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Summary (250 words max single spaced):

Background

Indigenous Canadians have higher rates of chronic conditions than their non-Indigenous counterparts. Geographic isolation and colonial-based structural barriers have led to lower rates of primary care utilization, creating a situation where many chronic conditions go undetected. Mass screening programs for certain chronic diseases in Indigenous populations has been demonstrated to be successful in identifying disease burden and then engaging the health care system to treat or monitor the appropriate subgroups.

Methods

A literature search strategy was prepared in consultation with the Aboriginal Health Librarian at the University of Manitoba. Our search was focused on mass screening programs performed in Indigenous communities for hypertension, diabetes and chronic kidney disease.

Results

The initial search revealed 4680 abstracts, of which 4527 records were excluded. This left 153 records eligible for full text analysis, nine of which were included in the final analysis. We found that the rates of diabetes, CKD and hypertension were 2-3 fold higher than non-Indigenous rates in the same countries. The included studies spanned three continents several communities, yet consistently found similar prevalence rates and drew similar conclusions.

Conclusions

It is our hope that the results of this systematic review will inform the implementation of screening initiatives for rural and remote Indigenous communities in Manitoba, Canada. These screening guidelines can be used in concert with the previously published research on delivering culturally safe care in Indigenous populations. When used together, this body of literature can provide comprehensive, safe and informed care to all Indigenous people.

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INTRODUCTION

Indigenous peoples have higher rates of chronic diseases than their non-Indigenous counterparts.¹⁻⁹ The higher prevalence of disease in indigenous populations spans the entire chronic disease spectrum, from chronic kidney disease (CKD), cardiovascular disease, malignancy, mental health, musculoskeletal ailments and respiratory conditions.

Diabetes, CKD and hypertension are significant public health concerns in Indigenous communities due to their high prevalence rates and disproportionate contribution to morbidity, mortality, and poor health related quality of life in this population. Each one of these conditions is easily detectable, has an evidence based intervention guidelines and has medications that are widely available and accessible. The treatment guidelines for diabetes, CKD and hypertension are considered to be a level one/grade A intervention, the highest rated level of evidence. These treatments are born out of highly competent randomized control trials and are considered to be the gold standard of evidence and clinical care. These treatment interventions are highly effective when prescribed and studies have shown that the systematic treatment of diabetes, CKD and hypertension have significantly improved patient outcomes.¹⁰

There is a sizable collection of writing on the proper engagement of Indigenous communities and peoples in a manner that is culturally safe and relevant. These writings and guidelines reach into a variety of situations and contexts and cover many areas including health care, research and business. These outlines for safe and relevant engagement are born out of a history of interactions between Indigenous communities and outside organizations that saw the Indigenous contingent considered as the lesser of the two parties involved. In some situations the Indigenous community was seen as a pool of suitable subjects for outside researchers to study and then leave without ever being heard from again. In other situations Indigenous people were treated in a manner that was not conscious of colonial history, which left individuals feeling disrespected and unsafe. It was out of these situations that guidelines around cultural safety and research principles such as Ownership, Control, Access and Possession (OCAP) were developed. This literature allows Indigenous people to be an equal party at the table when dealing with outside organizations and outlines way in which to consider, navigate and respect the historical context in our interactions.

Lower rates of primary care utilization due to issues of trust, availability and accessibility have created a situation where easily identifiable chronic conditions remain unidentified.¹¹ It has been shown that there are higher rates of morbidity and mortality due to diabetes, CKD and hypertension in Indigenous populations and the progression through the natural history of these three illnesses is much more rapid than non-Indigenous persons.¹² Given the characteristics of this population, coupled with the higher disease prevalence, that early detection, prioritization treatment of diabetes, CKD and hypertension is imperative in the Indigenous community. This systematic review is aimed to inform the evidence-based provision of care to Indigenous populations by directing the course of screening activities undertaken by primary care providers.

