DRINKING WATER ADVISORIES AND PATHWAYS FORWARD

ONE INDIGENOUS COMMUNITY'S JOURNEY TOWARDS WATER SECURITY: A TRANSDISCIPLINARY REFLECTION ON DRINKING WATER ADVISORIES AND PATHWAYS FORWARD

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Lay Abstract

When water is known, or suspected, to be unsafe for human consumption, communities are placed under a Drinking Water Advisory (DWA). Indigenous communities have some of the worst water quality in Canada and many are subsequently under DWAs. Despite the widespread impact of DWAs on health and wellbeing, little is known about First Nation individuals' thoughts, feelings, and experiences living under one.

The goal of this thesis was to unpack and explore the broad health, social, cultural, and economic impacts of a Boil Water Advisory (BWA) from the perspective of community members on a reserve in Northern Ontario and provide considerations for BWA management.

Responses pointed to gaps where education surrounding how to best protect health would be crucial, especially for women who were highlighted as an important target audience. Points also emerged where communication would be key to understanding the impacts and outcomes of DWAs moving forward.

Abstract

Background: Water quality in on-reserve Indigenous communities in Ontario is concerning, with issues ranging from deteriorating water quality to issues with regulation and support. As a result, many communities are placed under a Drinking Water Advisory (DWA), which, at its most severe, indicates water is not safe for use or consumption. Between 2004 and 2013, approximately 70% of all on-reserve communities in Ontario were under at least one DWA. While designed to protect physical health, DWAs have widespread impacts on health and wellbeing. However, little is known about First Nation individuals' thoughts, feelings, and experiences living under a DWA.

Purpose: To unpack and explore the broad impacts of a Boil Water Advisory (BWA) from the perspective of community members on a reserve in Northern Ontario and provide considerations for current and future BWA management.

Methods: Methodological choices were driven by the principles of community-based participatory research. Questionnaires and interviews were used to collect data. Two hundred and twenty-six questionnaires were distributed. Fifteen Elders and 22 key informants (KIs) were contacted for an interview.

Results: Forty-four (19.5%) individuals completed a questionnaire. Eight Elders and 16 KIs participated in 20 interviews. Questionnaire sections were used to frame the data analysis, which fell under five major themes: 1) Community Context; 2) Knowledge of BWAs; 3) Living Under a BWA; 4) Water and Health; and, 5) Pathways Forward.

Conclusions: Responses illuminated gaps where education surrounding best practices for protecting health would be crucial moving forward. They also highlighted that women are an important target audience for education. Points also emerged where communication with community members and stakeholders would be key to understanding the impacts and outcomes of DWAs. Additionally, this community, and others experiencing a DWA, should consider greater involvement in water management by younger individuals, to ensure that all perspectives are adequately represented.

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List of Abbreviations

BWA	Boil Water Advisory
CBPR	Community-Based Participatory Research
DNCA	Do Not Consume Advisory
DNUA	Do Not Use Advisory
DWA	Drinking Water Advisory
HC	Health Canada
IDWPO	Indigenous Drinking Water Projects Office
INAC	Indian/Indigenous and Northern Affairs Canada
ISC	Indigenous Services Canada
TK	Traditional Knowledge
WaSH	Water, Sanitation, and Hygiene
WHO	World Health Organization
WS	Western Science
OCAP	Ownership, Control, Access, and Possession

Dedication

I would like to dedicate this project to Wauzhushk Onigum Nation and all individuals and communities living with a drinking water advisory – you have endured more than you should.

Declaration of Academic Achievement

Unless explicitly stated, I declare that I am the sole author of this thesis. I completed all research work and was provided with guidance and feedback from my supervisors (Dr. Sarah Dickson-Anderson and Dr. Corinne Schuster-Wallace) as well as committee members (Dr. Susan Watt, Dr. Lalita Bharadwaj), and my external reviewer (Dr. Fran Scott).

The text of Chapter 3 is being submitted for publication in a peer-reviewed journal. Co-authors of this paper are: Sarah E. Dickson-Anderson, Corinne J. Schuster-Wallace, Derek Skead, and Kathleen Skead.

I understand that my thesis will be electronically available.

Chapter One: Introduction

1.1 Overview

Drinking water advisories (DWAs) are issued when water is known, or suspected, to be unsafe for human consumption. This can occur as a consequence of equipment or contamination issues within a water system, system type and management, or when there is a lack of personnel needed to oversee a water system (Indigenous Services Canada, 2019c). Three types of DWAs of varying severity have been identified: (1) boil water advisories (BWAs), when water is safe to use and consume only after being boiled; (2) do not consume advisories (DNCAs), when water is not safe to consume but can be used for other purposes; and (3) do not use advisories (DNUAs), when water is not safe for use or consumption (Indigenous Services Canada, 2019c). As of August 2019, 56 long-term (i.e. 1 year or longer) and 42 short-term DWAs in Indigenous Services Canada (ISC)-funded reserves in Canada were still standing (Indigenous Services Canada, 2019a, 2019c). An additional 11 drinking water advisories in non-public, non-ISC funded drinking water systems on reserves were also in place (Indigenous Services Canada, 2019b).

To First Nations people, water is not just life-sustaining – water *is* life and water *has* life or a spirit (Anderson et al., 2011; Arsenault et al., 2018; McGregor, 2014). In some First Nations traditions, there is a belief that all aspects of life and life-sustaining processes are deeply interconnected. As a result, the lack of safe water and restrictive measures in place under DWAs do not affect just one facet, but all aspects of the lives of First Nations people (McGregor, 2012). Despite this deep connection to the environment, Indigenous people in Canada lack meaningful involvement in, and control over, issues of water quality because water governance is mainly

under federal and provincial jurisdiction (Lukawiecki, 2017; McGregor, 2012). In addition, though many First Nations communities rely on surface water for their source water, it is difficult for them to engage in discussions about source water concerns because watersheds extend beyond reserves and are provincially managed (Human Rights Watch, 2016). Though communities are supposed to be involved in water management, in actuality Indigenous control is limited and, typically, the government spearheads decision-making (Human Rights Watch, 2016; McGregor, 2014).

Water policies have been proposed to ameliorate unsafe water on reserves, but most have been created without consultation and partnership of First Nations people (McGregor, 2012). Additionally, many Indigenous communities have not given the government the right to dictate how they should govern their lands and resources in the first place. Thus, the typical method of engaging First Nations people as stakeholders in issues of water governance and protection undermines Indigenous authority and rights to governance, damaging potential collaborative relationships and delaying environmental and water-related decision-making (Von Der Porten & de Loë, 2013). Furthermore, many Indigenous people see Western approaches to water governance, management, and treatment as disregarding or disrespecting the components that they consider important, making this approach inadequate at addressing the larger regional or national challenges leading to unsafe water (Lawless et al., 2015; McGregor, 2012).

Research by and with Indigenous people and communities has been, and in many cases still is, guided by a non-Indigenous, Eurocentric, and colonial worldview (Castleden et al., 2012; Schnarch, 2004). Colonization is closely tied to racism against Indigenous people, systemic oppression, and control over when, how, and if Indigenous cultural practices, ceremonies, and opinions can be expressed (Victor, 2007). Indigenous communities have been plagued by

"helicopter" researchers who, as the name suggests, enter a community only for as long as data collection necessitates and do not engage the community before, during, or after the research process (Bharadwaj, 2014; LaVeaux & Christopher, 2009; Wallerstein & Duran, 2008). Although it is recognized by many that this way of doing research is inappropriate, the postcolonial academic sphere continues to lack an understanding of Indigenous beliefs, concerns, and ways of knowing (Getty, 2010). To move away from these colonial practices, many researchers seek the individual and collective voices and views of Indigenous people as subjects of their research, but not as part of the research team. Although not ill-intentioned, this behaviour continues to perpetuate oppressive and ethnocentric systems by leaving interpretation to non-Indigenous researchers and failing to integrate Indigenous understanding (Getty, 2010; Victor, 2007). Indigenous people have identified several other areas of concern regarding how research has been conducted in their communities, including lack of involvement and tokenism, irrelevant research outcomes, misalignment of values, pressure to participate, a lack of data ownership, no capacity building or transfer of skills, disrespectful practices, and little recognition or compensation for their investment in the research (ITK and NRI, 2006; Koster et al., 2012; Schnarch, 2004). Thus, research needs to be carried out, from inception to completion, with members of the community as fundamental research partners. Community-based participatory research (CBPR) is one approach to conducting research with First Nations people that involves true community participation, education, action, and capacity-building in the pursuit and production of knowledge (Bharadwaj, 2014; Castleden et al., 2012; Holkup et al., 2004; Koster et al., 2012; Wallerstein & Duran, 2003). A scoping review of drinking water and health in Indigenous communities in Canada supports CBPR in the context of water research, recommending that future research is needed that follows the principles of CBPR to not only

focus on the scientific understanding of these issues, but to build on the culturally sensitive, "action oriented" research required by this population (Bradford et al., 2016).

Residents of an Anishinaabe First Nations community in Ontario, Canada are currently under a BWA for their drinking water as a result of a water treatment plant system that does not meet provincial standards. The Lake of the Woods waterbody where they live holds significant cultural and traditional value for the community even though water quality has been steadily declining. This community faces many infrastructure, source water protection, and water management challenges and has lacked the resources to deal with these barriers.

Despite the negative history of research with Indigenous people, communities recognize that research done "the right way" is necessary for growth and evidence-based decision-making (ITK and NRI, 2006). Currently, little is known about residents' beliefs and experiences living with a BWA. Therefore, there is a need to unpack and explore the true costs of a BWA from the perspective of community members in order to inform a bonded Western Science (WS) (engineering, natural, health, social) and Traditional Knowledge (TK) interpretation of this issue and provide considerations for current and future DWA management.

1.2 Research & Operational Objectives

The goal of this thesis is to identify and deconstruct the broad costs and consequences of a BWA and to explore ongoing threats to the water supply in a First Nations community in Northern Ontario from the perspective of the residents of this community.

The operational objectives of this thesis are:

1) To explore health, social, cultural, and economic impacts of the BWA on community members;
2) To understand any differential impacts of the BWA on men and women;

3) To understand any changes in individual and community practices as a result of the BWA; and,
4) To provide considerations that promote strategic objectives, enhance local water security, and reduce any negative impacts arising from contamination events or water advisories.

1.3 Scope

This thesis contains four chapters in addition to the first introductory chapter:

Chapter 2 contains a literature review that covers: (1) the linkage between drinking water quality and human health outcomes, including Indigenous health perspectives; (2) an overview of DWAs in Indigenous communities in Canada; and (3) a brief history and summary of CBPR, particularly in the Indigenous context.

Chapter 3 provides the methodology, results, analysis, and discussion used to achieve the above research objectives. Chapter 3 is also being submitted to a peer-reviewed journal.

Chapter 4 provides a reflection on the process of CBPR and knowledge system bonding and highlights limitations of this research.

Chapter 5 draws conclusions for research and practice and synthesises the findings of the previous chapters.

In addition, Appendix H presents supplementary water quality data collected at the request of the community in areas on Lake of the Woods identified as important to them. While not directly related to the BWA under study, they represent source water quality in the Lake of the Woods more broadly and have been provided back to the community for analysis.

Chapter Two: Literature Review

Chapter 2 will position this research in the literature by reviewing the following areas of importance:

1) The linkage between water quality and human health outcomes, including Indigenous health perspectives;
2) An overview of DWAs in Indigenous communities in Canada; and,
3) A brief history and summary of CBPR approaches, particularly in the Indigenous context.

2.1 Water Quality and Health

Water, sanitation, and hygiene (WaSH) have an important relationship with health because all are transmission pathways for infectious diseases. Globally, an estimated 829,000 deaths per year are a direct consequence of inadequate WaSH, with 485,000 attributed to unsafe drinking water (Prüss-Ustün et al., 2019). Poor WaSH is responsible for almost 60% of all diarrhoea-related deaths annually, equivalent to 297,000 deaths in children alone (Prüss-Ustün et al., 2019). Moreover, evidence suggests that poor WaSH is associated with increased child and maternal mortality, of which diarrhoea is just one cause of death (Cheng et al., 2012). Diarrhoeal symptoms can also lead to secondary health challenges, such as malnutrition and result in losses in literacy and productivity (Bartram & Cairncross, 2010; Hunter et al., 2010; Schuster-Wallace et al., 2008; Schwarzenbach et al., 2010).

Sanitation and water have a reciprocal relationship, with poor sanitation negatively impacting water quality and inadequate water supplies leading to poor sanitation. For hygiene, though it does not necessarily beget poor water, inadequate water supplies prevent good hygiene and health (Hunter et al., 2010). One study has illustrated that the incidence of illness in adults decreased by over 10% following water quality improvements (Zhang, 2012). Another showed

that improved WaSH had a positive effect on children's nutritional status (Dangour et al., 2013). However, a more recent study in children showed that improved WaSH had no benefit on health outcomes (Humphrey et al., 2019).

One percent of Canadians do not have access to safely managed drinking water, equivalent to approximately 373,000 people (WHO & UNICEF, 2019). The United Nations urges member states, of which Canada is one, to leave no one behind and "achieve universal and equitable access to safe and affordable drinking water for all" (United Nations General Assembly, 2015). To protect the health and wellbeing of all people living in Canada, this should be a serious consideration.

2.1.1 Biological Contaminants in Water

Human and animal feces pose the greatest microbiological contamination risk to water quality through disease-causing bacteria, viruses, and protozoa (Federal-Provincial-Territorial Committee on Drinking Water of the Federal-Provincial-Territorial Committee on Health and the Environment, 2017; World Health Organization, 2017). Estimates suggest that 29% of the world's population does not use drinking water sources free from contamination (WHO & UNICEF, 2019). Much of the contamination assessment is based on the concentration of *Escherichia coli (E.coli)* in water, which is an indicator of recent fecal contamination (Bain et al., 2014; Federal-Provincial-Territorial Committee on Drinking Water of the Federal-Provincial-Territorial Committee on Health and the Environment, 2017; World Health Organization, 2017). Individuals who consume water contaminated with *E.coli* may experience acute gastrointestinal symptoms, such as bloody diarrhea, cramping, and vomiting. In severe cases, acute kidney failure and haemolytic anemia, together known as haemolytic uremic syndrome, may occur (Olsen et al., 2002; World Health Organization, 2017). Waterborne *E.coli* also has the capacity

to cause community-wide infection and may affect many individuals at once, multiplying the effects of one infection (World Health Organization, 2017). Other biological waterborne contaminants include *Campylobacter*, *Cryptosporidium*, *Giardia*, *Legionella*, *Mycobacterium*, *Salmonella*, and *Shigella*; most cause gastrointestinal symptoms (Fawell & Nieuwenhuijsen, 2003; Schwarzenbach et al., 2010; World Health Organization, 2017).

2.1.2 Chemical and Metal Contaminants in Water

Negative effects to human health resulting from chemicals or heavy metals in water may be acute, but are more often chronic, meaning that they occur after long periods of repeated and regular exposure (World Health Organization, 2017). Chemical contaminants in water can come from many sources and vary widely in their interactions with water, the environment, and humans (Schwarzenbach et al., 2010; Zhang, 2012). Runoff from farms, homes, and other agricultural businesses can cause high levels of pesticides and fertilizers such as nitrogen and phosphorus to be present in water, which support the growth of damaging blue-green algal blooms that excrete cyanotoxins (Buratti et al., 2017; Schwarzenbach et al., 2010). Cyanotoxins are chemical compounds that can cause gastrointestinal symptoms, respiratory distress, rashes, and neurodegenerative effects in humans (Buratti et al., 2017). Humans may be exposed to cyanotoxins by drinking or accidentally ingesting contaminated water, and by consuming fish or crops that have been exposed to cyanotoxins (Buratti et al., 2017). High nitrogen concentrations in water can also cause methemoglobinemia, or “Blue Baby Syndrome”, in infants. This is characterized by an inability to carry oxygen in the blood and can be fatal (Knobeloch et al., 2000). Additionally, consuming water contaminated with dichlorodiphenyltrichloroethane (DDT), a strong pesticide and persistent organic pollutant (POP), has been know to cause endocrine disruption in humans (Freeman, 2018).

Other POPs, such as polybrominated diphenyl ethers (PBDEs) and polychlorinated biphenyls (PCBs), are found in many everyday items and can make their way into water from improper handling or disposal. Since they are bio-accumulative, animals higher on the food chain are at a greater risk of experiencing deleterious health effects, including people that consume fish and other animals that come into contact with contaminated water (Schwarzenbach et al., 2010). Pharmaceuticals and personal care products (PPCPs) cover a wide variety of contaminants, including human and animal medications, insect repellents, sunscreens, and cosmetics (Ebele et al., 2017; Yang et al., 2017). These may enter water sources through sewage treatment plants, as leachate from landfills, or as runoff from animal farming (Ebele et al., 2017; Yang et al., 2017). PPCPs are associated with many negative effects on the environment, particularly on reproduction: for example, endocrine disrupters from urban wastewater effluent can cause hormone disruption in fish and harmful effects on disease causation and progression in humans (Fawell & Nieuwenhuijsen, 2003; Gore et al., 2015; Kabir et al., 2015; Schwarzenbach et al., 2010).

The process of extracting minerals and metals through mining can cause leaching agents or heavy metals such as sulphuric acid, cyanide, mercury, copper, nickel, and iron, to come into contact with water sources (Schwarzenbach et al., 2010). These pose acute and chronic risks to human health and may also result in negative effects on the environment, for example in the form of massive fish die-offs (Schwarzenbach et al., 2010). Naturally occurring contaminants, including arsenic, fluoride, selenium, and chromium, can also leach into water (Schwarzenbach et al., 2010). The effects of prolonged ingestion of these substances can result in cancer from arsenic, skeletal deformity from fluoride, and hair, skin, nail, or nervous system concerns from selenium (Fawell & Nieuwenhuijsen, 2003; Federal-Provincial-Territorial Committee on

Drinking Water of the Federal-Provincial-Territorial Committee on Health and the Environment, 2017). Lead, another drinking water contaminant, is known to have negative impacts on the renal and cardiovascular systems in humans. Lead also impacts the nervous system, where its effects are most deleterious in children, who may experience severe neurodevelopmental delays (Rosen et al., 2017). Additionally, natural or engineered nanoparticles (<100nm) such as silver, zinc, titanium, and silicon are emerging water contaminants that pose potential respiratory, cardiac, and vascular functioning health risks to humans (Bakshi et al., 2015; Westerhoff et al., 2018).

2.1.3 Radiological Contaminants in Water

The most commonly found radionuclides in water are those in the family of alpha-radiation emitters – uranium, radium, and radon (Canu et al., 2011). They are usually present in water from naturally occurring radionuclide sources in the earth that leach into the water supply. When water contaminated by radionuclides is consumed, a proportion of the radionuclides will accumulate in organs and tissues, which become damaged (Canu et al., 2011). Exposure to radionuclides in drinking water may result in nephrotoxicity, leukemia, and other cancers of the lung, breast, thyroid, bone, digestive organs, and skin (Canu et al., 2011; Federal-Provincial-Territorial Committee on Drinking Water of the Federal-Provincial-Territorial Committee on Health and the Environment, 2017).

2.1.4 Drinking Water Quality Guidelines and Standards

The World Health Organization (WHO) defines safe drinking water as that which does not represent a significant threat to health from infancy to the end of life (World Health Organization, 2017). Using Ontario as an example throughout, safe drinking water guidelines are published at the international level by the WHO and the federal level by the Government of Canada, while standards are published at the provincial level by the Government of Ontario

(Federal-Provincial-Territorial Committee on Drinking Water of the Federal-Provincial-Territorial Committee on Health and the Environment, 2017; Government of Ontario, 2018a; World Health Organization, 2017). The WHO's guidelines are the top-level water quality resource, serving as a reference for federal regulating bodies to adopt or adapt to their own guidelines (World Health Organization, 2017). The Canadian government's Federal-Provincial-Territorial Committee on Drinking Water then provides their own guidelines to the provinces and territories who determine how to apply them, as drinking water quality management falls under provincial or territorial jurisdiction in Canada. In the drinking water context, the terms "guidelines" and "standards" are not interchangeable – guidelines are not legally binding, while standards are. This means that out of the WHO, the Government of Canada, and the Government of Ontario, only the parameters defined by Ontario must be met as a legal requirement. In Ontario, this is a direct consequence of the Walkerton tragedy in 2000, in which seven people died and over 2,000 became ill from drinking water contaminated with *E.coli* and *Campylobacter jejuni* (O'Connor, 2002b). The resulting Crown Provincial Inquiry (the Walkerton Inquiry) prompted the creation of the Ontario Safe Drinking Water Act (2002) and the Ontario Drinking Water Quality Standards, referenced as O. Reg. 169/03. Besides being legally binding, the Ontario standards are more stringent than the federal guidelines. This may be because all provinces and territories must agree on the federal guidelines and expectations for quality differ across Canada based on industry and other historical factors.

2.1.5 Indigenous Models of Health

The Indigenous definition of human health and wellness differs from the Western biomedical model, which sees health as the absence of disease (FN Health Society, 2010; Harfield et al., 2018; Svenson & Lafontaine, 1999). In many Indigenous models of health, there

are four components to wellbeing – physical, mental, emotional, and spiritual health (FN Health Society, 2010; Graham & Stamler, 2010; Richmond et al., 2007; Traditional Wellness Working Group & First Nations Health Authority, 2012). These elements are often considered or likened to the four quadrants of the Medicine Wheel, an important symbol in Indigenous belief systems (FN Health Society, 2010; Graham & Stamler, 2010; Svenson & Lafontaine, 1999). Braids are also symbolic in Indigenous health models, which is where Barney's Braid Theory of Health emerged. The three strands of the braid represent the mind, body, and spirit, which weave together to form the complete braid (Victorian Order of Nurses for Canada, 2010). The terms "holism" or "holistic" are often used when describing the components of Indigenous health because each of the elements must be balanced or aligned and "free from complications, limitations, and frustrations" for a person to be in optimal health (FN Health Society, 2010; Graham & Stamler, 2010; Harfield et al., 2018; Richmond et al., 2007; Svenson & Lafontaine, 1999; Traditional Wellness Working Group & First Nations Health Authority, 2012).

