# BE LIKE THE RUNNING WATER: EXPLORING THE INTERACTIONS OF HEALTH AND WATER SECURITY WITH SIX NATIONS OF THE GRAND RIVER FIRST NATION

# BE LIKE THE RUNNING WATER: EXPLORING THE INTERACTIONS OF HEALTH AND WATER SECURITY WITH SIX NATIONS OF THE GRAND RIVER FIRST NATION

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements for

the Degree Doctor of Philosophy

McMaster University

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DOCTOR OF PHILOSO	PHY (2021)	McMaster University
(Anthropology of Hea	lth)	Hamilton, Ontario
TITLE:	<i>Be Like the Running W</i> and Water Security wi	<i>ater:</i> Exploring the Intersections of Health th Six Nations of the Grand River First Nation
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NUMBER OF PAGES: xi, 226

#### Lay Abstract

The goal of this doctoral dissertation was to explore the connections between water security and health with Six Nations of the Grand River First Nation, to explore the nuanced factors that inform perceptions of drinking water and better understand who in the community faces higher challenges and barriers throughout the water crisis. This project was co-created research using Indigenous Knowledge (IK) with medical anthropology approaches to understand water security, satisfaction, quality, and relationships as they relate to Haudenosaunee health. Water security was explored through tap and well water contamination tests, survey data, and interviews and focus groups. Water insecurity was reported for 57.5% of 66 households in this sample, with 21.2% having *E. coli* contamination in their tap water, 25.4% having mercury in their tap water exceeding provincial drinking water limits, and 77% of households relying primarily on bottled drinking water rather than their tap water. While water insecurity experiences were quite high in this study, Western metrics are not able to capture the crucial elements of Indigenous water relationships, such as community and cultural relationships with the land, environmental racism, and the consequences of environmental degradation, such as grief or poor mental health, relating to water and climate crisis. Water insecurity experiences are best understood as highly localized experiences that have mental health, physical health, and environmental consequences for Indigenous communities. To fully untangle the specific cultural, spiritual, racial, and colonial landscapes or structures that have shaped Six Nations experiences and perceptions of their local water, co-created and flexible placebased methodologies are needed.

#### Abstract

This doctoral dissertation examines the holistic health and wellbeing of a First Nation community to understand several factors relating to environmental racism and water contamination that support and hinder community health and wellbeing to inform future policy. This dissertation incorporates a mix of methodological approaches across three interrelated research studies to better understand the direct and indirect factors influencing water security and community health and wellbeing.

Study 1 consists of a theoretical approach to co-creating knowledge between Indigenous collaborators and medical anthropologists. It highlights the importance of community-based participatory research in medical anthropology and frames the co-creation of a health survey through three phases as a boundary object that can create dialogical space for Indigenous and settler-scholar pedagogies and priorities. It demonstrates how CBPR and co-creation work allows for the reciprocal development of long-term partnerships that work in solidarity with the Two-Row Wampum (Kaswentha) treaty established by the Haudenosaunee Nation and European settler nations.

Study 2 presents an analysis of household water access, quality, and use, specifically how *E. coli* and mercury contaminations of household tap water are related to reported household health conditions for a sample of 66 households (representing 226 individuals) living in Six Nations First Nation. Logistic regression models were built to identify possible associations with water use and treatment variables for mental health, eczema, and gastroenteritis, with a second model adding contaminants as predictor variables. In the second model, *E. coli* was found to be a significant predictor for the presence of mental health conditions within the household, and households primarily purchasing bulk bottled water were more likely to report mental health conditions. Those using bleach/chlorine to treat their tap water were more likely to report gastroenteritis. Reported tap water uses indicated that 57% of contaminated tap water was still being used for activities that may heighten exposure risks (such as washing produce). Investigating household tap water uses beyond drinking water demonstrates alternative pathways for contaminant exposures for Six Nations Peoples, who have deep cultural relationships with water.

Study 3 contains a mixed methods approach to investigate the effects of water access, satisfaction, and experiences of water insecurity for the sample of 66 households in Six Nations of the Grand River First Nations, to inform culturally effective ways of assessing water insecurity for Indigenous Nations experiencing long term water shortages, contamination, and other water-related concerns. Water security was measured using the Household Water InSecurity Experiences (HWISE) scale and Likert-scale questions on water access at household, community, service, and environmental levels, and contextualized using interviews. Results demonstrate a high level of water insecurity in the sample of Six Nations households (57.5%, n=38); women were more dissatisfied with their drinking water (p=0.005), and younger participants were more likely to report contamination issues (p=0.02) and higher monthly water costs (p=0.03). Qualitative interviews informed these results, revealing that experiences of water insecurity and poor health were shaped by the degradation of traditional lands. This posed specific barriers for Six Nations women, who face physical and geographical barriers to household and community water access while caretaking for their communities and fulfilling their roles as water protectors.

# Dedication

To Six Nations and for current and future generations of water protectors

As an outsider, I am indebted to the residents of Six Nations for granting me the honour to work with their community and gifting me so many friendships.

This is dedicated to all those who contributed to this research and this story, for trusting me with your experiences and perspectives on water and health, for always bringing *kariiwio* to each space we shared. Your voices are the heart and soul of this thesis.

Nia:wen kowa, Ó:nen ki' wáhi

## Acknowledgements

There are an incredible number of people to which I owe a great deal of gratitude for their help in the making of this dissertation. Each contributed in big and small ways to my intellectual growth, emotional wellness, and social safety and connectedness. I started this PhD when I was 23 years old and six months pregnant, so to say that it took a village is an understatement. It took no less than the sprawling Greater Toronto Area, Hamilton, Six Nations, Guelph, and Peterborough to help me raise my little one and pursue this work. Family and the next generation are an important part of Haudenosaunee life, and this understanding of family has resonated with me. There are several different forms of families that supported me both within and beyond the PhD.

At McMaster University, my supervisor, Dr. Tina Moffat, worked tirelessly to guide my academic development with her encouragement, wisdom, and guidance – even if it meant two hour Zoom meetings during a global pandemic. To Dr. Dawn Martin-Hill, for inviting me into this Global Water Futures project and her community, supporting my intellectual independence, and fostering a research community of incredible young women and mothers. To my final committee member(s), Dr. Shanti Morell-Hart, for her ability to challenge my writing and approaches, and for all the hallway catch-ups. Thank you to my external, Dr. Chantelle Richmond, for her incredibly thoughtful and engaging review of this work as well. My intellectual growth is a direct product of these women and their mentorship.

I would also like to express my gratitude to the many Haudenosaunee co-creators and collaborators, Lori Davis-Hill, Julie Wilson, Sara Curley Smith, Karissa Johnson, Makasa Looking-Horse, Cody Looking-Horse, Denise McQueen, and the SN Girls Lacrosse team, thank you for support, direction, and trust in me to do this co-creation work with you all. To Mary Sandy and Chief Arnold, I will never forget that hilariously cold lunch or watching the Raptors finals with you in the middle of the Prairies. *Nia:wen kowa*.

Within academia, I have had the pleasure of building a community of amazing people who contributed tremendously to this work. Danielle Gendron, Savannah Jordan, Colin Gibson, Kathryn Chen, Hannah Grewall – your perspectives have always been a tremendous support, but above all, our shared laughs, or sometimes laugh-cries, and friendships have been such a strong foundation and I cannot thank you all enough for this.

A network of friends-as-family have supported me and my own little family in such beautiful ways, and I can firmly say I would not have finished writing this without you all. Special thanks to Catherine Cook, for always showing up with an armful of gifts for my daughter and for driving all the way out to Mimico even during the worst storms. To Sydney Gautreau, for always being there with no less than three types of snack dips after a rough day, and early morning Bloomer's meetings to work through any problem, personal or professional. To Karen O'Grady, Rylee Booroff, Sarah Campbell, Hina Mistry, Alex Rodriguez, Jenny Lee, Katie Laliberte, Tiffany Traverse, Trina Moyles, Carolyn Van, Iván Wagydmar – thank you for all the love and encouragement, the coffee dates, the pandemic FaceTimes, the hikes and the reminders to reconnect to the earth and food and water in

much deeper ways. I also owe a sincere thank you to Rey's co-parent and six grandparents for their supportive childcare. I quite literally could not have done my fieldwork or written this dissertation without you caring for this energetic squirrel child.

Without a doubt, the number of single mothers that I have met along this research and career journey have influenced and inspired me in ways that I will never begin to express my gratitude for properly. You have motivated me through the challenges that come with not only doing a PhD, but also the intense struggles of balancing this academic work with the grim lockdowns and endless months of solo parenting and homeschooling my daughter through COVID-19. It has been no small feat to take on motherhood and a PhD at the same time, but you have always believed in me and supported me, even when I doubted myself.

To Adrian, for your endless supply of bagels during writing weekends, and for always bringing me back to the importance of the present moment. You've been a constant joy and love in the last year of my PhD for which I am endlessly appreciative. Thank you for always being a safe place to land.

Finally, to my beautiful, hilarious, strong daughter, Rey: thank you for reminding me what this was always about, making a better world for future generations. I love you ten hundred.

# **Table of Contents**

Half title page	i
Title page	ii
Descriptive notes	iii
Lay abstract	iv
Abstract	v
Dedication	vi
Acknowledgements	vii
Table of contents	ix
List of figures and tables	xiv
List of all abbreviations	xvi
Declaration of academic achievement	xvii
CHAPTER 1: INTRODUCTION	1
Research Question and Dissertation Objectives	2
Background and Context	3
Canada's Colonial and Racist Indian Act: Impact on Intergenerational Health and Wellbeing	3
Water Policy Vacuums	7
Indigenous Knowledge of Health and Wellbeing	9
Haudenosaunee Health and Wellbeing	10
A Brief Overview of the Haudenosaunee Peoples and Cultural History through Teachings	; 11
Six Nations First Nation and Current Lands	12
The Creation Story	15
The Great Law of Peace	15
Ohen:ton Karihwatehkwen	16
The Kaswentha Treaty	17
The Grand River's Biocultural Profile	19

Guiding Theoretical Frameworks	21
Haudenosaunee IK in Co-Creating Water and Health Knowledge	22
Biocultural Approaches to Water Security	23
Political Ecological Approaches to Race, Colonialism, Health, and Environment	27
Political Ecology of Health Framework	29
Political Ecologies of Race and Colonialism	30
Chapter Outlines and Overview of Research Studies	33
Chapter 3 (Study 1): Using boundary objects to co-create community health and water knowledge with community-based medical anthropology and Indigenous Knowledge	33
Chapter 4 (Study 2): There's something in the water: mental and physical health conseque associated with tap water contamination in Six Nations of the Grand River First Nation	ences 34
Chapter 5 (Study 3): Be like the running water: assessing gendered water insecurity exper- using mixed methods approaches with Six Nations First Nation	iences 34
Chapter 6: Discussion & Conclusion	35
CHAPTER TWO: METHODS & POSITIONING SELF WITHIN THE RESEARCH	37
Introduction	37
Positioning Self Within Research	40
Project Development	43
Ethics Approval from Six Nations Research Ethics Board	45
Memorandum of Understanding	46
Ethics Approval from SN REB, SN Confederacy, HiREB, and MREB	46
Community Navigators	47
Sampling Frame	48
Participant Recruitment	49
Quantitative Data Collection - The Water Use and Health Survey	50
Survey Co-Development	50
Demographics	51

FNRHS Health Questions	52
Source Water Protection Survey Questions (Access, Drinking Water Satisfaction, and Water	
Use)	52
HWISE Water Insecurity Scale	54
Other survey metrics	55
Qualitative Data Collection - Focus Group and Individual Interviews	56
Formatting Questions and Interviewing Styles	56
Co-Created Research Methodologies	59
Data Analysis	61
Statistical Analysis of Quantitative Water Security and Access Questions, Health and	
Contamination	61
Computer-Assisted Qualitative Data Analysis (QDA)	64
Using Mixed Methods: The Many Hats of Co-Created Research	65
Validity and reliability of mixed methods	66
Summary: Co-Created Methodologies	68
CHAPTER 3: USING BOUNDARY OBJECTS TO CO-CREATE COMMUNITY HEALTH AND WATE	R
KNOWLEDGE WITH COMMUNITY-BASED MEDICAL ANTHROPOLOGY AND INDIGENOUS	
KNOWLEDGE	69
ABSTRACT:	69
INTRODUCTION	70
Community-based Participatory Research with Six Nations of the Grand River First Nation	71
CO-CREATION OF INDIGENOUS WATER QUALITY TOOLS PROJECT	73
Water Contamination Concerns at Six Nations of the Grand River	73
Community Health Assessment Survey	75
UNDERSTANDING AND DEFINING COMMUNITY WITH SIX NATIONS OF THE GRAND RIVER	76
HAUDENOSAUNEE ENVIRONMENTAL AND POLITICAL PHILOSOPHIES	78
DECOLONIZING INDIGENOUS RESEARCH	79

Decolonizing community-based participatory research work within medical anthropology	81
COMMUNITY HEALTH PROJECT FORMATION	81
Ethics Approval from Six Nations Research Ethics Board	82
COMMUNITY HEALTH SURVEYS AS BOUNDARY OBJECTS	83
Survey Version 1: A General Longform Health Survey	85
Survey Version 3: Culturally Centered Haudenosaunee Health and Wellbeing Survey	88
TOWARDS A CULTURALLY CENTERED HEALTH ASSESSMENT DOCUMENT	89
Community-based Participatory Research as Philosophical Stance in Medical Anthropology	90
A way forward: Boundary work in medical anthropology	92
Creating safe health dialogues through boundary objects	93
Institutional Barriers	95
FUTURE DIRECTIONS	96
REFERENCES	98
CHAPTER 4: THERE'S SOMETHING IN THE WATER: MENTAL AND PHYSICAL HEALTH	
CONSEQUENCES ASSOCIATED WITH TAP WATER CONTAMINATION IN SIX NATIONS OF T	'HE
GRAND RIVER FIRST NATIONS	103
PREAMBLE:	103
Environmental racism through Canadian water contamination responses	105
SIX NATIONS OF THE GRAND RIVER AND ITS HOUSEHOLD WATER	106
ABSTRACT:	109
2 SIX NATIONS OF THE GRAND RIVER AND ITS HOUSEHOLD WATER	111
3 METHODS	113
3.1 Data collection	113
3.1.1 E. coli and Mercury Analysis Methodology	113
3.1.2 Water Use and Health Survey	115
3.2 Statistical Analysis	116
4 RESULTS	117

4.1 Tap Water Contamination, Drinking Water Sources, and Water Uses	118
4.1.1 Water Treatments	119
4.1.2 Tap Water Uses	120
4.2 Health Conditions and Regression Analyses for Water Treatments and Contaminants	121
5 DISCUSSION	125
5.1 Drinking water uses, sources, and treatments	126
5.2 Water Quality, Access, and Health	127
5.2.1 Mental Health	128
5.2.2 Gastroenteritis	130
5.3 Strengths and Limitations	132
6 CONCLUSION	134
REFERENCES CITED	135
CHAPTER 5: BE LIKE THE RUNNING WATER: ASSESSING GENDERED AND AGE-BASED W	ATER
INSECURITY EXPERIENCES WITH SIX NATIONS FIRST NATION	142
ABSTRACT:	142
Introduction	143
Research Setting: Understanding Gender-Based Water Security through Treaties and	
Indigenous Knowledge	144
Methods	146
Quantitative Data Analysis	146
Household water insecurity	146
Gender and Age Analysis	147
Qualitative Data Analysis	147
Results	148
Descriptive survey results	148
Water Security	149
Drinking water satisfaction	150

Water access for households, community, services, and traditional lands	151
Number of Children Living in the Home	152
Statistical Analysis of Water Security and Access	152
Age-based experiences of water security and drinking water satisfaction	152
Gender-based experiences of water security and satisfaction	153
Qualitative Analysis	154
"Good Water" Differs by Generation	155
Women and Water Insecurity	157
Community Degradation Related to Increased Water Contamination	159
Discussion	161
Six Nations Water Insecurity as Environmental Dispossession	163
Gendered experiences of drinking water satisfaction	165
Age-based experiences of water	165
Study Limitations	166
Conclusion	167
References Cited	168
CHAPTER SIX: DISCUSSION AND CONCLUSION	172
6.1 Introduction	172
6.2 Main Findings through Three Bodies	173
Individual Bodies	174
Social Bodies	176
Body Politic	178
6.3 Contributions to the Medical Anthropology and Co-Creation Studies	179
Culturally Appropriate Ways to Co-Create Research	180
Household Health, Water Quality, and Use Knowledge	181
Gendered Experiences of Water Insecurity	181
Boundary Work, Co-Creation, and Sovereignty Spaces	182

6.4 Risk Communication and Sharing of Results	184
6.5 Conclusion	185
6.6 Directions of Future Research	187
References Cited (Chapters 1, 2, and 6)	190
APPENDIX A - RECRUITMENT SCRIPT (EMAIL)	206
APPENDIX B - INTERVIEW RECRUITMENT POSTER	207
APPENDIX C - LETTER OF INFORMATION/CONSENT (SURVEY)	208
APPENDIX D - SURVEY	214
APPENDIX E - INTERVIEW SOCIODEMOGRAPHIC DATA	225
APPENDIX F - INTERVIEW PROMPTS	226

# **List of Figures**

Figure 1.1 - Historic and Current Haudenosaunee Territory from honourthetworow.org (used with permission)	12
Figure 1.2 - The Haldimand Tract and Six Nations reserve as of 2015, used with permission from Decolonial Atlas under Decolonial Media License 0.1	14
Figure 1.3 - The Grand River Watershed of southern Ontario from Veale & Cooke (2016), used with permission from Taylor & Francis Online	20
Figure 2.1 – Timeline of CCIWQT Research Project	39
Figure 2.2 - Co-Creation of Indigenous Water Quality Tools deliverables, created by Colin Gibson (used with permission)	44
Figure 3.1 – Key groups working in their rows to honour the Kaswentha, while meeting and building relationships at the boundaries through the health survey	76
Figure 3.2 – Timeline of community health survey development	85
Figure 4.1 – Pillars of environmental racism affecting Six Nations water crisis	108
Figure 5.1 – Reports of access to water in household, community, infrastructure services, and in rivers and streams around Six Nations lands	152

# List of Tables

Table 1.1 - Major themes in political ecology and relevance to dissertation; adapted from Robbins (2004)	29
Table 3.1: Overview of survey types and stakeholders involved in development	84
Table 4.1 – Household demographics and water source, treatment, contaminations, and use characteristics	117
Table 4.2 – Chi square correlations for tap water sources and water contaminants	119
Table 4.3 –Chi square correlations for tap water treatments and water contaminants	120
Table 4.4 – Chi square correlations for tap water uses and water contaminants	121
Table 4.5 – Gender, age, and health conditions of household members (n=226)	122
Table 4.6 - Model 1, logistic regression of household health conditions and water treatment predictor variables	123
Table 4.7 - Model 2, logistic regression of household health conditions and water treatment and contaminant variables	124
Table 5.1 – Survey respondent demographics, income, and household expenses	148
Table 5.2 – Water insecurity scores (n=66)	149
Table 5.3 - Chi square significant for water security variables	150
Table 5.4 - Household drinking water satisfaction	151
Table 5.5 – Kruskal Wallis test for water security and access by age, One Way ANOVA *significant at p<0.05	153
Table 5.6 – Mann Whitney U tests for water security and access by gender, ** significant at $p<0.01$	154
Table 6.1 - The Three Bodies Foundation for Discussion of Main Findings	174

#### List of all Abbreviations and Symbols

BIPOC - Black, Indigenous, People of Colour BWA - Boil water advisory CBR – Community-based research CBPR – Community-based participatory research CCIWQT – Co-Creation of Indigenous Water Quality Tools CIs - 95% confidence intervals CMA - critical medical anthropology DAPL – Dakota Access Pipeline **DOD** - Doctrine of Discovery DWA - Drinking water advisory FDA – Food and Drug Administration FNIGC - First Nations Information Governance Centre FNFNES - First Nations Food, Nutrition, and Environment Survey FNRHS - First Nations Regional Health Survey **GR** - Grand River **GRCA - Grand River Conservation Authority GWF – Global Water Futures** HC - Haudenosaunee Confederacy Hg - Mercury HiREB- Hamilton Integrated Research Ethics Board HWISE - Household Water InSecurity Experience scale IK - Indigenous Knowledge MMIWG - Missing and Murdered Indigenous Women and Girls MOU - Memorandum of Understanding MREB - McMaster Research Ethics Board OCAP - Ownership, Control, Access, and Possession, the First Nation Principles **OPP** - Ontario Provincial Police OR - odds ratios PEH - Political ecology of health PI - Principal Investigator **ODA - Oualitative Data Analysis** PAR - Participatory action research **RA - Research Assistant** RCAP - Report of the Royal Commission on Aboriginal Peoples **RCoP** - Research Community of Practice **RCMP - Royal Canadian Mounted Police** REB - Research Ethics Board SN – Six Nations SNEC – Six Nations Elected Council SNHS - Six Nations Health Services SPSS - Statistical Package for the Social Sciences SWP - Source Water Protection (study and survey) SV - Survey Version UNDRIP - United Nations Declaration on the Rights of Indigenous Peoples

## **Declaration of Academic Achievement**

This thesis contains three original research studies, all of which have been submitted to peer reviewed journals for publication. The research problem, objectives, and relationships between various manuscripts are outlined in Chapter 1 and 2.

# The currently published research manuscript is:

# Chapter 3:

Duignan, S.E., Moffat, C.S., & Martin Hill, D. (2020). Using boundary objects to co-create community health and water knowledge with community-based medical anthropology and Indigenous Knowledge. *Engaged Scholars Journal*, *6*(1), 49-76.

## Manuscripts submitted for peer-review are:

# Chapter 4:

Duignan, S.E., Moffat, T., Chow-Fraser, P., de Lannoy, C.F., Macri, J., McQueen, C., Davis-Hill, L., & Martin Hill, D. There's something in the water: mental and physical health consequences associated with tap water contamination in Six Nations of the Grand River First Nation. Submitted to American Journal of Human Biology on July 2, 2021. Peer Review Revisions Received August 4, 2021.

# Chapter 5:

Duignan, S., Moffat, T., & Martin Hill, D. Be like the running water: Assessing gendered water insecurity experiences using co-created mixed methods with Six Nations First Nation. Submitted to *Social Sciences & Medicine* August 2, 2021.

These original research chapters have all been co-authored with my thesis supervisors, with Chapter 4 also being co-authored by research team members involved in the data collection and analysis of *E. coli* and mercury in household tap water samples. As the first author, I was primarily responsible for data collection and analysis, with each chapter being co-written for publication.

#### **CHAPTER 1: INTRODUCTION**

Ohneka'shon: 'a Onen ehnon:we ientsitewakie:rate ne ohneka'shon: 'a tsi rawe:ren tsi enkahnekonionke ne tsiionhontsia:te. Ne ehonon:we nitewehtha ne aionkwaha'tana:wen non:nen enionkwania'tathen. Nia'teka'satstenhsera:ke tewaienete:ri-tsi ieiohnekehn:shon, tsi iokenno:res, tsi iaonhaw:nes tanon' tsi kanonhwaratonhshera. Ehtho niiotonha'k ne onkwa'nikon:ra.

The Waters, we give thanks to all the waters of the world for quenching our thirst and providing us with strength. Water is life. We know its power in many forms - waterfalls and rain, mists and streams, rivers and oceans. With one mind, we send greetings and thanks to water's spirit. Now our minds are one. (King, 2007, p. 449).

The Haudenosaunee Thanksgiving Address (*Ohen: ton Karihwatehkwen*) is a teaching that instructs Six Nations Peoples to understand and believe in the interrelatedness of all the parts of the natural world. Haudenosaunee Peoples believe that to properly gain an understanding of any part of the natural world, respect is needed for the interrelated web of relationships that exist and form the natural environment. The *Ohen:ton Karihwatehkwen* are the words said before all else, and the words I start this dissertation with, as a reminder of the mindset and intentions that has guided every phase of this research project and all relationship building. As this research is co-created with Indigenous Peoples for Indigenous Peoples, starting with words about water from the *Ohen:ton Karihwatehkwen* serves as a reminder of the guiding principles that inform all phases of this. Haudenosaunee teachings demonstrate the interconnectedness of all living things, and so this work is informed by understand water as it relates to all its relations in the natural world.

This research investigates how Six Nations' relationships with water are shaped by ongoing water contaminations and barriers to accessing clean and reliable drinking water. The relationship between safe and reliable drinking water and Indigenous health remains a prominent and ongoing concern for Indigenous Peoples living in the lands known as Canada. The nuances of water quality and its impact on Indigenous health are deeply interconnected with unique place-based, gendered, and culturally specific relationships with water, and colonial forces of oppression, genocide, and forced land dispossessions. The guiding argument that is woven across all chapters is that the practices of the Canadian federal government - through the Indian Act and ongoing policies and actions - are practices that aim to gain access to Indigenous lands and water for extraction of resources, while aiming to reduce the Indigenous population to which the federal government has long standing obligations and treaties with. The water contamination and insecurity that Haudenosaunee Peoples are subjected to is in direct relation to these settler colonial structural forces of oppression and genocide.

Six Nations of the Grand River First Nation is surrounded by five major urban centres (Toronto, Guelph, Kitchener, Waterloo, Hamilton) in Canada's most densely populated Golden Horseshoe region of Ontario. The ongoing water crisis Six Nations Peoples are subjected to is due to a mire of complicated and continued colonial oppression, and risks for particular water related health concerns, while also shaping their perceptions of drinking water and their cultural relationships with water. These elements have been largely underexplored, particularly in ways that co-create knowledge with Indigenous collaborators and guided by community concerns. To understand and unpack the existing issues of water insecurity and health concerns with Six Nations Peoples, it is important to illustrate the ways their relationships with the lands and waters around the Grand River have changed and been impacted by colonial forces.

This chapter introduces the original research studies contained within three chapters that make up the doctoral dissertation, along with a methods chapter and conclusion chapter. The introduction lays out the context of the social, cultural, environmental, political, racial, and gendered systems that influence Indigenous community health within the boundaries of this dissertation. Next, the dissertation's research questions and objectives are presented. Three guiding frameworks are necessarily interwoven – co-creation, biocultural approaches to water security, and political ecology – to create space to discuss racism and colonial dispossessions of land to inform our understandings of health and wellbeing within the research. Finally, the details of chapters 3, 4, and 5 are outlined to demonstrate how they operate together to address the research gaps and objectives discussed in this chapter.

### **Research Question and Dissertation Objectives**

This dissertation explores the ways that we can co-create knowledge about water contamination, insecurity, and its impacts on physical, mental, social, and gendered health through three original studies, which are outlined below and in chapters 3, 4, and 5. These studies seek to address the following overall research question, "how can we co-create comprehensive assessments of community health and water security with Indigenous Nations that adequately reflect both their community concerns for health and wellbeing, while respecting their cultural, social, spiritual, and environmental philosophies?" The key objectives used in the dissertation to address this research question include:

- 1. To develop a better understanding of the unique challenges, barriers, tensions, and successes involved in a community based and co-created health assessment (Study 1);
- 2. To examine how household water contaminations and uses influence physical and mental health of individuals and households (Study 2);

- 3. To explore how water security measurements accurately reflect the gendered and agebased challenges of the water crisis for Six Nations Peoples (Study 3);
- 4. To generate evidence that informs future community health assessments, water governance and policy, and future water contamination testing that will support community wellbeing and adaptation to climate change and environmental degradation (Study 1, Study 2, and Study 3).

# **Background and Context**

# Canada's Colonial and Racist Indian Act: Impact on Intergenerational Health and Wellbeing

The historical and contemporary injustices to Indigenous Peoples in Canada have had lasting and intergenerational impacts on the health, wellbeing, and identity for these communities (Adelson 2005; Martin-Hill 2011; McGregor 2012; RCAP 1996). The objectives of the colonial regimes were best revealed through the implementation of *The Indian Act* of 1876, where a focus on settling treaties with Indigenous Peoples was swiftly followed by the goals of assimilating them into 'mainstream' settler society through violent residential school systems, and eliminating their land rights and sovereignty (Waldon, 2018). As one of the most consequential treaties negotiated by colonizers, *The Indian Act* disrupted the landholding traditions of Indigenous Nations across these lands (Truth and Reconciliation Commission of Canada, 2015).

The colonial legacy of *The Indian Act* enacted forced governance that remains detrimental to rematriation<sup>1</sup> efforts, healing, and Indigenous sovereignty today. The Act put in place elected Band Councils for Indigenous Nations, dismissing the traditional confederacies or councils' communities had in place (Henry & Tator, 2006). Instead, elected band councils assumed that Indigenous Peoples were wards of the federal state, and stripped Indigenous women of their traditional political powers and leadership roles within their communities. These policies have become embedded in the nation-state identity of Canada, as the expansion of provincial and federal lands was dependent on the forced dispossession of Indigenous lands and the removal of Indigenous children from their families through the residential school system. The residential school system was understood to be one of the most effective ways to 'resocialize' Indigenous children, as it became illegal by 1920 for them to attend any other form of school. Residential schools strategically separated Indigenous

<sup>&</sup>lt;sup>1</sup> Rematriation is a concept that centres holistic Indigenous approaches to repatriation efforts, and in more recent years has expanded to represent counter-movements to the exclusionary reconciliation efforts that came with the Truth and Reconciliation (TRC) report (Media Indigena, 2019). One of the most encompassing definitions is from Bazinet (2016) who explains it as the return of Mother Earth to Indigenous Peoples, and as a movement that empowers and re-centralizes Indigenous women as the spiritual foundation of their communities. It has been applied to food sovereignty movements (such as seed rematriation), and also how Indigenous women's voices are heard in #MeToo conversations (Media Indigena, 2019; Rematriation, 2018; Schmidt, 2019; White, 2018).

children entirely from their families and cultures to forcibly assimilate them into white settler religions and practices (Truth and Reconciliation Commission of Canada, 2015). Colonial governments viewed education as a tool to gain control over Indigeous Peoples through their youth, while simulataneously occupying their lands and indoctrinating them into Euro-Christian beliefs. The formal institution of the residential school system was a veil hiding the intentions of achieving colonization and land dispossession.

As Canada expanded beyond mercantile and trading post structures of capital during the 1700s and 1800s towards the industrial capitalism and resource extraction for global neoliberal markets of today, nation-state identities were shifted towards market-state identities (Robinson, 2015; Waldron, 2018). Canadian capitalism creates heightened exploitation of labour conditions, and positions Indigenous communities as in contention with their goals of resource extraction for global profit. This means that the health and wellness of Indigenous communities are at direct odds with capitalist agendas, and communities are positioned in landscapes where they are more vulnerable to environmental and health burdens related to policies, infrastructures, and extractions. The creation and maintenance of a nation-state such as Canada is not only colonial and capitalistic, but inherently racialized, as it organizes space and land based on interpretations of race and acts as a driver for the sustained racial hierarchies and inequalities (Omi & Winant, 1994). Most importantly, the forced oppression and dispossession of land sovereignty directly informs ongoing social and health disparities for Indigenous people and their communities (Peters 1996; Scott 2001).

Intergenerational experiences of colonial oppression, racism, and forced dispossessions of land have put Indigenous Nations at heightened risks for negative physical, mental, social, and spiritual health consequences. The ongoing recoveries of over 1500 unmarked children's graves at residential schools highlights the prolonged trauma of residential school survivors and the families of all the victims (Talaga, 2021; Tk'emlúps te Secwépemc, 2021). Intergenerational traumas are widely agreed by Indigenous scholars to occur when the damage and impact of trauma are experienced by more than one generation, becoming internalized within families and within their communities as well (Yellow Horse Brave Heart, 1998; Gagné, 1998; Menzies, 2008). Gagné (1998) identified residential school experiences as one of the key elements informing cycles of trauma for Indigenous families. Many scholars argue that these experiences of intergenerational trauma are under-explored, as colonial oppression of Indigenous Peoples has occurred for over 400 years (Armitage, 1995; Couture, 2000). Among the various intentions of residential schools (such as socializing potential labour forces, or reprogramming children to return to their communities with settler perceptions of landscape), one of the most related to this work is the intention to remove generations of Indigenous Peoples from their lands and waters. This was for the purposes of resource extraction, there is a direct and ongoing connection between the health of Indigenous Peoples, their continued lack of access to clean water, to Missing and Murdered Indigenous Women and Girls (MMIWG), and to intergenerational traumas, violence, and experiences of environmental grief and anxiety (Marsh et al., 2020; Stote, 2015).

While there are many ways to distance the language of research from the harsh and violent realities of the trauma that residential schools have caused for survivors and families, this project acknowledges that the root of all Indigenous health concerns is Canada's continued colonial presence on the land, and continued genocide of Indigenous Peoples. White domination of sovereignty is argued to be a key feature of settler colonialism, where this domination is an "ongoing encounter" that features land acquisition as the main incentive for wealth, power, and opportunity (Wolfe, 2001). Another feature is capitalism, where land and space are transformed, created, and consumed for profit by white people, while Indigenous Peoples are dispossessed, removed, erased, and expropriated to ensure these profits are maintained (Coulthard, 2014; Wolfe, 2001). Hanrahan (2017) notes that Indigenous Peoples represent a direct existential threat to the Canadian identity, as they are displaced people that hold values in clear opposition with the neoliberalism that shapes Canada. For the constructs of Canada to be maintained, the activities that support its existence (possession of stolen lands and heavy resource extractions), Indigenous Peoples have to "be pushed to the figurative and literal fringes and rendered invisible" (Hanrahan, 2017, p. 69).

These are not merely historical injustices, instead continuing today in overt and insidious ways. Given anthropology's tendency to distance itself away from racial conversations, I aim to position myself within the field of medical anthropology as an ally to Indigenous Peoples and Indigenous-led research. I recognize the privileges that come with being a white woman and the responsibility of this role to ensure that I use, share, and care for the knowledge from this research in ways that will sustain and build future scholars. I pull from Kirkness and Barnhardt's (1991) Four R's framework of respect, relevance, reciprocity, and responsibility in my methodological approaches to working with Indigenous community members. I also recognize that through my allyship, I can speak to the difficulties of my Indigenous collaborators' experiences of feeling as though they have to legitimize their knowledge and science, as the general acceptance of

Indigenous approaches in academia has been slow to materialize (Coburn, 2013; Deloria, 1998; Witt, 7007).

In extension of this, I also use the term so-called Canada across chapters as a reminder of the colonial boundaries and powers that enforce Canada's Nation-State status while rejecting the Nation-State status of the Haudenosaunee and other sovereign Indigenous Nations. Current settler colonial societies operate in both tangible and symbolic ways to maintain economic, gendered, racial, and state power, with the goals of dispossessing Indigenous Peoples from their lands and sovereign self-determination, while creating the foundations for turning these lands into settler property and capitalist development opportunities (Coulthard, 2014; Wolfe, 2001). These actions are seen most recently in the RCMP violence against land defenders in Wet'suwet'en, attacks on Miq'maw fishermen that directly impact that livelihoods and subsistence practices, the ongoing scoop of Indigenous youth by Children's Aid Society, the sterilization of Indigenous women and youth, the OPP surveillance and action against Six Nations land defenders protected their unceded territories from real estate development (CBC's The Current, 2018; Denny, 2020; Dhillon & Parish, 2019; Forrester, 2021; Stote, 2015). All these instances occurred within 2020 to 2021, and all instigated by the federal and provincial governments across Canada, in what is clearly a violent opposition to Indigenous land rights and sovereignty and contributes to intergenerational traumas and chronic health conditions.

The ongoing water crisis experienced by Indigenous Peoples is directly related to colonial forms of land and water dispossession. Murdocca (2010) argued that during the time that Indigenous Peoples were forcibly displaced and moved into reserved lands, water quality issues quickly emerged. Often, these reserves were set up on lands where institutions and churches wanted to isolate Indigenous communities, and in poor land areas that were largely unsustainable (RCAP, 1996). Those who signed these treaties were often under the pretense of these lands being shared, with their cultures and relationships respected, without the full knowledge shared that they would be confined to these increasingly small allotments indefinitely (Hanson, 2010; RCAP, 1996).

The siting of these reserves has contributed to the water quality issues endured by communities today, due to the complicated blend of poor land areas, isolation, and legal loopholes. Indigenous First Nations reserves have increasingly shared their concerns about the water safety and quality of their communities, despite federal election platforms dedicated to ending all drinking water advisories and substantial funding being directed at water infrastructure for reserves (White et al., 2012; Hogan, 2021). Canada as a nation-state is an incredibly water-rich country, holding

over 9% of the global renewable water supply while having only 0.5% of the world's population (Biro, 2007; Natural Resources Canada, 2007). While Canada has the capacity to deliver clean water and treat sewage water anywhere across these lands, there is a complex water governance and regulation system that has continued to create policy vacuums that oppress the governance and sovereignty of Indigenous Nations (Phare, 2009; White, Beavon, & Spence, 2008). Even as of 2021, no concrete water policy exists across Canada (Government of Canada, 2021).

### Water Policy Vacuums

Water regulations for Indigenous Peoples are intentionally murky. Essentially, the federal government positions itself such that they may be responsible for the provisions of funding, but it is up to First Nations to deliver the water, with 80% of the water infrastructure costs being covered for some projects via the elected band councils, but up to 20% of costs ending up as the responsibility of the community (White et al., 2012). Additionally, Indigenous communities are solely responsible for monitoring their water supplies through drinking water advisories<sup>2</sup>(DWAs) (AANDC, 2010). These legal barriers contribute to the diffusion of responsibility away from the very structure and policy that contributed to these oppressive forces.

Source water contamination and decentralization of water governance has contributed to the persistence of water insecurity and the inability to access safe, reliable drinking water for many Indigenous Nations in Canada (Awume et al., 2020; Hanrahan et al., 2014; McGregor 2008; von der Porten et al., 2016; Patrick, 2011). There are many gaps in national, provincial, and local water governance that impacts the perception that many Indigenous Peoples have about the quality and reliability of their drinking water. While drinking water quality regulations are typically part of a provincial government's jurisdiction, the safety of drinking water for First Nations Peoples falls within federal jurisdiction. Apart from the province of Manitoba, there are no single departments or spaces in other provincial governments with a direct responsibility for drinking water quality regulation (Phare, 2009). There is a 'policy vacuum' for water and Indigenous rights within Canadian legislation (Phare 2009, p. 26). Any significant and needed changes to water policy are

<sup>&</sup>lt;sup>2</sup> Drinking water advisories (DWAs) are long-term advisories from federal government that are generally precautionary and issued prior to drinking water problems emerging, taking three forms: do not consume, do not use, and boil water (Government of Canada, 2021). Boil water advisories (BWAs) are the most common and are issued to protect human health from the potential presence of disease-causing parasites, bacteria, or viruses. DWAs tend to show the long-term view of why a BWA would be issued and show the relationship between community size and frequency of short term BWAs (Government of Canada, 2021).

often obstructed due to this policy vacuum, which negatively and pervasively impacts the social and environmental burdens that Indigenous Peoples face daily.

Despite several efforts made by Indigenous and federal governments to lift long-term DWAs for First Nations communities since 2015, many communities still lack access to safe and reliable drinking water. A 2021 audit of the federal government's progress in this commitment suggested that they did not meet their promises in a satisfactory manner: "overall, Indigenous Services Canada did not provide the support necessary to ensure that First Nations communities have ongoing access to safe drinking water" (Hogan, 2021, p. 4). While it was noted that some temporary measures were provided, no long-term solutions were implemented to address the underlying issues with water systems, which will take years to complete (Hogan, 2021). The majority of DWAs are issued in response to technical issues (83% in 2017), however the proportion of contamination specific DWAs in First Nations communities is much higher than in non-Indigenous communities across Canada (Government of Canada, 2021).

Even after DWAs are lifted, many Indigenous communities rely on bottled water (Dupont et al., 2014; Simms et al., 2012). There is little research identifying how community perceptions of water quality influence their use of tap or bottled water at the household level, or how that impacts health conditions for household residents. Most research on the water quality of Indigenous communities has focused on the quality of municipally treated tap water, or untreated raw drinking water (Bernier et al., 2009; Harper et al., 2011; Dupont et al., 2014). Research has shown that use of contaminated tap water for other uses beyond drinking remains a public health concern (Wright et al., 2018, Waldner et al., 2017). The punctuated or ongoing periods of water contamination and insecurity for Indigenous Peoples creates many short- and long-term uncertainties for community health. Most of the research on water quality and detrimental impacts of contamination have been focused on the physical impacts of drinking contaminated tap water, or the potable water available to communities.

These details are important for evaluating the social burdens of water inequity and the long-term impacts of water insecurity on individual, household, and community health (Hoover, 2017). The relationship between Indigenous Peoples and water is far deeper than just the quality of drinking water. For many Indigenous Nations, water is a responsibility, it is not just a resource, and each Indigenous Nation has a unique and spiritual relationship with water. These relationships inform place-based water governance and source water protection work, and help communities adapt diverse and culturally specific strategies for combating drinking water challenges (Leonard,

8

2021; Robinson et al., 2018). How water is used, treated, and perceived at the household level within Indigenous communities is an important consideration in understanding the specific household health concerns that arise for communities facing chronic water insecurity.

## Indigenous Knowledge of Health and Wellbeing

For any discussion about Indigenous Knowledge (IK), it is important to iterate that a universal IK paradigm does not exist (Loppie, 2007). Indigenous Nations include members with different cultural relationships, personal histories, and levels of access to resources and social support. The creation, implementation, or analysis of health services and research would benefit from being contextualized in a way that supports different individual and community perceptions to have the greatest impact on the health and wellbeing of a community. What is often overlooked in research on health is not only the ways in which community members perceive health or wellbeing, but also the ways in which these perspectives affect their participation in health-related behaviours, research, and community involvement.

Localized IK frameworks are personalized sets of concepts that are used to understand various aspects of the world (Charmaz, 2000). IK varies by place and Peoples, and are dynamic, contextual, and tailored to fit the circumstances under which they are told. IK represents ways to connect elements of the natural world that are "central to individuals, communities, and social processes" (Loppie, 2007, p.276). They evolve through time with the people and cultures that share them, and their use in context-specific moments helps to guide specific problem resolution and decisions (Loppie 2007). When working in health research and services, the biomedical concept of health is a singular concept of health as the absence of disease, and typically the only paradigm to which all treatments and services operate. Indigenous scholars emphasize that wellbeing is directly tied to language, land, and culture (Martin-Hill, 2010). A solely biomedical approach to health heightens negates the role of cultural health for Indigenous Peoples. Indigenous practices, treatments, and modes of healing are not focused on isolating ailments or symptoms. Revitalizing traditional ways of healing and medicine is an essential solution to promoting community wellness and healing (Soucy & Martin-Hill, 2005).

The IK paradigm frames wellness indicators through contextual histories, colonial impacts, and identity (Adelson 2005). Social determinants of health are deeply informed by relationships with ecosystems. Swain et al. (2006) argue that while it is risky to homogenize the cultures and belief systems of First Nations, water is one area where communities widely share similar attitudes

and beliefs. Water is perceived to sustain life, and additionally was "traditionally a means of transportation, or source of food, or both, for every First Nation and remains central to the lives of many communities today" (Swain et al. 2006:32). In IK, water degradation "directly impacts the people, permeating every aspect of their lives. It threatens their very survival. First Nations maintain unique perspectives (and relationships with) water and feel these perspectives should form an integral part of water governance" (McGregor 2012:10).

The development of culturally strategic approaches to health and wellness is critical to address the health crises many First Nations communities are facing. The use of traditional medicine and knowledge frameworks are critical ways to accomplish this. Warry (1998) identifies several key ways to promote these strategies, including 1) preventative focus over intervention, 2) cultural care and traditional practices, 3) programs emphasizing collective, familial support on holistic scales, 4) long term care for younger demographics: children, youth, and prenatal care, 5) culturally informed diagnoses and assessment tools, 6) education of institutions and communities, and 7) capacity building, recruitment, and retention of Indigenous health care professionals. Revitalizing traditional ways of healing and knowing underscores many of these suggestions, not only to reduce destructive individual behaviours, but as a way to promote personal accountability for wellbeing on a collective scale (Warry, 1998).

Many community health assessments have been historically and continually funded through federally bodies, such as Health Canada (Health Canada, 2011a). These partnerships offer regulatory services that restrict health services and perspectives to fit within Health Canada's singular model of health and wellbeing (Health Canada 2011b). To better serve the needs of First Nations communities, the development of research that is co-created, guided by Indigenous Peoples for Indigenous Peoples is better able to inform the conception, design, and methodologies that shape what knowledge is being assessed and captured, and how that can inform flexible and expansive community concerns and priorities.

### Haudenosaunee Health and Wellbeing

For the Six Nations of the Grand River community, there are multiple perspectives informing how people understand their own health, as well as their community and environment's health. Health is understood not only to be physical, but also cultural, spiritual, and emotional, with personal health being directly related to household, community, and environmental wellbeing. Given the wide array of perspectives, experiences, and spirituality within the Six Nations community, the Western medical approach to healing is not sufficient for the treatment or healing process, both at the individual and community level. More culturally centered and co-created knowledge and tools that support the sovereign governance of Six Nations Peoples may help to alleviate illness in ways that are more meaningful and aligned with broad community perspectives.

## A Brief Overview of the Haudenosaunee Peoples and Cultural History through Teachings

The Haudenosaunee Nations (People of the Longhouse) is one of the oldest Indigenous groups in North America. The word Haudenosaunee translates to "They Build Houses" (Six Nations, 2021). Long before the 55,000 acre plot of land along the Grand River in present-day southern Ontario became known as Six Nations of the Grand River First Nation, the Haudenosaunee Confederacy was created hundreds of years ago and comprised by six linguistically-related nations in the eastern Great Lakes region: the Mohawks (Kaiienkehaka, The People of the Flint), Oneidas (Onyota'a-ke, the People of the Standing Stone), Cayugas (*Gayohkohnyoh*, the Dwellers of the Swamp Lands), Senecas (Onodawwahgah, the People of the Great Hill), Onondagas (Onodada-ge, the People of the Hills), and Tuscarora (*Skarureh*, the People of the Shirt) (George-Kanentiio, 2008). Historically, they have been known as the Iroquois Confederacy by the French, and as the Six Nations by the British. In the early 17<sup>th</sup> century, the Tuscaroras joined as the sixth Nation in the Confederacy. The Haudenosaunee today primarily live across fifteen different communities: Mohawks live around New York State, Ontario, and Quebec, the Oneidas are located in New York State, Wisconsin, and Ontario, the Onondagas live in central New York State and Ontario, the Senecas are in western New York State, Oklahoma, and Ontario, and the Cayuga live amongst other Nations of the Haudenosaunee (Ransom & Ettenger, 2001). The Tuscarora are less known to Haudenosaunee history but live in New York State and Ontario (Ransom & Ettenger, 2001). Figure 1.1 depicts the traditional territories of the Haudenosaunee Nations.