METHODS

A systematic search of the literature was carried out in July 2016 in consultation with a Health Sciences Librarian experienced in Indigenous studies. The population defined for

this included Indigenous peoples from Canada, Australia, New Zealand and the US, including Alaska and Hawaii. Several publications were consulted to define the scope of chronic diseases for which screening is applicable and relevant in Indigenous populations. The initial definition of chronic disease was guided by the Indigenous-informed publication, *The Crisis of Chronic Disease among Aboriginal Peoples* (Reading, 2009). Several other works were consulted (Kralik, 2010; Mendis (2014); Public Health Agency of Canada 2016)

Searches included a search of the term Chronic Disease as a MeSH term in Medline and an Emtree term in EMBASE along with keyword searching of the term in each database.

Identified chronic diseases is defined as a subset of chronic diseases selected by the research team, based on the definition of chronic disease in the publications noted above and the prevalence of these diseases in Indigenous populations. Each chronic disease was mapped to the Medline (MeSH) term or EMBASE (Emtree) term and exploded as applicable to the database index.

The search strategy encompassed searching for articles about chronic disease in Indigenous populations along with searching for specific chronic diseases in Indigenous people. Subsequent searching of (Mass Screening & Indigenous Peoples OR Chronic Disease [exploded] in Indigenous Peoples) was designed to capture additional references that would be overlooked in the other searches.

Limits applied in both databases were:

- i. Publication date = 1990 to 2015
- ii. Articles published in English
- iii. Studies indexed as Human

Additional citations were retrieved from the following sources:

- i. Scanning the tables of contents for key journals that are not sufficiently or wholly indexed in Medline or EMBASE (International Journal of Indigenous Health, formerly Journal of Aboriginal Health, and Pimatisiwin Journal)
- ii. Checking the references noted in systematic reviews of the literature related to chronic diseases in Indigenous peoples
- iii. CINAHL was searched and the result was that 24 records were retrieved in CINAHL when the search was carried out excluding Medline records; 3 were compared to results from EMBASE/MEDLINE to see if they were unique but proved to be duplicates.

Inclusion criteria

A further set of criteria was developed above and beyond the criteria used to generate records through the database searching. These inclusion criteria were used to screen the abstracts and built on the already established requirements of English language studies on human populations published from 1990 to 2015.

Population

Indigenous populations in North America, New Zealand and Australia involved in randomized control trials and observational studies

Intervention

Mass/population based screening initiatives, targeted or opportunistic, for chronic diseases that were completed in Indigenous communities

Chronic Diseases

Cardiovascular/Diabetes: type II diabetes, hypertension dyslipidemia, chronic kidney disease, peripheral arterial disease/peripheral vascular disease

Malignancy: breast, lung, prostate, cervical and colon cancers

Respiratory Conditions: COPD, asthma, chronic lung disease, chronic respiratory infections

Infectious Diseases: HIV, Hepatitis B, Hepatitis C, TB

Mental Health: anxiety, depression, suicide, substance use, PTSD, schizophrenia

Outcome

Any quantitative, reported chronic disease endpoint

We imported the search results into Endnote (Thompson Reuters) and duplicate records were removed. All titles and abstracts were screened in duplicate with each reviewer (SO and SD) independently assessing the records against the inclusion criteria. Disputes on record inclusion were settled by discussion with a third reviewer (PK).

Strobe analysis was completed on the included articles for risk of bias. ^{13,14}

RESULTS

The initial search revealed 4680 abstracts, of which 4527 records were excluded, leaving 153 records eligible for full text analysis. At this point in the project it was decided to focus the inclusion criteria further and limit the chronic disease focus to diabetes, hypertension and chronic kidney disease. This decision brought the final number of full text articles included for qualitative and quantitative down to nine.

Table 1 shows studies that were incorporated into the full text data extraction. The screened population and disease along with the screening test(s) used are also noted in the table. Among the nine studies there is a wide variety of Indigenous people represented from Canada, the United States and Australia. This diversity demonstrates the high chronic disease prevalence in unique populations, which speaks to the shared experiences of Indigenous peoples around the world.

