

**EVALUATION OF THE KIDNEY CHECK PROJECT USING AN APPLIED
TWO-EYED SEEING APPROACH**

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Abstract

Indigenous people in Canada experience rates of chronic kidney disease (CKD) higher than those of non-Indigenous Canadians as a direct result of colonization. Early detection and prevention through screening is a critical public health strategy in optimizing patient outcomes and reducing burden to the health care system. As such, a screen, triage and treat initiative called Kidney Check is currently offering point of care kidney health screening in sixteen First Nations in British Columbia (BC). One of the important aims of the Kidney Check project in its current iteration is to assess the value, acceptance, and sustainability of the project, with the aim of making a case for expansion and continuity. This thesis describes a culturally safe and respectful framework to understand these parameters from the perspective of Kidney Check team members responsible for organization and implementation of the program in community. A two-eyed seeing evaluation approach combining principles from Indigenous evaluation frameworks with qualitative approaches to evaluation was used to ensure a respectful, relational, and academically rigorous evaluation. Specifically, a narrative approach was taken to honor the tradition of oral knowledge sharing and to ensure that the evaluation priorities were set by community members themselves. Ten members of the Kidney Check screening team told their stories through conversational interviews. Interviews were transcribed verbatim and then thematically analyzed in collaboration with an Indigenous Knowledge Holder to maintain an Indigenous perspective throughout. Themes relating to value are described within the framework of the 4R's; Respect, Relevance, Reciprocity and Responsibility. Themes around sustainability include levers and barriers. Levers to sustainability are intimately connected to the value of Kidney Check. Subthemes around barriers to sustainability include cost, staffing and logistics. The Indigenous metaphor of cedar bark weaving is described as an appropriate visual representation of how the themes illuminated by participants are interconnected and woven together, creating a wholistic evaluation. The results of this evaluation have important implications for both the field of public health as it relates to Indigenous communities and health policy in BC.

Lay Summary

Indigenous people in Canada have higher rates of chronic kidney disease (CKD) than non-Indigenous people, because of the effects of colonization. Screening for CKD is an important way to find kidney disease early and improve peoples' health. The Kidney Check project offers on the spot kidney health screening in First Nations communities in British Columbia (BC). This thesis collected stories from the team who organized the screening to understand the value and sustainability of Kidney Check. Team members felt the project was valuable and sustainable because it was respectful, relevant, reciprocal, and responsible to Indigenous communities. The team members felt that cost, staffing and logistics would be the barriers to sustainability. The Indigenous metaphor of cedar bark weaving was used to describe the relationships in people's stories. There are important implications for both the field of public health and health policy in the province.

Preface

This dissertation is the original, unpublished work of the author Simone Dew. This project was approved by The University of British Columbia (UBC) Behaviour Research Ethics Board (BREB) and underwent a harmonized review with the FNHA. The number of the UBC BREB certificate that covered this work was H20-02695.

The work presented in this thesis was conducted under the supervision of Dr. Adeera Levin and Dr. Patricia Spittal. Additional guidance was received from the supervisory committee. Dr. Susan Cox contributed insight into the qualitative methods, and Catherine Turner guided the work throughout as an Indigenous Knowledge Holder.

The identification of the project was based upon the evaluation framework laid out in the Charter Agreement between the FNHA and the Can-SOLVE CKD Research Network. The study design was conceived by Simone Dew, with assistance from Dr. Cox and Mrs. Turner. The ethics application was conducted by Simone Dew, with guidance from Mrs. Turner. The conversational interviews were conducted by Simone Dew, with assistance from Dr. Cox and Mrs. Turner in the interview guide development and the recruitment. The thematic analysis of the transcripts was done in partnership between Simone Dew and Mrs. Turner who ensured an Indigenous perspective was maintained in this phase. Finally, the thesis writing was completed by Simone Dew and reviewed by committee members.

The Métis identity statement included in the Methods chapter and the reflection featured in the Results chapter was provided by Catherine Turner, and is her own writing. The principals of OCAP are to be respected.

The teaching around cedar and cedar bark weaving included in the Results chapter was provided by Nalaga Avis O'Brien, and belongs to her, her community, and her ancestors. The principals of OCAP are to be respected.

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List of Abbreviations

4R's	Respect, Relevance, Reciprocity and Responsibility (Kirkness & Barnhardt)
BC	British Columbia
BREB	Behavioral Research Ethics Board
Can-SOLVE CKD	Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease
CKD	Chronic Kidney Disease
COVID-19	Coronavirus Disease 2019
eGFR	estimated Glomerular Filtration Rate
ESDR	End-stage Renal Disease
FNHA	First Nations Health Authority
FNHGS	First Nations Health Governance Structure
KDIGO	Kidney Disease: Improving Global Outcomes
MoH	Ministry of Health
OCAP	Ownership, Control, Access and Possession principles
POCT	Point-of-Care Testing
RISe	Researcher Information Systems
RN	Registered Nurse
RRT	Renal Replacement Therapy
SES	Socioeconomic Status
TCPS	Tri-Council Policy Statement
UACR	Urine Albumin:Creatinine Ratio
UBC	University of British Columbia
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples Act

Glossary

Aboriginal: A collective term for the descendants of the First Peoples of North America. This term was imposed through external creation and has been largely rejected and replaced with “Indigenous Peoples”.

Can-SOLVE CKD: A National patient-oriented research network with core infrastructures supporting eighteen research projects dedicated to improving kidney health for Canadians.

First Nations: Groups of Indigenous people in Canada, classified as distinct from Métis or Inuit people. Includes those with or without Status under the Indian Act.

Indigenous Peoples: An umbrella term comprised of those who are descendants of the First Peoples of North America including Aboriginal, First Nations, Métis or Inuit. Includes those with or without Status under the Indian Act.

Settler: A non-Indigenous person living on the traditional territory of Indigenous people.

Wholistic: a spelling of ‘holistic’ that is not deficit based.

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~

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~

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~

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~

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~

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past, present and future.

Chapter 1: Introduction

1.1 Locating Myself

The Kidney Check project offers kidney health screening in sixteen First Nations in British Columbia. The research in this thesis focuses on a culturally safe and respectful method to evaluate the Kidney Check project's value and sustainability from the perspective of those organizing and implementing the screening.

Integral to this research journey has been the ongoing process of self-evaluation and reflection. Cultivating a deep, critical understanding of myself, my perspectives, and my identity has allowed me to investigate both how I came to this research project and what I will leave behind in it. This practice of continual reflexivity is a necessary prerequisite to determining, expressing, and evaluating my positionality as a researcher and locating myself in the research (1,2). This has been a challenging task, but it is essential to both producing meaningful qualitative research and respecting Indigenous ways of knowing and doing (2,3). As Absolon and Willett (2) articulate, "...location is more than simply saying you are of Cree or Anishinabe or British ancestry; from Toronto or Alberta or Canada; location is about relationships to land, language, spiritual, cosmological, political, economical, environmental, and social elements in one's life". So here is my commitment to addressing some of these important concepts and sharing them with my audience as way to begin this dissertation respectfully, authentically, and in a good way.

This commitment begins with investigating and critically reflecting on my heritage and history. I do this with the knowledge that it requires engaging with and moving through feelings of discomfort, evoking the state of what has been called "settler uncertainty" (4). However, borrowing from the words of Eva Mackey (5), it is "a discomfort that may need to be embraced instead of resisted in order to participate in the difficult work of decolonization". As the work of this thesis attempts to take a decolonizing approach to this evaluation, it is essential to work through this discomfort.

I was born and raised on land now called Toronto, Ontario. It wasn't until my twenties, when I began investigating my connection to land and place, that I learned the true histories of the land which supported, protected, and provided for me. Toronto, a name stolen from the Mohawk *Tkaronto*, meaning "where there are trees in the water", is the traditional, ancestral

territory of the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee, and the Wendat peoples, and many other Nations met in and traveled through this area, as it was rich in natural recourses and trade (6). It is covered by the Toronto Purchase, Treaty 13, signed by the Mississaugas of the Credit, however in acknowledging this treaty land, the land I come from, I am also acknowledging a history of deceit and exploitation (7). The original deed signed in 1787 for Treaty 13 was blank- lacking both a description of the land that was “sold” and the signatures of chiefs who allegedly agreed to the sale- these were instead affixed to the document on a separate paper (8). When it was renegotiated in 1805, the Crown purchased an immense tract of land for an absurdly small sum of money, which is why, in 2010, the Canadian government was forced to make the largest land claim settlement to date- a small step towards reconciliation and righting past wrongs (8).

It is essential for me to understand and acknowledge the history of Treaty 13 because – despite its turbulent inception – having been raised on this territory makes me a treaty person. I received a teaching from an Elder when I was taking part in the KAIROS Blanket Exercise which changed how I conceptualize my relationship to land and treaties; she told me that the treaties were made between people, not governments. Meaning, if you are living on treaty land, you have a responsibility to understand and honor the treaty as if you personally had signed it. Being born on this land, in fact, though all the small mundane acts of “living” I did growing up here, I was exercising a treaty right that was negotiated for me centuries ago. While I did not come to these realizations until later in my life, they have become integral to how I view myself and how I look back on my history, examining the things that give me the lens I have today.

Both of my parents are British, born in England but brought here by their parents at a young age, making me a first-generation settler in Canada. My maternal grandparents were both born to blue-collar families in England, where they met and married and then moved to Port Elgin so my Grandpa could work at the Bruce Nuclear Generating Station. My paternal Grandmother, also born to a working-class family, sent my father to Canada as a war child to protect him during the World War II Battle of Britain, and then joined him in Toronto at the end of the war where she settled and built a life as a single mother. The move to Canada represented for each of them the possibility of a better life for them and their children (my parents)- both in terms of economic opportunities and freedom from the trauma of war. It is also true that neither

family considered the implications of their settling - the Nation on whose land they were settling or the treaties which made their settling possible. Thus, likely without realizing it, they actively embodied colonialism. To echo the words of Laura Murray (4), “I have been most comfortable critiquing colonialism at a safe distance” and so to see it in my ancestral line, only one generation removed, is both uncomfortable and difficult to reconcile with the work I am pursuing today. But, there is value in speaking aloud their truth and working to understand my ancestral line and the oppression existing within it. I borrow from the words of Murray (4) again as she writes, “As I walk in the world, I try to keep both heritages, the familial and the colonial, the granted and the stolen, the cherished and the denied, in mind. Reconciling them isn’t my aim, but facing the truth is, and trying to do justice to the conflicts and possibilities between them”.

My heritage and the histories of my grandparents are relevant to this positionality statement and this work because their experiences shaped the lens that both of my parents hold, which in turn has shaped the lens I bring to this research. Both my parents are liberal and open-minded. I was raised discussing politics, global news, social disparities, and other such topics around the dinner table, influencing not only the views on these topics I hold now but also my willingness and enjoyment in engaging in these difficult discussions. I grew up in Cabbagetown, a neighborhood where people of very different income levels live side by side, meaning wealth disparity was sometimes very obvious. My mother and father never shied away from talking about that disparity and its causes, exposing me to complex topics like homelessness, addiction, and poverty.

That being said, I do question many ingrained values I hold as a result of my upbringing. Both my parents carry beliefs born from their British upbringing and those beliefs have influenced me. For example, I never heard nor understood the meaning of the term “white privilege” or “colonialism” until my post-secondary education. While my parents were versed in and willing to discuss the effects of systemic problems, there wasn’t the same dialogue or perhaps understanding surrounding their root causes; namely the systemic racism and colonialism built into the foundation of all societal institutions, from education to healthcare. It wasn’t until my undergraduate and graduate education that I started to better understand the unearned privilege I as a cis, able-bodied white woman hold and how that physical manifestation of self has influenced how I have been able to walk through this world. And it wasn’t until I took

a course in Indigenous Public Health that I began to understand the history of colonization in Canada, its pervasiveness in institutions, and the immense depths of colonial harms. There have been a myriad of other influences in my life that have shaped my perspectives but my upbringing is undoubtably one of the longest and most significant; leaving a lifelong imprint that will influence my epistemology and axiology both in the past and in the future. I will never be able to disentangle myself fully from my upbringing however I can practice engaging in dispassionate observation, allowing myself to unearth unconscious biases and question my inherent values and their origin as they relate to this research.

Looking back, I realize now it was these difficult conversations my parents exposed me to at a young age that planted a seed of interest in what I now know as the social determinants of health. I pursued my undergraduate education in biomedical science, learning a lot about the basic cellular mechanics of health and disease; but the courses I was most interested in looked at the larger, more contextual factors contributing to health. When I finished my undergraduate degree and critically reflected on what my genuine interests were, I realized that I wanted to learn more about these larger societal factors that make populations healthy or well- specifically focused on global health and health disparities among different countries.

In the year following my undergraduate degree, I moved to a small fishing town in rural Thailand to teach English at a primary school. Wanting to promote cultural exchange with my students, and answer their incessant questions about where I was from, I began to plan lessons about Canada, with one of them focused on Canadian history. Engaging in research for this lesson, I found the history that I wasn't taught in grade school; a history of violent colonialism, stolen land, cultural genocide and ongoing oppression. When I returned home to Canada and entered my graduate degree in population and public health, I realized my interests had shifted from contributing to achieving health equity globally to critically examining how we could achieve the same domestically. With my interest and passion for health equity, and equipped with a new viewpoint on Canada, I felt the need to find a project that could allow me to develop these two interests, which led me to this research. It presented me the opportunity to learn about and understand the complex factors contributing to health inequities, specifically in the kidney sphere, and to work with a team committed to community driven, culturally safe ways to address these inequities.

I come to this research as a settler with a non-Indigenous lens. I recognize I will not be able to fully understand the Indigenous experiences presented here because I have not lived them. Nor will I be able to fully embody an Indigenous methodology as a settler, or contribute to the self-determination in the way an Indigenous scholar could. However, I have committed to the work of constant self-reflection and evaluation, to open and authentic learning and listening, and to placing myself as an equal in the learning circle. Indigenous research is relational, as Dr. Margret Kovach (9) states, “...research is relationships”. I have committed the last eighteen months to cultivating authentic relationships with Indigenous people on this project and beyond who have taught me much about how to do this work in a way that centers and privileges Indigenous ways of knowing and doing. Above all else I commit to reciprocity and ethical engagement that acts to ultimately promote the goal of improved kidney health and wellness of Indigenous people in Canada.

1.2 Overview & Summary

This thesis contains four chapters. The first chapter offers an overview of relevant literature regarding the landscape of Indigenous health, chronic kidney disease (CKD), CKD screening and CKD in Indigenous communities, and explains the Kidney Check project and the goals of this evaluation. The second chapter describes the theoretical framework that guided this research and offers a methodological analysis explaining how I came to the methodology ultimately used to conduct this evaluation. This chapter also details the methods used for the evaluation itself including the impacts of COVID, the involvement on the Indigenous Knowledge Holder, recruitment, interviews, coding and analysis and the ethical considerations surrounding the work. The third chapter explains the results of the evaluation showcasing the themes that emerged from the stories participants told divided into two categories: those that spoke to value of the project and those that spoke to sustainability. These results are further described by an Indigenous metaphor and teaching, and reflections on my experiences illuminated using my field notes are also shared. In the fourth chapter, the results are contextualized within the broader landscape, the implications of the results for both public health and policy are described. As well, the complexities of the pandemic are described, and the

tensions between prioritizing cultural safety and operating on academic timelines is explored. Here, the strengths and weaknesses and future implications of the work are also described.

1.3 Background

1.3.1 Indigenous Health & Wellness

Descriptions of Indigenous health in Western academic literature are often deficit-based, describing a lack of health, and focusing on Western notions of sickness rather than Indigenous understandings of wellness (10,11). The truth is that Indigenous people in Canada have conceptualized and embodied health and wellness at an individual, community, and Nation level since time immemorial (12). It is recognized that Indigenous wellness before European contact and subsequent colonization far surpassed where it stands in the present day.

While Indigenous communities are numerous and diverse in their culture and ceremony, wholistic perspectives of wellness which approach the person as an integrated whole, with balance between mind, body, spirit, and with community at the center of health is one common thread connecting them (13,14). In contrast to Western perspectives on health, wellness - conceptualized as balance - is seen relating to factors beyond the self as King et. al (10) argue, “Balance extends beyond the individual realm such that good health and healing also require that an individual live in harmony with others, their community, and the spirit worlds. For Indigenous peoples, land, food, and health are key components of being alive well”. But for centuries since contact, these factors that are important to “being alive well” have been either directly outlawed or undermined through paternalistic colonial institutions which have according to Jongbloed, (12) “historically, and in the present, undermined Indigenous rights, freedoms, sovereignty, and Nationhood”. So, braided into the concept of Indigenous wellness is self-determination, defined by Corntassel & Bryce (15) as the “unconditional freedom to live one’s relational, place-based existence, and practice healthy relationships” that is “asserted and acted upon, not negotiated or offered freely by the state”.

One way the impact of colonization on health can be addressed is through the reinstatement of that Indigenous self-determination - both at an individual and a community level (16). Importantly, this restoration must come from Indigenous origin, and feature Indigenous people asserting their own needs and interests and in turn promoting their own healing (13). In

the context of health, it has been found repeatedly that self-determination can act as its own important determinant of health for Indigenous people and communities (10,17). Specifically, the incorporation of traditional healing and Indigenous worldviews into patient care can help promote feelings of ownership and self-determination for some Indigenous people. This in turn can lead to better long-term results at a systems level, but more importantly at an individual, and community level (13). As stated by Auger et al. (17) “At a systemic level, self-determination has been cited as a critical determinant of Indigenous health and is often conceptualized as a strength-based antithesis countering the ongoing impacts of colonialism”. Thus, it is absolutely imperative that work in the sphere of Indigenous health acts to support the restoration of self-determination, as this is an essential component to Indigenous wellbeing.

1.3.2 Landscape of Health in Indigenous People in Canada: The Enduring Legacy of Colonization

It has been clearly documented that Indigenous people in Canada experience disease and poor health outcomes at rates higher than those of non-Indigenous Canadians as a result of complex historical and contemporary oppression imposed on them (18). The staggering inequity between Indigenous and non-Indigenous people living in Canada has been demonstrated in a growing body of literature that uses standard health indicators to compare overall health trends between these populations. Studies show that infant mortality rates in Indigenous populations are more than twice as high as those of the general Canadian population (19), risk of suicide is more than three times as high in Indigenous communities (20), rates of Type II diabetes are three to five times the national average (18), and tuberculosis rates are six times greater in Indigenous populations and almost fifty times greater in Inuit populations than the national averages (21). Overall, First Nations men were twice as likely to die from avoidable causes and First Nations women, two and a half times as likely (22). These statistics speak to just how vast the gap in health is between Indigenous and non-Indigenous people in Canada as a result of the extensive trauma Indigenous communities have survived, because of colonization and the systematic and institutional oppressions therein (17,23). They also speak very emphatically to a much deeper issue with regards to a lack of effective, community-based interventions, with which to address these persistent gaps. This issue illustrates how important it is to inform and subsequently enact

new policy geared toward initiatives that can close this gap. As succinctly stated by Adelson (18) “...time and again health disparities are directly and indirectly associated with social, economic, cultural and political inequities; the end result of which is a disproportionate burden of ill health and social suffering upon the Aboriginal populations of Canada”.

The landscape of Indigenous health in Canada must be understood in the context of the extensive trauma Indigenous communities have survived and continue to survive, as a result of colonization (17,23). Duran et. al (24) describe colonization as a collective “soul wound” that has caused a historical trauma response for Indigenous people caused by the “...multigenerational, collective, historical, and cumulative psychic wounding over time, both over the life span and across generations”. Historical governmental policies sought to destroy traditional ways of life in order to colonize and assimilate Indigenous people. Indian Residential Schools, the 60’s Scoop, and Indian Day Schools and Indian Hospitals were only a few of the means by which to accomplish this goal. The traumatic effects of these horrific legacies continue to be felt today in the form of survivor and intergenerational trauma linked to said historic trauma response (23). Disruption to traditional languages, laws, ceremonies, and food systems coupled with barbaric dispossession and displacement from traditional lands and territories have caused the destruction of Indigenous economy, autonomy, culture, tradition and history; pointing to colonization as its own proximal and distal determinant of health for Indigenous people (25). It is important to also understand that colonization is not in the past; it persists in a contemporary setting enacted by the colonial settler-state and continues to effect Indigenous people in a very real way. We have yet to heal the “soul wound”, nor have we yet to even address the root cause of that wound.

Colonization introduced and also perpetuates anti-Indigenous racism that is now deeply entrenched in the Western health care system in Canada (26). A growing body of literature documents the predominantly negative experiences Indigenous people have with the Canadian healthcare system. The racism saturating this system means that engaging with healthcare providers can be dangerous at best and fatal at worst for Indigenous people (27). Literature speaks to the limited options for an Indigenous person in need of care: they must either anticipate negative treatment and determine how to mitigate its impact on the quality of care received, or avoid care altogether in an effort to protect oneself (28). This racism acts to sustain these health

disparities and makes it necessary for Indigenous people to use avoidant behaviors for personal protection. This speaks to an urgent need for culturally competent care. Looking specifically at British Columbia, where this project takes place, a report commissioned by the Minister of Health called “In Plain Sight” outlines the sordid extent to which racism impacts Indigenous people’s health and wellbeing and their ability to interact with the Western healthcare system. Described within this report (29) is a picture of the “B.C. health care system with widespread systemic racism against Indigenous people. This stereotyping, discrimination and prejudice results in a range of negative impacts, harm, and even death”. Learning about the experience of accessing healthcare for Indigenous people here in B.C. is essential to contextualizing this evaluation work in place.

1.3.3 Chronic Kidney Disease

According to the Kidney Disease: Improving Global Outcomes (KDIGO) organization CKD Work Group (30), chronic kidney disease (CKD) is stated to be “a general term for heterogeneous disorders affecting kidney structure and function with variable clinical presentation, in part related to cause, severity and the rate of progression”. To be formally diagnosed with CKD, one must have structural or functional abnormalities of the kidneys for 3 or more months, as manifested by (1) kidney damage, with or without decreased estimated Glomerular Filtration Rate (eGFR) or (2) eGFR $< 60 \text{ ml/min}/1.73 \text{ m}^2$, with or without kidney damage (31). Patient presentations of CKD can be classified into five stages based on severity and potential treatment avenues, with the fifth and final stage being end-stage renal disease (ESRD) (31). Once a patient has reached ESRD, renal function has declined so severely that kidneys can no longer function independently, and renal replacement therapy (RRT) is necessary to maintain health (32). Importantly, CKD is challenging for health systems as it is largely asymptomatic until its later stages, when ESRD and kidney failure are largely unavoidable and symptoms present secondary to kidney function decline (30,33). Symptoms of delayed kidney function can only be treated by addressing the root cause of these symptoms either by hemodialysis or transplantation, with both of these treatment options carrying their own burdens (30).

CKD is recognized globally as an important public health problem (30,31,34). The disease burden of CKD in Canada specifically is high, with both incidence and prevalence increasing in recent years. Studies estimate that around 12.5% of Canadians currently have CKD, a figure representing over three million people (35). While less than 0.1% of Canadians have CKD which has progressed to ESRD, the financial burden associated with dialysis and transplantation is exorbitant, with 1.2% of total annual health care budgets being consumed by this less than 0.1% of the population (36,37). Additionally, a diagnosis of CKD significantly reduces both lifespan and quality of life (30,36–38). Specifically, progression to ESRD and being placed on dialysis results in patients suffering both physical consequences from the stress of the illness on the body and social consequences due to social withdrawal or self-isolation leading to drastically reduced health-related quality of life (36,37). Perhaps most concerning is the relationship between chronic kidney disease and cardiovascular disease (CVD). Studies point to a bidirectional relationship between these two conditions, termed “cardiorenal syndrome” where each may in turn result in the progression of the other (39–41). Patients with ESRD who are on hemodialysis have a thirty fold increased risk of cardiovascular mortality, with over 50% of ESRD patients dying from a cardiovascular event (41,42). Even patients with less severe CKD still have significantly increased risk of CVD and its consequences (43).

CKD does not impact all populations equally; there is evidence of disadvantaged populations bearing a disproportionate burden of disease (44). This is likely caused by the complex interplay between social determinants of health; CKD is closely linked with socioeconomic status (SES) in a large body of literature as its risk factors are more commonly observed in populations of low SES (45,46). SES can influence CKD risk a variety of different ways including demographically, biologically, clinically, behaviorally, or through access to health systems (47). For example, biological risk factors for CKD include diabetes, which is the leading cause of CKD and ESRD worldwide, and hypertension – both conditions heavily linked to SES and impacted by other related social determinants of health (48–51). The complex interaction between social determinants of health and systematic and institutional racism in society predisposes racialized people and ethnic minorities to CKD as well. Studies show that Black, Indigenous and Asian populations have significantly higher rates of CKD compared to their white counterparts (52). However, because CKD is so heavily associated with the social

determinants of health which can be influenced through proper social supports both within and outside of the health care system, there are important opportunities for prevention, or delayed progression through primary, secondary and tertiary interventions (52,53).

