The Western Desert Kidney Health Project

This thesis is presented for submission for the degree of Doctor of Philosophy of the University of Western Australia School of Primary, Rural and Aboriginal Health Care
By Dr Christine Andrea Jeffries-Stokes MBBS, B Med Sc, MPH, FRACP
2017
I would like to thank the Aboriginal people of the Eastern Goldfields, especially the Wongutha, Mulba-Ngadju, Anagu, Ngalia and Kuwarra people for sharing their land, their culture, their wisdom, their hearts and their lives with me during this project.

I would especially like to acknowledge my co-investigator, Annette Stokes, for her incredible hard work, her grace, her dignity, her patience and her friendship – without Annette this project truly would not have been possible.

And Geoffrey, without whom I would never have found my home in the Goldfields.
Thesis Abstract

The Western Desert Kidney Health Project - Health Status of Aboriginal and Non-Aboriginal Adults and Children in a Remote Area of Australia
The increasing burden of kidney disease and type 2 diabetes (T2DM) is a worldwide problem, especially for Indigenous populations. The average life expectancy at birth of Aboriginal Australians is significantly less than for non-Aboriginal Australians. National figures suggest the disparity in remote areas is even more marked. Contributing factors to this reduced life expectancy are the effects of T2DM, kidney disease, their associated conditions and complications.

The Western Desert Kidney Health project (WDKHP) was an innovative research project that grew from the despair of the Aboriginal people of the Goldfields of Western Australia and their desire to understand more about diabetes and renal disease to reduce the effects these diseases are having in their communities.

**Aims**

The aims of the WDKHP were

1) To develop and evaluate community education and community development strategies to reduce the prevalence of the risk factors for T2DM and kidney disease, using a community arts for community development model.

2) To determine the prevalence of type 2 diabetes (T2DM), kidney disease and the risk factors for these diseases in Aboriginal adults and children in a remote area of Western Australia

3) To compare with prevalence rates for non-Aboriginal adults and children living in the same locations

4) To compare those prevalence rates with national rates

5) To determine the age at which the risk factors are appearing

**Methods**

The WDKHP was a community based participatory research project featuring annual cross sectional surveys over 3 years. It was conducted in 5 towns and 5 remote Aboriginal communities over lands of people of Western Desert Language groups – primarily Wongutha, Mulba-Ngadu and Anagu-Pitjantjatjara language groups. Participation was offered to all people regardless of age or ethnicity.

The project involved Aboriginal researchers embedded in the community and extensive consultation and involvement of these communities with a pilot project to demonstrate the methods to the communities.

A mobile research team made up of Aboriginal researchers, collaborating researchers, artists and medical students, spent 2 to 3 weeks annually for 3 years, starting in 2010,
in each of the study communities. Data collection included personal and family medical history, clinical assessment and investigations using point-of-care machines.

Results
Participation was good - 79% (n=818/1035) of the Aboriginal population (175 men, 250 women, 393 children) and 12% (n=297/2475) of non-Aboriginal population (74 men, 114 women, 109 children) completed at least one health assessment.

The WDKHP found higher than predicted rates of T2DM, hypertension, haematuria and elevated ACR in Aboriginal and non-Aboriginal adults and children. Prevalence of overweight and obesity were similar to national rates. Risk factors were found in children as young as 2 years.

A difference in rates of disease between Aboriginal and non-Aboriginal people was not as marked as predicted. There was no difference between Aboriginal and non-Aboriginal children and no difference between participants living in towns compared to those living in remote communities. Aboriginal women were the highest risk group.

More than 95% of Aboriginal participants had spent most of their lives in rural or remote areas but 91.5% of non-Aboriginal participants had grown up in urban settings.

More than 400 people (37% of participants) responded to evaluation questionnaires. There was no negative feedback about the arts based strategies or the project in general, except for expressions of dismay that the project was limited to 3 years. Qualitative data demonstrated community change in behaviour although the study period was too short to demonstrate change in the biomedical markers.

Conclusion
Long term relationships with Aboriginal researchers embedded in the community, with cultural authority, who understand the cultural nuances and are able to engage the community leaders were a critical feature of this research.

The innovative arts and community based engagement strategies contributed to good participation and community satisfaction with the project.

The rates of T2DM, hypertension and markers for kidney disease for Aboriginal and non-Aboriginal participants were, in general, much higher than expected suggesting ethnicity might be less important that environmental and lifestyle factors. There was no increase in rates of disease or the biomedical markers during the study.

More research is needed to examine potentially modifiable factors - food supply, exercise opportunities, water quality and living conditions, offering scope for interventions to reduce the risk and burden of these diseases.
DVD – Introduction to the Western Desert Kidney Health Project

This DVD will assist the reader to develop a picture of the place and hear the voices of the people involved in this project so that the remainder of this thesis has meaningful context.
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Acknowledgements

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Statement of Candidate’s Contribution
This thesis is my own composition, all sources have been acknowledged and my contribution is clearly identified in the thesis.

I am first author on two peer-reviewed journal articles and one book that have been published and form part of this thesis. I have the permission of all co-authors to include this work in my thesis, and there is a declaration to this effect accompanying this thesis, signed by me and also by my supervisor/s.

**First Author on work with other authors**

**Published works**

Jeffries-Stokes C, Stokes A, McDonald L, Stokes S, Daly J. A complex Aboriginal health project and the challenges for evaluation. Aust N Z J Public Health. 2011;35(3):204-6. (Chapter 9 of this thesis is based on the work in this paper and the paper is included as Appendix 1) (Candidate's contribution 75%)

Jeffries-Stokes C, Stokes A, McDonald L. Pulkurlkpa: The joy of research in Aboriginal communities. J Paediatr Child Health. 2015;51(11):1054-9. (Chapter 13 of this thesis is based on the work in this paper and the paper is included as Appendix 2) (Candidate's contribution 75%)

**Books**

Mara Yungu – Authors and Editors Jeffries-Stokes C, Stokes A, McDonald L (Appendix 31) (Candidate's contribution 60%)

I am an author on work related to this thesis topic that is co-published with other authors


The Western Desert Kidney Health Project Booklet and DVD – Aiton S, Stokes A, McDonald L, Jeffries-Stokes C (Appendix 30)

Works in Preparation for Publication
Parna Nhurraku (our place, our land) - The Western Desert Kidney Health Project - Health Status of Aboriginal and non-Aboriginal Adults in a Remote, Arid Area of Australia. Jeffries-Stokes C, Stokes A, McDonald L, Wright S, Evans S, Anderson L, Robinson P, The Western Desert Kidney Health Project Group (Candidate's contribution 60%)

Tjitji Pirni – Associations and Biomedical Markers for Renal Disease and Diabetes in Aboriginal and non-Aboriginal Children in a Remote, Arid, Area of Australia, The Western Desert Kidney Health Project. Jeffries-Stokes C, Stokes A, McDonald L, Wright S, Evans S, Anderson L, Robinson P, The Western Desert Kidney Health Project Group (Candidate's contribution 60%)

I Supervised a student who undertook a pilot study used in research of this thesis.
Nagi A - Aboriginal Perspectives on Diabetes and Kidney Disease in the Eastern Goldfields of Western Australia (Appendix 6)

Presentations I have given based on the work in this thesis.

2007 Myaee! - An Innovative approach to increasing fruit and vegetable intake in a remote Australian Aboriginal community. June 2007 International Union for Health Promotion and Education (IUHPE) World Congress, Vancouver. With Annette Stokes

2007 Wanti Sugarba – Rural Clinical School Rural Medicine Conference, Geraldton WA

2009 Dulgoo Tjitji Pukul-Ba – Arts and health in the Western Desert. The Royal Australasian College of Physicians Week 2009, Sydney May 2009,

2009 Myaee Go – Rural Clinical School Annual Scientific Meeting, Bunbury, August 2009. With Annette Stokes


2014 The Western Desert Kidney Health Project. Durham University, Centre for Medical Humanities, Seminar – the Western Desert Kidney Health Project, June, Durham, UK. With Annette Stokes

2014 The Western Desert Kidney Health Project. National Regional Arts Conference, Speaker, October, Kalgoorlie. With Annette Stokes and Lachlan McDonald


2015 Royal Australian College of Physicians – Purkurlpa – the Joy of research in Aboriginal communities. Cairns, May 2015 – **Awarded Rue Wright Memorial Award for Excellence in Research**

2015 Australasian Society of Genetic Counsellors Meeting - Engaging with Indigenous Communities – Mapping international experiences in Genetic Counselling onto local practice. Perth, August 2015. With Annette Stokes
2015 Human Genetics Society of Australia 39th Annual Scientific Meeting Pulkurlkpa – The joy of research in Aboriginal Communities (Plenary). Perth, August 2015. With Annette Stokes

2016 Medical Humanities Workshop, Purlkurlpa – the Joy of research in Aboriginal communities. UWA, Perth. March 2016. With Annette Stokes
Co-author agreements

Verbal approval has been received from Samuel Stokes and Linda Anderson but, due to distance and lack of access to electronic devices they were not able to provide signed statements.

Co-author agreement

By signing below the co-author gives permission to include the aforementioned publications in this thesis and acknowledges the listed percentage of contribution.

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Steven Aiton

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Samuel Stokes

Signed ___________________________ Date 4/4/16
Timeline of Thesis
Timeline of Thesis

2006 July – Application to commence PhD

2006 July – Ethics application submitted for Wanti Sugarba – the Northern Goldfields Kidney Health Project (the Pilot)

2010 - Funding secured for Western Desert Kidney Health Project

2010 June – Western Australian Aboriginal Health Ethics Committee approval for Western Desert Kidney Health Project

2010 August - Human Research Ethics Committee approval (UWA) for Western Desert Kidney Health Project

October 2010 to October 2013 - Data collection and field work

2013 November to November 2014
   Data entry, cleaning and checking
   Sabbatical in United Kingdom and Denmark

2015 February - Data exported to SAS for analysis

2015 February to April - Data analysis and writing.

2016 April – Thesis submission
Background, Rationale and Logic for the Project

This chapter explains how this project grew from the concerns of the Aboriginal community of the Goldfields to become a major research project.
The Western Desert Kidney Health Project (WDKHP) began its life in a series of conversations at funerals about the tragic loss of life and potential in the Western Australian Aboriginal community as a result of kidney disease and diabetes.

Our research team all have close ties to the communities of the Goldfields and Western desert and have been conducting research and clinical work in the region since 1991.

**The Key People**
I came to the Goldfields in 1991 as a Paediatric Registrar to work on a project for my Master of Public Health Degree. [1] That project led the establishment of a very successful maternal and infant health service for the region – Ngunytju Tjitji Pirni (NTP).

Annette Stokes, co-chief investigator for the Western Desert Kidney Health Project and senior woman of the Wongutha Tribe, was instrumental in the establishment of NTP. It was also through that process I met and married Geoffrey Stokes, Annette’s brother and senior man of the Wongutha Tribe.

Lachlan McDonald has a long association with myself, the Stokes family and the people of the region. He and his wife were instrumental in the development of NTP – they were community artists who worked with me on the arts activities during the initial consultations that resulted in the formation of NTP. [1]

Annette and I have worked on a number of research projects in the region over the last 20 years. By working with Geoffrey and the wide, extended family we have established the Wongutha Birni Aboriginal Corporation and cultural centre. Through Wongutha Birni the community has participated in many research collaborations and consultations. [2-11] These activities have generated excitement and enthusiasm for research and a desire in the community to initiate and play an active role in medical research.

**Community Interest**
In about 2005 we found increasing interest from the community in the problems of renal disease and type 2 diabetes. Community members were at a loss to understand why so many people were dying of complications of these diseases and why even people who appeared to live healthy and morally good lives were still the victims of these diseases. It was clear that medical care was not working, cultural and spiritual practices were not helping and there seemed to be little hope. But it was also clear that this was a change from the past – young people dying of these diseases is something relatively new and there seemed to be a rapid escalation in people being diagnosed with kidney disease and diabetes. Australia wide, from 2001 to 2008, the number of Indigenous
Australians being treated for end stage kidney disease increased by more than 70% and the increase was most noticeable in rural and remote areas [12].

The link to high insulin levels seemed significant and we had noticed that many children were developing acanthosis nigricans, an indicator of high insulin levels, at an early age and long before the development of diabetes and renal disease. [13] There was a critical moment when I was at a basketball carnival for Aboriginal children with co CI, Annette Stokes. We were watching our children play, their arms in the air, wearing their basketball singlets, and it seemed to us there was just a sea of black armpits, all affected by acanthosis nigricans. We then ordered insulin-glucose tolerance tests on 10 of the children and teenagers in our extended family and all of them showed high fasting insulin and excessive insulin response, even thought they were young, fit, active and not overweight. We shared this information with the family and as a group the family resolved to work together with the community to try to address the problem with the hope of relieving the burden of disease in adulthood.

**Possible Mechanisms and Solutions**

We examined the literature and found that change in diet and lifestyle factors could possibly prevent the development of these diseases or at least minimise complications and slow progression. Early detection and management of the diseases that contribute to the development of diabetes and kidney disease (such as hyperinsulinism, hypertension, obesity, and albuminuria) could halt or slow the progression and complications. [14]

We went on to consider the factors contributing to change in lifestyle and life conditions that have occurred over the last 100 years or so in the Goldfields – since white settlement. Gold was discovered at what is now Coolgardie in 1892 [15], sparking a gold rush that brought thousands of non-Aboriginal people into the area, and into contact with Aboriginal people for the first time. This was the beginning of colonisation in the Goldfields, and was soon followed by the establishment of the Missions (small settlements administered by church groups, to which Aboriginal people were relocated, often forcibly), implementation of the stolen generations programs (the removal of children of mixed Aboriginal and non-Aboriginal parentage from their Aboriginal families) and rapid change in lifestyle and diet for Aboriginal people, as well as enormous social disruption. [16] The ramifications of the introduction of miners and settlers continue even today, with ongoing stresses for Aboriginal people which would all need to be considered in the design of the Western Desert Kidney Health Project. In addition there has been a worldwide change in lifestyle and eating habits and food
availability associated with the worldwide escalation in rates of obesity, T2DM and renal disease. This is summarised in Figure 1.

Figure 1 Contributing factors to Type 2 Diabetes and Renal Disease in Australian Aboriginal Communities

The team and community members saw that many of the contributing factors could be identified and their effects potentially modified but, given the lack of resources and the historical effects of colonisation and the resulting traumas on individuals and communities this would be an enormous and difficult task. [16-18]

Despite the knowledge held by the medical community of the risk factors and contributing factors for renal disease in the Aboriginal community, Aboriginal people themselves are poorly informed. Aboriginal people very often present late or not at all - particularly with chronic illness that has only generalised, non-specific symptoms, such as diabetes, hypertension and renal disease. Compliance may also be an issue. All of these factors are related to poor understanding of the mechanism of disease and treatment. Understanding and communication are affected not only by language barriers but also by the differing world view between the Aboriginal patient and medical staff - and these are often poles apart [17, 19] Work in the Northern Territory and Tiwi
Islands by teams led by Wendy Hoy, Kerin O'Dea, Richard Trudgen and in the Goldfields by our own research team has shown that through the development of relationships and real partnerships with Aboriginal people many of these difficulties can be overcome.  

**Important Community Considerations**

The National Medical Health and Research Council's (NHMRC) guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research requires research projects to demonstrate commitment to six core values: Spirit and Integrity, Reciprocity, Respect, Equality, Survival and Protection and Responsibility. This can be a daunting task and, for many researchers and health care providers, may seem outside the scope of much of their work. However these values are critical to all community based research. For the Western Desert Kidney Health Project the need for immediate action and benefit for the community was great – reciprocity would need to be a guiding principle for the project, as would respect for the community, their views, their experience and their culture. This project would need to foster pride and hope in the Aboriginal community in order to focus on survival of the people and culture – requiring an innovative and creative approach.

Our previous work on the NTP project, the otitis media project, our clinical work and social encounters had taught us that Aboriginal people in the region wanted to know what the disease processes were and how protective and exacerbating factors worked so that they could make informed choices about their lifestyle. They did not want to be “Told what to do and what not to do” which reminded them of the mission days or times when they had little control over their lives. Many Aboriginal people reported that they felt that in the past they had been treated as children or as not capable of understanding and making appropriate choices. It was important to show respect and explain the disease process in ways that were not simplistic but that community could understand.

Our work with the Wongutha Birni Corporation and our past arts and health projects had demonstrated the effectiveness and great enthusiasm in the community for this method of using community arts for community development and health educations so it was a natural progression to use this method for the Western Desert Kidney Health project.

During the pilot project a young woman from a remote community told us that often people don’t look after themselves and their families because they carry such a burden
of pain, grief and guilt, and if we were not able to find a way to help with that then we would be wasting our time. The arts method would allow communities and individuals to take their own experiences, good and bad, and use them to help others.

Community Consultation
In 2005 we began consulting with the community about doing a research project to explore the prevalence of kidney disease and T2DM in the community and to look for contributing factors for these diseases. We consulted widely about how best to do such a project so that it would bring immediate benefit to the community. Informed by those consultations and with support from the Rural Clinical School of Western Australia we conducted a pilot for the project in 3 communities the Northern Goldfields in 2006 and 2007 (Wanti Sugarba - The Pilot Project, Chapter 10 and Appendix 7).

The Wanti Sugarba project was enthusiastically received by the community and there was demand from the other communities in the region to extend the project. The success of the pilot project and the enthusiasm from the community generated support and interest from local health service providers, government health funding bodies, arts funding bodies, philanthropic donors and local mining companies. (See Appendix 5, The Western Desert Kidney Health Consultation Document, 2008)

Following the Wanti Sugarba Project the chief investigators visited every community in the Goldfields to discuss expanding and refining the research project, holding meetings with Aboriginal community councils and organisations and with other stakeholders including health service providers and other service providers. (See Appendix 14 – Mara Yungu, the Story of the Western Desert Kidney Health Project)

After much thought, extensive consultation and many animated discussions with community members, stakeholder groups and academic advisors we settled on 5 aims and 3 key messages for the Western Desert Kidney Health Project (WDKHP):

1) To develop and evaluate community education and community development strategies to reduce the prevalence of the risk factors for type 2 diabetes and kidney disease, particularly for the children, using a community arts for community development model

2) To determine the prevalence of type 2 diabetes (T2DM), kidney disease and the risk factors for these diseases in Aboriginal adults and children in a remote area of Western Australia

3) To compare with prevalence rates for non-Aboriginal adults and children living in the same locations
4) To compare those prevalence rates with national rates
5) To determine the age at which the risk factors are appearing

The Key Messages
Health messages needed to be presented to the community in ways that would be fun, exciting and empower them to find innovative ways to overcome the challenges to healthy behaviours.

Three messages were developed and phrased to be positive:
1) Eat well – meaning to eat fresh fruit and vegetables, eat native animal meat and other bush tucker, drink water.
2) Get some exercise
3) Reduce your stress

It was acknowledged that much of this change was beyond the scope of our project and would require not only personal change but structural change for the towns and communities so individuals and communities would need to be empowered to advocate for change themselves, using the information our project would provide. Building capacity and resilience would need to be important focus areas in the project design.

Funding became available to expand the project and in 2010 the Western Desert Kidney Project was launched.

Project Timeline

Timeline
2006 July – Ethics application submitted for Wanti Sugarba – the Northern Goldfields Kidney Health Project (the Pilot)

2006 September to December – Gardeners in residence in Laverton, Mt Margaret and Leonora.

2007 January to April – My family and I lived at Mt Margaret Community. Arts intervention pilot in Laverton, Mt Margaret and Leonora

2007 February – March – First data collection in Laverton, Mt Margaret and Leonora

2007 July – Second data collection in Laverton, Mt Margaret and Leonora
2007 September to December – Tjitjiku Myaee – Survey of the diet of young people in remote Western Australia

2008 March – Third data collection in Laverton, Mt Margaret and Leonora

2009 Negotiations with funding bodies, service providers and communities to expand the project to 10 communities with annual residencies for 3 years – The Western Desert Kidney Health project.

2010 Funding secured for Western Desert Kidney Health Project

2010 June – Western Australian Aboriginal Health Ethics Committee approval for Western Desert Kidney Health Project

2010 August - Human Research Ethics Committee approval (UWA) for Western Desert Kidney Health Project

2010 October – Commencement of Western Desert Kidney Health Project with data collection and arts intervention in Kurrawang community

   November 2010 – Coolgardie
   February 2011 – Norseman
   March 2011 – Menzies
   May 2011 – Mt Margaret
   June 2011 – Mulga Queen
   July 2011 – Laverton
   August 2011 – Coonana
   September 2011 – Leonora
   November 2011 – Coolgardie
   December 2011 – Kurrawang
   February 2012 – Norseman
   April 2012 – Mt Margaret
   May 2012 – Laverton
   June 2012 – Tjuntjuntjara
   August 2012 – Leonora
   September 2012 – Menzies
   October 2012 – Mulga Queen
   October 2012 – Kurrawang
November 2012 – Coolgardie
February 2013 – Tjuntjuntjara
March 2013 – Norseman
May 2013 – Laverton
June 2013 – Mt Margaret
August 2013 – Leonora
September 2013 – Menzies
October 2013 – Mulga Queen

2013 November to November 2014
Data entry, cleaning and checking
Production and distribution of Mara Yungu book
Feedback to communities
Literature Review

This chapter presents the findings from review of the literature. It is presented in 7 sections.

Part 1 describes the study communities

Part 2 is a review of the literature in relation to the use of arts based methods to improve health.

Part 3 is a review of the literature around type 2 diabetes.

Part 4 is a review of the literature relating to renal disease.

Part 5 discusses the role of metabolic acidosis in type 2 diabetes and renal disease

Part 6 discusses the potential role of drinking water contamination with chloramines, nitrates, uranium and arsenic in the development of type 2 diabetes and renal disease

Part 7 is a review of the literature around behavioural change in relation to diabetes and renal disease
Part 1 - The Study Communities

Living conditions

Many families experience significant stress related to living in remote areas. Remoteness can result in difficulties in accessing health services, sport and recreation opportunities, housing, healthy food and other necessities.

In the towns and communities in this study housing is often overcrowded and of poor quality so housing stress is significant. Water quality in the towns and communities is often poor - in 2013 and 2014 drinking water tests for Naegleria or E. coli were positive in eighty per cent of remote Aboriginal communities in Western Australia. Water contamination with nitrates and uranium is also a problem for many communities. Power, water and sewerage supplies are often disrupted and housing maintenance is poor. Support and service provision for remote communities from Government is poor – during the time of this project one community had all services withdrawn and the community has effectively closed with the residents forced to relocate to town or other remote communities.

Poverty

The median household income in Aboriginal households in Laverton in 2011 was $578 per week, compared to the Australian median of $1,043. In the Goldfields in 2011 the employment rate for Aboriginal adults (aged 15 to 64) was 39.6% compared to a total rate of 76.5%. The Aboriginal unemployment rate in the Goldfields as 17.4% compared to a total rate of 4.3%. The cost of living, particularly the cost of food, is higher in remote areas. In 2013 the West Australian Food Access and Cost Survey healthy food basket in remote and very remote areas, including the Goldfields, was estimated to cost 20% more than an equivalent basket of food purchased in the capital city, with the greatest differences in the prices for fresh fruit, vegetables and dairy.

Diet

Cost of food is a problem – but availability is probably more of a problem. At the start of the project three of the communities and two of the towns had no grocery shop – to obtain store-bought food community members must drive up to 400km, often on gravel roads, to shop in the nearest town. Availability and quality of fresh foods is often variable. Community members can only buy foods they can afford, that will survive the long journey home (difficult for fresh foods and frozen foods in the extremely hot climate) and that will last until the next trip to town.
Hunting requires significant resources. Game is to be found some distance from towns and communities. Hunters need to have a car with sufficient fuel. A gun is needed and the hunter must have a gun license and meet the conditions for this – guns must be stored in an approved gun safe which must be secured inside a house. [42]

**Health Services**

Health services are very limited - several of the communities have only occasional visiting community nurse services. The towns have small hospitals but struggle to keep doctors and one of the towns had only occasional locum services for the duration of the project. The other towns had a single doctor for most days of the week, but none had full 24 hour, 7 days per week cover by a doctor. Four of the towns and one remote community have resident community nurses and community health centres, the remaining town and one remote community have weekly visiting community health nursing services, three remote communities have no visiting or resident health services. None of the towns or communities have resident allied health services, although the towns have intermittent allied health visits.

**Education and Recreation**

All the towns and communities had primary schools but most had limited access to high school classes for the students. [43]

Recreation and sporting facilities are limited – 4 of the 5 towns in the WDKHP have swimming pools that are open over the summer months if operators and life guards are available. The towns have basketball courts, ovals and various other sporting venues – but most do not have enough teams, coaches and other supports to run regular sporting events, and sporting equipment is generally not available for purchase. All five towns have pubs, some more than one. Café’s, churches and other community meeting points are limited. The remote communities have sporting equipment and courts at the schools but limited other sport and recreation facilities.
Part 2 – Community Arts for Health

This study employed a community based participatory research model. This approach to research has been found to be effective in other areas, particularly with indigenous communities, with relationships between the community and the research team critical to conducting successful, ethically sound research. The Western Desert Kidney Health Project team grew out of the relationship of the Aboriginal community of the remote Goldfields and Western Desert areas of Western Australia with the principal researchers embedded in the community.

Status in the Aboriginal communities of the Western Desert and Eastern Goldfields is afforded on the basis of spiritual features and cultural standing, rather than academic achievement. It is imperative that the value of community members and team members be held as equal and, although very different, all team members and community participants feel that their important contributions were equally valued, in keeping with the NHMRC guidelines for research in indigenous communities.

Community arts as the vehicle for community engagement, education and community development was chosen because it allowed us to address many issues that would otherwise be beyond the scope of the project. It allows for meaningful reciprocity.

The National Health and Medical Research Council’s advice on Values and Ethics states that “Reciprocity requires the researcher to demonstrate a return (or benefit) to the community that is valued by the community and which contributes to cohesion and survival”.

“Reciprocity – that research and practice should reflect community priorities and explicitly aim to provide useful service”

The Community Arts method replicates traditional methods of teaching and reinforces them. It allows communities to explore and develop educational materials and community development strategies that would work for them. It introduces new skills to the community, especially for the children and allows them to interact with senior artists. It results in personal and community satisfaction and kudos.

“Arts practice and creative expression are at the heart of a community’s vitality. People have always come to sing, to tell stories, to enact rituals, to celebrate, to mourn and to
mark significant events in their lives. Besides being able to see great art, people need to actively participate in these activities. This is what is meant by the term "community arts": it might be a new name but it is not a new idea." [52]

Resilience

In designing this project we were mindful of the literature surrounding resilience. [53] Many of the children and adults who would be participants in this study have had, and continue to have, many stressors and very difficult lives – for example at one community more than half of the children attending the school are in foster care with extended family and their parents are either dead or absent due to incarceration and/or substance abuse problems. Many of the adults who would be eligible for participation in the project would have been affected by the stolen generations’ policies, forcibly removed from their families and placed in “Missions” to grow up under the care of the state. Almost all participants would suffer from issues common in Indigenous and remote communities (poverty, housing stress, food security issues, personal safety issues, poor literacy and poor health). [33, 37, 40, 54, 55]

We know that

“Children who experience chronic adversity fare better or recover more successfully when they have a positive relationship with a competent adult, they are good learners and problem-solvers, they are engaging to other people, and they have areas of competence and perceived efficacy valued by self or society” [56]

Despite the hardships, life in these communities can be a rich and rewarding experience if community members have resilience and are able to make the most of opportunities. The community arts method provides opportunities to assist with the development of resilience in a community and the arts projects can help communities and individuals to:

- develop knowledge about the health issues and ways to prevent, improve or overcome them so that not only could they have the knowledge but they would become important and respected for that knowledge
- develop skills that could provide personal satisfaction and avenues of expression for stress reduction
- Develop creative problem solving skills
- Receive recognition from respected and senior arts practitioners from outside their communities
- Be engaged with the community, the project team and the artists in residence – especially those children who were disengaged
- Receive recognition and applause from their community for their achievements with the showcase at the end of each residency, and from outside the community with display of their works on YouTube, websites and with ongoing publications, exhibitions and performances.

Even though the arts residencies may be quite short in the scale of the lives of participants they can still have potential to be significant because of their novelty, their intensive nature, their focus on doing something important that would have wide benefit not only for the host community but for a much wider audience and because of the high standing of the artists involved. “Spare time” activities can significantly enhance resilience because:

“They can help to promote a sense of belonging to a family or valued social group / mattering to people who are important to the child and counting for something in a context that matters to the child.” [57]
Part 3 - Insulin and Type 2 Diabetes

In my clinical work I had noticed that very often newborn infants whose mothers had T2DM during the pregnancy or gestational diabetes had problems with hypoglycaemia in the first few days of life. Over my years in Kalgoorlie I noticed that many of those infants who had problems with hypoglycaemia in the neonatal period were growing up to be children who presented with obesity, acanthosis nigricans and ultimately early onset T2DM – suggesting that insulin control and hyperinsulinism had probably been problems since before birth, and that the hyperinsulinism had perhaps never been controlled.

I examined the literature and found that this clinical impression is consistent with the international experience that babies born to women with diabetes in pregnancy are reported to be at higher risk for the development of obesity, insulin resistance and T2DM later in life [58-64].

The literature also suggests that early detection and management of the diseases that contribute to the development of diabetes and kidney disease (such as hyperinsulinism, hypertension, obesity, and albuminuria), and changes in diet and lifestyle might halt or slow the progression and complications [14, 65].

So what is the mechanism of disease?

Type 1 diabetes is uncommon in Aboriginal people in Western Australia [66]. The mechanisms appear to be quite different – type 1 diabetes is the result of failure of the pancreatic Beta cells to produce insulin, T2DM is related to excess insulin production and insulin resistance, with Beta cell failure a late feature of the disease.

T2DM and hyperinsulinism are common and increasing problems worldwide, but especially in indigenous communities both in Australia and internationally [25, 67-80].

Hyperinsulinism and diabetes are problems for Australian Aboriginal people and start at a much younger age than non-Aboriginal people. Rates appear to be increasing [63, 81, 82]. Studies in different areas have estimated the prevalence of T2DM in the Australian indigenous community to be between 9% to 30%, among the highest rates of T2DM in the world. It is 2 to 4 times more common in the Australian indigenous population than in non-indigenous population [83-88]. The rate is higher for Indigenous Australians living in remote areas and very remote areas compared to those living in urban locations [88].
As T2DM is often asymptomatic it may not be diagnosed until complications occur, so the incidence may be much higher than is known. The incidence of hyperinsulinism and the age at appearance in childhood in the Australian indigenous community is not known.

Hyperinsulinism and T2DM contribute to the development and progression of other risk factors for chronic disease, particularly renal disease and associated hypertension, albuminuria and vascular disease so their early detection is vital in preventing the development of complications. [63, 76, 81, 89-97]

Hyperinsulinism, insulin resistance, metabolic syndrome and T2DM appear to be related and possibly represent the progression of a single process with excess insulin production at its core. The big question, therefore, is what is causing the increase in insulin levels?

**Insulin**

The gene for insulin is located on the short arm of chromosome 11 in humans. [98]

Insulin is produced by the Beta cells in the islets of Langerhans in the pancreas. [98] The islets of Langerhans are made up of at least 4 different cell types. The Beta cells secrete amylin as well as insulin. The Alpha cells secrete glucagon, the Delta cells secrete somatostatin and the PP or F cells secrete pancreatic polypeptide. [98-100] Insulin inhibits glucagon secretion. Amylin can inhibit insulin secretion. Somatostatin inhibits secretion of both insulin and glucagon. [99]

**Stimulation of Insulin secretion**

Insulin secretion is primarily stimulated by glucose although other agents can also affect insulin release from the Beta cells. Blood glucose levels work via a feedback loop to control insulin release. Glucose entry into the Beta cells is not controlled by insulin – so when blood glucose levels rise the levels of glucose entering the Beta cells also rise, stimulating an increase in insulin release. As insulin exerts its actions on the body blood glucose levels fall, Beta cell glucose levels fall and insulin production decreases again. [98] Insulin acts to keep the blood sugar levels in the normal range by diverting excess glucose circulating in the blood to be stored, especially as glycogen in the liver and as fat.
Diet
Excessive intake of carbohydrates, particularly foods high in refined carbohydrate and sugar will stimulate insulin production by the pancreas. The change of diet for many populations to a western style diet may be an important factor in the increase in insulin production.

The so-called “Western diet” is high in processed foods, high in saturated fats, sugars, salt, refined carbohydrates and meat protein and low in monounsaturated and polyunsaturated fats and low in fruit and vegetables (therefore low in proteins and micronutrients from plants and low in fibre). Chronic excess carbohydrate and sugar intake associated with the Western diet has been shown to be associated with chronic excess insulin production, metabolic syndrome and T2DM.

The “Western diet” is associated with many adverse health outcomes including increased risk of metabolic syndrome, hypertension, obesity, T2DM, cardiovascular disease, cancer, osteoporosis and kidney disease.

Other sugars such as fructose and mannose can stimulate insulin secretion as can amino acids and Beta keto acids. Fructose is a common food additive. It can compete with glucose in the liver so that, if there is an excess of fructose, glucose metabolism is affected resulting in elevated blood glucose levels and therefore increased stimulus to insulin production.

Medication
Some medications, including theophylline and caffeine have been found to stimulate insulin release by the pancreas. Some studies suggest positive benefits for drinkers of both caffeinated and decaffeinated coffee with T2DM and those with insulin resistance. It appears that there are factors other than caffeine that are important in coffee.

Corticosteroid medications are well known to cause hyperglycemia and can result in “drug induced” T2DM in some patients. Corticosteroids contribute to insulin resistance, reduce glucose uptake by muscle and stimulate the liver to release glucose from glycogen.

Hormones and Stress
Hormones including glucagon, gastrin and secretin can increase insulin secretion. Endogenously produced steroids such as cortisol, produced in response to stress, have similar actions. Chronic stress can contribute to hyperinsulinemia, metabolic
syndrome and the development of T2DM. Other hormones including glucagon, gastrin and secretin can increase insulin secretion.

Stress, often chronic stress from early childhood, is a problem for people in remote areas and especially for indigenous people in Australia and internationally as they are often marginalized, subject to discrimination, dispossession and poverty and their communities are often disrupted. These factors contribute to what is known as the “Allostatic load”.

Ethnicity
Some population groups seem particularly prone to hyperinsulinism, especially indigenous communities. This may be due to a predisposition to excessive insulin response to a carbohydrate load, a concept known as the “Thrifty Gene Hypothesis”. It may also be due to clustering of known risk factors for diabetes in these populations with socioeconomic and environmental conditions contributing to increased risk as discussed throughout this document.

Hyperinsulinism is likely to be a complex interplay between genetic predisposition, socioeconomic and environmental factors. (Figure 1, Page 31)

Insulin production
Insulin is synthesised in the endoplasmic reticulum of the Beta cells. It is a polypeptide made up of 2 chains of amino acids joined by disulphide bridges. Initially it is joined to C-peptide (connecting peptide) and is called proinsulin.

From the endoplasmic reticulum the insulin and C-peptide are transported to the Golgi apparatus where it is packaged into membrane bound granules. The granules make their way, via microtubules, to the cell membrane where they fuse with the cell membrane, releasing the insulin and C-peptide by exocytosis. C-peptide and the insulin molecule are separated in the Beta cell and packaged together in the granules, with a small amount of proinsulin, to be released into the blood stream. C-peptide stimulates activation of 2 enzyme systems – sodium-potassium ATPase and endothelial nitric oxide synthetase.
Where does the insulin go?

Insulin produced by the pancreas enters the portal vein and is taken to the liver – therefore the liver is exposed to concentrations of insulin that are many times higher than other tissues. Hepatic tissue is more sensitive to insulin than other tissues. [98]

Elimination of Insulin

80% of secreted insulin is used up in the liver and kidneys. [98] The kidneys are important in the elimination of insulin. Insulin is filtered from the blood in the glomerulus and some is reabsorbed in the proximal tubule, but some is lost in the urine. In the proximal tubule insulin is broken down by proteases and it is removed from the circulation. Insulin also diffuses from the peritubular capillaries in to the distal nephron tubules where it binds to the membranes of tubular cells. In the tubule it acts to stimulate sodium reabsorption as well as reabsorption of phosphate and glucose. [134]

Actions of Insulin

Plasma contains insulin and other molecules that have insulin like activity (proinsulin, insulin like growth factors I and II and protein bound IGF). [98]

Insulin is anabolic – it stimulates the storage of glucose, fatty acids and amino acids. [98] The primary action of insulin is to move glucose into cells, especially in muscle, fat and other tissues by stimulating an increase in the glucose transport pathways across the cell membranes. However insulin is not involved in glucose transport in most of the brain (except for part of the hypothalamus), kidney tubules, intestinal mucosa, liver and red blood cells and Beta cells. [98]

In the liver, insulin does not affect movement of glucose across the cell membrane, instead it stimulates glycogen synthesis, increasing glucose storage as glycogen and decreasing release of glucose from the stored glycogen in the liver. [98] Insulin promotes the formation of fatty acids from excess glucose entering the liver cells if it cannot be converted to glycogen. These fatty acids are converted to triglycerides and very low density lipoproteins which are released into the blood for transport to adipose tissue (fat cells). [133]

Insulin stimulates uptake of glucose in the muscles, which, if not used immediately for energy, is stored as glycogen in muscles. [133]

In healthy people it seems that excess insulin will have few effects on the kidney but in people with insulin resistance or T2DM urinary albumin excretion is increased, sodium
and uric acid excretion is decreased, perhaps contributing to the common co-morbidities of albuminuria, hypertension and hyperuricaemia. \[^{[135, 136]}\]

**Other Actions of Insulin**

The actions of insulin are not limited to glucose metabolism. Insulin increases the transport of amino acids and potassium into the insulin sensitive cells. The extracellular fluid contains a large amount of sodium but only a relatively small amount of potassium while the intracellular fluid has smaller amounts of sodium and much larger amounts of potassium. In order to maintain this difference the cell membrane has specific and active transport mechanisms. \[^{[133]}\] Insulin causes potassium to enter the cells resulting in a fall in extracellular potassium. \[^{[98]}\] Insulin increases the activity of sodium-potassium ATPase in cell membranes resulting in active exchange of sodium and potassium across the cell membrane. This may be secondary to activation of the transport system that exchanges intracellular hydrogen ions (H\(^+\)) for extracellular sodium resulting in a rise in intracellular sodium and a rise in intracellular pH (fall in H\(^+\)). \[^{[98]}\] Systemic potassium depletion increases insulin secretion. \[^{[98]}\] Metabolic acidosis results in depletion of potassium. Metabolic acidosis also contributes to insulin resistance independent of the effect on potassium. \[^{[137]}\]

Insulin promotes movement of amino acids into the cells, stimulating protein synthesis, decreasing protein degradation and, as a result, fostering growth as long as an adequate supply of glucose is available. \[^{[98]}\]

The actions of insulin on glycogen synthetase promotes glycogen storage and lipogenesis. \[^{[98]}\] Insulin stimulates uptake of lipids by the cells and production of triglycerides while inhibiting lipolysis, promoting the accumulation of fat. \[^{[133, 138]}\]

Insulin has effects on vascular tone – C-peptide released with insulin does not have any insulin-like activity but it does have effects on membrane receptor sodium-potassium ATPase and endothelial nitric oxide synthase activity. Nitric oxide can cause vasodilation and so c-peptide will affect production of nitric oxide which will affect vascular tone. \[^{[99]}\]

**The effects of hyperglycaemia**

Hyperglycaemia and T2DM seem to occur when the Beta cells fail. \[^{[139]}\] The initial response to hyperglycaemia is for glucose to spill into the urine. This increases the osmolality of the urine, drawing more water into the urine resulting in an osmotic diuresis and polyuria, contributing to dehydration. \[^{[133]}\] There is dehydration at the
cellular level as well – excess glucose in the extracellular fluid draws water out of the cells by osmosis. With the increased urine output potassium is also lost, contributing to systemic hypokalaemia.

Chronic hyperglycaemia results in tissue damage and dysfunction. The blood vessels are particularly affected and eventually undergo structural changes that result in reduced and inadequate blood supply to tissues, contributing to ischaemic vascular disease. This is exacerbated by the additional effects of atherosclerosis resulting from altered lipid metabolism associated with dysfunction of the insulin pathways. [110, 133, 140]

**Hyperinsulinaemia**

The effects of hyperinsulinaemia are wide ranging. Hyperinsulinaemia precedes the onset of T2DM, often by many years. [139, 141] Insulin resistance and ultimately T2DM are well recognised consequences of hyperinsulinaemia but excess insulin has other effects.

Hyperinsulinaemia has a number of effects on the body including [110]

- Increasing reactive oxidative species and advanced glycation end products
- Increased insulin like growth factor-1 (IGF-1)
- Increased triglyceride and fatty acid production
- Effects on hormones and cytokines
- Acanthosis nigricans
- Metabolic Syndrome
- Renal disease
- Increasing reactive oxidative species and advanced glycation end products

Reactive oxidative species are chemically reactive molecules that contain oxygen such as peroxides and oxygen ions. They are produced as part of the normal metabolic reactions in cells and are often important in regulating the cell functions, homeostasis and cell signalling. [142] In excess they have been linked to cancer, early aging, Alzheimer’s disease and endothelial damage. Hyperinsulinemia is linked to excess reactive oxygen species production although the mechanism is not clear. [110, 143-145]

There appears to be an epidemiological association between cancer and diabetes, especially T2DM. [146, 147] The mechanism for this association is not clear and is probably multifactorial but insulin, directly and via its action in increasing the bioavailability of IGF-1, has been associated with cancer cell proliferation and metastasis. [146]
**Hormones and cytokines**

Insulin is important in appetite control. Hyperinsulinemia increases appetite. Obesit\[110\] Obesity is a very significant risk factor for the development of hyperinsulinism, T2DM, hypertension, Syndrome X and renal disease. [148-161] Hyperinsulinemia contributes to obesity, especially abdominal fat deposition. [162-164] Adipose tissue produces hormones and cytokines, hypertrophic adipose tissue contributes to inflammation and decreases insulin response so obesity can be both an effect of, and a factor in causing, hyperinsulinemia and T2DM. [110, 165]

Obesity, especially the pattern associated with metabolic syndrome and hyperinsulinism, is associated with excess oestrogen and androgen production and disruption of female fertility and menstrual cycles. [166-168] Polycystic ovarian syndrome and associated infertility are often found in women who have hyperinsulinism, obesity and other features of the metabolic syndrome. [167, 169, 170]

**Acanthosis nigricans**

One of the early clinical signs suggestive of hyperinsulinism is acanthosis nigricans - the thickening of the skin in areas of friction - such as the axillae, back of the neck and the groin. In people of Caucasian descent this can be difficult to detect but in people who have darker skin the areas affected become increasingly pigmented and it is easy to see with the naked eye. As it progresses skin tags also develop. [171-174] The mechanism of acanthosis nigricans in hyperinsulinism is thought to be direct or indirect activation of the insulin like growth factor 1 receptor by high levels of circulating insulin. [81, 171-184]

**Metabolic Syndrome**

Metabolic syndrome or Syndrome X are the names given to the clustering of diseases which appear to be linked to hyperinsulinism - obesity with an android pattern of fat distribution in both men and women, impaired glucose tolerance, T2DM, hyperinsulinism, hypertriglyceridemia, hypertension, polycystic ovarian disease and premature cardiovascular disease. [82, 185-187] There is increasing evidence of this cluster of diseases in Australian Aboriginal people and of its contribution to the high rates of these diseases in the Aboriginal community. [25, 67, 69-73, 82-86, 95, 185, 188-194]

**Hyperinsulinemia and the kidney**

Hyperinsulinemia contributes to the development of renal disease through many different pathways. It contributes to hypertensive renal damage by increasing sodium...
retention and through direct effects on the blood vessels (described above). It contributes to vascular disease, and to increasing body mass index and therefore renal load. Hyperinsulinemia selectively increases albumin loss from the kidney.
Part 4 - Renal Disease

There is no doubt that hyperinsulinemia, T2DM and their effects contribute to the high rate of renal disease in Australian Aboriginal populations but a review of renal biopsies in 2012 has shown that less than half the biopsies showed diabetic changes – there is more to the story of renal disease in Aboriginal communities.[198]

Diet and kidneys
Worldwide the change to a modern “Western diet” has occurred at the same time as an increase in the incidence of chronic kidney disease and there appears to be a correlation between them. The increased risk of diabetes and hypertension associated with the Western diet contributes to an increased risk of renal disease, but there appears to be an increase in the risk of renal disease independent of these associations.[199, 200]

Albuminurin
Albumin is a small protein, produced by the liver and found in the blood. About 50% of the protein in the plasma is albumin. It is important in maintaining the oncotic pressure of the blood. It is a transport protein for ions and molecules that would otherwise be poorly soluble in the blood (including free fatty acids and calcium ions).[201] In the normal kidney albumin should not cross the glomerulus so it is not found in the urine. For albumin to reach the urine there must be changes or damage to the glomerular filtration barrier and damage or dysfunction of the glomerular endothelium. The mechanism of damage is not well understood but it seems that reactive oxygen species, inflammatory cytokines and growth factors are involved, particularly in the renal disease associated with both type 1 and T2DM, and that the glycocalyx portion of the glomerular filtration barrier may be the principal site of damage.[202] Conditions associated with systemic endothelial damage or dysfunction are associated with albuminuria, including hypertension, peripheral vascular disease, cardiovascular disease, hyperinsulinemia, obesity, sepsis and inflammatory diseases, such as inflammatory arthritis and inflammatory bowel disease.[202]

Albuminuria has been found to be common in some Aboriginal communities across all age groups.[72, 203] Similarly it has been found that most renal disease in Aboriginal communities is marked by albuminuria, and renal failure arises in people with a history of progressive albuminuria. [70, 189, 190] Increasing albuminuria is associated with decreasing glomerular filtration rate (GFR) and progressive loss of renal mass.[187] It is measured using the albumin creatinine ratio in the urine (ACR). Albuminuria has been
found to be significantly correlated with other risk factors for renal disease - low birth weight, skin infection and infestation, a history of post streptococcal glomerulonephritis, obesity, hypertension, hyperlipidemia, hyperinsulinism and T2DM. [189, 191] Albuminuria has been found to have a strong predictive value for renal failure and for non-renal deaths - including cardiovascular deaths. [187, 191] Increasing amounts of albumin in the urine is a measure of progressive renal damage as well as progression of the other associated diseases such as diabetes, cardiovascular disease and hypertension. [204] Albuminuria can occur during childhood and may be transient although it is not clear whether transient albuminuria is associated with increased risk of renal disease later in life.

**Hypertension**

Hypertension is a risk factor for renal disease and also contributes to the increased mortality and morbidity in end stage renal disease – so both a cause and an effect of renal disease. [205] It has been significantly and directly related to micro-albuminuria which is an early indicator of renal disease. [206] This relationship has been demonstrated in the Aboriginal community. [191] Up to 14 percent of adults in some communities have been found to be hypertensive. [27] There is little information available about the prevalence or patterns of hypertension during childhood in Australia, although some studies in Indigenous communities have suggested hypertension is a problem beginning in childhood. [82, 207-210] National figures predicted that about 23% of Aboriginal and non-Aboriginal adults and 12% of children would be found to be hypertensive. [209, 211]

The mechanisms by which hypertension contributes to renal disease and ultimately end stage renal failure are many and inter related.

**Disease of the kidney will often cause hypertension**

Systemic disease such as diabetes and diseases or lesions of the kidney that reduce the ability of the kidney to excrete sodium and water will result in rise in blood pressure. [133] Diseases that reduce blood flow to the whole kidney, such as renal artery stenosis, or diseases that restrict perfusion of parts of the kidney, such as atherosclerosis, can cause hypertension as a mechanism to try to return renal perfusion, and ultimately glomerular filtration rate, to normal. Diseases that cause a fall in glomerular filtration rate (GFR) have similar effect – including glomerulonephritis which results in thickening and inflammation of the glomerular capillary membranes, causing obstruction to the normal filtration mechanisms in the kidney. [133]
Aging results in loss of nephrons, most commonly benign nephrosclerosis and glomerulosclerosis. This process is accelerated in people with diabetes and hypertension. [133]

Hypertension will, in turn, contribute to renal damage. In the kidney hypertension increases the perfusion pressure through the glomeruli and small arterioles, stretching and damaging them. This causes scarring or sclerosis of the tiny blood vessels and, eventually, destruction of the glomeruli. The scarring and loss of glomeruli in turn signals to the body that renal perfusion is inadequate, stimulating renin, angiotensin II and aldosterone secretion to reduce salt and water loss by the kidney, stimulating a further rise in blood pressure and contributing to a destructive, vicious cycle. [133]

**Obesity**

A person is born with all the nephrons they will ever have. [212, 213] If the work of the nephrons is increased their life span may be affected, accelerating glomerulosclerosis. [207, 212, 214] Obesity is a condition of increased metabolic demand and therefore a condition that will increase demand on the nephrons. In most people this does not seem to be a major problem, as they have sufficient reserve, but in those who have other renal insults, such as smaller kidneys at birth or disease which damages nephrons, such as hyperinsulinism, insulin resistance and T2DM or episodes of glomerulonephritis, the risk of end stage renal disease is increased. [196, 214]

Increased metabolic demand from obesity is not the only problem. Adipocytes secrete adipokines that are involved in cell signalling. These adipokines (Leptin, Resistin, Visfatin) have been associated with falling glomerular filtration rate and increased albuminuria. [161] Obesity has been found to cause inflammation in metabolic tissues and this may be another mechanism by which obesity can contribute to the development of end stage renal disease, especially in people with clustering of diseases such as obesity, hypertension, diabetes and vascular disease. [215]

**Renal insults during childhood**

Little is known about rates of renal disease in childhood and very little epidemiological data for children in Western Australia has been published. It is thought that renal insults during childhood can contribute to renal failure during childhood and later in life. [216-218]

In the early stages of development for this project we examined the West Australian Maternal and Child Health Research Database for hospital admissions for renal disease in the paediatric population of Western Australia for the period 1980 to 2000. [219] We found that Aboriginal children were over represented in all diagnostic
categories for renal disease with particularly high rates of renal stones, glomerulonephritis, urinary tract infection, acute and chronic renal failure.[219] (Table 1)

Table 1. Rates of hospital admission for renal disease in Aboriginal and non-Aboriginal children from 1980-2000 in Western Australia. Children hospitalized per 100,000, aged 0-16 yrs (number of cases). (Source - The West Australian Maternal and Child Health Research Database)

<table>
<thead>
<tr>
<th>Renal disease</th>
<th>Non-Aboriginal Rate (number)</th>
<th>Aboriginal Rate (number)</th>
<th>Rate Ratio (Aboriginal: non-Aboriginal),</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute glomerulonephritis</td>
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<td>45.5 (122)</td>
<td>21.7</td>
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<tr>
<td>Chronic glomerulonephritis</td>
<td>0.3 (14)</td>
<td>1.9 (5)</td>
<td>6.4</td>
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<td>Nephrotic syndrome</td>
<td>2.4 (115)</td>
<td>6.7 (18)</td>
<td>2.8</td>
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<td>38.4 (103)</td>
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<td>Acute renal failure</td>
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<td>20.9 (56)</td>
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<td>3.0 (143)</td>
<td>12.3 (33)</td>
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<td>4.1 (11)</td>
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<tr>
<td>Renal sclerosis, unspecified</td>
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<td>Disorders relating to impaired renal function</td>
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<td>7.1 (19)</td>
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</tr>
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<td>Small kidney of unknown cause</td>
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<td>1.9 (5)</td>
<td>4.5</td>
</tr>
<tr>
<td>Infections of kidney</td>
<td>16.2 (774)</td>
<td>70.9 (190)</td>
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<td>Hydronephrosis</td>
<td>5.2 (247)</td>
<td>8.2 (22)</td>
<td>1.6</td>
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<tr>
<td>Calculus of kidney, ureter and lower urinary tract</td>
<td>1.9 (93)</td>
<td>63.8 (171)</td>
<td>33.6</td>
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<tr>
<td>Renal colic</td>
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<td>2.6 (7)</td>
<td>8.7</td>
</tr>
<tr>
<td>Renal dialysis status</td>
<td>0.1 (7)</td>
<td>0.8 (2)</td>
<td>8.0</td>
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**Urinary Tract Infections**

Urinary tract infections (UTIs), especially if there is pyelonephritis, can cause renal scarring which in turn can lead to hypertension and renal failure.[220, 221] UTI can be difficult to diagnose as it can be asymptomatic and suitable urine samples may be difficult to obtain from children. In remote areas it may be difficult to have urine samples processed for microscopy and culture as the laboratory is so far away and transport to a laboratory is infrequent. However the presence of nitrites, blood and leukocytes in urine is suggestive of UTI.[222-224]
The review of the West Australian Maternal and Child Health Research Database showed that Aboriginal children in Western Australia had a rate of hospital admission for urinary tract infection more than 4 times the rate for non-Aboriginal children. [219] For adults urinary tract infection in pregnancy is a common problem for Australian Aboriginal women [225-227] People who have diabetes are at higher risk of UTI and increased risk of complications of UTI. [221, 228, 229]

Post-streptococcal glomerulonephritis
Post-streptococcal glomerulonephritis in childhood was thought to be a self-limiting disease which would completely resolve with no long term sequelae. [187] However in the Aboriginal community this does not appear to be the case and it may be a significant risk factor for renal disease in adulthood. [230, 231] In most populations post streptococcal glomerulonephritis follows streptococcal throat infection but there is increasing evidence to suggest that streptococcal skin infections are associated with increased risk of glomerulonephritis and rheumatic fever in Aboriginal communities in Australia. [198, 216, 230-235]

Renal Stones
Aboriginal children in remote communities suffer very high rates of urolithiasis and at an unusually young age with most cases occurring in the 0 to 3 year age group. [216, 236-240] Renal stones are generally asymptomatic unless they cause obstruction or renal colic however haematuria can be a sign of renal stones. The cause of these stones is unexplained as the children in these studies have not been found to have any metabolic condition which could cause the stones. It has been postulated that they are the result of poor nutrition, dehydration and harsh living conditions in an arid environment. Renal stones in young children may be the result of chronic metabolic acidosis resulting from lactose or disaccharide intolerance. [236]

Low birth weight
Low birth weight (a marker of intrauterine malnutrition) may be a risk factor for the development of chronic nephropathies and subsequent renal failure in adulthood. In some Aboriginal communities a correlation between low birth weight and renal disease has been demonstrated. [207, 241] It is speculated that low birth weight predisposes to renal failure through impairment of nephrogenesis - that is babies who have poor growth in utero will have less renal reserve than appropriately grown babies. [187, 207, 242] In general, at birth a person has all the nephrons they are ever going to have, nephrogenesis is largely complete by 35 weeks gestation. [212, 213] If a baby is small at birth then their kidneys will be small, having fewer nephrons than a larger baby. If a
baby is born before 34 weeks gestation some new nephrons may be formed after birth but these are not generally normal and often show cystic degeneration, resulting in fewer functional nephrons. [243]

Low birth weight is common in the Aboriginal community – in the past, up to one quarter of Aboriginal babies born in Australia were under 2500g at birth. [189] These are, of course, the adults of today. Encouragingly the rate of low birth weight seems to be improving, in the Goldfields and Midwest regions of Western Australia, between 2007 and 2011, 5.8% of all babies and 12.5% of Aboriginal babies were of low birth weight. [244]
Part 5 – The Role of Acidosis

An acid load will result in metabolic acidosis as the body strives to maintain blood pH at all costs. Buffers are used initially and then renal excretion of acid (H⁺) increases. Urine pH falls but urine pH cannot fall lower than about 5. Once this limit is reached urate and ammonia are formed to “mop up” excess H⁺ ions. Metabolic acidosis will stimulate the kidney to excrete H⁺ ions through the action of glutaminase and other enzymes in the renal tubules. The activity of these enzymes is governed, at least in part by increased pituitary ACTH production. The increase in ACTH will result in increased cortisol and aldosterone production. These hormones act on the renal tubules to increase ammonia production to facilitate H⁺ loss. Cortisol will have other effects – in particular promoting an increase in visceral fat, reducing the effectiveness of insulin and contributing to the development of insulin resistance and T2DM. Aldosterone will stimulate the kidney to retain sodium along with H⁺ and potassium loss. In the kidney, metabolic acidosis results in a fall in urinary citrate, increased urinary production of urate and ammonia and increased risk of renal stones.