Spiritual health, which is not typically referenced in Western views on health, can take many forms for Indigenous individuals. Some actions that promote spiritual health include expressing gratefulness, learning and speaking one's language, learning more about one's culture and values, practicing traditions, and using traditional medicines (FN Health Society, 2010; Graham & Stamler, 2010). A connection to nature and the land is also an important component of health; this has been referred to as the belief that "if the land is well the people will be well" (FN Health Society, 2010; Svenson & Lafontaine, 1999; Traditional Wellness Working Group & First Nations Health Authority, 2012).

2.1.6 Indigenous Water-Health Connection

To First Nations people, water is not just life-sustaining – water *is* life and water *has* life or a spirit (Anderson, 2010; Anderson et al., 2011; Arsenault et al., 2018; Craft, 2014; Human Rights Watch, 2016; McGregor, 2012, 2014). This is in opposition to the Western worldview of water as a resource or commodity that can be bought and sold, making it potentially difficult for those coming from a Western perspective to understand the depth of First Nations peoples' connection to water (Arsenault et al., 2018; Craft, 2014; McGregor, 2014; Phare, 2009). Since water is believed to be a living entity, it has the ability to form relationships and engage with others. Indigenous people have an important and long-lasting relationship with water; issues related to water quality and availability impact this relationship, thus impacting an essential facet of Indigenous life (Arsenault et al., 2018; Latchmore et al., 2018).

Indigenous women also have a unique relationship with water. They are seen as the keepers of water for many reasons, including the connection between water and childbirth (Anderson, 2010; Anderson et al., 2011; Chiefs of Ontario, 2008; Craft, 2014; Human Rights Watch, 2016; Lawless et al., 2015; McGregor, 2012). The Earth is also known as the "great Mother", with the waterways across her surface carrying water like the veins and arteries of humans and animals carry blood (Anderson et al., 2011). Although women have a special connection to water, there is a shared responsibility among all people to care for Mother Earth, including, and especially, her waters (Anderson, 2010; Anderson et al., 2011; Chiefs of Ontario, 2008; Craft, 2014; McGregor, 2012, 2014). Many Indigenous stories also support that water is the first medicine, has healing properties and, although the water of one's homeland is the most healing, all water carries spirit (Anderson, 2010; Anderson et al., 2011; Chiefs of Ontario, 2008; Craft, 2014; Sanderson, 2008; Wilson, Harris, Joseph-Rear, Beaumont, & Satterfield, 2019).

However, water is known to be dangerous when it's not able to serve its true purpose and can take life in the same way it can give life (Anderson et al., 2011; Craft, 2014).

Aside from these beliefs about water, there is also the relationship to Indigenous natural law, sacred law, or *inaakonigewin* to the Anishinaabe. These laws dictate how people relate to the Creator and to all things made by the Creator (Craft, 2014; McGregor, 2014). In these laws, people are responsible for things that give or sustain life, like water, and these responsibilities cannot be shirked or the ensuing relationship broken (McGregor, 2014). These laws are difficult to compare to Western laws. Natural laws cannot be changed because they come from the Creator, while Western laws evolve (Craft, 2014). Indigenous people have always had the rights and responsibilities that come with these laws because they started at time immemorial and at no point have they been forfeited (Phare, 2009). Additionally, natural laws are not meant to tell people what to do like Western laws; they are meant to be a guide used to make decisions about looking after all things in Creation (Craft, 2014). Western laws and water governance strategies are not seen as holistic enough or appropriate to look after water and protect human life (McGregor, 2012). Thus, there is a growing realization that Western laws are insufficient and Traditional Knowledge (TK) needs to be incorporated into water governance and management (Danard, 2010; McGregor, 2014).

2.2 Drinking Water Advisories

As outlined above, the Government of Ontario has drinking water standards that are legally binding. Thus, within Ontario, all municipal water systems must meet the provincial standards for drinking water or risk being issued a DWA. O. Reg 170/03: Drinking Water Systems is an Ontario regulation under the Safe Drinking Water Act which, most notably, describes the requirements for municipal and non-municipal water systems, and the duty of water

systems to meet the Ontario Drinking Water Quality Standards and to report adverse test results (Government of Ontario, 2018b).

Treatment requirements for drinking water exist for both primary disinfection, which occurs before water leaves the plant, and secondary disinfection, which protects water quality in the distribution system between the plant and the consumer (Government of Ontario, 2018c). In Ontario, water systems are issued "log removal credits" based on the treatment technologies available. Log credit requirements vary based on source water type – ground, surface, or groundwater under the direct influence of surface water. Regardless of the finished water quality, a system that does not have adequate log removal will be placed under a DWA. This means that although treated water samples may not return adverse results, the system poses a risk of illness due to inadequate treatment technologies.

Additionally, a DWA may be issued if a water system has the appropriate log credits, but the treated water leaving the plant does not meet Ontario Drinking Water Quality Standards. A situation where this may occur is when there is a non-biological contaminant in the water that a treatment system cannot remove easily, such as heavy metals or radioactive particles. DWAs are issued and rescinded by inspectors from the Ontario Ministry of the Environment and Climate Change and public health officials.

Only 1-2% of DWAs in Canada are Do Not Consume Advisories (DNCAs) or Do Not Use Advisories (DNUAs) – the remaining DWAs are BWAs (Environment and Climate Change Canada, 2018; Health Canada, 2015). Of all BWAs, data from 2017 indicate that 17% were due to *E.coli* or other microbiological contaminants while the vast majority (83%) were due to equipment and process-related issues (Environment and Climate Change Canada, 2018). Reasons for issuing a BWA that fall within this category may include: water main breaks or drops in

pressure, equipment failure or operational issues, changes in source water quality or quantity, and suspected or confirmed cross-connections with backflow (Environment and Climate Change Canada, 2018; Health Canada, 2015). Boiling water is not effective at removing non-volatile chemical or radiological contaminants – in these instances, a BWA is not appropriate and a DNCA or a DNUA is issued (Health Canada, 2015).

Depending on the circumstances in which a BWA was issued, there are several reasons why one is rescinded. These include repeat negative *E.coli* or microbiological tests, when water-borne illness outbreaks in the community have been resolved, or when equipment, distribution, or operational issues have been corrected (Health Canada, 2015).

2.2.1 Drinking Water Advisories in Indigenous Communities

DWAs can be issued for any community in Canada but are more complicated in an Indigenous context. This is because water systems in Ontario must meet the provincial standards rather than federal guidelines. However, despite Ontario residency, reserves are under federal jurisdiction because they are on Crown Land. Thus, the onus for water treatment and management falls on Indigenous communities and the Government of Canada, specifically Indigenous Services Canada (ISC), and Health Canada (HC) (Health Canada, 2017; Human Rights Watch, 2016). ISC support is primarily financial or technical, while HC advises and supports Chief and Council in making decisions about water quality and monitoring. This decision-making is based on the Guidelines for Canadian Drinking Water Quality, not the more comprehensive and stringent Ontario Safe Drinking Water Act (2002), although communities may opt to apply the latter (Health Canada, 2017). Additionally, since 2016, technical support for reserves in Ontario is provided through Ontario's Indigenous Drinking Water Projects Office (IDWPO), established through a tri-lateral technical working group. Ultimately, when a concern

arises, it is Chief and Council who are responsible for issuing a DWA in their community based on the information available and rescinding it after the problem has bee rectified (Health Canada, 2017). Although the Federal Government does have a Protocol for Safe Drinking Water for First Nations Communities and a Safe Drinking Water for First Nations Act, it has been noted that the complicated government structure involving ISC, HC, and IDWPO leads to insufficient drinking water regulation on reserves (Arsenault et al., 2018; Basdeo & Bharadwaj, 2013; Bradford et al., 2016; Human Rights Watch, 2016; Indigenous and Northern Affairs Canada, 2013). In addition, though many First Nations communities rely on surface water for their source water, it is difficult for them to engage in discussions about source water concerns because watersheds extend beyond reserves and are provincially managed (Human Rights Watch, 2016). Though communities are supposed to be involved in water management, in actuality Indigenous control is limited and, typically, the government spearheads decision-making (Human Rights Watch, 2016; McGregor, 2014).

In Ontario, some of the worst water quality is historically noted to be in Indigenous communities (O'Connor, 2002a). Water treatment systems have not been designed appropriately or to the same standards afforded to Canadians off-reserve (Human Rights Watch, 2016; O'Connor, 2002a). Between 2014 and 2015, 43% of First Nations water systems funded by what is now ISC were considered medium- to high-risk for producing unsafe drinking water should they encounter a problem (Environment and Climate Change Canada, 2016). Issues related to water on reserves range from deteriorating source water quality to regulatory problems and a lack of funding and support to maintain water infrastructure and ongoing water management (Human Rights Watch, 2016; Lawless et al., 2015; O'Connor, 2002a). Additionally, approximately 39% of Canada's Indigenous population lives in rural areas, a greater proportion

than in cities of any size (Statistics Canada, 2017). Globally, drinking water is found to be over three times more contaminated in rural areas than in urban ones (Bain et al., 2014; WHO & UNICEF, 2019). Indeed, between 2010 and 2017, the majority of BWAs issued in Canada were in communities with a population of less than 500 (Environment and Climate Change Canada, 2018; Galway, 2016). Additionally, small populations with small water treatment systems have advisories that last longer on average than larger systems (Thompson et al., 2017).

Between 2004 and 2013, 402 DWAs were issued in First Nation communities in Ontario alone, with approximately 70% of all First Nations under at least one DWA (Galway, 2016). A similar figure was seen from 2004 to 2014 across Canada, with 66% of all First Nations experiencing at least one DWA (Thompson et al., 2017). In 2011, First Nations were 2.5 times more likely to be under a BWA than non-Indigenous communities (Patrick, 2011). Reasons for DWAs on reserves are most often due to water treatment system design, function, or operation but may also be due to insufficient quality of the finished water (Galway, 2016; Human Rights Watch, 2016; Thompson et al., 2017). The Indigenous connection to water is also in opposition to many Western water treatment methods, which "disrespect the spirit of water" (Lawless et al., 2015). For this reason, treatment options that are most like natural purifying processes, such as sand filtration, are often preferred by Indigenous communities, but may not be appropriate or ideal for protection of health from a Western frame of reference (Lawless et al., 2015).

As of August 2019, 56 long-term (i.e. 1 year or longer) and 42 short-term DWAs in ISC-funded reserves in Canada were still standing (Indigenous Services Canada, 2019a, 2019c). An additional 11 drinking water advisories in non-public, non-ISC funded drinking water systems on reserves were also in place (Indigenous Services Canada, 2019b). Justin Trudeau made ending DWAs a "top priority" during his campaign for Prime Minister in 2015 (The Canadian Press,

2015). This may be due, in part, to the national attention DWAs had garnered in the years prior. On World Water Day in 2016, newly appointed Prime Minister Trudeau announced an almost $4.6 billion investment in reserves, with $1.8 billion specifically going towards water and ending long-term DWAs by 2021 (Arsenault et al., 2018; Human Rights Watch, 2016; Morneau, 2016). This was followed by the dissolution of Indigenous and Northern Affairs Canada and the creation of both the Department of Indigenous Services Canada and the Department of Crown-Indigenous Relations and Northern Affairs in 2017, which have a greater focus on relationship-building, Indigenous autonomy, and improving service delivery on reserves (Government of Canada & Trudeau, 2017). Overall, 81 long-term DWAs had been lifted since November 2015 (Indigenous Services Canada, 2019a). Prime Minister Trudeau and the Canadian government's goal is to have all of these long-term drinking water advisories lifted within 2 years, by March 2021.

Issues related to water management can be traced back to the early colonization of Indigenous lands and people, beginning with the Indian Act in 1876 (Basdeo & Bharadwaj, 2013; Patrick, 2011). Since the Indian Act, many pieces of legislation, reports, and other government responses have been proposed to manage water on reserves, not all well received. Figure 1 illustrates a non-exhaustive timeline of these measures and reports over the past 15 years. See Appendix A for a full description of each timeline event.

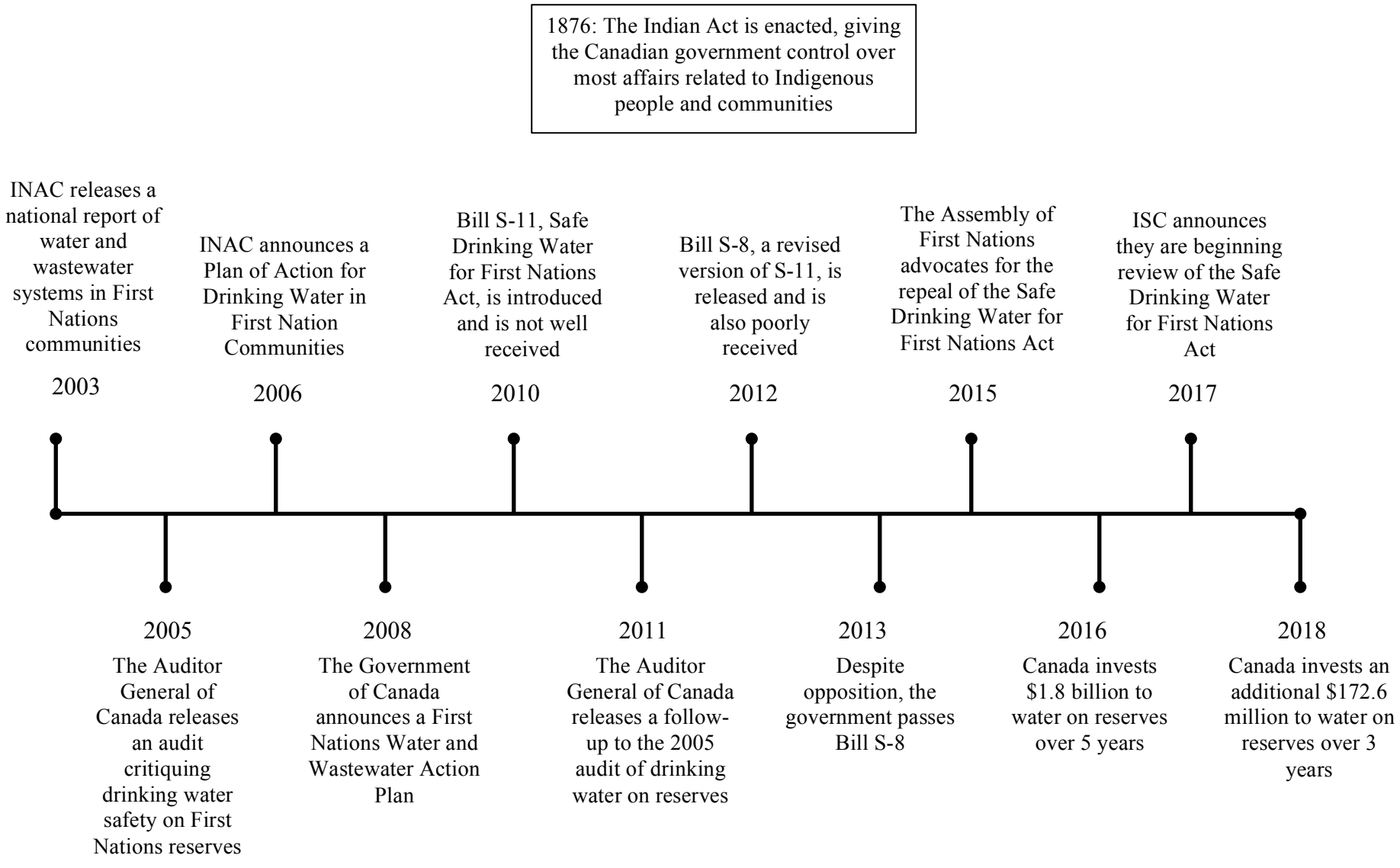

Figure 1: Timeline of legislation, reports, and government responses to drinking water management on reserves in Canada

2.3 Community-Based Participatory Research Methods

CBPR was established in the 1940s, when the psychologist Kurt Lewin started discussing action research as a way to overcome social inequalities in what was coined the "Northern tradition" (Ferreira & Gendron, 2011). He challenged the belief that researchers must distance themselves from the community of interest to be objective, or that they had to be objective at all, which was a central tenet of the dominant positivist paradigm (Bharadwaj, 2014; Ferreira & Gendron, 2011; Hartwig et al., 2006; Holkup et al., 2004; Wallerstein & Duran, 2008). In the 1960s, crises within the academic, societal, and political spheres and tensions in the relationship between them launched a search for new ways of doing research that addressed intellectual ownership, power dynamics, and the role of the researcher and the community (Wallerstein & Duran, 2008). In the 1970s, Paulo Freire brought participatory research to the forefront in South America with his belief that communities should be the ones to identify what issues needed to be addressed and how best to do this, beginning the shift from doing research *on* communities to doing it *with* them (Hartwig et al., 2006; Wallerstein & Duran, 2008). Freire was also a proponent of the "Southern tradition": emancipatory research which opposes oppression, colonizing practices and the control over knowledge by those with power (Ferreira & Gendron, 2011; Wallerstein & Duran, 2008). Freire's participatory research was first brought to Canada by Budd Hall in the mid-1970s and, later, to the United States by Peter Park (Ferreira & Gendron, 2011). Now, as Lewin and Freire established, it is recognized that research does not have to be, and in fact is not, neutral or unbiased; it can be used for emancipation and social justice ends just as it can for oppression.

In the field of participatory and action research, there are many interchangeably used terms with essentially the same meaning and same philosophical underpinnings. All are an

approach to research that includes community partnership and is driven by community wants and needs. All involve including people with lived experience on the research team and working towards action-oriented outcomes. Other than CBPR, some of these terms may include community-based research, action research, participatory research, participatory action research, or tribal participatory research (Holkup et al., 2004). Typically, this approach to research can be viewed along a continuum, with the Northern tradition on one end and the Southern on the other, though some researchers do not differentiate between Lewinian action research and Freireian participatory research (Ferreira & Gendron, 2011; Holkup et al., 2004; Wallerstein & Duran, 2008). The term community-based participatory research is employed in the context of this research because of its use in the field of health and health disparities research (Wallerstein & Duran, 2008; E. Wilson et al., 2018). It is also situated closer to the Southern tradition end of the research spectrum, which is purposefully decolonizing and more relevant to research with marginalized populations. It should be noted that CBPR is not merely a research methodology – rather, it is an approach to doing research that influences all aspects of the process and from which methodologies flow (Burke et al., 2013; Ferreira & Gendron, 2011).

2.3.1 Key Principles of Community-Based Participatory Research

Israel et al. (1998) identified the first well-defined set of CBPR principles from their experiences in public health. In the years that followed, those principles were refined to the sentinel nine principles of CBPR used today (Israel et al., 1998, 2003):

1. CBPR recognizes community as a unit of identity.
2. CBPR involves systems (partnership) development through a cyclical and iterative process.
3. CBPR facilitates collaborative, equitable partnership in all phases of the research.

4. CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners.
5. CBPR promotes co-learning and capacity-building among all partners.
6. CBPR builds on strengths and resources within the community.
7. CBPR emphasizes local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease.
8. CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process.
9. CBPR involves a long-term process and commitment.

Within these tenets are many elements that need to be considered when employing a CBPR approach, including partnership and participation, reciprocity, power dynamics, empowerment, and community capacity building. True partnership between academic researchers and communities is critical and ultimately results in research outcomes that are relevant to the very individuals seeking knowledge from research (Baydala et al., 2013; Bharadwaj, 2014; Laycock et al., 2011; Wallerstein & Duran, 2008). In CBPR, it is important to be wary of "pseudo-participation", which is a sense of community participation that, in fact, does not exist because the community is "slowly coerced into going along with the researchers, but without real commitment" (Arieli et al., 2009). Reciprocity, or exchange, fosters equality and levels power differences between the research team and community, best accomplished by devoting time and resources to building long-term relationships (Maiter et al., 2008). This is important in relation to power dynamics, which may be imbalanced between academic partners and community members based on race, gender, education, or other socioeconomic factors similar to the social determinants of health (Bryant et al., 2011; Wallerstein & Duran, 2008).

CBPR requires transparency in power relationships – recognizing the powers and privileges partners do or do not have and addressing them accordingly, usually by recognizing that people with lived experience have different but equal knowledge (Maiter et al., 2008; Wallerstein & Duran, 2008). Being blind to these differences can end up perpetuating oppressive narratives. In relation to empowerment, Arieli et al. (2009) write that participatory action research is:

> based on the belief that the oppressed and relatively powerless can be empowered by helping them become aware of their own resources, by increasing their problem solving capacity, and by becoming more self-reliant and less dependent (p.264)

However, in some instances, researchers may need to use their social capital to advocate for reform alongside the community (Arieli et al., 2009). To achieve this, CBPR should be designed to inherently diminish the barriers that have kept marginalized populations from actively engaging in research (Etmanksi et al., 2014). Finally, for community capacity building, it should be noted that CBPR isn't done to "help" communities, but to liberate individuals, let them take back power and knowledge, and for social change (Warr et al., 2011). Involving community provides an opportunity for them to engage with people within and outside of their community and gain new skills and knowledge while sharing the skills and expertise that they do have (Warr et al., 2011).