1.3.3.1 Chronic Kidney Disease Screening

Early detection and prevention are critical public health strategies in managing patient outcomes and reducing financial burden on the healthcare system associated with chronic diseases like CKD (30,54). If diagnosed early, there is an important window of opportunity to manage and delay the progression of CKD to renal failure through behavioral interventions including smoking cessation, dietary management and pharmacological interventions that usually target the renin-angiotensin system to control hypertension and proteinuria (55–57). This delay is essential to ensuring optimal quality of life for the patient and avoiding the costly renal replacement therapies that are inevitable in the later stages of CKD. Unsurprisingly, studies have found that a referral to a nephrologist in earlier stages of the disease is associated with reduced morbidity, mortality and hospitalization rate (57,58). These facts make CKD an optimal candidate for screening programs which have been increasingly advocated for as a viable, minimally invasive, cost-effective secondary intervention that can identify CKD in its early stages, when implemented properly (59–61).

There are a number of different factors to take into consideration when implementing a screening program, as screening as a health care practice is not without risk (54,55,62,63). Firstly, the illness must be relatively prevalent in the screened population in order to make screening cost-effective and worthwhile. While generally true for CKD, previous literature has found CKD screening to be cost-effective only when implemented in high risk populations, such as those with hypertension, diabetes or above the age of 60 (59,61). Secondly, the performance characteristics of the screening test are also important to consider. To maximize the opportunity for disease detection and minimize the number of false positives (which could cause psychological distress and incur further costly testing) the test should have high sensitivity, specificity and positive predictive value (61). When looking at the two common tests used for CKD screening, the first is a urine albumin:creatinine ratio (UACR) and the second is an eGFR estimated from serum creatinine levels using equations factoring in other physiological parameters.

Both are widely accepted as reasonable screening measures, albeit there is some contention around a high false positive rate (64). That being said when screening is limited to populations of high risk, the positive predictive value of the test increases significantly (64). The screening test must also not impose undue physical or psychological harm, and this potential for harm must be outweighed by the possibility of attenuated disease progression (61). With these minimally invasive CKD screening tests requiring only a urine sample or blood draw, with low risk of stigmatization, and offering available treatment measures in the case of a positive result this is also the case (61). The last condition for screening is that identification must result in potential treatment, which is very much the case for CKD with more and more effective interventions targeting different physiological pathways becoming available (65).

Because early detection is so integral to successful treatment and because CKD screening is a viable clinical option and meets the considerations for ethical screening, it is essential that screening is considered and implemented in high-risk populations. These parameters have been integrated into healthcare practice guidelines in British Columbia, but lack the concerted, organized federal policy support necessary for widespread implementation. Additional robust, evidence-based, studies on screening are needed, especially in a Canadian context.

1.3.4 Bringing it all together: Improving Kidney Health in Indigenous Communities

As a direct result of complex historical and contemporary colonization experienced by Indigenous people, and the policies in place that act to marginalize communities, First Nations, Métis and Inuit people in Canada face inequalities in health and healthcare access and utilization (66,67). Looking specifically at kidney health, these inequalities have contributed to rates of CKD that are significantly higher among Indigenous people than non-Indigenous people (68–72). Furthermore, due to these gaps in care – both geographical and cultural – Indigenous people diagnosed with CKD are also more likely to have rapid rates of disease progression and four times as likely reach ESRD (72,73). Indigenous ESRD patients are also more likely to live remotely and have to travel further to seek care, are less likely to receive a transplant, and have lower survival rates in the period following dialysis (74). Looking further upstream, previous literature has found that rates of risk factors associated with CKD including obesity, hypertension and diabetes, are also disproportionately high in Indigenous communities, pointing

to a proximal factor associated with these CKD rates (68). The connection between these risk factors (and CKD) and colonization cannot be overstated. In referencing diabetes, author Halseth (75) states high rates are:

intimately connected to historic and contemporary colonization processes, including loss of traditional lifestyles and spirituality, displacement, marginalized land bases, sociocultural disruption, assimilation, systemic disadvantage, socio-economic marginalization, loss of control over one's lifeway, loss of overall community wellness, power imbalances, stress, racism, discrimination, and intergenerational trauma.

This statement holds true for all other risk factors of CKD as well. In this way, it is essential to understand the root causes of CKD rates through a lens of colonial harms whereby the complex interplay of various determinants of health are taken into account.

Regarding health systems care, Indigenous CKD patients are significantly less likely to visit a nephrologist and receive the coordinated care necessary to manage and treat CKD, and as a result are almost twice as likely to end up admitted to hospital (76). This is also a consequence of various systemic factors, including lack of access to care in remote locations, with previous studies showing that remote dwelling acts as an important risk factor for CKD among an Indigenous people (71). It is also important to consider that those individuals with CKD who reside on reserves in rural or remote locations who require renal replacement therapy (RRT) will have to travel a significant distance, with 20% of Indigenous patients having to travel over 250km to access a hemodialysis center up to three times a week (74). Travel and dialysis time together make it difficult to sustain employment, and being away from home makes it difficult to get much needed support from family and community members. Additionally, many Indigenous people find being on the land integral to their wholistic wellbeing. As Redvers (77) states, "...‘land’ is understood as a relational component of healing and wellbeing" so having to leave the land for dialysis treatment severs an important connection with potential consequences for wholistic health. To further complicate matters, home hemodialysis is challenging due to added utility costs which fall to patients, as well as lack of space, reliable energy sources and running water and is rarely offered as a treatment modality to those living on reserve (78). All these factors make early diagnosis of CKD through targeted screening programs in community an essential priority for improving Indigenous kidney health and wholistic wellbeing. Importantly, previous literature has found screening programs for CKD in Indigenous populations are in fact,

cost effective, and even more so for remote communities (79). However, it is essential that these programs are rooted in a culturally safe pedagogy as this is imperative for reducing or removing potential for harm and as Brooks-Cleater et al. (80) explain, “draw[ing] attention to the social, political, and historical factors that affect [Indigenous peoples] health-care experiences”.

1.3.4.1 The Kidney Check Model of Care

Given the importance, a screen, triage and treat initiative called “Kidney Check” is currently underway to offer screening for CKD for First Nations people in Ontario, Manitoba, Alberta and British Columbia. Each provincial context has a unique set of geographical and cultural circumstances, different resource profiles, and varies greatly in health service delivery infrastructure and organization. Therefore, different models of the initiative exist to best suit the population it would serve in each province; and further customized for each community within the province. Regardless of model, the Kidney Check program has a central tenet: to provide a screening service to identify and treat CKD to prevent invasive medical care necessary for progressed CKD such as dialysis and transplant where possible and improve health in Indigenous communities (81). Importantly, this initiative has been guided from its inception by the tenets of community-based research methods and respectful, ethical engagement with First Nations communities. For the purposes of this thesis, I will be focusing on how the Kidney Check initiative proceeds in sixteen First Nations in British Columbia.

In British Columbia, the Kidney Check project is done in partnership between the Can-SOLVE CKD network, which is a patient-oriented research network dedicated to early diagnosis, better treatments and innovative care for Canadians with CKD, and the Office of the Chief Medical Officer of the First Nations Health Authority (FNHA). The project was identified as a priority by Indigenous Patient Partners and Knowledge Holders and Elders, and has been guided since its inception in 2015 by a team of both Indigenous and non-Indigenous staff to ensure cultural appropriateness. The Kidney Check team in BC is made up of the Primary Investigator Dr. Adeera Levin, the Senior Research Coordinator, the project manager, three Indigenous patient partners, one of whom is the coordinator of the Indigenous Peoples Engagement in Research Council at the Can-SOLVE CKD Network, and the Kidney Check registered nurse.

To begin, information tables were hosted at regional and provincial Indigenous health conferences and events throughout 2018 and 2019. When community health leaders or community leaders approached the table and felt the project aligned with community health priorities, they were offered an expression of interest to submit. A total of 28 expressions of interest were submitted. The next step was to collect a community profile with more detailed information on size, location and infrastructure of the community. From the community profiles, the Kidney Check team went through a selection process aiming to ensure diversity in location, size and readiness for screening with the ultimate goal being to use the results from these communities to create a case that would expand screening to all interested First Nations in BC. A total of sixteen First Nations were ultimately selected to be a part of the Kidney Check project.

The screening model in BC is a mixed model with a strong focus on capacity building to foster sustainability and growth of knowledge, skills, and self-determination in communities. Nurses from each community were invited to a three-day training in Vancouver in September of 2019 where they were provided background information on CKD and the Kidney Check project. They were also trained in how to use the point-of-care testing (POCT) mobile screening equipment. The initial screening event is usually attended by the Kidney Check team who travels into a community with the equipment. They offer support with screening, providing a guided training refresher if necessary. The POCT equipment is subsequently left in community for continued use. This capacity building exercise allows for the now-trained nurses in community to continue to use POCT mobile screening equipment until screening targets are met. This model is important for building up the strength of community, an essential part of community-based research methods. Furthermore, it became even more important in the context of the COVID-19 pandemic, where screening visits from an external screening team were impossible, but with trained nurses in community, screening could continue uninterrupted.

Prior to beginning screening in community, extensive community engagement was a priority. Two representative members of the Kidney Check Team visited communities to give educational presentations on the importance of kidney health and to outline the Kidney Check project, and to make important connections with community members through informal discussion or shared meals. Essential to this community engagement step was the involvement of Indigenous patient partners who would share their lived experience with kidney disease,

alleviating fear and emphasizing the importance of screening. Traditional Indigenous protocols and culture were incorporated into these visits, with informal discussion and connection occurring over meals. Following the community engagement sessions, community members are then invited to attend screening events or make appointments for screening at their local health facility through social media campaigns, posters in health centers, and word-of-mouth.

When the screening team is in community supporting screening efforts the first point of contact in the screening experience is the Indigenous Research Coordinator (FNHA) who goes over the consent form; referencing specific ownership, control, access and possession (OCAP) principals, ensuring each individual understands what is done with their data, understands individual ownership of the screening process, understands they can opt out at any time, and that they control their health information. Once informed consent is obtained, baseline demographic information, blood pressure, and biochemical data are collected by the Kidney Check nurse and analyzed using POCT equipment. The resultant data is fed into an external iPad application which uses an algorithm to return a risk level (no, low, medium, or high risk) of renal failure in the next five years based on each individuals' unique parameters. After screening, each participant is educated and informed on how to best proceed, with culturally relevant educational material provided. Those with medium or high risk of CKD are referred immediately to a nephrologist for further care and advice on how to best manage their kidney health. Ideally after this initial screening visit led by the external Kidney Check team, nurses in community will continue screening on an ongoing basis following this same process of consent, screening and referral if necessary.

For some communities in BC, capacity building is not possible for a variety of reasons, including the lack of in-community nurses, or the lack of in-community nurses' capacity to dedicate to screening. In these cases, the Kidney Check project leverages its mixed model approach, with the project team going into community and carrying out screening themselves on planned screening days until quotas have been met, forgoing the training. It is important to note that this is a community driven initiative and as such, it must be flexible and responsive to the needs and abilities of community. The mixed model approach was created through efforts of constructing and deconstructing the program of work to allow for community participation regardless of resources.

1.3.4.2 The Expansion of Kidney Check & Rationale for Evaluation

One of the important aims of the Kidney Check project in its current iteration is to assess the value, acceptance and sustainability of the Kidney Check methodology and process. A follow-up evaluation was included in the original protocol. This evaluation suggested the use of mixed methods to determine the value, acceptance, and sustainability of the Kidney Check project from the perspective of two groups: community members who were screened and those involved in organizing and implementing the screening. Ultimately, this evaluation, and what is included in this thesis seeks to understand the value added of the Kidney Check project in terms of what is relevant to each specific community from the perspective of screening team members.

As an exploration of frameworks and methodologies that could be used for the evaluation phase proceeded, it was decided that a different methodological approach was necessary for each of the two groups. To collect the perspectives of community members who were screened, it also was decided that the most culturally appropriate way to seek this information would be through sharing circles in community (or interviews for those who prefer a private discussion) which would occur when the Kidney Check team returns to community for a celebratory feast and to share the aggregate results of the screening process. A narrative analysis would then occur in order to respect the relationality of the stories shared in the focus group sessions, honoring Indigenous ways of sharing, and allowing individuals to take ownership of their stories and experiences. In contrast, the information provided by the screening team could be collected through a virtual approach, as this information could be useful to guiding and improving screening efforts when the Kidney Check project resumes post-COVID.

This thesis tackles the second part of this evaluation, focusing on the perspectives of the screening team members in two communities who have recently achieved their targeting screening numbers. This comprehensive qualitative methodology, outlined below, allows for in depth investigation into the value and sustainability of the program from a stakeholder perspective. This information is vital to achieving one of the original aims set out by the Kidney Check Charter Agreement with the FNHA which was to “create a business case for this type of initiative to be funded by BC Ministry of Health for making it available for more communities”.

Chapter 2: Methodology

2.1 Theoretical Frameworks

Theoretical frameworks are essential tools in a qualitative researcher's arsenal. Indeed, the theoretical framework outlined in this chapter has guided and shaped this research from its inception. The framework has been a driving force for the research choices made throughout this lengthy process, including fostering the relationships built to support this research, the selection of certain methodological approaches, and of course the analysis and presentation of the findings (82). Margaret Kovach (82), a researcher of Nêhiyaw and Saulteaux ancestry equates theoretical frameworks with conceptual frameworks in that they both "connotate a theoretical knowledge system that governs the research". She further describes (82) "the content and form of the conceptual framework itself assists in illustrating the researcher's standpoint, thus giving the reader insight into the interpretive lens that influences the research". By outlining my theoretical framework, I hope to allow readers to understand the thought process and intention underpinning this work, to minimize the power dynamic which is a reality of interpreting and presenting findings, and to begin with truth and authenticity in the forefront. Additionally, the search for, and creation of, a theoretical framework is a step that has been found by many qualitative researchers to be integral to promoting reflexivity and reciprocity; both central tenants to my philosophy as a settler researcher in the field of Indigenous health, making this step even more crucial to doing this in a good way (83).

Selecting and embodying a theoretical framework is not an apolitical experience. Stated succinctly by Bainbridge et. al (84), "As researchers, our ways of knowing and being are inseparable from our ways of doing, and all ways of doing make epistemological claims". Many theoretical frameworks used in Western research privilege and center European epistemology, "thus manufacturing and reproducing Western epistemology as a normative standard within research" (82). As a non-Indigenous woman engaging with Indigenous health research, it was essential for me to choose a theoretical framework that:

- (1) acknowledges and challenges the power and privilege I have experienced because of systemic factors that favor people who share my white European background
- (2) counters Western epistemology and centers Indigenous knowledge and theory in an

active effort to decolonize this research process and counter that normative standard
(3) considers the social, historical and political context of Indigenous health in Canada and leads strengths-based research where respectful relationships are in the foreground
(4) accommodates institutional standards of an academically appropriate method of inquiry

It is a complex process to incorporate these concerns into a theoretical approach, and one that has required a large amount of revisiting and revisioning. Below I present the outcome of this extensive process; a framework aiming to be respectful and culturally safe, centering Indigenous epistemologies, and engaging in “the ethical space between” (85).

2.1.1 Etuaptmumk

An overarching principle central to this research, even to the creation of this theoretical framework itself, has been the approach of *Etuaptmumk* or “Two-Eyed Seeing” brought forward by Mi’kmaw elders Albert and Murdena Marshall, who are from the Eskasoni community, in Unama’ki (86). *Etuaptmumk* speaks to combining the strengths of both Western science and Indigenous ways of knowing and doing and using both together for the greatest benefit (87). In the words of Albert Marshal (88),

Two-Eyed Seeing adamantly, respectfully and passionately asks that we bring together our different ways of knowing to motivate people, Aboriginal and non-Aboriginal alike, to use all our understandings so that we can leave the world a better place and not compromise the opportunities for our youth (in the sense of seven generations) through our own inaction.

This approach is less about a research paradigm, and more about a way of life; an openness to new ways of knowing and doing and the humility to view these new ways alongside current knowledge systems without assigning superiority to one or the other (86). Importantly, the approach is seen as a link between Indigenous and Western knowledge systems and not the transplantation of Indigenous knowledge into a Western framework (86,89).

While reflecting on the practical means with which to authentically foster a two-eyed seeing approach in this work, I have leaned heavily on the work of Cheryll Bartlett and Murdena and Albert Marshall. They share lessons in how to weave Indigenous knowledge and mainstream science together. I know that I, as a non-Indigenous woman, am more predisposed to a Western worldview and am more familiar with and biased by (both consciously and subconsciously) this

knowledge system. However, with great humility over the past two years, I have been making genuine attempts to both understand and hold Indigenous knowledge as it is shared with me. The teachings I have received have given me a glimpse at a new knowledge system with which to view the world around me and my relationship to that world- the people, the animals, the land and the water. This practice does not always come easily, as I am constantly aware of and have grave concerns over appropriating versus appreciating this knowledge, and what my role in the Indigenous portion of two-eyed seeing can be. Here is where I relied heavily on the eighth lesson- learned which Bartlett et. al share (88): “Develop an advisory council of willing, knowledgeable stakeholders, drawing upon individuals both from within the educational institution(s) and within Aboriginal communities”. Working with the Indigenous Knowledge Holder on my committee, collaborating with her at every step of the research process, has helped me deepen my understanding of Indigenous knowledge systems and has assisted in fostering a genuine *Etuaptmumk* approach spanning this framework, the methodological approach, analysis and dissemination of this work.

2.1.2 Social Determinants of Indigenous Health

The social determinants of Indigenous health model represents an important lens through which to view the health disparities imposed upon Indigenous people in Canada, including those relating to kidney health described earlier in this thesis (18,90). This model takes into account the long history of inequities in social, historical, political and economic dimensions which occur as a result of historical and contemporary oppressions and articulates how these inequities interact to ultimately influence health (10,18,91,92). Importantly, including this as an essential component in my theoretical framework guiding this research ensures that I, and any readers of this dissertation, wholly comprehend and target structural components of health and are not asserting or presupposing individual responsibility for them. Central to this model, and thus central to my research paradigm, is the understanding that the multiple effects of historical and contemporary colonization are the source of many of the inequities and resulting health disparities observed in Canada, but that Indigenous people have their own strengths-based determinants of health as well (18,23).

There are some important differences between the Indigenous Health model and traditional models of social determinants of health applied to the broader population. Specifically, ‘health’ in this model discussed by Reading and Wien (90) represents a “[W]holistic concept of health that reflects physical, spiritual, emotional, and mental dimensions” and the complex interplay between these different dimensions of health”. Additionally, this model considers the impact social determinants can take across the life course; understanding that not only is health wholistic but experienced differently at different points in life (90). Lastly, while many of the conventional determinants of health do apply to Indigenous people (including income, social status, poverty, education, employment etc.), the Indigenous social determinants model describes Indigenous-specific determinants of health including aforementioned colonization, connection to land and self-determination, and includes determinants of health that have Indigenous specific impacts including globalization, racism and worldview (10,93).

The model described by Reading and Wein (2009) in the National Collaborating Center for Aboriginal Health report outlines three levels of determinants: proximal, intermediate and distal, each exerting different effects on health (90). Proximal determinants of health represent conditions which act on an individual level and have a direct impact on physical, emotional, mental or spiritual health (90). These include health behaviors like smoking, lack of exercise, and poor diet as well as physical environments, employment and income, education and food insecurity (90). It is important here to note that while proximal determinants act on an individual level, they are not the fault of the individual; rather, each one of these proximal determinants can in some way or another be traced back to colonization and its continual oppressive effects through intermediate and distal determinants. For example, looking specifically at poor nutrition as a proximal determinant of type II diabetes and cardiovascular disease; poor nutrition must be viewed within the larger context of food security which is impacted by land stewardship and community resources, which are ultimately tied to a history of land dispossession and economic exclusion through colonialism. Similarly, Indigenous people have consistently been excluded from the job market due to systemic racism resulting from colonial history and attitudes, which effects the ability to achieve a high socioeconomic status, which can lead to poverty resulting in increased psychosocial stressors leading to physical health consequences such as diabetes, high

blood pressure, and poor mental health (90). In this way, physiological pathways to disease are altered and mediated by larger circumstances and histories which are without question far beyond individual or even community control, which is essential to understand when interpreting proximal determinants of health.

Intermediate determinants of health are the overarching systems that contribute to and cause adversity that make negative proximal determinants of health a reality for Indigenous people. For example, an important intermediate determinant of health is access to appropriate educational systems. The reality for many Indigenous people is either limited access to education, or a lack of a culturally relevant curriculum, and a system which is not attentive or responsive to the barriers Indigenous children and youth may face (90). These factors contribute to lower education levels for Indigenous people, impacting employability and income levels, and resulting in poverty which is a proximal determinant of health itself. Other intermediate determinants include health systems, community infrastructure, resources and capacity, environmental stewardship and cultural continuity which is connected to all of the previously mentioned determinants (10,90). Defined as “the contemporary preservation of traditional culture”, cultural continuity appears in a variety of different ways including knowledge and use of traditional language, self-government, autonomy over land, intact families with Elder engagement and more (90,94,95). Cultural continuity is intimately related to each of the other intermediate determinants (90). Looking again at the example of education systems, those who have access to a ‘culturally competent’ curriculum, have higher retention rates, higher employment levels and better mental health (90). Looking at it from a strengths-based lens cultural continuity represents an important positive determinant of health. Previous research even points to cultural continuity as a protective factor against suicide, HIV and diabetes (95,96).

Lastly, the distal determinants of Indigenous health underscore all the other determinants and are the most impactful contributors to health as they, according to Reading and Wien (90) “represent the political, economic and social contexts that construct both intermediate and proximal determinants”. These contexts were created and continue to be perpetuated by colonialism and its closely related consequences including racism and social exclusion, and a lack of self-determination. Colonialism exerted and continues to exert both direct and indirect influences on health (25). Through the lens of the Indigenous social determinants of health

model, colonialism can be seen as the root cause of many, if not all, of the intermediate and proximal determinants of health which illustrates the depth and breadth of the effects of colonialism.

This thesis is framed within the essential context of the social determinants of Indigenous health as this allows for a comprehensive understanding of health and wellness and the societal factors detrimental to its attainment. Foremost to this work is an appreciation that all parts of the research process are contextualized within the political, historical and social circumstances that act to marginalize and oppress Indigenous people. This appreciation is fundamental to ensuring that we do not re-enact harmful colonial paradigms and essential to transmitting the knowledge acquired in a way that is both responsible and responsive to the experiences of the participants.

2.1.3 Post-Colonial Theory & Post-Colonial Indigenous Thought

Post-colonial theory is an essential component of the theoretical framework guiding this research. It provides an additional construct with which to contextualize and critically analyze the impacts of historical and ongoing colonization on Indigenous peoples' ability to prosper and thrive in today's Westernized society (97–99). Recognizing Canada is a country built on a foundation of colonization, this theory asserts that the intentional social stratification and 'othering' of Indigenous people was essential to the Nations success and used as a tool to occupy the territory and assert authority over its inhabitants (98,100). This has ultimately led to a socially constructed concept of race that heavily influences societies' perceptions and actions, resulting in deep power imbalances that act to create health disparities for Indigenous people (97,100). Stated succinctly by Indigenous scholars Sherwood and Edwards (98), this theory is "a framework of and for remembering...allowing the fragments or silent voices of the past to remember their history and the colonial experience". In this way, a post-colonialist framework requires uncovering legacies of colonization in the health sphere in order to analyze and ultimately respond to them in some way (100).

The use of this framework allows space for important resistance against narratives that have been created for Indigenous people through this colonial history (100). It allows us to understand and name colonization as an essential factor for the disparities currently existing in health. In this way, it is highly congruent with the social determinants of Indigenous health

model. It is also an important approach given the history of research *on* Indigenous people and the harm it has caused (98). Western academia carries a shameful legacy of research that has exploited and disrespected Indigenous people and created false truths which have further entrenched stereotypes and allocated individual blame to systemic problems. Most of the research has been done by settler scholars, using Western paradigms that unequivocally do not meet the needs of those on whom the research is focused. Historically, there has been no concern for including Indigenous people in the design, execution, or dissemination phases of research, and hence no regard for the importance for self-determination and direction in the research process. For this reason, including an anti-colonial theory in the creation of my theoretical framework was imperative as it simultaneously acknowledges this colonial history in research while demanding more (97).

