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Computerised Aboriginal and Torres Strait Islander health assessments in primary health care research

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Abstract

There has been insufficient research involving Aboriginal and Torres Strait Islander peoples living in urban areas to inform strategies required to improve inequitable health outcomes and life expectancy for Aboriginal and Torres Strait Islander peoples. The injustice of these health inequities motivated me to investigate the use of computerised Aboriginal and Torres Strait Islander health assessments in primary care as a source of research data which can be used to respond to community priorities. I conducted this research at the Inala Indigenous Health Service, a Queensland Government funded primary health care service for Aboriginal and Torres Strait Islander peoples. Inala is a suburb in south-western Brisbane with a strong sense of community and identity, but also significant social and economic challenges. Staff at the Inala Indigenous Health Service have been using Aboriginal and Torres Strait Islander health assessments for both clinical and research purposes since their introduction in 2004 for adults, and 2006 for children.

In this thesis, I used a mixed methods approach. The first two research projects of this thesis are situated in the postpositivist paradigm where researchers accept that scientific research produces evidence which helps establish the probability that a finding is true rather than truth itself. The first research project evaluated the feasibility of implementing computerised health assessments in primary care for dual clinical and research purposes. After finding that it was feasible, the second research project established that computerised health assessment data were sufficiently representative, complete, reliable, and valid to produce credible research findings.

The final two research projects of this thesis are situated in the transformative paradigm with the explicit goal of improving the social world. I acknowledge that my position as a white, non-Indigenous, male, medical researcher influenced the conduct and outcome of all the research projects in this inquiry. To minimise the risk that this research would reproduce the damaging effects of research for Aboriginal and Torres Strait Islander peoples conducted by non-Indigenous researchers, I listened to community voices to inform my approach to research using computerised health assessment information.

I conducted a qualitative study involving thematic analysis of semi-structured interviews with key informants in the Inala Aboriginal and Torres Strait Islander community regarding their priorities for health and research based on health assessment data. Rather than a discrete set of health priorities, key informants articulated an authoritative understanding of how interrelated, inter-generational, social, cultural, and environmental determinants of health operated in a “cycle” to influence the community’s health. Furthermore, some key informants were ambivalent about Aboriginal and Torres Strait Islander health assessments because of their biomedical emphasis. These findings supported the addition of questions to health assessments at the Inala Indigenous Health Service regarding psychosocial stressors, social determinants of health, and community participation. Because of key informants’ emphasis on the social determinants, I conducted an epidemiological investigation of social, cultural, and environmental determinants of health using adult computerised health assessment data. From this investigation, I found that the experience of a range of social, cultural, and environmental determinants of health varied significantly according to the age and sex of participants suggesting opportunities for demographically targeted policy intervention.

Findings from this doctoral research demonstrate that Aboriginal and Torres Strait Islander computerised health assessments can be implemented in the primary health care setting, and used to produce credible research findings which respond to community priorities. Presently, the widespread application of computerised health assessment based research has been limited by commonly used general practice software systems in Australia which include non-customisable health assessments, and are not suited to research. At the Inala Indigenous Health Service, future research based on computerised health assessments will seek to further investigate social, cultural, and environmental determinants of health, and could include longitudinal analysis and data linkage.

The results of key informant interviews and the investigation of social, cultural, and environmental determinants will be fed back to community organisations and health services as a community report. This community report was designed to assist community organisations and health services plan, monitor, advocate, and apply to policy makers for funding for activities, programs, and services to address social, cultural, and environmental determinants of health.

This research also revealed tensions inherent in attempting to reconcile the health priorities of community key informants situated in the social world with a medical researcher, a health service setting, and research tool, the health assessment, all situated within the privileged biomedical model of health. By positioning research in this thesis in the transformative paradigm using a mixed methods approach, I endeavoured to acknowledge and explore these tensions. These research findings encourage a policy discourse which does not emphasise the biomedical model of health, but rather

emphasises the importance of taking the holistic view of health expressed by both the National Aboriginal Health Statement Working Party and Inala Aboriginal and Torres Strait Islander key informants.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Publications during candidature

Peer-reviewed papers

Spurling GK, Bond CJ, Schluter PJ, Kirk CI, Askew DA. "I'm not sure it paints an honest picture of where my health's at." Identifying community health and research priorities based on health assessments within an Aboriginal and Torres Strait Islander community: a qualitative study. *Aust J Prim Health* 2017 Feb 8; doi 10.1071/PY16131.

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Publications included in this thesis

Spurling GK, Askew DA, Schluter PJ, Hayman N. Implementing computerised Aboriginal and Torres Strait Islander health checks in primary care for clinical care and research: a process evaluation. *BMC Med Inform Decis Mak* 2013;13:108.

This publication has been incorporated in Chapter 5 and is included in Appendix 2.

Contributor	Statement of contribution
Spurling G. (Candidate)	Conducted surveys (100%) Analysed data (80%) Wrote the paper (50%)
Askew D.	Analysed data (10%) Wrote the paper (20%)
Schluter P.	Analysed data (10%) Wrote the paper (20%)
Hayman N.	Wrote the paper (10%)

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This publication has been incorporated in Chapter 7 and is included in Appendix 5.

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Spurling G. (Candidate)	Conducted interviews (95%) Analysed data (60%) Wrote the paper (60%)
Bond C.	Analysed data (15%) Wrote the paper (15%)
Schluter P.	Analysed data (5%) Wrote the paper (10%)
Kirk C.	Conducted interviews (5%) Analysed data (5%)
Askew D.	Analysed data (15%) Wrote the paper (15%)

Contributions by others to the thesis

All my PhD advisors, Associate Professor Deborah Askew, Professor Philip Schluter, and Dr Chelsea Bond offered advice regarding the conception and design of this research, and analysis and interpretation of research data.

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Oceanic ancestry group, Aboriginal, Torres Strait Islander, primary health care, health assessment, mixed methods, computerised medical records systems.

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Abbreviations

AATSIHS	Australian Aboriginal and Torres Strait Islander Health Survey
ABCD	Audit and Best practice for Chronic Disease
ADC	Annual Diabetic Cycle of care
AIDA	Australian Indigenous Doctors’ Association
aPHQ-9	Adapted Patient Health Questionnaire 9
AUDIT	Alcohol Use Disorders Identification Test
BMI	Body Mass Index
CB	Chelsea Bond
CCM	Critical Communicative Methodology
CK	Corey Kirk
CI	Confidence Interval
COE	Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care
COREQ	Consolidated Criteria for Reporting Qualitative research
CQI	Continuous Quality Improvement
DALY	Disability Adjusted Life Year
GP	General Practitioner
GS	Geoffrey Spurling
HA	Health Assessment
HbA1c	Glycated Haemoglobin
HREC	Human Research Ethics Committee
ICC	Intraclass Correlation Coefficient

ICJ	Inala Community Jury for Aboriginal and Torres Strait Islander Health Research
IIHS	Inala Indigenous Health Service
IT	Information Technology
IUIH	Institute for Urban Indigenous Health
K10	10 point Kessler psychological distress scale
MAR	Missing At Random
MBS	Medicare Benefits Scheme
NACCHO	National Aboriginal Community Controlled Health Organisation
NAHS	National Aboriginal Health Strategy
NHMRC	National Health and Medical Research Council
NLES	Negative Life Event Scale
MNAR	Missing Not At Random
NTNER	Northern Territory National Emergency Response
OR	Odds Ratio
PAR	Participatory Action Research
PDF	Portable Document Format
RACGP	Royal Australian College of General Practitioners
RCT	Randomised Controlled Trial
RD	Risk Difference
RR	Relative Risk
SCEDH	Social, Cultural, and Environmental Determinants of Health
SEIFA	Socio Economic Indices For Areas

WHO	World Health Organization

Chapter 1 Introduction

Indigenous peoples around the world may be among the most researched peoples on Earth.[1-3] This proposition is usually advanced to highlight the problematic nature of research conducted by Western researchers motivated by imperialist and colonial influences.[1] Thus, it is perhaps surprising that, in Australia, published research data involving Aboriginal and Torres Strait Islander peoples living in urban areas have been found to be inadequate.[4,5] This research insufficiency in urban areas is thought to be in part due to deficiencies in identifying Aboriginal and Torres Strait Islander peoples, inaccuracies in data collection and analysis, and a lack of consistency of data collection across jurisdictions.[6] For example, there are no Aboriginal and Torres Strait Islander identifiers on databases such as the electoral roll or Medicare, the Australian Government funded universal health care system.[7,8] Furthermore, researchers may not see Aboriginal and Torres Strait Islander peoples living in urban areas as authentic compared with Aboriginal and Torres Strait Islander peoples living in rural or remote areas.[9] Yet the majority, an estimated 57%, of Aboriginal and Torres Strait Islander peoples reside in an urban setting.[10]

Eades argued that the number of research papers involving Aboriginal and Torres Strait Islander peoples living in urban areas was insufficient to inform the strategies required to Close the Gap.[4] Closing the Gap is the framework used to describe the Australian Commonwealth Government's ambitious target to close the gap in life expectancy between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians within a generation.[4,11,12] The life expectancy at birth in 2010-2012 for Aboriginal and Torres Strait Islander peoples living in major cities and inner regional areas was 68 years for males and 73 years for females.[12] By way of comparison, in 2010, the life expectancy for all Australians living in major cities and inner regional areas was 81 years.[13] Most of the health gap (60%) between Aboriginal and Torres Strait Islander peoples and non-Indigenous people, measured using disability adjusted life years (DALYs), is carried by Aboriginal and Torres Strait Islander peoples living in major cities and inner regional areas owing to the weight of population numbers in these settings.[14] The DALY measures the health gap between the population of interest against a reference population which in this case is the non-Indigenous Australian population.[14] Closing the Gap requires greater and more efficient government investment in health infrastructure for Aboriginal and Torres Strait Islander peoples, culturally appropriate primary health care, health promotion, and associated human resources.[15,16] More research, especially in urban areas, can help advocate for this investment, and inform new strategies for improving Aboriginal and Torres Strait Islander health.