Acidosis affects mitochondrial function in cells and can shortened mitochondrial life resulting in shortened cell life, particularly kidney cells and contributes, ultimately, to renal failure. This can be exacerbated by other factors as discussed above – low birth weight and small renal size at birth, urinary and systemic infections, stress with changes in cortisol-insulin- adrenalin pathways, smoking, diabetes and metabolic syndrome.

Metabolic acidosis causes a fall in total body potassium and this will be a stimulus to increased insulin secretion. Metabolic acidosis, even relatively mild degrees of acidosis, reduces skeletal muscle sensitivity to insulin, contributing to insulin resistance and other studies have reported an association between low urine pH and insulin resistance. Acidosis inhibits protein synthesis which may increase the activity of growth factors and protein kinase c, increasing insulin like growth factor contributing to insulin resistance.

The Western diet is associated with a high consumption of meat products and acidic drinks such as carbonated beverages which can contribute to metabolic acidosis. Fruit and vegetable intake tends to result in a more alkaline metabolic state, so the high meat protein intake and high acid drinks coupled with reduced fruit and vegetable intake might be an important factor in chronic metabolic acidosis and, ultimately, lower urine pH with increased renal demand.
Figures 2 and 3 are diagrammatic demonstrations of the causes and effects of acid load as discussed above.

Figure 2 Causes of low urine pH

- Not enough Vegetables
- Stress
- Diet: High sugar and Carbohydrates
- Illness and Infections
- Acid Load
  - Acidic Foods: Preserved foods, Proteins, Soft Drinks, Fruit Juices
  - Nitrates: Water and Food
  - Methaemoglobinaemia
  - Water: Ammonium Chloride, Nitrates, pH=8

Figure 3 Effects of acid load.

- Relative Metabolic Acidosis
  - Fall in Buffers: Ca$^{2+}$ released from bone, Falling Bicarbonate
  - Shortened Mitochondrial Life
  - Insulin Resistance
  - Renal Failure
Chloramine

Chloramine (NH₂Cl) is added to municipal water supplies as a disinfectant – it is added to the water in the pipeline that supplies Kalgoorlie, Boulder, Kurrawang, Coolgardie and Norseman. Chloramine dissociates to release chlorine and ammonia. Chloramine can convert organic materials to chlorocarbons including chloroform and carbon tetrachloride. Trihalomethanes may also form as a result of chloramination and have been linked to increased risk of cancer, particularly bladder cancer.

Some chloramine, or ammonia left in the water after dissociation, in the presence of chlorine, may convert to ammonium chloride (NH₄Cl). Ammonium chloride is used therapeutically in the treatment of severe metabolic alkalosis to reduce the pH of the blood – so it can cause metabolic acidosis.

Nitrates and Nitrites

Nitrates and nitrites are compounds found naturally in some foods (like vegetables) but also added to fresh meat and processed foods (like bacon, sausage, polony, salami, beer) as a preservative. Sodium nitrate is added to fresh red meat to keep it looking red and fresh as it binds to myoglobin. It is likely that the diet of people in the study towns and communities is high in nitrates as access to fresh food is limited so people must rely on processed, preserved and packaged food.

Nitrates are often present in water. Nitrates in drinking water can come from natural sources from the use of fertilizer, and as a result of breakdown of organic material leaching into the groundwater. Many of the towns and communities in the WDKHP are at risk from water contaminated with naturally occurring nitrates and this has been a longstanding problem. Over most of the last 10 years 3 towns, Menzies, Leonora and Laverton, have been exempt from the drinking water safety guidelines due to the high level of nitrate contamination. Many of the Aboriginal communities in the study region also have excessive nitrate contamination of their drinking water. (Figure 4)
There is some evidence that nitrates can be beneficial to human health, and they are used therapeutically. In excess, or in certain conditions, they can be detrimental – for example in the presence of protein and heat or acid, nitrates and nitrites form nitrosamines – a class 1 carcinogen.\textsuperscript{262, 263}

Nitrate and nitrite ingestion in food and water, probably through the actions of nitrosamines, are associated with increased risk of T2DM, non-alcoholic steatohepatitis (fatty liver), Alzheimer’s disease, hypertension and cardiovascular disease.\textsuperscript{264, 265} The effects on diabetes, hypertension and cardiovascular disease contribute to the risk of renal disease. One of the effects of nitrate poisoning is metabolic acidosis.\textsuperscript{266} Animal studies suggest an association between chronic nitrate ingestion and anaemia.\textsuperscript{266, 267} Ingestion of nitrate can result in methaemoglobinaemia as it acts on haemoglobin, resulting in oxidation of Fe\textsuperscript{II} to Fe\textsuperscript{III} in the haem molecule, and removing the ability of haemoglobin to bind to oxygen and transport it to the tissues, contributing to lactic acidosis.\textsuperscript{268, 269}
Uranium
Uranium leaches naturally from soils, rocks and natural deposits, but is also released through mining processes. Uranium can have effects due to ionising radiation, particularly if ingested and it can have effects as a heavy metal, in particular it can cause kidney inflammation and damage. [270-278] Haematuria is a sign of inflammation of the kidney or uroepithelium.

If uranium is ingested in states of acidosis and/or with high levels or nitrate then uranyl nitrate will form – this is very toxic to kidney cells. [279-281]

The Goldfields of Western Australia has extensive uranium deposits. [282] There is considerable overlap between the uranium deposits and the aquifers from which bore water is drawn. In the last two years Tjuntjuntjara, one of the communities in the WDKHP, failed 18 out of 22 tests for uranium contamination of drinking water, exceeding the safe limit of 0.017 mg/L. Some of these results were up to double the safe level. [33]

Information is difficult to obtain but it is likely that bore water throughout the Goldfields will have some naturally occurring uranium contamination. Even levels below the “safe” level can be a problem is there are coexisting high levels of nitrates in the water, resulting in uranyl nitrate formation.

Arsenic

Chronic exposure to arsenic in drinking water has been directly associated with increased risk of kidney disease. Arsenic may also contribute to renal disease indirectly through associations with increased risk of T2DM and hypertension. [283-288]

Bores in the Goldfields have been found to be contaminated with arsenic. [289] In the towns arsenic is filtered out of the drinking water. The safety guidelines recommend that the level of arsenic in drinking water should not be above 0.007 mg/l. In 2010 the raw water in Menzies has an arsenic concentration of <0.002–0.5 mg/l. [290] In 2007 the raw water in Laverton has an arsenic concentration ranging from 0.002 to 0.045 mg/l. [291] Information about the levels of arsenic in the drinking water in the other towns and communities was not available.
Part 7 - Change is not easy

The global experience is that even with intensive weight loss programs, targeting people who are actively seeking to lose weight, change is hard to achieve. Systematic review of commercial weight loss programs showed that most had high attrition and at best achieved 10% change in BMI, although most resulted in less than 5% change.

A well designed and implemented intensive program in a north-west Western Australian Aboriginal community in 2007 achieved significant improvements in community level dietary intake, physical activity and fasting insulin levels but no change in the prevalence of diabetes, being overweight or obese.

However, even small gains (or losses) are important. Improved diet and modest weight loss has been shown to be effective in reducing the risk, or delaying the onset of, T2DM, improving physiological responses to stress and improving cardiovascular and renal risk factors including hypertension.

Exercise, even modest or low intensity exercise, has also been shown to be beneficial in reducing risk of T2DM, cardiovascular disease as well as having beneficial effects on mental health, mobility and general health.

Stress is an important factor in diabetic control, and is involved in the development of obesity. Reduction in emotional stress and activities that help to reduce the physiological effects of stress can be beneficial in reducing risk of T2DM, hypertension, cardiovascular and renal disease. This is particularly important during childhood.

Clearly there are many factors including food availability, water quality, exercise facilities, stressors and access to medical services, as discussed above, that will require systemic change if meaningful improvements in the risk of T2DM and renal disease are to be achieved at a community level.
Wanti Sugarba – the Pilot Project

This chapter discusses the pilot project, conducted between 2006 and 2008, to provide insight into how the Western Desert Kidney Health Project might work and to demonstrate the methods to the community.
Wanti Sugarba - The Northern Goldfields Kidney Health Project was an action research project targeted at three Indigenous communities in the Northern Goldfields of remote Western Australia.

Wanti Sugarba is an expression in the Wongutha language that means “leave sugar alone”, it also means “leave diabetes alone” or “don’t get diabetes”.

**Aims**

The aims of the Wanti Sugarba project were:

1) To take a team of arts, health and community development workers to three communities in the Northern Goldfields of Western Australia to provide those communities with an empowering experience focused on the prevention of diabetes and kidney disease to encourage them to take control of their own lives and health and share that experience with the wider Aboriginal community in Australia. (The Wanti Sugarba Project)

2) Collect baseline data on health status in relation to type 2 diabetes and kidney disease in the region (The Northern Goldfields Kidney Health Project)

3) Pilot the data collection protocols and methods, particularly the use of point of care testing in remote, arid environments

4) Develop capacity in research, the arts and community development in the Aboriginal community of the region and to bring in expertise in the form of established community artists to transfer their skills to the community.

**Funding and support**

Funding for the Wanti Sugarba Project was provided by the Rural Clinical School of Western Australia with additional support from Healthway – go for 2 and 5 program, the Government of Western Australia through Country Arts WA and the Department for Culture and the Arts. Corporate partners were BHP Billiton Nicklewest and Barrick Mining. Indigenous Community Volunteers recruited and supported artists to work with the Wanti Sugarba team. Wongutha Birni Aboriginal Corporation, Wongutha Wonganurra Aboriginal corporation, Mt Margaret Community, Laverton, Leonora Aboriginal Cross Cultural Organisation and Leonora Aboriginal Corporation were the community partners. Bega Garnbirringu Aboriginal Health Service and the West Australian Country Health Service were our delivery partners.

**Ethical Approval**

Ethical approval for the Wanti Sugarba Project, including this survey, was obtained from the West Australian Aboriginal Health Information and Ethics Committee, the
University of Western Australia Human Research Ethics Committee and the West Australian Country Health Service Ethics Committee.

**Consent**

Consent to participate in the survey was obtained from the community councils and organizations. Individual participants gave written consent. Where literacy or language was a problem verbal consent was recorded. Where appropriate, children gave assent and consent was also obtained from their parents.

**Time line**

The three communities, Leonora, Laverton and Mt Margaret, were consulted and engaged during 2006. These communities were chosen because they had expressed interest in the project and many members had been involved in developing the project proposal. They were easily accessible and had sufficient infrastructure to support the research team.

A team of permaculture gardeners, recruited through Indigenous Community Volunteers, spent 3 months in the communities from September 2006 teaching people how to set up home gardens and empowering the community to look at innovative ways to supplement the food supply.

In February 2007 our research team moved to Mt Margaret. The team included Dr Jeffries-Stokes, Annette Stokes, 3 Aboriginal health workers, medical students from the Rural Clinical School of WA and other volunteer researchers. One of the volunteer researchers, under supervision conducted a survey of knowledge, beliefs and attitudes to diabetes and kidney disease (Appendix 6 Nagi, A. Aboriginal Perspectives on Diabetes and Kidney Disease in the Eastern Goldfields of Western Australia).

In March 2007 a team of artists arrived in the Goldfields to work with us – 5 from Indigenous Community Volunteers (Rita Leuzzi, Viola Leuzzi, Genevieve Jones, James Houston and Christina McDonald) plus Lachlan McDonald and Andy Brown from Perth. They conducted 6 weeks of workshops with community members and children in the schools assisting them to produce their own health promotion materials and assist them to develop strategies to reduce the risk of diabetes and kidney disease for their communities. The 6 week program culminated in the Wanti Sugarba festivals – in Leonora on Monday, Laverton on Wednesday and Mt Margaret on Friday. There is a comprehensive report attached (Appendix 7 – Wanti Sugarba Report).
Community members were invited to participate in data collection looking for the risk factors for kidney disease and diabetes prior to the arts intervention in February 2007, again in September 2007 and a final assessment was conducted in March 2008.

From September 2007 we also conducted a survey of current dietary experience and habits of children in the region. (Chapter 11 - Tjitjiku Myaee – The diet of young people in remote Western Australia)

Clinical Assessment Methods
Data Collection.

A mobile research team, made up of Annette Stokes, Aboriginal health workers, doctors, collaborating researchers, artists and medical students conducted the clinical assessments and data collection.

Once consent was obtained participants answered a questionnaire to record medical, family and dietary history followed by a clinical assessment and investigations using point-of-care machines (Accutrend GC, Boehringer Mannheim for Blood Sugar; DCA2000, Bayer for Albumin Creatinine Ratio (ACR) and HbA1c; Bayer Clinitek Urinalysis machine). The testing machines were calibrated after each community visit and the DCA Vantage machines were calibrated and cared for by the Bega Garnbirringu Aboriginal Health Service QAAMS program team [317]. Point of care tests were performed immediately and samples disposed of in keeping with cultural beliefs that required that no samples be taken away or kept. Participants did not have to undress, also an important cultural requirement – skin infection was assessed by self-report and examination of exposed areas, acanthosis nigricans was assessed by examination of the axilla and back of the neck [318].

Three blood pressure measurements were taken using an electronic blood pressure machine with appropriate sized cuffs (OMRON IA1B) and checked with a manual sphygmomanometer where there were varying results.

Participants with history, existing diagnosis or confirmed current blood pressure over 140mmHg systolic or over 90mmHg diastolic were considered to have hypertension.

Participants with history, current treatment or HbA1c >7% on screening were considered to have T2DM.

Height and weight were measured with a personal weighing scale and stadiometer. Body Mass Index (BMI) was calculated and, for adults, categorised as underweight
(BMI <18.5 kg/m²), normal (BMI 18.5 – 24.9 kg/m²), overweight (BMI 24.9 – 30 kg/m²) or obese (BMI >30 kg/m²).

Participants were given immediate verbal and written feedback about the results. Those found to have abnormal results were referred to the doctor or health clinic of their choice for further investigation.

Results
As a result of the gardening interventions, the three schools have gardens and fruit trees, many homes have gardens and fruit trees and all the children and many adults know how to make compost, plant in pots and care for plants. The community members also learnt about healthy nutrition and were introduced to new foods. This part of the project was supported by BHP Billiton Nicklewest.

Participation
629 health data assessments were completed, 428 (351 Aboriginal, 77 non-Aboriginal) people were seen at least once. Of the 428 participants 42% (179/428) were children 16 years or younger including 147 Aboriginal children. Abnormal results were more common in Aboriginal participants.

Of the 428 participants on initial assessment:

- 54% were overweight with BMI > 25 – about 13% of the children were overweight compared to age specific norms. [319]
- 20% of adults were obese with BMI > 30
- The maximum weight recorded was 156 kg
- Acanthosis nigricans was present in 30% of Aboriginal participants. It was present in 20% of Aboriginal children and 50% of Aboriginal adults
- High Blood Pressure was present in 13% - only one child was found to be hypertensive.
- 20% of Adults were known to be Diabetic.
- 6% of participants were anaemic (tested with Haemacue point of care device)
- Proteinuria on dipstick testing was present in 35% of participants – including almost 30% of the children
- About 16% of adults had elevated HbA1C (≥7%) indicating uncontrolled diabetes.
- We found 12 people with ACR in the extreme range (ACR>25 mg/mmol) indicating current or imminent renal failure (3%)
At the final assessment in March 2008, of the 219 people seen on that occasion, 33 had ACR > 3.4 (i.e. 15% had Albumin in the urine above an acceptable level, placing them in a high risk group for renal disease and other complications)

This included:
- 5 children under 16 (5% of the children tested)
- 5 also had hypertension
- 4 also had random blood sugar over 6 (uncontrolled diabetes) and 9 were known to be diabetic
- 7 were known to have renal disease
- 23 had acanthosis nigricans
- 2 were not Aboriginal
- 30 had BMI over 25

Post Intervention Assessment.
There was significant movement within the population with people from the study communities relocating to other areas, and other people moving into the communities over the time of this study. This was expected, so the number of people who were available to be assessed both at the beginning and the end of the 12 month period was relatively small.

A total of 65 people were seen in Feb 07 and again in Feb 08 – so they had participated in the intervention activities and then been reassessed 12 months after their first assessment. Although these data have not been tested for statistical significance there was demonstrable change in this group and many had made dramatic changes to lifestyle and diet:
- 17 had lost weight (26%)
- 18 with BMI over 25 improved their BMI (28%) several people in this group had lost very large amounts of weight – up to 20kg
- 21 people had improved their cholesterol level (32%).
- 11 people had ACR over 3.4 initially and 9 of these people improved their ACR over 12 months (82%)

When asked how they had achieved improved results the participants told us they had followed the guidelines we had provided – decreased their carbohydrate intake, increased their intake of native animal meat and taken steps to reduce stress and increase exercise.
Evaluation

From January to April 2007 I moved, with my family, to Mt Margaret Community to observe and participate in the residency there – to pilot the clinical assessment methods and the arts residency. During this time I was able to gain important and meaningful insights into the implementation of the methods, as well as the complexities of all aspects of living in a remote community. Every Monday evening during this time I hosted a chilli night, inviting the whole community to come and share a meal and provide an opportunity to talk about the day to day operations of the project, provide feedback, insights and advice, usually resulting in animated and productive discussions. This allowed for the project to be responsive to community needs and the community to feel a real sense of ownership and involvement.

Qualitative assessments at the end of the project, conducted as a written questionnaire administered to 19 key community informants. Where literacy or language was a problem a scribe was provided. All responses showed an improvement in knowledge and understanding of diabetes and kidney disease and the lifestyle changes which can be implemented to reduce the risk of these diseases.

“Too much sugar in your diet, overweight, not enough exercise, family history.” 52 year old community worker
“Problems with insulin in the body” 33 year old non-Aboriginal woman
“To much protein and carbohydrate in the diet, not enough exercise, fresh fruit and vegetables.” 32 Year old Aboriginal woman

All the participants in the evaluation questionnaire were positive in their responses about the project – particularly in describing the community involvement and appreciation of the project:

“It was magic to see the pride on people’s faces when they got fruit trees” 22 year old Aboriginal woman
“It was really joyful to watch music and learn about good things” 22 year old Aboriginal woman
“Too much fun that ended too soon.” 32 year old Aboriginal woman
“I feel sad that diabetes is on the rise, but am hopeful that with the information, knowledge and support we can control it” 47 Aboriginal woman.
Lessons from the Pilot Project

The pilot project was very helpful in designing the Western Desert Kidney Health Project. The Pilot project was successful in demonstrating the method to the wider Goldfields community and there was demand from the pilot communities and other Goldfields communities to extend and expand the project. However we found that the pressures of travel, unpredictable weather and community conditions and the physical demands on the project team meant that it was only practical to spend 2 to 3 weeks in each community and to conduct one residency per month, allowing for at least 1 week at home between residencies. It became clear that it was not practical to conduct residencies in December and January due to the extreme weather conditions and school holidays. After extensive consultation 5 towns and 5 communities were included in the WDKHP.

We found that we needed mobile clinic trucks to transport staff and equipment and to provide appropriate spaces for the clinical assessments. During the pilot project we transported all the equipment in cars and set up in existing buildings in each community or town. This created problems because there was often no available, suitable space so time was spent finding a space, cleaning it and then setting up the equipment. The repeated packing and unpacking placed a heavy physical burden on the team and inevitably increased the wear and tear on the equipment. As a result of this experience the Western Desert Kidney Health Project design included purpose built 4 wheel drive trucks, one a mobile clinic with secure, stable storage compartments for the point of care machines and a second truck to transport arts and camping equipment.

During the pilot project many of the workers were volunteers, including many of the artists, recruited through Indigenous Community Volunteers. While this worked well in most cases it was, at times, difficult as we did not have any relationship with them before they arrived in the community and their expectations were sometimes different to the community or project team expectations. For the WDKHP we planned to recruit high level artists with whom we had some relationship, who were chosen both for their arts skills and for their personality and who had the ability to work well in a team and, most importantly, with Aboriginal community members and children. The WDKHP budget allowed for these artists to be appropriately paid and resourced.

The data sheets and clinical assessment methods were all piloted and refined during the Pilot Project. The point of care machines, methods of storage for the consumables and other equipment were also trialed and refined.
The Pilot Project gave us the opportunity to inform and involve the local health providers in the communities and the wider Goldfields medical community allowing opportunities for them have input into the project design and into how participants found to have abnormal results could be referred and followed up.
This chapter presents the findings of a survey of the diet of young people in the Goldfields, conducted as part of the pilot project.
Introduction

Poor nutrition and associated poor health in childhood can contribute to being underweight, overweight and obese, anaemia, reduced immune function, poor growth, physical discomfort, poor learning and behavior problems. In turn these can contribute to poor educational, sporting and occupational outcomes, mood disturbance, poor self-esteem and a lack of energy and enthusiasm for life. These can have life-long effects. Poor nutrition in childhood can be an important contributing factor to poor health and disease later in life and, as a result, reduced life expectancy. This is a particular problem for Australian Aboriginal people living in remote areas and an important contributing factor to the current epidemic of diabetes and renal disease affecting these communities [54, 71, 159, 320-325].

There are many factors that contribute to poor diet but availability of healthy food is critical and this is a major problem in the many remote and indigenous communities in Australia with limited fruit and vegetables availability and prohibitive cost. [54, 323] Affordability of food, family and individual preferences, cooking and presentation skills and knowledge of healthy diet are all important factors in whether or not individual children are offered and consume a healthy diet.

There is very little information about what children, especially children in remote areas, are actually eating – possibly because these are difficult studies to do. The Wanti Sugarba (Leave Diabetes Alone) Project was no exception. It was conducted in the Northern Goldfields of Western Australia, between October 2006 and June 2008. The three northern Goldfields communities were chosen because they had been enthusiastic supporters of the project and because they represent good examples of the diverse people and conditions in the region. As part of this project a survey of the dietary intake of young people in the region aged 6 to 18 years was undertaken in November 2007 to examine food intake, preferences and availability.

Methods

A paper-based, self-administered questionnaire asked about food intake in the previous 24 hours, usual diet, food experience and preference, cooking and shopping activities. Questions about whether specific foods had been eaten were presented with a picture of that food to overcome language and literacy problems. Where language or literacy was a problem a research assistant sat with the respondent to read questions and assist with recording answers.

All young people, attending school in the study areas, on the day of the survey and in classes where this would not interfere with other activities, were offered the opportunity
to participate. In addition young people up to the age of 18 years living in the community were invited to participate. Each community has only one school – Town A and Town B have Kindergarten to year 12 students and Community C has kindergarten to year 7 classes. Young people up to the age of 18 years who were not at school completed the questionnaire at their home.

None of the students asked to participate declined.

Eighteen years was chosen as the upper limit as this is in keeping with the bands used in the Dietary Guidelines for Australians [326]. The younger age limit was 4 years as this is when children can start school in Western Australia.

It is difficult to obtain a representative sample in these communities. School attendance is highly variable: The Western Australian Child Health Survey found that the median number of school days missed per year by Aboriginal children was 26 days [327]. There is considerable mobility between Goldfields towns so when the surveys were conducted in November and December 2007 – the end of the school year, enrolment figures included all children enrolled at any time during the year. While the survey was completed by 25% of children enrolled at a school in the region, all eligible children at school on the day of the survey and not involved in off campus activities filled in the survey. The schools had been extensively consulted and we enjoyed good cooperation from students and staff. The students had been involved other activities of the Wanti Sugarba Project so they were familiar with the team, the project and the aims of the study. Through the Wanti Sugarba project they were actively involved in activities to improve the health of their community and saw this nutrition survey as part of this process of empowerment.

Consent
Written consent to participate in the survey was obtained from the young people and also, in the case of primary school aged children, consent was obtained from their parents.

Ethical Approval
Ethical approval for the Wanti Sugarba Project, including this survey, was obtained from the West Australian Aboriginal Health Information and Ethics Committee, the University of Western Australia Human Research Ethics Committee and the West Australian Country Health Service Ethics Committee.
Responses to the questionnaire were entered into a Filemaker Pro database and exported and analyzed using descriptive statistics in EpilInfo v6.04d and STATA v10.

Results
All children at school on the day of the survey, who were offered the opportunity, agreed to participate. Seventy five young people completed the questionnaire. Fifty five respondents (73%) were Aboriginal. The respondents ranged in age from 6 to 18 years - 30% were primary school age (11 years or under) 4% were aged 18 and the remainder (66%) were high school students. Sex ratio was equal – 37 female and 38 male. The proportions for the Aboriginal respondents were the same as the group as a whole.

The majority of children had spent most of their childhood in the Goldfields. The structure of Aboriginal and non-Aboriginal households was similar. All children lived with at least one adult woman in the household. While two non-Aboriginal children were from single child families, all others lived in households with other children, with a slightly higher number of children in Aboriginal households (2-tailed t test, p 0.1). The average number of children living in a household was 3.6 children with a range of 1 to 8 children per household. The average number of adult men per household was 1. Women in the household were predominantly responsible for cooking and shopping and there was no significant difference between Aboriginal and non-Aboriginal households in work allocation.

The results showed more similarities than differences between Aboriginal and non-Aboriginal children’s food consumption patterns although Aboriginal children were more likely than non-Aboriginal children to consume kangaroo meat (RR 2.14, P < 0.01) and non-Aboriginal children were significantly more likely to consume coffee (RR3.21 p 0.02).

Overall 21% of children had missed at least one meal in the previous 24 hours and, although not statistically significant, Non-Aboriginal children were more than twice as likely to miss meals (RR 2.41, P 0.08) than Aboriginal children. Breakfast and lunch were the most commonly missed meals.

Diet was heavily carbohydrate based for all children and intake of fruit and vegetables was poor. Variety of fruit and vegetables actually eaten was an issue. However children reported a wide variety of experience of fruit and vegetables and the children indicated they were keen to try and grow a wide variety of fruits and vegetables.
Less than half the children could correctly state the number of serves of fruit and vegetables they should eat each day despite this being one of the points emphasized in the Wanti Sugarba project – 47% correctly identified 2 fruit and 37% correctly identified 5 vegetables. Reasons for not eating more fruit and vegetables are presented in Table 2.

**Table 2 Reasons for not eating more fruit and vegetables.**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Aboriginal %</th>
<th>Non-Aboriginal %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can’t get more vegetables</td>
<td>24%</td>
<td>25%</td>
</tr>
<tr>
<td>Can’t get more fruit</td>
<td>29%</td>
<td>25%</td>
</tr>
<tr>
<td>Can’t afford more vegetables</td>
<td>11%</td>
<td>10%</td>
</tr>
<tr>
<td>Can’t afford more fruit</td>
<td>27%</td>
<td>20%</td>
</tr>
<tr>
<td>They don’t like vegetables</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>They don’t like fruit</td>
<td>0%</td>
<td>5%</td>
</tr>
<tr>
<td>There are not enough different types of vegetables to choose from</td>
<td>18%</td>
<td>30%</td>
</tr>
<tr>
<td>There are not enough different types of fruit to choose from</td>
<td>20%</td>
<td>35%</td>
</tr>
<tr>
<td>Other (Veg)</td>
<td>5%</td>
<td>10%</td>
</tr>
<tr>
<td>No answer (veg)</td>
<td>35%</td>
<td>30%</td>
</tr>
<tr>
<td>No answer (Fruit)</td>
<td>24%</td>
<td>15%</td>
</tr>
</tbody>
</table>

**Water**

Most reported that they had drunk water in the preceding 24 hours but 3 children (4%) said they had not drunk any water in the preceding 24 hours. Thirty two percent of respondents reported drinking bottled water and the remainder reported drinking tap or rain water – 33% (n=18) of Aboriginal children reported drinking bottled water.

**Tea**

Almost half the respondents (35 = 47%) drank tea in the preceding 24 hours – the proportion of Aboriginal respondents and non-Aboriginal respondents was similar. The age range of tea drinkers was 6 to 18 years and they were fairly evenly spread across the three communities.
All but two added milk to their tea (94%), and all but three added sugar to their tea (91%) – range 1 to 4 teaspoons of sugar per cup. No child reported drinking more than 3 cups of tea per day.

**Coffee**

Coffee was not as popular as tea – only 13 (17%) respondents reported drinking coffee. Coffee drinking was more than three times as common among non-Aboriginal respondents. The age range was 11 to 17 years. All added milk and all but one added sugar (1 to 3 teaspoons per cup). Some children reported drinking as many as 7 cups of coffee per day although most reported drinking only 1 or 2 cups per day.

**Juice**

More than half the children had drunk juice in the previous 24 hours – 60% of both Aboriginal and non-Aboriginal respondents. This was mostly orange juice or an orange blend with other fruit.

**Carbonated Soft Drinks**

More than half the children (47 = 63%) had drunk carbonated soft drink (Cool Drink) in the previous 24 hours – 65% of Aboriginal children and 55% of non-Aboriginal children. Coca Cola was the most popular soft drink – with 70% of drinkers reporting they had Coca Cola. The next most popular was lemonade (Sprite). Most had chosen full sugar soft drink with only 4 reporting they had drunk a “diet” or low sugar drink.

**Milk**

49 respondents (65%) reported that they had drunk milk in the previous 24 hours. (36/55 Aboriginal = 65%) In most cases this was flavoured milk with chocolate and strawberry being the most popular flavours. Five children reported drinking coffee or Mocha flavoured milk.

**Usual intake and food preferences**

Respondents were also asked about the foods they usually ate and what foods they would choose to eat if they were available.

**Bread**

White bread was the most commonly eaten bread with 72% (n=54/75, 39/55 Aboriginal) of respondents usually eating white bread and 61% nominating white bread as their favourite sort of bread. Damper was the next favourite with 33% choosing it. Multigrain was the least popular at 7%.
Cereal
Weetbix was the most popular cereal with 63% (37 Aboriginal = 67%) of people saying they usually eat Weetbix, followed by Nutragrain, Cocopops, and porridge.

Meat
All but one respondent reported eating meat. Chicken was the most common meat consumed, followed by beef and kangaroo, although both Aboriginal and non-Aboriginal respondents reported eating a wide range of meats.
Two thirds (67%) of Aboriginal children and 40% of non-Aboriginal children nominated Kangaroo as their favorite meat, followed by chicken, beef, goanna, lamb, pork, bush turkey, turkey, emu, echidna and duck.

Almost three quarters of respondents (54/75 = 72%) reported eating meat every day. The proportion of Aboriginal and non-Aboriginal children eating meat every day was the same, 9% of Aboriginal and non-Aboriginal children reported eating meat only occasionally.

Eggs
Eggs were popular for both Aboriginal and non-Aboriginal respondents - 85% reported eating eggs – all ate chicken eggs and one also said they ate duck eggs. More than one third (36%) ate eggs every day, 22% ate eggs once a week and the remainder ate eggs occasionally.

Fish
Despite the remote location 66 (88%) reported ever eating fish (47 Aboriginal 85%). Five respondents (7%) said they eat fish every day but most (42/66 = 64%) said they only ate fish occasionally. The types of fish consumed reflected availability with 76% reporting that they had eaten “Fish and Chips”, frozen fish (62% had eaten “fish fingers”) and canned tuna (39%) or sardines (28%). Proportions were similar for Aboriginal and non-Aboriginal children.

Fruit
Almost ¼ (22%) reported that they had not eaten fruit in the previous 24 hours. Of those who had eaten fruit almost half (49%) had eaten apples. Others had eaten pears, oranges, bananas and lemons.
Reasons given for not eating fruit particularly related to availability and desire.

- “because there was no fruit to eat”
- “because I don't like it”

In response to a question about why people should eat fruit most respondents (55/75 = 73%) gave a general answer about the health benefits of eating fruit

- “because they are a healthy snack”
- “because it will get them active to do more things that they wanted to do”
- “because it has a lot of vitamins”

Vegetables
14 (19%) responded that they had not eaten any vegetables in the previous 24 hours. Reasons for not having eaten vegetables related particularly to lack of availability and access.

- “didn't have any”
- “wasn't home”
- “didn’t cook any”

The selection of vegetables eaten in the previous 24 hours was fairly limited – broccoli, cauliflower, corn, peas, capsicum, carrot, lettuce, cabbage, asparagus, potato, pumpkin, salad, sweet potato, beetroot, and beans.

In response to a question about why people should eat vegetables most respondents (52/75 = 69%) gave a general answer about the health benefits of eating vegetables

- “So more healthy”
- “make them have strong body”
- “nothing stops my family from eating vegetables”

Nuts
Eighty percent (n=60) (Aboriginal 42 = 76%) reported that they had ever eaten nuts with peanuts (77%) the most common. Respondents had also eaten almonds (51%), cashews (51%), hazelnuts (48%), pistachio (41%), quandong (28%), macadamia (27%), brazil nut (21%), pecan (16%) and sandalwood (8%). Proportions were similar for Aboriginal and non-Aboriginal respondents.

Legumes
One child reported ever eating baked beans but there was no other evidence of legume consumption in this survey.
Similarity

There was a high degree of similarity between the responses of Aboriginal and non-Aboriginal children although Aboriginal children tended to have larger households. (Table 3)

<table>
<thead>
<tr>
<th></th>
<th>Aboriginal</th>
<th>Non-Aboriginal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male Sex</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Age 6 to 11</td>
<td>31%</td>
<td>30%</td>
</tr>
<tr>
<td>Age 12 to 18</td>
<td>69%</td>
<td>70%</td>
</tr>
<tr>
<td>BMI over 25</td>
<td>45%</td>
<td>67%</td>
</tr>
<tr>
<td>BMI over 30</td>
<td>22%</td>
<td>30%</td>
</tr>
<tr>
<td>Haemoglobin under 110</td>
<td>17%</td>
<td>0</td>
</tr>
<tr>
<td>Childhood in the Goldfields</td>
<td>78%</td>
<td>60%</td>
</tr>
<tr>
<td>Zero adult men at home</td>
<td>7%</td>
<td>0</td>
</tr>
<tr>
<td>Zero adult women at home</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Zero other children at home</td>
<td>0</td>
<td>10%</td>
</tr>
<tr>
<td>More than 2 other children at home</td>
<td>51%</td>
<td>35%</td>
</tr>
<tr>
<td>Mother does cooking</td>
<td>58%</td>
<td>45%</td>
</tr>
<tr>
<td>Mother does shopping</td>
<td>58%</td>
<td>75%</td>
</tr>
<tr>
<td>Missed meals</td>
<td>16%</td>
<td>35%</td>
</tr>
<tr>
<td>Take away for lunch</td>
<td>29%</td>
<td>20%</td>
</tr>
<tr>
<td>Drank Water</td>
<td>96%</td>
<td>95%</td>
</tr>
<tr>
<td>Drank Tea</td>
<td>47%</td>
<td>45%</td>
</tr>
<tr>
<td>Drank Coffee</td>
<td>11%</td>
<td>35%</td>
</tr>
<tr>
<td>Drank Juice</td>
<td>60%</td>
<td>55%</td>
</tr>
<tr>
<td>Drank Soft Drink</td>
<td>65%</td>
<td>55%</td>
</tr>
<tr>
<td>Drank Milk</td>
<td>65%</td>
<td>65%</td>
</tr>
<tr>
<td>Eat White Bread</td>
<td>71%</td>
<td>75%</td>
</tr>
<tr>
<td>Eat Weetbix</td>
<td>67%</td>
<td>50%</td>
</tr>
<tr>
<td>Eat meat every day</td>
<td>71%</td>
<td>75%</td>
</tr>
<tr>
<td>Eat Kangaroo</td>
<td>85%</td>
<td>40%</td>
</tr>
<tr>
<td>Kangaroo is favourite</td>
<td>67%</td>
<td>40%</td>
</tr>
<tr>
<td>Eat eggs every day</td>
<td>29%</td>
<td>35%</td>
</tr>
<tr>
<td>Ever eaten fish</td>
<td>85%</td>
<td>95%</td>
</tr>
<tr>
<td>Ate Fruit Yesterday</td>
<td>78%</td>
<td>80%</td>
</tr>
<tr>
<td>Ate Vegetables Yesterday</td>
<td>80%</td>
<td>75%</td>
</tr>
<tr>
<td>Ever eaten nuts</td>
<td>78%</td>
<td>85%</td>
</tr>
</tbody>
</table>

Table 3 The dietary experience of Aboriginal and Non-Aboriginal children in the Goldfields
Discussion

The average life expectancy of Indigenous Australians is significantly less than non-Indigenous Australians. Life expectancy at birth for Indigenous West Australians is estimated to be shorter than for non-Indigenous West Australians by 12.5 years for men and 14 years for women. In rural and remote areas the disparity between life expectancy for Indigenous and non-Indigenous Australians is even more marked than in urban areas. In 2003 Vos et al found diet was found to be a contributing factor to the disparity in health status between Aboriginal and Torres Strait Islander people and attributed 16% of the disparity to high body mass index, 7% to high cholesterol and 5% to low fruit and vegetable intake.

Being overweight or obese are increasing problems in the Australian population generally and a particular problem among Australian children. Obesity is a very significant risk factor for the development of hyperinsulinism, TD2M, Syndrome X and renal disease. Rates of being overweight or obese are high in many Aboriginal communities, with up to 20% of adults either overweight or obese. The Children’s Nutrition and Physical Activity Survey in Australian in 2007 found that 72% of children were in the healthy weight range for height and age, 5% were underweight and 23% overweight or obese.

The Wanti Sugarba study included clinical assessment of 138 children, we found a high prevalence of nutrition related disease in the children of the northern Goldfields of Western Australian – being overweight or obese was prevalent with a much larger proportion of overweight or obese children than national figures suggest. The Tjitjiku Myaee nutrition survey suggests some reasons why nutrition related disease is so prevalent in this region

Fruit and vegetable intake is poor

In 2004-05 one in five (20%) Indigenous people living in remote areas reported no usual daily fruit intake compared with one in eight (12%) in non-remote areas. The difference was even greater for vegetables, where 15% of people in remote areas
reported no usual daily intake compared with only 2% in non-remote areas. In our study 22% had not eaten fruit and 19% had not eaten vegetables in the preceding 24 hours suggesting and even greater disparity.

The NHMRC guidelines recommend a minimum of five serves of vegetables and two serves of fruit per day and this is the message promoted through the “Go for 2 and 5” program in Western Australia (http://www.gofor2and5.com.au/). We found there was good recognition of the need to eat fruit and vegetables even though more than half the respondents could not identify the correct number of serves. There may be many reasons for this – lack of exposure to the message due to poor literacy, poor exposure to public health messages, or perhaps it seems unobtainable so the message is ignored.

The main barriers to increasing fruit and vegetable intake were that families could not afford more fruit and vegetables, could not get more fruit and vegetables or there was insufficient variety available.

There is evidence that poverty contributes directly to population risk of disease, especially chronic diseases such as cardiovascular disease and diabetes as people cannot afford or are unable to obtain healthier foods such as fresh fruit and vegetables. Poor diet in childhood will result in exacerbation of risk factors at an early age.

Our own experience living in the area where this study was conducted confirmed to us the limited availability and high cost of healthy food – the quality and variety of foods, especially fresh fruit and vegetables was poor and the cost was high. There was no shop in Mt Margaret and there is one small general store in Leonora and Laverton. Take away food was available in Leonora and Laverton from a take away food shop and the roadhouses attached to petrol stations. Deliveries of fresh fruit and vegetables to the stores come by road transport, usually once a week. It was our experience that it was often not possible to buy common fresh fruits and vegetables such as tomatoes, zucchini or lettuce as none were available. If they were available we found prices to be generally double or more than the price we would have expected to pay in Kalgoorlie (the nearest regional city). Locally grown fruit and vegetables were not available to purchase at all in any of the locations in this study. This is consistent with findings in other remote areas.
The children in this study ate a lot of highly refined carbohydrates and were not meeting recommendations for healthy diet

The dietary guidelines for Australian children and teenagers \cite{326} suggest that children aged 8 to 18 years should have, per day:

- 6 to 11 serves of Cereals – especially wholegrain cereals
- 3 to 4 serves of Vegetables or legumes
- 1 to 3 serves of fruit
- 2 to 3 serves of diary
- 1 serve of meat, fish, poultry, nuts or legumes

The responses from the children in this survey suggest that many are not meeting these targets, they appear to be consuming more carbohydrates than recommended and these are predominantly refined carbohydrates, with a high intake of high sugar drinks such as carbonated soft drink, juice and flavoured milk. There is increasing evidence that people who are at risk of T2DM, including those with a family history of diabetes and Indigenous people, should not have such a high intake of carbohydrates, especially refined carbohydrates.\cite{339-345} The Wanti Sugarba study suggests that hyperinsulinism is prevalent in this community with 17% of children having acanthosis nigricans – a clinical indicator of hyperinsulinism and so are at high risk for the development of T2DM and the associated complications.\cite{178-180, 182, 183, 346}

Meat intake is high and there is a high consumption of, and preference for native animal meat, especially Kangaroo meat.

Store bought meat in the northern Goldfields tends to be expensive and poor quality, often high in fat. In contrast native Australian animal meat is high in poly unsaturated fatty acids (PUFA), high in iron and low in saturated fat.\cite{347-349} The children in this study showed a clear preference for native animal meat – and would eat it in preference to other meats if it was available but this can be a problem. Currently access to native animal meat is difficult – some people continue to hunt but this is limited. Game close to settlements is largely “hunted out” so hunters must travel some distance – a suitable vehicle is required and sufficient fuel. Hunters now hunt with guns as this is the most efficient means and game is often sparse – to own a gun in Western Australia a person must have a gun license and be able to show that the gun will be stored in an approved gun safe which is bolted into a house. Therefore a person must have a permanent house and be able to buy and install a gun safe and in remote areas this is not always possible. In addition a hunters need access to land in order to hunt and this can also be a problem – in the northern Goldfields of Western Australia, as in many other areas, most of the land is under pastoral or mining lease so
access can be limited. The penalties for not complying with these requirements can be severe – large fines and even imprisonment. Wild caught native animal meat cannot be sold for human consumption in Western Australia as it has not been butchered through an accredited abattoir. Despite the difficulties native animal meat is highly prized by Aboriginal people. Beliefs about the medicinal and spiritual value of native animal meats are widely held in the community but it is only the most committed hunters who are able to secure valuable native animal meats for their families. However this does represent an area for intervention.

This study also found that there is a high degree of similarity between the nutritional experience of Aboriginal and non-Aboriginal children in remote areas – food experience relates most to availability and cost, rather than racial or cultural differences.

Food security is a problem. The World Food Summit of 1996 defined food security as “When all people at all times have access to sufficient, safe and nutritious food to maintain a healthy and active life”. Food security requires adequate food availability, adequate access to food and appropriate use of food to provide good nutrition. It is clear that affordability and supply of food are real problems in the Northern Goldfields. In our survey not only was the type of food consumed a problem but the availability of nutritious food to purchase a problem. Household food supplies were an issue - 1 in 5 children reported missing at least one meal per day. Breakfast and lunch were the most commonly missed meals. Non-Aboriginal children were at even higher risk of missing meals than Aboriginal children. The reasons for the difference between Aboriginal and non-Aboriginal children are unclear – but Aboriginal children who are at risk of missing meals at home may have more options – in most cases they would have relatives living nearby so if they were hungry they could go to the house of family members and be fed – non-Aboriginal families may be more likely to be isolated.

Limitations
There is very little information about what children, especially children in remote areas, are actually eating – possibly because these are difficult studies to do. This study was no exception.

Sample size is small because the population is limited. The questionnaire was, in most cases, administered at school and the response rate was limited by school attendance, which is highly variable in these communities. In this study only 25% of “eligible” children completed the survey. We defined “eligible” as enrolled at a school in the
region. The schools had been extensively consulted and involved in the Wanti Sugarba project and we enjoyed good cooperation and the response represents all eligible children at school on the day of the survey and not involved in off campus activities. The surveys were conducted in November and December 2007 – the end of the school year, while enrolment figures represent all the children enrolled at any time during the year – mobility is a problem for the communities in this region so the number of children actually attending each school is likely to be less than the total enrolment but we were unable to ascertain what the difference would be.

**Literacy and language**

Many children in the three remote communities have poor literacy and some do not speak standard English. The Western Australian Child Health Survey [327] found that 60% of Aboriginal children in the region had low academic performance. We did find that many children required assistance to complete the questionnaire so there may have been loss of some information due to errors in translation or understanding of the questions.

This survey might represent a “best case scenario” and underestimate the true rates as most of the surveys were completed at school so the sample may be biased towards children who have more functional or competent families – and children who were not at school might be at higher risk.

**Areas for intervention**

Overcoming poverty and commercial food supply issues are long term issues and beyond the scope of most interventions but there are areas that might make a real difference in nutrition and therefore reduce the risk of disease for children in the Northern Goldfields.

Improving household nutrition through education about nutrition, cooking and gardening are areas that are worth investing in and these are key facets of the Wanti Sugarba project and the Western Desert Kidney Health Project.

School based programs might be an important way to improve nutrition in at risk communities. The Red Cross Good Start Breakfast Program and Foodbank School Breakfast programs are available across Western Australia and provide a valuable safety net for children at risk.
Local initiatives such as the Mt Margaret School lunch program (supported by a nearby mining company) are very important. For this program the mining company supplies fresh fruit, sandwich fillings, bread and fruit juices and community volunteers make the lunches for the children. Corporate and business support for community nutrition programs can be beneficial for the whole community as healthy families support a healthy workforce.

School nutrition programs such as these breakfast and lunch programs help, not only to provide good nutrition to the children, but also provide a valuable opportunity to discuss healthy eating with the children and community volunteers. The children carry their knowledge home and assist with informing the whole family. Community based programs such as school and community gardens, the planting of fruit trees and vegetables in public gardens and access to community support programs such as Foodbanks and community nutrition support and education programs are also good investments in the future health of a community.

Advocacy to improve the standard and supply of food to remote areas is also worth the investment – the ancient African proverb that “it takes a village to raise a child” is really worth considering. It should be unacceptable in Australia today that children do not have access to decent, fresh food. In the long run it is the nation that will pay through the burden of disease and loss of potential that will result from poor nutrition in childhood – and, in the 21st century, it should be easy to provide children with 2 serves of fruit and 5 of vegetables every day in Australia.
A complex Aboriginal health project and the challenges for evaluation
Jeffries-Stokes C, Stokes A, McDonald L, Stokes S, Daly J.

This paper, published in 2011 in the Australian and New Zealand Journal of Public Health, was prepared at the beginning of the WDKHP, considers the challenges we anticipated, and lessons learnt during the pilot project, in developing and delivering such a large, complex project.

The paper can be found in Appendix 1.
A complex Aboriginal health project and the challenges for evaluation

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2011 vol. 35 no. 3 p 204 - 206

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Indigenous ill-health is a source of concern internationally. The Australian government is committed to reducing the 17-year gap in the mortality rates of Indigenous and non-Indigenous Australians. Kidney disease is of particular concern because its prevalence in Aboriginal Australians is more than six times that of other Australians and the discrepancy is even higher in communities living in the remote interior of the country. [351] The treatment of kidney failure by dialysis or transplant is expensive. Patients from remote areas have to relocate to cities for treatment and here they are isolated, dislocated and distressed. Given these problems, it makes sense to concentrate on devising effective prevention programs.

The Western Desert Kidney Health Project was designed to address the need for early detection and prevention of kidney disease. It also addresses type 2 diabetes which is both a precursor for kidney disease and itself a significant source of ill-health. The current focus of this project is on ten remote, predominantly Aboriginal communities, near Kalgoorlie, in the Western desert of West Australia. The project has evolved over many years, with considerable institutional support. As far as possible, team leaders are well known in the community. They include a paediatrician and an experienced Aboriginal Health Worker both of whom have long worked to improve the life and outcomes of the community. A local arts worker has been trained as a health worker. A key team member from outside is a project designer and lobbyist with a long association with team members. Together the core team members have high levels of clinical skills, social skills and some have cultural authority in these desert communities. They understand the complexities of the communities and share the grief and dismay caused by these diseases. Additional team members (volunteers, rural
medical students, and visiting artists and performers) share as many of these characteristics as possible. The approach of the team was piloted and refined in consultation with the communities who therefore have a sense of ownership. It goes without saying that a project as complex as this does not happen quickly.

The first aim of the project is to screen everyone in the ten communities, assessing the prevalence of, and risk factors for renal disease and Type 2 diabetes, starting with children, then adults. A first obstacle that the team faced was the lack of space, resources and services in many of the communities – there may be no clinic, no accommodation for team members, precarious supply of utilities such as water, electricity and communications. The team turned to institutional funders to cover the cost of two large, special-purpose, self-sufficient trucks. The first truck is a mobile screening unit from which test results are available on the spot in about ten minutes. A second truck provides accommodation for project staff, and material for additional activities.

Included in the aims of the Western Desert Kidney Health Project is an assessment of the age at which disease or indicators of risk first appear in children. At the start of the program staff were startled to find both diabetes and the early stages of kidney disease in primary school children, younger than 12 years. Anyone with significant risk factors or established disease is referred to local medical services for further assessment and treatment. While treatment can arrest the decline in kidney function, the drugs are expensive and have to be collected once a month. The drugs can be obtained free from an Aboriginal Health Service clinic but there are often long queues and time delays to access the service. Some communities do not have an outlet for this scheme and people have to travel hundreds of kilometres to get free access. Ideally clinical treatment is accompanied by prevention programmes, educating patients about risk factors with a view to reducing exposure to risks. A comprehensive diabetes program should include a comprehensive change of diet, increased exercise and a reduction in stress. \[352\] Even under ordinary circumstances many people are unable to make long-term changes of this kind. Simple interventions like information and counselling need to be enhanced with additional forms of support and attention before there is an improvement in health. \[353\] On the other hand, because of a sense of past neglect, people in remote communities may be more responsive to health messages. \[320\]

The first challenge for the project is to encourage people to present for testing. Fearing both the disease and the difficulties attending treatment, some community members may avoid the house-to-house calls with invitations to attend the screening program
and so this task needs to be carried out by a team member recognised and trusted by the community. When people do present and are given the news that they, or their loved ones, do indeed have kidney disease, they need a glimmer of hope, they need to know that something can be done about it and they need a trusted source of information and support. People’s capacity to come to terms with disease improves if there is support from family and community, if they know that their community understands what needs to be done. The prevention program is challenging, requiring changes in long-established dietary practices, including some that may be an intrinsic part of family rituals, and this requires a shift in the cultural understanding of the disease. The people called upon to make these changes may themselves be suffering economic hardship and social alienation. Such a complex problem deserves a complex response so it made sense to accompany the screening service with a program that engages with long-established social and cultural practices that need to change if prevention is to succeed. Located in the second purpose-built truck are the materials for an arts program. Team members work alongside experienced visiting artists and performers to engage communities in song, dance and other creative projects that are vigorous, engaging and fun. People who resist screening can be drawn into these activities and reassured: the projects build up new ways of expressing hopes and fears, and generate new ways of understanding the disease.

This project has been carefully designed to engage with the community, using the arts and culture sectors to complement clinical services and to build a collective commitment to change. The project is drawing on a growing understanding in the health sector that arts programs are an important way of changing both individual and community capacity for fundamental change to a way of life. While complex, multi-layered projects are promising, they are extremely difficult to evaluate. Clinical assessment, repeated annually for three years, can assess improvements in renal health but whether the programs show a clinical benefit or not, the effect of the arts and culture program on the community also needs to be assessed.

An Evaluation Model

The integrated clinical/arts program addresses kidney health, taking into account everything from human physiology to culture. Conceptualising such a multi-faceted program requires a systemic approach which recognises that we are dealing with different levels of a complex system, one in which these different levels interact, both interfering with and facilitating change. Let us start at the micro-level, that of physiology, the focus for diagnosis and treatment. But the physiology belongs in a person who has to make sense of the disease and the treatment process, in turn
needing support and understanding from family and community. These groups have their own understanding and values which mediate their response to individual needs. Community understanding derives, in part, from social institutions like the education system. The capacity for individuals or communities to effect changes is very much limited by the economic system that circumscribes the financial resources available to them, at the same time determining funding for screening and treatment facilities. Lastly, there are cultural traditions with values and priorities that people see as good and proper and these may vary considerably between communities with different cultural traditions.

A prevention program that addresses anything as pervasive as reducing the risk from diabetes and renal disease would, ideally, effect change at each level of the system that links individual to community and culture. Positive change in one level can then reinforce and can be sustained by change in the other. A person’s physiological state can be changed by medication with changes in risk measured by changes in blood pressure, blood sugar, haemoglobin, cholesterol, lipids, haematuria and albumin-creatinine ratio. Logging these changes in all members of ten communities represents a considerable logistical challenge but is relatively straightforward. After that the difficulties multiply. Individuals in screened communities often welcome educational materials explaining the anatomy, physiology and pharmacology of the disease, emphasising prevention and management strategies. These presentations are, ideally, tailored to age and level of understanding and increased understanding can be evaluated in feedback sessions. This again is relatively straightforward. At this stage better informed individuals may be eager to effect change in their lives but their capacity to do so is subject to the intricacies of family and community living. It may be near to impossible to assess response to the requirement for dietary change when, for example, it disrupts the role of food and drink in rituals of family mealtimes or community gatherings. The most resistant to change is likely to be the negative effect of the economic system. When people who are poorly paid or unemployed live in communities with a lack of refrigeration or fluctuations in the power supply, the cost of fresh food in the local community shop or supermarket may be too high, and the quality suboptimal.

More broadly, at the cultural level, remote-living Aboriginal families may be subject to multiple inequities extending well beyond economic disadvantage: high levels of serious illness and death, isolation and discrimination, incarceration and loss leading to grief, guilt and depression, perhaps contributing to family and interpersonal violence and substance abuse. The accumulation of these stresses affects not only individuals
but whole families, altering hormone levels and contributing to disease. The challenge, and it is a big one, is to acknowledge this social superstructure of disadvantage and to try to lighten the load.

These are the high aims of the program but how are they to be realized, and evaluated?

**How the arts intervention works**
The various, interactive levels of the system make it difficult for individuals to make sustained, radical change to their lives – but what is difficult is not impossible. The basic assumption of the arts program is that individuals know about their communities and it is they who can identify opportunities for change. The arts team’s role is to engage the community in activities that build skills and promote understanding.

An arts activity may commence with researchers and visiting artists teaching people a song and dance routine. They may draw on the traditional arts like sand painting and the cultural practice of storytelling to engage people in conversations about their fears and where redemption may lie. Commonly they devise dramatic presentations of ways to fight the ‘sugar monster’ resulting in a tale about the defeat of kidney disease and diabetes.2 In the process, community members may see better opportunities for effecting change and researchers will get a better insight into the problems that the community faces.

But how is this intimate process to be evaluated? One possibility is that the activities themselves and the art works created may be a direct source of joy that can be assessed in photographs showing the smiling faces, followed by film to show the generalizability of the joy across the groups of participants. If joy means less stress, the creative process has done its work and this should flow through to the clinical measures. When the creative project involves vigorous exercise associated with dancing or drumming, then documented participation should again count as a benefit. The various artistic creations are then brought together in a community performance, a celebratory event, often a large procession that tells the story of local Aboriginal history, with music and song, masked dancers, monsters (like the sugar monster) and heroes (good food and exercise) who defeat the monster. In the process, knowledge of disease and opportunities for change are built into community understanding.

Importantly, the products of the creative process provide culturally specific insights that can be recorded, filmed and broadcast well beyond the community so that there is growing recognition of Aboriginal history and traditions, perhaps even a reduction in racist views. The artistic quality of these products measures the success of the project...
but it also provides materials that can be used to enhance future information and education sessions, speaking to people in their own language, drawing on their own cultural traditions.
In creating these objects or routines, people learn new skills whether it is in making a mask for the sugar monster or dancing with joy at his defeat. Perhaps most importantly, when public display or performance is greeted with applause from community (again documented by photograph and film) this could be the first step to self-confidence in taking the steps required for preventing disease.