Post-colonial theory is still a theory born from Western epistemologies and has fallacies as a result of its origin. It cannot be confused with post-colonial Indigenous knowledge, which originates from Indigenous ways of being and doing (97). In the words of Mi'kmaq scholar Marie Battiste (101) "Post-colonial Indigenous thought is based on our pain, and our experiences, and it refuses to allow others to appropriate this pain and these experiences. It rejects the use of any Eurocentric theory or its categories". In this way, many scholars feel that post-colonial Indigenous thought is a much more appropriate lens, as post-colonial theory could never fully embody or convey the realities of colonization because it is not coming from an Indigenous (lived) experience. The difference in these two bodies of knowledge required me to take pause in the creation of my theoretical framework. I acknowledge that as a settler woman, I cannot partake in post-colonial Indigenous thought, and I did not want to center Eurocentric theories in this work and further entrench that normative standard of Western thought. Returning to the literature, I leaned on the work of Métis scholar Emma LaRoque (101) who argues that post-colonial theory can still be a valuable resource for non-Indigenous people to challenge their biases and beliefs and improve their research paradigms. Because of the importance of remembering and contextualizing this research within a history of colonization, I can justify the inclusion of post-colonial theory as valuable to the framework, as long as I acknowledge its pitfalls, and stay critically aware of them throughout.

2.1.4 Phronetic Approach

A fourth and final approach informing my theoretical framework for this work, is phronesis. A phronetic approach to research involves prioritizing and embodying practical wisdom or prudence, and focuses on how to act ethically and what that experience looks like (84,102). Essentially, phronesis involves focusing on the population with which you are engaging and then asking how to gear research towards helping this group with the problem they are facing (103). Indigenous health scholars in Australia have suggested using a phronetic approach to guide research with Aboriginal populations as it places importance on understanding the experience of Aboriginal people and how their history, culture, values, beliefs and worldviews permeate the research process (84). An important step in this approach is to articulate the dynamics between the researcher-researched dyad including values, interests and the power imbalances that may be present and rectifying these imbalances to improve outcomes (84). This involves de-centering the epistemologies, beliefs, and practices of dominant Eurocentric knowledge systems to better serve the needs of the community and “deliver social change for the common good” (84).

Practically, a researcher embodying a phronetic approach is pragmatic and context dependent; using an appropriate, ethical process for the specific community they are engaging. In my own evaluation practice, this translates into offering Nation-based protocols to begin the interviews, acting ethically by offering an appropriate protocol and in a context dependent manner by ensuring the protocol is specific to the Nation. Phronetic research also concerns itself with the variable of interest; in practice this looks means not taking more knowledge than necessary and focusing the evaluation on the practical outcomes. In Western research paradigms, there is often a belief that knowledge can be owned, and it has been the practice of many academics to harvest or extract as much knowledge as possible from participants (104). In an Indigenous paradigm, when you hold knowledge, you are in relationship with that knowledge, and you are accountable to that relationship (104). Thus, holding knowledge is a responsibility and you are encouraged to take no more than what is needed to answer the question of interest.

2.1.5 Braiding It Together

Each of these different bodies of thought bring important considerations with which to

guide the research. Using a two-eyed seeing approach allows me to privilege Indigenous knowledge throughout the evaluation and contributes to decolonizing the work. The Social Determinants of Indigenous Health model shares contextual knowledge that will help me understand my findings in the broader landscape. Post-colonial theory and post-colonial Indigenous thought ensures that the history of colonization and power imbalances is acknowledged in the work. Lastly phronesis grounds my work in place-based principles. These four components of my theoretical framework weave together to form one approach that promotes a respectful and culturally safe evaluation centering Indigenous epistemologies.

2.2 Methodological Analysis

Once I had conceptualized and articulated my theoretical framework, the next step was to select a methodological approach embodying both the values and the principles of my theoretical framework. Importantly, the process of selecting an appropriate methodology was not an easy one. Looking at the framework of Indigenous methodologies, I made the decision on how to move the work forward was made from an accountability perspective (105). That is to say, in the words of Sean Wilson (105) “...your methodology has to ask different questions: rather than asking about validity or reliability, you are asking how am I fulfilling my role in this relationship? What are my obligations in this relationship?” As a non-Indigenous researcher, I knew it would not be appropriate for me to adopt an Indigenous methodology. However, it was essential to understand the relational nature of the knowledge I was journeying to collect and incorporate these considerations into the process of finding an appropriate methodology. Additionally, it was equally important to incorporate and embody decolonizing methodologies wherever possible and to the extent I could as a settler woman.

Ultimately arriving at a methodology was a multilayered process, which I will explain below. To offer a contextual overview I began by investigating Indigenous evaluation frameworks and understanding the key components therein. Then I began to explore how I could use a decolonizing methodology, which was appropriate given my positionality and background, and which could also respect the core values of Indigenous evaluation. Here, I was looking for a way to engage in what has been called by William Ermine (85) “the ethical space”, which exists between Western worldviews and Indigenous ways when both parties observe alternative ways

of doing and respectfully engage with humility and reflexivity (106). Through this process I discovered qualitative evaluation and began to see some parallels between what could be achieved using this approach and the central tenets of Indigenous evaluation frameworks together. Further investigation revealed the use of narrative in qualitative evaluation and its congruency with Indigenous storytelling traditions. This specific methodology offered the space to be able to honor oral traditions of sharing, and to allow participants to set the agenda and priorities for evaluation. Internally, I shifted back and forth between these three main methodological pieces and my own positionality, coming to understand how they could fit together cohesively within the larger context of this work. This process was done with the support and guidance of the Indigenous Knowledge Holder on my committee whose perspective was invaluable throughout.

Overall, the process of coming to a methodology for this evaluation was lengthy and required time, thought, effort and much reflexivity on my positionality itself and appropriate ways for me to navigate it within the research methodology space. In many ways this was as much a learning as was the actual data collection and analysis itself. The careful consideration of different methodological approaches and evolution towards the methodological paradigm we proceeded with is what ultimately set the foundation for this evaluation to proceed in a respectful, relational, and academically rigorous fashion. For this reason, I am including a fulsome analysis of how I came to my methodology, with the intent being to contribute to the academic body of knowledge in a meaningful and unique way.

2.2.1 Indigenous Evaluation Frameworks

I began the process of understanding how to proceed with this evaluation by looking at Indigenous evaluation experiences and frameworks put forth by Indigenous scholars. Much like research, evaluation has a bad reputation among Indigenous communities as it has enacted the same harm through the ever-present colonial practices and disconnected methodologies (107,108). Historically, evaluations have been requested by external funding agencies, carried out by “outsiders”, and have abjectly failed to consider the concerns or priorities of the people who interface directly with the program being evaluated. As well as originating from agendas external to communities and their members, evaluations have also failed to take into account

Indigenous epistemologies and have used dominant Western evaluation paradigms leading to “false realities and stories about Indigenous people” that fail to recognize community strengths (107,108). One poignant example of this was shared in the Summary Report of a Provincial “Three Ribbons” Expert Consensus Panel convened in 2016 in Toronto. This panel brought together Indigenous and allied non-Indigenous scholars, health care professionals, and public health experts to discuss health service and program evaluations in an Indigenous context. The report describes how an evaluation was completed for a program in a First Nations community and low attendance was reported. This led to the program being deemed a failure. Instead, this finding should have been interpreted within the larger context of the community. Asking why community members were avoiding the program and how to improve it in the future is essential knowledge that was disregarded in this evaluation. This is just one example of many of how evaluations that fail to be aligned with the knowledge needs and priorities of the community fall short. As stated by Kawakami et. al (109), “Too many nonindigenous evaluators have stood with their feet planted firmly in their own worldviews and have themselves failed to gain any true understanding of our ways, our knowledge and our world”.

Often, the goals of evaluation for funding bodies do not align with the goals of an evaluation for community members, leading to these tensions and harms (108). While funding bodies look at evaluation as a tool to examine funding allocation, justify expenditures and ensure financial efficiency, community members priorities may lie with ensuring the program is effective and relevant for community members and their health priorities (108). This difference in motivation between external funders and community members combined with the fact that the funds for evaluation usually rest in the hands of external funders who assert their priorities as more important, often results in an evaluation that is not useful to community (107). In addition to priorities, the methodology, analysis, knowledge translation and impact are all vastly different depending on the evaluation context (109). For example, evaluations using Western, mainstream practices are usually quantitative in nature, with analysis heavily focused on statistical significance or the numerical size of effect, and use charts or reports to share the findings. In contrast, Indigenous evaluations are usually more qualitative with the data being comprised of information deeply steeped in cultural context, requiring analysis that accounts for both cultural and environmental significance (109). Most importantly perhaps is the difference in impact;

Indigenous evaluations are used to promote and assert self-determination and sovereignty through discussion of the value, and lessons learned while Western mainstream evaluations result in funding changes, most frequently a reduction (108).

As a result of these deep-seated issues with evaluation, Indigenous scholars have developed alternative Indigenous evaluation frameworks that are rooted firmly in Indigenous ways of knowing and doing (107). These frameworks house core values immensely different from those seen in Western evaluation paradigms, allowing for cultural safety and alignment throughout the evaluation process (107). While there are several different evaluation frameworks that exist and even more coming forward, each with unique features and contexts, they do share some core values. Firstly, Indigenous evaluation frameworks incorporate, privilege and prioritize Indigenous knowledge as an essential foundation for evaluation (107–110). Practically this means acknowledging stark differences in Western and Indigenous worldviews and placing “consideration of Indigenous identity, epistemology, values and spirituality” at the forefront, and using methodologies embodying these considerations and allow them to be incorporated into the evaluation (109). Closely related to this concept is the idea that the evaluation must be community based; the priorities, indicators and outcomes must be set by community. This may mean the evaluation may not just focus on program characteristics but will likely collect interrelated knowledge addressing larger topics like restoring community health, and self-determination. Additionally, these frameworks describe the importance of a place-based approach; contextualizing the evaluation methods, findings, and analysis within the specific cultural, historical and socio-political contexts of both individuals and communities (107–109). The evaluation must be wholistic in nature to allow for the capturing of these contextual nuances. An evaluation that is place-based also recognizes the sovereignty, strengths and gifts of the individuals and the community taking part in the evaluation (108). In this way, the evaluation does not break the program down into indicators and variables but appreciates the ‘whole’, i.e., looking at multiple ways to measure and define success. As stated by LaFrance et. al (110) in Indigenous evaluation frameworks “[W]holistic understandings of interconnectedness are valued more than postpositivist notions of isolating variables to explore causality and generalizability”. Ultimately, using Indigenous evaluation frameworks aids in conducting relevant evaluations that

further the self-determination and empowerment of communities, and in providing clear information that can be used to advance health goals (109).

As I engage in this research as a settler, it is imperative for me to understand how to embed core values from Indigenous evaluation frameworks into my own work respectfully and engage in that ethical space in between worlds. As a non-Indigenous researcher working within a Western academic framework, I know I cannot fully embrace an Indigenous evaluation paradigm. Paradigms are rooted in epistemologies and only those with lived experience can fully understand Indigenous ways of knowing and doing and embed this into the research. Additionally, the use of Indigenous methodologies by non-Indigenous researchers many argue is in fact re-colonizing. I have come to realize, and accept, that I do feel it is possible, and essential, to embed core values and teachings of Indigenous evaluation into this work, in order to avoid re-enacting the harms my fellow Western evaluators have inflicted over the years. This can only be made possible by opening my heart and head to teachings shared with me by the Indigenous members of my committee, by actively committing myself to reconsili-action, and by constantly learning and unlearning the biases I hold.

2.2.2 Qualitative Methodologies in Evaluation

While reflecting on how to embed the core values of Indigenous evaluation frameworks into my Kidney Check work, I came to the concept of qualitative evaluation. Qualitative research methodologies focus on gaining a deep understanding into the “how” or the “what” behind different phenomena (111). Using qualitative methodologies that attempt to capture the beliefs, perceptions, values, and lived experiences of the participants can ultimately lead to a better understanding of perceptions and behaviours in a population (111). In this way, qualitative research is much more investigative in nature than its quantitative counterpart, frequently used to confirm or dispute a previous hypothesis (112). Importantly, the past decade has seen an insurgence of qualitative methods in the field of health services evaluation, as these methods have a lot to offer in this world. Quantitative evaluations, deeply associated with a positivist approach, have dominated the field of health service evaluation across the globe in the past (113). These quantitative-based evaluations of health programs have focused on measuring things like cost efficiency of a program, an interventions physiological effectiveness, or its

ability to meet specific goals determined through proxy indicators (113). These program characteristics, while important, do not tell the full story of a health service and they can and should be evaluated on a broader scale, which qualitative evaluation methodologies allow for. Specifically, if a quantitative evaluation determines a program to be cost-effective, and that is the sole parameter for determining success, many valuable parameters that might either confirm or refute that success are not measured. For example, whether the program is useful in achieving the health priorities of the population it serves, and whether people are motivated to access the service and use it to its fullest potential. For these reasons, qualitative evaluations can unearth important characteristics relating to stakeholders lived experience with the program which is beneficial when looking at and assessing the overall success of a health service, understanding the experience of the program in different settings, and developing practical tools to improve the program moving forward.

Additionally, qualitative evaluation can give a voice to those who have historically been denied one in this sphere. Most qualitative evaluation frameworks incorporate and privilege the voices and lived experiences of stakeholders and participants rather than external funding bodies or removed oversight entities (113). In this way, qualitative evaluation addresses and attempts to remove power imbalances that could influence the outcome of the evaluation. In order to fully interrupt this dynamic however, and ensure the health service is not being developed or continued under the sole influence of distal stakeholders, the knowledge shared by participants and those with lived experience and the results of the evaluation must be translatable into actionable consequences (113). In this way, qualitative evaluation is highly action-based. It collects practical information about a program from those with hands-on experience, and it attempts to understand the value, the meanings, the challenges, the gaps and the needs of the program within that specific context (113). This information is then used to direct action to ultimately improve the service; either addressing challenges or further planning and implementing new iterations of the program. Lastly, qualitative evaluation is highly contextual, meaning it is fluid and adaptable, with its methodologies grounded in the needs and environment of the program it is assessing (114).

That being said, many critics claim that qualitative evaluation can be fraught with issues related to trustworthiness, validity and reliability (113,115). Because it is not possible to

‘standardize’ qualitative evaluation tools, many feel that bias and subjectivity can seep into the data collection and analysis thus tainting the findings (115). However, there are certain things researchers using qualitative evaluation methods can do to bolster the strength of the work at various levels of the research design including the selection of the research sites and research team, the design of data collection methods, and the implementation of analysis (115). It was important to remain aware of these concerns as I moved forward with shaping a methodological design for the Kidney Check evaluation and used them to strategically shape the evaluation process.

2.2.3 Narrative Framing to Evaluation

Qualitative evaluations can proceed using a variety of different methods including case-studies, interviews, focus groups, observation and written documents like field notes (116). It is up to the discretion of the evaluation team to select which method, or combination of methods are most appropriate for the specific program and its unique context. Using narrative methods in evaluation is a technique that has gained recent attention and interested me as an important potential method to use for the Kidney Check evaluation (117). Narrative methods in evaluation involve collecting peoples’ stories with the commodity being evaluated. In this way peoples stories become data with which to investigate and find answers to questions asked in the evaluation (118). As Costantino and Greene (117) state, “stories can offer a uniquely meaningful prism through which to observe and appreciate a program’s contextualized value”. Importantly, framing an evaluation in narrative allows for an appreciation of the program in its specific context as it relates to the individual telling their story, and allows for an authentic understanding of the value and benefit of the program to that individual (117). In this way, including narrative in evaluation gives a voice to participants and stakeholders, and allows them to raise organically what was important to them in their lived experience with a given program. This in and of itself is hugely important in the context of evaluation, as setting out with a predetermined agenda could invite evaluators to miss important program characteristics. Another important characteristic of narrative in evaluation is that it is highly contextual. The stories which people put forth about their experiences with the program are organically situated within their personal

experiences, culture, and histories (118). This allows for a comprehensive interpretation, keeping the experience with the program foregrounded in individuals' circumstances.

There are different ways of incorporating narrative into evaluation, including the most significant change model and narratives linked to a theory of change (119). The most relevant to this work is the idea of narratives with emerging themes. This model of narrative in evaluation involves using "stories... to understand context, culture, and participants' experiences in relation to program activities and outcomes" (119). This involves looking for themes or patterns emerging from individuals' stories, using a qualitative case study approach, and subsequently using participants' own stories to illustrate the themes. In this way, a narrative framing to evaluation diverges from a narrative methodology, where stories in their totality are the unit being analyzed. Here, stories are the medium with which codes, subthemes and themes can be discovered through narrative thematic analysis, but they themselves are not analyzed (118). This allows an authentic evaluation method, deciphering the understanding of the program holistically, as situated within the experiences of the stakeholders. The use of the participants' own words truly maintains that perspective and reality and grounds it from a personal lens.

2.2.4 Bringing it Together: Qualitative Evaluation Framed in Narrative and Informed by Indigenous Evaluation Frameworks

In many ways, the principles of qualitative evaluation compliment many of the core values in Indigenous evaluation frameworks (82). Things like emphasis on contextualizing the information in individuals and place, looking at findings holistically, and allowing participants to set the agenda appear central to both. As I was able to see these similarities, I was able to identify that a qualitative evaluation methodology could be an effective way to integrate teachings from the Indigenous evaluation framework into my Kidney Check evaluation paradigm. Hyett et. al (120) have stated "qualitative tradition has been particularly instrumental in integrating Indigenous and Western ways of knowing, because many qualitative methodologies embrace the existence of multiple truths and subjectivity of participant experience". Other scholars have echoed this sentiment, but others add the importance of also ensuring cultural appropriateness throughout, being mindful and respectful of cultural values and

practices at every step of the research process if using a qualitative approach to Indigenous health research (82,121).

Embedded within qualitative methodologies and specifically relevant to Indigenous ways of knowing and doing is the value placed on spoken words (121,122). Information collected through methodologies such as focus groups or interviews, are appreciated in their entirety, and valued as the raw data from which to build conclusions. Looking more closely at the specific methodology with which to move forward with a qualitative evaluation for the Kidney Check project, I investigated different ways to honor the practice of oral sharing. Previous papers have found collecting narratives to also be in line with Indigenous ways of knowing and doing, as the core principle of storytelling complements the oral traditions of Indigenous people (122,123). Highly relevant to a narrative approach is the idea that stories are co-created by the researcher and the storyteller; in this way the knowledge is co-constructed (123). This also honors another essential tenet as stated by Gorman and Tooms (123), “a collaborative approach between researchers and Aboriginal communities is pivotal to developing a research project consistent with Indigenous cultural values and health concepts”. Through this investigation, I began to understand that collecting stories for this evaluation would allow me to embed core values from an Indigenous evaluation framework and use a decolonizing methodology, without appropriating or exploiting Indigenous ways of knowing. In essence, this approach would allow me to exist and work in the ‘ethical space between’ worldviews. Further collaborative discussion with the Indigenous Knowledge Holder on my committee confirmed the appropriateness of this approach, thus supporting the view that my intentions and selection criteria resonated appropriately.

2.2.5 Kidney Check Evaluation Framework

Combining the learnings from Indigenous evaluation frameworks and qualitative evaluation using a narrative approach, and my own personal positionality the Indigenous Knowledge Holder on my committee and I came together and discussed how to incorporate these learnings into the Kidney Check evaluation. The following core values were determined to be central to this work:

1st Core Value: Evaluation is Community Driven:

The evaluation process must align with Kidney Check's guiding principle of being "Nation-led & Community-driven". To allow the community to drive the evaluation and set the agenda by providing information which is ultimately useful to them, I proposed using a narrative framing to the evaluation involving the collection of stories from screening team members about their lived and told experiences with the Kidney Check project. This narrative approach, which involves asking one or two open ended questions and then inviting the knowledge expert (interviewee) to share what they determine to be relevant allows for community members to drive the priorities of the evaluation and ensures the construction of evaluative standards by community members themselves.

2nd Core Value: Evaluation is Place-Based:

To be Nation-led & Community-based, the evaluation must be rooted in and contextualized by the history and culture of each individual community. Firstly, consultation with community members was done in advance of the evaluation interviews to ensure Nation-based protocols are practiced for each community (ie; the gifting of tobacco at the start of the interview to honor the wisdom shared and/or other relevant gifts). Additionally, a narrative approach was selected as the most appropriate methodology because being context-sensitive is essential; the stories interviewees share are situated within participants' personal experiences, culture, and histories.

3rd Core Value: Evaluation Promotes & Practices Indigenous Epistemologies:

As a settler, I understand I cannot adopt Indigenous research methodologies and thus cannot fully implement a decolonizing methodology. However, if constantly critical and reflexive of my own biases and assumptions and reflexive and consistently open to teachings, feedback and guidance from those on my advisory committee who are Indigenous, I am confident I can follow teachings that are embedded in Indigenous methodologies. Narrative methodologies rely on the storytelling process, which is an important component of Indigenous culture. In this way the evaluation can promote, practice and privilege Indigenous voices through Indigenous ways of knowing and doing.

2.3 Evaluation Process

2.3.1 COVID-19

COVID-19 was declared a global pandemic by the World Health Organization on March 11th 2020. This announcement and the global ramifications that resulted cannot be understated, and ultimately impacted this thesis work. It essentially narrowed the ways in which any evaluation of Kidney Check could be undertaken. As a result, like many researchers and students during this time, I pivoted. This involved collecting information from Kidney Check screening team members as opposed to community members who were screened, limiting my evaluation to the two communities that had reached their screening targets and completing all interviews virtually using Zoom. While this narrowed the scope of the evaluation, it allowed for the collection for valuable information that could be used to inform and direct the program in a post-COVID-19 era. Section 4.2.1 provides a more fulsome analysis of the impacts of COVID-19 on this evaluation and the larger Kidney Check project and the broader Indigenous research sphere.

2.3.2 Indigenous Knowledge Holder Catherine Turner

Absolutely central to this evaluation has been the guidance and oversight of the Indigenous Knowledge Holder on my committee, Catherine Turner. Catherine is a Métis woman whose family originates from the historic Red River Settlement in Manitoba. Catherine is the Indigenous Research Coordinator from the FNHA who works as a member of the Kidney Check team, and also works with the Can-SOLVE CKD Indigenous Peoples Engagement in Research Working Group and leads other Indigenous initiatives across the network. She also holds a graduate certificate in Indigenous Public Health from the Center for Excellence in Indigenous Health at UBC. She was the Indigenous Liaison Manager of the Kidney Foundation of Canada BC & Yukon Branch and was the past Chairperson of the National Aboriginal Diabetes Association and was a member of their executive board since 2004. Catherine has worked in health and primary prevention programs with Aboriginal and First Nations communities for the past two decades, including administering an Aboriginal diabetes initiative for eight years.

Catherine was involved at every step of this evaluation, and it was undoubtably her involvement that allowed the work to proceed using a genuine two-eyed seeing approach.

Catherine's role at each juncture is outlined below but generally, we met weekly throughout this process which allowed for open and consistent communication. Any suggestions that Catherine made in these meetings or at other points about the evaluation process – from selecting a methodology to analyzing the interview transcripts – were honored and implemented. Any questions that I had about cultural protocols or the best way to go about maintaining the cultural safety of the work were directed to Catherine who patiently gave me her guidance. In addition, any writing that was done for this thesis was sent first to Catherine to read for cultural appropriateness before it was sent to the rest of my committee. Catherine and I's weekly conversations and her steady guidance was instrumental in the evaluation.

Given how central Catherine is to this work, it is essential to introduce Catherine and for her to, as Absolon and Willett describe (124), locate herself as an Indigenous woman. Below is Catherine's Métis identity statement. This is Catherine's own writing, and the principles of OCAP are to be respected:

My name is Catherine Turner, I am a proud Métis woman whose family originates from the historic Red River Settlement in Winnipeg Manitoba.

My families Métis identity was verbally acknowledged only in 1983. I was to later discover that the security and safety to identify as Métis was related to the inclusion of the Métis as one of Canada's Aboriginal Peoples, guaranteeing them treaty rights, in the Canadian Constitution, Section 35. Following this revelation I embarked on a journey of self-discovery to learn what it meant to be Métis. I registered for first year undergraduate courses at the University of Manitoba, one of them being a Native Studies course taught by the Métis scholar Emma LaRocque. It was here that I learned of the complex history of the Métis nation in Manitoba. I recall leaving daily lectures in total disbelief, along with many mixed emotions about the history that I was learning. Further to the knowledge I acquired about my nation's history, I discovered that I was connected to a powerful figure in Métis politics and importantly his leadership in the Red River Rebellion. In fact Ambroise Lepine is buried next to Louis Riel in the St. Boniface Cemetery as a result of their close relationship and ties to the Red River Provisional Government.

