrep/x5307e/x5307e00.htm.

Faugier, J. & Sargeant, M. (1997). Sampling hard to reach populations. *Journal of Advanced Nursing, 26*(4), 790-797.

Finucane, M. L., Slovic, P., Mertz C.K., Flynn, J. & Satterfield, T.A. (2000). Gender, race, and perceived risk: The 'white male' effect. *Health, Risk, and Society, 2* (2): 159-172

Fiorino. D.J. (1990). Citizen participation and environmental risk: A survey of institutional mechanisms. *Science Technology Human Values, 15,* 226-243.

Flynn, J., Slovic, P. & Mertz, C.K. (1994). Gender, race, and perception of environmental health risks. *Risk Analysis, 14*(6): 1101-1108

Frank. O. & Snijders, T. (1994). Estimating the size of hidden populations using snowball sampling. *Journal of Official Statistics, 10(1)*, 53-67.

Freedman, D. M., Cantor, K.P., Lee, N.L., Chen, L.S., Lei, H.H. & Ruhl, C.E. (1997). Bladder cancer and drinking water: a population based case-control study in Washington County, Maryland. *Cancer Causes and Control, 8*, 738-744.

Frewer, L. (2004). The public and effective risk communication. *Toxicology Letters, 149,* 391-397.

Frewer, L.J., Howard, C & Shepherd, R. (1998). Understanding public attitudes to technology. *Journal of Risk Research, 1*(3), 221-235.

Frewer, L.J., Hunt, S., Brennan, M., Kuznesof, S., Ness, M. & Ritson, C. (2003). The views of scientific experts on how the public conceptualize uncertainty. *Journal of Risk Research, 6*(1), 75-85.

Frewer, L.J., Miles, S., Brennan, M., Kuznesof, S., Ness, M., & Ritson, C. (2002). Public preferences for informed choice under conditions of risk uncertainty. *Public Understanding of Science, 11*, 363-372.

Friedman, S.M., S. Dunwoody, and C.L. Rogers. (1999). Communicating uncertainty: Media coverage of new and controversial science. Philadelphia: Lawrence Erlbaum Associates

Gee, D. (2006). Late lessons from early warnings: toward realism and precaution with endocrine-disrupting substances. *Environmental Health Perspectives, 114*(1), 152-160.

Golafshani, N. (2993). Understanding reliability and validity in qualitative research. *The Qualitative Report, 8*(4), 597-607.

Gottleib, M.S., Carr, J.K., & Clarkson, J.R. (1982). Drinking water and cancer in Lousiana: a retrospective mortality study. *American Journal of Epidemiology, 116,* 652-667.

Graves, C. G., Matanoksi, G. M. & Tardiff, R.G. (2001). Weight of evidence for an association between adverse reproductive and developmental effects and exposure to disinfection by-products: A critical review. *Review Toxicology and Pharmacology, 34,* 103-124.

Haimes, Y.Y., Barry, T. & Lambert, J.H. (1994). When and how can you specify a probability distribution when you don't know much? *Risk Analysis, 14*(5), 661-706.

Health Canada. (1995). A national survey of chlorinated disinfection by-products in Canadian drinking water. Retrieved on November 10, 2006 from: http://www.hc-sc.gc.ca/ewh-semt/pubs/water-eau/by-products-sousproduits/index_e.html.

Health Canada. (2006a). Guidelines for Canadian drinking water quality: Guideline technical document – trihalomethanes. Retrieved on November 10, 2006 from: http://www.hc-sc.gc.ca/ewh-semt/pubs/water-eau/doc_sup-appui/trihalomethanes/index_e.html.

Health Canada. (2006b). Haloacetic acids in drinking water – Document for public comment. Retrieved on November 10, 2006 from: http://www.hc-sc.gc.ca/ahc-asc/public-consult/consultations/col/ha-ah/rep-rapp_e.html.

Health Canada. (2006c). It's your health – drinking water chlorination. Retrieved on November 10 from: http://www.hc-sc.gc.ca/iyh-vsv/alt_formats/cmcd-dcmc.

Holman, H. R. & Dutton, D. B. (1978). A case for public participation in science policy formation and practice. *Southern California Law Review, 51,* 1505 – 1534.

Jardine, C. (2003). Development of a public participation and communication protocol for establishing fish consumption advisories. *Risk Analysis 23*(3), 461-471.

Jardine, C., Predy, G. & A. MacKenzie. (2007). Stakeholder participation in investigating the health impacts from coal-fired power stations in Alberta, Canada. *Journal of Risk Research, 10*(5), 693-714.

Jo, W.K., Kwon, K.D. Dong, J.I. & Chung, Y. (2005). Multi-route trihalomethane exposure in households using municipal tap water treated with chlorine or ozone-chlorine. *Science of the Total Environment, 339*(1-3), 153-152.

Johnson, B.B. (2003). Further notes on public response to uncertainty in risks and science. *Risk Analysis, 23*(4), 781-789.

Johnson, B.B. & Slovic, P. (1995) Presenting uncertainty in health risk assessment: initial studies of its effects on risk perception and trust. *Risk Analysis 15*(4), 485-494.

Johnson, B.B. & Slovic, P. (1998). Lay views on uncertainty in environmental health risk assessment. *Journal of Risk Research, 1*(4), 261-279.

King, W. D., Dodds, L, & Allen, A.C. (2000a). Relation between stillbirth and specific chlorination by-products in public water supplies. *Environmental Health Perspectives, 108*(4), 383-390.

King, W.D., Dodds, L., Allen, A.C., Armson, B.A., Fell, D. & Nimrod, C. (2005). Haloacetic acids in drinking water and risk for stillbirth. *Occupational and Environmental Medicine, 62*(2), 124 – 127.

King, W. D., Marrett, L.D. & Woolcott, C.G. (2000b). Case-control study of colon and rectal cancers and chlorination by-products in treated water. *Cancer Epidemiology Biomarkers Preview, 9,* 813-818.

King, W. D. & Marrett, L.D. (1996). Case-control study of bladder cancer and chlorination by-products in treated Water (Ontario, Canada). *Cancer causes and Control, 7*(6), 596-604.

Kitzinger, J. (1995). Introducing focus groups. *British Medical Journal, 311*(7), 299–305.

Kitzinger, J. & Barbour, R.S. (1999). The challenge and promise of focus groups. In R.S. Barbour, & J. Kitzinger, (Eds.), *Developing focus group research: Politics, theory and practice* (pp. 1-20). London: Sage Publications.

Klotz, J. B. & Pyrch, L.A. (1999). Neural tube defects and drinking water disinfection by-products. *Epidemiology, 10*(4), 383-390.

Koivusalo, M., Pukkalo, E., Vartianienen, T., Jaakkola, J.J.K., & Hakulinen, T. (1997). Drinking water chlorination and cancer – a historical cohort study in Finland. *Cancer Causes and Control, 8,*192-200.

Koren, H. & Bisesi, M. (1996). Handbook of environmental health and safety – Principles and practices: Volume II. Boca Raton, Fl, Lewis Publishers.