Finally, the community experience can be assessed by observation, by one-on-one interview with those people who had most to gain from the process (those diagnosed with disease) and in focus group discussions with key people involved in community change.

**Conclusion**

Kidney disease and diabetes are a scourge in Western Australia’s desert communities. An efficient screening service is a necessary step towards improving health but more is needed. Entrenched inequities need to be acknowledged and, ideally, additional effort should go into addressing the social, cultural and economic obstacles to change.

The Western Desert Kidney Health Project represents an attempt to integrate a clinical program and an arts intervention with the aim of promoting opportunities for the changes that individuals and communities must make if health is to improve. This program is complex and multifaceted and it will be a difficult one to evaluate. We welcome suggestions for more effective ways to demonstrate the value of a program that produces performance rather than performance indicators. Finally, it is worth reflecting on those levels of the system that are the biggest impediment to change and these are found in the economic system. Reasonably priced fresh fruit and vegetables are often not available but somehow the delivery system is set up efficiently enough to ensure that there is always a refrigerator dispensing caffeine and sugar-rich cans of soft drink.
Pulkurlkpa – The Joy of Research in Aboriginal Communities

This chapter discusses the importance of Joy and the use of community arts for engagement, education and empowerment of the communities in the Western Desert Kidney Health project.

It has been published as:
Pulkurlkpa – The Joy of Research in Aboriginal Communities.

Abstract

Research in Australian Aboriginal communities is difficult unless meaningful community engagement can be achieved. The Western Desert Kidney Health Project (WDKHP) is an example of a research project that grew from the community. Community consultations identified high levels of stress as an important factor in the poor motivation and lack of resilience in the lives of many Aboriginal people. This was thought to be partly due to a lack of “Pulkurlkpa” – a soul felt happiness or deep joy.

Aims
The WDKHP aimed to develop and evaluate community education and community development strategies to reduce the prevalence of the risk factors for T2DM and kidney disease that would be engaging, enjoyable and empowering for participants.

Methods
The team was led by a senior woman of the main tribal group of the region, with strong cultural and family connections who is an experienced health researcher. Cultural considerations were of primary importance in the development of the research team and protocols. The project team presented health promotion strategies to the communities using a Community Arts for community development model to provide opportunities for meaningful reciprocity and Pulkurlkpa.

Outcomes
Almost 80% of the Aboriginal population participated in this research and almost 60% of the overall population were involved in the arts residencies.

Conclusions
Developing long term relationships with Aboriginal researchers who are embedded in the community, have cultural authority, understand the cultural nuances and are able to engage the community leaders is critical to research in Aboriginal communities.

www.westerndesertkidney.org.au
Meaningful research in Australian Aboriginal communities, whether remote or urban, is hard. There is often tension between the world view of Aboriginal people and the academic demands of research. Ideally research should be led by Aboriginal people but it may be difficult to find people who have seniority in the community and the necessary research, clinical and literacy skills for these leadership roles. The role of the Aboriginal researcher is complex but critical to success. Aboriginal research team members should shoulder responsibility for the research and the actions of the research team in the community, requiring a large amount of trust and commitment from them. The practical problems of conducting research in remote communities may be at odds with the procedures and policies of academic institutions. These issues can be difficult to overcome, but not impossible if sufficient commitment is given to developing relationships and engaging fully with the community. It takes time, often many years, but the rewards for the community, the team members and for research organisations can be great.

The Western Desert Kidney Health Project (WDKHP) was conducted in the Goldfields of Western Australia between 2010 and 2014. The WDKHP was developed to investigate the factors contributing to, and associated with the high rates of Type 2 Diabetes and renal disease in the Goldfields. At the same time the aim was to develop research skills in the community, while developing community capacity to combat these diseases and contribute to Pulkurlkpa – a deeply soul-felt sense of joy, hope, optimism and resilience.

Chief investigators A and B for this project are embedded in the community – they are sisters in law. CIB is a senior woman of the 3 main tribal groups for the region - the Wongutha, Mulba-Ngadu and Anagu tribes. She is also an accomplished and well known musician and artist. CIA is not Aboriginal and is a doctor. The third member of the development team is a senior Community Arts practitioner, who, although not living in the Goldfields, has long relationship with the community. This team has been working together in research and arts in the region for more than 20 years. The idea for the WDKHP began as a series of conversations at funerals – funerals of community members who had died from renal disease, diabetes or associated complications. The leading cause of avoidable mortality for Aboriginal people in the Goldfields of Western Australia is Type 2 diabetes [354]. The demand from the community that something be done to prevent this loss of life and potential was brought to our chief investigators as community members with skills and knowledge.
During development of the proposal CIB visited every community to ensure wide consultation, in accordance with cultural protocols, and to invite participation. Her cultural standing along with her research experience in this community meant that she was able to identify and talk frankly to senior community members and elders about the difficulties, cultural and practical, in undertaking such an extensive project, and they made meaningful input into the study design. Consultations occurred around camp fires, in kitchens over cups of tea, at social events, arts workshops and at formal community workshops.

The community consultations identified stress as a very significant factor in poor health and in the development of unhealthy lifestyle practices. Stress was seen to be multifaceted but largely contributed to by a burden of grief, guilt, anger, frustration and bitterness that many people carry. The high levels of stress seemed to contribute to poor motivation and lack of resilience in the lives of many Aboriginal people and communities. There was a lack of “Pulkurlkpa”.

The concept of “Mara Yungu” was important in the study design – this roughly translates as “to offer your hand”. It has many overlapping meanings - it can mean the way you offer your hand when meeting someone for the first time which, for the Goldfields and Western Desert tribal groups, also implies an opening of your spirit and a sharing of trust. It can mean offering your hand to help someone, ie “giving someone a hand” and it describes the process of two-way learning where people contribute different skills or knowledge to solve a common problem.

The delivery of the key health messages needed to be fun, exciting and empower participants to find innovative ways to overcome the challenges to healthy behaviours. Many of the changes would require not only personal but systemic change. An innovative approach and a highly skilled team were needed. Team members (research staff and artists) had to have sensitivity and skills to be able to work with children and communities that may have suffered significant trauma. They needed to be able to work within the complex “skin” system. Aboriginal team members had to be respected community members who could negotiate the subtle and demanding cultural considerations, complex kin relationships and who were also skilled health workers and artists. They needed to be open to mentoring and working with the non-Aboriginal members of the team. All team members needed to be able to live and work together, juggling family and community responsibilities while away from home for weeks at a time. They needed to be flexible and able to cope with the dynamic nature of life in remote areas with changes in weather, in community priorities and within the team,
able to change the process as the need arose. Partnering with an Aboriginal Community Controlled Health Service and an Aboriginal community based arts and cultural organisation allowed us to have a core of two Aboriginal researchers – one male and one female, and a pool of other appropriate Aboriginal researchers who rotated through the team. The team was complimented by artists, medical students, volunteer researchers and doctors (Paediatric registrars) who received invaluable cultural mentoring from the Aboriginal team members and in turn supported the Aboriginal researchers in literacy and clinical skills. Non Aboriginal team members were introduced to the community as friends by well-known and respected Aboriginal researchers who were also community members - immediately giving them family and “skin” status\[358\]. The great strength of this project was the coherent patchwork of people with a wide variety of skills, led by a senior and experienced Aboriginal researcher. As one of the artists expressed it:

“Even if you have never worked with an Aboriginal community before, you are able to cope as you’ve been shown, you know how to present your hand properly.”

What did it all look like?
The WDKHP team spent about a fortnight in each community annually for 3 years, collecting data on health status using a mobile clinic truck equipped with point-of-care machines. These machines were important in addressing the cultural concerns about collection and use of blood and body fluid samples – all samples were consumed by the testing and then disposed of, no samples were sent away or stored. Extensive history was collected from participants and recorded on paper data sheets, usually in a private but open air environment. (Figure 5) This was considered important as it demonstrated privacy without secrecy.
Phase 1 – Getting the Messages across
The first priority was to get the health messages into a form that would be suitable, attract the interest of community members and support cultural identity and pride. Community arts has community participation and dialogue at its core [11], we had used it successfully for many years. [2-5, 8, 9] We chose it as the vehicle for community development, engagement, education and to support the development of resilience. It allowed us to address many issues that would otherwise be beyond the scope of the project and allowed for meaningful reciprocity as well as opportunities for Pulkurlkpa. [28]

On advice from senior Aboriginal community members we used the traditional sand drawing technique of Milbindi to explain our plans and the health messages. This technique lent itself to animation.

Senior animation artists, with extensive Community Arts experience, were engaged as artists in residence to focus on the children, working through the schools. The Aboriginal researchers brokered culturally sensitive stories, incorporating the key health messages and assisted the visiting artists to identify key community participants, who had cultural authority, who could oversee the arts activities. The children transformed the story into an animated movie using images drawn in sand gathered from their own community (Parna – our country). The stories reflected unique features...
of the community and translated the health information into a form relevant to each community. At the end of each residency the whole community was invited to the movie premiere, the results of health screening were presented and a healthy supper was served. The creators of the animations were applauded and celebrated.

Phase 2 – Building capacity
The focus in phase 2 was to consolidate messages and to build capacity and problem solving skills. Sculpture, music and dance were the mediums were used to demonstrate innovative approaches to a problem and a stepwise process to achieve an outcome. In one community the children learned how the kidney functions to filter the blood – so they designed and built a water sculpture demonstrating the important filtering elements (Figure 6)

Figure 6 Photo Matt Scurfield – Kidney Water Sculpture
In another community, where many children reported feeling “invisible” and where there had been a number of youth suicides, they designed and created aprons showing how kidneys work and then wore these aprons as part of a portrait photography experience demonstrating “How amazing I can be”. (Figure 7)

Choice of art form was decided after consultation with community members about what would be most suitable for their community.
Phase 3 – Helping the Community find it’s Voice

Change in health behaviours, especially diet, requires major effort and community structural change. An important aspect of the project was to equip community members to advocate for change in their own communities. Singing, especially choral singing, was chosen as the medium because of the health benefits of singing, to give community members the skills and confidence to speak up for their communities, and to build the sense of community and shared purpose \[359-364\]. Choral singing has a long history in Aboriginal communities \[16\] and there was great enthusiasm in the community forums for it to be included.

An internationally recognized Choir Master, accompanied by CIB, spent several days in each community conducting singing workshops, with particular focus on the children. Community members then rehearsed by themselves over 6 months. The WDKP field work culminated with a public performance by the choir, presentation of results to the community and a celebration in the major regional town. (Figure 8)

Figure 8. Photo Matt Scurfield – Turlku Birni Choir Performance

Did it work?
Participation in the study was a marker of success of the engagement strategies. Almost 38% of the total population in the study communities, including 80% of the Aboriginal population, (n=1115) enrolled and participated in the study. In some
communities there was 100% participation. More than 2000 people, including all the children in the 10 community schools (n=1300), took part in the arts activities either as workshop participants or audience.

We used a number of different strategies for evaluation of the project – measuring change in health measures over time, questionnaires administered at the time of each data collection, participant observation strategies, targeted interviews and an innovative project using participatory video making. The evaluation strategies and results are reported elsewhere but in summary there was only positive feedback from the community except for expressions of dismay that the project was limited to 3 years. (Table 4)

| “It’s Palya!” – 24 year old Aboriginal man (Palya = really good) |
| “Indigenous people singing together achieve anything” – 63 year old Aboriginal woman |
| “It’s a great experience for everyone and community come together” – 16 year old Aboriginal man |
| “It’s medical evidence on wheels” 13 yr old Aboriginal boy |
| “Thank you guys for letting us be a part of something Fantastic!!” 42 yr old Aboriginal woman |
| “This project was a project that we knew and understood, that we owned” 35 Year old Aboriginal woman |

Table 4: Quotes from Evaluation of the Western Desert Kidney Health

There was clear demonstration of the absorption of the messages in the changes observed in the communities. Communities have been able to use the health status information, knowledge and support provided by the WDKHP to advocate for their communities and achieve change – all 5 towns now have a grocery store with an emphasis on fresh foods, prior to the study fresh fruit and vegetable supply was poor and two towns had no store. Two towns and two communities have planted fruit trees
in public gardens. All of the remote community schools and most of the town based schools now have new fruit and vegetable gardening programs.

Wider recognition has been very important in providing kudos and pride for the participants and the communities. The art works produced during the project demonstrate how the key health messages have been absorbed by the children who created them and communicated to a wider audience. The sand animations particularly demonstrate the translation of the key health messages and have received critical acclaim. They have been widely viewed, via the website (www.westerndesertkidney.org.au). “Alfie the Tooth Fairy” was awarded the MJA Ross Ingram Memorial Competition Prize in 2011[365] (http://youtu.be/qSGgYIdiai0).

The Choir Project has led to the formation of an ongoing choir for the region. The choir was invited to perform at major national arts festival in 2014 (The Fairbridge Festival and the National Regional Arts Summit). Several of the young choir members have been offered places in highly competitive tertiary music and performance courses. A skills development program is being developed with a tertiary college of the arts to be delivered to the children in the region annually.

The WDKHP was awarded “Good Practice” recognition by Creative Partnerships Australia, a national competitive program, in 2013.

So …

Life in Aboriginal communities can be a rich and rewarding experience if children have resilience and are able to make the most of opportunities.

Community Arts is a joyful, exciting and engaging method for health promotion, community development and the development of resilience, especially for children. This method can be used to provide immediate, meaningful reciprocity in community based research.

Despite the arts residencies being quite short in the scale of our participants lives they still had potential to contribute to resilience in participants because of their novelty, their intensive nature, and their focus on doing something important that would have wide benefit not only for the community but for a much wider audience, and the kudos and recognition they bring. [57]
The most important question is probably the most intangible and hardest to measure – did we bring Pulkurlkpa? During the WDKHP we have seen individual and shared joy from participants and research team members. The activities were fun to do, they brought the joy of discovering new talents, especially for the children, the joy of achieving something, the joy of making something and sharing it with others and the joy of recognition from friends, family and the wider community. From joy comes optimism and hope – the essence of Pulkurlkpa. The fact that we cannot quantify and test this for statistical significance makes it no less real, or important. Examples of this wonder and joy can be seen on our website (www.westerndesertkidney.org.au). Whether this will translate to lasting health benefits will be the subject of other papers and may take many years to determine.

Developing long term relationships with Aboriginal researchers who are embedded in the community, have cultural authority, who understand the cultural nuances and are able to engage the community leaders is critical to research and likely to bring Aboriginal and non-Aboriginal researchers a greater sense of personal Pulkurlkpa.

Ethical approval for this project was given by the Western Australian Aboriginal Health Ethics Committee and the University of Western Australia Human Research Ethics Committee. All participants gave their informed consent for participation and specific consent for the publication of images. The Authors have no conflicts of interest to declare.
The clinical research methods and results

These are presented separately for adults and children in the following 2 papers prepared for publication

Parna Nhurraku (our place, our land) - The Western Desert Kidney Health Project - Health Status of Aboriginal and non-Aboriginal Adults in a Remote, Arid Area of Australia

Tjitji Pirni – Associations and Biomedical Markers for Renal Disease and Diabetes in Aboriginal and non-Aboriginal Children in a Remote, Arid, Area of Australia, The Western Desert Kidney Health Project.
Long Title – Parna Nhurraku (our place, our land) - The Western Desert Kidney Health Project - Health Status of Aboriginal and non-Aboriginal Adults in a Remote, Arid Area of Australia

Short Title: Parna Nhurraku (our place, our land) - Maybe … it’s More About the Place.

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Abstract

Aims
The Western Desert Kidney Health Project (WDKHP) determined the prevalence of type 2 diabetes (T2DM), kidney disease and associated risk factors in Aboriginal and non-Aboriginal people in a remote area of Western Australia.

Methods
This action research project featuring whole of community, annual cross sectional surveys over 3 years was conducted in 5 towns and 5 remote Aboriginal communities in Western Australia. This paper presents initial health assessments for adult participants (over 17 years).

Results
79% (n=818/1032) of the Aboriginal population participated in the WDKHP with 613 adults (425 Aboriginal) completing an initial health assessment.

There was no difference in the prevalence of elevated markers for kidney disease (haematuria, proteinuria and/or ACR> 2.5 mg/mmol) for adults living in the towns compared to those living in remote communities (Aboriginal adults p 0.256, Non-
Aboriginal adults (p 0.811), 53.1% of Aboriginal adults and 29.0% of non-Aboriginal adults had at least 1 marker of kidney disease.

Both Aboriginal and non-Aboriginal adults had markers of kidney disease at a higher rate than predicted from national rates. Aboriginal women were the highest risk group (35% type 2 diabetes, 59% at least one marker of kidney disease, 40% ACR over 2.5 mg/mmol).

**Conclusion**

Rates of T2DM, kidney disease and hypertension were higher than expected compared to national rates for all participants, with Aboriginal women at highest risk, and no difference between regional towns and remote communities. Rates for non-Aboriginal participants were higher than expected suggesting potentially modifiable exposures might be more important than ethnicity.
Introduction

The increasing burden of kidney disease and type 2 diabetes (T2DM) is a worldwide problem, especially for Indigenous populations [366, 367].

The average life expectancy at birth of Aboriginal Australians is significantly lower than for non-Aboriginal Australians. [88] National figures suggest the disparity in remote areas is even more marked. [88] Contributing factors to this reduced life expectancy are the effects of T2DM, kidney disease, their associated conditions and complications. [88] The leading cause of avoidable mortality for Aboriginal residents of the Goldfields of Western Australia between 1997 and 2007 was T2DM which accounted for 20% of deaths while diseases of the kidney accounted for almost 6% of avoidable mortality. [354]

The estimated prevalence of T2DM in Australian Aboriginal people ranges from 8.2% to 20.8% and estimated prevalence of impaired glucose tolerance ranges from 4.7% to 21.1%. [88, 368] Prevalence increases with age and remoteness. Aboriginal women are reported to be at particular risk. [369] Acanthosis nigricans, a thickening of the skin in areas of friction such as the back of the neck and under the arms, can be a useful clinical sign of hyperinsulinism, which is associated with T2DM, insulin resistance and impaired insulin response. [370]

Diabetic nephropathy, primary glomerulonephritis and hypertension are the most common contributing factors for end stage renal disease (ESRD) in Aboriginal people [371]. Obesity, albuminuria, hypertension, nephritis, T2DM, poverty and living in remote locations are associated with increased risk of kidney disease, particularly for Aboriginal people. [88, 216, 368]

Studies in Australia suggest that between 11 and 16% of the general population will have at least one marker of kidney damage (proteinuria, albuminuria, haematuria, scarring detected by imaging tests, abnormal glomerular filtration rate) [372]. Aboriginal Australians may be more than 5 times more likely to have signs of kidney damage than non-Aboriginal Australians. [97]

Aims
The aims of the Western Desert Kidney Health Project (WDKHP) were to determine the prevalence of type 2 diabetes (T2DM), kidney disease and the risk factors for these diseases in Aboriginal people in a remote area of Western Australia and to compare
with prevalence rates for non-Aboriginal people living in the same locations and with national rates.

**Methods**
The Western Desert Kidney Health Project was an action research project conducted in five towns and five remote Aboriginal communities over lands of people of Western Desert language groups – primarily Wongutha, Mulba-Ngadu and Anagu-Pitjantjatjara language groups. The major regional town was excluded from the study. The study covered an area almost twice the size of Tasmania (Figure 9). The remote communities were only accessible by gravel road. Participation was offered to all people in the communities regardless of age or ethnicity.

**Consent**
The team was led by an experienced Aboriginal researcher (AS) who has cultural seniority in all of the tribal groups for the region who travelled to each study community to consult directly with key community elders about involvement in the study. Participants were provided with written information about the study and at enrolment verbal explanation was provided. Participants completed a written consent form, or, where literacy was a problem, verbal consent was documented.

**Ethics**
Ethical approval for this project was given by the Western Australian Aboriginal Health Ethics Committee and the University of Western Australia Human Research Ethics Committee. The authors have no conflicts of interest to declare.

**Data Collection.**
A mobile research team, made up of AS, Aboriginal health workers, doctors, collaborating researchers, artists and medical students, spent two to three weeks annually for three years, starting in 2010, in each of the study communities. The team travelled with a 4 wheel drive clinic on wheels and a support vehicle to transport equipment to support innovative community engagement strategies. (www.westerndesertkidney.org.au)

Once consent was obtained participants answered a questionnaire to record medical, family and dietary history followed by a clinical assessment and investigations using point-of-care machines (**Accutrend GC**, Boehringer Mannheim for Blood Sugar; **DCA Vantage**, Bayer for Albumin Creatinine Ratio (ACR) and HbA1c; Bayer Clinitek
Urinalysis machine) which were calibrated after each community visit and cared for by the Bega Garnbirringu Aboriginal Health Service QAAMS program team.\textsuperscript{317}

Point of care tests were performed immediately and samples disposed of in keeping with cultural beliefs that required that no samples be taken away or kept. Participants did not have to undress, also an important cultural requirement – skin infection was assessed by self-report and examination of exposed areas, acanthosis nigricans was assessed by examination of the axilla and back of the neck.\textsuperscript{318}

Three blood pressure measurements were taken using an electronic blood pressure machine with appropriate sized cuffs (OMRON IA1B). After exclusion of obvious errors measurements were converted to an estimated mean arterial pressure MAP=\(\{(2 \times \text{dias}) + \text{sys}\}/3\). The minimal value for MAP of the 3 measurements was then identified to be the most appropriate BP.

Participants with history, existing diagnosis or confirmed current blood pressure ≥ 140mmHg systolic or ≥ 90mmHg diastolic were considered to have hypertension. Participants with history, current treatment or HbA1c >6.5% on screening were considered to have T2DM.

Height and weight were measured with a personal weighing scale and stadiometer. Body Mass Index (BMI) was calculated and, for adults, categorised as underweight (BMI <18.5 kg/m\(^2\)), normal (BMI 18.5 – 24.9 kg/m\(^2\)), overweight (BMI 24.9 - 30 kg/m\(^2\)) or obese (BMI >30 kg/m\(^2\)).

Participants were given immediate verbal and written feedback about the results. Those found to have abnormal results were referred to the doctor or health clinic of their choice for further investigation.

Data were recorded onto paper data sheets and later entered into a data base constructed using EpiData Version 3.1 and exported to SAS Version 9.3.\textsuperscript{374}

This paper presents the information from the initial health assessments for adult participants (18 years and older).

**Statistical methods**

Categorical factors including recoded BMI group were tested for associations with Aboriginality and gender using chi square or Fisher’s exact test together with logistic
regression for multivariate comparisons. BMI and age were compared using Kruskal Wallis test as they were not normally distributed. Standardised ratios, were calculated for all variables where this information was available from national standards adjusted for age where possible.

Comparison data have been taken from the Australian Bureau of Statistics (ABS) Australian Aboriginal and Torres Strait Islander Health Survey, Australia, 2012-13 (cat. No 4727.0.55.003 [211, 368, 375]

Data collection was more than 93% complete however at times environmental factors affected biomedical data collection, reflected in missing data for some denominators.

Results

Using 2011 Australian Bureau of Statistics estimates of the population in the study region, 79% (n=818/1035) of the Aboriginal population (175 men, 250 women, 393 children) and 12% (n=297/2475) of non-Aboriginal population (74 men, 114 women, 109 children) completed at least one health assessment [376].

Non-Aboriginal men and women taking part in the study were older than the Aboriginal participants. Median age for non-Aboriginal men was 52yrs (IQR 41-60), and for Aboriginal men 37yrs (IQR 27–47), (p<0.0001). The age difference was less marked for women (non-Aboriginal women median age 42yrs (IQR 31-53), Aboriginal women median age 39yrs (IQR 28-50, p 0.07)).

All Aboriginal adult participants were born in Western Australia, 95.8% (n=407/425) had spent their childhood in the Goldfields. Of the non-Aboriginal adults 8.5% (n=16/188) had spent their childhood in the Goldfields and 91.5% (n=172/188) had grown up in an urban centre. (p<0.001). At the time of participation 36% (n=153/425) of Aboriginal and 12% (n=23/188) of non-Aboriginal adults were living in remote communities.

Biomedical markers are presented in Figure 10 with comparison to ABS data or other published information. [211, 368, 372, 375, 377, 378]

Rates of being overweight or obese in the study group compared to the ABS data were not significantly different when adjusted for age (Aboriginal SMR 0.91, 95%CI 0.75,1.1; non-Aboriginal 1.08, 95% CI 0.8,1.4).[379] For women BMI was significantly associated with Aboriginality (p 0.003) and age (p<0.001) but not with parity (p 0.72).
National figures predicted that about 23% of Aboriginal and non-Aboriginal adults would be found to be hypertensive. WDKHP rates (measured or on treatment) were higher for Aboriginal women (37\%, n=93/250, p<0.001), Aboriginal men (45\%, n=77/172, p<0.001), and non-Aboriginal men (48\%, n=35/73, p<0.001). Almost 20\% of men and 8\% of women found to be hypertensive but had not previously been diagnosed.

Diabetes
Twenty-two percent of Aboriginal adults (n=92/425) and 11.3\% of non-Aboriginal adults reported they knew they had diabetes (KDM). Sixty seven percent of Aboriginal (62/92) and 45\% of non-Aboriginal diabetics (9/20) were poorly controlled (HbA1C ≥ 7\%).

Aboriginal (32.3\%, n=124/384) and non-Aboriginal adults (12.4\%, n=22/177) in the WDKHP had a higher burden of diabetes than the ABS standard population (17.9\% and 5.1\% respectively) (p<0.001). The WDKHP identified 10.2\% (n=39/384) of Aboriginal adults with a new diagnosis of T2DM (HbA1C>6.5\%), SMR 3.6 (2.5-5.0).

The rate of Aboriginal adults at high risk of diabetes (HbA1c between 6.1 and 6.5, 10.2\%, n=39/384) was higher than the national rate of 4.7\% (p 0.001). There were no differences in the rates of newly diagnosed (p 0.56) or at risk of diabetes (p 0.30) for the non-Aboriginal participants.

Acanthosis nigricans, was detected in 34.8\% (n=87/250) of Aboriginal women and 18.3\% (n=32/175) of Aboriginal men. It was not recorded for non-Aboriginal participants as it is difficult to detect in people of Caucasian origin.

Renal disease
Skin infection has been linked to post streptococcal glomerulonephritis which is a risk factor for kidney disease. Aboriginal and non-Aboriginal men reported similar rates of infection (15 to 20\%, p 0.33) but non-Aboriginal women were more likely to report skin infection than Aboriginal women (19.3\%, n=22/114 cf 10.8\% n=27/250 , p 0.04).

National figures predicted that about 23\% of Aboriginal and non-Aboriginal adults would be found to be hypertensive. This study found higher rates of hypertension (measured or on treatment) than expected for Aboriginal women (37\%, n=93/250), Aboriginal men (45\%, n=77/172), and non-Aboriginal men (48\%, n=35/73). Almost 20\% of men and 8\% of women who were found to be hypertensive had not previously been diagnosed or treated for hypertension.
Aboriginal adults had albuminuria (ACR over 2.5 mg/mmol) at a similar rate to national figures (p 0.136) with 39% of Aboriginal adults (n=160/409, 16 missing) but non-Aboriginal adults had a higher rate than predicted (p<0.001, 14%, n=22/175) (p<0.001). [377, 378] (Figure 10)

Haematuria (greater than trace) was an unexpectedly common finding – 35.8% (n=86/240) of Aboriginal women, 20.7%, (n=23/111) of Non-Aboriginal women, 15.6% (n=26/167) Aboriginal men and 9% (n=6/67) of non-Aboriginal men had haematuria. Rates of proteinuria (excluding trace) were similar for men and women but Aboriginal adults (20.3%, n=83/408) had higher rates than non-Aboriginal adults (8.2%, n=14/171). Low urine pH was a common finding, 77% (n=448/585) of Aboriginal and non-Aboriginal adults had urine pH of 6 or less.

The presence of 1 or more markers of renal disease (proteinuria, haematuria and/or ACR>2.5 mg/mmol) in all participants was higher than previously reported [372]. This was particularly so for Aboriginal participants, especially Aboriginal women (p<0.001). (Figure 10)

Table 5 shows the multivariate analysis for associations between Aboriginality, gender, obesity, age, hypertension and diabetes mellitus, and biomarkers for kidney disease. Aboriginality was a significant predictor for the appearance of all biomarkers. Risk of having diabetes was associated with Aboriginality, obesity and increasing age but there was no independent gender effect. The risk of having at least 1 biomarker of kidney disease (haematuria, proteinuria and/or ACR>2.5 mg/mmol) was associated with Aboriginality and female gender but not independently with hypertension and obesity.

**Town vs Community**

There was no difference in the prevalence of one or more elevated markers for kidney disease (haematuria, proteinuria and/or ACR>2.5 mg/mmol) for adults living in the towns compared to those living in remote communities, 55.3% (n=147/266) of Aboriginal adults and 29.4% (n=45/153) of non-Aboriginal adults living in town had at least 1 marker of kidney disease compared to 49.3% (n=71/144) of Aboriginal adults and 26.1% (n=6/23) of non-Aboriginal adults living in remote communities (Aboriginal adults p 0.26, Non-Aboriginal adults p 0.81). (Table 5)
**Discussion**

We achieved a high participation rate in the WDKHP, particularly for Aboriginal people and in remote communities. There was good participation from people who were exposed to the engagement strategies and came into direct contact with the study team but the mobile clinics operated during working hours on week days limiting participation of some people, perhaps biasing the results of non-Aboriginal participants from the towns, contributing to higher than expected rates of disease.

The WDKHP found higher than predicted rates of T2DM and markers for kidney disease in both Aboriginal and non-Aboriginal adults. A difference in rates of disease between Aboriginal and non-Aboriginal people was predicted but was not nearly as marked as expected – this was interesting given that almost all the Aboriginal participants had spent most of their lives in rural or remote areas but 91.5% of non-Aboriginal participants had grown up in urban settings and many were temporary residents such as teachers, nurses, police and contract workers.

Ethnicity, therefore, might be less important than location or environmental factors. Poverty and living in remote locations has been associated with increased risk of disease, especially kidney disease and T2DM. [88, 368] The towns and communities in this study fall into the “Remote” RA4 or “very remote” RA5 groups and the lowest two SEIFA score groups for Relative Disadvantage. [354] Poverty and remoteness might limit access to mitigating factors such as fresh foods, especially fruit and vegetables, work and exercise opportunities [40, 297].

**Conclusion**

The WDKHP found higher than expected rates of T2DM, kidney disease and hypertension compared with national quoted figures, with Aboriginal women the highest risk group. There was no difference between participants living in regional towns compared to those living in remote communities. The rates for non-Aboriginal participants were, in general, much higher than expected suggesting diet, limited exercise opportunities and other environmental exposures may be more important than ethnicity. More research is needed to examine possible exposures. Many of the contributing factors are potentially modifiable – such as food supply, exercise opportunities and living conditions, offering scope for interventions to reduce the risk and burden of these diseases.
Figure 9 Map of Communities participating in the Western Desert Kidney Health Project
### Hypertension

<table>
<thead>
<tr>
<th></th>
<th>Aboriginal</th>
<th>ABS Aboriginal</th>
<th>Non-Aboriginal</th>
<th>ABS Non-Aboriginal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>62.7%</td>
<td>81.8%</td>
<td>77.8%</td>
<td>80.5%</td>
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<tr>
<td></td>
<td>9.0%</td>
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<td>5%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>28.1%</td>
<td></td>
<td>16.8%</td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>55.2%</td>
<td>77.5%</td>
<td>52.1%</td>
<td>76.6%</td>
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<tr>
<td></td>
<td>18.0%</td>
<td></td>
<td>19.2%</td>
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<tr>
<td></td>
<td>26.8%</td>
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<td>28.7%</td>
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### BMI

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<th>ABS Aboriginal</th>
<th>Non-Abnormal</th>
<th>ABS Non-Abnormal</th>
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</thead>
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</tr>
<tr>
<td></td>
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<td>16.8%</td>
<td>23.9%</td>
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<tr>
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</tr>
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<td></td>
<td>1%</td>
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<td>32.1%</td>
<td>31.6%</td>
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<td>21.7%</td>
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### Diabetes

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<th>ABS Aboriginal</th>
<th>Non-Abnormal</th>
<th>ABS Non-Abnormal</th>
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<tr>
<td>Women</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>52.5%</td>
<td>80.9%</td>
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<tr>
<td></td>
<td>12.6%</td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>8%</td>
<td></td>
<td>10.1%</td>
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</tr>
<tr>
<td>Men</td>
<td></td>
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<tr>
<td></td>
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<td>9%</td>
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### ACR

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<th>ABS Aboriginal</th>
<th>Non-Abnormal</th>
<th>ABS Non-Abnormal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>60.0%</td>
<td>56.0%</td>
<td>86.1%</td>
<td>93.4%</td>
</tr>
<tr>
<td></td>
<td>29.2%</td>
<td>31.0%</td>
<td>13.0%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>62.1%</td>
<td>56.0%</td>
<td>86.6%</td>
<td>93.4%</td>
</tr>
<tr>
<td></td>
<td>30.7%</td>
<td>31.0%</td>
<td>11.9%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 1 or more renal markers

<table>
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<th>Aboriginal</th>
<th>Non-Abnormal</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td></td>
<td></td>
<td>41.5%</td>
<td>58.5%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>67.0%</td>
<td>33.0%</td>
</tr>
<tr>
<td>Men</td>
<td></td>
<td></td>
<td>72.2%</td>
<td>27.8%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>77.6%</td>
<td>22.4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>84.0%</td>
<td>16.0%</td>
</tr>
</tbody>
</table>

Figure 10 The Western Desert Kidney Health Project Rates and Risk Factors for Kidney Disease and Type 2 Diabetes for Adults (ABS [211, 368, 375] and Chadban et al [372])
<table>
<thead>
<tr>
<th>Variable</th>
<th>Hypertension</th>
<th>Diabetes</th>
<th>ACR</th>
<th>Renal Biomarkers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR</td>
<td>95% CI</td>
<td>P value</td>
<td>OR</td>
</tr>
<tr>
<td>Aboriginality</td>
<td>2.0</td>
<td>1.33 , 3.08</td>
<td>0.0011</td>
<td>5.3</td>
</tr>
<tr>
<td>Male gender</td>
<td>1.9</td>
<td>1.38 , 2.66</td>
<td>0.0002</td>
<td></td>
</tr>
<tr>
<td>Female Gender</td>
<td></td>
<td></td>
<td></td>
<td>1.0</td>
</tr>
<tr>
<td>Obesity (BMI&gt;30kg/m²)</td>
<td>2.1</td>
<td>1.48 , 3.06</td>
<td>&lt;0.0001</td>
<td>2.1</td>
</tr>
<tr>
<td>Age (per 10y)</td>
<td>1.0</td>
<td>1.04 , 1.06</td>
<td>&lt;0.0001</td>
<td>1.0</td>
</tr>
<tr>
<td>Community vs town</td>
<td>0.7</td>
<td>0.53 , 1.17</td>
<td>0.243</td>
<td>0.8</td>
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<tr>
<td>Hyper tension</td>
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</tr>
<tr>
<td>Diabetes</td>
<td>3.8</td>
<td>2.43 , 6.02</td>
<td>&lt;0.0001</td>
<td>1.5</td>
</tr>
</tbody>
</table>

Table 5: The Western Desert Kidney Health Project results of multivariate analysis of risk factors and biomarkers of renal disease and Type 2 Diabetes.
Tjitji Pirni – Associations and Biomedical Markers for Renal Disease and Diabetes in Aboriginal and non-Aboriginal Children in a Remote, Arid, Area of Australia, The Western Desert Kidney Health Project.

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The Western Desert Kidney Health Project Group

Abstract
Rates of Type 2 Diabetes Mellitus (T2DM) and Kidney Disease are escalating worldwide especially in remote and indigenous populations. Onset is often in adolescence suggesting they have their origins early in life.

The Western Desert Kidney Health Project (WDKHP) was an action research project conducted in a remote, arid area of Western Australian that aimed to determine the prevalence of the risk factors for kidney disease and T2DM in children and the determine the age of appearance of the risk factor.

Results
502 children (aged 1 to 17 years, 393 Aboriginal) completed an initial health assessment, with 27% (n=137) living in remote communities.

Children demonstrated risk factors for T2DM and kidney disease from very early childhood. There was no significant difference in rates between Aboriginal and non-Aboriginal children and no difference for children living in town compared to those living in remote communities.

Type 2 diabetes was uncommon but acanthosis nigricans (AN) (an indicator of hyperinsulinism) was detected in 14.5% (n=57/393) of Aboriginal children, including of children as young as 2 years and 10% children of normal weight.
Almost 9% of Aboriginal and non-Aboriginal children (n=40/465) had ACR over 3.4 mg/mmol, similar to national rates of 7.3%. Haematuria and elevated ACR were detected in children of all ages.

Conclusion
Both Aboriginal and non-Aboriginal children in remote areas may be at high risk for early onset of renal and metabolic disease. Hyperinsulinism may be a problem from very early in childhood and may occur before excess weight gain.
The rates of Type 2 Diabetes Mellitus (T2DM) and Kidney Disease worldwide are escalating but rates in indigenous populations are particularly high. The onset is often in adolescence or early adulthood suggesting they have their origins very early in life. In Australia and New Zealand chronic kidney disease (CKD) is reported to occur at a higher rate, and at a younger age, in Indigenous people than in non-Indigenous people. The reasons for this are not clear although poverty and living in remote locations have been associated with increased risk of kidney disease and T2DM, reduced nephron numbers at birth associated with poor intrauterine growth. Renal insults including nephritis, renal stones, obesity and early onset T2DM are also important risk factors.

Aims
The aims of the WDKHP were to determine and compare the prevalence of T2DM, kidney disease and the risk factors for these diseases in Aboriginal and non-Aboriginal children in a remote area of Western Australia, to compare those rates to national figures and to determine the age at which the risk factors are appearing.

Methods
The Western Desert Kidney Health Project was an action research project featuring annual cross sectional surveys over 3 years from 2010. It was conducted in 5 towns and 5 remote Aboriginal communities over lands of people of Western Desert Language groups – primarily Wongutha, Mulba-Ngadu and Anagu-Pitjantjatjara language groups. The major regional town was excluded from the study. Participation was offered to all children in the towns and communities regardless of age or ethnicity. This paper presents the information from the initial health assessments for children (0 to 17 years of age).

Consent
The team was led by an experienced Aboriginal researcher (AS) who conducted extensive consultation with communities and families, in keeping with cultural considerations. Families were provided with written information about the study and, at enrolment, verbal explanation was provided. Parents or guardians gave consent for the participation of children and the children themselves were asked for assent and given to opportunity to withdraw from the study.

Ethics
Ethical approval for this project was given by the Western Australian Aboriginal Health Ethics Committee and the University of Western Australia Human Research Ethics
Committee. All participants gave informed consent for participation and specific consent for the publication of images. The authors have no conflicts of interest to declare.

Data Collection.
A mobile research team, made up of AS, Aboriginal health workers, doctors, collaborating researchers, artists and medical students, spent 2 to 3 weeks annually for 3 years, in each of the study communities to collect data and present innovative community engagement strategies.\[123\]

Once consent was obtained participants or carers answered a questionnaire to record medical, family and dietary history followed by a clinical assessment and investigations using point-of-care machines (Accutrend GC, Boehringer Mannheim for Blood Sugar; DCA Vantage, Bayer for ACR and HbA1c; Bayer Clinitek Urinalysis machine). The point-of-care testing required a finger-prick sample of blood, or a small amount of urine. Tests were performed immediately and then the samples disposed of in keeping with cultural beliefs about blood and body fluids that required that no samples be taken away or kept. Participants did not have to undress, also an important cultural requirement – skin infection was assessed by self-report and examination of exposed areas, otoscopy was performed for ear infection (OM) and chronic suppurative otitis media (CSOM), acanthosis nigricans was assessed by examination of the axilla and back of the neck.

Three blood pressure measurements were taken using electronic blood pressure machine with appropriate sized cuffs (OMRON IA1B). Children found to have systolic and/or diastolic BPs above the 95%ile for age were considered to be hypertensive.\[382\]

Height and weight were measured with a personal weighing scale and stadiometer. Body Mass Index (BMI) was calculated and age specific norms for were used to classify participants as underweight, normal, overweight or obese.\[319\]

The children and their carers were given immediate verbal and written feedback about the results. Those found to have abnormal results were referred to the doctor or health clinic of their choice for further investigation.

Data was recorded onto paper data sheets by the carer or participant. Assistance from a research assistant was provided where language or literacy was a problem. The data were entered into a data base constructed using EpiData Version 3.1\[373\] and exported to SAS Version 9.3.\[374\]
Statistical methods
Categorical factors including recoded BMI group were tested for associations with Aboriginality and gender using chi square or Fisher’s exact test together with logistic regression for multivariate comparisons. BMI and age were compared using Kruskal Wallis test as they were not normally distributed. Standardised ratios, were calculated for all variables where this information was available from national standards adjusted for age where possible.

Comparison data has been taken from the Australian Bureau of Statistics (ABS) Australian Aboriginal and Torres Strait Islander Health Survey, Australia, 2012-13 (cat. No 4727.0.55.003 [368, 375, 379]).

Data collection was more than 90% complete - at times environmental factors affected data collection so there are missing values reflected in the denominators. Compared to population estimates from the Australian Bureau of Statistics (2011) 79% (n=818/1035) of the Aboriginal population (393 children) and 12% (n=297/2475) of non-Aboriginal population (109 children) completed at least one health assessment. [376]

Age
The youngest participants in the study were 8 months old. This paper reports the findings of participants up to 17 years of age. The age distribution for Aboriginal and non-Aboriginal girls was similar (p 0.773) although the Aboriginal boys were slightly older than the non-Aboriginal boys (p 0.0246, Aboriginal median 10 years, inter quartile range (IQR) 7–13, Non Aboriginal median 8 years, IQR 6-11).

Childhood home
Most of the Aboriginal children in this study (96%, n=377/393) had spent their lives in rural or remote areas whereas 61% (n=64/109) of non-Aboriginal children, although currently residing in a remote area, reported spending the majority of their lives in urban areas.

BMI
Aboriginal and non-Aboriginal Children in the WDKHP had similar rates and patterns of being overweight (16.1%, n=75/465, 37 missing) and obese (12.5%, n=58/465) (boys p 0.615 and girls p 0.824) and also similar to national figures. Figure 11 [379, 383] However, being obese or overweight was a problem by the age of 5 years in both Aboriginal and non-Aboriginal children.
Signs of Hyperinsulinism
Acanthosis nigricans (AN) was observed in 18.0% (n=39/217) of Aboriginal girls and 10.2% (n=18/176) of Aboriginal boys (p 0.032). It was not recorded for non-Aboriginal children as it is more difficult to detect in Caucasian people.
AN was not seen in any children who were underweight (0/52). It was detected in 10% (n=21/211) of children of normal weight, 23% (n=13/57) of overweight children and 51% of obese children (n=23/45). Although the youngest child with AN was 2 years old it was more common in children over 10 years of age (<5 yrs 8.1% n=1/44, 5-9 yrs 4.4% n=6/134, 10-14yrs 21.9% n=34/155, 15–17yrs 28.8%, n=23/80).

Infections
For Aboriginal children ear infection (OM) and CSOM was less frequent than national figures would have predicted. Other studies predicted rates of up to 70% for Aboriginal children in remote areas. [384] OM and CSOM were detected in approximately 20.6% (n=66/321) of Aboriginal children in this study. Ear pathology was found in all age groups. Rates for non-Aboriginal children were lower (p 0.002) and only in children aged 5 to 10 years (6.1%, n=5/82), similar to national figures. [384]
Skin infection was most common in non-Aboriginal boys (30.2%, 13 of 42) – twice as frequent as Aboriginal boys (13.6%, 21 of 155, p 0.02) and Aboriginal (12.7%, 25 of 197) and non-Aboriginal girls (13.5%, 7 of 42). Skin infection was reported in all age groups. Rates of skin infection in Aboriginal children this region were lower than studies in Northern Australia where rates of up to 48% have been reported. [385]

Hypertension
Sixty one children (12%) were found to be hypertensive including 6 Aboriginal children and 1 non-Aboriginal child currently on treatment for hypertension. This was a similar rate to other studies. [209] There was no difference in the rates of hypertension for Aboriginal and non-Aboriginal children (OR 0.89, 95%CI 0.48-1.74, p 0.73) or for boys and girls (OR 0.98, 95%CI 0.57-1.69, p 0.95). Hypertension was present at all ages (Aboriginal girls Median age 7, IQR 5-11yrs, youngest 1yr; Non-Aboriginal girls Media 11 IQR 8-14, youngest 6yrs; Aboriginal boys median age 6.5, IQR 4.5 - 11yrs, youngest 2yrs; Non-Aboriginal boys median age 8 IQR 7-12, youngest 3yrs).

Diabetes
Three Aboriginal children had T2DM and 2 non-Aboriginal children had type 1 diabetes. Seven children had HbA1C between 6 and 7. The youngest child with elevated HbA1c was 9 years old
Kidney Disease

There was no significant difference between Aboriginal and non-Aboriginal children in the prevalence of markers for kidney disease. (Figure 11)

Elevated ACR was present in all age groups, 8.6% (n=31/359) of Aboriginal children and 9.3% (n=9/97) of non-Aboriginal children had ACR>3.4 with 5 Aboriginal children with ACR>25 mg/mmol (p 0.84).

Haematuria (excluding trace) was found in 20.6% (n=41/199) of Aboriginal girls and 7 of 51 (13.7%) non-Aboriginal girls, (p 0.23). Twenty-three of 160 Aboriginal boys and 4 of 45 non-Aboriginal boys (p 0.42) also had haematuria. There was no significant difference between boys and girls (p 0.10). Female gender was associated with a trend for haematuria (1.59 CI 0.93, 2.80). There were no other significant predictors (Aboriginality, obesity, age, hypertension, skin infection, ear infection, elevated ACR) possibly due to small numbers.

Proteinuria (excluding trace) was, overall, more common in girls (p 0.011), present in 19.1% (n=38/199) of Aboriginal girls and 14 of 50 non-Aboriginal girls, (Aboriginal vs non-Aboriginal girls p 0.18), 11.2% (n=18/160) of Aboriginal boys and 6 of 45 non-Aboriginal boys (Aboriginal vs non-Aboriginal boys p 0.79).

Abnormalities on urinalysis were found even in the youngest children in this study – one 2 year old had ACR 7.3 mg/mmol.

Town vs community

There was no difference in the prevalence of one or more elevated markers for kidney disease (ACR> 3.4 mg/mmol and/or haematuria and/or proteinuria greater than trace) for children living in the towns compared to those living in remote communities – 30.8% (n=74/240) of Aboriginal children and 33.7% (n=30/89) of Non-Aboriginal children living in town had at least 1 marker of kidney disease compared to 39 of 117 Aboriginal children and 1 of 7 non-Aboriginal children living in remote communities (Aboriginal children p 0.63, Non-Aboriginal children p 0.42).

Comparison data for children are difficult to find but these rates are well above the Australian Bureau of Statistics data that suggests that 19% of Aboriginal adults \[^{368, 381}\] will have at least one marker of kidney disease and the rate for Aboriginal adults in remote areas has been reported to be as high as 34% \[^{368}\].
Discussion
The WDKHP found high rates of risk factors and disease in adult participants. The development of renal disease must be multifactorial and the early onset in some population groups suggests factors occurring during childhood, infancy and even before birth are important. Clinical indicators of the early onset of the disease process can be helpful in finding opportunities for intervention. In this study we have used clinical measures (BMI, acanthosis nigricans and blood pressure) with point of care testing to look for early indicators of risk.

Albuminuria, measured as albumin-creatinine ratio (ACR) has been found to be significantly correlated with other risk factors for renal disease – including skin infection, a history of post streptococcal glomerulonephritis, obesity, hypertension, hyperinsulinism and T2DM. Albuminuria during childhood may be transient but there is little information about whether transient albuminuria is associated with increased risk of renal disease, although in a high risk population albuminuria in childhood is of concern. Renal failure arises in people with a history of progressive proteinuria and albuminuria.

Haematuria can occur as a result of inflammation, irritation or disruption of the uroepithelium anywhere along the renal tract. Nephritis (inflammation of the kidney), particularly following streptococcal disease, may be a significant risk factor for renal disease later in life. In most populations post streptococcal glomerulonephritis follows streptococcal throat infection but there is increasing evidence to suggest that streptococcal skin infection is associated with increased risk of glomerulonephritis in Aboriginal communities in Australia.

Hypertension is a risk factor for renal disease and also contributes to the increased mortality and morbidity in end stage renal disease. Hypertension is associated with micro-albuminuria. This relationship has been demonstrated in the Aboriginal community.

Obesity is an increasing problem in the Australian population generally and a particular problem among Australian children. Obesity is a risk factor for the development of hyperinsulinism, T2DM and renal disease. Rates of overweight and obesity are high in many Aboriginal communities, with up to 30% Australian children either overweight or obese. Early identification of overweight children represents an opportunity for intervention.
Hyperinsulinism and progression to T2DM are particular problems for Australian Indigenous people and start at a younger age than non-Aboriginal people. \[81\] Acanthosis nigricans - the thickening and darkening of the skin in areas of friction - is a useful sign of hyperinsulinism, although it is difficult to assess in Caucasian individuals. \[318\] The WDKHP detected acanthosis nigricans in very young children and children of normal weight suggesting that hyperinsulinism is occurring very early. In both Aboriginal and non-Aboriginal children overweight and obesity was seen in very young children.

The prevalence of T2DM in the Australian Indigenous community is reported to be 10 to 30\% - 2 to 4 times as common as in the non-Indigenous population, one of the highest rates in the world.\[83\] Hyperinsulinism and T2DM contribute to the development and progression of other risk factors for renal disease - particularly hypertension, albuminuria and vascular disease so their early detection is important in preventing the development of complications. \[367\]

Conclusions

The WDKHP found very early appearance and higher than predicted prevalence of acanthosis nigricans, obesity, hypertension, haematuria and albuminuria but, in contrast to other studies, no difference in in rates of the risk factors between Aboriginal and non-Aboriginal children. This suggests that exposures might be more important than ethnicity in the development of T2DM and renal disease in remote areas. Perhaps there is similar pathology affecting children living in the same place. Further research is needed to explore local factors that might be important, but lost in larger studies.
Figure 11. The Western Desert Kidney Health Project - Risk Factors for Kidney Disease and Diabetes in Aboriginal and Non-Aboriginal Children
Change over time

This chapter compares the findings from initial health assessments in year 1 to the final health assessments in year 3 to assess change over time.
Change over time

The study period for the WDKHP was too short to expect any dramatic changes in the prevalence of the risk factors for T2DM and kidney disease however these were evaluated to ensure there was no deterioration. The ability of the WDKHP to measure individual change over time was limited by a smaller than expected number of people available for follow up – that is participating in both initial and final health assessments, however community change could still be evaluated.

Follow up participation was affected by a number of factors – changing socioeconomic factors and a downturn in mining activity in the region were significant. The population of the study communities changed quite a lot over the time of the project, reflected in the change in public school enrolments.

The enrolments at Goldfields Regional Education schools in the study communities fell by 25% overall, a loss of 147 students, with Tjuntjuntjarra recording a 67% fall in enrolment and Leonora a 40% fall. (Table 6)

<table>
<thead>
<tr>
<th>School</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>%change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laverton/Mulga Queen/Cosmo Newbery</td>
<td>69</td>
<td>80</td>
<td>81</td>
<td>76</td>
<td>+17%</td>
</tr>
<tr>
<td>Mt Margaret Remote School</td>
<td>27</td>
<td>17</td>
<td>20</td>
<td>18</td>
<td>-26%</td>
</tr>
<tr>
<td>Leonora District High School (includes Primary school)</td>
<td>186</td>
<td>121</td>
<td>98</td>
<td>112</td>
<td>-40%</td>
</tr>
<tr>
<td>Menzies Community School</td>
<td>41</td>
<td>28</td>
<td>32</td>
<td>30</td>
<td>-22%</td>
</tr>
<tr>
<td>Coolgardie Primary School</td>
<td>61</td>
<td>38</td>
<td>39</td>
<td>39</td>
<td>-36%</td>
</tr>
<tr>
<td>Norseman District High School (includes Primary school)</td>
<td>144</td>
<td>129</td>
<td>120</td>
<td>130</td>
<td>-10%</td>
</tr>
<tr>
<td>Yintarni (Coonana)</td>
<td>10</td>
<td>6</td>
<td>7</td>
<td>Closed</td>
<td>-100%</td>
</tr>
<tr>
<td>Tjuntjuntjara Remote School</td>
<td>42</td>
<td>49</td>
<td>42</td>
<td>28</td>
<td>-67%</td>
</tr>
<tr>
<td>Total</td>
<td>580</td>
<td>433</td>
<td></td>
<td></td>
<td>-25%</td>
</tr>
</tbody>
</table>

Table 6: School enrolments at start of school year (source – Goldfields Regional Education Office)

*Cosmo Newberry Community did not participate in the WDKHP but as it is an annex of Laverton School separate figures were not available.
Coonana community was effectively closed during 2013, and the community members dispersed across the Goldfields and South Australia as no alternative housing was offered to them. Most were lost to follow up.

Environmental factors affected the ability of the WDKHP team to reach some communities – unseasonal rain and extreme wind made the gravel roads unpassable at times and meant the team could not work outdoors so residencies in some communities had to be changed, reduced or abandoned. There was little scope to change the dates for residencies during the last year of the project and participation was affected by unanticipated community events such as large funerals – the residency in Laverton in year 3 was particularly affected by “sorry business” following the death of an elder who was over 100 years old at the time of her death and who passed away the night before the WDKHP residency commenced.

We were aware that some people, having been advised of the results of their health assessment as part of the WDKHP, relocated to be closer to medical services and to improve diet, exercise, education and lifestyle opportunities.

Follow Up
Data collection was completed on 214 individuals in both year 1 and year 3 of the project.

![Figure 12 Participation in the Western Desert Kidney Health Project by year.](image)
Of the 1115 participants 318 people participated more than once in the data collection – 221 had 1 follow up and 97 had 2 follow ups. (415 follow up encounters) Figures 12 and 13

Figure 13 WDKHP follow up encounters for health assessments by ethnicity, age and year.

**Community change**

At each follow up visit, as part of the written survey, participants were asked “Have you noticed any change in your community since last visit?”

Almost 13% (53/415) of responders reported changed in their community since the last visit by the WDKHP team. All reported positive change.

23 Aboriginal adults (15 women and 8 men)  
15 Aboriginal children (5 boys and 10 girls)
11 non-Aboriginal adults (6 women and 5 men)
4 non-Aboriginal children (2 boys and 2 girls)

- “My Mum is changing her eating habits” – Aboriginal child
- “We are looking after ourselves better” – Aboriginal man
- “Most people stopped smoking” – Aboriginal child
- “Less grog and drugs” – Aboriginal woman
- “People walking more” – Aboriginal child
- “Children are healthier due to breakfast program” – Non-Aboriginal Man
- “People seem more aware of better health options” – Aboriginal man
- “People are more aware of kidney health; they see how kidney affects all” – Aboriginal woman
- “People have found they have sickness that they didn’t know about” – Aboriginal woman

Some people reported general impressions of “stories about people getting fixed up” and “not seeing people rushed to town for the hospital due to kidney problems”.

The study team also observed many positive changes in the communities – presented in the Pulkurlkpa paper(Chapter 13, Appendix 2). [123]

Individual change

The key messages were:
  o Eat well, meaning eat native animal meat, drink water and eat fruit and vegetables.
  o Get some exercise
  o Reduce your stress.

To assess the impact of the messages, during data collection, participants were asked: “Have you made any changes to your diet, exercise or stress management since the last time we saw you? If Yes, What changes?”