In an international context, the health gap for Australian Aboriginal and Torres Strait Islander peoples is relatively large. Reduced life expectancy for Indigenous populations compared to their non-Indigenous counterparts occurs in most of the 15 countries around the world where data are available for Indigenous peoples.[17] Aboriginal and Torres Strait Islander peoples live, on average, ten years fewer than their non-Indigenous counterparts; a gap second only to Canada's Inuit people among high income nations.[17] These gaps in life expectancy are often attributed to the legacy of colonisation, ongoing discrimination, and the resulting adverse impact on Indigenous peoples' social determinants of health.[17-19]

I am interested in how research in the primary care setting can help inform strategies which address the injustice of reduced life expectancy and poorer health outcomes for Aboriginal and Torres Strait Islander peoples. Since 2004, I have worked as a general practitioner and researcher at the Inala Indigenous Health Service (IIHS), administered by Queensland Health. However, my position as a white, male, non-Indigenous, medical practitioner and researcher conducting doctoral research in an Aboriginal and Torres Strait Islander community, working for an institution administered by a State with a history of dispossessing land and children from Aboriginal and Torres Strait Islander peoples, is intrinsically problematic. Using the practice of reflexivity, I acknowledge that my values are important to the conduct of this research, from the formulation of the research questions through to the choice of methodology and analysis of findings. Lincoln defines reflexivity as "the process of reflecting critically on the self as a researcher".[20(p115)] My epistemological positioning, or stance on the influence of values on my way of knowing, is consistent with the critical theory and transformative paradigms which I discuss further in Chapter 4, the methodology chapter. Consistent with the critical theory paradigm, I write using first person singular in this thesis where appropriate. The use of passive voice, often used in scientific writing, is consistent with a positivist paradigm where the researcher is assumed to be value neutral.[21] By writing in first person, I remind the reader of my positioning.

When they were introduced, I saw the Aboriginal and Torres Strait Islander health assessment (HA) as a way to collect clinically relevant research data in a manner that was minimally burdensome to participants. In 2010, to improve the utility of HAs for clinical and research purposes, I led the introduction of computerised HAs at the IIHS. In this thesis, I explore how researchers can use data from computerised Aboriginal and Torres Strait Islander HAs in an urban primary health care service. In this chapter, I start by discussing the national policy context regarding Aboriginal and Torres Strait Islander health and the setting for this research. I then discuss research with Aboriginal and Torres Strait Islander peoples and the Yolŋu Ganma metaphor.

1.1 Policy context: Closing the Gap

The current national policy discourse regarding the health of Aboriginal and Torres Strait Islander peoples centres on the "Closing the Gap" framework first proposed in the 2005 Social Justice Report.[18(p213)] This report recommended that the governments of Australia commit to achieving equality of life expectancy and health status between Aboriginal and Torres Strait Islander peoples and non-Indigenous people within a generation.[18] In response to this recommendation, the Australian State and Federal governments agreed to the Closing the Gap framework in 2007, and a statement of intent was signed in 2008. This statement of intent achieved the bipartisan support of the major political parties as well as the peak health bodies concerned with Aboriginal and Torres Strait Islander health.[11]

The Closing the Gap framework involves monitoring and reporting on targets including indicators for housing, employment, education, early childhood health, governance and safe communities.[22] Each year the Australian Prime Minister reports on progress against the goals of the Closing the Gap framework. The 2017 Prime Minister's report on the progress of the Closing the Gap framework indicated underwhelming results.[23] The only target on track to be met for Aboriginal and Torres Strait Islander peoples was Year 12 schooling attainment. Many targets were not on track to be met, including the gap in life expectancy which remained approximately ten years less for Aboriginal and Torres Strait Islander peoples than for non-Indigenous Australians.[23]

Australian Aboriginal and Torres Strait Islander health policy has had some areas of consistency since the Closing the Gap statement of intent was signed in 2008, but also significant changes in strategic direction with the change of Australian Government in 2013. The Australian Government's Department of Health continues to fund a number of policies and programmes which support the primary health care sector's efforts in improving the health of Aboriginal and Torres Strait Islander peoples. These policies include funding for community controlled health services, allowing Aboriginal and Torres Strait Islander health services to bill the Australian Government funded Medicare Benefits

Scheme (MBS) for consultations, funding for HAs for Aboriginal and Torres Strait Islander peoples, and continuous quality improvement (CQI) in primary health care through the Healthy for Life program.[24,25] However, in 2015, the Australian Government consolidated numerous programmes and policies for Aboriginal and Torres Strait Islander health into the Indigenous Advancement Strategy which is designed to support the aims of the Closing the Gap framework or strategy as it is now known.[26]

The Indigenous Advancement Strategy has five main themes: jobs; land and economy; children and schooling, safety and wellbeing; culture and capability and; remote Australia strategies. Biddle argued that there is “no chance” of meeting Closing the Gap strategy targets if the emphasis of government policies remains on remote areas because, as described above, the majority of the burden of disease for Aboriginal and Torres Strait Islander peoples is for those living in non-remote locations.[26] Also increasing the difficulty of meeting the Closing the Gap strategy targets was the decision by the Australian Government to reduce funding to programmes for Aboriginal and Torres Strait Islander health by $534 million over five years in the 2014/15 federal budget.[24,26,27] These reductions were not reinstated in the 2015/16 budget.[24,26]

The budget cuts by the Australian Government for programmes specifically designed for Aboriginal and Torres Strait Islander peoples suggests that policy makers are relying on mainstream services to make up any shortfall.[24] Mainstreaming was a policy articulated by former Prime Minister Howard, in 2005, which meant that programmes for Aboriginal and Torres Strait Islander peoples were to be delivered by the government department responsible for all the policies in a particular area rather than a specific agency or government department for Aboriginal and Torres Strait Islander peoples.[28] Proponents of a mainstreaming policy approach expected Aboriginal peoples living in urban areas in particular to access mainstream services because this would then free up funding for Aboriginal and Torres Strait Islander peoples living in remote areas.[29] However, in 2001, the Commonwealth grants commission had already reported that:

> “It is clear from all available evidence that mainstream services do not meet the needs of Indigenous people to the same extent as they meet the needs of non-Indigenous people”.[30(xv)]

Thus, in addition to insufficient research to inform strategies to Close the Gap, the emphasis on remote communities in the Indigenous Advancement Strategy combined with reduced funding and a reliance on mainstream services represent some of the reasons why the Closing the Gap strategy is failing to meet all its targets.

There are other criticisms of the Closing the Gap strategy. Altman is concerned about how the gap is measured, who decides which indicators should be used to measure the gap, and the potential for this framework to represent a universal top-down approach which does not respect local diversity or culture.[31] Moreover, the Closing the Gap strategy perpetuates a deficit discourse which reduces Aboriginal and Torres Strait Islander peoples to a numerical problem that needs to be monitored and fixed.[32] Using this approach, 'success' is achieved when Aboriginal and Torres Strait Islander peoples' narrowly defined health statistics reach the non-Indigenous "ideal".[32] Pholi et al. argue that individualistic biomedical analysis of disadvantage is inadequate, and a greater emphasis should be placed on community health, social determinants, and the relationship between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians.[32] These critiques need to be considered along with the capacity of Closing the Gap discourse to unify policy makers in a common purpose, so that they can clearly see the health status gaps, and therefore the need to work together to improve the health of Aboriginal and Torres Strait Islander peoples.[11] Furthermore, as a signatory to the United Nations declaration on the rights of Indigenous peoples, the Australian Government has a responsibility to ensure Aboriginal and Torres Strait Islander peoples realise their rights to "the highest attainable standard of physical and mental health"[33 (Article 24, Section 2)]

1.2 Research Context

Concerns about the failings of the Closing the Gap strategy described above reinforce the need for research to inform strategies aiming to improve the health of Aboriginal and Torres Strait Islander peoples. In responding to the call by Eades et al. for more research in urban areas,[4] I report on the context of my doctoral research including: Inala, the urban setting for this research; the IIHS, the primary health care service where this research was conducted; and computerised Aboriginal and Torres Strait Islander HAs, the research tools developed, implemented, and utilised in this research.

1.2.1 Community research context: Inala's origins, socioeconomic status and strengths

The suburb of Inala is located within the traditional lands of the Jagara people in South East Queensland, and approximately 19km southwest of the Brisbane central business district. Before colonisation, Aboriginal people lived in south eastern Australia for approximately 60,000 years.[34] Aboriginal people started to live in greater concentrations in South East Queensland approximately 6,000 years ago as sea levels rose, Moreton Bay formed, and there were more food sources.[35] Jagara people lived in an area that stretched west from what is now known as Moreton Bay between the Brisbane suburbs of Boondall and Wynnum on the coast, through the southern suburbs of Brisbane including Inala and the City of Ipswich. In the west, Jagara country was bordered by Esk to the north and Cunninghams Gap to the south.[36]

The Brisbane area was first colonised by the British in 1824, and, at that time, approximately 5,000 Jagara people lived in the Inala and Richlands area.[37] In 1843, Dr Stephen Simpson, originally from Warwickshire in England, was appointed “Protector of Aborigines” in Woogaroo, an area which would become Inala and surrounding suburbs.[38(p8)] He reported that the local Aboriginal and Torres Strait Islander people often moved through the area, and had created and maintained pathways which later formed the basis of colonial thoroughfares and ultimately paved roads.[38] Following colonisation by British settlers and convicts in Brisbane, the Woogaroo area was initially used by the colonists for sheep farming, dairy farming, and timber-getting.[37,38] In the 1940s and 50s, the dense scrub in the Inala area was cleared for small scale farming by mainly Italian immigrants who grew fruit and vegetables including grapes for wine-making.[37,38]

Following the Second World War, a group of ex-servicemen formed a co-operative in 1946 to buy land in the area and established accommodation for returned soldiers in a satellite town, called Serviceton, close to Brisbane.[38] This plan was only partially realised before the co-operative ran out of funds in 1954, and the area was purchased by the Queensland Commission of Housing.[38]