I was to later discover that my maternal grandmother was also Métis, and so it turns out that three of my grandparents are Métis, the fourth was French Canadian. I now have a greater understanding from both sides of my family why there was a denial about our Métis identity. I know that my maternal grandmother denied our Métis ancestry to protect her children from the residential school system and many other racist policies that existed to exterminate Indigenous children and their families. I believe that the family was taught that if you were Indigenous it meant that you were “less than”, dirty, unworthy, lazy, a drunkard, and we certainly weren’t THAT.

On my paternal side of the family, they did identify as Métis, although it was never discussed within my generation of siblings or cousins. Racism towards Métis individuals was rampant in the aftermath of the Red River Rebellion. As my father shared with me, not only were we Métis but we also had direct family lineage involved in the Red River Rebellion. My grandfather – Jean Baptiste, of five generations, was also involved in the Red River Rebellion, although he didn’t have as prominent a role as Ambroise did. I was appalled to learn of the silencing of our voices from that time onwards. Ambroise Lepine had his civil rights taken away, reinstated shortly before his death. After a great deal of exploring, uncovering and healing I have come to a place where I am proud of my heritage, my Métis identity, and I have been committed to improving the conditions for Indigenous people, in whatever capacity works and is available to me.

And so, although my identity as a Métis woman wasn’t ‘named’ until 1983, I have learned that my family and my community were indeed Métis. I can look back at the wonderful memories I hold of Métis cultural events and gatherings with my family. It is a very rich history and culture and I am grateful for it.

I moved to the Comox Valley in 1991 and started a professional career in supporting Indigenous individuals to achieve their best health outcomes. Since that time, I have been a founding member of a local Friendship Centre, and a local Métis Association, advocating for and delivering primary prevention

programs for Indigenous children, youth, women and families. I acquired my BA in Professional Communication from Royal Roads University in 2009, and recently completed a Graduate Certificate in Indigenous Public Health at the Centre for Excellence in Indigenous health at UBC

It has been my mission to not only advocate on behalf of those individuals in society who have been less fortunate, but also to do my very best in creating spaces and places that are safe and nurturing for Indigenous individuals, families and communities.

Since my involvement in the research realm began in 2016, I often questioned why it was that research is ‘done’ to Indigenous people, versus Indigenous people researching their own health and other issues. In light of this I believe that it is of utmost importance that until we get to that stage, and that as Indigenous peoples, where opportunity exists, we MUST guide the work being done in our Indigenous communities. When asked by Simone to support the work that she was about to initiate, I was more than happy and willing to do so. It has been a noteworthy experience where I have learned as much from her as she has from me.

2.3.3 Participants & Recruitment

Recruitment of participants began after UBC BREB approval was granted. A purposive sample of participants was included in this evaluation including: internal Kidney Check team members working with the Can-SOLVE CKD network, and external Kidney Check team members working in community, each requiring a different recruitment method. These different types of participants each held specific knowledge relating to different parts of the project, allowing for a well-rounded evaluation which captured elements of the program characteristics, how the program was received in community and ultimately how it was carried out.

Internal Kidney Check team members are participants who work directly with the Kidney Check project from the research network. These individuals were contacted directly by me via email where I shared information about the evaluation context and goal and invited interested individuals to respond for further conversation. External Kidney Check team members are

community members who work with the internal team to organize and implement screening on the ground for their community. These individuals have been in contact with the Senior Research Coordinator throughout the duration of the Kidney Check project. To ensure respectful and appropriate introductions, the initial contact was made by her, and those who were interested were invited to reach out to me. All replies from participants were followed up by me via email and then individuals were sent the informed consent to better understand the study and their rights as a participant. I answered any questions presented, collected the signed consent forms and scheduled dates and times for the interviews.

2.3.4 Conversational Interviews

Interviews were held over Zoom to allow for face-to-face interaction and connection between the researcher and the interviewee in a world without face-to-face interaction. Interviewees were reminded that they could turn their camera off and choose a pseudonym to share on the screen to increase comfort and anonymity, although none did. Pending permission, which was granted in all cases, the audio of the interview was recorded using an external recording device for later transcription.

The interview guide (Appendix A) was comprised of a beginning where I introduced myself and the project, outlined the interview process and invited participants to ask any questions. I started the interview in a casual manner, inviting conversation to flow between myself and the interviewee about light topics like the spring weather and weekend plans. This allowed the interviews to begin with a spirit of authenticity, humility and connection. For those knowledge experts who were Indigenous, a Nation-specific protocol was incorporated into the beginning of the interview, for example a tobacco offering to honor the knowledge being shared.

Using a conversational interview method, I then began by asking the knowledge experts a few questions about their role and responsibility within the Kidney Check project from the interview guide. I proceeded to ask about their experience of the Kidney Check project, with the aim of collecting stories from them about their true lived and told experiences. I also asked broad questions on the value and sustainability of the project. From what was shared I would ask further prompting questions meant to elicit additional clarification or expanded sharing. Importantly, the informal, conversational interview style allowed for the knowledge expert to

share the story of Kidney Check from their perspective, including communities values and priorities to guide the focus of the evaluation (107). In other words, it allowed for individuals to define the standards of the evaluation themselves, made evident in how and what they felt was important to share in response to the open ended questions (107).

The interview ended by thanking individuals for their time, explaining that there will be a “check-back” in the following weeks to ensure that Nation-based perspectives were accurately incorporated and reflected in the analysis and findings. Knowledge experts were also informed that at any point in the next two weeks they could opt to have their data removed from the evaluation.

Importantly, as the interviewer, I did advanced research on, and strove to incorporate, culturally safe and trauma-informed practices in these interviews. This was done to be prepared to receive and respond to disclosures about culturally unsafe events or issues in this project. Throughout the interview I kept the tenets of authentic, compassionate, and thoughtful communication foremost in my mind. I also received and incorporated a teaching from my Indigenous Knowledge Holder on being present throughout the process which was essential to the interview process. Specifically, she shared with me that this is an area where settler researchers, like myself, have struggled in the past due to operating within an academic framework which prioritizes timelines and rigorous structure. It was essential for me to unlearn these practices and focus on letting those attitudes go and instead focus on being present with, and quietly and humbly listening to, what individuals choose to share through their story.

The typical interview lasted around forty-five minutes to an hour. In it, participants responded to the three overarching questions in two different ways. Many of responses featured providing in-depth, elaborate answers illuminating participants’ perspectives and contextualized them within their own experience. On some occasions, participants told full stories when answering one of the questions, complete with a beginning, a challenge, and a resolution. It was very much in the nature of these open-ended conversational interviews that participants shared quite expansively.

2.3.5 Transcription, Coding & Analysis

With permission, the interviews were recorded on an external, digital audio-recording device. They were then transcribed verbatim by me. Important to note and understand in my analysis strategy is that while I collected elaborate answers and, in some cases, full stories from participants, I did not complete a narrative analysis. Rather, stories were the medium in which I found codes, subthemes and themes. To discover those themes, I began with coding. All of the open coding was then done by hand on printed, anonymized, copies of the transcripts and I used inductive coding to work through the qualitative data. I used highlighters, notes in the margin, sticky notes, mindmapping, cross-referencing, and writing memos to engage with the immense amount of data contained in the transcripts. I preferred to work with the data by hand, rather than using software as I felt it was important for me to become immersed in the data.

Coding occurred in a three-step process. First the transcripts were read in totality to familiarize myself with them, and to start understanding the stories within them. Next, I embarked upon the process of inductive, emergent coding; listening to the data and defining and assigning codes that were suggested through the data. Here I was careful to maintain the “wholeness” of the data, understanding that knowledge experts shared a story which was highly contextualized within spaces, places and relationships. It was important to me through the coding process to be flexible and mindful of maintaining the relationships and contexts in the data; making sense of and organizing what was shared without breaking it apart. To assist in maintaining that context, I used in-vivo coding as much as possible throughout this process to keep the data in the knowledge experts “own words” and not impose my own interpretation. This aided in maintaining a connection between the participant’s voice, intent and meaning and the analysis and allowed their own terms to guide the creation of themes. Next, I collected all the codes I created in the first round and began to organize them, looking at certain patterns and concepts which were emerging through these codes. Here I refined the codes by merging and renaming where necessary. With this refined set of codes, I went back through the data, carefully re-coding, with the lens of reflecting on categorization of these codes, and what potential and subthemes were coming up.

Next, I brought these refined codes and their groupings to the Indigenous Knowledge Holder on my committee, Catherine Turner, and together we worked through them ensuring that

she and I had both made note of the same quotes and were in agreement on how they should be coded. The discussion elicited by this process allowed me to broaden my understanding of the codes themselves, which was very valuable. We looked at potential themes that were emerging and naming those themes and subthemes. Her guidance here was valuable and imperative to maintaining the cultural competence of this analysis as it ensured my subconscious Western bias did not impose or supersede the knowledge experts own words. The collaborative nature of the data analysis, done in partnership with Catherine and myself, was important to having an embodied and intuitive analysis. The whiteboard depicting the thematic analysis that was the product of these collaborative discussions can be seen in Appendix B.

2.3.6 Ethical Considerations

This evaluation work was granted approval by the UBC Behavioral Research Ethics Board. It underwent a harmonized review with the FNHA ethics department where it was part of a pilot project that invited FNHA employees from outside of the ethics department to review and provide feedback on the application. This feedback was then collated by the ethics department who then scheduled a collaborative meeting with my Indigenous Knowledge Holder and myself to share the reviewers suggestions and to work together to make the evaluation stronger. This review process, and the First Nations lens it brought, was essential to ensuring that this work was in tune with Indigenous research ethics and principles and would move forward in a good way.

Also central to the ethical considerations of this work were the principles of Ownership, Control, Access and Possession (OCAP) and Tri-Council Policy Statement 2 (TCPS) Chapter 9. Both resources describe the essential considerations for engaging in research with Indigenous people, and these were used as guides for the development of the entire ethics application that was ultimately submitted to RISe. OCAP is a set of principles described as “self-determination applied to research” (125). It was born out of decades of research done *on* Indigenous people rooted in harmful colonial practice that has exploited Indigenous people and done significantly more harm than good. OCAP stands for Ownership, Control, Access and Possession; four principles central to the consideration of methodological process, and data maintenance and stewardship through this evaluation and of the larger Kidney Check project. Additionally, TCPS-2 Chapter 9 “Research Involving the First Nations, Inuit and Métis Peoples of Canada” was

another resource essential in creating an appropriate methodology. This chapter contains important context and guidance for researchers, including specific articles and the mechanics of their application.

Lastly, and perhaps most importantly, as previously mentioned Catherine offered guidance throughout the evaluation process. Having the guidance of an Indigenous Knowledge Holder was imperative in ensuring the evaluation proceeded in an ethical, culturally safe manner.

2.3.6.1 Member Checks

To help ensure the results were interpreted and represented correctly, and the perspective of the Nations were maintained through the coding and analysis, I incorporated a member-check step, completed in partnership with the Indigenous Knowledge Holder on my committee, Catherine Turner at the recommendation of the FNHA. Following the initial interview, I connected Catherine to the participants via email. Here, an outline of the knowledge expert's data, organized to include themes and subthemes as well as any excerpts of their transcript used to illuminate them was shared. This step was meant to ensure reciprocity between the participant and me, to ensure all the information shared had been interpreted correctly, and that the participants were comfortable with the way their voices and statements were being used in the analysis.

Chapter 3: Results

3.1 Introducing the Knowledge Experts

A total of ten participants were recruited and interviewed for this evaluation. Of these ten participants, five belonged to the internal kidney check team, meaning they worked within the Can-SOLVE CKD network. Another three participants were a part of the external kidney check team, meaning they worked to organize and carry out screening in community. Two participants had roles on both the internal team and the external team and were able to share knowledge on both aspects of the project. Of the ten participants, five were Indigenous, self-identifying as either First Nations or Métis, four were non-Indigenous, and one did not disclose their background. Participants held diverse roles, backgrounds, experience levels and amount of involvement with the project. The majority of participants were women, with only three men interviewed.

3.2 Qualitative Findings

Through reading and rereading the stories and in-depth answers shared by those interviewed, and the collaborative thematic analysis by Catherine and myself that followed, several themes emerged. Deciding how to organize and communicate these was a challenge. Initially, three categories of Value, Sustainability and Experience were created based on the three questions asked in the interview. Themes and subthemes were then placed into the categories based on which topic they spoke to. While this very Western approach organized the data very succinctly, it did not allow for the expansive overlaps that were appearing among the three categories and the themes within them. At Catherine’s suggestion, I removed the categories and looked at the data in its entirety. Notably, this step of the analysis exemplified an important epistemological difference between Catherine and I and affirmed the importance of doing the analysis collaboratively. As stated by Wright et. al (126), “ Indigenous ontology is described as interconnective, animated, and balanced, while Western ontology is made up of parts and wholes”.

Catherine’s feedback allowed me to see the data more holistically and different findings emerged. We began to see an overlap in groups of subthemes and the 4R’s of ethical Indigenous

engagement- Respect, Relevance, Reciprocity and Relationality. While this organization allowed for a better picture of the data in its entirety, there were still some pieces that did not fit within these four overarching themes, specifically the barriers to sustainability. To accommodate this important data, we went back to my original way of organizing the data and modified it. We ultimately combined the initial two approaches to best suit the data, and to engage in the “ethical space between”. A visual representation of this is presented in Figure 1. below.

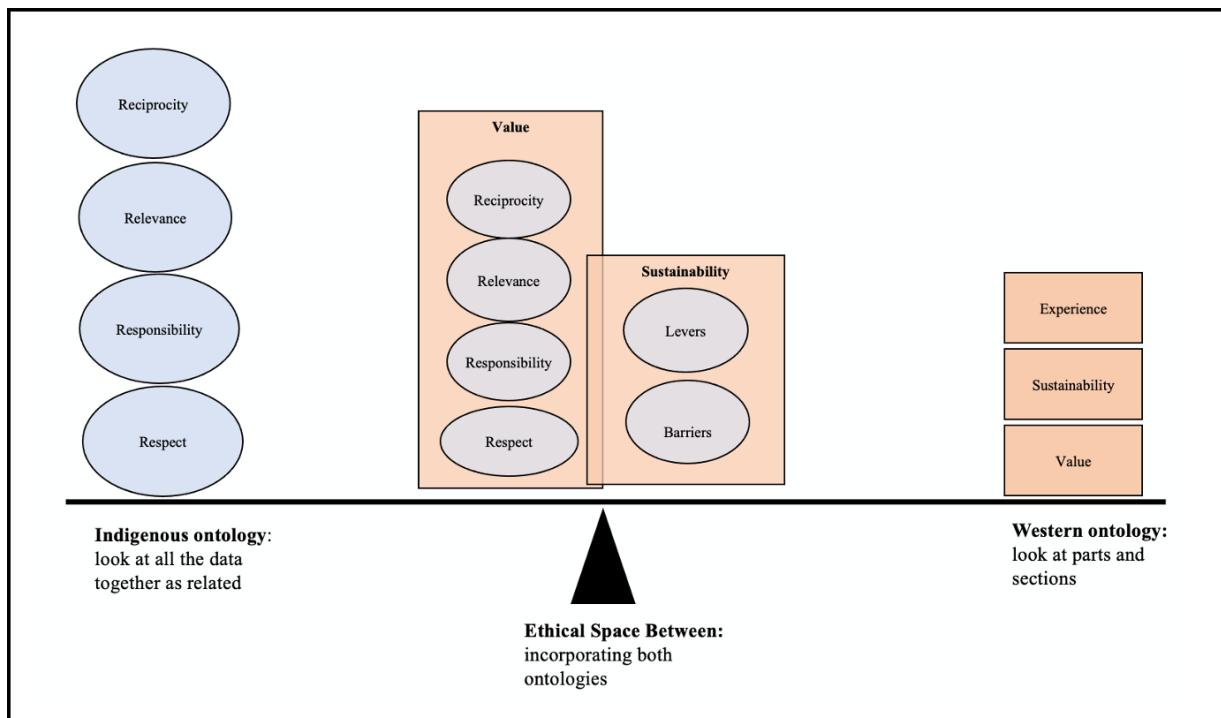


Figure 1. Different ontological approaches to analysis

This process is how we came to the two categories presented below: Value and Sustainability, and the themes and subthemes within them. While there are important relationships and overlaps between these two categories, the data was organized to be conducive to a deep understanding of the stories that were told and to align with the original intent of the evaluation laid out in the charter agreement between the FNHA and the Can-SOLVE CKD network. Important to note is that both of these categories, and all of these themes and subthemes within, rest on a foundation of the project being “Community Driven, Nation Based”. This concept resonated deeply throughout the interviews and was inseparable from the subthemes.

The first part of this Qualitative Findings section focuses on describing the project's value as communicated by screening team members. From the codes from the sections of the transcripts that addressed value, four themes emerged. These themes aligned with Kirkness & Barnhardt's framework of the 4R's of ethical Indigenous engagement and are appropriately named: Respect, Relevance, Reciprocity and Responsibility (127). Each of these R's, and its associated subthemes, represents a different dimension of the value of the project. The second part of the Findings section discusses the sustainability of the project through participants' eyes and two themes emerged: levers to sustainability and barriers to sustainability. Notably, the levers to sustainability and the overall value of the project were one and the same as further explained below. The barriers to sustainability that were raised by participants fall under the subthemes of cost, staffing, and logistics. The third section of the Findings uses an Indigenous metaphor and teaching to describe how these themes tightly related to each other. Here the imagery of cedar bark weaving is presented as a visual aid to describe the interconnectedness of the themes presented under the categories of value and sustainability. Understanding these themes as a whole is essential in painting a wholistic picture of the findings of this evaluation.

3.2.1 Part 1: Value of the Kidney Check Project

The value of the project was described in many ways by participants. Reflections about value emerged in response to all of the interview questions and was a large focus of participants stories. While organizing and grouping codes and devising themes, Catherine and I came to the framework of the 4 R's of ethical Indigenous engagement. These 4 R's – respect, relevance, reciprocity, responsibility – were first brought forth by Kirkness & Barnhardt in 1995 in work related to First Nations education (127). They have since been expanded and used in the context of Indigenous health research as principals of ethical engagement (126). The codes from the interview transcripts aligned with these four themes, each contributing a different aspect to the overall value of the project.

Importantly, the alignment of the codes to these four themes presented a practical example of what Kawakami et al. (109) describe as “an Indigenous perspective of ‘value’”. Evaluations rooted in Western epistemologies have a narrow definition of value, usually

focusing on benchmarks, deliverables, or cost savings. In contrast, in Indigenous epistemologies, Kawakami et al. (109) explains:

Value is situated with specific communities and people in a specific time and place and endures in these communities long after the completion of the final evaluation report. Value is viewed in terms of practical and respectful impact on the lives of the people and communities involved.

Using the 4R's as the themes to describe value of the project is appropriately in line with this definition. Presented below is a description of each of these themes and their respective subthemes in the words of participants. Additionally, Figure 2. presents a visual representation of the themes and subthemes within the category of Value, and illustrates the prominence each participant placed on the subthemes through the frequency with which they arose throughout the interview.

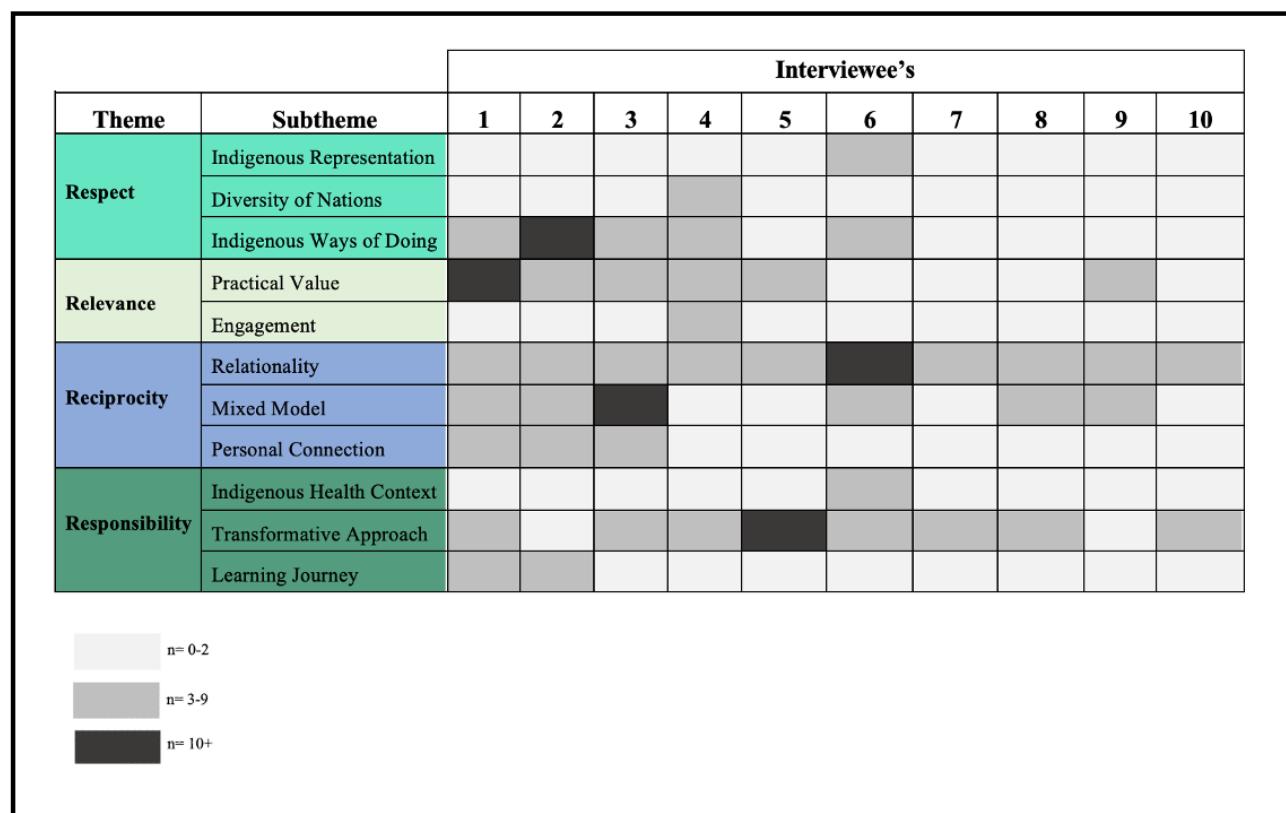


Figure 2. Matrix of the frequency of subthemes uncovered in interviews

3.2.1.1 Respect

Respect is the first general theme describing the value of the Kidney Check project. Interviewees described the ways that the project addressed the unique cultural identity of the Indigenous people it was serving and proceeded in a way that appreciated and promoted Indigenous ways of doing. Subthemes that demonstrated this element of respect included: having extensive Indigenous representation on the team, appreciating the diversity of Nations and perspectives, and ensuring that the project was grounded in Indigenous ways of doing. Referring back to Figure 2., Indigenous ways of doing were featured most prominently within the interviews, with five interviewee's mentioning this three to ten times throughout their interview organically.

Articulated quite clearly throughout the interviews was the importance of having Indigenous representation on the project and the value that it contributed. Notably, this representation existed at every level of the project, from the members of the team who held responsibility for the design and implementation, to the patient partners who were featured on keeper cards, to those who attended community engagement sessions. One non-Indigenous member of the internal kidney check team succinctly related this representation to value, saying:

“The value of having Indigenous folks on our team and Indigenous folks who are responsible for the project in BC and who are the face of the project ... that's pretty important.”

There were a number of different descriptions of why this representation was important, but all seemed to center around the idea of trust and understanding that comes from lived experience. One Indigenous participant explained:

“I love that I am the first point of contact for individuals because being an Indigenous person myself... [I have] a pretty good understanding of the healthcare system and unfortunate experiences that many Indigenous people have experienced with the health care systems”

Another Indigenous participant commented that Indigenous representation is important in the research sphere as it helps combat some of the inherent distrust born out of historical experiences:

“... [I am] a voice and a face for the program [who is] connected to community...I think with research often being able to recognize or see a familiar face...in the work just springs a little bit more trust or engagement in that work”

Notably this idea of Indigenous engagement went beyond just individual representation and extended to the representation by Indigenous bodies such as the FNHA. An Indigenous team member stated:

“I think the partnership with FNHA kind of allows that.. for communities to [know] it's endorsed or supported and partnered with FNHA. So [it's] a little bit of reassurance to community”

Another Indigenous participant explained the value of having Indigenous people sharing stories of lived-experience with CKD in community engagement sessions as well:

“I have seen the response from numerous Indigenous people when talking about chronic kidney disease of having... a real person with lived experience on the topic... Like the importance and the relevance of that. And further too sensing that First Nations people particularly ...would be drawn to an image of an Indigenous person...wearing their First Nations regalia.”