Diet

- 16.8% (71 of 422) reported that they had changed their diet since last visit, 8 reported changes in 2 different years (8 of 71)
  o 50 Aboriginal people - 24 adults (20 women, 4 men), 26 children (16 girls, 10 boys)
• 21 Non-Aboriginal people – 13 adults (7 women, 6 men), 8 children (6 girls, 2 boys)
• 45.9% (194/422) reported no change in diet since last visit
• 12.6% (53/422) did not know, 23.2% (98/422) did not answer
• 3.6% (15/422) made a general comment about positive dietary change - “eating healthy”, “eating the right foods” or general change in diet – “Grandma makes different food”
• 5% (21/422) reported a reduction in unhealthy foods – “Eating less chocolate, cakes, icecream and take-aways”, “Less amount of lollies”, “less white bread, less processed meats”.
• 3.8% (16/422) people reported an increase in healthy foods “Eat more meat, fruit and salad”, with 9 reporting an increase in fruit and vegetable intake.

Exercise
Almost 16% of respondents (66/422) reported a change in exercise since last visit.
• 47.6% (201/422) reported no change in exercise since last visit, 9.9% (42/422) did not know if they had changed their exercise habits and the remainder (107/422) did not respond to this question.
• 4 people reported they were doing less exercise since last visit but 56.1% (37/66) commented that they had increased the amount of exercise they were doing
• 10 people specifically reported they were walking more
  o “No longer drive the car”
• Others reported major change
  o “(I) bought a bike”
  o “Massive increase”
  o “Started running and weights”
  o “Cross Trainer for 20-30 minutes”
  o “Lot more walking”
  o “Joined gym through Red Cross”

Stress
Almost 6% (25/422) of respondents reported changes to their stress management since last visit (4 Aboriginal women, 4 non-Aboriginal women, 3 Aboriginal men, 1 non-Aboriginal man, 5 Aboriginal girls, 2 non-Aboriginal girls, 5 Aboriginal boys, 1 non-Aboriginal boy).
Almost 43% (180/422) reported no change, 14% (59/422) didn’t know, 62.6% (264/422) did not answer.

Responses varied considerably
- “Pray more”
- “Go for a walk”
- “Time on my own”
- “Knitting”
- “Managing it, I wasn’t doing anything before”
- “Walk away”
- “Worry less, exercise more”
- “Go bush and hunting”
- “Just relaxing the body”

Medication
Eleven people reported change to their medications since last visit. 7 Aboriginal adults, 2 Aboriginal children and 2 non-Aboriginal adults – one reported that they “Needed less”. Most (241/422) reported no change, 13 did not know, the remainder (151/422) did not respond.

Change in Biomedical markers
Similar to other studies, despite the reported community and individual change there was little overall change in the measured biomarkers for adults or children in the WDKHP. (Tables 7 and 8)

Statistical Methods
Univariate changes in categorical variables between periods 1 and 3 were tested using Fisher’s exact test. However, when considering the influence of contributory factors such as obesity and Aboriginality correlation between results of individuals seem at both time periods needed consideration. The GENMOD procedure in SAS was used to account for this repeated exposure while still identifying any community change.

Rates of Obesity did not change for adults but increased for children between year 1 and year 3 of the WDKHP. Risk of obesity was associated with Aboriginality and female gender for adults but for children there were no associations (Aboriginality, gender, age or place of residence).
Comparing participants in year 1 and year 3 (Tables 7 and 8) there was no change to the rates of:

- **Diabetes** - Risk of diabetes was associated with Aboriginality, obesity and age over 40 for adults. There were insufficient numbers of children with diabetes for analysis.

- **Elevated HbA1c (>6.5%)** - univariate analysis suggested an improvement in rates of elevated HbA1c for adults (p 0.002), but this was not supported after controlling for Aboriginality, gender, age over 40 and obesity (p 0.07). Risk of elevated HbA1c was associated with Aboriginality and age over 40. There was no association with obesity, gender or place of residence (town vs community). For children there were no associations between elevated HbA1c and Aboriginality, gender, age or place of residence.

- **Hypertension** – there initially appeared to be an improvement in rates of hypertension for adults from 40% to 30% (univariate p 0.02) however after controlling for Aboriginality, gender, age over 40 and obesity there was no significant change (p 0.08). Risk of hypertension was associated with Aboriginality, obesity, age over 40 and male gender. For children risk of hypertension was associated with obesity and age over 10.

- **1 or more markers of kidney disease** (proteinuria, haematuria or ACR>2.5) - Risk of any kidney marker was associated with Aboriginality and female gender for adults but only with age over 10 years for children.

- **ACR>2.5 mg/mmol** – For adults risk of having ACR>2.5 mg/mmol was associated with Aboriginality and age over 40 but not with obesity. Female gender was associated with increased ACR for children.

- **Low urine pH** (pH≤6) For adults risk of low urine pH was associated with Aboriginality but not obesity or age over 40 but for children there were no associations.

- **Haematuria** – For adults, after multivariate analysis, there was a reduction in the rate of haematuria (p 0.005) but no change for children. For adults risk of haematuria was associated with Aboriginality, female gender, and age over 40. For children haematuria was only associated with Aboriginality.

The lack of change in biomarkers could be due to any of a number of factors, most were beyond the scope of the WDKHP to measure.
Discussion

Change takes time so the 24 months between initial and final assessments may not have been sufficient for knowledge to translate to intention and then action for change. We know that communities have used their results to advocate for change but this has been slow. For example, after community pressure a supermarket was opened in Laverton – but after the end of the WDKHP. Other towns in the study have successfully lobbied for improvements in their food supply, such as planting fruit trees in public spaces, improved food supply to the shops, school nutrition programs – but most of these were not achieved until after the completion of the WDKHP.

Changing socioeconomic conditions in the region may be an important consideration. The closure of mines and declining population affects the ability of communities to adequately provide for the needs of community members. There is financial strain on families as work becomes even harder to secure. Local businesses such as shops and service providers have a reduced customer base resulting in reduced income, limiting their ability to offer a variety of goods and services and perhaps pushing up prices as their fixed costs (rent, transport etc.) need to be met. These are particularly important considerations in the availability, cost and variety of fresh food and items with limited shelf life in remote areas.

The difficulty with follow up and the fall in participants may mean that those people who intended to make changes may have moved to areas with better access to appropriate food supply and other facilities to support change.

Perhaps individual change will not be enough in the face of environmental factors such as nitrate and uranium contamination of the water. The effect of these contaminants might be such that no amount of individual effort can overcome these exposures. Perhaps there are other factors that we have not identified that are having more effect than individual change in diet, exercise and stress management can overcome.

The reduction in haematuria in adults in encouraging – it suggests a reduction in inflammation of the uroepithelium. However the mechanism and significance of this is unclear.

Perhaps we were not measuring the best markers of impact of the WDKHP – diabetes, hypertension and renal disease are chronic disease – so prevalence is not likely to change in a population. It is actually very encouraging that there was no change in these disease prevalence rates.
Table 7 WDKHP Year 1 compared to year 3 Changes in biomedical markers for adults

<table>
<thead>
<tr>
<th></th>
<th>Overall Change</th>
<th>Change over time</th>
<th>Aboriginality Multivariate</th>
<th>Gender</th>
<th>Obesity</th>
<th>Age over 40</th>
<th>Place of residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obesity</td>
<td>No change</td>
<td>p 0.06 RR 0.89 CI 0.77, 1.01</td>
<td>P &lt;0.001 RR 1.60 CI 1.32, 1.94</td>
<td>Female p 0.004, RR 1.23, CI 1.07, 1.41</td>
<td>No association</td>
<td>No association</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>No change</td>
<td>p 0.54 RR 1.06 CI 0.89, 1.26</td>
<td>p &lt;0.001 RR 2.88 CI 1.82, 4.55</td>
<td>No Association</td>
<td>p 0.02 RR 1.36, CI 1.05, 1.74</td>
<td>p&lt;0.001 RR 2.84 CI 1.99, 4.07</td>
<td>No Association</td>
</tr>
<tr>
<td>HbA1c &gt;6.5%</td>
<td>No change</td>
<td>p 0.07 RR 1.23 CI 0.98, 1.53</td>
<td>p &lt;0.001 RR 5.5 CI 2.85, 10.61</td>
<td>No Association</td>
<td>No Association</td>
<td>p &lt;0.001 RR 3.63 CI 2.44, 5.43</td>
<td>No Association</td>
</tr>
<tr>
<td>Hypertension</td>
<td>No change</td>
<td>p 0.08 RR 0.86 CI 0.72, 1.02</td>
<td>p 0.049 RR 1.26 CI 1.00, 1.58</td>
<td>male gender p 0.008 RR 0.13 CI 1.08, 1.63</td>
<td>p 0.002 RR 1.33 CI 1.11 – 1.58</td>
<td>p&lt;0.001 RR 2.07 CI 1.61, 2.65</td>
<td>No Association</td>
</tr>
<tr>
<td>1 or more marker of kidney disease (Haematuria, proteinuria, ACR &gt;2.5)</td>
<td>No change</td>
<td>p 0.06 RR 0.89 CI 0.77, 1.01</td>
<td>p&lt;0.001 RR 1.6 CI 1.32, 1.94</td>
<td>Female p 0.004 RR 1.23 CI 1.07, 1.41</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
</tr>
<tr>
<td>Haematuria</td>
<td>Reduction</td>
<td>p 0.005 RR 0.76 CI 0.62, 0.92</td>
<td>p &lt;0.001 RR 1.55 CI 1.23, 1.94</td>
<td>Female p &lt;0.001 RR 1.6 CI 1.32, 2.03</td>
<td>No Association</td>
<td>p 0.04 RR 0.84 CI 0.71, 0.99</td>
<td>No Association</td>
</tr>
<tr>
<td>ACR &gt;2.5</td>
<td>No change</td>
<td>p 0.29 RR 0.86 CI 0.65, 1.14</td>
<td>p &lt;0.001 RR 3.06 CI 2.01, 4.66</td>
<td>No Association</td>
<td>No Association</td>
<td>p &lt;0.001 RR 0.60 CI 0.46, 0.79</td>
<td>No Association</td>
</tr>
<tr>
<td>Urine pH</td>
<td>No change</td>
<td>p 0.19 RR 0.93 CI 0.83, 1.04</td>
<td>p 0.16 RR 1.16 CI 1.04, 1.30</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
</tr>
<tr>
<td>Marker</td>
<td>Overall Change</td>
<td>Change over time</td>
<td>Aboriginality</td>
<td>Gender</td>
<td>Obesity</td>
<td>Age over 10</td>
<td>Place of residence</td>
</tr>
<tr>
<td>------------------------------</td>
<td>----------------</td>
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<td>--------</td>
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</tr>
<tr>
<td>Obesity</td>
<td>Increase</td>
<td>P 0.03</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>Insufficient numbers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HbA1c &gt;6.5%</td>
<td>No Change</td>
<td>p 0.69 RR 1.31 CI 0.35, 4.91</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>No Change</td>
<td>p 0.41 RR 1.17 CI 0.8, 1.71</td>
<td>No Association</td>
<td>No Association</td>
<td>p 0.03 RR 1.68 CI 1.04 – 2.71</td>
<td>p &lt;0.001 RR 0.36 CI 0.21- 0.62</td>
<td>No Association</td>
</tr>
<tr>
<td>1 or more marker of kidney disease (Haematuria, proteinuria, ACR &gt;2.5)</td>
<td>No Change</td>
<td>p 0.71 RR 1.03 CI 0.87, 1.23</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
<td>p 0.003 RR 1.28 CI1.09, 1.5</td>
<td>No Association</td>
</tr>
<tr>
<td>Haematuria</td>
<td>No Change</td>
<td>p 0.37 RR 1.10 CI 0.9, 1.34</td>
<td>p 0.03 RR 1.37 CI 1.04, 1.80</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
</tr>
<tr>
<td>ACR &gt;2.5</td>
<td>No Change</td>
<td>p 0.33 RR 1.3 CI 0.77, 2.21</td>
<td>No Association</td>
<td>Female Gender</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
</tr>
<tr>
<td>Urine pH</td>
<td>No Change</td>
<td>p 0.16 RR 1.1 CI 0.97, 1.24</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
<td>No Association</td>
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</tr>
</tbody>
</table>
The Western Desert Kidney Health Project
Strengths, Weaknesses, Outcomes and
Conclusions
Strengths and Weaknesses

The WDKHP was an ambitious, complex, community based, participatory research project. The strengths of the project have been described throughout this document in detail and relate particularly to:

- the extensive and genuine community involvement at every level of the project,
- the enthusiasm, commitment and dedication of the Western Desert Kidney Health Field Team, despite the many hardships they endured,
- the commitment of the team members, stakeholders and funding bodies to this complex and challenging project,
- the use of embedded researchers, especially Aboriginal researchers resulting in the project being designed to meet local needs with understanding of the nuances of each community,
- the development of capacity in research, arts and other skills in the local community,
- the mobile design allowing for research in difficult to reach communities and flexibility of project design,
- the use of point of care machines allowing immediate feedback and referral where participants were found to have abnormal results.

The WDKHP was, inevitably, not without problems and difficulties:

- A team of three had designed the project and it took a great deal of time to transfer the context and purpose of the project to those who were tasked with delivering on the ground in communities. Much of the administrative burden fell to the Rural Clinical School (RCS) administration team who felt that their primary purpose was the education of medical students and that the WDKHP was peripheral to that so competing priorities were sometimes a problem.
- Completing over thirty residencies in three years meant that the Kalgoorlie RCS administration team had to get the touring teams of artists, Aboriginal health workers, medical students, and medical staff on the road every two weeks for ten months of the year. This was very taxing for the field team.
- The logistics of safely getting up to 17 people on each residency into some of Australia’s most remote communities, where sometimes swags and tents were the only accommodation option, were complicated and difficult. Living conditions were often harsh and being away from home was sometimes difficult and uncomfortable for the team.
• The Project had to pivot within very short time frames from one community to another due to unforeseen sorry business surrounding deaths or extreme weather events in some communities requiring extreme flexibility and often creating tensions as team members and the administration team had many competing demands and stresses.

• The funding required partnerships with other organisations, rather than funding the WDKHP directly for some staff. The partner organisations who supplied clinical staff had competing demands and were not always able to release staff as needed by the WDKHP, especially when the program had to be changed at short notice.

• A project review was held with representatives from all project delivery partners at the completion of year one and was facilitated by a senior University of WA Rural Clinical School academic from another site and neutral facilitator with extensive experience working in Aboriginal communities. This process clarified roles internally within the project team the RCS and also within the Project delivery partners and the project seemed to be much more settled for the next two years with intermittent pressure points.

• Follow up was not as good as expected as discussed in chapter 15.
Outcomes

The WDKHP was a complex, community based, participatory research project that examined the risk factors for type 2 diabetes and renal disease and brought more than research to the study communities:

1) The arts based strategies have fostered resilience because of their novelty, their intensive nature and their focus on doing something important that would have wide benefit not only for the community, but for a much wider audience, and the kudos and recognition they brought to the participants.

2) More than 2000 people, including 1,300 children in the 10 community schools, took part in the arts activities either as workshop participants or audience. In the smaller communities there was almost universal participation, giving them new skills and new experiences. Some have discovered talents and passions and found new career paths in the arts.

3) Communities have been able to use the health status information, knowledge and support provided by the WDKHP to advocate for their communities and achieve change – all 5 towns now have a grocery store with an emphasis on fresh foods. Two towns and two communities have planted fruit trees in public gardens. All of the remote community schools and most of the town based schools now have fruit and vegetable gardening programs.

4) Leonora and Laverton have secured ongoing medical services, including general practitioners, using innovative service delivery models developed and supported by local government after learning of the needs in their communities through the WDKHP.

5) Health services, communities and individuals are more aware of their health needs and have made changes to suit and provide ongoing support to their own communities.

6) Point of care machines have now been installed in many of the health services in the towns and communities in the Goldfields and their use has become common.
7) Wider recognition has been very important in providing kudos and pride for the participants and the communities. The art works produced during the project demonstrate how the key health messages have been absorbed by the children who created them and communicated to a wider audience. The sand animations particularly demonstrate the translation of the key health messages and have received critical acclaim. (See Appendix 13 The Western Desert Kidney Health Booklet and Sand Animations DVD). “Alfie the Tooth Fairy” was awarded the MJA Ross Ingram Memorial Competition Prize in 2011. [365] The methods described in the Pulkurlkpa paper have been recognised with the Rue Wright Memorial Award from the Royal Australasian College of Physicians in 2015.

8) The Choir Project has led to the formation of an ongoing choir for the region. The choir has received critical acclaim and was invited to perform at a major national music festival in 2014 (The Fairbridge Festival and the National Regional Arts Summit). Several of the young choir members have been offered places in highly competitive tertiary music and performance courses and a skills development program is being developed with a tertiary college of the arts to be delivered in the Goldfields annually.

9) The Wongutha Birni Aboriginal Corporation, the community partner in the WDKHP, has secured funding through a crowdfunding project to take over the vehicles and equipment so that these resources are not lost to the community, but can be used for ongoing projects.

10) The Wongutha Birni Aboriginal Corporation, previously run by volunteers, has secured sponsorship for a manager so that the community arts and community development activities can continue and develop, led by the Aboriginal community of the region.

The Western Desert Kidney Health Project has added to the body of knowledge

1) Hyperinsulinaemia and being overweight or obese are highly associated with the development of type 2 diabetes mellitus – we have shown that they are problems for the study population. The WDKHP found that being overweight or obese was a problem in children as young as 5 years and that almost 29% of children were overweight or obese, 69% of Aboriginal adults and 63% of non-Aboriginal adults were overweight or obese. In the WDKHP acanthosis
Acanthosis nigricans (AN) was observed in 34.8% of Aboriginal women, 18.3% of Aboriginal men, 18% of Aboriginal girls and 10% of Aboriginal boys. AN was not seen in any children who were underweight but it was present in 10% of Aboriginal children of normal weight, 23% of children who were overweight and 51% of those who were obese. That acanthosis nigricans was observed even in very young children and in people of normal weight suggests that it precedes weight gain – this is an area where further research is needed.

2) The WDKHP found that, in most communities between 60% and 84% of people had urine pH of 6 or lower on dipstick testing, suggesting a renal response to metabolic acidosis. This testing occurred over a very large geographical area, during winter and summer, in towns as well as remote communities. There was no difference between Aboriginal and non-Aboriginal people. Metabolic acidosis results in depletion of potassium. Systemic potassium depletion increases insulin secretion. Metabolic acidosis also contributes to insulin resistance independent of the effect on potassium. This is an area where more detailed study is needed.

3) Hypertension is an important risk factor for, and consequence of, renal disease. In the WDKHP, similar to other studies, 12% of children were found to be hypertensive. There was no difference in the rates of hypertension for Aboriginal and non-Aboriginal children. National figures predicted that about 23% of Aboriginal and non-Aboriginal adults would be found to be hypertensive. The WDKHP found higher rates of hypertension (measured or on treatment) than expected for Aboriginal women (37%, n=93/250), Aboriginal men (45%, n=77/172), and non-Aboriginal men (48%, n=35/73). Increased awareness of the importance of blood pressure measurement and control, especially for children, is needed.

4) Increasing albuminuria is a marker for renal disease. In people with insulin resistance or T2DM urinary albumin excretion is increased. The WDKHP found 39% of Aboriginal adults, 14% of non-Aboriginal adults and 9% of children had albuminuria with elevated albumin creatinine ratio.

5) Skin infection, particularly Group A Streptococcal infection, has been associated with increased risk of renal disease. Rates of skin infection in Aboriginal children this study were lower than studies in Northern Australia where rates of up to 48% have been reported. In the WDKHP skin
infection was most common in non-Aboriginal boys (30.2%, 13 of 42) – twice as frequent as Aboriginal boys (13.6%, 21 of 155, p 0.02) and Aboriginal (12.7%, 25 of 197) and non-Aboriginal girls (13.5%, 7 of 42). Skin infection was reported in all age groups.

6) Dietary factors in remote areas may increase the risk of hyperinsulinaemia in adults and children. The Pilot project of the WDKHP found the children were eating a diet high in refined carbohydrates and sugars and we have shown that excessive intake of carbohydrates, particularly those high in refined carbohydrate and sugar will stimulate insulin production by the pancreas. This seems to be an important factor in the change of diet for many populations to a “western style diet”, which is a highly processed diet, high in carbohydrates, sugar (especially sucrose and fructose) and fat. Chronic excess carbohydrate and sugar intake is associated with chronic excess insulin production, metabolic syndrome and T2DM. [102] [103] [104] This is an area where intervention might be productive.

7) Caffeine can increase insulin release from the pancreas. Children in the pilot study reported high intake of caffeinated drinks - 44% of children reported drinking Coca Cola, 47% reported drinking tea and 17% reported drinking coffee. Education and exploration of alternative drinks is needed.

8) The survey of diet conducted during the pilot project suggests that the children have the knowledge and desire to improve their diet, particularly fruit and vegetable intake, but their ability to do this was limited by availability and cost of fruit and vegetables. Actions to improve food supply and food security are likely to be beneficial for the health of these communities.

9) One of the key messages of the WDKHP was to drink water in preference to other drinks. The Tjitjiku Myaee survey of the diet of children in the region found that 96% of children reported drinking water in the previous 24 hours, some reported drinking bottled water but most had drunk tap water. More than half had also ingested drinks brewed with tap water - 47% reported drinking tea and 17% reported drinking coffee. We have found that the quality of the drinking water is less than optimal in most of the communities and contamination with nitrates, chloramine, uranium and arsenic are potential problems. Further research into water quality, contamination and the potential health effects of
water contamination in remote areas will be a priority for future research for our research team.

10) Many of the communities in the study area have water that is contaminated with naturally occurring nitrates, some above current recommended safety levels. This has been the case for a very long time. Health department and Water Corporation reports suggest that this has not been associated with any health problems – consultations for the WDKHP have revealed that medical practitioners and service providers were not aware of the high nitrate levels in the water and had not been aware of the potential health problems, especially methaemoglobinaemia. We have now informed the medical community and, since March 2016 testing for methaemoglobinaemia has become available in Kalgoorlie. As a result of the advocacy of the WDKHP team a pilot project to determine whether methaemoglobinaemia is a problem in the Goldfields commenced in March 2016.

11) Kidney Inflammation – Haematuria can be a sign of inflammation of the kidney or uroepithelium. In the WDKHP it was an unexpectedly common finding – 21% of people tested had haematuria (greater than trace). The cause and significance of this is not clear but there is concern that a contributing factor may be uranium contamination of the drinking water. The drinking water at Tjuntjuntjara community is heavily contaminated with uranium. One of the effects of uranium ingestion is renal inflammation and damage. The WDKHP found that 30% of people in Tjuntjuntjara had haematuria greater than trace and a further 24% had a trace of blood detected in their urine – a total of 54% of people having some degree of haematuria. Community members, medical practitioners and health service providers to Tjuntjuntjara have been informed of these results are now more aware of the potential for health effects resulting from uranium exposure.

12) It is likely that the drinking water in other communities is also contaminated with uranium but at lower levels. The information about these levels is not available. Where there is uranium and nitrate in the water uranyl nitrate will form and this is very toxic to kidney so even small amounts of uranium, below currently considered “safe” levels, may be toxic to kidneys in the presence of high levels of nitrate. We are attempting to get more information on the uranium levels in water supplies for the towns and communities in the Goldfields to help
determine the magnitude of the problem of uranium contamination of the drinking water.

13) The WDKHP team has investigated the options for improving water quality and is working with a company that currently supplies water treatment equipment to the Water Corporation of WA to develop low cost, low maintenance, water filtration systems that will eliminate nitrates, uranium, arsenic and other contaminants from the drinking water. A meeting with the state government minister for water is planned for mid 2016 when this information is available. This meeting has been requested by the minister after meetings between the WDKHP chief investigators and the representatives for the Goldfields.

14) The WDKHP found no difference between participants living in town compared to those living in remote communities in the prevalence of the risk factors for renal disease or diabetes. There is pressure from government to close remote communities and it has been argued that the health of residents would be better if they lived in town. This research provides important information that this is not the case.
Conclusion

The Western Desert Kidney Health Project was a complex community based participatory research project featuring annual cross sectional surveys over three years from 2010. It was conducted in five towns and five remote Aboriginal communities over lands of people of Western Desert Language groups – primarily Wongutha, Mulba-Ngadu and Anagu-Pitjantjatjara language groups. A strength of the project was that it grew from the concerns of the community and the research team revolved around senior, respected Aboriginal researchers from the community.

The project has achieved its aims:

1) To develop and evaluate community education and community development strategies to reduce the prevalence of the risk factors for T2DM and kidney disease, using a community arts for community development model.
2) To determine the prevalence of type 2 diabetes (T2DM), kidney disease and the risk factors for these diseases in Aboriginal adults and children in a remote area of Western Australia
3) To compare with prevalence rates for non-Aboriginal adults and children living in the same locations
4) To compare those prevalence rates with national rates
5) To determine the age at which the risk factors are appearing

This thesis has presented the results, in accordance with these aims, and has shown that community arts is a joyful, exciting and engaging method for health promotion, community development and the development of resilience, especially for children. This method can be used to provide immediate, meaningful reciprocity in community based research.

We have shown that the prevalence of type 2 diabetes (T2DM), kidney disease and the risk factors for these diseases is high for Aboriginal and non-Aboriginal adults and children in the study communities. The prevalence is higher than expected, in all groups when compared with national rates. The risk factors are appearing very early in childhood.

Developing long term relationships with Aboriginal researchers who are embedded in the community, have cultural authority, who understand the cultural nuances and are able to engage the community leaders is critical to research and likely to bring Aboriginal and non-Aboriginal researchers a greater sense of personal Pulkurlkpa.

As one 35 year old Aboriginal woman said:
“This was a project that we knew and understood, that we owned.”
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Appendix 1

Jeffries-Stokes C, Stokes A, McDonald L, Stokes S, Daly J.

A complex Aboriginal Health Project and the challenges for evaluation
A complex Aboriginal health project and the challenges for evaluation

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Indigenous ill-health is a source of concern internationally. The Australian government is committed to reducing the 17-year gap in the mortality rates of Indigenous and non-Indigenous Australians. Kidney disease is of particular concern because its prevalence in Aboriginal Australians is more than six times that of other Australians and the discrepancy is even higher in communities living in the remote interior of the country. The treatment of kidney failure by dialysis or transplant is expensive. Patients from remote areas have to relocate to cities for treatment and here they are isolated, dislocated and distressed. Given these problems, it makes sense to concentrate on devising effective prevention programs.

The Western Desert Kidney Health Project (www.artshealthfoundation.org.au/westerndesertkidney) was designed to address the need for early detection and prevention of kidney disease. It also addresses Type 2 diabetes which is both a precursor for kidney disease and itself a significant source of ill-health. The current focus of this project is on ten remote, predominantly Aboriginal communities, near Kalgoorlie, in the Western desert of West Australia. The project has evolved over many years, with considerable institutional support. As far as possible, team leaders are well known in the community. They include a paediatrician and an experienced Aboriginal Health Worker both of whom have long worked to improve the life and outcomes of the community. A local arts worker has been trained as a health worker. A key team member from outside is a project designer and lobbyist with a long association with team members. Together the core team members have high levels of clinical skills, social skills and some have cultural authority in these desert communities. They understand the complexities of the communities and share the grief and dismay caused by the diseases.

Additional team members (volunteers, rural medical students, and visiting artists and performers) share as many of these characteristics as possible. The approach of the team was piloted and refined in consultation with the communities who therefore have a sense of ownership. It goes without saying that a project as complex as this does not happen quickly.

The first aim of the project is to screen everyone in the ten communities, assessing the prevalence of, and risk factors for renal disease and Type 2 diabetes, starting with children, then adults. A first obstacle that the team faced was the lack of space, resources and services in many of the communities – there may be no clinic, no accommodation for team members, precarious supply of utilities such as water, electricity and communications. The team turned to institutional funders to cover the cost of two large, specially-purpose, self-sufficient trucks. The first truck is a mobile screening unit from which test results are available on the spot in about ten minutes. A second truck provides accommodation for project staff, and material for additional activities.

Included in the aims of the Western Desert Kidney Health Project is an assessment of the age at which disease or indicators of risk first appear in children. At the start of the program, staff were started to find both diabetics and the early stages of kidney disease in primary school children, younger than 12 years. Anyone with significant risk factors or established disease is referred to local medical services for further assessment and treatment. While treatment can arrest the decline in kidney function, the drugs are expensive and have to be collected once a month. The drugs can be obtained free from an Aboriginal Health Service clinic but there are often long queues and time delays to access the service. Some communities do not have an outlet for this scheme and people have to travel hundreds of kilometres to get free access.

Ideally clinical treatment is accompanied by prevention programs, educating patients about risk factors with a view to reducing exposure to risks. A comprehensive diabetes program
should include a comprehensive change of diet, increased exercise and a reduction in stress. Even under ordinary circumstances many people are unable to make long-term changes of this kind. Simple interventions like information and counselling need to be enhanced with additional forms of support and attention before there is an improvement in health. 6 On the other hand, because of a sense of guilt and neglect, people in remote communities may be more responsive to health messages.

The first challenge for the project is to encourage people to present for testing. Fearing both the disease and the difficulties attending treatment, some community members may avoid the house-to-house calls with reluctance to attend the screening program and so this task needs to be carried out by a team member recognised and trusted by the community. When people do present and are given the news that they, or their loved ones, do indeed have kidney disease, they need a glimmer of hope, they need to know that something can be done about it and they need a trusted source of information and support. People’s capacity to come to terms with disease improves if there is support from family and community as they know that their community understands what needs to be done. The prevention program is challenging, requiring changes in long-established dietary practices, including some that may be an intrinsic part of family rituals, and this requires a shift in the cultural understanding of the disease. The people called upon to make these changes may themselves be suffering economic hardship and social alienation.

Each complex problem deserves a complex response so it made sense to accompany the screening service with a program that engages with long-established social and cultural practices that need to change if prevention is to succeed. Located in the second purpose-built truck, the materials for an arts program. Team members work alongside experienced visiting artists and performers to engage communities in song, dance and other creative projects that are vigorous, engaging and fun. People who resist screening can be drawn into these activities and reassured: the projects build up new ways of expressing hopes and fears, and generate new ways of understanding the disease.

This project has been carefully designed to engage with the community, using the arts and culture to enhance community services and build a collective commitment to change. The project is drawing on a growing understanding in the health sector that arts programs are an important way of changing both individual and community capacity for fundamental change to a way of life.

While complex, multi-layered projects are promising, they are extremely difficult to evaluate. Clinical assessment, repeated annually for three years, can assess improvements in renal health but whether the programs show a clinical benefit or not, the effect of the arts and culture program on the community also needs to be assessed.

An Evaluation Model

The integrated clinical/arts program addresses kidney health, taking into account everything from human physiology to culture. Conceptualising such a multi-faceted program requires a systemic approach which recognises that we are dealing with different levels of a complex system, one in which these different levels interact, both interfering with and facilitating change.

Let us start at the macro-level, that of physiology, the focus for diagnosis and treatment. But the physiology belongs to a person who has to make sense of the disease and the treatment process, in turn needing support and understanding from family and community. These groups have their own understanding and values which mediate their response to individual needs. Community understanding derives, in part, from social institutions like the education system. The capacity for individuals or communities to effect changes is very much limited by the economic system that circumscribes the financial resources available to them, at the same time determining funding for screening and treatment facilities. Lastly, there are cultural traditions with values and priorities that people see as good and proper and these may vary considerably between communities with different cultural traditions.

A prevention program that addresses anything as pervasive as reducing the risk from diabetes and renal disease would, ideally, effect change at each level of the system that links individual to community and culture. Positive change in one level can then reinforce and can be sustained by change in the other. A person’s physiological state can be changed by medication with changes in risk measured by changes in blood pressure, blood sugar, haemoglobin, cholesterol, lipids, haematuria and albumin to name but a few. Longitudinal data on changes in all members of the community represents a considerable logistical challenge but is relatively straightforward. After that the difficulties multiply. Individuals in screened communities often welcome educational materials explaining the anatomy, physiology and pharmacology of the disease, emphasising prevention and management strategies. These presentations are, ideally, tailored to age and level of understanding and increased understanding can be evaluated in feedback sessions. This again is relatively straightforward. At this stage better informed individuals may be eager to effect change in their lives but their capacity to do so is subject to the intrinsics of family and community living. It may be near to impossible to assure response to the requirement for dietary change when, for example, it disrupts the role of food and drink in rituals of family meals or community gatherings. The most resistant to change is likely to be the negative effect of the economic system. When people who are poorly paid or unemployed live in communities with a lack of refrigeration or fluctuations in the power supply, the cost of fresh food in the local community store or supermarket may be too high, and the quality suboptimal.

More broadly, at the cultural level, remote-living Aboriginal families may be subject to multiple inequities extending well beyond economic disadvantage: high levels of serious illness and death, isolation and discrimination, incarceration and loss leading to grief, guilt and depression, perhaps contributing to family and inter-personal violence and substance abuse. The accumulation of these stresses affects not only individuals but whole families, altering hormone levels and contributing to disease. The challenge, and it is a big one, is to acknowledge this social superstructure of disadvantage and to try to lighten the load.

These are the high aims of the program but how are they to be realised, and evaluated?

How the arts intervention works

The various, interactive levels of the system make it difficult for individuals to make sustained, radical change to their lives - but what is difficult is not impossible. The basic assumption of the arts program is that individuals know about their communities and it is to this end that they can identify opportunities for change. The arts team's role
is to engage the community in activities that build skills and promote understanding.

An arts activity may commence with researchers and visiting artists teaching people a song and dance routine. They may draw on the traditional arts like sand painting and the cultural practice of storytelling to engage people in conversations about their fears and where redemption may lie. Commonly they devise dramatic presentations of ways to fight the "sugar monster" resulting in a tale about the defeat of kidney disease and diabetes. In the process, community members may see better opportunities for effecting change and researchers will get a better insight into the problems that the community faces.

But how is this intimate process to be evaluated? One possibility is that the activities themselves and the art works created may be a direct source of joy that can be assessed in photographs showing the smiling faces, followed by film to show the genuineness of the joy across the groups of participants. If joy means less stress, the creative process has done its work and this should flow through to the clinical measures. When the creative project involves vigorous exercise associated with dancing or drumming, then documented participation should again count as a benefit.

The various artistic creations are then brought together in a community performance, a celebratory event, often a large procession that tells the story of local Aboriginal history, with music and song, masked dancers, monsters (like the sugar monster) and heroes (good food and exercise) who defeat the monster. In the process, knowledge of disease and opportunities for change are built into community understanding. Importantly, the products of the creative process provide culturally specific insights that can be recorded, filmed and broadcast well beyond the community so that there is growing recognition of Aboriginal history and traditions, perhaps even a reduction in racist views. The artistic quality of these products measures the success of the project but it also provides materials that can be used to enhance future information and education sessions, speaking to people in their own language, drawing on their own cultural traditions.

In creating these objects or routines, people learn new skills whether it is in making a mask for the sugar monster or dancing with joy at his defeat. Perhaps most importantly, when public display or performance is greeted with applause from community (again documented by photograph and film) this could be the first step to self-confidence in taking the steps required for preventing disease. Finally, the community experience can be assessed by observation, by one-on-one interview with those people who had most to gain from the process (those diagnosed with disease) and in focus group discussions with key people involved in community change.

Conclusion

Kidney disease and diabetes are a scourge in Western Australia’s desert communities. An efficient screening service is a necessary step towards improving health but more is needed. Enshrined inequalities need to be acknowledged and, ideally, additional effort should go into addressing the social, cultural and economic obstacles to change.

The Western Desert Kidney Health Project represents an attempt to integrate a clinical program and an arts intervention with the aim of promoting opportunities for the changes that individuals and communities must make if health is to improve. This program is complex and multifaceted and it will be a difficult one to evaluate.

We welcome suggestions for more effective ways to demonstrate the value of a program that produces performance rather than performance indicators.

Finally, it is worth reflecting on those levels of the system that are the biggest impediment to change and there are found in the economic system. Reasonably priced fresh fruit and vegetables are often not available but somehow the delivery system is not sufficiently efficient to ensure that there is always a refrigerator dispensing caffeine and sugar-rich cans of soft drink.

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Erratum

The paper “Prevalence of neural tube defects in Australia prior to mandatory fortification of bread-making flour with folic acid” (ANZJPH 2010 Vol. 34 No. 4) failed to acknowledge prior publication of some of the material included in the paper. This material was previously published in a report to the Australian Institute of Health and Welfare, titled “Neural tube defects in Australia. An epidemiological report”, published online in November 2008.
Appendix 2

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Pulkurlkpa – The Joy of Research in Aboriginal Communities
Pulkurlpa: The joy of research in Aboriginal communities
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Meaningful research in Australian Aboriginal communities, whether remote or urban, is hard. There is often tension between the world view of Aboriginal people and the academic demands of research. Ideally research should be led by Aboriginal people, but it may be difficult to find people who have seniority in the community and the necessary research, clinical and literacy skills for these leadership roles. The role of the Aboriginal researcher is complex, but critical to success. Aboriginal research team members shoulder responsibility for the research and the actions of the research team in the community, requiring a large amount of trust and commitment from them. The practical problems of conducting research in remote communities may be at odds with the procedures and policies of academic institutions. These issues can be difficult to overcome, but not impossible if sufficient commitment is given to developing relationships and engaging fully with the community. It takes time, often many years, but the rewards for the community, the team members and for research organisations can be great.

The Western Desert Kidney Health Project (WDKHP) was conducted in the Goldfields of Western Australia between 2010 and 2014. The WDKHP was developed to investigate the factors contributing to, and associated with the high rates of type 2 diabetes and renal disease in the Goldfields. At the same time, the aim was to develop research skills in the community, while developing community capacity to combat these diseases and contribute to Pulkurlpa – a deeply soul-felt sense of joy, hope, optimism and resilience.

Chief Investigators A and B for this project are embedded in the community – they are sisters in law. CIB is a senior woman of the three main tribal groups for the region – the Woongatha, Mulka-Nyula and Anarga tribes. She is also an accomplished and well known musician and artist. CIA is not Aboriginal and is a doctor. The third member of the development team is a senior Community Arts practitioner who, although not living in the Goldfields, has long relationship with the community. This team has been working together in research and arts in the region for more than 20 years. The idea for the WDKHP began as a series of conversations at funerals – funerals of community members who had died from renal disease, diabetes or associated complications. The leading cause of avoidable mortality for Aboriginal people in the Goldfields of Western Australia is type 2 diabetes. The demand from the community that something be done to prevent this loss of life and potential was brought to our chief investigators as community members with skills and knowledge.

During development of the proposal CIB visited every community to ensure wide consultation, in accordance with cultural protocols, and to invite participation. Her cultural standing along with her research experience in this community meant that she was able to identify and talk frankly to senior community members and elders about the difficulties, cultural and practical, in undertaking such an extensive project, and they made meaningful input into the study design. Consultations occurred around campfires, in kitchens over cups of tea, at social events, arts workshops and at formal community workshops.

The community consultations identified stress as a very significant factor in poor health and in the development of unhealthy lifestyle practices. Stress was seen to be multifaceted, but largely contributed to by a burden of grief, guilt, anger, frustration and bitterness that many people carry. The high levels of stress seemed to contribute to poor motivation and lack of resilience in the lives of many Aboriginal people and communities. There was a lack of 'Pulkurlpa'.

The concept of 'Marra Yungu' was important in the study design – this roughly translates as 'to offer your hand'. It has many overlapping meanings – it can mean the way you offer your hand when meeting someone for the first time, which for the Goldfields and Western Desert tribal groups, also implies an opening of your spirit and a sharing of trust. It can mean offering your hand to help someone, that is 'giving someone a hand' and it describes the process of two-way learning where people contribute different skills or knowledge to solve a common problem.

The delivery of the key health messages needed to be fun, exciting and empower participants to find innovative ways to overcome the challenges to healthy behaviours. Many of the changes would require not only personal, but systemic change. An innovative approach and a highly skilled team were needed. Team members (research staff and artists) had to have sensitivity and skills to be able to work with children and communities that may have suffered significant trauma. They needed to be able to work within the complex 'skin' system. Aboriginal team members had to be respected community members who could negotiate the subtle and demanding cultural considerations, complex kin relationships and who were also skilled health workers and artists. They needed to be open to mentoring and working with the non-Aboriginal members of the team. All team members needed to be able to live and work together, juggling family and community responsibilities while away from home for weeks at a time. They needed to be flexible and able...
to cope with the dynamic nature of life in remote areas with changes in weather, in community priorities and within the team, able to change the process as the need arose. Partnering with an Aboriginal Community Controlled Health Service and an Aboriginal community based arts and cultural organisation allowed us to have a core of two Aboriginal researchers – one male and one female, and a pool of other appropriate Aboriginal researchers who rotated through the team. The team was complemented by artists, medical students, volunteer researchers and doctors educational registrars who received invaluable cultural mentoring from the Aboriginal team members and in turn supported the Aboriginal researchers in literacy and clinical skills. Non-Aboriginal team members were introduced to the community as friends by well-known and respected Aboriginal researchers who were also community members - immediately giving them family and 'skin' status. The great strength of this project was the coherent patchwork of people with a wide variety of skills, led by a senior and experienced Aboriginal researcher. As one of the artists expressed it:

Even if you have never worked with an Aboriginal community before, you are able to cope as you’ve been shown, you know how to present your hard property.

**What Did It All Look Like?**

The WDFNP team spent about a fortnight in each community annually for 3 years, collecting data on health status using a mobile clinic truck equipped with point-of-care machines. These machines were important in addressing the cultural concern about collection and use of blood and body fluid samples – all samples were consumed by the testing and then disposed of, no samples were sent away or stored. Extensive history was collected from participants and recorded on paper data sheets, usually in a private but open air environment. This was considered important as it demonstrated privacy without secrecy. (Fig. 1 Photo Roman Kutzowitz – data collection occurred in the open air in private, but not secret settings.)

**Phase 1 – Getting the Messages Across**

The first priority was to get the health messages into a form that would be suitable, attract the interest of community members and support cultural identity and pride. Community arts has community participation and dialogue at its core, yet we had used it successfully for many years. We chose it as the vehicle for community development, engagement, education and to support the development of resilience. It allowed us to address many issues that would otherwise be beyond the scope of the project and allowed for meaningful reciprocity as well as opportunities for Purlurkpa. On advice from senior Aboriginal community members, we used the traditional sand drawing technique of Milihedi to explain our plans and the health messages. This technique lent itself to animation. Senior animation artists, with extensive Community Arts experience, were engaged as artists in residence to focus on the children, working through the schools. The Aboriginal researchers brokered culturally sensitive stories, incorporating the key health messages and assisted the visiting artists to identify key community participants, who had cultural authority, who could oversee the arts activities. The children transformed the story into an animated movie using images drawn in sand gathered from their own community (Parna – our country). The stories reflected unique features of the community and translated the health information into a form relevant to each community. At the end of each residency the whole community was invited to the movie premieres, the results of health screening were presented and a healthy supper was served. The creators of the animations were applauded and celebrated.

![Fig. 1](https://example.com/fig1.jpg)
Phase 2 – Building Capacity

The focus in phase 2 was to consolidate messages and to build capacity and problem solving skills. Sculpture, music and dance were the mediums used to demonstrate innovative approaches to a problem and a stepwise process to achieve an outcome. In one community the children learned how the kidney functions to filter the blood – so they designed and built a water sculpture demonstrating the important filtering elements (Fig. 2 Photo Matt Scourfield – Kidney Water Sculpture). In another community where many children reported feeling ‘invisible’ and where there had been a number of youth suicides, they designed and created aprons showing how kidneys work and then wore these aprons as part of a portrait photography experience demonstrating ‘How amazing I can be’ (Fig. 3 Photo Matt Scourfield – How Amazing I Can Be – self sculpture taught skills in innovative problem solving as well as the arts). Choice of art form was decided after consultation with community members about what would be most suitable for their community.

Phase 3 – Helping the Community Find Its Voice

Change in health behaviours, especially diet, requires major effort and community structural change. An important aspect of the project was to equip community members to advocate for change in their own communities. Singing, especially choral singing, was chosen as the medium because of the health benefits of singing, to give community members the skills and confidence to speak up for their communities, and to build the sense of community and shared purpose. Choral singing has a long history in Aboriginal communities and there was great enthusiasm in the community forums for it to be included.

An internationally recognised Choir Master, accompanied by GNI, spent several days in each community conducting singing workshops, with particular focus on the children. Community members then rehearsed by themselves over 6 months. The WDKHP field work culminated with a public performance by the choir, presentation of results to the community and a celebration in the major regional town. (Fig. 4 Photo Matt Scourfield – Turinaha Hirri Choir Performance).

Did it Work?

Participation in the study was a marker of success of the engagement strategies. Almost 38% of the total population in the study communities, including 80% of the Aboriginal population (n = 1113) enrolled and participated in the study. In some communities, there was 100% participation. More than 2000 people, including all the children in the 10 community schools (n = 1300), took part in the arts activities either as workshop participants or audience.
"It's Pulju" - 24 year old Aboriginal man (Pulju = really good)
"Indigenous people singing together achieve anything" - 63 year old Aboriginal woman
"It's a great experience for everyone and community come together" - 14 year old Aboriginal man
"It's medical evidence on wheels" 13 yr old Aboriginal boy
"Thank you guys for letting us be a part of something fantastic!! 42 yr old Aboriginal woman
"This project was a project that we knew and understood, that we owned" 78 year old Aboriginal woman

Fig. 4  Photo Matt Scarsfield – Tuula Binni Choir Performance

Fig. 5  Quotes from Evaluation of the Western Desert Kidney Health Project.

We used a number of different strategies for evaluation of the project – measuring change in health measures over time, questionnaires administered at the time of each data collection, participatory observation strategies, targeted interviews and an innovative project using participatory video making. The evaluation strategies and results are reported elsewhere, but in summary, there was only positive feedback from the community except for expressions of disunity that the project was limited to 3 years (Fig. 5).

There was clear demonstration of the absorption of the messages in the changes observed in the communities. Communities have been able to use the health status information, knowledge and support provided by the WDKNP to advocate for their communities and achieve change – all five towns now have a grocery store with an emphasis on fresh foods, prior to the study fresh fruit and vegetable supply was poor and two towns had no store. Two towns and two communities have planted fruit trees in public gardens. All of the remote community schools and most of the town based schools now have new fruit and vegetable gardening programmes.

Wider recognition has been very important in providing joy and pride for the participants and the communities. The artworks produced during the project demonstrate how the key health messages have been absorbed by the children who created them and communicated to a wider audience. The hand animators particularly demonstrate the translation of the key health messages and have received critical acclaim. They have been widely viewed, via the website (http://www.westerndesertkidney.org.au), ‘Alle the Tooth Fairy’ was awarded the MJA Ross Ingam Memorial Competition Prize in 2011 (http://youtu.be/q52gOdxruo).

The Choir Project has led to the formation of an ongoing choir for the region. The choir was invited to perform at major national arts festival in 2014 (The Fairbridge Festival and the National Regional Arts Summit). Several of the young choir members have been offered places in highly competitive tertiary music and performance courses. A skills development programme is being developed with a tertiary college of the arts to be delivered to the children in the region annually.

The WDKNP was awarded ‘Good Practice’ recognition by Creative Partnerships Australia, a national competitive programme, in 2013.

So...

Life in Aboriginal communities can be a rich and rewarding experience if children have resilience and are able to make the most of opportunities.

Community arts is a joyful, exciting and engaging method for health promotion, community development and the development of resilience, especially for children. This method can be used to provide immediate, meaningful reciprocity in community based research.
Despite the arts residencies being quite short in the scale of our participants’ lives, they still had potential to contribute to resilience in participants because of their novelty, their intensive nature and their focus on doing something important that would have wide benefit not only for the community, but for a much wider audience, and the love and recognition they bring.¹⁹

The most important question is probably the most intangible and hardest to measure – did we make Pullarkopj? During the WDKHP we have seen individual and shared joy from participants and research team members. The activities were fun to do; they brought the joy of discovering new talents, especially for the children, the joy of achieving something, the joy of making something and sharing it with others and the joy of recognition from family, friends and the wider community. From joy comes optimism and hope – the essence of Pullarkopj.¹⁹ The fact that we cannot quantify and test this for statistical significance makes it no less real, or important. Examples of this wonder and joy can be seen on our website (http://www.westernreddesertfund.org.au). Whether this will translate to lasting health benefits will be the subject of other papers and may take many years to determine.

Developing long-term relationships with Aboriginal researchers who are embedded in the community, have cultural authority, who understand the cultural nuances and are able to engage the community leaders is critical to research and likely to bring Aboriginal and non-Aboriginal researchers a greater sense of personal Pullarkopj.

Ethical approval for this project was given by the Western Australian Aboriginal Health Ethics Committee and the University of Western Australia Human Research Ethics Committee. All participants gave their informed consent for participation and specific consent for the publication of images.

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Participatory video making for research and health promotion in remote Australian Aboriginal communities: Methodological and ethical implications

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Abstract

This paper describes the participatory video (PV) method as a means of engaging children in remote Aboriginal communities as participants in health research.

The PV method was piloted in two remote communities in the Goldfields region of Western Australia. There was widespread community acceptance of this approach and preliminary findings are discussed with reference to the key themes of perspectives on health, benefits to participants and benefits to communities. The PV method has a number of strengths, including flexibility to respond to community priorities, a lack of dependence on verbal or written data collection and the capacity to generate immediate benefits for participants.

While not without methodological problems, these pilot projects suggest that the PV method is well suited to the remote Aboriginal communities who participated. The ethical implications of the PV method are discussed with specific reference to published ethical guidelines.
Introduction

Across the world, colonisation has led to the systematic oppression of Indigenous peoples through racial discrimination, dispossession of traditional lands and the fracturing of cultural, linguistic and familial connections (Daniel et al. 2011). In Australia, this has resulted in complex inter-generational effects, including socioeconomic disadvantage (Daly and Smith 1996), poorer educational outcomes (Johnston et al. 2009), increased morbidity and reduced life expectancy (Australian Institute of Health and Welfare 2011) among Aboriginal and Torres Strait Islander people.

Successive governments have prioritised research and health promotion aimed at addressing these disparities. However, the 'Western' approach to research has proven problematic in Aboriginal and Torres Strait Islander communities (Humphery 2001). The implicit valuing of Western worldviews and ways of knowing has led to culturally inappropriate research methods, which have further marginalised communities (Getty 2010, Smith 1999). The resultant mistrust among Aboriginal and Torres Strait Islander communities of institutions responsible for research and health promotion has slowed progress in addressing health disparities (Lowell et al. 2012, Trudgen 2000).

Recognition of these problems and consultation with Aboriginal and Torres Strait Islander communities has led to a revised research agenda, which demands that researchers acknowledge holistic perspectives on health, commit to partnering with communities to identify areas for research (Bull 2010) and deliver benefits to communities (Saggers and Gray 2007). The National Health and Medical Research Council (NHMRC) ‘Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research’ states that the core values of ‘reciprocity’, ‘respect’, ‘equality’, ‘responsibility’, ‘survival and protection’ and ‘spirit and integrity’ should underpin research involving Aboriginal people (National Health & Medical Research Council 2003).

In the field of health promotion, researchers have progressively recognised the importance of adopting community-based, participatory approaches, which partner with Aboriginal and Torres Strait Islander communities to identify priority areas, and involve local people as collaborators in the generation of relevant and culturally appropriate health promotion resources (Barnett and Kendall 2011, Davis et al. 2004, Hunter et al. 2009). The need for effective health promotion to improve child health has come with a recognition of the importance of understanding children’s representations of health and the contexts in which health is experienced (Docherty and Sandelowski 1999) and has led to a search for appropriate methods that enable children to participate as collaborators in research (Jacquez et al. 2013). Alongside this, advances in technology and broader access to digital recording devices have enabled innovative methods for achieving health promotion goals, including the use of visual media (Kindon 2003). The Photovoice method was first described in rural China (Wang, 1999) and has since been employed as a participatory research tool in a number of health promotion settings (Castleden et al. 2008, Martin et al. 2010, Wilkin and Liamputtong 2010). Participatory video (PV) has also emerged as a method of enabling community members (including children) to develop and share their own perspectives in community-based health promotion through the creation of films (Kindon 2003, Stewart et al. 2008). The PV method typically involves researchers working collaboratively with
community members, using iterative cycles of action (i.e., film-making) and reflection. Research ‘data’ is yielded from both the creative process and participant reflections on this process and is ideally interpreted collaboratively by participants and researchers (Kindon 2003). The final product is one or more videos that exist as a community-controlled resource, archiving the research process and enabling communication to a broader audience (Parr 2007). Importantly, the participant-directed nature of the process is proposed to privilege issues and perspectives that are valued by participants.

Advocates of PV propose that the collaborative research relationships destabilise traditional power imbalances between ‘researcher’ and ‘researched’ (Kindon 2003). Others have asserted that the collaborative framework of PV is, in itself, empowering for participants, citing Freire’s notion of ‘transformative change towards critical consciousness’ (Freire 1996) as an achievable outcome for participants within the PV paradigm (Mistry and Berardi 2012, Stewart et al. 2008). It has been suggested that, in comparison to traditional research techniques, the visual and performative emphasis of the PV approach is more accessible for young and/or non-literate participants. PV has also been endorsed as a way of documenting and celebrating the oral traditions prevalent in many Indigenous communities (Hunter et al. 2009, Mistry and Berardi 2012, Stewart et al. 2008).

Some critics of participatory research methods have questioned whether they are truly participatory (Gallacher and Gallagher 2008, Jacquez et al. 2013). Others have challenged the implicit assumption that knowledge generated in collaborative or participant-directed ways is inherently superior (Gallacher and Gallagher 2008). Pointed critiques have emerged in response to the use of PV with children, with some suggesting that power imbalances, resource limitations and ethical constraints can lead to participatory research techniques defaulting to a tightly managed and bounded research relationship in which equal collaboration is difficult or impossible (Jacquez et al. 2013, Lomax, 2012). This has led to recognition that the positionality and motivations of those initiating PV, and those who participate, are of prime importance in evaluating whether participatory research methods truly achieve their collaborative goals (Jacquez et al. 2013). In research involving Indigenous communities, it is also important to acknowledge the ways that relationships and positionalities are racialised and to understand how this might impact the use of PV methods.

In this context, it is interesting to consider whether participatory research methods, and PV in particular, might play a role as part of a revised agenda for research with, rather than on Aboriginal and Torres Strait Islander communities. As a research method, PV appears to satisfy the ethical principles for studies involving Aboriginal and Torres Strait Islander communities. The generation of collaborative knowledge, through iterative cycles of action and reflection, requires commitment, close relationships and reciprocity (Tobias et al. 2013). Previous PV projects have documented practical benefits for participants associated with skill development and self-confidence (Kindon 2003, Stewart et al. 2008). The production of community-controlled resources that can be shared between communities or used in advocacy to governing bodies might enable a more equitable distribution of the benefits of research for Aboriginal and Torres Strait Islander communities.
This paper describes the PV methodology as a way of engaging children in two remote Aboriginal communities as partners in health promotion research. We describe our use of the PV technique and present empirical data (participant and facilitator reflections, and thematic analysis of completed films) yielded from two field trips to trial the method. An evaluation of the methodological and ethical implications of using PV as a research tool, and its feasibility in remote Aboriginal communities, is presented with reference to existing literature and established ethical frameworks for research involving Aboriginal and Torres Strait Islander peoples (National Health & Medical Research Council 2003).

Methods

Study setting

The PV project described in this article was part of a broader project to evaluate the impact of the Western Desert Kidney Health Project (WDKHP 2011), an innovative arts/health intervention aimed at reducing diabetes and kidney disease in ten (predominantly Aboriginal) communities in the Goldfields region of Western Australia http://westerndesertkidney.org.au. The Western Australian Aboriginal Health Information Ethics Committee (287: 05/10), and the University of Western Australia Human Research Ethics Committee (RA/4/1/5401) approved the study methods. Representatives from two of the participating communities were approached by the research team in May 2012 and agreed to partner with researchers and assist in planning for field trips in September 2012. A third remote community was also identified, however, the withdrawal of services and ongoing problems with availability of basic infrastructure meant that the community was almost completely empty during the time available for conducting the PV project.