In 1953, the suburb was renamed Inala as Serviceton was a common name in post-war Australia, and caused confusion with mail delivery.[37] Inala has variously been reported to mean “peaceful place”[37] and “good place to camp”[38] in an unknown Aboriginal language. Around this time, in the 1950s, Aboriginal families often camped by local creeks around Inala.[39] Reflecting the solidarity and community spirit of a satellite town with a number of recently returned servicemen, many amenities opened in Inala in the 1950s and 60s. These amenities included a Returned Services Leagues club, hotels, a number of churches, multiple sporting clubs, a municipal library, primary and secondary schools, and an arts centre.[38] One family alone, the Boss family, was responsible for constructing a cinema, a nationally renowned skating rink, an Olympic-sized swimming pool, and approximately 1,000 government funded houses in Inala.[37]

Through the latter half of the 20th century, Inala's population increased with waves of immigration, and a further 4,000 government funded houses were built up to the 1970s. This concentration of families living in government funded houses was and continues to be associated with intergenerational unemployment and socioeconomic disadvantage. Coinciding with the rise in socioeconomic disadvantage, a number of amenities such as the cinema, pool, and skate rink had closed by the 1990s.[38] Census data from 2011 indicate that the Inala-Richlands area continued to consist of a significant proportion of government funded housing.[40] Further evidence of socioeconomic disadvantage experienced in Inala comes from the 2015 "Dropping of the edge" report. The "Dropping off the edge" report indicated that Inala was the only local government area listed in the most disadvantaged areas of Queensland that was located in an urban location.[41] These reports used a number of social indicators to measure socioeconomic disadvantage including unemployment, incarceration rates, income, and internet access.[41] For Aboriginal and Torres Strait Islander peoples living in Inala and Richlands (an adjoining suburb), 79% lived in rental accommodation including government funded housing. This is a higher level than for the greater Brisbane area where 60% of Aboriginal and Torres Strait Islander peoples lived in rental accommodation (including government funded housing), and also higher than for non-Indigenous people in the Inala and Richlands area (where 51% resided in rental accommodation).[40]

Despite Inala's social disadvantage, Inala has always retained a strong sense of its community identity, and this is no less the case for the Aboriginal and Torres Strait Islander peoples living in Inala.[42] Census data from 2011 show that 6% of the Inala and Richlands population report identifying as being of Aboriginal and/or Torres Strait Islander ethnicity, one of the highest proportions in Brisbane.[40] By way of comparison, in 2011, 3% of the national Australian population identified as being of Aboriginal and/or Torres Strait Islander ethnicity.[10] The relatively large number of Aboriginal and Torres Strait Islander people in Inala can help people feel at home and with their "mob".[42(p405)] As with other urban communities around Australia, the Aboriginal and Torres Strait Islander peoples now living in the Inala area are a heterogeneous and mobile group, and identify their family origins as coming from many different parts of Queensland and New South Wales. Notwithstanding this heterogeneity, coming from Inala allows residents to make the significant identity claim that they are a "real Black fellow".[42(p403)] This identity is reinforced in Inala-specific graffiti tags, songs, language, celebration of the Inala football team, participation in the National Aboriginal and Islander Day Observance Committee week, and the Stylin' Up youth festival which started in Inala in 2001.[38,42]

1.2.2 Primary health care for Aboriginal and Torres Strait Islander peoples in Inala

Aboriginal and Torres Strait Islander peoples living in Inala experienced difficult access to health care for most of Inala's history. After the Serviceton/ Inala suburb was founded in 1946, the train line did not service Inala. Residents were dependent on scant bus services unless they could afford their own car. Therefore, a visit to the doctor could take all day as there were no doctors in Inala.[37] In 1977, the opening of the Inala community health centre greatly improved access to medical care for the community.[37] However, when Dr Noel Hayman, one of Queensland's first Aboriginal medical graduates, came to Inala in 1995 he found that only 12 Aboriginal people attended the Inala community health centre general practice.[43] At that time, the only culturally appropriate primary health care service in Inala for Aboriginal and Torres Strait Islander peoples was a weekly satellite clinic run by the Aboriginal Medical Service in Woolloongabba.[44] At the community health service, Dr Hayman found access barriers to primary care including racist attitudes, and an associated unwillingness to accommodate Aboriginal and Torres Strait Islander peoples' cultural needs.[43] In 1995, he established the IIHS, engaged with the community and ameliorated access barriers. The Queensland Government funded IIHS grew through several stages before becoming the Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care (COE) in 2013.[43,45] With over 3,000 regular patients in 2016, the clinical sector of the COE now operates in a stand-alone building across the road from the Inala Community Health Centre. Regular patients have attended the service at least three times in the preceding two years.

1.2.3 Aboriginal and Torres Strait Islander Health Assessments

The expansion of the IIHS was facilitated by a number of factors including State funding for new infrastructure, the capacity to claim Medicare benefits, and the introduction of Aboriginal and Torres Strait Islander HAs.[43] In 2006, the Federal government allowed clinical staff at the IIHS to claim Medicare payments for Medicare services in general practice including Aboriginal and Torres Strait Islander HAs. With the aim of ensuring early diagnosis and intervention for treatable conditions,[46] the Australian Government introduced HAs for Aboriginal and Torres Strait Islander adults aged 55 years and over in 1999, adults aged 15 to 54 years in 2004, and children aged 0 to 14 years in 2006. The Australian Government funded the addition of these HAs to the MBS such that GPs could claim approximately $200 for each patient when an HA was conducted.[47] As clinicians conducted more HAs, the IIHS generated more revenue, and therefore the IIHS could afford more clinical staff who could then conduct more HAs.[43] This escalation of staff numbers from HA revenue played an important role in facilitating the growth and expansion of the IIHS.[43,45]

In addition to the clinical focus on Aboriginal and Torres Strait Islander HAs, researchers at the IIHS used data from paper-based HA templates to provide evidence supporting the use of child and adult HAs to identify risk and protective factors for chronic disease, detect previously undiagnosed conditions, and provide new opportunities for preventive health care.[48] [49] However, this research involved a laborious, error-prone process of data transfer from hand written paper-based HAs to a computer database. In 2010, the IIHS implemented computerised HAs which is described in Chapter 5. Since 2010, clinical staff at the IIHS directly input patient information into these computerised HAs while conducting patient assessments. Computerised HA data can be extracted into Excel spread sheets (Microsoft Corporation, Redmond, WA, USA) which allows for the rapid creation of a large database of Aboriginal and Torres Strait Islander peoples' health information that can be used for research purposes.

1.3 Research with Aboriginal and Torres Strait Islander peoples

Notwithstanding the benefits for health research of a large database, Nakata expressed concern that the storage of Indigenous knowledge by scientists on electronic networks was like colonial enterprises which "…co-opted land, resources, and labour in the interest of their own prosperity…".[50(p2)] These concerns are relevant to research involving the rapid generation of a large computerised HA database of sensitive health information. Reflecting on Nakata's work, I was concerned that my research involving this database might benefit me and my career more than the community whose health data were contained in this database.

For this doctoral research, I was initially interested in using computerised HA data to explore the oral health problems faced by Aboriginal and Torres Strait Islander patients attending the IIHS. This interest came from my concern about the oral health problems of people attending the IIHS, and the inadequacy of access to dental health services. However, a research interest in Aboriginal and Torres Strait Islander peoples' teeth without sufficient self-reflection or consideration of community priorities is reminiscent of unhelpful research produced by previous white, non-Indigenous doctors and researchers. For example, in 1939, Dr Price published his descriptions of the severe tooth decay experienced by Aboriginal peoples, and attributed the decay to Aboriginal peoples' primitive nature and exposure to the food consumed by modern, non-Indigenous, white people.[51] In Chapter 7, I describe in more detail how Dr Price's characterisation of Aboriginal peoples as primitive is linked with the negative consequences of colonisation.

1.3.1 A brief critique of colonial control via Western research agenda and methodologies

According to Indigenous peoples, Western researchers like Dr Price have consistently misrepresented Aboriginal and Torres Strait Islander peoples' cultural practices, and described these cultural practices in ways that reflected non-Indigenous researchers' values, beliefs, and prejudices.[1,2,52,53] These values, beliefs, and prejudices held by Western researchers have been influenced by imperialism and colonisation.[1,54,55] The result is research conducted by non-Indigenous, Western researchers involving Aboriginal and Torres Strait Islander peoples which has a long history of being damaging, patronising, and offering nothing of value to the researched.[1,53,55] Thus, I wanted to avoid damaging research using HA data, and endeavoured to ensure that research findings were of benefit to the Inala Aboriginal and Torres Strait Islander community.

1.3.2 Avoiding exploitation: ethical research and the Yolŋu Ganma metaphor

For this research, I have been informed by the National Health and Medical Research Council's (NHMRC) guidelines for ethical conduct in Aboriginal and Torres Strait Islander research and the NHMRC's Road Map II which provides a strategic framework for research priorities with Aboriginal and Torres Strait Islander communities.[56,57] Additionally, the knowledge sharing possibilities described by the Yolŋu Ganma metaphor, involving reflexivity and dialogue, offer ways for non-Indigenous researchers to avoid exploitative research findings of minimal or no value to the researched.[58]

Ethical health research conduct with Aboriginal and Torres Strait Islander peoples

The guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research build on,[56] and should be read alongside the National Statement on Ethical Conduct in Research Involving Humans.[59] These guidelines were developed following a review of all relevant literature, consultation with stakeholders including researchers and Aboriginal and Torres Strait Islander peoples, and public consultation. These guidelines emphasise six core values including spirit and integrity, reciprocity, respect, equality, survival and protection, and responsibility.[56] I have sought to incorporate these values in all stages of this research including planning, conduct, and dissemination.