By weaving Indigenous representation into the project at every level, the unique cultural contexts of First Nations were considered and respected; undoubtably contributing to the value of the project.

Respect for the diversity of Nations evolved as another sub-theme. This project included sixteen communities across BC, each quite different. The Kidney Check project acknowledged each community's unique culture and context and incorporated this consideration into the protocol. One Indigenous participant explained:

“The differences as well in Nations throughout Canada I think that things maybe can't be done exactly the same across the board like there are definitely...standardization that it should be done in terms of the research portion of it, but there's also some protocol pieces that are different amongst the First Nations so just...taking that into account... having nation specific protocols.”

Given the diversity, screening protocols had to remain flexible allowing communities to guide screening to fit their needs. This is described by one non-Indigenous participant:

“I think every community is going to bring different barriers and facilitators and things that work for them. Probably another reason why the community-run pieces is so important because it's not a one-size-fits-all. What works in [Island Health] is not going to work in [Interior Health].”

This adaptable method avoided a pan-Indigenous approach that overlooks the diversity in First Nations in BC, and each community's needs. This was an intentional feature of the program that contributed to the theme of respect.

Perhaps the most important Respect subtheme raised by participants was how Indigenous ways of knowing and doing were incorporated into the program. Screening team members describe how different this project was compared to others, with one non-Indigenous participant describing the focus on a strengths-based approach:

“It is a wellness check so I think it's that...in research we are always looking for what is wrong with people or...you know the blood, the labs, this is off - so it's that shift... we're checking how well your kidneys are doing and this is a wellness project we're not looking at how sick you are or...what's wrong with you”

Other participants described the place-based nature, and face-to-face relationship-building that had been incorporated and maintained through community engagement. One non-Indigenous team member stated:

“We would have a community event prior to doing the screening or during the week of the screening and it was a really good chance to...really just kind of um connecting with the community in that way it was really nice often there was meals...and some fun and games as well so that was a really nice piece”

It was also noted how the project honored community and their space. Another non-Indigenous participant described treading lightly as a guest when working in community:

“It was important to work with the communities' existing infrastructure...because it just set the tone of...us as visitors um but allowing this to be...[their] project. We are here to support it but really this project lives with you so we're here to make it work for you guys.”

The Kidney Check model also provided screening participants an immediate benefit which contrasted heavily to a typical research experience, but honored Indigenous principles of reciprocity. One non-Indigenous team member described:

“I think for me personally in research everything takes so long...years and years and years and years before you can get data before you can translate that knowledge get it out there hopefully, so I think ...the thing I love about kidney check is the results and the personal connection is immediate with the individuals within the community and it doesn't feel like research you know?”

Most importantly perhaps, this project honored and supported the self-determination of both individuals and communities from its inception to its completion. An Indigenous team member stated:

“The whole approach that I've taken with this project has been...not me imposing what I feel the community needs, or what I feel the community wants, or how I feel this would work best for them. So from the beginning the approach that I have taken has been honoring the self-determination of communities.”

Through embodying Indigenous ways of doing and incorporating principals of strengths-based, placed-based programming rooted in reciprocity, self-determination and honoring communities, the Kidney Check exemplified respectful programming. Participants described this as a major contribution of value.

3.2.1.2 Relevance

The second theme participants described as something that makes the Kidney Check project valuable, was the relevance that it held for community members. Relevance, in the context of Indigenous health, is ensured through alignment with Indigenous perspectives, experiences, and priorities. This project embodied relevance through the provision of care – point-of-care kidney health screening in community – for those interested. The practical value contributed to both client and community engagement and both are subthemes described in the overall theme. Looking again at the matrix in Figure 2., it is apparent that practical value was a subtheme that was discussed quite frequently. Six of the ten interviewee's raised codes associated with practical value three to ten times through the course of their interviews. Engagement was discussed less frequently, with only one interviewee raising it more than three times.

Speaking to the practical value, the Kidney Check program provides assessments of kidney health, using point-of-care testing, in community. Participants – almost unanimously - commented on the ability of the program to inform clients immediately about their risk of kidney failure and related health implications. As stated by one non-Indigenous participant:

“So we know that with CKD for example, the earlier someone can be found to have some element of CKD, the more interventions are available, and the more powerful those interventions are...um similar with diabetes and hypertension as

well so if we can capture those diseases in their early processes we know outcomes for clients are better in the long run and so there's that very tangible hands-on piece that people are hopefully getting that early intervention and getting support faster so that hopefully diseases won't progress as quickly.”

Participants talked about the relevance of this information being provided to both individuals and health systems. An Indigenous participant stated:

“I think that it would serve you know government health services to quite a degree in it being basically primary prevention so informing people are identifying people who needs... who have greater needs within the kidney health systems and to have those addressed far sooner than reaching out at the point of end stage renal disease.”

Others spoke of the value of obtaining these parameters and offering subsequent education or preventative care to increase health empowerment and involvement. One non-Indigenous team member described:

“They...have that...number to work with and have that conversation, about where they're at with their kidney health and the prevention side of things. I really like that...we're not meeting people where you know - when their disease has progressed to a space where it's going to be harder...for their body to come back, it's nice to kind of be able to create more awareness and education around things and have people involved in that and... get involved at an earlier stage.”

Further to this, participants also spoke of the appropriateness and relevance of using POCT to “close the circle” with community members by being able to share their screening results almost immediately and “not have to ship stuff off to a lab and wait for days and finally get answers”. Participants were emphatic about this point, especially for First Nations communities where barriers to care can be extensive. One non-Indigenous team member described:

“...we were taking away some of those barriers – it didn't require a primary care provider visit, it didn't require a lab visit and those results were all done kind of within 30 minutes people would know their results, so the accessibility is a big piece that's very positive to it.”

Participants said they believed community members found this POCT, with its quick turn-around-time, a big part of the positive aspects of the screening experience. A non-Indigenous participant stated:

“And I think that the clients really appreciated them being able to get their number right on site because it felt like it was kind of wrapped up the

appointment, whereas a lot of times we come and do something and then they have to go away and wait for a phone call or follow up- and that kind of sometimes gets lost- I think that's hard in terms of our health care system, so I think it was really nice on both ends for us to be able to share that time and for it to come full circle.”

Contributing as well to the practical value of the program is that the screening was offered locally, in community. Participants again, almost unanimously, commented on the importance of this approach increasing access to care in a way that was appropriate and respectful. One Indigenous participant stated:

“Because...we're bringing it to people rather than them having to come to some center and having to access a... say an island health facility or something like that so we're bringing this with our own nurses right into their communities and making it...so that makes it more accessible for them.”

Another non-Indigenous participant commented on the barriers to accessing care outside the community:

“ I think the accessibility as well is really important so we've heard from some people that they knew they...should be getting some kidney screening done so they have that concept...but a lot of people especially in some of the more remote communities....felt like it was very difficult to connect with the primary care provider um and go through that process...and they expressed that there were barriers to that...a lot of people didn't have a primary care provider or they were only in community for a number of days and so they wouldn't be triaged as a high priority visit and things like that, it's difficult to get to a laboratory, some people had transportation issues as well and so a huge benefit to kidney check was bringing that accessibility into community for people so that we were taking away some of those barriers.”

The combination of these three factors, the physiological benefit of screening, the use of POCT with quick resulting and in-community access- are all important in aspects of the practical value that this program holds. This value is very relevant to the unique challenges to accessing care faced by First Nations people.

Community and client engagement was one way that relevance was tangibly described in the participants' interviews. They spoke to this concept as being very much related to the potential sustainability of the Kidney Check program. One non-Indigenous team member articulated:

“I think in general people like on the ground are interested. All of our clients who came in, our participants, were generally engaged and curious and wanting to know where their kidney health was at. In terms of interest, it was nice to see people coming out and being curious and engaged in that piece. So I think that is sustainable in terms of people will always continue to be kind of curious and engaged in their health.”

This sentiment was expressed as well at the community level; this is important because community support is needed for the overall program success. An Indigenous participant described her experience with this:

“There was there was lots of questions from them [the communities]... they uh they wanted to know more about it and so it was engaging the people.”

Some participants related the client and community engagement to the community-led approach that the Kidney Check project has taken. One Indigenous team member describes:

“But really looking to...have communities own it? But I think through that, community has probably become more involved. You know, just greater uptake and a presence within the community which I think hopefully increases...the ability for community members to learn about it and also to be screened and have greater ownership of their health.”

Engagement in the program is important; it speaks directly to the relevance that the Kidney Check program holds for community members. This relevance contributes directly to the value of the program on a broader scale.

3.2.1.3 Reciprocity

Reciprocity is the next general theme arising from participants’ responses about value. Reciprocity is a central tenet in Indigenous ways of doing. It refers to the mutual benefit and exchange that must be present throughout the research process. Interviewees describe the reciprocity that is present through the subthemes of relationality shared by screening team members and community members, the mixed model approach that builds capacity in community, and the personal connection that screening team members feel to the project. Important to note is that relationality was the subtheme that was explored most often by participants through the interviews. Going back to Figure 2., it can be seen that relationality was referenced a minimum of four times by nine of the ten participants and was discussed up to

twenty times in one interview. The mixed model approach was also heavily referenced, with six of the ten discussing it 3 to thirteen times in their interviews.

The first subtheme explored by participants in their descriptions of reciprocity was relationality. Relationality was ever present throughout the project, layered on through relationships and collaboration among team members as well as the foundational groundwork that was laid with communities, and even the screening interactions had with clients. Relationality refers to creating authentic connections with people and existing “in relation with them”. The screening team describes relationships with each other as “really meaningful, and respectful”. Others spoke to the level of collaboration and cohesion in the team. One Indigenous team member described this:

“Just seeing the team here in BC that's been kind of put together to...roll out and kind of project... so just seeing you know how so much of the team kind of comes together as well to do this work”.

Relationality was also described beyond the Kidney Check team, among the broader collaborators. One non-Indigenous participant noted:

“And also just the involvement from, you know, broader team members [who are] such a mentor and such a wealth of knowledge and just guidance in this project...some of the folks at First Nations health authority who were in the beginning conversations just personally seeing all of these groups come together and just work together has been has been really great.”

Relationality was featured in explanations of the years of groundwork that was necessary for this project. One non-Indigenous participant described the relationship and trust building that occurred over the years:

“It's not just going and talking to community. It's about building that relationship and building that trust with the community and having and sharing a meal with the community and all these more ceremonial aspects that we wouldn't normally do in the research...”

Relationality was also described in community settings. One example of relationality among community members was the support that came from community leadership for the program and how they acted as models. One non-Indigenous team member remembered:

“A lot of the communities had their... Chiefs attend the screening events...that's a really powerful message it's like “Oh leaderships going so this is a good thing.”

There was also evidence of relationality in interactions between the registered nurses and those being screened. One non-Indigenous team member described this:

“You know, it's not just about their kidneys, it's about their experience with the health care system.... Once you kind of create that space, it was a lot of sharing, a lot of stories and connection. And I think that in and of itself is very powerful. You know they're there for the Kidney Check, but we're also creating space for other conversation and just give space for other people to share their experience and connect and so ...you want to make sure that people have the space and it was there for them to share what they wanted to share, bring up what was ever coming up for them, and to build that connection.”

These meaningful relationships built at various levels of the project represent an important mutual benefit that contributes to the overall reciprocity of the project.

An integral part of the approach taken by the BC Kidney Check project, and an aspect that sets it apart from other provinces, is the mixed model that it employs. This model provides tiered support matched to community preferences. For those communities without nursing staff, the Kidney Check team can fly into community and offer screening themselves. For communities with nursing staff, the Kidney Check team can offer trainings, equipment and supplies to build the capacity of community nurses to do the screening on their own. This approach works to build capacity and strength in community, while simultaneously providing support that allows communities to lead the project in a way that works best for them. This mixed model embraces the concept of reciprocity. While the researchers involved with the Kidney Check project benefit through academic recognition, the community benefits through gaining access to POCT equipment and supplies, and training that contributes to the capacity of community nurses to carry out Kidney Screening in the future. This model is described in the words of a non-Indigenous participant:

“In BC is a real mixed methods approach...where we do have a screening team and they do travel into communities where there aren't the nurse's...nursing resources to support the program ... in other communities they have nursing staff on the ground so we trained them to do the screening themselves...um so that was that was one of the examples of community led.”

Importantly, this model was extremely successful. Participants interviewed for this evaluation who took part in the training spoke very highly of it and felt it helped them develop skills for

screening. One non-Indigenous participant who works doing screening in community recalled feeling very well-trained:

“So being able to be off site and have uninterrupted training and then have [the training nurse] come on site, the combo of that was really good so I felt super prepared by the time [they] left.”

Likewise, the training team also found the model successful. One non-Indigenous participant said that:

“Once someone was trained and once the community teams were running with it they were quite autonomous we really only checked in once in a while as needed for ordering, for technical questions, for checking in around number of people screened...”

Importantly, this mixed model facilitated greater success of the overall program. By training community nurses to do the screening themselves, individuals who were wanting to access screening could see the nurses who they knew and trusted. One non-Indigenous participant described:

“That's a piece of why in BC we went with the mixed model capacity building model is because we do have that awareness that the relationship does matter and keeping programs within the communities does matter and so it's a lot more than just me or whatever team going in and out it's about building that up...”

This model of care and the extension of community capacity is a strong example of the reciprocity built into this model. This model and its mutual benefits amongst stakeholders is an enabling force and a critical value associated with the BC Kidney Check project.

Reciprocity implies give and take, and mutual benefit. The Kidney Check team benefited from the personal connection participants felt, for and about the project. This is the third subtheme emerging from participants' shared experiences of pride, connection, positivity, or impact. In many ways this project extended beyond a professional experience and into something that individuals felt personally responsible for and attached to. About team members, one non-Indigenous participant shared about other team members:

“...they really connect on a community level and on a personal level you can tell it is our job but it's not just a job it's like they really care about what they're doing and it shows and I think the whole experience for me has been really positive.”

That personal connection seemed to come from the relationships that had been developed among team members. Another Indigenous individual acknowledges that their sense of pride in the work is attached to the team and said:

“I feel really proud of the work. I think it's been a really meaningful, respectful relationship between everyone who's been involved.”

Interviewees spoke about loving what they were doing; it was very clear through words, body language and tone that there was a true, deep passion for the work- as stated here by an Indigenous team member:

“Oh there are no parts of it that I don't like, yeah, there is so, so much richness in it...in the relationships with the team itself...the relationships with individuals in community, maybe bringing home to community members in terms of improved health outcomes...”

While it is difficult to capture enthusiasm with written words on the page, it was incredibly clear to me through how the participants told their stories in our interviews that there was an immense sense of personal pride in the work, and that the appreciation and commitment to the project transcended that of a typical professional engagement. In this way, participants benefited from their involvement through positive interaction with and attachment to the project.

3.2.1.4 Responsibility

Responsibility is the final general theme coming from the Kidney Check project values dialogues. In Indigenous health contexts, responsibility refers to understanding the context of the work and fulfilling obligations within that responsibility. Responsible engagement in the context of the Kidney Check project was further described by subthemes. The first subtheme was around the recognition of the specific historical context of Indigenous health. The second spoke to the transformative approach that was taken to do this work. Team members recognized the historical contexts of Indigenous health and they created a transformative approach that would promote self-determination at the individual and community level, and incorporate cultural safety and relevance. This, like relationality was a subtheme heavily discussed by participants. Referencing Figure 2., eight of the ten interviewees discussed the transformative approach taken by the project more than three times. One interviewee touched on codes related to the transformative approach twenty times in her interview. It was clear that this was an important aspect of the

project that contributed to its responsibility. The third subtheme centered around team members personal learning journeys that allowed them to engage in this work appropriately.

Integrated in participants' transcripts was a comprehensive understanding of the historical context of Indigenous health, and how it was imperative to integrate that knowledge into the approach. One Indigenous participant notes that the clients in community who are accessing screening are "people...who have experienced a lot of racism, a lot of unequal care and treatment". Others discussed how the historical context becomes part of the journey of the individual. One non-Indigenous team member working in community described:

"Not only were we there to do the Kidney Check, but people would be opening up about their experience, you know...sharing their stories of their childhood or residential schools or things like that, that just comes up because it's part of their journey, it's part of their health story."

This knowledge being integrated into the screening program demonstrates responsibility to the community members and people accessing screening.

Another subtheme of responsibility is the transformative approach employed by the project. There is a bleak historical context of research itself. Further, Indigenous communities have all-too-frequent experiences with piecemeal, albeit well-intentioned, programming that disappears when the grant has run its course. This project recognized this history and developed a different paradigm, a transformative approach, intended to empower both individuals and communities. One Indigenous participant recalled:

"Well from the beginning...the message that I got from the work was that for Indigenous people things were going to be different...and front of mind was hey this is going to be different... how so...I mean on a broad level and a personal level too, you know how am I going to ensure that this is going to be different...what differences is it really going to make? And you know, I strongly believe that it does have the opportunity to do that."

This difference comes the inversion of a typical research paradigm which has significant power imbalances between the researcher and the researched. Participants described using the OCAP principles in research design to return ownership of the programming back to individuals and communities. A non-Indigenous participant explained this:

"Just going back to the history and the principles of OCAP so when it's community-driven, community-run there's that ownership piece -like you can use all the principles -like in terms of ownership they actually own this program in a

sense and they run it how they want to and there's the control they can control when they do the screening who's doing it. There's access because it should be open to anyone in the community and they don't need to travel far to be able to access this program and they possess all the data and at the end of the day they have all of the data and they, they are in control of that."

Participants reported that the historical power imbalances were so deep that some community members were not familiar with OCAP principles. The same non-Indigenous team member emphasized:

"If you talk to anyone about OCAP in community...like 99% are like "I haven't heard of that"...its not common, OCAP principals, its not something that like taught or known really."

Other participants emphasized this sentiment, noting how it speaks to the dearth of culturally safe research programs currently underway, and how ingrained research-related power imbalances are. OCAP principals were integrated in the project approach and explicitly stated on the consent form. One Indigenous participant who consented clients said:

"Right from the consent, its very much letting them know what we're going to do...letting them know that its completely voluntary and they don't have to do it if they're not comfortable."

In this way, individuals were invited to take responsibility for their own health choices and then were empowered to do so. Participants discussed how the approach was reflected in transformative screening encounters with clients and community members. They described noticing tangible changes in participants upon their realization of how different this project was. One non-Indigenous participant recalled:

"You show up with a consent form and it's got UBC and all our logos -First Nations Health Authority and everything is on there... and you can see people... you can see their body language- they're kind of closed off, arms crossed...they're not really open maybe at the beginning some are some aren't...but as Catherine walks them through you can see them starting to open up a little bit and realize it's not a research study and so by the end it's almost like the person's transformed a little bit...its like "That was wonderful, thank you for hearing me"... its totally different."

The screening approach was also innovative in how space for ample time for client-provider interaction was maintained. Healthcare providers often embody an authoritarian figure, directing community members. In this approach, clients were treated as equals through the screening and

kept informed and educated throughout the process. The success of this approach was described by one non-Indigenous participant:

“So we did receive feedback from people just saying thank you so much for explaining things the way that you did because we did have the luxury of time with clients to be able to really talk them through as we were meeting with them.”

This supported the creation of the Kidney Check project transformative end goal. This was described by an Indigenous team member:

“That’s ultimately the end goal right so I think that's the goal of kidney check as well is that we want people to live a good life and have kidneys that are functioning as best that they can and make that difference...”

Ultimately, this transformative approach exemplifies responsibility. Historical learnings were considered in the approach and the research paradigm was inverted so it served both the researched and the researcher with neither being disadvantaged. The value in Kidney Check’s transformative approach was clearly recognized by participants.

Another aspect of responsibility was the personal learning journey that participants described undertaking. At the onset was the process of unlearning and relearning. Many participants, specifically those who were non-Indigenous, spoke of letting go of pre-conceived expectations as to how the community screening ought to proceed. In a clear example of this, one non-Indigenous screening team member stated:

“I think I've had to let go of all of my former research [ideas], the way research is run and let that go [...] In the beginning of this project I had GANTT charts, I had each community GANTT charts, I had it all laid out- when we were doing the screenings, in which communities and now that I've let it all go and we're still following a schedule but I have had to let a lot go...”

Other participants speak to the challenge of changing their thinking to align with a project run very differently than prior work they had done in clinical spheres. One non-Indigenous participant described:

“It's been challenging for me in a really in a positive way because oftentimes as nurses you're trained to be very task focused in some ways and so I always have this impulse of like wanting to get the tasks done wanting to see as many people as I possibly can...”

Some participants revealed how they felt their worldview was incongruent with the way the work was being done; that a shift in their fundamental thinking was required to have this work proceed respectfully. As one non-Indigenous team member shared:

“We took a very colonial, for lack of a better word, perspective on the project because that's my worldview [...] and it took us a couple years to really get it off the ground in a good way...”

Through these stories it became evident that non-Indigenous team members recognized that proceeding with this work in a good way required them to apply different learnings and thinking's to their work, with many of them describing it as “a huge paradigm shift”. There was a consensus that doing this work well required both an unlearning of old thinking and a relearning of new thinking. Comments about letting go- of beliefs, expectations, ideas – were often followed by remarks on the importance of flexibility. Once participants were able to unlearn their Western beliefs, flexibility was a catalyst for shifting to community-centered practices focused on community wishes. One non-Indigenous participant explained:

“I think you get used to going with the flow...it's really just flowing with them [the communities] and learning how to do that and not stressing too much...”

Non-Indigenous participants with an in-community role described this shift recurring as they travelled through each of the communities, ultimately adjusting to meet the needs of each community:

“I constantly had to re-orient myself to a new community to a new clinic to a new program and adjust my expectations and adjust my teaching whether to the community members or to the nurses...so it did require a lot of flexibility on my part”

Also embedded into the learning journey was the importance of actively learning how to better engage in, what some participants described as their “first time working on a project that involves First Nations communities”. Screening team members who were interviewed discussed the value in seeking out and learning “the history and culture and cultural humility”. Individuals said how essential foundational trainings, specifically San'yas Indigenous Cultural Safety Training and The Principles of OCAP, were to them. These trainings acted as conduits to better understanding the historical context specific to Indigenous people, and helped participants shift

their own beliefs and perspectives about research methodology within the Indigenous health sphere. One non-Indigenous participant described regret at not accessing these resources sooner:

“One of the first things I would have done would be to have taken the San’yas training and have taken the OCAP training and whatever other training I could access and had all the team members taken that... take that training as well from the get go so that we would have those trainings in hand from the time that we started...”

Participants communicated the importance of engaging with Indigenous team members to gain valuable first-hand knowledge saying they focused on “just really listening to [name of Indigenous team member] of course and our patient partners.”. Both Indigenous and non-Indigenous screening team members, also described self-reflection, with some specifically coming to understand their own positionality as it related to Indigenous health research and this project. One non-Indigenous team member stated:

“I've learned that I have white privilege, I am white and I'm in a position of power and privilege and when I started with the network if you had told me that I would have said ‘No, I've worked really hard for where I am’ and I still believe I've worked very hard to get where I am but I know that I've had advantages in getting there and some of those advantages were because I'm white.”

Team members voiced discomfort in acknowledging the differences between themselves and those who may be accessing the Kidney Check project, an important step in cultural humility. As one Indigenous participant stated:

“One part that I felt a little kind of uncomfortable with too was...I live in a place where access to healthcare is like I can walk down the street to the hospital and get care and I'm sure they can walk or travel to the... nursing station or hospital that's there too but I think we're talking about kidney check and kidney disease when it gets to those later stages like access to much more serious stuff that you might need a hospital.”

Additionally, participants described how these learnings have been transformative in the sense that they have contributed to changing practice in a broader context, separate from Kidney Check. Some participants say the work has “probably challenged me in ways I never thought I would be challenged” and that perspectives and beliefs have been shifted. In a clinical context, one non-Indigenous participant shared that:

“This has really kind of helped me look at my approach with people and instead of going in with my own agenda...kind of flipping it around to be as client-

centered as possible within our [the programs] parameters and say what are you interested in learning about?”