The two participating communities are small, remote settlements in arid environments, situated 360km and 500km from the nearest regional centre. They both have fluctuating populations of between 30 and 100 people and occasional access difficulties due to flooding of unsealed roads. One community was established by missionaries during the 1920s, while the other was founded in the 1980s following negotiation between local Elders and government officials to occupy and maintain traditional Aboriginal homelands. Community infrastructure is minimal, with no shops, health clinics or rubbish collection. Running water is sourced from bores and electricity is generated locally. Each community has a small school providing early childhood and primary education, while access to high school education requires commuting or relocating to a nearby regional township.

Importantly, both of the communities have a positive history of engagement with the broader Western Desert Kidney Health Project research team, with ongoing contact over several years. The team of researchers facilitating the specific PV projects in each community consisted of an Aboriginal health worker with family ties into the participating communities (Samuel Stokes), a (non-Aboriginal) health researcher (Craig Sinclair) and a (non-Aboriginal) community artist with skills in film and music production (Peter Keelan). A non-Aboriginal paediatrician (Christine Jefferies-Stokes) and an Aboriginal health researcher (Annette Stokes) also provided input into project design and assisted with the initial engagement of the partnering communities.
As with other artist residencies delivered as part of the Western Desert Kidney Health Project, the PV project in each community lasted for two weeks. The researchers arrived in each community a week in advance of the project commencement to enable introductions and build a rapport with community members. Initiation of the PV project began with approvals from the community coordinator, local Elders and (non-Aboriginal) school teachers. In partnership with teachers, young people were invited to join the PV project. Researchers visited the parents or guardians of young people in the community to explain the PV project and seek their consent.

Procedures

The community artist supplied compact, easy to operate, GoPro digital cameras and video-editing equipment for community use during the residency and ran introductory film-making workshops for participants in the project. Practical activities illustrated lighting, composition, camera care and ethical conduct in recording video footage. The Aboriginal health worker provided input about culturally appropriate use of cameras, particularly local rules regarding ‘out of bounds’ places.

Participants were asked to create a short movie about ‘being healthy in your community’. Group discussions and community excursions generated ideas, which were refined by planning scenes and shots visually on ‘storyboards’. Further refinement of ideas occurred during practical attempts to record and edit video footage. Wherever possible, the research team facilitated participants to develop and execute their own film-making ideas. Periods of active film-making were interspersed with reflection and feedback, during which participants commented on the evolving film. Photographs documented the film-making process, while participant and community member reflections were recorded and collected in field notes by the researcher. These notes and participant reflections were used to inform research team discussions about the films, as not all of the authors were on-site for the entire period of fieldwork. Both films took the form of short (five to seven minutes) documentary style films in which participants narrated stories or descriptions over audio-visual footage, which included landscapes, interviews and acted scenes. With approval from participants, the completed films were screened at community events held at the school and attended by community members. Copies of films were provided to participants and community members in useable formats (typically DVD) and the films were later uploaded to a public website (http://www.westerd eskidney.org.au/resources) with agreement from community leaders.

Results

The PV projects were well received in both communities, with positive feedback from community members, participants and teachers. The findings extrapolated from participant and community member reflections, and the completed films, are explored with reference to the key themes of ‘perspectives on health’, ‘benefits to participants’ and ‘benefits to communities’. The methodological and ethical implications for the use of PV as a research tool in remote Aboriginal communities is discussed with reference to existing literature and ethical guidelines.
Perspectives on health

Participants identified and represented health broadly, consistent with the idea of 'holistic' conceptions of health (Boddington and Raisanen 2009). In addition to demonstrating an understanding of individual agency and its impact on health (e.g., exercising for fitness), participants demonstrated a detailed understanding of the role of ecological factors, including their reliance on the local environment (e.g., the right time of year to look for different bush foods) and community infrastructure (e.g., water pumps) to support health. Participants showed pride in their ability to hunt and gather bush foods or to grow their own fruits and vegetables to share with others in the community. Physical prowess, expressed in athletic, sporting or hunting ability was also prized and provided a motivation to exercise and eat healthy foods. There was a notable lack of material relating to Western medications or health services. Instead, participants referred to traditional bush foods or ‘healing places’ as methods of maintaining their health. This may reflect prevailing community attitudes regarding the health benefits of a traditional cultural lifestyle. However, it is also important to acknowledge that both participating communities exist with minimal contact from mainstream health services.

Benefits to participants

The PV project provided a visual and performative medium in which young people could express their perspectives. Participants took readily to this medium and appreciated the chance to develop skills.

It's really good. Like if you were ever going to make your own film, you'd know what to do. (Participant)

In some cases, the participant-directed process was demonstrably effective in generating transformative change. One male student was initially tentative about contributing his own artistic decisions to the project, instead seeking direction from the community artist, “What should I do? Should I film this now?” With encouragement and mentoring, he demonstrated a greater willingness to contribute his own input into the project and experienced the reward of having his input valued by his peers; “I came up with that idea and the others liked it.” While this vignette demonstrates the potential for PV approaches to encourage transformative change within participants, it also illustrates the powerful influence of the peer group on participant responses to the PV method (Lomax 2012).

Benefits to communities

The PV project received strong support from participating communities. Significant creative input from participants, together with oversight from community leaders, contributed to the acceptance of the completed films, with public screenings being well attended by almost the whole community. During both arts residencies, the research team did not receive any indications of concern relating to the PV project. This is likely due to the extensive period of engagement with the broader WDKHP team in the lead up to this residency and the cultural guidance and arts facilitation provided by dedicated staff. Participants expressed enthusiasm about sharing their films with other communities to ‘show [them] how we keep healthy’, while one local elder encouraged
the researchers to "show it to everybody, everywhere you go." This illustrates the ways that the films were perceived by community members to have value, particularly as tools for health promotion. One adult community member reflected on the benefits of the PV process, talking of the children's enjoyment of the film-making and her pride in their participation and social cohesion.

It's pretty good you know. Like... all the kids you know. They're pretty happy when they're doing their little shots. And it makes me proud to see all of them all together you know? Doing their own little bits and pieces for the camera. (Adult community member)

Discussion

The PV methods piloted in these two communities were clearly well accepted, however, it is also important to consider the effectiveness of this process in generating knowledge relevant to improving Aboriginal health. The following section focuses on the methodological and ethical implications associated with this research method, with reference to existing literature and published ethical guidelines.

Methodological implications

Converging sources of evidence support the value of traditional, arts-based approaches in Aboriginal health research (Barnett and Kendall, 2011, Davis et al. 2004, Mikhailovich et al. 2007, Ware, 2014). Others have suggested that discussion centred around an artistic process can facilitate deliberation, potentially resulting in richer data or new insights (Downey et al. 2009). The performative aspects of film-making (Gibson et al. 2011), together with the capacity for the screening of completed films (Kindon 2003), provide innovative methods for building consensus around research findings and disseminating messages further.

Despite these benefits, there are a number of problems associated with the PV method. Perhaps the most pressing concern is the difficulty in being certain that participant perspectives are reflected in the finished films. Some authors have suggested that the themes explored by participants in PV projects can be interpreted as symbolic of their own perspective (Stewart et al, 2008). However, it is hard to be certain as to whether the themes portrayed in each film reflected participant priorities, as opposed to expedient options within the time and resource limitations of the PV project. When communities are engaged in a PV project, it is to be expected that some community members will have ‘stronger voices’ than others. It is also important to acknowledge the motivations and positionality of both participants and researchers in the research process, particularly when children are involved (Lomax 2012). From an evaluative stance, it is important to acknowledge the positionality from which the WDKHP researchers come to the task of collaborating with community members to conduct evaluation research for a project that they have been instrumental in delivering. These issues suggest the importance of documenting the context in which the research takes place, either through participant observation, participant reflections or by interviewing key informants from within the community.
In the Aboriginal health research context, it has been suggested that the ‘processes’ of research are at least as important as the ‘outcomes’ generated from research (Cochran et al. 2006). Acknowledging the ways in which research has previously been deployed as part of a colonial political agenda (Smith 1999), the PV method has potential as a ‘decolonising’ research method. Community-based participatory research methods, such as PV, allow participants significant input into research conducted in their communities and the method itself relies on developing knowledge within a relational context that accommodates cultural difference (Dudgeon et al. 2010). The existing relationships between the WDKHP Aboriginal health workers and the participating communities is a key component that enables the use of innovative research methods and the brokering of agreements about implementing these methods in culturally appropriate ways (Jeffries-Stokes et al. under review). The design of the WDKHP has placed a central emphasis on the research process, building on the community engagement developed through previous research projects (Wenxiong et al. 2011). It may be that ‘findings’ generated from such research methods are context specific and difficult to generalise. However, the learning that occurs through PV projects, together with the completed films, can deliver immediate benefits to participants and communities. From this perspective, it is the strength of the community engagement in the PV process that provides the strongest evidence of methodological soundness (Gibson et al. 2011).

**Ethical Implications**

The following section illustrates some of the ethical issues associated with the PV research method, with specific reference to the NHMRC ‘Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research’ (National Health & Medical Research Council 2003). The guidelines emphasise six core values of ‘reciprocity’, ‘respect’, ‘equality’, ‘responsibility’, ‘survival and protection’ and ‘spirit and integrity’ in research involving Aboriginal and Torres Strait Islander communities.

**Reciprocity**

Reciprocity refers to an inclusive research relationship that ensures that “research outcomes include equitable benefits of value to Aboriginal and Torres Strait Islander communities or individuals” (National Health & Medical Research Council 2003, p.10). Delivering benefits that are valued by research participants, and the community as a whole, requires a commitment to inclusiveness and consultation during project development and flexibility on the part of the research team, expressed by a willingness and capacity to adjust the project based on community feedback. The PV methodology can demonstrate reciprocity by providing opportunities for research participants to work collaboratively with researchers, defining the research agenda and taking control of decisions about how to portray film content. The collaborative relationship not only increases the richness and relevance of the data collected, but also contributes to cultural safety in the relationship between the ‘researcher’ and the ‘researched’. In the longer term, participants report pride and self-confidence associated with developing creative and technical skills (Hunter et al. 2008; Stewart et al. 2006), and the community benefits from the creative products that portray locally relevant issues from a local perspective (Hunter et al. 2009).
Respect

A respectful research relationship promotes the dignity of research participants, particularly by understanding and valuing difference, and provides adequate recognition for the contribution of participants to a research project (National Health & Medical Research Council 2003). The PV methodology is grounded in respect for the knowledge possessed by research participants and relies on respectful relationships as a vehicle for developing shared understandings between researchers and participants, which can then be conveyed to others through the film-making medium. The contribution of research participants is also made explicit by their public acknowledgement as ‘film-makers’. However, while public acknowledgement can affirm dignity, the exposure of research participants or the community to negative evaluation can also lead to humiliation or ‘shame’, particularly in small, tight-knit communities where participants are highly visible. Researchers should be vigilant in this respect, seeking input from participants and community leaders about the appropriateness of films for public presentation. Private screenings of ‘rough cuts’ can minimise risk in this area (Kindon 2003) and may also be a source of further insights. For some projects, the discussion of rough cuts may constitute valuable research data. In the present project, Aboriginal health workers, community leaders and research team members with cultural authority (acknowledged as such by community members) were consulted for advice regarding preliminary versions of the film. While such relationships minimise risk of harm to communities and constitute important ethical safeguards, it is important to acknowledge how collaborative research can be mediated by the perspectives of senior community members, potentially marginalising the views of research participants.

Equality

Equality in the research relationship is reflected in a commitment to fairness and justice, and a willingness to contest discrimination, while appreciating and respecting the rights of Aboriginal and Torres Strait Islander peoples to be different (National Health & Medical Research Council 2003). This requires valuing the knowledge and wisdom of research participants and distributing the benefits of the research equally between all partners in the research project. As a collaborative endeavour, PV requires that participants are actively engaged in the process of generating shared understandings about the meaning of decisions made during the creative process and researchers resist any temptation to ‘objectify’ participants. Encouraging ongoing reflection by research participants during the PV process about their perspectives on the meaning of the film can contribute to equitable relationships in drawing conclusions from the film. The provision of equipment and training to enable film-making by Aboriginal and Torres Strait Islander peoples is an example of how this technique can promote equality, particularly by challenging the ‘digital divide’ experienced by those without the means to develop new media skills (Hunter et al. 2003). However, researchers should also be aware that exposure to PV, without some provision for participants to sustain their participation beyond the conclusion of the project, can highlight existing economic inequities. Our research team chose to use affordable, easily accessible film-making equipment. One community member endorsed this approach, expressing an intention to purchase a similar camera so that the children could continue their film-making beyond the end of the project.

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However, for others with less access to financial resources, these measures alone did not enable ongoing participation. One community member spoke of wanting to show the completed film to visiting family members, but not having access to a television. Some have cautioned that participatory research methods conducted without sensitivity to the local contexts may reinforce the very forms of power and inequity that they seek to challenge (Kesby et al. 1997).

Responsibility

The ethical concept of responsibility requires researchers to recognize the responsibilities held by Aboriginal and Torres Strait Islander peoples to their kinship networks, communities and country, and to not adversely affect these community structures in the conduct of their research. In addition, this principle demands that researchers ‘do no harm’ and establish processes to guarantee their accountability to the Aboriginal and Torres Strait Islander communities who choose to participate in research (National Health & Medical Research Council 2003). Responsibility begins with the processes by which communities and researchers interact, to discuss the aims and methods of a proposed research project, the conduct of researchers in the community, the process for disseminating results and the distribution of benefits associated with the research. In the development of this PV project, the research team met with community representatives to discuss the proposed methods and seek their approval. Further consultation with community members indicated that they would feel comfortable with the use of video cameras in and around their community provided that there were appropriate controls over the use of the material. One community expressed concern about a previous photography project (conducted approximately 20 years prior) in which some photos had later appeared on commercially produced postcards without community consent. The Aboriginal health worker employed by the project provided ongoing guidance to researchers and participants about the appropriate use of cameras, including culturally significant places that should not be filmed. The Aboriginal health worker had family ties into both communities, meaning a direct system of accountability through traditional kinship networks. Importantly, the non-Aboriginal members of the research team needed to recognize that, within the prevailing cultural norms for this region, the Aboriginal health worker employed as part of the project would be accountable to the community for the actions of the entire research team. Research funders must recognize the burden of these responsibilities when making decisions about appropriate remuneration and professional support for those Aboriginal people who take on cultural stewardship roles within research projects.

Survival and Protection

Traditional approaches to research have led to exploitation and marginalisation of Aboriginal and Torres Strait Islander communities (National Health & Medical Research Council 2003, Humphrey 2001, Dudgeon et al. 2010). The ethical principle of survival and protection requires that researchers acknowledge and respect the cultural distinctiveness of Aboriginal and Torres Strait Islander peoples and commit to opposing any further erosion of this distinctive set of values, which, collectively, unite Aboriginal and Torres Strait Islander peoples (National Health & Medical Research Council 2003). A number of authors have suggested that community-based participatory research (CBPR) methods, such as participatory video-making, are
generally consistent with a respect for the cultural distinctiveness and social cohesion of Aboriginal communities (Dudgeon et al. 2010, Cochran et al. 2008). Developing processes by which communities can work collaboratively with researchers to ensure culturally appropriate research methods can make the research process more accountable to Indigenous ‘ways of knowing’ and less likely to repeat past mistakes in which research has objectified and colonised Indigenous peoples (Cochran et al. 2008). However, it is important to recognise that institutional barriers sometimes limit the extent to which the participatory aims of CBPR are practically achieved (Jaquez et al. 2013).

In the context of this specific PV project, we recognise the importance of adopting whole-community approaches during research design, implementation and dissemination. Trudgen (2000) has documented how even well-intentioned projects can undermine the traditional position of Elders as keepers of knowledge and, hence, destabilise familial and community networks if the projects are targeted at just the children within a community. While children were the main participants in these PV projects, we attempted to engage the broader community wherever possible and Elders were consulted for their approval of the completed films. In addition, these specific PV projects built on extensive whole-community engagement associated with the broader WDKHP. We acknowledge that not all communities will have such pre-existing relationships with research teams and recommend a cautious approach in respect to this ethical principle.

**Spirit and Integrity**

Spirit and integrity is considered to be an overarching ethical construct, encompassing all of the other ethical concepts. It entails a respect for the cultural inheritance of Aboriginal and Torres Strait Islander peoples, which is exemplified in both motivation and action. From this perspective, we suggest that, in considering ‘spirit and integrity’, it is imperative that research governance structures enable researchers to deliver positive motivations to work collaboratively with people in Aboriginal communities. Ensuring that adequate time and resources are available to facilitate relationship building and to support participation in research is imperative. Research governance should also ensure that researchers maintain contact with participating communities to facilitate collaborative decision-making regarding the dissemination of research findings. Good ethical practice in these areas may lead to stronger community acceptance of research and greater potential for research findings to be translated into policy and practice to benefit Aboriginal health outcomes.

**Conclusion**

This paper outlines the PV method as an innovative approach to conducting community-based participatory health research in remote Aboriginal communities. Initial pilot studies of this method have shown promising results, although it is important to note that the outcomes demonstrated here might be partly due to the history of positive engagement between the WDKHP and these communities, built up over a number of years. While this method is not without methodological and ethical challenges, we suggest that PV methods meet the pressing need for greater community control over the Aboriginal health research agenda and align with other principles outlined in published ethical guidelines.
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1 In one community (with a school population of approximately 80 students), teachers identified a small group of five upper primary school students to participate. In another community (with a small school population of approximately 20 students of predominantly primary school age), all of the students participated.
Sinclair, C. et al.

Positive Community Responses to an Arts-Health Program Designed to Tackle Diabetes and Kidney Disease in Remote Aboriginal Communities in Australia: A Qualitative Study.
Title: Positive community responses to an arts-health program designed to tackle
diabetes and kidney disease in remote Aboriginal communities in Australia: A
qualitative study

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Abstract

Objective: The Western Desert Kidney Health Project (WDKHP) is an innovative clinical screening, arts-health and community development program, staffed by Aboriginal health workers. The WDKHP is aimed at prevention and early detection, improving the chance of better management of kidney disease among people in ten predominantly Aboriginal communities in rural Western Australia. This paper aimed to understand community responses to the WDKHP in three of these communities.

Methods: Interviews were undertaken with 26 Aboriginal people living in three remote communities. Community responses were analysed with attention to the social organisation of participants in each community, with a focus on the perspectives of key groups, identified here as 'community leaders', 'homelanders', 'refuge seekers' and the 'dislocated'.

Results: Participants from all groups reported that the WDKHP was highly acceptable, and an effective means of drawing attention to the need for prevention, early detection and management of diabetes and kidney disease. The integration of Aboriginal health workers to explain the project contributed to the high rates of participation in clinical screening.

Conclusions: Outreach clinical services can be an appropriate method of engaging people in remote communities in addressing diabetes and kidney disease.

Implications: The remote community setting can act as an 'enabler' of healthy lifestyle for Aboriginal people, particularly when augmented by well-designed outreach programs.
Objectives

The state of Aboriginal health in Australia is widely seen as a national disgrace. Aboriginal life expectancy is about a decade less than for other Australians\(^1\). This discrepancy is attributed to multiple intergenerational causes. Racism experienced by Aboriginal people has been described as “enough to make you sick”\(^2\), but this is exacerbated by poor education, inadequate and overcrowded housing, and lack of access to health services. These discrepancies are much worse for Aboriginal people living in remote areas of Australia. Here the difference in life expectancy rises to 17 years\(^3\).

If Aboriginal health in remote areas is a major cause for concern, one might expect a concentration of clinical and preventive services in these areas. The opposite is true. In 2014, the Australian Federal government cut more than $500 million from Aboriginal programs\(^4\), including health programs, with the expectation that state governments would pick up the shortfall. In more recent times both the Australian Federal and Western Australian State governments have indicated their intentions to withdraw services, leading to the closure of more than 100 of the state’s remote communities, citing social disadvantage, poor health and the need to centralise services for economic reasons\(^5\).

The history of treating kidney disease in remote areas shows why this is the wrong way to go. End-stage renal disease in seven times higher among Aboriginal people\(^6\), but in remote areas it has been assessed as 30 times the national average\(^6\). When patients relocate into towns for access to dialysis and other specialist services, they experience heavy social, emotional and financial cost from family and cultural
disruption. Many choose to forego treatment to die at home. In the process, the
cost to government is transferred to patients, families and communities.

The most cost-effective solution to treating kidney disease in remote communities is
well known: comprehensive clinical services focused on early detection and
treatment of diabetes, supplemented by prevention programs to facilitate lifestyle
changes. There are substantial challenges when implementing any of these
strategies in isolated remote communities. Cultural differences, along with a deep
fear of kidney disease and its consequences, may contribute to new interventions
being viewed with suspicion. Effective programs that engage communities can take
many years of planning, with close attention to developing trust and rapport.

The Western Desert Kidney Health Project (WDKHP) took on this challenge, aiming
to reduce the prevalence and burden of diabetes and kidney disease in ten
predominantly Aboriginal communities in the Goldfields region of Western
Australia through early diagnosis together with a better understanding of
prevention of these diseases. A truck was equipped to deliver a clinical screening
program. It visited each community annually for three years, staying for
approximately two weeks each time. The aim was to screen all community members
for diabetes and kidney disease. The clinical team was led by Aboriginal health
workers, including one with close family ties and cultural authority within the
communities. They met with the community, invited people to participate in clinical
screening and provided culturally appropriate explanations of the project aims.

A screening service, while important, is insufficient for these communities. The
diagnosis of a feared disease, without accompanying support, could be a source of
trauma for people\textsuperscript{13}, who fear kidney disease and know of the burden associated
with relocation for treatment\textsuperscript{14}. An innovative component of this project was the
use of a second truck that delivered community arts programs focused on positive,
culturally-appropriate health messages. Artists engaged community members to
convey the message that kidney disease can be confronted and prevented. In one
arts intervention, community members were then encouraged to use traditional
sand-drawing techniques to produce community-led stories with locally relevant
messages about kidney health\textsuperscript{15}. Each arts residency typically coincided with the
clinical truck visit, lasting for two-weeks and ending with participants exhibiting or
performing their creative work to the entire community. Following each visit, a
community development officer (based with the WDKHP team in the regional city)
worked with the community, facilitating solutions to structural issues. This work
ranged from community advocacy (e.g. towards provision of healthy foods in shops
or roadhouses), to assistance in preparing grant applications for community
infrastructure\textsuperscript{16}.

Conducting a program like this is challenging but it is even more difficult to assess
whether the effects are positive. The project's clinical outcomes can only be
assessed over a longer period of time and the data are under preliminary analysis.
Our focus in this paper is on an essential early part of the project: to assess
community responses to the WDKHP, and the suitability of this outreach program
within the remote community context in which it was delivered.
Methods

Conventional research methods have been criticised for privileging Western world views, and marginalising Indigenous world views. Sherwood argues that research itself must be ‘decolonised’, in particular by understanding the contexts within which knowledge and practice originate. Our aim was to conduct a qualitative interview study but to ensure that our methods were responsive to these contexts, in particular the specific circumstances and commitments experienced by those living in the remote community setting. The study methods were approved by the University of Western Australia Human Research Ethics Committee, and the Western Australian Aboriginal Health Ethics Committee.

Study Design

We knew from the results of the first visit to these communities that the majority of the population had markers for kidney disease. That means that most people in the community were affected by the diagnosis either personally or through a family member. Despite this, participation in clinical screening among Aboriginal people across the ten communities was documented to be over 80%, with higher uptake among a number of the remote communities. This suggested that the combined program was addressing the fear engendered by the disease. The question then was to identify how this came about.

Field trips began in September 2012 at the same time as the second annual visit of the trucks to three desert communities. Aboriginal co-researchers with connections to each community were employed, joining the research team to advise on culturally
appropriate behavior, oversee the data collection and vouch for the main
interviewer (CS) in each community. Additional activities such as playing music and
basketball, and accompanying community members on excursions to the
surrounding bushland, helped to build rapport. The main interviewer and co-
researcher went from house to house, explaining the study and inviting people to
take part in video-taped or audio-taped interviews.

We needed broad eligibility criteria to assess community responses among this
shifting, difficult-to-define population. Research team members with cultural
authority and knowledge of the local community guided initial recruitment to ensure
that participants were broadly representative of people present and active in each
community. In addition to ensuring that different age groups and genders were
represented, we also ensured that there were sufficient people with direct
experience with kidney disease, either personally or in a close family member. As
data accumulated it became clear that there was remarkable agreement in approval
of the program. Different reasons for this approval emerged from the interviews as
data analysis proceeded. Following standard qualitative research procedures, the
sample was diversified, eventually going beyond people resident in the communities
at the time to include those who had had to move to regional centres like Kalgoorlie.

All participants in the study provided written consent. Twenty-six adult community
members with a broad age range (11 male, 15 female), evenly representing the
three communities were interviewed, and only one person declined an invitation to
participate. Participants were interviewed in locations where they felt comfortable.
Owing to time constraints, family responsibilities or mobility issues, some people
were interviewed at home, but mobile recording equipment and a four-wheel drive vehicle enabled some participants to be interviewed outdoors, in places of special significance to them.

Due to the large distances involved, and time and budgetary constraints, data collection took place during concentrated periods of field-work, lasting 2-3 weeks in each community. Interviews were conducted in English and employed a ‘yarning’ approach. We report verbatim the language used by the people interviewed because it shows how they expressed ideas that could be challenging for them.

Some specific terms were spoken in Wongutha language; these were translated by the Aboriginal co-researcher. Prompts such as ‘how is it for your health living in [community]?’ and ‘what sorts of things do you do to keep healthy?’ were used to generate discussion about health. During the latter part of the interview, participants were asked about the impact of the WDKHP on themselves and their community.

The transcript from each interview was reviewed by the researchers and discussed at team meetings. The main interviewer kept reflective journal entries relating to each interview, as well as a daily log of observations during the seven-week period of field-work. One of the researchers (AS), a senior Wongutha woman, confirmed translations and provided input regarding the cultural context of participants’ responses.
Results

The three Aboriginal communities where the interview study was to be conducted represented unique settings and the first research act was to understand the communities from the perspective of the people living there.

It is only two generations since the Western Desert people roamed large tracts of land without building permanent dwellings or cultivating crops; they lived on what they gleaned from the desert. The discovery of rich gold deposits in the late 19th century and an influx of miners of predominantly European origin led to dispossession of traditional land by mining and later pastoral leases. Some Aboriginal people gravitated to camps on the fringes of these settlements or sought refuge in church missions set up to house them.21,22

The missions have now closed but desert communities survive, including the three small communities (referred to with pseudonyms) where our interview study was based. They are situated 200 – 500 km from the nearest regional centre (Kalgoorlie) and have fluctuating populations of approximately 50 people. ‘Salt Lake’ started as a mission in the early 1900’s but then returned to Aboriginal community control. ‘Claypan’ was the site of a ration depot in the 1980’s until negotiation between local Elders and government officials endorsed its role in maintaining a traditional Aboriginal homeland. ‘Spinifex’ was established to repatriate Aboriginal peoples displaced by nuclear weapon testing in the 1950’s21, who were for a time resettled at a mission before being displaced again due to water shortages.
These communities provide basic services like a primary school (with computing facilities), a co-ordinator's office, maintenance equipment, diesel generator, dam or water pump. There are no shops or public waste disposal services. Health clinics previously existed in all three communities, but have been withdrawn. While the communities sometimes appear deserted, there is a steady flow of people who live between multiple communities, as well as visitors from other communities and towns. Residents often travel or relocate for extended periods (due to family obligations, ceremonial duties or accessing health services). The cultural authority of traditional Elders is integral to the maintenance of social norms. An important example is the banning of alcohol consumption, through the establishment of by-laws that mark these as 'dry' communities.

Interpreting the Interviews

Early in the process of data analysis it became evident that there was almost complete agreement from everyone interviewed that the WDKHP was very good, addressed community needs and should be extended. There was unanimous support for the value of an outreach clinical screening service. The children's sand animation videos were greeted with pride and joy. This posed a problem: it was unclear whether this unanimity reflected genuine support for the WDKHP, or was instead a product of the enmeshed relationships in the small communities involved. We turned our attention to the study setting, trying to understand the social organisation of the communities, and the conditions in which people were living, to provide contextual explanations for the strong uniform views expressed. Based on close reading and categorization of participant narratives as well as the contextual
information, we identified four categories of respondents: ‘Community Leaders’, ‘Homelands’, ‘Refuge-Seekers’ and the ‘Dislocated’. These categories cannot adequately capture the complexity of participants’ lives or social roles in their communities, but they show how differences in circumstance contributed to the different reasons given in support of the WDKHP.

Community Leaders

Six of the respondents were identified as Community Leaders; these people included Elders, with ceremonial responsibilities and cultural authority based on family lineage, as well as community co-ordinators (typically middle-aged), who undertook practical leadership roles on a daily basis. What they all had in common was strong links to Country. One of the men interviewed explained that people in this desert region were all living “under one big umbrella”, the overarching connection to the Country of the desert people. Within this umbrella people have their own specific Country, defined by either maternal or paternal ancestry. These connections to Country are ever present for the Community Leaders but they also appear to be retained even when people move away to other communities or regional towns.

The Community Leaders felt qualified to speak on behalf of their communities, emphasising the importance of education and traditional culture for maintaining health. One Elder, a ‘law-man’, recalled how in his youth, people lived a traditional lifestyle and did not know of kidney disease. The transition to towns and loss of culture had led to drinking alcohol and other unhealthy behaviours, passed on through family networks:
In long time ago been bush, been our great grandfather they been eating meat, kangaroo meat, emu... you know bush meat, grow up on that... But today people you know, they forgot about their culture, they learn the new things in towns and cities, where there's pubs you know? Open, just to drink to enjoy their life you know, our people today. And they get sick, end up in hospital. Our little young generation today, they catch it from their parents, you know?

In Claypan, a community coordinator spoke of the difficulties people experienced when the community health clinic closed; hence the importance of mobile outreach services:

[Regional health service], they've got a mobile clinic, and we really need them to come out but they haven't been out here and Western Desert mob [WDKHP] they have been out here a second time, which we are grateful for. It's helping us and all our children... it's really preventing us from going that way of kidney failure and diabetes.

In Salt Lake, the son and daughter-in-law of the community's respected Elder, illustrated their symbolic acceptance of the WDKHP. Despite having been screened in Salt Lake during a previous visit from the WDKHP, they made a conscious decision to publicly support the WDKHP, by also visiting a nearby town to get screened when the WDKHP arrived there. They felt that this public support for the project would encourage others to participate:
Well I know a lot of Wongis said “My kidney’s good”, like all would say that you know... “Oh we’re right and we don’t need to go” and whatever. But we had [WDKHP truck] out here, but we still went into [rural town] and supported them, and encouraged people to all come along too. [People said] “oh mission mob all here”. And we all went into town. That’s when [the WDKHP] first started off.

While community leaders are committed to the survival and protection of their communities, the communities themselves can be fragile. A year after the first visit from the WDKHP, Spinifex had effectively ceased to exist. The meagre range of government services were withdrawn, and despite the efforts of Elders, community relations soured and people had moved away.

The Homelander

The eight respondents identified as Homelander did not have formal leadership roles, but spoke of strong ongoing connections to community, an affinity to bush life and a sense of belonging, of being at home. They had all spent some time away, due to family or work obligations, but always returned to their own community. They valued the active lifestyle, availability of healthy bush foods, and lack of access to alcohol or takeaway foods. Many of them had young children, for whom the remote community provided a safe environment. Being aware of the prevalence of diabetes and kidney disease in the community, they accepted the need for screening and were concerned about the lack of health services and facilities in the community. Hence the arrival of the WDKHP truck was very welcome. One of these participants
referred to the problem of people having to travel to regional towns for health care:

"Mainly all the single, little young family, haven't got cars."

The service provided by the WDKHP was generally seen as better than what they could access in town. One woman particularly appreciated the Aboriginal health workers employed by the WDKHP:

Well we knew the people who came, because I've known them for a long time... They talked to us, told us what's going to happen. Yeah, encouraged us and explained it so we could understand what it was about. And that's good, they explain it to us, so we know. Because when you go into town, they don't explain too much properly. They use all the big words. Whereas, we know them, and they explain it so that we can understand.

Others expressed appreciation about having access to health workers of the appropriate gender, to discuss sensitive health issues. One community member talked about her fear that the screening might show up kidney disease, and relief when the test showed that everything was clear. Along with others in the community, she was also initially wary of the screening, thinking that it might reveal recent instances of alcohol consumption after a trip into town. Explanations by the health workers were able to allay her concerns and encourage participation.

Refuge Seekers

Five of the study participants described difficult social situations, and viewed the remote community as a place where they could escape unhealthy influences, and adopt a healthier lifestyle. One man came to Claypan while on parole from prison,
and appreciated the improvement in his diet and the lack of access to alcohol. One young woman spoke of escaping from a negative family situation in a regional town, by coming to Claypan with her daughter, to stay with family members. An older woman decided to relocate to Salt Lake, seeking a change in her lifestyle after being diagnosed with diabetes. All of these participants talked of previous difficulties with alcohol, and cited the lack of access to alcohol in the remote community as a key benefit. The idea of escape was prominent for this group, as exemplified by this man who moved to Claypan after a family member died from kidney disease:

My wife she’s real happy that we moved out here, because I don’t do much drinking anymore... when I was in [town] used to be a everyday thing for me. Used to wake up, you know go and look for a drink or anything, but now don’t do that anymore.

These views fit with the aims of Claypan’s Elder who had participated in the 1980s transition of Claypan from a ration depot to a community focused on maintaining traditional Aboriginal values. His commitment is that the community should provide support for lifestyle changes:

And I try and help and tell them “You come up here, well, we try to help you to keep off the drink and all that stuff, you know, drugs and stuff.” That’s why we build this place up ... So that’s how [Claypan] start getting going then.

These respondents valued the role of their community as a place of refuge, and hence welcomed the WDKHP’s outreach service, which meant that they could access health services, without having to return to town, where alcohol is freely available:
When I was in [town] I was drinking, you know? I get off the drink for my health, don’t want to go backward. But when I see other people drinking then, you know, when you been there it’s a bit easy, a bit easy to say yes to it...

Many of the people in these communities had been warned about kidney disease but ignored the warnings. When the WDKHP screening process detected kidney disease, as it did in the majority of the people screened, it was a shock but, as one woman recorded, the WDKHP health workers were there to support her to make a change in her lifestyle:

[My health] was pretty terrible, but when I met [WDKHP health workers] you know it really opened my eyes up about my health and that... stop drinking and smoking.

Further follow up reinforced the need to stop smoking, stay sober and eat fresh fruit and vegetables to prevent further harm to her kidneys. She started eating “bush tucker” and kangaroo meat. The gains that flow from the WDKHP are real, but there are also practical difficulties associated with adopting healthier lifestyles. She talked about having to save money for the long drive into town, where fruit and vegetables “cost an arm and a leg”.

Another man who had relocated to Claypan spoke of the value of the education and health promotion provided by the community arts aspect of the WDKHP:
We look forward for the kidney mob come out... well my kids... they really
look forward to it, all the movies and sand animation and all that there, and
they even come home and lecture me what to eat, what’s right and wrong.

Here we see an example of the role of the WDHHP’s arts-health approach,
generating in the children new confidence in knowing about healthy lifestyle and
exercising a positive influence within their family.

The Dislocated

The most difficult interviews were with community members who had been forced
to relocate to town. Seven respondents were identified as ‘Dislocated’ from their
communities, and were interviewed in Kalgoorlie, or outlying towns. Like the
Homelands, they appreciated the health benefits of life in the remote community
and lamented their experience of being forced into town.

In the case of the Spinifex community, the withdrawal of health services and closure
of the shop and school led to immense pressures on community members. Following
the withdrawal of the community nurse, one man with an ongoing heart condition
felt he had to move to Kalgoorlie, to be closer to medical help. One woman had
previously worked at the Spinifex community school, teaching the children in
Wongutha language, and struggled with the transition to life in Kalgoorlie, where
classes are taught in English and her children feel ‘shame’ when going to school. She
experienced constant worry about the authorities taking her children into custody,
despite her long history of responsible parenting and community service.
Ongoing health problems were a common reason for relocation. One senior man was forced to relocate to Kalgoorlie, even though "it broke my heart" that he had to go on dialysis for his kidney disease. Now, he says: "... my life is horrible, like I'm stuck up on the kidney machine...". Those with important community responsibilities felt the loss of personal identity, as well as the loss of connection to Country. Some senior people talked about how they would return to Country to undertake important obligations, even when this meant missing a dialysis appointment. But those forced to relocate to town did not come alone. Entire families were uprooted. Family members who accompanied them had to find a place to live, either with extended family or friends, short-term hostels, or squatting in fringe camps.

The two participants who had been forced to move away from their communities to seek treatment for kidney disease strongly endorsed the preventive role of the WDKHP, as a way of "helping people to look at what is the causing the problems" and thereby preventing future generations from experiencing the same fate. One man spoke of how the WDKHP arts residencies conveyed an important message to the children:

"The truck and the kidney things, they can explain to the children, they might get [kidney disease] the same too, you know... They might get sick and be in the same boat."

He felt that the WDKHP should visit more often, and that program staff could advocate for increased health services, particularly dialysis units in remote communities.
Conclusions

This interview study faced considerable logistical challenges and this placed limits on
the number and range of the interviews that could be conducted. Still, the messages
that emerge from the interviews are starkly clear.

The WDKHP screened for kidney disease and health workers diagnosed this problem
in the majority of the people in these communities. The people here have reason to
fear kidney disease so this was very bad news. Contrary to what might have been
expected, people responded positively to the program. The majority of the target
population participated in clinical screening\textsuperscript{16}, Community Leaders publically
endorsed the project, many participants committed to changing their lifestyle, and
all endorsed the preventive message for others, especially the young. The data
suggest that this outreach clinical service and community-based approach to health
promotion is well-accepted, and worth implementing more broadly.

The WDKHP provides a clinical and preventive health service that brings necessary
high-technology medicine to these isolated areas in a way that is acceptable to the
community, and positively received. What is critically important, however, is the
careful integration of skilled Aboriginal health workers, to encourage participation
and clearly communicate health information. Community members valued this
component of the project, and in some cases this was contrasted with the poor
communication in mainstream health services, a finding mirrored in previous
research\textsuperscript{25–26}. It seems likely that sustained integration of Aboriginal health workers
and community in an ongoing program would benefit the understandings needed for
better prevention and management of kidney disease.
While the clinical component of the WDKHP is of clear importance, this does not mean that the community is a passive recipient of the service. The problems associated with programs or health services that engender dependence, or undermine the social organisation of the community, have been well documented\textsuperscript{37}. The extensive consultation and planning that preceded the WDKHP, and its sensitive delivery, was delivered in ways that reinforced the messages of Elders and Community Leaders; who strongly promote the health benefits of traditional bush lifestyle, with lots of exercise and healthy ‘bush tucker’\textsuperscript{38}. This alignment in the delivery of health promotion messages likely contributed to the strong endorsement the WDKHP received from Elders and Community Leaders. The authority exercised by these community leaders represents a valuable preventive health resource.

Better collaboration between governments and community leaders might harness this potent, localised, resource, thus achieving better outcomes for people in remote communities. One practical outcome in the communities in this study would be supporting community leaders to ensure that shops established in the community sell healthy food, and reasonably priced fresh fruit and vegetables\textsuperscript{39}.

The value of the WDKHP outreach clinical service was illustrated most strongly by those who had relocated to a remote community, seeking refuge and a chance to escape unhealthy influences\textsuperscript{30}. These participants reported that the remote community setting enabled the adoption of a healthier lifestyle, and a chance to escape unhealthy influences. Previous research has shown that enmeshed social networks and familial obligations can both facilitate, and hinder, the adoption of a healthy lifestyle\textsuperscript{11}. For some participants in this study, adopting a healthy lifestyle
first required ‘escape’ and then ‘refuge’ in a community of other people also
committed to healthier living. In this context, the provision of outreach clinical
services can reduce exposure to unhealthy influences associated with regular visits
to town. Importantly, this study shows how Aboriginal people based in towns or
regional cities responded to illness or unhealthy situations by relocating to remote
communities, in order to adopt a healthier lifestyle. This study therefore cautions
against the use of community-based disease prevalence as an indicator of ‘unhealthy’
conditions at a local level.

There were high rates of participation in both the clinical screening and arts-
health components of the project, and it is difficult to separate the unique
contributions made by each. We note from participant responses that in addition
to promoting participation in clinical screening, the arts-health residencies made
unique contributions to the health promotion messages of the WDRIP, and
produced a range of community arts outcomes that can be used to further
promote these health promotion messages in the future.

Limitations

While a number of measures were taken to build rapport with participants, some
interviews were relatively short, with an absence of detail to contextualise responses.
In some cases, there may have been discomfort associated with being interviewed
by a non-Aboriginal researcher, or being interviewed in the presence of an Aboriginal
co-researcher of the opposite gender. Where possible, the co-researcher was the
same gender as the participant.
Most of the interviews were conducted with middle-aged or older adult community members. Due to the relatively small number of younger adults residing in these communities at the time, there were only a few interviews with young adults. As the interviews show, Community Leaders make a major commitment to maintain a place for younger people, who might return from the city seeking refuge, but based on the current study we could not tell how commonly this scenario occurs.

Implications

The communities in this study have social and economic value that is easily overlooked. While structural problems (such as difficulty accessing fresh fruit and vegetables) persist, the remote setting can enable and encourage physical activity, traditional 'bush Tucker' diet, and connection to culture. Strong social organization provides a framework for enforcing bans on alcohol and making these communities a place of refuge for those whose family or social situation makes it difficult to adopt healthy lifestyles. Remote communities have the potential to be health-promoting settings, and this can be further augmented by sensitively structured and integrated programs, like the WDKHP, visiting on a regular basis. In this way the communities can provide a health and social service, which is of considerable benefit to the health system. On the other hand, the social and financial cost associated with the breakdown of communities like Spinifex can be immense. The withdrawal of government services can effectively close down these communities.

The responses of community members in this study endorsed the design and implementation of the WDKHP. We conclude that an outreach clinical service, staffed and led by Aboriginal health workers, and integrated with arts-based
approaches that reinforce messages from Elders, is an appropriate method of engaging communities in the prevention, early detection and management of diabetes and kidney disease.
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Appendix 5

The Western Desert Kidney Health Project
Consultation Document 2008
WESTERN DESERT KIDNEY HEALTH PROJECT

2008 - 2011

Compiled by Lockie McDonald, Dr Christine Jeffries Stokes
And Annette Stokes

27 March 2008

A PARTNERSHIP BETWEEN

Wonqutha Birni Means All Of Us

The Rural Clinical School
of Western Australia
This project has been assisted by the Australian Government through the Australia Council, its arts funding and advisory body.
Western Desert Kidney Health Project
Was written by Lockie McDonald, Dr Christine Jeffries Stokes and Annette Stokes on behalf of;
The Rural Clinical School, University of Western Australia, Notre Dame University and Wongutha Birni Aboriginal Corporation

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AUSTRALIAN PATRON

Professor Fiona Stanley AC

Named Australian of the Year in 2003, Professor Stanley is a vocal advocate for the needs of children and their families.

Born in Sydney in 1946, she moved to Perth with her family in 1956. She studied medicine at the University of Western Australia and practised in hospitals for two years before going to the United Kingdom and USA for further training in epidemiology (the science of describing and explaining the occurrence of disease in populations), biostatistics and public health.

Professor Stanley is the founding Director of the Telethon Institute for Child Health Research, established in Perth in 1990. The Institute is multi-disciplinary and researches prevention of major childhood illnesses. It currently has more than 400 staff and students. She is a Professor in the School of Paediatrics and Child Health at the University of Western Australia.
Professor Stanley is also the Executive Director of the Australian Research Alliance for Children and Youth, a national collaboration of researchers, policy makers and practitioners from a broad range of disciplines who are committed to building a better future for Australia's children and young people.

In 2004, Professor Stanley was honoured as a “National Living Treasure” by the National Trust. She is the UNICEF Australian Ambassador for Early Childhood Development.

Professor Stanley has more than 200 published papers in scientific journals, is a member of the Prime Minister’s Science, Engineering and Innovation Council and the Australian Statistics Advisory Council. She has given many presentations, both nationally and internationally, on the socio-economic determinants of child health.

Professor Stanley is married to Professor Geoffrey Shellam. They have two daughters.

http://www.ichr.uwa.edu.au/people/fiona_stanley
Vusi Mahlasela
Award-winning South African singer-songwriter and poet-activist.

Growing up in Mamelodi, Vusi taught himself to play on a homemade guitar made of tin cans and fishing line and was a seasoned performer and songwriter by age 17.

An accomplished guitarist, percussionist, composer, arranger and band leader, Vusi has wowed the world with his songs that interweave political and social themes. He is featured in the film, Amandla! A Revolution in Four-part Harmony, about the importance of music and song in South Africa’s anti-apartheid struggle. His latest album, Naledi Ya Tsela (Guiding Star), features special guests, Xavier Rudd, Ladysmith Black Mambazo and Dave Matthews.

“He was the voice during the revolution, a voice of hope like a Woody Guthrie or Bob Dylan of South Africa, and he still is” – Dave Matthews

“Vusi Mahlasela sings as a bird does in total response to being alive. Vusi’s music is here to stir and delight us. He is a national treasure” – Nadine Gordimer

OSCAR-NOMINATED ‘VOICE’ COMES TO TOWN
As far as nicknames go, South African musician Vusi Mahlasela 's got a pretty good one: “The Voice.”- Boston Globe

http://www.vusimahlasela.com
GOOMBU-BA: WESTERN DESERT KIDNEY PROJECT 2008 - 2010

BACKGROUND
A pilot Northern Goldfields Renal Health Project was trialed in three communities in the Northern Goldfields of Western Australia during 2006-08. The aim of the project was to determine the prevalence of risk factors for end stage kidney disease in the Aboriginal community of the Northern Goldfields of Western Australia and show they can be reduced by the provision of culturally appropriate advice about the disease process, diet and lifestyle. The project had a number of strategic initiatives; a Gardening Project, Health Screenings with data collection, a community developed shadow puppet play, and a Wanti Sugarba (Stop the sugar) Festival.

In the past strategies for reducing kidney disease in Aboriginal communities in Australia have focused on detection of established disease and drug therapy to delay the progression of disease. This project focused on education and empowerment of Aboriginal people to understand and modify lifestyle factors contributing to the risk of renal disease in the community using a community cultural development model. There was a particular emphasis on educating participants about the mechanisms of disease and the reasons for diet and lifestyle change. The health promotion messages delivered through arts activities focused on change to a reduced refined carbohydrate diet, increased exercise and reduction of stress.

Data collected during the initial 12 month three-community project, qualitative and quantitative, have been critical to the development of this project design. It was clearly identified that there is a lack of affordable fresh fruits and vegetables available to the Indigenous population in these communities. Water quality is poor and this contributes to a high consumption of carbonated soft drinks. Ten percent of people who answered a questionnaire in all three communities said they had not drunk any water in the previous twenty-four hour period. Clearly significant long-term structural and cultural change on many levels is needed to make noticeable changes to health. This will take time, five to ten years, through a raft of complex, health, education, community development and cross-cultural governance and management initiatives before a positive health dividend is achieved.

The goal of this project is the expansion of the Northern Goldfields Renal Health project to service ten regional Indigenous communities in Western Australia, with a multi disciplinary approach to deliver an effective model for improving health, with the ultimate aim of eliminating the preventable causes of kidney disease.
CONTEXT

Kidney disease in Indigenous Australia

The average life expectancy of Indigenous Australians is approximately 20 years less than non-Indigenous Australians. Major factors contributing to this reduced life expectancy are kidney disease and diabetes.

Aboriginal people are diagnosed with renal disease four times as often as non-Aboriginal people and in some areas the rate is as high as 30 times higher. The known risk factors for End Stage Renal Disease (ESRD) are recurrent urinary tract infection, renal calculi, obesity, hyperinsulinism and type 2 diabetes, hypertension, post streptococcal glomerulonephritis, albuminuria and Syndrome X. There is little information about the prevalence of these risk factors in the Aboriginal community and virtually no information available about prevalence in childhood or the age at which the risk factors appear. The prevalence of type 2 diabetes in the Australian Indigenous community is 10 to 30% - that makes it two to four times as common as in the non-Indigenous population and this is the fourth highest rate of type 2 diabetes in the world.

Kidney disease in Leonora, Laverton and Mt Margaret

During the Pilot project in 2007 and 2008 just over 500 people were screened – just over 80% of these were Aboriginal and the remainder were non Aboriginal residents of the three communities.

- almost half are over weight (BMI over 25)
- 16% had uncontrolled hypertension
- 26% had the early signs of diabetes but only 11% had a diagnosis of Diabetes
- more than 7% had uncontrolled diabetes
- 2 % had signs of established, significant kidney disease and a further
- 12% had the early signs of kidney disease (compared to a national rate of kidney failure for Indigenous people of less than 0.1%) –
- Preliminary results suggest that we are finding a rate of kidney disease more than 10 times higher than the worst estimates

The 12 % of people in the three communities with early signs of kidney failure can be treated and progression to kidney failure avoided or significantly delayed with appropriate treatment - but they would not have even known they were sick without screening that was conducted during the pilot project.
Existing health organizations in the Western Desert

Medical services for the Western Desert region are a mix of private and public services and are patchy at best.

Leonora, Laverton and Norseman have small hospitals and nursing staff provided through the Health Department of Western Australia but the towns are responsible to recruit their own doctors – a very difficult task in the current medical workforce shortage. Leonora has not had a GP for more than 12 months. The GP in Laverton has just left so attempts to recruit a new GP are just starting.

Communities like Kurrawang, Mt Margaret, Morapoi and Mulga Queen have no resident medical services but have visiting community nurses one or two days a month. Community members must travel over gravel roads up to 120 km to see a doctor and often lack the financial capacity to do so.

Coonana, Tjuntjuntjarra and Menzies have nursing posts and a visit from the Royal Flying Doctor Service for a few hours once a fortnight or once a month. Coolgardie has a GP service several days per week and a nursing post.

Overall services are aimed at acute care and are grossly inadequate especially for the management of chronic disease and preventative health. They also rely on patients being aware of their potential illness and presenting for care – apart from immunization surveillance there is virtually no proactive primary care and prevention programs operating in the region.

The design of this project maximizes synergies with existing Indigenous Health providers in the region. Bega Garnbirringu Aboriginal Health Service will support the project and Aboriginal Health Workers from the Bega Garnbirringu Health Worker training school will be involved in the implementation of the project.

Succession and planning sustainability

At the end of 3 year trial period it is envisaged that Bega Garnbirringu will take over the service delivery aspects of the project and the Clinical Truck will be handed to Bega to operate regional chronic disease management services, using the protocols developed as part of this project. The Arts vehicle will be handed to Wongutha Birni Aboriginal Corporation.

The Rural Clinical School will continue to be involved in research, evaluation, and the opportunities for medical students to participate in remote community visits will continue and be enhanced by this relationship.
STAKEHOLDERS

Extensive consultations have taken place over the 10 years leading up to this proposal. The Indigenous community in the region has been involved at all levels.

All health service providers to Aboriginal communities in the Western Desert and Goldfields region have been consulted during the development of this proposal. Individual consultation meetings were held with each organizations and round table meetings were held with representatives of these organizations on Wednesday 2007 and Friday 2007.

Stakeholder health and community organisations:

Representatives from the following organizations and communities were consulted during the design of the Western Desert Kidney Health Project;

- members of the Goldfields Indigenous communities;
- Staff from the Rural Clinical School University of Western Australia and Notre Dame University;
- Wongutha Birni Aboriginal Corporation;
- Bega Garnbirringu Aboriginal Corporations;
- Nooda Ngulegoo Aboriginal Corporation;
- Goldfields Esperance Area Consultative Committee Inc;
- Goldfields Esperance Development Commission;
- Goldfields Esperance General Practice Network;
- Medical Practitioners from Kalgoorlie Regional Hospital;
- West Australian Health Department, Public Health Division;
- Department of Indigenous Affairs WA;
- Kalgoorlie Consolidated Gold Mines;
- Barrick Gold Australia LTD;
- BHP Billiton, Nickel West.

USING A MODEL THAT WORKS

The Western Desert Renal Health Project is based on the NTP model, which was implemented in 1992. NTP is a self-determined Indigenous organization with a strong track record of Aboriginal Health that is internationally renowned. NTP was introduced to the community through an arts project and the model of visiting specialised trained Aboriginal health workers, backed up with community development strategies and combined with research has successfully improved the health of women and children in
the Kalgoorlie-Boulder area. The NTP model has been successfully exported to the Kimberly and Queensland.

The development team for the Western Desert Kidney Health team (A Stokes, C Jeffries-Stokes and L McDonald) were all involved in and instrumental to the development and implementation of the NTP project.

**TEN COMMUNITIES THREE YEARS**

The success of the initial pilot project has created demand to expand the service to the following communities;

1. Mulga Queen
2. Laverton
3. Mt Margaret
4. Leonora
5. Menzies / Morapoi
6. Kurrawang
7. Coolgardie
8. Coonana
9. Tjuntjunjarra
10. Norseman

The ten communities represent a diverse cross section of urban and remote Indigenous Communities spread over a vast area and with great distances between them. Tjuntjunjarra is the most isolated Indigenous community in Australia and Coolgardie and Norseman are situated on major highways, i.e. See figure 2.

Cosmo Newberry has not been included as the health services for this community are supplied through Ngaanyatjarra Health from Alice Springs (Northern Territory).

In the future we would anticipate expanding the project to the central desert if it was requested by these communities and supported by Ngaanyatjarra Health.

Kalgoorlie-Boulder has not been included in this proposal because it is well serviced by Bega Garnbirringu and the other health providers for the region and it is anticipated that the community development strategies and health promotion and education strategies will be developed in Kalgoorlie in cooperation with Bega Garnbirringu and the Wongutha Birni Cultural Centre so there will be flow on benefits for the Kalgoorlie-Boulder community without the need for the project in Kalgoorlie-Boulder.
Figure 2. Map courtesy of the West Australian Department of Indigenous Affairs
MAJOR PROJECT ELEMENTS
The five facets of the project are;

- **Clinical Services and Evaluation**: Early detection and disease management. Evaluation of the methods of delivery and health outcomes. Research into the disease prevalence, patterns and methods of health care delivery, education, health promotion and community development.

- **Mobile Arts Unit**: Community cultural development and health promotion.

- **Community Development**: Implementing structural and cultural change.

- **Marketing and Public Relations**: Production of culturally appropriate health promotion methods and materials.

- **Cross Cultural Governance and Management**: Governance and management structures will meet the combined needs of rigorous financial management and reporting to funding stakeholders and simultaneously respect Indigenous protocols and authorities. These are very distinct and different sets of needs.
Clinical Services and Evaluation

Clinical services will be provided by a mobile clinic staffed with a doctor and 4 Aboriginal health workers or nurses.

Evaluation will be conducted through the Rural Clinical School and there will be opportunities for ongoing research.

Mobile Arts Unit

2008 - Western Desert Training Project 1
Karrawang Community Event

2009 - Western Desert Training Project 2
Touring to Ten Communities.

Oct - Vusi Mahlasela and John Butler residency and tour.

2010 - Dust a Musical and key projects

Community Development

The appointment of a fulltime community development Officer to the project who has international experience in third and fourth world communities and

Marketing and Public Relations

Consulting with communities to produce culturally appropriate promotional materials contracting senior Indigenous advice and marketing personnel on a project

Governance

Broad community ownership of the project that respects traditional Indigenous authorities and protocols is essential. A steering committee with a representative from each of the ten communities will guide the project in collaboration with Wongutha Birni Aboriginal Corporation.

Administration

The Rural Clinical School of WA will employ a team of administrative staff with substantial financial, clinical and arts management experience to manage the project. The planned level of resources ensures the core business of the Rural Clinical School of WA, training, is not threatened.