The importance of the Yolŋu Ganma metaphor

Striving for new knowledge consistent with the Yolŋu Ganma metaphor in accordance with the guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research is an important motivating force for this thesis. Ganma is a metaphor from the Yolŋu people who are Aboriginal people from north-eastern Arnhem Land in northern Australia. This metaphor refers to the foam created when the river from the sea (Gumatji clan) meets and mixes with the river from the land (Wangurri clan).[60] The foam, or product of this mixing, represents a new kind of knowledge.[60] Like the two bodies of water, the Western researchers and Aboriginal people can be

> "close, but apart, we share deeply without losing our integrity, just like the Ganma rivers".[61(p380)]

When the rivers are sharing, they maintain their integrity. For the Yolŋu Ganma metaphor to work in research, there has to be trust, a sense of community, sufficient time, a willingness to be reflexive, a willingness to share knowledge, and a willingness to translate new knowledge into action.[61] For this research, the two ways of knowing are represented by me as a Western, non-Indigenous researcher and Inala Aboriginal and Torres Strait Islander community members.

In Western thought, a dialogue between two parties aimed at emancipatory outcomes is consistent with Habermas' theory of communicative action which I describe in more detail in Chapter 4.[62] I have sought to operationalise the Yolŋu Ganma metaphor and Habermas' theory of communicative action using critical communicative methodology (CCM) which I also describe in more detail in Chapter 4.

1.4 Thesis aim and scope

1.4.1 Aim

The aim of this thesis was to produce research information within an urban Aboriginal and Torres Strait Islander community using data from Aboriginal and Torres Strait Islander HAs which reflects community priorities, and helps community members, policy makers, and health services pursue appropriate strategies to resolve community health concerns. The overarching research question for this thesis is, "What is the validity and applicability of computerised Aboriginal and Torres Strait Islander HAs to health research in urban Aboriginal and Torres Strait Islander primary health care?" The research questions, including specific research questions are described in more detail in Chapter 3.

1.4.2 Scope

The research contained within this thesis has been conducted in one urban Aboriginal and Torres Strait Islander community and within one primary health care service. While I discuss some of the controversy in the literature in Chapter 2 regarding the clinical benefit of HAs, this research does not investigate the clinical effects of HAs. Other issues that are beyond the scope of this research are the community attitudes to research, the design and implementation of a reference criterion for evaluating computerised HA data, and a full policy analysis of the Closing the Gap strategy.

1.5 Terminology

Reflecting the cultural diversity and preference of descendants of the original inhabitants of the continent and surrounding islands now called Australia, I have used the terminology "Aboriginal and Torres Strait Islander peoples" consistent with NHMRC guidelines.[56] I used "Indigenous" only to refer collectively to peoples around the world who were the original inhabitants of their lands. I use the term "non-Indigenous" to refer to people who do not identify as either Aboriginal or Torres Strait Islander.

In this thesis, I refer to Aboriginal, Aboriginal and Torres Strait Islander, and Torres Strait Islander peoples as distinct ethnic groups rather than racial groups. Like Bhopal, I define ethnicity as,

> "a multi-faceted quality that refers to the group to which people belong, and/or are perceived to belong, as a result of certain shared characteristics, including geographical and ancestral origins, but particularly cultural traditions and languages".[63(p441)]

Unlike ethnicity, the concept of race was founded in an unjustified biological hierarchy whereby some groups defined by their physical characteristics were perceived to be superior to others.[63] [64] However, the genetic differences between different races, defined by Pearce et al. as groups of people from different continents, are small, and these small differences do not account for important differences in health outcomes.[65] Nonetheless, the consequences of racial thinking persist, and are evident in ongoing racialised inequities of health outcomes for Aboriginal and Torres Strait Islander peoples.[66]

According to the National Aboriginal Community Controlled Health Organisation (NACCHO), recognition of Aboriginality requires three components; a person needs to prove their parent is of Aboriginal or Torres Strait Islander descent; a person identifies as an Aboriginal or Torres Strait Islander and; the community accepts the individual is Aboriginal or Torres Strait Islander.[67] For this thesis, I have used the same criteria for defining ethnicity as the IIHS where Aboriginality is recognised if the individual self-identifies as Aboriginal, Torres Strait Islander or both.

I use the term Aboriginal and Torres Strait Islander HA in this thesis because this is how this Medicare service is described in the MBS.[68] The Aboriginal and Torres Strait Islander HA has previously been referred to as an Indigenous health check.[48] Internationally, the most recent systematic review referred to the HA as a health check.[69] Other terms used for the HA include: periodic health examination, health evaluation, periodic screening, annual physical examination, multiphasic check-up, preventive screening or primary care screening.[69]

The health service where this research is set, and computerised HAs are conducted was known as the IIHS until 2013, when it was officially renamed the Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care or COE. This research was conducted between 2011 and 2017. However, after 2013, the COE was still widely known and referred to as the IIHS. I have chosen to retain IIHS for consistency, and to avoid confusion.

Computerised HAs were constructed using the variable “sex” to denote the biological differences between men and women, so I use the term “sex” to refer to this biological definition. However, elsewhere, I use the term “gender” which refers “to the socially constructed characteristics of women and men”.[70]

Where I use the phrase social, cultural, and environmental determinants of health (SCEDH) in this thesis, I acknowledge that the social, cultural, and environmental conditions in which people live represent health for Aboriginal and Torres Strait Islander peoples, and they are not only considered determinants of health.

I use the term policy makers in this thesis to refer to representatives of Commonwealth, State, and Territory Governments of Australia who make decisions about resource allocation that affects Aboriginal and Torres Strait Islander peoples.

1.6 Overview of the thesis

This thesis contains nine further chapters. In Chapter 2, I briefly describe health research and Aboriginal and Torres Strait Islander peoples including my role as a non-Indigenous researcher and the sparsity of health research involving Aboriginal and Torres Strait Islander peoples in urban areas. I also describe the development of Aboriginal and Torres Strait Islander HAs, the evidence for their clinical benefit, and their roles in the health system. Next, I describe gaps in the research literature relevant to Aboriginal and Torres Strait Islander HA research which inform the thesis research questions described in Chapter 3.

In Chapter 4, I describe the methodology used to investigate these research questions. In this chapter, I describe my positioning, and how it informs my mixed methods approach.

In Chapter 5, I found that it was feasible to implement computerised HAs in Aboriginal and Torres Strait Islander primary care. In Chapter 6, I found that computerised HA data were of sufficient quality to be useful for research purposes.

In Chapter 7, I describe the findings of key informant interviews with Inala Aboriginal and Torres Strait Islander community members regarding their health priorities. These health priorities informed future research directions using computerised HA data. Some key informants were uncertain about the benefits of Aboriginal and Torres Strait Islander HAs, and were concerned about how a cycle of interlinked SCEDH was important to the health of their community.

In Chapter 8, I describe the results of an epidemiological investigation of the SCEDH measured using computerised HA data by demographic variables age, sex, and ethnicity. Computerised HAs provided information on the experience of a range of SCEDH which varied significantly according to age and sex. The results of this epidemiological investigation will be distributed to community organisations along with the findings of Chapter 7 as a community report attached in Appendix 1.

In Chapter 9, I discuss the important findings of the thesis. Computerised HAs can produce credible research findings which are relevant to community health priorities. This doctoral research also revealed tensions between a researcher, research tool, and health system emphasising the biomedical model of health, and community priorities emphasising SCEDH. These findings inform the implications and conclusions described in Chapter 10 for community members, clinicians, researchers, and policy makers.

Chapter 2 Literature review

2.1 Introduction

In the introductory chapter, I briefly described the Closing the Gap policy framework, and highlighted the lack of research being conducted regarding the health of Aboriginal and Torres Strait Islander peoples living in urban areas. I also introduced the research setting (IIHS) and the place of HAs in Aboriginal and Torres Strait Islander primary health care. In this chapter, I discuss and critique the research literature informing the research conducted for this thesis. This research literature review includes; a brief history of research conducted with Aboriginal and Torres Strait Islander peoples; theories relevant to the conduct of research with Aboriginal and Torres Strait Islander peoples; tensions regarding the use of HAs in primary care; the use of HAs for research purposes; and proposed future directions pertinent to Aboriginal and Torres Strait Islander health research.

2.2 Health research and Aboriginal and Torres Strait Islander peoples

For millennia, Aboriginal and Torres Strait Islander peoples observed the natural world in a way that many Western scientists would recognise as research. These observations informed Aboriginal and Torres Strait Islander peoples' bush calendars, horticulture, the timing of ceremonies, knowledge of astronomy, and hunting practices.[71,72] Similarly, over millennia, Aboriginal and Torres Strait Islander peoples developed their own medical and health systems which include bush medicine, traditional healers, and an emphasis on the role of social and spiritual dysfunction causing illness.[73,74]

Following the colonisation of Australia by the British in 1788, the first Australian medical journals began to appear in the late 1840s.[75] However, the first mention of Aboriginal people in an Australian medical journal did not occur until 1870.[75] This debut was motivated by the surprise of a non-Indigenous doctor in New South Wales who reported that an Aboriginal man's spear wound had healed after being treated by Aboriginal people using a poultice of gum leaves and shoots.[75] Around the turn of the twentieth century, published medical papers reported that Aboriginal peoples were a doomed inferior race who were vulnerable to introduced colonial elements of civilisation including infections like syphilis, smallpox, and donovanosis.[75] The exclusively non-Indigenous authors of these portrayals wrote with a sense of superiority as if assured there would be no Aboriginal and Torres Strait Islander readers.[75]