The comparison of the reported prevalence rate for each study involving chronic kidney disease, diabetes and hypertension is shown in Table 2. For each disease the reported prevalence rate is compared with the known background rate for each of the comparison populations, Canada, United States, Australia. The background rates were generated from a variety of studies and national reports. Each background rate was matched as best as possible to the year of the study to provide the closest comparison of disease rates. For each of chronic conditions examined in this systematic review it is noted that the reported prevalence rates in the studies are consistently 2-3 times higher than the reported background rate for the rest of the population.

The population size screened and the screening rates for each of the studies included in the full text data extraction is reported in Table 3. Both of these statistics were reported in the study and extracted during full text analysis. The nine included studies reported a wide range of population size and screening rates

Table 4 shows a compilation of screening study characteristics, the reported challenges, community engagement methods, the duration of time-spent screening and the reason for screening.

DISCUSSION

In our systematic review of mass screening studies in Indigenous population, we found that the rates of diabetes, CKD and hypertension were 2-3 fold higher than non-Indigenous rates in the same countries. The included studies spanned three continents several communities, yet consistently found similar prevalence rates and drew similar conclusions. Together these findings suggest that indigenous populations worldwide face similar health challenges and may benefit from well-organized screening and treatment initiatives

In the Indigenous context, the diabetic, CKD and hypertensive disease burden is significantly higher than the background rates when compared to the rest of Canadians, Americans and Australians. The disease burdens outlined in Table 2 were consistently 2-3 times higher than the background rate, with some comparisons showing disease prevalence as high as 4-5 times the national rate. This observational data demonstrates need to consider population wide screening and interventions for chronic disease programs in Indigenous communities. This call for screening is further strengthened by the ease at which diabetes, CKD and hypertension can be detected and the level of evidence behind the guidelines that outline their treatment and intervention.

The origins of these disparities in prevalence rates are highly complex and multifactorial. The largest and most influential factor is the presence of colonial based structural barriers. This historical yet ever-present obstacle has created a health care system that is unable to identify and treat chronic conditions like of diabetes, CKD and hypertension. Part of the problem in the health care setting is that the structure itself that is underfunded, understaffed and overwhelmed. This system is not, and never was, designed to carry out preventative care and chronic disease management. The other half of this equation is the Indigenous patients themselves. These communities have been subjected to a colonial history of trauma and injustices. This has created a population that is burdened with issues with of trust and consent and a population saddled with so many larger economic and societal matters than remembering to check blood sugars or take high blood pressure pills.

The way in which chronic diseases are discovered, triaged and managed in the western primary care model are done so in a way that is not feasible in Indigenous communities. The creation of occasions for opportunistic screening that are seen in the western model of care just don't present themselves in the Indigenous model for a variety of reasons. Access to a family physician as an Indigenous person for yearly asymptomatic checkups is extremely difficult. Many communities do not have a steady family physician that cares for the entire population, but rather coverage from a large pool of available physicians. A continual supply of new faces in an already difficult colonial context creates issues of

trust and safety for the Indigenous patient and creates challenges for the physician in providing continuity of care and building trusting and relationships with their patients. Many of these communities are underserved and when they physician is in the community their schedule quickly fills with urgent matters leaving the yearly checkups or chronic disease management appointments unseen. These factors leave deters many people from seeing the doctor until something is wrong, and in the case of diabetes, CKD and hypertension, this is often the point in the disease trajectory that is past the optimal point for intervention and treatment. The existing system is overburdened due to these multitudes of factors. In order to create an efficient, effective and sustainable screening program that can identify, triage and manage chronic cases in a way that is culturally safe and relevant, we must look outside the current primary care structure.