Figure 1.1 - Historic and Current Haudenosaunee Territory from honourthetworow.org (used with permission)

# Six Nations First Nation and Current Lands

The contemporary Six Nations First Nation is the largest populated reserve in Canada, with 12,892 individuals on reserve and a total band membership of 27,559 (Six Nations, 2021). The reserve is located in southern Ontario, southwest of the city of Hamilton, and surrounded by several communities such as Brantford, Hagersville, Caledonia, and Mississauga's of the New Credit First Nation. Many of the current population are descendants of the Mohawk and Cayuga Nations, who had been forcibly dispossessed from their traditional lands around New York State during the American Revolution and the War of 1812 (Monture, 2014; Johnson, 1964). The Haudenosaunee worked in allyship with the British during this war (not as subjects of the British), and afterwards received \$80,000 and the Haldimand Tract as thanks after they lost most of their traditional lands during the war to the Americans (Monture, 2014). This money was later appropriated for the

infrastructure that would significantly alter these traditional landscapes (Johnston, 1964). Figure 1.2 outlines the agreed upon tract of land and the current boundaries of the reserve. These lands were part of the Haldimand Proclamation of 1784:

Whereas His Majesty having been pleased to direct that in Consideration of the early Attachment to His Cause manifested by the Mohawk Indians, & of the Loss of their Settlement they thereby sustained that a Convenient Tract of Land under His Protection and should be chosen as a Safe and Comfortable Retreat for them and others of the Six Nations who have either lost their Settlements within the Territory of the American States, or wish to retire from them to the British - I have, at the earnest Desire of many of these His Majesty's faithfull Allies purchased a Tract of Land, from the Indians situated between the Lakes Ontario, Erie, & Huron and I do hereby in His Majesty's name authorize and permit the said Mohawk Nation, and such other of the Six Nations Indians as they wish to settle in that Quarter to take Possession of, & Settle upon the Banks of the River commonly called Ours or Grand River, running into Lake Erie, allotting to them for that Purpose Six Miles deep from each side of the River beginning at Lake Erie, & extending in that Proportion to the Head of the said River, which them & their Posterity are to enjoy forever (Haldimand, 1784, as cited in Johnston, 1964, p.50-51).

However, as explored further in Chapter 5, these lands on the Haldimand tract have been slowly and intentionally taken from the Haudenosaunee through colonial activity, with over 95% of their lands within the tract used for settler-colonial activities, including flooding to create the Welland Canal, private and industrial agriculture, and increased population of settler municipalities upstream and surrounding the reserve (Hill, 2017). The forced dispossession of the Haudenosaunee from their lands has been more recently seen in the 1492 Land Back demonstrations, as an encroaching settler housing development was attempting to create housing in an area of land unceded by the Haudenosaunee (Protect the Tract, 2020).



Figure 1.2 - The Haldimand Tract and Six Nations reserve as of 2015, used with permission from Decolonial Atlas under Decolonial Media License 0.1

Haudenosaunee philosophies, thoughts, and culture are rooted in stories, with four major cultural elements informing the foundation of their knowledge, science, and history: the Creation Story, the *Ohen:ton Karihwatehkwen* (The Thanksgiving Address, or the Words That Come Before All Else); the *Kaianeraserakowa* (The Great Law of Peace); and the *Deíhaenihiyawa' íkhon* (Myth of the Earth Grasper). The Creation Story has been recounted in many ways and across different mediums, and as Mohawk scholar Susan Hill argues, "considering the themes of creation and the belief that creation is a constantly occurring and recurring process rather than something that happened once in the long-ago past, it is understandable that the story of creation cannot be expressed in a single form" (2017, p. 17). Given this, it's important to also acknowledge that my

retelling or summarizing of these histories is inherently Western, and we as Westerners have attempted to create "definitive" versions of these stories to fit within our colonial and capital binaries, centered in religious elitism (Hill, 2017). Seneca scholar John Mohawk understands that "the actual story, a classic myth with a powerful ritual tradition, contains nuances buried within the languages which defy unambiguous translation, a characteristic which I tried to leave in tact" (1993, p.168). This is a single form of retelling that does not do the full and complex teachings justice, but aims to provide background information on Six Nations Peoples in ways that inform the research project within this dissertation and the overall Co-Creation of Indigenous Water Quality Tools project at large.

### The Creation Story

The Creation Story itself touches on the important powers that are held within the earth, brought from a combination of everything brought into existence, including Sky Woman, the sacrifices of the turtle and muskrat to aid Sky Woman, and the nutrients provided within her body for her twins (Hill, 2017). Creator used the power of the earth to create all living things within it, as Gibson and Hewitt depict: "indeed this earth is alive, be it known, so therefrom I took up earth by which I made all the things I have planted and I have finished living bodies, so that is the reason they are severally alive and that in their bodies severally they will die, that earth will become again" (Gibson & Hewitt, 1928, p. 498). These teachings (in their full form) shape the foundation of all Haudenosaunee Knowledge and science: earth is the life force for all humans and all other living and nonliving things.

### The Great Law of Peace

The HC is governed by the *Kayannerenkó:wa*, or the Great Law of Peace, and the Nations have been governing themselves under this law since time immemorial, serving as the oldest and most continuous constitutional democracy in the world (Lightfoot, 2021). The Great Law of Peace came to the Haudenosaunee from the Peacemaker, who taught them how to live in a balance with each other as a collective territory (Hill, 2017). This came to them after a period of great darkness, where greed and violence became the foundations for maintaining and governing territories; while descriptions of this time vary by scholar, it contrasted with the Creator's directions for humans and so he sent a messenger to return them into the original intentions (Monture, 2014). This messenger is known in English as the Peacemaker, who brought the Great Law of Peace with him which led to the formation of the Haudenosaunee Confederacy (Monture, 2014). Prior to the Great Law,

travelling between territories was seen as uncertain and dangerous, as the Peacemaker recounts through his journeys and encounters (Hill, 2017).

The Great Law maintains a clearly structured and ordered legal system that instructs land philosophies, land as identity, and collective responsibilities and rights (Ransom & Ettinger, 2001). The Peacemaker carried a message of Skennen (Peace), Kasehstenhsera (Power), and Kanikonhri:yo (a Good Mind), sharing it as he travelled south from the northern shores of Lake Ontario (Gibson & Woodbury, 1992). Through sharing his message with villages and communities on his journey, he gathered support that established the Haudenosaunee Confederacy and the original Grand Council representing 49 clan families under the then-five united nations. The Great Law organizes the nations through clans, with clan identities passed down by mothers in a matrilineal system (Six Nations, 2021). Clans represent three animals from the water (turtle, eel, and beaver), the land (bear, wolf, and deer), and the sky (heron, hawk, and snype (Six Nations, 2021). According to the Great Law, each clan would be led by a chief and a clan-mother, and aided by sub-chiefs, and a male and female Faith Keeper, each with unique responsibility to both their families, communities, and to the Great Peace (Hill, 2017; Six Nations, 2021). Successors of chiefs are selected with deliberation from Clan-Mothers (Six Nations, 2021). After the establishment of the Ayenwahtha wampum belt, the Council was divided by Nation, with the belt serving as a map of their traditional homelands, a map connecting their relationships and duties to each other (Thomas, 1989).

In terms of land and relationship to it, even the names of each Nation describe them based on geographical elements of their homelands and communities, highlighting the "relationship to the land the people came from, the land they belonged to. Through this naming, the Peacemaker intended that the land - the territory - would define the Haudenosaunee and how they would relate to the rest of the world" (Hill, 2017, p. 36). The Great Law of Peace governs and instructs the Haudenosaunee in ways that maintain their right to self-determine, long before this concept emerged in modern human rights discourses (Lightfoot, 2021). Traditionally, through HC, decisions are made through deliberation and consensus rather than through individual voting, and the process of selecting chiefs is not a hereditary process but instead a democratic one, where Clan Mothers consensus is required (Lyons, 1986).

#### Ohen:ton Karihwatehkwen

Haudenosaunee environmental philosophies are contained with the *Ohen:ton Karihwatehkwen*, or Thanksgiving Address, the words they say before all else. This address acknowledges all parts of Creation and offers respect and gratitude to them for upholding their responsibilities. The opening address bring us to one mind, as it reminds us of our relationship to all and that we are so loved, that all we need is provided to us. In return, we are to be thankful to our life sustainers and uphold our part in maintaining the wellness of our Mother for future generations (King, 2007).

#### The Kaswentha Treaty

The Kaswentha, or Two-Row Wampum, which was the first treaty between Europeans and Indigenous Nations on Anowarakowa Kawennote (Great Turtle Island, or North America), represents self-determination and a friendship treaty between these two nations. The first Kaswentha was established between the Haudenosaunee and the Dutch settlers of eastern New York. The Two Row Wampum belt is woven with white and purple beads or shells. It can be seen as two boats on a river, with the purple rows representing the paths each boat makes as they travel down the river, one for the European ship, and the other for the Haudenosaunee canoe (Haudenosaunee Grand Council, 1982). The Haudenosaunee speak to how this treaty should be interpreted as an agreement, with treaty partners "like Brothers ... we shall travel the river together, side by side, but in our own boat. Neither of us will make compulsory laws nor interfere in the internal affairs of the other. Neither of us will try to steer the other's vessel" (Haudenosaunee: Kahnawake Branch of the Mohawk Nation). Inside each boat is what defines it as a society: customs, laws, and ways of life. This symbolizes respect for autonomy for their own way of life and governance. The three white rows represent the river of life, and relationships based on *skennen* (peace), kariwiio (good mind), and kasastensera (strength); the fringe on the belt indicates that the relationship is unending (Hallenbeck, 2015; Ransom & Ettenger, 2001). Water represents both the river of life, but also the medium or foundation on which the *Kaswentha* agreement is based.

The *Kaswentha* became the foundation of later treaties with the French, British, and United States, as they all aimed to create alliances (both military and political) with the powerful Haudenosaunee Confederacy. In 1874, the Treaty of Canadaigua was signed in peace and friendship while defining boundaries between the Haudenosaunee Confederacy and the more recently established United States government (Whitefield-Madrano, 2011). To end the War of 1812, the 1815 Treaty of Ghent was signed between the United States and Britain, which explicitly demonstrated the existence of the Haudenosaunee Confederacy as separate from the other direct treaty parties and insured that the HC would retain their rights prior to the war (Lightfoot, 2021). These multiple and international treaties are understood as evidence of Haudenosaunee sovereignty, as they recognize the nation-to-nation relationships (between Canada, the United
States, and the Haudenosaunee) developed through these terms, as "you don't make treaties with your own citizens" (Joe Health, confra McChesney, 2010, ¶3).

Despite these early treaties, the *Kaswentha* treaty has been broken and tarnished, with over 400 years of dehumanizing assimilation, ongoing colonization, and violence on the part of whitesettler society. Environmental destruction of the lands in and around Haudenosaunee territory is a form of this continued settler-colonial violence. There are ample and devastating reports of the strong connections between the environmental destruction of lands and water and the removal of Indigenous Peoples from their traditional territories and its contribution to gender violence (Kuokkanen, 2015; Maracle, 2002; Lawrence, 2004; Lawrence & Anderson, 2003; Schneider, 2013). There have been (and continue to be) a wide array of harmful strategies to destroy not only Indigenous Peoples, but also destroy their sense of being as people through environment, language, culture, and more (Tuhiwai Smith, 2008). These connections between gendered violence and violence against the land were most recently seen in the 2019 final report on the Canadian national inquiry into Missing and Murdered Indigenous Women and Girls (Reclaiming Power and Place, 2019).

Recognizing the role of water in the *Kaswentha* is important in understanding how settler colonialism has transformed the land and waterways. Through spatial reconfiguring, settlers transformed land and the deep connection to it, re-territorializing waters, bodies, and beings (Schneider, 2013). Schneider (2013) argues that within settler-colonial studies, there has been a critical neglect of how land (and land ownership) is connected to power, gender violence, and settler colonialism. "Because sexual violence has served as a tool of colonialism and white supremacy, the struggle for sovereignty and the struggle against sexual violence cannot be separated" (Schneider, 2013, p. 150). Hallenbeck (2015, p. 353) argues that centering these discussions around water "opens up a space for political and relational attention towards the bodies, being, stories, and histories that run through it." Colonization has removed the Haudenosaunee from the Grand River, and the contamination of the Grand and surrounding waterways and watershed must be understood as directly connected to the gendered dispossession of Haudenosaunee territory.

To be in solidarity with the Kaswentha, then, is to practice non-interference as a western researcher, to work in ways within our communities and families that is not exploitative. It is to understand that to decentre settle-colonial states, we need to work not only against power and control, but in ways that reimagine alternative institutions and relationships. For co-creation projects and partnerships to work, they must raise the value of Indigenous Knowledge and "give it recognition and respect as science" of Indigenous Peoples (Ransom & Ettenger, 2001, p. 221). Our project aims to do this through creating actions and knowledge based on our collective responsibility and relationship to the land, understanding that decolonization is a process that involves ongoing commitments and long-term relationships between Indigenous and western partners.

## The Grand River's Biocultural Profile

While much of this research is focused on the health and wellbeing of the Six Nations Peoples that live on and around the Grand River, the river itself has a long history of use from a variety of different communities. Given the Haudenosaunee relations to water and land being more integral to their way of life and cultural practices, understanding the river's biocultural properties is important in understanding the current and ongoing concerns that many Haudenosaunee Peoples have about its mistreatment and contaminations.

The Grand River is a 'working river,' flowing from Dundalk to Port Maitland, so the quality of the river, its offshoots, and its connected reservoir systems tends to vary relative to the shifting geographies, land use and management practices, and sediments running off into the river (Cooke & Boyd, 2017). A study in 2004 found that while there were no confirmed traces of *E. coli* in water samples taken along the river, there were coliforms found in some of the river's tributaries during initial investigations (Dorner et al., 2004). These earlier investigations did not find any statistically significant differences between coliform levels up and downstream (Dorner et al., 2004). However, research on the Grand River's quality in more recent years now diverges.

While COVID-19 has suspended the annual reporting of the Grand River water quality conditions by the GR Conservation Authority, a 2017 report provides the conditions of the river between 2013-2015. Six Nations is located in the southern Grand River sub-basin, which accumulates the sediments and properties from upstream, all while flowing through the Haldimand Clay Plain (Figure 1.3). Flowing onto this clay plain accounts for the increased turbidity of the water, as sediment in the water becomes suspended in water columns (Cooke & Boyd, 2017). More recent research has demonstrated the presence of drugs and artificial sweeteners in the river, with evidence that these wastewater discharges from upstream communities have the potential to contaminate downstream drinking water sources, albeit at relatively low concentrations (Rodayan et al., 2016; Spoelstra et al., 2013).



*Figure 1.3 - The Grand River Watershed of southern Ontario from Veale & Cooke (2016), used with permission from Taylor & Francis Online* 

More recent research on impact of contaminants for local fish species within the Grand River ecosystem has detected "measurable amounts of pharmaceuticals and personal care products throughout the Grand River, where the levels increased downstream from the Waterloo Municipal Wastewater Treatment Plant", including antiepileptics, anti-inflammatories, and anti-depressants (Hodgson et al., 2020). These three were particularly concerning, as they are not easy to break down in treatment plants and have remained in high concentrations after being released into the Grand, despite more recent upgrades to the wastewater treatment plants (Hodgson et al., 2020; Srikanthan, 2019). Predictive modelling on the flow of trace organic contaminants (TOC) in the Grand River also found that predicted concentrations of TOCs in the river were higher closer to Six Nations, as the river is wider at this point and moves slower (Zeeb, 2021). Modelling also found that TOCs in the river at points closer to Six Nations (or the village of Ohsweken as the authors describe it), were more sensitive to autotrophic biodegradation rates, meaning that these forms of treatments might be more successful for pollutant removal in Six Nations drinking water treatment (Zeeb, 2021).

## **Guiding Theoretical Frameworks**

There are three main theoretical frameworks that drive all three of the studies in this dissertation: 1) Haudenosaunee Indigenous Knowledge as the foundation for co-creating health and water research; 2) biocultural approaches to water and health; and 3) political ecology approaches to environmental racism and dispossessions. I understand the relationship between Haudenosaunee IK and biocultural approaches to medical anthropology as a Venn diagram, where they are able to interconnect – with the Two Row Wampum teaching and the critical medical anthropology and community-based methods strategies working to achieve the same common goal of co-creation through differing perspectives.

While my work is informed and guided by Haudenosaunee IK, I work through my own medical anthropology background to navigate the co-creation process, using biocultural approaches to explore the intersections of water security and health, because this theoretical orientation is best aimed to explore the connections between biological, sociocultural, and environmental experiences of Six Nations Peoples. Socioeconomic, systemic, and cultural factors mediate the community and individual relationships with the waters in and around Six Nations, and the embodiments of water security and contamination. There are many ways to anthropologically explore the embodiment of environmental and economic stressors, such as the body proper or local biologies (Lock & Farquhar, 2007; Niewöhner & Lock, 2018; Pfister & Encinosa, 2021; Yates-Doerr, 2017), but these fail to account for the Indigenous perspectives, or specifically Haudenosaunee expressions of embodiment in this context.

The research is Indigenous-centered and applied, founded on the use of co-creation, and using complementary models of community based participatory research within critical medical anthropology and local (Haudenosaunee) IK. The specific teachings around the flexibility and ongoing nature of creating from the Creation Story, coupled with the respect and reciprocity taught in the *Kaianeraserakowa* and the *Kaswentha* are how I operate and situate my own research and approaches to co-creation. As the Creation Story teaches, creation cannot be expressed in one single form, rather it takes on different meanings and roles in different settings, which guides how I understand our interdisciplinary research – each section of the team understands the co-creation process a bit differently, in terms of how our work is to be designed, and who is involved in the cocreation as local or academic collaborators. As Hallenbeck (2015) demonstrates in paddling to honour the Two Row, working on these processes by discussing around water allows for a more tangible integration of how the river and its offshoots relate to the bodies, stories, and histories that pass through it. I view this as how we co-create: in ways that are flexible, ever changing like the river passing through, and in ways that honour how different bodies and histories encounter the water.

I present an overview of key arguments and themes within each of these areas. I conclude by discussing how each of these key topics relates and contributes to the development and production of collaborative research on water security and health with Six Nations of the Grand River First Nation. The research objectives discussed throughout this thesis draw on a variety of theoretical frameworks to effectively explore the nuanced and intractable forces that create not only settler-colonial spaces but drive the experiences and health consequences for minoritized people, such as Indigenous Nations. Each of the three studies here required a tailored theoretical lens, as each work was co-created for specific audiences and collaborators (discussed further in Chapter 2).

### Haudenosaunee IK in Co-Creating Water and Health Knowledge

This dissertation was conducted as part of the broader Co-Creation of Indigenous Water Quality and Tools (CCIWQT) research project funded by <u>Global Water Futures</u>. The project is interdisciplinary and led by Dr. Martin Hill, with Indigenous and non-Indigenous researchers cocreating knowledge about the water crisis, founded in local Indigenous Knowledge of our collaborators and community stakeholders. The co-creation of knowledge and tools is the underlying force informing all elements of this project and the relationships and discussions that surrounded its creation. This innovative co-creation approach uses the strengths of different epistemologies, such as IK and Western science, to develop corroborative and complementary methodologies. The cultural diversity of Indigenous Peoples is addressed directly through IK that is uniquely attached to diverse languages, landscapes, and cultures from which the knowledge itself emerges (Kandasamy et al., 2017). Despite the strength and innovation that IK offers, there remains a limited recognition in how IK frameworks and co-creation processes can inform the processes of climate change or inform tools and action that can mitigate the outcomes of climate change adaptations (Parsons et al., 2016).

For Haudenosaunee Peoples, four main cultural legacies inform and shape all research in the CCIWQT project: the *Ohen:ton Karihwatehkwen* (The Thanksgiving Address, or the Words That

Come Before All Else); the *Kaianeraserakowa* (The Great Law of Peace); the *Kaswentha* (The Two-Row Wampum Belt treaty), and the *Deíhaenihiyawa´ íkhon* (Myth of the Earth Grasper). United, these teachings and legacies form the foundation of Haudenosaunee law and ecological knowledge, which in turn creates a strong backbone for the conception and design of culturally based environmental protection processes and research. Within the Haudenosaunee framework, the rapid development and destruction of land is manifested and reflected in the health and responsibility of the community. The holistic model embedded throughout every aspect of the project is critical to a research design that fully embraces and utilizes IK.

These teachings are complex, culturally bound, and attached to the landscapes and People that carry these to future generations. These Haudenosaunee frameworks have shaped my research trajectory, but I do not claim these as my own novel interpretations. I understand this work to be co-created, and see my own work and contributions as using an applied anthropological lens in order to access and learn from Indigenous Knowledge foundations. There are risks to co-creation as a process, particularly in not appropriating the methodologies or broadening them into universal approaches to working with diverse Indigenous Peoples. Rather, it is beneficial to build an understanding that each collaboration, and each community, comes with diverse relationships to the natural world and culturally specific frameworks, laws, and ecological knowledges that inform their own concerns and goals.

The pluralisms of IK are familiar for qualitative non-Indigenous researchers, who are used to multiple ways of perceiving the world and making sense of the social landscape (Hart, 2010; Olsen, Lodwick, & Dunlap, 1992). In this respect, qualitative researchers are well positioned to respect alternative ways of seeing the world and adapting their research framework accordingly. Adopting pluralistic IKs as the foundation of research can be seen as a decolonizing act, working to advance the interests of Indigenous peoples in the face of traditional Western understandings of science and knowledge. Decolonizing acts are critical responses to colonialism that empower Indigenous ways of knowing, being, and doing (Smith, 1999).

## **Biocultural Approaches to Water Security**

The consequences of continued (and intergenerational) poor water quality and access to overall human health are driven by the interrelated forces of social, cultural, biological, racialized, and environmental factors. As biocultural approaches allow for holistic perspectives on the interactions of sociocultural and biological phenomena, this approach is the overarching framework driving this research (Goodman, Dufour, & Pelto, 2012). Biocultural approaches have no strict definition but

aim to theorize and examine human interactions with local environments, particularly in how these relationships face physical, biological, and sociocultural challenges to health and biological functions (Wiley & Cullin, 2016). Created through the integration of anthropological and human physiological disciplines in the 1970s, these biocultural approaches emphasize the range and limitations of humanity's physiological capacities, often in extreme environmental scenarios that allow for a broader grasp of our phenotypic variations and genetic adaptations (Brewis et al., 2020; Zuckerman & Martin, 2016). Challenges are framed as stressors, which tend to be environmental contaminants, infections, or resource insecurity (Maxfield, 2020; Schell, 2020; Rosinger, 2018; McDade et al., 2013).

I contend that the investigation of stressors - and human adaptations - should not be reduced to the individual structural parts of a much broader colonial whole. Much biocultural research focuses on the physiological sides of adaptation, rather than the cultural adaptations or flexibilities that have allowed many Indigenous Nations to navigate centuries of oppression and forced dispossessions. More recently, biocultural anthropologists have recognized that more of a focus on the social inequalities within human health are needed to amplify these all-encompassing approaches to investigating biocultural interactions (Leatherman & Goodman, 2019; Wiley & Cullin, 2016). Leatherman and Goodman (2019) identify the need for what they term critical biocultural approaches for this, where political-economic engagements with social inequalities are examined as they relate to human health, in addition to human evolution and adaptability. These approaches do recognize the embodiments of race as having very real biological effects on the health of individuals and communities (Goodman, 2013; Gravlee, 2009).

However, there are still some limitations in that they maintain that these biosocial and biocultural interactions "can take many forms, often expanding from political economic processes. They might emphasize psycho-bio-social integration, cognitive dimensions and dissonances, social and disease stigma... Yet all benefit from a close attention to the historical contexts and social relations that define human experience in local environments" (Leatherman & Goodman, 2019, p.6). While I agree with their broadening the term to take more critical approaches, I also maintain that the lack of discussion around settler colonialism within North America or Turtle Island, and our own American and Canadian histories and identities within a system severely limits our discussions, as it fails to reflect on our own complicity and power, particularly for those of us who are white academics. Rather than limit the discussion to the specific biological adaptations or challenges faced in environmental and cultural landscapes, it is also important to explore the cultural relationships *with* the environment, and how the degradation of those parts of the natural

world influence and connect to heightened risks that BIPOC communities may face. Additionally, it is important as anthropologists to recognize the ways that continued examination of the disenfranchisement and oppression of BIPOC communities through direct and indirect racism (including environmental racism) creates or sustains problematic narratives that stigmatize Black and Indigenous Peoples in particular.

In the early 1990s, Singer and colleagues developed syndemics theory to build on an explanation as to why minoritized communities are more heavily impacted by new epidemics, and how they often face other ongoing threats to their health (Singer 1989; 1996; Singer & Snipes, 1992). The main argument was that these health conditions not only co-occurred, but the synergy of various epidemics acting on a community made each worse (Singer, 1989). While syndemics theories provide useful operational terms to explore the complicated choreography of environmental, political, social, and economic threats to community health, they tend to neatly avoid directly dealing with racism outright, or the impact of colonial structures and policies, particularly in the United States and Canada.

In a content analysis of *Medical Anthropology* journals from 1977 to 2002, Gravlee & Sweet (2020) found that medical anthropology research displays a relatively low frequency of race and ethnicity concepts (discussed in less than 30% of all articles). When isolating just for race, it appears by itself in less than 5% of articles (Gravlee & Sweet, 2020). While these results present some conflicts - that in other disciplines such as biomedicine, race is used habitually and with no consideration of how to measure or define racialized categories, Gravlee and Sweet (2020) argue that avoiding racial inequalities in health discussions risks making medical anthropology largely irrelevant as a discipline that is supposedly rooted in looking at health through social and cultural lenses.

Since water security and the relationship to water are such integral components to understanding the holistic health of individuals, households, and communities, a discussion of the anthropology of water is an important field for medical anthropologists. This field is only beginning to blossom in recent years, with more nuanced measurements and assessments of water security led by anthropologists becoming more represented in the broader literature (Awume et al., 2020; Hanrahan, 2017). Anthropologists who study food have had a longer history of exploring the relationships between biological, cultural, social, economic, environmental, and feminist intersections that play out within food and foodways (Abawa, 2018; Brickley et al., 2014; Di Chiro, 2017; Larsen, 2014; Selhub et al., 2014). Food has been explored from every angle: the political, the symbolic, the structuralist elements of cultural dishes have led to broader connections around preparation and consumption (Eckert et al., 2018; Garcia Polanco & Rodriguez-Cruez, 2019; Hayes-Conroy & Hayes-Conroy, 2008; Kepkiwiez & Rotz, 208; Lesnik, 2017; Ruby & Heine, 2011). There are endless ways in which food can be prepared, presented, and understood. Water, however, is not as easy to culturally shape and modify, and the relationships we have to it are quite often left explored only as a relationship between resource and biological bodies, rather than the embodied or cultural relationships we unknowingly inhabit.

Water's cultural roles are often undervalued beyond biological-health relationships relating to household or individual water use and associated risks of mental duress or contaminant exposure. Anthropologists have established a strong body of research examining the relationships between physical health and water access and insecurity, particularly as it relates to gastrointestinal illness and pathogenic risks (Piperata et al., 2020; Rosinger & Tanner, 2015; Wright et al., 2018). Similarly, there has been a well-documented relationship between mental health stressors (such as psychological duress, emotional stress, and caregiver depression) and water insecurity across diverse communities in the Global South (Brewis et al., 2019a; Mushavi et al., 2019; Stevenson, 2019; Tallman, 2019; Workman & Ureksoy, 2017). Documentations of emotional or mental stress relating to consistent water insecurity have been found in those who identify as women, especially mothers or community caregivers (Brewis et al., 2019b; Ennish-McMillan, 2001; Stevenson et al., 2012; Wutich, 2019). Much research has focused on the Global South's challenges accessing water, with less exploration of the ways minoritized populations in the Global North - and specifically the United States and Canada - have experienced water insecurities as a direct consequence of colonial oppression, and the biocultural elements that inform heightened exposures and health risks for Indigenous Peoples. To examine this, it is critical to co-create with Indigenous Peoples and collaborate with Nations in ways that serve their diverse traditional ecological knowledge, languages, and cultures.

These shifts in perspective are needed with the changing environmental and political climates that anthropologists, social scientists, and scientists work within. With the more pressing realities of climate change and pandemics facing us globally, the relationship we have to the natural world, and the particular understanding of natural elements as resources, is brought back into consideration. Notably, settler understandings of water are challenged as mythologies, tied to cultural understandings of nation-state identities (Mascarenhas, 2017). As part of the settler colonial narratives, we create understandings of water that allow us to continue our extraction and exploitation of it, for personal and for industrial profit.

More recently described as "modern water," these understandings of water are rooted in the urban history and uses of water in Europe and then the United States and Canada (Schell, 2020). Constructions of modern water are the sets of discourses, practices, and perspectives around water that are founded in water needing to be managed as a resource, often by high-income countries (Banister & Widdifield, 2014; Linton, 2010). These discourses of modern water notably hide the neoliberal and capitalistic understandings of water as a resource and present it as a uniform security that embodies the liberal ideals of water governance and management and infrastructure (Furlong, 2014; Lawhorn et al., 2018). These anthropocentric assumptions about water as a resource for human use separate water from its social, spiritual, and cultural landscapes (Barker, 2019; McGregor et al., 2020; Schmidt & Shrubsole, 2013; Zannotti, 2018). Accordingly, it also influences not just political and infrastructural developments, but the ways that research and policy are designed globally, for high and low-income countries alike (Furlong, 2014; Lawhorn et al., 2018). By creating Eurocentric assumptions around what good "modern water" should be for diverse Peoples across the globe using myths around water, this heightens the risk of continued water crises (Meehan et al., 2020).

Within this thesis, a biocultural exploration of water recognizes the intersections of race, environment, politics, landscapes, capitalism, colonialism, and physical, mental, and spiritual health as elements that interact and shape human relationships to water. The literature on water insecurity is growing at an exciting pace, and I argue that our research can expand biocultural research in more applied ways by grounding our understandings of water colonial and cultural landscapes and knowledge systems that shape our perceptions of the world. At its core, water insecurity is a human health risk, and signals a deteriorating environment. Rather than focusing on the measured experiences of water insecurity alone, I take an applied approach that aims to create more tangible tools and knowledge around water uses, perceptions, access, and stressors that can help build more promising solutions for applied health programming and governmental policies as well.

### Political Ecological Approaches to Race, Colonialism, Health, and Environment

At its core, political ecology challenges the aspects of economic and political structures that prevent human rights and needs from being properly fulfilled, offering insights into the social causes that inform environmental risks and challenges, providing alternatives that aim to improve the quality of life while addressing the intersections of gender, sex, race, and class (Baer, 1996; Merchant, 1992). Political ecology has a deep concern for human-environment relationships, and a focus on the political and power dynamics that shape inequalities (D'Alisa et al. 2017). These perspectives have most commonly been used in Global South contexts, or research that offers insight into how environmental degradation has been shaped by power dynamics of various actors (Baijius & Patrick, 2019). However, political ecology also affords exploratory space beyond the usual climate crisis narratives that centre on inaccessible or inappropriate technologies, control of population growth, or poor land use management, all of which may continue to create lasting stigmas against global populations that are and have been oppressed by settler colonizers (Baijius & Patrick, 2019; Patrick, 2009).

In the early 1990s, McElroy argued that "there are conceptual canyons separating biocultural researchers and political economists" (1990, p. 383), and while many biocultural anthropologists recognize the significance of political structures on their analyses, a firm and clear analysis of the particular settler and colonial forces, narratives, and mythos that have shaped our understandings of bounded landscapes and relationships to the land have yet to be considered in the interpretation of data. There are two central narratives within political ecology discourses that guide the discussion and interpretation of this dissertation data: political ecologies of health, and political ecologies of race and colonialism. Together, these operate as a means of exploring the power dynamics between the federal Canadian government and Indigenous Nations, such as Six Nations First Nation. As this research investigates experiences of water insecurity and its impact on overall wellbeing and health for Haudenosaunee Peoples, a foundational understanding of the fiduciary and constitutional responsibilities of the government to Indigenous Peoples is necessary for appreciating the depths of how the water crisis many Indigenous Peoples face is both produced and sustained.

McCarthy (2002) argues that political ecology is well-suited as a theoretical framework to approach these issues, and that the lack of focus on this approach in the Global North is largely due to geography – that resource conflicts in "late capitalist, 'First World' countries" such as the U.S. or Canada often fail to "engage the political and theoretical sympathies of academics, leftists, and environmentalists who had been broadly sympathetic to movements elsewhere that shared similar characteristics and claims" (McCarthy 2002:1282). The direct relevance of these approaches to Indigenous (and Black and POC communities) in the Global North is that they share similar overarching themes, presented in Table 1.1. Throughout this dissertation, the usefulness of these themes as they relate to the water crisis experienced at Six Nations is explored.

*Table 1.1 - Major themes in political ecology and relevance to dissertation; adapted from Robbins* (2004)

Themes	Political ecological views (from Robbins, 2004; McCarthy, 2002)	Adaptation within thesis
Degradation of environment and dispossessions of land	Earlier focus in literature of land degradation blamed on minoritized local communities; political ecology aims to put in political and economic context	Degradation of environment and changing of landscapes to more industrial while dispossessing Indigenous Peoples of their original lands; incorporation of theories around environmental dispossession and repossession
Environmental conflicts	Views environmental conflicts as part of struggles with race, class, and gender	The particular ways that conflicts (e.g., extractive settler and industrial relationships) inform gendered and racialized barriers to Indigenous relationships to the land (e.g. missing and murdered Indigenous women and links to resource extraction)
Conservation and control of land	Conservation failures or exclusion of Peoples in politics/economic decisions	Impact of genocidal <i>Indian Act</i> and intentional Canadian policy vacuums around water for Indigenous Peoples at oppressing sovereignty and how this informs relationships with water/water access
Identities in relation to environment	In political ecology, political and social struggles linked to livelihoods and environmental protections	Deeper exploration in thesis around the spiritual and cultural relations to water - led by IK and Haudenosaunee frameworks

The struggle over the control and meaning of environmental resources is not exclusive to the contexts of the Global South and has been argued to be equally relevant to peripheral communities within advanced capitalist economies (Nesbitt & Weiner, 2002). With political ecology's fundamental concerns about ecological and political inequality and explicit or implicit violence to communities, it allows for a close analysis of the visible and invisible colonial causes of structural inequalities (Chitewere et al. 2017).

# Political Ecology of Health Framework

While biomedical population health can broadly outline the determinants of health, its focus on sociopolitical dimensions is limited. A political ecology of health (PEH) framework allows extended focus on the contextualization of health and disease outcomes via political, environmental,

economic, and social forces and the dimensions that shape health inequalities (Jackson & Neely 2015; King, 2010; Mayer, 1996; Richmond et al., 2005). More importantly, PEH can explore how local understandings of health or disease relate or disagree with institutional representations, and the power dynamics that lead to particular interpretations of health and disease being produced and legitimized in particular (Western) frameworks (King, 2010).

For contexts where pollution or contamination are of interest, PEH can examine how these processes become forms of slow violence, and how they contribute to the gradual decline in the health of bodies and environments (Sultana, 2012). Of particular interest to this research is how PEH approaches can demonstrate the complexity of environmental issues and how this impacts knowledge translation in communities. PEH allows for the examination of how the social production of knowledge by powerful stakeholders promotes lasting perceptions of drinking water quality, along with toxicity origins or problems (D'Alisa et al., 2017). This is important when working with Six Nations, as the community is surrounded geographically by many major cities with universities, along with corporations that have all taken a vested interest in the use of water and the study of the ecology of the Grand River. For a community facing research fatigue and constant, potentially contradictory, academic, and corporate narratives about water health and security, a discussion of the role of these stakeholders and their impact on social knowledge is a necessary step in understanding sociopolitical influences underscoring wellbeing.

Political ecologies of health typically take geographic perspectives, using changing landscapes and "uneven geographies" as ways to develop dynamic interpretations of disease ecologies (Collins, 2002; Jackson & Neely 2015, p. 48). Political ecology approaches to health initially focused on developing nations, examining how underlying forces such as colonialism, labour migration, or refugee crisis impacted human agency, health, and disease (see Turshen, 1984; Hunter, 2003). A key argument from much of this research is that knowledge of the spread of disease (e.g., parasitic, infectious) is not lacking in local contexts, but rather there has been a failure of coordinated knowledge applied to ecological problems (Hunter, 2003). Deeper understanding of how colonial forces and histories inform landscapes where there is simply not enough structural capacity or funding to apply to ecological problems has generally been quietly avoided.

### Political Ecologies of Race and Colonialism

This dissertation locates its analysis in the experiences of environmental racism formed through colonial systems, policies, and infrastructures in Canada. Political ecologies of race understand

these relationships as racial-colonial politics that unfold through nature and environmental practices of the past and present in the United States and Canada (van Sant et al., 2019). As Waldron (2018, p. 17) argues, it is "not possible to understand environmental racism independent of other forms of violence that impact minds, bodies, cultures, and lands of Indigenous and Black peoples." Much of the research and public engagement around environmental degradation has a lens of justice for the environment, rather than an acknowledgement of who is more severely impacted by the degradations due to intentional spatialization of race, or the denaturalization of geographies (Razack, 2000).

Given that much of the groundbreaking work on political ecologies was focused on developmental processes in the Global South, the extension of political ecologies of race and colonialism in the Global North address Wainwright's argument that "doing political ecology in postcolonial spaces carries the responsibility of engaging with colonialism, because we cannot understand these spaces outside of, or prior to, or apart from the fact of the colonial experience" (2005, p. 1034). Current environmental racism is then analyzed in its colonial present, situated within these spaces as related but "irreducible, and to conceptualize them as elements of dynamic formations with diverse mechanisms, regimes, and territories" (van Sant et al., 2019, p. 630-631). By acknowledging the interrelatedness of racial politics and colonial forces as they extend to built landscapes, this allows for a discussion that does not minimize whiteness or make settler colonialism iself cannot be reduced to just the racialization of communities or their resistance towards it, but it is important to understand the intersections of race and environment to develop stronger critical analysis of settler colonialism itself (Byrd, 2011).

One of the most damaging and oppressive forces that shaped colonialism and the subsequent growth of racialized capitalism, particularly in how it impacts the lives of Indigenous Peoples, is the Doctrine of Discovery (DOD) and the idea of *terra nullius*. This doctrine was developed by Eurocentric nations to deny Indigenous Peoples as subjects of international law in the fifteenth and sixteenth centuries, yet remains the primary legal precedent that continues to control Indigenous rights and affairs in primarily four countries (Miller et al., 2010). Historically, the DOD was established to justify the forced possessions of new lands outside of Europe, and to justify their claims of sole property rights over the Indigenous inhabitants of these lands (Reid, 2010). These four countries, Australia, Canada, New Zealand, and the United States, are all former English colonies, and this has heavily influenced how they treat Indigenous Peoples and their disregard for Indigenous sovereignty in law, language, and lands (Miller et al., 2010; Reid, 2010; Pineda, 2017).

31

In 2007, the United Nations General Assembly adopted the now widely known UN Declaration on the Rights of Indigenous Peoples (UNDRIP), which was created, negotiated, and advanced by Indigenous Peoples from across the world over 20 years leading up to the General Assembly (UNDRIP, 2007; Coulter, 2009). The votes for the adoption of UNDRIP were 143:4, with the 4 countries that voted against also being the four same former English colonies that are heavily steeped in colonial law - Australia, Canada, New Zealand, and the United States (Miller et al., 2010). Since this historic vote, many scholars have noted the symbolic and structural reasonings behind these four countries voting against UNDRIP essentially being due to these four countries sharing common colonial histories, and that they applied and utilized the DOD to maintain their justification of forcibly dispossessing Indigenous Peoples of their lands for profit (Reid, 2010).

The DOD maintains the legal forces that define the limits and boundaries of all land claims in Canada to present day, as well as the need for creating or maintaining land claims in general (Reid, 2010). Land claims in and of themselves are for the federal and provincial governments to make, to make a continued claim to stolen lands, based on their foundations of the DOD entrenched in not only law but overall ideas of white superiority (Reid, 2010; Steinhauer, 2006). In respect to water, the ways that DOD has created complicated legal systems that are intentionally vague about their fiduciary responsibilities to Indigenous Peoples' water. Despite sporadic federal promises to end the Indigenous water crisis, efforts have largely failed, in part because no Canadian water policies or acts exist that directly protect or advance the autonomy of Indigenous water governance (Patrick, 2011; Phare, 2009). Curley (2019) sees settler colonial water laws in the United States as examples of colonial enclosures, with water settlements a continued form of white supremacy that denies Indigenous sovereignty. These ongoing and intentionally complicated water settlements create legal landscapes that attempt to strip diverse Indigenous cultural relationships to water, and "quantify natural systems into 'scientific forms of management" (Curley, 2019). Water settlements, and water insecurity then becomes understood as a form of racial governance, that are understood as crucial to the expansion and persistence of colonial rule. It is clear, through the insidious legacy of the DOD into colonies' understandings of law and land as property, that Western forms of law shape the landscape in damaging and extractive ways.

Through this lens of the political ecology of race and colonialism, coupled with understandings of health through critical biocultural and medical anthropology and political ecologies, it becomes a more dynamic and integrated discussion that broadens our understandings of how spatial histories of racialization then inform the intersections of race, gender, culture, and class, and how these experiences are unique and place based. Together, these form the central arguments driving this work with Six Nations of the Grand River First Nation, in order to build a more transparent and applied understanding of how water insecurity truly is understood to impact Six Nations community members, and how co-creation of knowledge with IK and medical anthropology can create locally specific knowledges and tools to mitigate their continued challenges with land dispossession, water contamination, and the heightened and gendered health risks that may come with it.

## **Chapter Outlines and Overview of Research Studies**

This thesis consists of six chapters, of which Chapters 3, 4, and 5 are standalone papers that have been formatted and submitted for publication in academic journals. This is part of the McMaster University "sandwich thesis" structure. Chapter 2 provides an outline of the study design and methods used to frame and collect the data reported in the thesis, as well as a discussion on positioning myself within the research as a settler, and how that informs my interpretations and the space I occupy in the research project at large. The chapter also outlines the ethics process, and a discussion on the theoretical questions that arise using mixed methodology. The standalone papers are outlined below.

# Chapter 3 (Study 1): Using boundary objects to co-create community health and water knowledge with community-based medical anthropology and Indigenous Knowledge

The third chapter, published in the *Engaged Scholars Journal* (December 2020, Volume 6, Issue 1), explores how IK with medical anthropology can co-construct community health knowledge through community based participatory research (CPBR), including methodologies and design strategies that are able to reflect Indigenous Nations' unique health perspectives and concerns more accurately. The article employs the notion of "boundary work", and in particular the use of boundary objects is explored as a way of creating dialogical space for Indigenous and settler perspectives to develop relationships, identify common goals, and navigate power hierarchies and settler colonial tensions. The co-creation project between Six Nations of the Grand River First Nation and McMaster researchers is used as a case study to ground theoretical discussions of CBPR and boundary work. While the health research within this dissertation is informed by my medical anthropology background, it operates primarily by listening to how Six Nations stakeholders wish to conduct the research and assess their own community health status. Given the history of mistrust and abuse between anthropologists and Indigenous communities, framing the discussions and relationship building throughout the research design process is an important exercise that helps situate the power dynamics of our research partnerships more transparently, in an effort to work towards creating more culturally centered and Indigenous led knowledge together.

# Chapter 4 (Study 2): There's something in the water: mental and physical health consequences associated with tap water contamination in Six Nations of the Grand River First Nation

The fourth chapter examines how exposures to bacteriological and heavy metal contaminants in household tap water affect the physical and mental health of Six Nations community members who simultaneously experience low water access. Previous reports have found that many of the wells in Six Nations are old and in poor condition, which impact both water quality and quantity (Neegan Burnside, 2005). The paper identifies these exposures and the historical processes that led to this water crisis as products of environmental racism and colonialism. Household tap water testing results for *E. coli* and mercury, survey responses on household water uses and members' health conditions, household drinking water sources, and household water treatments were analyzed with logistic regression models to investigate associations between reported health conditions and potential exposure variables for 66 households, representing 226 individuals in the community. For the 66 households that participated in both the survey and water testing, 14 (21.2%) of the households' tap water tested positive for *E coli*, and 17 (25.4%) of households contained Total Mercury (Hg) concentrations above  $1.00 \pm 0.02$  ppb ( $\mu$ g/L), exceeding the provincial drinking water guidelines (Health Canada, 2020; Public Health Ontario, 2019). This work attempts to connect longstanding knowledge within the community about possible contaminations with water uses, and health conditions directly for the first time to appropriately address Indigenous health concerns, and help to shape more appropriate interventions and health care programming that is reflective of the relationship between drinking water perspectives and long held distrust of tap water.

# Chapter 5 (Study 3): Be like the running water: assessing gendered water insecurity experiences using mixed methods approaches with Six Nations First Nation

The fifth chapter builds off the co-creation approaches and relationships from Chapter 3, using mixed methods approaches to investigate the experiences of water insecurity at Six Nations First Nation. It uses both survey data for 66 households and interviews and focus group discussions from 25 community members to understand how water insecurity is experienced and framed by various community members. Water security is measured using the Household Water InSecurity Experiences (HWISE) scale, as well as Likert-scale questions around water access (household, service, and environmental). These results are tested against gender and age categories and

contextualized using interview data. Water security was found to be quite high amongst survey participants (57.5%, n=38 households), and women were more statistically likely to be dissatisfied with their drinking water. Younger participants were more likely to report contamination issues and high monthly water costs. Interview analysis found that water insecurity and poor health were shaped by the degradation of traditional lands. This posed additional barriers for Six Nations women, who faced physical and geographical barriers to water access while caretaking for community members, family, and fulfilling their roles as water protectors. This study situates the results through the cultural history of Haudenosaunee women and their roles in governance and protection of water for future generations, as well as the colonial degradation and environmental dispossession that shifted their roles and how they experience water insecurity.

### **Chapter 6: Discussion & Conclusion**

The final chapter uses an adapted version of Scheper-Hughes and Lock's (1987) concept of the Three Bodies (individual, social, and the body politic) to examine how each of the three studies relate and contribute to our knowledge about Indigenous experiences of water security and community health. This dissertation looks at water security in multiple ways: from direct understandings of tap water contamination and household water uses, perceptions of drinking water quality and experiences accessing water, and discussing cultural, social, and spiritual relationships with water bodies that inform how individuals, households, and the general community of Six Nations understand their local water situation in and around the reserve. To have a comprehensive discussion of the diverse methods and analyses used, I adapted Hoover's (2017) framework of the Three Bodies to structure the discussion about the understandings and comments that emerged on the impact of water contamination and health issues.

