

THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Report by - DONISHA DUFF - 2015 Churchill Fellow

THE BOB & JUNE PRICKETT CHURCHILL FELLOWSHIP to investigate chronic kidney disease programs for Aboriginal First Nations people in New Zealand, the United States of America and Canada.

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Signed:

Dated:

Acknowledgements

The Bob and June Prickett Churchill Fellowship has allowed me to undertake this professional development opportunity overseas. I am greatly indebted to 'Tropical' Bob Prickett for his sponsorship and continuing interest in improving health for all Australians.

I am very grateful to the host organisations whom I visited while on my travels. Thank you to the staff for spending time with me and for imparting your experience. I hope to stay in contact and share information and knowledge.

I would also like to sincerely acknowledge and thank:

- The Winston Churchill Memorial Trust for investing in the professional development of such a wide variety of people and projects;
- My family and friends for their ongoing support, encouragement and belief of what I am capable of achieving.

Executive Summary

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Project Description

The Bob and June Prickett Churchill Fellowship enabled me to explore the incidence, experience and impact of kidney disease and the range of community-based programs targeting risk factors for chronic kidney disease (CKD) in Aboriginal First Nations communities.

Over 5 weeks from 1 May to 4 June, I travelled through Auckland & Christchurch (New Zealand), Hawaii & Seattle (USA), Vancouver and Winnipeg (Canada). I met with health clinicians and Māori, Pasifika, Native Hawaiian, Native American, and Aboriginal Canadian peoples to understand their experiences and share information about the approaches which were being developed within communities and in primary care in order to prevent and intervene.

Highlights

While I was able to visit some of the most beautiful places in the world, it was truly sobering to recognise the similar shared life experiences of our Aboriginal First Nations peoples. I found it also very remarkable and inspiring that among the devastation of ill health and abject poverty, there were Aboriginal First Nations people working in very trying situations to change the course. For me, the highlight of the Fellowship was spending time with these people – whose passion, determination, enthusiasm, like-mindedness, intelligence and patience will stay with me.

Major findings, dissemination and implementation

Tragically, Aboriginal First Nations peoples in Australia, New Zealand, the US and Canada have very similar poor health and social outcomes. This includes risk factors, diagnosis of CKD, and progress to ESKD.

Many local and regional health services visited were over-worked and under-resourced to manage the grossly complex and disadvantaged circumstances of their people. However, a range of intervention programs were being developed across the spectrum of care to prevent poor health and social outcomes including; farming sustainability and food supply, nutrition and physical activity, childhood health screening, opportunistic screening for adults, and elder's cultural support.

The report findings, recommendations and actions will be disseminated through my existing networks within the kidney community. Three (3) articles have already been published in the Kidney Health Australia community newsletter. An abstract was accepted to the Lowitja Institute International Indigenous Health and Wellbeing Conference in Melbourne in November 2016. Other opportunities for presentations will also be explored.

The recommendations and actions of the report will form part of my ongoing work at Kidney Health Australia.

Table of Contents

Acknowledgements	2
Executive Summary	3
Programme	6
Main Body	7
Kidney Health in Australia: the Aboriginal & Torres Strait Islander experience	8
Kidney Health Australia	9
Kidney Health in New Zealand: the Māori & Pasifika experience	12
Kidney Health New Zealand (KHNZ)	13
Kidney Society of Auckland (KSA)	15
Kidney Health in the USA: the Native Hawaiian & Native American experience	17
National Kidney Foundation of Hawaii	19
Kidney Health in the USA: the Native American experience	22
Urban Indian Health Institute (UIHI)	22
Kidney Health in Canada: the Canadian Aboriginal experience	24
Vancouver Native Health Society (VNHS)	25
Nanaandawewigamig First Nations Health and Social Secretariat Manitoba (FNHSSM)	27
Diabetes Integration Project	27
Aboriginal Diabetes Initiative	28
Food Matters Manitoba	28
Conclusions	29
Recommendations and Actions	34
References	36

Programme

New Zealand	Organisation	Person
Auckland	Kidney Society of Auckland	Nora Van der Schrieck Executive Director
		Leigh Jenkins Social Worker
	Greenlane Home Haemo Unit	Dave Lilley Home Haemo Trainer
Christchurch	Kidney Health New Zealand	Max Reid Chief Executive Officer
		Carmel Gregan-Ford Education Manager
USA		
O'ahu, Hawaii	Kidney Foundation of Hawai'i	Ashley Graham Director of Community Initiatives and Health Innovations
		Glen Hayashida President & Chief Executive Officer
Seattle	Institute for Urban Indian Health (IUIH)	Byron Larson Chief Executive Officer
	Staff Forum Discussion/ Q&A	Scott, Melissa, Leah, Germaine, Joshua, Callum, Sarah, Meg
Canada		
Vancouver	Vancouver Native Health Society	Tina Braun Clinical Manager
	Staff Forum Discussion/ Q&A	Tina, Jen, Marr, Georgia, David
Winnipeg	Nanaandawewigamig First Nations Health Secretariat	Wendy McNab-Fontaine Partners for Engagement and Knowledge Exchange Coordinator
	Food Matters Manitoba	Tim Stevenson Northern and Indigenous Program Liaison
	Assembly of Manitoba Chiefs	Leona Starr Research Associate & Regional Health Survey Coordinator
	Children's Hospital Research Institute of Manitoba	Dr Allison Dart Nephrologist
	Diabetes Integration Project University of Manitoba	Caroline Chartrand & Team
	National Aboriginal Diabetes Association	Jeoff LaPlante Executive Director

	Health Canada	Frances Desjarlais Aboriginal Diabetes Initiative (ADI) Regional Diabetes Coordinator Nutrition and Diabetes Wellness Unit First Nations and Inuit Health
	Health Canada	Marlene Delpino Child Health Nurse Nutrition and Diabetes Wellness Unit First Nations and Inuit Health
	Ojibway Language and Cultural Class	Barbara & Clarence Nepinak Elders and Language Teachers

Main Body

The primary aim of my Churchill trip was to explore the circumstances and key elements of effective community-based chronic kidney disease prevention health programs focusing on Aboriginal First Nations’ peoples in New Zealand, the United States of America and Canada.

The view was held that given the similarity in historical, socio-economic, cultural and health outcomes, there may be the possibility to learn and share information in order to empower our communities.

Other key secondary questions that were considered in gathering information as part of the visits were:

- What level of government interest and support is there?
- What level of community involvement and support is there?
- To what extent are there CKD preventative health programs for Aboriginal First Nations’ people in primary care?
- What is the model of delivery of these preventative health programs?
- What outcomes/impact do they have?
- What is needed?

In considering the effectiveness and appropriateness of community-based CKD prevention health programs, it was important to understand and be aware of the circumstances in Australia with Aboriginal and Torres Strait Islander peoples.

Kidney Health in Australia: the Aboriginal & Torres Strait Islander experience

In Australia, as with other chronic disease, CKD and end-stage kidney disease (ESKD) are more common among Aboriginal and Torres Strait Islander people than non-Indigenous Australians¹.