2.3.2 Ethics of Community-Based Participatory Research

When working on a CBPR project with partners from a variety of backgrounds and with diverse experiences and degrees of power, one is likely to encounter ethical problems and challenges (Banks et al., 2013). Thus, researchers must consider and address the ethics of working with communities, especially marginalized or under-served ones, and respect ethical principles within the community (Buchanan et al., 2007; E. Wilson et al., 2018). Some ethical

challenges in CBPR may surround partnership and power, roles and obligations, ownership and dissemination of data, confidentiality, and ethics review processes (Banks et al., 2013; Damianakis & Woodford, 2012; E. Wilson et al., 2018). Relating to the ethics of partnerships and power, there may be disagreements surrounding values, goals, and expectations between academic and community stakeholders and on how to approach addressing them (Banks et al., 2013; E. Wilson et al., 2018). For roles and obligations, the nature of CBPR is such that individuals may experience a sense of dissonance when taking on the role of both researcher and community member or friend, and find it difficult to compartmentalize the two (Banks et al., 2013). Additionally, because of their role in the research and relative social capital, researchers from academia may find it difficult to separate themselves from decisions made while in that role and be left with lasting regret or guilt from their choices (E. Wilson et al., 2018). Ethical tensions may also arise about what data to publish, where to publish, and authorship based on who "owns" the data (Banks et al., 2013; Holkup et al., 2004). When communities are small and relationships exist between researchers and participants outside of the project, it may be more difficult to assure confidentiality than in non-community-based research (Damianakis & Woodford, 2012; Holkup et al., 2004). Furthermore, there is little precedent for navigating ethics when some participants may want to be named alongside their stories, while others may not (Banks et al., 2013). Finally, ethics review boards may not be adequately equipped to evaluate the ethics of CBPR because relationships, tensions, and challenges are not as straightforward as in traditional research and because the ethics of the academy may not align with the ethics of the community; researchers familiar with CBPR echo this lack of understanding by review boards (Banks et al., 2013; E. Wilson et al., 2018). Though this is not an exhaustive list, it highlights some of the many ethical tensions anticipated when engaging in CBPR.

2.3.3 Community-Based Participatory Research with Indigenous Populations

Research by and with Indigenous people and communities has been, and in many cases still is, guided by a non-Indigenous, Eurocentric, and colonial worldview (Castleden et al., 2012; Schnarch, 2004). Colonization is closely tied to racism against Indigenous people, systemic oppression, and control over when, how, and if Indigenous cultural practices, ceremonies, and opinions can be expressed (Victor, 2007). These communities have been plagued by "helicopter" researchers, who enter a community only for as long as data collection necessitates and do not engage the community before, during, or after the research process (Bharadwaj, 2014; LaVeaux & Christopher, 2009; Wallerstein & Duran, 2008). Indigenous communities have identified several research concerns, including lack of involvement and tokenism, irrelevant research outcomes, misalignment of values, pressure to participate, a lack of data ownership, no capacity building or transfer of skills, disrespectful practices, and little recognition or compensation for their investment in the research (ITK and NRI, 2006; Koster et al., 2012; Schnarch, 2004). Therefore, this population requires a research approach that includes members of the community as fundamental research partners from inception to completion and beyond.

CBPR is one approach to doing research with Indigenous people, preferred, in part, because it involves true community participation, education, action, and capacity-building in the pursuit and production of knowledge (Bharadwaj, 2014; Castleden et al., 2012; Holkup et al., 2004; Koster et al., 2012; Wallerstein & Duran, 2003). Although CBPR is not exclusively Indigenous, its approaches are consistent with Indigenous research paradigms (Koster et al., 2012).

The four core values of research with Indigenous communities are known as the "four R's": respect, responsibility, reciprocity, and relevance (Kirkness & Barnhardt, 1991). They are widely referred to in the literature and by researchers as foundational principles in CBPR with

Indigenous people and communities (Arsenault et al., 2018; Castleden et al., 2012; Koster et al., 2012; Kurtz, 2013; Morton-Ninomiya & Pollock, 2017; Snow et al., 2016). A fifth R – relationships – has also been suggested (Jull et al., 2018). There is clear overlap between these core values and the nine sentinel tenets of CBPR, especially in terms of reciprocity, relevance, and relationships.

Many researchers have sought to address the ongoing need for further tenets, principles, considerations, and best practices in Indigenous research. Six guiding principles for engaging in research with Indigenous communities, which could be applicable to CBPR, have been developed (Snow et al., 2016). More recently, research from Arsenault et al. has offered 15 recommendations of best practices in Indigenous research (Arsenault et al., 2018).

Additionally, Israel et al.'s sentinel CBPR principles have been contextualized for research in Indigenous communities, and an additional nine principles tailored to the Indigenous context have been added, including (LaVeaux & Christopher, 2009):

1. Acknowledge historical experience with research and with health issues and work to overcome the negative image of research;
2. Recognize tribal sovereignty;
3. Differentiate between tribal and community membership;
4. Understand tribal diversity and its implications;
5. Plan for extended timelines;
6. Recognize key gatekeepers;
7. Prepare for leadership turnover;
8. Interpret data within the cultural context; and,
9. Utilize Indigenous ways of knowing.

These additional considerations ensure that CBPR is conducted in a meaningful way with communities, and that the interests of Indigenous populations are not lost within the research process. The work of LaVeaux and Christopher (2009) has since been expanded by presenting the additional nine Indigenous principles in real-life research project examples (Christopher et al., 2011).

In the Canadian context, CBPR with Indigenous people may further be guided by the principles of Ownership, Control, Access, and Possession (OCAP). OCAP is a reference for researchers navigating the ethics of research with Indigenous people in light of colonial research misconduct by providing ethical considerations beyond those required by research ethics boards when conducting research with First Nations people and communities (Schnarch, 2004). It should be noted that OCAP is not law, and communities or researchers may have their own terms of engagement that they choose to espouse. However, OCAP may be particularly helpful for communities that do not use Band Council Resolutions, Research Agreements, or their equivalent, as part of the engagement process.

A five-phase, non-linear framework for building partnerships with First Nations people has also been developed to help researchers engage in CBPR with Indigenous communities (Bharadwaj, 2014). At each of these phases – pre-research, community consultation, community entry, research, and research dissemination – academic researchers are challenged to transcend the traditional Western research practices they are familiar with. This involves a fundamental re-evaluation of their research motivations, which may be for themselves or for the community, with or without social change in mind, and, of equal importance, their values.

2.4 Gaps in Literature

Most studies on DWAs in First Nation communities in Canada only look at the causes and proposed solutions from a Western Science perspective. Little data exist from the perspective of community members, particularly in the form of TK, and from people close to the community. Additionally, few research projects have been conducted using a community-based participatory approach to partnering with First Nations on issues of water quality and these have mainly been undertaken in Western Canada.

This study aims to address these gaps and explore the impact of DWAs on health and wellbeing from the community perspective. Additionally, it seeks to provide considerations to community leadership for DWA management based on the experiences and beliefs of their community members.

Chapter Three: "People deserve the right to have safe water - end of story": One Indigenous Community's Perceptions of Ongoing Boil Water Advisories and Pathways Forward

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Keywords: First Nations; Indigenous; Drinking Water; Water Advisories; Community-Based Participatory Research; Traditional Knowledge; Canada

3.1 Introduction

In Ontario, Canada, some of the worst quality drinking water is found in Indigenous (on-reserve) communities (O'Connor, 2002a). Issues range from deteriorating water quality to regulatory problems and a lack of support for water management and accompanying infrastructure (Human Rights Watch, 2016; Lawless et al., 2015). Further, it has been noted that water treatment systems have not been designed appropriately or to the same standards afforded to Canadians off-reserve (Human Rights Watch, 2016; O'Connor, 2002a). Between 2014 and 2015, 43% of First Nations water systems funded by what is now Indigenous Services Canada (ISC) were considered medium- to high-risk for producing unsafe drinking water should they encounter a problem (Environment and Climate Change Canada, 2016).

When water is known, or suspected, to be unsafe for human consumption, communities are placed under a Drinking Water Advisory (DWA). The type of DWA depends on the nature of the problem, with advisories ranging from boiling tap water before consuming to not consuming or using tap water under any circumstances. DWAs can be issued for any community in Canada but are more complicated in an Indigenous context. This is because water systems in Ontario must meet the provincial standards rather than federal guidelines. However, despite Ontario residency, reserves are under federal jurisdiction because they are on Crown Land. Thus, the

onus for water treatment and management falls on Indigenous communities and the Government of Canada, specifically ISC and Health Canada (HC) (Health Canada, 2017; Human Rights Watch, 2016). ISC support is primarily financial or technical, while HC advises and supports Chief and Council in making decisions about water quality and monitoring. This decision-making is based on the Guidelines for Canadian Drinking Water Quality, not the more comprehensive and stringent Ontario Safe Drinking Water Act (2002), although communities may opt to apply the latter (Health Canada, 2017). Additionally, since 2016, technical support for reserves in Ontario is provided through Ontario's Indigenous Drinking Water Projects Office (IDWPO), established through a tri-lateral technical working group. Ultimately, when a concern arises, it is Chief and Council who are responsible for issuing a DWA in their community based on the information available and for rescinding it after the problem has been rectified (Health Canada, 2017). Although the Federal Government does have a Protocol for Safe Drinking Water for First Nations Communities and a Safe Drinking Water for First Nations Act, it has been noted that the complicated government structure involving ISC, HC, and IDWPO leads to insufficient drinking water regulation on reserves (Arsenault et al., 2018; Basdeo and Bharadwaj, 2013; Bradford et al., 2016; Indigenous and Northern Affairs Canada, 2013).

The Indigenous framing of human health and wellness differs from the Western biomedical model, which sees health as the absence of disease (FN Health Society, 2010; Harfield et al., 2018). In many Indigenous models of health, there are four components to wellbeing – physical, mental, emotional, and spiritual health (FN Health Society, 2010; Traditional Wellness Working Group & First Nations Health Authority, 2012). The terms "holism" or "holistic" are often used when describing the four components of Indigenous health because each of the four elements must be balanced or aligned and "free from complications,

limitations, and frustrations" for a person to be in optimal health (FN Health Society, 2010). A connection to nature and the land is also an important component of health; this has been explained as "if the land is well the people will be well" (FN Health Society, 2010).

To First Nations people, water is not just life-sustaining – water *is* life and water *has* life or a spirit (Anderson et al., 2011; Arsenault et al., 2018; McGregor, 2014). Since water is considered to be a living entity, it has the ability to form relationships and engage with others. Although women have a special connection to water, there is a shared responsibility among all people to care for Mother Earth, including, and especially, her waters (Anderson et al., 2011; Craft, 2014; McGregor, 2014). Indigenous people have an important and long-lasting relationship with water; issues related to water quality and availability impact this relationship, thus impacting an essential facet of Indigenous life (Latchmore et al., 2018). Many Indigenous stories also support that water is the first medicine and has healing properties (Sanderson, 2008; N. J. Wilson et al., 2019). However, water is recognized to be dangerous when it's not able to serve its true purpose and can take life in the same way it can give life (Anderson et al., 2011; Craft, 2014).

Between 2004 and 2013, 402 DWAs were issued in First Nation communities in Ontario alone, with approximately 70% of all First Nations under at least one DWA (Galway, 2016). In 2011, First Nations were reportedly 2.5 times more likely to be under a Boil Water Advisory (BWA) than non-Indigenous communities (Patrick, 2011). As of August 2019, 56 long-term (i.e. 1 year or longer) and 42 short-term DWAs in ISC-funded reserves in Canada were still standing (Indigenous Services Canada, 2019a, 2019c). An additional 11 drinking water advisories in non-public, non-ISC funded drinking water systems on reserves were also in place (Indigenous Services Canada, 2019b). Despite DWAs impacting many people living on-reserve in Ontario,

currently little is known about First Nation residents' experiences living with a BWA. In this study, we present information shared with us by members of a community who have lived with BWAs on and off for many years, and a long-term BWA since 2017. This work highlights their thoughts, feelings, and impacts from living with a BWA and their outlook toward the future. The goal of this paper is to unpack and explore the BWA from the perspective of community members and provide considerations for current and future BWA management based on the community's understanding of appropriate and meaningful pathways forward.

3.1.1 Positionality

This statement of positionality is inspired by that of von der Porten, de Löe, and McGregor (von der Porten et al., 2016). It is recognized that who we are and where we come from drives our interests, fields of study, and collaborative approaches. Two authors (D. Skead and K. Skead) are Indigenous Anishinaabe, with a broad understanding of Indigenous Traditional Knowledge (TK) and experience living under a BWA. Three authors (K. Lucier, S. Dickson-Anderson, and C. Schuster-Wallace) are non-Indigenous, allied, settler scholars who study population and public health, hydrology, water security, and water and health. The authors recognize that research by and with Indigenous people and communities has been, and in many cases still is, guided by a non-Indigenous, Eurocentric, and colonial worldview (Schnarch, 2004). Colonization is closely tied to racism against Indigenous people, systemic oppression, and control over when, how, and if Indigenous cultural practices, ceremonies, and opinions can be expressed (Victor, 2007). Indigenous communities have identified several research concerns, including lack of involvement and tokenism, irrelevant research outcomes, misalignment of values, pressure to participate, a lack of data ownership, no capacity building or transfer of skills, disrespectful practices, and little recognition or compensation for their investment in the research

(ITK and NRI, 2006; Schnarch, 2004). Therefore, this population requires a research approach that includes members of the community as fundamental research partners from inception to completion and beyond. As such, this study is situated in community-based participatory research (CBPR) approaches tailored for the Indigenous context in Canada.

3.1.2 Community-Based Participatory Research

CBPR is not a prescriptive research methodology – rather, it is an approach to conducting research that influences all aspects of the process and from which methodologies flow (Burke et al., 2013). CBPR is one approach to doing research with Indigenous people, preferred, in part, because it involves true community participation, education, action, and capacity-building in the pursuit and production of knowledge (Bharadwaj, 2014; Koster et al., 2012). Although CBPR is not exclusively Indigenous, its approaches are consistent with Indigenous research paradigms (Koster et al., 2012).

The four core values of research with Indigenous communities are known as the "four R's": respect, responsibility, reciprocity, and relevance (Kirkness & Barnhardt, 1991). They are widely referred to in the literature and by researchers as foundational principles in CBPR with Indigenous individuals and communities although they continue to evolve, particularly through the incorporation of additional principles and best practices taken from Indigenous research (Arsenault et al., 2018; LaVeaux & Christopher, 2009; Snow et al., 2016). These additional considerations ensure that CBPR is conducted in a meaningful way with communities, and that the interests of Indigenous populations are not lost within the research process. Despite the negativity associated with much of the research previously undertaken in their communities, Indigenous people recognize that research done "the right way" is necessary for growth and evidence-based decision-making (ITK and NRI, 2006).

3.2 Methods

Residents of an Anishinaabe First Nations community in Ontario, Canada are currently under a BWA for their drinking water as a result of a water treatment plant system that does not meet provincial standards. The Lake of the Woods waterbody where they live holds significant cultural and traditional value for the community even though water quality has been steadily declining. This community faces many infrastructure, source water protection, and water management challenges and has lacked the resources to deal with these barriers. Through discussions with Chief and Council around water-related challenges facing the community and which were most pressing, the research question was determined: From the perspective of the community, what are the consequences and costs of a BWA in a First Nation population in Northern Ontario in 2018?

Methodological choices were driven by the principles of CBPR and situated in anti-colonial approaches to research. Two data collection methodologies were employed: questionnaires and interviews. Data collection instruments were finalized in partnership with Chief and Council and all data collection was completed together with a community research associate. The engagement of this individual, with lived experience in the community, in the research was critical to ensuring ongoing research relevance and community support as well as increasing the long-term community capacity to engage in research and the empowerment of self (Vaughn et al., 2018). Prior to engagement with the community, community Elders conducted a water ceremony. The data collection process started with a community feast, during which the project genesis, process, and participation were explained, and members given the opportunity to ask questions. This research received ethics approval from the McMaster Research Ethics Board

(Certificate #2017 197 – Appendix B) and the University of Saskatchewan Research Ethics Board (Certificate #504 – Appendix C).

3.2.1 Questionnaires

Each person 18 or older living in the community was eligible to participate through the questionnaire. Questionnaire packages were developed by the academic partners with guidance from community partners. The questionnaire consisted of four short sections that focused on: 1. basic information about the respondent (e.g., age; education); 2. knowledge of the BWA (e.g., How did the respondent hear about the BWA? Did they seek more information about the BWA?); 3. water sources and uses before and during the BWA (e.g., What was/is the source of respondent's drinking water? What was/is the source of water for food preparation?); and, 4. impacts of the BWA upon the respondent's life (e.g., What was the financial impact of the BWA on respondent and their family? What was their emotional response to the BWA?). For full questionnaire, see Appendix E. Questionnaire packages were first distributed at the community feast, and then house-to-house. To ensure that each person was given only one questionnaire, a log was kept with the name of each recipient and, if possible, their street and house number. The study team was available to assist with completing the questionnaires through interviews for anyone who requested. An Ojibwe translator was also available, if necessary. During these questionnaire interviews, the study team would ask the written questions aloud and record participants' verbal responses on the physical questionnaires. Respondents could drop the surveys off at the Band Office or give them to the study team when they went house-to-house. Questionnaires were returned in envelopes provided to protect anonymity, particularly if community members decided to return a blank questionnaire.

At the community's request to incentivize return of completed questionnaires, participants could be entered into a raffle for one tablet computer by completing the appropriate opt-in section of the questionnaire consent form. Respondents were then entered into a draw. The winning participant was drawn by a non-community member working out of the Band Office and was discreetly contacted and given their prize to maintain the anonymity of participants.

Completed questionnaires were scanned and uploaded to a password-protected server at McMaster University. Completed consents were scanned and uploaded to the same server in a separate folder, to ensure the anonymity of the participants. Data from completed questionnaires were manually entered into an Excel file in preparation for coding and analysis. Hard copy completed questionnaires and consents were then shredded.

3.2.2 Interviews

Community partners and Chief and Council identified key informants (KIs) based on whom they perceived could best provide contextual information about the drinking water issues in their community. Within this context, gender and age representation were targeted to be as diverse and inclusive as possible. KIs were both internal and external to the community. Elders were also identified as key holders of Traditional Knowledge (TK). Community leadership identified these individuals. Elders were offered tobacco when asked to participate in an interview and given a $125 honorarium at the end of their interviews as compensation for the TK shared.

Twelve interview questions or prompts were developed by the academic partners, with feedback from community partners. For full interview questions and prompts, see Appendix F. KIs and Elders were offered interviews either in-person, over the phone, or over Skype; all but one interview was conducted in-person. KIs and Elders were audio-recorded when consented,

although some chose not to be audio-recorded. In these instances, the study team made every effort to capture interviews in their notes. Interview recordings were uploaded to a password-protected server at McMaster University, as were scanned interview notes. Recordings were then deleted from recording devices. Interviews were transcribed with the help of Dragon NaturallySpeaking Software, de-identified, and stored on the same password-protected server, at which time the recordings were destroyed.

Interview transcripts were imported into NVivo 12 for analysis. Interviews were coded according to questions asked in interviews and emerging themes. Data were coded by the lead author with assistance from co-authors. An inductive approach was taken to develop the final code set once the initial coding hierarchy, based on questions asked in the interview script, was created (Appendix G). KI and Elder interviews were coded separately as each offered unique perspectives.

3.2.3 Co-Analysis

The academic partners synthesized preliminary findings between November 2018 and May 2019. These preliminary findings were presented in June 2019 for co-analysis and discussion of themes after a second water ceremony. An inductive approach to data analysis was used to look for emerging themes rather than assigning data to pre-existing themes. Two meetings were held to this end: a presentation of synthesised data and discussion with 1. Chief and Council and, 2. Elders. The Elders discussion of the data was accompanied by the giving of tobacco and a feast. Prompting questions to guide discussion included: “Does this make sense?”, “What jumps out and why?” and “Why do you think community members said what they said?”. During analysis, data were disaggregated by gender to illustrate any differences between men and women. Data were not disaggregated by age because some of the age sub-groups were very

small and not reflective, proportionally, of that age group. The final results were reported back to the community at another feast.

3.3 Results

Two hundred and twenty-six questionnaires were distributed; 44 (19.5%) were returned completed and 11 (4.9%) were returned blank. Fifteen Elders and 22 KIs were contacted through written and verbal invitation. In total, 8 Elders and 16 KIs participated in 20 interviews, as some non-Elder KI interviews had more than one person participating. The questionnaire sections were used to frame the data analysis. The data are presented according to five major themes explored through data collection: 1) Community Context 2) Knowledge of BWAs; 3) Living Under a BWA; 4) Water and Health; and, 5) Pathways Forward.

3.3.1 Community Context

3.3.1.1 Demographics: Demographic information for questionnaire respondents be found in Table 1. Demographic information for KIs and Elders was not collected. Questionnaire respondents were split fairly evenly in terms of gender, with 43% identifying as male and 55% identifying as female. The majority of respondents (75%) were over the age of 40 and had lived on the reserve for at least 10 years (84%). Just over half of respondents (55%) had lived elsewhere at some point in time, mainly for work or studies. Almost two-thirds of respondents (57%) indicated that their highest level of formal education was high school/GED and one-fifth had completed post-secondary education (21%). Respondents also commented on many traditional forms of education, including family knowledge (9%), Elders (5%), medicine teachings (5%), and living off the land (5%). Census data from 2016 indicated that 300 people 15 years of age or older lived on the reserve. Of those, 80 (27%) were between 15 and 24 years old and 155 (52%) were 35 years of age or older (Statistics Canada, 2018). This indicates that,

although every effort was taken to provide all adults with the opportunity to participate, the average age of the sample was older than the average age of the eligible population.