Hoover's (2017) and my subsequent uses of the Three Bodies loosely adapts from Scheper-Huges and Lock (1987). Hoover (2017) utilizes these three elements of the body to determine what Akwesasne community members see as sources of their health issues, and how those might be effectively addressed. Table 6.1 highlights the variations on this approach from Scheper-Hughes and Lock, Hoover, and my adaptation of this structural approach to guide this final chapter. Within my discussion, I conceptualize the individual body as more bounded by household, the social body as the complexity of the Six Nations as a community and the research community of practice (RCoP) and use the environmental body rather than the body politic to understand the implications of health concerns on environment. The chapter demonstrates how integrating diverse methodologies and knowledge systems can be used holistically to improve water security assessments in culturally centered, Indigenousled, and co-created ways. The findings of this research show that while water insecurity experiences are relatively high, Western metrics are not able to capture crucial elements of Indigenous experiences of water insecurity, such as community and cultural relationships with the land, structural violence, environmental racism, and the consequences of environmental degradation such as grief relating to water quality and climate change. Understanding how Indigenous Nations uniquely relate to water helps to inform research design, analysis, and potential future policies and water governance systems. This chapter discusses the directions that future studies will take to deepen the baseline understandings of Indigenous water insecurity, and how to integrate cultural, social, and environmental health into community health and wellbeing assessments.

### **CHAPTER TWO: METHODS & POSITIONING SELF WITHIN THE RESEARCH**

# Introduction

Finding meaningful solutions to mitigate the water crisis facing Indigenous Peoples means that it is imperative we find more Indigenous-centric approaches, methods, and ways of sharing knowledge. Bjornerud (2019) makes the distinction between whose idea of time is rewarded in current American and Canadian cultures - those who are the highest paid, rewarded for their algorithms that capture time as measured in seconds. Haudenosaunee Peoples understand time in a very different way, through the *Kaianerekowa (*The Great Law of Peace), which positions leaders in governance to take actions only "after contemplating their likely effects on the 'unborn of the future Nation... whose faces are yet beneath the surface of the ground" (King 2007, p. 447). The seventh-generation approach considers the lives of those spanning at least through a century and a half of descendants, which is certainly more than the three to four year political and funding arcs that academia and government are more used to working within. This dissertation acknowledges that constructs of time are irrevocably different for settlers and Indigenous collaborators, and that even methodologies, data analysis, and discussions within this methods chapter are informed by settler approaches to time. Water governance and contamination policy needs to reflect more secure, long-term solutions rather than fit within the confines of four-year election or three-year funding cycles.

This chapter begins outlining the larger interdisciplinary research project this PhD research is situated within, as well as our timeline of research. I then speak to my own identity as a white settler and academic working within this co-created research project. I then provide a brief timeline of the development of this dissertation project, including cultural training, ethics approval, community-appropriate sampling strategies, recruitment of participants, data collection, and data analysis methods used. I then provide more detail on the mixed methods used for data collection conducted for this dissertation. While the methods used for this research project are discussed in the manuscript-based chapters following this methods section, they are described in greater detail here. I then outline the considerations taken to build this research in a way that navigates multiple stakeholders and audiences. Due to the sandwich thesis structure of my dissertation, the description of research methods within each of the subsequent chapters are limited due to varying journal article word limit restrictions.

# Co-Creation of Indigenous Water Quality Tools Project (CCIWQT)

The CCIWQT project is an interdisciplinary, community-led project that facilitates the sharing and integration of contemporary Western science and local Indigenous Knowledge in response to water quality threats within Six Nations. It's research objectives are to:

- a) Monitor source waters with continuous environmental sensors, accessed through mobile apps and translated into difference Indigenous languages
- b) Investigate the cause of health issues related to contaminated water and explore mitigation options
- c) Examine the socioeconomic, health, food and water security impacts of climate change based on local climate trends;
- d) Contribute to development of tools that are appropriate for community-based safe water solutions, inclusive of source water protection, customizing source-based treatments, and fish and wildlife protection; and
- e) To co-develop a youth culturally based training program to develop stronger community research sovereignty

Within this project, there are the community health assessment team (co-lead by Dr. Moffat and Dr. Martin Hill), the water sensors and data team (lead by Dr. Ravi Selvanapthy), and the ecosystem health assessment team (co-led by Dr. Pat Chow Fraser and Dr. Charles de Lannoy). A timeline of research (thus far) and community interactions is presented in Figure 2.1.

# Co-Creation of Indigenous Water Quality Tools Timeline



Fig 2.1 Timeline of CCIWQT Research Project

I have played a role within each stage of the larger CCIWQT community health team's research project, and was responsible for coordinating local community navigators and research assistants, though these individuals were hired by the project's PI (Martin-Hill) who is a community member of Six Nations. Research assistants and community navigators assisted with survey

collection, but all interviews were conducted by me, and sometimes with community navigators on the team there as well (particularly when those being interviewed were not familiar with myself or the project).

While I did not reside in the community during data collection, I did hold positions and office spaces at Six Nations for two phases of the research project. My first position was through Six Nations Health Services (SNHS) for 4 months in early 2018; while this position was not part of the dissertation research itself, it helped to establish a relationship between myself and SNHS employees, the director, and health care providers. It also allowed me to begin to understand the nuances of the history of health care and community health at Six Nations, politics, and governance shaping water access and health issues. After this, I worked out of the Haudenosaunee Environmental Task Force office near Public Works at Six Nations for most of my days during field work (May 2019 to February 2020). While I had intended to maintain my presence at the office and to be more visibly accessible to community members involved in the project, due to the beginning of the COVID-19 pandemic, all physical workspaces at Six Nations were closed from March 2020 onwards. Six Nations as a community shut their borders to non-residents due to the higher risks posed for their community and the longer history of Western people spreading infectious disease in Indigenous communities. However, I continued to maintain relationships and gatherings virtually to ensure relationships with SNHS employees and community members were maintained.

Several trips throughout the survey and interview period were made to meet with SN community stakeholders on the projects, Band Council, and the Haudenosaunee Confederacy. These were often as part of the broader CCIWQT project updates to these groups, to review the emergent data we were collecting and ensure that community research objectives were being respected. I presented the preliminary results of the interview analyses in March 2019 to the Haudenosaunee Confederacy and SNEC, and preliminary survey results to SNHS in February 2019.

## **Positioning Self Within Research**

As a white, non-Indigenous woman collaborating on a research project with an Indigenous community, it is important to discuss this transparently, given the long and painful history of western academic abuse and dishonesty with Indigenous communities globally, and the racist roots of anthropology as a discipline. I have often been asked by family, friends, academics, and Indigenous and non-Indigenous persons what motivates me to do this work, and more particularly, how I negotiate my own whiteness in this collaborative research project.

These questions are particularly important in the 2020s, as at the time of this writing, we are undergoing one of the largest civil rights movements in history, with the Black Lives Matter

40

protests that began after the death of George Floyd, Breonna Taylor, and Regis Korchinski-Paquet, and the details of mass graves associated with Canada's residential schools confirming the murders of over 1500 Indigenous children spanning between 1899 to 1997. The public reaction and grief from these horrific events of police and state brutality has called for many institutions, organizations, brands, and individuals to reflect on their own power and privileges as non-Black and non-Indigenous individuals. It has asked us to be more accountable for the ways in which those who present as white benefit from systemic oppression and racism. While writing this methods section, these global calls to action and protests also took place in the city of Toronto where I was living at the time, and they have allowed me to recognize the space that I occupy as a white woman in academia working with Indigenous Peoples.

I am originally from the small town of Nogojiwanong, or Peterborough, Ontario, which is roughly 30 minutes south of Curve Lake First Nation, and 30 minutes north of Hiawatha First Nation. I grew up with classmates and teachers who were Anishinaabe and Metis, who reminded us of which territories we lived on, despite this not being a part of the Ontario educational curriculum. During the fall of 2005, roughly 800 members of Kashechewan First Nation were evacuated from their northern reserve after a severe *E. coli* contamination was 'officially' discovered in their water system, despite the community being under a boil water advisory for nearly two years. My teacher at the time was an Anishinaabe man from Curve Lake with connections to Kashechewan First Nation, and he arranged for many of the families evacuated from Kashechewan to stay with community members of our town and Curve Lake First Nation. This came around a time when in our curriculum, we were learning about Canada's foundations and peacemaking identity as a nation. These in-class lessons ran very counter to the evacuated Kashechewan youth. Despite having a semblance of understanding that the ways in which my Anishinaabe peers lived were different from mine, this experience forever altered and challenged my understanding of Canadian history. It is impossible to reconcile these two narratives being presented simultaneously: being told that our country is defined by its peacemaking efforts overseas while witnessing Kashechewan youth being dispossessed from their lands and the legacy of harm caused to from this water contamination. This sparked a lifelong interest in better understanding the First Nation water crisis experience across Canada.

During my Master's degree, I lived in Winnipeg, a city that has the most visible Indigenous demographic of any major city in Canada at 11%. Visible everywhere within Winnipeg was the lasting trauma caused to local Indigenous Peoples living in the city after having been forcibly displaced from their lands. My teaching assistant position at the time was for a course specifically

created to help engineers better understand the relationship between Indigenous Peoples and the land for their work on pipelines, hydroelectric dams, and other intensive and land-degrading projects. This allowed me to connect the visible trauma and violence in the city with the 1960 flooding of many Anishinaabe nations in Manitoba, with zero provincial government aid in housing security, trauma counselling, or healthcare from the Manitoba government. While my research at the time was rooted in bioarchaeology, the day-to-day experiences of living in Winnipeg made me recognize I could work in more clear and actionable ways in the academic system with Indigenous Peoples to unsettle the system.

Coursework with the Social Work department at McMaster on community-based research allowed me to recognize my own identity in more methodological ways, particularly the power dynamics of my presence in Indigenous spaces may at any point represent the long history of helicopter researchers working on and not with Indigenous communities. Would community members see me as yet another white researcher coming to collect data and run, without giving anything of benefit in return? Or would I be perceived as a white savior that wanted to tell them how to be healthy?

Early meetings with the CCIWQT team members and community stakeholders were incredibly important in how I would approach my research involvement and my relationships with community members throughout the course of the project and beyond. While the community health assessment deliverables certainly had changed from the beginning of my involvement (November 2017) to now, my skills were considered in how they could be used appropriately within different stages of the project in order to meet community and CCIWQT needs and interests. As my relationships with community members involved in the project began to deepen beyond simply just co-workers on a team, I became more concerned with what I may unintentionally do or not do that could be viewed as a microaggression. Whiteness can represent violence in even the most seemingly mundane spaces – even just getting coffee or having lunch together. From the guidance and wisdom of our team's PI, the Health Services Director, and the friends from Six Nations and McMaster ISP, I was provided the key instructions of always showing my respect to who I was engaging with, and always, always coming into discussions and events with a good mind that was willing to listen.

During interviews or discussions, I was reminded that for the Haudenosaunee, clean water is not a right but a responsibility. This message was something I have with my own work within the project, in interactions with the community and the research team it is my responsibility to represent the goals of our research project accurately, and to show respect to the friendships and relationships that formed around the project.

# **Project Development**

Project development for CCIWQT began formally in 2016, when Dr. Martin-Hill received the first grants for CCIWOT and corroborative projects that would address water resource protection and development challenges that predominantly impact Indigenous Peoples across Canada. There were several key goals across disciplines, which intersected with the use of complementary knowledge systems of Indigenous Knowledge (IK) and western science (WS). There are two established teams within the CCIWQT project that carry out the work for the project's deliverables, the Traditional Ecological Knowledge (TEK) team, led by Dr. Martin Hill, and the Ecosystem Health Team, led by Dr. Chow Fraser (Fig 2.2). The TEK team was responsible for the community health assessment (the water and health survey and a community garden), IK through citizen science and youth training programs, water governance research, and environmental contaminant assessment in household water. The Ecosystem Health team was tasked with an assessment of the McKenzie and Boston Creeks for bacteriological presence, as well as hydrological modelling projections related to climate change. The project sought to determine the anticipated impacts of climate change on water resources for Six Nations and Lubicon communities and identify the possible ways to prevent contamination of drinking water, protect source water, and treat drinking water. Discussions around co-creation of questionnaires to determine community health status began in October 2017, as teams were being established for the pillars of CCIWQT projects.



*Figure 2.2 - Co-Creation of Indigenous Water Quality Tools deliverables (graphic credit: Colin Gibson, CCIWQT Project Manager)* 

My PhD supervisor Dr. Moffat was the McMaster co-lead on the community health assessment team (with Dr. Martin Hill and Lori Davis Hill, director of Six Nations Health Services), and student researchers were needed for developing the health assessment and community survey. The survey was to help identify the human health risks that may be associated with known water quality contaminants. The contribution of water safety and quality to the health of Indigenous communities was identified using community surveys and testing of biological samples. While there were shifts in research trajectories and available health assessment researchers, the primary goal was identifying how health was informed by water security and quality, led by Indigenous authorities and IK to develop more appropriate and Haudenosaunee centered science and governance data that would aid in future water governance as well as health programming and policy. The community health team was tasked with co-creating a questionnaire around water status and health. Early meetings centered around cultural training and preparation for engaging with Six Nations and Lubicon communities. Group meetings, Elder guidance, and workshops enabled for the foundational relationships between researchers and community to begin. Tools that would be used to assess water quality and health relationships were centered in honouring Indigenous models of wellness, that encompassed mind, body, emotion, and spirit.

To capture community health data, we decided to use mixed methodologies, with qualitative interviews to correspond with quantitative surveys and situate the experiences and water use practices of participants through their own narrative experiences. Previous data collection from the First Nations Regional Health Survey (FNRHS) was not able to be used, as there was no ability to connect individual outcomes with the planned testing of household water samples for biological and metal contaminations. SNHS also was interested in having more data sovereignty and localized data, as they are not able to extract Six Nations data from the FNRHS aggregated data. The aim was to create a comprehensive translational study about water and health, where a snapshot of the community's current lifestyle was given, inclusive of sociodemographic and economic variables, dietary sources, water sources, water use practices, and current health status.

# Ethics Approval from Six Nations Research Ethics Board

Ethics approval for the project-at-large was obtained in January 2018 from Six Nations Research Ethics Board, which represented the approval of Six Nations Band Council. Verbal agreements and approval were expressed from the Haudenosaunee Confederacy in January of 2018 as well. This umbrella approval from Six Nations REB is an important factor in the application for ethics from McMaster's REB (MREB). As this approval was granted for the large, interdisciplinary project, and did not provide the details of each phase and step of the project, MREB found this more difficult to comprehend.

We expressed to MREB that these ethics approvals from the two governing bodies of Six Nations were granted as umbrella approvals only due to the volunteer nature of the community REB and that many of those who worked on the REB were over-worked in multiple spaces. Coming to them with new formal addendums for each small part of the research project would be more work for them that would take away from other important community work. To work around these issues of capacity, the PI has had ongoing communication with both governing bodies at Six Nations, the Haudenosaunee Confederacy and Six Nations Elected Council (SNEC), to share updates and progress of research and ask for assistance and insight onto key issues and concerns they may have around water and environmental health as they come up.

As a research team, our work is ongoing with the community as we continue with a renewal grant from 2021 to 2024. Throughout the process, we ensure regular visits to both Band Council and Confederacy (where appropriate) to share our knowledge and updates from our work and seek guidance on next directions that they wish us to focus on. A great challenge to this sort of work is that these partnerships remain open and flexible. For the academic research team, we are clear on consistent community partners, navigators, leaders, and participants, but also open and flexible to emerging needs, directions, opportunities, and concerns that community partners may bring forward as research progresses (Ball, 2014).

## Memorandum of Understanding

As the work continued to unfold, we worked out a Memorandum of Understanding (MOU) with Six Nations Health Services as a formally written and co-signed (between our PI and the Director of Health Services) to establish understandings and outline key principles for the conduct of research involving community members and leaders. MOU documents are often called upon to reinforce or recall agreements and can be used to introduce new team members to the principles and procedures on which a community partnership is built (Ball & Janyst, 2008). This is particularly helpful in research situations where there are large collaborative networks of investigators (such as the case with CCIWQT research team) and for when students cycle through projects at various points (Ball, 2014).

The MOU outlined the details of the partnership between Six Nations Health Services and the CCIWQT health researchers (which involves both community navigators and McMaster researchers). These were written and co-signed in September of 2018. MOUs are not contracts, so that all parties have the right to withdraw from the project or change the nature or extent of their participation at any time. This was made clear throughout the formal document as well. Establishing these clear expectations and outcomes for both sides allowed for the development of on-going open communication about each side's needs, wants, and abilities that they can bring to this work.

### Ethics Approval from SN REB, SN Confederacy, HiREB, and MREB

After the preliminary meetings in the fall of 2017, teams began to branch off to begin working on their separate sections of the project. For the community health assessment team, the research

group was composed of medical anthropologists (myself and Dr. Moffat), and a health sciences team that had ongoing work with biological sampling. Ethics clearance from Hamilton Integrated Research Ethics Board (HiREB) was obtained in early 2018 for preliminary interviews with community members, which would assist in understanding community-specific concerns around water and health to incorporate into the community health survey. The ethics application initially went through HiREB as the health assessment team was originally co-led through Health Sciences at McMaster, as it was originally planned that we would be taking blood samples to correlate with water contaminants. This project element later changed, and so we decided to create a baseline household water use and health pilot survey that would relate to the household water sampling tests for *E. coli* and mercury (Hg) contaminants. While the biological sampling portion of the study was not actualized, the work on the health survey itself continued in collaboration with Six Nations Health Services. Due to this change in research trajectory, the HiREB ethics application was closed in September 2018, and no more interviews were conducted by the community health team at that time. I submitted the McMaster Research Ethics Board (MREB) ethics application for my dissertation research (that didn't include biological samples) and encompassed the community health survey pilot we had co-developed between the community health assessment team and the community stakeholders.

The community health survey development is explored in greater detail in Chapter 3. However, for the ethics approval process, it is important to note that there were two separate phases of survey development. The first phase was for a longform community health survey, cocreated by Six Nations Health Services and the community health team, to serve as an assessment of self-reported health concerns that were broadly encompassing. This survey development paused in December 2018, due to limited capacity from community stakeholders at the time to ensure its full delivery. After this, the community health assessment team developed a shorter, pilot version of the health and water use survey that complemented the household water testing of the ecosystem health team from the summer of 2018. Using the water-related questions and condensed health questions from the co-created long form survey, the ethics application was put forward to the MREB in February 2019 for the pilot version and interviews and cleared in March 2019.

## **Community Navigators**

As one of the core pillars of our CCIWQT project, Indigenous Knowledge led the format of each subteam within the project. Each team worked with community navigators who were residents of Six Nations, and in some cases also McMaster University or University of Waterloo students as well. Community navigators is a term used to describe team members who were members of a Nation and live on Six Nations. The process of recruiting research assistants was predominantly through the broader CCIWQT Indigenous leads and PI, given their personal relationships in the community.

Community navigators were assigned to the community health team based on their own research interests and data needs for their programs of study. Given their own long-term relationships with community members, two main community navigators assisted in introducing myself and other team members to the community in respectful and reasonable ways and aided in the recruitment of individuals for the water use and health survey pilot. We would meet intermittently to go over the development of the survey in 2019 as well as coordinate visits for water testing and surveying on weekends in late 2019 and early 2020 (before COVID). Community navigators also provided their views on the protocols to be followed by the research team when meeting with new community members, particularly Elders, as well as offering insights on upcoming events and activities that project members could contribute to to build lasting relationships and community presence, such as water days, medicine garden building, anti-Nestle protests, and a river clean-up day.

### Sampling Frame

Participation in surveys was directly related to participation in previous household water tests throughout summer 2018 and 2019 by the Ecosystem Health sub-team of CCIWQT. The intention was that the water use, and health survey could be directly connected to the tap, well, and cistern water sample results from *E. coli* and heavy metal testing to assess any relationships between contamination and health, or water use and heightened exposure risks. Participation was arranged primarily through email and phone calls by community navigators and me. Email and phone information scripts used to follow up from the water testing sampling frame are found in Appendix A. Only participants who met the inclusion criteria were included for the survey (over the age of 16 years old and could speak for the households' water uses and had previously had their tap or well water tested). Interview participation was arranged through email, and only those who met the criteria (above the age of 16 and a Six Nations resident, and able to give consent) were included.

The age range for the survey and interview participation were chosen based on the guidance of community collaborators who represented health care services. Health care providers at SNHS suggested we consider those aged 16 and above as adults, given that Indigenous populations tend to age "faster" than non-Indigenous populations, and it would be important to consider those who became parents young, and maintained household and family responsibilities

at a younger age. For interviews, ongoing transcription as I conducted interviews allowed me to identify when saturation had been met, with 25 participants across diverse life stages as a final sample for thematic analysis.

### Participant Recruitment

Due to ongoing work with SNHS, the director of SNHS (Davis Hill) and staff identified several issues with traditional approaches to the past development of community health assessments with Six Nations. The federal Regional Health Surveys had insisted that systematic random sampling strategies be maintained to have a representative data set, but this ran counter to the community's preference for snowball sampling. As well, systematic sampling strategies were based on mail or telephone contact; these impersonal methods of communication with households were mostly ignored, and therefore many households were left out of surveys.

For the preliminary interviews of 2018, participants were recruited for discussions through community events, where the entirety of the CCIWQT team would hold gatherings and discussions around water-related concerns. Recruitment posters were created to share at events (Appendix B). At these events, we would have tables for separate parts of the project after presentations, and community members and researchers engaged in conversations around these tables. There were sign-up sheets for those interested in completing interviews, with phone numbers and emails taken down. Of these, there were 12 individuals who expressed interest in being interviewed, and 7 who agreed to interviews during a follow up email or phone call.

The recruitment for the water-use and health survey and the subsequent focus group and individual interviews was primarily through contacting the 78 households who had already had their tap and well or cistern water tested. Potential participants were recruited primarily through phone calls and emails, seeking their potential interest in the follow-up health survey and discussion of their water concerns if they were interested. Most phone calls were made by community navigators, as they were more familiar with community participants. There were some households that did not have any available contact information, and for these homes, it was decided that it would be more appropriate if community navigators and researchers would be the face of the door-to-door canvassing for surveys. These did not prove to be overly successful, with only 2 households responding to these forms of engagement. The letters of information and consent forms for both surveys and interviews are available in Appendix C. Once a household representative agreed to participate in the survey, research assistants and I would go to visit the home on an agreed upon time to fill out the physical paper-and-pen surveys. These were opted for

due to time constraints around the CCIWQT project and dissertation timelines, though online versions of the eventual longform survey were discussed in prior meetings. All participants of the survey were remunerated with a \$25 gift card to a coffee shop as a thank you for their participation upon completion of the survey. Those who participated in an interview or focus group were also compensated with an additional \$25 gift card for their time.

# **Quantitative Data Collection - The Water Use and Health Survey**

While the details of the health survey construction can be found in Chapter 3, a brief outline of its construction and intention will be outlined here as well. The full survey can be found in Appendix D, with the letter of information and consent in Appendix C. The health and water use survey were sectioned into 5 main parts:

- 1. Demographics
- 2. Water Use and Treatment
- 3. Water and Food Security and Consumption
- 4. Self-reported Health Conditions
- 5. Water Contamination Knowledge and Governance Concerns

# Survey Co-Development

After extensive research on existing health assessments for Indigenous Peoples globally, and a request by the health centre to develop an assessment tool that provided a snapshot of community health, two surveys were developed over the summer of 2018 in collaboration with Six Nations Health Centre. While there have been several provincially or federally funded community health assessments over the years at Six Nations, there has not been a consistent assessment tool that remains as an autonomous measurement of health for and owned by Six Nations peoples. Federally funded surveys are often conducted in ways that are not appropriate for Six Nations peoples. While the FNRHS is created by First Nations, for First Nations Peoples, they are not designed for local contexts or local data ownership, and participants are recruited from random selection off a band or community membership list provided to the surveyors from Band Council. These approaches were problematic for Six Nations, as this meant that participation in the survey would be matched only to band status and was not a preferred method of recruitment. Once the data are collected, they are only shared with First Nations as aggregated reports, so that First Nations do not have access to the raw data and are not able to use the data to assist them with local community health assessment or planning.

The first 30-page health survey began co-development with Six Nations Health Services to match Haudenosaunee wellness models while containing measurements of individual health that

would be able to compare Haudenosaunee health statistics with other First Nations Peoples' health outcomes. It was also developed to be eventually used as an autonomous tool, separate from federal and provincial funding bodies, and had appropriate snowballing recruitment strategies. Health within this survey is understood not only to be physical, but also cultural, spiritual, and emotional, with personal health being directly related to household, community, and environmental wellbeing. This first health survey attempted to meet the needs and interests of many different and equally important perspectives and voices within the community. A large challenge we ran into through the development of this survey was the limited capacity of Six Nations community leaders and navigators, as many were already overworked on several other important projects relating to health and wellness, community infrastructure, water quality, and other projects. Additionally, as the survey began to grow in length, it became a less realistic survey to send out and expect high completion levels. The survey was tabled in December 2018 to return to the concept when there was more capacity to do so and is currently in development through SNHS for a fall 2021 launch.

The second, shorter survey was 10 pages and more directly connected with water quality and use with household-level health experiences, as the community health team recognized more context was needed to interpret the household water tests that were previously conducted. This survey tool was developed in January of 2019, with ethics approval obtained from McMaster Research Ethics Board in February 2019 and brought to Six Nations Band Council and Confederacy on two separate retreat days in March 2019 and met with approval. These data will directly correspond with data from the ecosystem health assessment dimension of the CCIWQT project, which tested the tap, well, and cistern water of 78 households for biological and heavy metal contamination. This survey is the primary data set examined throughout this dissertation, with individual and focus group interviews providing important context and local IK that informed the interpretation and dissemination of the results.

### **Demographics**

The first section of the water-use and health survey captured sociodemographic data as background information on the participants and all those who resided in the household with them for the majority of the time (Appendix D). Information on participant's age, gender, and Nation, as well as household demographics such as the number of individuals in the home (with age), and annual household income were collected in Part A of the 11-page survey. Traditional survey markers of level of education and occupation were not collected, as this information was not a useful variable for SNHS and was also suggested by community co-creators that it may cause some levels of discomfort among participants in relation to income versus education. These questions also situate participants in more Western sociodemographic classes that do not align with Haudenosaunee frameworks for health indicators.

### FNRHS Health Questions

Health questions were developed based on the 2015 First Nations Indigenous Governance Centre's (FNIGC) First Nations Regional Health Survey (FNRHS) for Indigenous Peoples. The FNRHS is the first and only national health survey created by Indigenous researchers for First Nations health assessment. It collects a wide range of health information about First Nations Peoples living both in northern communities and reserves, capturing both "western and Traditional understandings of health and wellbeing" (FNIGC, 2020). The health conditions used in the water use and health survey pilot were taken and adapted from the Phase 3 FNRHS Adult Questionnaire, from the Health Condition section, question 30 chart to assess health conditions experienced in the past six months or longer (Appendix D). For this water use and health survey, the chart was adapted to extend to health conditions experienced in the last 12 months, as water testing was conducted from 6 to 12 months prior to health survey response collection.

Physical and mental health conditions deemed relevant from the FNRHS to Six Nations by Health Services were included in a chart that included conditions, age at diagnosis, and whether the individual with the condition was currently undergoing treatment. Unlike the FNIGC surveys, the health conditions section was altered to allow participants to include other household members that were experiencing health conditions. This was again at the request of SNHS for capturing broader data on general health conditions, and for use by the CCIWQT research to assess the prevalence of water-related health conditions in relation to contaminated household tap water. The intention behind using this FNRHS format was so that SNHS could compare their health condition results with regional data from the FNIGC if desired, but SNHS could still retain sovereignty over their own data, without aggregation with other First Nations health data.

### Source Water Protection Survey Questions (Access, Drinking Water Satisfaction, and Water Use)

For questions relating to household water sources, uses, and access, many of the questions were developed based on a 2010 source water protection (SWP) survey developed by community member Paul General for Six Nations of the Grand River. This SWP survey was developed after a collection of secondary data related to water resources was comprehensively searched (SWP, 2010). Through this secondary data search, sub-dimensions were developed to create a framework that was able to capture and represent the situation of First Nations and source waters (SWP, 2010). The SWP survey assessed the water situation for 100 households in Six Nations in 2010,

52

capturing household water uses and sources, water experiences and perceptions, decision making and governance of water, and demographic information (gender, age, number in household, marital status, employment status).

The CCIWQT water-use and health survey pilot used in this dissertation incorporated questions from the SWP about household water uses, sources, and experiences and perceptions, as well as a few questions at the end of the survey about governance and decision making around water. These questions were slightly adapted, particularly in the wording about household tap and drinking water sources, based on communication with the CCIWQT team engineers and biologists who had previously sampled tap, well, and cistern water and had a better sense of the water systems used by households. These were also assessed by community navigators for coherence and clarity, to ensure that the water source questions adequately captured the wide range of household drinking and tap water sources and treatments that they knew were used by community members.

The SWP also asked questions about access to water at the household, community, infrastructural and environmental levels, in single-answer multiple choice structured questions. These were adapted to become a Likert-like scale in the water use and health survey, to assess the internal reliability and consistency of responses using Cronbach's alpha, and to later compare to the HWISE water security scale to see if responses to these questions could support and match HWISE measurements and determine if it is a reliable indicator of water insecurity. Additionally, some of the wording was changed for the environmental access question at the request of SNHS and Six Nations team members, to reflect the waters "in and around Six Nations" and to illustrate that access to water extends beyond colonial boundaries of the reserve.

The questions were developed to be self-administered and require the participant to respond to statements about water access by checking "very poor," "poor," "okay," "good," or "very good". These responses were coded on a scale of 1 to 5 for statistical analysis (1 being very poor, 5 being very good) and used to examine gender and age-based experiences of water access at these different levels (Study 3, Chapter 5). While being able to use this Likert scale allows for an internal consistency test to be run, it does maintain some limitations that are inherent with any survey tools. As this format restricted participants' responses to close-ended questions, it did not allow for the contextualization about what specifically influenced their ratings of household, community, infrastructural, and environmental water access. Recognizing this limitation allowed these data to be integrated with qualitative interview data to allow for a deeper contextualization of the water experiences, access, and perceptions being studied, particularly as it relates to gendered barriers to water in the community and how Elders and youth are affected by poor water access.
#### HWISE Water Insecurity Scale

To assess the prevalence of household water insecurity experiences within Six Nations, the Household Water InSecurity Experience scale was used (HWISE). This is the first scale to quantify experiences of household water insecurity in a validated way for low- and middle-income countries (Young et al., 2019). The 12 item questionnaire probes respondents about household water access, adequacy, reliability, and safety to compare universal water insecurity experiences (Young et al., 2019). The recall period for these 12 items is 4 weeks, with Likert-style responses individually scored between "never," "rarely," "sometimes," "often," or "always" (0-4). The four-week recall period was selected based on Young and colleagues (2019) ongoing ethnographic work, as well as evidence from food insecurity literature (Jepson et al., 2017; Jones et al., 2013). Water insecurity is scored based on the total responses in the 12-item scale, ranging from a possible total of 0 to 48. Water insecurity is scored at a 12 or higher rating (Young et al., 2019). However, as has been developed for food insecurity scores, Jepson et al. (2021) further defined five subcategories of the HWISE scale using cut-off points. This aids when running ranked statistical analysis tests, especially when other household factors may inform water insecurity experiences, rather than "assess correlates of a less meaningful one-point change" in the HWISE scores (Jepson et al., 2021, p. 4).

Within this study, HWISE scores are presented in a Likert-style format to test the internal consistency of responses. A question on contamination concerns was added at the base of the HWISE scale section in the survey at the request of SNHS and other community collaborators, to capture potential ranges of experiences with this concern and correlate with actual household water contamination. This question was not included in the calculation of HWISE scores or Cronbach's alpha calculations relating to water insecurity presented in Study 3 (Chapter 5). They were integrated into original logistic regression models for Study 2 (Chapter 4), though were removed from the models after they were deemed not statistically relevant to the health outcomes on which the models focused.

While there are of course limitations in recall questions, due to their reliance on the retrospective memory of participants, these are lessened with a water security scale compared to food or dietary recall questionnaires, as they are less specific and don't ask for specific recalls about portions or consumption. The focus within the HWISE scale is more on recalling the number of incidents where water has not been available enough, or there have been interruptions to services and access. One of the limitations of using the HWISE scale is that it is reductionist due to its aims of assessing universal experiences of water insecurity. It has also only been validated for lower- and middle-income countries and is not used widely in North American contexts.

However, HWISE is in the process of global validation, and water insecurity experiences for Indigenous Nations are expected to be aligned with experiences of water insecurity in Global South communities more so than non-Indigenous settler households in nearby areas. The creators of the HWISE scale recognize the reductionist nature may inhibit place-based knowledge and contexts of water insecurity and encourage scholars to add supplemental items and modules to evaluate local experiences in complementary ways (Young et al., 2019). Within this study, we supplemented the scale with questions developed and adapted from SWP questions about water access, as well as questions about water satisfactions and contamination experiences. Affordability of water was also a salient experience for Six Nations residents, as they largely rely on purchasing water for their households, so questions were asked about monthly costs of purchasing water and related to annual household incomes. The HWISE scale does not include a specific measure of affordability, but instead examines more emotional concerns around access and availability, despite its adaptation for lower- and middle-income countries. The other considerable limitation within this scale is that is has not been validated for use in higher income countries, despite wide discrepancies in water access for certain communities within the United States and Canada. These limitations will be discussed with more detail to the study in the Discussion (Chapter 6).

#### *Other survey metrics*

There were other survey metrics captured in the water use and health survey pilot that have not been covered within this dissertation. Much of these were more secondary metrics about food as it related to water use that fell outside of the immediate community interests and needs around water security and will be analyzed at a later point following the release of water security and contamination results. These sections included recall questions about foods that require more water (such as soups, broths, stews), food security scores using a 6-item scale, and traditional food consumption in the past twelve months. The questions about traditional food consumption including freshwater fish from in and around Six Nations were developed based on the FRNS survey tool and may prove to be important data for Six Nations due to ongoing concerns with surface water contaminations of the Grand River and associated creeks. The pilot survey afforded a test run of the success of these questions and their structure that has been integrated into a renewal phase of the GWF project that began in 2021 with a food and water survey that will relate to hair sample testing for heavy metals.

#### **Qualitative Data Collection - Focus Group and Individual Interviews**

Pilot interviews were carried out over the spring and summer of 2018 by community navigators Denise McQueen and Makasa Looking Horse and I working together to hold focus groups and interviews. Further interviews with participants recruited from the water use and health survey pilot and community leaders were conducted between March 2019 and February 2020. We asked questions about community and household health, water concerns and knowledge around environmental health and teachings. Interviews were with one participant at a time, running 30-45 minutes, and focus groups were held with 2-3 participants at a time, usually running around 45-60 minutes each. These interviews and focus groups were held in households and community centres at Six Nations, and food was catered in from local kitchens.

## Formatting Questions and Interviewing Styles

Interviews remain a primary methodology in medical anthropology, with its ability to capture the more in-depth information and experienced knowledge about complex situations (Britton, 1995). These interviews examined the perceptions that participants had about their water security, community and family health, and Haudenosaunee relationships with water. The information provided in interviews for this research allowed participants to share more context around their water uses, challenges, or the relationships they fostered with water in or around the community, adding much needed context that aided with survey data interpretation.

Semi-structured interviews were used within this research, as it maintains the more informal free quality of unstructured interviewing that allows participants to explore avenues a researcher may not consider but relies on an interview guide. Interview guides create a set of questions and topics that should be covered in a specific order by the researcher, with prompts that may allow the interview to follow unique leads of the participant (Bernard, 2016). For both focus groups and individual interviews, semi-structured interviews were conducted with the same interview guide (Appendix F). Semi-structured interviews work well to promote the discussion of more detailed descriptive data, particularly in complex matters like Indigenous water governance and environmental degradation (Arsenault, 2021; Hoover, 2017; Lucier, 2019; Meissner et al., 2018; Sarkar et al., 2015; Spicer, 2020).

This style of interviews worked well within this community, as it was broad enough to spur many different concerns and perspectives on a wide variety of health and water issues. I quickly became comfortable having a baseline of questions to jump to for prompting discussion on eight key questions, but flexible with the shape and direction of the leads that individuals chose to take in the interview. As Six Nations has a tremendous amount of demographic variation, this project was unique in being able to capture the perspectives on water and health from youth, mothers, hunters and fishers, Elders, and community health care and environmental leaders, with each having different relationships to their household and community water, and their traditional lands. The ability of semi-structured interviews to promote the detailed descriptive data allows for identifiable themes to emerge through the data, such as seen in Awume and colleagues' (2020) research on Indigenous perspectives of water security in Canada. This type of data is particularly useful in developing stronger understandings and answers around questions that are harder to measure, such as perceptions, attitudes, and beliefs around drinking water or overall water quality (Bernard, 2016; de franca Doria et al., 2005; Hu et al., 2011; Lam et al., 2017).

All interviews were conducted and led by the researcher (n=25), and some were assisted by community researchers and navigators (n=6). All participants consented to have their interviews recorded, and none withdrew. Questions were designed to investigate perceptions of water and health challenges in the community and household, experiences with water insecurity, contamination, and cultural knowledge or relationships with water that informed perceptions, satisfactions, and daily experiences of participants in relation with water. Questions began with a focus on individual and community health challenges or strengths, and then led into questions around the health of the water in the community, challenges or experiences accessing water at the household, and personal knowledge about water relationships. Open-ended questions were designed to promote a more general discussion in response to the specific question but allowed for the possibility of following participant leads into new topics (Appendix F). Examples of questions included:

What does health mean or look like to you? What do you think makes for a healthy community? What does water mean to you, or what role does it play in your life? How do people use water in your community? Does it vary by season? What challenges do you feel your community faces when it comes to water?

These questions were all designed to stimulate a discussion that were guided by survey topics of water use and health, and create a relatively straightforward path between topics, though allowing for space for the participant to have more non-linear leads about specific community challenges or water knowledge when they felt necessary. The preliminary interviews and focus groups were conducted with 7 community members, ranging in age from 19 to 50, and predominantly identifying as female, and mostly self-identifying as mothers. These interviews were conducted prior to the finalization of the health survey in February 2019. Subsequent interviews that were

held with those who had their water tested and filled out a survey were more varied. There were 15 individuals who were interviewed due to their expression of interest at the end of the water use and health survey, and 3 participants who were sought for their expertise as community leaders in health or the environment.

Overall, community members were very eager to share their knowledge and stories with us. The importance of meeting with diverse community members, being flexible with interview locations (providing a neutral space as an option for those who were not comfortable with me visiting their living spaces) and following cultural protocols prior to requesting interviews was discussed as having increased the degree of comfort they felt with myself as a non-local researcher for these interviews. Individual interviews lasted between 45 minutes to an hour, and group interviews tended to last between 1 to 2 hours, often beginning with an informal thanksgiving. Interviews often included breaks, food sharing, and a lot of jokes and laughter in the informal spaces outside the discussions.

The location of each interview varied based on the interviewee's preferences. Many interviews were conducted in the homes of the participants, but several interviews took place in neutral community gathering spaces, such as the Dajoh Youth Centre for younger interviewees, the Environmental Task Force Office our project was based out of, and The Sweet Spot Juicery (afterhours), thanks to the owner's permission and collaboration with the project) for those living in Ohsweken who preferred to meet in the evenings. Once the interviews were complete and the audio-recording device had been shut off, participants and I would often reflect upon what had been discussed, along with some hopes for what our water project could do for the community. All individuals were offered an honorarium at the conclusion of their interviews, as a means of further thanking them for their participation.

While working with team members to craft the interview questions and prior to the beginning of interview data collection, I was aware that my presence as a white woman and outsider to Six Nations may make participants feel uneasy or feel that they would have to censor themselves around sharing specific information. I tried to ensure that my questions asked were never prodding or pointed, and always left individuals with the ability to have an open-ended response, or even a simple yes or no. From my training and coursework, I knew that Haudenosaunee Peoples often felt researched to death, and I wanted to make sure that this experience and discussion was a safe and reflective environment where they felt comfortable answering only what they wanted to.

After my first round of interviews in 2018, I realized that many people within the community were more eager to share their experiences with water quality issues than I expected, and never got the sense that their responses were restricted because of my presence. In many discussions, the participants were avid and often long-time activists for various community issues around water and land agreements, and so they viewed these discussions as opportunities to share their valuable experiences doing this work. As participants were recruited through snowball strategies for water testing and interviews, the knowledge of water contamination issues may be more heightened, as these were participants who had expressed interest in working with us on mitigating water quality issues. Many participants shared instances where white people had caused harm or pointed to the more broadly systemic racism, they experienced in various spheres due to white settler colonialism, and in doing so, we were able to share in a vulnerable discussion around our separate identities.

In some instances, my role as an outsider was beneficial to gathering more specific information from interviews. As I had no clear community political or spiritual leanings, participants noted they felt very comfortable sharing specific concerns that they normally didn't feel able to share. I was also unaware of the more specific details surrounding past events and occurrences in the community than the community members working within our team, so my follow-up questions around these events led to more deeper and reflective conversations around how these events had impacted the community or the family I was speaking with.

I believe much of this is due to having the PI of the CCIWQT team that was from the community, and many of our research team being from Six Nations or other First Nations. They often had long term established relationships and friendships with the families recruited for interviews, and so a degree of trust that this project was being led by Six Nations members for Six Nations members undoubtedly assisted the comfort level participants experienced throughout their interviews.

#### **Co-Created Research Methodologies**

Briefly, it is important to mention that due to this research being co-created by Indigenous community collaborators and interdisciplinary team members, there were many disciplinary perspectives guiding various elements of the broader dissertation. I will briefly highlight the ways that my general tone and argumentative angles had to change to capture and translate knowledge to specific audiences.

In Study 1 (Chapter 3), this paper takes a largely theoretical exploration into the more realistic elements of co-created research. Rather than expressing what makes for the most efficient co-creation process, it aims to be honest about the challenges, tensions, and flexibility needed to bring a co-created research question into a project reality. Within this, I aim to reach medical anthropologists and applied anthropologists, explaining one way to create space as medical anthropologists to co-create applied knowledge with collaborators that may have diverse needs and stakes in the project. It takes a more theoretical tone in the hopes that it creates a more tangible and general understanding of co-creation work with Indigenous Peoples, avoiding white saviorism or helicopter research approaches that have been used in the past.

In Study 2 (Chapter 4), the article aims to convey the water contamination results to a blended natural, health, and social sciences audience, assuming that many have little to no background knowledge about Indigenous Knowledge or co-creation. This assumption is especially relevant for those in the natural sciences spaces who had no formal experience working with humans. The work was co-created with Indigenous researchers, as well as engineers and biologists. Unsurprisingly, this resulted in many different perspectives on how to structure the discussions and analysis of the data, but in the final iteration as lead author I decided to use Haudenosaunee IK with social science frameworks of environmental racism as an analytical lens to contextualize the empirical data presented. After many Zoom discussions and email threads, consensus was achieved on a message that worked for all team members, without reducing the central issue of the connections between colonialism and ongoing water contamination impacting the health risks for Indigenous Peoples.

In Study 3 (Chapter 5), the goal of the manuscript was to extend the discussions of water security outside of the measured western methodologies. I integrated discussions of forced land dispossessions, the relationship between gendered violence and environmental contaminants, and land-based healing and rematriation into a broader understanding of water security experiences for Indigenous Peoples. I went in with the intention of critically reflecting on whether water insecurity should only be measured at the household level, or if those boundaries are only meaningful in post mid-20<sup>th</sup> century American and Canadian understandings of nuclear families. By including perspectives on community water access and Haudenosaunee relationships to water in the health and water use survey and interviews, I was able to highlight the importance of this issue beyond just household water contamination. There remains a clear challenge in capturing the attention of the public and federal and provincial governments when it comes to the Indigenous water crisis: appealing to these audiences is fueled by a need for concrete numbers, and most numbers reflecting

60

the crisis are based on geographically remote and northern First Nations that are actively under a long term DWA or short term BWA. As I argue later, BWAs are not consistently assessed, and do not effectively encompass the complexity of the water crisis, nor how it relates to local knowledge and contexts. Using mixed methods, I aim to integrate the measured water insecurity scores with more insights about how gender, age, and culture inform perceptions of drinking water quality, community water access and quality, and the overall relationships with land and water.

#### **Data Analysis**

# Statistical Analysis of Quantitative Water Security and Access Questions, Health and Contamination

All quantitative survey data were coded numerically, and SPSS (v24) was used to manage and analyze survey data. Survey responses were initially analyzed with descriptive statistics. Studies 2 and 3 both required statistics to analyze different relationships: in Study 2, the relationship between household health conditions and water contamination exposure was investigated, factoring in water treatments, number of children at home, and annual household income. In Study 3, the relationships between water security, access, and satisfaction and gendered and age-based experiences were explored. Specific statistical tests were used to determine internal consistencies within the data and demonstrate the relationships between variables.

For Study 2 (Chapter 4), quantitative data was analyzed by descriptive frequencies, 2 tailed Pearson correlations, and building two logistic regression models to identify the influence of water contamination and use on three main health conditions. The effects of the risk factors or independent variables (demographics, source of water, water treatment, and tap water contamination) on the self-reported health conditions or dependent variables were analyzed through binary logistic regression to determine the odds ratios (ORs) and 95% confidence intervals (CIs).

Binary logistic regressions were conducted to determine the odds ratios (ORs) and 95% confidence intervals (CIs) on all the dependent health variables. The health conditions run in analysis (mental health, eczema, and gastroenteritis) were selected for analysis based in part on the insights and concerns of community collaborators prior to data collection. Elders and youth had spoken on several occasions of the mental health challenges associated with water, and preliminary interviews and conversations with young mothers in the community suggested that rising eczema rates were of a concern, and they were unclear if contaminated water was a driving factor in the heightened cases. Additionally, these three health conditions have been documented in relation to

water insecurity and contamination, and could reasonably develop within the year between tap water tests and surveying, unlike other environmentally linked conditions (such as some cancers).

One of the limitations within this study is that it is incredibly difficult to capture chronic health conditions or those related to long-term exposure to *E. coli* or heavy metal water contamination. Six Nations individuals can be highly mobile in their living situations, and the amount of time participants and household members spent at their addresses recorded in the survey was not captured. Additionally, it is hard to know with certainty the consistent presence of E. coli or heavy metals in tap water for households without longitudinal water testing data. We decided that conditions such as mental health, eczema or dermatitis, and gastroenteritis could be assessed and potentially connected with household tap water tests, as these three general health conditions could develop within this shorter period. Regression models included variables that were deemed relevant to exploring the direction of the relationship between each health condition and water contaminations, treatments, or sources. Two regression models were run, restricted to household-level data for a sample of 66 households (that represented 226 individuals). This was to determine if household treatments, sources, contaminants, or demographic factors influenced the presence or absence of a health condition reported for any household member. As the contaminant testing was conducted 6-12 months prior to surveying, the first regression model examined the water treatment and household variables, and then the second regression model was run with the addition of *E. coli* and mercury as predictor variables.