The increased incidence of CKD in Aboriginal and Torres Strait Islander communities is multi-factorial. The high incidence of risk factors, increased levels of inadequate nutrition, incidence of diabetes, alcohol abuse, streptococcal throat and skin infection and poor living conditions are contributing factors².

Nationally, an estimated 59,600 (1 in 5) Aboriginal and Torres Strait Islander adults are living with biomedical markers of CKD³. Alarming, 90% of these Aboriginal and Torres Strait Islander people who have indicators of CKD are not aware they have the killer disease⁴.

There is significant variation in the number of Aboriginal and Torres Strait Islanders in each State and Territory living with CKD. These are Northern Territory (32.4%); Western Australia (22.8%); Queensland (18.4%); South Australia (17.5%) and New South Wales (14.6%).

State/Territory	Status	Number	Percentage
Australia	Non-Indigenous	1,712,500	10%
	Indigenous	59,600	17.9%
Northern Territory	Non-Indigenous	9,800	7.9%
	Indigenous	12,000	32.4%
Queensland	Non-Indigenous	345,100	10.2%
	Indigenous	16,200	18.4%
New South Wales	Non-Indigenous	586,400	10.6%
	Indigenous	15,400	14.6%
Western Australia	Non-Indigenous	176,900	10.1%
	Indigenous	10,200	22.8%
South Australia	Non-Indigenous	106,000	8.4%
	Indigenous	3,300	17.5%

Source: ABS Customised report 2015

There is also regional variation in the incidence of Aboriginal and Torres Strait Islander adults with signs of CKD⁵:

- Major Cities (11.8%)
- Inner Regional (10.7%)

¹ AIHW 2011, *Projections of the incidence of treated end-stage kidney disease among Indigenous Australians, 2009-2020: A Working Paper*.

² O'Dea 2005, *Preventable Chronic Diseases Among Indigenous Australians: the Need for a Comprehensive National Approach*.

³ ABS. *Customised report*. 2015.

⁴ ABS. *Australian Aboriginal and Torres Strait Islander Health Survey: Biomedical Results, 2012-13*. 2014. Report No: 4727.0.55.003, Canberra.

⁵ ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. Available at: <http://www.anzdata.org.au>; 2016

- Outer Regional (17.7%)
- Remote (27.6%)
- Very remote (36.7%)
- Australian average (10%)
- Self-reported kidney disease (1.8%)

For very remote and remote Aboriginal and Torres Strait Islander people, many experience inequitable access to ESRD treatment services because of the location of treatment centres⁶. It has been estimated that 70-80% of Aboriginal and Torres Strait Islander patients with CKD are required to relocate for dialysis treatment.

For remote and very remote Aboriginal and Torres Strait Islanders, the commencement of kidney dialysis necessitates relocating to a regional area and subsequent dislocation from their families, communities and cultural lands. Not only are they managing a new treatment regime, many are also alone and facing issues with accommodation, employment, transportation, and keeping children in school.

Many others simply choose not to relocate for treatment and, given dialysis is a life-saving treatment, people who choose to not relocate will pass away much more quickly than those on dialysis. There are significant economic, social, and cultural ramifications for families and communities

There is also variation in the clinical management of Aboriginal and Torres Strait Islanders with CKD. This contributes to sub-standard care and adverse health outcomes due to the complex nature of Indigenous disadvantage.

Kidney Health Australia

Kidney Health Australia (KHA) is the national peak, non-government charitable organisation representing the interests of kidney stakeholders including clinicians, individuals and their families to improve kidney health outcomes for those affected by the disease.

Our mission is: “To promote good kidney health through **education, advocacy, research and support**”

Our vision is: “To save and improve the lives of **all** Australians affected by kidney disease”

⁶ Cass, et al 2001. Regional variation in the incidence of end-stage renal disease in Indigenous Australians in *MJA* 2001; 175:24-27.

For Aboriginal and Torres Strait Islander people and families, **health** is defined as:

“not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total well-being of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life. Health care services should strive to achieve the state where every individual is able to achieve their full potential as human beings and thus bring about the total well-being of their community.”

National Aboriginal Health Strategy 1989

Kidney Health Australia works across the spectrum of CKD progression, including some of the following:

Prevention:

- Resources (Awareness)
- Social Media Messaging
- Kidney Stories & I Kidney Check Gallery

Education:

- KCAT Training & Resources for GPs, Practice Nurses and Aboriginal Health Workers

Early Intervention:

- My Kidneys, My Health: Living with early stage CKD
- KHIS Phone Line & Peer Support

Management & Support:

- CKD Management in General Practice Handbook
- KHA- Caring for Australasians with Renal Impairment (CARI) Clinical Guidelines
- Kidney Klubs
- Consumer Committees
- State-wide advocacy on Out-of-pocket costs to consumers
- Big Red Kidney Bus

Organ Donation:

- Advocacy to establish the Federal Government “*Living Donor Leave Scheme*”

Palliative Care:

- Joint policy with Palliative Care Australia

Aboriginal and Torres Strait Islander Kidney Health

While our strategic approach to improving Aboriginal and Torres Strait Islander kidney health has only been in place just over 18 months, there is promising work that is underway. This includes:

Education: The development of a training module and resources for Aboriginal and Torres Strait Islander Health Workers to understand what is chronic kidney disease, how to prevent it and encouraging early detection. These resources were developed and tested in Queensland with the Aboriginal Community Controlled Health Organisations (ACCHOs). They are free to access on our website and training is also offered free.

Advocacy – KHA is advocating for the establishment of a National Taskforce on Aboriginal and Torres Strait Islander Kidney Disease. The National Taskforce will oversee the development of a detailed and costed strategy that coordinates and redresses the complex and fragmented health and social supports for Aboriginal and Torres Strait Islanders and families devastated by kidney failure. In the 2016 election, both the Australian Labor Party and the Australian Greens supported and developed election commitments for the National Taskforce. Advocacy with the new Coalition government will continue.

Research – Discussions are underway to develop “Clinical Guidelines for the management of CKD in Aboriginal and Torres Strait people and Maori”. This will address the variation in the clinical management of Aboriginal and Torres Strait Islanders with chronic kidney disease (CKD) that is occurring across Australia, which contributes to sub-standard care and adverse health outcomes due to the complex nature of Indigenous disadvantage. There are no national clinical guidelines specific to the prevention, early detection and best-practice management of the full spectrum of CKD among Aboriginal and Torres Strait Islanders in Australia.

Support – Ongoing work is underway to develop culturally appropriate prevention, educational resources and social media messaging for Aboriginal and Torres Strait Islanders. There is also access to Indigenous peer support through the KHIS phone line.

Emerging Priorities:

Aboriginal and Torres Strait Islander kidney health is identified as a priority for KHA. Given the greater burden of disease and significant disadvantage that is experienced by many Aboriginal and Torres Strait Islanders, there are some key areas of immediate need emerging and

potential to collaborate with other Indigenous and non-Indigenous organisations. In addition to the abovementioned work, these include:

- Prevention and Awareness of Chronic Kidney Disease in Aboriginal and Torres Strait Islander communities
- Nutrition and Food Supply
- Training of the Aboriginal and Torres Strait Islander health workforce
- Clinical guideline development for CKD management
- Embedding best practice CKD management in ACCHOs

Kidney Health in New Zealand: the Māori & Pasifika experience

In New Zealand, the numbers of Māori and Pasifika people starting dialysis is increasing. There are approximately 998 Māori and 726 Pasifika people being treated with ESKD⁷.