Table 1: Questionnaire Respondent Demographic Information (excluding those who left a question blank or preferred not to answer)

	n (%)
Gender (N=44)	
Male	19 (43)
Female	24 (55)
Age (N=44)	
18-29	4 (9)
30-39	6 (14)
40-49	14 (32)
50+	19 (43)
Years Living in Community (N=44)	
<1 year	0 (0)
1 to <3 years	1 (2)
3 to <5 years	2 (5)
5 to <10 years	2 (5)
≥10 years	37 (84)
Lived Elsewhere? (N=44)	
Yes	24 (55)
No	18 (41)
Highest Formal Education (N=44)	
Elementary School	0 (0)
High School/GED	25 (57)
Vocational Training	3 (7)
University/College	9 (21)
Graduate Degree/Professional Credentials	2 (5)

3.3.1.2 Water Sources and Uses (Table 2): When asked about their water sources and uses both when under and not under a BWA, over half of responses (58%) indicated that participants use tap water for cleaning their teeth, which is a documented disease transmission pathway if water contamination is suspected. Approximately one-quarter of responses indicated that participants use tap water for food preparation and cooking (23% and 27%, respectively), with 6% using lake water, and 1 (2%) using boiled water for both tasks. Three KIs identified that they could boil their tap water to make food, soup, coffee etc. With this additional context, it is difficult to

ascertain whether the 23% and 27% of questionnaire respondents were referring to using tap water for all food preparation and cooking, which could pose a health risk, or just to foods that could be boiled.

Table 2: Water Sources and Uses (excluding those who indicated a question was not applicable or who entered invalid data)

	Tap %	Lake %	Bottled %	Well %	Spring %	Boiled %	Blank %
Where do you get your water for the following purposes? Check all that apply.							
Drinking							
No BWA (N=52)	27	6	63	2	0	0	0
BWA (N=46)	9	0	87	2	0	0	2
Food Preparation							
No BWA (N=47)	43	9	45	2	0	0	2
BWA (N=48)	23	6	65	2	0	2	2
Cooking							
No BWA (N=49)	45	8	43	2	0	0	0
BWA (N=48)	27	6	60	2	0	2	2
Cleaning Teeth							
No BWA (N=49)	61	14	22	2	0	0	0
BWA (N=48)	58	8	29	2	0	0	2
Hand Washing							
No BWA (N=50)	70	22	6	2	0	0	0
BWA (N=47)	70	15	11	2	0	0	2
Bathing							
No BWA (N=50)	74	22	2	2	0	0	0
BWA (N=47)	75	15	6	2	0	0	2
Cleaning							
No BWA (N=50)	76	22	0	2	0	0	0
BWA (N=46)	76	13	7	2	0	0	2
Laundry							
No BWA (N=49)	78	20	0	2	0	0	0
BWA (N=46)	80	13	0	2	0	0	2
Ceremonies							
No BWA (N=47)	32	6	26	2	2	0	11
BWA (N=46)	17	7	33	2	2	0	15

3.3.2 Knowledge of BWAs

3.3.2.1 Notification: Many avenues of BWA notification were identified, including: the Band Office (18%) and community fliers, posters, or bulletins (16%). A significant number of respondents indicated that they always consider themselves under a BWA (14%); "[I] never drink uh, water from the tap because [I] don't know whether it's uh, it's on or not" (E9). It should be noted that a lack of access to the Internet was perceived to be a barrier to receiving BWA notifications.

3.3.2.2 Causes: Elders and KIs had various opinions on the cause of the BWA on the reserve, including the fact that the water wasn't "fresh" or potable, although this is actually the reason and not the cause. Causes given included treatment plant issues such as ageing equipment, mechanical breakdowns, a lack of regulation, and a lack of qualified personnel to run the plant (n=5), as well as pollution from people and their waste, garbage, and boats (n=10). One Elder summed this up by saying "too many of us are using the lakes" (E9). Other causes given are collectively described as water management challenges (i.e., dams, eutrophication) (n=3) or broader governance issues (n=2): "government…uhh a lack of direction, a lack of money." (KI15).

3.3.2.3 Approved Practices (Table 3): Respondents expressed the most uncertainty in whether they should boil their tap water before bathing babies and young children (27% did not know), use a Brita filter to decontaminate tap water (23% did not know), and if the BWA applies only to their tap water (11% did not know). Some respondents identified engagement in risky behaviours in terms of believing that they could drink their tap water as long as it is clear (16%), use their tap water to make ice (16%), or use their tap water to clean their teeth (71%), which is advised against under a BWA. When looking at knowledge of practices by gender, we see that men know the practices they should be following about the same or more often than women. For example,

84% of men but only 67% of women knew they could not drink their tap water even if it was clear and twice as many men than women knew they could not use their tap water to brush their teeth.

Table 3: Knowledge of Practices When Under a BWA, by Gender (excluding those who indicated a question was not applicable or who entered invalid data)

	Yes n (%)	No n (%)	I Don't Know n (%)	Blank n (%)
YES or NO during BWA (N=44)				
Applies only to my tap water				
Male (N=19)	14 (74)	5 (26)	0 (0)	0 (0)
Female (N=24)	14 (58)	1 (4)	5 (21)	4 (17)
I can drink my tap water as long as it is clear				
Male	3 (16)	16 (84)	0 (0)	0 (0)
Female	4 (17)	16 (67)	4 (7)	0 (0)
I should not drink my tap water				
Male	15 (79)	3 (16)	0 (0)	0 (0)
Female	14 (58)	8 (33)	1 (4)	1 (4)
I should boil my tap water to prepare food				
Male	15 (79)	3 (16)	0 (0)	0 (0)
Female	17 (71)	5 (21)	2 (8)	0 (0)
I can use my tap water to make ice				
Male	3 (16)	16 (84)	0 (0)	0 (0)
Female	4 (17)	19 (79)	1 (4)	0 (0)
I can bathe/shower using my tap water				
Male	18 (95)	0 (0)	1 (5)	0 (0)
Female	23 (96)	1 (4)	0 (0)	0 (0)
I can give my babies and young children a sponge bath using my tap water				
Male	10 (53)	4 (21)	2 (11)	3 (16)
Female	15 (63)	5 (21)	2 (8)	1 (4)
Before preparing meals, it is okay to wash my hands with tap water				
Male	14 (74)	5 (26)	0 (0)	0 (0)
Female	20 (83)	2 (8)	2 (8)	0 (0)
I can use my tap water to clean my teeth				
Male	12 (63)	5 (26)	1 (5)	1 (5)
Female	18 (75)	3 (13)	3 (13)	0 (0)
I should boil my tap water before I drink it				
Male	15 (79)	3 (16)	0 (0)	1 (5)
Female	18 (75)	5 (21)	1 (4)	0 (0)

I should boil my tap water before I bath my babies and young children				
Male	7 (37)	8 (42)	3 (16)	1 (5)
Female	4 (17)	8 (33)	9 (38)	2 (8)
I can use a Brita filter to decontaminate my tap water				
Male	10 (53)	6 (32)	2 (11)	1 (5)
Female	7 (29)	8 (33)	8 (33)	1 (4)
I should drink bottled water				
Male	19 (100)	0 (0)	0 (0)	0 (0)
Female	23 (96)	1 (4)	0 (0)	0 (0)

***3.3.2.4 Adherence to BWA**:* The majority of questionnaire respondents (61%) indicated that they always adhere to the BWA, while 36% occasionally adhere, which includes those who sometimes adhere, adhere when convenient, or rarely adhere. When stratified by gender, there was a clear difference in reported adherence between men and women. While 79% of men indicated they always adhere to the BWA, less than half of women said the same (Table 4).

Table 4: Adherence to BWA, by Gender (excluding those who preferred not to disclose their gender)

	Always Adhere n (%)	Occasionally Adhere n (%)	Never Adhere n (%)
How seriously are you taking the BWA? (N=44)			
Male (N=19)	15 (79)	4 (21)	0 (0)
Female (N=24)	11 (46)	12 (50)	1 (4)

Additionally, there were clear disconnects between knowledge and practice; some people are overly protective while others expose themselves unnecessarily to risk of illness through their behaviours, yet believe they are adhering to the BWA. For example, 4% of respondents indicate that they always adhere to the BWA, but use tap water for drinking. Eleven percent of responses indicate respondents always adhere to the BWA, but use tap water for food preparation, while 13% of responses indicate respondents always adhere to the BWA, but use tap water for cooking. The largest disconnect between practice and knowledge was centred on teeth cleaning: 41%

percent of responses indicated that respondents always adhere to the BWA, but also indicated that they use tap water for cleaning their teeth.

3.3.3 Living Under a BWA

When asked about how the BWA made them feel, participants most often indicated that they were worried (22%), unhappy (17%), and angry (14%). Participants also identified additional feelings including afraid, stressed, confused, and safe. A few participants also felt neutral (8%) and 2% indicated the BWA made them feel happy.

When asked about negative impacts of the BWA, only 9% of respondents did not indicate a negative impact of any kind for any of the categories. Eighty-nine percent of respondents indicated some impact or greater and 59% reported high impact or greater in one or more categories. Additionally, there appeared to be a difference in impact between women and men (Table 5). Proportionally, more women (42%) than men (32%) indicated a significant or high physical impact. Similarly, more women (46%) than men (32%) indicated a significant or high impact on their time as a result of the BWA. Conversely, 47% of men but only 17% of women were significantly or highly impacted spiritually. Additionally, a greater proportion of women than men indicated little or no impact financially (33%) and psychologically (42%).

Table 5: Impacts of BWA, by Gender (excluding those who preferred not to answer about their gender or invalid responses to questions about impact)

	Significant/High Impact n (%)	Some Impact n (%)	Little/No Impact n (%)	Blank n (%)
Negative Impacts of BWA (N=44)				
Financially				
Male (N=19)	6 (32)	9 (47)	3 (16)	1 (5)
Female (N=24)	3 (13)	10 (42)	8 (33)	3 (13)
Physically				
Male	6 (32)	9 (47)	4 (21)	0 (0)
Female	10 (42)	5 (21)	7 (29)	1 (4)

Psychologically				
Male	5 (26)	6 (32)	7 (37)	1 (5)
Female	7 (29)	4 (17)	10 (42)	3 (13)
Socially				
Male	5 (26)	3 (16)	11 (58)	0 (0)
Female	7 (29)	3 (13)	11 (46)	3 (13)
Spiritually				
Male	9 (47)	2 (11)	7 (37)	1 (5)
Female	4 (17)	5 (21)	11 (46)	4 (17)
Time Burden				
Male	6 (32)	7 (37)	5 (26)	1 (5)
Female	11 (46)	6 (25)	5 (21)	1 (4)

In addition to the expected negative impacts of the BWA, some qualitative responses indicated benefits of the BWA. One KI believed the BWA had a positive impact on the community:

> "I think the project as a whole has actually brought everybody together uh, more closely because uhm, there's a lot of, there's a lot of action… I think it's just sort of brought everybody together to, to work on the solution, so it's, it's been a positive experience." (KI17)

Other inadvertent benefits expressed in questionnaires and interviews included increased government awareness and facilitation, more communication and relationship building, having clean bottled water to drink, and that the BWA protected the health of the community. These may help to explain the feelings of happiness and safety identified by questionnaire respondents.

3.3.4 Water and Health

Many stories were shared about experiences with waterborne diseases, especially those causing diarrhoea. One participant had heard of people contracting giardiasis and cryptosporidiosis and needing antibiotics (KI11). However, another KI indicated that there had not been any reportable diseases recently that they would consider related to water (KI18). *Helicobacter pylori*, a pathogen associated with poor drinking water quality and sanitation, was referenced multiple times by KIs (n=2) and questionnaire respondents (7%). Other specific

health concerns identified included hair loss (E8) and itchy skin (E1) or eczema (5%), with one participant thinking the cause "might be whatever they put in the in the water" (K12). Four participants also commented on their concerns for the health of wildlife, including "fish with lumps on bodies" (E8) and fish "full of mercury" (E9). One KI commented on the health of wildlife specifically but related it to human health: "it also affects the wildlife or uh, our food. They drink the water, they get sick and then we eat the meat, we get sick" (KI12). One KI described what this relationship meant in the context of water:

> "You respect all life right from the tiniest insect to the biggest animal and they're here too for a reason. And we all depend on water to survive. We all drink water. And that's what we have to protect… all creation comes from water. And without the without the water we all die. Without the bugs we all die. Everything has a balance." (KI12)

3.3.5 Pathways Forward

Elders and KIs were asked to share solutions to the ongoing water problems on the reserve. Three shared their thoughts on resolving the BWA in traditional ways, and two by turning to Mother Earth (E6) or Elders (E8). One discussed the role of spirits:

> "we talk to the, to the entities, the spirits, entities whatever you want to call them, and they uh they set things right for us. And uh it's something that science can't explain. Sometimes I can't explain it. But it happens." (KI12)

Three participants believed cleaning the lake or stopping pollution would solve the BWA (E2, E4, KI12). Several Elders and KIs mentioned the role of the government in finding a solution, or being part of the solution, to the BWA, including the need for money and trust from the government (KI5) and future or existing commitment to deal with BWAs on reserve (KI17,

KI19, KI20). One Elder went a step further, saying that it was the government's responsibility to pay for the solution because the reserve did not contaminate the water in the first place (E4).

Thirteen participants talked about getting the community's water piped in from the closest city as a potential solution:

> "Hooking up with the city of {name} is like bang, they're there. They're trained, they've got their qualifications they don't go into a water plant unless they are qualified" (KI3)

This reflects an ongoing planning process that started within the period of study. Many KIs noted that it was less expensive and faster to implement this solution than other options, like upgrading the community's water treatment plant. In terms of cost, participants shared that a pipeline would be funded 100% by ISC (KI5, KI20) and that this solution would not "displace the membership…our workers in regards to uh [potentially] losing employment" (KI19). Individuals also believed this solution would benefit business and economic development (KI7, 19, 20). Two KIs noted that this solution does not come without risks – one said they were scared to be told their water would be shut off if they did not pay their water bill (KI5).

Nine interview participants talked about upgrading or getting a new community water treatment plant as a potential solution, but many did not think this was the best solution compared to hooking up to the city. One shared that they believed they would have a water plant eventually, but it was not a solution in the near future (E9). The positive cost and time factors associated with the water pipeline may have influenced why it was the better, but perhaps not the preferred, solution over a community treatment plant. One questionnaire respondent chose to provide an additional comment illustrating this, saying:

> "I hope that the water is drinkable someday…With the agreement to be connected to the {name} water system, I hope the work starts as soon as possible. I do however, think that we should have gotten our own water plant instead of connecting to {name}." (ID007)

Several participants also mentioned how part of the solution to the BWA would be to get individual water filtration systems to the homes that could not be connected to a community water distribution system.

Other less-cited solutions included an unidentified "filter" (KI12) and finding a water source other than the lake (E6). As part of the solution, one KI noted that septic systems on the reserve "need to be enlarged and improved" but that it costs money the reserve does not have (KI5) and one Elder said the city needs to be part of the conversation to end the BWA (E10). Finally, when asked for their perspective on the best solution, one KI shared that, no matter the final decision, a solution will be possible "as long as the partnerships between uhm Chief and Council or the community {name}, the city of {name} and the federal government" continue (KI18). Regardless of solution, there is an overwhelming desire:

> "to have at the end of the day have clean, safe drinking water for our membership so they could actually have that luxury of going to their tap, opening it up, and having a drink of water" (KI19)

3.4. Discussion

3.4.1 Community Context

Comparisons between census data and demographic information collected for this project indicated that the average age of the sample was older than the average age of the eligible population. It was noted throughout the project that older community members in general

appeared to share a greater interest in the study. It is possible that older individuals felt better situated to comment on the BWA and the state of their waterbody, considering the changes they had witnessed to water over their lifetime. It is also possible that younger individuals purposefully chose not to participate out of respect for their Elders, who are considered key holders of TK, values, and teachings.

3.4.2 Knowledge of BWAs

Community members and key informants shared many reasons for why they believe the reserve is under a BWA. Often, these perspectives depended on the individual's relationship to the community (i.e., community member, Council member, or non-Indigenous person). Since there are power differentials to consider between TK and Western Science and in individuals' roles, this makes prioritization for remediation further down the line potentially more difficult.

Though two-thirds of respondents believed they always adhere to the BWA, many indicated practices that conflict with recommendations under a BWA. In this way, some individuals believe they are following all precautions when, in fact, they could be at unnecessary risk of illness. This may indicate a lack of understanding about the best practices to protect health under a BWA. Based on this lack of understanding, educational programs about practices that pose a risk to human health, and what one should do instead, are encouraged. Though this has the potential to benefit everyone, education aimed at women may have more of an initial impact, as this population indicated adherence to BWA practices less often and less of an understanding about the correct practices to follow under a BWA when compared to men. They are also primary caregivers for children. In addition, it should be emphasized for all that appearance is not the best indicator of safety – clear water does not mean potable water, despite

this being widely misunderstood (Levison, 2010). A risky practice that has not caused illness in the past is still a pathway for disease in the future.

3.4.3 Living Under a BWA

Most respondents expressed one or more negative feelings towards the BWA. Worry was the most common feeling, reported almost 10% more than anger. While both are negative emotions, anxiety most often comes from a place of uncertainty and fear about handling an injustice, while anger comes from the need to blame someone for an injustice (Barclay & Kiefer, 2019). The worry that community members feel about the safety of their water, combined with uncertainty about daily practices to promote health, may be overshadowing their anger towards those responsible for their lack of safe water. This points to the immediacy of concerns for health and wellness when living under a BWA versus the longer-term action required to remediate underlying causes, such as pollution or a lack of oversight by the government. Emotional wellbeing is also an important component in Indigenous models of health; failure to address these negative emotions perpetuates poor health outcomes.

Additionally, differences emerged in impacts felt by women and men. Indigenous women have a unique relationship with water. They are seen as the keepers and carriers of water for many reasons, including the connection between water and childbirth (Anderson et al., 2011; Craft, 2014; Lawless et al., 2015). The Earth is also known as the “great Mother”, with her waterways carrying water similar to veins and arteries in people and animals (Anderson et al., 2011). Within this context, it is not surprising that men and women are impacted in different ways. For women, the most significant impacts are physically and on their use of time, which are both tied to their roles as water collectors and caregivers. For men, the impact is mainly spiritual. Spirituality can take the form of learning more about one’s culture and values, practicing

traditions, and using traditional medicines, practices which may be lost by the restrictions in place when living under a BWA (FN Health Society, 2010; Graham & Stamler, 2010).

3.4.4 Water and Health

The many stories of individuals experiencing symptoms from waterborne disease can be linked to the practices that expose them to risk of illness, like brushing teeth or cooking with tap water. There was some discord between the diseases that individuals reported and lab-confirmed cases of disease, but this does not discredit community members' experiences with illness; several individuals commented on *H. pylori*, which has been associated with poor drinking water conditions and can lead to chronic stomach and digestive issues (Aziz et al., 2015; McColl, 2010). It is possible that diagnoses were made on symptoms alone, perhaps because of the frequency with which they presented in the population. Additionally, under-reporting of infectious gastrointestinal illnesses in Ontario is high, with each case reported to the province representing up to several hundred unreported cases (Majowicz et al., 2005).

Reflecting on the interconnectivity of land, water, people, and animals, four participants were concerned for the health of wildlife. This consideration for animal life points towards the importance of animals in Indigenous traditions related to wellness (McGinnis et al., 2019). Thus, when water quality impacts animals it also impacts their human counterparts. In this context, water has been referred to as "first medicine" (Sanderson, 2008). This may indicate that future BWA management in Indigenous populations needs to include risk mitigation for animals, if not because animal life is sacred, then because protecting animal wellbeing is a form of health promotion for humans.

3.4.5 Pathways Forward

As there were many perspectives on the cause of the BWA, so too were there many perspectives on how to end the BWA. This is unsurprising, as it indicates a variety of valid avenues through which remediation can occur and through which individuals want to see action taken. Many solutions referenced would require extensive resources and external stakeholders, forfeiting some autonomy in the name of clean water. The justification for reliance on outside sources may come from the frustration and worry associated with a decades-long aspiration for clean, safe drinking water. This can be seen in peoples' contentment with a water pipeline from the city, even though their ultimate preference may lie elsewhere.

Conceivably, in a bid to hold onto community independence and water self-governance, there appears to be an interest in how the reserve can help directly with the BWA. They also expressed a strong desire to fulfill their responsibility as stewards of the lake; many community members share a drive to be involved in issues relating to their environment and to fulfill the duties to the water that they have had since time immemorial. As such this information may be helpful for other communities working towards ending their DWA.

3.5 Limitations

Some general methodological limitations were identified in this research process. First, the questionnaire response rate (44/226; 19.5%) was lower than anticipated. Though questionnaires were disseminated to every adult, in an effort to give everyone a voice, many homes appeared to return one questionnaire that was intended to be representative of the knowledge, actions, and beliefs of all adults in the residence. This was mitigated through the tablet draw and repeated verbal reminders that we were collecting, and interested in, individual voices. Nonetheless, this was an important unintended finding, as it may help to direct surveying

procedures for future community-wide studies. Secondly, discomfort in the relationship to the community research associate, who was a community member, or with the otherness of non-Indigenous members of the study team, may have deterred potential KIs from participating or prevented participating KIs from sharing sensitive stories. This limitation was anticipated and mitigated by allowing interviewees to choose which of the facilitators were or were not present during their interview. Finally, although these findings represent the health, social, cultural, and economic costs and consequences to this community, First Nations' perspectives and knowledge varies widely. This research was also exploratory and based much of its findings on judging and interpreting the knowledge of a sub-set of an already small population. Thus, the results are not generalizable, but they are useful for other communities navigating life with DWA.