Tap water treatments were focused on as variables in the regression models to explore, as particular types of treatments may reduce exposure to certain contaminants. While in-line<sup>3</sup>, post-tap, water softeners, and bleach or chlorine were provided as treatment options on the survey question, only treatments thought to reduce exposure levels were included in the regression models. After consultation with the engineers on the CCIWQT leading the heavy metal tap water testing, it was hypothesized that households using in-line water treatments would have a lower rate of mercury exposure risk. While boiling water will not reduce or remove heavy metals from water, in-line water treatments are well equipped to remove or make heavy metals insoluble in tap water. Common forms of in-line water treatments are reverse osmosis (RO), which uses a system of pre- and post-filters that demineralize and deionize tap water to remove lead, mercury, fluoride, and chlorine. Many of the Six Nations households reporting in-line water treatment spoke of their use of RO systems. Additional in-line water treatments that can remove heavy metals are ion

<sup>&</sup>lt;sup>3</sup> In-line water treatments are point-of-use water treatments that treat water directly before ingestion (usually installed on the tap head or under the kitchen sink), reducing and eliminating heavy metals, with some of the most popular forms being reverse osmosis and ultraviolet light.

exchange resins (which remove heavy metals by activating with carbon), and kinetic degradation fluxion (KDF), which uses an oxidation process to reduce the cations of heavy metals until they are insoluble and is able to remove up to 98% of water-soluble heavy metals (Osterhoudt, 1997). The addition of bleach or chlorine to water supplies (e.g., adding a cup of bleach or chlorine to the well once a month) was hypothesized to reduce the likelihood of exposure to *E. coli*, as consistent chlorination can provide protection against biological pathogen intrusion in water source (Payment et al., 1997).

For eczema, number of children in the household, as well as household income, bleach and chlorine, and water treatments were key variables to include in the regression models, as there were community collaborators concerned with the emergence of heightened eczema and skin rashes in youth and either the absence of water or the use of water that was contaminated or contained too much chlorine or bleach. The number of children in the household was included as a variable to see if this controlled for the prevalence of eczema or mental health conditions in the household, as eczema is primarily a disease of childhood, and increased number of children in the house may inform heightened feelings of mental stress. Originally, another regression model was built to look at the relationship between water uses and presence of health conditions, controlling for contamination exposures, but there were no significant relationships in these models. Instead, chi-square tests were conducted to instead look for directional relationships between water uses and contaminations.

In Study 3 (Chapter 5), non-parametric tests were used to assess the ways that gender and age inform experiences with water insecurity, drinking water satisfaction, and access to water in the household, community, infrastructure, and environment. HWISE water security scores were tested against household income, and monthly water costs. Water security ratings were also compared to water quality responses, to see if there was a correlation between higher water insecurity levels and more dissatisfaction with household water and community water sources beyond the household. Age and gender-based statistical analyses were run on water security, access, and quality questions to identify any significant differences in responses between age groups or gender groups. As the data were non-normally distributed, non-parametric Kruskal Wallis tests were performed for age categories of survey respondents (broken into five categories that represented the age ranges of participants: 20-29, 30-39, 40-49, 50-59, and 60 or above). If there were significant differences across age groups, a post hoc pairwise test was performed to determine the ranked age groups most affected by variables. Due to the important role of gender in Six Nations relationships to water, Mann-Whitney tests were run to compare any differences in

perceptions of water quality or water security by gender. Statistical significance was set at the p<0.05 level for all statistical analyses.

These tests were chosen because the data were non-normally distributed, and the sample size was small. Kruskal Wallis and Mann Whitney were used to identify significant differences amongst the means in two or more groups, which for this study meant between age groups and gender groups. These analyses were important due to previous research on water perceptions indicating that there were significant differences in drinking water satisfaction between genders for Six Nations, and differences in water access by age (Dupont et al., 2014; Plummer et al., 2013).

# Computer-Assisted Qualitative Data Analysis (QDA)

All interviews were manually transcribed by me. Upon completion of the transcription of each interview, hard copies of the interviews were printed out, and read in tandem with the audio recording to ensure that the transcript was accurately depicted. An element of the transcription process that was important was to ensure that the tone and language of each interview participant was honoured through the transcription. To analyze the interview transcripts, flexible coding methodologies were used, as explained in Chapter 5.

Flexible coding is a more recent method that is aligned with the use of modern QDA software to relate qualitative data variables from semi-structured interview protocols, combining deduction and literature-based coding (Deterding & Waters, 2018). This method takes more advantage of QDA software and situates empirical, qualitative research as being "in dialogue with existing theory and findings from previous studies, including quantitative research" (Deterding & Waters, 2018, p. 720). As these interview questions were co-developed with community collaborators who had both personal experiential knowledge and informed by previous quantitative research, the analysis for these semi-structured interviews is a good fit for flexible coding strategies. These methods involve beginning with the indexing of transcripts for the salient big pictures of water security and quality concerns within the data. This helps to anchor the transcript content to the interview protocols (or guides) and helps hypothesize relationships that were developed between the concepts emerging from these big picture codes. After indexing, the first author developed analytic codes that were more focused on sections of the interview transcripts, representing specific water security concepts that were sought for this article on the perceptions of water quality and relationships with water in the community, and their impact on wellness. The final stage used NVivo software to validate the concepts, build models, and test the data-driven coding.

As stated earlier, I believe the use of flexible coding methodologies such as the Deterding and Waters method are of utmost importance when co-creating knowledge with Indigenous communities. From my own perspective as a researcher, the assumption of inductive methodology aligns too much with the settler assumptions of *terra nullius*, or the Doctrine of Discovery discourse we see informing western law and governance structures as well. It dismisses the very real, local IK that has been informing Indigenous Peoples since time immemorial, and dismisses that Indigenous Knowledge is science, and there can be multiple types of scientific knowledge held at once in order to co-create research.

# Using Mixed Methods: The Many Hats of Co-Created Research

Mixed methods approaches are inclusive of both qualitative and quantitative data sets used in combination to create a singular dataset. In this project, mixed methods were used as an integrated approach, with interviews and surveys being co-created in tandem to better understand the prevalence of water-related health conditions and water insecurity by household, and then to contextualize how perceptions, experiences, and IK about water informed daily and broader relationships with water and health.

Despite mixed-methods approaches being used quite widely in anthropological research, particularly in medical and biocultural research projects, there is debate about their ability to truly integrate the data sets in meaningful ways (Almalki, 2016; Fetters et al., 2013). These are often due to researchers' insistence that data be generalizable and able to be reproduced in different settings, often linked to epistemological differences in STEM sciences versus social sciences (Nelson et al., 2021). The reproducibility "crisis," as Nelson and colleagues (2021) describe it, has created a division within health research particularly, given that qualitative and quantitative methodologies have divergent roots in constructivism and logical empiricism, often presented within a binary or as opposing paradigms (Creswell and Plano Clark, 2007; Pluye et al., 2009). These are important tensions to explore using mixed methodologies, as this allows space to acknowledge multiple knowledge and frameworks that exist in structured landscapes, and that the health of a community will be variable based on local knowledges. Some of the most important anthropological research on health care has been able to address the ways that local knowledge and contexts shape the beliefs, both clinical and popular, around health and disease experiences (Davison et al., 1992; Kaufert et al., 1993).

#### Validity and reliability of mixed methods

A mixed methods approach to the study of water security and health relationships allows for the combination of traditionally biomedical health data, tap water contamination data, and water use and access reports with IK and the social, spiritual, and cultural contexts that inform Haudenosaunee experiences. Co-creating these methodologies similarly allows for these mixed methods to be more integrated from the beginning: from early on research design and scope was formulated based on concerns and research priorities of community leaders and Elders, who quickly pointed to their concerns about youth and young families' mental health related to the degradation of the Grand River and the day-to-day water use challenges in the home.

However, the differences in the underlying goals of quantitative and qualitative research have made the evaluation and integration of data sets more difficult. Fundamentally, the reliance on making data valid, reliable, or reproducible has made for the acceptance of qualitative data more difficult in research spaces that are traditionally quite quantitative (Golafshani, 2003; Pluye et al., 2009). Within this data set, much of the quantitative data is receptive to tests of internal consistencies, and the use of validated scales allows for some data to be more generalized. However, these same approaches are more difficult to achieve with qualitative data because the very nature of interview analysis does not assume objective truths, particularly when using semistructured interviewing.

I argue throughout Chapter 5 in discussion of my methodological choices for interview data analysis that some of these discrepancies are due to outdated interview coding strategies. Often, researchers come with limited qualitative research knowledge or training prior to data collection or analysis (Deterding & Waters, 2019). Most interview coding methods are described as being based in grounded theory, which for much contemporary research is largely an impossible methodology to use. Grounded theory for coding argues that the researcher has almost no *a priori* knowledge of a particular topic for which they will be conducting an interview on (Weiss, 1994). Some researchers have very colorfully described grounded theory approaches as "epistemological fairy tales", noting that this more pathological advocating for inductive research ignores how researchers actually work (Wacquant, 2002, p. 1481).

Grounded theory approaches assume that the researcher has had no previous knowledge or engagement with the research community or the research questions they are looking at. Given the advances of technology, the fast spread of global news, and the expectation that most academic researchers have to pull together funding applications and proposals prior to beginning research with a community, it seems unlikely that many researchers would come in without a sense of the particular problems or concerns a community is facing (Deterding & Waters, 2018). In this instance with Six Nations, the Indigenous water crisis is not novel, it has been going on for decades (if not arguably centuries), and Six Nations community activists and leaders have been advocating and researching their water quality and health concerns long before this grant was funded. Additionally, for any work that involves truly co-creating with an Indigenous community, the researcher comes in with the knowledge and concerns of the collaborators, which inform how they design their research goals and objectives.

Beyond research design itself, analysis of qualitative data often fails to acknowledge its antiquated processes. Much qualitative interview coding doesn't take advantage of how to use qualitative data analysis (QDA) software, such as NVIVO. When QDA software was first developed in the 1980s, it was structured to replicate the contemporary guidelines for qualitative analysis based in grounded theory. This meant that most of the researchers were coding (and still code) line for line, writing memos into the coding, and combining codes into broad, abstract codes. In a study of how sociologists used QDA software, White and colleagues (2012) reported that most were merely using the software as virtual sticky notes and sorted piles of electronic note cards rather than develop more novel approaches to analysis. In a quick scan of YouTube and website tutorials for even the most up to date NVivo software uses, how-to's are still based in the very foundational grounded theory approaches, rather than exploring alternative uses. Deterding and Waters (2018) argue that using QDA software in the exact opposite way that grounded theorists approach the software will help to create more reliable and powerful data sets:

Researchers should get to know their data by indexing transcripts with broad codes that reflect the questions they asked in their interviews and the concepts they sought to examine as they went into the field. By writing analytic memos during this process, they can generate conceptual themes that appear across cases. Then, capitalizing on the existing index for data reduction, they can apply more fine-grained codes to subsections of the interviews. Finally, analytic coding can be examined across respondent attributes to document the depth of textual evidence for the claims about key relationships the analyst makes. (Deterding & Waters, 2018, p. 715).

By using software this way, it allows researchers to use the programs in ways that extend beyond a digital replication of the low-tech sticky notes and extends beyond easy quote retrieval as well.

Finally, and most importantly, there are particular tensions worth exploring in terms of who really benefits from validated and reliable data sets. Validated scales, such as the food insecurity scoring system, or the Household Water Insecurity Experience Scale used within this study, are scores that have been validated by Western researchers for use by other Western researchers. Standardized testing, such as IQ testing, has been demonstrated to serve specific racial, economic, and individual moralities. They operate with a presumptive logic that whiteness and homogenization are the standard to which diverse and multicultural peoples are expected to maintain (Au, 2019). Through these expectations, standard testing reproduces social hierarchies and racial inequalities (Bowles & Gintis, 2011). Like standardized testing, standardized measurements or validated scales originate, develop, and are contaminated within these matrices of whiteness, colonialism, and white supremacy or domination (Collins, 2009). While the water security scales used within this dissertation certainly provide meaningful data on the prevalence of water insecurity at the household level, it is important to also acknowledge the limitations of these validated scales, particularly as they are focused on measuring bounded experiences around a topic, without acknowledging or capturing the frameworks and experiences of other communities, cultures, or Nations.

# **Summary: Co-Created Methodologies**

This chapter outlines the data collection methods that were used to investigate the relationship between water security and health, as co-created with Six Nations collaborators. A mixed methods approach was used to combine quantitative co-created water use and health surveys with E. coli and heavy metal testing to assess contaminant exposure risks on human health, and mixed methods were also used by integrating water security measurements from the survey with interviews and focus groups. These specific combinations of methods were designed to produce a co-created, interdisciplinary, and integrated view of how water quality and access for Six Nations community members are challenged by environmental contaminants and are influenced by gender and age regarding water access, health risks, and drinking water satisfaction. The sampling strategies chosen reflected the goals and needs of Six Nations collaborators, given the past issues with government-led surveys insisting on random sampling strategies that ran counter to community preferences<sup>4</sup>. While all methods have limitations, this dissertation aimed to mediate problems in ways that best suited the community needs and research goals, and the integration of multiple forms of data evidence provided a more thorough examination of water quality and access from interdisciplinary and co-created angles. The following chapter 3 (Study 1) examines the nature of co-created research more thoroughly using boundary objects while building relationships in boundary work.

<sup>&</sup>lt;sup>4</sup> FNIGC is a survey generated by Indigenous researchers, not by federal or provincial governments. However, the FNIGC survey only allows for aggregated data to be shared with local health care providers, and so the Six Nations collaborators had more issue around data ownership, thus choosing to frame in ways that can be similarly assessed for comparative purposes, but maintaining data sovereignty of community health data.

# CHAPTER 3: USING BOUNDARY OBJECTS TO CO-CREATE COMMUNITY HEALTH AND WATER KNOWLEDGE WITH COMMUNITY-BASED MEDICAL ANTHROPOLOGY AND INDIGENOUS KNOWLEDGE

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Article published in the journal Engaged Scholars Journal on December 16, 2020.

#### **ABSTRACT:**

This article explores how Indigenous Knowledge and medical anthropology can coconstruct community health knowledge through boundary work and the use of boundary objects. It will highlight how community-based participatory research (CBPR) in medical anthropology can help co-develop methods and strategies with Indigenous research partners to assess the human health impact of the First Nations water crisis. We draw on a case study of our community-based approach to health research with Six Nations of the Grand River First Nation community stakeholders and McMaster University researchers. We highlight how framing a co-constructed health survey as a boundary object can create dialogical space for Indigenous and western academic pedagogies and priorities. We also explore how this CBPR anthropology approach, informed by Indigenous Knowledge, allows for deeper foundations of culturally centered health to guide our work in identifying current and future community health needs concerning these ongoing water contamination and access issues. Through three health survey versions, priorities and research questions shifted and expanded to suit growing community health priorities. This led to collaborative action to communicate specific messages around water contamination and access across governance, community, and institutional boundaries. We demonstrate how our coconstructed approach and boundary work allows for the respectful and reciprocal development of these long-term research partnerships and works in solidarity with the Two-Row Wampum (Kaswentha) treaty established by the Haudenosaunee Nation and European settler nations.

KEY WORDS: Indigenous knowledge; community-based methods; biocultural health; water governance and health; environmental determinants of health; co-creating knowledge

# **INTRODUCTION**

We have a great opportunity to learn from the past, reorient our relations, and build a relationship based on mutual respect and partnership in the sharing of responsibility in this land and natural world. To achieve this, we must transcend our individualistic motivations and move away from thinking in material terms.

# - the late Chief Harvey Longboat (as cited in Blaser et al., 2001)

Indigenous health research has a painful legacy as rooted in western academic science. With significant health disparities between Indigenous and non-Indigenous populations in Canada, there has been growing attention towards building culturally sensitive Indigenous health assessments. The reliance on umbrella approaches to Indigenous health at times offers superficial tools and methodologies that focus on tailoring health approaches to be culturally sensitive or culturally competent (Wallerstein et al., 2019). These approaches look at Indigenous health through surface cultural structures, such as using specific food examples in dietary recalls, or culturally relevant symbols and imagery in health spaces (Resnicow et al., 1999). Often programs explore individual participant health or apply evidence-based approaches without seeking direction and leadership from the community to address their matters (Tremblay et al., 2019). In doing so, this reduces or ignores deeper cultural structures, such as community values, language, Local Knowledge, or the specific sociocultural and environmental challenges that a cultural community face.

In Canada, Indigenous Peoples' water supplies are in crisis due to poor water quality and quantity, lack of access to technology (such as real-time data and transparent standards for drinking water treatment), and skilled management systems. The ongoing legacy of colonialism has created and enforced structural barriers, and socioeconomic burdens for Indigenous Peoples across Canada that directly affect their daily access and quality of water and life. Inadequate infrastructure increases the health burden of these communities in ways not seen in mainstream Canadian society. The water crisis of Indigenous Peoples in Canada profoundly connects to the ongoing struggle to have Indigenous voices heard in the governance and decision-making processes. Bunch and colleagues (2011) suggest, "actions that address both biophysical and social environments have the potential to create a 'double dividend' that improves human health, while also promoting sustainable development (p. 8)."

While there is research exploring the physical health impacts of the longstanding Indigenous water crisis in Canada, the extent to which the water crisis impacts Indigenous health (as defined and understood by Indigenous communities) is less understood. In 2015, there were 105 long-term drinking water advisories issued in over 90 Indigenous communities, affecting more than 50,000 people across Canada (Indigenous Services Canada, 2019). Health inequities for Indigenous populations in Canada persist, and in many instances appear to be increasing with climate change, environmental contamination, and political tensions. The need to move beyond generic approaches to Indigenous health is critical for creating more effective and sustainable solutions to these human and environmental health issues. Indigenous wellness must center on land, language, community, cultural identity, and empowerment (Martin-Hill, 2009).

A growing body of work represents this shift away from former health intervention approaches towards co-creation of research that respectfully addresses and centers communities' specific concerns and needs around health and wellness. Community-based participatory research (CBPR) approaches have been particularly useful ways to work with Indigenous communities in health research (Hoover, 2017; Trembley et al., 2019; Tobias et al., 2014; Wallerstein et al., 2019; Zurba et al., 2019). CBPR approaches involve "collective, reflective, and systematic inquiry in which researchers and community stakeholders engage as equal partners in all steps of the research process, with the goals of educating, improving practice, or bringing about social change" (Trembley et al., 2018, p. 2). This work is best understood as a philosophical approach and not just a methodology (Coombes et al., 2012).

#### Community-based Participatory Research with Six Nations of the Grand River First Nation

This paper explores the ways that Indigenous Knowledge (IK) and medical anthropology can coconstruct community health knowledge that is culturally centered using boundary objects within CBPR approaches. We draw on a case study of our community-based health research with Six Nations of the Grand River First Nation community stakeholders and McMaster University researchers. Our trans-disciplinary research project works with Six Nations of the Grand River Peoples in the lands known as Ontario to investigate a range of water challenges by co-creating knowledge and tools. Six Nations has endured generations of limited access to clean water and socioeconomic and human health hardships. The project is community-led, facilitating the sharing and integration of contemporary western science and Indigenous/ Local Knowledge in response to water quality threats.

To build respectful relationships within our research community of practice (RCoP) of Six Nations community stakeholders and university researchers, we use the emerging concept of boundary work to frame our co-construction of culturally centered health knowledge. Boundary work, and the use of boundary objects, are emerging concepts from health geography and other allied fields within design research and natural resource management (Zurba et al., 2019). Boundary work is "those acts and structures that create, maintain, and break down boundaries" (MacMynowski, 2007, p. 3). Boundary work involves and promotes collaborative action towards a particular issue and promotes mental flexibility about the roles or ways of engaging in the work (Wenger, 2000). Boundary objects are often integral to boundary work. Cash and Moser (2000) described boundary objects as "items that are valued on both sides of the boundary, and provide a site for cooperation, debate, evaluation, review, and [institutional] accountability" (p. 115). These objects are more tangible than boundary work itself.

As part of this boundary work, we co-created a community health survey and, in this paper, we discuss how the three versions of this health survey operate as boundary objects between sub-groups within our RCoP as our relationships and research priorities grew over 1.5 years. As the community health survey shifted through three distinct versions (or phases), community health priorities and the discussions around the survey led to collaborative action and communication about water contamination and access across community and institutional boundaries.

Through this boundary work, we also explore how CBPR approaches in medical anthropology informed by Indigenous Knowledge allow more culturally centered health practices to guide research by identifying current and future community health needs in relation to ongoing water contamination and access issues. We demonstrate how our co-constructed approach and boundary work allow for the respectful and reciprocal development of this long-term research partnership and work to be in solidarity with the Two-Row Wampum (*Kaswentha*) treaty established by the Haudenosaunee Nation and European settler nations.

We also outline important considerations and challenges experienced by Indigenous and western researchers during the first year of the project. We specifically look at the capacity that western researchers and anthropologists have to be reflexive of our positionality and biases, and how these approaches can help to decolonize the spaces and research collaborations we have with Indigenous Peoples in ways that are respectful of community knowledge and socioeconomic capacity.

# **CO-CREATION OF INDIGENOUS WATER QUALITY TOOLS PROJECT**

Co-Creation of Indigenous Water Quality Tools (CCIWQT) is our trans-disciplinary, community-led project, which works with Six Nations of the Grand River First Nation in southern Ontario, and with Lubicon Lake First Nation in northern Alberta. The project is funded through Global Water Futures (GWF), a seven-year research initiative aiming to find solutions that protect water quality and quantity across Canada and the cold regions of the world (GWF, 2020). GWF research projects provide governments, businesses, and communities with the risk management tools they need to tackle threats for Canada's water supply and quality, particularly in the face of dramatically increasing climate change risks (GWF, 2020).

The principal investigator for CCIWQT (DMH) is an associate professor in the Indigenous studies program and the anthropology department at McMaster University and is a member and resident of Six Nations. The large multi-disciplinary team of university researchers includes engineers and biologists, mental health professionals, obstetrician-gynecologist (OB- GYNs), anthropologists, lawyers, philosophers, and Indigenous scholars, and Indigenous health care professionals from Six Nations Health Services and the Birthing Centre. Together, teams work in four separate but related teams: (1) community health; (2) ecosystem health; (3) water governance and Indigenous Knowledge; (4) and water quality monitoring. The research team also includes community navigators, research assistants, and project managers who are members and residents of Six Nations.

This article focuses on the collaborative health assessment work between CCIWQT's health research team and Six Nations stakeholders through three phases of developing a health survey. The community health team members were engaged with Six Nations community stakeholders and research partners to co-develop the community health assessments. The ecosystem health team members engaged in household water testing for organic and inorganic contaminants, briefly reported here as it relates to human health concerns and water use.

#### Water Contamination Concerns at Six Nations of the Grand River

Six Nations of the Grand River First Nation reserve is Canada's most populated First Nation community and geographically situated in the densely developed Greater Horseshoe region of Ontario (Baird et al., 2013). It is a large urban reserve occupying around 19 hectares of land. Despite having a water treatment plant within the community, drinking water quality remains a problem. Community leaders and collaborators have identified primary concerns around water: the quality of drinking water, the ecological integrity of water sources in and around the Six Nations lands, and the governance of these waters.

Drinking water treated by the water treatment plant is primarily sourced from the Grand River. However, according to an investigative piece in *The Guardian* in 2018, 91% of homes are not connected to the community water treatment plant, and many do not have access to clean drinking water (Shimo, 2018). The direct impacts of water quality and access on community health are less documented for Six Nations but remain primary concerns for many in the community. The majority of residents at Six Nations rely on wells or cisterns (a large water tank or underground water reservoir). While this is a traditional form of water access, many of the wells were not properly built and have not been maintained. Due to pervasive concerns about water contamination, many households at Six Nations rely on purchasing bulk bottled water from the Six Nations water treatment plant or third-party water services and often transport this water to their homes themselves.

In 2003, a water quality survey of domestic wells in Six Nations found a widespread problem with *E. coli* contamination and total coliforms in groundwater (Baird et al., 2013). Concerns emerged about the treatment and distribution of drinking water, along with agricultural runoff, landfill contamination, and poor quality of well water (Baird et al., 2013). Six Nations has experienced enteric infections, and it is suspected many undocumented health problems are caused by contaminated drinking water sources (Baird et al., 2013). Despite the community initiating source water planning processes, the concerns over water quality, treatment, and autonomy are still significant for many community members. A 2010 survey conducted by Six Nations Elected Council (SNEC) found that 76% of residents used bottled water, rather than well or cistern water, as their primary drinking source (Baird et al., 2013). This was mostly due to their knowledge of how contaminated well water had been, and from previous reserve boil-water advisories.

In 2018, our project tested tap water samples from 75 households for pathogenic bacteria, metals, minerals, and organics. The tests revealed 22 of the household samples (29%) were contaminated with E. coli, compared to 19% and 27% in similar studies carried out in 2003 and 2004, respectively (CCIWQT Report 2019; Neegan Burnside 2005). The water samples from the wells, cisterns, and taps of 78 households were also tested for 26 metals, minerals, and organics. Of this sample, 32 of the households (41%) found to have elevated levels of at least one contaminant: chromium in one household (1.5%), aluminum in 14 households (21.5%),

manganese in three households (4.6%), arsenic in one household (1.5%), mercury in 18 households (27.7%), and uranium in one household (1.5%) (CCIWQT Report, 2019).

#### Community Health Assessment Survey

Despite increasing concerns over water contamination from Six Nations community leaders and members, there remained uncertainty about water use at the household level, and connections between water use, contamination, and human health risks were unclear. As part of this broader project on water quality tools, the McMaster health research team (Tina Moffat, Sarah Duignan, Dawn Martin-Hill) and a community member and McMaster student assistant were requested by the Six Nations Health Services to assist in co-developing a community health assessment with Six Nations Health Services team.

This assessment included co-creating a health survey tool with Six Nations Health Services that accurately reflects Haudenosaunee values and wellness models that would provide an understanding of water use and security issues for households and the community a snapshot of holistic health. The health research team thought they could connect this survey assessment to the water contamination tests and analyze the relationship between water use and human health for residents now and for future generations.

Past community health assessments at Six Nations were carried out by external parties (often federally funded) and structured in ways that did not encompass Haudenosaunee health models. This resulted in decreased engagement rates and a decision to not participate in the First Nations Regional Health Survey (FNRHS) in 2017. While the use of IK is critical during every phase of the Co-Creation of Indigenous Water Quality Tools project, having IK guide the co-construction of health assessments, and framing them within CBPR philosophies allowed for the development of a health survey through three distinct phases: (1) A general and expansive community health survey based on previous federal Indigenous health surveys; (2) a short pilot water use and health survey that tackled the water-specific concerns emerging from the community and was integrated the ecosystem health team's water testing results; and finally (3) a holistic health and water survey centered in Haudenosaunee understandings of holistic health and more recent concerns about COVID-19.

In this study, we use three phases of health survey co-creation to discuss the collaborative relationships built between Six Nations and McMaster team members between January 2019 and August 2019. We explore how the survey helped to center Haudenosaunee-specific health models reflecting the interests, concerns, and assessment structures meaningful for Six Nations peoples,

framing the survey as a boundary object co-constructing knowledge and helping navigate relationships between different stakeholders. Ultimately, having a boundary object created a space for fruitful dialogical discussions between local Haudenosaunee and western anthropological pedagogies. Figure 3.1 provides an outline of the main stakeholders working together through the health survey assessment.



Figure 3.1. Key groups working in their rows to honour the Kaswentha, while meeting and building relationships at the boundaries through the health survey

# UNDERSTANDING AND DEFINING COMMUNITY WITH SIX NATIONS OF THE GRAND RIVER

Understanding who constitutes a community for Six Nations is best explored through the historical and current governance of the reserve. The Haudenosaunee Nations (People of the Longhouse) are sometimes referred to as the Iroquois or Six Nations and are one of the oldest Indigenous groups in North America. The Six Nations Confederacy was created hundreds of years ago by five linguistically related nations in the eastern Great Lakes region: the Mohawk, Oneida, Cayuga, Seneca, and Onondaga Nations. In the early 17th century, the Tuscarora Nation joined as the sixth Nation in the Confederacy. Often within Indigenous health research, the collaborating community stakeholders are solely at the level of First Nation Bands. In Canadian contexts, a First Nation band refers to "the collective of recognized members of a First Nation who have had lands set apart for their use by the Crown or are declared to be a band within the Indian Act" (Tobias et al., 2013, p. 132). The Indian Act of 1876 formalized restrictions for Indigenous Peoples within Canada, "including the dissolution of all existing traditional councils and the establishment of a federally approved elected-council system, as a means of controlling activity on reserves" (Monture, 2014, p. 69). As is the case with many First Nations communities, there are multiple forms of governance operating within Six Nations, which shapes not only community but land and water governance as well.

The Haudenosaunee Confederacy has been in place since time immemorial. Also known as the League of Nations, the five separate Nations agreed to live under the Great Law of Peace (or *Kaianerekowa*) provided by the Peacemaker (Monture, 2014). The symbol of the Confederacy is the longhouse, which was provided by the Peacemaker; it initially signified living together as families of the same house, but today is understood as a symbol that supports the traditional ways and values of the Haudenosaunee (Haudenosaunee Confederacy, 2020).

After the American Revolution, many of the Six Nations Peoples were displaced from traditional lands and moved to Upper Canada, where they were provided with the Haldimand Tract of land by the British Crown in and around the Grand River tract (Hill, 2017). However, much of this land was lost over time due to land sales, leases, and squatters (Haudenosaunee Confederacy, 2020). What land remained became Six Nations Indian Reserve Number 40 in 1842. The Haudenosaunee Confederacy have long maintained their sovereign nationhood (Monture, 2014).

The federally recognized Band Council also exists and operates within the reserve. This band council, Six Nations Elected Council (or SNEC), was enacted by the Canadian federal government in 1924 (Hill, 2017). Six Nations Elected Council (SNEC) represents the Band Council as defined by the Indian Act (Indian and Northern Affairs Canada, 2002). The community's water treatment plant operates under Public Works, which is within the jurisdiction of SNEC, as is Six Nations Health Services.

While these two governing bodies represent different community identities and relationships, it remains of great importance to develop reciprocal relationships with each governing body for this work. Conceptualizing community in referral only to SNEC or only to the Confederacy would be limiting, as the community is not homogenous, and Six Nations community members hold diverse spiritual, social, and political perspectives that impact their concerns and priorities.

#### HAUDENOSAUNEE ENVIRONMENTAL AND POLITICAL PHILOSOPHIES

As a project led by Six Nations of the Grand River peoples, we frame our work within several Haudenosaunee guiding principles, which will be briefly outlined here. Haudenosaunee environmental philosophies are contained with the *Ohen:ton Karihwatehkwen*, or Thanksgiving Address, the words they say before all else. This address acknowledges all parts of Creation and offers respect and gratitude to them for upholding their responsibilities (King, 2007). An important message for our work from the *Ohen:ton Karihwatehkwen* is that when the land is sick, the people become sick too (Haudenosaunee Environmental Task Force, 1992). For sickness in the community to be healed, sickness in the environment must first be addressed.

This teaching is a keystone to understanding how to center health assessments in Haudenosaunee culture. With federal health assessments that look at individual physical and mental health, such as the First Nations Regional Health Survey (FNRHS), these important connections between health and the environment are not addressed in relation to physical, social, and spiritual health issues. For Six Nations as a community, this means that past health assessments have not been anchored in how they understand health, and so important conditions and concerns around health may likely have been missed, misinterpreted, or under- explored.

The Kaswentha, or Two-Row Wampum was the first treaty between Europeans and Indigenous Nations on Anowarakowa Kawennote (Great Turtle Island, or North America), established between the Haudenosaunee and the Dutch settlers of eastern New York. It became the foundation of later treaties with France, Britain, and the United States and represents selfdetermination and a friendship treaty between these two nations. The Two Row Wampum belt is woven with white and purple beads or shells, depicting two boats on a river, with the purple rows representing the paths each boat makes as they travel down the river, one for the European ship, and the other for the Haudenosaunee canoe. While the boats travel alongside one another, their paths do not cross. Inside each boat is what defines it as a society: customs, laws, and ways of life. This symbolizes respect for autonomy for their own way of life and governance. The three white rows represent the river of life, and relationships based on *skennen* (peace), *kariwiio* (good mind), and *kasastensera* (strength) (Haudenosaunee Confederacy, 2020). The fringe on the belt indicates that the relationship is unending (Hill, 2017). Water represents both the river of life, but also the foundation on which the *Kaswentha* agreement is based. Recognizing the role of water in the *Kaswentha* is important in understanding how settler colonialism has transformed the land and waterways. Through spatial reconfiguring, settlers transformed and re-territorialized waters, bodies, and beings (Schneider, 2013). In doing so, they have broken and tarnished the *Kaswentha* treaty: there have been over 400 years of dehumanizing assimilation, ongoing colonization, and violence on the part of white-settler society. Environmental destruction of the lands in and around Haudenosaunee territory is a form of this continued settler-colonial violence. Hallenbeck (2015) argues that centering research discussions around water "opens up a space for political and relational attention towards the bodies, being, stories, and histories that run through it" (p. 353). The contamination of the Grand River and surrounding waterways must be understood as directly connected to the dispossession of Haudenosaunee territory and subsequent health concerns.

To be in solidarity with the *Kaswentha* is to practice non-interference as a western researcher, to work in ways that are not exploitative. To decentre settler-colonial states, we need to work not only against power and control, but in ways that reimagine alternative institutions and relationships. Working with boundary objects helps to create spaces in which these difficult conversations may arise. Using a health and water use survey as a boundary object, discussions can emerge around the dispossession of Haudenosaunee territory, while decolonizing bodies of water like the Grand River in the process.

# **DECOLONIZING INDIGENOUS RESEARCH**

Decolonizing research has been a priority for Indigenous researchers, community members, and advocates for decades. Māori scholar Linda Tuhiwai Smith (2008) defines decolonization as "a process to undo harmful effects of colonization, including land theft, genocide, and assimilation" (p. 3). Decolonization is more of a praxis that matches theory with practice at every phase of research. Increasingly, we are seeing scholars implementing these approaches into their research, combatting western structures of power and knowledge. To do this, decolonization efforts might include involving elders, community members, and youth at all phases of research.

Language is a powerful tool in decolonization, so understanding key terminology and how it may be used (and how these uses may differ from project to project) is critical to building a foundation of respectful and appropriate work. There can be some confusion between indigenization and decolonization as terms. Indigenization often involves making a space "Indigenous" by including Indigenous peoples, as their presence brings a different perspective. This does not mean that these spaces are challenging white-settler frameworks. Decolonization attempts to challenge these systems of academic and western knowledge. Frequently, there are components of direct action taken to challenge injustices or systems that perpetuate the exclusion and/or assimilation of Indigenous peoples and their knowledges (Drawson, Toombs, & Mushquash, 2017). Decolonization will look different from place to place and project to project.

Decolonization of research includes using IK as the framework and foundation for much research. IK and traditional medicine have been hard to define, as many understandings and descriptions from Indigenous peoples are rooted in deeply localized contexts (Martin-Hill, 2009). While definitions vary, one of the most used definitions of IK frames it as the "complete knowledge system with its own concepts of epistemology, philosophy, and scientific and logical validity... which can only be understood by means of pedagogy traditionally employed by these people themselves" (Daes, 1994, p. 3).

IK approaches to health will vary based on the culture, language, and place of the communities collaborating on research. Donatuto and colleagues (2014) note, however, that IK concepts around wellbeing are "structured in content and internal logic and comprise practices and knowledge about connections between human beings, nature, and spiritual beings " (p.356). While the particular relationships between humans, nature, and spirit are understood and acted on differently across Indigenous cultures, these more profound responsibilities work within a network of sacred relationships that distinguishes IK from western perspectives on health and sustainable practices (Kealiikanakaoleohaililani & Giardina, 2016). It is a participatory process and an experiential one – it is "not just about understanding relationships, it *is* the relationship with Creation" (McGregor, 2008, pp. 145-146).

While it is problematic to homogenize the cultures and belief systems of First Nations, water is one area where communities widely share similar attitudes and beliefs: water is life (Swain et al., 2006). For Six Nations Peoples, their teachings share that water is the first environment in our lives (in our mother's wombs). In IK, water degradation "directly impacts the people, permeating every aspect of their lives. It threatens their very survival" (McGregor, 2012, p. 10). Local relationships with water and their impact on community health are significant considerations that often get left out of First Nations health assessments. Understanding the histories and politics of water governance specific to each community is helpful in moving towards a more culturally centered assessment of community health.

# Decolonizing community-based participatory research work within medical anthropology

CBPR is seen by many Indigenous communities as a necessary standard if research is to continue with academic institutions, given the research abuses by academics in the past (Hoover, 2017). CBPR has been used across many research projects as a way of reducing health disparities for marginalized communities and ensuring health care programming that is culturally appropriate for Indigenous communities across a spectrum of health issues (Garwick & Auger, 2003; Chrisman et al., 1999; Dignan et al., 2005; Strickland, 2006; Trembley et al., 2016; Zurba et al., 2019). Most importantly, CBPR builds a research foundation of a community's right to participate *and* a community's ability to refuse participation as central to ethical research with Indigenous communities in Canada and Indigenous communities in Australia due to its ability to enhance equity and relationships within these research partnerships (Robinson & Wallington, 2012; Zurba & Berkes, 2013; Porter & Barry, 2014; Maclean & The Bana Yarralji Bubu Inc., 2015).

The traditional and cultural values of Six Nations Peoples are well aligned to work on codeveloping a CBPR project and have used this approach with success in the past (Gordon et al., 2018). Their collective thinking, concern about how current decisions will impact future generations, and ability to approach gatherings and situations with *kariwiio* (a good mind) showcase their longstanding strength and autonomy as a Nation. The community has multiple decentralized community services, programs, and research projects, including their own research ethics board in relationship with SNEC, and other autonomous and consistent protocols through Confederacy to help create safer and more reciprocal research partnerships with academic institutions. For this phase of the research and beyond, we look to the *Kaswentha* as a reminder of how we can work together in our own rows to develop tools and programs.

#### **COMMUNITY HEALTH PROJECT FORMATION**

The health dimension of the Co-Creation team began discussions of community needs and concerns in January 2018 with Six Nations Health Services (Director Lori Davis Hill and portfolio team members). Ph.D. candidate Sarah Duignan began to work with Six Nations Health Services as a research assistant over a six-month period, compiling data from over twenty years of health assessments conducted with or by Six Nations Health Services to identify areas of health assessments that were consistently prioritized (or lacking) across multiple and varied household

surveys and questionnaires. This allowed us to establish a baseline of what information was known about community health, and what (and who) was missing from the profile.

After realizing how much community health was inconsistently assessed or not understood, Six Nations Health Services voiced interest in the development of a community health assessment survey that would eventually become an autonomous tool, to use now and for future community health assessments, independent of academics or other institutions such as the federal government. Connected to this was an existing gap in knowledge around how water contamination and water insecurity directly affects human health for Six Nations community members, and whether or not there were correlations between household water sample tests and health experiences. There had been previous work beginning to explore this through the 2010 Source Water Protection Survey through the Haudenosaunee Environmental Task Force, and these community stakeholders wanted to continue this exploration.

In co-constructing and using a survey, the degree of research fatigue experienced by community members must be considered. Six Nations Peoples are surrounded by four major universities, and their proximity to urban locations means they have an abundance of researchers interested in working with them. It is common to hear "We have been researched to death," which can feel like an understatement given Six Nations' size and geographical proximity to major research institutions in southern Ontario. This sentiment runs deeply across many First Nations communities, and feelings and experiences of research fatigue have been factored into ownership, control, access, and possession (OCAP) principles (First Nations Information Governance Centre, 2014).

Having an Indigenous scholar as principal investigator and a research team with diverse gendered and racialized identities certainly does matter and helps to make Indigenous researchers central in Indigenous research. For those of us on the project who are non-Indigenous, and speaking particularly to our anthropology backgrounds, it is important to be aware of the ugly history of anthropology rooted in racist science, and how we can actively work to unlearn biases through this collaborative work and in adherence to OCAP principles and local protocols and ethics (Marks, 2012; Smedley & Smedley, 2005).

#### Ethics Approval from Six Nations Research Ethics Board

Ethics approval for the project-at-large was obtained in January 2018 from Six Nations Research Ethics Board, which represented the approval of Six Nations Elected Council. Verbal agreements and approval were expressed from the Haudenosaunee Confederacy in January of 2018 as well. The umbrella approvals from SNEC and the Haudenosaunee Confederacy were necessary for the application for ethics from the McMaster REB. As this approval was granted for the large, interdisciplinary project, and did not provide the details of each phase and step of the project, institutional ethics boards found this more difficult to comprehend.

We expressed to the institutional REB that these approvals from the two governing bodies of Six Nations were granted as umbrella approvals only, due to the volunteer nature of the community REB and that many of those who worked on the REB were over-worked in multiple spaces. Coming to SNEC and the Confederacy with new formal addenda for each small part of the research project would be more work for them that would take them away from other important community work.

To work around these issues of capacity, the PI (DMH) and co-investigators have engaged in ongoing communication with both governing bodies of Six Nations. They share progress updates and ask for assistance and insight on critical issues and concerns they may have around water and environmental health as they arise.

As the work continued to unfold, we worked out a memorandum of understanding with Six Nations Health Services, formally written and co-signed between our principal investigator and the director of health services. This established understandings and outlined key principles for the conduct of the research partnership involving community members and leaders. These were written and co-signed in September of 2018. Establishing these clear expectations and outcomes for both sides allowed for the development of ongoing open communication about each side's needs, wants, and abilities that they can bring to this work.

# **COMMUNITY HEALTH SURVEYS AS BOUNDARY OBJECTS**

The co-construction over two years (2018-2019) of a community health assessment served as the boundary object, or document, from which we were able to bring together parties within our research community of practice for the collective process and construction of a tool that would serve both Six Nations and McMaster collaborators' aims and goals.

There have been three primary versions of the community health survey over the two years, each operating as a boundary object between community and academic collaborators, and in different and overlapping ways. Table 3.1 outlines which stakeholders were involved at each stage in this boundary work. *Figure 3.2* shows a timeline of the community health assessment survey development through the three versions.

Survey Version	Stakeholders Involved	Use of Survey
1: General Longform Health and Water Survey	<b>McMaster:</b> community health team, mental health team <b>Six Nations:</b> Six Nations Health Services stakeholders, SNEC, Confederacy	Broad: focused on similar assessments as FNRHS but to use autonomously and comparatively; physical, mental health focus
2: Water use and health pilot	<b>McMaster:</b> Community health team, ecosystem health team <b>Six Nations:</b> SNEC, Confederacy, community members	Specifically targeted to households whose water was tested for contaminants to assess water use, self-reported health, and better understand role of water in health concerns
3: Culturally centered health, wellbeing, and water survey	McMaster: community health team, mental health team, ecosystem health team, OB- GYNs Six Nations: SNEC, Six Nations Health Services, the Birthing Centre, dietician, Grandmother's Council, community fishers and hunters	Informed by pilot (SV2) and ongoing feedback, co-constructed health and water use survey grounded in Haudenosaunee values

Table 3.1. Overview of survey types and stakeholders involved in development



#### Figure 3.2. Timeline of community health survey development

### Survey Version 1: A General Longform Health Survey

The health survey version 1 (SV1) was developed over the summer of 2018 in collaboration with Six Nations Health Centre. SV1 was a lengthy 30-page survey that reflected Haudenosaunee wellness models while containing measurements of individual health that would be comparable with other First Nations Peoples' health outcomes, as requested by Health Services. It was also developed to be eventually used as an autonomous tool, separate from federal and provincial funding bodies, and had community appropriate snowballing sampling strategies.

Conversations arose during the co-construction of questions in meetings between Six Nations Health Services employees and McMaster researchers around the importance of understanding community traumas. Many Health Services employees wanted trauma-informed questions addressing personal and collective intergenerational and historical trauma. These were important to understand better physical and mental health trends (around chronic pain and mental illness in particular). These meetings became spaces where community members within the RCoP vocalized and engaged in difficult and often personal topics. Structuring the health survey to reflect these diverse forms of collective and individual trauma, which are often bypassed by white-settler approaches to health, helped to challenge traditional power structures and allowed for vulnerable exchanges between stakeholders. This became one of the first steps in the co-creation process, where power was redistributed in the development of a health survey. As surveys administered within Six Nations in the past often failed to consider and hold community values, re-centering this survey allowed for the knowledge, values, and belief systems held by community stakeholders to be prioritized. The survey as a boundary object helped navigate the boundaries of work between Six Nations Elected Council, Health Services, and McMaster researchers; at survey construction meetings withincommunity dialogues arose from crucial questions the health survey brought up.

Three main concerns arose: (1) prioritizing health beyond the physical, individual level; (2) engaging community sub-groups who were often left out; and (3) effective and accessible ways to conduct and launch the survey. These were often interrelated concerns, as the generic approach to federal surveys operated through random sampling of households. This meant that the survey would target the person in the home holding the most knowledge of the family (often a femaleidentifying person) but would only ask questions specific to their person. Additionally, these surveys were administered as pen-and-paper to be mailed back to the survey collectors, which is a tedious and inaccessible method for many, particularly younger generations. The result was consistently having men and youth under-represented in survey data, as well as biases in what health concerns were prioritized. Finally, by centering the survey in the Six Nations Health Services we were attempting to decolonize the research process by questioning who has the capacity to launch the survey, how the survey is conducted, and data storage. While these latter points are still being worked out with the upcoming survey version 3 (SV3), the primary goal of creating these surveys is to eventually have a consistent community health assessment for future use that can be stored in SNHS, and conducted with aid from community navigators, community research assistants (RAs), and McMaster researchers.

McMaster stakeholders also engaged in discussion between separate co-teams within the project. The mental and community health researchers were able to hold conversations around merging our health questions as per the recommendations of Health Services employee recommendations and experiences. Further, it helped non-Indigenous researchers more strongly understand the diversity of perspectives and priorities within different Six Nations Health Services operations and allowed us all better insight into just how big of an undertaking it would be to co-create a tool that was useful and appropriate for the community and useful for academic forms of research and publication. The long form survey was paused in December 2018, due to increasingly limited capacities of some relevant SNHS stakeholders. While the long form survey was paused, the Co-Creation of Indigenous Water Quality Tools project focused on how to address the specific results of the household water quality tests with other community stakeholders.

#### Survey Version 2: The Piloted Water Use and Health and Water Use Survey

With the realization that household water testing required a focused survey for the specific households engaged in water testing, survey version 2 (SV2) was shortened to 10 pages and more directly connected water quality, use, security, and perspectives on water governance with measured household-level health experiences. This was developed in January of 2019, with ethics approval obtained from McMaster Research Ethics Board in February 2019 and brought to Six Nations Band Council and Confederacy on two separate retreat days in March 2019 and met with approval. As explained above, the McMaster researchers in the ecosystem health assessment dimension of the CCIWQT project tested the tap, well, and cistern water of 75 households (selected through snowball sampling) for biological and heavy metal contamination. Those who participated in their water testing in the summer of 2018 were invited to complete the SV2 during a household visit.

These retreats and meetings further allowed for community partners to express their interest in helping support the dissemination of the health survey, as it relates to the water testing results that both SNEC and Haudenosaunee Confederacy were made aware of during these meetings. Going through the survey questions prompted discussions around specific water concerns for SNEC members, and with Confederacy it inspired discussions of teachings around water's role in the community.

SV2 was launched in April 2019, and then operated as a boundary object between the research team and community members as well. A team of research assistants (RAs) that were both Indigenous and non-Indigenous worked within the community making household visits for those who consented to participate in the survey. The survey acted as a jumping-off point for more discussion in many instances. Questions on the survey prompted discussion between community participants and RAs: personal and family health experiences were shared on both sides, perspectives around water's role in health and wellbeing arose, and many concerns around water contamination were prompted in working through the survey.