Haemodialysis is the most common modality, however there appears to be a strong focus on home haemodialysis and home peritoneal dialysis (PD). This is supported by ANZDATA, who found that in 2013, 32% of Māori patients and 20% of Pasifika peoples commenced peritoneal dialysis (PD). The percentage of Māori (25%) treated with home haemodialysis remained similar, while Pasifika (20%) people increased⁸.

Among Māori and Pasifika people, the excess rate is concentrated among older groups. There is no gender difference. In addition, Māori (15%) and Pasifika (22%) people are more likely to be referred late to treatment⁹.

Cardiovascular disease was the leading cause of death amongst Māori (47%) and Pasifika (45%) people¹⁰. Diabetes (68%) is the most common cause contributing to the high rates of ESKD in Māori and Pasifika people¹¹. This can be directly attributed to obesity, diet, nutrition and lack of exercise.

For Māori and Pasifika people, there is a strong link between poverty, diet and the nutrition value of food eaten, with many lower income families struggling to provide healthy and nutritious options for their families.

Childhood obesity was identified as a significant issue, particularly for Pasifika children. Cultural beliefs and practices were believed to play a part in contributing to this because of the social

⁷ ANZDATA Registry 2014, 37th Annual Report

⁸ ANZDATA Registry 2014, 37th Annual Report

⁹ ANZDATA Registry 2014, 37th Annual Report

¹⁰ ANZDATA Registry 2014, 37th Annual Report

¹¹ ANZDATA Registry 2014, 37th Annual Report

importance placed on food at Pasifika gatherings. Indeed, a big baby or child is traditionally been viewed as strong, healthy and well cared for, in contrast, a small baby or skinny child is considered weak, unhealthy and possibly neglected¹².

Pasifika children were least likely to bring their food from home to school and most likely to buy it from a canteen, shop or takeaway. They were also less likely to have eaten breakfast at home every day and more likely to have consumed high sugar and soft drinks¹³.

Māori (65%) and Pasifika (78%) people live in the most deprived neighbourhoods, according to the 2006 NZ Index of Deprivation¹⁴. The statistics indicate that one in three children from Māori or Pasifika families is living in poverty.

Kidney Health New Zealand (KHNZ)

Kidney Health New Zealand (KHNZ) is the sister organisation in New Zealand to Kidney Health Australia. They are a small charitable organisation located in Christchurch and overseeing the whole of the North and South Island in terms of interests in kidney health. Their key stakeholders include people with kidney disease, their families and supporters, kidney health professionals, researchers and 18 independent kidney patient support organisations.

The mission of KHNZ is to be: “The national voice for people with kidney disease and their families”

The vision is: “Better kidney health for all New Zealanders”

Kidney Health NZ works across the areas of Prevention, Support and Research, on activities such as:

Prevention:

- Resources (Awareness)
- Audio-visual resources (in many Pasifika languages)
- Community

¹² Controller and Auditor-General New Zealand 2013, *Extent to which Māori and Pasifika parents see child obesity as an important issue for their community*.

¹³ Statistics New Zealand, *Health and Pacific Peoples in New Zealand*.

¹⁴ Barclay, S 2014. 'Feeding the Nation: Obesity, Poverty and Nutrition' in NZ Herald, 24 January 2014.

Support:

- Information on Travel and Accommodation support
- Information on Holiday Dialysis
- Promotion of organ transplantation
- Nutrition and Recipe Information
- Decision Aid for Treatment of Kidney Disease for Health Professionals
- Chronic Kidney Disease in GP Guide
- CKD Consensus statement
- Immunisation Guidelines

Research:

- Funded Research Projects

Māori and Pasifika Kidney Health

KHNZ are a very small organisation with only 4 people employed. While their capacity is significantly limited by funding and workforce, there is a strong focus on advocacy and community education.

KHNZ have indicated that the Pasifika population are a priority group, given the increasing numbers living with CKD. There are a range of social issues impacting on both Māori and Pasifika families, given the significant poverty and disadvantage. Many families are living in overcrowded and substandard conditions, due to the high cost of housing accommodation. The cost of food and food options continues to be an ongoing challenge. There are also ongoing issues with access to electricity and clean water in some of the rural areas.

While many of these issues are very difficult to address, KHNZ work with patient support organisations (such as the Kidney Society of Auckland) to address some of the issues facing patients.

One of the strengths of KHNZ is the range and quality of their community education. KHNZ have developed a range of multi-lingual resources and pamphlets. In addition, they also attend community health events to promote good kidney health.

Going forward, KHNZ have indicated interest in developing a language resources for Tongan and Samoan Islander and their families, who are living with CKD. In addition, there is interest in developing educational videos about peritoneal dialysis and case studies.

Emerging Priorities:

- Organ donation
- Prevalence of CKD in South East Asian/Pasifika groups
- Social Determinants – housing, water and power costs
- CARI guidelines development (in partnership with Australia)
- Advocacy on away from home holiday dialysis with Australia
- Tongan/ Samoan language resource development

Kidney Society of Auckland (KSA)

The Kidney Society of Auckland (KSA) is an independent kidney patient support organisation located in Auckland, covering the Northland, Auckland, Waikato, Bay of Plenty, Lakes, Tairāwhiti & Hawkes Bay regions.

Their mission is: “To promote the welfare of people with kidney failure and their families by providing ongoing support and by monitoring and influencing renal services”



Their vision is: “People with kidney failure and their families achieving for themselves an acceptable lifestyle and quality of life”

KSA works to support both the healthcare services and the patient. They provide advice and assistance to healthcare professionals about the patient experience and also support patients and their families to understand how they can get the best out of their treatment and healthcare services.

KSA provides personal community support and information for people with kidney failure and their families. There are over 2500 patients and families in the regions registered with KSA for assistance and support services, such as:

- Home visits
- Phone support
- Welfare support – budget, housing, and benefits information and advice
- Group support events

- Wellness Programme – nutrition, medications and keeping fit
- Community Dialysis Houses (3)
- Community events and presentations
- Training GPs
- Training and supporting new patients and consumer representatives

RSA staff are very passionate and determined people who are or have been affected by the kidney disease. They are independently funded through self-generation, philanthropy and bequests. They have a strong patient and family support focus.

RSA operate dialysis houses, where home haemodialysis trained patients can use a dialysis machine for respite from the home situation, before going back to a hospital self-care unit or before taking one home. There are 10 chairs in each house and patients are allocated a room to use and access. The rooms have recliner chairs, chairs for visitors, TV with headphones, radio and a phone and look like ordinary family living rooms. There is a shared dining room, kitchen, bathroom and garden with BBQ tables.