Kraft, M.E. (1998). Evaluating technology through public participation: The nuclear waste disposal controversy. In *Technology and politics,* eds. M.E. Kraft and N.J. Vig, 253.-277.

Krasner, S.W., 1999. Chemistry of disinfection by-product formation. In: Singer, P.C. (Ed.), Formation and Control of Disinfection By-Products in Drinking Water (pp.197-210). Denver, CO: American Water Works Association.

Krasner, S. W., McGuire, M.J., Jacangleo, J.G., Patania, N.L., Reagan, K.M., & Aieta. E.M. (1989). The cccurrence of disinfection by-products in U.S. drinking water. *Journal of the American Water Works Association, 81*(8), 41-53.

Kriebel, D., Tickner, J., Epstein, P., Lemons, J., Levins, R., Loechler, E.L., Quinn, M., Rudel, R., Schettler, T. & Stoto, M. (2001). The precautionary principle in environmental science. *Environmental Health Perspectives, 109*(9), 871-876.

Kriebel, D. & Tickner, J. (2001). Reenergizing public health through precaution. *American Journal of Public Health, 91*(9), 1351-1361.

Krueger, R.A. (2000). Focus groups: A practical guide for applied researchers – Second Edition. Thousand Oaks, CA: Sage Publications.

Kvale, S. (1996). Interviews – An introduction to qualitative research interviewing. Thousand Oaks, CA: Sage Publications.

Lapadat. J. C. & Lindsay, A.C. (1999). Transcription in research and practice: From Standardization of Technique to Interpretative Positionings. *Qualitative Inquiry, 5*(7), 64-86.

Lewis, C., Suffet, I.H. & Ritz, B. (2006). Estimated effects of disinfection by-products on birth weight in a population served by a single water utility. *American Journal of Epidemiology, 163*(1), 38–47.

Lipworth. W. (2007). Managing scientific uncertainty in health legislation. *Internal Medicine Journal, 37,* 119–123.

Lomas J. & Veenstra, G. (1995). If you build it, who will come? *Policy Options, 16*(9), 27 – 40.

Lombard, M., Snyder-Duch, J., & Bracken, C.C. (2002). Content analysis in mass communication: assessment and reporting of intercoder Reliability. *Human Communication Research, 28*(4), 587-604.

Lynberg, M., Nuckols, J.R., Langlois, P., Ashley, D., Singer, P., Mendola, P., Wilkes, C., Krapfl, H., Miles, E., Speight, V., Lin, B., Small, L., Miles, A., Bonin, M., Zeitz, P., Tadkod, A., Henry, J., & Forrester, M.B. (2001). Assessing exposure to disinfection By-Products in women of reproductive age living in Corpus Christi, Texas, and Cobb County, Georgia: Descriptive results and methods. *Environmental Health Perspectives, 109*(6), 597-604.

MacKean, G. & Thurston, W. (1999). A Canadian model of public participation in health care planning and decision-making. In M. Stingel & D. Wilson (Eds.), Efficiency versus equality: Health reform in Canada. Halifax, Nova Scotia: Fernwood Books Ltd.

McDaniels, T.L., Gregory, R.S., & Fields, D. (2006). Democratizing risk management: Successful public involvement in local water management decisions. *Risk Analysis 19*(3): 497-510

McGeehin, M. A., Reif, J.S., Becher, J.C. & Mangione, E.J. (1993). Case-control study of bladder cancer and water disinfection methods in Colorado. *American Journal of Epidemiology, 138*(7), 492-501.

McLellan, E., MacQueen, K. & Neidig, J.L. (2003). Beyond the qualitative interview: data preparation and transcription. *Field Methods, 15*(1), 63-84.

Miles, S. & Frewer, L. (2003). Public perception of scientific uncertainty in relation to food hazards. *Journal of Risk Research, 6*(3), 267-283.

Miller, S. (2001). Public understanding of science at the crossroads. *Public Understanding of Science, 10*, 115-120.

Miller, W. L. & Crabtree, B.F. (1999a). The Dance of Interpretation. In B.F. Crabtree & W.L. Miller (Eds)., *Doing Qualitative Research*, 2nd edition (pp. 127 – 144). Thousand Oaks, CA: Sage Publications.

Miller, W. L. and B.F. Crabtree. (1999b). Using Codes and Code Manuals – A Template Organizing Style of Interpretation. In B.F. Crabtree and W.L. Miller (Eds). *Doing Qualitative Research, 2nd edition* (pp. 127 – 144). Thousand Oaks, CA: Sage Publications.

Mills, C.J., Bull, R.J., Cantor, K.P., Reif, J., Hrudey, S.E. & Huston, P. (1998). Health risks of drinking water chlorination by-products: Report of an expert working group. *Chronic Diseases in Canada, 19*(3), 91-102.

Morgan, D.L. (1996). Focus Groups. *Annual Review of Sociology, 22,* 129-152.

Morris, R. D., Audet, A.M., Angelillo, I.F. Chlamers, T.C. & Mosteller, F. (1992). Chlorination, chlorination by-products and cancer: A meta-analysis. *American Journal of Public Health, 82*(7), 955-963.

National Research Council. (2008). *Public participation in Environmental Assessment and decision making.* Panel on Public Participation in Environmental Assessment and Decision Making. T. Dietz & P.C. Stern. (Eds). Committee on the Human Dimensions of Global Change. Division of Behavorial and Social Sciences and Education. Washington, D.C.: The National Academies Press.

Nieuwenhuijsen, M., J. Mireille, B. Toledano, N. E. Eaton, J. Fawell and P. Elliot. (2000a). Chlorination Disinfection By-Products in Water and Their Association with Adverse Reproductive Outcomes: A Review. *Occupational and Environmental Medicine, 57*, 73-85.

Nieuwenhuijsen, M., Mireille, J., Toledano, B. & Elliot, P. (2000b). Uptake of chlorination disinfection by-products: A review and a discussion of its implications for exposure assessment in epidemiological studies. *Journal of Exposure Analysis and Environmental Epidemiology, 10*, 586-599.

Nuckols, J.R., Ashley, D. L., Lyu, C., Gordon, S.M., Hinckley, A.F., & Singer, P. (2005). Influence of tap water quality and household water use activities on indoor air and internal dose levels of trihalomethanes. *Environmental Health Perspectives, 113*(7), 863-870.

Oskenberg, L., Cannell, C. & Kalton, G. (1991). New strategies for pretesting survey questions. *Journal of Official Statistics, 7*(3), 349-365.

Pellizzoni, L. (2003a). Uncertainty and participatory democracy. *Environmental Values, 12*, 195-224.

Pellizzoni, L. (2003b). Knowledge, uncertainty and the transformation of the public sphere. *European Journal of Social Theory, 6*(3), 327-355.

Peterborough Utilities Commission. (2007). Retrieved on October 30, 2006 from: http://www.puc.org/puc/faq.html

Peterman, R.M. & Anderson, J.L. (1999). Decision analysis: a method for taking uncertainties into account in risk-based decision-making. *Human and Ecological Risk Assessment, 5*(2), 231-244.

Petts, J. (2004). Barriers to participation and deliberation in risk decision: Evidence from waste management. *Journal of Risk Research, 7*(2), 115-133.