Many community members who participated in the survey expressed tremendous dissatisfaction with water services and governance in the community. Even those who were financially comfortable enough to purchase bottled drinking water believed that there was much work to be done on improving the health of the Grand River and its offshoots: if they could not use the water and lands around it the same way generations before could, could the community really be healthy? Indigenous RAs spoke on a more personal level with household and community members and were able to put a face to the research, which was important for building long standing relationships. Further, it gave space for all of us working at our boundaries to better understand each other: for the medical anthropologists, it was a time to listen actively and bring the participants' values and perspectives back to the table when we met with other McMaster researchers on the project and the community stakeholders at further meetings.

#### Survey Version 3: Culturally Centered Haudenosaunee Health and Wellbeing Survey

The third version of the survey (SV3) was adapted from SV1 and was co-constructed over the summer of 2019 during multiple face to face and digital roundtables with representatives from Six Nations Health Services, the Birthing Centre (*Tsi Non:we Ionnakeratstha/Ona:grahsta'*), a McMaster OB-GYN with longstanding research relationships with the Birthing Centre, the CWIQT mental health and wellness and community health teams, a registered dietitian, community fishers and hunters. Additionally, the survey was reviewed by a Grandmother's Council through meetings with the mental health team.

This process involved several meetings between interested stakeholders to go through an array of past health surveys (an ongoing Birthing Centre study, examples from the mental health team, and the pilot SV2) to work towards a co-constructed longform survey that represented Haudenosaunee health values. These meetings opened up room for much deeper discussions, as our relationships with each other had grown over the year and a half. Many of us were mothers, and informal discussions about our children then led to much more nuanced discussions of maternal-specific health risks related to water quality for Six Nations residents (e.g., contaminated water and sitz baths postpartum, or lack of access to clean water for traditional medicine making). These were questions none of us had previously considered assessing through research. However, the space provided through these survey- centric meetings allowed us all to draw more reliable culturally centered connections between water and health for the Six Nations community and to think about more representation from the more vulnerable community members.

Meetings with Faith Keepers and Clan Mothers of the Confederacy helped the survey take a more Haudenosaunee shape. Questions were framed in ways that were open enough for all Six Nations community members (regardless of spiritual or political views), but still reflected fundamental traditional teachings and IK. This was, at times, a more challenging element of coconstructing questions, given the particular skills and tools that academics were used to working with for studies not always being in line with the ways Six Nations collaborators wanted the questions constructed.

Working on questions around mental health at times proved challenging, as most mental health assessments are formatted within validated Likert scale formats (such as positive and negative affect scales, and resiliency scales) or with checklists (such as for post-traumatic stress disorder and trauma-related altered states of consciousness). While validation of scales is useful if the goal is to compare a research study's results to the results of other study populations, this is not a priority for the SNHS. Cross-comparisons are not useful in any immediate sense for the Six Nations community, especially given that the psychosocial burdens around mental health for Six Nations Peoples will be very different from other communities' given their unique relationships to water and land.

There have been numerous surveys exploring western-centric mental health assessments over the years at SNHS, so health care providers were more interested in prioritizing more predominant gaps in knowledge to help frame future programs and policies around mental health and environmental connections. Rather than use these generic validated scales, the group determined it would be best to explore the relationship between one's mental or social health and water quality by asking Likert scale questions such as "I seek out opportunities to spend time around natural sources of water" or "I feel better when I am around natural sources of water." These questions then lead to more specific questions around water-related health practices, such as picking traditional medicines or canoeing and kayaking on the Grand River. These questions were much more relatable for the community than generic mental health questions. They also create a space allowing for more open discussion afterwards about traditional medicine use and access with future participants, because traditional teachings are infused across the survey.

# **TOWARDS A CULTURALLY CENTERED HEALTH ASSESSMENT DOCUMENT**

By framing the health surveys as boundary objects that reflect the boundary work between Six Nations and McMaster team members, we were able to move towards a more culturally centered approach to health assessments that are reflective of CBPR principles. The ongoing development allowed for reflection on the relationships and research goals for all members of the RCoP. Each phase incorporated more communal learnings into the research partnership, and more space for Six Nations community members to participate in the research process.

For many marginalized populations, they have dynamic collective consciousnesses rooted in land and language but must respond to oppressive mainstream sociopolitical structures that
impact their health (Airhihenbuwa & Liburd, 2006). Rooting this health assessment in relationships to land, language, and community identities speaks to more dynamic and deeper understandings of health and the social, cultural, and political barriers that Six Nations Peoples face. A health assessment based on traditional teachings around water and land is also a step towards more empowerment and autonomy in their community health research.

As stated earlier, a foundational teaching within the *Ohen:ton Karihwatehkwen* is that when the land is sick, the people become sick, too. Rather than researching just how Six Nations Peoples are becoming sick and isolating these experiences from the contamination and degradation of their lands, we are working towards building tools that connect these elements more holistically. This creates tools that are more engaging and empowering, as community members see their values and experiences reflected in the structure of questions. In the case of the smaller community health and water use pilot survey, the survey became a springboard for conversations between participants and the community RAs. They could highlight their own experiences, share important lessons, and know that these conversations will be honoured in the ways the work is shared back with community stakeholders and at events in the future. For us, as medical anthropologists, it has been an ongoing reflection and assessment of power in health research. This means that we mobilize our power and skill sets as researchers to support broader partnerships within the community as research continues, and recognize the specific skills, interests, and concerns that all parties bring to the table. We are able to reflect upon these through how the survey versions adapted as we brought more parties into our research community of practice. Rather than build longer and longer surveys where community and research needs were roughly patched together without considering how to make them more cohesive, we were able to structurally change the documents so that the foundation was rooted in community IK. The lives and needs of Six Nations Peoples are the core that drives this research forwards, and these engage with non-Indigenous academic lives and approaches along the way.

#### Community-based Participatory Research as Philosophical Stance in Medical Anthropology

As medical anthropologists working within CBPR approaches, community partnerships are essential sites for co-constructed meaning-making. To honour local IK here means reflecting on our power and privileges as researchers. Tobias and colleagues (2013) argue that for social scientists working within CBPR initiatives with diverse Indigenous communities, this work "should ideally pursue a set of common objectives: to equalize power differences within the research process; to build trust between the researchers and community; and to foster a sense of ownership tied to generating momentum toward social change" (p. 132).

For a genuinely respectful co-creation partnership, it should also centre decolonizing methods. Dakota scholar Kim TallBear (2013) argues that "rather than integrating community priorities with academic priorities, changing and expanding both in the process, decolonizing methods begin and end with the standpoint of Indigenous lives, needs, and desires, engaging with academic lives, approaches, and priorities along the way" (p.20). For non-Indigenous researchers, this sets new expectations for how we approach our work: we are expected to seek and incorporate community suggestions and directions for research, while being open to learning and accommodating changes to research trajectories and timelines along the way (Hoover, 2017).

The literature on CBPR approaches within medical anthropology is scant, though there is some research on participatory action research (PAR) with similar lenses. The medical anthropology research that does explore CBPR usually discusses it relative to graduate studies, education, and training opportunities with marginalized communities, and not specifically with Indigenous Peoples (Jessee et al., 2015; Sheehan et al., 2014). There is work within archaeological research that utilizes CBPR, though CBPR is often used as a tool and not as a decolonizing philosophical approach (Atalay, 2007; Hollowell & Nicholas, 2009; Nelson, 2017; Gonzalez et al., 2018; Alvarez, Larrain & McCall, 2019). Atalay (2019) argues that while CBPR within archaeology is growing, the need for more decolonized models and collaborative, sustainable systems are needed for true systemic change within the discipline.

Watson (2019) argues that with the increased interest in PAR and the 'action turn' in anthropology, it is beneficial to repurpose the language of PAR to facilitate more nuanced discussions of what PAR (and CBPR) can be within anthropology. By using CBPR as an approach to research and relationship-building *with* community stakeholders, and not just as a tool for assessing health, medical anthropologists can engage in deeper understandings of these relationships between health, community, and land. Cochran et al. (2008) note that what may be most important in CBPR projects is *how* researchers acquire knowledge working with Indigenous communities, as these methods "may be as critical for eliminating health disparities as the actual knowledge that is gained about a particular health problem." (p.22). The process of respectful relationship building helps challenge power hierarchies shaped by past academic abuses and is integral to mending and co-creating health knowledge.

Medical anthropology has moved away from biomedical approaches of health towards a critical medical anthropology (CMA) over the years. Recent research is more reflexive of

biomedical practices, moving away from viewing biomedicine (and western health systems) as an "objective adjudicator of truth and fact that is somehow removed from cultural influences" (Newnham et al., 2016, p. 2). Work within CMA takes a political ecology of health lens, where economic, political, social influences that shape locally contextualized health and disease outcomes – and particularly dimensions that shape health inequalities (Jackson & Neely, 2015; King, 2010; Mayer, 1996; Richmond et al., 2005). Still, there remains space to improve medical anthropological approaches through decolonization and CBPR approaches.

A crucial difference between CBPR and CMA approaches is the shape that fieldwork takes. For traditional fieldwork within CMA, anthropologists spend time trying to participate and learn from the communities they work with, acting as learners and participators. Anthropologists working within CBPR approaches want community members to be collaborators, learning how to conduct investigative work and participating in research-as-culture (Cartwright & Schow, 2016). Given the differences in the roles of community members and researchers between traditional fieldwork and CBPR research, this results in fundamentally different research designs, analyses, and outcomes as well.

Thinking of CBPR approaches as being complementary to traditional anthropological methods does a tremendous disservice to the "transformative logic" of CBPR (Watson, 2019, p. 23). CBPR approaches to medical anthropology research mean that the very process of fieldwork itself is subverted. Through "pursuing research within the context of action," a research project's methodologies and fieldwork will change, "most often in non-linear and unexpected ways, as much as the situation at hand" (Watson, 2019, p. 24). To use CBPR within medical anthropology is to use it as a theoretical lens to approach health research *with* a community. Working with Indigenous communities, this means centering the health concerns, priorities, and values that are brought forward by the community we intend to serve and embrace any changes in direction and interest along the way.

#### A way forward: Boundary work in medical anthropology

IK understands environmental wellness as inclusive of the people that inhabit it and sees degradative processes as manifesting in community health and wellness as well (Arquette et al., 2014). Given that we come at the construction of a community health assessment with two culturally different understandings of health, it is useful to explore these differences together through boundary work. Within collaborative research, boundary work serves to support and further legitimize marginalized knowledge, such as IK of health (Zurba et al., 2019). Boundary work supports knowledge sharing across traditional boundaries and enhances the co-creation of

knowledge within research partnerships. This work can help translate research outcomes into onthe-ground action as well, such as implementing programming and services. The partnership between Six Nations Health Services and McMaster operates within boundary work as a way of brokering interactions between these knowledge systems that may not have worked in shared spaces prior. As stated earlier, the research process is just as important as the final products of collaborative partnerships. However, to our knowledge, these concepts have not been applied within anthropological frameworks.

By using CBPR and boundary approaches within medical anthropology, it shifts the very nature and shape of how this research is carried out. While our health research is informed by our approaches to health as medical anthropologists, it mainly operates by listening to how Six Nations stakeholders wish to conduct the research and assess their own community health status. Given the history of mistrust and abuse between anthropologists and Indigenous communities in the past, framing the discussions we had leading up to and during the co- creation of a health assessment is a useful exercise to better understand the nuanced power dynamics within our research partnership and work towards creating more equitable and culturally centered health knowledge together.

## Creating safe health dialogues through boundary objects

Boundary objects are often simple to understand across different members of a research collaboration. They are also structured to work at the margins of communities in order to enhance communication and reach across these boundaries to those with differing perspectives (Sapsed & Salter, 2004). The success of the boundary object is not so much in its ability to bring consensus within a research community of practice, but in its effectiveness to create a space for discussion (Star, 2010). Through the three versions of the health survey over several years, many diverse perspectives and stakeholders were involved in conversations that contributed to the shape the survey took. More importantly, having a tangible document as a foundation for conversation allowed relationships to be built, and for them to grow and expand as trust and rapport was developed, and community concerns and needs shifted. With the history of unethical health research practiced on and not with Indigenous Peoples in Canada, having a boundary object helped to discuss the impacts and ripple effects of previous harm and dishonesty. Importantly, this allowed conversations to de-centre settler colonial perspectives and needs in favour of the concerns and priorities of Six Nations Health Services and community stakeholders on the project.

Zurba and colleagues (2019) argue that it is important to reflect on how the boundary object facilitates boundary work for those working within a research collaboration, but also to assess how to use a boundary object to communicate outwardly. In our case, when we reflect on the community health assessment tool as a boundary object, it created a dialogical space between Indigenous and non-Indigenous research collaborators during its co-development. During the time in which community members were recruited and the household health and water use survey was administered, it operated as a communicative foundation with Six Nations community members. As community work continues to expand and results of preliminary research are shared, the survey will still serve as a boundary object to converse with community members.

#### **CHALLENGES AND BARRIERS TO CO-CREATION**

As co-creation is a process involving multiple voices and perspectives, we wanted to present a brief discussion of the challenges and struggles we faced, as these are a realistic component of the research process. There are several instances where community leaders and partners have been over-worked within Six Nations, and our research project was not a priority, or leaves of absence were taken in response to emerging health and wellness concerns. There are the practical issues of finances, multiple jobs, or being spread too thin as well. These are elements that are difficult to navigate from an institutional perspective for community collaborators as well.

As Ball (2014) points out, "in the bureaucracy of a postsecondary institution, the policies, procedures, and timing that govern matters such as travel advances, expense claim reimbursements, payroll timesheets, cheque disbursements, and food purchases can seem labyrinthine and protracted, even to the most conditioned employees" (p. 35). These slow- moving practical matters were particularly challenging for community members who worked as RAs, where there were bureaucratic delays or policies around processing their wages that were frustrating, particularly for those balancing multiple other jobs and roles in the community. At times this led to departure, with new community members joining the team. This starts the process of relationship and trust-building again, and also means providing more time and space for these newer members to catch up to the speed of the project.

It certainly takes time to build relationships, which is a crucial way of ensuring a more respectful and equitable working partnership. For the health team, establishing relationships with the community navigators who lead and suggest who to reach out to within Six Nations for participation is important. Understanding each other's work ecologies and limitations (particularly as a graduate student researcher working with a community RA who holds multiple roles within both community and university) helps lay a working relationship foundation. And humour, above all, remains a good way of working through challenges and building relationships that will last beyond funding and research periods.

#### **Institutional Barriers**

Within this research project, McMaster and Six Nations collaborators moved in two different ways, similar to the Two Row Wampum. The university as an institution has elaborate self- regulating structures and is slow to change. On the community side there are more fluid movements: leadership, circumstances, goals, and needs can and have changed within shorter periods of time. Singular community events can lead to large changes to the research process and eventual outcomes and dissemination, which means as academic researchers it is important to stay open and flexible, on a journey of discovery rather than being determined to meet specific and timely outcomes. There also feels, at times, a pressure to have immediate outcomes from research that will lead to immediate social changes, rather than accepting that the tools and knowledge that come from this co-creation will take time and may be more ambiguous throughout the process than expected.

The McMaster research team itself has a wide array of knowledge, expertise, and backgrounds, so it can be difficult sometimes to harmonize our work or work at similar speeds. For example, the time-sensitive biological sampling tests of tap and well-water by the ecosystem health team were difficult to perform at the same time as a household visit to do the water use and household health survey. The water samples needed to be back to the McMaster lab within a short time frame, and household visits for the surveys took a much longer time, averaging an hour per home visit. When we made singular trips to a household, those who were able to work more quickly (testing tap water would take 15 minutes per home) at times felt frustrated when the conversations stemming from the health survey made for 45 minutes to hour-long visits per house. Navigating these details and how to create work that is respectful of participants' time as much as respectful of each other's time was a challenge and one that we continue to reassess as we progress with the research.

Within this ambiguity also lies important considerations for academic researchers interested in engaging in this research. Co-creation of knowledge means that collaborators need to be comfortable with high levels of ambiguity and rapid (or punctuated) shifts in needs and directions as led by the community. For more novice researchers such as graduate students, this can be a difficult (albeit fruitful) learning experience to develop more adaptable ways of

95

understanding emergent details and directions while maintaining academic and degree requirements. Guidance from community navigators and senior scholars is quite useful in these instances to help students remain on track, particularly from Indigenous researchers, as they are more experienced working within and between two worlds that may sometimes conflict with one another.

## **FUTURE DIRECTIONS**

This paper reflects on the process of relationship building and co-developing tools and knowledge, and the dissemination process has not been discussed. Sharing knowledge and disseminating tools is itself a huge effort, in part because of the different ways that we can share the information and knowledge that comes from these health assessments for different audiences. We plan to share this knowledge as stories (digital and oral), as toolkits, and in ways that are useful for Six Nations Health Services to build increasingly more autonomous and resilience programs and policies to prevent illness and promote cultural and physical healing. In ways, the sharing of this knowledge will lead to more partnerships and mobilization of community and global Indigenous collaborations. Already, we are seeing the project grow with more moving parts and expand into important new territories of knowledge and needs as we begin to share findings with the community and expand our networks in varied ways.

We believe this paper contributes to the work of decolonizing medical anthropology by demonstrating how the co-production of a boundary object (through the example of health surveys) assists in bridging cultural and social boundaries. Most importantly, the discussions (or boundary work) around the health survey over the past two years have been spaces of important and respectful dialogue around sensitive issues of community and personal health, historical and intergenerational trauma, water and environmental relationships, and spirituality. The tradition of anthropology, and within that, medical anthropology, has centered itself as "explaining, representing, and exploring the unfamiliar for over a century" (Cartwright & Schow, 2016, p. 137). If we are to continue exploring the unfamiliar, it is time for us to explore how we can build reciprocal, respectful relationships with the communities we work with, and explore the unfamiliarity of challenging conventional research structures and expectations.

It is important to assess the capacity for co-created research and work at the boundaries of cultural groups with a legacy of colonial power hierarchies. Ball (2014, p. 43) states that "In the expanded terrain of community-university engagement, risks are real and must, therefore, be carefully assessed. Before university-based and community partners venture onto the ice, they

must be reasonably certain it is strong enough to withstand having holes drilled into it without risking lives." For our work on water quality and community health and resilience, this ice is much like the white rows of the *Kaswentha*, the river of life upon which our relationships are built and based in peace, strength, and a good mind. In times of challenges or emergent/ divergent research orientations, coming back to this foundation helps to revitalize our strengths working in harmony as western and Indigenous researchers.

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# CHAPTER 4: THERE'S SOMETHING IN THE WATER: MENTAL AND PHYSICAL HEALTH CONSEQUENCES ASSOCIATED WITH TAP WATER CONTAMINATION IN SIX NATIONS OF THE GRAND RIVER FIRST NATIONS

#### **PREAMBLE:**

This article was submitted to the American Journal of Human Biology on Jul 2, 2021 and received peer review revisions on Aug 2, 2021. The fully revised document is written below, but many important historical and theoretical foundations had to be reduced during peer revisions to meet word counts and journal scope (specifically staying more broadly focused on human biology, less on sociocultural histories and politics between Canada and Six Nations). The following preamble provides the original historical and social contexts that situate the scientific inquiry into water contamination at Six Nations, as these elements contribute to how the community and the research team perceive and make sense of the analysis.

National mythologies of Canada as a benevolent nation-state have informed public perceptions, which herald Canada as a champion of multicultural and egalitarian modernity (Gosine & Teelucksingh, 2008). However, these mythologies do not address Canada's embedded, institutionalized racism (Gosine & Teelucksingh, 2008). A lack of federal regulation on water in Canada, and specific policy vacuums on the federal regulation of drinking water on Indigenous reserves in Canada have diffused fiduciary responsibilities (Phare, 2009; Boyd, 2011). The racist colonial legislation of the 1876 Indian Act continues to serve and advance the devastating practices of social and cultural genocide of Indigenous Peoples (Jacobs, 2010). These are tacitly approved by the government and have led to the long-term degradation of Indigenous lands and environments, with industrial resource extractions such as mining, logging, dam-building, pipelines, and other development projects directly polluting their traditional lands, and with it, their relationships to the natural world (Henry et al., 2000; McGregor et al., 2020).

Settler colonialism in North America has disrupted diverse Indigenous Nations' connections and their relationships to the environment, which informs how Indigenous Peoples understand the climate crisis (McGregor et al., 2020; Reo & Ogden, 2018). Indigenous Peoples maintain that sustainable futures require anti-racist, decolonizing actions and a consideration of natural relations impacted (Jacobs, 2010; McGregor et al., 2020; Whyte, 2017). Although Indigenous Nations maintain diverse spiritual and cultural understandings of the world, all Indigenous Peoples generally understand the Earth and the natural world as "alive and imbued with spirit," rather than as a commodity to extract as a resource (McGregor et al., 2020, p. 35). Spiritual relationships and connections to the land and waters are acknowledged through ceremonies and thanksgiving. Haudenosaunee Peoples (who we co-create knowledge with for this project) have a Thanksgiving Address *(Ohenton Kariwatehkwen),* which instructs on the interrelatedness and interdependence of all parts of the natural world and teaches that in order to gain a proper understanding of any aspect of the natural world, respect must be shown for the entire web of relationships that form our natural environment.

Consequently, the ongoing colonial environmental dispossession, exploitation, oppression by settlers and their industries in Canada has targeted and put Indigenous Peoples at risk for mental, physical, and spiritual health consequences. The recovery of at least 1333 unmarked children's graves at residential schools run by the federal government and Catholic churches highlights the intergenerational and prolonged trauma that is experienced by residential school survivors and their families (Talaga, 2021; Tk'emlúps te Secwépemc, 2021). Intergenerational traumas are widely agreed by Indigenous scholars to occur when the damage and impact of traumatic experiences are experienced by more than one generation, becoming internalized within families and within their communities as well (Yellow Horse Brave Heart, 1998; Gagné, 1998; Menzies, 2008). Gagné (1998) identified residential school experiences as one of the key elements informing cycles of trauma for Indigenous families. Many scholars argue that these experiences of intergenerational trauma are under-explored, as colonial oppression of Indigenous Nations has occurred for over 400 years (Armitage, 1995; Couture, 2000).

The longstanding and ongoing violence of the federal nation state of Canada and the involvement of Catholic and Christian churches in human violations has been increasingly recognized globally as acts of genocide (Bombay et al., 2014; Stote, 2015; Talaga, 2021). Intergenerational trauma positions the nation state and religious governance of Canada as violators, with increased global recognition of the profound human violations of the church and government (Bombay et al., 2014). As argued by Chrisjohn and Young, "The federal government of Canada bears primary responsibility for adopting and implementing an explicitly genocidal policy" (1997, p. 28). Despite this, Indigenous Nations have survived these atrocities and continue to build strong efforts to rematriate their knowledge, languages, and relationships to the land. However, witnessing the extractive relationship of colonial settlers continuing to degrade traditional lands and propel climate change has put Indigenous youth in particular at risk of environmental and climate driven grief (Jacobs, 2010; McKay et al., 2020; Middleton et al., 2020; Ohneganos Ohnegahde:gyo, 2020). The strongest examples of environmental racism in Canada are exemplified in the Indigenous water crisis, as the inadequate access to clean, safe drinking water poses major public health concerns for many Indigenous Nations despite Canada being one of the world's most water-rich countries.

#### Environmental racism through Canadian water contamination responses

Several *E. coli* outbreaks in the province of Ontario during the early 2000s illustrate the huge discrepancies in the standard of care provided for Indigenous and non-Indigenous communities during environmental crises. In 2000, both the predominantly white city of Walkerton, Ontario, and the remote fly-in-only Pikangikum First Nation reserve had water system failures that led to significant *E. coli* contaminations of their water supplies (Chambers, 2017). In 2005, Kashechewan First Nation in northern Ontario found *E. coli* bacteria in its water system, resulting in the emergency evacuation of 800 community members by the Ontario provincial government after the Federal Government refused to assist and take responsibility (Jacobs, 2010).

Walkerton's outbreak received national attention that led to a provincial inquiry into water regulation and a federal development of protocols that would help with the management of water. Meanwhile, Pikangikum and Kashechewan First Nations water systems issues remain unresolved nearly two decades later. Ongoing outbreaks and contaminations of water sources in these northern reserves are known to provincial water agencies, with the Ontario Clean Water Agency reporting 2 years prior to their evacuation that Kashechewan was a 'Walkerton-in-waiting scenario' (Gosine & Teelucksingh, 2008). These discrepancies in federal actions are significant: Whether intentional or not, the practice of inaction demonstrates that knowledge of environmental contamination for Indigenous and non-Indigenous communities is not handled with the same considerations as settler communities, thus differentially impacting the long-term exposure of Indigenous Nations to bacteriological contaminations.

Drinking water standards have clearly been more stringent for white communities in Canada than for Indigenous communities, with discrepancies in the treatment, sympathies, and concerns towards First Nations Peoples who have suffered more heightened and long-term exposures to contaminated water sources and environments. Despite several promises from the current Federal Government to end all long-term drinking water advisories for select First Nations, a 2021 audit of the federal government's progress in its commitment deemed its actions unsatisfactory. The audit found that the government had not provided the necessary support to ensure ongoing access to safe drinking water for First Nations, with no long-term solutions implemented to address underlying issues (Hogan, 2021). Even after short-term boil water advisories (BWA) are lifted, ongoing or punctuated contaminations of source water and water systems limitations necessitate the continued consumption of bottled water on many reserves (Dupont et al., 2014; Simms & De Loë, 2010). Most of the research on water quality and the detrimental impacts of contamination for Indigenous Peoples has been focused on the physical impacts of drinking contaminated tap water, the potability of water, and the quality of tap and raw, untreated drinking water (Bernier et al., 2009; Dupont et al., 2014; Harper et al., 2011). There is little research identifying community perceptions of water quality – especially for those experiencing chronic or punctuated contamination of their waters – and how these perceptions influence household uses of tap or bottled water, or how that impacts health conditions for household residents. Research has shown that use of contaminated tap water for other uses beyond drinking remains a public health concern (Waldner et al., 2017; Wright et al., 2018). How water is used, treated, and perceived at the household level is an important consideration in understanding the specific household health concerns for Indigenous communities facing chronic water insecurities and contaminations. These details are important for evaluating the social burdens of water inequity and the long-term impacts of water insecurity on individual, household, and community health in culturally specific ways (Hoover, 2017; Leonard, 2019; J. Robinson et al., 2018).

# SIX NATIONS OF THE GRAND RIVER AND ITS HOUSEHOLD WATER

Settled around the banks of the Grand River, Six Nations' land claims extend to 6 miles on either side of the river for a 378-acre tract of land granted to them in the Haldimand deed in 1784 by thengovernor of Quebec, Frederick Haldimand (Hill, 2017). This area of land was chosen due to being part of the traditional lands of Haudenosaunee Peoples for thousands of years (Johnston, 1964; Parker, 1916). Working in allyship with the British (not as subjects of the Crown), they additionally received over \$80,000 for this military alliance during the war, money which was later appropriated by Simcoe and Jarvis for creating the infrastructure of southern Ontario, including the Grand River Navigation Company, as well as for building dams and roads (Johnston, 1964). These early accounts of deceit around original promises to the Haudenosaunee by the British state (and then the Canadian state) have continued to shape their forcible dispossession of lands around the Grand River and informed their current drinking water crisis.

Drinking water for Six Nations is primarily sourced from the Grand River, with offshoot creeks and streams used mainly for irrigation, fishing, recreation, and waste. The proximity of Six Nations reserve to the fast-growing populations along the Grand River watershed (GRW) poses significant concerns. The watershed is a direct drinking water supply for roughly one million people living in southern Ontario, and its rivers and tributaries receive treated wastewater from as many as 600,000 people (Grand River Conservation Authority, 2020). The ongoing growth and

intensification of the river's use raises serious concerns for its water quality and the health of those that depend on it for their drinking water supply. The impacts of upstream agricultural runoff, urban development, and landfill contamination all have detrimental impacts to the river, and thus, to the drinking water supply. The environmental contamination and degradation of the Grand River influences First Nations peoples' cultural relationships with their water and surrounding traditional lands, as expressed in their Thanksgiving Address (*Ohen:ton Karihwatehkwen*).

Environmental racism occurs here through three main pathways: 1) that Six Nations People were relocated to a tiny tract of land (the Haldimand Tract) that continues to be slowly encroached and taken over in unlawful ways by settler colonial structures and actions; 2) a continued lack of access to clean and reliable drinking water due to being downstream of polluting industries and lacking funding and infrastructure to extend watermain lines; and 3) ongoing policy vacuums, or legal loopholes in the federal constitution (Section 91, subsection 24) that created a jurisdictional nightmare denying Indigenous Nationhood, while maintaining reserves as federal lands, but water as a social service (and therefore provincial). Figure 4.1 provides an overview of how these three forces co-exist to produce this persistent water crisis for many Haudenosaunee people living at Six Nations.



Figure 4.1 - Pillars of environmental racism affecting Six Nations water crisis

#### ARTICLE:

## There's something in the water: mental and physical health consequences associated with

### tap water contamination in Six Nations of the Grand River First Nation

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Submitted to the American Journal of Human Biology July 2, 2021. Peer review received August 4, 2021. Revised edition below:

## **ABSTRACT:**

**Objectives**: In collaboration with Six Nations First Nation, we a) investigate household level tap water and drinking water sources and uses, and b) examine the associations between *E. coli* and mercury tap water contamination with water treatments and self-reported household health conditions to better understand contributing factors to the ongoing water quality crisis within the reserve.

**Methods**: Water taps were tested for 66 households for mercury and *E.* coli contaminants. A co-created survey collected responses on self-reported health conditions, household water use, drinking water sources, water treatments, and health conditions for the 66 households. Logistic regression models analyzed associations between reported health conditions and demographic, contaminant, and water treatment variables.

**Results**: E. coli was found in 21.2% (n=14) of household tap water, and mercury was found in 25.4% (n=17) of households tap water in levels exceeding the provincial drinking water guidelines. No significant associations were found between water contamination and health conditions, though households primarily purchasing bulk bottled water were more likely to report mental health conditions, and those using bleach/chlorine to treat their tap water were more likely to report gastroenteritis. Reported tap water uses indicated that 57% of contaminated tap water was still being used for activities that may heighten exposure risks (such as making beverages with unboiled water).

**Conclusions**: Investigating household tap water uses beyond drinking water indicates potential alternative pathways for contaminant exposures. Chronic *E. coli* contamination may be causing gastrointestinal distress for some people. Relying on purchased water is associated with higher reported mental health conditions for Six Nations Peoples, who have deep cultural relationships with water. Together, these conditions inform colonially imposed environmental racism for Six Nations.

Key words: environmental racism; Indigenous health; E coli; mercury; water contamination

#### **1 INTRODUCTION**

Indigenous communities are disproportionately exposed to hazardous pollutants and more likely to be situated near contaminated environments, resulting in significant consequences for the health of these communities. The intentional siting of polluting industries, landfills, and other hazardous waste sites in areas that are mainly inhabited by poor and minoritized communities in North America has been well-documented and understood as environmental racism by colonial forces (Bullard, 1993; Carmody, 2016; Chavis Jr. & Lee, 1987; Cook, 2008; Dhillon & Young, 2010; Gosine & Teelucksingh, 2008; Gravlee, 2020; Hamilton, 1995; Hier & Bolaria, 2007; Hines, 2015; Hoover, 2017; Schell, 2020; T.M. Robinson et al., 2018; Waldron, 2018). For Indigenous Peoples across Turtle Island (the term that Indigenous Peoples use to describe North America without colonial boundaries), these patterns of environmental racism are compounded with colonial policies of genocide. These experiences of racism are entangled with the dispossession of their homelands, and the ongoing extraction of resources from their traditional lands and waters (Gobby et al., 2021; Marsh et al., 2016). This has most recently been publicly demonstrated in the cases of #NODAPL, the Grassy Narrows First Nation mercury contamination, the burning of sovereign Mikmaki lobster traps by white fishers, and the forced removal of Wet'suwet'en land defenders protecting their unceded lands from the Royal Canadian Mounted Police (RCMP, the federally imposed government in western Canada) and Coastal GasLink Pipeline (Gobby et al., 2021; Philibert et al., 2020; Pulido, 2017; Whyte, 2017; Wilson, 2021; van Meijeren Karp, 2020).

Settler colonialism in North America has disrupted diverse Indigenous Nations' connections and their relationships to the environment, which informs how Indigenous Peoples understand the climate crisis (McGregor et al., 2020; Reo & Ogden, 2018). Indigenous Peoples maintain that sustainable futures require anti-racist, decolonizing actions and a consideration of the impact on natural relations (Jacobs, 2010; McGregor et al., 2020; Whyte, 2017). Although Indigenous Nations maintain diverse spiritual and cultural understandings of the world, all Indigenous Peoples generally understand the Earth and the natural world as "alive and imbued with spirit," rather than as a commodity to extract as a resource (McGregor et al., 2020, p. 35). Haudenosaunee Peoples (who we co-create knowledge for this project) have a Thanksgiving Address *(Ohen:ton Kariwatehkwen)* which teaches that in order to gain a proper understanding of any aspect of the natural world, respect must be shown for the entire web of relationships that form our natural environment. Most of the research on water quality and the detrimental impacts of contamination for Indigenous Peoples has been focused on the physical impacts of drinking contaminated tap water, the potability of water, and the quality of tap and raw, untreated drinking water (Bernier et al., 2009; Dupont et al., 2014; Harper et al., 2011). Research has shown that use of contaminated tap water for other purposes beyond drinking remains a public health concern (Waldner et al., 2017; Wright et al., 2018). How water is used and treated at the household level is an important consideration in understanding the specific household health concerns for Indigenous communities facing chronic water insecurities and contaminations. These details are important for evaluating the social burdens of water inequity and the long-term impacts of water insecurity on individual, household, and community health in culturally specific ways (Hoover, 2017; Leonard, 2019; J. Robinson et al., 2018).

This research is part of a larger Co-Creation of Indigenous Water Quality Tools (CCIWQT) project that investigates the prevalence of *E. coli* and mercury contamination of tap water sources for households in Six Nations First Nation of the Grand River in Ontario, Canada. The research objectives are to (a) identify household-level tap and drinking water sources and uses; and (b) examine the associations between tap water sources, treatments, and contaminants and health conditions reported within households. For the self-reported health conditions, we hypothesize that water treatments, sources and contaminations will be associated with the presence of mental health conditions, gastroenteritis, and eczema within this sample of households.

Our results highlight the ways that environmental racism influences the ongoing water contamination for Six Nations Peoples, and how this contributes to water-related health conditions and environmental health for the community. We also highlight the importance of understanding household water use behaviour to inform exposure risks.

#### 2 SIX NATIONS OF THE GRAND RIVER AND ITS HOUSEHOLD WATER

Six Nations of the Grand River First Nation is Canada's largest and most densely populated First Nation reserve. Located in the Golden Horseshoe region of southern Ontario, it has a population of 12,892 individuals on reserve and a total band membership of 27,559 (Six Nations, 2021). The Golden Horseshoe region has a total population of 7,826,367 people in its core and 9,245,438 in its greater area, accounting for over 21% of Canada's population, and more than 55% of the province of Ontario's population (Ontario Government, 2019). Drinking water for Six Nations is primarily sourced from the Grand River, with offshoot creeks and streams used mainly for irrigation, fishing, recreation, and waste. The proximity of Six Nations reserve to the fast-growing populations along the Grand River watershed (GRW) poses significant concerns. The watershed is a direct drinking water supply for roughly one million people living in southern Ontario, and its rivers and tributaries receive treated wastewater from as many as 600,000 people (Cooke, 2006; Grand River Conservation Authority, 2020). The ongoing growth and intensification of the river's use in agriculture and industry raises serious concerns for its water quality and the health of those that depend on it for their drinking water supply.

Six Nations has been subject to several BWAs over the years, though no long-term federal drinking water advisories (DWAs) have been issued in relation to these local advisories. Between 2003 and 2013, Six Nations was under a band council ordered BWA, with over 300 households lacking access to treated water, and 86% of households drinking from water wells found to be contaminated with *E. coli* (Baird et al., 2015; Dupont et al., 2014; Pecoski, 2013). As most residents rely on either a well or a cistern for their drinking water, investigations into the quality of these water sources in 2005 found that many wells in the community were old and in poor condition (Neegan Burnside, 2005). In response to growing concerns, the community has helmed source water protection processes and governance initiatives since 2013 through public organizations like the Haudenosaunee Environmental Task Force and Six Nations Ecological Centre.

By 2014, the community had installed a state-of-the-art water treatment plant that sourced water from the Grand River. However, only about 9% of the 12,892 community members are connected to the watermain from the treatment water plant (TWP). Existing watermain lines service approximately 500 houses and businesses, primarily in the community's downtown village of Ohsweken (Six Nations Public Works, 2016). The watermains were also installed for some households on Fourth and Third Lines, but there is a connection fee to install services that averaged \$350, which some households are not able to afford. Access remains inconsistent to the TWP watermain lines due to this mix of infrastructural limitations, financial barriers, and geographical location of households within the reserve. While there are plans for expanding the watermains, funding was unavailable both to operate the plant at full capacity and for expansion of service to more households in Six Nations (Chattopadhyay, 2018). The TWP did help curb the short-term BWAs, but deficiencies in the quality of wells and cisterns remains a prominent concern for most Six Nations residents, as approximately 91% of households in the community rely on alternative water sourcing. Households with wells and cisterns fill these with either pick-up water from onreserve pumping stations that supply water from the Six Nations Treatment Plant, and many residents also have bottled water delivered by third-party provider companies or find other sources of potable water on their own. Many are still not able to access clean tap water and distrust

their wells and cisterns due to previous contamination results from the 2003, 2004, and 2010 studies (Baird et al., 2015; Dupont et al., 2014; Source Water Protection, 2010).

## **3 METHODS**

Our team used a co-creation methodology, having an Indigenous Knowledge (IK) lead train and participate in every sub-team of our broader research project. Co-creation is an interconnected and integrated method, which allows for Indigenous collaborators to guide the shape, design, and research questions. This informs how data should be analyzed and shared, with interdisciplinary collaborations between Indigenous scientists, anthropologists, biologists, engineers, and water governance researchers taking clear directives and research priorities from both Six Nations governments, Elders, and Haudenosaunee health care providers.

## 3.1 Data collection

Households that had previously participated in water testing (n=78) during the spring and summer of 2018 were invited to participate in the water use and health survey in spring 2019. A total of 66 households were recruited from the tap water testing sample. Of the 12 households that did not participate, 2 had the heads of household pass since the time of testing, 6 had new household owners uninterested in the survey, and 6 were unable to be contacted. Six Nations currently has approximately 2800 household units on reserve, so this survey represents 2.3% of households in the community. Convenience sampling was used for the original water testing recruitment, as community stakeholders advised this was the most appropriate way to engage with community members. Recruitment for these tests was predominantly done through word-of-mouth, stemming from the PI's community networks, along with some recruitment from outreach events held in early 2018. Eligibility requirements were that the primary respondent was 16 years of age or older, and able to speak comfortably about household water sources, treatments, and uses for the household. Community research assistants engaged with households to set up visits for both the water testing and household survey visits, to ensure familiarity and comfort with a process that can feel invasive.

# 3.1.1 E. coli and Mercury Analysis Methodology

For *E. coli* testing, the tap water was run for two minutes prior to sample collection, to ensure that any water sitting in the pipes had been emptied. A sterile Whirl-Pak bag was filled about threequarters full of tap water and the bag was closed tightly by twirling it at least twice. In all cases, a sodium thiosulfate tablet had also been added to the bag beforehand to neutralize any chlorine that had been added to the tap water. The bag was then placed in a cooler and transported back to the lab at McMaster University. All samples were analyzed with the TECTA<sup>™</sup> B-16 detection system (Pathogen Detection System, Kingston, ON) within 6 hours of collection. The TECTA<sup>™</sup> B-16 is an automated microbiological system sold by Canada's Pathogen Detection System, approved for EPA use following a verification study (James et al., 2014). The performance of TECTA<sup>™</sup> B-16 was evaluated by Bramburger and colleagues (2015), comparing its detection time and accuracy to those of two common culture-based methods, which are widely used for recreational water quality monitoring in Canada. Their results demonstrated that *E. coli* densities inferred by the TECTA method were generally in agreement with those generated by standard culture methods (Bramburger et al., 2015). Prior to testing samples for this study, positive and negative controls were run in triplicate for quality assurance.

After thoroughly mixing the sample in the Whirl-Pak, we poured 100 mL into a TECTA<sup>™</sup> EC/TC cartridge, and then tightly closed the cap. The cartridges were swirled for about 2 minutes until the growth medium was completely dissolved. The "Standard Mode Operation" setting was used to conduct all tests. The maximum incubation period was 18 hours for uncontaminated samples, but highly contaminated samples could be completed within 2 hours of incubation. All results were recorded as number of colonies forming units (CFU) per 100 mL of water for *E. coli*. Any water sample with more than 0 CFU/100 mL of *E. coli* is considered positive for fecal contamination and not suitable for human consumption.

For heavy metal analysis, tap water was primarily collected from kitchen taps or the most frequently used taps in the household as indicated by a household member. The tap water was allowed to run for 2 minutes prior to collection. Water samples were collected in unused, individually sealed 500 mL polymer sample bottles (Fischer Scientific). No preservation chemicals were added. All bottles were labeled with participant ID number, bottle ID number, date of collection, and source location. If accessible, a second and sometimes third water sample was collected from the water source or sources, either a cistern or a well.

An Agilent 8800 triple quadrupole inductively coupled mass spectrometer (ICP-MS)<sup>™</sup> (Santa Clara, CA) connected to an autosampler, with subsequent data analysis in Masshunter software used to scan across different heavy metals (Li, Be, B, Al, V, Cr, Mn, Fe, Co, Ni, Cu, Zn, As, Se, Mo, Ag, Cd, Sn, Sb, Ba, Pt, Hg, Ti, Pb, U), without any individual heavy metal targeted specifically for analysis, as there was no indication from discussion with community members that any one heavy metal would be a particular concern. All metals were measured for their total concentration; chemical speciation was not analyzed. Specifically, Total Mercury (Hg) was analyzed which includes metallic, organic, and inorganic Mercury. Mixed ICP-MS standards were used for calibration and concentration verification (Lebel et al., 20201; Manochehry et al., 2018; Nori de Macedo et al., 2013). Detection limits for each element varied. The detection limit of Hg was 0.02 ppb ( $\mu$ g/L).

#### 3.1.2 Water Use and Health Survey

Data collection for the community health assessment was conducted through a water use and health survey with Six Nations Health Services (SNHS). Water use and satisfaction questions were developed with community stakeholders (Elders and SNHS workers) involved in environmental assessment committees and based on prior surveys administered by the community (Source Water Protection, 2010). Community governments, Elders, and SNHS indicated their concerns about the mental health outcomes associated with ongoing water insecurity and contaminations, particularly for women and youth in the community. The survey was pilot tested with community members that worked within the project to ensure the questions were culturally appropriate and relevant for Haudenosaunee health and water research. Protocols for community-based research were closely followed, obtaining Six Nations REB, oral approval from the Haudenosaunee Confederacy, developing a Memorandum of Understanding with SNHS, and clearance granted through McMaster's REB (MREB #579).

The paper and pen questionnaire gathered three kinds of information: (1) sociodemographic profiles of respondents (age, gender, household income, etc.); (2) information on exposure variables, such as drinking water and tap water sources, water treatments, and tap water uses in the household; and (3) self-reported health conditions experienced in the past year for the survey respondent and those also living in the household, and age at diagnosis.

For socio-demographic profiles gender was prompted with options of woman, man, nonbinary, gender-fluid, gender-queer, or other (with room to specify if desired). Youth were defined as 15 or below, based on discussions with SNHS senior research leads, as legal minors (16-18 years of age) in Indigenous populations tend to 'age faster' or experience different health experiences at a faster rate than non-Indigenous Canadians (e.g., earlier parenthood, or earlier onset of chronic diseases) (Duignan et al., 2020). Household income was reflective of the combined annual income of all household members, as this survey was meant to represent the household's general water uses, members, and health conditions.

Known health conditions for all household members was reported by the participant, with health questions modelled after the First Nations Regional Health Survey (FNRHS) health assessment questions (FNIGC, 2018). At the request of Six Nations Health Services, some additional health conditions were added to capture emerging concerns identified at Six Nations: eczema/dermatitis (skin rashes), and chronic pain (not specific to back pain, and not related to arthritis). Tap and drinking water source questions followed the format from the 2010 Source Water Protection Survey (through Haudenosaunee Environmental Task Force, SWP 2010). Drinking water source was asked to determine if alternative sources were used for drinking water other than the household taps. Water treatment questions asked respondents to check off each form of water treatment used for their tap water, tailored to the local context. Treatment was defined by any act to change the quality or taste of water reported in the survey. As drinking water with living pathogens may lead to gastrointestinal problems, we identified tap water uses with higher risks, including drinking tap water without treatment, using water in beverages without boiling beforehand (e.g., making juice from concentrate), and using water for washing produce or brushing teeth. Drinking beverages that required boiling water, such coffee and tea, were not considered high-risk as the boiling process has the potential to inactivate some or all the bacteria.

#### 3.2 Statistical Analysis

Statistical analysis was performed using SPSS Statistics (IMB, Version 23). Initial analysis of the data included univariate descriptive frequencies and chi-square tests for demographic groups, exposure variables, and reported health conditions. The effects of the risk factors or independent variables (demographics, source of water, water treatment, and tap water contamination) on the self-reported health conditions or dependent variables were analyzed through binary logistic regression to determine the odds ratios (ORs) and 95% confidence intervals (CIs). Firthlogit was applied using an R extension package for SPSS to minimize the bias associated with wide CIs that would come with a small sample size

Logistic regressions were used to assess the relationship between the presence or absence of reported health conditions and independent variables. The outcome variable for the binary regression was a compilation of respondents' yes or no responses to questions about self-reported health effects to themselves or to other members of their households. Self-reported health conditions were considered absent for the analysis if the responses to each were reported as negative for all members of the household.

The regression model presented was restricted to household-level data for the 66 study households. This was to determine if household water treatments, sources, contaminants, or demographic factors influenced the presence or absence of a health condition reported for any member of the household. Health conditions were mental health (including anxiety, depression, bipolar type 2, and PTSD), gastroenteritis ("nausea and/or vomiting, diarrhea – sometimes containing blood) and skin conditions (dermatitis or eczema). As the contaminants testing was done months prior to the household survey, the regression model was run first to examine the water treatment and household variables, and then re-run with the addition of *E. coli* as a predictor variables. This is the first time that mercury contamination of tap water was reported in this community, but unfortunately, given the long-term nature of mercury exposure and its association with health risks, we were unable to connect mercury contamination with any long-term health conditions.

# **4 RESULTS**

The survey responses from 66 households represented a total of 226 individuals, which is roughly 2.3% of the Six Nations on-reserve population of 12,892. Table 4.1 presents the household demographics, tap and drinking water sources, water treatments, and water contamination results (n=66).