The final element of participants’ learning journeys, was the importance of place-based learning that could only occur while in community. Participants conveyed how essential it was to “be in community to meet people face-to-face”. Place-based learning appeared to be important for building relationships with community members for both Indigenous and non-Indigenous team members. One non-Indigenous person stated that the experience of meeting encouraged them to reflect more closely on their role within the project:

“I had the opportunity to travel to one of the communities in [name of place] a couple years ago, and meeting the people- meeting the community members, the nursing staff, some of the knowledge keepers, and the chief was really was really great and insightful experience and provided a different perspective of the project- for my role in the project.”

Another Indigenous participant described how visiting community was important to gaining an experiential understanding of the differences between themselves and community members:

“Yeah...I enjoyed traveling there to other places too like the communities around BC here that are involved in Kidney Check just to like see where people like are living ...'cause I mean I've grown up mostly in the city so I think my experience compared to people who live in in remote and rural communities is like much different.”

It was evident through people’s stories that being in community enhanced the learning experience for them and was an integral step in the learning journey. One non-Indigenous individual reflected on her experience in community and how it impacted how she viewed her own positionality, saying:

“Traveling to the communities really puts that [white privilege] in your face and you see it... yeah it's one thing to sit in your office or your second bedroom and you know navigate things from your keyboard...”

Through these reflections, participants describe a learning journey which is integral to the Kidney Check project experience, and which continues beyond it. It illustrates how this project both supports and exemplifies the concepts of responsibility and respect.

3.2.1.5 Overlap

There is significant overlap between the four themes of Respect, Relevance, Reciprocity and Responsibility and their respective subthemes and how each contributes to the overall understanding of value. Importantly, all of the themes that contribute to the value of Kidney Check rest on a foundation of it being a Community Driven project. This is illustrated in Figure 3. below and further explored in section 3.2.3.

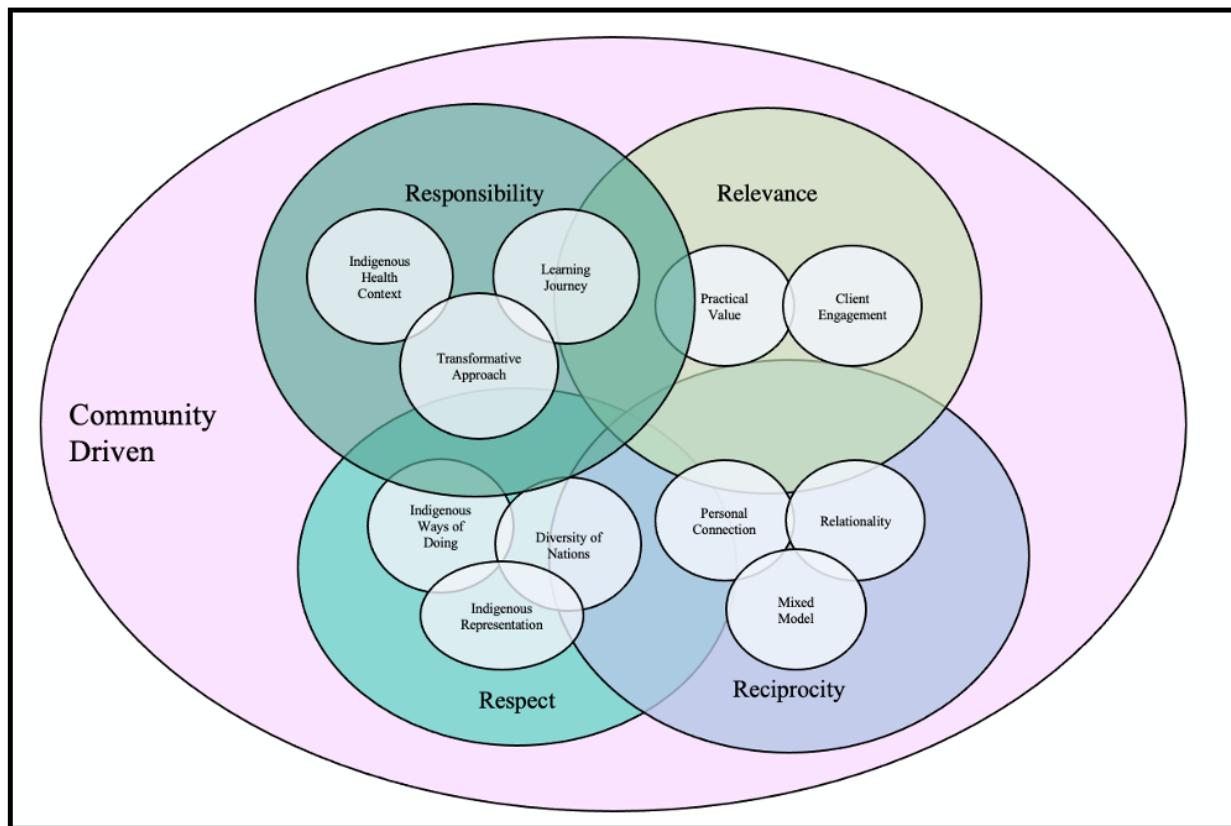


Figure 3. Relationships between the 4 R's

3.2.2 Part 2: Sustainability of the Kidney Check Project

Another intention of this evaluation set out in the Charter Agreement between the FNHA and the Can-SOLVE CKD network was to explore the sustainability of the Kidney Check model. There are many definitions of sustainability within a health programming context. For this evaluation, sustainability refers to the ability of current communities to continue community-led, point of care, kidney health screening beyond the finite financial confines of the current grant. It

also considers the potential for expansion of this program to other communities, specifically, the evaluation was to contribute to the creation of “a business case for this type of initiative to be funded by BC Ministry of Health for making it available for more communities”. Participants were asked “What are your thoughts on the sustainability of the Kidney Check model?” to draw out their perspectives. Care was taken not to presuppose sustainability in my asking of this question, leaving space for participants to describe why it may not be. All of the participants, without being prompted, answered the question by sharing ideas on how the model could be adjusted to continue and expand. The manner participants chose to address sustainability was telling; it was as if the continuity of this program was a foregone conclusion in their minds. The two themes that emerged around sustainability were levers to sustainability and barriers to sustainability. The theme of levers to sustainability is unique. It was determined in the thematic analysis that the primary lever that would drive this program to continue and expand was the value of it, at all of the levels. In Figure 4, barriers, and its associated subthemes are also depicted in a matrix that illustrates the frequency of each barrier in the interviews. Below I provide an in-depth account of the stories shared by screening team members about both the levers and barriers to sustainability.

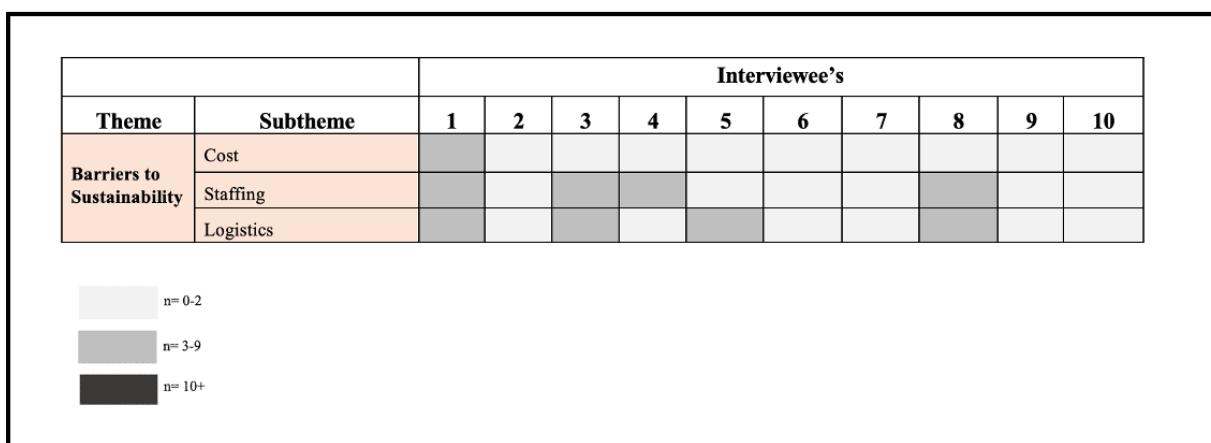


Figure 4. Matrix of the frequency of subthemes of barriers uncovered in interviews

3.2.2.1 Levers to Sustainability

During the thematic analysis of the transcripts, it became clear that the value of the project and levers that would drive its sustainability are inseparable. The themes that elucidated what the value of the project was, were the same themes that would allow for its sustainability moving forward. Here it was imperative to use a lens that understands knowledge as connected, not binary. In conceptualizing the relationship between these themes, neither value nor sustainability were given priority. Instead, it was about the integration of both and the impact they had on each other. One specific connection between these two themes that was highlighted consistently by participants: the community-driven, capacity building approach. This was a principal value and consistently cited as well as a main source of sustainability. One Indigenous participant explained:

“I think the I think there's real opportunity for sustainability....where, you know, the staff from the project are working with community...to increase their capacity, their knowledge, their ability to, to take this program and deliver it within the community. So I really appreciate the idea, the concept of, ways to support and increase the capacity from within the community. And, and I think that's what this has done.”

Another Indigenous team member described how capacity building generates community ownership of the program:

“I think it's a very practical thing to support for health care providers and leaders in First Nations communities to be offering this service yeah “nothing about us without us” in a way, you know, they are creating their own healthcare programs... I mean they would own the program right so and I think that I think that's a very doable outcome.”

Some participants felt so strongly that they expressed “the only way it will continue on is if it is community driven”. Screening team members said that the sustainability of the project was front of mind when designing the approach, and that setting up the program with the needs and abilities of communities in the forefront was a conscious decision related to sustainability. One non-Indigenous team member described:

“...and so I think it was just...a different kind of approach and a more community-led approach 'cause we realized as well we would be there for maybe four days whereas the hope would be that the screening would continue on based on... the local community workers so we really wanted to make it work for them

so that it would be sustainable, it would be set up in a way that would work for that community.”

This connection between a community-driven approach that builds capacity in community staff and sustainability was repeated at every level of the screening team- from those working in community, to those connected to collaborating bodies. One Indigenous participant articulated the foundation of why this approach is essential for sustainability:

“Certainly, I think any opportunity to increase the capacity within community is a really important factor of any project really. One of [the] directives through FNHA is community driven. And really, that self-determination- you know communities know their communities best, their needs the best, the setup of their community, how their community would likely respond to programs and services, the utilization of things, so any...opportunity we have to increase the sort of knowledge training of community members so that they in turn can deliver it in the way that they feel is best is really ...the most effective way to try to gain traction with any of these services.”

Central to understanding what the sustainability of the project is in a grander sense, is (1) conceptualizing the value of the project as a driving force to moving forward and (2) recognizing community ownership is ultimately what will allow it to be sustainable.

3.2.2.2 Barriers to Sustainability

Another important theme revealed in the stories of participants was their description of what they believed would be barriers to sustainability. These barriers are essential to consider as the team looks to continuing or expanding this project. The barriers voiced by both core team members and those in community include cost, in-community nursing capacity and staff turnover, point of care testing (POCT) equipment challenges and community logistics. Looking at Figure 4., it can be seen that both staffing challenges and logistical challenges were tied for being mentioned most frequently, with four of the interviewee’s raising these barriers between three and nine times in their interviews. Important to note however, is that in the descriptions of these barriers no participant suggested these challenges would be insurmountable. Instead, barriers were described in a way that indicated participants felt these were areas to pay close attention to for future planning. In the stories that participants told, continuing this program was a foregone conclusion, an important finding in and of itself.

The first barrier raised by screening team members was cost. One non-Indigenous participant responsible for many of the logistical aspects of the project and has first-hand knowledge of the billing states:

“The cost is tremendous... when we're flying nurses in... and they're staying for a week...and the cost of all the QC, and this equipment, and nursing time... so ...the dollar value or sort of the dollars it cost to screen...they are tremendous and we need to figure out a way to sort of get that down a bit.”

Said here and referenced by others, there are a number of aspects to this project that make it expensive, one of them being the “\$10,000, \$20,000 equipment” itself, as well as the necessary reagents, and then “the cost of shipping things to these very remote communities”. Cost was very much a concern when considering how the project could continue or expand. When discussing the feasibility of continuity, participants noted that it would only be possible “given that funds are available to carry it out throughout the province”. Participants felt that the current cost of the program would be a deterrent to a stable, long-term funding body necessary to take over the program such as the BC Ministry of Health. A non-Indigenous team member described:

“...conversations with the Ministry of Health so they can take this over but I think we're not quite there yet because it is very expensive to run this program.”

Another non-Indigenous participant noted the economic calculation was complex and that there may actually be “savings in the end” when you consider the downstream cost of not having access to screening programs:

“What is the dollar cost to screen the way we have it...versus having someone on dialysis three days a week in and out of hospital?”

Another concern from a non-Indigenous team member was optimal utilization of supplies once they had been ordered and shipped to communities, for those continuing screening without visits from the mobile screening team:

“Some of these supplies are thousands of dollars and they have a shelf life of three months so if they're not being used then that's kind of a huge waste, right?”

This comment highlights some of the overlap between barriers mentioned in the stories, another concern being the capacity of nurses in community to actually complete the screening once supplied with training, equipment, and reagents. Without the hands-on, in-community nursing team using supplies to screen in a timely manner, cartridges with short lifespans may go to

waste, upping the overall costs. As noted previously, participants generally felt that this was an obstacle that could be overcome with careful planning and did not diminish the value of the program. A non-Indigenous team member confirmed:

“So I think there's a way to do this... there's a huge value to this there's no doubt but I'm trying to be the practical one.”

The second barrier raised mostly by those participants working in community, was the nursing capacity to support the project. Participants noted an adequate number of staff to dedicate time and effort to this project was an essential, saying “you need a strong presence of staffing that can help with the logistics”. Unfortunately, screening team members found that that in their experience “oftentimes each community will have only one nurse who would be able to be dedicated to the project”. Even more of a challenge was retaining staff that were committed to carrying out screenings. Interviewees from community describe difficulties with nurse turnover and the impacts that had on the project. A non-Indigenous participant described this issue:

“ Yeah one issue we found and this did occur in more than one community that we were in, where we trained a community nurse and the nurse said a great job and did continue on with some screenings but then the nurse would leave that community for a different position...and so the staffing piece of the at the community level does make a difference...”

Relatedly, participants note that a factor contributing to high turnover has been scheduling; screening has not been done consistently. Rather, visits to community to screen have been done over time, as a result of circumstantial delays. An Indigenous team member articulated:

“...because we've delayed it now where's that nurse that we trained? You know-is she gone off somewhere else? So we've had to... every time we start up we're having to train new nurses to do it...to do this this project.”

One non-Indigenous participant succinctly stated that they believe that:

“Staffing honestly might be a barrier in terms of just having enough staffing to be able to support long term support side projects like this. Yeah.”

Importantly, even in communities with adequate numbers of trained nurses, the dedicated project time is too low. One non-Indigenous screening team member recalls seeing this in one of the nurse trainings:

“I mean I know the nurses as much as they’re keen about this program I could tell that some of them were a little hesitant as to their capacity to be able to actually do the screening.”

Participants who were nurses reported feeling like “we’re kind of like bursting at the seams” with the amount of work already required with day-to-day tasks, creating stress when being asked to take on additional work effort. This caused feelings of distress for some nurses. A non-Indigenous participant carrying out screening described:

“When you feel like there’s not enough staff and there’s not enough resources to be able to pull it all together, it can sometimes become more anxiety provoking and a little bit burdensome. You just don’t know where to put your energy.”

Indeed, the workload for nurses in community is already high, and some nurses reported being “the only regulated health care professional here” in community. One Indigenous participant expressed concerns for the long-term consequences of that workload:

“With like personnel in community...I know that communities are already stretched ...thin I think with other community health initiatives that they have to run as well and keeping people engaged and uh and informed about health initiatives and things that can hopefully improve the health of the community so I think there's no hearing about how burnout effects community health workers...”

Additionally, even for those who did not express feelings of over work, reality is that nurses in community are responsible for many programs, and often have to juggle competing priorities.

One non-Indigenous team member articulated that:

“The other challenge at the community level is just time... time barriers and competing priorities...we’ve heard... some communities have really been wanting to restart screening but their nurses have just been called in different directions and so they’re really not able to dedicate the time to learning the program and implementing the program...so that’s been a really big challenge from the community piece.”

Indeed, the challenge for the Kidney Check project will be to address this barrier and find a way to both adequately staff the program and ensure dedicated time for staff who take on screening.

One Indigenous screening team member summarized this well:

“Adding more to the plate of communities can be a little overwhelming sometimes so you know how to mitigate some of those challenges as well for communities to support, support their health but not...adding to the plate.”

The third barrier described by participants are the logistical barriers to program implementation. This includes both the equipment that is required for POCT and in the remoteness of the communities themselves. POCT equipment is quite complex and requires specific cartridges and reagents, many of which must be kept within a certain temperature range to ensure validity of the results. One non-Indigenous participant describes the challenges associated with getting these reagents to community:

“We did find that the transportation of equipment and supplies...so a lot of those re-agents [for the POCT equipment] have short expiry dates or need to be sent at a certain temperature so if it freezes or if it gets too hot or if it's delayed we can have issues and may not be able to do the quality control and so...it still does require transportation in a really specific manner and it does require people in community to be able to monitor the temperature of the fridge and check the expiry dates and run quality control and all of those pieces and so all of those things do... take time.”

Having supplies arrive in community at the right temperature and ensuring that communities were able to maintain appropriate temperatures was essential to ensuring ultimate success in the screening process. However, the intricacies and logistics around the supplies was not something that was initially taken into consideration. One non-Indigenous participant heavily involved in logistics stated that:

“There's just like a lot of little things because of course you don't want to run this program with supplies that are not valid or, you know, ready to go. So from my end there was a lot of learnings of just the initial setup of all the equipment...the initial setup was a little bit trickier than anticipated.”

Another concern shared by many of the in-community screening team members, which was the arduousness of the quality control process necessary before completing screening. A non-Indigenous participant described:

“They [the devices] require a lot of QC- quality control and quality assurance processes- to make sure that their results are...true and those protocols are very cumbersome and can take up to an hour for the nurses to perform before they can start the actual screening and in a clinic nurses just don't have that kind of time to...so it's very burdensome for the staff.”

While this step was necessary in successfully being able to run screenings, many nurses commented on how long the process takes and importantly, how it has to be redone any time the

equipment is moved, which according to this participant happened quite frequently. One non-Indigenous participant explained her experience with this:

“We need to calibrate it every time we get to new community basically cause every time it's moved, which is basically almost every clinic that you do, and sometimes we can't even keep it there overnight, so it's a good hour in the morning for setup and calibrate.”

The Kidney Check team members who were doing frontline screening also expressed concern over the unfamiliarity of the equipment, and raised questions around troubleshooting should things go wrong, especially given the remoteness of many of the community screenings. A non-Indigenous participant articulated:

“I think there was a little bit of anxiety around just the newness of the equipment and making sure that everything was calibrated. And if it wasn't, who are we going to call and a little bit of anxiety in terms of the timing of that. I think when we're working with technology...its slightly unpredictable. If something were to go wrong, what would we do? Like, the troubleshooting is a little bit stressful, especially when you're kind of out in the middle of nowhere and you're like, OK, what are we going to do next?”

Other logistical concerns around the remoteness of the communities was discussed in peoples' stories. Another non-Indigenous team member expressed concern in this realm:

“I think the main things that I think about moving forward on this team and being a part of this is, logistics is a lot to manage because of the distance between our communities and some of the remoteness of the communities to travel.”

One Indigenous team member describes the amount of time it takes to get into community driving on logging roads and the complications that arise as a result:

“So... that is one of the things is...you know, just transporting it all that far yeah... and then getting there and getting enough people done in the amount of time that we would have left in the day once we get there.”

Overall participants felt that this concern could be overcome through planning, adequate staffing and resourcing, saying distance is simply a reality of rural health service provision.

3.2.3 Part 3: Weaving It Together- Cedar Bark Weaving

Through the transcript analysis, significant thematic overlaps emerged. Stories were interconnected in complex ways, themes seemed to connect to each other, diverge and then

reconnect at other points. Given that the wholistic nature of evaluation is integral to Indigenous evaluation frameworks, it was important for me to lean into and honor this interconnectedness, despite the challenges it posed to my own Western understandings. These connections are illustrated in Figure 4, although even this diagram can't fully embody the complex relationships between categories, themes, and subthemes.

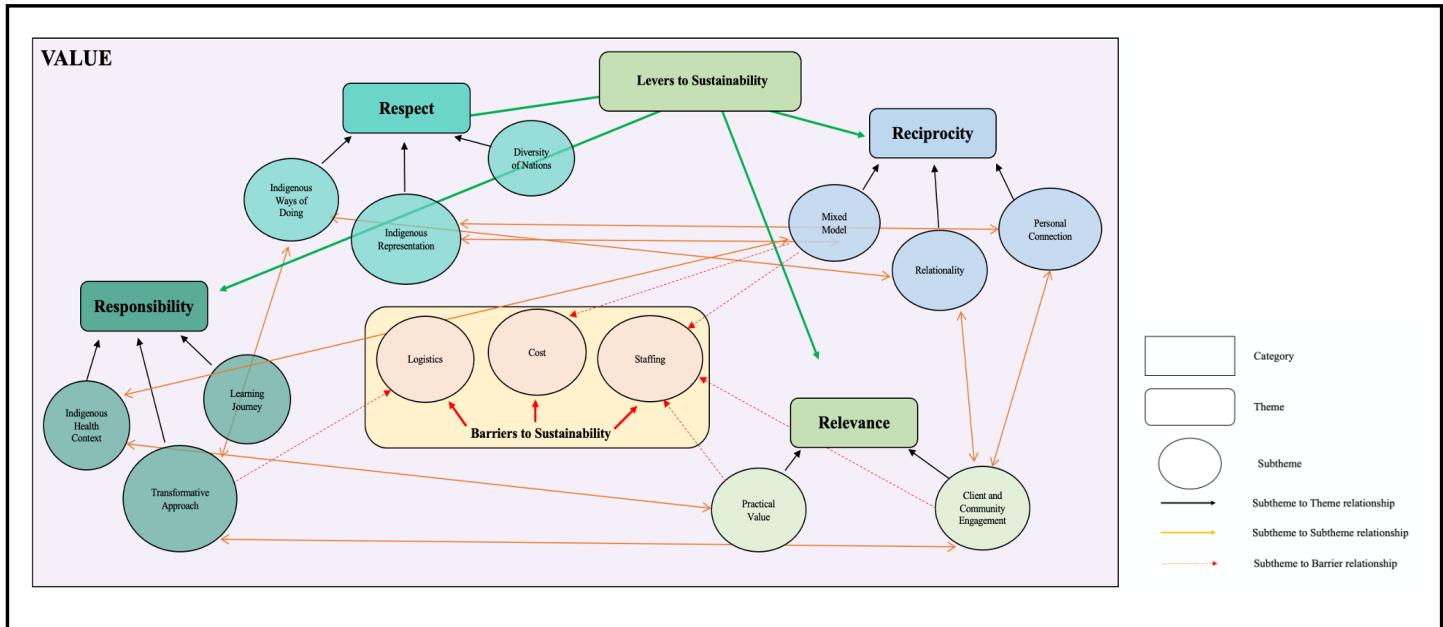


Figure 5. Map of connection between themes, subthemes and categories

In considering how best to present these findings in a way that fully embodied the knowledge contained within, Catherine and I contemplated what interconnectedness could look like in a metaphorical sense. Metaphor is used in qualitative research to, according to Carpenter (128), “illuminate the meanings of experiences”. By simplifying complex stories, metaphors can add a greater depth of understanding to the findings (128). Metaphors must be selected intentionally for alignment with the data to ensure no change of meanings or obfuscations of important findings (128). We sought a metaphor that would communicate how the broader context of interwoven themes was more important than the set of themes described in isolation. In discussing this with Catherine suggested that cedar bark weaving, an important cultural practice of Northwest Coast Indigenous Peoples, could be a fitting metaphor. Using an Indigenous metaphor to represent this work aligned with my theoretical framework; it provided

another layer to a two-eyed seeing approach for all aspects of the work. It felt important that the metaphor further decolonize this work by privileging Indigenous ways of knowing and doing.