3.6 Conclusion

This project began as a conversation with Chief and Council about water challenges in the community and how community members felt, individually and collectively. Through questionnaires and interviews, themes emerged surrounding community knowledge of the BWA, living under a BWA, water and health, and perceived pathways for moving beyond the water advisory. Participants shared their thoughts on what factors were causing their lake to be polluted, why they believed the BWA was issued, and what solving their water challenges looked like to them. Out of these responses came important points where education surrounding best practices for health would be crucial moving forward, considering the impacts upon human and animal health that were shared by participants. Responses also highlighted that women are in most need of education, and thus are the most important target audience. So too emerged points where communication within the community and with stakeholders involved in BWA management on reserves, particularly in relation to causes and solutions, would be keys to

understanding the impacts and outcomes. Additionally, this community, and others experiencing a DWA, should consider greater involvement in water management by younger individuals, to ensure that all perspectives are adequately represented.

Many First Nations communities rely on surface water, and thus the watershed, in some capacity for their source water. However, it is difficult for them to engage in discussions around water management issues that extend beyond the jurisdiction of Chief and Council. However, clean water solutions should not come at a cost of disempowerment from a lack of autonomy over decision-making. This is particularly unsettling when acknowledging that Indigenous people see themselves as, and have always been, keepers of the environment and that many people in this project linked their poor lake water quality to the activities of non-Indigenous individuals and the legacy of colonization. Additionally, in the Indigenous belief system, there is a feeling of responsibility for things that give or sustain life, like water, and these responsibilities cannot be shirked.

The elimination of DWAs on reserves should remain a priority for the Government of Canada. Indigenous communities do not have the luxury of taking DWAs off the agenda like lawmakers and politicians can – when water is life, it permeates all spheres of wellbeing. Until balance is restored, communities will continue to fight for their basic human rights to clean water and their rights as First Peoples to govern and guard the environment.

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Chapter Four: Reflections and Limitations

4.1 Reflections

This process has afforded many opportunities for reflection on what worked, what did not, and what could have been done better or differently when conducting this project. Sharing these reflections is intended to aid Indigenous partners and researchers working with Indigenous communities in their journey towards bonded Traditional Knowledge and Western Science data synthesis. This chapter touches on reflections from community-based participatory research, partnering with Indigenous communities, and on moving forward from this project. It also includes a discussion of limitations and how these were mitigated.

4.1.1 Community-Based Participatory Research

I knew going into this project that using a CBPR approach to research would be challenging because of the participatory process. Initially, I found that describing the research to community members who were not intimately involved with the project was often tedious because the explanation was lengthy and caused people to lose interest. It became clear that community partners and academic partners had different ways of engaging and explaining the research. Although we had both been involved since its inception and were ultimately saying the same things, I was told that my way was too wordy, confusing, or did not capture the essence of the project from the community's perspective. Since the research lead in CBPR is the community, I found myself torn between a desire to take on their language and approach to project engagement and my obligation to explain the research in a way that satisfied the research ethics board (REB). Having a community research associate was one way that we overcame this obstacle because they were able to translate the WS description into a message that resonated with their community. Engaging a community research associate is common in CBPR and

rightfully so, as it was of enormous benefit to the project. Based on debriefing conversations, it was also of benefit to the community research associate by building their capacity to conduct research, collect data, and bridge the TK and WS knowledge systems. The community research associate was also excited about the prospect of adding university-mandated training to their portfolio. This provided a great lesson in perspective and expectations; whereas I saw this training as an inconvenience or obligation to the process and assumed that they would feel the same, they saw this as an opportunity and advantageous to their job outside of research.

CBPR also made scheduling difficult because of the difference in approach between the community and academic partners. While in academia we rely on emails and technology to coordinate team members, the community preferred to plan in person or, at the very least, over the phone. This was challenging because regular in-person meetings were not possible when 1,800km separated us; yet we had a strong desire to engage frequently with our community partners. Since CBPR necessitates community partner engagement and partnership throughout, we had to find a balance between these paradigms and often had to blindly put our trust in the process. This meant agreeing on dates that worked for community partners and booking flights without set plans in the belief that all things would work themselves out. Out of this came a lesson that, in CBPR, flexibility and trust are everything. Be prepared for the process to move in any direction on any given day and be content in the knowledge that this is what was meant to be.

Ultimately, CBPR is a roadmap to working between partners with differing perspectives and engaging communities from under-served populations, providing an outlet for research and academic partnership. As an academic partner, it is not lost on me that CBPR also provides an opportunity for me to build respectful and fruitful relationships with individuals in these

communities; the benefits of CBPR go both ways.

4.1.2 Working in Partnership with Indigenous Communities

While CBPR itself can be challenging, I found there were also challenges unique to working with Indigenous communities. Working between knowledge systems became a point of learning for me, particularly in terms of consent. The consent requirements from the REB – for individuals to sign and acknowledge their consent to participate – were different to the views on consent in the Indigenous context. Many people said that by voluntarily participating in interviews or submitting surveys that the consent was implied and that they did not want to sign a consent document to prove it. While I saw these stringent consent requirements as being protective, I realize now that the reluctance to sign a consent form is not surprising in light of the history of Indigenous people being forced into signing away their land and their rights; signing documents has a certain negative connotation connected to it. Although I could not bypass the REB requirements, it gave me a lot to consider in terms of how REBs navigate ethics in Indigenous communities and whether, in instances like these, it would be appropriate to allow REBs to defer to community practices.

In a small Indigenous community like the one in this project, navigating intra-community relationships provided a chance for reflection. As an outsider, I went in with the belief that because everyone was experiencing the same problem, there would be a sense of cohesiveness about the cause and the solution. I also believed that, altruistically, everyone would want to participate in research about an ongoing issue that affected themselves and their families. In reality, an Indigenous community is like any other community, with tensions and a history between individuals and families that adds to a myriad of relationship dynamics. Knowing how to engage in a way that did not upset or disrupt relationships required a certain tactfulness on our

behalf. To this end, the community research associate was invaluable for their insider knowledge on the nuanced relationships in the community.

There were also many successes that made working with the community all the more rewarding. Spending time making a connection with our community peers became a huge part of the process and ensured that the research ran smoothly. It was so important to connect on a personal level, as individuals sharing in the human experience and respecting the trials and tribulations that brought us to this point. I believe building long-term personal and professional relationships should be seen as an outcome in itself, regardless of the other intended outcomes of the project, because of what it adds to the experience. Prioritizing relationship building ensured individuals felt comfortable and trusted us enough to share their experiences, ultimately leading to a better project and opening the door to future research together.

4.1.3 Pathways Forward

In reflecting on the end of this project and beyond, I have recognized how important debriefing meetings with the community were. These debriefs included conversations about my final reflections and thoughts, but most importantly created space for the community to come to their own conclusions and lead data analysis and knowledge translation. The community needed to be engaged in these debriefs to ensure relevant outcomes and analyses that made sense. At these final debriefs, many people came to us with an interest in future projects together, which I see as a result of the mutual respect and relationship building that occurred throughout the process. Reflecting on our relationship, I've watched it grow and evolve to a place where we trust the community and, more importantly, the community knows we will keep coming back and supporting them.

However, that ongoing support also posed a challenge for me. The community specifically asked for recommendations from the data, which I hesitated to provide. Ultimately, instead of using the term recommendation, I chose to call them considerations. Although it may seem to be a matter of semantics, there is a certain power in the word recommendation that consideration does not carry. I spent a lot of time reflecting on how we could support what the community recommended rather than providing all of the recommendations ourselves and why they asked this of us in the first place. My thought was that, unfortunately, because of the burden associated with validating TK that does not exist in WS, the community may have been looking for the support and social capital that comes with recommendations from academia.

4.2 Limitations

Reflecting on the research helped identify some general limitations. First, fewer community members responded to the questionnaire than anticipated. Though questionnaires were disseminated to every adult, many homes appeared to return one questionnaire that was intended to be representative of the knowledge, actions, and beliefs of all adults in the residence. This was mitigated through incentives and repeated verbal reminders that we were collecting, and interested in, individual voices. Additionally, despite our best efforts, time constraints limited our ability to continue to collect surveys and improve the response rate. Time constraints also limited the number of KIs and Elders that could be interviewed.

In line with interview limitations, the intimacy of KI and Elder interviews may have deterred potential KIs and Elders from participating or prevented participating KIs and Elders from sharing sensitive stories. In particular, this may have occurred if they were uncomfortable with their relationship to the community research associate, who was a community member, or with the otherness of non-Indigenous members of the study team. This limitation was anticipated

and mitigated by allowing interviewees to choose which of the facilitators were or were not present during their interview. Personal biases of the academic partner and community research associate may also have come out during interviews. Using a standard script to ask questions and remaining neutral when probing or responding to answers mitigated this.

Finally, although this research represents the health, social, cultural, and economic costs and consequences to this community, First Nations perspectives and knowledge varies widely. This research was also exploratory and based much of its findings on analyzing and interpreting the knowledge of a sub-set of an already small population. Thus, the results are not generalizable, but they are useful for other communities navigating life with a BWA or other DWA.

Chapter Five: Considerations and Conclusions

5.1 Considerations

Considerations for moving forward are informed by the data and community-based analyses for this project. Although the sample size was small, there is validity in observation and in the themes that emerged from individuals' experiences and beliefs. Based on the data, the community might want to consider the following:

1. Focusing education efforts about water safety at women. This may take the form of DWA education components added to pre-natal classes. Emphasis should be put on practices that pose a risk to human health and what one should do instead. This should include avoiding the following practices under a BWA:
    a. Bathing babies and young children with tap water;
    b. Using a Brita filter to decontaminate tap water;
    c. Drinking tap water;
    d. Using tap water to make ice; and,
    e. Using tap water to clean teeth.
2. Including the younger demographic in water research and management, to be more representative of the community as a whole. This may take the form of interactive classes at the high school level and involvement of high school students as community research associates.
3. Adding a component to DWA education that includes best practices for protecting the health of animals.
4. Sharing the data collected with other Indigenous communities as an aid for ending their DWA. Sharing data collection instruments may also be helpful for other communities

that want to collect the information from the perspective of their own membership.

5. Sharing the data collected with non-Indigenous partners and stakeholders who are involved with DWA management on reserves. In particular, the information collected about perceived causes and preferred solutions may prove helpful when managing outcomes secondary to ending DWAs.

The community may wish to consider other pathways forward, research proposals, and uses for the data based on how it speaks to them and their experiences. In the end, there is no one right way to handle DWAs that satisfies the preferences of every individual affected. However, DWAs can be better managed in ways that include the voices of the community, its leadership, and its members, particularly around communicating DWA status, causes, and solutions.

Considerations also emerge from personal reflections throughout this process. Based on these reflections, the academic and community partners might want to consider the following:

1. Engaging a community research associate to explain the research in a way that resonates with the community and helps navigate community dynamics. In the same vein, building this adapted research narrative into REB applications.
2. Being mindful of personal perspectives and expectations and how these may differ from those of academics and individuals in the community, including the community research associate.
3. Trusting and believing in the process. Likewise, being prepared for the process to move in any direction on any given day and being satisfied with this.
4. Attending to gaps in how research ethics boards navigates projects with Indigenous communities and finding ways to reach a common ground or defer to community practices.

5. Prioritizing relationship building, from which respect and trust flow.
6. Creating space for the community to come to their own conclusions and form key messages. This may include support and advocacy for TK on behalf of academic partners.

5.2 Conclusions

In conclusion, through this research, themes emerged surrounding the community's knowledge of the BWA, living under a BWA, water and health, and perceived pathways for moving beyond the water advisory. Out of individual responses and personal reflections came important points of consideration for the community, researchers, and other stakeholders involved in DWA management on reserves.

This thesis contributes to existing research by exploring DWAs in a First Nation community in Canada from a bonded TK and WS approach. It explores the impact of DWAs from the perspective of community members and other individuals with a relationship to the community using a CBPR approach. It also provides considerations and key messages that come from the data and personal observations and reflections from the community and academic partners.

Our society continues to deny that Indigenous people have had knowledge for thousands of years and that Western Science has been weaponized against them rather than being undertaken in a manner offering a complementary source of knowledge, power, and liberation. Canada also denies Indigenous people their right to health and wellbeing through ongoing DWAs on reserves. With partnership, persistence, and conviction there is hope that, one day, all drinking water advisories in Canada will be lifted.

"Weweni wiiji'idig" - Go with each other respectfully

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Appendices

Appendix A: Timeline of Water Management on Reserves in Canada

2003: Indigenous and Northern Affairs Canada (INAC – now ISC) releases the National Assessment of Water and Wastewater Systems in First Nation Communities: Summary Report. It determines that 75% of water systems on reserves studied are at medium to high risk for negative impacts on water quality (Indian and Northern Affairs Canada, 2003). Common water-related problems include issues with treatment plant design and technology; operation and maintenance; monitoring; operator training; equipment concerns; and water sources (Indian and Northern Affairs Canada, 2003).

2005: The Auditor General of Canada releases an audit of drinking water safety on First Nation reserves. They find that "the design, construction, operation, and maintenance of many water systems is still deficient", causing a "significant proportion" of First Nations communities to have unsafe drinking water (Auditor General of Canada, 2005). Additionally, because "there [were] no laws and regulations governing the provision of drinking water", First Nations communities on-reserve did not have the same level of drinking water protection as people living off-reserve (Auditor General of Canada, 2005). Several recommendations to improve conditions moving forward are identified.

2006: INAC announces a Plan of Action for Drinking Water in First Nation Communities. Out of the action plan comes the Report of the Expert Panel on Safe Drinking Water for First Nations (Volume I and II), released the same year to help the Federal Government develop a regulatory structure for water on reserves noted to be lacking in the 2005 audit (Swain et al., 2006; Willms & Shier Environmental Lawyers LLP, 2006). The action plan also spawns the Protocol for Safe Drinking Water in First Nations Communities, which outlines the "standards for design,

construction, operation, maintenance, and monitoring of drinking water systems in First Nations communities" (Indian and Northern Affairs Canada, 2006).

2008: The Government of Canada announces a two-year, extended to eight-year, First Nations Water and Wastewater Action Plan, which includes funding and support for water and wastewater services on reserves (Indigenous and Northern Affairs Canada, 2008). This same year, the Chiefs of Ontario release the Water Declaration of the Anishinaabek, Mushkegowuk, and Onkwehonwe in Ontario: Resolution 08/87 about their "inherent responsibilities and intimate relationships to the waters" (Chiefs of Ontario, 2008).

2010: The Federal Government introduces legislation known as Bill S-11, An Act Respecting the Safety of Drinking Water on First Nation Lands (short title: Safe Drinking Water for First Nations Act). It is not well received by Indigenous people – the Chiefs of Ontario formally reject the legislation – and ultimately is not passed (Chiefs of Ontario, 2011; Simeone & Troniak, 2012).

2011: The Auditor General of Canada releases a follow-up to the 2005 audit of drinking water on reserves. They find that many of the recommendations and actions regarding drinking water testing outlined in the 2005 report were not implemented. The also find that there remains no laws and regulations for drinking water on reserves and that it still may be years before one is in place (Auditor General of Canada, 2011).

2012: Since Bill S-11 is so poorly received, the Federal Government releases a revised piece of legislation known as Bill S-8. It is much the same as S-11, but with some changes to address peoples' concerns of S-11 (Simeone & Troniak, 2012). Due to the limited number of alterations

to the bill, S-8 is also widely rejected by First Nations groups, including the Chiefs of Ontario (Chiefs of Ontario, 2013).

2013: Despite opposition in the years prior, the Federal Government passes the Safe Drinking Water for First Nations Act.

2015: Resolution 76/2015 passes at the Assembly of First Nations (AFN) Annual General Assembly, for AFN to advocate for the repeal of the Safe Drinking Water for First Nations Act (Assembly of First Nations, 2015). This same year, Justin Trudeau is elected Prime Minister of Canada.

2016: Budget 2016 invests $1.8 billion to water on reserves over 5 years, in an effort to end long-term boil water advisories by 2021 (Morneau, 2016).

2017: ISC announces they are beginning review of the Safe Drinking Water for First Nations Act (Indigenous Services Canada, 2018). Engagement remains ongoing in 2019.

2018: Budget 2018 invests an addition $172.6 million to water on reserves over 3 years, in a push to meet the 2021 drinking water advisory deadline (Morneau, 2018).

Appendix B: McMaster University Research Ethics Board Approval

McMaster University
Inspiring Innovation and Discovery

McMaster University Research Ethics Board (MREB)

c/o Research Office for Administrative Development and Support, MREB Secretariat, GH-305/H, e-mail: ethicsoffice@mcmaster.ca

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

Application Status: ☑ **New** ☐ **Addendum | Project Number:** 2017 197

TITLE OF RESEARCH PROJECT:

One Indigenous Community's Struggle for Water Security: A Transdisciplinary Reflection on Radionuclide Contamination and Pathways Forward

Faculty Investigator(s)/ Supervisor(s)	Dept./Address	Phone	E-Mail
S. Dickson	Engineering		sdickso@mcmaster.ca

Co-Investigator(s):
C. Schuster-Wallace, S. Watt, T. Latchmore, L. Sioui, L. Stovern

Student Investigator(s)	Dept./Address	Phone	E-Mail

Co-Investigator(s):

The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:
☐ The application protocol is cleared as presented without questions or requests for modification.
☑ The application protocol is cleared as revised without questions or requests for modification.
☐ The application protocol is cleared subject to clarification and/or modification as appended or identified below:

COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.

Reporting Frequency:	Annual: Oct-05-2018	Other:

Date: Oct-05-2017 **Chair, Dr. S. Bray**

Appendix C: University of Saskatchewan Research Ethics Board Letter of Acknowledgement

UNIVERSITY OF SASKATCHEWAN

Research Ethics Board (REB)
Letter of Acknowledgement

Name of Institution conducting Primary REB Review: McMaster University	**Name of Researcher's Home Institution:** University of Saskatchewan
McMaster University REB File #: 17-197	**U of S REB File #:** 504
Title of Research Project: One Indigenous Community's Journey Towards Water Security – A Transdisciplinary Reflection on Drinking Water Advisories and Pathways Forward	
Sponsor or Funding Agency: McMaster University	
Name of Principal Investigator(s): Sarah Dickson-Anderson and Corinne Schuster-Wallace	**Name of Local University of Saskatchewan Investigator, if applicable:** Corinne Schuster-Wallace

Dear Drs. Dickson-Anderson and Schuster-Wallace:

This letter serves as acknowledgement that the University of Saskatchewan [U of S] is in receipt of the above named research project application and associated Certificate of Ethics Approval from the McMaster University Research Ethics Board (REB).

The U of S REB has issued a Letter of Acknowledgement in lieu of a Certificate of Approval. All post-approval research activities including continuing ethics review or the review of amendments to the project will be conducted by the "Primary Institution/REB". It should be noted that you are also responsible for bringing any project specific deviations, unanticipated problems, or new project information related to the research project to the attention of the "Primary Institution/REB".

When the research project completion report is filed with the "Primary Institution/REB", you must also provide a copy to the University of Saskatchewan Research Ethics Office (ethics.office@usask.ca).

The University of Saskatchewan will retain this Letter of Acknowledgement and would ask that you provide a copy to the "Primary Institution".

This agreement is limited to and applicable only to the above named research project.

Acknowledgement:

Date: Oct 12/18

Diane Martz, Interim Chair
Behavioural Research Ethics Board
University of Saskatchewan

Appendix D: Detailed Methodology

Questionnaires

Questionnaire content and packages were developed by academic partners, with guidance from community partners and Chief and Council. Each questionnaire package contained a letter of information, a consent form, a questionnaire, the consent form and schedules for sharing circles, a small white envelope for completed consent forms, and a large brown envelope for completed questionnaires. The questionnaire consisted of five short sections that focused on: 1. basic information about the respondent (e.g., age; education); 2. knowledge of the BWA (e.g., How did the respondent hear about the BWA? Did they seek more information about the BWA?); 3. water sources and uses before and during the BWA (e.g., What was/is the source of respondent's drinking water? What was/is the source of water for food preparation?); and, 4. impacts of the BWA upon the respondent's life (e.g., What was the financial impact of the BWA on respondent and their family? What was their emotional response to the BWA?). Questionnaire packages were first distributed at the community research information session on October 4th, 2018. For those unable to attend the meeting or who did not take a questionnaire during the meeting, questionnaires were distributed house-to-house until October 29th, 2018. To ensure that each person was given only one questionnaire, a log was kept with the name of each recipient and, if possible, their street and house number – to this end, our community research associate proved invaluable. For those who approached the study team indicating they had lost or discarded their questionnaire but wished to participate, a questionnaire interview was initiated to ensure their responses were recorded, but that they were not given a secondary copy of the questionnaire. The study team were also available to assist with completing the questionnaires through interviews for anyone who requested. An Ojibwe translator was also available, if necessary. During these interviews, the study team would ask the questionnaire questions aloud

and record participants' verbal responses on the physical questionnaires. The study team went house-to-house reminding residents of the questionnaire and picking up completed questionnaires until October 31st, 2018. Questionnaires could also be dropped off in the Band Office until this time. Questionnaires were returned in envelopes provided to protect anonymity, particularly if community members decided to return a blank questionnaire. In total, 226 questionnaires were distributed, 44 (19.5%) were returned completed and 11 (4.9%) were returned blank.