Figure 3.
MOBILE RENAL CLINIC

TRANSPORT
To get to some of the ten target communities means crossing extremely harsh terrain by four wheel drive. For this reason the project will use two all 4WD vehicles on ISUZU NPS 300 Crew Cab chassis.

1. Mobile Renal Clinic – Single cab
2. Arts Participation and Education Vehicle – Twin Cab

One vehicle will be equipped as a mobile clinic using a converted truck equipped with examination couch and equipment as well as point of care machines for immediate assessment of blood sugar, HbA1C, Hb, Cholesterol, Creatinine, Urinalysis and Urine ACR. This will allow on the spot assessment of health and immediate feedback to the participants as well as education and intervention as appropriate.

The clinic will be staffed with a doctor and 2 Aboriginal clinical health workers or nurses with assistance from 2 Arts-Health workers. Where local health staff are available they will be encouraged to be part of the assessment team.

The truck will travel to each community once per year and stay in the community for between 1 and 3 weeks (depending on the size of the community) to offer screening to every member of the community. Participants found to have risk factors, established disease or other abnormalities will be either commenced on appropriate management or referred for appropriate investigation and treatment. The inclusion of a doctor in the team is critical so that participants can be referred for further investigation or assessment, commenced on treatment immediately and prescribed appropriate medication where indicated. Summary information will be available to the participants, the local clinic and the participant’s nominated General practitioner. Follow up during
the rest of the year would be provided by existing medical services (visiting or resident).

The mobile clinic will be equipped with a computer, software and internet capability so it can be part of the region’s secure virtual network and compatible with the general practice software programs, pathology, radiology, Bega Garnbirringu, HDWA and hospital data systems.

The trucks are designed as a purpose built module which is attached to a standard Chassis so that if there are mechanical problems with the vehicle, or the vehicle ages then the module can be transferred to a new chassis to ensure longevity.

This model of mobile clinic has been shown to be effective in reaching difficult to reach population groups and also sturdy for travel in remote areas as similar vehicles have been in use for several years by the Geraldton Aboriginal Medical Service and also the Perth Street Doctor Program.

In the long term clinical services can be partly funded through health department, MSOAP or Medicare but the initial set up, evaluation and capital cost of the clinic truck will need to be funded from grant or other funds. These consultations will in most cases meet and go beyond the requirements for, the Child and Adult Health check as described under the Medicare item numbers 704, 710 and 708.
EVALUATION

The aims of this project are:

1. To determine the prevalence of the risk factors for Diabetes and End Stage Kidney Disease (ESRD) in the Western Desert Region of Western Australia.
2. To develop effective treatment protocols and methods of service delivery for people identified as being at risk of diabetes and renal disease.
3. To determine the age at which risk factors for renal disease appear in these Goldfields Aboriginal Communities.
4. Develop and deliver culturally appropriate interventions for reduction in prevalence and prevention of risk factors for diabetes and ESRD using a combination of clinical, community development arts, and health promotion.
5. Evaluate intervention based on 2 and 4.

The evaluation is being conducted through the Rural Clinical School of Western Australian with the support and advice from the Telethon Institute for Child Health Research. There will also be opportunities for much needed research into disease prevalence and associations, causality, treatment, program development and delivery, health promotion and education, the role of community development in health and many other areas as a result of this project.

It will provide the opportunity for the community to benefit not only from the service delivery aspects of the project but also from being actively involved in research and through the strong community involvement and governance structure the community will have an important role in prioritising research, in research proposal development and implementation. There will be opportunities for indigenous people for the region to train and be employed in research as well as health care delivery.

MOBILE ARTS UNIT

Four skilled Arts/Health workers trained in a variety of art forms will staff the Mobile Arts Unit. Over the first three years of the project the team will receive training spread over twelve months and then tour to all ten communities. The team will accompany the clinical team, staying in each community for 1 to 3 weeks per year conducting activities around the themes of health promotion and disease prevention. These activities will introduce new art and performance skills to the communities and result in the development of health promotion materials that are engaging and appropriate for these communities and language groups – and many will also have much wider application.

This process will help to identify artists and performers who may wish to be involved in a more substantial project and the third year of the project will involve the staging of performance productions and the staging of exhibitions with community participants to promote Renal Health.

The establishment of the Mobile Arts Unit will be staged to accommodate local and national training with fundamental and then high-level skills development so that people of the Western Desert will retain the skills.
A community Arts model has been chosen because it is similar to traditional Aboriginal teaching methods – using visual images, dance and song rather than the written word to help people to learn, understand and then teach complex concepts. In addition the methods used will result in the production of art works – these art works will bring pleasure to the creators of them as well as Kudos resulting in improved self esteem, pride and ownership of the issues with improved motivation to tackle the problems facing individuals and the community. The art works will also be available to be used for exhibitions and performances in other communities to help in health promotion. Some of the artworks will endure in the community providing ongoing reinforcement for the behaviour and lifestyle changes that are the focus of the intervention.

The communities chosen for this study are quite fragmented and there are major problems with substance abuse, domestic and interpersonal violence, family feuding, incarceration, unemployment, apathy and poverty. The community development aspects of the intervention will assist with drawing people together to tackle some of their problems, providing an important focus for people to come together to work towards a common goal. This will, in turn, help to build a sense of community and support for participants who are striving to make lifestyle and environmental changes.

MOBILE ARTS UNIT SCHEDULE OF ACTIVITIES

2008

PHASE ONE – 6 weeks – THE WESTERN DESERT TRAINING PROJECT 1.

Intensive Skills Development

For six weeks local health workers and artists will be provided with intensive skills development in a variety of art forms that can be used in a community context. The trainee artists will also be trained in basic event management skills and how to engage broad community participation.

Eight local Goldfield trainees will work with some of Australia’s leading community practitioners to develop a cross section of skills. The trainees will be indigenous people with training or qualifications as Aboriginal Health workers or nurses. An additional 4 places will be offered to community arts workers.

- History of community arts in post colonial Australia;
- Project initiation and design;
- Event planning and management
- Community Consultation and protocol who to ask and why;
- Methods of delivering projects;
- Funding and the importance of cross sectoral partnerships;
- The importance of effective Public Relations and Marketing;
- Documentation;
- Evaluation;
- Hands on creative activities;
PHASE TWO – A Four Week Community Residency

The trainees will work on a distinct project culminating in an event for NAIDOC Week 2008 in September. The residency is designed to give the trainees an opportunity to spread their wings and put their newfound knowledge into practice.

Evaluation Two days

At the completion of this phase of the project the trainers and the trainees will evaluate the effectiveness of the community residency and discuss ways in which the project can be delivered more effectively.

AIMS

The aim of the National Desert Training Project is to establish a base of skills so that health workers and artists can work then work alongside the clinical team in the ten Western Desert Indigenous communities.

Each of the Trainees will also visit some of the ten Western Desert communities accompanying the Clinical Team.

2009

PHASE THREE -

March – June 10 weeks National Western Desert Training Project 2.

Following the six months of basic community arts training across a range of genres the second Western Desert Training Project will introduce the trainees to some of the Country’s leading Indigenous and Community Artists for blocks of training;

- History of Indigenous arts in post colonial Australia;
- Processional and ceremonial events
- Theatre – acting and devising theatre for communities
- Puppetry in a community context
- Choral Work in a community context
- Film and digital animation in a community context.
• Visual arts and painting

The specific aim of some of the National Western Desert Training Project 2, is to develop material for major performance and exhibition projects that will come to fruition in 2010 the major project being a musical.

PHASE FOUR

July – November

Four trainees will then be employed to accompany the Mobile Renal Clinic to the ten Western Desert Communities. At the completion of each community residency the Arts Team will produce an event.

2010

Performance Projects and Exhibitions

Eg. DUST A MUSICAL Working title only
COMMUNITY DEVELOPMENT
There are complex sets of community and service provision issues that hinder renal health in Australia’s Western Desert regions. High-end community development expertise will afford these Indigenous communities an important and effective tool to address some of the structural problems.

The appointment of a full time Kalgoorlie based Community Development Officer at Wongutha Birni Aboriginal Corporation will provide the project with vital strategies to address long term structural issues such as the lack of fresh fruit and vegetables.

The Community Development Officer requires a formally qualified person with previous International experience work in third world and fourth world communities.

MANAGEMENT
Cross cultural partnership
The management of the project will be a rigorous cross-cultural partnership between Wongutha Birni Aboriginal Corporation and The Rural Clinical School or Western Australia. Each organization a figure

Indigenous and community relationships
Wongutha Birni Aboriginal Corporation, WBAC, will be the key broker in the development and maintenance of Indigenous protocols and community relationships. Wongutha Birni Aboriginal Corporation will play a key role managing the major Governance instrument for the project the Western Desert Kidney Health Project Aboriginal Reference Group. A senior woman from the Aboriginal community (Annette Stokes) will lead this project.

Finance and administration
The Financial management for the project will be in the hands of the University of Western Australia through the Rural Clinical School. A unit has been established within The Rural Clinical School of Western Australia to administrate the project. team who is an experienced researcher and Health Worker. While in Kalgoorlie project, staff will be housed between the offices of the Rural Clinical School and Wongutha Birni Cultural Centre, which are a few hundred metres apart.

Partner organisations and stakeholders
Bega Garnbirringu, the Goldfields-Esperance General Practice Network, the Health Department of Western Australia, regional and visiting medical specialists and the Royal Flying Doctor Service will be invited to sit alongside The Western Desert Kidney Health Project Aboriginal Reference Group. They will work with the Western Desert
Kidney Health Project Aboriginal Reference Group to ensure that best practice, coordination of medical services, financial management, protocols, and succession and sustainability planning is developed and implemented.
GOVERNANCE

Western Desert Kidney Health Project Aboriginal Reference Group

A broad regional Governance mechanism will be established to ensure Indigenous communities have control of the project. One person will represent each of the ten communities on the Western Desert Renal Health Project Aboriginal Reference Group. Sitting fees, travel and accommodation have been budgeted accordingly. The Western Desert Renal Health Project Aboriginal Reference Group will be responsible for governance of the project.

Partner organizations, such as Bega Garnbirringu, the Goldfields-Esperance General Practice Network, the Health Department of Western Australia, regional and visiting medical specialists and the Royal Flying Doctor Service will be invited to sit alongside The Western Desert Kidney Health Project Aboriginal Reference Group.

Ongoing community consultation

Formal consultation will remain ongoing with each community. During the final stages of the study further consultation will occur to inform the community of the results and seek their assistance with the development of materials for publications and promotional material. This consultation will be during the community visits - face to face, as well as written correspondence and phone calls.

At every community visit there will be time set aside for community members and in particular key leaders to sit with the research team and yarn about the visit, the process, the intervention and the findings. Their input will be used to assist the project team to ensure appropriate behaviour of the project team and refine the study procedures and intervention.

Each community will be visited when the analysis is complete for presentation of the results to community members. The results will be presented as a verbal report with opportunity for questions and explanation. Written reports will be presented to each community and the community will be asked to comment and assist with developing materials for publication.

Terms of reference

The Western Desert Renal Health Project Aboriginal Reference Group will provide the Project Team with comment and advice on:

- The relationship between the Project, cultural, spiritual and social values with respect for the richness and integrity of the cultural inheritance of Aboriginal people;
- The management of data, publications, artworks and the protection of individual and/or community identities during the project*;
- The methodology, conduct, dissemination of results and potential outcomes of the Project;
• Diabetes and Kidney Failure and how they are dealt with in a culturally sensitive way;
• Project documents such as Consent Forms and Participant Information Sheets, interview guides, questionnaires and health promotion resources;
• The Western Desert Kidney Health Project Final Report and draft manuscripts before they are disseminated and any materials to be published in scientific journals, and
• The preparation and development of lay summaries for dissemination.

*After the project has been completed the management of data, publications, and the protection of individual and/or community identities will be overseen in the longer term by a body suggested by the Western Desert Kidney Health Project Aboriginal Reference Group.

Values Underpinning the Terms of Reference
The Aboriginal Consumer and Community Reference Group Terms of Reference are underpinned by the National Health and Medical Research Council (NHMRC) Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research and the Consumers Health Forum’s Model Framework for Consumer and Community Participation in Health and Medical Research (NHMRC, 2004).

Australia Council For the Arts Indigenous Protocol Guides.

The five guides cover protocols for producing Indigenous Australian media arts, music performing arts, visual arts and writing. They were written for the Australia Council by eminent Indigenous intellectual property lawyers Terri Janke and Robynne Quiggin.

• Protocols for producing Indigenous Australian visual arts
• Protocols for producing Indigenous Australian performing arts
• Protocols for producing Indigenous Australian music
• Protocols for producing Indigenous Australian writing
• Protocols for producing Indigenous Australian media arts
RISK MANAGEMENT

There are many risks involved while establishing a new service for Indigenous communities that involve the integration of other cultures and particularly a western model.

- Third party interests: there is danger that the perception of other Indigenous service provider in the region that the project may threaten their core business. There has been a vigorous dialogue to allay these fears by consulting with these organizations and partnering with them.

- Inadequate resources: The scope of the project needs to be adequately resourced in terms of administrative and management support so that the core business of the Rural Clinical School is not threatened.

- Loss of Aboriginal control: It is paramount that the Governance of the project be driven by broadly representation of Indigenous people who are from the communities the projects seeks to service.

- Conflicting systems of authority: Indigenous Australian authority is often attributed on the basis of seniority or people who have been given spiritual significance. European Australian authority is attributed according to the status of the job an individual is appointed to or if they someone is elected to a position of authority. The two systems of authority can conflict if there is not a clear Governance mechanism to bridge the gap. The Aboriginal Community Reference Group must have senior elder representation.

- The employment of skilled qualified people in their discipline who have had extensive experience working in Indigenous communities is critical to the success of this project. All positions must have qualified people or there must be a process in place to mentor people so they can accomplish the tasks they are required to do.

- Provision of cultural leave and Indigenous managed work teams: It is imperative that Indigenous and non-Indigenous employees of the project meet the productivity workload that is required of their individual position. This can be achieved with the provision of culturally appropriate work practices that include cultural leave.

- Clear parameters, resources and authority for all parties involved in the project. There will inevitably be structural problems in a small but complex team working across cultures. This will need close monitoring and adjustment to suit the needs of the communities the project seeks to service.

- Transparent and articulated means of conflict resolution for all elements of the project with the provision of external mediation through UWA and senior Indigenous mentors. Should conflict stall the project and internal resolution process will be the first port of call. If that course of action fails external mediation will be sort.
PERSONNEL

Clinical
Chief Investigator Dr Christine Jeffries Stokes
Clinical Doctor
Health workers / Arts workers x 4

Clinical Manager
Annette Stokes

Mobile Arts Unit
Director Lockie McDonald

Community Development Officer
TBC

Operations Financial Manager
TBC

Marketing and Promotion
This is not a full time position but will be contracted out on a project-by-project basis.

Trainees
Local Goldfields Trainees 8 (Includes the four Artworkers/Healthworkers)
Australian invited trainees 4

Western Desert Training Project 1 – Artists
  ○ Textile Artists TBC
- Ceremonial processional theatre – Lockie McDonald
- Visual Arts/Puppetry – Cecile Williams TBC
- Music/ Percussion – Peter Keelan TBC
- Hip Hop/Beat Boxing TBC
- Storytelling – Oral script writing Lockie McDonald

**Western Desert Training Project Senior Australian 2. Artists** – TBC - not confirmed

Rhoda Roberts – Australian Indigenous Contemporary Overview

Wesley Enoch – Theatre

Neil Cameron – Outdoor festivals, ceremonial theatre

Sandy McKendrick - Puppeteer

Martin Meader – Choral Guru
MANAGEMENT TEAM

Lockie McDonald - Biography

By opening up lines of communication Lockie assists communities to find lasting solutions. He often works across sectors using the arts and community development as tools to address social issues. He has worked with Indigenous communities designing, implementing projects, mentoring individuals, and communities for the past twenty years in the Northern Territory, Queensland, South Australia, Christmas Island and extensively throughout Western Australia. Lockie has recently completed a four-year contract with Perth International Arts Festival where he managed a range of nationally acclaimed Indigenous projects and a team of Indigenous staff members.

He is known for excellent artistic outcomes that provide sustained legacies. Prior to working with PIAF, Lockie worked with communities using theatre, circus, literary programmes and large outdoor events to increase community capacity. From Cape Town to Kalgoorlie, Albury to Albany, Lockie’s diverse experience has seen him work with Firemen, Speedway Clubs, Aboriginal Communities, Islamic Communities, Librarians and Maximum Security Prisoners.

As a Writer, Director and Performer he is known for his powerful but deft collision of genres in epic outdoor events to intimate one-person theatre works. Lockie produced and co directed, Shishka-Car, the smash hit of the Adelaide Festival 2002, as Producer of Community, Regional and Special Events with the Perth International Arts Festival his major achievement was working with Indigenous Communities and in particular the Ngallak Koort Boodja Group, Our Heartland Group, who represent family groups from across the Noongar Nation of the South West of Australia. This project has been heralded as a historic cross-cultural milestone in Western Australia.

….arguably done more for black white relations in Perth than any single event in the city’s history. Victoria Laurie, The Australian

Qualifications

Registered Nurse.

Royal Brisbane Hospital School of Nursing 1981-1984.

Awards

**2005 Ros Bower Award** - $50 000 National award from the Australia Council for the Arts for a lifetime commitment to community cultural development

**2000-01 - Australia Council for the Arts Fellowship** awarded by the Community Cultural Development Board.

Clients

- **BHP Billiton Iron Ore** 2006 and 2007 – Project design and consultation in Port Hedland.

- **University of Western Australia and Notre Dame University Rural Medical Clinic** 2007 – Renal Health Community Development Project in Leonora, Laverton, and Mt Margaret Community with members of the Wongutha Community.

- **Adelaide International Arts Festival** 2002 – Artistic Director and Producer of Shishka-Car addressing high rates of teen autocide in rural communities.

- **Department for Culture and the Arts** 2002 – Artrage Festival – Commissioned to restructuring the organization with the Board and consulting with key community stakeholders to create a new more broadly owned vision.

- **Arts Katherine** 2002 – Short scoping study in 16 communities surrounding Katherine which designed the cross sectoral project – *Long Yarn Slow Tucker* with the NT Health Department introducing the slow food movement to community owned stores.
Annette Stokes – Curriculum Vitae

Date of Birth  4 February 1965

Education

Kalgoorlie Primary School  Kalgoorlie W.A
Eastern Goldfield High School
Advanced Certificate of Aboriginal Health Worker Training

Interests and activities

Music – Vocal, Guitar and Keyboards

Visual Arts – Painting, Ceramics, Fabrics

Languages

English and Wongutha

Work History

1979 – 1987 Aboriginal Education Worker, Mt Margaret
1986 Skillshare Child care, Kalgoorlie
1996, 1997 Ngunytju Tjitji Pirni Aboriginal Education Worker and Aboriginal Health Worker
1998, 1999 Laveton Best Start Program Playgroup leader
2001-2004 Senior Aboriginal Researcher – Telethon Institute for Child Health Research, Otitis Media Project, Kalgoorlie
2006 – Present Senior Aboriginal Researcher – Northern Goldfields Kidney Health Project
2007 Senior Aboriginal researcher for Northern Goldfields Kidney Health Project

 Volunteer experience

Youth Projects with Ninga Mia and Wongtha Birni
(Danaya Wadala, Buyu, Fireplace Project , Warru)

Rural Clinical School Aboriginal Cultural Education Mentor – 2003 - 2006

Hobbies

Basketball, Volleyball, Bush outing, Painting, Carving

References

Dr Deborah Lehman - Telethon Institute for Child Health Research, Perth

Extracurricular activities

Music

Basketball

Volleyball

Community activities

Worship Leader, Ninga Mia Christian Fellowship

Arts Experience

1998 to Present – Wongutha Birni Aboriginal Corporation – Committee member

Involved in all Wongutha Birni Projects

2001  Danaya Wadala – artist and backstage

2002  The Rhythms of the Outback Parade – musician and logistics

2003  Fireplace – Artist

2003  Buyu project and exhibition – Artist and logistics
2003  Country exhibition - Artist
2004  Waru – Artist, backstage and logistics
2005  Nya exhibition – Artist and logistics
2006  Turlku Pukurlpa Pirni - performer
2006  PIAF Performance – S.O.R.R.Y. Brother E-Right - Performer
2003 to present - The restoration of the Cultural Centre Building - Volunteer

Naidoc Week Parade every year

2007  Coordinator and Performer for Wanti Sugarba Project

Awards

Fiona Stanley Medal for Contribution to Medical Research 2004

Publications


Presentations

International Otitis Media Conference – Amsterdam 2004

International Breastfeeding Conference Hobart 2004

International Health Promotion and Education Conference – Vancouver June 2007

Courses

Focus Group Interviewing – Telethon Institute for Child Health Research 2006

Conferences

Diabetes in Indigenous People Forum Melbourne 2006
Dr Christine Jeffries – Stokes - Curriculum Vitae

Date of Birth: 10th May 1963
Place of Birth: Hobart, Tasmania
Marital Status: Married to Geoffrey Stokes (Wongutha Nungarni)

Children – Lachlan DOB 27/6/1999
Rebecca DOB 1/8/1996
Craig, Luke and Benjamin – all over 16 yrs.

Tertiary Education:

1986 - Bachelor of Medicine and Surgery from University of Tasmania.
1994 - Fellow of Royal Australian College of Physicians in Paediatrics
1996 - Master of Public Health, University of Western Australia (with distinction). Thesis title: Goolleelar Ngoodah! A qualitative study of the attitudes of the Aboriginal people of the Eastern Goldfields of Western Australia to the health services offered to them and comparison with the perceptions of the medical staff providing those services.

Awards

1986 Kathleen Menzies travel Scholarship
1986 Commonwealth Medical Foundation Medical Elective Bursary
1992 Eva K. Nelson Scholarship
1993 Telethon Fellowship

Employment

1987 - Intern at Royal Hobart Hospital, Tasmania
1988-91 – Resident/Registrar at Princess Margaret Hospital, Perth Western Australia
1992 - Advanced trainee with Royal Australian College of Physicians
   Medial Officer - Child Sexual Abuse Unit of Princess Margaret Hospital
   Tutor – University of Western Australia, Faculty of medicine – Public Health and Paediatrics
1993 - Full time student, Masters of Public Health, University of Western Australia
1994 - Registrar (part-time) at Princess Margaret Hospital, Perth Western Australia
   Part-time student, Masters of Public Health, University of Western Australia
1995 – Member NHMRC grant assessment panel
1997-2001 - Senior Lecturer, University of Western Australia, Department of Paediatrics – Rural Unit, Kalgoorlie
1995-present - Pediatrician in Kalgoorlie, Western Australia
2002 – 2005 Principal Investigator - TVW Telethon Institute for Child Health Research, Otitis Media Research Team
2003 and 2004 University of Western Australia Rural Clinical School Associate Lecturer
2005 – Current - Senior Lecturer in Rural and Remote Medicine, Rural Clinical School, University Western Australia and University of Notre Dame
2006 Member of steering committee for NHMRC funded Happy Kids project
2006 and 2007 Member of steering committee for the Alcohol in Pregnancy Project – Telethon Institute for Child Health Research

2004 – Present - Honorary Research Fellow – Telethon Institute for Child Health Research

2007 (Ongoing) Chief Investigator Northern Goldfields Kidney Health Project

1995 to Present Paediatrician – Goldfields Western Australia

Publications


Renal Stones and Carbohydrate Intolerance in Children Under the age of five years in the Goldfields of Western Australia. *Journal of Paediatrics and Child Health* 2003 Vol 39, p 381-385 - June 2003


This paper was also presented as an oral presentation at the Royal Australian College of Physicians Annual Scientific Meeting, Hobart 2003.


Posters Presentations:

An Aboriginal Perspective of Ear Disease in the Arid Zone of Western Australia – Presented at the Royal Australian College of Physicians Annual Scientific Meeting, Hobart 2003 and the Pacific Rim Indigenous Doctors Congress, Cairns 2004.

Buyu – Good Smoke Bad Smoke - Presented at the Royal Australian College of Physicians ASM, Canberra 2004, the Pacific Rim Indigenous Doctors Congress, Cairns 2004 and the Princess Margaret Hospital Research and Advances seminar 2003.

Note: No information from MPH Thesis has been published as it was considered by the Aboriginal women involved in the study that the information was culturally sensitive. The thesis is not available for viewing except with the written permission of the committee of Ngunytju Tjitji Pirni.
Oral Presentations


1999 Royal Australian College of Physicians College Annual Scientific Meeting, Perth – Aboriginal Cultural Considerations

2003  Australian Indigenous Doctors Association Annual Conference, Melbourne - Renal disease and Aboriginal Children


2004  Pacific Rim Indigenous Doctors Association Annual Conference, Cairns. Nephrolithiasis and Carbohydrate Intolerance


2007 "Myaee! - An Innovative approach to increasing fruit and vegetable intake in a remote Australian Aboriginal community."  June 2007 IUHPE World Congress, Vancouver

2007 Wanti Sugarba – Rural Clinical School Rural Medicine Conference, Geraldton WA

Multiple training seminars in Aboriginal Cultural Considerations, Aboriginal Health and Paediatrics for Kalgoorlie Regional Hospital, Princess Margaret Hospital, Diploma of Child Health students, RACGP registrars, University of Western Australia (Undergraduate and postgraduate students), Royal Australian College of General Practice, Hospital Chaplain’s Association and other business and community organizations.

Research Interests

Aboriginal Health
Otitis Media
Type 2 Diabetes
Renal Disease
Renal Stones and Carbohydrate Intolerance in Children
Insulin resistance

Research Grants
Socioeconomic risk factors and treatment seeking behaviour for otitis media in the Aboriginal population of the Kalgoorlie-Boulder Region – NHMRC Otitis Media Strategic Research Grant ($158,000)

Quantitative and qualitative studies of otitis media to improve ear health – Health Promotion Foundation of Western Australia ($290,000) Principal Investigator.

Northern Goldfields Kidney Health Project – Principal Investigator - $580,000 from The Rural Clinical School, $50,000 from BHP Billiton Nickelwest, $25,000 from the Myer Foundation, $25,000 from Barrick Gold, $21,000 from Healthway.

Sugarba – Health promotion Puppet show - $10,000 from Healthway

Other Appointments and Memberships

1999 – 2002 Member of Royal Australian College of Physicians Indigenous Health Committee
1997 – Current Member of Australian Medical Association
1999, 2000 Member of Executive Committee of Ngunytju Tjitji Pirni Aboriginal Corporation
1998 - Current Member of Executive Committee of Wongutha Birni Aboriginal Corporation
2005 Member Rural Doctors Association Specialist Working Group
2005 Member Royal Australasian College of Physicians Working Group – the Health of Paediatrician
2008 Delegate Australia 2020 Summit - Canberra

Arts Experience

1978 and 1979 Puppetry and Performance Workshops - Tasmania
1980 Matriculation Fine Arts – with distinction (Tasmania)
1981 to 1983 Ceramics and Sculpture
1989 to 1993 Volunteer with the Ran Dan Club
1991 to 1994 Surdo drummer with the Sambanistas
1998 to Present – Wongutha Birni Aboriginal Corporation – committee member, Public Officer and Grants Officer

Participant Artist in:

2001 Danaya Wadala
2002 The Rhythms of the Outback Parade
2002  Country exhibition
2003  Fireplace
2003  Buyu project and exhibition
2004  Waru
2005  Nya exhibition
2006  Harmony Week Breakfast
2006  Turlku Pukurlpa Pirni - performer
2006  PIAF Performance – S.O.R.R.Y. Brother E-Right - Performer
2003 to present - The restoration of the Cultural Centre Building
Naidoc Week Parade every year
2006  Sugarba!
2007  Wanti Sugarba – the Northern Goldfields Kidney Health Project
Appendix 6

Nagi, A.

Aboriginal Perspectives on Diabetes and Kidney Disease in the Eastern Goldfields of Western Australia
Aboriginal Perspectives on Diabetes and Kidney Disease in the Eastern Goldfields of Western Australia

Abstract
The average life expectancy of Indigenous Australians is approximately 20 years less than non Indigenous Australians. In rural and remote areas the disparity between life expectancy for Indigenous and non Indigenous Australians is even more marked. A major contributing factor in this reduced life expectancy is the effect of diabetes and renal disease. To better understand Aboriginal perspectives regarding the etiology, social determinants and possible appropriate interventions of these diseases, 11 adult semi-structured interviews were conducted in the Aboriginal Mission community of Mount Margaret as part of a wider cohort study of the Northern Goldfields Kidney Health Project in Western Australia. Being understudied, the literature remains sparse. Initial findings suggest that while there is some knowledge of the risk factors for diabetes and renal disease, there is obvious fear and anxiety related to the diseases as well as a plea for culturally sensitive and appropriate community based interventions.

Aboriginal Perspectives on Diabetes and Kidney Disease in the Eastern Goldfields of Western Australia

Background
Aboriginal Australians experience an average life expectancy approximately 20 years less than non Indigenous Australians, with those in rural and remote areas being more severely affected. A key culprit is chronic disease which is currently responsible for 60% of global disease burden. Unfortunately, by 2020, with an ageing population, this burden is projected to increase to 80%. Undoubtedly, as chronic disease targets lower socioeconomic groups and reaches epidemic proportions, this poses significant challenges for healthcare systems worldwide. A major contributing factor in this reduced life expectancy is the effect of diabetes and renal disease. Being more susceptible, Indigenous communities are disproportionately diagnosed, experience unique barriers to access and struggle to find suitable solutions for optimal health care. This therefore is a significant burden - not only in mortality, morbidity and suffering but also the loss of vital human resources and leadership potential in the Aboriginal community.

Diabetes Background
It is well established that Aboriginal populations fall prey to diabetes more readily than their Non Aboriginal counterparts, regardless of geography. For example, in contrast to the general population, mortality risk is double for male and quadruple for female Aboriginal Canadians. Furthermore, age-adjusted prevalence rates of 5–10% in Indigenous populations are two to four times the national prevalence rate of 2.5%. As a leading cause of morbidity and mortality among native North Americans, non-insulin-dependent diabetes
mellitus (NIDDM) is also emerging as an increasingly critical health concern among Indigenous peoples of the Americas, South Pacific, New Zealand and Australia. A major recent review in Australia concluded that the overall prevalence among Indigenous people was between 10% and 30%. In addition, sequela of diabetic complications are greater for Aboriginal than for non-Aboriginal populations with rates per case of outpatient visits and hospital admissions for diabetic Aboriginal people doubling those of non-diabetic Aboriginal people. Unfortunately, diabetes prevalence in Aboriginal communities continues to increase despite being a priority concern for health agencies.

**Renal Disease Background**

Aboriginal people are diagnosed with renal disease four times as often as non-Aboriginal people and in some areas the rate is reported as 30 times higher. Almost 1000 per million Aboriginal people in Australia are affected by end-stage renal disease (ESRD), with an expected doubling of the figure in the next four years. This represents approximately 150 new cases per year, at a cost of $78,600 per person receiving treatment for ESRD annually. Age-related incidence rates of ESRD in the Top End of the Northern Territory, Central Australia and the Goldfields of Western Australia are between 22 and 36 times the overall Australian rates. The incidence of ESRD in the Goldfields was 1,300 cases per million from 1993-1990. Interestingly, in contrast to non-Aboriginals, ESRD rates in Aboriginals are higher in women than men and tend to present at earlier ages. In Western Australia the rates of both acute and chronic renal failure for Aboriginal children are four times the rate of the general population. Undoubtedly, the epidemic of ESRD is beginning in childhood, and risk factors include low birth weight and infant malnutrition, infections (scabies, post streptococcal glomerulonephritis), increasing adult weight, high blood pressure, increasing glucose levels, insulin resistance, dyslipidemia, and heavy drinking. Akin to diabetes, Aboriginal people with renal disease also have a poorer prognosis than non-Aboriginal people - the case fatality rate is about 9 times the total Australian rate and deaths from chronic kidney disease represent 2.5% of all Indigenous deaths.

The current epidemic is probably explained by the confluence of many risk factors over a condensed time period, associated with dramatic lifestyle changes and serious socioeconomic disadvantage. The burden of illness is amplified since Aboriginal people with ESRD are more likely than non-Aboriginal people to have NIDDM (48% v. 24%; P = 0.002). Furthermore, these proportions have increased recently: for diabetes from 37% pre-1993 to 60% in 1993-1996 (P < 0.005). Given that Aboriginal diabetes rates are reported as highest in the world on some indicators, coupled with the predicted doubling of ESRD, disease burden and sequela are enormous for the Australian Indigenous population.
Gaps in Current Knowledge
Despite the high prevalence of diabetes and renal disease amongst Australian Aboriginals, the number of studies relevant to improving health tailored to this population is limited. Moreover, research identifying prevalence of disease, Aboriginal perspectives on etiology, feelings, prevention strategy or culturally appropriate support is sparse. Studies that do exit tend to focus on renal disease and diabetes in a wider context such as pathophysiology, known risk factors, prevention and medical interventions from Western perspectives. Moreover, when intuitive relevance of local perceptions of behavioural social determinants and effective interventions are secured, despite strong consistency in certain key recommendations made by Indigenous Australians for changing self-harming behaviours, such proposals are rarely adopted into policy and program planning.\(^{16}\)

Research has not contributed in significant or systematic ways to improved health outcomes for Aboriginal populations\(^ {17} \). While significant exploration has been conducted, there is little published information available about Aboriginal perspectives on diabetes or renal disease. Naturally, these are key components to dismantling barriers to effective prevention. In order to be successful, interventions must target the social context of health behaviours and the realities of everyday life\(^ {18} \), including the qualitative study of people’s perceptions regarding health status and interventions\(^ {19} \).

This paper employs qualitative methodologies to elicit health beliefs of Aboriginal Australians as part of a larger Western Australian Goldfields study which includes a community intervention aimed at enhancing awareness and understanding about diabetes, renal disease and their antecedents.

Methodology

Study Site and Population
The study was conducted in the semi-arid Eastern Goldfields region of inland Western Australia, situated approximately 800 kilometres from Perth, the State’s capital. Study participants were predominantly Wongutha people from the Mission town of Mount Margaret. Identification of potential participants was straightforward as almost all of the town’s 70 inhabitants are Aboriginal. The region’s post-European history spans just over 100 years. There has been rapid growth in the non-Indigenous population of the area during this time, with the current Eastern Goldfields region population estimated to be 52,487 people, of which 7% (3,553 people) identify as Aboriginal, although the true proportion may be higher as a further 7% of respondents in the recent census did not state their ethnicity\(^ {20} \). Mining and pastoral industry expansion, government and church-run institutional residence, and commercial and social service provision have had a dramatic impact on the lives of Aboriginal people in the area. In 2001 the median income for the region’s Indigenous population was $13,000 per annum compared with $28,600 in the non-Indigenous population\(^ {20} \).
Qualitative Study Design
A descriptive, grounded theory, applied research design using largely qualitative methods was used for an in-depth study of Aboriginal perceptions on diabetes and renal disease. Interview questions were derived over time in conjunction with the team’s Aboriginal research workers. The questionnaire was designed by the Chief Investigators (CJS), the resident researcher (AN) and the study’s senior Aboriginal research assistant (AS), with fieldwork conducted over 12 months (Appendix 1). The interviews, all with Aboriginal people, were organised by the senior Aboriginal research assistant and conducted by the resident researcher. Semi-structured interviews were used to identify perceptions regarding the etiology of diabetes and renal disease, feelings and concerns about the diseases and factors leading to increased prevalence in Aboriginal communities as well as prevention, intervention and support systems that would be aligned with the study participants’ perceptions. Individual interviews averaging approximately a quarter of an hour’s duration (ranging between 5 minutes 42 seconds to 37 minutes and 34 seconds) were conducted in participants’ homes (73%) or at the school (27%) in Mount Margaret. All interviews were taped using a portable tape recorder in addition to handwritten notes on the questionnaire form.

Qualitative Study Sample
Of the 70 residents of Mount Margaret, an opportunistic sample of participants were selected, that is, a mix of key informants were chosen for their knowledge, experience and position in the community. Accordingly, 11 Aboriginal individuals were interviewed, five male and six female. One person without diabetes refused to be interviewed attesting to great shyness. Age categorization was relatively representative: 36% of the participants were aged 16-25 years, 28% aged 25-40 years, with 36% being over 40 years old. 73% of the participants lived in Mount Margaret or the peripheral communities of Leonora and Laverton, both within a half-hour drive. 18% lived in Kalgoorlie or similar larger towns and only 1 participant (9%) was from another State.

Ethical Aspects
Ethical clearance for the study was granted by the Western Australian Aboriginal Health Information and Ethics Committee, the Northern Goldfields Health Service and Nursing Education Ethics Committee (Kalgoorlie), the Ethics Committee of Princess Margaret Hospital, the HDWA Committee for Confidentiality of Health Information Systems, and endorsed by the two local Aboriginal health services in the area: Bega Garnbirringu Health Services Aboriginal Corporation and Ngunytju Tjitji Pirni Inc. Study participants were recruited individually by the research team. Home visits were arranged by the senior research assistant who, with the resident researcher, discussed the study, its purpose, ethical issues, type of research questions proposed, and any queries. Participants gave informed written consent, including management of taped interviews, and anonymity was preserved.
Data Management

Data were coded on both hard and electronic copies. Tape-recorded data were transcribed and compared against handwritten notes taken during the interview. Further analysis of the data was performed manually in order to search for emergent themes. Results are presented descriptively in response frequencies and verbatim quotes.

Results

Diabetes

Incidence

Twenty eight percent of persons with established diabetes were interviewed, with 17% (1/6) affected by Gestational Diabetes Mellitus (GDM); one person without diabetes refused to be interviewed. 82% of participants had relatives who were affected by diabetes.

Etiology

Eight key causes of diabetes were identified by the sample population: Excess sugar, poor diet, insufficient or lack of exercise, alcohol, genetic predisposition, hypertension, dehydration and cultural impact (Figure 1). While there was unanimity on the influence of excess sugar and poor diet, the role of hypertension and cultural impact were less commonly identified.

Figure 1.

Perceptions of Diabetic Etiology
Characteristic responses to perceptions surrounding diabetic etiologies

What causes diabetes?

Sugar—that’s the one thing I know for sure (22 yo woman, Kalgoorlie)

Change of living—for thousands of years we were hunters and gatherers and today we just go to the shop buy what we want to eat, there’s no digging involved, there’s no effort of getting food (44 yo male, Kalgoorlie)

Aboriginal bodies are adapted for desert environment—we might not eat for three or four days until we kill…our bodies are adapted for 40,000 years and all of a sudden we’re eating all day, every second of the day and our bodies, our system can’t cope with the stuffing of the food! (44 yo male, Kalgoorlie)

Feelings about Diabetes

In addition to fear and concern, a sense of responsibility and sadness was also reported to a greater extent than anger or unsureness. The need for prevention and the role of genetic influence were also mentioned (Figure 2).
Characteristic responses to feelings about diabetes
How do you feel about diabetes?

I wouldn’t like to have it…you’d have to muck around with too much tablets
(30yo female, Mount Margaret)

When I was pregnant, I had gestational diabetes, going back ad thinking about that time, I wouldn’t wish diabetes on a dog, because those months were a dark time for me…diabetes is a very slow death and I don’t think it would be a good thing for anybody to have it
(52 yo female, Leonora)

I feel like I’d like to do more to help my mom with diabetes, I have to be there for her when she needs to take more meds
(47 yo female, Mount Margaret)

I think it’s something that needs to be addressed…specially in kids because they’re always wanting to eat more lollies
(33yo female, Mount Margaret)
I think it’s sickening! It’s a death sentence, it’s like when someone says you’ve got sugar diabetes, a fear come upon you…because when the Wongi people get diabetes, they die

(44 yo male, Kalgoorlie)

Factors Affecting Increased Incidence of Diabetes in Aboriginal Populations
Lifestyle, cultural impact, excess alcohol, lack of access to service, financial constraints, lack of education and research and genetic predisposition were all highlighted as possible pitfalls causing an increase incidence of diabetes in Indigenous people (Figure 3).

Figure 3.

Characteristic responses to reasons for increased incidence of diabetes in Aboriginal populations
Diabetes is very common in Aboriginal people ~ why do you think it is such a common problem?

They don’t care for what they eat-as long as they get a feed, it doesn’t worry them…they’re more worried about the alcohol-that’s the main thing they like doing

(19yo male, other state)
Lifestyle, in the olden days we lived in the bush—healthy, busy collecting wild food, now the food in the shop makes most people sick (47yo female, Mount Margaret)

Aboriginal people have been living on traditional food all their lives, then they bring foreign foods that they like to try and eat [which causes diabetes] (29yo female, Laverton)

Being more remote—maybe the research might find that there may be a difference in actually where people live (52yo female, Leonora)

**Concern for Future Diabetic Diagnosis**

Of those that had not yet been affected by diabetes, a significant proportion was concerned of acquiring the disease in the future. More participants were unsure of how they felt than those that expressed little or no concern for possibly become diabetic (Figure 4).

Figure 4.
Issues of Concern Regarding Diabetes

There was significant concern regarding fears of becoming diabetic, coupled with thoughts of death and weakness, not to mention amputation and dependency (Figure 5).

Figure 5.

Characteristic responses to reasons for concern regarding diabetes

*What worries you about diabetes?*

Family had it, so I might get it     (22yo male, Laverton)

With my Christian faith, I pray I wouldn’t get any sicknesses like that and I really try to eat better to prevent it     (52 yo female, Leonora)

It’s like another big load has been put on my back—you’ve got all the pressures of life on you, kids, to do the right thing, take the tablets, you need to eat the right food…and sometimes we can’t do that because we can’t afford it     (44 yo male, Kalgoorlie)
My uncle had his leg cut off for diabetes, I just don’t want it to happen to any of my family…I think I’d just avoid it than having to deal with it  
(33yo female, Mount Margaret)

Worried about getting sick and depending on family and having to take tablets  
(47yo female, Mount Margaret)

**Renal Disease**

**Incidence**

Eighteen percent of persons interviewed felt that they had renal disease. This was also the same percentage of those that had relatives with renal disease.

**Etiology**

Unlike diabetes, there were fewer consensuses as to etiological factors for renal disease. Perceived variables included alcohol, excess sugar, poor diet, cultural influence, smoking and specific drinks such as coffee and orange juice, though this did not seem to be a common perception (Figure 6).

Figure 6.

![Perceptions on Renal Disease Etiologies](image-url)
Characteristic responses to perceptions surrounding renal disease etiologies
What causes kidney disease?

Alcohol, smoking and bad health-those that don’t look after your body (29yo female, Laverton)

The things we eat and drink-alcohol, food, lots and lots and lots of sugar…our bodies have not adapted-the sugar we eat today is raw (44yo male, Kalgoorlie)

It was a big shock to me, I don’t even know how it came about (52 yo female, Leonora)

Coffees and I think that orange juice can affect the kidneys-too much of it (33yo female, Mount Margaret)

Feelings Surrounding Renal Disease

Worry, death and other negative sequela, sadness and a call for more education prevailed as the common feelings surrounding kidney disease (Figure 7).

Figure 7.
Characteristic responses to feelings about renal disease
How do you feel about kidney disease?

Not so happy with it because you can lose a kidney—and then you’d only have one kidney…and I’d rather have two kidneys working in my body (29yo female, Laverton)

Worried because you don’t live too long (30yo female, Mount Margaret)

We’ve got to look after our organs…especially our Wongi people, so many people are on dialysis and leaving their lands and going to strange lands being on dialysis machines, it’s like their lives are being robbed (52yo female, Leonora)

I hate it! Because it’s killing a lot of our people and a lot of young people who should have lived a healthy life (44yo male, Kalgoorlie)

Factors Affecting Increased Incidence of renal disease in Aboriginal Populations
There seem to be little consensus with the variety of variables suggested as forces increasing the incidence of renal disease in Aboriginal populations. These include: alcohol, lifestyle, cultural impact, dehydration, financial issues, hereditary predisposition, medical incompliance, ignorance and infection (Figure 8)

Figure 8.

Reasons for Increased Incidence of Renal Disease in Aboriginals

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td>60%</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>50%</td>
</tr>
<tr>
<td>Cultural Impact</td>
<td>40%</td>
</tr>
<tr>
<td>Dehydration</td>
<td>30%</td>
</tr>
<tr>
<td>Financial Issues</td>
<td>20%</td>
</tr>
<tr>
<td>Hereditary</td>
<td>10%</td>
</tr>
<tr>
<td>Unsure</td>
<td>0%</td>
</tr>
<tr>
<td>Medical Incompliance</td>
<td>10%</td>
</tr>
<tr>
<td>Ignorance</td>
<td>0%</td>
</tr>
<tr>
<td>Infection</td>
<td>0%</td>
</tr>
</tbody>
</table>

301
Characteristic responses to reasons for increased incidence of renal disease in Aboriginal populations

Kidney disease is very common in Aboriginal people ~ why do you think it is such a common problem?

The way Aboriginal people drink alcohol, more than others (22yo female, Kalgoorlie)

Again, because of time…the food we eat now is not of our culture, see its been 40 years since the 1967 referendum that gave Aboriginal people voting rights in this country, and its like opening the door…the door into the candy shop-into Western eating (44yo male, Kalgoorlie)

Concern for Future Diabetic Diagnosis

The majority of participants were concerned that they could be affected by renal disease. Again, a larger percentage of participants were unsure of the future possible diagnosis than those who felt confident that they would not be susceptible (Figure 9).

Figure 9.
Issues of Concern Regarding Renal Disease

Though few concerns were highlighted – dialysis, personal limitations and the desire to preserve self dignity, the issues raised were not inconsequential (Figure 10).

Figure 10.

Characteristic responses to reasons for concern regarding renal disease

What worries you about kidney disease?

You’d be stuffed, you’d be on dialysis and wouldn’t be able to be active

(22yo female, Laverton)

Ending up on dialysis-my uncle’s on it, my aunty’s on it, and it was pretty bad; I felt sad for them

(22yo female, Kalgoorlie)

Don’t want to be on machines for the rest of my life, without any privacy and other people working on you and cleaning you

(47yo female, Mount Margaret)
Intervention

Several suggestions were put forth as possible interventional techniques used to combat diabetes and renal disease. Aside from lifestyle modification and aboriginal responsibility, most of the other variables of education, research, clinical evaluation, government support, housing, spiritual support, empowerment and sense of belonging called to other bodies to collaborate in the interventional process (Figure 11).

Figure 11.

Characteristic responses to suggested interventions for diabetes and renal disease

What do you think should be done about diabetes and kidney disease?

I think we as individuals must learn to understand what all these disease are about and work towards making ourselves healthy, but then again, I think there is a big consideration that has got to start at the top… I think the government can quiet easily make healthy foods cheaper, they could easily make grog [alcohol] more expensive than the good food like if it was more expensive, I wouldn’t be able to buy it

(52yo female, Leonora)
Someone should go around talking to more people about it (22yo female, Kalgoorlie)

The government—federal, local, state government needs to do education for the people. They should take it on board as their number one priority because what’s happening right now is basically murder! They tried to killing us with their guns, but we’re here. Now with sugar diabetes, and kidneys, and the type of diet we eat and the lack of education, its killing our people (44yo male, Kalgoorlie)

Empower them to get up! Get up and go forward. It seems like our people are not going anywhere, they’ve got no vision, no drive, no nothing…again, the government and education should give them a vision (44yo male, Kalgoorlie)

Access to housing, proper housing, water, hospitals…the tools to access clinics, Aboriginal people running clinics—give Aboriginal people the responsibilities to take care of their own communities in educating their own communities (44yo male, Kalgoorlie)

A type of belonging…I belong. I belong to Kalgoorlie, I belong here, everybody knows me and I know them…you don’t see that [anymore] (44yo male, Kalgoorlie)
Prevention

Key concepts such as empowerment, prevention strategies, access and funding, exercise initiatives, education, research alcohol reduction and home visits were advocated as plausible avenues for prevention of chronic disease in Aboriginal communities (Figure 12).

Figure 12.

Characteristic responses to suggested prevention strategies for diabetes and renal disease

What do you think should be done to prevent diabetes and kidney disease?

We should empower the Aboriginal community—we’ve got Aboriginal doctors—we need them people to come along and tell us that we can get sugar diabetes easy, and sugar diabetes and blood pressure and kidney failure is preventable…you don’t have to get it.
They need to educate us, in the schools they should be teaching [this]  

(44yo male, Kalgoorlie)

The sad thing about health care workers is that they come when we’re sick…they should come there before we get sick and prevent us getting sick instead of looking after us after we get sick  

(44yo male, Kalgoorlie)

We need to promote sports-running, jumping, you name it, so that our bodies can get the 20 minutes of exercise  

(44yo male, Kalgoorlie)

Teaching them how to eat right, show them how to grown they’re own fresh vegetables  

(33yo female, Mount Margaret)

More surveys, workshops and health education  

(47yo female, Mount Margaret)

**Supports**

Medical, psychosocial, family, friends, access, education, housing, government, health promotion, Aboriginal Health Care workers, community space, interpreters and organ donation were all hailed as well suited sources of support for those battling diabetes and renal disease (Figure 13).

Figure 13.
Characteristic responses to suggested support systems for diabetes and renal disease

What sorts of supports should there be for people with diabetes and kidney disease?

Doctors to give them the right medication (30yo female, Mount Margaret)

Help lines, counsellors for people to talk to, get it through their heads

(19yo male, other state)

They need every support...they need social workers-some people on dialysis are the sole earner, they need support with their grandchildren and children and in the community. There's a whole range of stuff-like the pressure of living in Australia today...so we need support that we can go to so we can get that help (44yo male, Kalgoorlie)

Lots of family to “be with the person until they finish” (30yo female, Mount Margaret)

Brochures, commercial ads on TV to promote kidney disease and diabetes

(29yo female, Laverton)

If they had a swimming pool...or access to all the things they get in town in the community, I think we can prevent kidney and sugar and high blood pressure problems...but we don’t have it. This morning I went up the hill for a walk...that’s all you can do. (44yo male, Kalgoorlie)

Offer them a kidney...(would only do it for my family or close friend) (22yo male, Laverton)

Discussion

Diabetes

Sadly, study participants exhibited diabetes prevalence equal to that of the National rate of Aboriginal Australians (28% versus 30%) with 82% of participants having diabetic relatives! It is noteworthy that one participant denied that any of his family members were affected by diabetes, when in fact, many members were battling the disease by employing a variety of strategies. This highlights the extent to which diabetes may be under recognized in this already high risk population.

The areas that have been well reported in the literature regarding diabetes are the risk factors and etiologies. While excess sugar was espoused by the masses as a key ingredient in acquiring diabetes, no link was made to the role of obesity. Of note, suggestions such as orange juice and dehydration though reported by a minority of participants implied that perhaps there was an incomplete or incongruent understanding of the well established etiological causes verified by experts and researchers. Interestingly, though dialogued in
informal settings, no participant discussed alternative theories that may predispose one to diabetes such as disharmony, lack of balance, spirits or sins.

Undoubtedly, feelings surrounding diabetes articulated holistic emotions which were coloured with themes of marginalization, disadvantage, concern about self and others and of negative sequela. Oftentimes, the latter would be expressed as extreme scenarios such as amputation, dialysis and death versus the more common and chronic conditions such as microvascular compromise.

Similarly, a historical undertone was echoed by many participants. Given that Aboriginal Australians have only recently recovered many basic freedoms, the effect of colonization, decolonization and culture remained key variables of Indigenous susceptibility to chronic disease. Such issues of social determinants of health such as access to healthy food at affordably prices are reflected in suggestions advanced by participants to narrow the gap when providing customized intervention strategies. Accordingly, a simple intervention of a veggie garden has the possibility to tackle issues on many fronts ~ from easing financial burden and increasing education, to adopting healthier lifestyles, returning to traditional foods and providing a platform of empowerment while possibly, nurturing a springboard for community cohesiveness.

Kidney Disease

The study population had a prevalence of 18% and 18% had affected family members. Interestingly, the definition of “kidney disease” was deliberately open ended so as to ascertain what kidney disease represented to the participant. Perspectives on etiologies for kidney disease were not as comprehensive as that put forth for diabetes. This may have been linked to a limited understanding of what kidney disease encompassed that is, a general lack of awareness of renal disease. As with the discussion on diabetes, cultural connections were again strongly articulated. Interestingly, while similar extreme outcomes such as death generated great anxiety over renal disease, the thought of dialysis provoked an unparallel concern regarding the preservation of bodily functions, personal limits and self dignity that was not voiced in the diabetes interview section.

It is worthwhile to highlight that there were several instances-noted via “I don’t know” responses-where participants felt ignorant, unaware or ill prepared to comment. This only reiterates the need for better culturally sensitive and tailored education.

Prevention, Intervention and Support

In keeping with the medicine wheel model of medicine-that is a holistic perspective which addresses the body, mind, emotions and spirit, many of the comments underlined key factors in each of these categories. Recognition of the need for lifestyle changes, improved diet, decreased alcohol consumption, suitable housing, regular exercise, intermittent clinical reviews and therapeutics was clear. The onus on the government to foster those requirements as well as supporting increased research, education, prevention and inclusion of Aboriginal health care workers was echoed repeatedly. Emotionally, participants noted
the paramount significance of family, friends, community networks as well as professional support systems such as help lines and health teams and interpreters, ensuring that access should be facilitated. The call for empowerment and a sense of belonging marked the participants’ desire for a therapeutic alliance to tackle the breadth and depth of burden of these chronic diseases.

**Strengths and limitations of the study**

Strengths of the study include strong Aboriginal involvement (including Aboriginal research and interview staff) and direct presentation of Aboriginal proposals in our results. The purposive blend of participant profiles (Aboriginality, rural and remote residency, gender, age) and the largely locally representative sample of Aboriginals affected directly or indirectly by diabetes and renal disease provides meaningful insight into reasons behind Aboriginal perspectives on these chronic diseases, their etiologies, participant feelings and concerns as well as suggestions for prevention, intervention and support.

With regard to study limitations, a social network bias may have resulted from established social relationships between participants and the study’s recruiting Aboriginal research assistant. However this assistant described an overall spread of education and religious affiliation among participants and interviewer observations of specific factors (English fluency, home environment and familiarity with interview concepts) which also indicated a comprehensive socio-demographic profile. The small qualitative sample suggests that results should not be generalised to other regions without further research.

**Conclusion**

Aboriginal perspectives on diabetes and renal disease are largely understudied. While the participants had some knowledge of factors affecting these chronic diseases, greater awareness and education is required. In so doing, concern and anxiety which seems strongly related to the diseases could be allayed. It is imperative that cultural nuances not be overlooked when discussing etiologies, perspectives and feelings, let alone for responding to the plea for culturally sensitive and appropriate community based interventions.

**Recommendations**

Interventions addressing a holistic approach to chronic disease should be incorporated into Aboriginal diabetes and renal disease intervention strategies. Based on this study’s findings, such interventions would address the concerns that plague the Aboriginal people with respect to diabetes and renal disease. Such communal interventions are rare, despite their intuitive logic and the consistency with which Aboriginal people propose them. Such oversights may significantly hamper the success of Indigenous Health initiatives.
Acknowledgements

All Aboriginal families and individuals who agreed to take part in the study

Dr. Christine Jeffries-Stokes, Principal Investigator of the umbrella Research Project, The Northern Goldfields Kidney Health Project in Western Australia for her guidance and support in planning, recruiting, implementing and overseeing this component of the study.

Ms. Annette Stokes, Senior Aboriginal Researcher who assisted in recruiting study participants.

Ninga Mia Aboriginal Community and Wongutha Birni Aboriginal Corporation for assistance with approval and space to conduct interviews

Goldfields’ South East Health Region for extending office use support
Appendix 1: Interview Questionnaire

Northern Goldfields Kidney Health Project

Data Sheet 2

Pretest Interviews

i) Researcher __________________________

ii) Date of data collection __/__/__

iii) Site of data Collection

- Leonora
- Laverton
- Mt Margaret
- Kalgoorlie
- Other

iv) Place of interview

- Home
- Clinic
- Hospital
- Other

v) Consent Obtained Yes / No

Office Use Only
First we would like to know a little bit about you.