Powell, M., Dunwoody, S., Griffin, R. & Neuwirth, K. (2007). Exploring lay uncertainty about an environmental health risk. *Public Understanding of Science, 16,* 323-343.

Presser, S. (1994). Informed consent and confidentiality in survey research. *Public Opinion Quarterly, 58*, 446-459.

Public Works and Government Services Canada. (2005). Tri-Council policy statement - Ethical conduct for research involving humans. Retrieve on October 20, 2006 from: http://http://pre.ethics.gc.ca/english/pdf/TCPS%20October%202005_E.pdf

Ravetz, J. (1999). Comments on 'Lay views on uncertainty in environmental risk assessment'. *Journal of Risk Research, 2*(1), 1-2

Reif, J. S., Hatch, M.C., Bracken, M., Holmes, L.B., Schwetz, B.A., and Singer, P.C. (1996). Reproductive and developmental effects of disinfection by-products in drinking water. *Environmental Health Perspectives, 104*(10), 1056-1061.

Renn, O., Webber, T., & Wiedemann, P. (eds). (1995). *Fairness and Competence in Public Participation: Evaluating Models for Environmental Discourse.* Dordrecht, Netherlands: Kluwer Academic Press.

Richardson, S. D. (1998). Drinking Water Disinfection By-Products. In R.A. Meyers (Ed.), *Encyclopedia of Environmental Analysis and Remediation* (pp. 1398-1421). New York: John Wiley & Sons.

Rodriguez, M.J., Vinette, Y., Serodes, J.B., & Bouchard, C. (2003). Trihalomethanes in drinking water of greater Quebec region (Canada): Occurrence, variations and modeling. *Environmental Monitoring and Assessment, 89*, 69-93.

Rook, J.J. (1974). Formation of haloforms during chlorination of natural waters. *Water Treatment and Examination, 23,* 234-243.

Rowe, G. & Frewer, L.J. (2000) Public participation methods: A framework for evaluation. *Science, Technology and Human Values, 25*(1), 3–29.

Rowe, G. & Frewer, L. J. (2004). Evaluating public participation exercises: A research agenda. *Science, Technology and Human Values, 29*(4), 512-556.

Rowe, W.D. (1994). Understanding Uncertainty. *Risk Analysis, 14*(5), 743–749.

Sarantakos, S. (1998). *Social Research, 2nd edition.* South Yarra, Australia: MacMillan Publishers.

Savitz, D. A., Singer, P.C., Herring, A.H., Hartmann, K.E., Weinberg, H.S. & Makarushka, C. (2006). Exposure to drinking water disinfection by-products and pregnancy loss. *American Journal of Epidemiology, 164*(11), 1043–1051.

Schaeffer, N.C. & Presser, S. (2003). The science of asking questions. *Annual Review of Sociology, 29*, 65-88.

Schoenen, D. (2002). Role of disinfection in suppressing the spread of pathogens with drinking water: possibilities and limitations. *Water Research, 36*(15), 3874-3888.

Scott, A. (2001). Technological risk, scientific advice and public 'education': groping for an adequate language in the case of GM foods. *Environmental Education Research, 7*(2), 129-139.

Shaw, G.M., Ranarunga, D., Quach, T., Neri, E., Correa, A. & Neutra, R.R. (2003). Trihalomethane exposures from municipal water supplies and selected congenital malformations. *Epidemiology, 14*(2), 191-199.

Slovic, P. (1986). Informing and educating the public about risk. *Risk Analysis,* 6(4), 403-415.

Snary, C. (2002). Risk communication and the waste-to-energy incinerator environmental impact assessment process: A UK case study of public involvement. *Journal of Environmental Planning & Management, 45*(2), 267-283.

Statistics Canada. (2007a). Census 2006 – Community Profiles- Edmonton. Retrieved on September 15, 2007 from: http://www12.statcan.ca/english/Profil01/CP01/Details/Page.cfm?Lang=E&Geo1=CMA&Code1=835__&Geo2=PR&Code2=48&Data=Count&SearchText=Edmonton&SearchType=Begins&SearchPR=01&B1=All&GeoLevel=&GeoCode=835

Statistics Canada. (2007b). Census 2006 – Community Profiles – Winnipeg. Retrieved on September 15, 2007 from: http://www12.statcan.ca/english/Profil01/CP01/Details/Page.cfm?Lang=E&Geo1=CMA&Code1=602__&Geo2=PR&Code2=46&Data=Count&SearchText=Winnipeg&SearchType=Begins&SearchPR=01&B1=All&GeoLevel=&GeoCode=602.

Stewart, D.W., & Shamdasani, P.N. (1990). Focus groups: Theory and practice. London: Sage Publications.

Symons, G.E. (2006). Water treatment through the ages. *Journal of American Water Works Association, 98*(3), 87–98.

U.S. EPA. (2001). Stage 1 disinfectants and disinfection by-products rule: A quick reference guide. Retrieved on November 10, 2006 from http://www.epa.gov/safewater.

U.S. EPA. (2006). Setting standards for safe drinking water. Retrieved on November 10, 2006 from: http://www.epa.gov/safewater/standard/setting.html

U.S. National Research Council. (1996). *Understanding Risk: Informing Decisions in a Democratic Society.* National Research Council, National Academy Press, Washington, D.C.

U.S. Presidential Congressional Commission. (1997). Framework for environmental health risk management - Final Report Volume 1.

Varkevisser, C.M., Pathmanathan, I., & Brownlee, A. (2003). Module 14: Pre-testing the methodology in designing and conducting health systems research projects: Volume I. Retrieved from Accessed at http://www.idrc.ca/en/ev-56623-201-1-DO_TOPIC.html

Villanueava, C.M., Cantor, K.P., Cordier, S., Jaakkola, J.J., King, W.D., Lunch, C.F. Porru, S., & Kogevinas, M. (2004). Disinfection by-products and bladder cancer: a pooled analysis. *Epidemiology, 15*(3), 357 – 367.

Viscusi, W.K., Magat, W.A. & Huber, J. (1991). Communication of ambiguous risk information. *Theory and Decision, 31*, 159-173.

Waller, K., Swan, S.H., DeLorenze, G. & Hopkins, B. (1998). Trihalomethanes in drinking water and spontaneous abortion. *Epidemiology, 9*(2), 134-140.

Waller, K., Swan, S. H., Windham, G.C. & Fenster, L. (2001). Influence of exposure assessment methods on risk estimates in an epidemiologic study of total trihalomethane exposure and spontaneous abortion. *Journal of Exposure Analysis and Environmental Epidemiology, 11*, 522-531.

Weiss, C. (2003). Scientific uncertainty and science based precaution. *International Environmental Agreements: Politics, Law and Economics, 3,* 137 – 166.

Welch, S. (1975). Sampling by referral in a dispersed population. *Public Opinion Quarterly, 39,* 237-245.

White, G.C. (1999). Handbook of chlorination and alternative disinfectants (4th Ed.). New York: John Wiley and Sons Inc.

Wigle, D.T. (1998). Safe drinking water: A public health challenge. *Chronic Diseases in Canada, 19*(3), 103-7.