Through the latter half of the twentieth century, research involving Aboriginal and Torres Strait Islander peoples by non-Indigenous researchers increased significantly. This research effort included anthropologists as well as medical researchers. From the late 19th century until the early 20th century, anthropologists, influenced by biological and evolutionary conceptions of race, often described Aboriginal peoples as an inferior race divided into two groups; the authentic, traditional, whole-blooded Aboriginal person and the non-traditional, half-caste person of Aboriginal descent.[76] From the mid-twentieth century, as the biological basis of race was discredited, anthropologists turned their attention to describing the social and cultural practices of Aboriginal and Torres Strait Islander peoples.[76] Australian medical researchers and practitioners saw their role as preventing the spread of diseases from Aboriginal peoples to European populations, and naming and knowing Aboriginal bodies and diseases in the name of science before they died out.[77] Only 113 health articles regarding Aboriginal and Torres Strait Islander peoples had been published in the Medical Journal of Australia (regarded, by many, as Australia's premier medical journal) prior to 1950, but the number of these health articles rose each decade after 1950 to over 250 published between 1990 and 1999.[77] This increase in research, often of little apparent value to the researched, supported assertions that Indigenous peoples were the most researched peoples on Earth.[1-3] In 2001, Brough argued that research, specifically epidemiological research, may serve to construct unhelpful popular imaginings of Aboriginal and Torres Strait Islander peoples.[78] For example, statistical portraits of deficit may reinforce negative perceptions of Aboriginal and Torres Strait Islander peoples in the community. To maximise value to the researched and minimise harm, Brough argued that an ongoing critical, reflexive examination of research involving Aboriginal and Torres Strait Islander peoples is essential.[78]

2.3 Decolonising research with Aboriginal and Torres Strait Islander peoples

Critiques of research involving Aboriginal and Torres Strait Islander peoples and communities have a long history. Humphrey describes a sense of Indigenous activism emerging in the 1970s with calls for research to involve and be controlled by Aboriginal and Torres Strait Islander peoples.[55] Control of research agendas and activities by Aboriginal and Torres Strait Islander peoples makes it more likely that the researched rather than the researcher is the primary beneficiary of research inquiry.[55] Bainbridge et al. argued that researchers need to listen to Aboriginal and Torres Strait Islander peoples' voices to hear how this health benefit from research should be defined.[79]

The need for research to have a clear and positive impact on health is a key principle of the Lowitja Institute.[80] Established in 2010, the Lowitja Institute is Australia's national institute of Aboriginal and Torres Strait Islander health research. In 2011, The Lowitja Institute published a practical guide for researchers involved in Aboriginal and Torres Strait Islander health research.[58] This practical guide includes the advice of Aboriginal and Torres Strait Islander scholars who discuss decolonising methodologies such as the Indigenist Research Framework and the knowledge sharing potential of the Yolŋu Ganma metaphor described in Chapter 1.[58]

As a non-Indigenous researcher coming from a Western knowledge system aiming to conduct research with an Aboriginal and Torres Strait Islander community, I need to be cognisant of decolonising methodologies, and what Nakata calls "the Cultural Interface" where contested knowledge systems meet in a collaborative research setting.[50] Next, I define and discuss decolonising methodologies including the Indigenist Research Framework, the role of non-Indigenous researchers in collaborative research, and the Cultural Interface.

2.3.1 Decolonising methodologies

In response to the concerns about exploitative research offering little to Indigenous peoples described in Chapter 1, Rigney proposed the Indigenist Research Framework. This framework is an example of a decolonising methodology which challenges the dominant Western ways of knowing, and emphasises the role of Indigenous peoples in research.[58] Research conducted within the Indigenous Research Framework is emancipatory for Aboriginal and Torres Strait Islander peoples, led by Aboriginal and Torres Strait Islander researchers, and resists oppressive forces.[53] Martin expanded on the Indigenous Research Framework by emphasising recognition of Aboriginal and Torres Strait Islander worldviews, honouring social mores, and the importance of social, historical, and political contexts.[81]

Advocates of the Indigenist Research Framework emphasise the importance of involving Aboriginal and Torres Strait Islander researchers in health research, and developing research processes which privilege Aboriginal and Torres Strait Islander voices in order to overcome exploitation, suspicion, misunderstanding, and prejudice.[2,53,57,81-84] Christie cites a number of examples showing how research consistent with this framework achieved better understandings from research findings owing to the involvement of Aboriginal people.[85] For example, the reasons some Yolŋu people sleep rough in Darwin, away from their traditional lands, were only properly understood when Yolŋu researchers were involved in the research interviews and analysis. By conducting interviews in Yolŋu language, the Yolŋu interviewers discovered that the Yolŋu people slept rough in Darwin because they felt they could live more authentic lives in Darwin compared with the "poisonous, sorcery-ridden life on the 'mission' at their remote community".[85(p83)] Overall, the Indigenist Research Framework emphasises the importance of Aboriginal and Torres Strait Islander ways of knowing, and challenges Western research paradigms consistent with other decolonising methodologies.

Internationally, Indigenous academics have advocated similar decolonising methodologies in Canada,[86] the United States[87], and New Zealand where Smith describes kaupapa Māori research.[1] Both the Indigenist Research Framework and kaupapa Māori research share the fundamental principle that Indigenous voices should be privileged in Indigenist research.[53] Kaupapa Māori research is about providing a culturally safe way of conducting research by Māori which produces knowledge that is important to Māori communities.[1,88]

2.3.2 The role of non-Indigenous researchers in Aboriginal and Torres Strait Islander health research

The role of non-Indigenous researchers in research involving Aboriginal and Torres Strait Islander peoples, and their relationship with Aboriginal and Torres Strait Islander researchers is complex and contested.[85] Much of this difficulty is due to the ongoing impact of colonisation. Rigney argued that with colonisation, Indigenous knowledge systems were

> "replaced with non-Indigenous Australian systems on the assumption that the 'race' of Indigenous people were sub-human".[89(p4)]

This oppressive and systematic devaluing of Aboriginal and Torres Strait Islander knowledge systems influences both non-Indigenous and Aboriginal and Torres Strait Islander researchers regarding the types of research questions asked, the methodologies used, and the nature of relationships between researcher and researched.[89]

Rigney acknowledges that there is a role for non-Indigenous researchers where their research supports genuine Indigenous self-determination.[53] Self-determination involves the definition and control of research by Aboriginal and Torres Strait Islander communities.[53] To support Indigenous self-determination, non-Indigenous researchers should acknowledge power imbalances, develop self-reflective, culturally safe research practices that adhere to ethical guidelines, are in the community's best interests, and work with the differences in Western and Indigenous ways of knowing.[3]

The way non-Indigenous researchers interact with Aboriginal and Torres Strait Islander communities occurs along a continuum.[8,85] At one end of the continuum, the non-Indigenous researcher cedes all control of the research project to community members and only works to serve the community's interests.[8] Closer to that end of the continuum would be a participatory action research (PAR) approach where research is initiated, driven and implemented by Aboriginal communities consistent with an Indigenous Research Framework.[90] At the other end of the continuum, Pyett uses the example of a double-blind, placebo controlled randomised controlled trial (RCT) where participants are actively excluded from knowledge production through research techniques such as blinding and randomisation.[8] However, research methods are less important than the degree of control the community has over the research process. For example, RCTs can be conducted within a participatory action framework to produce useful findings for community.[90] Between the ends of the continuum exists "collaborative research" where an equal partnership between researcher and community is the objective.[8(p333)]

There are tensions for all research collaborations between non-Indigenous researchers and Aboriginal and Torres Strait Islander research participants. A power imbalance often exists where the researcher has more time, skills, and expertise to conduct and analyse the research.[8] This imbalance potentially confers more control and power to the researcher regarding the research agenda, publication, interpretation, and dissemination of findings.[8] Another concern is that the non-Indigenous researcher may not know who the most appropriate community representatives are with whom they should be collaborating.[8] These tensions threaten to disrupt the equality of partnerships between researchers and Aboriginal and Torres Strait Islander peoples participating in collaborative research.

2.3.3 Cultural Interface

Tensions in collaborative research, between non-Indigenous researchers and Aboriginal and Torres Strait Islander communities, occur at what Nakata calls "the Cultural Interface".[50(p5)] Nakata, like Rigney, accepts the value of integrating two forms of knowledge, such as the traditional and Western ways of thinking, which interact at the

Cultural Interface to produce new knowledge that can improve the social world for Aboriginal and Torres Strait Islander peoples. The Cultural Interface is a place that accepts the interaction of different knowledges and discourses which inevitably produce tensions and uncertain outcomes. By acknowledging the Cultural Interface, researchers and communities accept that knowledge systems including research are culturally embedded, dynamic, respond to changing circumstances, and are constantly evolving.[50] Researchers who ignore the Cultural Interface risk producing “terra nullius research”; research done without permission, consultation, or involvement of Aboriginal people.[83(p203)]

One example of research conducted at the Cultural Interface was a qualitative evaluation of sporting projects with Australian Aboriginal communities initiated by non-Indigenous researchers.[91] The non-Indigenous researchers describe in detail how they grappled with their Western ways of knowing, Aboriginal ways of knowing, reflexivity, and how working at the Cultural Interface influenced their research conduct and findings.[92] The non-Indigenous authors noted that embracing reflexivity was crucial to properly listening to Aboriginal community members, gaining mutual respect, and producing their research findings.[92] Their research found that while there were both positive and negative effects of sports programs in Aboriginal communities, there was sufficient evidence of benefit to recommend sport as a development tool.[91] This research finding would have been more credible if Aboriginal people were involved not only as participants, but also as researchers controlling the research agenda, direction, and were in a position to interpret the research findings.

2.4 Research with Aboriginal and Torres Strait Islander peoples living in urban areas.

While historically research with Aboriginal and Torres Strait Islander peoples in Australia has been problematic, I have described how non-Indigenous researchers can work with Aboriginal and Torres Strait Islander peoples provided non-Indigenous researchers effectively address the tensions inherent in working at the Cultural Interface in collaborative research projects.