Demographic	Frequency (n=66)
Annual household income	
No income <\$19,0000 \$20,000-49,999 \$50,000-79,999 \$80,000-150,000 Prefer not to answer	4 (6%) 20 (30.3%) 13 (19.6%) 10 (15.1%) 3 (4.5%) 16 (24.2%)
Number of people living in house	
1 2 3-5 6-9 Missing	12 (18.1%) 14 (21.2%) 29 (43.9%) 9 (13.6%) 2 (3%)
Tap water source	
On TWP watermain lines From treatment plant to well From treatment plant to cistern Bulk water delivery to cistern (third party) Bulk water delivery to well (third party) Drilled well Well (general, unspecified)	3 (4.5%) 5 (7.5%) 6 (9%) 23 (34.8%) 18 (27.2%) 4 (6%) 7 (10.5%)

Table 4.1 -	Household	demoaraphics	and water source	treatment.	contaminations.	and use of	characteristics
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Drinking water source					
Tap water directly from TWP	2 (3%)				
Tap water directly from well	13 (19.4%)				
Tap water directly from cistern	11 (16.4%)				
Bulk water picked up from treatment plant	5 (7.5%)				
Bulk bottled water purchased by household	33 (49.3%)				
Water delivery service (third party)	2 (3%)				
Household Water Treatments					
Chlorine or bleach added	14 (21.2%)				
In-line filtration used	18 (27.2%)				
Post-tap treatment used	7 (10.4%)				
Mercury levels in household tap water					
below 0.69 ± 0.02 ppb	33 (49.3%)				
between 0.99 and 0.70 ppb	16 (23.9%)				
1.00 ± 0.02 ppb (μg/L)	17 (25.4%)				
<i>E. coli</i> coliforms in household tap water					
Absent	52(78%)				
Present	14 (21.2%)				
Tap water uses					
Drinking tap water	16 (33%)				
Making beverages with unboiled tap water	13 (27.7%)				
Making beverages with boiled tap water	22 (45.8%)				
Washing produce	37 (77%)				
Washing dishes	46 (98%)				
Food preparation	29 (43.3%)				
Brushing teeth	42 (87.5%)				
Showering	47 (98%)				
Did not answer	18 (27.2%)				

# 4.1 Tap Water Contamination, Drinking Water Sources, and Water Uses

*E. coli* was found in 21.2% (n=14) of household tap water samples, and Total Mercury (Hg) concentrations above the 1.00  $\pm$  0.02 ppb (µg/L) provincial drinking water limits were found in 25.4% (n=17) of household tap water samples (Health Canada, 2020; Public Health Ontario, 2019). No mercury above acceptable limits was found in tap water in sampled households that were connected to the main line, though only 4.5% of households (n=3) were on the watermain lines. Both mercury and *E. coli* were present in 6% of total surveyed households (n=4).

Drinking water sources differed from tap water sources, with 77% (n=51) of households preferring purchased water for drinking, inclusive of purchasing water in bulk individually, relying on third party providers, or purchasing water from the treatment water plant (TWP) (Table 4.1). One household (1.5%) specified that their well was not connected to their tap, instead drinking spring water drawn from a pail, noting that this was the traditional way for their community to source drinking water. No significant relationships were found between tap water sources and presence of mercury or *E. coli* (Table 4.2).

Variable	E. coli Pearson Correlation	Mercury Pearson Correlation
On TWP main line	-0037 (p=0.772)	-0.07 (p=0.576)
TWP to Well (pick up)	-0.065 (p=0.61)	-0.122 (p=0.323)
TWP to Cistern (pick up)	0.091 (p=0.476)	-0.07 (p=0.576)
Bulk water delivery to well (third party or individually)	0.071 (p=0.58)	0.178 (p=0.152)
Bulk water delivery to cistern (third party or individually)	-0.058 (p=0.649)	-0.06 (p=0.631)

*Table 4.2 – Chi square correlations between tap water sources and water contaminants (n=66)* 

# 4.1.1 Water Treatments

Household tap water treatments varied, with some households using up to three different forms of treatment (Table 4.1). In-line filtration forms varied, including the use of UV filtrations or reverse osmosis. Only 27.2% of the 66 households reported using an in-line water treatment for their tap water. Those who added bleach or chlorine (n=14) to their tap water reported adding approximately 1 cup of bleach (35.7%, 5 of 14 households), once a month (14%, 2 of 14) or once every few months (21.4%, 3 of 14).

Chi-square tests indicated that households with tap water contaminated with *E. coli* were significantly more likely to treat their water with bleach or chlorine (0.314, p=0.025), but not more likely to treat their water using other forms of treatments (Table 4.3). No significant relationships were found between elevated mercury in tap water samples and any form of water treatment (Table 4.3). It is unclear whether the tap water treatments were instigated after knowledge of

water contamination from the water tests or if they had been in place prior to our project's 2018 testing.

Variable	E. coli Pearson Correlation (n=50)	Mercury Pearson Correlation (n=54)	
Bleach or chlorine added	0.314 (p=0.025)*	-0.225 (p=0.102)	
In-line water treatments	-0.157 (p=0.275)	0.131 (p=0.348)	
Post-tap water treatments	0.094 (p=0.517)	-0.166 (p=0.235)	

Table 4.3 – Chi-square correlations for tap water treatments and water contaminants

\*Significant at p<=0.05

## 4.1.2 Tap Water Uses

Tap water uses (n=48) were correlated with tap water contamination results (Table 4.4). While 14 households had tap water contaminated with *E. coli*, only one of these households with *E. coli* contamination reported drinking their tap water without treatment. As the questions about tap water uses were structured to check all that apply, the frequency of use is not known, and it is not clear what sources were being used for households that did not report tap water use for these activities. Households with *E. coli* in their tap water were significantly less likely to be using their tap water for riskier uses, such as drinking straight from the tap or making beverages with unboiled tap water (Table 4.4). However, while households with contaminated tap water were aware of the risks related to drinking untreated tap water, 57% of households were still using the tap water to prepare foods, wash produce, and brush their teeth. These may be important exposure routes to explore in future research.

Variable	E. coli Pearson Correlation	Mercury Pearson Correlation
Drinking tap water	-0.359 (p=0.014)*	0.298 (p=0.042)*
Making beverages with boiled tap water	-0.417 (p=0.004)**	0.422 (p=0.003)**
Making beverages with unboiled tap water	-0.483 (p<0.001)**	0.309 (p=0.035)*
Washing produce	-0.339 (p=0.021)*	0.059 (p=0.694)
Washing Dishes	-0.322 (p=0.029)*	0.187 (p=0.209)
Food preparation	-0.510 (p<0.001)**	0.236 (p=0.128)
Showering	-0.225 (p=0.132)	0.130 (p=0.382)
Brushing teeth	-0.445 (p=0.002)**	0.221 (p=0.136)

*Table 4.4 – Chi-square correlations for tap water uses and water contaminants (n=48)* 

\*Significant at p<=0.05, \*\* significant at p<=0.01

# 4.2 Health Conditions and Regression Analyses for Water Treatments and Contaminants

Of the 226 individuals whose health conditions were reported by a representative in one of the 66 households, 85 individuals (37.6%) were reported to have at least one health condition (Table 4.5). The most frequently reported health condition was mental health: anxiety (n=17, 8%) and depression (n=11, 5%) were the most common. Other mental health conditions reported were bipolar disorder II (n=2, 0.8%), and post-traumatic stress disorder (n=1, 0.4 %).

Sociodemographic Variable	Number of Participants (%)
<i>Gender</i> Women Men Missing	90 (39.8) 72 (31.9%) 64 (28.3%)
Age 0-15 16-19 20-29 30-39 40-49 50-59 60-69 70+ Missing	68 (30%) 15 (6.6%) 28 (12.3%) 31 (13.7%) 23 (10.2%) 32 (14.1%) 10 (4.4%) 2 (0.8%) 17 (7.5%)
Household health conditions reported by primary respondent	Number of individuals with reported condition (%)
Mental health conditions	42 (18.5%)
Eczema or dermatitis (skin rashes)	21 (9.2%)
Gastroenteritis	8 (3.5%)

Table 4.5 – Gender, age, and health conditions of household members (n=226)

The regression was run without contaminants (Model 1, Table 4.6) and with the contaminants as predictors (Model 2, Table 4.7).

	Mental Health Conditions (n=30)		Eczema/Dermatitis (n=30)		Gastroenteritis (n=30)	
	OR (95% CI)	Sig.	OR (95% CI)	Sig.	OR (95% CI)	Sig.
Household income	0.76 (0.29-2.02)	0.59	2.93 (0.74-11.6)	0.126	0.463 (0.1- 2.1)	0.32
Number of youth in household	0.81 (0.48-1.38)	0.44	1.636 (0.87-3.07)	0.126	1.134 (0.46- 2.7)	0.78
In-line treatment of tap water	2.38 (0.28-19.97)	0.42	0 (0-0)	0.999	0.676 (0.02- 15.8)	0.81
Bleach or chlorine added to tap water	1.11 (0.17-7.11)	0.91	0.283 (0.02-4)	0.353	21.065 (0.66- 72.3)	0.08
Drink bottled/bulk water	10.5 (0.95-15.84)	0.045 *	0.623 (0.068-5.7)	0.657	0.839 (0.05- 14)	0.903
Post-tap treatment	0.258 (0.017-3.83)	0.325	1.23 (0.63-24.1)	0.88	5.763 (0.2- 15.2)	0.29

Table 4.6 – Model 1, logistic regression of household health conditions and water treatment predictor variables

\*Significant at p<=0.05

	Mental Health Conditions (n=29)		Eczema/Dermatitis (n=29)		Gastroenteritis (n=28)	
	OR (95% CI)	Sig.	OR (95% CI)	Sig.	OR (95% CI)	Sig.
Household income	1.12 (0.28-4.4)	0.872	1.7 (0.4-7.1)	0.5	0.544 (0.09-3)	0.49
Number of youth in household	0.615 (0.269-1.4)	0.251	1.8 (0.9-3.6)	0.08	1.1 (0.46-2.45)	0.88
In-line treatment of tap water	11.93 (0.50-80.9)	0.124	0 (0-0)	0.999	0.874 (0.03-25.3)	0.94
Bleach or chlorine added to tap water	0.938 (0.08-10.7)	0.959	0.55 (0.034-9.2)	0.68	11.9 (0.75-90.69)	0.05*
Drink bottled/bulk water	35.6 (0.867-65.4)	0.05*	0.36 (0.03-9.2)	0.42	0.87 (0.05-15.2)	0.92
Post-tap treatment	0.004 (0-14)	0.186	2.78 (0.04-79.5)	0.63	0.72 (0.04-14.2)	0.82
E. coli present	1.28 (1-1.6)	0.046*	0.91 (0.74-1.1)	0.41	1.01 (0.87-1.16)	0.89
Mercury (Hg) present	3.55 (0.09-28.04)	0.159	0.45 (0.02-7.7)	0.59	0.5 (0.02-10.5)	0.66

Table 4.7 – Model 2, logistic regression of household health conditions and water treatment and contaminant predictor variables

\*Significant at p<=0.05

In the regression Models 1 and 2, no water treatments were significantly associated with the likelihood of a member of the household reporting a mental health condition. However, households that primarily drank purchased bottled water were more likely to report a mental health condition in both models (Table 4.6 and Table 4.7). Households with *E. coli* contamination were more likely to have reported a mental health condition in Model 2 (Table 4.7). The addition of chlorine or bleach was not found to have a statistically significant relationship in either Model 1 or 2 with predictor

variables (Table 4.6 and Table 4.7). Despite community concern, the presence of *E. coli* or mercury in tap water was not significantly associated with any increased risk of eczema/dermatitis, nor was the use of bleach or chlorine to treat water (Table 4.7). When the contaminants were added into Model 2, households where chlorine or bleach was added to treat tap water were 12 times more likely to report experiences of gastroenteritis (Table 4.7).

## **5 DISCUSSION**

This research provides data on self-reported health conditions and household water-use behaviour data for a sample residents and households of the Six Nations Grand River First Nation population. Results from household tap water tests found that some members of these households may have had some exposure to *E. coli* and mercury contaminations through their taps. Three key findings drive the discussion: 1) *E. coli* and mercury were found in household tap water in concentrations higher than the provincial upper drinking water limits – with mercury being a new finding for the community; 2) reported mental health conditions within the household were significantly correlated with the reliance on bottled drinking water and the presence of *E. coli* in tap water; and 3) reported physical health conditions that were hypothesized to be associated with *E. coli* tap water contamination were not correlated, though gastroenteritis was found to be significantly correlated with households treating their water with bleach or chlorine.

This survey represents the preliminary efforts by community and academic collaborators to document physical and mental health outcomes connected to household water contamination for Six Nations Peoples. The levels of *E. coli* in the tap water within this small sample size are similar to previous reports, and consistent with previously reported community concerns around contaminated tap water that informed residents' preference for drinking bottled water (Dupont et al., 2014; Neegan Burnside 2005). This is consistent with previous studies conducted in 2003 and 2004 that showed 19% and 27%, respectively, testing positive for fecal contamination from the Neegan Burnside studies (CCIWQT Report, 2019; Neegan Burnside, 2005). During the 2003 and 2004 investigations, quantity of water in the well was found to be related to bored wells not being dug deep enough to reach the water table; a lack of funding influencing well construction; and bored wells having a more limited water supply due to unfavourable geological conditions (Neegan Burnside, 2005). Observations from the CCIWQT reports have maintained these quality and quantity issues have not improved much since the initial 2005 findings (CCIWQT Report, 2019).

While the households tested in our study are not the same ones tested in the 2003 and 2004 reports, it is long held that *E. coli* contamination has been under-reported in Six Nations, since Health Canada only tests for coliforms at the request of homeowners (Collins et al., 2017; Human
Rights Watch, 2016; Pecoski, 2013). We do not know the length of contamination for these household water sources, whether households have maintained the same degree of biological contamination since our tests were done in 2018, or whether their water has been effectively treated since then. *E. coli* contamination of water can also vary significantly across seasons, so it is difficult to determine long-term household water contamination from cross-sectional surveys and one-time water tests (White et al. 2021). As the survey respondents were recruited approximately 6-12 months after having their tap water tested, we can roughly link potential exposure to *E. coli* and mercury contaminants from the tap water tests to the self-reported health conditions experienced within the past year.

#### 5.1 Drinking water uses, sources, and treatments

Household water use findings in this study indicate that most household respondents reported not using tap water as their main source of drinking water, though 67% used tap water to prepare beverages, 77% of households used tap water to wash their produce, and 96% of households used their tap water to wash their dishes. While there were few households with contaminated water drinking unboiled tap water or using it for powdered drinks, there were surprisingly high uses of unboiled tap water for washing produce, food preparation, and brushing teeth. These uses may be important exposure pathways to biological and heavy metal contaminants, and an investigation into the source of contamination and risks is needed. Households that participated in the survey demonstrated a preference for purchasing bottled water, either from third-party sources off reserve from private companies or retail stores.

Previous research on risk perception of drinking water quality across Indigenous and non-Indigenous communities in Canada found that Six Nations participants were more likely to believe that someone had gotten sick from drinking water than non-Indigenous participants, and Six Nations reported a higher number of respondents who had health concerns related to their tap water than other Ontario First Nations included in the study (Dupont et al., 2014). Another study exploring water vulnerabilities found that Six Nations was overall less vulnerable to the water insecurity measurements captured in the study than other First Nations in Ontario but did report a higher vulnerability to environmental pressures related to water inaccessibility (Plummer et al., 2013). The water quality and use data reported in our study are likely reflective of collective memories around boil water advisories on the reserve. Next to the question about monthly expenses of drinking water, one participant wrote in the margins of the survey that "they shouldn't have to pay in the first place" which resonates with ongoing community frustration that the responsibility placed on the individual or household for maintaining a safe and reliable drinking water source. This is consistent with previous research that found Six Nations residents' distrust in drinking water may partially be accounted for by factors such as lack of institutional trust, service dissatisfaction, and a loss of cultural control (Dupont et al., 2014).

Many households participating in the study reported attempts to fill gaps in the community provision of clean water by applying a variety of their own tap water treatments in their households. Bleach and chlorine treatments are a quick and accessible solution for reducing bacteriological contamination exposure, as well as being a more affordable option for low-income households. Reliance in the community on these treatments is likely due to public health campaigns that helped to develop water treatment literacy (Health Canada, 2019; Public Health Ontario, 2019). It is not clear from the surveys, however, how accurately and systematically households are applying bleach/chlorine treatments to their well/cistern water. In-line treatments, such as reverse osmosis are more likely to be effective if maintained but are more expensive household water treatment options. Boiling water was not something that any household reported doing as a means of treating tap water. Given that some households with *E. coli* contamination did not treat their water in any way and were still using tap water for household tasks and in preparation of food and beverages that could expose them to contamination, future public health messaging should tailor messages to reduce exposure risks related to these water-use activities.

## 5.2 Water Quality, Access, and Health

Three health conditions were considered relevant for statistical analysis with water: gastroenteritis, mental health, and eczema. Of these, mental health was highlighted by community members, government, and Elders as a prominent area of concern. Higher eczema rates among children in recent years was raised by community members as possibly related to water quality. They pointed out that there has been no attention or collection of quantitative data and water to align with these health priorities. These intellectual contributions from community contributions shaped the direction and shape of health research for the team early on. While previous research on water quality with Indigenous Peoples has suggested associations between eczema and water contamination (Bradford et al., 2015; Waldner et al., 2017), we did not find any strong associations between the presence of eczema and water treatments or contaminations. This does not mean that such a relationship does not exist, but it may be due to other issues of water quality and/or quantity not directly related to E. coli and mercury contamination. The increase in commodifying safe water, aging infrastructures, and climate crises events compounds the scarcity of water globally (Rosinger & Brewis, 2019). Water insecurity is used as an analytic concept by human biologists to understand what influences water access and quality, though water's central role in shaping human biology is less documented (Rosinger & Brewis, 2019). Much research on water insecurity reflects household dynamics of low to middle income countries, though higher-income countries have been found to have more hidden water insecurities (Doyle et al., 2018). The more transient experiences of people living within the United States (such as those in mobile houses) point to consistently unreliable tap water sources that drive bottled water consumption (Pierce & Gonzalez, 2016; Rosinger et al., 2018). A 2015 report on American housing found that low-income, minoritized households were more likely to perceive their tap water as unsafe to drink, relying on bottled water, which can result in thousands of dollars of increased costs for households (He et al., 2008; Javidi & Pierce, 2018). Even perceptions of tap water being unsafe have driven alternative hydration strategies that have health consequences, with heightened reliance on sweetened beverages (Onufrak et al. 2014).

This study highlights the importance of cultural contexts for understanding the perceptions and behaviours of households facing water insecurity. Indigenous households in Canada have been historically subjected to water contaminations and scarcity with little public or governmental action to shift structural and environmental racism. A 2014 study that explored diverse First Nations (including Six Nations) and non-First Nations communities in Canada found that bottled water was perceived as safer by First Nations respondents when compared to non-First Nations respondents, particularly for First Nations communities in southern Ontario (Dupont et al., 2014). For Six Nations, the cost of purchasing drinking water can directly and negatively affect mental health, as it can be a major expense, particularly for those living in low-income households. Having to buy bulk bottled water also has indirect impacts, such as a lack of a sense of personal control over a household's water situation, or in the long-term, due to the community's lack of governance over their drinking and source waters.

#### 5.2.1 Mental Health

Our regression models found that even without contaminants as predictor variables, households that relied on bottled water for drinking were 10.5 times more likely to report the presence of a mental health condition within the household. While this does not suggest a direct causal relationship between water contamination and mental health conditions, the correlations speak to community concerns about water quality. Interview data (not reported here) revealed that physical mobility and financial constraints around hauling bottled water contributed to mental

stress for household caregivers, particularly mothers (Duignan et al., forthcoming). Similarly, Indigenous Nations in the lands known as Canada have experienced persistent water insecurity, chronic contamination, and source water concerns (Awume et al., 2020; Dupont et al., 2014; Hanrahan, 2017).

Over the last five years, research has demonstrated the associations between mental health concerns and poor water quality and access for communities with longstanding water contamination worldwide (Brewis et al., 2020; Bharadwaj and Bradford, 2018; Barreau et al., 2017; Cuthbertson et al., 2016; Ford et al., 2019; Wutich et al., 2020). Studies from Black communities in Flint, Michigan address the pressing need for sustained attention to mental health for other BIPOC communities facing similar long-term water crisis situations (Cuthbertson et al., 2016). The reasons for poor mental health stemming from contaminated environments can be both direct and indirect. A national American study on the relationships between drinking tap, bottled, and public water found that Black and non-white Hispanic individuals were also more likely to drink bottled water primarily than tap water (Rosinger et al., 2018). While this study did not include Indigenous participants, it points to environmental inequities where lower-income and BIPOC communities are less likely to trust their tap water, and more likely to drink bottled water. These results are not surprising, given that Black and Indigenous communities are more likely to be geographically situated in landscapes that have higher risks of contamination due to ongoing resource extraction by nation-states (Waldron, 2018; Hoover, 2017).

The relationship between relying on bottled water and poor mental health among Indigenous communities across Turtle Island is not well-documented in the literature, and it is important to view these findings through an Indigenous lens. Beyond physical health outcomes associated with contaminated environments, Indigenous Peoples have spiritual and cultural relationships and responsibilities to lands and waters, so environmental degradation impacts their health in more profoundly negative ways (Mascarenhas, 2007; McGregor et al., 2020; McKay et al., 2020; Phare, 2009; Philibert et al., 2020; Pulido et al., 2017; Waldron, 2018; Whyte, 2017). Wutich and colleagues (2020) identify that the relationship between mental wellbeing and emotionally meaningful interactions with water is important, especially for Indigenous-centric research. This is inclusive of understanding water as sacred, and the relationship between ceremonies, water, and mental wellness as essential (Cooper et al., 2019; McGregor, 2015; Wilson et al., 2019). Increased access to "blue spaces" such as rivers, oceans, and lakes for a study in urban New Zealand was found to reduce psychological distress (Nutsford et al., 2016). However, the ways that water is spiritual, emotional, and cultural are varied for Indigenous Nations, and local knowledge must guide research and interpretations.

For the Haudenosaunee, water is life, and treated as a responsibility rather than a resource to extract. During this project's timeline, Nestlé's water bottling company was extracting water from the nearby Aberfoyle aquifer using expired permits (Lui, 2019). Haudenosaunee women take on additional roles as water protectors and caretakers for their families and community, which shapes their heightened risks for water insecurity (Duignan et al., forthcoming). Indigenous women and youth connect mental health conditions with environmental grief and dispossession, the reminder of colonial/settler extraction of traditional waters; the reliance on bulk bottled water in the household, may exacerbate mental health conditions for community members (Daoud et al., 2013; Middleton et al., 2020).

The siting of these water bottling extractions on traditional lands of the Six Nations also highlights this water crisis as a case of environmental racism. Digital water stories produced by Six Nations youth and anti-Nestlé activist events within the community suggest that watching their waters being exploited and contaminated have profound mental health consequences (ResilienceInWaterStories, 2019; Ohneganos Ohnegahdę: gyo, 2020; Lui, 2019). Our study was conducted at the household level, and so the nuanced relationship between mental health distress, poor water quality, and traditional relationships with the land are not fully captured by householdlevel survey. However, the findings from this study do provide the first statistically significant association between poor mental health and the household-level water contamination and stressors, which warrants further investigation.

#### 5.2.2 Gastroenteritis

The lack of any significant relationship between *E. coli* contamination and self-reported gastroenteritis may be because only one survey respondent from a household with tap water contaminated by *E. coli* reported that they drank tap water. Given that Six Nations has experienced BWAs throughout the period from 2003 to 2013, the recent memories of public health campaigns around drinking water and continued community concern may have influenced how households source their drinking water and tap water avoidance strategies. When contaminants were added as predictor variables to the model, households using bleach or chlorine treatments were 11.9 times as likely to report gastroenteritis within the home. This finding is somewhat surprising, given that consistent chlorination of water at a residual of 0.2-0.5 mg/L in distribution networks can provide protection against pathogen intrusion in water sources (Payment et al., 1997). Households in this study reported adding one cup of bleach or chlorine per month (approximately 236.5 ml). It may be

possible that households are adding too much bleach or chlorine to their water, but it is more likely that the consistency of homeowner chlorine distribution is less constant than community distribution networks, such as the water treatment plant. It is unclear how frequently many of the households were adding bleach or chlorine, as only some participants provided this information, though those who did respond said they averaged a cup of bleach or chlorine every month added to their well or cistern. Health Canada recommends shocking wells with chlorine every 3-4 months following a contamination, with varying amounts based on the depth of the well; for wells 6 feet deep, 100-300mL is recommended (Health Canada, 2019).

The relationship between bleach and chlorine treatments and the presence of gastrointestinal-related illness in the household may be more likely a result of ongoing community problems with *E. coli* contamination of wells and cisterns. Treating water with bleach or chlorine is a fairly common practice for community residents, as these are the most accessible and cost-effective water treatments to reduce *E. coli* risk. Gastroenteritis is likely not directly caused by drinking bleach-treated water, so chlorine/bleach treatments are probably a proxy indicator of chronic problems with *E. coli* contamination in the household taps (Wright et al., 2018). It may also indicate the existence of water storage methods that are more conducive to E. coli contamination, such as poorly maintained cisterns, which may also explain this statistically significant association. Previous Six Nations reports found that many of the wells in the community were old and in poor condition, with bored and dug wells receiving surface water run-off, poorly maintained wells having damaged lids or concrete casing cracks, and standard wells not having vermin-proof lids (Neegan Burnside, 2005).

Within human biology, there is much research on the correlations between primary water source and cases of gastrointestinal illnesses (Huock et al., 2020; Piperata et al., 2020; Rosinger & Tanner, 2015). Some communities have water acquisition strategies, such as consuming water-rich foods, that reduce the probability of gastrointestinal illness lessen gastro-illnesses, such as consuming water-rich foods that reduce the probability of illness (Rosinger & Tanner, 2015). The installation of water treatment plants has also been demonstrated to reduce urinary and gastrointestinal infections (Huock et al., 2020). However, Huock and colleagues also highlight that even when water treatment plants are installed, it is important to address community concerns with tap water safety after punctuated or chronic contamination periods. The Six Nations TWP is very effective, but with the difficulty for many community members to access watermain lines, community perceptions and physical and mental health are impacted by ongoing concerns with contaminated wells and cisterns.

131

#### 5.3 Strengths and Limitations

The present study is subject to several limitations. While the sample size is small (2.3% of the total population), this is consistent with previous studies done at Six Nations by federal government, universities, and by with Six Nations itself. Due to the small sample size, the confidence intervals within the regression analysis are quite large, which impacts the odds ratios reported. The community has experienced a tremendous degree of research fatigue given their proximity to 6 major cities that all have research institutions with ongoing interest in working in Six Nations. As other researchers working with Indigenous communities have highlighted, non-responses for Indigenous respondents can also be the result of cultural reasons and research fatigue (Newell et al., 2020).

SNHS recommended a convenience sampling strategy as a more culturally appropriate recruitment method, though it creates a biased sample. Those who did participate represented a group within the community that wanted their tap water tested, due to their own concerns with community water sources, and were more aware of historical and current contaminations within the reserve. Given a broad range of other ongoing health and cultural concerns, water is not often prioritized at large within the community, so the results may speak to a more heightened awareness that exists within this subgroup.

There was no control population included in this study, such as a proportionate number of households on the watermain lines. It is therefore difficult to ascertain whether the people in this community experience disproportionately higher health conditions due to water contamination and poorer water access compared to a less-exposed proportion of the population. Employment status and location are unknown, as these were not deemed appropriate to be asked by our collaborators. Due to this, it is also unknown what water sources are at work locations, on or off reserve, and how these sources might mitigate overall exposure to contaminated water. Those who work within the reserve would also have varied water exposure at work, as those working in the village of Ohsweken within Six Nations would be on the watermain lines throughout the working hours, but school employees, midwives, and others employed at other locations outside of Ohsweken may have varying water sources. It is also difficult to determine the length of time each member of households had lived in the home, as many individuals within the community are highly mobile between households (Curley-Smith, personal communication).

Like the FNIGC (2018) First Nations Regional Health Survey that our survey was modelled on health conditions are self-reported. Health conditions were reported by the primary household respondent for all household members residing with them at the time. This limits the interpretation of results in two ways: 1) some households have more mobile or transient individuals that do not stay within the whole period of study, and may not have been included in their reports; and 2) only known health conditions are reported by the primary respondent, and some household members may have more confidential or unknown conditions to the primary respondent.

As this is a cross-sectional study, we do not have the ability to measure long-term effects of contaminated water, nor can we cross-compare with other data sources. This means that health conditions are under-represented within the sample population. It is also not possible to examine chronic health conditions reported in this survey associated with mercury exposure, given the lack of information around duration of individual household residency and the duration of household tap water contamination given the cross-sectional nature of the study. Though mercury exposure is associated with higher risk of damage in the lungs, brain, and kidneys, as well as increased risk of gastric cancer, we did not have enough reports of these conditions to test for statistical associations (Clifton, 2007; Kim et al., 2020). These impaired functions also accumulate with long term mercury exposure, but the length of mercury contamination as well as residency for all household members is unknown given high levels of individual mobility in the community.

We cannot be certain that the associations between water treatments, sources, and selfreported health conditions can be strictly understood from a cause-and-effect relationship. Treatments and sources of drinking water may represent a marker for other factors related to these health conditions. It was unclear whether the application of water treatments or buying water was initiated by households before or after the knowledge of their tap water contamination. Additionally, the time the survey data was collected fell between 8-18 months after the tap water samples were collected, during which time water quality may have changed seasonally, and health conditions may have emerged or changed considerably.

While it is reasonable to conclude that many individuals represented within these results have encountered elevated contaminants in their household tap water, the actual degree of exposure (through water use at the individual level) is unknown, and there are many uncertainties surrounding the duration and intensity of these exposures, or how this may vary with season and individual mobility. Given the small sample size, and the lack of information of years in residence at the household level, this limits our ability to draw conclusions for any strong associations. Due to these limitations, the results of this water-use and health survey cannot be causally connected with the tap water contamination results. They are also not generalizable beyond the study sample, due to the low representation of the study population within the sample at 2.3%. However, having locally specific water and health data created with and by the community is important in building

more Indigenous-centric tools reflective of the unique localized relationships between Haudenosaunee Peoples and water.

## **6 CONCLUSION**

This study demonstrates that *E. coli* and mercury are present in the tap water of some Six Nations households, though more water testing is needed, including an investigation into the sources of contamination. Mental health was found to be associated with the presence of *E. coli* in tap water, as well as the reliance on purchasing bottled drinking water, and gastroenteritis was associated with bleach treatments. The relationships found in this study are not necessarily cause-and-effect, though they do highlight the multiple, and in some instances, expensive and arduous household interventions community members are making with their knowledge of water contamination around their community. These relationships between physical and mental health with water treatments and sources do provide alarming indicators of the negative health consequences of environmental racism, as these treatments and sources are a direct product of having to mitigate long term water contamination on the reserve.

While the results support the broader emergent literature relating water quality and mental health in human biology, it also identifies cultural and spiritual contexts that are unique to Indigenous Peoples facing water contamination and environmental degradation. Water is life for Six Nations Peoples, and their relationship with traditional waters is incredibly nuanced, affecting their social, spiritual, and mental health as much as physical. This relationship has previous been identified for Black communities in the United States facing similar water contamination and access issues but has been under-explored for Indigenous communities across Turtle Island. Given the long histories of environmental racism and intentional situating of BIPOC communities near polluted lands, a continued exploration into the specific and place-based contaminations impact on holistic health is important for understanding current and future health concerns. To appropriately address Indigenous health concerns, acknowledging the cultural values related to water is an important first step. It also helps to shape more appropriate interventions and health care programming that is reflective of the relationship between drinking water perspectives and long held distrust of tap water.

#### The authors have no conflicts of interest to declare.

#### Acknowledgements:

Our work was supported by the GWF grant for Co-Creation of Indigenous Water Quality Tools. We thank our community collaborators at Six Nations Health Services, Six Nations Band Council, the Haudenosaunee Confederacy, and Six Nations Public Works for their generous support of this research and its dissemination.

#### Ph.D. Thesis - S. Duignan; McMaster University - Anthropology of Health

#### Author contributions:

S.D conceptualized the study, designed the analysis, analyzed the data, and wrote the primary draft of the document. T.M., L.D.H., and D.M.H. contributed to the conception of the study. C.F., P.C.F., and T.M. co-designed the research methodologies. T.M. C.M., C.F., and P.C.F. contributed to data collection. C.M., J.M., P.C.F. and T.M. contributed to the analysis of their respective data sets (mercury, bacteriological samples, health survey results). T.M. contributed to the design of the regression analysis, edits, and revisions of draft. contributed to the editing and revisions of the draft. All authors prepared and approved the draft.

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# CHAPTER 5: BE LIKE THE RUNNING WATER: ASSESSING GENDERED AND AGE-BASED WATER INSECURITY EXPERIENCES WITH SIX NATIONS FIRST NATION

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Article submitted to Social Science & Medicine on August 2, 2021.

## **ABSTRACT:**

A mixed methods approach was used to investigate the effects of water access, satisfaction, and experiences of water insecurity for a group of 66 households in Six Nations of the Grand River First Nations, to inform culturally effective ways of assessing water insecurity for Indigenous Nations experiencing long term water shortages, contamination, and other water-related concerns. Water security was measured using the Household Water InSecurity Experiences (HWISE) scale (household, community, service, and environmental water access measured with Likert-scale questions) and contextualized using interviews. Results demonstrate a high level of water insecurity in a sample of Six Nations households (57.5%, n=38); women were more dissatisfied with their drinking water (p=0.005), and younger participants were more likely to report contamination issues (p=0.02) and higher monthly water costs (p=0.03). Qualitative interviews informed these results, revealing that experiences of water insecurity and poor health were shaped by the degradation of traditional lands. This posed specific challenges for Six Nations women, who face physical and geographical barriers to water access while caretaking for their communities and fulfilling their roles as water protectors. Understanding the cultural history of Haudenosaunee women and their role in the governance and protection of water for future generations, as well as the colonial degradation of their roles and bodies, helps to situate the ways water security is experienced in gendered ways for the community.

KEY WORDS: Gendered water security; environmental dispossession; drinking water satisfaction; water access and perceptions; Indigenous water crisis; maternal Indigenous health

#### Introduction

Indigenous Peoples' experiences of water insecurity have not been meaningfully assessed to determine the relationship between household, community, and environmental access to reliable, affordable, and adequate water. Well-established methods of assessing water security tend to operate on measuring at the household level (Young et al., 2019). In Canada, large disparities exist in the access to safe and affordable drinking water for Indigenous Nations, with Indigenous households 90 times more likely to be without running water than non-Indigenous households (Boyd, 2011). However, measurements of Indigenous water insecurity in Canada rely on federal boil water advisories (BWAs) for Indigenous communities, and research leans towards qualitative community-level descriptions of water access and quality (Awume et al., 2020; Bharadwaj & Bradford, 2019; Latchmore et al., 2018). While there is some consideration of water vulnerabilities at the community level across research, household and individual water insecurity remains largely unexamined in Canada (Dupont et al., 2014; Plummer et al., 2014).

Water insecurity is compounded by racial and cultural barriers in the U.S. and Canada, with water contamination, poor housing, and plumbing poverty spatially clustering in Indigenous, Black, and non-white Hispanic households (Switzer & Teodoro, 2017). Water insecurity should be understood in relation to these racialized structural inequalities that exacerbate wealth and class gaps, as conventional data aggregation tends to hide the scale and scope of the racialized housing-water nexus (Meehan et al., 2020). Disaggregating at the household level aids in unveiling the geographic clusters that are fundamentally racialized (Wutich et al., 2017). It is unknown how impactful a baseline household water insecurity measurement is for understanding the severity of the Indigenous water crisis. The exploitation of traditional lands is deeply intertwined with the deteriorating health of Indigenous Peoples as relationships with the natural world provide nourishment, medicines, and landscapes to engage with local Indigenous Knowledge (IK) (Tobias & Richmond, 2014). The spiritual and cultural toll of ongoing water contamination for Indigenous Peoples is not often considered a relevant marker of health for water security assessments.

To better understand this, research questions and methods were co-created with Haudenosaunee (Six Nations) collaborators to assess water insecurity experiences at Six Nations of the Grand River First Nation. Through survey and interview data, we examine the relationships between household water security, drinking water satisfaction, and perceptions of water access for the community. The analysis is contextualized in political ecologies of race frameworks to examine how racial-colonial politics are imbricated in environmental practices and landscapes as intimately related but irreducible mechanisms (Van Sant et al., 2021). We situate the current water insecurity

143

and community health of Six Nations as entangled in colonial structural violence, as we cannot understand these experiences prior to historical traumas (Yellow Horse Brave Heart et al., 2011).

# Research Setting: Understanding Gender-Based Water Security through Treaties and Indigenous Knowledge

Six Nations is the largest reserve in Canada and has a population of 12,892 individuals on reserve and a total band membership of 27,559 (Six Nations, 2021). The community is located in the densely populated southern Ontario region, which holds 21% of Canada's entire population (Ontario Government, 2021). While a water treatment plant was built in Six Nations in 2014, only 9% of households are connected to treatment plant water mainlines and the community has experienced persistent concerns with water contamination and access (Plummer et al., 2014). The remaining 91% of community members rely on alternative water sources, such as wells or cisterns, and have to get their water for these storage systems trucked in by third-party providers or drive to pick up bulk water from the main water treatment plant or off the reserve. A recent water testing project found *E. coli* in 21.2% (n=14) of household tap water, and mercury was found in 25.4% (n=17) of households' tap water in levels exceeding the provincial drinking water guidelines (Duignan et al., forthcoming). Reported tap water uses from the associated survey indicated that 57% of contaminated tap water was still being used for activities that may heighten exposure risks (such as making beverages with unboiled water) (Duignan et al., forthcoming). These experiences highlight the need for a consistent index to quantify household water insecurity experiences, and a more systematic identification of who in the community is at a heightened risk for the health consequences of water insecurity.

Haudenosaunee IK creates an eco-centric framework to situate their approaches to health and water. The Thanksgiving Address, or *Ohèn:ton Karihwatéhkwen* creates a framework of knowledge that understands and respects the interrelated web of relationships that exist and form the natural environment. Water is the first environment in life, and Haudenosaunee women are understood to have a central responsibility for protecting water (King, 2007). While the water and community duties of Haudenosaunee matriarchs have been maintained through oral culture, colonial agencies and religious missionaries attempted to strip the Haudenosaunee Confederacy (HC) and women of their governance roles while enforcing status cards that documented identity through paternal lineages (Jacobs, 2010). Indigenous water insecurity experiences are a direct consequence of colonization, and exacerbated by ongoing contaminations, poor infrastructural resources for water monitoring, and environmental dispossession. Environmental dispossession encompasses "the processes through which [Indigenous] people's access to the resources of their traditional environments is reduced" and shaped by environmental contamination, resource extraction, land right disputes, forced assimilations, and widespread displacements of peoples from their traditional lands (Richmond & Ross, 2009, p. 403). Maintaining these relationships with the land and IK improves physical health as well as self-esteem and cultural pride (Parlee & Berkes, 2005). IK understands health as inclusive of the physical, spiritual, emotional, and mental wellbeing of a people (Martin-Hill, 2009).

Canadian water policies have been intentionally murky. Through the Indian Act in 1867, the federal government forcibly imposed their responsibility to Indigenous Peoples, despite an early royal proclamation outlining those lands belong to First Nations unless taken into the Crown (Slattery, 2015). The Indian Act forced a patriarchal form of governance which dismissed traditional confederacies or councils already in place and stripped Indigenous women of their traditional political powers and roles within their communities (Henry & Tator, 2006). While the federal government has fiduciary responsibility, it maintains that they are solely responsible for monitoring their water supplies through drinking water advisories (Phare, 2009). These policies have become embedded in the modern nation-state of Canada, as the expansion of provincial and federal lands was dependent on the forced dispossession of Indigenous lands and the removal of Indigenous children from their families through the residential school system (Truth and Reconciliation Committee of Canada, 2015). There is a direct connection between the health of Indigenous Peoples, their continued lack of access to clean water, and to intergenerational traumas and experiences of environmental grief (Stote, 2015). The gendered nature of environmental dispossession frames these extractive processes as contributing to the demise of Indigenous women's health in particular (Hanrahan & Mercer, 2018).

Six Nations is currently governed by the HC and Six Nations Elected Council (SNEC). The HC was formed to create an alliance under the Great Law of Peace, or *Kayannerenkó:wa*, with a matrilineal governance with a Grand Council of 50 male chiefs (Confederacy, 2020). After working in allyship with the British during the War of 1812 (not as subjects of the Crown), Six Nations was granted \$80,000 for their allyship and the Haldimand tract, due to this area being part of their traditional lands for thousands of years (Johnston, 1964). This money was later appropriated for infrastructure that would significantly alter these traditional landscapes (Johnston, 1964). The combination of early settler reneges on allyship coupled with ongoing forced dispossessions of their traditional lands around the Grand River has informed the dynamics of the current drinking water crisis (Ottenhof, 2021).

145

#### Methods

Water security was investigated through a co-created survey and semi-structured interviews and focus groups. Research ethics was approved by Six Nations REB, oral approval from the HC, and McMaster's REB (MREB #579). Survey participants (n=66) were recruited through a previous household tap and well water sampling study affiliated with this project (see Duignan et al., forthcoming). Interview participants were recruited through community events and the survey, with 18 individual interview participants and 7 individuals participating in two focus groups. All participants for both surveys and interviews were provided with a coffee store gift card for participation. No participants who volunteered for the study were later excluded, and none wished to withdraw. Data collection occurred between February 2019 and January 2020 by the first author.

Surveys were collected with assistance from community navigators and research assistants. Interviews lasted between 45-90 minutes, expanding on the topics covered in the survey to elaborate on the specific household and community concerns with water quality, access, and the impacts these have on Six Nations community and individual health. The paper and pen questionnaire gathered information on sociodemographic profiles (age, gender, household income), household tap and drinking water sources, drinking water satisfaction, and water security and access. Gender options were man, woman, non-binary, gender-fluid gender-queer, o other (with room to specify if desired), and youth were defined as 15 or younger. Indigenous collaborators indicated that this would help capture younger adults (legal minors age 16-18) that tend to experience earlier parenthood or earlier onset of chronic diseases (Duignan et al., 2020). Household income was reflective of the combined annual income of all household members, as the survey represented the household's general water uses, members, and experiences.

#### Quantitative Data Analysis

Data from the health and water use survey were coded numerically and manually. SPSS (v26) was used to manage and analyze survey response data. For the Likert-style questions, a Cronbach's alpha test was run to test internal consistency amongst questions. Survey data on perceptions of water quality and household water security ratings were analyzed using descriptive statistics and two-tailed Pearson correlations for gender, age, household income, monthly spending on water, and water security.

#### Household water insecurity

Household water insecurity was measured with the 12 item HWISE scale, the first validated scale quantifying household experiences of water insecurity for low and middle-income countries (Young

et al., 2019). Likert-style responses were asked for a 4 week recall period, individually scored between 0 (never or not applicable) to 4 (more than 20 times), with a 12 or above scored water insecure (Young et al., 2019). Five further subcategories were later developed (marginal to extreme water insecurity) using cut-points rather than "assess correlates of a less meaningful one-point change" in the HWISE scores (Jepson et al., 2021, p. 4). We used these categories to run ranked statistical analysis on household variables contributing to household water insecurity experiences.

Likert-type responses were used to assess interactions with water at the household, community (access to water around Six Nations for drinking or other uses in the community), service (access to water lines, or other public water services. Respondents were also asked to rate the quality of water in the rivers and streams in and around the reserve, to capture perceptions of water in natural and built spaces. This was to acknowledge that water contamination concerns extend past reserve geographies and encompasses a deeper relationship with traditional lands. The recall period for these questions was four weeks, with a scale of "not very satisfied" to "very satisfied."

## Gender and Age Analysis

Age and gender-based statistical analyses were run on water security, access, and quality questions. Non-parametric Kruskal Wallis tests were performed for age categories. Age categories were broken up into five categories of participants (<29, 30-39, 40-49, 50-59, 60+). Post hoc pairwise tests were conducted when there was a significant difference in age ranks. Mann-Whitney U tests were run to compare any differences in perceptions of water quality or water security by gender. Statistical significance was set at the p<0.05 level for all statistical analyses.

## Qualitative Data Analysis

All interviews were manually transcribed and analyzed by the first author and inputted into NVIVO software for data management and analysis, following the flexible coding of in-depth interview process for qualitative data analysis (QDA) as outlined by Deterding and Waters (2018). The analysis for these semi-structured interviews is a good fit for the flexible coding methodologies, as questions were co-developed with community members with prior knowledge of water concerns. Transcripts were indexed for salient "big pictures" of water security and quality concerns in the data, anchoring transcript content to interview protocol. Then, hypothesized relationships were developed between the concepts emerging from these big picture codes. After indexing, the first author developed analytic codes that focused on sections of transcripts that represented water security concepts, such as perceptions and relationships with water and the impact water has on

wellness. The final stage used NVIVO software to validate the concepts, build models, and test the data-driven coding.

# Results

# Descriptive survey results

The survey respondent demographic information for the 66 participating households is presented in Table 5.1.

Demographic		Frequency (n=66)
Gender		
Fema Male	le	48 (72.7%) 18 27.3%)
Age		
20-29 30-39 40-49 50-59 60-69 70 or	) ) ) ) older	6 (9.1%) 15 (22.7%) 13 (19.6%) 24 (36.3%) 6 (9.1%) 2 (3%)
Number of chi	ildren living in home	
0 1-2 3-5 6-7		30 (48%) 19 (30.6%) 12 (19.3%) 1 (1.6%)
Household Inc	come (CAD)	
<\$19, \$20,0 \$50,0 \$80,0 \$150, Prefe	0000 00-49,999 00-79,999 00-149,999 000 or more r not to answer	4 (6%) 20 (30.3%) 13 (19.6%) 10 (15.1%) 3 (4.5%) 16 (24.2%)

Table 5.1 - Survey Respondent Demographics, Income and Household Expenses

Drinking water source			
Tap water from treatment plant	3 (4.5%)		
Tap water from well	7 (10.6%)		
Tap water from cistern	8 (12.1%)		
Bulk water picked up from treatment plant	5 (7.5%)		
Bulk bottled water purchased yourself	43 (65.1%)		
Water delivery service (third party)	3 (4.5%)		
Other	1 (1.5%)		
Average Monthly Water Expenses			
<\$99	36 (54.5%)		
\$100-199	22 (33.3%)		
\$200-299	4 (6.1%)		
\$300-399	1 (1.5%)		
Prefer not to answer	3 (4.5%)		

# Water Security

There was good internal consistency for the HWISE scale ( $\alpha$ =0.815), indicating that its component statements are effectively measuring the same construct. HWISE scores ranged from 0 to 33, with a mean of 14.4 (±8.6). Water insecurity was reported for 57.5% of households (n=38). Water security scores are presented by Jepson and colleague's classifications in Table 5.2. Only one household recorded a water score of zero, which would still be classified as marginal water insecurity per Jepson et al. (2021).