Wilkins, J. R. & Comstock, G.W. (1981). Source of drinking water at home and site-specific cancer incidence in Washington County, Maryland. *American Journal of Epidemiology, 114,* 178-190.

Williams, D.T., Lebel, G.L. & Benoit, F.M. (1997). Disinfection by-products in Canadian drinking water. *Chemosphere, 34,* 299-316.

Winnipeg Regional Health Authority. (2006). Community health advisory councils. Retrieved on November 10, 2006 from: http://www.wrha.mb.ca/about/chac/index.php.

Woodward, R.T. & Bishop, R.C. (1997). How to decide when experts disagree: uncertainty-based choice rules in environmental policy. *Land Economics, 73*(4), 492-507.

Wynne, B. (1992). Misunderstood misunderstanding: social identities and public uptake of science. *Public Understanding of Science, 1*, 281-304.

Wynne, B. (2006). Public engagement as a means of restoring public trust in science – Hitting the notes, but missing the music? *Community Genetics, 9*, 211-200.

Yosie, T.F. & Herbst, T.D. (1998). Using stakeholder processes in environmental decision-making: An evaluation of lessons learned, key issues, and future challenges. Washington, D.C.: Ruder Finn.

Young, T.B., Wolf, D. A., & Kanarek, M.S. (1981). Epidemiologic study of drinking water chlorination and Wisconsin female cancer mortality. *Journal of the National Cancer Institute, 67,* 1191-1198.

Zierler, S., Feingold, L. Danley, R.A. & Craun, G. (1988). Bladder cancer in Massachusetts related to chlorinated and chloraminated Drinking Water: A case control Study. *Archives of Environmental Health, 43*(2), 194-200.

Zussman, D. (1997). Do citizens trust their governments? *Canadian Public Administration, 40*(2), 234–254.

Zwiener, C., Richardson, S. D., De Marini, D.M., Grummit, T., Glauner, T. & Frimmel, F.H. (2007). Drowning in disinfection by-products? Assessing swimming pool water. *Environmental Science & Technology, 41*(2), 363-372.

Appendices

Appendix A

Public Role and Responsibility in the Risk Management of Emerging Scientific Knowledge: A Case Study of Disinfection By-Products (DBPs) in Drinking Water

Ethics Certificate – Phase I Stakeholder Interviews

Faculty of Agriculture, Forestry, and Home Economics
Human Research Ethics Board
Approval

is hereby granted to:

Cindy Jardine, Principal Investigator for

05-39 Public role and responsibility in the risk management of emerging scientific knowledge: a case study of disinfection by-products (DBPs) in drinking water

for a term of one year, provided there is no change in experimental procedures. Any changes in experimental procedures must be submitted in writing to the HREB.

Granted: August 4, 2005

Debra Davidson, Chair, HREB

Appendix B

Finalized List of Stakeholder Interview Questions

As mentioned previously, the researcher which formed the basis of this thesis is part of a larger research study. The list of questions below is all of the questions asked of the stakeholder participants in this phase of the research. The **three** questions utilized in this research are bolded and the associated question number referenced at the end of the question.

Uncertainty of Science

1. When does science become credible or reliable in your viewpoint?
2. When you confronted with one study or report indicating "x" concern, does that change your habit or practice?
3. If no, at what point would you change your practices or process?
4. What is your understanding of the precautionary principle? Do you and your agency utilize this principle? How often and when?

Disinfection by-products

1. Does the appearance or odour of a water source change how you use it?
2. How concerned are you about disinfection by-products in drinking water?
3. How would you rank this concern compared to other concerns related to drinking water safety? (*Examples if needed – microbial, watershed, infrastructure concerns*)
4. What is your knowledge of potential health concerns surrounding the presence of disinfection by-products in drinking water?
5. Do you think the concerns warrant applying the precautionary principle and stop using chlorine as our primary means of disinfection?
6. How concerned do you think the public is about disinfection by-products?
7. Do you think the public view chlorination as an involuntary or voluntary risk to their health?

Organization Practice

1. Does your agency investigate complaints about aesthetic concerns such as taste or odour?
2. Are there restrictions as to who can speak to the public about drinking water concerns? Does this differ in emergency situations?
3. Do you have any type of outreach program or resource materials available for members of the public? *Probe: What type of materials?*
4. Do you recommend or provide information about home treatment options to members of the public?
5. Do you allow for public input into your policies or procedures?

Role of the Public

1. Is it always appropriate for the public to provide comments about health concerns?
2. **Does the role the public play change when the science is uncertain?(S-3)**
3. **Do you think there are sufficient opportunities for the public to be involved in setting policy or regulations? (S-1)**
4. Do you think the public wishes to play a larger role in how policy or regulations are created?

Regulatory

1. How aware are you of the regulatory world regarding drinking water? What is the extent of your involvement in regulatory development? *(Note: Has not been generally necessary to ask these question, depends on the person)*
2. How much influence do you think the regulatory world has on setting the agenda for scientific agenda? Do you see any problems with that relationship?
3. Sometimes a regulation is set at a more stringent level than dictated by the science to be precautionary:
    a. Do you think this affects the relationship between the regulator and the public? If so, how?
    b. Do you think this affects the relationship between the regulator and industry? If so, how?

The closing questions are directed towards your expertise and knowledge obtained throughout your career. Therefore your responses may be based on your personal opinion or experiences outside of the current practices of the agency you represent. As these questions may place you in conflict with your agencies practices, please be aware you are under no obligation to respond to the following questions.

Closing

1. **In your experience, do you feel the public's opinion is valued? (S-2)**
2. Do you feel the public values its drinking water? What about their drinking water do they value?
3. Do you feel the public pays sufficiently for its drinking water?
4. Are there sufficient funds available to maintain the current standards? What about future improvements to meet potentially tougher standards?
5. Is there a limit to how effectively we can make our drinking water?
    Probe: Are we there yet, if so both chemically/microbiologically?
6. Are their other stakeholders who need to be consulted in this process on how or what role the public should play?

Appendix C

Stakeholder Information Sheet and Consent Form

INFORMATION SHEET for the University of Alberta Research Project:

Public Role and Responsibility in the Risk Management of Emerging Scientific Knowledge: A Case Study of Disinfection By-Products (DBPs) in Drinking Water

Purpose: This research project seeks to better understand the role of the public in the risk management of issues and situations where the scientific knowledge is emerging and characterized by uncertainty.

Background: The assessment of hazards and the associated risks posed to human health is based on varying levels of direct evidence and therefore reflects varying levels of certainty. Risks based on emerging and equivocal scientific knowledge pose distinct challenges to decision-makers in the formulation of appropriate policy directives for effective risk management. When the scientific evidence is weak or incomplete, other factors (i.e. economic, social, cultural, ethical, political and legal considerations) must take on greater influence in risk management. The role of the public in helping to shape public policy and regulations is increasingly important under these circumstances.

We are trying to better understand the role of the public under these circumstances using the control of Disinfection By-Products (DBPs) in drinking water as a case study. Epidemiologic studies have found associations between elevated levels of DBPs and increased risks of cancer and adverse reproductive outcomes. However, the evidence remains ambiguous, largely because of inadequate characterization of exposure. This makes it an ideal case study to explore the role of the public in decision-making under conditions of scientific uncertainty. We believe the results from this study will be transferable to other situations involving managing risks in the face of emerging scientific knowledge.