<u>2.4.1 Sparse research in urban populations</u>

The need for further health research involving Aboriginal and Torres Strait Islander peoples living in urban areas is clear. The NHMRC identifies improving the health of Aboriginal and Torres Strait Islanders peoples as a major issue regardless of location, and, owing to demographic distribution, most of the gap in life expectancy (60%) is attributable to Aboriginal and Torres Strait Islander peoples living in non-remote locations, like Inala.[14,93] As described briefly in Chapter 1, a brief review of research in urban Aboriginal and Torres Strait Islander populations found insufficient data to support and discover effective strategies to improve the health of Aboriginal and Torres Strait Islander peoples.[4] An analysis of Aboriginal and Torres Strait Islander child health research from 1958 to 2005 found that only 10.6% of research papers involved studies conducted in metropolitan locations.[5] Additionally, in 1992, Lake et al. found that only a small proportion (3%) of research published over a ten year period in the Aboriginal Health Information Bulletin involved Aboriginal peoples living in capital cities.[94]

Community perceptions that Aboriginal and Torres Strait Islander peoples are not real or authentic Aboriginal and Torres Strait Islander people may explain the paucity of research in urban areas. Brough describes the historical development of notions of non-Indigenous imaginings of Aboriginal identity based on an urban/ remote dichotomy.[78] Within this dichotomy, urban Aboriginal people are seen as modern, part-Aboriginal, and non-authentic while remote Aboriginal peoples are seen as traditional, full blooded, and authentic.[78] These imaginings of Aboriginal people have meant that the realities and health needs of Aboriginal and Torres Strait Islander peoples living in urban areas have been neglected.[78]

The basis of the call by Eades et al. for more research in urban areas was the result of a search of Medline over a five year period, between 2004 and 2009, looking for articles reporting primary research data about Aboriginal and Torres Strait Islander peoples living in urban areas.[4] The Medline search (2004-2009) by Eades et al. found that out of the 555 articles reporting data on the health of Aboriginal and Torres Strait Islander peoples, only 47 (9%) focussed exclusively on the health of people living in urban areas.[4]

This self-described brief review has some similarities with the emerging and poorly defined rapid review methodology in which systematic reviews are expedited to respond to healthcare demands for the most recent evidence to inform decision making.[95] Rapid reviews differ from systematic reviews in that they may limit the databases searched, the timeframe for searching, grey literature searching, research setting, quality appraisal of included studies, and the languages accepted.[95] While expedient, these limitations represent shortcomings for rapid reviews which can limit the authority of their findings.

In addition to concerns with rapid review methodology, the brief review by Eades et al. did not describe the search terms they employed in an area where search term selection is a recognised difficulty.[96] Consistent with rapid review methodology, Eades et al. limited their database searching to Medline, but they could also have searched other databases including the Australian Indigenous HealthInfoNet.[97] Furthermore, the review states that it aimed to increase understandings about the contribution research publications have made to policy for Aboriginal and Torres Strait Islander peoples living in urban areas, but there was no clearly articulated research question.[4]

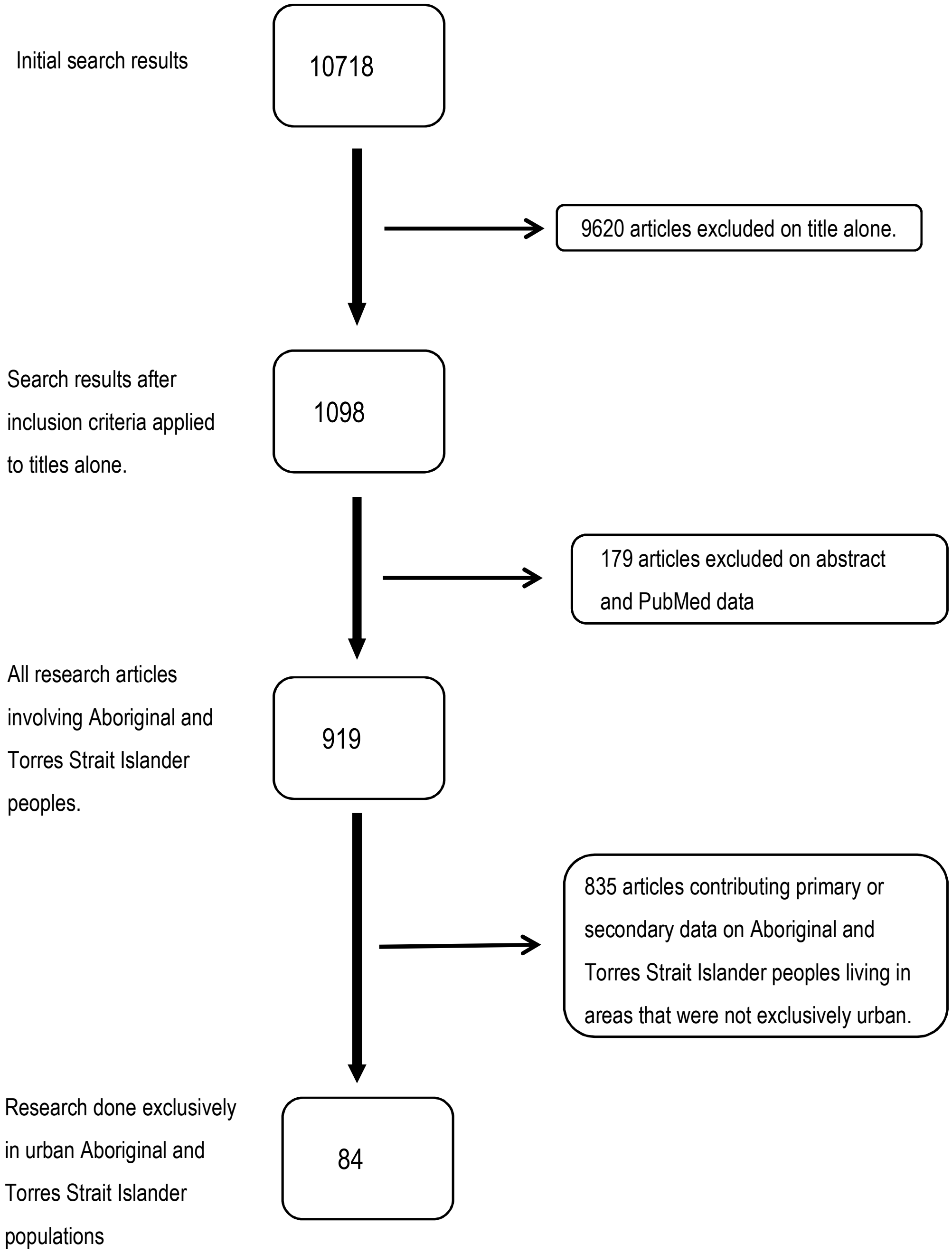
Despite these limitations, a brief or rapid review involving one relevant database over a recent five year period provides useful information on the quantity of research produced in a given setting which was the aim of the review by Eades et al.[4] Moreover, one evaluation of four rapid reviews found that their findings, while not as extensive, did not differ greatly from four completed systematic reviews on the same topics.[98]

2.4.2 A rapid review of urban Aboriginal and Torres Strait Islander health literature (March 2011- February 2016)

The findings of the Eades review are now more than five years old. I attempted to replicate their brief review with the primary aim of confirming the relevance of urgent calls to increase research in urban areas. My secondary aim for this search was to provide a systematic base for my evaluation of the recent literature on Aboriginal and Torres Strait Islander health. My research question was, “What proportion of all research articles contributing primary or secondary health research data involving Aboriginal and Torres Strait Islander peoples have concentrated exclusively on urban areas?” I chose to concentrate on research articles set in an exclusively urban location because computerised HA research described in this thesis is exclusively conducted in urban primary care, and to compare with the corresponding proportion (9%) reported by Eades et al.[4]

Given this research question, I searched PubMed in February 2016 over the most recent five year period (March 2011-February 2016) using the search terms, "’Oceanic Ancestry Group’[Mesh] OR Indigenous OR Aboriginal OR Torres Strait Islander”. This broad search strategy, designed to be inclusive, yielded 10,718 references. My initial inclusion criteria for screening search results were studies providing primary or secondary data (qualitative or quantitative) on exclusively Australian Aboriginal and Torres Strait Islander peoples. Most articles in this very large initial search result were easily excluded on title alone as they were clearly not focussed on Aboriginal and Torres Strait Islander peoples, were conducted overseas, or did not include original primary or secondary research data. From the 10,718 references, I selected 1,098 articles for closer evaluation. After examining the abstracts and PubMed data of these 1,098 articles, I excluded a further 179 articles leaving 919 articles in total. The process of article selection from the initial search results is illustrated in Figure 2.1. These 919 articles represent all the research articles indexed on PubMed in the years March 2011-February 2016 contributing primary and secondary data on Aboriginal and Torres Strait Islander peoples in Australia. Thus, 919 was my denominator.

Figure 2.1 Flow diagram for inclusion of research articles in a rapid review which contributed data on health that were exclusively about Aboriginal and Torres Strait Islander peoples living in urban areas.



There were many research articles which included undifferentiated urban and non-urban Aboriginal and Torres Strait Islander populations conducted at the state or national level. These studies were not included. Of the 919 articles, 84 research articles (9%) contributed data exclusively on the health of Aboriginal and Torres Strait Islander peoples living in urban areas, and are listed in Table 2.1.