The reported and background rates for hypertension in the Australian literature do not follow the rest of the data trends. this section of the data the background rates are higher than the reported rate. Hypertension is a chronic condition that is known to increase in incidence and prevalence with increases in age.¹⁶ The likely explanation for this deviation in the data is that there is a discrepancy in the age of the population in the community that was screened and the sample of people in the study that generated the background disease burden. Indigenous communities have a population structure that has a large proportion of their population in their youth. For example, the community screened by Riediger et al. reported that 50% of the population of 4100 people was under 19 years of age.⁷ The sample that was used in the AusDiab study was a representative sample of the population.¹⁶ This sample likely had an average age much older than the Indigenous communities screened in Australia, and therefore would have a higher rate of hypertension due to the discrepancy in age.

In reviewing the literature for this systematic review, the amount of studies that addressed the disparities in chronic disease rates among Indigenous communities was quite underwhelming. Despite staggering prevalence rates within Indigenous communities for diabetes, CKD and hypertension that can be up to 4-5 times the background rate there seems to be a gap in the literature on initiatives undertaken to address these inequalities. This hole can be a real in that there is no published literature on the topic because no work is being undertaken to correct the problem. Or, this hole can be perceived in that there are initiatives that are ongoing to tackle these extremely high rates but there is no published literature documenting the work or results. Further analysis of the grey literature should be undertaken to determine the exact state of affairs.

The reasons for pursuing a mass-screening program, outlined in table 4, centres around the high prevalence of chronic conditions observed in Indigenous communities. The majority of studies made mention of the disease burden in their reason for screening whether it be to investigate the rate or to try and determine risk factors for the underlying chronic condition. Riediger et al. cited the limitations in administrative data as one of their reasons for mass population based screening and this is a very important consideration for the chronic diseases that were examined in this systematic review. Type II diabetes, CKD and hypertension all have a long, asymptomatic course that allow individuals with these conditions to continue on with day-to-day activities unbeknownst to them that they are diabetic, proteinuric or hypertensive. These diseases do not have the pain, discomfort or immediate functional decline that may lead someone to seek medical attention like other conditions. These features cause there to be underreporting of actual disease burden, and more importantly do not signal the individual to seek care at the

optimal point in the disease trajectory. These characteristics supplement the need for mass screening, especially when the interventions that are available are inexpensive, effective and are backed by large bodies of strong evidence to delay or prevent more serious health outcomes such as cardiovascular events, kidney failure, and early mortality.

Community engagement strategies were not well reported in the articles analyzed for full text. Only three of nine made mention of their attempts and strategies to make the community aware of their screening programs. All three studies used similar approaches to encourage the community to participate. The use of the existing community infrastructure for recruitment was a common theme, the community health centre, schools as well as community and provincial radio stations. It is unfortunate that only three of the articles included their community engagement methodology, as this is a very important component of any screening initiative. Given some of the historical context already mentioned, getting the community out for screening events can be a real challenge. It is important to ensure that community support is in place for the program, not only from a respect and equal participation standpoint, but also from an efficiency perspective. Screening programs can be quite costly, especially when communities are in remote locations. It is important that proper planning and community engagement is undertaken to ensure the program can maximize their time in the community and reach as many people as possible. More work must be completed in order to determine the correct approach to community engagement in the implementation of mass screening initiatives.

One of the limitations for this systematic review is the small subset of chronic disease on which the literature was focused. We decided to concentrate on diabetes, CKD and hypertension because they are major public health concerns that had evidence based guidelines for intervention and treatment. Although this compartment of chronic diseases is a good starting point for the analysis and subsequent case for mass screening of Indigenous populations, more work needs to be done to cover all of the chronic conditions that burden this population. In the screening of abstracts and full texts we decided to only include population based screening of asymptomatic Indigenous individuals. This is a limitation to our systematic review as it eliminates other initiatives that are taking place to screen a subset of the Indigenous population already diagnosed with conditions such as diabetes. Although screening programs such as SLICK in Alberta did not meet the criteria for this systematic review, that program and others are conducting important work and research that will also be able to contribute to the case for population base screening of chronic conditions in Indigenous communities. The studies that were included in the full text analysis of this systematic review had very heterogeneous approaches to reporting their results and conclusions. The decision was made not to meta-analyze any of the findings. Although the lack of meta-analysis is a limitation to this review, the reporting of the staggering prevalence rates in these communities is enough to get the our message across.