This research is being funded by the Social Sciences and Humanities Research Council (SSHRC).

Methods: This is the second stage of collecting information for this study. In the first stage, we spoke to a variety of individuals who have a responsibility or interest in drinking water regulations. In this second phase, we would like to talk to you, as an informed member of the public about health issues to see what viewpoint or opinion you would have about the role of the public in emerging science.
We will be asking you some general questions on emerging scientific knowledge, DBPs, and what the role of the public is or should be in the public policy decision-making process. We anticipate that the interview will take 30 to 60 minutes to complete. We will return our initial summary of the results to you for verification of our

interpretation before the information is incorporated in any report or paper resulting from this research.

Confidentiality: With your permission, this interview will be recorded on audiotape. This will ensure that we have an accurate record of your responses when we summarize and interpret the information you provide. As a participant you will be representing your agency's viewpoint but may as well share personal perspectives that you feel might compromise your position within the agency. While you may consider it neither necessary nor desirable for your identity to remain confidential, please inform us if you have any concerns, so we can remove your name from any reports or publications that use your interview.

Benefits: The process of public participation in risk decision-making has implications for both the public and those involved in the development of public policies for health protection. It is important to ensure that the perspectives and issues of concern of all parties be taken into account so that the resulting recommendations from this research study reflect all viewpoints. These interviews will allow you the opportunity to provide your input. Hopefully they will also ensure that the results contribute to a better understanding of how to effectively utilize public participation in the development of appropriate and accepted drinking water policies.

Risks: There are no direct risks to participating in this study. However, two indirect risks may be attributed to your participation: (1) You may feel at risk from reprisal from your employer if you are critical of the agency procedures or practice; and (2) your identity could be determined based on what you say. To address these concerns, we will not use information which could personally identify or attribute comments to you by name without your permission and all recordings or notes from the interview will be only be accessible to researchers directly involved in the study.

Withdrawal from the Study:

Even after you have agreed to do the interview you can decide at any point you do not wish to continue. You may also decide that you do not wish to do a second interview, if requested. Up to one month following the interview(s), you may decide that you do not want what you said to be used. The researchers then cannot use this information.

Use of the Information:

The results from this research will provide a systematic basis upon which to assess the role of the public in risk management involving emerging and equivocal scientific knowledge, resulting in recommendations on appropriate policy options for the incorporation of a public participation component into the legal management of these

risks. The results may also be used for academic presentations and peer-reviewed publications.

Contacts: The Principal Investigator for this study is Dr. Cindy Jardine from the University of Alberta. Drs. S. Michelle Driedger of the University of Ottawa and Larry Reynolds of the University of Alberta are co-investigators. Merry Turtiak, with the Centre for Health Promotion Studies at the University of Alberta, will be conducting much of the research as part of the requirements for her master's research. You can contact the researchers via Dr. Jardine at (780) 492-2626 or at cindy.jardine@ualberta.ca.

Additional Contacts:

If you have any complaints or concerns about this research that you feel you cannot discuss with the researchers you can contact:

Georgie Jarvis , Secretary to the Human Research Ethics Board
2-14 Ag/For Centre, University of Alberta, Edmonton AB T6G 2P5
Ph. (780) 492-4931, Fax (780) 492-0097

CONSENT FORM

To Participate in the University of Alberta Research Project:

Public Role and Responsibility in the Risk Management of Emerging Scientific Knowledge: A Case Study of Disinfection By-Products (DBPs) in Drinking Water

Principal Investigator:
Dr. Cindy Jardine, Asst. Professor
Dept. of Rural Economy
University of Alberta
(780) 492-2626

Researcher:
Merry Turtiak, MSc Candidate
Centre for Health Promotion Studies
University of Alberta

Do you consent to being audio-taped?	Yes	No
Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you can quit taking part in this study at any time? You do not have to say why.	Yes	No
Has the issue of confidentiality been explained to you?	Yes	No
Do you understand who will have access to the records from these discussions?	Yes	No
Do you understand that the information you provide will be used to make recommendations on an appropriate public role in policy and regulatory development?	Yes	No
Can we use this information in the future to look at other problems related to risk and public participation, and for presentations and publications?	Yes	No

This study was explained to me by: _____

I agree to take part in this study.

_____ _____ _____

Signature of Research Participant Date Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____ _____

Signature of Investigator Date

Appendix D

Public Role and Responsibility in the Risk Management of Emerging Scientific Knowledge: A Case Study of Disinfection By-Products (DBPs) in Drinking Water

Ethics Certificate – Phase II Public Focus Groups

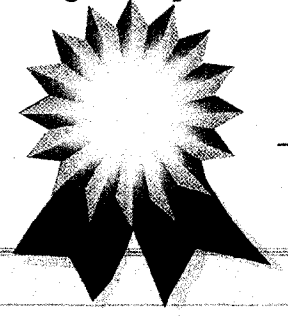
Faculty of Agriculture, Forestry, and Home Economics
Human Research Ethics Board
Approval

is hereby granted to:

Cindy Jardine, Principal Investigator for

06-19 Public role and responsibility in the risk management of emerging scientific knowledge: a case study of disinfection by-products (DBPs) in drinking water

for a term of one year, provided there is no change in experimental procedures. Any changes in experimental procedures must be submitted in writing to the HREB.



Granted: June 14th, 2006

for Debra Davidson, Chair, AFHE REB

Appendix E

F-1: Invitation Letter to Informed Public Focus Group Participants – Community Health Councils (Winnipeg Regional Health Authority)

F-2: Invitation Letter to Informed Public Focus Group Participants – Water Sniffing Program (EPCOR)

June 7, 2006

Re: Focus Group Participation

Dear Sir or Madam:

On behalf of the University of Alberta and myself, I would like to extend you an invitation to participate in a research study.

This research is trying to understand the role of the public when science cannot provide clear answers of possible risks to a person's health. As a member of one of Winnipeg Regional Health Authority's Community Health Advisory Councils, you have explored and provided suggestions for addressing important health issues. We would like to learn from your experience what role the public would like to have and what information they need when science is uncertain.

As part of our focus group, we will ask you some general questions on what the role of the public is now or should be. We will also ask some questions about drinking water issues such as disinfection by products. You do not need to be a drinking water or science expert to participate. We are interested only in your opinion.

We anticipate that the focus group will take two hours to complete. We are planning to host these sessions in Winnipeg on:

Monday, June 19th and Tuesday, June 20th
Start time: 7 PM
Location: Hampton Inn – 260 Main Street, Winnipeg

Please note you only need to attend one of these sessions, but space is limited so please register quickly. In addition, the researchers are also pleased to offer a *fifty ($50) honorarium* to those individuals who participate in either session as a token of our appreciation for your time.