Being a settler myself and Catherine not being from the West Coast, she suggested seeking guidance from Haida/Kwakwak'wakw artist and Land Based Cultural Empowerment Facilitator Nalaga - who practices and teaches cedar bark weaving - on the appropriateness of incorporating this metaphor into my work. This step was crucial in ensuring that we were not appropriating or misusing the imagery. On hearing about the evaluation, its goals, and the interconnectedness of themes, Nalaga agreed cedar bark weaving was an appropriate visual illustration. Nalaga was offered an honorarium in exchange for her guidance and the images she shared, as was appropriate.

In presenting cedar bark weaving as a metaphor for my results it is important to understand and contextualize this practice to appreciate and situate the findings within it. Nalaga shared a teaching on cedar and cedar bark weaving for this purpose and has given me permission to share that knowledge here. Nalaga belongs to the Kaa'was Staa'stas Eagle Clan from the Village of K'yuusda in Haida Gwaii and the Gigəlğəm nəmīna sa Liğwildaħʷ, one of the 18 Tribes of the Kwakwaka'wakw. This knowledge belongs to her, her community, and her ancestors and should be respected as such. The OCAP principles of ownership, control, access, and possession are to be respected:

To understand cedar bark weaving, you must first start by understanding the importance of cedar. Cedar is called the tree of life for West coast Indigenous people; cedar is the first thing we touch as we come from the spirit world; we are born on a cedar birthing matt, and it is the last thing we touch before we return; we are buried in a cedar box. Our survival depended on the cedar tree, and it gave us everything we needed: food, clothing, housing, transport, regalia, ceremony, healing. Everything came from the cedar tree. We refer to the tree as female, she is a grandmother, a daughter, or an auntie, someone who has teaching to offer us.

When harvesting cedar we hug the tree, pray, and put down an offering of medicine or water, reflecting the sacred practice of reciprocity, of give and take.

We ask permission to harvest, if there is a sense that the tree doesn't want to be harvested, we respect that.

Cedar weaving is medicine. She absorbs our energy: mental, physical, spiritual, and emotional. Whatever you think or feel goes into the work. It is a mindfulness practice. When you are creating something to give to someone you cultivate love and good energy. If you are weaving for healing, and are putting forward feelings of anger or sadness, you wouldn't give that work to someone you would burn it or bury it. Cedar is the most powerful medicine we have here on the Northwest Coast; it protects us as we wear it.

Nalaga's woven cedar baskets in Figure 1., reflect the interlacing of themes of this evaluation. Envisioning this weaving can be a conduit to a deeper understanding of the whole evaluation. In these cedar baskets, no single strand of cedar bark could frame a complete basket, much like no single theme can tell the whole of the Kidney Check project story. Themes need be entwined to create the patterns - the results - of this evaluation for it to be understood.



Figure 6. Nalaga's cedar bark weaving

3.3 Results in Reflection

It is also important to share in the results of this evaluation, themes illuminated by my own experiences, and those of the Indigenous Knowledge Holder on my committee, Catherine Turner, having undertaken this work together. Significantly, this evaluation illuminated themes like relationality, collaboration, personal learning journey, and connection to the work. These themes are mirrored in my own experience as seen through the field notes taken after each interview outlining my personal thoughts, feelings, and experiences of doing this evaluation work. Similar, and other unique themes are also seen in Catherine's reflections written at the conclusion of our experience together. The experience of fostering an authentic two-eyed seeing approach was challenging and rewarding for each of us, for different reasons. Our individual reflections on this journey offer insights into the realities of working in 'the ethical space between' our worldviews and the work, and trust, that it has required.

3.3.1 Catherine's Story

Below is the reflection shared from Catherine on this research journey and her experience. This is Catherine's own writing, and the principles of OCAP are to be respected:

July 19, 2021

My personal reflections on working with Simone Dew on her thesis.

I was both humbled and pleasantly surprised when Simone asked if I would serve as a committee member for her thesis defense in addition to providing my Indigenous lens to the work that she undertook, ensuring that she was doing this work in a culturally appropriate way.

The fact that Simone was sensitive to the cultural needs of the Indigenous individuals she interviewed, speaks volumes in my opinion. Not only was she extremely sensitive to the needs of the individuals involved, but she was also intent on carrying out relevant protocols in every aspect of her evaluation work. In the beginning of our working relationship, I was a bit hesitant as to her intentions. I have previously come across professionals who claim to want to do their work with Indigenous people and community in a culturally safe way, but when it comes down to it, it is only a box to be ticked or a process to be completed

to further their own professional gain. This is unfortunate. After giving this invitation some serious thought, I realized that it would be in my best interest to give Simone the guidance that she was seeking, wanting to ensure that the work would be carried out in a good way. Knowing that she had been accepted into medical school, I thought this would be an excellent exercise, and an excellent learning opportunity, if she was going to be honest with her proposed intent. She didn't ever disappoint.

In my professional role, and personally, I take every opportunity to ensure that work with Indigenous people and communities is being done authenticity and in a culturally safe way. This was even more important given that I lead the Kidney Check project in BC, having established meaningful, trusting relationships over the past three years.

Throughout this process, Simone has impressed me in many ways. She is a very conscientious young woman who works extremely hard. It was a pleasure working with her and seeing how committed she was to the work that she undertook. A few months ago, we had a conversation, where we both expressed interested in understanding the steps in achieving a genuine 'Two Eyed Seeing Approach' working on Indigenous projects. I appreciate that she shared the same curiosity that I did about it. We discussed that there was likely opportunity to do that throughout this process. I believe that we successfully accomplished that.

A statement that stands out for me in Simone's paper and in understanding a Two Eyed Seeing Approach is where Simone discusses taking a 'phronetic approach' to this research 'using an appropriate, ethical process for the specific community they are engaging' - 'prioritizing and embodying practical wisdom or prudence and focusing on how to act ethically and what that experience looks like'. The work that I have done with the Kidney Check project in BC, as well as with previous projects, has been based on my own ways of being, understanding and knowing in the world, and as an Indigenous woman/professional. This 'phronetic approach' to research is framed in a western framework. From my Indigenous worldview I understand this phronetic approach to research as a

natural assessment of community strengths and weaknesses. Something that I do automatically, and thereby looking for any and every opportunity to provide Indigenous people and community the ownership, control, access, and possession to any work that might be carried out with them.

I am pleased that Simone carried out her work by privileging Indigenous ways of being and doing and to see that she became comfortable within that ethical space. This led to a genuine partnership between the two of us. I never once questioned her authenticity and eagerness to learn how to do this work in a good way.

I feel that in this work, Simone has added yet another layer to the success of the Kidney Check project. It has been a pleasure working with her on this aspect of the project and her thesis, and I trust that she will be an exemplary role model for her non-Indigenous colleagues moving forward in her career. She has truly embodied the slogan of ‘Nothing about us without us’.

I thoroughly enjoyed being a part of Simone’s ways of doing and being. I would do it again in a heartbeat!

Catherine

3.3.2 My Story

Auto-ethnography, is according to Ngujiri et al. (129) a “qualitative research method that utilizes data about self and context to gain an understanding of the connectivity between self and others within the same context”. This highly reflexive methodology has been previously found by scholars to be complementary to Indigenous research as it allows for the relationship between the self and the research process to be articulated. It supports the notion that the self cannot ever truly be separated from the subject of the research and disrupts typical power imbalances between researcher and researched (130). According to Graeme (130), committing to this kind of methodology requires “surrendering to the fact that one cannot turn off one’s context and privilege, and contemplating how one can use this context and privilege to ensure that Indigenous knowledge and methodologies are inherent to the process in Indigenous health research”. While not a complete auto-ethnography, I borrow from this methodology to provide a

reflection of my own experience of the interview and analysis process using my field notes as supportive evidence. I provide an account of my own story, sharing insights into the deep learning and adapting which came out of the interview and analysis process.

My field notes echo participants' experiences of a learning journey. At the beginning of the interviews, it is evident that I was struggling to unlearn my Western practices and wholly commit to the methodology:

"I feel like an elastic band being stretched and pulled into a new way of doing research. But like an elastic band, I feel myself being pulled back to my resting state of Western practice. I feel a constant discomfort or tension, like I have to fight this impulse to return to my resting state."

I was experiencing discomfort as I completed these initial interviews. Some of that discomfort stemmed from using an unfamiliar methodology that I wasn't well versed in. I feel – in these initial stages of my learning journey – that I was still holding a subconscious bias that privileged my Western ways of doing things. In one early entry I stated:

"I feel myself pulling back to my Western ways as I monitor my inner dialogue through these interviews. I want so much to ask directed questions, to ask the things that I want to know, to extract that information. I have to constantly remind myself to be flexible and trust in the process."

Here I see experiences that participants shared mirrored in my own words, particularly the importance of flexibility through this adaptation process. As I continued with interviews, my field note descriptions of this tension became less frequent, in my last account I wrote:

"I find myself sitting back to listen more deeply- putting my own thoughts aside to absorb the knowledge that they shared with me. I remember that whatever participants share is what is meant to be shared, even if it doesn't align with what others have described, each story is important."

Notably as I reflect on this journey and how it is written in my field notes, I recognize that as I was doing the interviews using a new methodology, I was going through the uncomfortable and often awkward process of unlearning and relearning. Integral to this process was adjusting my own expectations and attitudes and being constantly mindful of my inner dialogue. Again, echoing participants, I comment on the importance of relationships with Indigenous people in this process:

"I am so grateful for the Indigenous folks that I have met through the network, talking to

them helps me understand...see the bigger picture in this evaluation.”

That said, that unlearning, and relearning served me well as I undertook the analysis as I had begun to think about the knowledge differently, in a way that was much more compatible with Indigenous knowledge paradigms. This ultimately made it easier to analyze the stories in a way that was compatible with how they were told. I describe one breakthrough:

“I had an aha moment, I was trying to draw relationships between themes as a pyramid. But I realized that I was thinking in Western binaries: this theme before this one. The more I puzzled with it, the more I realized that the themes all interconnect, overlap and weave together. The image of a braid or weaving is much more appropriate to truly visualize the relationships.”

Later in that same entry through, I describe the same elastic feeling mentioned above- being pulled back to my pre-existing ways of thinking:

“If everything is interconnected, then how do I separate them to describe them in my results chapter? I can’t wrap my head around this”

It is here that I see in myself representations of a young learner, one who is starting to conceptualize and understand, but is still uncomfortable with integrating those new learnings into practice. As a dispassionate observer here, I can recognize how that may affect the analysis and communication of the results, and the knowledge that I am co-creating in this evaluation.

I also describe similar feelings of discomfort as screening team members as I recognize my own positionality, and the privileges that I have had and how they differ starkly from some of the community members served by this program. In one interview, a participant mentioned to me that in the community they served, it had been ten years since there was a regulated care professional on-reserve. In my field notes from this interview I stated:

“I felt uncomfortable when they mentioned that they were the first care provider the community had had in 10 years. How many times have I had difficulties accessing care in this country? Not once.”

Below, in that same entry I ask myself an important question:

“How many times have I taken things for granted? This interview made me realize how unaware I am of how deep some of my privilege is... How do I learn to see my blind spots better?”

Inherent to these entries is a description of the interview experiences contextualized and situated within my own political lens. In this way, as I read through these entries, I am able to see my positionality reflected in the evaluation work. I keep in mind the words of Margaret Kovach (82) as she says “decolonizing one’s mind and heart … It is about examining whiteness. It is about examining power. It’s ongoing”. I take this to heart. This exercise of self-reflection has helped me understand how it is that I exist in the knowledge co-created between myself and participants in this evaluation work. It has also given me insight into the deep learning and adapting that I did as I moved through the research process. I feel gratitude for those who have facilitated my growth and understanding, namely Catherine, and my sense I can bring my relearning’s to bear in some way at some point in the future. Grounding this work through Indigenous knowledge and methodologies made it more challenging on a personal level but all the more rich and powerful.

3.3.2.1 Holding Multiple Subject Positions: Insider & Outsider

Another aspect that came from critical self-reflection through the process was an understanding of the multiple subject positions I hold in this evaluation space and the impact that may have on the work itself. In many ways, I am both an insider and an outsider to this work. I am an insider in that I have worked alongside the Kidney Check team, have developed personal relationships with some of them and have contributed to some small aspects of the project. I am an outsider in that I have visited neither community. I have only engaged with the project on an indirect level. I feel that this multiple subject position has uniquely contributed to being able to bring forth this evaluation. I know enough about the project to have a deep contextual understanding of its foundation, its contexts, and its intentions. This has allowed me to appreciate the stories that were shared in a more thoughtfully and viscerally than an external evaluator with a limited prior knowledge. However, this insider position could also limit my objectivity, which could influence interpretation of the stories, introducing a possibility of bias. It was important to be aware of that potential through the analysis process to minimize any effect it could have.

It is also important to consider is how the participants regard me. Their perception could influence the telling of their story, both in terms of subject matter and the style in which it was

told. For some core Kidney Check team members, it was evident that I was viewed as an insider; they were comfortable and informal through the evaluation interview. Contrastingly, for those who I interviewed in community, there was a more professional, detached feel to the conversations. My hypothesis was that the participants who viewed me as an outsider would be more forthcoming about barriers or challenges in this program, as they would not feel any pressure from a perceived impartial evaluator to support the program. Interestingly, this was not the case and the subject matter and stories shared were remarkably consistent regardless of my perceived status.

Chapter 4: Discussion

4.1 Discussion

4.1.1 Findings

Indigenous people in Canada face significant oppression resulting from the ongoing legacy of colonization. This oppression manifests itself in the context of health as higher rates of illness, one example being chronic kidney disease (CKD). The Kidney Check project is attempting to address this disparity by offering point-of-care kidney health screening in community, to identify disease in its early, more treatable stages and both educate and empower people about kidney health. One intention of the project is to create a business case to advocate for the continuity of kidney health screening in First Nations communities. The results of this evaluation indicated that screening team members felt it was both valuable and sustainable, but some important barriers to sustainability were also raised. Ultimately, the information in this evaluation is essential in the consideration of how this work can move forward to improve the health of First Nations people.

Four themes around value emerged from peoples' stories of the project. These four themes of respect, relevance, reciprocity, and responsibility demonstrate the importance of Indigenizing programs. Specifically, they illuminate how the value of this project is associated with its ability to take a respectful and responsible approach that is relevant to community members and offers reciprocity. Consistent with previous literature on Indigenous evaluation, these measures of value differ starkly from what might define value in a Western context. This reinforced the importance of using methodologies that allow for value to be described and defined by participants themselves. The overlaps and connections between the four dimensions of value confirm the complexities of programming offered in an Indigenous context and the layers of considerations that must be appreciated. Similarly, when looking to the barriers to sustainability that participants described, these findings are consistent with much of what is already known about the challenges of offering care in an Indigenous context. The lack of financial resources, human resources, and the practical challenges of offering care to very remote locations have all been raised in similar research. This consistency speaks to the depth of these problems and the fact that very little has been done to address them over the years.

There were some findings that deviated from my expectations. For example, the positivity of the results exceeded my expectations. I had expected participants to voice more concerns about the project itself or the barriers or challenges they faced while implementing it. Upon deep reflection, I realized that it was possible that I held these expectations because of my unconscious and unrealistic mental picture of the resources in community. It is also possible that these barriers and challenges did exist, but that participants chose not to share them.

Despite these promising evaluation results, it is important to understand that these are initial findings and they must be further validated through expansion of the evaluation to other communities. Additionally, while collecting information from screening team members is important, these perspectives cannot be solely used to evaluate the project. Collecting perspectives from the community members who themselves were screened will be essential to a complete understanding of the value and sustainability of the project. Another future direction for this work is the critical step of knowledge dissemination of this evaluation back to the two communities involved and to the provincial Kidney Check team. Further knowledge dissemination in the form of publications or presentations will also need to be explored with the input of the two communities and the Kidney Check team to conform to ethical agreements about how this will be done.

4.1.2 Public Health Implications

The results of this evaluation have important implications in the larger field of public health. Like many institutions founded from Western notions, the field of public health has historically failed to meet the unique needs of Indigenous people (131). Public health initiatives aimed at improving Indigenous health have been rooted in a paternalistic approach, which assumes superior knowledge of community needs and wishes. In many cases, this has resulted in more harm than benefit, contributing to a deep mistrust of the entire medical establishment (132). In response, an urgent need has been identified to incorporate community capacity building and self-determination into public health approaches (131,133).

The Kidney Check model is designed to be community-led, and Nation-based, promoting self-determination at the individual and community level. It is a practical example of a public health program embracing a new, more culturally appropriate paradigm. The results of this

evaluation speak to the successes of doing just that. Participants described the relevance that the Kidney Check project held for communities and the engagement at the client and community level as a result. The evaluation also highlighted the relationship between sustainability and community capacity building, exemplifying why capacity building must be a strategy used in Indigenous public health. In many ways, the approach that Kidney Check has taken and the success that it has had paves the way for other appropriate public health programming.

4.1.3 Policy Implications

There is ample literature suggesting that Canadian Indigenous health policy is at a critical juncture (134). Current policy reflects a violent colonial history that cannot support the modern health needs of Indigenous people in Canada (134). There is an urgent need to shift towards and enact policy that both recognizes and prioritizes the fundamental rights of Indigenous people in Canada to health and wellness (134).

British Columbia, as a province, has made the first, critical step, with the development of the First Nations Health Governance Structure (FNHGS). This was signed into existence in 2011 by Health Canada, BC Ministry of Health, and the BC First Nations (135). This framework was the product of many years of negotiations; it was designed in a manner that returns decision-making, policy and service delivery back to First Nations in BC from the Federal government (135). As previously mentioned, the Kidney Check project has proceeded in partnership with the First Nations Health Authority (FNHA) which is one of the four components for the FNHGS responsible for “planning, management, service delivery and funding of health programs” (135). The relationship with the FNHA was integral to the success of the program. This is just one example of how the development of the FNHGS has actively contributed to providing relevant, culturally safe programming to support the health of First Nations in BC.

There are other policy considerations to take into account when seeking an understanding of the Kidney Check evaluation findings and how to contextualize them within the larger landscape of reconciliatory action. This evaluation is intended to provide evidence that can inform future policy, around relevant, reciprocal, respectful and responsible health programming that supports the self-determination of First Nations in BC. To do so, it is necessary to delve into the themes

around value of the project and barriers to its sustainability that were illuminated and examine them in the context of provincial health policy.

The BC Ministry of Health (MoH) 2020/2021- 2022/2023 Service Plan mentioned - first and foremost- a commitment to Indigenous health and reconciliation. The Kidney Check project is well aligned with and well positioned to support the MoH in achieving its own performance objectives. The first objective in this service plan is to develop “A primary care model that provides comprehensive, coordinated and integrated team-based care”. The key strategies with which to achieve this objective state (136) the MoH intends to “...support the integration of Indigenous primary health care services....[and] leverage provincial research activities that support the implementation of primary and community care transformation”. The Kidney Check project represents exactly that; a research project that has successfully demonstrated a novel way to provide care in First Nations communities, by building the capacity of community nurses and health workers. Through provision of centralized training resources and access to point-of-care testing equipment and its supplies, this project has proven itself successful. This ties directly with the evaluation’s theme of relevance- improved access to care in community- and demonstrates an important triangulation between the MoH service plan, the Kidney Check project, and its value in the eyes of screening team members.

Another MoH objective is to implement “effective population health, health promotion, and illness and injury prevention services”. The Kidney Check model of screening, which seeks to identify chronic kidney disease in its earliest stages achieves this objective. The POCT devices used also measure other physiological parameters like blood glucose and blood pressure. These values could prove useful in flagging other health concerns like hypertension or diabetes earlier as well. The project provides health education to increase health literacy and health empowerment in screened individuals. The educational material has been designed by Indigenous patient-partners and staff to be culturally relevant and appropriate for First Nations people. As stated in the evaluation findings, the Kidney Check project supports community self-determination through individual communities’ project ownership. The return of self-determination is integral to promoting Indigenous health (15). In these three ways the Kidney Check project supports MoH objectives by offering health promotion and illness prevention that honors and contributes to self-determination. This project supports two of the large objectives of

the MoH 2020/2021- 2022/2023 Service Plan. There is a tight alignment between this project and policy goals; that itself champions any decisions for the project's continuation.

Two of the three barriers to sustainability noted by the Kidney Check team members have roots in policy- specifically cost and staffing. For this project to be sustainable it requires a funding source beyond its currently finite grant funding. The likely source would be the MoH- either directly or indirectly through the FNHA. Health promotion, illness prevention and a commitment to Indigenous health and reconciliation are Service Plan goals. It would be anticipated the government would allocate funding towards projects as aligned with their own health goals- like Kidney Check. In the current Ministry of Health Annual Report, a key highlight from 2019/2020 was the collaboration “with health system partners to enact the Declaration on the Rights of Indigenous Peoples Act passed in November 2019”. Given that the province has recently committed to enacting UNDRIP, which reinforces the rights of Indigenous people to self-determination and health, Kidney Check feels even more relevant and worthy of their financial support. Ideally, there would be additional policy in place that directs financial support to meaningful programs. Policy supporting funding of these programs is one step towards achieving meaningful reconciliation and meeting the service plan goals.

The second barrier relates to staffing and nursing capacity in community. The evaluation found many in-community nurses reported juggling competing priorities and being stretched thin. This speaks to an under-resourcing of care professionals in rural and remote settings. The 2019/20 MoH Annual Report highlighted that funding had been provided “for up to 200 new general practitioners....and 200 nurse practitioner positions in settings throughout BC”. It is unclear how many of these new staff are intended for work in remote or First Nations communities. It is understood that health care professionals not well versed in the historical context of Indigenous health and how to provide culturally competent care, can do tremendous harm to Indigenous people in their health care interactions. The concerted effort to increase the number and capacity of health care professionals committed to offering rural health services must be done in tandem with increasing and promoting trainings to non-Indigenous health care professionals that improve cultural safety of interactions.

At this juncture, it is time for the government to commit to Truth and Reconciliation. This evaluation, and similar policy-informing research is necessary to support the health of First

Nations people in BC. It is important to use this research to inform and enact policy that empowers projects like Kidney Check which boost community self-determination and reinforces communities' strength and capacity. It must be a priority to pass informed policy that respects and supports, financially or through other means, the fundamental human rights of Indigenous people in Canada as per the UNDRIP and Truth and Reconciliation Commission. It is far past time.

4.1.4 Recommendations

The purpose of this evaluation was to collect information from the two communities with completed screening to gain insight about the value and sustainability of the Kidney Check project. An anticipated outcome was recommendations for course correction as the project restarts in the other fourteen communities, post-COVID. Given the results, it is apparent that no obvious course correction is required. External Kidney Check team members working to organize and implement screening in both communities shared very positive feedback about the project and their experience with it.

This evaluation did provide focus on an important connection between sustainability and building community capacity. Building community capacity - investments in training nurses, provision of POCT equipment and supplies, improved supply chain logistics, dedicated project time - in community should continue. This ensures each community feels supported enough to maintain the project and helps ensure its future sustainability.

4.2 Contextual Factors Underlying This Evaluation

This section examines the contextual factors which underly this evaluation to provide insight into the complex environment in which it took place. This is being created in the context of my new understandings regarding Indigenous ways of learning and Western expectations around timelines and products. The work completed is not as it was intended but is nonetheless meaningful and of value to me and the program of work. The balance of respectful culturally safe engagement for the purposes of evaluating a program of work, and the requirements for ethics review, and meeting timelines disrupted by the pandemic has led to this. Appreciating the

environment provides context and will situate the strengths and limitations as I move into section 4.3.

4.2.1 COVID-19

The COVID-19 pandemic struck as I was finishing my first year at the School of Population and Public Health. I had been working as a part of the Kidney Check team for three months and had just formalized the evaluation of the Kidney Check project for my thesis research. The intention was to continue learning about and understanding the Kidney Check project during the coming months, attending screening events in-person to fully immerse myself. As screening targets were met in communities, I would begin the evaluation work. The original evaluation plan that was laid out in the Charter agreement between Can-SOLVE CKD research network and the FNHA, was to go back into communities where screening had been completed to participate in a celebratory feast. Here we would share the results of the screening initiative with interested community members including participants, community leaders and Elders or Knowledge Keepers. While in community, sharing circles (or focus groups) with screened community members were planned to hear their experiences and collect insight into its value and sustainability. The learnings would be used (1) to course correct based on community feedback and (2) to contribute to a business case to expand this project. The use of face-to-face, in community, sharing circles would contribute to the cultural safety and appropriateness of the evaluation and was considered essential. When the pandemic struck, it became clear that returning to community to complete this celebration and carry out the sharing circles could not occur, for an indefinite period. As time went on and the pandemic persisted, the medical community (and the rest of the world) began to adapt through the use, among other things, of virtual platforms.