The largest strength of this systematic review of mass screening of chronic diseases among Indigenous communities is that it is the first of its kind. To our knowledge there is no other systematic review in the literature that examines this particular issue in the Indigenous population. Another strength of this review is that it advocates for a different approach to Indigenous health care. The methodology of population-based screening program could be a welcome addition to the primary care structures already in place as

this type of screening will improve patient outcomes without adding burden to an already overwhelmed system.

CONCLUSION

Using the systematic review framework we were able to conduct an analysis of the literature on screening programs for diabetes, CKD and hypertension within Indigenous communities. The studies examined in the full text review portion of the analysis were conducted in Canada, the United States and Australia. The ten screening programs had different challenges, screening rates and duration of time in the communities, but similar reported community engagement strategies and reasons for tackling the issue. The main finding of this systematic review is we found that the prevalence rate of these chronic conditions is consistently 2-3 times higher than the background rate with some being 4-5 higher than the national comparator.

The next step for this project is to complete other systematic reviews the rest of the chronic disease groupings, conditions such as mental health, malignancy and infectious diseases. Together with this systematic review we hope that that this body of literature can be used to inform Indigenous specific guidelines in an evidence based manner on population wide screening practices for chronic conditions.

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TABLES AND FIGURES

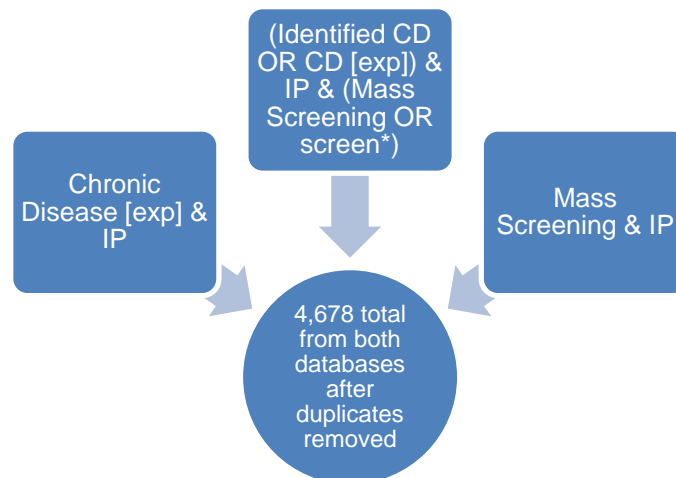
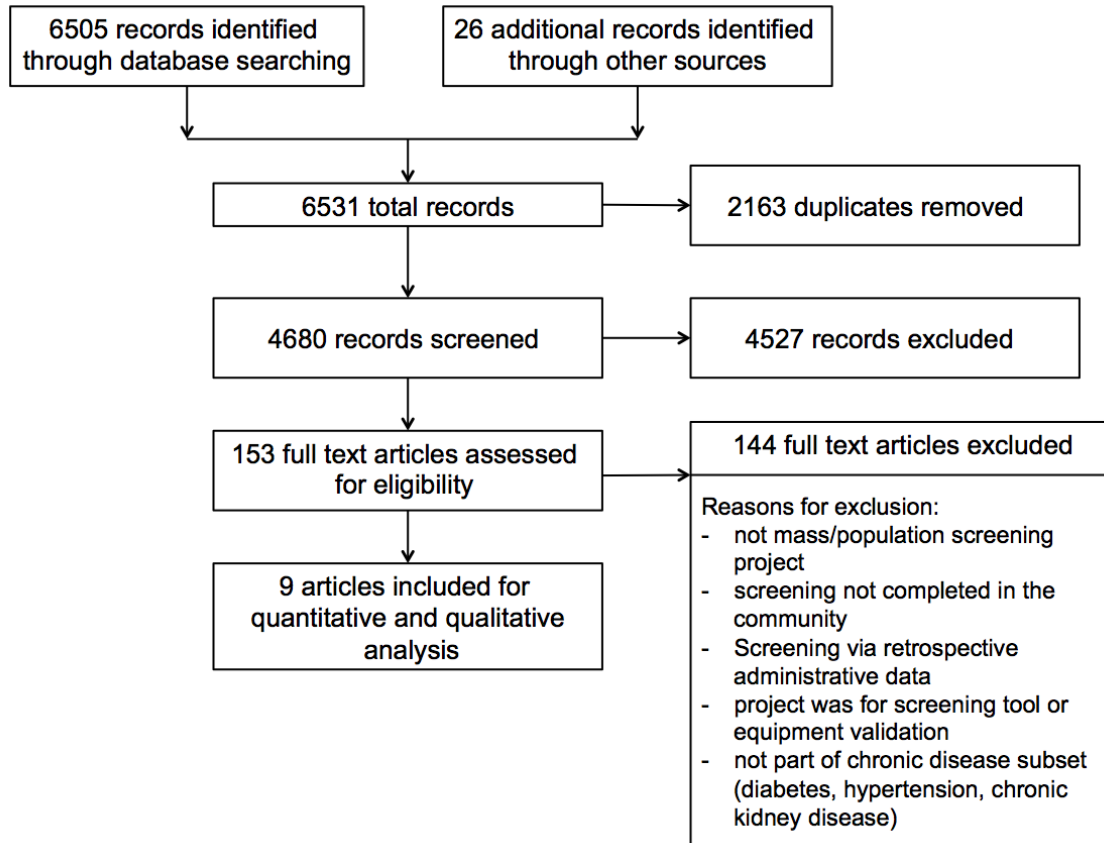