At the community's request to incentivize return of completed questionnaires, participants could be entered into a raffle for one Samsung Galaxy Tab E tablet ($200 value) by completing the appropriate opt-in section of the questionnaire consent form. These forms were then entered into a draw, taking place on November 1st, 2018. The winning participant was drawn by an unbiased, non-community member working out of the Band Office and was discreetly contacted and given their prize, to ensure anonymity.

Completed questionnaires were scanned and uploaded to a password-protected server at McMaster University. Completed consents were scanned and uploaded to the same server in a separate folder, to ensure the anonymity of the participants. Data from completed questionnaires were manually entered into an Excel file in preparation for coding and analysis. Hard copy completed questionnaires and consents were then shredded.

Interviews

KIs were identified by community partners and Chief and Council based on whom they perceived could best provide contextual information about the drinking water issues in their community. Gender and age representation was chosen to be as diverse and inclusive as possible. KIs were both internal and external to the community and Chief, Council, and community

partners were considered KIs if they wished to participate. Elders were also identified as key holders of Traditional Knowledge (TK). Community leadership identified these individuals.

Twelve KI questions or prompts were developed by academic partners, with feedback from community partners. Fifteen Elders and 22 KIs were contacted through written and verbal invitation. In total, 8 Elders and 16 KIs participated in 20 interviews, as some non-Elder KI interviews had more than one person taking part. As is customary, Elders were offered tobacco to participate in an interview and given a $125 honorarium at the end of their KI interviews as compensation for the TK shared.

KIs and Elders were offered interviews either in-person, over the phone, or over Skype; all but one interview was conducted in-person. KIs and Elders were audio-recorded when consented, though some chose not to be audio-recorded. In these instances, the study team made every effort to capture interviews in their notes. Interview recordings were uploaded to a password-protected server at McMaster University, as were scanned interview notes. Recordings were then deleted from recording devices. Interviews were transcribed with the help of Dragon NaturallySpeaking Software, removing any identifying information (names etc.) and stored on the same password-protected server, at which time the recordings were destroyed.

Water Quality Sampling

Community partners, Chief, Council, and the community research associate chose water-sampling sites in the Lake of the Woods water body for testing based on community importance. Eleven sites were identified and tested over the course of three days: October 19th, October 24th, and November 1st, 2018. The boat required for sampling was provided by the community research associate, who went on all sampling trips, and was operated by a community member who was familiar with the water body and comfortable navigating to all sites. Nine sites were

sampled at shallow (1m) and deep (varied) depths and two sites were sampled at shallow (1m) depths only. At each site, the study team recorded the site name and code, weather, GPS coordinates, any other relevant information about sampling conditions, depth of sample, temperature of sample, and time sample was taken. Photographs of the sites were also captured.

Water samples were obtained using a Vernier water depth sampler and sent to an accredited laboratory (ALS Environmental Laboratory – Thunder Bay) for analysis. Analyses comprised of General Chemistry Package 3, Total Kjeldahl Nitrogen (TKN), and Total Phosphorus (TP). See **Supplementary 1** for a breakdown of analyses included in General Chemistry Package 3. Samples were stored and shipped to the laboratory on the day of collection in large coolers with ice packs. The completed chain-of-custody forms were also emailed to laboratory staff to ensure prompt processing and analysis. For a detailed Lake Sampling Standard Operating Procedure, off which our water sampling was based, refer to **Supplementary 2**.

Limitations

Some general methodological limitations were identified when conducting this research. First, the questionnaire response rate (44/226; 19.5%) was lower than anticipated. Though questionnaires were disseminated to every adult, in an effort to give everyone a voice, many homes appeared to return one questionnaire that was intended to be representative of the knowledge, actions, and beliefs of all adults in the residence. This was mitigated through the tablet draw and repeated verbal reminders that we were collecting, and interested in, individual voices. Nonetheless, this was an important unintended finding, as it may help to direct surveying procedures for future community-wide studies. Secondly, the intimacy of interviews may have deterred potential KIs and Elders from participating or prevented participating KIs and Elders from sharing sensitive stories. In particular, this may have occurred if KIs and Elders were

uncomfortable with their relationship to the community research associate, who was a community member, or with the otherness of non-Indigenous members of the study team. This limitation was anticipated and mitigated by allowing interviewees to choose which of the facilitators were or were not present during their interview. Finally, although these findings represent the health, social, cultural, and economic costs and consequences to this community, First Nations perspectives and knowledge varies widely. This research was also exploratory and based much of its findings on judging and interpreting the knowledge of a sub-set of an already small population. Thus, the results are not generalizable, but they are useful for other communities navigating life under a BWA or other DWA.

Supplementary 1

General Chemistry Package 3

Metals	Inorganics	Major Anions
Aluminum (Al)	Alkalinity (Speciated)	Bromine (Br)
Antimony (Sb)	Ammonia	Chlorine (Cl)
Arsenic (As)	Colour	Fluorine (F)
Barium (Ba)	Conductivity	NO_3
Beryllium (Be)	DOC	NO_2
Bismuth (Bi)	pH	PO_4
Boron (B)	TDS	SO_4
Cadmium (Cd)	Turbidity	
Calcium (Ca)	Anion/Cation Sum	
Chromium (Cr)	Hardness	
Cobalt (Co)	Ion Balance	
Copper (Cu)	Langelier Index	
Iron (Fe)	Saturation pH	
Lead (Pb)	Silica Calc	
Magnesium (Mg)		
Manganese (Mn)		
Molybdenum (Mo)		
Nickel (Ni)		
Phosphorous (P)		
Potassium (K)		
Selenium (Se)		
Silicon (Si)		
Silver (Ag)		
Sodium (Na)		
Strontium (Sr)		
Thallium (Tl)		
Tin (Sn)		
Titanium (Ti)		
Tungsten (W)		
Uranium (U)		
Vanadium (V)		
Zinc (Zn)		
Zirconium (Zr)		

Supplementary 2

Lake Sampling Standard Operating Procedure

ENGINEERING | McMaster University

This standard operating procedure (SOP) describes the methodology to be employed for collecting water quality samples from lakes.

Materials Required:

- field note book and pencil
- Sharpie
- cell phone with GPS capability
- camera
- gloves
- measuring tape
- Vernier depth sampler
- distilled water (from pharmacy)
- bottles or sample containers (number and size will depend on project requirements – to be order from lab)
- ice packs and cooler (loose or bagged ice should never be used in the shipping containers because of the possibility of contamination)
- boat, canoe or kayak
- paddles and motor
- anchor
- personal flotation device (PFD) for each crew member
- flare or waterproof flashlight
- bailer
- sound-signaling device
- if motor is inboard or fuel tank is fixed – a fire extinguisher is required
- if it is misty or rainy or the visibility is poor – navigation lights are required (note: there is no reason to sample between sunset and sunrise, so please don't).

TIPS AND TRICKS

- Collect samples first from sites with the least amount of contamination.
- Minimize the number of sample handling steps.
- Use the clean hands/dirty hands technique when sampling for trace constituents.
- Collect enough QA/QC samples.

Procedure:

1. Determine where the samples are to be collected with your supervisor prior to embarking on the boat. In this project, you will be sampling each geographic location at two depths to collect samples from both the epilimnion and hypolimnion. Collect the epilimnion sample from 1 m below the surface. Collect the hypolimnion sample from 15 m below the surface. Endeavour to measure the temperature at both of these locations as well.
2. Prior to collecting a sample, it must be ensured that the anchor is secure and the boat is pointed into the wind.
3. Position yourself securely on the floor of the boat or on one of the seats; do not stand in the boat to obtain the water sample. Notify other crew members that you will be sampling so that they may counterbalance the boat.
4. In your field note book, record: date, weather (cloudy, sunny, temperature etc.), sample location including both a written description and GPS coordinates (or dropped pin on Google maps offline and save), sample depth, photographs of location, and anything else you think might be important.

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5. Ensure the Vernier depth sampler has been properly rinsed with distilled water (at least five times), including the discharge tubing, prior collecting each sample.
6. Ensure that one end of the retrieving line is securely fastened to the cording connected to the eyebolt in the side of the sampler, and the other end is fastened to the boat.
7. Arm the sampler by pulling both balls directly outwards at the same time and then fold them over the body of the sampler (Figure 1).
8. Slip the two metal tubes together, aligning the holes and insert the trigger pin through holes (Figure 1).
9. Mark the retrieving rope for the sample collection depth (note: it may be useful to mark 1 m increments on the retrieving rope with a Sharpie prior to embarking on the sampling trip.
10. Drop the sampler from a small height into the water. This will flood the white balls causing the sampler to sink. Lower the sampler to the appropriate depth.
11. Take a firm grip on the retrieving line then pull sharply upward (a quick tug of a few inches) to capture the sample.
12. Slowly pull the sampler back out of the water.
13. Retrieve the sampler and set on a clean flat surface in a horizontal position.
14. Wear gloves to discharge sample from sampler; use a fresh pair for each sample.
15. Release the pinch clamp sealing the plastic tubing to allow the water sample to flow out of the sampler. Discharge the first 10-20 mL to clear any potential contamination on the valve. Fill the sample collection bottles to the brim using the remaining water.
16. Don't invert the sample collection bottles or overfill them. The laboratory has pre-prepared some bottles with preservatives, which must remain as part of the sample.
17. Tightly cap each sample bottle as it is filled.
18. Label each sample immediately upon putting it in the sample bottle – ID protocol: Year-month-day-sampler initials-water body-sample number e.g., 2018-10-08-SED-LOW-01 (where LOW stands for lake-of-the-woods) – you can make up your own acronyms, and be sure to record their meanings in your field book.
19. Place all samples upright in the cooler with ice packs for transport. Be sure that any glass bottles are not in contact with each other by placing plastic bottles between them.
20. Courier samples in a cooler with ice packs on the same day as collection, together with the chain-of-custody form. This is VERY important as no lab will process the samples without a chain of custody.

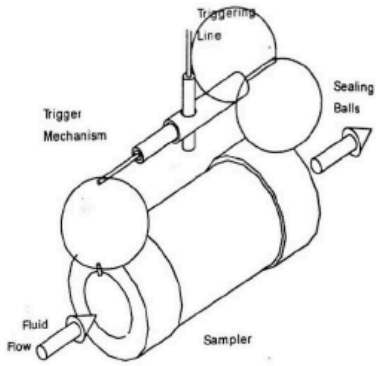


Figure 1: Schematic diagram of a Vernier depth sampler (source: Vernier Depth Sampler Instructions)

QA/QC

Quality control is vital for data interpretation and assessment and yields information from which confidence brackets can be applied to the data collected. There are several sampling elements in a proper QA/QC program, including: lab blank samples, field blank samples, duplicate samples, split samples, and spiked samples. Duplicate describes the taking of a second sample or performance of a second measurement or determination. Split samples describe two or more representative portions taken from a sample or subsample and analyzed by different analysts or laboratories. Split samples are used to replicate the measurement of the variable(s) of interest. A spiked sample is a sample prepared with a known concentration of a specific analyte. This protocol outlines the methods for collecting lab blank and field blank samples, as they are the only QA/QC samples you will be required to prepare within this sampling protocol.

Lab Blank Sample: A laboratory blank sample is collected to ensure that laboratory cleaning methods are adequate and are not contaminating samples. Reagent grade water (distilled water) should always be used to collect these samples. Submit on a regular schedule.

- One sample is collected for each sampling week, when noted as needed by the project quality assurance plan or deemed necessary by the project manager.
- The sample is collected by running reagent grade water through all plasticware that will be used in the field during a particular sampling week.
- The sample will aliquoted into each type of bottle provided by the laboratory (i.e., for each suite of analyses).
- Label with a "32" in the sample number ID code.

Field Blank Sample: A field blank sample is collected to ensure that field cleaning methods are adequate and are not cross-contaminating samples. Reagent grade water should always be used to collect these samples. Submitted on a regular schedule.

- One sample is collected for each sampling trip, when noted as needed by the project quality assurance plan or deemed necessary by the project manager.
- The sample is collected by running reagent grade water through any plasticware that is used at more than one station. Water should be aliquoted in a manner that is consistent with normal sampling procedures.
- The sample will be aliquoted into one of each type of bottle provided by the laboratory (i.e., for each suite of analyses).
- Label with a "33" in the sample number ID code.

Clean Hands/Dirty Hands Technique

Clean Hands/Dirty Hands techniques require two or more people working together.

- At the field site, one person is designated as Clean Hands (CH) and a second person as Dirty Hands (DH). Although specific tasks are assigned at the start to CH or DH, some tasks overlap and can be handled by either, as long as the prescribed care is taken to prevent contaminating the sample.
- CH and DH wear appropriate disposable, powderless gloves during the entire sampling operation and change gloves frequently, usually with each change in task. (Wearing multiple layers of gloves allows rapid glove changes but impedes dexterity).

CH takes care of all operations involving equipment that contacts the sample; for example, CH:

- Handles the surface-water sampler bottle
- Handles the discharge end of the sample tubing
- Prepares a clean work space (inside vehicle) - Sets up processing and preservation chambers
- Places equipment inside chambers (for example, sample bottles, filtration and preservation equipment)
- Works exclusively inside chambers during collection/processing and preservation
- Changes chamber covers, as needed
- Sets up field-cleaning equipment and cleans equipment

DH takes care of all operations involving contact with potential sources of contamination; for example, DH :

- Works exclusively exterior to processing and preservation chambers
- Prepares and operates sampling equipment, including pumps and discrete samplers, peristaltic pump switch, pump controller, manifold system
- Operates cranes, tripods, drill rigs, vehicles, or other support equipment
- Handles the compressor or other power supply for samplers
- Handles tools such as hammers, wrenches, keys, locks, and sample-flow manifolds
- Handles single or multiparameter instruments for field measurements
- Handles the churn carrier, including outer protective bags
- Handles stream-gaging or water-level equipment
- Sets up and calibrates field-measurement instruments
- Measures and records water levels and field measurements

Appendix E: Questionnaires

Letter of Information

Dear Wauzhushk Onigum Nation Resident:

As you are aware, there have been longstanding issues with your drinking water and the treatment plant. Wauzhushk Onigum Nation has been under a drinking water Boil Water Advisory (BWA). A team from Wauzhushk Onigum Nation, McMaster University, and the University of Saskatchewan have designed a study that will 1) understand how the BWA has affected lives of residents in Wauzhushk Onigum Nation, and 2) attempt to understand vulnerabilities for future contamination events. It is intended that this study will benefit your community by consolidating your perceptions, traditional knowledge, and needs as they pertain to drinking water in order to give your voice to the feasibility study process for a drinking water solution.

To understand more about contamination vulnerabilities, we will look at maps and reports, map potential contaminant points from community knowledge, test for contaminants in the water, and create a map of potential contaminant transport.

To understand how the BWA has affected the community, you can participate by sharing your experiences by completing an anonymous questionnaire and by participating in a small gathering circle with some of your neighbours. The questionnaire consists of five short sections that focus on 1. Basic information about you (e.g., age; education); 2. Your knowledge of the BWA (e.g., How did you hear about the BWA? Did you seek more information about the BWA?); 3. Water sources and uses before and during the BWA (e.g., What was/is the source of your drinking water? What was/is the source of water for food preparation?); and, 4. Impacts of the BWA upon your life (e.g., What was the financial impact of the BWA on you and your family? What was your emotional response to the BWA?). The questionnaire can be completed in the privacy of your own home, but if you prefer, one of our research team members would be pleased to ask you the questions in an interview and record them on your behalf. This interview can be arranged by contacting Kayla or community partners to confirm a time and private location for this to occur.

In this package we have provided you with:

1. this information letter;
2. consent form for questionnaire;
3. questionnaire;
4. consent form and schedule for small sharing circles;
5. small white envelope; and,
6. large brown envelope.

Once you receive the package, you have several options available for your confidential participation:

1. **If you wish to complete the questionnaire on your own, the consent form should be completed, signed, and placed in the small white envelope.** It should then be returned along with your completed questionnaire that should be placed in the large brown envelope. Please seal both envelopes before returning them. The questionnaires will be picked up from your home on Tuesday October 16th, or you may drop it off at the Band Office no later than Wednesday October 17th. If you would like to return the envelopes directly to Kayla or Derek, please call Kayla at 905-906-4218. You are not obligated to respond to any questions that you do not wish to.
2. **If you wish to complete the questionnaire through an interview, either call Kayla and Derek at 905-906-4218 or verbally request the interview when they come back to pick up the questionnaire on Tuesday October 16th.** The consent form should be completed and placed in the small white envelope but do not seal the large brown envelope. The interviewer will record your verbal answers on the questionnaire. Once the interview is finished, the interviewer will seal your consent form in the small white envelope and place the completed questionnaire in a large brown envelope which will be sealed and returned for data processing.
3. **If you do not wish to participate in the survey, please seal your consent form in the small white envelope and place the questionnaire in the large brown envelope, seal it, and return to the research team when they come to collect it on Tuesday October 16th, or to the Band Office by Wednesday October 17th.**

This package also describes an opportunity to share your thoughts in a small gathering circle of community members. These circles will focus on community, rather than individual, responses to the BWA (e.g., What were the community impacts of the BWA? How did the BWA affect community leadership and participation?). **If you would like to participate in one of these sharing circles, please complete and sign the consent form and indicate your first and second preference for a specific date and time. This form should also be placed in the white envelope. We will do our best to accommodate one of these choices.**

While there are no physical risks to participating in this study, there may be some psychological and social risks and we would ask you to consider those in considering your willingness to be a participant. Thinking about the impacts of the BWA may cause you some anxiety, as may recalling specific details of your experiences in adjusting to water advisories in your community. We do not believe that this anxiety is any greater than your day-to-day experiences living with the BWA. We also recognise that there may be some social risks surrounding sharing of your views on the BWA. Therefore, we have taken clear steps to ensure the anonymity of your individual responses to the questionnaire (e.g. consent forms are separated from questionnaire, there is no identifying information on the questionnaire itself, questionnaires will be returned regardless of participation, and researchers have taken oaths of confidentiality). Wauzhushk Onigum Nation is a relatively small community. These safeguards should ensure that people will know about your participation in the research only if you tell them. Because the information provided in the questionnaire is anonymous, it cannot be withdrawn once submitted back to the research team.

While participants in the sharing circles will be reminded that all shared information is confidential, we cannot guarantee that everyone will comply with this understanding. Sharing circle digital recordings will be transcribed without reference to participants. Because we cannot identify individual participants by voice within the sharing circle, participation cannot be withdrawn once the circle begins. However, if you decide at any point during the sharing circle that you do not wish to continue, you may remain silent.

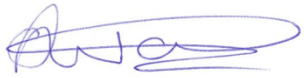
The information collected from the questionnaires and the sharing circles will be coded and stored on a password protected university computer (MacDrive). We will analyse and summarise the results using Excel© and NVivo©. These analyses will be given to the Band Council for their secure storage and use. The research team will compile all of the different information collected as part of the study (including these analyses) and generate a report for the community. Community partners will share the report and our findings at an appropriate community event. Additionally, the data will be used in the preparation of academic publications. All members of the research team, including community partners, will be co-authors on these publications. Copies will be filed with the Tribal Council.

This research project has received ethics approval from McMaster Research Ethics Board and has been reviewed by the Anishinaabeg of Kabapikotawangag Resource Council. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
E-mail: ethicsoffice@mcmaster.ca

We look forward to working with you to resolve this major community problem. If you have any other questions, please contact the principle investigators.

Sincerely,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Susan Watt, D.S.W.
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Faculty of Social Sciences
wattms@mcmaster.ca

Consent

Questionnaire Consent (with Interview Option)

Participant Name: .....

Have you been informed about what this research involves?	[ ] Yes	[ ] No
Have you had the opportunity to ask questions?	[ ] Yes	[ ] No
Do you agree to participate in a questionnaire?	[ ] Yes	[ ] No
Do you understand that your information is anonymous and therefore, cannot be withdrawn once submitted?	[ ] Yes	[ ] No

Participant Signature:

……..

Date: .....

If you would prefer an interview to complete the questionnaire, community partners or Kayla Lucier would be happy to schedule a time and interviewer for you. Please contact them through the office.

Interviewer Signature (if applicable):

……..

Interviewer Name: .....

Date: .....

I understand that there will be a raffle prize for one (1) Samsung Galaxy Tab E tablet.	[ ] Yes	[ ] No
I consent to my completed consent form being submitted as a ballot for this prize draw.	[ ] Yes	[ ] No
I have returned the complete package as per the instructions to participants.	[ ] Yes	[ ] No
Preferred method of contact:		

Questionnaire Instrument

Wauzhushk Onigum Nation Drinking Water Questionnaire (Community Mei

A: Personal Information

1. What is your gender? ☐ Male ☐ Female ☐ Prefer to not answer

2. How old are you?

☐ 18-29 yrs. ☐ 30-39 yrs. ☐ 40-49 yrs. ☐ 50 + yrs. ☐ Prefer to not answer

3. How many years has Wauzhushk Onigum Nation been your primary residence?

☐ < 1 yr. ☐ 1 to < 3 yrs. ☐ 3 to < 5 yrs. ☐ 5 to < 10 yrs. ☐ ≥ 10 yrs ☐ Prefer not to answer

4. Have you lived elsewhere for a substantial period of time (i.e., more than 6 months)?

☐ Yes ☐ No

4a. If yes, why?