HWISE Score (0-33)	Frequency (n=66)	
Marginal water insecurity (0-3)	5 (7.5%)	
Low water insecurity (4-11)	23 (34.8%)	
Moderate water insecurity (12-20)	21 (31.8%)	
High water insecurity (21-29)	14 (21.2%)	
Extreme water insecurity (30-36)	3 (4.5%)	

Household water insecurity ratings were tested against access variables as informed by community members, presented in Table 5.3.

Variable	Pearson Correlation	
Drinking water satisfaction	-0.314*	
Household water access	-0.356**	
Community water access	-0.252*	
Water infrastructure or service access	-0.273*	
Drinking primarily bottled water	-0.094	
Gender	0.000	
Age	-0.031	
Household income	-0.197	

Table 5.3 – Chi square significance for water security variables

\*Pearson correlation significantly significant, P-value<=0.05

# Drinking water satisfaction

Drinking water satisfaction scores for the total sample are presented in Table 5.4. There was a significant negative correlation found between gender and drinking water satisfaction, with women being more dissatisfied with drinking water than men (p=0.05). Increased age was also significantly correlated with increased drinking water satisfaction (p=0.042). There was no significant relationship found between drinking water satisfaction and income, or between drinking water satisfaction and drinking water satisfaction and income, or between drinking water satisfaction and drinking water satisfaction.

Table 5.4 – Household Drinking Water Satisfaction

Household Drinking Water Satisfaction		
Not satisfied at all	19 (28.8%)	
Somewhat satisfied	10 (15.2%)	
Neutral	14 (21.2%)	
Satisfied	15 (22.7%)	
Very satisfied	8 (12.1%)	

Water access for households, community, services, and traditional lands

Water access questions had a low Cronbach  $\alpha$  (0.614), which can be attributed to a lower interindividual variation, as 54.5% of respondents scored poor or very poor on all four items. Figure 5.1 depicts the results of each of these Likert-style questions. Of those who rated their access to water infrastructure more positively (either good or very good, n=12), only one respondent was on the main water lines from the treatment plant.

There was a significant correlation between higher water access ratings reported at home and higher water access ratings reported in the community (p=0.014). There was also a significant correlation between the higher ratings of access to water services and infrastructure and higher ratings of access to water in the community (p<0.001). There was also a correlation between higher ratings of water quality in and around the reserve with higher ratings of access to water in the community (p=0.02).



Figure 5.1 - Reports of access to water in household, community, infrastructure services, and in rivers and streams around Six Nations lands

## Number of Children Living in the Home

Female respondents had a higher number of children living in the home (p=0.003), and there was an increased number of children living in the home for older respondents (p=0.03). Less money was spent on water per month with more children in the home (p=0.03), and respondents with more children in the home were more dissatisfied with their drinking water situation (p=0.007). There was no significant association between water security scores and the number of children living in the home.

# Statistical Analysis of Water Security and Access

## Age-based experiences of water security and drinking water satisfaction

Table 5.5 presents the results of the Kruskal Wallis test for experiences of water insecurity, access, and drinking water satisfaction by age.

	Kruskal Wallis H
Water security	1.409
Household income	6.195
Monthly spending on water	10.578*
Drinking water satisfaction	8.019
Contamination issues	11.062*
Water access at home	8.784
Water access in community	3.379
Water service access (infrastructure)	5.692
Water quality in and around Six Nations lands	1.269
Drinking bottled water	5.944

Table 5.5 - Kruskal Wallis Test for Water Security and Access by Age - One Way ANOVA

\* Kruskal Wallis H significant at p<0.05

Age was statistically significant factor in monthly water expenses (H=10.576, p=0.03) and for contamination issues (H=11.062, p=0.026). Post hoc tests for pairwise comparisons found that those aged 40-49 had significantly higher monthly expenses for water compared to those aged 30-39 (p=0.005), and to those aged 50-59 (p=0.02). For contamination issues, post hoc tests found that those under the age of 29 had significantly higher rates of contamination issues than those aged 30-39 (p=0.02), and those aged 50-59 (p=0.001).

# Gender-based experiences of water security and satisfaction

Gender based results for water security, water access, and water satisfaction are presented in Table 5.6. Women were more likely to be dissatisfied with their drinking water (U=304.5, p<0.01).

	Mann-Whitney U
Water security	421
Household income	261
Monthly spending on water	348
Drinking water satisfaction	304.5**
Contamination issues	263.5
Water access at home	394
Water access in community	411
Water service access (infrastructure)	418.5
Water quality in and around Six Nations lands	392
Drinking bottled water	417

Table 5.6 - Mann Whitney U Tests for Water Security and Access by Gender

\*\* Mann Whitney U significant at p<0.01

## Qualitative Analysis

Three major water security discourses were used by participants to explain their knowledge of water quality, access, and community health connections: 1) Definitions of "good water" differed by generation; 2) women were experiencing more heightened health and social challenges due to water insecurity; and 3) the community degraded more as water became more contaminated.

## "Good Water" Differs by Generation

Participants identified a difference in how generations understood what constituted "good water," with "old timers" and "younger generations" being referenced by participants. The "younger generation" perspective tended to be held by individuals who were in their forties or younger. "*I classify tap water as water, but then the good water is bottled water. So I would, if I was out of tap water, I would use the good water" (Female, 42, P#16).* Old timers were understood to be seniors, aged 60 and above. Participants in their forties and fifties had clear memories of being able to swim in the Grand River as children, and their parents and grandparents using traditional water sourcing, such as fetching water from creeks with buckets and pails without needing to boil it.

Growing up I lived in Caledonia, my dad's non-native. So until I got my status, the water I drank in Caledonia is extremely hard. My grandpa would go get water out of the crick, go get the buckets, and then he'd keep it in a great big metal bin, with the cup - metal cup thing - on the side. When I got to my grandpa's, I would drink a ton of water, because that water tasted so good and so fresh. Drink a ton of it! It was always so cold, but I wouldn't drink the water at home. (Female, 46, P#19).

For a participant that had to negotiate identity through status card legalities, traditional well water represented an immediate connection with cultural practices she otherwise felt distanced from in childhood. An older male participant highlighted the value of traditional water sources as a way to reconnect relationships to water. *"When we hook up to the water line, we divorce ourselves of the responsibility we have to the water, people don't understand their wells are their responsibilities, and they don't know how to use or care for it. This goes beyond just household care and extends into a deeper care for community health, for environmental relationships" (Male, 69, P#12).* Settler-colonial values were integrated into many participants' understandings of recent shifts in thought about tap or running water quality as "good" water. These values were also incorporated into many understandings of the water treatment plant and watermain lines. One younger participant identified traditional values as being difficult to work with.

There's a general acceptance, I think in our community, that the water is bad. And for a lot of older people, they're okay with it. Um, I've heard people not want to even make it an issue and say, 'Oh, I drank out of that. Well, since I was four years old, you know, I'm 70, I'm healthy as a horse. Just add a little bit of bleach every little bit, you'll be fine.' You know, like it's that kind of mentality that in a lot of younger people don't want to drink it, but the pressure from older people is stop being such a, you know, such a wimp. (Male, 21, P#21). Some participants stressed that these older values were difficult to maintain with current water contaminations, but that older people didn't want to be squeaky wheels, especially when living in low-income households or with limited mobility. *"Elders are staying at home not doing a lot of stuff, wanting to get out, share their knowledge with the youth… everybody needs a use. If you have a use, you're part of the community, you're loved, right?" (Female, 46, P#18).* Mobility challenges including getting water trucked in for their wells, since lifting the jugs or making the drive out to get water was harder to do with deteriorating physical health. Participants identified water access being important not only for hydration but also hygiene. *"Water is the core of healing to me. I was diagnosed as a pre-diabetic last summer, and drinking my water - the treated water, and sometimes bottles. That's all I did. I drank water all the time, and now I am not considered pre-diabetic." (Female, 62, P#10).* Older participants were keenly aware of the importance of water for their good health, for navigating new health conditions and connecting to cultural practices.

Older participants considered 'good water' as flowing naturally, noting a distrust of taps connected to mainlines or "Western" wastewater practices. Many of these distrusts of tap water were explained as being due to community governance changing in more recent years.

When I was younger, the people didn't wanna be Onkwehonwe, they didn't wanna be Native, they moved off the reserve... And now they're moving back with their kids, coming back and now taking over band council or doing whatever. They're trying to make the decisions down here, when the people that have always lived here, we see how things are, and it's very cut and dry on how we're supposed to be." (Male, 42, P#11).

Some tensions in how water contamination not being prioritized emerged from generational differences in perspectives. "*There are people that follow traditional ways, and then people that are more towards the Council ways, but... it's not really their fault they're like that, because of the split, it's from colonization... just kinda respect each other's views to make the community healthy" (Female, 24, P#2).* 

Younger participants understood 'good water' more by accessibility of drinking water. "It makes a big difference when you don't have running water. I have to get pails, a pan to boil, and keep it in the bathroom." (Female, 35, P#18). The higher costs associated with driving for bottled water was mentioned as a barrier as well. "To have to like, haul water so much, cause I know different people have to get their water every month or every couple weeks, cause they need to do their laundry and you know? (Female, 21, P#3). For younger households struggling to haul water, water sharing between homes was a strategy.

A lot of times my brothers would come over and shower, because they didn't have running waters... out where he lives, it stunk! Because of the sulfur in it. Couldn't cook with it, shower, use the toilet. It's kind of a struggle, for people" (Male, 21, P#21).

There was also more open discussion amongst younger participants around traditional water sourcing not always being appropriate because of contamination.

My child's family doesn't have running water, they don't have a tub, they have to fetch their water out of a bucket from a well... the mice and the mould, I don't know how people find the norm in that. But it's the way you were brought up, how your parents were raised, and they think that's, you know, healthy for you. Like you don't need running water, you can boil the water. But it's - like times are different now, water's being affected, things are getting old" (Female, 23, P#1).

Younger participants felt that many community members normalized older and deteriorating housing and well infrastructure, built in the 1960s and 1970s, because they couldn't access the watermain lines.

Participants also spoke about younger generations being more mentally impacted by intergenerational traumas and immense grief from many of their peers committing suicide. Water acts as a medicine for some participants and their young adult children. *"My son has struggled mentally since losing his [family member]. So there's been times when I've needed to calm him… I literally sit him down to drive him, get there, take socks and shoes off, and get him and walk him in that water" (Female, 42, P#16).* Beyond accessing the river, water in its other forms (sweat, tears, drinking, looking at it) were mentioned as ways that youth would ground themselves in moments of crisis. *"Just somehow whether they're ingesting it or it's coming out of us or we're immersing ourselves in the water again. That's what calms [my kids] spirit in one way or another, is that water, it's a release." (Female, 41, P#20).* Youth awareness of the climate crisis and its effect on their community's health, water quality and access are understood as extending beyond individual use and more integrated with environmental and community health.

## Women and Water Insecurity

Participants spoke to the significant gendered challenges that came with accessing water. Mothers, both new and more seasoned, expressed their access concerns for themselves, their children, and elderly ailing parents they took care of. *"Especially having [her elderly mother's condition], she gets diarrhea quite a bit. I need to use a lot of water to do her laundry and bathe her, it's hard to ration towards the end of the month" (Female, 35, P#18).* Several women reported rationing water

deliveries, to make sure it lasts each month for their households. "You have to budget your needs and prioritize against access to water, I spend about \$120 a month on trucking water into my, into my cistern. Another 10 to 15 bucks on drinking bottled water." (Female, 33, P#17). Schedules changed for mothers who had to balance the water deliveries and septic truck schedules that always seemed to be at odds with each other.

There was always a period every single month that I would be freaking out like, don't flush the toilet unless it's a number two, don't do the dishes in the sink, dump the water outside in a bucket and stuff. (Female, 47, P#6).

The coordination of septic maintenance and well water delivery was important to ensure their wastewater is properly disposed of. Mothers also recounted physical challenges of hauling bottled water jugs for their families. *"I have to drive 10 kilometers to get my bottled water, if my husband isn't here to do it, and those are 30 or 40 pounds. It's hard to lift that for doing dishes" (Female, 29, P#14).* Respondents spoke to how heavy their bottled water jugs were while holding young children. While the drive and hauling of water from off reserve feels normalized, growing concerns with more children and aging bodies adds to the daily stress of accessing clean water.

Postpartum mothers faced significant challenges with water access for physical healing after delivery. Many did not have clean water at home to prepare either traditional medicines or Western sitz baths needed for perineum healing, relying on others to assist them during a period of limited physical mobility postpartum.

I had to bring my - had to have my water made by my midwife, she brought it to me in a jug to drink. I didn't have a place where I could make a big pot of medicine, that's how you're supposed to. So it interferes with my practices, my beliefs, that I don't have enough water to make my medicines. (Female, 24, P#2).

No clean water meant that many new mothers became dehydrated, which affected their ability to breastfeed. *"If a mother's not drinking enough water, I've seen it affect breastfeeding, the amount of milk she makes. If she's dehydrated and you tell her that you need to increase your milk, um, by drinking water, it's a direct correlation" (Female, 44, P#9).* For those that wanted to pursue formula feeding, they also worried about boiling their water enough if their household water was dirty. *"I don't have access to clean water, it's been tested and was positive for bacteria contamination, it's unsafe to drink. And I make formula for my youngest, but I don't want to use that water. So, I don't have the water to actually make the formula. Everything's increased cost, poor health, you know what I mean?" (Female, 29, P#14).* 

Household water insecurity extended into feelings of shame or upset as mothers reiterate to their children they have to conserve water. *"It's shitty having to say don't flush the toilet. You can't do the laundry. You can't have a shower today, you know? Makes you feel like, I don't know shameful, but not for the outside world, but just from my mom's perspective" (Female, 42, P#16).* These intertwined with emerging concerns that several young mothers had about the rise of eczema and skin rashes their young children had.

Like it's bad. My Healthy Babies worker said she had about 12 clients and at least half of them had babies with severe eczema. They're all kinda thinking it maybe ties to water, like how, um, when my son bathes, his eczema breaks out, and it gets worse, it gets really itchy and it gets really dry... I don't know if it's the hard water in that general area, if it's something in the ground, or it's something we're eating or? ... I don't know anybody our age or even around our age that has eczema as bad as all of our kids do now. (Female, 23, P#1).

Perceptions of the source of the rashes was a bit divided, with some suggesting it was from tap water bleach treatments, and others suggesting it was a lack of water in the household that made rashes persist. *"Bleach is the answer to all our water problems here. That's what everyone says, just put bleach in it" (Female, 33, P#17).* These concerns all contributed to feelings of mother-guilt or shame about what their children had to normalize.

#### Community Degradation Related to Increased Water Contamination

Participants identified that environmental degradation of the Grand River was linked with the degradation of community health. There were many concerns about agricultural activities in the surrounding area impacting the water table. *"We get the swill water from farms right out back from our property, and all the lagoon water levels are connected to how much water is moving from that swill, that impacts my well water quality" (Male, 56, P#24).* Concerns about population growth and activity upstream were identified as potential sources of harm. *"We live downstream of a million people - and that keeps growing - and we have a spiritual attachment to the river. We're almost genetically attached, we've been living by this river so long. We have many concerns about its contamination by settlers" (Male, 37, P#4).* 

Nearly all participants spoke about the abandoned gypsum mine as contributing to community water contamination or that it impacted the water table levels.

That gypsum mine that... they were never supposed to dig under our reserve, and they dug under, and it affected the... some watersheds, some, some places where water was, it affected it, and... so I know some - there are some places that are bad. (Female, 33, P#5). There was no clear consensus on how it was impacting water quality and availability, but it was understood to affect the physical environment and play a role in shaping community values. *"When I look outside my yard, I don't see anything but recklessness. It's very outrageous, it's very unreal… there's no regard for environment at all. Understanding that's what sustains us, it's hard not to worry about what's going on upstream." (Female, 59, P#8).* 

Imagery of whiteness was used to explain the degradation of river water quality. One participant recounted this through a story of growing up and swimming in the Grand as a child: "My sister grabbed me and threw me into the river, and when I came up to the top, there were roots in the bank and I was climbing up on them and saw lab rats there. They were white and had pink eyes! I screamed my head off" (Female, 46, P#8). Another participant mentioned that she didn't feel completely trusting of sediment coming out of her taps that were connected to the treatment plant. "I still get this white stuff that comes out of my taps. And they came out and checked it and said "There's nothing there!" and it's like, okay, but it still comes out" (Female, 47, P#7). An older male participant spoke of Nestle's aquifer extraction through the return of the bald eagles to the river around the same time. "Our symbol for Six Nations is the white pine, the tree of peace, and it has an eagle perched on the top of it. When the bald eagles returned to the river, when Nestle came in, I was uncertain what it meant. It's either, uh, the return of the river to good health, or it's the threat of American companies, seeing our water as prey" (Male, 76, P#13). This imagery spoke to the relationship between their community and the environment being interrupted and extracted by whiteness - medical, chemical, and industrial changes to their waters and Peoples occurring simultaneously.

Participants described financial values as being prioritized within the community, which were seen as out of line with traditional relationships to nature, impacting the health of the environment, languages, and culture.

Ain't nobody really giving thanks to those waters no more ... like they say once nobody can speak our language anymore, that we'll be no different than white people. Language is important, cause that makes you sovereign... so that goes into our mind-setting. (Male, 37, P#4).

As water is so intricately tied to wellbeing, having clean, flowing water was also seen as critical for the sovereignty and health of their people.

Water stagnancy was mentioned by many participants, inclusive of sewage pools, upstream damming projects, and muddy river water. This informed participants' understanding of early treaties between settler European and Haudenosaunee Peoples.

*P#4 (Male, 37): To me it feels like those big industries are all polluting the water on purpose to keep - they're buying these parts of the land, where they can get the good water, so that everybody will have to buy water off 'em. This is where they're going. But our original treaties that we've made have stood for the duration of time so far has been... as long as the grass grows, the water flows, and the sun rises, our treaties will always be honoured.* 

While participants understood treaties were to be honoured while water flowed, the increasing stagnancy of water is a reminder of settlers failing to live up to these treaties.

Despite all participants acknowledging their river water is contaminated, some participants suggested that there were ways to reconnect and heal the water and their relationship to it. "A part of our teachings I was told was that no matter what happens, if you speak the right words to it, it will still serve its purpose the way it's supposed to." (Female, 35, P#18). The sacred relationship with water was a source of inspiration to continue fighting for clean and accessible water. "A teaching I got when facing challenges was to be like the running water, and how it will always find a way through. If it keeps flowing long enough, it will create its own path." (Female, 56, P#15). These visuals of flowing water remind participants of the treaties established and the relationships and responsibilities they have to their water and their community.

#### Discussion

Despite a wide range of household incomes amongst survey participants, it was not a statistically significant indicator of water security, access, or satisfaction amongst participants. Similarly, the number of children within a home were not significantly associated with increased water insecurity. These results are surprising, as the costs of purchasing and treating water cause financial stress for other marginalized communities, with many households spending disproportionate amounts of income on sourcing water from informal vendors (Brewis et al., 2019). Given the persistence of water insecurity and water contamination experienced by Six Nations community members over generations, it is possible that some degree of water issues are normalized by older community members influenced how water insecurity was understood and rated. Water quality is not always a priority for many community members, due to more prevailing concerns around personal health and the impacts of intergenerational trauma. The acceptance of lower water access or quality may also be influenced by this for older generations, while younger generations demonstrated in interviews and survey data that they are more outraged and dissatisfied with their water situations.
The wide diversity in water sourcing within the community contributes to the high level of water insecurity captured in this data. Some households are on the main waterlines, others able to adequately access bulk bottled water for their wells, and some have no running water in their homes, limited physical or financial ability to haul water or truck water in. Water discourses in interviews demonstrated that participants understand household water security through access, affordability, and quality, but that water security was also more deeply entangled in community and environment health, and concerns for future generations. Personal accounts demonstrated water insecurity was navigated through high mobility, water sharing, and other adaptive behavioral changes to make household water last longer. Women, and particularly mothers, were the most distressed about their household water situation. A strong focus on maintaining an emotional and spiritual relationship with water informs how water security is understood in more culturally appropriate ways.

Indigenous water insecurity experiences extend past household experiences, with previous research on American plumbing poverty finding Indigenous households had greater odds of having incomplete plumbing, even after accounting for income and other sociodemographic variables, suggesting that experiences were more dependent on infrastructure access being racialized (Deitz & Meehan, 2019; Pulido, 2017). In interviews, participants identified community and environmental health as being heavily influenced by the degree of industrial extraction and colonial presence on the land. Being on or around water bodies was healing to mental and emotional duress and allowed people to connect to Haudenosaunee teachings through watering sovereign gardens or picking medicines riverside. The land sustains the Indigenous Peoples health, so when communities are environmentally dispossessed, they are no longer able to properly respect and connect with living and nonliving things (Berkes & Ross, 2013).

Haudenosaunee IK demonstrates that water is sacred. McQueen (2020) highlights how Mohawk language situates water: *nek ne ohné:ka íken* means "it is all water"; *kahnekanó:ron* means precious or rare water, and *yóken tsi kanó:ron* means visibly precious, which is how they speak about the rain. These teachings demonstrate the vitality of water for all living things. Language, beliefs, and gendered identities are all shaped by the importance of water, and so perpetual issues of water insecurity, contamination, and poor access felt socially, spiritually, and culturally as well. Haudenosaunee water insecurity encompasses individual, household, community, and environmental relationships with water.

#### Six Nations Water Insecurity as Environmental Dispossession

While the term water insecurity was not used much across interviews, understandings of water insecurity (issues of access, affordability, and quality) were entangled in understandings of community, culture, environment, and future generations. Indigenous experiences of water insecurity elsewhere have also demonstrated that they have more nuanced experiences that extend past household boundaries of water access. A study on American plumbing poverty found that Indigenous households had greater odds of having incomplete plumbing, even after accounting for income and other sociodemographic variables (Deitz & Meehand, 2019). This suggested that plumbing poverty itself was not so much dependent on housing conditions, degree of rurality, or income, but influenced by the infrastructure provision access being racialized (Deitz & Meehand, 2019; Pulido, 2017; Ranganathan, 2016).

Similar to experiences of plumbing poverty being shaped by racism, long-term experiences with racism are more likely to inform these water insecurity experiences than household income. In interviews, participants connected community health degrading with the water and land contaminations and connected both to colonialism and encroaching industrial and settler values. Water was not only needed for daily household and hygienic uses, but being on or around bodies of water was a source of joy, aiding in healing from mental or emotional duress, and was identified as a way to connect to Haudenosaunee teachings and practices in tangible ways (such as watering sovereign gardens or picking riverside medicines). As the land sustains the health of Indigenous Peoples, when communities are environmentally dispossessed from their lands, they are no longer able to properly respect and connect with living and non-living things (Berkes & Ross, 2013; Richmond et al., 2005; Tobias et al., 2013).

This study found that environmental dispossession occurred directly (through the physical separation of Haudenosaunee Peoples from their land) and indirectly (violent assimilations and cultural genocide) for Six Nations participants (Lewis et al., 2021). The contamination of the Grand River leaves community members unable to participate in traditional practices, and worried about pollution of wild game and gardens. New mothers experienced dehydration, and their connections with their children suffered because of not being able to breastfeed. Similar experiences of direct environmental dispossession were documented in the Mohawk community of Akwesasne in Quebec, where industrial chemical dumping into the St. Lawrence River contributed to high levels of PCBs, found at high levels in Akwesasne mothers' breastmilk (Schell, 2020).

Indirectly, Six Nations has been environmentally dispossessed through ongoing and forced reduction of their unceded territories, and increased upstream settler populations, industry, and

agriculture contributing to the downstream pollution of the Grand River. By 2021, over 95% of the lands originally granted to Six Nations after the war of 1812 had been intentionally flooded for the Welland Canal, turned into private plots, farms, or absorbed by settler municipalities, such as Waterloo and Kitchener (Hill, 2017). These attempts to reduce Six Nations territories was most recently seen in the 1492 Land Back Lane protests. In July 2020, a group of Six Nations community members protested Caledonian housing development at McKenzie Meadows in a tract of land that had not been ceded by the HC. The HC placed a moratorium on development in March 2020, based on their Land Rights Statement (2006), aiming to "end the exploitation of lands and resources along the Tract" (Protect the Tract, 2020, **9**4). After six months and several court injunctions against the land defenders, it was revealed that the Ontario Provincial Police had spent \$16.3 million on policing and surveilling those blockading MacKenzie Meadows (Forrester, 2021). These ongoing development projects encroaching on what is left of Six Nations lands highlight the level of policing, surveillance, and violence used to dispossess contemporary Haudenosaunee Peoples from their lands and has a long-term impact on the health of the community.

Colonial water laws, and specifically water settlements, maintain racial capitalism through the denial of Indigenous sovereignty (Curley, 2019). Curley argues that colonial water governance is a form of racial governance that creates colonial enclosures, which are "built on a lineage of law that replicates and perpetuates edicts of dispossession and colonialism that are foundational to the United States" (2019, p. 719). By enclosing on Indigenous sovereignties through western legal frameworks, these extractive legacies and relationships actively dispossess future Indigenous generations of lands and waters and increase vulnerabilities to mental health issues and suicide (Noronha et al., 2021).

As interview participants discussed, the slow degradation of the water reduced their access to plants and water used for traditional medicines. Traditional medicine practices allow Indigenous communities to restore their balances and heal by integrating traditional medicine into activities and ways of life (Martin-Hill, 2009; Wesley-Esquimaux, 2009). Preserving these community practices for Indigenous Peoples is found to decrease group distress and promote spiritual health (Cianconi et al., 2019). Participants shared that working through trauma is best accomplished through land-based healing, as the land and waters are the intervention. Having the control and power to access land is vital for this healing.

### Gendered experiences of drinking water satisfaction

From survey data we found that women were more dissatisfied with their drinking water situations due to quality, source, and cost. The consequences of water insecurity are far reaching, and globally, women are more likely to report water insecurity and gendered barriers to reliable drinking water while also taking on most household water acquisition responsibilities (Brewis et al., 2020). These roles affect emotional stress, mental and physical health, and infant feeding practices (Schuster et al., 2020). Indigenous women and girls are more regularly discriminated against and experience more inequalities in their rights to safe drinking water and sanitation in many parts of the world (UN World Water Development Report, 2019). Other studies exploring Indigenous drinking water satisfaction have found that gender influences perception of drinking water quality, along with past experiences of BWAs, water supply trust, and cultural perceptions of water (Bermedo-Carrasco et al., 2018).

Interviews revealed that women faced more barriers accessing water for their households. Many of the women are caretakers for their families and communities, and sourcing water was more physically challenging and emotionally straining for them. Haudenosaunee IK understands the gendered roles of water protection and acquisition within Six Nations extend beyond household boundaries and inform women's drinking water dissatisfaction. Haudenosaunee women have always been spiritual and political leaders for their protection of lands and waters, with Clan Mothers authority demonstrating the value in feminine characteristics like peace and compassion (Jacobs, 2010). The impact of colonialism on Haudenosaunee women's status and power had a fragmentary effect on both societal and familial structures (Anderson, 2000). Water security and drinking water satisfaction for Haudenosaunee women is central for identities, spirituality, and cultural wellbeing as well.

## Age-based experiences of water

Age was found to be a significant factor for monthly water expenses. Those aged 30-39 were significantly more likely to spend more per month on water expenses, though no significant age-based differences in water insecurity scores. These results speak to the complexity of how water insecurity experiences may be buffered, as there were not significant relationships between water insecurities with income across age groups. Six Nations experience high levels of mobility, with multiple generations living within the home in transient ways (Duignan et al., 2020). As younger households were more likely to report higher monthly water expenses, it is not clear whether this is

due to supporting inter-generational or inter-house mitigations, or if water insecurity and other health concerns were incorporated into these expenses.

Interviews demonstrated a clear difference in how younger and older generations understood water quality, or what constituted "good water." They also address that older community members were facing higher challenges accessing water, given their low mobility and low household incomes. Younger generations spoke readily of many different community resources that they relied upon, as well as increased concerns with local water contamination. Many interviewees were concerned about consumptive industrial water takings (through permits to take water from aquifers or removing groundwater from the source). There were significantly concerning for Haudenosaunee youth interviewed, and to the community at large (Doan, 2018; Gerber, 2021; Nohorona et al., 2021). Majeed and Lee (2017) argue that due to environmental uncertainty that climate change creates, youth globally may be more susceptible to depression and anxiety in general. Specific sources of stress, such as poor water quality, explain "why environmental change and degradation reverberate so powerfully" within Indigenous communities (Seltenrich, 2018, p. 2). The statistical associations and interview data all demonstrate the strong cultural connections between water, plants, and animals, as expressed in the Ohèn:ton *Karihwatéhkwen*, and highlight the importance of creating more culturally appropriate and placebased ways to assess how people are impacted by the water and climate crisis.

#### **Study Limitations**

A small sample size and gender bias limit this study's interpretations. The survey accounts for 2.3% of the population living at Six Nations First Nation, and respondents were overwhelmingly female. While there were no statistically significant relationships between gender and water security, a more gender balanced study sample might have revealed stronger directional relationships. This is a limitation from a statistical analysis perspective, but the female respondent bias is consistent with who is more likely to participate in studies at Six Nations. Community health assessments have been consistently over-represented by women in the community, particularly women aged 50 or above, with less known about the health or water uses of men in the community (Source Water Protection Survey, 2010). The survey was based on self-reports and was cross-sectional, limiting causal inferences that can be made. In instances where missing responses were excluded, the sample size was further limited (particularly around household income). As other researchers have suggested, non-responses, particularly for Indigenous communities, can be the result of cultural reasons or due to survey length and research fatigue in the community (Newell et al., 2020).

## Conclusion

Six Nations community members experience high levels of water insecurity that are informed by the degradation of their traditional lands. While many older individuals were not as dissatisfied with household drinking water or access, interviews revealed that they struggle with accessing water, particularly if they have personal mobility issues. Many Haudenosaunee women, particularly those with children, face physical and geographical barriers to water access while caretaking and fulfilling their roles as water protectors. The gendered experiences of water security are situated through an exploration of how harmful colonial legislature such as *The Indian Act*, the Royal Proclamation, and racial enclosures through western water laws have forcibly dispossessed Haudenosaunee Peoples from their lands and opposed Haudenosaunee women's traditional roles as water protectors for future generations. While the survey results around water security and access are more linked to household-level experiences, data on community and environmental access demonstrated that cultural expressions of water insecurity also encompass land rights, environmental degradation, IK, and intergenerational healing. Across Indigenous Nations, women and water are interconnected, and so in determining how to create water secure futures, it is vital that Indigenous women not only participate, but lead the decision making, research design, and dissemination for their communities.

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## **CHAPTER SIX: DISCUSSION AND CONCLUSION**

## **6.1 Introduction**

The purpose of this research was to explore the connections between water security and health and well-being at Six Nations of the Grand River First Nation, with the goal of understanding the nuanced factors that inform perceptions of drinking water, heighten exposure risks to water contaminations, and identify who within the community faces has higher risks of water insecurity. This project was a co-created research endeavor that integrated Indigenous Knowledge (IK) with biocultural approaches to understanding water security, satisfaction, quality, and relationships as part of the broader foundation of Haudenosaunee health. An overarching question across all studies within this dissertation was "how can we co-create comprehensive assessments of community health and water security with Six Nations that adequately reflect community research interests, concerns, while respecting Haudenosaunee cultural, social, and spiritual, and environmental frameworks?"

Three separate (but interrelated) studies, formatted as journal articles, explore these research questions:

- A theoretical analysis of the realistic co-creation processes that frames the development of a health survey as a boundary object used to build relationships and explore tensions, successes, and barriers to knowledge (Chapter 3, Study 1);
- An examination of household taps and well water contamination in relation to the physical and mental health of individuals living in a sample of households from Six Nations, and an assessment of tap water uses that may heighten exposures to *E. coli* and mercury (Chapter 4, Study 2);
- Gendered and age-based perceptions of drinking water quality, water security experiences, and assessment of water access at community, infrastructural, and environmental levels (Chapter 5, Study 3).

These studies reveal how water security is experienced and understood for Six Nations Peoples, and how this can inform the co-development of tools and future research that is tailored to local knowledge and water relationships. These three studies were designed to create new interdisciplinary knowledge about community health as it relates to water security. Additionally, they provide an integrated examination that can inform future community health assessments as well as any potential programming or policies around community wellbeing and adaptation through climate change and environmental losses.

Within this chapter, I discuss the major themes of the three studies through an exploration of the three bodies, individual, social, and politic, that interact with water and health within Six Nations. I then discuss key findings within each chapter that contribute to critical medical and biocultural anthropology. Finally, I provide a summary of how they contribute as an integrated whole to help guide future research directions for co-created water and health research with Indigenous Peoples.

## 6.2 Main Findings through Three Bodies

This thesis consists of three interrelated studies, as Chapters 1 and 2 highlight. Each chapter broadly examines one element of water as it relates to Haudenosaunee health, be it through theoretical and methodological explorations, known water contamination and self-reported health, or personal experiences of water security and relationships with the natural world. To weave these findings together, I adapt Hoover's (2017) framework of the Three Bodies to structure the discussion about the findings that emerged on the impact of water contamination and health issues.

Hoover's approach is a loose adaptation of Scheper-Hughes and Lock's three levels of the body (1987): the individual body-self, the social body, and the body politic. Hoover (2017), however, utilizes these three elements of the body to determine what Akwesasne community members see as sources of their health issues as they relate to environmental contamination, and how those might be effectively addressed. Table 1 highlights the variations on this approach from Scheper-Hughes and Lock's theoretical article, Hoover's analysis, and my adaptation of this structural approach to guide this final chapter. This discussion will take a similar approach to Hoover's, but I conceptualize the individual body as more bounded by household, the social body as the complexity of the Six Nations as a community and the research community of practice (RCoP). Like Hoover, I use a similar understanding of the body politic to Hoover to understand the implications of co-creation research, multiple governments, and community collaborators as they intersect on health and environment research.

	Scheper-Hughes and Lock (1987)	Hoover (2017)	Duignan (2021)
Individual Body	The singular human body as the imitation of heaven and earth in all its details	Individual bodies in relation to environmental health, dependent on the balance of the natural world, and the health of one organ depending on relationship with other organs	Understanding of individual bodies informed by <i>Ohen: ton</i> <i>Karihwatehkwen</i> and interrelatedness of one body to others; household as a body in and of itself (as statistical analysis understands individual physical and mental health in Study 2 as related to household water use)
Social Body	Described as a natural symbol to use in thinking about nature, society, and culture; a body in health is seen as a model of wholeness	In traditional Haudenosaunee culture, the elements of the natural world (including humans) are part of the social body	Aligns with Hoover's social body; human health effects can be shared with ecological, cultural, and racialized effects; understands the community as a body ("when the community is sick"), even if household or individual bodies vary in their experiences of sickness or health.
Body Politic	Stability of body politic rests on body's ability to regulate populations and discipline social bodies; exerted on individual bodies as well	Recognizing the complicated, and sometimes contentious politics of Akwesasne; inclusive of two separate local governments, three state and provincial governments, two separate longhouses, religious establishments, two separate health clinics, and outsider political bodies	Recognizing the complexities of local governance through Haudenosaunee Confederacy and SN Elected Council, health services, co-creation with McMaster researchers who have in their own team interdisciplinary approaches and act as outsider political bodies as well; the provincial and federal governments; industrial bodies such as Nestle (or currently Blue Triton Water)

Table 6.1 - The Three Bodies Foundation for Discussion of Main Findings

# Individual Bodies

In Western and biomedical health settings, the individual body is at the centre of the issues needed to be addressed. Similar to Hoover's (2017) discussion of individual health in the case of environmental contamination in Akwesasne, there have been prominent concerns within Six Nations over data sovereignty in past health research, as past health research did not share data in ways that could identify contamination exposure or health risks at the individual level. Part of the driving force behind co-creating the community health and water surveys over the last five years was that past health research was conducted by federal or research institutional bodies that

aggregated data to situate health as in the community, or the social body. Individual health data are captured here, partially, as they relate to individual health experiences, specific household water sources, uses, treatments, and contaminations.

The individual body in this discussion is representative of individual health as it was related to gender and age (Study 3 interviews), but more generally understood as within the household. I situate the household within this, as it is near impossible within the data sets to detach the 226 individuals represented in the survey from the locus of the household that forms their relationships to water contamination. While individuals may embody their tap or well water in different ways and may take on different roles in the household dynamics, each member within the household largely relies on the same water sources, treatments, and uses.

Discussions of individual bodies came up predominantly as it related to physical and mental health that was seen as connected to water quality or access. This was especially true with mental health, skin conditions such as eczema for children, and gastroenteritis (Study 2). Individual body experiences of poor health were understood not as individually faulty bodies so much as bodies without total control. There were few if any discussions of individual bodies being in poor function because of personal choices, with the dominant paradigm being that individual bodies experienced water contamination and insecurity in localized ways that many felt they had little to no control over. As an example, in Study 3, many young mothers in interviews mentioned their struggles with their newborns and toddlers having extreme cases of eczema and other skin rashes. While these were reported at individual levels, they all drew the connections to the rashes as arising from either dirty water or a lack of water.

One of the struggles that seemed to emerge from these individual experiences and perceptions was that there was, at times, a normalization of continued water contamination or poor access, particularly by the older generation. This may have impacted how particular survey questions around drinking water satisfaction and household water security were answered. As noted in Study 3 by one interviewee, many people who were older wanted to avoid being seen as the squeaky wheel. These findings point to how a certain level of normalization may occur for some households or individuals living within a community that has led to water contamination and land degradation remaining unchallenged. Drinking water satisfaction can be hard to quantify, and this study demonstrates that perceptions of drinking water vary based on household ability to purchase or treat water. While it was expected that household water access would be quite low and related to high water insecurity scores, this was not always the case. Not only was there a wide range of household incomes (ranging from as low as \$19,000 CAD annually to \$150,000 CAD or more

annually), but there was also a range of spiritual practices, and generational and gendered identities that further informed the extent to which water contamination and inaccessibility were felt by individuals and households. Qualitative data captured in the survey and through interviews suggests that many individuals feel incredibly dissatisfied, if not entirely angry or frustrated, with the responsibility of securing safe and reliable water falling on individuals or heads of households, as this means having to pay out of pocket for something that they understand as a human right. Previous research with Six Nations also found that there was a distrust in drinking tap water, due to a lack of institutional trust, service dissatisfaction, and a loss of cultural control (Dupont et al., 2014).

### Social Bodies

The social body of Six Nations was encapsulated in conversations with participants about whether "the community" was sick or healthy. As demonstrated in Haudenosaunee Knowledge frameworks, the foundational understanding of "the community" was also in direct relation to the land: when the land is sick, the community is sick too (or, conversely, if the land is healthy, the people are healthy). The idea of "community" can be contentious, in that it flattens the diversity of perspectives and experiences (Firestone, 2003; Kepe, 1998). I argue that when exploring water insecurity within a community that has a broad range of religious and political beliefs, income, education, family, and social responsibilities, having one particular definition of community does not always provide an identity that fits everyone within it. Certainly in my own use of the word community throughout this dissertation that term evokes changes within each study: in Study 1, there is a community understood through a research relationship, in the development and maintenance of a Research Community of Practice (RCoP); there are also community stakeholders, who are people within the community that have elevated knowledge or experiences that create the initial representations of what research design and direction is wanted by the full Six Nations population.

In Study 2, community is understood as the grouping of 66 households that represent 226 individuals, within which vastly different experiences of water are held. There are those within the community who are hooked up to the watermain lines, and those who must rely on trucked-in well or cistern water, and those who predominantly drink bottled water. There are those within the community whose water is contaminated with *E. coli* or mercury, and those whose water is deemed safe by the measured standards of our own research team. In Study 3, the broader understanding of community begins to take a fuller shape, as interviewees refer to "the community's health" when speaking about water security perceptions and drinking water challenges. The water quality

perception data across studies is likely a reflection of collective memories around boil water advisories on the reserve.

This community's water experiences are shaped by gender and age as demonstrated in Study 3, which points to the specific water challenges or barriers that certain demographics face. Haudenosaunee women are water protectors, and the women I spoke with in interviews repeatedly demonstrated these identities and roles in their community, which informed their worries, angers, disappointments, and stresses about water. In turn, they also informed their coping and healing strategies, understanding how to teach themselves, their children, and their communities how to turn to their relationships with water to find joy and reconnect with their natural relations.

Previous research that looked more at water vulnerabilities found that Six Nations was overall less vulnerable to their water insecurity measurements (which were different from the water security measurements within this study), but they did report having a higher vulnerability to environmental pressures related to water inaccessibility (Plummer et al., 2013). This corresponds well with the findings across the studies within this dissertation, as concerns and experiences with water insecurity extended beyond household boundaries and were connected more with longstanding concerns about environmental degradation, forcible dispossession of their lands, and encroaching industry and settler land developments upstream on the Grand River or in nearby townships.

Understandings of the social body as it relates to water extend beyond the social bodies of humans within this research with Six Nations Peoples. Whyte (2013) demonstrates the relational approach and responsibilities to the natural world that are embedded in community health and wellbeing, but which are not often incorporated into community health assessments. While this research is predominantly situated within the household experiences of water, it does begin to bridge the connection between the individual and social bodies as inclusive of non-human bodies, such as bodies of water and land that influence the contamination of wells, cisterns, streams, and creeks within and around Six Nations. As anthropocentric assumptions about water as a resource for human use separate water from its social, spiritual, and cultural landscapes, contextualizing research with local IK that understands the interrelatedness of all living things creates a more dynamic understanding of how humans and environments interact and relate (Barker, 2019; Hoover, 2017; McGregor et al., 2020; Schmidt & Shrubsole, 2013; Zannotti, 2018). The Grand River itself is an integral element of this social body, as the experiences of water access and health experienced by the human community is inextricably related to the health of the river and all the plants and animals that it sustains. Interviewees demonstrated the river's inclusion in the social

body when discussing how the river has changed and been altered, and with it, how cultural and spiritual practices and behaviours (such as sourcing traditional medicines or reconnecting with oneself or the natural world through a paddle on the river) are enacted.

#### Body Politic

Six Nations is affected and interacts with several political bodies, both within the community (Band Council and Haudenosaunee Confederacy), and outside (federal, provincial, academic institutions). Occurring both separately and simultaneously, these external political bodies have and continue to seek control in some form over Six Nations or Haudenosaunee Peoples, contributing to long standing distrusts (in varying capacities) by community members. The relationships between the federal and provincial governments, and its impact on the current water crisis for Six Nations, are discussed more thoroughly in Chapter 1, but demonstrate the perceptions of these political bodies from the social and individual bodies experiencing their control in some domains, but also their absence or lessened governance when it comes to water.

Recognizing these dynamics as researchers, Study 1 outlined the varying boundary relationships and behaviours that contributed to a research community set on connecting water and Haudenosaunee health. Governing bodies have contributed to the undervaluing of cultural roles of water for Indigenous Peoples, and institutional bodies have maintained the focus on the individual body as the locus of control, through water research that looks at physical health consequences of contamination (such as seen in Piperata et al., 2019; Rosinger & Tanner, 2015; Wright et al., 2018). Similarly, there has been a well-documented relationship between mental health stressors (such as psychological duress, emotional stress, and caregiver depression) and water insecurity across diverse communities in the Global South by medical anthropologists (Brewis et al., 2019a; Mushavi et al., 2019; Stevenson et al., 2019; Tallman, 2019; Workman & Ureksoy, 2017). With the more pressing realities of climate change and pandemics facing us globally, the relationship we have to the natural world, and the understanding of natural elements as resources, is brought back into consideration. Notably, our understandings of settler understandings of water are more recently challenged as mythologies, tied to cultural understandings of nation-state identities (Mascarenhas, 2017; Meehan, 2020). Settler colonial narratives create understandings of water that continue to extract and exploit it for personal and industrial profit. Study 3 examined the impact this has had on the social relationships between Haudenosaunee People and their water bodies.

Considering the body politic at times feels less tangible than the direct relationships between individual and social bodies and water security and health. Many of the political bodies exist behind the scenes, and are drenched in histories of intentionally vague laws, the Doctrine of Discovery, and its legacy within the *Indian Act*. While these political bodies may not be physically visible within the research, the consequences of their actions are explored throughout all three studies, with a particular focus on how they have informed the connections between environmental racism and the forced dispossession of traditional lands discussed in Studies 2 and 3. The particular political bodies that affect Six Nations I locate within Canada's settler-colonial state, understanding that together, these institutional and governmental political bodies perpetuate and represent environmental injustices that is both racialized and gendered (Waldron, 2018). The manifestations of these political bodies and environmental racism and forced dispossessions live together and inform dominant discourses about "modern water" that shape it as a resource to be extracted, rather than a responsibility to take care of (Linton, 2010; Schell, 2020). The political bodies that Six Nations encounter and are affected by maintain these Eurocentric assumptions around what makes for "good water," which are discourses in constant tension and opposition with Haudenosaunee understandings of good water. In doing so, this maintains an oppressive state where Indigenous Peoples are at a heightened risk for continued water crises.

#### 6.3 Contributions to the Medical Anthropology and Co-Creation Studies

The findings from these three research studies can be integrated to paint a dynamic and nuanced picture of the wide ranges of water security and health experienced by diverse community members of Six Nations of the Grand River First Nation. This project advances our ability to work in interdisciplinary ways while maintaining applied anthropological approaches to understanding the dynamics between health, culture, racism, gender, environment, colonialism, and governance. As a complex whole, this dissertation research has theoretical, methodological, and analytical contributions that demonstrate the important gaps within anthropology and advance our understandings of how to work in applied and co-created manners. This study contributes five central elements to the field of applied medical and critical biocultural anthropology:

 Culturally appropriate ways to co-create research with Indigenous collaborators and a theoretical discussion of how we can create more space for local Indigenous Knowledge in medical anthropology;

- 2. Knowledge on the impact of bottled water reliance and water contamination on mental and physical health of an Indigenous community;
- 3. Expanding understandings of local water insecurity through gendered and age-based experiences and relationships with water within and beyond the household;
- 4. Methodological development of boundary work to navigate power dynamics in research; and
- 5. Interweaving three pillars (of Indigenous Knowledge, political ecology, and biocultural approaches) into a theoretical framework that both informed and was informed by my study.

## Culturally Appropriate Ways to Co-Create Research

Study 1 explored how community based participatory research (CBPR) could work within medical anthropology in more explicit ways and conceptualizing this with CBPR as a theoretical lens to approach health research working *with* a community. Coupled with the boundary work, this allows for the centering of community health concerns, priorities, and values. This work is effective because it creates spaces for conversations, both formal and informal, where relationships deepen and can handle the flexible and shifting needs of the community.