Figure 1 Database search strategy

Figure 2 Flow chart of systematic review process ¹⁵

| <u>First Author</u> | <u>Year</u> | <u>Population</u> | <u>Size</u> | <u>Disease</u> | <u>Screening Test</u> |
|---------------------|-------------|------------------------|-------------|--|--|
| Gaut et al. | 1996 | Australian Aboriginal | 437 | Diabetes | 75g OGTT |
| Hoy et al. | 2005 | Australian Aboriginal | 1070 | Chronic Kidney Disease, Diabetes, Hypertension | ACR, urine dipstick, random glucose, HbA1c, BP measurement |
| Hoy et al. | 1998 | Australian Aboriginal | 487 | Chronic Kidney Disease, Diabetes, Hypertension | ACR, BP measurement |
| Komenda et al. | 2016 | Canadian First Nation | 1346 | Chronic Kidney Disease | ACR |
| Leonard et al. | 2002 | Torres Strait Islander | 592 | Diabetes, Hypertension | 75g OGTT, BP measurement |

| | | | | | |
|------------------|------|----------------------|------|--|---|
| Nelson et al. | 1989 | Pima American Indian | 2728 | Chronic Kidney Disease | ACR |
| Riediger et al. | 2014 | Canadian Ojibway | 482 | Diabetes, Hypertension | BP measurement, fasting blood glucose |
| Shah et al. | 2003 | Zuni American Indian | 9228 | Chronic Kidney Disease, Diabetes, Hypertension | ACR, HbA1c BP measurement |
| Zacharias et al. | 2013 | Canadian Ojibway | 483 | Chronic Kidney Disease, Diabetes, Hypertension | ACR, urine dipstick, fasting glucose, HbA1c, BP measurement |