Table 2.1 Research articles contributing primary data exclusively on Aboriginal and Torres Strait Islander peoples living in urban areas from PubMed search, 2011-2016. (N=84)

Research identifier	Research paper study design	Research conducted at health service
Whish-Wilson et al. 2016[99]	Cross-sectional design	No
Arrow 2016[100]	Cross-sectional design	No
Pires et al. 2015[101]	Cross-sectional design	Yes[a]
Gardner et al. 2015[102]	Cross-sectional design	No
Lalla et al. 2015[103]	Cross-sectional design	Yes
Radford et al. 2015[104]	Cross-sectional design	Yes
Hopkins et al. 2015[105]	Cross-sectional design	No
Arjunan et al. 2015[106]	Cross-sectional design	No
Katzenellenbogen et al. 2015[107]	Cross-sectional design	No
Pearce et al. 2015[108]	Cross-sectional design	No
Spurling et al. 2014[109]	Cross-sectional design	Yes[a]
Scott et al. 2014[110]	Cross-sectional design	No
Timms et al. 2014[111]	Cross-sectional design	No
Chung et al. 2014[112]	Cross-sectional design	Yes
Askew et al. 2013[113]	Cross-sectional design	Yes[a]
Lopez et al. 2014[114]	Cross-sectional design	No
O'Connor et al. 2014[115]	Cross-sectional design	No
Liddle et al. 2014[116]	Cross-sectional design	Yes[a]
Roberts-Thomson et al. 2014[117]	Cross-sectional design	No
Miller et al. 2014[118]	Cross-sectional design	No
Reeve et al. 2014[119]	Cross-sectional design	No
Amarasena et al. 2014[120]	Cross-sectional design	No
Maher et al. 2014[121]	Cross-sectional design	Yes[a]
Spurling et al. 2013[122]	Cross-sectional design	Yes[a]
Comino et al. 2012[123]	Cross-sectional design	No
Paradies et al. 2012[124]	Cross-sectional design	No
Paradies et al. 2012[125]	Cross-sectional design	No
Wong et al. 2011[126]	Cross-sectional design	Yes
Coleman et al. 2011[49]	Cross-sectional design	Yes[a]
Priest et al. 2011[127]	Cross-sectional design	Yes
Maple-Brown et al. 2011[128]	Cross-sectional design	No
Durey et al. 2016[129]	Qualitative	No
Waterworth et al. 2016[130]	Qualitative	No
Hepworth et al. 2015[131]	Qualitative	Yes[a]
Bond et al. 2015[132]	Qualitative	Yes[a]
Tsourtos et al. 2015[133]	Qualitative	No
Brown et al. 2015[134]	Qualitative	No
Armstrong et al. 2015[135]	Qualitative	No
Kerpan et al. 2015[136]	Qualitative	No
Jobling et al. 2015[137]	Qualitative	No
Canuto et al. 2014[138]	Qualitative	No
Baba et al. 2014[139]	Qualitative	Yes
Jennings et al. 2014[140]	Qualitative	Yes
Lee et al. 2014[141]	Qualitative	Yes
Deshmukh et al. 2014[142]	Qualitative	Yes
Thorpe et al. 2014[143]	Qualitative	No
Waterworth et al. 2016[130]	Qualitative	No
DiGiacomo et al. 2013[144]	Qualitative	Yes
Gould et al. 2013[145]	Qualitative	No
Lee et al. 2013[141]	Qualitative	Yes

Table 2.1 Research articles contributing primary data exclusively on Aboriginal and Torres Strait Islander peoples living in urban areas from PubMed search, 2011-2016. (N=84)

Research identifier	Research paper study design	Research conducted at health service
Foley et al. 2013[146]	Qualitative	Yes[a]
Catts et al. 2013[147]	Qualitative	No
Browne-Yung et al. 2013[148]	Qualitative	No
Cusack et al. 2013[149]	Qualitative	No
Adams et al. 2012[150]	Qualitative	Yes
Bainbridge 2011[151]	Qualitative	No
Ramjan et al. 2015[152]	Mixed methods	No
McKenna et al. 2015[153]	Mixed methods	Yes
Gould et al. 2015[154]	Mixed methods	No
Jersky et al. 2015[155]	Mixed methods	No
Dennis et al. 2015[156]	Mixed methods	No
Govil et al. 2014[157]	Mixed methods	Yes
Thomas et al. 2013[158]	Mixed methods	No
Canuto et al. 2013[159]	Mixed methods	No
Homer et al. 2012[160]	Mixed methods	No
Larkins et al. 2011[161]	Mixed methods	No
Harris et al. 2014[162]	Cohort study	No
McDonald et al. 2014[163]	Cohort study	No
Jamieson et al. 2013[164]	Cohort study	No
Knight et al. 2013[165]	Cohort study	No
Webster et al. 2013[166]	Cohort study	No
Davis et al. 2012[167]	Cohort study	No
Robinson et al. 2012[168]	Cohort study	No
McDonald et al. 2012[163]	Cohort study	No
Craig et al. 2011[169]	Cohort study	No
Dutton et al. 2015[170]	Before-after	Yes
Daws et al. 2014[171]	Before-after	No
Malseed et al. 2014[172]	Before-after	Yes
Conigrave et al. 2012[173]	Before-after	No
Dorrington et al. 2015[174]	Quality improvement	Yes
Ballestas et al. 2014[175]	Health services evaluation	Yes
Canuto et al. 2012[176]	Randomised controlled trial	No
Widdup et al. 2012[177]	Case-control	No

[a]Research conducted at the Inala Indigenous Health Service

This rapid review is not an authoritative systematic review, and suffers from the previously described limitations of rapid reviews. Moreover, single author data extraction is likely to result in more errors than if a second author had also independently conducted the data extraction.[178] Notwithstanding these limitations, this rapid review replicates as closely as possible the Eades et al. review, but for a more recent five year period March 2011-February 2016. Additionally, a defined research question and search strategy were stated here.

The absolute number of research papers has increased from 47 in 2004-2009[4] to 84 in this rapid review (a 44% increase). However, the proportion of research papers (9% - as described above) contributing data regarding the health of Aboriginal and Torres Strait Islander peoples living in urban areas has not changed between periods. It is important to contextualise the absolute increase in research papers given the number of all Australian health and medical research publications has also been increasing.[179] A PubMed search for "Australia NOT comment NOT letter" for the five year periods 2005-2009 and 2011-2015 shows a 47% increase in publications from 76,415 to 145,230. This overall increase (47%) in Australian health research publications is similar to the increase in research papers found in the rapid review described above (44%).The brief review by Eades et al. and the rapid review I present here only comment on the quantity of research papers and do not assess the quality of the research papers published.

Further analysis of these 84 research papers showed that the most common site for research participant recruitment were health services specifically serving Aboriginal and Torres Strait Islander peoples which comprised 29 (35%) research papers including 10 (12%) from the IIHS. The majority of the 84 research papers I identified were descriptive with 32 using cross-sectional design (38%), 25 qualitative papers (30%), and 10 (12%) papers using mixed methods (Table 2.1).

I found higher proportions of mixed methods or qualitative research articles (42%) in this set of 84 research articles than did Priest et al (7%) in 2005 who were only looking for papers involving Aboriginal and Torres Strait Islander children.[5] The higher proportion of mixed methods and qualitative research papers which I found between 2011 and 2016 may indicate that qualitative and mixed methods research is less likely to be conducted with children, is more likely to be conducted in urban areas or has become a more commonly used research method since 2005. Nevertheless, the 25 qualitative and 11 mixed methods research articles found in my search set still represents a minority compared to those articles using only quantitative methods. Priest et al. were concerned that low numbers of mixed methods research articles may indicate a lack of involvement by Aboriginal and Torres Strait Islander peoples in the research process.[5] Priest et al. did not present evidence that mixed methods was associated with research more relevant to Aboriginal and Torres Strait Islander peoples, but, as described later, the Lowitja institute also recommend mixed methods and qualitative research with the aim of privileging Aboriginal and Torres Strait Islander voices.[82]

As well as cross-sectional, qualitative, and mixed methods papers, the rapid review found one each of a quality improvement paper, health service evaluation, case-control paper, and RCT. The remaining studies included four before-after designs and nine utilising birth cohorts (Table 2.1). Out of these 84 research papers, 41 research papers provided observational data on a wide variety of health areas with varying sample sizes, and the majority of these observational studies did not include a non-Indigenous comparator (71%) (Table 2.2).

Of the 84 research papers, 69 (82%) involved large participant burden. Large participant burden is defined here as studies where participants are asked to respond to surveys or interviews where the primary purpose is research. These search results support Biddle's concern that Aboriginal and Torres Strait Islander people experience a large participant burden when involved in health research. Biddle recommends taking the most efficient approach possible to data collection and analysis in order to minimise participant burden.[180]

In summary, research data published in the last five years and indexed on PubMed, involving exclusively Aboriginal and Torres Strait Islander peoples living in urban areas has not greatly increased compared to the period 2004-2009, has not increased at all as a proportion of all Aboriginal and Torres Strait Islander research papers, and often involves large participant burden. The call by Eades et al. to increase the quality and quantity of health research for Aboriginal and Torres Strait Islander peoples living in urban areas is still relevant.[4]

Table 2.2 Sample size of observational research articles (n=41) identified from rapid review (described in Chapter 2) of research regarding Aboriginal and Torres Strait Islander peoples living in urban areas.

Study identifier	Health area addressed	Sample size[a]	Non-Indigenous comparator
Reeve et al.[119]	Diabetes	10,439	Yes
Katzenellenbogen et al.[107]	Aboriginal health liaison	8,041[b]	No
O'Connor et al.[115]	Chlamydia	7,103[b]	Yes
Dutton et al.[170]	Health assessments	1,169[b]	No
Maple-Brown et al. (Druid study)[128]	Albuminuria	860	No
Lopez et al.[114]	Ischaemic heart disease	833[b]	Yes
Hopkins et al.[105]	Psychological resilience	677	No
Arjunan et al.[106]	Tobacco use	663	No
Jamieson et al.[164]	Oral health	469	No
Spurling et al. (IIHS)[109]	Otitis media	453[b]	No
Coleman et al. (IIHS)[49]	Child health assessments	432[b]	No
Askew et al. (IIHS)[113]	Stressful events in children	344[b]	No
Lalla et al.[103]	Oral mucosal disease	342	No
Radford et al.[104]	Dementia	336	No
Whish-Wilson et al.[99]	Birth outcomes	301	Yes
Roberts-Thomson et al.[117]	Oral health	251	No
Dorrington et al.[174]	Pap smears	213	No
Gardener et al.[102]	Children	205	No
Wong et al.[126]	Midwifery services	193	No
Paradies et al. (Druid study)[124]	Racism and depression	185	No
Liddle et al. (IIHS)[116]	Paediatric referrals	183[b]	No
Amaresena et al.[120]	Oral health	181	Yes
Comino et al. (Gudaga study)[123]	Pregnancy outcomes	178	Yes
Harris et al. (Gudaga study)[162]	Immunisation	178	Yes
Widdup et al.(Gudaga study)[177]	Infant health	175	Yes
Luke et al.[181]	Suicidal thoughts	172	No
Priest et al.[127]	Racism	172	No
Paradies et al. (Druid study)[125]	Racism	164	No
Craig et al. (Gudaga study)[169]	Breast feeding	159	Yes
Webster et al (Gudaga study)[166]	Child growth	157	No
Scott et al.[110]	Sexual health	155	No
Miller et al. (Gudaga study)[118]	Child language assessment	150	No
Arrow[100]	Oral health	145	No
McDonald et al. (Gudaga study)[163]	Childhood development	134	No
Davis et al. (Freemantle diabetes study)[167]	Diabetes	125	Yes
Robinson et al. (Gudaga study)[168]	Antenatal care	122	Yes
Gould et al.[154]	Smoking	121	No
Maher et al. (IIHS)[121]	Antenatal care	82[b]	No
Chung et al.[112]	Diabetes	65	No
Timms et al.[111]	Otitis media	46	Yes
McKenna et al.[153]	Mental health liaison	37	No

[a] only Aboriginal and Torres Strait Islander participants included

[b] routinely collected data

2.5 Health assessments within health systems: tensions and opportunities

As I discussed in Chapter 1, the research conducted for this thesis responds to the call by Eades et al., reinforced by my rapid review, for more health research in urban Aboriginal and Torres Strait Islander communities through the development, evaluation, and use of the computerised HA as a research tool. In Chapter 1, I briefly described the introduction of Aboriginal and Torres Strait Islander HAs to the MBS as part of the Australian health care system. Here, I describe the history of HAs, tensions regarding motivations for their use, the clinical benefits of HAs, and their use in Aboriginal and Torres Strait Islander populations.