Only patients that are approved and trained by the local Middlemore Home Haemo Unit are accepted. RSA pays for the running costs from donations and fundraising. Middlemore Hospital pays for power and water used for dialysis.

Māori and Pasifika Kidney Health

As at February 2016, RSA were providing support to approximately 724 Māori and 651 Pasifika people with kidney failure and their families across their service region.

For Pasifika families, there are significant cultural issues that impact on the management of CKD. Children often become carers for their parents. There is a strong cultural tradition of caring for Elders in Pasifika cultures. This often results in children missing days at school and/or dropping out of school. There are then limited opportunities for further employment and the cycle of poverty and living of welfare benefits in disadvantaged situations is perpetuated.

There is a large Pasifika community located in South Auckland. For Cook Islanders, who are New Zealand citizens, access to renal treatment requires relocation to Auckland. Often, parents are flown at short notice, due to late diagnosis and referral, to commence haemodialysis treatment in Auckland. They are often separated from their children and family and will likely stay with extended family in Auckland. This exacerbates overcrowding in many families who are already disadvantaged.

After the 2010 Christchurch earthquake, a significant amount of the population relocated to Auckland and have not returned. This has impacted on the cost of living, particularly the

current cost of housing in Auckland. Often there are several families residing in the one house, and even families living in the garage space of public and rental houses.

Emerging Priorities:

- Live donation – peer support program
- Prevalence of CKD in Indian /Pasifika groups
- Visa issues and access to renal dialysis by Samoan & Tongan groups
- Social Determinants – housing and overcrowding and social issues
- No public holiday dialysis available
- Home Haemodialysis – achieving a 50% target

Kidney Health in the USA: the Native Hawaiian & Native American experience

There are close to 1.2 million people in the United States who identified as Native Hawaiian/Pacific Islander¹⁵. Of these, approximately 356,000 are living in the Hawaiian Islands.

Native Hawaiians and Pacific Islanders generally experience poorer health than the American population as a whole: they are more at risk of developing and dying from cancer, heart disease, diabetes and other chronic diseases. They are also the population at most risk of diabetes and kidney disease, with more than 162,000 residents of Hawaii suffering from the disease – 30% higher incidence rate than the rest of the US.

There are approximately 3,139 people in Hawaii with end stage kidney disease (ESKD)¹⁶. Of this group, Native Hawaiian and Pacific Islanders comprise 1,096 patients. Diabetes is the leading cause of ESKD. This can be directly attributed to obesity, diet, nutrition and lack of exercise.

While the Hawaii State obesity rate (23.6%) was one of the lowest in the US, 44% of Native Hawaiian adults were found to be obese¹⁷. For Native Hawaiians, there is a strong link between poverty, diet and nutrition. The National Centre for Chronic Disease Prevention and Health Promotion 2012 found¹⁸:

- 56.4% were overweight or obese according to their BMI.
- Only 33% of adults reported having consumed fruits at the recommended level of 2 or more times per day.
- Only 26.8% of adults reported having consumed vegetables at the recommended level of 3 or more times per day.

¹⁵ US Census Bureau 2012. *The Native Hawaiian and Other Pacific Islander Population: 2010 Census Briefs*.

¹⁶ American Nephrology Nurses' Association 2014, Hawaii Kidney Disease Fact Sheet.

¹⁷ Office of Hawaiian Affairs 2015. Native Hawaiian Health Fact Sheet 2015. Vol 1, Chronic Diseases.

¹⁸ National Center for Chronic Disease Prevention and Health Promotion 2012. *Overweight and Obesity: Hawaii State Nutrition, Physical Activity and Obesity Profile*.

- In addition, 20.8% drink sugar-sweetened beverages daily.

Similarly with Pasifika people, there is a strong cultural and social tradition placed on food and family gatherings. Access to fresh, affordable and healthy food in Hawaii presents a significant issue, given reports that Hawaii imports almost 90% of what it eats at a cost of \$3b each year. Most food products are shipped in from the US mainland, and the cost of shipping those items across the ocean is reflected in the high price of groceries - sometimes up to 66% higher than the US mainland.

For those low paid wage earners, locals and the homeless, food insecurity and accessibility is a constant barrier in this place of dual economies. The average price of having a meal on a night out in Honolulu can range from US\$40-\$65¹⁹. In comparison, a combo meal is US\$8 from McDonalds. Even more alarming, 1 kg of apples averages US\$7 while the local Spam Musubi is selling from \$US2.



Food insecurity among households in Hawaii has been found to affect native Hawaiians and other pacific islanders (35.7%) the most.

Hawaii has the highest rate per capita of homelessness in the USA with some 487 homeless per 100,000 people²⁰.

A 2009 report found quite confronting circumstances in Hawaii²¹:

- Statewide, 12-15,000 people are homeless at some point of the year
- At least 6,000 are homeless at any given day
- Children make up 23.5-39% of the homeless
- 17-42% of Hawaii's homeless are employed full-time
- 37% of the homeless are of Native Hawaiian ethnicity

Many live on the streets, under overpasses and on secluded beach sites. These places are without basic life necessities that are often taken for granted, such as electricity, fresh water,

¹⁹ <https://www.expatistan.com/cost-of-living/honolulu>

²⁰ US Census Bureau 2012. *The Native Hawaiian and Other Pacific Islander Population: 2010 Census Briefs*.

²¹ <http://www.hawaiihomeproject.org/homelesshawaii.html>

and toilets. They also include people from all walks of life; veterans, young people and many older people who struggle daily finding enough to eat.

While there are many factors behind why people are homeless, a number of Hawaiian reports have highlighted the loss of employment, low wages and high cost of living (rent, food, electricity, etc) as significant contributing factors.

Indeed for local workers in Hawaii, homelessness is sadly a prospect facing many of the lowly paid and a crisis that continues to bubble just below the surface.

National Kidney Foundation of Hawaii

The National Kidney Foundation of Hawaii (NKFH) is an affiliate to the National Kidney Foundation (USA), developing and delivering kidney health programs and services to communities and individuals.

NKFH is the leading voluntary health agency dedicated to the detection, prevention and treatment of kidney and urinary tract diseases. There are more than 1,000 volunteers to working with NKFH to provide support and assistance through patient and community services, advocacy, public and professional education, research and organ donation programs.