_____

_____

5. What form of traditional education have you received?

Please describe:

_____

OR ☐ None

6. In addition to your traditional education, what is the highest level of formal education that you have completed?

☐ Elementary school ☐ High school ☐ Vocational training

☐ University/college ☐ Graduate degree/professional credentials ☐ Prefer not to answer

B: Knowledge of Boiled Water Advisory (BWA)

7. How long have you lived under a BWA?

_____

8. Based on your experience, please categorise the following statements as YES or NO during a BWA?

Applies only to my tap water	☐ YES	☐ NO	☐ I DON'T KNOW
I can drink my tap water as long as it is clear	☐ YES	☐ NO	☐ I DON'T KNOW
I should not drink my tap water	☐ YES	☐ NO	☐ I DON'T KNOW
I should boil my tap water to prepare my food	☐ YES	☐ NO	☐ I DON'T KNOW
I can use my tap water to make ice	☐ YES	☐ NO	☐ I DON'T KNOW
I can bathe / shower using my tap water	☐ YES	☐ NO	☐ I DON'T KNOW
I can give my babies and young children a sponge bath using my tap water	☐ YES	☐ NO	☐ I DON'T KNOW
Before preparing meals, it is okay to wash my hands with tap water	☐ YES	☐ NO	☐ I DON'T KNOW
I can use my tap water to clean my teeth	☐ YES	☐ NO	☐ I DON'T KNOW
I should boil my tap water before I drink it	☐ YES	☐ NO	☐ I DON'T KNOW
I should boil my tap water before I bath my babies and young children	☐ YES	☐ NO	☐ I DON'T KNOW
I can use a Brita filter to decontaminate my tap water	☐ YES	☐ NO	☐ I DON'T KNOW
I should drink bottled water	☐ YES	☐ NO	☐ I DON'T KNOW

9. How did you hear about the BWA in Wauzhushk Onigum Nation?

_____

_____

10. Is there anything else you would like to share concerning the BWA in Wauzhushk Onigum Nation?

_____

_____

_____

_____

C: Water Sources and Uses

11. Please identify (with a check mark) where you get your water for the following purposes when there isn't a BWA:

Purpose	Source				Not Applicable
	Tap	Lake	Bottled	Other (please describe)	
Drinking					
Food preparation					
Cooking					
Cleaning teeth					
Hand washing					
Bathing					
Cleaning					
Laundry					
Ceremonies					
Other use (please describe)					

12. Please identify (with a check mark) where you get your water for the following purposes under a BWA:

Purpose	Source				Not Applicable
	Tap	Lake	Bottled	Other (please describe)	
Drinking					
Food preparation					
Cooking					
Cleaning teeth					
Hand washing					
Bathing					
Cleaning					
Laundry					
Ceremonies					
Other use (please describe)					

D: Impact of BWA and DNCA

13. Which of the following face(s) best describes how the BWA makes you feel? (Circle as many as apply.)

Other(s):

_____

14. How seriously are you taking the current BWA (select one)?

- ☐ Always adhere
- ☐ Sometimes adhere
- ☐ Adhere when convenient
- ☐ Rarely adhere
- ☐ Never adhere

15. How significant were any **negative** impacts that you experienced under a BWA?

	Significant Impact	High impact	Some impact	Little impact	No impact
Financially					
Physically (health)					
Psychologically					
Socially					
Spiritually					
Time Burden					

16. Please use this space if you would like to share additional information regarding these **negative** impacts:

_____
_____
_____
_____

17. Please describe any **positive** impacts of being under a BWA?

_____
_____
_____
_____

OR ☐ I cannot think of any **positive** impacts

18. Is there anything else you would like to say about water resources in your community and/or the BWA? Please use this space if you would like to share additional information:

_____
_____
_____

Appendix F: Interviews

Letter of Information

Dear _____,
Please allow me to introduce myself. I am a member of a community-based research team that is collecting data and information on the current and historical status of drinking water in the community of Wauzhushk Onigum Nation (WON). We want to understand how drinking water advisories have affected the lives of residents in WON. It is intended that this study will benefit the community by consolidating their perceptions, traditional knowledge, and needs as they pertain to drinking water.

You have been identified as an individual who can provide contextual information to the drinking water issues faced by residents of WON. [We would like to invite you to participate in a key informant interview by telephone or Skype, to be arranged at your convenience. If you are willing to talk to a member of the research team, please reply to this email indicating your availability for a 30-minute interview between [*date range to be fixed*]. If none of these dates work, we are happy to find another mutually convenient time.] OR [We would like to invite you to participate in an in-person key informant interview to be arranged at your convenience. If you are willing to talk to a member of the research team, please reply to this email indicating your availability for a 30-minute interview between [*date range to be fixed*] when we will be in WON If none of these dates work for you, we are happy to find another mutually convenient time by telephone or Skype.]

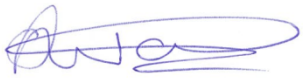
We will be recording the interview, which will be anonymously transcribed into text and stored on a password protected server at McMaster University. At that point, the recording will be destroyed. We recognise that there may be some social risks surrounding sharing of your views on the drinking water status in WON, particularly as it pertains to the drinking water advisories. Therefore, we have taken clear steps to ensure the anonymity of your individual responses to the interview questions (e.g. there will be no identifying information transferred to the transcription of the interview and researchers have taken oaths of confidentiality).

This research project has received ethics approval from McMaster Research Ethics Board and has been reviewed by the Anishinaabeg of Kabapikotawangag Resource Council. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
E-mail: ethicsoffice@mcmaster.ca

If you have any other questions, please contact the principle investigators.

Sincerely,


Sarah Dickson, Ph.D., PEng.	Corinne Schuster-Wallace, Ph.D.	Susan Watt, D.S.W.
Associate Professor	Adjunct Faculty	Professor Emerita
Faculty of Engineering	Faculty of Engineering	Faculty of Social Sciences
sdickso@mcmaster.ca	corinne.schusterwallace@gmail.com	wattms@mcmaster.ca

Informed Consent and Log

Consent

Participant Name: .....

Have you been informed about what this research involves?	[ ] Yes	[ ] No
Have you had the opportunity to ask questions?	[ ] Yes	[ ] No
Do you agree to participate in a key informant interview?	[ ] Yes	[ ] No
Do you agree to be audio-recorded?	[ ] Yes	[ ] No

Participant Signature:

……..

Date: .....

Log

[Password protected file stored on MacDrive accessed only by Principle Investigators]

Interview Code	Interviewee Name	Position	Organisation	Interviewer Name	Date

Interview Instrument

Hello. Thank you for agreeing to participate in this interview. Just to remind you, I will digitally record our conversation, which will be transcribed without any identifying data. We will destroy the recording and save the anonymized transcript on a protected server. Your participation is voluntary and you may stop participating at any time, or decide not to answer a question. Do you have any questions before we start? If this is agreeable to you, I will start the recording now.

[*Start Recording*]

For the record, before we start the questions, can you please confirm that you consent to participating in this interview? [*pause*]That you have been provided with the background information on the project? [*pause*] That you don't have any additional questions? [*pause*] And that you agreed to have this interview recorded? [*pause*]

1. Can you tell us about your relationship to Wauzhushk Onigum Nation, particularly as it pertains to drinking water?

2. Have you been involved in the boil water advisories in Wauzhushk Onigum Nation in any way? If so, what was your role?

3. How do you think the boil water advisory affects the residents of Wauzhushk Onigum Nation?

4. Has there been any impact for you as an individual? If so, what?

5. Advisories can be very stressful and create tension in relationships. What has the period of the boil water advisory been like for you in terms of your relationship with people/others in Wauzhushk Onigum Nation?

6. What do you believe to be the critical problems resulting in the boil water advisories in Wauzhushk Onigum Nation?

7. Do you believe there is a solution to the water problems in Wauzhushk Onigum Nation?

8. What do you think is the best solution for the drinking water problems in Wauzhushk Onigum Nation?

9. What do you think it will take to achieve this outcome?

10. What do you think will be the actual outcome?

11. Is there any historic information about the relationship between Wauzhushk Onigum Nation and your organisation / department that would help us to better understand the current situation in Wauzhushk Onigum Nation?

12. Is there anything else that you think we should know about the drinking water situation and/or advisories in Wauzhushk Onigum Nation?

Appendix G: NVivo Coding Node Structure

An inductive approach was taken to develop the final code set and look for emerging themes once the initial coding hierarchy, based on questions asked in the interview script, was created. KI and Elder interviews were coded separately as each offered unique perspectives. Codes in red were either added or removed from the initial coding hierarchy to establish the final code set.

Elder Coding Structure

1. Water Resources
    a. Water Pollution Causes
        i. People
            - Cottagers
            - ~~Overpopulation~~
        ii. Boats
        iii. Oil
        iv. Dams
        v. Septic Fields/Sewage
        vi. Logging
        vii. Dump
        viii. Mining
            - ~~Heavy Metals~~
            - Sultana
        ix. Algae
        x. Farm and Agriculture
    b. Lake Levels
        i. Dams
            - ~~Higher Levels~~
                a. ~~Wild Rice~~
            - Lower Levels
                a. ~~Rocks~~
    c. Natural Habitat
        i. Animal
        ii. Vegetation
    d. Changes Over Time
        i. Intra-Annual (Seasonal)
            - Lake Smell
            - Lake Colour
        ii. Inter-Annual
            - Lake Smell

- Lake Colour
- Activities

2. Water and Health

    a. Meaning of Water
        i. Life-Sustaining
        ii. Commodity
    b. Physical Health
        i. Of People
            - ~~H.pylori~~
            - Losing Hair
            - Skin Rash or Itch
        ii. Of Wildlife
        iii. Cause
    c. Water Sources
        i. Kenora Pipeline
            - Positive
            - Negative
        ii. Lake
        iii. Tap
        iv. Bottled
        v. Changes Over Time
    d. Water Uses
    e. Treating Water
        i. Community-System
            - Responsibility
                a. Government
                b. Community
        ~~ii. Private System~~
            - ~~Untreated~~
        ~~iii. Changes Over Time~~

3. BWA

    a. Burden
        i. Financial
            - Positive
            - Negative
        ii. Collection
            - Vulnerable Groups/Age
        ~~iii. Time~~
        iv. Access/Use
        v. Insufficient Supply
            - Hoarding
    ~~b. Inadvertent Benefits~~

~~i. Long-Term Solution (Government awareness/facilitation)~~
~~ii. Relationships (Ex. Kenora water guys & WON, Health Canada &WON)~~

c. Knowledge
    i. Cause
        - Treatment Plant
        - Pollution
            a. People
            b. Boats
            c. Dams
            d. Septic Fields/Sewage
            ~~e. Logging~~
            f. Dump
            ~~g. Mining~~
            h. Algae
    ii. Notification
        - Type
            ~~a. Band Office~~
            ~~b. Community Poster~~
            ~~c. Leaflet~~
            d. Friends/Word of Mouth
            e. Radio
        - Preference/Insufficient
    iii. Practices
        - Meet BWA
        - ~~Don't Meet BWA~~
    iv. Need for Information
    v. Potential Solutions
        - Kenora Pipeline
        - Government Funding
        - Traditional Ways
        - Clean LOTW
        - Community Treatment

4. E~~quity/Power Disconnect~~ Relationships

    a. Between/Among Residents of WON
        i. Gender
    b. Between WON and Kenora
        ~~i. Water Operators~~
        ~~ii. Drinking Water Standards~~
    c. Between WON and Urban Centres
        ~~i. Water Operators~~
    d. Between WON and Canada
        i. Mistrust
5. Other Topics
6. Useful Quotes

Key Informant Coding Structure

1. Water Resources
    a. Water Pollution Causes
        i. People
            - Cottagers
            - Overpopulation
        ii. Boats
        ~~iii. Oil~~
        iv. Dams
        v. Septic Fields/Sewage
        vi. Logging
        vii. Dump
        viii. Mining
            - Heavy Metals
            - Sultana
        ix. Algae
    b. Lake Levels
        i. Dams
            - Higher Levels
                a. Wild Rice
            - ~~Lower Levels~~
                ~~a. Rocks~~
    c. Natural Habitat
        i. Animal
        ii. Vegetation
    d. Changes Over Time
        ~~i. Intra-Annual (Seasonal)~~
        ii. Inter-Annual
            - ~~Lake Smell~~
            - Lake Colour
            - Activities

2. Water and Health
    a. Meaning of Water
        i. Life-Sustaining
        ii. Commodity
    b. Physical Health
        i. Of People
            - H.pylori
            - ~~Losing Hair~~
            - Skin Rash or Itch
        ii. Of Wildlife
    c. Water Sources

i. Kenora Pipeline
- Positive
- ~~Negative~~

ii. Lake
iii. Tap
iv. Bottled
v. Changes Over Time

d. Water Uses
e. Treating Water
i. Community-System
- Responsibility
  a. Government

~~ii. Private System~~
- ~~Untreated~~

~~iii. Changes Over Time~~

3. BWA

a. Burden
i. Financial
- ~~Positive~~
- Negative
- Treatment Plant

ii. Collection
- Vulnerable Groups/Age

iii. Time
iv. Access/Use
v. Insufficient Supply
- Hoarding

vi. Mental Health
vii. Commerical

b. Inadvertent Benefits
i. Long-Term Solution (Government awareness/facilitation)
ii. Relationships (Ex. Kenora water guys & WON, Health Canada &WON)
iii. Health of Community

c. Knowledge
i. Cause
- Treatment Plant
  a. Qualified Personnel
- Pollution
  a. People
  b. Boats
  ~~c. Dams~~
  d. Septic Fields/Sewage
  ~~e. Logging~~
  ~~f. Dump~~

g. ~~Mining~~
h. Algae
- Individual Systems
- Political

ii. Notification
- Type
  a. ~~Band Office~~
  b. Community Poster
  c. ~~Leaflet~~
  d. ~~Friends/Word of Mouth~~
  e. Health Canada
  f. Social Media
  g. Door to Door
- Preference/Insufficient

iii. Practices
- Meet BWA
- Don't Meet BWA

iv. Need for Information

v. Potential Solutions
- Kenora Pipeline
  a. Risks
  b. Benefits
  c. Resources Required
- Government Funding
- Traditional Ways
- Clean LOTW
- Community Treatment
- Individual Systems
- Resources

4. ~~Equity/Power Disconnect~~ Relationships

a. Between/Among Residents of WON
   i. Gender
   ii. Access
b. Between WON and Kenora
   i. Water Operators
   ii. Drinking Water Standards
c. Between WON and Urban Centres
   i. Water Operators
d. Between WON and Canada
   i. Mistrust
e. Inequities

5. Role
6. Other Topics
7. Useful Quotes

Appendix H: Lake Water Quality

These data were collected at the request of community and, although not included in this thesis, will be used in future publication. These data have been provided back to the community.

Current Water Quality

Water quality on Lake of the Woods was assessed through water sampling at 11 sites identified by community research partners as important to the community from mid-October to early November 2018. Environment and Climate Change Canada (ECCC) also conducts bi-annual sampling at 33 locations on Lake of the Woods. A report published in 2016 by the International Rainy-Lake of the Woods Watershed Board (IRLWWB) synthesized ECCC data collected on Lake of the Woods between 2012 and 2014, which included many of the same parameters tested for this project. The IRLWWB report separated sampling sites by basin, as designated by the ECCC; of the 11 sites sampled for this project, nine fell within basin 5 and two within basin 3b.

Findings from the IRLWWB report and from this project were compared to illustrate any changes over time. For most parameters, average values remained fairly constant, even though samples were collected four years apart and at different sites on Lake of the Woods. Note that for both this project and for the ECCC, sites were sampled at two depths: shallow, typically 1m to 2m from the surface, and just above lake bottom.

For chloride, Water Quality Guidelines for the Protection of Aquatic Life from the Canadian Council of Ministers of the Environment (CCME) suggest short-term chloride concentrations should not exceed 640 mg/L and long-term to not exceed 120 mg/L. The concentrations for chloride in Lake of the Woods were far below these recommendations, averaging between 1.9 and 2.2 mg/L for all basins and depths (Figure 2).

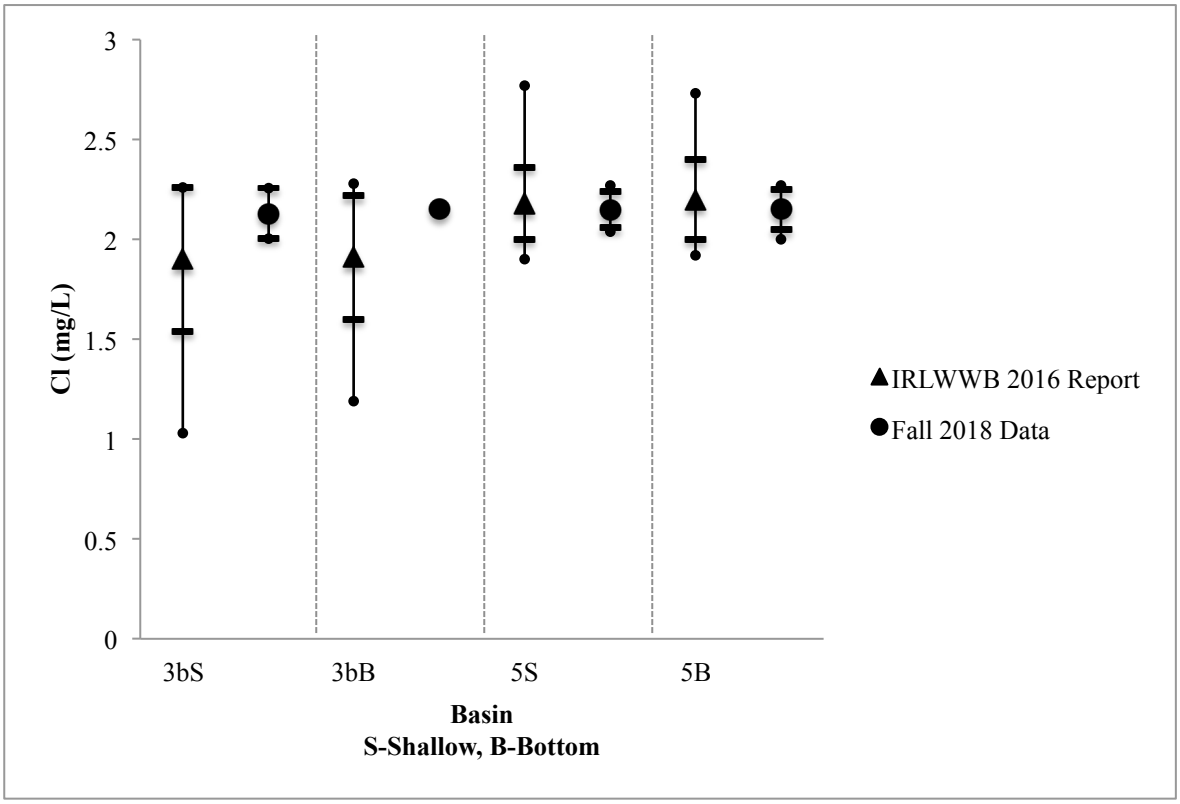


Figure 2: Average Chloride (Cl) Concentration in Lake of the Woods Basins[1]

While the CCME does not provide any recommendations for sulfates, sulfate concentrations measured in Lake of the Woods as part of this study averaged between 3.8 and 4.7 mg/L (Figure 3), below those reported over time in the IRLWWB report.

[1] On all water quality graphs, unless otherwise indicated, symbols represent the mean, dashes signify one standard deviation above and below mean, and the high and low points on the whiskers through the mean indicate maximum and minimum values.

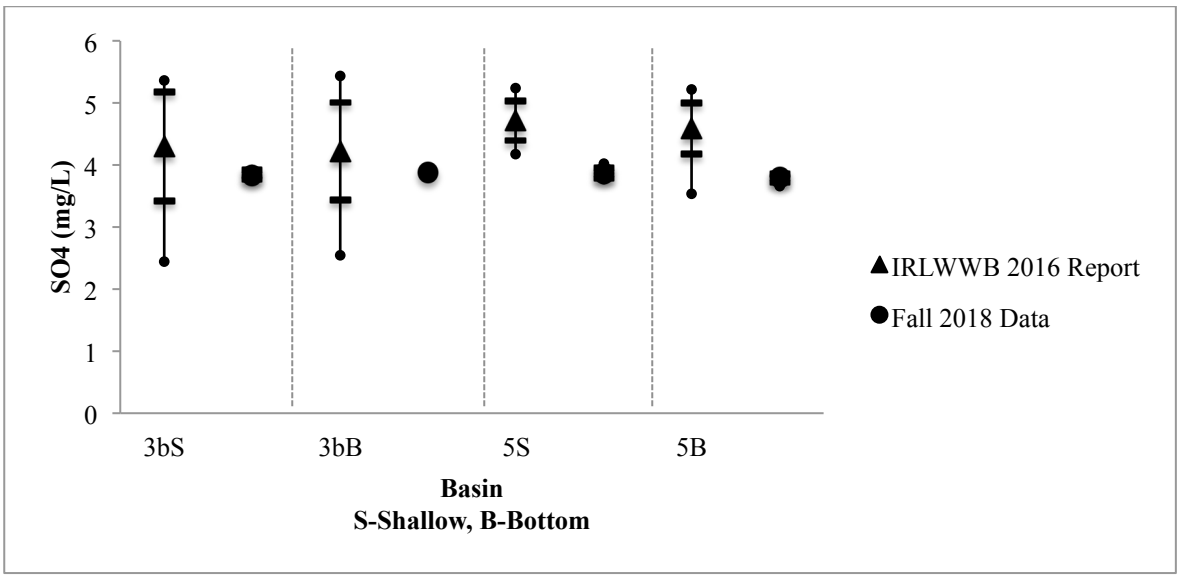


Figure 3: Average Sulfate (SO_4) Concentration in Lake of the Woods Basins

The Ontario Drinking Water Standards indicate that concentrations over 20 mg/L may affect individuals on low-sodium diets. The average sodium concentrations in Lake of the Woods ranged from 2.61 to 3.07 mg/L, well below concentrations of concern (Figure 4). Additionally, average sodium concentrations from the most recent sampling in 2018 were below those from the IRLWWB report.