If you are interested in participating, please register with either:

- Colleen Schneider at cschneider1@wrha.mb.ca or (204) 926-8073.
- Merry Turtiak at mturtiak@ualberta.ca or (780) 220 - 1120

Please be aware that the WRHA is not involved with this research. They are assisting us by mailing information about the focus groups to members of the Councils. To maintain your confidentiality, this letter is being sent by the Winnipeg Regional Health Authority. If you decide to participate, please expect a follow-up phone call or email.

I look forward to seeing you at one of the sessions!

Sincerely,

Merry Turtiak

Merry Turtiak, B.Sc., CPHI(C)
MSc. Candidate, University of Alberta

June 15, 2006

Re: Focus Group Participation

Dear Sir or Madam:

On behalf of the University of Alberta and myself, I would like to extend you an invitation to participate in a research study.

This research is trying to understand the role of the public when science cannot provide clear answers of possible risks to a person's health. To explore this issue we are using a drinking water issue, disinfection by products as an example. As a member of EPCOR's Home Water Sniffing Program, you are familiar with drinking water issues particularly those in Edmonton. We would like to learn from your experiences on what role the public would like to have and what information they need when science is uncertain.

As part of our focus group, we will ask you some general questions on what the role of the public is now or should be. We will also ask some questions about drinking water issues such as disinfection by products. You do not need to be a drinking water or science expert to participate. We are interested only in your opinion.

We anticipate that the focus group will take two hours to complete. We are planning to host these sessions in Edmonton on:

Monday, July 17th and Tuesday, July 18th
Start time: 7 PM
Location: University of Alberta, Human Ecology Building
Room 3-36 (see enclosed map)

Please note you only need to attend one of these sessions, but space is limited so please register quickly. In addition, the researchers are also pleased to offer a *fifty ($50) honorarium* to those individuals who participate in either session as a token of our appreciation for your time.

If you are interested in participating, please register with either:

- Kerryanne Doyle at kdoyle@epcor.ca or (780) 412 - 3019
- Merry Turtiak at mturtiak@ualberta.ca or (780) 220 - 1120

Please be aware that the EPCOR is not involved with this research. They are assisting us by mailing information about the focus groups to members of the Home Water Sniffing Program. To maintain your confidentiality, this letter is being sent by the EPCOR, however to confirm your attendance please expect a follow-up phone call or email.

I look forward to seeing you at one of the sessions!

Sincerely,
Merry Turtiak
Merry Turtiak, B.Sc., CPHI(C)
MSc. Candidate, University of Alberta

Appendix F

Finalized List of Question for Public Focus Group Sessions

As mentioned previously, the researcher which formed the basis of this thesis is part of a larger research study. The list of questions below is all of the questions asked of the stakeholder participants in this phase of the research. The **seven** questions utilized in this research are bolded and the associated question number referenced at the end of the question.

General – Role of the Public

1. **What role do you expect the public to play in decision-making? (P-1)**
    a. **Do you think the public have a responsibility to participate? (P-2)**
    b. **Do you think the public's opinion is valued? (P-4)**
2. Is there certain policy issues that you feel the public should play a more important role in?
3. What do you think your role should be when decision makers are making policies about health issues?
4. **Do you currently think you have sufficient opportunities to be involved in decision-making? (P-3)**
    a. Please give specific examples of these opportunities
    b. If you feel you have not had sufficient opportunities, what would you like to see?

General – Science

Segue: Many factors are involved when decision makers create policies or regulations. One of these factors is science.

5. **What role do you think science should play in decision-making? (P-5)**
6. Where do you get your science information from?
7. How influenced are you when you hear about a new study reported in the media?
8. Are there specific instances or times when you have questioned the reported scientific information?

Disinfection By-Products

Segue: A lot of research has been done and is still ongoing to make sure that the drinking water produced by water utilities is safe.

9. **When scientific studies come to different conclusions, do you think there is a different role for the public to play? (P-6)**
10. What are you general concerns about drinking water?
11. Are you concerned about the use of chemicals in the treatment of our drinking water?
    a. (If necessary as a follow up) Are you concerned about the use of chlorine or other chemicals used in drinking water treatment?
12. What do you know about disinfection by-products?

- *Depending on responses here, information may be provided about the benefits of chlorination, how water treatment occurs and is distributed and concerns about DBPs*

13. Knowing this, what do you think water utilities should do?
14. Do you think chlorination is a chosen risk or an imposed risk to your health?
15. **What role do you think the public should play in a case like this when science is uncertain but policy decisions still need to be made? (P-7)**

Role of the Public in Uncertain Science

16. Keeping the previous discussion in mind, what role do you think the public should play in a case like this when science is uncertain but policy decisions must still be made?
17. What kind of information would you need to feel knowledgeable enough to participate in public consultation?
18. Do you think the degree of uncertainty was communicated clearly to the public?
19. How confident are you in the regulator in making decisions based on limited science? Why or why not?

Appendix G

Public Focus Group Information Sheet, Demographic Survey and Consent Form

INFORMATION SHEET for the University of Alberta Research Project:

Public Role and Responsibility in the Risk Management of Emerging Scientific Knowledge: A Case Study of Disinfection By-Products (DBPs) in Drinking Water

Purpose: This research is trying to better understand the role of the public when science can not provide clear answers of possible risks to a person's health.

Background: Risks to human health are based on different levels of scientific facts. As a result, science has differing levels of certainty. What actions to take about risks based on unclear science are very hard to answer. However, decision makers must still decide on what to do. Other factors, such as cost, legal or social issues are also taken into consideration on how to manage the risk. The role of the public in helping to decide on these policies also becomes more important.

To learn more about the role of the public when science is unclear an example will be used. This example will be Disinfection By-Products (DBPs) in drinking water. DBPs are formed during the disinfection process when raw water is treated with chlorine to make it fit for us to drink. Some studies have found a link between higher levels of DBPs and cancer. Other studies have found link between DBPs and poor pregnancy outcomes such as miscarriages. However, the evidence is confusing because it is difficult to measure negative effects in exposed people. This makes it a good example to explore what role the public should play when science is uncertain. These results will also be valuable in other similar situations.

This research is being funded by the Social Sciences and Humanities Research Council (SSHRC).

Methods: This is the second part of this research study. In the first stage, we spoke to a variety of individuals who have a responsibility or interest in drinking water regulations. In this second phase, we would like to talk to you, as an informed member of the public. We consider you an informed member of the public as you have or currently provide feedback to decision makers on health issues. We would like know your view about the role of the public when science is uncertain.
As part of our focus group, we will ask you some general questions on what the role of the public is now or should be. We will also ask some questions about drinking water issues such as DBPs. You do not need to be a drinking water or science expert to participate. We are interested only in your opinion. We anticipate that the focus group will take two hours to complete.

Confidentiality: With your consent, the focus group will be recorded. This will ensure that we have an accurate record of your responses when we review the recording. None of your responses will be used in a way that will identify you. Your personal contact information will not be released to anyone. If you are concerned about a response you made, please tell us so we can remove that comment from the results.

Benefits: Many decision makers would like to improve how and when the public should be consulted. This focus group session will allow you the opportunity to provide your view about how and when you would like to be consulted. Your input will help decision maker's identify how to work with the public when science does not provide an answer.

Risks: There are no direct risks to you if you decide to be involved. You may become more aware about some issues with drinking water. This higher awareness is not expected to be harmful to you.