The mission of: “The National Kidney Foundation, a major voluntary non-profit health organization, is to prevent kidney and urinary tract diseases, to improve the health and well-being of individuals and families affected by these diseases and to increase the availability of all organs and tissue for transplantation in Hawaii”

Their goal is to: “Lessen the effects of kidney disease for a healthier Hawaii”

NKFH works across the five (5) stages of chronic kidney disease (CKD):

Early Intervention Programs (Stage 1 & 2)

- Kidney 101 Community Presentations
- Kidney-Urine Screening + Analysis (KUSA)
- Kidney Early Detection Screening (KEDS)
- KEEP Healthy – educating people about their kidneys and risk factors

Education Programs (Stage 2 & 3)

- Kidney Interactive Workshops & Information (KIWI) – patient focused interactive sessions on diabetes, hypertension, diet, exercise and medication management

- CKD Support Group – quarterly meetings
- Shaping Healthy Individuals for Tomorrow (SHIFT) a classroom-based programs for students
- Keiki & Kidneys – Aids for Student learning
- Your Kidneys & You – Teen and Parent sessions about healthy choices
- Keiki Kidney Camp

Patient Services (Stages 4 & 5)

- Kidney Options for Patient Empowerment (KOPE) – free workshops to address transition to life with kidney failure
- Peer Mentoring Program (PMP)
- Patient, Family and Caregiver Support Groups
- Calabash Cookbook
- Emergency Patient Assistance Fund
- Kidney Patient Information & Resources
- Medical Identification Jewellery

Nutritional Programs

- Ask The Dietitian
- Nutritional Presentations, Farm Tours and Cooking Demonstrations

Self-Management Programs

- My Health, My Choice (MHMC) – 6-week services to improve self-management for chronic conditions
- Diabetes Self-Management Program (DSMP)

NKFH have been successful in increasing the screening rates for kidney disease and are working with primary care physicians to identify and refer those at risk to early intervention programs. NKFH provide referred patients with nutrition information, cooking help, disease management training and related non-medical services that help patients.

As part of a longitudinal national screen program – Kidney Early Evaluation Program (KEEP), Hawaii was one of the national key sites to examine the association between key susceptibility factors and measures of chronic kidney disease in Asian American and Native Hawaiian participants.

The research outcomes found that there were significant ethnic differences in the occurrence of chronic kidney disease found, with Japanese having the lowest occurrence of chronic kidney

disease (18%) and Native Hawaiians the highest (40%)²². The disparity in end stage renal disease among Asian Americans and Pacific Islanders also extended into earlier stages of chronic kidney disease as the precursor of end stage renal disease.

Increasing age, lower educational attainment and being a former smoker were associated with an increased occurrence of chronic kidney disease among Native Hawaiians. Native Hawaiians were also more likely to have no health insurance than any other group.

Significant associations also were found between chronic kidney disease occurrence and the presence of diabetes mellitus, hypertension, cardiovascular disease and overweight/obesity^{23,24}.

NKFH are set to increase their capacity to offer innovative programs to help patients and families affected by CKD with the establishment of a new resource centre on O'ahu. Located in projected growth area of Kapolei, the community resource centre will provide accessibility to an underserved group.

Emerging Priorities:

- Growing prevalence of CKD and ESKD in Native Hawaiian & Asian groups
- Significant overcrowding and social issues on outer islands
- Early detection and Screening
- Training & support new patients
- Nutrition & Physical Activity clinics

²² Mau, M; West, M; Shara, N; Efird, J; Alimineti, K; Saito, E; Sugihara, J & R. Ng 2007. "Epidemiologic and clinical factors associated with Chronic Kidney Disease among Asian Americans and Native Hawaiians", in *Ethnicity and Health*. Vol. 12, No. 2, April 2007, pp. 11-127.

²³ Kataoka-Yahiro, M; Wong, K; Tamashiro, J; page, V; Ching, J & D. Li 2012. "Evaluation of the National Kidney Foundation of Hawai'i's Kidney Early Detection Screening Program" in *Hawai'i Journal of Medicine & Public Health*, July 2012. Vol. 71, No. 7.

²⁴ Kataoka-Yahiro, M; Page, V & D. Li 2016. "Relationship of Associated Cardiovascular Risk Factors and Chronic Kidney Disease with Participants Enrolled in the National Kidney Foundation of Hawai'i Kidney Early Detection Screening (KEDS) Program", in *Journal of Health Disparities Research and Practice*, Vol. 9, Issue 2, Summer 2016.

Kidney Health in the USA: the Native American experience

There are approximately 2.5 million people that identify themselves as American Indians or Alaska Natives (AI/AN)²⁵.

Approximately 38% of the AI/AN populations live on reservations, mostly in the western US. The majority of AI/AN populations now live in urban locations.

The AI/AN population is relatively young, with a median age of 27.8 years and relatively poor with 32% living below the poverty line²⁶.

The AI/AN population have one of the highest rates of end stage kidney disease (ESKD) in the US, mainly driven by the increase in rates of Type 2 diabetes. In some tribes, 30% to 50% of the population are diabetic²⁷. Diabetes rates are rising across all age groups, with the most alarming increase in adolescents and young adults.

The rate of end stage renal disease among AI/AN with diabetes is six times higher than among non-Native Americans²⁸.

The burden of ESKD has become a community-wide problem among many tribes, and significant efforts have gone into establishing dialysis services on reservations. Reservations-based dialysis services have improved the access of patients to renal replacement therapy, but barriers to improving health outcomes remain. These include: the geographic isolation of reservations that make traveling to facilities difficult owing to distance and road conditions; high rates of poverty, difficulty in recruiting and retaining staff; language and cultural differences; and the high numbers of patients with diabetes and complex renal health issues.

A multidisciplinary clinical approach integrated with community-based interventions, including prevention are required to slow the growth of ESKD amongst AI/ANs²⁹.

Urban Indian Health Institute (UIHI)

The Urban Indian Health Institute (UIHI) is a Division of the Seattle Indian Health Board and seeks to:

- Study the health issues affecting urban AI/AN
- Address the lack of sufficient research data to deal with those health concerns

²⁵ Narva, A 2001. "Kidney Disease in Native Americans" in *Journal of the National Medical Association*. Vol. 94, No. 8. August 2002.

²⁶ *ibid*

²⁷ *ibid*

²⁸ *ibid*

²⁹ Narva, A 2003. "The Spectrum of Kidney Disease in American Indians" in *Kidney International*. Vol. 63. Supplement 83 (2003), ppS3-S7.

The mission of the UIHI is to: “support the health and wellbeing of urban Indian communities through information, scientific inquiry and technology”.

The UIHI is one of 12 tribal epidemiology centres funded by the Indian Health Services to study disease burden and impact in tribal regions, in order to improve the health of communities. The UIHI focuses on the nationwide urban AI/AN population.

The UIHI serves 33 Urban Indian health Organisation (UIHOs) across the US who provide either direct health or referral to AI/ANs living in selected urban counties. UIHOs provide traditional health care services, cultural activities and a culturally-appropriate place for urban AI/ANs to receive health care³⁰.

The UIHI has access to resources, information and data that can be used to better understand the health status of the urban AI/AN population, identify health problems and disparities and provide information to support program planning, research, reports, grant writing and advocacy.

The UIHI have undertaken significant work in profiling, monitoring and reporting on a range of public health, communicable and chronic diseases in the Tribal Council areas, in order to inform health policy, program planning and delivery.

Federal policies and practices towards AI/ANs have fragmented AI/AN communities by restricting resources to those who are members of federally-recognised people of AI/AN heritage. Information on urban AI/AN communities and health disparities has been difficult to collate, as the urban AI/AN identity is broad and may encompass people of AI/AN heritage that may not have access to this federally defined AI/AN status.

The UIHI national analysis on health disparities in urban AI/AN populations have found that approximately 71% of AI/ANs now live in urban areas and are facing alarming disparities in chronic disease morbidity and mortality³¹.