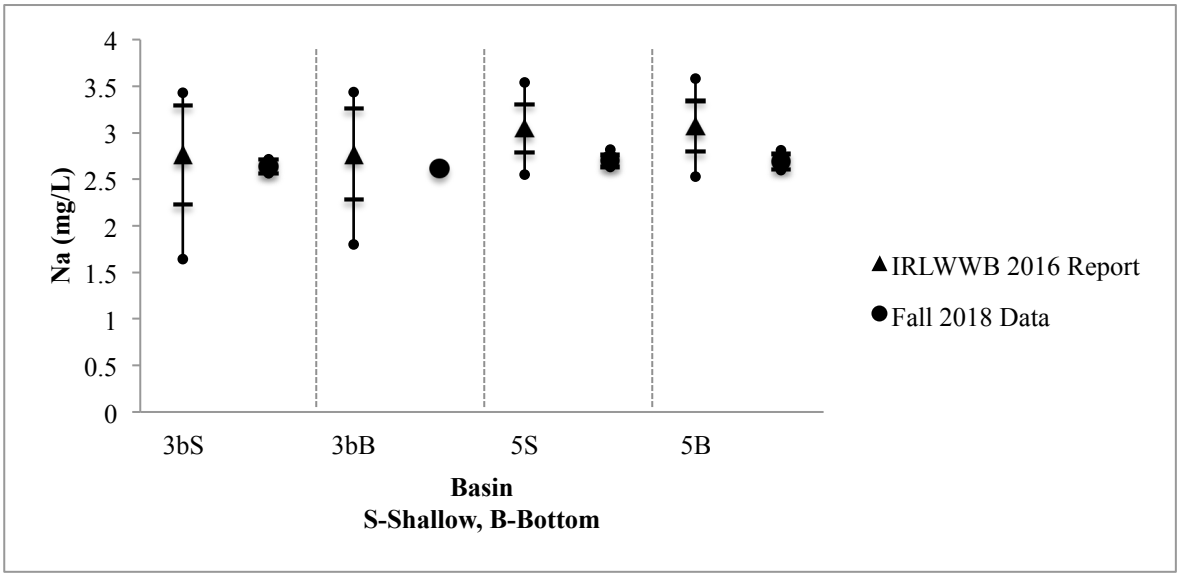


Figure 4: Average Sodium (Na) Concentration in Lake of the Woods Basins

The average dissolved organic carbon (DOC) concentrations in Lake of the Woods ranged from 9.3 to 10.6 mg/L. While not a direct health concern, higher levels of DOC (greater than 2 mg/L[2]) can generate challenges for drinking water treatment, making it more complicated and costly. DOC can affect the colour of finished drinking water and in very high concentrations (greater than 5 mg/L) can interact with chlorine during water treatment to form disinfection by-products, chemicals that are known carcinogens.

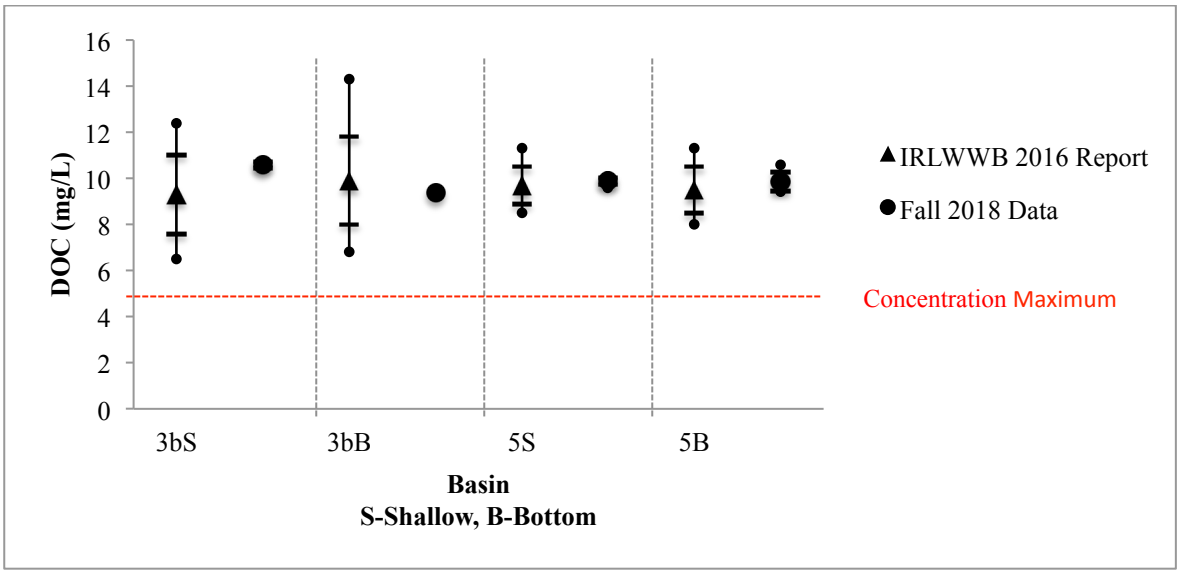


Figure 5: Average Dissolved Organic Carbon (DOC) Concentration in Lake of the Woods Basins

The average concentrations for total phosphorus in Lake of the Woods were between 0.021 and 0.050 mg/L (Figure 6), which according to the Water Quality Guidelines for the Protection of Aquatic Life indicates that Lake of the Woods ranges from meso-eutrophic to eutrophic. Eutrophic lakes are typically murkier, have a high level of biological activity, and commonly experience algal blooms due to the availability of nutrients. This may explain some of the water colours and cloudiness observed by Elders and KIs. Additionally, a maximum concentration value taken from lake bottom samples in basin 5 from the IRLWWB report

[2] http://www.saskh2o.ca/PDF-WaterCommittee/DissolvedOrganicCarbon.pdf

indicates phosphorus levels that greatly exceed 0.1 mg/L (0.337 mg/L), indicating a hyper-eutrophic lake. Hyper-eutrophic lakes have very high nutrient contents and may experience severe algal blooms. This same extreme value was not seen during Fall 2018 sampling, possibly because algal blooms form in warmer weather and samples were not taken until late October.

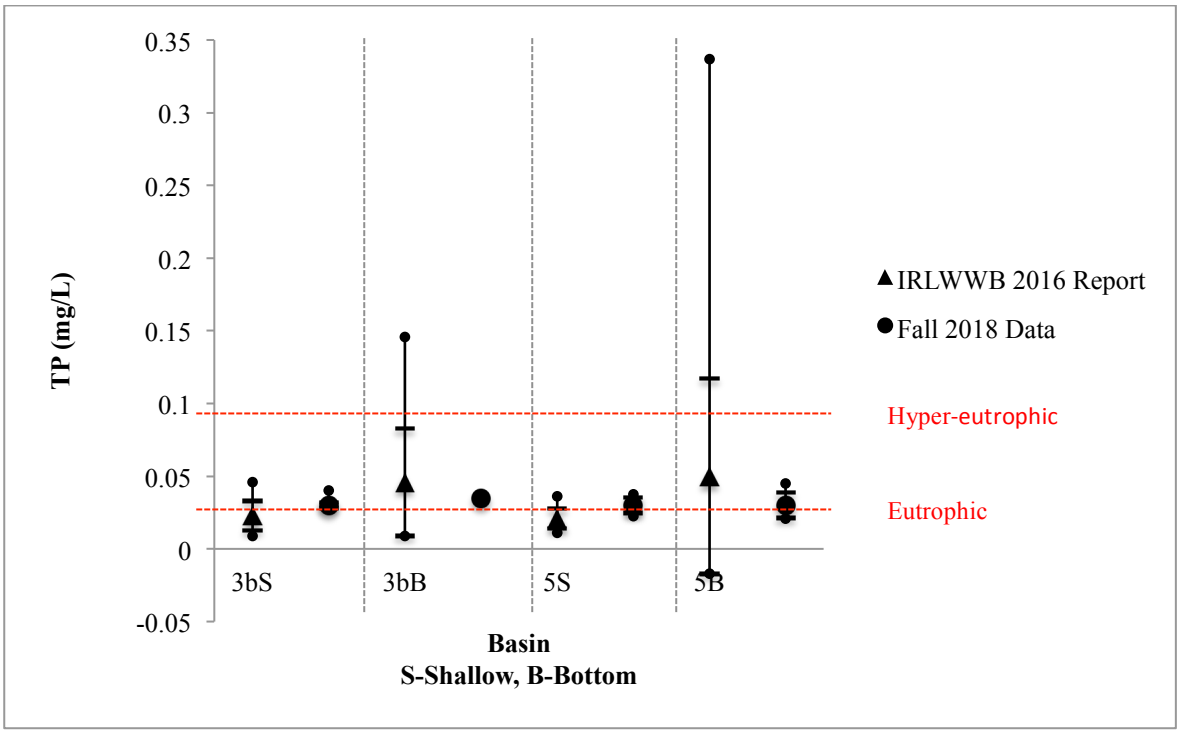


Figure 6: Average Total Phosphorus (TP) Concentration in Lake of the Woods Basins

The average concentrations for total phosphorus in Lake of the Woods vary over time. Seasonally, total phosphorus is lower in the summer and increases by the fall (Figure 7). Average concentrations for shallow samples in all basins increased from 0.0184 mg/L in June to 0.0319 mg/L in September and 0.0307 mg/L in October. Average concentrations for bottom samples increased from 0.0215 mg/L in June to 0.0446 mg/L in September and 0.0306 mg/L in October.

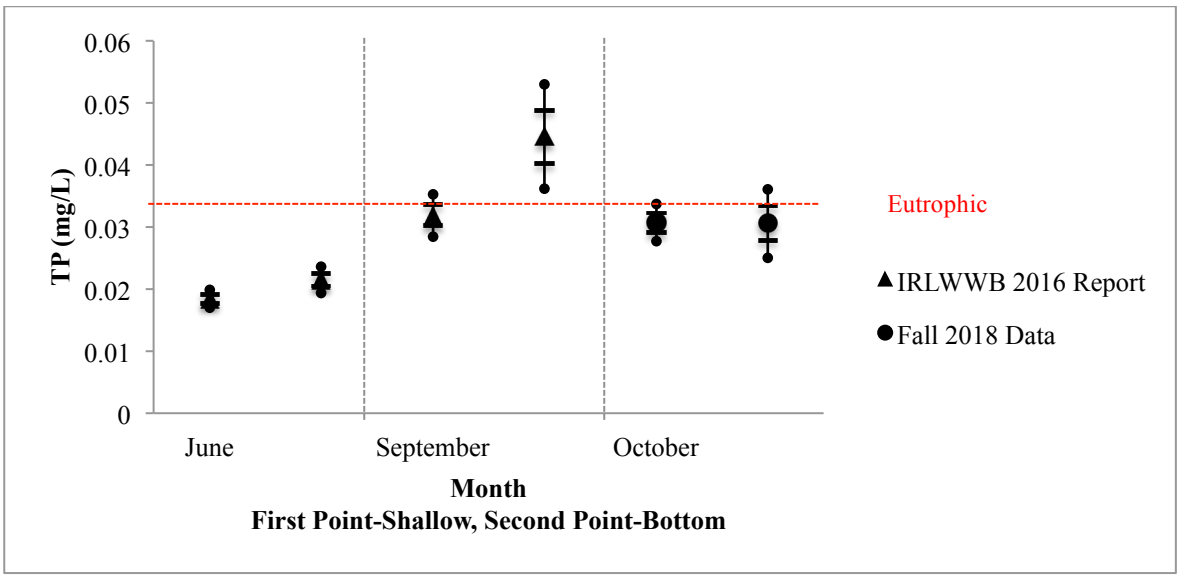


Figure 7: Average Total Phosphorus (TP) Concentration in Lake of the Woods By Season[3]

The average concentrations for dissolved phosphorus in Lake of the Woods were between 0.008 and 0.031 mg/L (Figure 8). One bottom sample from basin 5 taken from the IRLWWB report indicated a maximum dissolved phosphorus concentration of 0.258 mg/L, which exceeded the maximum value for basin 5 (bottom) from the October 2018 sampling by 0.243 mg/L.

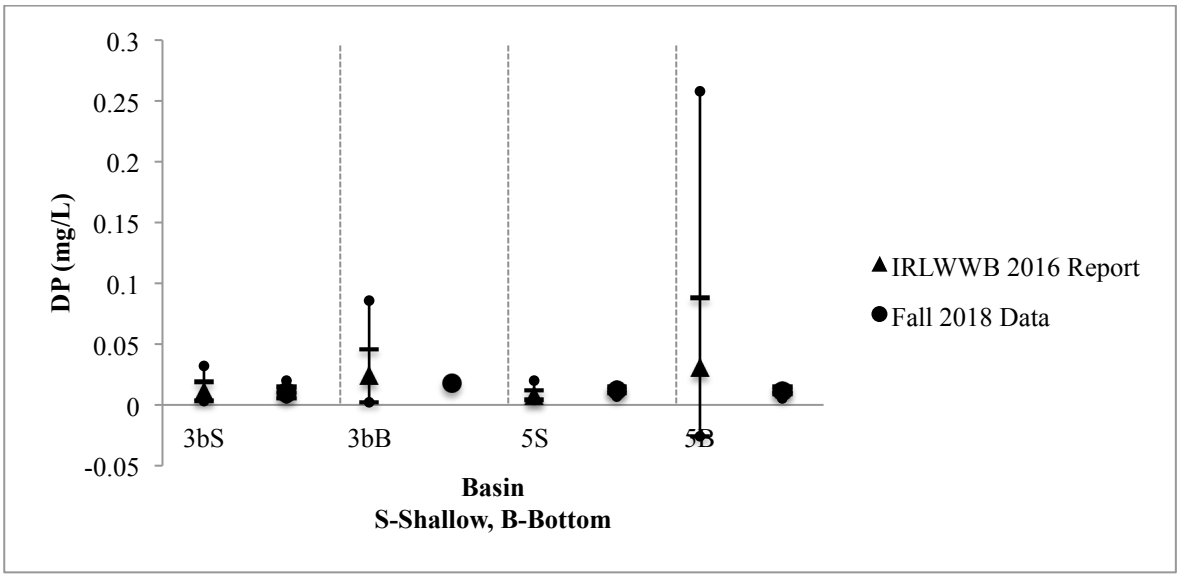


Figure 8: Average Dissolved Phosphorus (DP) Concentration in Lake of the Woods Basins

[3] For this figure only, dashes indicate one standard error above and below mean. High and low points along the line through the mean indicate 1.96*standard error above and below mean.

Similar to total phosphorus, a high total nitrogen concentration is indicative of greater biological activity and a higher trophic level. The average concentrations for total nitrogen in Lake of the Woods were between 0.45 and 0.84 mg/L (Figure 9), which indicates that Lake of the Woods ranges from mesotrophic to eutrophic.[4] Additionally, a maximum concentration value taken from lake bottom samples in basin 5 from the IRLWWB report indicates nitrogen levels that exceed 1.2 mg/L (1.88 mg/L), indicating a hyper-eutrophic lake. This value exceeded the maximum value for basin 5 (bottom) from the October 2018 sampling by 1.17 mg/L.

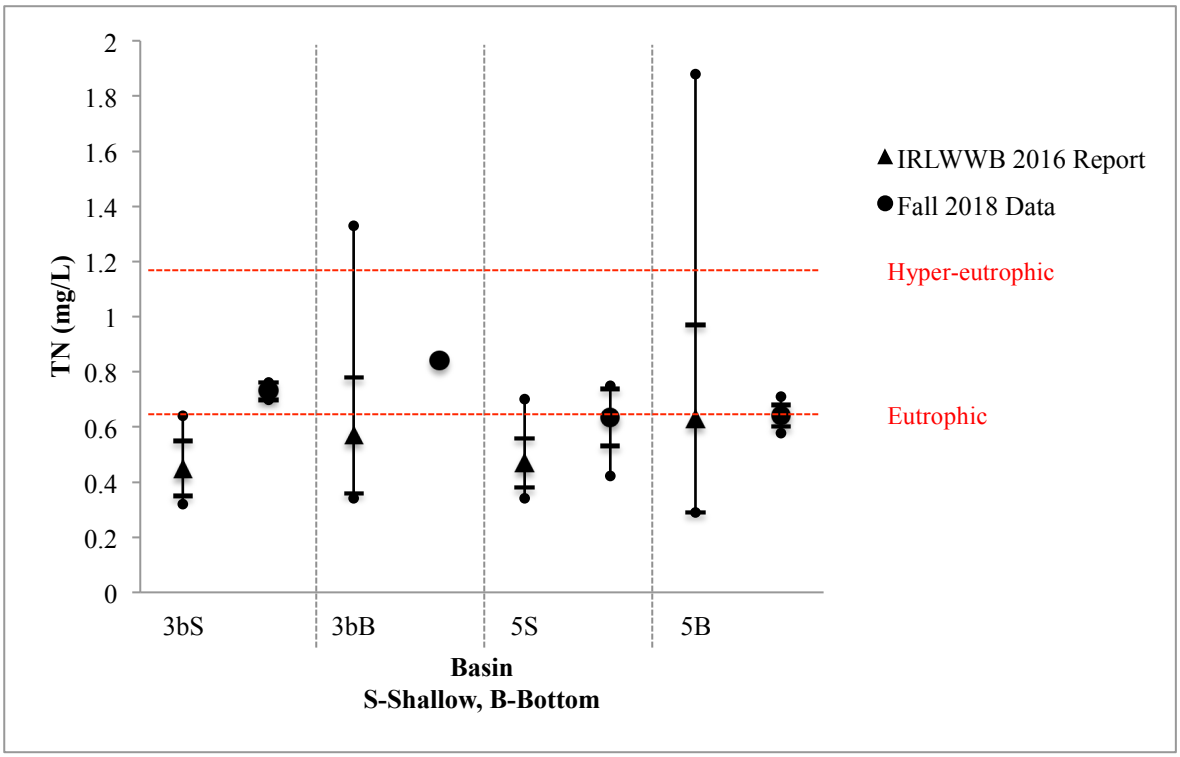


Figure 9: Average Total Nitrogen (TN) Concentration in Lake of the Woods Basins

The average concentrations for nitrite/nitrate in Lake of the Woods were between 0.012 and 0.090 mg/L (Figure 10). The Ontario Drinking Water Standards indicates a maximum nitrite concentration of 1 mg/L and maximum nitrate concentration of 10 mg/L separately, but together

[4] Nürnberg, G. K. (1996). Trophic state of clear and colored, soft-and hardwater lakes with special consideration of nutrients, anoxia, phytoplankton and fish. *Lake and Reservoir Management*, *12*(4), 432-447.

they should not exceed 10 mg/L. Assuming a maximum concentration of nitrite is present, the value of nitrite/nitrate should not exceed 0.1 mg/L. One bottom sample from basin 5 taken from the IRLWWB report indicated a maximum nitrite/nitrate concentration of 0.24 mg/L, more than double the acceptable maximum. For all basins and depths, the average nitrite/nitrate concentrations were greater in Fall 2018 than from the IRLWWB report in 2016.

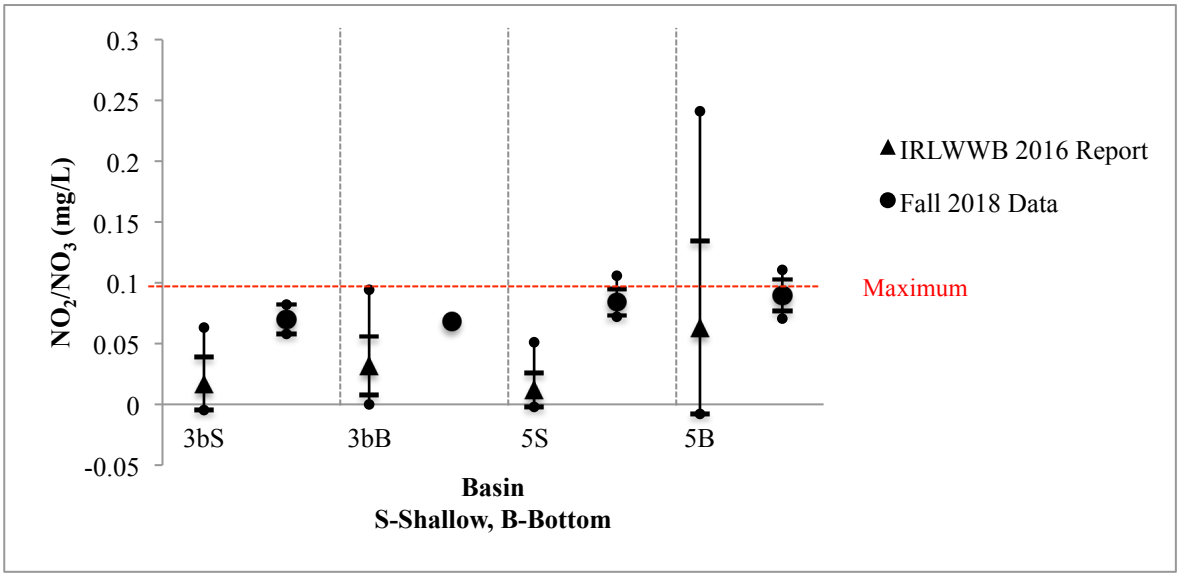


Figure 10: Average Nitrite/Nitrate (NO_2/NO_3) Concentration in Lake of the Woods Basins