While the first study explored how to co-create knowledge and tools with an interdisciplinary team of Indigenous and non-Indigenous collaborators through boundary work, it also served as a theoretical discussion about the current state of medical anthropology. This paper works to decolonize medical anthropology by demonstrating how the co-production of a boundary object (the health survey) assists in bridging cultural, social, and racial boundaries. Importantly, the discussions around the health survey created spaces where important and respectful dialogue flowed around sensitive and traumatic issues of community and personal health, water insecurity and environmental relationships, intergenerational traumas, and spirituality. This study sets a solid theoretical and methodological foundation for the subsequent Studies 2 and 3, as it situates the dissertation in a space where every element and phase of the research project is co-created and led and informed by IK and Indigenous collaborators and community intentions.

This dissertation also provides discussion on the challenges facing medical anthropology in how it engages with its colonial legacies and asks us to consider shifting what research questions are asked (by community rather than by researcher), and how community collaborations can be folded into research design and knowledge sharing around health and environmental interactions. The use of CBPR, co-creation, and boundary work within medical anthropology has not been used extensively but can be very helpful in recognizing that we are bridging the diverse perspectives of academics and Indigenous collaborators. This opens more space for dialogue and operates by listening to the needs of the communities we work with, and rather than make assumptions based on western scientific strategies. These are challenging but important practices for anthropologists to better understand and situate the nuanced power dynamics within our research partnerships while striving to create more equitable and culturally appropriate research designs, analysis, and knowledge.

#### Household Health, Water Quality, and Use Knowledge

The second study presents statistical analyses that model relationships between self-reported household health conditions and water contamination and treatment variables. Additionally, it presents correlations between water use variables and known tap water contaminations to evaluate potential pathways for contaminant exposure for Six Nations households beyond drinking water. There were several important takeaways from this research, but some of the overarching findings contribute to a more comprehensive understanding of household water stressors and contamination. The single most important finding was that while Six Nations households had experienced tap and well water contamination in the past, the prevalence of *E. coli* contamination for tap water sources has not changed or improved in any significant ways in at least two decades. The last confirmed studies that tested for *E. coli* were conducted in 2003 and 2004, and the rates of bacteriological contamination found from our team's research (21.2% of 66 households) were around the same percentage as was found in these earlier studies, which were 19% and 27% respectively (Neegan Burnside, 2005). Additionally, 25.4% (n=17) of the 66 households had mercury levels that were at or above provincial drinking water limits for Ontario, and 77% of households primarily drank purchased bulk bottled water. Together, these results suggest that long term concerns about drinking water contamination within the community have continued to impact how people source their drinking water and impact mental wellbeing at the household level.

#### Gendered Experiences of Water Insecurity

Study 3 (Chapter 5) consists of a mixed methods approach to examining gendered and age-based experiences of local water security, using survey and interview data to explore how water security is understood, and the specific challenges that generations of men and women face around their relationships with water. Three key quantitative findings from the health survey data drove the analysis and integration with interview themes: 1) that respondents experienced high levels of

water insecurity, though this was not correlated with household income or monthly water expenses; 2) women had lower drinking water satisfaction than men; and 3) younger participants were more likely to report contamination issues and high monthly water expenses. These findings connected with interview themes that demonstrated a generational divide in what constitutes good or safe water, a strong perceived link between the degradation of the environment with a degradation of the community's health, and water security being strongly shaped by gendered and age-based barriers to household and community water.

While water security was not a term widely used by participants in the interviews, and not mentioned in the surveys, measurement of water security in this study relied on the HWISE scale which incorporates ability to access drinking water and the mental and emotional concerns relating to insecure water access, affordability, and reliability. It additionally used previous constructed community Likert scales to understand potential differences in water access at household, community, and environmental levels. The study went beyond HWISE however to incorporate local IK about water for cultural practices and relationships with water. For Haudenosaunee Peoples, water is life, and local IK frameworks understand that water is vital for all living things, including language, beliefs, and gendered identities and social roles. Perpetual issues of water insecurity and poor access to bodies of water are felt as much individually and physically as they are socially, spiritually, and culturally. Additionally, water insecurity is maintained through the forcible and ongoing dispossession of traditional Haudenosaunee lands by colonial and settler forces. While these occur in direct and indirect ways, they contribute to ongoing and growing environmental grief, and Haudenosaunee women and youth remain at a higher risk of the detrimental consequences of this.

This study challenges how we understand modern water, and how we measure and assess water security among Indigenous Peoples. While it is certainly important to have validated scales that allow for cross-community comparisons and provide more meaningful, individual data to inform the Indigenous water crisis, it would be risky to remove the localized and place-based Indigenous Knowledge that shape Indigenous Nations' relationships with water, and their understandings of what it means to be water secure.

### Boundary Work, Co-Creation, and Sovereignty Spaces

Study 1 (Chapter 3) describes the co-creation of health and water research between McMaster researchers and Six Nations community stakeholders and collaborators through three phases of research design of a community health assessment survey. Within the study, I frame the ever-

expanding and shifting health survey as a boundary object that reflects the boundary work between collaborators. Given that we come at the construction of a community health assessment from different cultural backgrounds and understandings of health, exploring these differences and sitting with them through boundary work is helpful in building reciprocal and trusting working relationships. The ongoing development of the survey allowed for a regular space where relationships and research goals could be reflected on for all members of the collaboration.

One of the major findings in this theoretical analysis of the health survey as a boundary object was the importance of building cohesive tools to successfully co-create a research project. Rather than create a patchwork of long and unorganized questions to meet diverse research needs, working on ways to structurally change the health survey document to ensure it was rooted in IK allowed for the lives and needs of Six Nations Peoples to be at the forefront of the design process.

By its very nature, co-creation allows our research team to disrupt the traditional binaries of who gets to be researcher and who is subject and blurs the lines between community stakeholders and scientists. All the research designs and questions, as well as variables used for analyses, were guided by Indigenous leads and IK. Six Nations collaborators negotiated and determined how and what was going to be researched when it came to water and health. This work was collaborative and distilled the strict boundaries of participant and researcher that are typically seen in community-based research, as many of the researchers within our broader team, including our Principal Investigator, are community members. If we are truly interested in challenging the social and racial dynamics of power within scientific research going forward, this form of cocreation allows for significant changes to environmental, water, and health research (Ottinger & Cohen, 2011).

### Interweaving Three Pillars into Theoretical Foundation

As outlined in chapter 1, this work weaves three main pillars of Indigenous Knowledge, biocultural approaches to medical anthropology, and political ecology together to offer an integrated theoretical analysis of the water crisis affecting Indigenous Peoples. Using local Haudenosaunee Knowledge as a key pillar, the teachings from Haudenosaunee Creation Stories, treaties such as the Two Row Wampum Belt, and the Great Law of Peace, have impacted now only how I operate as a researcher, but the ways I share knowledge carefully and respectfully, and how I show up as an ally to Indigenous People in community spaces, but also in other public and academic spaces. The Haudenosaunee creation story demonstrates that creation is a constantly " occurring and recurring process, rather than something that happened once in the long-ago past" and because of that, it can

be expressed in multiple forms (Hill, 2017, p. 17). This teaching has guided how I understand knowledge formation from the research – in that there are multiple forms of data that can be woven together to share this story of water insecurity and contamination, and share the stories of the participants that guided this work. It also shapes how different team members share their research and the ways that they understand co-creation. By centering the Grand River as a social element of the project, it also pays tribute to the Two Row approach to knowledge construction, and situates all of our histories and bodies in relation to it: while our team is incredibly diverse in backgrounds and expertise, we all have a common experience in working with the River, and that allows us to acknowledge how our histories of using this space have differed significantly, too.

Using these teachings shaped the design and knowledge sharing of my research, and helps me understand that to create together, multiple forms are needed. Integrating political ecology and biocultural approaches were important to situate the power dynamics of settler colonial histories in ways that informed the myths of modern water. Understanding that water security is not only a measurable household experience, but also one that is shaped by colonial laws and policy vacuums, experiences of forcible dispossession of lands, gender roles, cultural modes of healing, and families within Six Nations. It also asks new questions, specifically in what knowledges get prioritized presently and in the past, and how we can co-design strategies or methods to navigate these inequities in the future.

#### 6.4 Risk Communication and Sharing of Results

The research presented within this dissertation is a slice of the larger and interdisciplinary project led by Dr. Martin Hill through Co-Creation of Indigenous Water Quality Tools. The health research was intentionally designed to correspond with the tap, well, and cistern water testing of the engineer and biologists working within a different component of this research project, all guided by the Indigenous researchers who use Traditional Ecological Knowledge (TEK) and local Indigenous Knowledge to inform how we assess the water crisis in appropriate ways for the community. As such, I am also aware that there is a tremendous element of risk involved in bringing forth new information about the water contamination experienced by some households, as well as the knowledge of *E. coli* and mercury contaminations in the water sources in the community. While some community members have long suspected these contaminations, there is a real risk to documenting and sharing this information without plans for support and crisis care that may arise. Two elements of Western research that create ongoing problems within this type of interdisciplinary work are described by Smith (2004): a) the absence of tangible community benefit from research, and b) the treatment of Indigenous partners as subjects of research. While the cocreation approach positions Indigenous partners as leaders and their knowledge as the foundation to our work, in terms of sharing results, the defaults of Western scientific approaches certainly present the challenge of what is considered a tangible community benefit.

The results of the tap water contaminations were shared via letters to households that had participated in the study, working in collaboration with Six Nations Public Works, the Environmental Task Force, and with Six Nations Health Services to provide the resources needed for those experiencing crisis or risk after receiving the news of contamination. As we continue in our collaborated work, we strategize with Six Nations partners to identify the mental health resources that are needed as new research arises on the water contaminations. One major limitation has been that while the study results were being finalized and tap water and survey data were being analyzed in 2020, the COVID-19 pandemic began. The pandemic has limited our ability to hold ongoing community meetings and town halls to talk about these issues in person, though we have maintained our efforts as best we can virtually until it is safe to meet in person. We presented our findings to Six Nations Elected Council via Zoom in April 2021, sharing results with SNEC after they had a change in leadership with the intention of working together to determine next steps for mitigation. The sister project to CCIWQT, Ohneganos (also led by Dr. Martin Hill, Lori Davis Hill of Six Nations Health Services, and Beverly Jacobs of Six Nations) has produced an ongoing video podcast, Ohneganos Let's Talk Water, where Six Nations youth lead an hour of conversation weekly, and researchers from our team come on the show regularly to update the community of our findings and implications, while taking questions and considerations to incorporate into our project's structures.

#### 6.5 Conclusion

From this dissertation, I conclude that water security experiences are best understood as highly localized experiences that have generalizable physical, mental, and environmental consequences to consider in broader global discussions of water. By this, I mean that it is impossible to untangle the specific cultural, spiritual, racial, and colonial landscapes or structures that have shaped any single community's experiences with water. How water security is understood will be unique to each community, and even within communities will vary considerably by households. In this research, water security was assessed by incorporating tap water tests for *E. coli* and heavy metal contaminants, an investigation of household tap water uses, drinking water sources, drinking water satisfaction, water access at household, community, service, and environmental levels, and with a validated water security assessment scale.

Water insecurity was reported for 57.5% of 66 households surveyed (n=38), with 21.2% of households having *E. coli* contamination in their tap water, 25.4% having mercury contamination above the provincial drinking water limits, and 77% of households relying primarily on bottled drinking water rather than their tap water. Households that had a *E. coli* contamination or relied on drinking bottled water had significantly greater odds of reporting at least one mental health condition within the household, and those who treated their tap water with bleach or chlorine had a greater odds of reporting gastroenteritis (though this is more likely a correlation that reflects the results of ongoing community issues with *E. coli* contamination of wells and cisterns that is punctuated throughout the seasons). Despite the clear evidence that there is significant water-related stress and insecurity, Six Nations is not recognized federally as a community experiencing a water crisis.

The reliance on governmental BWA and DWA classifications is incredibly limiting and fails to acknowledge the nuances of the source water contamination and ongoing decentralization of Indigenous water governance that perpetuate these water insecurities quietly. The intentionally vague water policies, exclusion of Indigenous women's voices, and environmental dispossessions of Indigenous communities from their traditional lands maintains a colonial weaponization of the land and water. This is maintained by institutions, industry, and government that imposes long-term water insecurity and uncertainty through vague policies and water legislations. Water insecurity remains inconsistently assessed for Indigenous communities, with BWAs as a standard point of measurement that flatten community experiences into one singular number. While measurements may vary in the meaning they hold between cultures and Nations, having a standard point of measure that is more expressive of diverse household experiences begins to bridge a knowledge gap.

Importantly, the findings on water security were contextualized with an analysis of key themes from individual and focus group interviews to understand how the local variables shaping water quality, uses, and perceptions inform household levels of water insecurity, and who in the community experiences higher water insecurity or higher levels of stress and worry around water. While water insecurity experiences are relatively high, Western metrics are not able to capture crucial elements of Indigenous experiences of water insecurity, such as community and cultural relationships with the land, structural violence, environmental racism, and the consequences of environmental degradation such as grief relating to water quality and climate change. Understanding how Indigenous Nations uniquely relate to water helps to inform research design, analysis, and potential future policies and water governance systems.

#### **6.6 Directions of Future Research**

This dissertation uses a variety of methodologies and data analysis to assess water security and community health with Six Nations Peoples. The diversity of data and methodological choices were used to address the limitations of different research methods and assess their effectiveness to align and co-create with Indigenous collaborators. When co-creating research approaches, as demonstrated across all three studies within this dissertation, there are critical limitations to how this knowledge and drawn conclusions can be generalized, which in turn impact the broad ability to inform water and health policy.

I believe it is important that this work not be entirely generalizable, but rather centered on the localized knowledge frameworks. Indigenous Nations often become homogenized within the academic literature, and while cultural relationships with land and water are highly localized and diverse, it becomes all too easy to create pan-Indigenous identities and strip the nuance of local IK and the specific environmental, political, racial, and cultural landscapes that inform and interact with these knowledge frameworks. It is certainly useful to have standardized measurements of variables that inform cultural experiences, such as measurements of mercury or *E. coli* in tap water samples, or a water security scale that has global validation, in that the prevalence of water insecurity or contamination within Six Nations can be translated to be better understood by Western audiences on a global stage. Numbers carry a weight that is hard to ignore, and allow for more pressure to be placed on federal governments, particularly if we can situate the prevalence of water insecurity in Indigenous communities with a more personal household number rather than a generalized community boil water advisory that has been inconsistently measured over the years.

Despite these important elements of quantification and validated scales, I still argue that the local contexts must not be separated from these data points within the research. The approaches we took allowed for the research to fully explore water insecurity from a holistic lens, but also ensured that the issue was explored in ways that were timely and relevant to community collaborators and based in IK. Water (in)security itself is a highly fluid and diverse experience within Six Nations reserve. There are many individuals and households who normalize decades of poor water access, framing water satisfaction around their ability to treat their own water, and not wanting to raise any red flags or be the squeaky wheel. There are others in the community who experience high levels of water insecurity and dissatisfaction, and feel more anger, stress, and worry about this constant threat. Mothers, women, and younger generations all consistently demonstrated their unique barriers to water access that extend past household experiences into

barriers of accessing traditional lands and waters that are needed for maintaining mental and spiritual health.

Given the results of this research, I would suggest that future research continues to use mixed and co-created methods to gain deeper understandings of localized water contaminations and impact on community health. A key element of these research studies was looking at health and water as it was bounded by our understandings of the household. This provided important details on how families used and related to water, but also became tricky given that there is mobility between households, water sharing, and intergenerational water strategies that extend beyond households. Within interviews, and between the lines of survey responses, it was clear that water security was highly connected to individual and community relationships with water. Water is life, and Haudenosaunee Knowledge reminds us of this throughout our research journeys. Future research will investigate how relationships to the land and water can be assessed, and how IK can shape our quantitative analyses of these embodied relationships. The launch of an integrated community health assessment survey that incorporates more Likert-style questions about community water access and activities will be rolled out in conjunction with a revamped version of the community health assessment survey that was tabled in December 2018.

With a renewal grant, the next direction in research is also to act on community interest in assessing how heavy metal contaminations become embodied in all their relations: we will be investigating the levels of mercury in local fish, in surface waters around the community, and the levels of mercury in human hair samples to correlate with a new community health survey that incorporates questions about food and water. Together, these continue to build on our co-created methodologies, and we have designed a new phase of the project that is founded on more long-standing relationships and grounded in the voices and perspectives of the participants from the first phase of the research program.

There is a long history of at best poor and at worst unethical research practices involving Indigenous Peoples, particularly so for anthropologists and other researchers. The phrase "helicopter researcher" has been used in Indigenous literature to address these detrimental research practices, as researchers would fly in to address a research question they were interested in and fly out the moment they got what they needed. The most important question that needs to be addressed (and reassessed consistently and respectfully) is what does the community want to ask, and how would settler scholars be of help in answering them? We need to be incredibly mindful of how and why we are doing research, and how we conduct ourselves within fieldwork and outside of that as we interact and develop relationships with Indigenous communities. For this work, it would be inappropriate to leave so abruptly after the first phase of research had completed, when it feels we are just scratching the surface of a story that weaves water, health, environment, and history in such complex and dynamic ways. Being able to not only engage, but to co-create our research with the Six Nations community will make the research more impactful, not just in terms of broadening a research field, but in the way that it is more likely to have tangible use in decision making situations. The trajectories of this work move in ways that are not always aligned with the institutional or funding timelines, to grow and collaborate in more meaningful ways that have a direct and hopefully beneficial output for communities.

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## **APPENDIX A - RECRUITMENT SCRIPT (EMAIL)**

#### Survey RECRUITMENT SCRIPT (Email)

#### Co-Creation of Indigenous Water Quality Tools Sarah Duignan, PhD Candidate

Subject Heading: McMaster and Six Nations Water Quality Survey – Invitation to Participate

Dear [Name],

My name is Sarah Duignan and I'm a research assistant and PhD Student on Dawn Martin Hill's water project in your community. You expressed interest in having your tap water tested [or have had your tap water tested] and we would like to ask you to participate in a water use and access survey to help us better understand some of the concerns you may have about how your water is impacting health and wellbeing in Six Nations. This research will also be part of my PhD dissertation work.

The survey itself would take 15-20 minutes of your time and will remain confidential. Any identifiers will be removed from the response.

I have attached a letter of information and a consent form that details possible risks or benefits from the study with full details if you'd like to look over, or if you have questions ahead of time. If you are still interested, please let me know and we can work on setting a day and time to meet.

Generally, the risks to participating in this study are low. You may feel upset at some of the questions relating to your personal or family's health or community wellbeing or questions about water access and quality. This survey is not anonymous, and it might be possible to identify you through some of your responses. We will remove any identifiers from the data so there is minimal risk, and only myself and Dr. Tina Moffat, the Health lead on this project, will have direct access to your responses. McMaster researchers who are also Six Nations community members will not have direct access to your responses, only the overall results of the survey responses. If you are still interested, please let me know and we can work on setting a day and time to meet.

You can stop being in this study any time during the interview and afterwards up to six months following the interview. This study has been reviewed and cleared by the McMaster Research Ethics Board. If you any have concerns or questions about your rights as a participant or about the way the study is being conducted you can contact:

The McMaster Research Ethics Board Secretariat Telephone: (905) 525-9140 ext. 23142 c/o Research Office for Administration, Development and Support (ROADS)

É-mail: ethicsoffice@mcmaster.ca

You can contact me at 647-992-4434 or by email (<u>duignase@mcmaster.ca</u>) if you have any follow-up questions or would like to schedule an interview.

Have a good day! Nya:weh, Sarah Duignan

## **APPENDIX B - INTERVIEW RECRUITMENT POSTER**



# INTERVIEWS ON

We need your help!

We would like to ask for your opinion about how water quality and access affect your health. We would like to meet with you and discuss this in more detail in a 1-on-1 or focus group interview setting.

These interviews will be taking place between November 2018 and June 2019, locations TBD.

The results of these discussions will help shape current cocreate health surveys in partnership with Six Nations Health Services, and help highlight key concerns you have about individual and community health and wellbeing. This study will identify links between water, ecosystem health and human health in your community.

Please contact us by e-mail at duignase@mcmaster.ca (Sarah) or call us at 647-992-4434 with your availability. We will work with you to arrange a suitable time.

Co-Creation of Indigenous Water Quality Tools





GLOBAL WATER FUTURES JOLUTIONS TO WATER THREATS IN ARI LEA OF GLOBAL CHARGE ARE YOU CONCERNED ABOUT YOUR WATER?

DO YOU WANT YOUR OPINION HEARD ABOUT WATER AND HEALTH?

DO YOU HAVE 1 HOUR TO SHARE YOUR THOUGHTS WITH US?

ARE YOU 18 YEARS OR OLDER?

Co-Creation of Indigenous Water Quality Tools

McMaster University

Funded by: Canada First Research Excellence Fund

## **APPENDIX C - LETTER OF INFORMATION/CONSENT (SURVEY)**

Date: \_\_\_\_\_

## Water Use Survey - CCIWQT Research Project LETTER OF INFORMATION/CONSENT

Title of Study: Co-Creation of Indigenous Water Quality Tools (CCIWQT) Principal Investigator: Dr. Dawn Martin Hill, Department of Indigenous Studies, Department of Anthropology, McMaster University, Hamilton, ON, Canada dawnm@mcmaster.ca

**Co-Investigator(s), Department/Institution:** Dr. Tina Moffat (Co-Investigator), Department of Anthropology, McMaster University moffatcs@mcmaster.ca, Dr. Pat Chow-Fraser, Department of Biological Sciences, McMaster University chowfras@mcmaster.ca

**Student Investigator(s):** Sarah Duignan, Department of Anthropology, Denise McQueen, Department of Indigenous Studies

Funding Source: Global Water Futures

## About the Survey

The purpose of this survey, made in partnership between Six Nations community collaborators and McMaster University, is to work for community members to ensure water quality and health at Six Nations of the Grand River for future generations. This survey asks you about your household's water use, the quality of your water, and any concerns you have about accessing, affording, and using your water.

We are working to holistically explore health as it relates to your water use and access alongside Western approaches. Six Nations members are scientists, in the way they understand and appreciate the connections between the environment and people.

We have created a survey that reflects the knowledge and values of Six Nations community members. By participating in the survey, you will contribute to knowledge of your community, and will also help the Six Nations Environmental Health Task Force understand current and future issues around water for the community.

Your contribution to this research is vital, because it will create a baseline of understanding about water-related health and wellbeing issues for Six Nations residents. The baseline is important to establish so that we know where to concentrate our efforts and build tools to improve water quality and community wellbeing. It also allows us to be able to track how this may change and improve over time. In order to decide whether or not you want to be part of this study, you should understand what is involved and any potential risks and benefits. This form gives you information about the Water Use and Quality Survey and the Research Project, which we will also discuss with you in person.

Once you understand the study, you will be asked if you would like to participate and sign a consent form if so. Please take your time in making this decision.

The financial costs associated with this study are being provided by Global Water Futures. None of the research investigators will receive any direct financial or political benefit from carrying out this study, beyond any academic recognition from presenting the results

#### WHY IS THIS RESEARCH BEING DONE?

Working with community partners, we have co-created a survey that asks you about your experiences with water quality, access, and concerns you may have around water in the Six Nations community. We are interested in examining the health effects of polluted water. We aim to understand your experiences in ways that honour Haudenosaunee models of health and wellness (mind, body, emotion, spirit) and Indigenous Knowledge of water and the environment. We ask you about your water source(s), use and consumption and any associated costs, traditional diet and behaviours relating to water, and general health of your household. More broadly, this project seeks to co-create sensors, data analysis, and culturally relevant tools to build long term capacity in Six Nations for current and future uncertainties in water quality.

#### WHAT IS THE PURPOSE OF THIS STUDY?

You are invited to complete a 10-page survey about your water uses, experiences, and general health of your household and community relating to water. We are hoping to learn about the health effects relating to water in your community: any daily stressors, physical health conditions, or environmental issues that might connect to a holistic understanding of Six Nations health. This is a line of research that we hope to continue in the future and will use your data, should you consent to participate, for this project as well as future related studies. We hope to speak with some of you during followup interviews or focus groups to learn more about your personal experiences and concerns around water quality and health at Six Nations. The data collected from this study will also be used for Student Researcher Sarah Duignan's PhD research, community presentations, conference presentation, and publications.

## WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THIS SURVEY?

If you volunteer to participate in this survey, we will ask you to do the following things:

- 1. Read over this letter and sign the attached consent form.
- 2. Participate in the survey, which will take about **15 to 20 minutes to complete.** The student researchers will be sitting with you and can help you if you have any questions or concerns while you're filling out the questionnaire. These surveys are **NOT anonymous**, but will remain confidential.
- 3. Indicate whether you would be interested to be contacted for future investigators and/or whether you would like to be informed for the results of the study. If so, provide your contact information on the sheet of paper attached at the end of the survey package. This contact information will be separated from the questionnaire, so that there will be no personal contact information stored with your questionnaire.

#### WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

This study has some social and mental risk, but little to no risk physically. We do not anticipate any physical risks or discomforts in participating in the survey. While we will de-identify the responses collected and keep your information confidential, there may be a risk of being identified through your results as Six Nations is a small community.

There may be some **emotional and social risks** associated with participating in the survey. You will be asked about your personal and family member's health, and experiences with water and food insecurity, which may cause some emotional discomfort or distress. You will be encouraged to communicate your honest responses and understandings of water quality and your personal and family health, as well as the health of your community. There is a chance you may feel uncomfortable when asked some questions about your health or issues relating to water and food access or quality (or other questions).

While we are not collecting and keeping directly identifying information (such as names, ages, household locations) for analysis, it may be possible to identify you by putting together separate pieces of information. Data will be confidential, with only Dr. Tina Moffat and PhD Sarah Duignan having direct access to your confidential responses. All information will be de-identified before sharing with other McMaster researchers or community members.

While we are interested in your responses, **you do not need to answer questions that you do not want to answer** or that make you feel uncomfortable. There is always a "prefer not to answer" selection for these multiple-choice questions, or you may skip the questions altogether. You may stop participating at any point during the survey or withdraw your responses at any point after the survey. If you stop half way through or withdraw your questionnaire from the study at a later point in time, you will still be compensated with the \$20 gift card. If you decide that you do not want to participate in this survey, you can still have your household water tested. We describe below the steps we are taking to protect your privacy.

## WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR MY COMMUNITY?

We cannot promise any personal benefits to you from participation in this study. However, possible benefits include the opportunity to participate and have your experiences, concerns, and perspectives contribute to a stronger understanding of the connections between community health and water quality in Six Nations.

## WHO WILL KNOW I PARTICIPATED IN THE STUDY?

You are participating in this study confidentially. We will not use your name or any information that would allow you to be identified. No one but our research team will know whether you were in the study unless you choose to tell them. Steps will be taken to keep your responses confidential, but this will not be an anonymous survey. Please keep this in mind when deciding what to tell us in your responses. Since your community is small, others may be able to identify you on the basis of some responses. Please keep this in mind when deciding what to tell us.

Your personal data will not be shared with anyone except with your consent or as required by law. All personal information such as your name, affiliation, and phone number will be removed from the data and will be replaced with a study number. A list linking the number with your name will be kept in a secure place, separate from your file. The data,

with identifying information removed will be securely stored in a locked filing cabinet in a locked office at McMaster University. All data will be uploaded to a secure data share for long term storage, and ownership transferred to Six Nations upon completion of this study in 2020.

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the McMaster Research Ethics Board may consult your research data. However, no records which identify you by name or initials will be allowed to leave McMaster University. By signing this consent form, you or your legally acceptable representative, authorize such access.

If the results of the study are published, your name will not be used and no information that shows your identity will be released or published without your specific consent.

#### WHAT IF I CHANGE MY MIND ABOUT BEING IN THE STUDY?

If you want to stop taking the survey, you can stop at any point. If you complete the survey and decide at a later point that you want your responses withdrawn, please contact Sarah Duignan (duignase@mcmaster.ca) at any point up to six months after you take the survey and she will remove your responses from the data and destroy your physical survey responses.

We understand that you may feel pressured to fill out a survey due to family or social pressures given that some team members are also Six Nations community members. Please do not feel obligated – we will be able to recruit enough people from the community and need to make sure we have representation from a wide variety of backgrounds.

## WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

You will receive a \$20 gift card. You will be compensated with this gift card regardless of whether or not you complete the survey responses, or whether or not you decide to withdraw your responses at a later date.

#### WILL THERE BE ANY COSTS?

Your participation in this study will not have any direct costs to you.

#### HOW WILL THE DATA BE STORED SHORT AND LONG TERM?

Data from the discussion will be stored short term on a secure data share platform (RedCAP) and on a password protected computer at McMaster University during data analysis. Audio recordings will be deleted immediately after interviews have been transcribed. As this project follows the principles of OCAP for working and collaborating with Indigenous communities, the de-identified data will remain the sole property of Six Nations, which is governed by the Six Nations Band Council. Any contact information, such as email addresses will be removed from data sets and destroyed before being shared with Band Council.

## HOW DO I FIND OUT ABOUT THE STUDY'S RESULTS?

We expect to have this study completed by approximately September 2019. If you would like a brief summary of the results, please let me (Sarah Duignan) know how you would like it sent to you in the sheet at the end of the survey package.

#### IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have questions or need more information about the study itself, please contact our primary investigator, **Dr. Dawn** Martin-Hill at (905) 525-9140 ext. 27605 or dawnm@mcmaster.ca

This survey is part of a study that has been reviewed and cleared by Six Nations Ethics Committee and the <u>McMaster</u> <u>Research Ethics Board</u> (MREB). The MREB protocol number associated with this survey is. <u>MREB 2018 579</u>. You are free to complete this survey or not. If you have any concerns or questions about your rights as a participant or about the way the study is being conducted, please contact: **McMaster Research Ethics Secretariat**, **Telephone 1-(905) 525-9140 ext. 23142, C/o Research Office for Administration, Development and Support (ROADS). E-mail: ethicsoffice@mcmaster.ca** 

#### **CONSENT STATEMENT**

## By signing this form, I agree that:

- 1. I am 16 years of age or older
- 2. I have read the information presented in the information letter about the study being conducted by Drs. Martin Hill, Chow-Fraser, and Moffat of McMaster University.
- 3. I understand that I have the right to not participate, and the right to stop at any time.
- 4. I understand that I can ask questions relating to the study at any time.
- 5. I understand that my personal information will be kept confidential.
- 6. I agree to have my survey responses used for this project and future related projects.
- 7. I agree to be contacted about a follow up interview and understand that I can always decline the interview upon request.
- 8. I understand that I will receive a copy of this form for my personal records.
- 9. I understand that if I agree to participate in this study, I may withdraw from the study at any time and may request to withdraw my survey responses at any time up **August 30**th, **2019**.

## **Consent to Participate**

Having read the above, I understand that by checking YES below, I agree to take part in this study under the terms and conditions outlined in the accompanied letter of information.

## [ ] YES, I agree to participate

[ ] NO, I do not agree to participate

Signature	Date
Name of Participant:	
Telephone Number:	
Mailing address (for returning results	of survey study):

## Person obtaining consent (researcher):

I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

Name, Role in Study:	
Signature:	

## **APPENDIX D - SURVEY**

Household number: Participant ID:	

## PART A: DEMOGRAPHICS

- Gender (please check the answer that best reflects your identity, or if it is not listed, please write it in the space provided).
  - □ Male
  - Female
  - Other (e.g. Two-Spirit, LGBTQ+, Gender-queer, Gender-fluid, non-binary):
- What is your age? \_\_\_\_\_
- 3. What is the main nation in your household? (This is your mother's nation.)
  - Mohawk
  - Cayuga
  - Seneca
  - Onondaga
  - Oneida
  - Tuscarora
  - Mississauga
  - Other (specify): \_\_\_\_\_\_
- Please indicate how many people (including yourself) currently live in your household (or live there the majority of the time): \_\_\_\_\_\_
- 5. Please indicate the age of those living in your household (including yourself):

Household Members	Age
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	

- 6. For the previous year (2018), please think of your total household income from all sources. Please include income from social assistance, child tax benefits, disability benefits, workers compensation, etc. What income range does it fall into?
  - □ No income
  - Under \$19,999 per year
  - Between \$20,000 to \$49,999
  - \$50,000-\$79,999
  - □ \$80,000 and \$149,999
  - Above \$150,000
  - Prefer not to answer

# PART B: YOUR HOUSEHOLD WATER USE

7. This table asks you to identify your household source of tap water from the options below.

	Tap Water
Directly from treatment plant to tap (on the main line)	
From treatment plant to <b>well</b>	
From treatment plant to <b>cistern</b>	
Bulk water delivery for cistern (not from treatment plant)	
Bulk water delivery for well (not from treatment plant)	
Other (please specify):	

 This table asks you to identify the source of your drinking water for your household from the options below.

	Drinking Water
Tap water from treatment plant	
Tap water from well	
Tap water from cistern	
Pick up water from treatment plant	
Buy bottled water in bulk yourself	
Water delivery service (spring, pure, or distilled water)	
Source water ( <b>please specify</b> if it is from a river, creek, stream, spring, rainwater, etc.):	
Other ( <b>please specify</b> ):	

- 9. Do you use your tap water (from question 6) for any of the following? Check all that apply.
  - Drinking water
  - Coffee/tea
  - Strawberry juice
  - Washing produce (fruits and vegetables)
  - Washing dishes
  - Food prep
  - Showering/taking a bath
  - Laundry
  - Brushing teeth
  - Powdered drinks
     Other (please specify): \_\_\_\_

- 10. Apart from the treatment at the Six Nations water treatment plant (if you are on the water line or if you pick up water from the treatment plant), do you treat your **tap water** in some way? Check all that apply for your household.
  - In-line treatment (e.g. RO treatment system)
  - Post-tap treatment (e.g. Brita filter)
  - Water softeners
  - Bleach or chlorine
  - Other (please specify): \_\_\_\_\_\_
- 11. If you add bleach/chlorine to your water, please estimate how often and how much you add?

12. a) Please rate your satisfaction with your drinking water situation.

- Not satisfied at all
- Somewhat satisfied
- Neutral
- Satisfied
- Very satisfied

b) Please briefly explain your rating decision – what makes you satisfied or dissatisfied with your drinking water?

13. If you purchase water, how much money do you spend in total in a month (on average) on all sources of water?

- Under \$99
- \$100-199
- \$200-299
- \$300-399
- \$400 or more (please specify your best estimate): \_\_\_\_\_\_
- I don't purchase water
- Don't know/not sure

14. Have you ever experienced any issues with your tap water? Check all that apply.

- Taste/smell/appearance
- Contaminated/not safe
- Sulphur
- □ Iron
- Hard water
- □ Smells like chlorine
- Don't know
- Not applicable

# PART C: WATER AND FOOD CONSUMPTION

15. We would like to understand how much water you get from beverages and foods that are high in water.. For each item listed below, please respond with your best estimate.

	Did you have any in the past week? Circle your response		Number of times per week	Source of Water for Food or Drink Item (e.g. bottled water, Tim Horton's, tap water, etc.)
Water	YES	NO		
Coffee	YES	NO		
Tea (iced or hot)	YES	NO		
Hot chocolate	YES	NO		
Juice made from concentrate or crystals	YES	NO		
Powdered milk	YES	NO		
Broth or soup	YES	NO		
Stew	YES	NO		
Other food/drink that needs water to make (please specify):	YES	NO		

16. Please rate your access to the following:

	Very Poor	Poor	Okay	Good	Very Good	Don't know/Not applicable
Water use for inside your home (drinking,						
household cleaning, clothes washing,						
bathing)						
Water in your community (i.e. rivers,						
streams) for use outside your home (such						
as ceremonial, fishing, boating)						
Water infrastructure services (e.g. water						
supplied to your home by a water main,						
pick up at treatment plant)						

	Never	Rarely	Sometimes	Offen	Always	Don't Know	I Don't Have This
How frequently did you or anyone in your household <b>worry</b> you would not have enough water for your household needs?							
Has your main water source been interrupted or limited (e.g. water pressure, or less water than expected?)							
How frequently has there not been enough water to <b>wash clothes</b> ?							
How frequently have you or anyone in your house had to <b>change</b> <b>schedules or plans</b> due to problems with your water situation? (E.g. caring for others, doing household chores, work on the land, income-generating activities)							
How frequently have you or anyone in your household had to <b>change</b> <b>what was being eaten</b> because there were problems with water (e.g. for washing foods or cooking?)							
How frequently have you or anyone in the household had to go without washing hands after activities (e.g. changing diapers, gardening) because of problems with water?							
How frequently have you or anyone in your household felt their <b>personal</b> <b>hygiene (body)</b> was lower than desired because of problems with water (e.g. not enough water, unsafe?)							
How frequently has there not been as much water <b>to drink as you would</b> <b>like</b> for you or anyone in your household?							

## For the following experiences, please mark with an X how often they occur within an average month for your household.

c

How frequently did you or anyone in your household <b>feel angry about your water situation</b> ?				
How frequently have you or anyone in your household gone to <b>sleep</b> <b>thirsty</b> because there wasn't any water to drink?				
How frequently has there been <b>no</b> <b>usable or drinkable water</b> whatsoever in your household?				
How frequently have problems with water caused you or anyone in your household to feel ashamed, excluded, or at risk of being stigmatized because of your water situation?				
How frequently did you or anyone in your household worry that your drinking water will become <b>contaminated?</b>				

18. For the following statements around your household's food, please respond with: never true, sometimes true, or often true, for you and other household members in the past 12 months.

	Never True	Sometimes True	Often True
I/we worried about whether my/our food would run			
out before I got money to buy more			
The food that I bought just didn't last, and I didn't			
have money to buy more			
I/we couldn't afford to eat balanced meals			
I/we regularly relied on a few low-cost foods in order to avoid running out of money to buy more food			
I/we skipped meals because there wasn't enough money to buy food			
I/we did not eat for a whole day because there wasn't enough money for food			

19. In the past 12 months, how often have you eaten the following traditional foods?

Traditional Foods	Not at all	Once a Year	Couple Times a Year	Once a Month	Weekly (when in season)
Fresh water fish from Six Nations					
Fresh water fish from outside of Six					
Nations					

(If applicable, specify where fish is sourced:)			
Large land-based animals (moose, bear, deer, etc.)			
Game birds (goose, duck, etc.)			
Small game (rabbit, muskrat, etc.)			
Berries			
Corn (or corn soup)			
Beans			
Squash			
Wild Rice			
Other (specify food item and frequency):			

# PART D: FAMILY HEALTH

- 20. In general, would you say that your health is...
  - Excellent
  - Very good
  - 🗆 Fair
  - Poor
  - Don't know/unsure

21. In general, would you say that the members of your household's health is...

- □ Excellent
- Very good
- 🗆 Fair
- Poor
- Don't know/unsure
- 22. This section asks you to report if you or members of your household have experienced or been told by a health care professional that you've had any of the following health conditions in the past year? Please specify who in the field below.

Condition	Family Member, Gender, and Current Age (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	lf Yes →	Age at diagnosis (if known)	Is the for member current underg treatmost YES	amily er ly joing ent? NO
Allergies					
Alzheimer's or Dementia					
Anxiety					
Arthritis					

7

Asthma					
Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD)					
Blindness or other vision problems (can't be corrected with glasses)					
Cancer Breast Prostate Lung Colon Bladder Leukemia Lymphoma Malignant melanoma Ovarian Pancreatic Other (specify):					
Condition	Family Member (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	lf Yes →	Age at diagnosis (if known)	Is the for member yoursel current underg treatme	amily er (or lf) ly joing ent?
Condition	Family Member (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	lf Yes →	Age at diagnosis (if known)	Is the for member yoursel current underg treatmo YES	amily er (or lf) ly joing ent? NO
Condition Chronic pain	Family Member (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	lf Yes →	Age at diagnosis (if known)	Is the for member yoursel current underg treatmo YES	amily er (or lf) loing ent? NO
Condition Chronic pain Eczema or dermatitis (skin rashes)	Family Member (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	lf Yes →	Age at diagnosis (if known)	Is the for member yoursel current underg treatmo YES	amily er (or lf) loing ent? NO
Condition Chronic pain Eczema or dermatitis (skin rashes) Depression	Family Member (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	lf Yes →	Age at diagnosis (if known)	Is the for member yoursel current underg treatmo YES	amily er (or lf) loing ent? NO
Condition Chronic pain Eczema or dermatitis (skin rashes) Depression Diabetes I Type 1 Gestational	Family Member (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	If Yes →	Age at diagnosis (if known)	Is the for member yoursel current underg treatmony YES	amily er (or lf) ily joing ent? NO
Condition Chronic pain Eczema or dermatitis (skin rashes) Depression Diabetes Type 1 Type 2 Gestational Digestive problems	Family Member (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	If Yes >	Age at diagnosis (if known)	Is the for member yoursel current underg treatmo YES	amily er (or f) ly joing ent? NO
Condition Chronic pain Eczema or dermatitis (skin rashes) Depression Diabetes I Type 1 Gestational Digestive problems Effects of stroke (brain hemorrhage)	Family Member (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	If Yes	Age at diagnosis (if known)	Is the for member yoursel current underg treatmo YES	amily er (or f) ly joing ent? NO
Condition         Chronic pain         Eczema or dermatitis (skin rashes)         Depression         Diabetes         Type 1         Type 2         Gestational         Digestive problems         Effects of stroke (brain hemorrhage)         Bronchitis (chronic)	Family Member (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	If Yes	Age at diagnosis (if known)	Is the for member yoursel current underg treatmo YES	amily er (or f) ly joing ent? NO

Fibromyalgia					
Gastroenteritis (nausea and/or vomiting. diarrhea, sometimes containing blood)					
Hearing loss or difficulty					
Heart Disease					
High cholesterol					
HIV/AIDS					
Kidney problem					
Liver disease (not including hepatitis)					
Traumatic brain injury					
Osteoporosis					
Hepatitis  Type A Type B Type C					
Condition	Family Member (e.g. "Self, M, 40", "Partner, F, 38" or "Daughter, F, 16")	lf Yes →	Age at diagnosis (if known)	Is the for member yoursel current underg treatme YES	amily er (or lf) ly joing ent? NO
High Blood Pressure Unrelated to pregnancy Related to pregnancy					
Other health condition(s) not listed above:					

23. To the best of your knowledge, have you or has anyone in your household ever become sick from drinking the tap water in your home?

- □ Yes
- □ No
- Don't know

24. If yes to question 23, what did you or they become sick with? Please specify:

Skin rash or eczema

Diarrhea

- Nausea
- Stomach cramps (abdominal pain)
- Loss of appetite

Fever

Dehydration

Vomiting

- Dehydration
- Other (please specify below):

## PART E: DRINKING WATER EXPERIENCES AND PERCEPTIONS

- Please rate your perception of the quality of lakes, rivers, and streams located in and around Six Nations.
  - Very poor

  - □ Good
  - Very good
  - Don't know/prefer not to answer
- 26. What are the main reasons you value water resources?
  - Drinking water
  - Ecosystem support (for aquatic life, trees, plants)
  - Recreational (swimming, boating, kayaking, canoeing, walking along trails)
  - Agricultural use
  - Cultural and/or spiritual uses
  - Industrial use
  - Water is pleasing to look at
  - Don't know/prefer not to answer
  - Other (please specify):
- Are you aware of anything that is affecting water quality in Six Nations? (e.g. pesticides, heavy metals, bacteria?)
  - No
  - Yes (please specify): \_\_\_\_
  - Don't know/prefer not to answer

28. Has water ever been a source of conflict in Six Nations? Check any that apply.

- No, water has not been a source of conflict in Six Nations.
- Water quality
- Access to water
- Political issues
- Treatment plant
- Don't know/prefer not to answer
- Other (please specify:

## PART F: RESPONSIBILITY AND CONNECTIONS TO WATER

29. Please rate the following according to the level of responsibility each should have with respect to water quality in Six Nations. Choose the **best response** for each option, does not have to be in a ranked order.

Level	No responsibility	Very little responsibility	Lots of responsibility	Sole responsibility
Individual				
Community				
Elected council (Band Council)				
Traditional government				
(Confederacy)				
Ontario government				
(provincial)				
Federal government of Canada				

#### 30. Please rate the following in terms of importance to YOU

	Not important	Somewhat important	Neutral	Important	Very Important
Traditional foods					
Water for "making a living" (day to day use)					
Water for cultural purposes					

#### 31. Please rate the following in terms of importance to your COMMUNITY

	Not important	Somewhat important	Neutral	Important	Very Important
Traditional foods					
Water for "making a living" (day					
to day use)					
Water for cultural purposes					

32. Is there anything else you would like to comment on that hasn't been touched on in this survey? (This can be anything either water or health related):

## THANK YOU FOR COMPLETING THE SURVEY! PLEASE SEE NEXT PAGE FOR DETAILS ON STUDY RESULTS.

## **APPENDIX E - INTERVIEW SOCIODEMOGRAPHIC DATA**

DO NOT Put your name on this sheet.

Participant ID #\_\_\_\_\_

## FOCUS GROUP/INTERVIEW BACKGROUND INFORMATION SHEET

**INSTRUCTIONS**: Please fill in this that will provide us with some basic background information about you.

1. I'm (Check one): Male Two-Spirited Cartering Transgender Gender Neutral Other

## 2. I'm (Check one):

between the ages of 18-20
between the ages of 21-29
between the ages of 30-39
between the ages of 40-49
between the ages of 50-59
between the ages of 60-69
between the ages of 70+

3. Where does your drinking water come from?



Please turn over this brief information sheet and let the focus group organizer know when you've completed it. Thanks.

## **APPENDIX F - INTERVIEW PROMPTS**

## INTERVIEW GUIDE (INDIVIDUAL INTERVIEWS) **Co-Creation of Indigenous Water Quality Tools** Sarah Duignan, PhD candidate

Please note that these are open-ended questions, meant to start conversations about water and health. The facilitator (Sarah) will NOT control the conversation in an effort to get community members' own ideas/concerns/perspectives on the topic. The prompts are there in case the conversations get stalled, and as a reminder to the facilitator of possible topics that may arise. If conversation strays too far away from health and water, the facilitator will also use the prompts to steer the discussion back to the relevant topic.

## General Health

- 1. What does "health" mean or look like to you?
- 2. What do you think makes a healthy community?

#### Household Water Use

- 1. What is affecting water quality in Six Nations?
- What does "water quality" mean to you?
   Who in your household is usually responsible for getting water?
- 4. Do you experience any issues with water quality in your home?
- Does your water use vary with season?
- 6. Do you store water at any point in the year?
- 7. Do you feel that you drink enough water?
- Do you have any strategies to help when you feel worried or upset about accessing. drinking water?

#### Traditional Knowledge and Water

- What does water mean to you, what role does it play in your life?
- 2. How common is Traditional Knowledge on water in Six Nations? How is it shared or acauired?
- 3. Have you heard any stories about how the river or other water sources have changed, or experienced any of these changes yourself?
- 4. How do you feel when you're on or around natural water sources, like the McKenzie Creek or Grand River?

#### Community Water Governance and Health

- 1. Are there any health issues in your community you feel are connected to water?
- 2. What challenges do you feel you and/or your community faces with water?
- 3. How do you feel when you think about the current water situation in Six Nations?
- 4. Are there any other stories or knowledge you'd like to share about water?