Cardiovascular disease (CVD) mortality is currently the leading cause of death in urban AI/AN populations. The disproportionately high prevalence of multiple chronic disease risk factors, such as smoking and obesity may explain the high rates of CVD³².

³⁰ UIHI 2015. Fact Sheet: Urban Indian Health Institute: Supporting Healthy Urban Indian Communities.

³¹ UIHI 2015. Fact Sheet: Health Disparities in UIHO Service Areas.

³² UIHI 2015. Fact Sheet: Health Disparities in UIHO Service Areas.

Significant disparities also exist in social and emotional wellness, as well as socio-economic conditions. It is estimated that 15% of AI/ANs living in urban areas have frequent mental distress with an estimated 30% prevalence rate for depression³³.

Urban AI/ANs also fare worse in socio-economic determinants of health. Approximately 24% have not finished high school and are therefore more likely to be unemployed and living below the poverty line.

Emerging Priorities:

- Surveillance of Diabetes and other chronic disease
- Significant overcrowding and social issues
- Reporting Health Disparities in Tribal areas
- Developing culturally safe research methodologies
- Prevention: Food sovereignty (community gardens)
- Effectiveness of clinical practice informed by research

Kidney Health in Canada: the Canadian Aboriginal experience

There are three (3) recognised Indigenous groups in Canada: Aboriginal (status and non-status), Inuit and Métis making up an estimated 1.3 million or 4.4% of Canada's population³⁴.

Colonisation and the historical treatment of these different groups has resulted in differential experience of inter-generational poverty and disadvantage. Disadvantage is demonstrated through the high rates of unemployment, scarce economic opportunities, poor health, overcrowded housing, low literacy and educational attainment, as well as meager community resources.

The Métis tend to experience higher levels of socio-economic status than Aboriginal people, who fair better than Inuit peoples³⁵. With the exception of the Métis, Aboriginal people are much more likely to live in overcrowded housing conditions. Approximately 22% of Aboriginal youth drop-out of high schools or are pushed out, resulting in lower literacy and employment opportunities and increased poverty for future generations³⁶.

³³ UIHI 2015. Fact Sheet: Health Disparities in UIHO Service Areas.

³⁴ Yeates, K & M Tonelli 2010. "Chronic kidney disease among Aboriginal people living in Canada" in *Clinical Nephrology*. Vol. 74 – Suppt. 1/2010 (S57-S60)

³⁵ Reading, C & F. Wien 2009. *Health Inequalities and Social Determinants of Aboriginal Peoples' Health*. Prince George, BBC: National Collaborating Centre for Aboriginal Health.

³⁶ Reading, C & F. Wien 2009. *Health Inequalities and Social Determinants of Aboriginal Peoples' Health*. Prince George, BBC: National Collaborating Centre for Aboriginal Health.

Aboriginal people living in remote reserve communities face considerable food insecurity related to challenges acquiring both market and traditional foods. The cost of transporting market foods to remote communities means that healthy, nutritious food is not affordable to most families³⁷. The high prevalence of food insecurity for Aboriginal people contributes to poorer health outcomes including chronic conditions, obesity, distress and depression. In addition, lack of exercise and poor diet has been associated with the epidemic of Type 2 diabetes among Aboriginal adults and the increasing rates among youth.

High rates of diabetes are also experienced among Aboriginal Canadians and are an important contributing factor to the increasing rates of CKD and as the leading cause of kidney failure³⁸. It is estimated that approximately 20% of the Aboriginal population or 4 times the national average is living with diabetes (Type 2)³⁹.

The prevalence rates of CKD and ESKD among Canadian Aboriginal is also increasing. Aboriginal people with ESKD are⁴⁰:

- Younger and more likely to have diabetes and to be obese
- More likely to live in remote areas and travel much further to receive treatment
- Less likely to receive kidney transplantation
- Tend to have lower patient survival rates following initial dialysis treatment.



Given the greater complexity of health conditions and the poor survival outcomes, there is significant need for appropriate and effective prevention, intervention and management of CKD in earlier stages.

Vancouver Native Health Society (VNHS)

The Vancouver Native Health Society (VNHS) is a well-known, respected community-based, primary health care organisation that delivers unique programs and services from the four quadrants of the medicine wheel: the physical, the emotional, the spiritual and the mental aspects of the individual.

The Medicine Wheel, sometimes known as the Sacred Hoop, has been used by generations of various Native American tribes for health and healing. It embodies the Four Directions, as well as Father Sky, Mother Earth, and Spirit Tree—all of which symbolize dimensions of health and the cycles of life.

³⁷ Reading, C & F. Wien 2009. *Health Inequalities and Social Determinants of Aboriginal Peoples' Health*. Prince George, BBC: National Collaborating Centre for Aboriginal Health.

³⁸ Yeates, K & M Tonelli 2010. "Chronic kidney disease among Aboriginal people living in Canada" in *Clinical Nephrology*. Vol. 74 – Suppt. 1/2010 (S57-S60)

³⁹ Bell, A 2009. "The Aboriginal Diabetes Initiative – tackling Type 2 Diabetes in Canada" in *DiabetesVoice*, June 2009, Vol. 54, Issue 2.

⁴⁰ Canadian Institute for Health Information 2013. *End-Stage Renal Disease Among Aboriginal Peoples in Canada: Treatment and Outcomes*. February 2013.

The missions of VNHS is mission to: “improve and promote the physical, mental, emotional and spiritual health of individuals, focusing on the Aboriginal community residing in Greater Vancouver.

VNHS delivers comprehensive medical, counselling and social services to Vancouver’s Downtown Eastside Aboriginal community. The majority of our clients struggle with overlapping and complex health and social issues such as substance abuse, mental health, chronic disease, homelessness and poverty.

VNHS estimates that they have between 16,000-20,000 active clients accessing their health services. Of these approximately 65-75% are Aboriginal Canadians.

Their priority is on decreasing the prevalence of Hepatitis C in their client population. Once clients were in the door, they work on opportunistic screening for other health issues.

One of the Doctors said that with most of their clients ‘once they start getting well, they often leave Vancouver City and return to their homelands’. Kidney disease is not seen as a priority for these urban populations, given the significant drug, alcohol and social issues that are present.

A new cultural element to their primary health model of care, was the establishment of the Elders’ Program. This was initially established as a pilot program with paid Elders (male & female), who work with the clinic staff to address social, emotional and cultural issues of clients. They integrate traditional practices and knowledges into their counselling sessions, as well as smudging and other spiritual healing practices. They were often asked for by many of the clients. There were also a number of classes held which taught some cultural skills, such as weaving and traditional foods/cooking. Other traditional cultural practices are also celebrated and honoured such as the solstice, harvesting and burnings and welcoming new babies.