Because the evaluation information to be collected from communities that had completed screening was valuable to the project's future, I considered how to use virtual platforms to assist with evaluation. A proposal was made to complete virtual sharing circles through Zoom. After consultation with the community that had finished screening and would be the focus of this work, it became clear that their infrastructure was better suited to phone calls. This required changing the methodology from sharing circles to individual phone interviews. Concerns were

raised about the cultural safety, and logistics of this new approach, calling into question whether this pivot would be appropriate. Simultaneously in the larger landscape of British Columbia, Indigenous communities were being prioritized in the vaccine roll out. This important step forward towards a post-COVID-19 “normal” increased the likelihood of returning to the original evaluation methodology as communities and Kidney Check team members were fully vaccinated. This would honor the initial evaluation methodology and felt most appropriate. An important piece of the original evaluation plan was to collect information from screening team members on their experience organizing and implementing the screening. It was agreed by the Kidney Check team and my advisory committee that this piece of the evaluation could safely proceed virtually in the interim. It is within this current world of uncertainty and changing plans that I come to present the work in this thesis.

The challenges COVID-19 brought to the Kidney Check team evaluation cannot be overstated. The pandemic added a layer of complexity that had to be front of mind throughout this uniquely challenging time. There is a larger historical context of pandemics for Indigenous communities and people, and emotional trauma woven into that history. One devastating consequence of contact for Indigenous people was massive amounts of sickness and death as a result of epidemics of European diseases like smallpox, measles and influenza (137,138). Important to note here however, is that in many cases the disease spread was not passive - it was an active agent of colonization. Historical accounts outline the intentional exposure of Indigenous people to disease through infected gifts, and state that many would have lived if they had been provided access to basic medical care or vaccines (137,138). Important to consider in this modern time, is the cultural effect of these past epidemics and how these are felt intergenerationally in the present. Historically, the rapid loss of life meant the death of Elders and Knowledge Holders who traditionally passed down important oral history and knowledge (137). Disruption also occurred to traditional healing ways as healers were overwhelmed and exposed to sickness themselves, disruption in harvesting and ability to supply and maintain food stores occurred also (137). Many people believe that it was the sickness and its effects that “clear[ed] the way for the colonization and repression that followed” (137). It is imperative to acknowledge that history during this modern pandemic, given that the First Nations people engaged in this evaluation might be facing heightened emotional responses and stress. It is

necessary to be taking cues from community, respecting their capacity and availability, and incorporating a trauma-informed practice into the evaluation. The pandemic did more than create logistical barriers like lack of access to community, it raised emotional barriers that were essential for me to be aware of throughout.

As I proceeded with evaluation work, a barrier I experienced was the lack of valuable face-to-face communication and interaction with participants. This created challenges in relationship building - a Kidney Check core value and important part of Indigenous health research. The team and I were faced with the question of how to maintain relationality in a virtual environment. To quote Margaret Kovach (9) “Research is relationships”. How then, could we move forward with this evaluation work in a relational way without the essential component of in-person, authentic, face-to-face communication?

I recognize the Kidney Check project, and my evaluation, are far from being the only projects that have had to navigate the pandemic. This is a problem facing the entire field of Indigenous health research, and even more broadly, the field of community based participatory research (139). Adjusting to the new virtual world is challenging for Indigenous health research for several different reasons, one being a lack of infrastructure in community to support platforms that are becoming ubiquitous in these days of Zoom technology. Another challenge is that this kind of relationship building has not been done online in the past. As stated by Harding et. al (139) “pre-pandemic...facilitating health research consultations with Indigenous Elders or Knowledge Keepers by videoconference would have been inconceivable”. That noted, this project and the broader field of Indigenous health research have worked to build and maintain authentic relationships through these virtual mediums. For this evaluation, I used whatever communication medium the participant had access to, and consistently ensured time for informal conversation and discussion to build up our relationship and open the work in a good way. For those participants whose Nation-based protocols included offering tobacco, I did so in front of the camera to be accepted virtually, and then either mailed the offering to the participant or laid it down myself with a prayer. These modifications allowed the evaluation to proceed in a good way, building relationships and maintaining protocols despite this new environment. According to Harding et al. (139) there may be some positives to come out of this time, saying “It is important for the medical community to witness how protocols evolve as our country moves

through and beyond the pandemic, and to bring this spirit of adaptability to clinical and research work.” The learnings that have come from proceeding with valuable work during this time have demonstrated the capability of the Indigenous health sphere to pivot and adapt. That said, face-to-face communication will always be important to honor Indigenous ways, and as the world returns to “normal”, I am excited to recoup this lost in-person time.

On a larger scale, the pandemic impacted the Kidney Check project itself. In the wake of the global circumstances of COVID-19, in March 2020 the Kidney Check project came to a standstill. All community engagement visits being made by the team were halted to comply with public health guidelines, and screening in communities ended as they, and the world, went into lockdown. There was much uncertainty at many levels. To respect the “Community-driven, National-led” mandate of the Kidney Check project, the team stepped back, realizing that community priorities were elsewhere as attention and resources were diverted to the pandemic. At this point, there was complete uncertainty about the timeframe that this would take to resolve. The team focused its efforts on preparing resources and ways to support community for if and when they were ready to begin screening again.

The effects of this halt due to COVID-19 were felt deeply by the team; both those who were part of the internal screening team and those working within community. COVID-19 effectively stalled screening procedures and interfered with the original training paradigm that was so instrumental in ensuring success of the mixed-model. The pandemic eliminated access to kidney health screening through this project for more than 18 months. Unfortunately, this is not an isolated circumstance. At the beginning of the pandemic, health systems responded to mounting demand by pausing nonessential healthcare services to divert crucial resources to the COVID-19 response. This resource re-allocation resulted in the suspension of most routine screening procedures, diagnostic tests and preventative care used to identify disease in its earliest, most treatable stages (140). Unfortunately, the effects of this necessary decision on future health will be felt profoundly as health systems rebalance and return to normal post-COVID-19. Screening tests and routine diagnostics do not become less necessary during a pandemic. On the contrary, individuals still develop disease, but it goes unchecked without access to these important interventions, potentially becoming more serious. Preliminary evidence suggests that diagnostic delays due to the COVID-19 response will result in avoidable deaths

from late-stage presentation of disease (140). These can only be minimized through a concerted response by the healthcare system, led and supported by relevant policy, to address the gap caused by this lack of access and make up for these missed windows of diagnostic opportunity.

Despite the challenges it has brought, COVID-19, and its consequences, have made the Kidney Check screening project even more relevant and essential. Primary preventative screening is an intervention with which gaps in care caused by COVID-19 can be addressed, and unchecked chronic illnesses can be identified and subsequent follow up care offered, improving patient outcomes. Access to POC screening that returns on-the-spot levels of risk for kidney failure is one way to improve health in First Nations communities moving forward into a post-pandemic era. Indeed, one of the strengths of the project has been its ability to adapt to the new realities of COVID-19 and restart screening. As stated in the results, the mixed-methods model that was developed, that is unique to BC Kidney Check, has been integral in allowing for this. By building community capacity through virtual training and offering the equipment and supplies to nurses in community, screening can, and has, restarted much earlier than in provinces with other models of the project. This evaluation has collected perspectives that highlight the effectiveness of the modified virtual training program, and how successfully community nurses have been able to reach screening targets once trained and provided with equipment. This project is exceedingly well-situated to continue offering essential screening to community members in this difficult time.

4.2.2 Navigating Tensions: Timelines & Cultural Safety

Another learning which is essential to fully contextualize the evaluation work presented here, is that the utmost priority was given to maintaining cultural safety throughout. There were times when cultural safety could have been put at risk because of academic timelines and requirements. Additional efforts were necessary to keep cultural safety at the forefront. The juxtaposition of the need to respect time and access in a culturally safe and respectful manner, and academic requirements to complete the work by a specific date and formed a challenging nexus. Managing this tension provided me with a unique learning experience; the purpose of this section is to share my experience with others who might take on this kind of research, and to describe my path through these challenges.

4.2.2.1 Relationships Building Doesn't Happen on a Timeline

As mentioned previously, relationship building is a cornerstone of Indigenous health research and is an essential first step in laying a foundation for any work. This initial relationship building is even more important as I consider my own positionality and situate this evaluation within the principles of my theoretical framework. For a non-Indigenous person to engage with Indigenous health research, using a two-eyed seeing approach rooted in post-colonial theory and phronesis, it is important (1) to understand how research has acted as an agent of colonization in the past and (2) to actively resist that process by using a decolonizing approach. Relationality has been identified as a key tool for settlers aiming to engage with a decolonizing paradigm as it provides, according to Gerlach (141), “the necessary epistemological scaffolding to actualize the underlying motives, concerns, and principles that characterize decolonizing methodologies”. Authentic relationship building takes time, it cannot be rushed. Essential to this work proceeding in a good way has been the guidance and support of the Indigenous Knowledge Holder on my committee, Catherine Turner. I worked with Catherine on Kidney Check and other Indigenous cultural health and safety projects on the Can-SOLVE CKD research network. It took time to develop our relationship to the point where it felt appropriate for me to invite her to sit on my committee and offer on-going, hands-on guidance. Once that request was made and accepted, it took time to further develop trust, honesty, and collaboration. These essential pieces woven into our relationship provided me the space to ask questions like “How do I appropriately offer a Nation-specific protocol?” or “Is this language appropriate in my interview guide”, without trepidation. Catherine’s perspective has been invaluable to both this evaluation work and to my own learning journey as a non-Indigenous woman walking the path of truth and reconciliation. The notion that one can relationship build within an imposed academic timeline is incongruent, presenting a challenge for all students who want to engage in this type of work well. The standard milestones and academic expectations are in direct juxtaposition to core values of relationship building. I did deviate from a typical timeline, respecting and allowing time for relationship building. The result was that my research proceeded at a different pace relative to my colleagues in this program. Ultimately, the relationships that I built in that time broadened

my thinking and understanding of Indigenous health and community-led research, two factors without which this evaluation work could not have proceeded.

4.2.2.2 Ethical Review: Different Circumstances Require Different Processes

The second step - the ethical review process – provides another example of this tension. Historically, low-risk studies like this evaluation receive a delegated review which proceeds quite efficiently. The review process for this work followed a different progression. The evaluation proposal first went through multiple rounds of discussions with the Research, Knowledge Exchange, and Evaluation department of the FNHA before going to a review with the UBC BREB. Once an application had been submitted to the UBC BREB, there was another harmonized review with the FNHA. This project was then selected to be a part of a new collaborative review process, whereby the application is reviewed and commented on by an Indigenous staff member. The purpose of this is to ensure that an Indigenous perspective is maintained through the review. In the spirit of collaboration, the provisos were not sent back through the RISE portal, as is standard within academic organizations. Instead, a meeting was set up with myself, the Indigenous Knowledge Holder on my committee, and two individuals from the FNHA ethics department. This meeting provided an opportunity to work through the comments on the application and to collaborate, discussing options for how to best modify the evaluation and optimize cultural safety. The entire ethical review process was extremely collaborative which allowed for a multiplicity of lenses to be involved. This approach is in keeping with Indigenous ways of doing. Much like the first step of this research (relationship building) however, this review took longer than standard university processes and ethics reviews that do not involve Indigenous participants. It was at this step of the research that I realized the extent to which my original timelines would need to be modified to create the space to do this work well. My expectation that this review would take several weeks was founded on a Western conceptualization of the research process, one I thought I had moved away from. It was at this point that I felt the difference between conceptual and practical understanding of an Indigenous health research paradigm. This experiential learning influenced me to further broaden my understanding of the differences between Western and Indigenous research paradigms.

4.2.2.3 Data Collection: A Balancing Act

On a broad scale, my experience with data collection showed how Western academic requirements may impede authentic community-based research. For research to truly embody this paradigm, it must be flexible and responsive to the community needs and desires of community members. This may conflict with structures and rules regarding which elements must be completed for a research project to be considered “finished” or fulfill grant or faculty requirements. In many cases, the original goals of the research may not be met, at the request and guidance of community members. Nonetheless there can be learnings and knowledge gained. These truths resonate in this evaluation. For example, several participants I recruited responded by indicating that now was not a good time for them to engage in this work and that their attention was needed elsewhere in community. In a community-based paradigm that values self-determination – as this evaluation strives to do – the needs of the community members supersede those of the outside evaluator. I have had to reflect on the impact this lack of access to community members has had on the work. It reduced the number of participants which can call into question the ‘trustworthiness’ of the evaluation using Western constructs and parameters like validity and generalizability, which are then used to judge rigor of the work. Balancing authentic community-based research against the need for an accepted ‘amount’ of data necessary for this evaluation to be perceived relevant was challenging. With the guidance of my committee, I proceeded with the stories that I was able to collect; these offered deep reservoirs of insight into the project. I recognized and stated the limitations that this decision would have in terms of breadth of the evaluation. Respecting the wishes of community above my own notions of a complete evaluation was crucial in embodying the values and principles laid out in my research framework and proceeding in an authentic, community-based way.

4.2.2.4 Holding Knowledge Respectfully Takes Time

Lastly, academic timelines also do not necessarily support respectfully engaging in and holding the collected knowledge in an Indigenous research paradigm. In Western epistemologies, knowledge is something that is individually sought after, gained, and then owned or possessed (105). In a Western paradigm then, once someone has acquired that knowledge, it is theirs to do with as they please. In an Indigenous paradigm, and in my case as a settler researcher working to

respect Indigenous knowledge systems, knowledge is relational and in that way knowledge seekers (like myself through this evaluation) are accountable to other people, and, in fact, all of their relations (105). It requires time to navigate this accountability and ultimately hold and proceed with that knowledge in a respectful way. This involved exploring my findings and analysis with Catherine, to maintain an Indigenous perspective, and doing member checks with the team members who did share their experience with me to ensure their voice was accurately represented. It also included taking the time to reflect, myself, ensuring that I was correctly interpreting what was shared and not imposing my own lens and perspective on to it. All these steps require reflection, clear communication, and thoughtfulness only enabled by ample amounts of time; time which may be lacking when there are firm deadlines to meet. Time and space for these components need to be woven into the research plan from the outset. I personally did not start out with that understanding, it's something that I found as I proceeded, and a learning that is valuable for those who are who endeavor to complete this type of research.

4.2.2.5 Summary

Balancing the competing demands of completing this work in a culturally safe way while adhering to academic standards or timelines created tension at multiple steps of the research process. A new learning came out of navigating these conflicts at each step. From foundational relationship building all the way to analysis and dissemination I gained a better appreciation for how to practically embody the principles in my theoretical framework and engage with an authentic community-based evaluation. Navigating these two contrasting priorities required critical thinking, ongoing reflexivity, and ultimately a commitment to place cultural safety above all else- specifically my own preconceived notions, and externally imposed timelines and processes. The insights that came from this experience are unique to this type of research and represent an important learning to come out of this dissertation work. The path that I have taken through this evaluation process has deeply impacted my understanding of cultural safety in research and what the practical implications are in maintaining it as the priority.

4.3 Strengths & Limitations of The Evaluation

4.3.1 Strengths

The fundamental strength of this evaluation is derived from (1) the methodology it employed and (2) the commitment it made to prioritizing and maintaining cultural safety throughout. From the development of the theoretical framework to the intentional decision to proceed using a qualitative evaluation approach rooted in Indigenous evaluation frameworks, the work was able to proceed in a way that embodied genuine two-eyed seeing. This made the evaluation all the more powerful as it was rooted in the strengths of both Western and Indigenous ways. This also contributed to its cultural safety and relevance to participants, specifically those who were Indigenous. Overall, the thoughtful considerations that were taken at each step of this work to understand my own positionality and be accountable to the information and knowledge that I was collecting also act as a strength to the work.

This is also the first publicly available program evaluation to integrate the core values of Indigenous evaluation frameworks into a qualitative evaluation methodology framed in narrative. The evaluation model that this work has created in this integrated methodology acts as a significant strength of the work as it is novel and innovative and could be applied to further evaluation work for the Kidney Check project and beyond. The findings from this evaluation demonstrate how successful this methodology is in capturing information that is relevant to participants and communicating it to a broader audience, all in a culturally safe way.

4.3.2 Limitations

There were limitations to this evaluation, distal to the contextual factors outlined in section 4.2. Firstly, the evaluation was inherently limited by the number of interviews that were conducted. The evaluation included ten peoples' stories representing both the internal and external Kidney Check screening team. Though the information shared was comprehensive and complex, the actual number of participants could represent a limiting factor. There were fourteen people who met the inclusion criteria and whose input would be relevant. The stories collected represent 70% of those available. Additionally, all four who declined to be interviewed were members of the external kidney check team meaning there was not an equal proportion of

internal and external screening team perspectives. This could limit the breadth of evaluation information, especially as it relates to the practicality of programming in community. This limitation is distal to the overall impacts of COVID-19; individuals working in community were busy with multiple priorities. While an extended timeframe might have encouraged more participation, repeating codes and themes began to appear as the number of interviews increased which indicated potential saturation regardless.

Secondly this evaluation included perspectives from two of the sixteen communities that participated in the Kidney Check project. While these were the only communities with completed screening; this limits the comprehensiveness of the evaluation. It is likely the other fourteen communities hold valuable information about the project's value and sustainability. This limitation is also a product of COVID-19; it was originally anticipated most, if not all, of the communities would have completed screening at this point. Despite this, the results are important as they provide a deeper understanding of the project and could suggest course correction as Kidney Check restarts post-COVID-19. The two Nations represented in this evaluation are very different in terms of resourcing, community infrastructure, geography, and access, so there was diversity included. It will be important to return to the other communities, as they complete screening to supplement this initial evaluation.

Thirdly, a limitation could arise through the strategy used to select both communities and interviewees. Only the two communities that had met their screening targets were included in this evaluation. The exclusion of communities who had not yet reached their targets could be a limitation in that there may be valuable information held by those communities struggling to reach these targets that could contribute to the overall program evaluation. Completing evaluation work at the midpoint of the target number may be informative and something for future consideration. This could provide insight into any difficulties in reaching the targets, while still allowing time for community course correction. Additionally, a purposive sampling strategy was used to select interviewees and there are biases that this study population might hold. Kidney Check team members may be predisposed to bias in favor of the project continuing because of their own personal and professional investment in it. This could limit the objectivity of the data collected and skew the results towards a more positive description of value and sustainability. It will be important to complement this evaluation with one from the perspectives

of community members who were screened to overcome this potential for bias and create a wholistic picture of the program.

In a typical Western research paradigm, these three limitations which resulted in a small sample size in terms of both communities and participants could impact the generalizability of the work. That said, qualitative work is, according to Leung (142) “meant to study a specific issue or phenomenon in a certain population or ethnic group, of a focused locality in a particular context, hence generalizability of qualitative research findings is usually not an expected attribute”. This is even more relevant within an Indigenous research paradigm, and specifically an Indigenous evaluation framework, where concepts like value are rooted in place and community context. Qualitative research concerns itself with transferability, which is defined by Korstjens and Moser similarly to generalizability but a key difference is that it is the responsibility of the qualitative researcher not to ensure transferability but instead to “facilitate[] the transferability judgment by a potential user” (143). I did this by providing ‘thick descriptions’ of the context of this evaluation and sharing information around the Kidney Check project itself. I also included many quotes from participants themselves which were steeped in context and place.

I was also concerned with confirmability and credibility of my evaluation results (118,143). These were ensured through a variety of different strategies. Credibility, sometimes referred to as internal validity, was maintained through member checks with the participants, investigator triangulation through collaborative analysis, and a strong understanding of positionality and biases stated at the outset of my thesis. Confirmability, sometimes referred to as reliability, was ensured through the lengthy description of my research process, also known as an ‘audit trail’ provided in section 2.3.

Lastly, when looking at the interviews themselves, the fact that they were relegated to a virtual environment and proceeded over Zoom also represents a limitation of the evaluation distal to COVID-19. There is a significant amount of non-verbal information that can be conveyed through tone, posture, gesture and other forms of body language in a qualitative interviews. Unfortunately, these non-verbal cues cannot be reliably interpreted over Zoom, especially if internet connection is intermittent. Several interviewees were located in community or in other remote areas across Interior and Island health regions, and stable internet connection

was a problem. There were disruptions to the flow of the conversational interview, and many cases of having to ask some participants to repeat themselves or wait until they were no longer ‘frozen’ on screen. This meant that information conveyed through tone or body language may have been lost. Internet connection is still a very real problem in First Nations across Canada, with the National Aboriginal Health Organization reporting that only 35% of First Nations households on-reserve having access to high-speed internet (144). This is yet another area where infrastructure is comparatively lacking and must be a consideration when proceeding with virtual engagement in the sphere of Indigenous health.

This limitation could have resulted in disruptions to the credibility of the results, often referred to as internal validity in quantitative research (118). However, the impacts to credibility were mitigated through the use of member checks, where interpretations of quotes shared by participants were validated by the participants themselves. This ensured that the lack of non-verbal communication did not result in a misinterpretation. At this time, participants were also invited to share anything they felt was relevant to the evaluation work, however nothing was added. This cannot make up for the lack of non-verbal data that could have been shared through using a different platform but ensures that what was conveyed in this evaluation was credible.

4.4 Conclusion

Using a uniquely suited theoretical framework that incorporated and privileged Indigenous knowledge and theory, contextualized the work within a broader historical landscape, and promoted pragmatic ethical engagement as a guide, this evaluation combined the principles of an Indigenous evaluation framework with qualitative evaluation to engage in an evaluation of the value and sustainability of the Kidney Check project framed in narrative. The study presented findings that illustrate the complex and tightly related dimensions of value including respect, relevance, reciprocity, and responsibility. It also illuminated the relationship between value and levers to sustainability and explored potential barriers to sustainability as well. The results of the evaluation have both public health and policy implications. In terms of public health, the evaluation illuminated the critical need for public health initiatives focused in Indigenous communities to integrate self-determination and community capacity building into the approach in order to maximize success and minimize the risk of harm. In terms of policy, the Kidney

Check project embodies many of the goals put forth in the 2020/2021- 2022/2023 Service Plan indicating a potential alignment. However, further tangible policy support is necessary to address some of the barriers to sustainability including cost and staffing. Further research is needed to illuminate screened community members' perspective on the Kidney Check project, as this will allow the patient voice, and community voice to be heard and a wholistic understanding of the project to be achieved. Tangentially, this thesis also described the tensions between maintaining cultural safety while incorporating Indigenous ways of doing and contrasting Western academic expectations. It also contextualized the evaluation work within the uniquely challenging landscape of the COVID-19 pandemic. Lastly, it showed the successes and strengths associated with applying a genuine two-eyed seeing approach to research, rooted in the strengths of Western and Indigenous knowledge systems.

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Appendices

Appendix A Interview Guide

Preamble:

Hi, my name is Simone Dew, I am a Master's student at the School of Population & Public Health and I work with the Kidney Check project. In the interview today, I will be asking you questions relating to your experience with and perspective on the Kidney Check Screen, Triage and Treat program. You can decline to answer any of these questions. You may stop the interview at any time without giving any reason, you can also ask me to retract (delete from the transcript) anything you have said. I expect this conversation to take about an hour of your time. I will be recording the conversation, as per the consent form, and transcribing it. I will then be working with the other interviews to try and come up with some common themes and experiences. I will check back with you in a few weeks to ensure that what I have analysed accurately represents what you wished to have shared with me.

*For Community Members: "If knowledge is shared that is not directly related to this evaluation, what would you like done with this knowledge? How should it be honored or followed up on?"

*For Staff Members: "Given what we will be talking about today, if you share something with me about relationships with others on the network, or the project I would like to come back to that piece at the end of the interview to make sure that I am properly honouring and holding the experience you shared. It might be helpful to look at policies in place that navigate how to deal with interpersonal issues in the workspace, or to consult a network Knowledge Keeper. All of this would only be done at your request and with your agreement and if this comes up"

Are you ready to begin?

1. Introductions:

- What is your title and what is your role within Kidney Check?
- How long have you been in this role?
- Why do you do the job that you do? What do you like about your role?
- Could you please walk me through what your specific responsibilities have been in regard to the Kidney Check screening in X
- Could you please walk me through what your specific responsibilities have been in regard to the Kidney Check screening in Y

2. Open Ended Questions

- Tell me about your experience with the Kidney Check project.
- Tell me what your thoughts are on its value?
- Tell me what your thoughts are on its sustainability moving forward?

Exit:

Thank you so much for sharing your time with me, I will reach out in the next 2 weeks to schedule a date for a check back to ensure that the themes that I derive represent what you meant to share. You can reach out at any point within those 2 weeks to have your data taken out of this project if you wish.

Appendix B Thematic Analysis Whiteboard