Withdrawal from the Study:

At any time during the focus group session you can decide that you do not wish to continue. You will not need to provide a reason as to why you do not want your comments used. The researchers will disregard your comments in the transcript and not use this information.

Use of the Information:

From this research, recommendations will be made to decision makers about what role the public should play when science is unclear. The results may also be used in academic presentations and be published in academic journals.

Contacts: The Principal Investigator for this study is Dr. Cindy Jardine from the University of Alberta. Drs. S. Michelle Driedger of the University of Manitoba and Larry Reynolds of the University of Alberta are co-investigators. Merry Turtiak, with the Centre for Health Promotion Studies at the University of Alberta, will be conducting much of the research as part of the requirements for her master's research. You can contact the researchers via Dr. Jardine at (780) 492-2626 or at cindy.jardine@ualberta.ca.

Additional Contacts:

If you have any complaints or concerns about this research that you feel you cannot discuss with the researchers you can contact:

Georgie Jarvis , Secretary to the Human Research Ethics Board
2-14 Ag/For Centre, University of Alberta, Edmonton AB T6G 2P5
Ph. (780) 492-4931, Fax (780) 492-0097

CONSENT FORM

To Participate in the University of Alberta Research Project:

Public Role and Responsibility in the Risk Management of Emerging Scientific Knowledge: A Case Study of Disinfection By-Products (DBPs) in Drinking Water

Principal Investigator:
Dr. Cindy Jardine, Asst. Professor
Dept of Rural Economy
University of Alberta
Ph: (780) 492 - 2626

Researcher:
Merry Turtiak, MSc. Candidate
Centre for Health Promotion Studies
University of Alberta
Ph: (780) 220 - 1120

Do you consent to being audio-taped?	**Yes**	**No**
Do you understand that you have been asked to be in a research study?	**Yes**	**No**
Have you read and received a copy of the attached Information Sheet?	**Yes**	**No**
Do you understand the benefits and risks involved in taking part in this research study?	**Yes**	**No**
Have you had an opportunity to ask questions and discuss this study?	**Yes**	**No**
Do you understand that you can quit taking part in this study at any time?	**Yes**	**No**
Has the issue of confidentiality been explained to you?	**Yes**	**No**
Do you understand who will have access to the records from these discussions?	**Yes**	**No**
Do you understand that the information you provide will be used to make recommendations on an appropriate public role in policy and regulatory development?	**Yes**	**No**
Can we use this information in the future to look at other problems related to risk, public participation and for presentations and publications?	**Yes**	**No**

This study was explained to me by: _____

I agree to take part in this study.

_____

Signature of Research Participant Date Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____

Signature of Investigator Date

Demographic Collection Form

This information will be used to help us generally describe the people we talk to in these focus groups (e.g. "we talked too 20 people, 10 male and 10 female, ranging in age from 18-66 years of age"). We may also use to describe your responses anonymously (e.g. "Winnipeg male age 46 said..."). This information will be kept separate from any identifying information, such as your name and address.

Gender: ☐ Female ☐ Male

Age: ☐ 18 – 24 years ☐ 25 – 34 years ☐ 35 – 44 years
☐ 45 – 64 years ☐ 65 years or older

Marital Status: ☐ Married / Common – Law ☐ Single
☐ Divorced/Separated ☐ Widowed

Employment Status: ☐ Full Time Employed ☐ Part Time Employed
☐ Homemaker ☐ Student
☐ Retired ☐ Unemployed

Last level of education completed:

☐ Some high school ☐ Completed High School
☐ Some college/university ☐ Completed College/University

Appendix H

Distribution of Responses by Focus Group Participants

Question P-1: What role do you expect the public to play in creating public policy?										
Group/Code	1.1	1.2	1.3	1.4	2.1	2.2	2.3	3.0	4.0	5.0
WI#1	5	1	1		4	4				1
WI#2	5	2	1		4	5			1	
WR#1	4	2			1	3				
WR#2	9							3		
EI#1	8		1	2	3	2		2		1
EI#2	6		2	1		4				1
EI#3	6	1		1	2	2		1		1
ER#1	2				1		2			
ER#2	1	1			1	4	1		1	
Total	45	7	5	4	16	24	3	6	2	4

Codes	
1.1	Public role - Involvement
1.2	Public role - Self educate
1.3	Public role - Ensure decision makers are acting responsibly
1.4	Trust elected or appointed officials
2.1	Decision maker role - Identify the process of participation
2.2	Decision maker role - Provide balanced and complete information
2.3	Decision maker role - Provide an opportunity to share their opinion
3.0	Difficulty of getting public input
4.0	Identifying the public
5.0	Apathy

Question P-2: Do you think the public have a responsibility to participate?													
GroupCode	1.1	1.2	1.3	1.4	1.5	2.1	2.2	2.3	2.4	3.1	3.2	3.3	3.4
WI#1	2	2	1			5		1	2				2
WI#2	1		1			1	5	1	2				4
WR#1	1	1	1			1			2	1			2
WR#2		2				1		1		1			
EI#1	1	2					2		1				1
EI#2	3						1				4		
EI#3	6	2	2					1		2		2	2
ER#1	3		2	1	1								1
ER#2		1		2	2								
Total	17	10	7	3	3	8	8	4	7	4	4	2	12

Codes	
1.1	Public responsibility - Sharing their opinion with decision makers
1.2	Public responsibility - Self educate
1.3	Public responsibility - Responsible to participate, not to make the decision
1.4	Public responsibility - Accepting decisions
1.5	Public responsibility - Right and responsibility
2.1	Decision maker responsibility - Determine the process of participation
2.2	Decision maker responsibility - Ensure Transparency of a decision
2.3	Decision maker responsibility - Provide an opportunity for involvement
2.4	Decision maker responsibility - Listen
3.1	Barrier - Ensuring representative participation
3.2	Barrier - Inadequate education about the decision-making process
3.3	Barrier - Too busy
3.4	Barrier - Need to be personally affected

Question P-3: Do you currently think you have sufficient opportunities to be involved in decision-making?

Group/Code	1.1	1.2	2.1	2.2	2.3	2.4	2.5
WI#1							
WI#2	1		1	3	1		
WR#1	9	10		2	2		
WR#2	3		1		3		
EI#1	4					2	
EI#2	1		2	1	1	1	
EI#3	5		4		3		2
ER#1			1		1	4	1
ER#2	3			1		3	

Total	26	10	9	7	11	10	3

Codes	
1.1	General negative responses
1.2	No - opportunities did not promote active participation
2.1	Yes but process of participation is unclear
2.2	Yes but barriers present
2.3	Yes but do not take advantage of opportunities
2.4	Yes but unknown opportunities
2.5	Yes but no influence

Question P-4: Do you think the public's opinion is valued?