Emerging Priorities:

- Significant homelessness and social issues
- Significant drug and alcohol issues of patients
- Opportunistic screening for chronic disease
- Cultural determinants of health - Elders program within model of care

Nanaandawewigamig First Nations Health and Social Secretariat Manitoba (FNHSSM)

The Nanaandawewigamig First Nations Health Secretariat (FNHSSM) graciously hosted me during my visit to Winnipeg, Manitoba, Canada. Through their *Partners for Engagement and Knowledge Exchange (PEKE)* Program, FNHSSM seeks to bring together traditional knowledge keepers, service providers, researchers and decision-makers to share learning and encourage the framing of wise practices through a conceptual lens⁴¹.

A forum was held which was attended by PEKE partners including: University of Manitoba, Diabetes Integration Project and other key health organisations. This was followed by key discussion as follows:



Diabetes Integration Project⁴²

- The First Nations Community Based Screening to Improve Kidney Health and Prevent Dialysis (FINISHED) Project was developed in partnership with the Manitoba Renal Program.
- FINISHED provides a mobile, mass screening initiative to all Aboriginal people 10 years and older in rural and/ remote communities.
- 11 Aboriginal communities targeted within 2 Tribal Councils.
- Interdisciplinary team-based approach established to assess, counsel and refer participants.
- Stakeholder consultation and protocols obtained.
- A total of 1480 people were screened, which was 21% of all community members.
- Some initial findings indicated 20% young children/youth have hypertension. Among children over 10 years who were at-risk, 28% were already displaying renal impairment (early CKD).

Emerging Priority:

- Screening those at risk of CKD, with documented hypertension or diabetes represented good value for money, whereas mass screening of the general population did not.

⁴¹ FNHSSM 2015, *Factsheet: PEKE*.

⁴² Lavalle, B; Chartrand, C; McLeod, L; Rigatto, C; Tangri, N; Dart, N; Gordon, A; Opey, S & P. Komenda 2015. "Mass screening for chronic kidney disease in rural and remote Canadian first nations people: methodology and demographic characteristics" in *Canadian Journal of Kidney Health and Disease*, Vol 2, Issue 9.

Aboriginal Diabetes Initiative⁴³

- The Aboriginal Diabetes Initiative (ADI) seeks to reduce Type 2 diabetes and its complications through a range of culturally relevant health promotion and prevention services, delivered by trained health service providers and diabetes workers.
- Phase 1 saw the development of culturally appropriate locally programming to increase participation in preventive activities.
- The ADI delivers programmes and services to more than 600 communities throughout Canada.
- Phase 2 seeks to expand and improve health promotion, screening and treatment services.
- The ADI includes walking clubs, weight-loss groups and fitness classes, community kitchens and gardens, and a range of activities for children in schools.
- Vending machines selling sugar-sweetened soft drinks and high-sugar, high-fat snacks have been removed from schools.
- Community-based initiatives include traditional activities such as berry picking, picnics, dancing and games. These assist in preserving and sharing valuable traditional knowledge.
- Approximately 3,900 activities were held in Aboriginal communities over a 2-year period. There were around 94,000 participants in prevention and promotion activities. Over 13,000 people were screened for Type 2 diabetes.
- Over 300 workers were trained as community diabetes prevention workers with education on culturally relevant health promotion.

Emerging Priorities:

- The ADI supports increased and regular screening for early diagnosis of diabetes complications through population-based and opportunistic screenings.

Food Matters Manitoba⁴⁴

- Food Matters Manitoba (FMM) partners with local communities to make food more available and affordable.
- The vision of FMM is: “Food security and sustainability of the food systems in Manitoba”
- Through building local greenhouses and gardens, FMM teaches kids and families how to **harvest, prepare** and **share** healthy meals at community cooking classes.
- FMM provides a range of programs around food supply, food systems, nutrition awareness and education.

⁴³ Bell, A 2009. “The Aboriginal Diabetes Initiative – tackling type 2 diabetes in Canada” in *DiabetesVoice*, June 2009, Vol. 54, Issue 2.

⁴⁴ <http://www.foodmattersmanitoba.ca>

- FMM's *Our Food Our Health Our Culture* project is creating healthier environments where traditional and healthy foods are valued and accessible. The project focuses on reclaiming traditional, healthy foods – connecting cultural foods as an important part of a healthy, modern diet.
- To address food access and other key food issues in the Downtown and Inkster neighbourhoods, FMM has undertaken two community food assessments to identify and address food challenges.
- FMM partners with northern communities to grow good food, share traditional skills and build healthy futures.
- As part of FMM's *Our Food, Our Health, Our Culture* program, a Summer Youth Program gives inner city youth a chance to learn about Indigenous culture, while also learning about the importance of healthy food.

Emerging Priorities:

- Food systems, food supply and food labelling
- Community gardens and cultural harvests that engage disenfranchised young people

Conclusions

The Bob and June Prickett Churchill Fellowship enabled me to explore the incidence, experience and impact of kidney disease and the range of community-based programs targeting risk factors for chronic kidney disease (CKD) in Aboriginal First Nations communities.

This is a once in a lifetime experience for which I am truly grateful. It was wonderful to meet, share and learn from other Aboriginal First Nations people in New Zealand, the US and Canada who are working in very similar dire and trying circumstances.

Tragically as is well documented, Aboriginal First Nations peoples in Australia, New Zealand, the US and Canada have very similar poor health and social outcomes. This includes risk factors, diagnosis of CKD, and progress to ESKD.

Major conclusions

Many local and regional health services visited were over-worked and under-resourced to manage the grossly complex and disadvantaged circumstances of their people. However, a range of intervention programs were being developed across the spectrum of care to prevent poor health and social outcomes including; farming sustainability and food supply, nutrition and physical activity, childhood health screening, opportunistic screening for adults, and elder's cultural support.

There were several key themes which emerged and need to be addressed in order to improve the health outcomes and wellness for our peoples. These include:

1. Poverty, homelessness and disadvantage
2. Communities targeting nutrition, physical activity and wellness
3. Early screening of children and young people for diabetes and CKD
4. Increasing rates of diabetes progressing to CKD/ESKD
5. Cultural strength, resilience and openness to share

The levels of poverty, homelessness and disadvantage was often very confronting. Many Aboriginal First Nations people in the US & Canada are severely disadvantaged. In each of these cities, the local Aboriginal health services and organisations I was meeting were located in lower socio-economic areas. These areas often had clusters of homeless camps, under freeways, in parks and gardens. The major of these people were Aboriginal First Nations people who had left their homelands and were stuck living on the streets. Many of the health and social services were struggling to help these mob get back healthy and engaged enough to return to their homelands or employed – given the depressed state of the economy.

Given the often dire and impoverished circumstances of many Aboriginal First Nations communities, unless specific programs and strategies are in place to address the social determinants of health, namely housing, nutrition, transportation, access to clean water and electricity, very little will change to prevent the progression of ill health.

Application: Poverty, homelessness and disadvantage are also issues in Australia for Aboriginal and Torres Strait Islander people. This is an area in which many non-government organisations, including Kidney Health Australia with the Close the Gap Campaign coalition advocate to governments for a comprehensive approach to the social and cultural determinants of health.