1. What are your initials _________________________

2. Are you Male or female? Male ☐ Female ☐

3. Are you Aboriginal Yes ☐ No ☐ Don’t Know ☐

4. What year were you born? ________

5. How old are you? ________________ Years

9. Where do you usually live now?
   - Leonora ☐
   - Laverton ☐
   - Mt Margaret ☐
   - Kalgoorlie ☐
   - Other ☐
Interview Questions

D1  Do you have Diabetes? Yes □    No □    Don’t Know □    □

D2  Does anyone in your family have Diabetes?
    Yes □      No □    Don’t Know □    □

D2  What do you think causes Diabetes?

D3  How do you feel about Diabetes?

D4  Diabetes is very common in Aboriginal people – why do you think it is such a common problem?

D5  Are you worried that you might get diabetes?
    Yes □      No □    Don’t Know □    □

    If Yes

D6  What worries you about diabetes?
Interview Questions

K1  Do you have Kidney Disease?
    Yes    No    Don’t Know

K2  Does anyone in your family have Kidney Disease?
    Yes    No    Don’t Know

K3  What do you think causes Kidney Disease?

K4  How do you feel about Kidney Disease?

K5  Kidney Disease is very common in Aboriginal people – why do you think it is such a common problem?

K6  Are you worried that you might get Kidney Disease?
    Yes    No    Don’t Know
    If Yes

K7  What worries you about Kidney Disease?
What do you think should be done about Diabetes and Kidney disease?

What do you think could be done to prevent diabetes and kidney disease?

What sort of supports should there be for people with kidney disease and diabetes?
References


19. Amir and Donath, 2002, Dewan et al., 2002

Appendix 7

Wanti Sugarba Report
Wanti Sugarba

A Report of the Intervention Phase of the Northern Goldfields Kidney Health Project

July 2007

Contact Person - Dr Christine Jeffries-Stokes MBBS, FRACP, MPH, B Med Sc
University of Western Australia, Rural Clinical School, PO Box 1654, Kalgoorlie Western Australia 6433. Email Geoffstokes@bigpond.com or cjeffrie@rcs.uwa.edu.au. Phone 0407387602.
Wanti Sugarba was a project of the Rural Clinical School of Western Australia, Wongutha Birni Aboriginal Corporation and the Aboriginal communities of Leonora, Laverton and Mt Margaret. The project could not have occurred without the support of Indigenous Community Volunteers, BHP Billiton Nicklewest, Barrick Mining, the Myer Foundation, St John of God Healthcare, Healthway – Go for 2 and 5, Boulder Rotary Club, Curtin Volunteers, the Shires of Leonora and Laverton, Laverton District High School, Leonora District High School, Mt Margaret Remote Community School and the health services and providers of the Northern Goldfields.

Community consultations resulted in selection of a name for this project - “Wanti Sugarba” which means “Leave Sugar alone” and also means “Don’t get Diabetes”.

The aims of the project were:
To determine the prevalence of risk factors for end stage renal failure in the Aboriginal community of the Goldfields of Western Australia and show they can be reduced by the provision of culturally appropriate and relevant advice about the disease process, diet and lifestyle.

Problem Statement
The average life expectancy of Indigenous Australians is approximately 20 years less than non-Indigenous Australians. Major contributing factors in this reduced life expectancy are renal disease and diabetes.

Problem Summary
Aboriginal people are diagnosed with renal disease four times as often as non-Aboriginal people and in some areas the rate is as high as 30 times higher. The known risk factors for End Stage Renal Disease (ESRD) are recurrent urinary tract infection, renal calculi, obesity, hyperinsulinism and type 2 diabetes, hypertension, post streptococcal glomerulonephritis, albuminuria and Syndrome X. There is little information about the prevalence of these risk factors in the Aboriginal community and virtually no information available about prevalence in childhood or the age at which the risk factors appear. The prevalence of type 2 diabetes in the Australian Indigenous community is 10 to 30% - that makes it two to four times as common as in the non-Indigenous population and this is the fourth highest rate of type 2 diabetes in the world.
Methods

Gardening Project

The overall project focuses on encouraging lifestyle change to reduce risk factors for diabetes and kidney disease – particularly reducing stress, reducing caffeine intake, increasing exercise and reducing refined carbohydrate intake.

Food availability is a major problem in the northern Goldfields with limited fruit and vegetables available to purchase and the cost is prohibitive for many families. The Sustainable Gardens intervention focused on promoting a health diet, low in refined carbohydrates and increased intake of fruit and vegetables. In order for participants to improve their diet and therefore their access to supplies of fresh fruit and vegetables is critical so the introduction of community and home gardens to grow fruit and vegetables was an important strategy for the project. Gardening also provides exercise and can be very relaxing. The sense of achievement for establishing a garden, watching shoots appear and then harvesting the fruits of your labour is also important in general well being. During the development of the project design we were very fortunate to have Thom Scott from City Farm and Men of the Trees come and spend some time with us in the three communities to advise us as to what might be needed and possible. The link with City Farm has been wonderful and our team of ICV volunteers all spent a day with Thom in Perth before coming out to the Northern Goldfields. He provided them with important information and background for the project and remained a resource for them throughout the project.

Before the gardening project began we surveyed about 50 community members about diet and their experience of fruit, vegetables and gardening – we were assisted in this by Judy Steele, Jennene Marum and Heidi Muencberger, all from ICV.
The Sustainable Gardens Part of the project was supported by Indigenous Community Volunteers who will supplied Volunteers with sustainable horticulture skills to teach community members about gardening. The volunteers lived in the 3 communities for 3 months from September 2006 - Kim and Suzie in Leonora, Harry in Mt Margaret and John and Matt in Laverton. They focussed on teaching people how to set up sustainable home gardens. They spent time in the schools working with the children and with the Home and Community Care groups. The aim was not to establish large scale market gardens but to give people an experience of gardening and give them the skills needed to start a garden of their own, either in pots or in the ground.

The project exceeded our wildest dreams – all the children learned how to grow a plant in a pot and about manure, mulch and setting up a garden. Many families established home gardens and every house in Leonora had at least one fruit tree growing by the end of the project.
Planting fruit trees at Leonora School

We used whatever we could find to make raised garden beds.

Susie and Jessie Evans mulching Jessie’s new garden

It was hard work but lots of fun!

The seed, seedlings and trees were supplied by our project team thanks to the generous support of BHP Billiton Nicklewest.
Perhaps one of the volunteers tells the story better that we can:

**Vegies for health**

By ICV Volunteer Kim Hill (ICV Volunteer to Leonora)

Hi everyone
The community gardening project at Leonora finished up last week, so here’s some news about how it went.

Susie and I were in Leonora (240km north of Kalgoorlie) for 3 months to work with the indigenous community on developing fruit and vegetable gardens. We worked with individual households, the local school and the CDEP group (Community Development Employment Program, a work for the dole program for indigenous communities).

The project is being co-ordinated by Dr Christine Jeffries-Stokes, of the UWA Rural Clinical School in Kalgoorlie. Christine has identified the high rates of diabetes and kidney disease among the indigenous population in the area, and is working with them to achieve good health through diet and lifestyle, and thereby reducing the incidence and impact of these diseases. One part of this project is to educate the communities about growing fruit and vegetables, for improved nutrition, exercise, stress reduction and community development. The nearby communities of Laverton and Mt Margaret are also participating in this project.

I was recruited for this project by Indigenous Community Volunteers, after a request from the community for assistance with learning these skills. ICV provided cultural awareness training, and gives volunteers an allowance for the duration of the project.

A major part of the project was to provide a fruit tree for every indigenous household in town. We found that early evening was a good time to drive around delivering trees, as most people were home and happy to chat. We gave each household a citrus tree (with a choice of lots of varieties), with a bag of manure and a flyer with information about the project, and how to site, plant, and care for the tree. Everyone was happy to take on the responsibility, and many planted their trees immediately. There was also lots of interest in buying more trees.

A few people had already established gardens, but for most this is their first experience of growing anything. So with fruit trees growing at all 60 indigenous households in town, fruit growing has become part of the culture, and the trees are being well cared for.

Another aspect of the project that kept us busy was conducting gardening lessons at the local school. Each week in term 4, we had a half hour lesson with each of the six classes, from pre-primary to secondary. Over the five weeks, the students had the opportunity to:

- Raise plants from seed. Each child made potting mix and planted a few different seeds in a pot which they then took home to care for. They enjoyed taking on this responsibility and were excited to see things germinate and grow.
- Build a garden bed at school and plant out seedlings and seeds. This was done in the yabby farm enclosure, which was shaded, secure and located so that the gardens get
the nutrient-rich wastewater from the yabby tanks. Hopefully there will be lots of yummy food for the students when they return after the school holidays.
• Make compost, and feel the temperature in the middle of the pile a few days later.
• Plant a fruit tree. Parts of the schoolyard have been transformed into an orchard, and the groundsman intends to plant some more fruit trees.

The CDEP worksite was also transformed, with lots of garden beds created and trees planted, and two shadehouse structures in the process of being built. I spent two mornings a week at CDEP conducting workshops, supervising activities and assisting the workers to gather resources to develop the site.

All the workers enjoyed being involved in establishing the gardens and learning about permaculture. They were conscientious about watering, and excited to see things growing. I worked with them to develop a design for the site, which includes lots more trees, gardens and structures, and a huge rainwater tank donated by a nearby BHP mine. The site was used for community workshops during the project, and is intended to be a demonstration site, showing composting, mulching, and a range of fruit and vegetable plants.

With 25 workers, and lots of visitors to the site, this is an ideal location for a community garden and demonstration site, and a very effective means of raising awareness and providing skills to the community.

By linking with another community project, we were able to conduct two field trips to nearby properties with well established gardens and orchards. We learnt about gardening in arid regions, and collected some cuttings and seeds. There were about 10 participants on each field trip, all interested to learn about growing techniques and unfamiliar plants.

There's lots of useful stuff dumped in the bush around Leonora. We managed to glean trellises, fences, compost bins, buckets, polypipe, ladders, mulch, flyscreens, and I even found a 6m high tankstand.

Some afternoons and weekends were spent at one of the many swimming holes, lakes and dams nearby, or on expeditions out bush to find bushfoods and cook kangaroo, goanna and damper on a campfire. One spectacular evening was spent swimming in a freshwater lake at sunset, under a rainbow, while lightning filled the sky and a light rain fell.
It was so exciting to see things sprouting and know we did it ourselves.

Kim with Samantha and James and their garden!
Health Screening

All Aboriginal people in Mt Margaret Community, Laverton and Leonora in the Eastern Goldfields of Western Australia were invited to participate in the Wanti Sugarba project. Our team of Dr Christine Jeffries-Stokes, Annette Stokes (Senior Researcher), Joshua Williams (Aboriginal health Worker) and Charmaine Champion (Aboriginal Health Worker) accompanied by Medical Students from the Rural Clinical School travelled to the communities in February 2007, spending 1 week in each community to conduct the screening. Lauren Pilz (medical student from Sydney) and Dr Ashnoor Nagi (Visiting from Canada) also assisted with the project.

Prior to the health screening, with supervision from Dr Jeffries-Stokes, Dr Ashnoor Nagi, conducted in depth interviews of 11 people to assess their knowledge, experience and feelings about diabetes and kidney disease.

Clinical screening at Mt Margaret was conducted at the community clinic, in Leonora at Community Health building and in Laverton at Wongutha Wonganurra. An additional day in April was spent in each place screening people who had missed out. Screening was also conducted in the school in each place.

Eve with participants at Wongutha Wongaurra in Laverton.

Chevaun checking Kado Muir’s Blood Pressure in Leonora.

Denni and Anna with Francis and her family.
More than 300 people aged between 8 weeks and 72 years were assessed for the presence of known risk factors for renal disease (urinary tract infection, glomerulonephritis, chronic infection, obesity, hyperinsulinism, diabetes, syndrome X, proteinuria) using clinical examination, history and “Point of Care” technology. All participants found to have established risk factors or disease were referred to their General practitioner for further investigation and treatment.

Initial results indicate that half the people assessed were overweight and one quarter were obese. One third had signs of excessive insulin production and 13% had hypertension. Twenty percent of adults had uncontrolled diabetes and over one third of adults and children has signs of kidney damage with 3% found to be in kidney failure.

Participants will have health screening on two further occasions over 12 months with qualitative and quantitative assessment of the impact of the intervention. The assessment, investigation, treatment and intervention protocols will be suitable to use in any setting with indigenous people in Australia or overseas, and once shown to be effective could be implemented through many existing Indigenous and mainstream health services and organisations.

**Intervention.**

Despite the knowledge held by the medical community of the risk factors and contributing factors for renal disease and diabetes in the Aboriginal community, Aboriginal people themselves are poorly informed and lack understanding of the mechanism of disease and treatment. This study included an intervention aimed at truly informing Aboriginal people in the Eastern Goldfields about the current knowledge about ESRD and diabetes and providing them with strategies they can implement in their daily life to reduce their risk of ESRD and the associated problems of diabetes, obesity and cardiovascular disease.

The intervention took a community development approach using a community arts focus. A community Arts model was chosen because it is similar to
traditional Aboriginal teaching methods – using visual images, dance and song rather than the written word to help people to learn, understand and then teach complex concepts. In addition the methods used resulted in the production of art works – these art works brought pleasure to the creators of them as well as Kudos resulting in improved self esteem, pride and ownership of the issues with improved motivation to tackle the problems facing individuals and the community. The art works will also be available to be used for exhibitions and performances in other communities to help in health promotion. Some of the artworks will endure in the community providing ongoing reinforcement for the behaviour and lifestyle changes that are the focus of the intervention.

The communities chosen for this study are quite fragmented and there are major problems with substance abuse, domestic and interpersonal violence, family feuding, incarceration, unemployment, apathy and poverty, especially in Leonora and Laverton. The community development aspects of the intervention will assist with drawing people together to tackle some of their problems, providing an important focus for people to come together to work towards a common goal. This will, in turn, help to build a sense of community and support for participants who are striving to make lifestyle and environmental changes.

Sugarbal!

It began with the “Sugarbal!” Puppet Show.

The “Sugarbal!” puppet show was developed in Kalgoorlie through the Wongutha Birni Aboriginal Cultural Centre. We received funding from Healthway for the development of the puppet show and were very fortunate to have Jane Davies, a Master Puppeteer, as Artist in Residence for the project. Jane worked with our research team, Aboriginal health workers from the Public and Primary Health Care team, volunteer craftspeople, Wongutha Birni Artists and artists from Eastern Goldfields Regional Prison to develop a show that told the story of diabetes and its complications in images and language that would engage Aboriginal people from the Goldfields. This part of the project began with a community information night attended by about 40 people. They were shown a DVD about diabetes and asked to think about out images to tell the story to their community. Out of this process we developed the images of the sugar monster, the insulin character and many of the other images that later were refined by the arts team and presented in the puppet show. The puppet show was presented at Wongutha Birni and then performed in Leonora, Laverton and Mt Margaret at the start of the Clinical screening phase and again during the “Wanti Sugarba” festivals.
Floris working on the puppets.

Backstage!

Tracey Laidlaw

Jane Davies – Master Puppeteer

Theonie Redmond
Most interventions for reduction of ESRD in Aboriginal communities in Australia have focused on early detection of disease and drug therapy to delay the progression of disease. This project focused on education and empowerment of Aboriginal people to understand and modify lifestyle factors that are contributing to risk of renal disease in the community using a community arts for community development model. There was a particular emphasis on educating participants about the mechanisms of disease and the reasons for diet and lifestyle change. The health promotion messages focused on change to a reduced refined carbohydrate diet, increased exercise and reduction of stress.

For this part of the project a team of Artists was recruited through Indigenous Community Volunteers – James Houston (Music and community development), Rita Leuzzi (drumming and performance), Christina McDonald (2 and 3 dimensional visual arts), Genevieve Jones (Dance, yoga and graphic arts). They were assisted by Andy Brown (Clown Doctor, pyrotechnition and Film maker), Paul Burton (Pyrotechnition) and Lachlan McDonald (Community Development and Event Coordinator). These artist had a crash course in the pathology and physiology of diabetes and kidney disease and then worked with the communities to develop their own understanding of these diseases and artworks that told the story of these diseases in and to their community – visual images, music, dance and film. The resulting artworks included musical performance, t-shirts, sculpture, flags, paintings, film, banners and installations culminating in the Wanti Sugarba Festivals.

The arts team got a crash course in the pathology and physiology of Diabetes and Kidney disease.
The ICV Team (Viola, Rita, Genevieve, James and Christina) with Geoffrey Stokes and Shayden Barnes-Stokes.

The schools took on the project with great enthusiasm, especially the high school students in Laverton, led by teacher Steve Soames – they focused the whole of first term on the diabetes and kidney disease message. The students developed a range of brochures for public education about diabetes as well as some great recipes promoting the low refined carbohydrate diet.
The Wanti Sugarba project culminated in 3 festivals during the April school holidays – the first was in Leonora and was attended by about 300 people, the second was in Laverton and also attended by about 300 people, the final one was in Mt Margaret, attended by about 200 people. All 3 festivals were supported by the shires and we were grateful for the support and attendance of the volunteer firefighting and ambulance crews – although each of the festivals went off without a hitch. Paul Burton and Andy Brown, assisted by Steve Soames engineered fabulous fireworks displays for the festivals – the like of which had never been seen in these remote communities.

One of the great features of the festivals were the “BHP Billiton Big Feeds”. The generous support of BHP Billiton Nicklewest allowed us to bring a Cook (Viola Leuzzi) and a Chef (Richard Trenorden) to teach about preparing new and exciting vegetable dishes and to demonstrate the low carbohydrate diet at the festivals. The support of Healthway – Go for 2 and 5, and the Cancer Council allowed us to supply community participants in the cooking workshops with aprons and cook books. Rita and Richard worked with community members to prepare sumptuous feasts for each of the festivals. The Water Corporation supplied bottled water for the festival goers to drink.
Rita – Drum Master – Bellissimo!

The Calcium Cow Girls – fighting for a healthy diet!

Michael and the Flag parade
Locky Mc Donald and the Calcium Cowgirls

Annette Stokes – our Lead Researcher and Musician

Dr Sherry Jacobs

Samantha and James Calyun
Andy Brown – Clown Doctor and Film Maker

Richard Trenorden – our Chef in Residence had a really keen audience for his cooking sessions.

Geraldine Hogarth and Mrs Redmond

Viola and Lauren slaving over hot barbeques
New Foods

Sugarba the Sugar monster

New Ways of Cooking

Finally at Mt Margaret the Sugar Monster was caught

New Chefs!

And Vanquished!
The Fireworks were amazing – Certainly Mt Margaret had never seen anything like this before!

Flags and Banners

Our team worked with community members, teaching about what causes kidney Disease and diabetes and encouraging them to think about their experience and feelings about these diseases. The artists encouraged the community participants to translate what they had learned into visual images to tell the story of kidney disease and diabetes in their community and educate community members about how these diseases can be prevented.

Flags and Banners were used to display these images for the parades and festivals.
Stress and Relaxation

Stress is a major factor in the development of diabetes and kidney disease as it changes hormone levels in the body and contributes to hypertension and unstable blood sugar control.

For many Aboriginal people stress is an unavoidable part of life so we took the approach that the physical effects of stress on the body could be reduced by learning how to relax and to find activities that were pleasurable and satisfying to reduce the effects of stress. Gardening, dance, music, painting, drumming and yoga were all examples of stress reduction.

The Yoga project at Mt Margaret School was especially successful – Artist in Residence Genevieve Jones led the children in yoga sessions every day for a week. This not only gave the children new skills and exercise but the emphasis was on recognising the physical effects of relaxation – slow breathing, slow heart rate, release of muscle tension etc. The children learnt ways to control their own body and recognise the feeling of relaxation. At the end of the week we ran a workshop and the children
were encouraged to find word to describe the feelings they had experienced during the yoga sessions.

Then the children were told a scary story – they were then encouraged to recognise and find words to described their feelings – alertness, fast heartbeat, muscle tension etc. These are the same feelings and physiological changes that stress induces and the link between the feelings and the concept of stress was made by the children. Then the children were invited to convert these concepts into visual images. The images were really exciting and we chose some of them to be transferred onto flags and T-Shirts for the festivals. The children were also encouraged to develop strategies to assist them to relax in stressful situations and to help others in their community relax or avoid stress.

Shayden Barnes-Stokes aged 5 –
and his Dad
wearing his design.
Lachlan Stokes – aged 7. This picture shows the things that Lachlan considered necessary for health and happiness. There is a Bush turkey because bush tucker is good for you and Bush Turkey tastes the best. There is a traditional Wiltja or house which Lachlan described as “A Home”. It also shows the Aboriginal flag inside a circle indicating that if Aboriginal People and everyone else (“We”) all work together we can mend our hearts.

Laverton School

Kirra Laidlaw’s interpretation of the Insulin Cycle

You get hungry and your brain tells you to eat.

You eat food with lots of sugar, fat and carbohydrates.

Pancreas tries to cope and makes lots of insulin.

Insulin reduces sugar in blood.

Insulin makes your body store sugar as fat.
The Laverton High School spent all of first term studying Type 2 Diabetes and developing strategies for their community to educate people and reduce the risk of diabetes. They held cooking classes in low carbohydrate cooking, they participated in the Gardening project, they developed pamphlets for doctors waiting rooms and wrote magazine articles about diabetes. Kirra Laidlaw’s article was published in the local magazine – the Stuart Pea.

They all also participated in the activities of the NGKHP intervention.

Forgiveness

Community consultations in the development of the project proposal identified stress as a very significant factor in all 3 communities. This stress was though by community members to be multifaceted but largely contributed to be a burden of grief, guilt and bitterness that many people carry. In traditional Aboriginal culture the response to many of these problems would be to seek payback but it was recognised that in modern society this is not usually possible and probably not desirable or healthy so the concept of forgiveness (of self and others) was very important. It was recognised that for people to make major lifestyle change the spiritual and emotional aspects of the burdens people carry needed to be addressed so special Easter ceremonies were held in Leonora. These were very well attended with people travelling from Perth, Morapoi Station and Mulga Queen community to attend them. The pathology and physiology of diabetes and kidney disease and the contribution of stress was explained during the ceremonies. There were many powerful and emotional moments during the ceremonies and the artists, the research team and the community were moved.
What Next?

In July 2007 Geoffrey, Christine, Annette and Shaneane Weldon (Manager of Mt Margaret Community) attended the World Health Promotion and Education Conference in Vancouver – along with almost 4,000 delegates from around the world. They presented the project to a very interested audience. It was also an opportunity to meet and network with other researchers from around the world who are working in the area of Diabetes and Kidney disease in Indigenous Populations.
We are now about to commence the second round of health screening and evaluation of the intervention to assess the impact of the project on the community. Feedback has been very encouraging but we now need to see if this translates to real health gains.

**Acknowledgement of Sponsors**

Banners supplied by sponsors were displayed at all events. The T-Shirts had the logos printed on the sleeve.

Healthway Go for 2 and 5 supplied T-Shirts, Hats and Aprons and these were distributed at the festivals and worn for all the festival events.

The final slide of the powerpoint presentations and the puppet show displayed the logos of the sponsors and verbal acknowledgement was given at all events and presentations.
The Northern Goldfields Kidney Health Project
Appendix 8

The Northern Goldfields Kidney Health Project
Fruit and Vegetable Questionnaire
Northern Goldfields Kidney Health Project - Fruit and Vegetable Questionnaire

Office Use Only

i) Interviewer _________________________________________

ii) Date of Interview  ____/____/____

iii) Place of Interview

Leonora  

Laverton  

Mt Margaret  

Kalgoorlie  

Other  

iv) Record No  ____  ____  ____
Thank you for helping us with our research.

To start with we would like to know a bit about people in the Northern Goldfields and about the foods that people usually eat.
First we would like to know a little bit about you.

1. What are your initials ____________________________
2. Are you Male or female? Male □ Female □
3. What year were you born? □□□□□□
4. How old are you? ________________ Years
5. Where were you born? _____________________________
6. Were you part of the Stolen Generation? Yes □ No □
7. Where did you spend most of your childhood? ______________________
8. Where do you usually live now? _____________________________
9. Who usually lives with you?
   9a. How many adult men? □□
   9b. How old are they? _____________________________
   9c. How many adult women? □□
   9d. How old are they? _____________________________
   9e. How many children? □□
   9f. How old are they? _____________________________
10  Who usually does the cooking in your house or family?

__________________________________________________________  

11  Who usually does the shopping for your family)?

__________________________________________________________  

12  Are you Aboriginal  

Yes  

No  


Gardening

Now I’m going to ask a few questions about growing things like fruit, vegetables and flowers.

G1 What do you think about gardening?

_____________________________________________________
_____________________________________________________

G2 What do you think about growing things like fruit and vegetables?

_____________________________________________________
_____________________________________________________

G3 Before this project (The Northern Goldfields Kidney Health Project)

G3a Was there any garden where you are living now?

Yes □ No □

G3b If Yes:

What was growing in your garden?

Flowers Yes □ No □
Fruit Yes □ No □
Vegetables Yes □ No □
Other ________________________________________________ □□□

G4a Before this project had you ever done any gardening yourself?

Yes □ No □
4b If Yes:

What did you grow?

Flowers

Yes ☐ No ☐

Fruit

Yes ☐ No ☐

Vegetables

Yes ☐ No ☐

Other ________________________________ ☐

G5a When you were a child did you grow anything or do any gardening? ☐

Yes ☐ No ☐

G5b If yes where was that? ________________________________ ☐

G6 Did you do any gardening as part of this project? ☐

Yes ☐ No ☐

G6a If Yes:

Did you enjoy this? ☐

Yes ☐ No ☐

G6b Why do you say that?

______________________________________________________

______________________________________________________
G6c  Have you learnt anything new as part of this project?  

Yes □  No □

G6d  If Yes: what did you learn?

_____________________________________________________

_____________________________________________________

G7  Would you like to learn more about growing things and gardening?  

Yes □  No □

G8  What would you like to grow?

Flowers  Yes □  No □

Fruit  Yes □  No □

Vegetables  Yes □  No □

Other  ________________________________________________

G9  Why would you like to grow these things?

_____________________________________________________

_____________________________________________________

361
What do you think are the good things about gardening?
Food

Now we would like to know about what people from the Goldfields eat

D1 What did you have for breakfast today?

_____________________________________________________

_____________________________________________________

D2 What did you have for dinner last night?

_____________________________________________________

_____________________________________________________

D3 What did you have for lunch yesterday?

_____________________________________________________

_____________________________________________________

D4 What did you have for snacks yesterday?

_____________________________________________________

_____________________________________________________
Id Number __________ F&V

Yesterday did you drink any:

D5a Water: Yes □ No □

D5b If Yes was it from a tap or was it bottled water? Tap □ Bottle □

Yesterday did you drink any:

D6a Tea: Yes □ No □

D6b Was it Normal" or De-caffeinated? Normal □ De-caffeinated □

D6c How Many cups? □□

D6d Did you add Sugar? Yes □ No □

D6e How Many Spoons? □□

D6f Did you have Milk? Yes □ No □

Yesterday did you drink any:

D7a Coffee: Yes □ No □

D7b Was it Normal" or De-caffeinated? Normal □ De-caffeinated □

D7c How Many cups? □□
D7d  Did you add Sugar? Yes ☐  No ☐

D7e  How Many Spoons?  ☐  ☐

D7f  Did you have Milk?  Yes ☐  No ☐

Yesterday did you drink any:

D8a  Juice:  Yes ☐  No ☐

D8c  What sort? __________________________________________

Yesterday did you drink any:

D9a  Cool drink:  Yes ☐  No ☐

D9b  What sort of Cool Drink did you drink? (Please tick your answer)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>How many Bottles or cans</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coke</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Coke Zero</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Diet Coke</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Drink</td>
<td>Image</td>
<td>Column 1</td>
<td>Column 2</td>
</tr>
<tr>
<td>--------------</td>
<td>------------------------</td>
<td>----------</td>
<td>----------</td>
</tr>
<tr>
<td>Sprite</td>
<td><img src="image" alt="Sprite" /></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sprite Zero</td>
<td><img src="image" alt="Sprite Zero" /></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lemonade</td>
<td><img src="image" alt="Lemonade" /></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fanta</td>
<td><img src="image" alt="Fanta" /></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Solo</td>
<td><img src="image" alt="Solo" /></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Passiona</td>
<td><img src="image" alt="Passiona" /></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet Passiona</td>
<td><img src="image" alt="Diet Passiona" /></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (What?)</td>
<td><img src="image" alt="Other" /></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Id Number __________ F&V
Yesterday did you drink any:

D10a Milk:  Yes [ ]  No [ ]

D10b What sort of Milk did you drink? (Please tick your answer)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Lactose free</th>
<th>Soy</th>
<th>How many Bottles, cartons or glasses?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fresh</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Powdered</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chocolate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strawberry</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coffee</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mocha</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Flavour</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In Tea or Coffee</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Bread

**D11** What sort of bread do you *usually eat*? (Please tick your answer)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>How many slices or rolls</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td><img src="image" alt="White Bread" /></td>
<td></td>
<td><img src="image" alt="White Bread" /></td>
</tr>
<tr>
<td>Brown or Whole meal</td>
<td><img src="image" alt="Brown Bread" /></td>
<td></td>
<td><img src="image" alt="Brown Bread" /></td>
</tr>
<tr>
<td>Multigrain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Damper</td>
<td><img src="image" alt="Damper" /></td>
<td></td>
<td><img src="image" alt="Damper" /></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
D12  What sort of bread is your **favourite**? (Please tick your answer)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brown or Whole meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multigrain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Damper</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### D13 What sort of bread do you eat most of? (Please tick your answer)

<table>
<thead>
<tr>
<th>Bread Type</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brown or Whole meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multigrain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Damper</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>What?</td>
<td></td>
</tr>
</tbody>
</table>
**Breakfast Cereal**

D14 What sort of breakfast cereals do you *usually eat*?  

(Please tick your answer – you can tick more than one)

<table>
<thead>
<tr>
<th>Picture</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weetbix</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Porridge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutragrain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cocopops</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>If Other, what?</td>
<td></td>
</tr>
</tbody>
</table>
# Meat

D15 What sorts of meats do you eat? (Please tick your answer – you can tick more than one)

<table>
<thead>
<tr>
<th></th>
<th>Picture</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>![None]</td>
<td></td>
<td>![None]</td>
</tr>
<tr>
<td>Kangaroo</td>
<td>![Kangaroo]</td>
<td></td>
<td>![Kangaroo]</td>
</tr>
<tr>
<td>Beef</td>
<td>![Beef]</td>
<td></td>
<td>![Beef]</td>
</tr>
<tr>
<td>Lamb</td>
<td>![Lamb]</td>
<td></td>
<td>![Lamb]</td>
</tr>
<tr>
<td>Pork</td>
<td>![Pork]</td>
<td></td>
<td>![Pork]</td>
</tr>
<tr>
<td>Emu</td>
<td>![Emu]</td>
<td></td>
<td>![Emu]</td>
</tr>
<tr>
<td>Goanna</td>
<td>![Goanna]</td>
<td></td>
<td>![Goanna]</td>
</tr>
<tr>
<td>Echidna</td>
<td>![Echidna]</td>
<td></td>
<td>![Echidna]</td>
</tr>
<tr>
<td>Chicken</td>
<td>![Chicken]</td>
<td></td>
<td>![Chicken]</td>
</tr>
</tbody>
</table>
D16  What sort of meat is your **favourite**? (Please tick only one)

<table>
<thead>
<tr>
<th>Picture</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
</tr>
<tr>
<td>Kangaroo</td>
<td></td>
</tr>
<tr>
<td>Beef</td>
<td></td>
</tr>
<tr>
<td>Lamb</td>
<td></td>
</tr>
<tr>
<td>Pork</td>
<td></td>
</tr>
<tr>
<td>Emu</td>
<td></td>
</tr>
<tr>
<td>Animal</td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
<td>--</td>
</tr>
<tr>
<td>Goanna</td>
<td></td>
</tr>
<tr>
<td>Echidna</td>
<td></td>
</tr>
<tr>
<td>Chicken</td>
<td></td>
</tr>
<tr>
<td>Bush Turkey</td>
<td>Bush Turkey</td>
</tr>
<tr>
<td>Turkey</td>
<td></td>
</tr>
<tr>
<td>Duck</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>What?</td>
</tr>
</tbody>
</table>

D17 How often do you eat Meat?

- [ ] Every day
- [ ] Less than once a week
- [ ] About once a week
- [ ] More than once a week
- [ ] Only occasionally
**Eggs**

D18a  Do you eat eggs?  
Yes ☐  No ☐

D19b  What Sort? (Please tick your answer – you can have more than one)

<table>
<thead>
<tr>
<th>Chicken</th>
<th>Duck</th>
<th>Emu</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.jpg" alt="Chicken" /></td>
<td><img src="image2.jpg" alt="Duck" /></td>
<td><img src="image3.jpg" alt="Emu" /></td>
<td><img src="image4.jpg" alt="Other" /></td>
</tr>
<tr>
<td>Yes ☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

D20  How often do you eat Eggs?  

- Every day ☐
- About once a week ☐
- Less than once a week ☐
- More than once a week ☐
- Only occasionally ☐
Fish

D21  Do you **ever** eat fish? Yes □  No □

If Yes

D22  How often do you eat fish?

Every day □  Less than once a week □

About once a week □  More than once a week □

Only occasionally □

D23  What sorts of Fish do you eat? (Please tick your answer – you can tick more than one)

<table>
<thead>
<tr>
<th>Picture</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td>□</td>
</tr>
<tr>
<td>Fresh</td>
<td></td>
<td>□</td>
</tr>
<tr>
<td>Fish and Chips</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>Frozen</td>
<td></td>
<td>□</td>
</tr>
<tr>
<td>Fish Fingers</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>Tuna</td>
<td></td>
<td>□</td>
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<td><img src="Sardines" alt="Image" /></td>
<td><img src="Prawns" alt="Image" /></td>
</tr>
<tr>
<td>--------</td>
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</tr>
<tr>
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<td><img src="Sardines" alt="Image" /></td>
<td><img src="Prawns" alt="Image" /></td>
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<tr>
<td>Prawns</td>
<td><img src="Sardines" alt="Image" /></td>
<td><img src="Prawns" alt="Image" /></td>
</tr>
<tr>
<td>Scallops</td>
<td><img src="Sardines" alt="Image" /></td>
<td><img src="Prawns" alt="Image" /></td>
</tr>
<tr>
<td>Squid</td>
<td><img src="Sardines" alt="Image" /></td>
<td><img src="Prawns" alt="Image" /></td>
</tr>
<tr>
<td>Other</td>
<td><img src="Sardines" alt="Image" /></td>
<td><img src="Prawns" alt="Image" /></td>
</tr>
</tbody>
</table>
Fruit

F1  Did you eat any fruit yesterday?  Yes  No

F2a  If yes: What fruit did you eat?

F2b  If No: Why was that?

F3  How many serves of fruit do you think you should eat each day? _____

F4  What fruits do you like to eat?

F5  What do you think stops people in your family eating more fruit?
    (You can choose more than one)
    __________
    Can’t get more fruit
    Can’t afford more fruit
    They don’t like fruit
    There are not enough different sorts of fruit to choose from
    Other – please explain
Have you **ever eaten** any of these fruits?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Fresh</th>
<th>Dried</th>
<th>Frozen</th>
<th>Canned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apple</td>
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<td></td>
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</tr>
<tr>
<td>Apricots</td>
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</tr>
<tr>
<td>Banana</td>
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<tr>
<td>Blackberry</td>
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<tr>
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</table>
F6 Have you **ever eaten** any of these fruits?

<table>
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<th>Frozen</th>
<th>Canned</th>
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</tr>
<tr>
<td>Guava</td>
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<td></td>
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</tr>
<tr>
<td>Honeydew Melon</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lemon</td>
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<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Mandarin</td>
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<tr>
<td>Mangoes</td>
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<td>Nectarines</td>
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<tr>
<td>Orange</td>
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<tr>
<td>Passionfruit</td>
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</table>
F6 Have you *ever eaten* any of these fruits?

<table>
<thead>
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<th>Frozen</th>
<th>Canned</th>
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<tr>
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<td>Plums</td>
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<td>Quandong</td>
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</tr>
<tr>
<td>Raspberry</td>
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</tr>
<tr>
<td>Rockmelon</td>
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</tr>
<tr>
<td>Starfruit</td>
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</tbody>
</table>
Would you like to try any of the fruits on this list?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Apple</td>
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<tr>
<td>Apricots</td>
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<tr>
<td>Banana</td>
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<td>Blackberry</td>
<td></td>
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<tr>
<td>Blueberry</td>
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<td>Cherries</td>
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<td>Custard apple</td>
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</tr>
<tr>
<td>Fruit</td>
<td>Yes</td>
</tr>
<tr>
<td>-------------------</td>
<td>-----</td>
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<tr>
<td>Figs</td>
<td></td>
</tr>
<tr>
<td>Grapefruit</td>
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</tr>
<tr>
<td>Grapes</td>
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</tr>
<tr>
<td>Guava</td>
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</tr>
<tr>
<td>Honeydew Melon</td>
<td></td>
</tr>
<tr>
<td>Lemon</td>
<td></td>
</tr>
<tr>
<td>Mandarin</td>
<td></td>
</tr>
<tr>
<td>Mangoes</td>
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</tr>
<tr>
<td>Nectarines</td>
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</tbody>
</table>

Would you **like to try** any of the fruits on this list?
<table>
<thead>
<tr>
<th>Fruit</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Orange</td>
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<tr>
<td>Passionfruit</td>
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<td></td>
</tr>
<tr>
<td>Peaches</td>
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<td></td>
</tr>
<tr>
<td>Pineapple</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plums</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quandong</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Raspberry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rockmelon</td>
<td></td>
<td></td>
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</tbody>
</table>
F7  Would you **like to try** any of the fruits on this list?

<table>
<thead>
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<th>No</th>
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</thead>
<tbody>
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<tr>
<td>Strawberry</td>
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<tr>
<td>Tangello</td>
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<tr>
<td>Watermelon</td>
<td></td>
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</tr>
</tbody>
</table>

F8  If Other, what? ____________________________________________________________________
Would you **like to grow** any of these fruits?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>Apple</td>
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<tr>
<td>Apricots</td>
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<td></td>
</tr>
<tr>
<td>Banana</td>
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</tr>
<tr>
<td>Blackberry</td>
<td></td>
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<tr>
<td>Blueberry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cherries</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Custard apple</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Figs</td>
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<td></td>
</tr>
<tr>
<td>Grapefruit</td>
<td></td>
<td></td>
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<tr>
<td>Fruit</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>----------------------</td>
<td>-----</td>
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<tr>
<td>Grapes</td>
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<td>Guava</td>
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<td>Honeydew Melon</td>
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<td>Lemon</td>
<td><img src="image3.png" alt="Image" /></td>
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<td>Mandarin</td>
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<td>Mangoes</td>
<td><img src="image5.png" alt="Image" /></td>
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<tr>
<td>Nectarines</td>
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<tr>
<td>Orange</td>
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<tr>
<td>Passionfruit</td>
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</table>

F9 Would you **like to grow** any of these fruits?
<table>
<thead>
<tr>
<th>Fruits</th>
<th>Image</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peaches</td>
<td><img src="image" alt="Peaches Image" /></td>
</tr>
<tr>
<td>Pineapple</td>
<td><img src="image" alt="Pineapple Image" /></td>
</tr>
<tr>
<td>Plums</td>
<td><img src="image" alt="Plums Image" /></td>
</tr>
<tr>
<td>Quandong</td>
<td><img src="image" alt="Quandong Image" /></td>
</tr>
<tr>
<td>Raspberry</td>
<td><img src="image" alt="Raspberry Image" /></td>
</tr>
<tr>
<td>Rockmelon</td>
<td><img src="image" alt="Rockmelon Image" /></td>
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</tbody>
</table>
**F9**  Would you **like to grow** any of these fruits?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Starfruit</td>
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</tr>
<tr>
<td>Strawberry</td>
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<td></td>
</tr>
<tr>
<td>Tangello</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watermelon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>What?</td>
<td></td>
</tr>
</tbody>
</table>
Vegetables

V1 Did you eat any vegetables yesterday?  Yes [ ]  No [ ]

V2 If yes: what vegetables did you eat?

________________________________________________________________

V3 If No: why was that?

________________________________________________________________

V4 How many serves of vegetables do you think you should eat each day?

________________________________________________________________

V5 What do you think stops people in your family eating more vegetables?

(You can choose more than one)

[ ] Can’t get more vegetables

[ ] Can’t afford more vegetables

[ ] They don’t like vegetables

[ ] There are not enough different sorts of vegetables to choose from

[ ] Other – please explain

______________________________
V6  What vegetables do you **like** to eat? (Please tick)

<table>
<thead>
<tr>
<th>Picture</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asparagus</td>
<td></td>
<td><img src="Image" alt="Asparagus Picture" /></td>
</tr>
<tr>
<td>Avocado</td>
<td></td>
<td><img src="Image" alt="Avocado Picture" /></td>
</tr>
<tr>
<td>Beans</td>
<td></td>
<td><img src="Image" alt="Beans Picture" /></td>
</tr>
<tr>
<td>Broccoli</td>
<td></td>
<td><img src="Image" alt="Broccoli Picture" /></td>
</tr>
<tr>
<td>Brussel Sprouts</td>
<td></td>
<td><img src="Image" alt="Brussel Sprouts Picture" /></td>
</tr>
<tr>
<td>Cabbage</td>
<td></td>
<td><img src="Image" alt="Cabbage Picture" /></td>
</tr>
<tr>
<td>Carrots</td>
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<td><img src="Image" alt="Carrots Picture" /></td>
</tr>
<tr>
<td>Cauliflower</td>
<td></td>
<td><img src="Image" alt="Cauliflower Picture" /></td>
</tr>
</tbody>
</table>
V6 What vegetables do you **like** to eat? (Please tick)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>Corn</td>
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<tr>
<td>Cucumber</td>
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</tr>
<tr>
<td>Lettuce</td>
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<td></td>
</tr>
<tr>
<td>Onion</td>
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</tr>
<tr>
<td>Peas</td>
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<tr>
<td>Potatoes</td>
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<tr>
<td>Pumpkin</td>
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</tr>
<tr>
<td>Squash</td>
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<tr>
<td>Sweet Potato</td>
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<tr>
<td>Taro</td>
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<tr>
<td>Id Number __________ F&amp;V</td>
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<table>
<thead>
<tr>
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<th>Picture</th>
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<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tomatoes</td>
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<tr>
<td>Yam</td>
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<tr>
<td>Zucchini</td>
<td><img src="image" alt="Zucchini" /></td>
<td>☐</td>
<td></td>
</tr>
</tbody>
</table>

V7 Have you ever eaten any other vegetables not on this list? Yes ☐ No ☐ ☐

V8 If Yes – What? ☐ ☐

V9 Would you **like to try** any of the vegetables on this list?

<table>
<thead>
<tr>
<th>Picture</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asparagus</td>
<td><img src="image" alt="Asparagus" /></td>
<td>☐</td>
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<tr>
<td>Avocado</td>
<td><img src="image" alt="Avocado" /></td>
<td>☐</td>
</tr>
<tr>
<td>Beans</td>
<td><img src="image" alt="Beans" /></td>
<td>☐</td>
</tr>
<tr>
<td>Item</td>
<td>Image</td>
<td>Checked</td>
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<tr>
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</tr>
<tr>
<td>Broccoli</td>
<td><img src="image" alt="Broccoli" /></td>
<td>☐</td>
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<tr>
<td>Brussel Sprouts</td>
<td><img src="image" alt="Brussel Sprouts" /></td>
<td>☐</td>
</tr>
<tr>
<td>Cabbage</td>
<td><img src="image" alt="Cabbage" /></td>
<td>☐</td>
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<tr>
<td>Carrots</td>
<td><img src="image" alt="Carrots" /></td>
<td>☐</td>
</tr>
<tr>
<td>Cauliflower</td>
<td><img src="image" alt="Cauliflower" /></td>
<td>☐</td>
</tr>
<tr>
<td>Corn</td>
<td><img src="image" alt="Corn" /></td>
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</tr>
<tr>
<td>Cucumber</td>
<td><img src="image" alt="Cucumber" /></td>
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<tr>
<td>Lettuce</td>
<td><img src="image" alt="Lettuce" /></td>
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</table>
V9  Would you **like to try** any of the vegetables on this list?

<table>
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<th>No</th>
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<tbody>
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<tr>
<td>Peas</td>
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<td>☐</td>
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<td>Potatoes</td>
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<td>☐</td>
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<td>Pumpkin</td>
<td></td>
<td>☐</td>
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<tr>
<td>Squash</td>
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<td>☐</td>
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<tr>
<td>Sweet Potato</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Taro</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Tomatoes</td>
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<td>☐</td>
</tr>
<tr>
<td>Yam</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Zucchini</td>
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<td>☐</td>
</tr>
</tbody>
</table>
V10 Would you **like to grow** any of these vegetables?

<table>
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<tr>
<th>Picture</th>
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<tbody>
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<td>Asparagus</td>
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<td>Avocado</td>
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<td>Beans</td>
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<td>Carrots</td>
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</tr>
<tr>
<td>Cucumber</td>
<td>☐</td>
</tr>
<tr>
<td>Lettuce</td>
<td>☐</td>
</tr>
</tbody>
</table>
V10  Would you **like to grow** any of these vegetables?

<table>
<thead>
<tr>
<th>Vegetable</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Onion</td>
<td></td>
</tr>
<tr>
<td>Peas</td>
<td></td>
</tr>
<tr>
<td>Potatoes</td>
<td></td>
</tr>
<tr>
<td>Pumpkin</td>
<td></td>
</tr>
<tr>
<td>Squash</td>
<td></td>
</tr>
<tr>
<td>Sweet Potato</td>
<td></td>
</tr>
<tr>
<td>Taro</td>
<td></td>
</tr>
<tr>
<td>Tomatoes</td>
<td></td>
</tr>
<tr>
<td>Yam</td>
<td></td>
</tr>
<tr>
<td>Zucchini</td>
<td></td>
</tr>
</tbody>
</table>
### Nuts

**N1**  Do you ever eat nuts? Yes ☐  No ☐  ☐

**N2**  If Yes, what sort of nuts?

<table>
<thead>
<tr>
<th>Picture</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peanuts</td>
<td>☐</td>
</tr>
<tr>
<td>Almonds</td>
<td>☐</td>
</tr>
<tr>
<td>Cashews</td>
<td>☐</td>
</tr>
<tr>
<td>Brazil</td>
<td>☐</td>
</tr>
<tr>
<td>Pistashio</td>
<td>☐</td>
</tr>
<tr>
<td>Hazlenut</td>
<td>☐</td>
</tr>
<tr>
<td>Peacan</td>
<td>☐</td>
</tr>
<tr>
<td>Macadamia</td>
<td>☐</td>
</tr>
<tr>
<td>Quandong</td>
<td>☐</td>
</tr>
<tr>
<td>Sandalwood</td>
<td>☐</td>
</tr>
<tr>
<td>Other</td>
<td>What? ☐</td>
</tr>
</tbody>
</table>
D24 Why do you think people should eat fruit?

________________________________________________________________________

________________________________________________________________________

D25 Why do you think people should eat vegetables?

________________________________________________________________________

________________________________________________________________________

D26 Is there anything else you would like to say?

________________________________________________________________________

________________________________________________________________________

Thank you very much for your help.
Appendix 9

The Northern Goldfields Kidney Health Project Data Sheet
Northern Goldfields Kidney Health Project

Data Sheet 1

i) Researcher

ii) Date of data collection

iii) Site of data Collection
    - Leonora
    - Laverton
    - Mt Margaret
    - Kalgoorlie
    - Other

iv) Place of assessment
    - Home
    - Clinic
    - Hospital
    - Other

v) Consent Obtained
    - Yes / No
First we would like to know a little bit about you.

1. What are your initials ___________________________

2. Are you Male or female?  
   - Male [ ]  
   - Female [ ]

3. Are you Aboriginal  
   - Yes [ ]  
   - No [ ]  
   - Don’t Know [ ]

4. What year were you born?  

5. How old are you? ________________ Years

6. Where were you born?  

7. Were you part of the Stolen Generation?  
   - Yes [ ]  
   - No [ ]

8. Where did you spend most of your childhood?  
   - Northern Goldfields [ ]  
   - Kalgoorlie [ ]  
   - Southern Goldfields [ ]  
   - Other [ ]

9. Where do you usually live now?  
   - Leonora [ ]  
   - Laverton [ ]  
   - Mt Margaret [ ]  
   - Kalgoorlie [ ]  
   - Other [ ]
10  Who usually lives with you?

10a  How many adult men?  

10b  How old are they?  

10c  How many adult women?  

10d  How old are they?  

10e  How many children?  

10f  How old are they?  

Who usually does the cooking in your house or family?

Who usually does the shopping for your family?

Data Collection.

Past medical history

Have you ever had

D1  Diabetes   Yes [ ]  No [ ]  Don’t Know [ ]
D2  High blood pressure Yes [ ]  No [ ]  Don’t Know [ ]
D3  Kidney problems  Yes [ ]  No [ ]  Don’t Know [ ]
D4  Kidney failure  Yes [ ]  No [ ]  Don’t Know [ ]
D5  A Urinary tract infection Yes [ ]  No [ ]  Don’t Know [ ]
D6  A Heart attack  Yes [ ]  No [ ]  Don’t Know [ ]
D7  Rheumatic Fever  Yes [ ]  No [ ]  Don’t Know [ ]
D8  Pneumonia  Yes [ ]  No [ ]  Don’t Know [ ]
D9  Diarrhoea  Yes [ ]  No [ ]  Don’t Know [ ]
D10  Lactose Intolerance  Yes [ ]  No [ ]  Don’t Know [ ]
D11  Runny ears  Yes [ ]  No [ ]  Don’t Know [ ]
D12  Any other illness  Yes [ ]  No [ ]  Don’t Know [ ]
D13  – What ________________________________
Now we need some information about your birth if you can provide it

D14 Birth weight - kg

D15 Gestation - weeks

(Were you born on time? If not - how many weeks early or late?)

D16 Did your mother have Gestational Diabetes or diabetes in pregnancy?

Yes  No  Don’t Know

For Women

D18 Have you ever been pregnant? Yes  No  Don’t Know

D19 How many times?

D20 Have you any children? Yes  No

D21 How many?

D22 How much did they weigh at birth?

D23 When you were pregnant did you have any problems?

Yes  No  Don’t Know
D24 Did you have diabetes in Pregnancy?

Yes [ ] No [ ] Don’t Know [ ]

D25 Did you have High Blood Pressure when you were pregnant?

Yes [ ] No [ ] Don’t Know [ ]

For Everyone

Has anyone in your family ever had

D26 Diabetes

Yes [ ] No [ ] Don’t Know [ ]

D26a If Yes Who? Mother [ ]
D26b Father [ ]
D26c Sister or brother [ ]
D26d Child [ ]
D26e Grandparent [ ]
D26f Other [ ]

D27 Diabetes in Pregnancy

Yes [ ] No [ ] Don’t Know [ ]

D27a If Yes Who? Mother [ ]
D27b Sister [ ]
D27c Child [ ]
D27d Grandmother [ ]
D27e Other [ ]

- 408 -
28  High blood pressure  Yes □  No □  Don’t Know □  □

   D28a  If Yes  Who?  Mother □  □
   D28b  Father □  □
   D28c  Sister or brother □  □
   D28d  Child □  □
   D28e  Grandparent □  □
   D28f  Other ________ □  □

D29  Kidney problems  Yes □  No □  Don’t Know □  □

   D29a  If Yes  Who?  Mother □  □
   D29b  Father □  □
   D29c  Sister or brother □  □
   D29d  Child □  □
   D29e  Grandparent □  □
   D29f  Other ________ □  □

D30  Kidney failure  Yes □  No □  Don’t Know □  □

   D30a  If Yes  Who?  Mother □  □
   D30b  Father □  □
   D30c  Sister or brother □  □
   D30d  Child □  □
   D30e  Grandparent □  □
   D30f  Other ________ □  □
<table>
<thead>
<tr>
<th>D31</th>
<th>A Heart attack</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>D31a</td>
<td>If Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Who? Mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D31b</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D31c</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D31d</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>D31e</td>
<td></td>
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<td>D31f</td>
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</tbody>
</table>

<table>
<thead>
<tr>
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<th>Rheumatic Fever</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th></th>
</tr>
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<tbody>
<tr>
<td>D32a</td>
<td>If Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Who? Mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D32b</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>D32c</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>D32d</td>
<td></td>
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<tr>
<td>D32e</td>
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<tr>
<td>D32f</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
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<th>Pneumonia</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>D33a</td>
<td>If Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Who? Mother</td>
<td></td>
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<tr>
<td>D33b</td>
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<td>D33c</td>
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<td>D33d</td>
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<tr>
<td>D33e</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D33f</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
D34  Any other illness  
    Yes ☐  No ☐  Don’t Know ☐  ☐

    If Yes  Who?

D34a  Mother  ☐  What __________  ☐
D34b  Father  ☐  What __________  ☐
D34c  Sister or brother  ☐  What __________  ☐
D34d  Child  ☐  What __________  ☐
D34e  Grandparent  ☐  What __________  ☐

D35  Are you taking any medicines at the moment?  
    Yes ☐  No ☐  Don’t Know ☐  ☐

D36  What (please record names of medications)

________________________________________________________
________________________________________________________

D37a  Oral Hypoglycaemic agent  ☐  ☐
D37b  Insulin  ☐  ☐
D37c  Antihypertensive  ☐  ☐
D37d  ACE inhibitor  ☐  ☐
<table>
<thead>
<tr>
<th>Id Number __________ D1</th>
</tr>
</thead>
<tbody>
<tr>
<td>D37e  Antibiotic</td>
</tr>
<tr>
<td>D37f  Oral Contraceptive</td>
</tr>
<tr>
<td>D37g  Other  1</td>
</tr>
<tr>
<td>D37h  Other  2</td>
</tr>
<tr>
<td>D37i  Other  3</td>
</tr>
</tbody>
</table>
Physical examination

E1 Height ____________ cm

E2 Percentile ____________

E3 Weight ____________ kg

E4 Percentile ____________

E5 (BMI) ________________

E6 Abdominal girth ____________ cm, 

E7 Hip girth ________________ cm

E8 (Waist hip ratio) ____________/______________

Acanthosis Nigricans

E9 Neck Yes ☐ No ☐ Don't Know ☐

E10 Axilla Yes ☐ No ☐ Don't Know ☐
<table>
<thead>
<tr>
<th>Id Number</th>
<th>D1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>E11</strong></td>
<td><strong>Skin infection</strong></td>
</tr>
<tr>
<td><strong>E12</strong></td>
<td><strong>Ear discharge</strong></td>
</tr>
<tr>
<td><strong>E13</strong></td>
<td><strong>Other infection.</strong></td>
</tr>
</tbody>
</table>

**Blood Pressure**  
*Take blood pressure in right arm – 3 times*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>E14a</strong></td>
<td>_____ / _____</td>
</tr>
<tr>
<td><strong>E14b</strong></td>
<td>_____ / _____</td>
</tr>
<tr>
<td><strong>E14c</strong></td>
<td>_____ / _____</td>
</tr>
</tbody>
</table>
Blood Pressure

Adults - If over 140 systolic or 90 diastolic refer for investigation

In Children if over 95th refer for investigation

<table>
<thead>
<tr>
<th>Age</th>
<th>Systolic</th>
<th>Diastolic</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>106</td>
<td>64</td>
</tr>
<tr>
<td>7</td>
<td>108</td>
<td>72</td>
</tr>
<tr>
<td>8</td>
<td>110</td>
<td>76</td>
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<tr>
<td>9</td>
<td>114</td>
<td>80</td>
</tr>
<tr>
<td>10</td>
<td>118</td>
<td>82</td>
</tr>
<tr>
<td>11</td>
<td>124</td>
<td>82</td>
</tr>
<tr>
<td>12</td>
<td>128</td>
<td>84</td>
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<td>13</td>
<td>132</td>
<td>84</td>
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<td>14</td>
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<td>15</td>
<td>140</td>
<td>88</td>
</tr>
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<td>16</td>
<td>140</td>
<td>90</td>
</tr>
<tr>
<td>17</td>
<td>140</td>
<td>92</td>
</tr>
<tr>
<td>18</td>
<td>140</td>
<td>92</td>
</tr>
</tbody>
</table>
Investigations

(Random – not fasting)

I1 Blood Sugar If Random BSL over 6 refer for HBA1C and Investigation
I2 Cholesterol If over 4.5 refer for further investigation
I3 Haemoglobin If under 100 refer for further investigation

HBAIC required for anyone who has BSL>6, acanthosis nigricans, history of diabetes or currently treated for diabetes.