Table 1 Studies included in full text analysis

| <u>Study</u> | <u>Prevalence</u> | <u>Background Rate</u> |
|-------------------------------|-------------------|------------------------|
| CHRONIC KIDNEY DISEASE | | |
| Hoy et al. (2005) | 18% | 6.9% ¹⁶ |
| Hoy et al. (1998) | 24% | 7.5% ¹⁶ |
| Komenda et al. | 25.5% | 12.5% ²¹ |
| Nelson et al. | 30.4% | 12.5% ²¹ |
| Shah et al. | 22.9% | 15.6% ²⁰ |
| Zacharias et al. | 20.0% | 12.5% ²¹ |
| DIABETES | | |
| Gaut et al. | 9.4% | 8.5% ¹⁶ |
| Hoy et al. (2005) | 8.0% | 8.5% ¹⁶ |
| Hoy et al. (1998) | 12.0% | 8.5% ¹⁶ |
| Leonard et al. | 26.2% | 8.5% ¹⁶ |
| Riediger et al. | 25.9% | 6.7% ¹⁸ |
| Shah et al. | 16.0% | 6.7% ¹⁷ |
| Zacharias et al. | 29.0% | 6.6% ¹⁸ |
| HYPERTENSION | | |
| Hoy et al. (2005) | 20.0% | 35.0% ¹⁶ |
| Hoy et al. (1998) | 24.0% | 32.7% ¹⁶ |

| | | |
|------------------|-------|---------------------|
| Leonard et al. | 32.1% | 32.7% ¹⁶ |
| Riediger et al. | 39.4% | 17.7% ¹⁹ |
| Shah et al. | 41.0% | 28.4% ²² |
| Zacharias et al. | 43.0% | 17.7% ²¹ |

Table 2 Comparison of reported prevalence rates and national background rates for diabetes, CKD and hypertension

| <u>Study</u> | <u>Screened Population Size</u> | <u>Screening Rate</u> |
|-------------------|---------------------------------|-----------------------|
| Gaut et al. | 437 | 80.0% |
| Hoy et al. (2005) | 1070 | 90.0% |
| Hoy et al. (1998) | 487 | 89.0% |
| Komenda et al. | 1346 | 22.4% |
| Leonard et al. | 592 | 10.0% |
| Nelson et al. | 2728 | 81.0% |
| Riediger et al. | 596 | 28.0% |
| Shah et al. | 1483 | 16.0% |
| Zacharias et al. | 483 | 36.0% |

Table 3 Screened population and rates

| <u>Study</u> | <u>Noted Challenges</u> | <u>Community Engagement Methods</u> | <u>Screening Duration</u> | <u>Reason for Screening</u> |
|-------------------|-------------------------|-------------------------------------|---------------------------|--|
| Gaut et al. | N/A | N/A | 1 year | To see if a traditional style of living and traditional diet were protective against chronic diseases. |
| Hoy et al. (2005) | N/A | N/A | 3 years, 6 months | Increase in CV, diabetes, and CKD related deaths are all increasing in this population. |

| | | | | |
|----------------------|---|--|-------------------|---|
| Hoy et al. (1998) | N/A | N/A | 3 years | Explore high renal disease prevalence and increasing incidence in this population. |
| Komenda et al. | Geography, competing community events, weather, structural challenges, transportation logistics, mistrust of external providers | Presentations to the school administration, teachers, and eligible students, door hangers hand delivered to each home, advertisement on provincial and local radio stations | 260 days | Assess whether the guidelines to online screen high-risk people for CKD can be applied to FN communities. |
| Leonard et al. | Internal community politics, religious beliefs | Recruitment activities by community health staff and the survey team, health centre records and local knowledge to identify all eligible residents and encourage participation | 3 years, 8 months | To describe the lifestyle risk factors effect on prevalence of obesity and diabetes in this community. |
| Nelson et al. | N/A | N/A | 6 years | To determine the prevalence of abnormal albumin excretion in a population at high risk of diabetes. |

| | | | | |
|------------------|-----------------------------------|--|-------------------|---|
| Riediger et al. | Sample size, sample dependability | Recruitment through advertisement at the community health centre and via a local radio station, word of mouth, and home visits from community research assistants, transportation offered to all participants. | 1 year | High disease prevalence and increasing incidence in this population, existing studies focus on admin data, don't consider people not diagnosed. |
| Shah et al. | N/A | N/A | 3 years, 2 months | To investigate high prevalence of ESRD amount Zuni people |
| Zacharias et al. | N/A | N/A | 1 year | Determine prevalence and risk factors for albuminuria in high risk population |

Table 4 Study characteristics