Group/Code	1.1	1.2	1.3	1.4	2.1	2.2	2.3	2.4	3
WI#1									
WI#2	1	1	2			2			3
WR#1					1				1
WR#2	4	1							
EI#1	3	3			2			2	
EI#2								2	
EI#3		1	3		4	1	1	2	1
ER#1	1	1	1	2					
ER#2	1		1	5	1	1	1		

Total	10	7	7	7	8	4	2	5	5

Codes	
1.1	Not valued - No usage of collected public opinion
1.2	Not valued - Public relations exercise
1.3	Not valued - No influence
1.4	Not valued - Ineffective process
2.1	To have value - Self educate
2.2	To have value - Timing
2.3	To have value - Marketable
2.4	To have value - Who is listening
3.0	Not as valued - Decision has to be made

Question P-5: What role do you think science should play in decision-making?												
Group/Code	1	1.1	1.2	2.1	2.2	2.2.1	2.2.2	2.2.3	3.1	3.2	3.3	3.4
WI#1	1	1		1				4				
WI#2	1	1		1	3	2	3		2	3	1	
WR#1	2	3		1		1				1		3
WR#2		1	1									
EI#1	1	1				1	1				1	
EI#2	2	2							3		1	
EI#3	2	1	1									
ER#1	3	2	1									
ER#2		3										
Total	12	15	3	3	3	4	4	4	5	4	3	3

Codes	
1.0	Science generally plays a role
1.1	Scientific contribution - Provide information
1.2	Science contribution - Make sure a decision is safe
2.1	Needs to be - Lack of knowledge about what makes good science
2.2	Needs to be - Credible
2.2.1	Needs to be - Credible - Source of the research
2.2.2	Needs to be - Credible - Reproducible
2.2.3	Needs to be - Credible - Publicly funded
3.1	Limitations - Science not the only consideration
3.2	Limitations - Science changes over time
3.3	Limitations - Science can make mistakes
3.4	Limitations - Science can be manipulated

Question P-6: When scientific studies come to different conclusions, do you think there is a different role for the public to play?

Group/Code	1.1	1.2	1.3	1.4	1.5	2.1	2.3	2.4	2.2	2.5	3
WI#1	4			1	1		3				
WI#2		1	1				2				
WR#1		1		1			1	2		2	
WR#2			2		2			2	1	1	
EI#1											2
EI#2	2			3							
EI#3		1	1	1			2				
ER#1	4				1	2			1		
ER#2	2	1						1			

Total	12	4	4	6	4	2	8	5	2	3	2

Codes	
1.1	Public's role - Make their own decision
1.2	Public's role - Self-educate
1.3	Public's role - Get involved
1.4	Public's role - Support and encourage further research
1.5	Public's role - Not sure what role should be
2.1	Decision maker's role - Define the issues
2.2	Decision maker's role - Educate
2.3	Decision makers' role - Review and identify bias
2.4	Decision maker's role - Act safely
2.5	Decision maker's role - Follow the rules of majority (democracy)
3.0	Overwhelmed

Question P-7: What role do you think the public should play in a case like this when science is uncertain but policy decisions still need to be made?

Group/Code	1.1	1.2	1.3	2.1	2.2
WI#1		1			2
WI#2					
WR#1					
WR#2	4				1
EI#1			1		1
EI#2	1				1
EI#3					
ER#1	2			2	4
ER#2		2			4

Total	7	3	1	2	12

Codes	
1.1	Public's role - To be involved and provide new ideas
1.2	Public's role - Request further research
1.3	Public's role - Self educate
2.1	Decision maker's role - Provide opportunity for the public to give opinion
2.2	Decision maker's role - Educate and explain the issue

Appendix I

Summary of Categories by Question

Question P-1: What role do you expect the public to play in decision-making?				
Category	**Sub-categories**			
Roles of the public	Involvement	Self educate	Ensure decision makers are acting responsibly	Trust elected or appointed officials
Roles of the decision maker	Identify the process of participation	Provide balanced and complete information	Opportunity to share their opinion	
Difficulty of getting public input				
Identifying the public				
Apathy				

Question P-2: Do you think the public has a responsibility to participate?					
Category	**Sub categories**				
Responsibilities of the public	Sharing their opinion with decision makers	Self educate	Responsible to participate, not to make decisions	Accepting decisions	Right and responsibility
Responsibilities of the decision maker	Determine process of participation	Ensure transparency	Provide an opportunity for involvement	Listen	
Barriers to participation	Ensuring representative participation.	Inadequate education about the decision-making process	Too busy	Need to be personally affected	

Question P-3: Do you currently think you have sufficient opportunities to be involved in decision-making?					
Category	**Sub-categories**				
Negative responses	General negative responses		Opportunities do not promote active participation		
Positive responses or are they?	Process of participation is unclear	Barriers • Trying to survive • Education level • Access	Do not take advantage of opportunities	Unknown opportunities	No influence

Question S-1: Do you think there are sufficient opportunities for the public to be involved in setting policy or regulations?				
Category	**Sub-categories**			
Positive or "Yes" responses	Opportunities attended	Mandatory practice	Limitation: Available for educated individuals	Limitation: Getting public involvement
Negative or "No" Responses	Identifying the public	High cost to conduct effective consultation	Access difficulty for some	Lack of opportunity for water issues
We "try" responses	Try to reach the public but participant needs to be personally affected.			

Question P-4: Do you think the public's opinion is valued?				
Category	**Sub-categories**			
Why is the public's opinion not valued?	No usage of collected public opinion.	Public relations exercise	No influence	Ineffective process
What is needed for the public opinion to have value?	Self educate	Timing	Marketable	Who is listening?
When is public opinion not valued?	Decision just have to made			

Question S-2: In your experience, do you think the public's opinion was valued?				
Category	**Sub-categories**			
Yes or Positive responses	Public opinion is important	Responsibility of employment	Influence decisions	More value when: • Factual basis • Properly channeled
Constraints on the value of public's opinion	Not all decision makers value public opinion in the same way	Not fully consider opinion even when it is collected		

Question P-5: What role do you think science should play in decision-making?			
Category	**Sub-categories**		
Scientific contributions to decision-making	General - plays an important role	Specific – provide information	Specific – make sure a decision is safe
What science needs to be	Lack of knowledge about what makes good science	Science needs to be credible • Source of research • Reproducible • Publicly funded	
Limitations of science	Not the only consideration	Changes over time	Can make mistakes / Can be manipulated

Question P-6: When scientific studies come to different conclusions, do you think there is a different role for the public to play?					
Category	**Sub-categories**				
Public's role and scientific uncertainty	Make their own decisions	Self-educate	Get involved	Support and encourage further research	Not sure what role should be
Decision maker's role and scientific uncertainty	Define the issue	Educate	Review and identify bias	Act safely	Follow the rules of majority (democracy)
Overwhelmed					

Question P-7: What role do you think the public should play in a case like this when science is uncertain but policy decisions still need to be made?			
Category	**Sub-categories**		
Public's role and scientific uncertainty	Involvement and provide new ideas	Request further research	Self educate
Decision maker's role and scientific uncertainty	Provide opportunity for the public to give their opinion	Educate and explain the issue	

Question S-3: Does the role of the public change when the science is uncertain?			
Category	**Sub-categories**		
No change in the public's role but there are limits	Getting public involvement without personal involvement	Good representation	
Role of decision maker changes	Decision be made on what is best for the majority	Inform the public to let them make their own decisions	Control outrage reactions from the public