I3 HBAIC If HBAIC over 6.5 refer for further investigation

Urinalysis

I5a Glucose If Positive refer for Blood Sugar level
I5b Bilirubin If Positive refer
I5c Ketones If Positive refer
I5d Specific Gravity
I5e Blood If Positive refer for MSU
I5f pH
I5g Protein If Positive refer for ACR
I5h Uroblinogen If Positive refer
I5f Nitrites Negative Positive If Positive refer for MSU
I5g Leucocytes If Positive refer for MSU
Urine ACR

I6a  Albumin
I6b  Creatinine
I6c  ACR

I7  Any abnormalities  Yes / No

I8  Referred to  GP  Yes / No  Who? ___________
     Specialist  Yes / No  Who? ___________

Investigations requested

I9  Renal Ultrasound  Yes / No

I10  Result  Date  _____/_____/____  Normal / Abnormal

I11  Blood tests  Yes / No
<table>
<thead>
<tr>
<th>Requested</th>
<th>Result 1</th>
<th>Normal (N) / Abnormal (A)</th>
<th>Result 2</th>
<th>Result 3</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>FBC</td>
<td></td>
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<tr>
<td>U&amp;E</td>
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<td>TFT</td>
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<tr>
<td>Iron Studies</td>
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<tr>
<td>Fasting BSL</td>
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<tr>
<td>Fasting HDL</td>
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<td>Fasting LDL</td>
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<td>HBAIC</td>
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<td>Progesterone</td>
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<td>Testosterone</td>
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<td>SHBG</td>
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<tr>
<td>LH</td>
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<td></td>
</tr>
<tr>
<td>Oestradiol</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urine MCS</td>
<td></td>
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</tr>
<tr>
<td>Urine ACR</td>
<td></td>
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</tr>
</tbody>
</table>
C1 The Western Desert Kidney Health Project
First Clinical Data Sheet
Western Desert Kidney Health Project

Clinical Data Sheet 1

H1 Researcher ________________________________

ii) Date of data collection

<table>
<thead>
<tr>
<th>Date (Day)</th>
<th>Month</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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</tbody>
</table>

H2 Site of data Collection

<table>
<thead>
<tr>
<th>Location</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Laverton</td>
<td>Kalgoorlie</td>
</tr>
<tr>
<td>Mt Margaret</td>
<td>Kurrawang</td>
</tr>
<tr>
<td>Mulga Queen</td>
<td>Coolgardie</td>
</tr>
<tr>
<td>Leonora</td>
<td>Norseman</td>
</tr>
<tr>
<td>Menzies</td>
<td>Coonana</td>
</tr>
<tr>
<td>Morapoi</td>
<td>Tjuntjuntjarra</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

H3 Consent Obtained Yes [ ] No [ ] (Do not continue if consent not obtained)

H4 History and examination complete [ ]
First we would like to know a little bit about you and confirm your details

HD1  What are the first 2 letters of your first name?  ____  ____

HD2  What are the first 2 letters of your last name?  ____  ____

HD3  Are you Male or female?  Male  [ ]  Female  [ ]

HD4  Are you Aboriginal  Yes [ ]  No [ ]  Don’t Know [ ]
**WDKHP C1 Data Sheet**

**HD5**  Date of Birth

<table>
<thead>
<tr>
<th>Date (Day)</th>
<th>Month</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
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<tr>
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</tbody>
</table>

**HD6**  How old are you? _____________ Years  (months for babies)

**HD7**  Where do you usually live now?

<table>
<thead>
<tr>
<th>Laverton</th>
<th>Kalgoorlie</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mt Margaret</td>
<td>Kurrawang</td>
</tr>
<tr>
<td>Mulga Queen</td>
<td>Coolgardie</td>
</tr>
<tr>
<td>Lenora</td>
<td>Norseman</td>
</tr>
<tr>
<td>Menzies</td>
<td>Coonana</td>
</tr>
<tr>
<td>Morapoi</td>
<td>Tjuntjuntjarra</td>
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<tr>
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- 423 -
### Physical examination

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<th>E1</th>
<th>Height</th>
<th>cm</th>
<th>E1a</th>
<th>Percentile</th>
</tr>
</thead>
<tbody>
<tr>
<td>E2</td>
<td>Weight</td>
<td>Kg</td>
<td>E2a</td>
<td>Percentile</td>
</tr>
<tr>
<td>E3</td>
<td>Head Circumference</td>
<td>cm</td>
<td>E3a</td>
<td>Percentile</td>
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<td>E4a</td>
<td>Percentile</td>
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<td>If over 30 refer to Doctor</td>
</tr>
<tr>
<td>E5</td>
<td>Abdominal Girth</td>
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<td>E6</td>
<td>Hip Girth</td>
<td>cm</td>
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<td>E7</td>
<td>Pulse</td>
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<td>E8</td>
<td>Blood Pressure 1</td>
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<td>E8a</td>
<td>Mean BP 1</td>
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<td>E9</td>
<td>Blood Pressure 2</td>
<td></td>
<td>E9a</td>
<td>Mean BP 2</td>
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<td>E10</td>
<td>Blood Pressure 3</td>
<td></td>
<td>E10a</td>
<td>Mean BP 3</td>
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Blood Pressure

**Adults** - If over 140 systolic or 90 diastolic refer for investigation

**In Children** if over 95th refer for investigation

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<tr>
<th>Age</th>
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<th>Diastolic</th>
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<tr>
<td>7</td>
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<tr>
<td>18</td>
<td>140</td>
<td>92</td>
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**Action Needed?**  Yes [ ]  No [ ]  Don’t Know [ ]  Red Sticker
<table>
<thead>
<tr>
<th>E11</th>
<th>Axilla (under arm)</th>
<th>Yes / No</th>
<th>E12</th>
<th>Neck</th>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td>E13</td>
<td>Ears</td>
<td>Yes / No</td>
<td>E14</td>
<td>Runny Ears</td>
<td>Yes / No</td>
</tr>
<tr>
<td>E15</td>
<td>Hearing</td>
<td>Good / Poor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E16</td>
<td>Teeth and Gums</td>
<td>Good / Poor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E17</td>
<td>Vision</td>
<td>Good / Poor</td>
<td>E19</td>
<td>Visual Acuity</td>
<td>Right</td>
</tr>
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<td>Left</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>____/ ____</td>
</tr>
<tr>
<td>E21</td>
<td>Chest</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E22</td>
<td>Skin</td>
<td>Yes / No</td>
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<tr>
<td>E23</td>
<td>Sexually Transmitted Infection</td>
<td>Yes / No / Declined / Don’t Know</td>
<td>E24</td>
<td>STI Check Today</td>
<td>Yes / No</td>
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<td></td>
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<td>Swab</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Urine</td>
</tr>
</tbody>
</table>

A1  Action Needed?  Yes □  No □  Don’t Know □

A1a  If Yes – What?

Red Sticker
Investigations

**Blood Tests**

**i1** Has the person eaten or drunk anything in the last 4 hours?

- [ ] Yes
- [ ] No
- [ ] Don't Know

<table>
<thead>
<tr>
<th></th>
<th><strong>Blood Sugar</strong></th>
<th></th>
<th><strong>Cholesterol</strong></th>
<th></th>
<th><strong>Haemoglobin</strong></th>
<th></th>
<th><strong>Triglyceride</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>I2</td>
<td>If Random BSL over 5.5 refer for HBA1C and Investigation</td>
<td>i5</td>
<td>If over 5.5 refer for further investigation</td>
<td>I3</td>
<td>If under 110 refer for further investigation</td>
<td>i6</td>
<td>If over 2 refer for further investigation</td>
</tr>
<tr>
<td>I4</td>
<td>HbA1C required for anyone who has BSL&gt;6, acanthosis nigricans, history of diabetes or currently treated for diabetes</td>
<td></td>
<td>If HBAIC over 7 refer for further investigation</td>
<td></td>
<td></td>
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<td></td>
<td>Urinalysis</td>
<td>i 17</td>
<td>ACR</td>
<td></td>
<td></td>
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<tr>
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<td>------</td>
<td>-----</td>
<td></td>
<td></td>
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<tr>
<td>I 7</td>
<td>Glucose</td>
<td>i 18</td>
<td>Albumin</td>
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<td>I 8</td>
<td>Bilirubin</td>
<td>i 19</td>
<td>Creatinine</td>
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<td>Specific Gravity</td>
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<tr>
<td></td>
<td>If Positive refer for MSU</td>
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<td>I 14</td>
<td>Urobilinogen</td>
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<td>I 15</td>
<td>Nitrites</td>
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<td></td>
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<td>I 16</td>
<td>Leucocytes</td>
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</table>

A2 Action Needed? Yes [ ] No [ ] Don’t Know [ ]

Red Sticker
Please do ISTAT if

- ACR high
- History of kidney disease
- Blood in Urine
- HbA1C over 7
- If BP over 140/90

<table>
<thead>
<tr>
<th>ISTAT</th>
<th></th>
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<tbody>
<tr>
<td>I 20</td>
<td>Na (Sodium)</td>
</tr>
<tr>
<td>i 26</td>
<td>Glucose</td>
</tr>
<tr>
<td>I 21</td>
<td>K (Potassium)</td>
</tr>
<tr>
<td>i 27</td>
<td>Urea</td>
</tr>
<tr>
<td>I 22</td>
<td>Cl (Chloride)</td>
</tr>
<tr>
<td>i 28</td>
<td><strong>Creatinine</strong></td>
</tr>
<tr>
<td>I 23</td>
<td>TCO₃</td>
</tr>
<tr>
<td>i 29</td>
<td>Haematoscrit</td>
</tr>
<tr>
<td>I 24</td>
<td>Anion Gap</td>
</tr>
<tr>
<td>i 30</td>
<td>Haemoglobin</td>
</tr>
<tr>
<td>I 25</td>
<td>Ca (Calcium)</td>
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A3  Action Needed?  Yes [ ]  No [ ]  Don’t Know [ ]  Red Sticker
## Action

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<tr>
<th></th>
<th>Referred to</th>
<th>Yes / No</th>
<th>Which Doctor?</th>
<th></th>
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<tr>
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<td></td>
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<tr>
<td>A5</td>
<td>Specialist</td>
<td></td>
<td></td>
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<tr>
<td>A6</td>
<td>Other Referral</td>
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</table>

A4a

A5a

A6a
# Investigations requested

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<tr>
<th>Investigation requested</th>
<th>Date of Request</th>
<th>Result</th>
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<td>Yes / No</td>
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<td>FBC</td>
<td>Yes / No</td>
<td></td>
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<tr>
<td>U&amp;E</td>
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<tr>
<td>LFT</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Calcium</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>PO₄</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Iron Studies</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Vitamin D</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Fasting Blood Sugar</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>HbA1C</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Fasting Insulin,</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>C Peptide</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Fasting Cholesterol</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Fasting Lipids</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Thyroid Function</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Kidney Ultrasound</td>
<td>Yes / No</td>
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</table>

- 431 -
### Other investigations

<table>
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<th>Result</th>
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<td>Insulin Glucose Tolerance Test</td>
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<td>STI tests</td>
<td>Urine</td>
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<td>Swab</td>
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### For Polycystic Ovarian Disease

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<td>Free Androgen Index</td>
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<td>Prolactin</td>
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<td>Pelvic Ultrasound</td>
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Anaemia is defined as Hb less than the lower limit of the reference range for age:

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<th>Age</th>
<th>Lower limit of normal range of Hb (g/l)</th>
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<tr>
<td>2 months</td>
<td>90</td>
</tr>
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<td>2 - 6 months</td>
<td>95</td>
</tr>
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<td>6 - 24 months</td>
<td>105</td>
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<td>2 - 11 years</td>
<td>115</td>
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<td>&gt; 12 years</td>
<td>girls - 120</td>
</tr>
<tr>
<td></td>
<td>boys - 130</td>
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</tbody>
</table>

(Royal Children's Hospital Melbourne Clinical Practice Guidelines)

---

**Table 4** International cut off points for body mass index for overweight and obesity by sex between 2 and 18 years, defined to pass through body mass index of 25 and 30 kg/m² at age 18, obtained by averaging data from Brazil, Great Britain, Hong Kong, Netherlands, Singapore, and United States

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Body mass index 25 kg/m²</th>
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<th>Body mass index 30 kg/m²</th>
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<tr>
<td></td>
<td>Males</td>
<td>Females</td>
<td>Males</td>
<td>Females</td>
</tr>
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<td>2</td>
<td>18.41</td>
<td>18.02</td>
<td>20.09</td>
<td>19.81</td>
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<tr>
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<td>30</td>
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</tr>
</tbody>
</table>
Appendix 11

H1 The Western Desert Kidney Health
Project First History Data Sheet
Western Desert Kidney Health Project

History Data Sheet 1

H1 Researcher _____________________________

ii) Date of data collection

<table>
<thead>
<tr>
<th>Date (Day)</th>
<th>Month</th>
<th>Year</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

H2 Site of data Collection

<table>
<thead>
<tr>
<th>Laverton</th>
<th>Kalgoorlie</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mt Margaret</td>
<td>Kurrawang</td>
</tr>
<tr>
<td>Mulga Queen</td>
<td>Coolgardie</td>
</tr>
<tr>
<td>Leonora</td>
<td>Norseman</td>
</tr>
<tr>
<td>Menzies</td>
<td>Coonana</td>
</tr>
<tr>
<td>Morapoi</td>
<td>Tjuntjuntjarra</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

H3 Consent Obtained  Yes [ ]  No [ ]  (Do not continue if consent not obtained)

H4 History and examination complete  [ ]
History incomplete - [ ] Child unable to answer

[ ] Language difficulty

[ ] Other ________________

Examination incomplete

[ ] Patient refused

[ ] To be completed at another time

[ ] Other ________________
First we would like to know a little bit about you and confirm your details

HD1  What are the first 2 letters of your first name?  ____ ____

HD2  What are the first 2 letters of your last name?   ____ ____

HD3  Are you Male or female?     
     Male  
     Female 

HD4  Are you Aboriginal     
     Yes   
     No    
     Don’t Know

HD5  Date of Birth

<table>
<thead>
<tr>
<th>Date (Day)</th>
<th>Month</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

HD6  How old are you? ____________ Years       (months for babies)

HD7  Where do you usually live now?

<table>
<thead>
<tr>
<th>Laverton</th>
<th>Kalgoorlie</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mt Margaret</td>
<td>Kurrawang</td>
</tr>
<tr>
<td>Mulga Queen</td>
<td>Coolgardie</td>
</tr>
<tr>
<td>Lenora</td>
<td>Norseman</td>
</tr>
<tr>
<td>Menzies</td>
<td>Coonana</td>
</tr>
<tr>
<td>Morapoi</td>
<td>Tjuntjuntjarra</td>
</tr>
<tr>
<td>Other</td>
<td>Please Specify</td>
</tr>
</tbody>
</table>
HD8  Where were you born?

<table>
<thead>
<tr>
<th>Laverton</th>
<th>Kalgoorlie</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mt Margaret</td>
<td>Kurrawang</td>
</tr>
<tr>
<td>Mulga Queen</td>
<td>Coolgardie</td>
</tr>
<tr>
<td>Lenora</td>
<td>Norseman</td>
</tr>
<tr>
<td>Menzies</td>
<td>Coonana</td>
</tr>
<tr>
<td>Morapoi</td>
<td>Tjuntjuntjarra</td>
</tr>
<tr>
<td>Esperance</td>
<td>Perth</td>
</tr>
<tr>
<td>WA – Other</td>
<td></td>
</tr>
<tr>
<td>Please Specify</td>
<td></td>
</tr>
<tr>
<td>South Australia</td>
<td></td>
</tr>
<tr>
<td>Please Specify</td>
<td></td>
</tr>
<tr>
<td>Other Australia</td>
<td></td>
</tr>
<tr>
<td>Please Specify</td>
<td></td>
</tr>
<tr>
<td>Overseas</td>
<td></td>
</tr>
<tr>
<td>Please Specify</td>
<td></td>
</tr>
</tbody>
</table>
HD9 Where did you spend most of your childhood?  You can tick more than one box

<table>
<thead>
<tr>
<th>Laverton,</th>
<th>Kalgoorlie</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mt Margaret</td>
<td>Kurrawang</td>
</tr>
<tr>
<td>Mulga Queen</td>
<td>Coolgardie</td>
</tr>
<tr>
<td>Lenora</td>
<td>Norseman</td>
</tr>
<tr>
<td>Menzies</td>
<td>Coonana</td>
</tr>
<tr>
<td>Morapoi</td>
<td>Tjuntjuntjarra</td>
</tr>
<tr>
<td>Esperance</td>
<td>Perth</td>
</tr>
<tr>
<td>WA – Other</td>
<td>Please Specify</td>
</tr>
<tr>
<td>South Australia</td>
<td>Please Specify</td>
</tr>
<tr>
<td>Other Australia</td>
<td>Please Specify</td>
</tr>
<tr>
<td>Overseas</td>
<td>Please Specify</td>
</tr>
</tbody>
</table>

HD10 Did you spend any part of your childhood at a Mission?  
Yes □  No □  Don’t Know □

HD11 If Yes, Where

<table>
<thead>
<tr>
<th>Mt Margaret</th>
<th>□</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kurrawang</td>
<td>□</td>
</tr>
<tr>
<td>Norseman</td>
<td>□</td>
</tr>
<tr>
<td>Other</td>
<td>□</td>
</tr>
</tbody>
</table>
Who usually lives with you?

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Male/Female</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>HD12.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.6</td>
<td></td>
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</tr>
<tr>
<td>HD12.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD12.13</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>HD12.14</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Past medical history**

Have you ever had

<table>
<thead>
<tr>
<th>HP</th>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>HP1</td>
<td>Diabetes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP2</td>
<td>High Blood Pressure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP3</td>
<td>Kidney Problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP4</td>
<td>Kidney Failure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP5</td>
<td>Urine Infection</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP6</td>
<td>Kidney Stones</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP7</td>
<td>Glomerulonephritis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP8</td>
<td>Rheumatic fever</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP9</td>
<td>Heart Attack</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP10</td>
<td>Stroke</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP11</td>
<td>Pneumonia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP12</td>
<td>Other breathing problem - What?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP13</td>
<td>Cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP14</td>
<td>Lactose intolerance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP15</td>
<td>Runny ears</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP16</td>
<td>Any other illness</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
HP 18 Are you a carer for someone?

Yes ☐  No ☐  Don’t Know ☐

HP19 Are you cared for by another person?

Yes ☐  No ☐  Don’t Know ☐

HP20 Who? ________________________________

(Please record relationship, not name – eg mother, paid carer etc)
Birth History

HB1  Birth weight - kg  Don’t Know □
      (How much did you weigh at birth?)

HB2  Gestation - weeks  Don’t Know □
      (Were you born on time? If not - how many weeks early or late?)

HB3  Did your mother have Gestational Diabetes or diabetes in pregnancy?
      Yes □  No □  Don’t Know □
For Women

HW1 Are you pregnant?  Yes ☐  No ☐  Don’t Know ☐

HW2 Have you ever been pregnant?  Yes ☐  No ☐  Don’t Know ☐

HW3 If Yes please tell us about those pregnancies and births

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Gestation (How many weeks at delivery?)</th>
<th>Birthweight</th>
<th>Did you have diabetes during this pregnancy?</th>
<th>Did you have high blood pressure during this pregnancy?</th>
<th>Any other problems during this pregnancy?</th>
<th>If Yes, What?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes / No</td>
<td>Yes / No</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td>Yes / No</td>
<td>Yes / No</td>
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<td></td>
<td>Yes / No</td>
<td>Yes / No</td>
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<td></td>
<td>Yes / No</td>
<td>Yes / No</td>
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<td></td>
<td>Yes / No</td>
<td>Yes / No</td>
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<td>Yes / No</td>
<td>Yes / No</td>
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<td>Yes / No</td>
<td>Yes / No</td>
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<td>Yes / No</td>
<td>Yes / No</td>
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<td></td>
<td></td>
<td></td>
<td>Yes / No</td>
<td>Yes / No</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
HW4 Have you ever had a PapSmear? Yes ☐ No ☐ Don’t Know ☐

HW5 If yes, When was your last one? _______________________

HW6 Have you ever had a breast check? Yes ☐ No ☐ Don’t Know ☐

HW6 If yes, When? _______________________

HW7 Have you ever had a mammogram? Yes ☐ No ☐ Don’t Know ☐

HW8 If yes, When? _______________________
# Family History

For Everyone - Has anyone in your family ever had

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
<th>Don't Know</th>
<th>If Yes – Who?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
<td></td>
<td>Mother = M</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Father = F</td>
</tr>
<tr>
<td>HF2 High Blood Pressure</td>
<td></td>
<td></td>
<td></td>
<td>Sister = S</td>
</tr>
<tr>
<td>HF3 Kidney Problems</td>
<td></td>
<td></td>
<td></td>
<td>Brother = B</td>
</tr>
<tr>
<td>HF4 Kidney Failure</td>
<td></td>
<td></td>
<td></td>
<td>Child = C</td>
</tr>
<tr>
<td>HF5 Urine Infection</td>
<td></td>
<td></td>
<td></td>
<td>Grandparent = G</td>
</tr>
<tr>
<td>HF6 Kidney Stones</td>
<td></td>
<td></td>
<td></td>
<td>Aunt/Uncle = A</td>
</tr>
<tr>
<td>HF7 Glomerulonephritis</td>
<td></td>
<td></td>
<td></td>
<td>Other = O</td>
</tr>
<tr>
<td>Blood in the urine</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HF8 Rheumatic fever</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HF9 Heart Attack</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HF10 Stroke</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HF11 Pneumonia</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HF12</td>
<td>Other Breathing problem – What?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HF13</td>
<td>Cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HF14</td>
<td>Lactose intolerance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HF15</td>
<td>Runny ears</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HF16</td>
<td>Any other illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HF17</td>
<td>If Yes – What</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Medications

HM1 Are you taking any medicines at the moment?

Yes ☐  No ☐  Don’t Know ☐

HM2 If Yes, What (please record names of medications – prescribed or over the counter)

_________________________________________________________
_________________________________________________________
_________________________________________________________
_________________________________________________________

<table>
<thead>
<tr>
<th>HM3</th>
<th>Oral Hypoglycaemic</th>
<th>HM7</th>
<th>ACE Inhibitor</th>
</tr>
</thead>
<tbody>
<tr>
<td>HM4</td>
<td>Insulin</td>
<td>HM8</td>
<td>Antibiotic</td>
</tr>
<tr>
<td>HM5</td>
<td>Antihypertensive</td>
<td>HM9</td>
<td>Oral Contraceptive</td>
</tr>
<tr>
<td>HM6</td>
<td>NSAID</td>
<td>HM10</td>
<td></td>
</tr>
</tbody>
</table>
Smoking

HM11 Do you Smoke cigarettes?  Yes ☐ No ☐ Don’t Know ☐

HM12 If Yes, how many per day?  ________________

HM13 Would you like to quit?  Yes ☐ No ☐ Don’t Know ☐

Now / Later

If No

HM14 Are you an ex smoker?  Yes ☐ No ☐ Don’t Know ☐

Alcohol and other drugs

HM15 Do you Drink Alcohol?  Yes ☐ No ☐ Don’t Know ☐

HM16 If Yes  every day / most days / not very often

HM17 Do you use any drugs?  Yes ☐ No ☐ Don’t Know ☐

HM18 If Yes  every day / most days / not very often

HM19 If Yes, What?

______________________
<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you allergic to anything?</td>
<td>Yes [ ] No [ ] Don't Know [ ]</td>
</tr>
<tr>
<td>If Yes, What?</td>
<td></td>
</tr>
<tr>
<td>Are you allergic to any medicines?</td>
<td>Yes [ ] No [ ] Don't Know [ ]</td>
</tr>
<tr>
<td>If Yes, What?</td>
<td></td>
</tr>
<tr>
<td>Have you been immunized?</td>
<td>Yes [ ] No [ ] Don't Know [ ]</td>
</tr>
<tr>
<td>If Yes, What vaccinations have you had?</td>
<td></td>
</tr>
<tr>
<td>Childhood vaccinations</td>
<td>Yes [ ] No [ ] Don't Know [ ]</td>
</tr>
<tr>
<td>If Yes</td>
<td>All [ ] Some, but not all [ ]</td>
</tr>
<tr>
<td>Teenage Vaccinations</td>
<td>Yes [ ] No [ ] Don't Know [ ]</td>
</tr>
<tr>
<td>Other</td>
<td>Yes [ ] No [ ] Don't Know [ ]</td>
</tr>
<tr>
<td>If Yes, What?</td>
<td></td>
</tr>
</tbody>
</table>
Diet

Please tell us about your diet

Yesterday did you have

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>HC1 Breakfast</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC2 Lunch</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC3 Dinner</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC4 Snacks</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC5 Soft (Cool) Drink</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC6 Lollies / Chips / Chocolate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC7 Take away foods</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC8 Any Fruit</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC9 If Yes What?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
WDKHP Primary History Sheet O/10

Id Number ________________

HC10  How many serves

HC11  Any Vegetables

HC12  If Yes What?

HC13  How many serves
Do you usually eat – please circle

<table>
<thead>
<tr>
<th>Meat</th>
<th>How often</th>
<th>You can circle more than one answer</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes / No</td>
<td>Every day</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Most days</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
</tr>
<tr>
<td></td>
<td>HC14</td>
<td></td>
</tr>
<tr>
<td></td>
<td>HC15</td>
<td>What sorts of meat do you eat?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Beef</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lamb</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pork</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Chicken</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Kangaroo</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Emu</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Turkey</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Goanna</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sausages</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Salami / Polony / Ham</td>
</tr>
<tr>
<td></td>
<td>HC16</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes / No</td>
<td>Every day</td>
</tr>
<tr>
<td>----------</td>
<td>----------</td>
<td>-----------</td>
</tr>
<tr>
<td><strong>Eggs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC17</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>HC18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC19</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Yes / No</th>
<th>Every day</th>
<th>What sorts of Fish do you eat?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fish or seafood</strong></td>
<td></td>
<td></td>
<td>Fresh</td>
</tr>
<tr>
<td>HC20</td>
<td></td>
<td></td>
<td>Frozen</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Canned</td>
</tr>
<tr>
<td>HC21</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th></th>
<th>Yes / No</th>
<th>Every day</th>
<th>What sorts of Milk do you drink?</th>
</tr>
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<tbody>
<tr>
<td><strong>Milk</strong></td>
<td></td>
<td></td>
<td>Normal</td>
</tr>
<tr>
<td>HC23</td>
<td></td>
<td></td>
<td>Low Fat (Hi Lo, Skim)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Lactose Free</td>
</tr>
<tr>
<td>HC24</td>
<td></td>
<td></td>
<td>Flavoured</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Soy</td>
</tr>
<tr>
<td>HC25</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other dairy products</td>
<td>Yes / No</td>
<td>Every day</td>
<td>What sorts of Dairy products do you eat?</td>
</tr>
<tr>
<td>---------------------</td>
<td>----------</td>
<td>-----------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td>Cheese</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td>Yoghurt</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td>Custard</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
<td>Ice Cream</td>
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</table>

<table>
<thead>
<tr>
<th>Fruit</th>
<th>Yes / No</th>
<th>Every day</th>
<th>What sorts of Fruit do you eat? Please specify</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Vegetables</th>
<th>Yes / No</th>
<th>Every day</th>
<th>What sorts of Vegetables do you eat? Please specify</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
<td></td>
</tr>
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</table>

HC26
HC27
HC28
HC29
HC30
HC31
HC32
HC33
HC34
<table>
<thead>
<tr>
<th></th>
<th>Yes / No</th>
<th>Frequency</th>
<th>What sorts of [Food Item] do you drink? Please specify</th>
</tr>
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<tbody>
<tr>
<td><strong>Soft (Cool) Drink</strong></td>
<td></td>
<td>Every day</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
<td></td>
</tr>
<tr>
<td>HC35</td>
<td></td>
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<td></td>
</tr>
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<td>HC36</td>
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</tr>
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<td>HC37</td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Fruit Juice</strong></td>
<td></td>
<td>Every day</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
<td></td>
</tr>
<tr>
<td>HC38</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC39</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC40</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Legumes / Beans</strong></td>
<td></td>
<td>Every day</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
<td></td>
</tr>
<tr>
<td>HC41</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC42</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC43</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bread</td>
<td>Yes / No</td>
<td>Every day</td>
<td>What sorts of bread do you eat?</td>
</tr>
<tr>
<td>-------</td>
<td>----------</td>
<td>-----------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>White</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Damper</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Wholemeal (Brown)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Multigrain</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Take away foods</th>
<th>Yes / No</th>
<th>Every day</th>
<th>What sorts of Take away foods do you eat? Please specify</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chips, lollies, chocolate</th>
<th>Yes / No</th>
<th>Every day</th>
<th>What sorts? Please specify</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

HC44
HC45
HC46
HC47
HC48
HC49
HC50
HC51
HC52
Exercise

HE1 Do you do any exercise?  
Yes [ ]  No [ ]  Don’t Know [ ]

If Yes,

HE2 How often?  
Once a week  
Yes / No

2 or 3 times per week  
Yes / No

30 minutes on 5 days per week or more  
Yes / No

HE3 What sort of exercise do you do?

________________________________________________________________________

________________________________________________________________________

HE4 Why do you do that?

________________________________________________________________________

________________________________________________________________________
**Stress**

How do you feel today?  You can choose more than one

<table>
<thead>
<tr>
<th>HS1</th>
<th>OK</th>
<th>Yes ☐</th>
<th>No ☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>HS2</td>
<td>Happy</td>
<td>Yes ☐</td>
<td>No ☐</td>
</tr>
<tr>
<td>HS3</td>
<td>Sad</td>
<td>Yes ☐</td>
<td>No ☐</td>
</tr>
<tr>
<td>HS4</td>
<td>Angry</td>
<td>Yes ☐</td>
<td>No ☐</td>
</tr>
<tr>
<td>HS5</td>
<td>Stressed</td>
<td>Yes ☐</td>
<td>No ☐</td>
</tr>
<tr>
<td>HS6</td>
<td>Don’t Know</td>
<td>Yes ☐</td>
<td>No ☐</td>
</tr>
</tbody>
</table>

HS7  Do you do anything to help reduce your **stress**?

Yes ☐  No ☐  Don’t Know ☐

HS8  If Yes, What do you do?

_________________________________________________________

_________________________________________________________

HS9  Why do you do that?

_________________________________________________________

_________________________________________________________
WDKHP Primary History Sheet O/10

Id Number ____________________

1. Your age group
   - Under 35 years
   - 35 – 44 years
   - 45 – 54 years
   - 55 – 64 years
   - 65 years or over
   [ ] 0 points
   [ ] 2 points
   [ ] 4 points
   [ ] 6 points
   [ ] 8 points

2. Your gender
   - Female
   - Male
   [ ] 0 points
   [ ] 3 points

3. Your ethnicity/country of birth:
   3a. Are you of Aboriginal, Torres Strait Islander, Pacific Islander or Maori descent?
   [ ] No 0 points
   [ ] Yes 2 points

   3b. Where were you born?
   - Australia
   - Asia (including the Indian sub-continent), Middle East, North Africa, Southern Europe
   - Other
   [ ] 0 points
   [ ] 2 points

4. Have either of your parents, or any of your brothers or sisters been diagnosed with diabetes type 1 or type 2?
   [ ] No 0 points
   [ ] Yes 3 points

5. Have you ever been found to have high blood glucose (sugar) (for example, in a health examination, during an illness, during pregnancy)?
   [ ] No 0 points
   [ ] Yes 6 points

6. Are you currently taking medication for high blood pressure?
   [ ] No 0 points
   [ ] Yes 2 points

7. Do you currently smoke cigarettes or any other tobacco products on a daily basis?
   [ ] No 0 points
   [ ] Yes 2 points

8. How often do you eat vegetables or fruit?
   - Every day
   - Not every day
   [ ] 0 points
   [ ] 1 point

9. On average, would you say you do at least 2.5 hours of physical activity per week (for example, 30 minutes a day on 5 or more days a week)?
   [ ] Yes 0 points
   [ ] No 2 points

10. Your waist measurement taken below the ribs (usually at the level of the navel, and while standing):
    Waist measurement (cm) ________________

    For those of Asian or Aboriginal or Torres Strait Islander descent:
    [ ] Men
    - Less than 90 cm
    - 90 – 100 cm
    - More than 100 cm
    For all others:
    [ ] Women
    - Less than 80 cm
    - 80 – 90 cm
    - More than 90 cm
    [ ] 0 points
    [ ] 4 points
    [ ] 7 points

Add up your points ______________________

Your risk of developing type 2 diabetes within 5 years*:
   [ ] 5 or less: Low risk
      Approximately one person in every 100 will develop diabetes.
   [ ] 6-11: Intermediate risk
      For scores of 6-8, approximately one person in every 50 will develop diabetes. For scores of 9-11, approximately one person in every 30 will develop diabetes.
   [ ] 12 or more: High risk
      For scores of 12-15, approximately one person in every 14 will develop diabetes. For scores of 16-19, approximately one person in every 7 will develop diabetes. For scores of 20 and above, approximately one person in every 3 will develop diabetes.

*The overall score may overestimate the risk of diabetes in those aged less than 25 years.

If you scored 6-11 points in the AUSDRISK you may be at increased risk of type 2 diabetes. Discuss your score and your individual risk with your doctor. Improving your lifestyle may help reduce your risk of developing type 2 diabetes.

If you scored 12 points or more in the AUSDRISK you may have undiagnosed type 2 diabetes or be at high risk of developing the disease. See your doctor about having a fasting blood glucose test. Act now to prevent type 2 diabetes.
Evaluation

HX1 What do you think about the Western Desert Kidney Health Project?

________________________________________________________________________

________________________________________________________________________

HX2 Why do you think that?

________________________________________________________________________

________________________________________________________________________

HX3 Do you have any comments or things you would like to tell us?

________________________________________________________________________

________________________________________________________________________
Appendix 12

HC2 The Western Desert Kidney Health Project Follow Up Data Sheet
Western Desert Kidney Health Project

Data Sheet 2

H Was this participant screened last year?  Yes / No
If yes then continue,  If No then please use C1 and H1 Forms

H1 Researcher ________________________________

ii) Date of data collection

<table>
<thead>
<tr>
<th>Date (Day)</th>
<th>Month</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

H2 Site of data Collection

<table>
<thead>
<tr>
<th>Location</th>
<th>Site</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laverton</td>
<td>Kalgoorlie</td>
</tr>
<tr>
<td>Mt Margaret</td>
<td>Kurrawang</td>
</tr>
<tr>
<td>Mulga Queen</td>
<td>Coolgardie</td>
</tr>
<tr>
<td>Leonora</td>
<td>Norseman</td>
</tr>
<tr>
<td>Menzies</td>
<td>Coonana</td>
</tr>
<tr>
<td>Morapoi</td>
<td>Tjuntjuntjarra</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

H3 Consent Obtained  Yes ☐ No ☐ (Do not continue if consent not obtained)

- 466 -
H4  History and examination complete  

History incomplete -  

Child unable to answer

Language difficulty

Other ______________________

Examination incomplete  

Patient refused

To be completed at another time

Other ______________________
First we would like to know a little bit about you and confirm your details

HD1  What are the first 2 letters of your first name?  ________

HD2  What are the first 2 letters of your last name?  ________

HD3  Are you Male or female?  Male  □

Female □

HD4  Are you Aboriginal  Yes □  No □  Don’t Know □

HD4a  If No what is your nationality?  _______________________

HD5  Date of Birth

<table>
<thead>
<tr>
<th>Date (Day)</th>
<th>Month</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

HD6  How old are you? ___________ Years  (months for babies)

HD7  Where do you usually live now?

Laverton  Kalgoorlie
Mt Margaret  Kurrawang
Mulga Queen  Coolgardie
Lenora  Norseman
Menzies  Coonana
Morapoi  Tjuntjuntjarra
Other
Please Specify
HD7 Have you moved in the last year? Yes / No

HD8 If yes where did you live in the last year? __________________________
### Past medical history

Have you ever had

<table>
<thead>
<tr>
<th>HP</th>
<th>Disease</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>HP1</td>
<td>Diabetes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP2</td>
<td>High Blood Pressure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP3</td>
<td>Kidney Problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP4</td>
<td>Kidney Failure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP5</td>
<td>Urine Infection</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP6</td>
<td>Kidney Stones</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP7</td>
<td>Glomerulonephritis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Blood in your urine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP8</td>
<td>Rheumatic fever</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP9</td>
<td>Heart Attack</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP10</td>
<td>Stroke</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP11</td>
<td>Pneumonia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP12</td>
<td>Other breathing problem - What?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP13</td>
<td>Cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP14</td>
<td>Lactose intolerance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP15</td>
<td>Runny ears</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP16</td>
<td>Any other illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HP17</td>
<td>If Yes – What</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
WDKHP Follow Up Data Sheet O/10

Id Number ________________

For Women

HW1  Are you pregnant?   Yes ☐  No ☐  Don’t Know ☐

HW4  Have you ever had a PapSmear?  Yes ☐  No ☐  Don’t Know ☐

HW5  If yes, When was your last one?  _______________________

HW6  Have you ever had a breast check?  Yes ☐  No ☐  Don’t Know ☐

HW6  If yes, When?  _______________________

HW7  Have you ever had a mammogram?  Yes ☐  No ☐  Don’t Know ☐

HW8  If yes, When?  _______________________
**Medications**

**HM1**  Are you taking any medicines at the moment?

Yes ☐  No ☐  Don’t Know ☐

**HM2**  If Yes, What (please record names of medications – prescribed or over the counter)

_________________________________________________________

_________________________________________________________

_________________________________________________________

_________________________________________________________

**HM3**  Oral Hypoglycaemic  ☐  **HM7**  ACE Inhibitor ☐

**HM4**  Insulin ☐  **HM8**  Antibiotic ☐

**HM5**  Antihypertensive ☐  **HM9**  Oral Contraceptive ☐

**HM6**  NSAID ☐  **HM10**

**HM7**  Has there been any changes to your medications since the last time we saw you?

Yes ☐  No ☐  Don’t Know ☐

**HM8**  If Yes, What changes?

_________________________________________________________

_________________________________________________________
Smoking

HM11 Do you Smoke cigarettes?    Yes  No  Don’t Know

HM12 If Yes, how many per day?    ___________________

HM13 Would you like to quit?       Yes  No  Don’t Know

Now / Later

If No

HM14 Are you an ex smoker?        Yes  No  Don’t Know

Alcohol and other drugs

HM15 Do you Drink Alcohol?        Yes  No  Don’t Know

HM16 If Yes  ☐ every day  ☐ most days  ☐ not very often

HM17 Do you use any drugs?        Yes  No  Don’t Know

HM18 If Yes  every day / most days / not very often

HM19 If Yes, What?

________________________
Allergies and Immunizations

HA1  Are you allergic to anything?  Yes [ ]  No [ ]  Don’t Know [ ]

HA2  If Yes, What? ______________________________________

HA3  Are you allergic to any medicines?  Yes [ ]  No [ ]  Don’t Know [ ]

HA4  If Yes, What? ______________________________________
Please tell us about your diet

Yesterday did you have

<table>
<thead>
<tr>
<th>HC</th>
<th>Item</th>
<th>Yes</th>
<th>No</th>
<th>Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>HC1</td>
<td>Breakfast</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC2</td>
<td>Lunch</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC3</td>
<td>Dinner</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC4</td>
<td>Snacks</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC5</td>
<td>Soft (Cool) Drink</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC6</td>
<td>Lollies / Chips / Chocolate</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>HC7</td>
<td>Take away foods</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC8</td>
<td>Any Fruit</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC9</td>
<td>If Yes What?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC10</td>
<td>How many serves</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC11</td>
<td>Any Vegetables</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC12</td>
<td>If Yes What?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HC13</td>
<td>How many serves</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

HC9 If Yes What? __________________________

HC10 How many serves __________________________

HC11 Any Vegetables __________________________

HC12 If Yes What? __________________________

HC13 How many serves __________________________
Do you usually eat – please circle

<table>
<thead>
<tr>
<th></th>
<th>How often</th>
<th>You can circle more than one answer</th>
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</thead>
<tbody>
<tr>
<td><strong>Meat</strong></td>
<td>Yes / No</td>
<td>Every day</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Most days</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
</tr>
<tr>
<td>HC14</td>
<td></td>
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</tr>
<tr>
<td>HC15</td>
<td></td>
<td><strong>What sorts of meat do you eat?</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Beef</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lamb</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pork</td>
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<td></td>
<td></td>
<td>Chicken</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Kangaroo</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
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<td>Turkey</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Goanna</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sausages</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Salami / Polony / Ham</td>
</tr>
<tr>
<td>HC16</td>
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<td><strong>Eggs</strong></td>
<td>Yes / No</td>
<td>Every day</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Most days</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
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<td>HC17</td>
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<td>HC18</td>
<td></td>
<td><strong>What sorts of eggs do you eat?</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Chicken</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Duck</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Emu</td>
</tr>
<tr>
<td>HC19</td>
<td></td>
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</tr>
<tr>
<td>Fish or seafood</td>
<td>Yes / No</td>
<td>Every day</td>
</tr>
<tr>
<td>-----------------</td>
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<td>------------</td>
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<td>HC20</td>
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<table>
<thead>
<tr>
<th>Milk</th>
<th>Yes / No</th>
<th>Every day</th>
<th>What sorts of Milk do you drink?</th>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Normal</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Low Fat (Hi Lo, Skim)</td>
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<td></td>
<td></td>
<td></td>
<td>Lactose Free</td>
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<td></td>
<td></td>
<td></td>
<td>Flavoured</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>Soy</td>
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<td>HC23</td>
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HC21
HC22
HC24
HC25
<table>
<thead>
<tr>
<th>Other dairy products</th>
<th>Yes / No</th>
<th>Every day</th>
<th>What sorts of Dairy products do you eat?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td>Cheese</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td>Yoghurt</td>
</tr>
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<td></td>
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<td>Less than once a week</td>
<td>Custard</td>
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<td>Ice Cream</td>
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</table>

<table>
<thead>
<tr>
<th>Fruit</th>
<th>Yes / No</th>
<th>Every day</th>
<th>What sorts of Fruit do you eat? Please specify</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
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<table>
<thead>
<tr>
<th>Vegetables</th>
<th>Yes / No</th>
<th>Every day</th>
<th>What sorts of Vegetables do you eat? Please specify</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
<td></td>
</tr>
<tr>
<td>Soft (Cool) Drink</td>
<td>Yes / No</td>
<td>Every day</td>
<td>What sorts of Soft Drink do you drink?</td>
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<td>-------------------</td>
<td>----------</td>
<td>-----------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td>Please specify</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
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</table>

<table>
<thead>
<tr>
<th>Fruit Juice</th>
<th>Yes / No</th>
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<th>What sorts of Fruit Drink do you drink?</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Most days</td>
<td>Please specify</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than once a week</td>
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HC35
HC36
HC37
HC38
HC39
HC40
<table>
<thead>
<tr>
<th>Question</th>
<th>Frequency Options</th>
<th>Additional Information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Legumes / Beans</strong></td>
<td>Yes / No</td>
<td>What sorts of beans do you eat? Please specify</td>
</tr>
<tr>
<td></td>
<td>Every day</td>
<td>HC41</td>
</tr>
<tr>
<td></td>
<td>Most days</td>
<td>HC42</td>
</tr>
<tr>
<td></td>
<td>Once a week</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Less than once a week</td>
<td></td>
</tr>
<tr>
<td><strong>Bread</strong></td>
<td>Yes / No</td>
<td>What sorts of bread do you eat?</td>
</tr>
<tr>
<td></td>
<td>Every day</td>
<td>White, Damper, Wholemeal (Brown), Multigrain, Other</td>
</tr>
<tr>
<td></td>
<td>Most days</td>
<td>HC44</td>
</tr>
<tr>
<td></td>
<td>Once a week</td>
<td>HC45</td>
</tr>
<tr>
<td></td>
<td>Less than once a week</td>
<td>HC46</td>
</tr>
<tr>
<td><strong>Take away foods</strong></td>
<td>Yes / No</td>
<td>What sorts of Take away foods do you eat? Please specify</td>
</tr>
<tr>
<td></td>
<td>Every day</td>
<td>HC47</td>
</tr>
<tr>
<td></td>
<td>Most days</td>
<td>HC48</td>
</tr>
<tr>
<td></td>
<td>Once a week</td>
<td>HC49</td>
</tr>
<tr>
<td></td>
<td>Less than once a week</td>
<td></td>
</tr>
<tr>
<td><strong>Chips, lollies, chocolate</strong></td>
<td>Yes / No</td>
<td>What sorts? Please specify</td>
</tr>
<tr>
<td></td>
<td>Every day</td>
<td>HC50</td>
</tr>
<tr>
<td></td>
<td>Most days</td>
<td>HC51</td>
</tr>
<tr>
<td></td>
<td>Once a week</td>
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</tr>
<tr>
<td></td>
<td>Less than once a week</td>
<td>HC52</td>
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</tbody>
</table>
Have you made any changes to your diet since the last time we saw you?

Yes ☐  No ☐  Don’t Know ☐

If Yes, What changes?

_________________________________________________________

_________________________________________________________
Exercise

HE1  Do you do any exercise?  Yes ☐  No ☐  Don’t Know ☐

If Yes,

HE2  How often?  Every day

Most days

Once a week

Less than once a week

HE2a  Do you do 30 minutes of exercise on 5 days per week or more?  Yes / No

HE3  What sort of exercise do you do?

__________________________________________________________

__________________________________________________________

HE4  Why do you do that?

__________________________________________________________

__________________________________________________________

HE5  Have you made any changes to your exercise since the last time we saw you?

Yes ☐  No ☐  Don’t Know ☐
HE6  If Yes, What changes?

____________________________________________________________________

____________________________________________________________________
Stress

How do you feel today? You can choose more than one

HS1 OK

HS2 Happy

HS3 Sad

HS4 Angry

HS5 Stressed

HS6 Don’t Know

Do you do anything to help reduce your stress?

Yes No Don’t Know

If Yes, What do you do?

__________________________________________________________

__________________________________________________________
HS9  Why do you do that?

________________________________________________________________________

________________________________________________________________________

HS10  Have you made any changes to your stress management since the last time we saw you?

Yes ☐ No ☐ Don’t Know ☐

HS11  If Yes, What changes?

________________________________________________________________________

________________________________________________________________________
Evaluation

HX1  What do you think about the Western Desert Kidney Health Project?

________________________________________________________________________

________________________________________________________________________

HX2  Why do you think that?

________________________________________________________________________

________________________________________________________________________

HX3  Have you seen any changes in your community as a result of the Western Desert Kidney Health Project?

Yes / No

HX4  If Yes, What Changes?

________________________________________________________________________

________________________________________________________________________
HX5  What Changes would you like to see?

__________________________________________________________

__________________________________________________________

HX4  Do you have any comments or things you would like to tell us?

__________________________________________________________
# Physical examination

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>E1</td>
<td>Height</td>
<td>Cm</td>
<td>E1a</td>
</tr>
<tr>
<td>E2</td>
<td>Weight</td>
<td>Kg</td>
<td>E2a</td>
</tr>
<tr>
<td>E3</td>
<td>Head Circumference</td>
<td>Cm</td>
<td>E3a</td>
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<td>E4</td>
<td>BMI</td>
<td></td>
<td>E4a</td>
</tr>
<tr>
<td></td>
<td>If over 30 refer to Doctor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>E5</td>
<td>Abdominal Girth</td>
<td>Cm</td>
<td></td>
</tr>
<tr>
<td>E6</td>
<td>Hip Girth</td>
<td>Cm</td>
<td></td>
</tr>
<tr>
<td>E7</td>
<td>Pulse</td>
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<tr>
<td>E8</td>
<td>Blood Pressure 1</td>
<td></td>
<td>E8a</td>
</tr>
<tr>
<td>E9</td>
<td>Blood Pressure 2</td>
<td></td>
<td>E9a</td>
</tr>
<tr>
<td>E10</td>
<td>Blood Pressure 3</td>
<td></td>
<td>E10a</td>
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</table>
Blood Pressure

Adults - If over 140 systolic or 90 diastolic refer for investigation

In Children if over 95th refer for investigation

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<th>Age</th>
<th>Systolic</th>
<th>Diastolic</th>
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<td>18</td>
<td>140</td>
<td>92</td>
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Action Needed? Yes ☐ No ☐ Don’t Know ☐
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<thead>
<tr>
<th>Acanthosis Nigricans</th>
<th></th>
<th>Infection</th>
</tr>
</thead>
<tbody>
<tr>
<td>E11 Axilla (under arm)</td>
<td>Yes / No</td>
<td>E12 Neck</td>
</tr>
<tr>
<td>E13 Ears</td>
<td>Yes / No</td>
<td>E14 Runny Ears</td>
</tr>
<tr>
<td>E15 Hearing</td>
<td>Good / Poor</td>
<td></td>
</tr>
<tr>
<td>E16 Teeth and Gums</td>
<td>Good / Poor</td>
<td></td>
</tr>
<tr>
<td>E17 Vision</td>
<td>Good / Poor</td>
<td></td>
</tr>
<tr>
<td>E21 Chest</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>E22 Skin</td>
<td>Yes / No</td>
<td></td>
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<tr>
<td>E23 Sexually Transmitted Infection</td>
<td>Yes / No / Declined / Don’t Know</td>
<td></td>
</tr>
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</table>

A1 Action Needed?  Yes □ No □ Don’t Know □

A1a If Yes – What?  __________________________________________

________________________________________

________________________________________
**Investigations**

**Blood Tests**

**i1** Has the person eaten or drunk anything in the last 4 hours?  
Yes [ ]  No [ ]  Don’t Know [ ]

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<thead>
<tr>
<th></th>
<th><strong>Blood Sugar</strong></th>
<th></th>
<th><strong>Cholesterol</strong></th>
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</thead>
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<tr>
<td>12</td>
<td>If Random BSL over 5.5 refer for HBA1C and Investigation</td>
<td>5</td>
<td>If over 5.5 refer for further investigation</td>
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</table>

<table>
<thead>
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<th><strong>Triglyceride</strong></th>
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<tbody>
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<td>13</td>
<td>If under 110 refer for further investigation</td>
<td>6</td>
<td>If over 2 refer for further investigation</td>
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</table>

<table>
<thead>
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<th><strong>HbA1C</strong></th>
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</thead>
<tbody>
<tr>
<td>14</td>
<td>required for anyone who has BSL&gt;6, acanthosis nigricans, history of diabetes or currently treated for diabetes</td>
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If HBA1C over 7 refer for further investigation
<table>
<thead>
<tr>
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<th><strong>ACR</strong></th>
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<tr>
<td></td>
<td></td>
<td>i 17</td>
<td></td>
</tr>
<tr>
<td>I 7</td>
<td>Glucose</td>
<td>i 18</td>
<td>Albumin</td>
</tr>
<tr>
<td>I 8</td>
<td>Bilirubin</td>
<td>i 19</td>
<td>Creatinine</td>
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<td>I 9</td>
<td>Ketones</td>
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<td>I 10</td>
<td>Specific Gravity</td>
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<td>I 11</td>
<td>Blood</td>
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<td>If Positive refer for MSU</td>
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<td>I 12</td>
<td>pH</td>
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<tr>
<td>I 13</td>
<td>Protein</td>
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<td>Nitrites</td>
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<tr>
<td>I 16</td>
<td>Leucocytes</td>
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</tbody>
</table>

**A2 Action Needed?**
- Yes ☐
- No ☐
- Don’t Know ☐
Please do ISTAT if

ACR high

History of kidney disease

Blood in Urine

HbA1C over 7

If BP over 140/90

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<tr>
<th>ISTAT</th>
<th>Value</th>
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<td>I 20</td>
<td>Na (Sodium) i 26 Glucose</td>
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<td>I 21</td>
<td>K (Potassium) i 27 Urea</td>
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<tr>
<td>I 22</td>
<td>Cl (Chloride) i 28 Creatinine</td>
</tr>
<tr>
<td>I 23</td>
<td>TCO₃ i 29 Haematocrit</td>
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<tr>
<td>I 24</td>
<td>Anion Gap i 30 Haemoglobin</td>
</tr>
<tr>
<td>I 25</td>
<td>Ca (Calcium)</td>
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A3 Action Needed? Yes [ ] No [ ] Don't Know [ ]
### Action

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<tr>
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<th>Yes / No</th>
<th>Which Doctor?</th>
<th></th>
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<tr>
<td>A4</td>
<td>GP</td>
<td></td>
<td></td>
<td>A4a</td>
</tr>
<tr>
<td>A5</td>
<td>Specialist</td>
<td></td>
<td></td>
<td>A5a</td>
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<tr>
<td>A6</td>
<td>Other Referral</td>
<td>Yes / No</td>
<td></td>
<td>A6a</td>
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### Investigations requested

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<tr>
<th>Investigation requested</th>
<th>Date of Request</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urine Culture</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>FBC</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>U&amp;E</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>LFT</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Calcium</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>PO₄</td>
<td>Yes / No</td>
<td></td>
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<tr>
<td>Iron Studies</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Vitamin D</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>C3</td>
<td>Yes / No</td>
<td></td>
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<tr>
<td>C4</td>
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<tr>
<td>IgA</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Fasting Blood Sugar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test</td>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>-------------------------------</td>
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<td></td>
</tr>
<tr>
<td>HbA1C</td>
<td>Yes / No</td>
<td></td>
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<tr>
<td>Fasting Insulin,</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>C Peptide</td>
<td>Yes / No</td>
<td></td>
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<tr>
<td>Fasting Cholesterol</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Fasting Lipids</td>
<td>Yes / No</td>
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<tr>
<td>Thyroid Function</td>
<td>Yes / No</td>
<td></td>
</tr>
<tr>
<td>Kidney Ultrasound</td>
<td>Yes / No</td>
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Other investigations

<table>
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<tr>
<th>Investigation requested</th>
<th>Date of Request</th>
<th>Result</th>
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</thead>
<tbody>
<tr>
<td>Insulin Glucose Tolerance Test</td>
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<td>STI tests</td>
<td>Urine</td>
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<tr>
<td>Swab</td>
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For Polycystic Ovarian Disease

<table>
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<tr>
<td>Testosterone</td>
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<td>SHBG</td>
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<td>Free Androgen Index</td>
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<td>Prolactin</td>
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<td>Pelvic Ultrasound</td>
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Anaemia is defined as Hb less than the lower limit of the reference range for age:

<table>
<thead>
<tr>
<th>Age</th>
<th>Lower limit of normal range of Hb (g/l)</th>
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<tr>
<td>2 months</td>
<td>90</td>
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<tr>
<td>2 - 6 months</td>
<td>95</td>
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<td>6 - 24 months</td>
<td>105</td>
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<td>2 - 11 years</td>
<td>115</td>
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<td>&gt; 12 years</td>
<td>girls - 120, boys - 130</td>
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</tbody>
</table>

(Royal Children’s Hospital Melbourne Clinical Practice Guidelines)
Appendix 13

The Western Desert Kidney Health Project –
Sand Animations Booklet
with Sand Animations DVD
and Sparky’s Dad DVD

Appendix 14

Book - Mara Yungu
The Story of the Western Desert Kidney Health Project