Nutrition, physical activity and wellness is sadly often not considered the norm in many of our communities. We are so used to dealing with illness and mental distress that it is often hard to know a state of good cultural health and wellness. It was inspiring to learn about such programs as Food Matters Manitoba, who are partnering with communities to embed a cultural approach to sustainable food supply, sharing and celebrations. Recent discussions in Hawaii have also centred around food sustainability and growing more local produce. There is an emerging theme of communities going back to cultural traditions and growing or harvesting local and traditional foods. This is not just good cultural health and wellness, but can also be a good business opportunity.

Application: Nutrition and physical activity are current priorities on the Australian national agenda. For example, food labelling and marketing of sugar and salt have been recent successful campaigns. Further consideration is required on what this means in the Aboriginal and Torres Strait Islander context where food supply and cost are significant barriers to choice. Cultural wellness is yet to be properly considered outside a medical 'mental health and suicide' model in Australia.

Early screening of children and young people for diabetes and CKD has been highlighted as a priority at all the sites visited. Within a cultural context, our children are the next generation of leaders and families want a better future for our children. Many health services at the local and regional levels are targeting health assessments of children. They are limited by capacity and funding to provide a consistent, systemic and scalable approach.

Application: Early childhood screening is also a priority within Aboriginal Community Controlled Health Organisations (ACCHOs) in Australia. Many ACCHOs provide Mums and Bubs services which span from pregnancy to early childhood. Adolescent development and screening is a gap which needs to be considered in systemic and scalable way.

While in Canada, it was interesting to learn that an Australian model of care for a chronic disease outreach program was considered to be best practice. This program was established in the Northern Territory to address the issues of:

- Servicing remote and very remote communities that are geographically isolated
- Lack of workforce sustainability on the ground
- Increasing population profile of chronic disease

The model provides:

- Community-based multidisciplinary teams
- Nurse practitioner –led with an Aboriginal Health Worker (key member)
- Implementation of evidence-based protocols to target blood pressure, glycemic control, cardiovascular risk factors

Application: Innovative models of care for chronic disease need to be shared and considered for scalability.

Overall, what struck me the most was the similarity in Indigenous histories, experiences of colonization and the prevailing intergenerational impact, which we as Aboriginal First Nations peoples, communities and organisations are working to overcome. There is much strengthen, resilience, compassion and willingness to share information and work together on a global scale. This is profoundly warming and inspirational.

Application: There are established Indigenous health and research networks between Australia, New Zealand, the US & Canada. These can be used as a mechanism in which to showcase, connect and share. For example: The Lowitja Institute International Indigenous Health and Wellbeing Conference is being held in Melbourne in November 2016. Several Winnipegians have expressed interest in attending and I have already facilitated connections for a more strategic level of knowledge partnership and translation.

Dissemination of Information

From the beginning of my Fellowship, I have considered the ongoing dissemination of information at various levels. I have actively promoted the Fellowship on my social media (Facebook, Twitter & Instagram). In addition, I created a blog on WordPress for some of my more informal insights.

Three (3) articles have already been published in the Kidney Health Australia community newsletter. Through my networks in the Indigenous health and kidney community, there have already been several requests for my report.

Prior to my Fellowship, I submitted an abstract to the Lowitja Institute International Indigenous Health and Wellbeing Conference in Melbourne in November 2016. The abstract was successful in being accepted.

In addition, other key NGOs which I have worked with have expressed interest in my report and presenting my findings at their member conferences in 2017.

Unscheduled Activities

While some contacts were unfortunately unable to meet with me when I was in country, there were other unexpected and fruitful opportunities which enriched the Fellowship journey for me.

In Auckland, I was introduced to Dave Lilley through Leigh Jenkins. Dave is the Home Haemo Trainer at the Greenlane Home Haemo Unit. He very happily talked to me at limited notice about his work and the many successes he had getting a range of different people on home dialysis.

In Winnipeg, I spent time speaking with Leona Starr from the Council of Manitoba Chiefs about their Regional Health Survey, Indigenous data governance, and Health Profiling of On-Reserve Native Aboriginal Canadians. This is an area of my work at home that I'm very interested in and found extremely fascinating.

Again in Winnipeg, I was fortunate to be introduced to Barbara and Clarence Nepinak. They are respected Ojibway Elders and language speakers, who showed me around Winnipeg and introduced me to many other friends. I attended one of their language classes and learned much about Ojibway and First Nations culture. I even attended my first pow-wow with them, which was a very memorable and enjoyable experience. I'm eternally grateful for their hospitality and friendship.



Recommendations and Actions

The following recommendations are made from the concluding discussions and themes arising:

Recommendation 1: Poverty, homelessness and disadvantage

Kidney Health Australia, with the Close the Gap Campaign Coalition, advocate to Federal and State Governments for a comprehensive approach to address the social and cultural determinants of health.

Recommendation 2: Nutrition and physical activity

Kidney Health Australia collaborate with the (new virtual) Centre for Healthy Food and Nutrition Futures for Australia's First Peoples (virtual) to focus on food and nutrition, and raising the profile and importance with Federal and State Governments.

Further consideration is required on what this means in the Aboriginal and Torres Strait Islander context where food supply and cost are significant barriers to choice. Cultural wellness is yet to be properly considered outside a medical 'mental health and suicide' model in Australia.

Recommendation 3: Early Childhood screening

Kidney Health Australia engage with the Aboriginal Community Controlled Health Organisations (ACCHOs) network in Australia, to better understand the prevalence of Type 2 diabetes and CKD in children and young adults. Adolescent development and screening is a gap which needs to be considered in systemic and scalable way.

Recommendation 4: Chronic Disease Models of Care

Kidney Health Australia promote and advocate for innovative models of care for chronic disease (such as the NT model) to be considered for scalability in other remote and very remote areas.

Recommendation 5: Maintaining Indigenous health and research networks

Develop a network of contacts from this trip to share opportunities to showcase, connect and share information and partnership. For example: The Lowitja Institute International Indigenous Health and Wellbeing Conference is being held in Melbourne in November 2016.

Actions Arising from Fellowship meetings:

New Zealand

- Kidney Health Australia will share our proposed community consultation approach on the development of CARI Clinical Guidelines for the “Management of CKD in Aboriginal and Torres Strait Islanders and Māori” with Kidney Health New Zealand. Discussions to continue.
- Follow-up discussions about cross-Tasman holiday dialysis with Kidney Health New Zealand.

USA

- National Kidney Foundation of Hawaii to share knowledge and research articles on SEEK project about disparities in ethnicities for consideration about clinical management approaches. Discussions to continue.
- Urban Indian Health Institute and Kidney Health Australia to discuss and share knowledge about cultural methodologies in research and community consultation.
- UIHI will share their Culturally Safe Research Methodologies and Toolkit.

Canada

- Vancouver Native Health Society to sharing knowledge and research articles about their Elder’s program evaluation and impact on their model of primary health care.
- Kidney Health Australia will contact Dr Allison Dart regarding their research on clinical guideline development. Discussions will continue.
- Kidney Health Australia will facilitate contacts between FNHSSM and the Lowitja Institute regarding international partnerships for knowledge and research translation.
- Food Matters Manitoba and Kidney Health Australia to continue discussing strategies on food system, food supply and nutrition.

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