2.5.1 Motives for health assessments: health equity or surveillance instruments?

Across the last 150 years or more, there have been calls to introduce HAs to detect and remedy risk factors for diseases before they became major health problems for patients.[182-184] One of the earliest reports advocating the routine conduct of HAs was written in 1861 by an English physician, Horace Dobell.[182] He was convinced that diseases could and should be detected in their vestigial forms, and then remedied or at least ameliorated by treating physicians. Dobell called on physicians to intervene at the origins of morbidity and mortality, and was particularly concerned that HAs should be accessible to the poor.[182] Similarly, in 2004, NACCHO argued for the introduction of HAs in Australia on the grounds that Aboriginal and Torres Strait Islander people were missing preventive health opportunities, had high rates of undetected risk factors for chronic disease, and had unequal and inadequate access to primary care.[183]

In addition to the calls for the introduction of HAs on the grounds of clinical benefits and improved health equity, insurance companies and medical organisations saw self-interest as a reason to promote HAs in the early 20th century.[184] Insurance companies with more health information regarding their customers, garnered through HAs, could better manage the financial risks associated with their insurance policies. Medical organisations also supported HAs as they facilitated the extension of the medical sphere of influence beyond diseases treated in hospitals to the prevention of diseases and identification of risk factors in the community.[184]

Armstrong refers to this extension of medical influence into the community using the Foucauldian term, “surveillance medicine”.[135(p3)] According to Armstrong, the surveillance of others in medicine serves to problematise normal, targets everyone as being at risk, and especially concerns children whose rapid growth and psychosocial development attract close medical attention.[135] Foucault saw surveillance of others and the way in which bodies are gazed upon as elements of an apparatus that enable power flows in varying contexts including prisons, hospitals, and psychiatric clinics.[185] Thus, State funded HAs could be seen as surveillance instruments which may enable both State and medical power.

Foucault's observations regarding surveillance, power, and control are relevant to the practice of colonial Aboriginal protectors who could compel Aboriginal peoples to a medical examination.[186,187] In Queensland, these compulsory medical examinations were permitted by the 1897 Aboriginals Protection and Restriction of the Sale of Opium Act.[187] Under this Act, the segregation of Aboriginal people to reserves was justified by colonial powers owing to concerns about the corrupting influence of European society on Aboriginal health.[187] However, non-Indigenous people were primarily concerned about protecting their own health, and were especially concerned about contracting sexually transmitted and other infectious diseases from Aboriginal peoples.[187] For example, in Queensland, a medical examination was compulsory for Aboriginal peoples seeking exemption from the Act to ensure their body was not an infectious threat to the white population.[78] The Aboriginals Protection and Restriction of the Sale of Opium Act was not repealed until 1965.[188]

Matters of surveillance, power, and control were again present at the launch of Aboriginal and Torres Strait Islander HAs in 2004. In his speech launching Aboriginal and Torres Strait Islander HAs, Abbott, the then Minister for Health and Ageing at that time, said that HAs would encourage doctors to be “the health strategists for the Indigenous people who are their patients” in order to keep chronic and complex conditions “under control”.[189] Perhaps the implication was that Aboriginal and Torres Strait Islander peoples could not be their own health strategists, or keep their diseases under control.

In 2007, tensions between surveillance and equity motives rose sharply with the deployment of child Aboriginal and Torres Strait Islander HAs during the Northern Territory National Emergency Response (NTNER). The NTNER was devised by the Australian Government as their policy response to reports of child sexual abuse in Aboriginal communities in the Northern Territory.[190] As part of the NTNER, the Australian Government created a special medical workforce, supported by the Australian Medical Association, to systematically conduct compulsory child HAs. At the launch of the NTNER in June 2007, Prime Minister of Australia, John Howard, confirmed that compelling medical examination of Aboriginal children as part of a child HA remained an option.

> “Journalist: Will these tests be compulsory and do you think you would have the power to actually force children under 16 to have a medical examination?
>
> Prime Minister Howard: Well we would hope that communities will cooperate and let’s hope that compulsion and the like is not necessary, but all parents have responsibilities to allow medical examination of their children where there is a good need for that…”[191]

According to the Australian Indigenous Doctors’ Association’s (AIDA) assessment of the NTNER, child HAs were made voluntary soon after the policy’s release in response to community and medical concern about the implication that Aboriginal parents did not care enough about their children to obtain an HA.[192] The Australian Government also realised that a medical consultation and physical examination alone could not detect cases of child abuse.[192]

AIDA initially saw the government’s investment in the child Aboriginal and Torres Strait Islander HA as part of a wider positive policy which promoted equity of access to services. However, following consultation with key stakeholders and community groups, AIDA became concerned that the way child HAs had been deployed as part of the NTNER provoked fear, re-traumatised Aboriginal children, stigmatised Aboriginal men as child sex abusers, disempowered local health services who had been conducting child HAs independent of the NTNER, and had not actually resulted in any improvement in child health.[192]

In summary, the Australian Government has a seemingly obvious altruistic agenda in promoting Aboriginal and Torres Strait Islander HAs. This agenda is about improving Aboriginal and Torres Strait Islander health by encouraging doctors to get chronic diseases under control, and institute preventive health measures in the primary health care setting. However, there has been an ongoing history of surveillance by the State, which includes the involvement of medical personnel, that has often not served the interests of Aboriginal and Torres Strait Islander peoples. The ongoing process of colonisation can lead to what Fanon describes as,

> “the sense of alienation from colonial society and the mistrust of the representatives of its authority, are always accompanied by an almost mechanical sense of

> detachment and mistrust of even the things that are most positive and profitable to the population".[193(p139)]

Thus, despite their seemingly beneficial role, HAs may be viewed with mistrust and ambivalence by Aboriginal and Torres Strait Islander peoples.

2.5.2 Mixed evidence for the clinical benefits of health assessments

The evidence for improved health and clinical outcomes as a result of implementing HAs is mixed. Many of the individual preventive health measures included in HAs are supported by level one or two evidence which means these measures have been shown by systematic reviews or RCTs to improve health or reduce mortality.[194] While it may seem reasonable to assume that combining many of these effective screening and preventive health measures in one HA would result in additive benefits, the evidence of improved health and clinical outcomes as a result of HAs is contested.

In 2007, a systematic review by Boulware et al. reported beneficial clinical outcomes for HAs, based on 33 research articles including ten RCTs and 23 observational research articles. To be included, research articles needed to compare one or more HAs delivered by a health care provider with usual care and measure benefits and harms of HAs.[195] The reporting of this systematic review suggests that it was consistent with Centre for Evidence-Based Medicine appraisal criteria for systematic reviews[196] and high quality because it included an appropriately focussed research question, comprehensive search strategy, appropriate quality appraisal of included studies, and exploration of outcome heterogeneity. The authors found five RCTs with mortality as a clinical outcome which provided mixed results. The authors defined mixed results as meaning that some research articles showed beneficial effects while others showed no effects or harmful effects. The authors found clear benefit of HAs for increased uptake of cervical cancer screening, colon cancer screening, cholesterol screening, and reduced patient worry.[195] These findings for benefit were mainly based on RCT evidence.[195] While the authors appeared justified in recommending the ongoing implementation of HAs by health care providers and funders, their findings regarding mortality were inconclusive.[195]

However, the next systematic review published on HAs by Krogsbøll et al. came to more definitive conclusions.[69] This was a high quality Cochrane review published in 2012 which included 16 RCTs and over 180,000 participants from a number of different countries. This Cochrane review specifically investigated the effects of HAs on morbidity and mortality. It included studies involving people receiving HAs compared with those not receiving HAs, conducted in either community or health service settings. People aged over 65 years and those with known risk factors or diseases were excluded.[69] Owing to the size and quality of the review, the authors appeared justified in recommending against the implementation of HAs given the robust findings for lack of benefit regarding their predefined clinical outcomes of morbidity and mortality.[69] Additionally, this review found that having more than one HA did not alter their findings.[69]

Notwithstanding the findings of the Cochrane review,[69] the question of HA benefit conducted in primary care for selected vulnerable groups remains unresolved. Doubts centre on concerns about the benefits of HAs in varying health settings, advances in preventive health, and benefits of HAs for target populations. Regarding health settings, the majority of trials and patients in the Cochrane systematic review were conducted in the community setting where participants were invited to participate; an acknowledged feature which could result in selection bias favouring the well.[69] There have been changes in the emphasis of preventive health between 1960 and 1980. In the 1960s, RCTs investigating HAs were almost solely concerned with risk factor detection whereas in the 1980s researchers conducting RCTs were concerned with risk factor detection and also interventions to manage these risk factors.[197] Given nine of the 14 RCTs included in the Cochrane systematic review were published before 1980, the authors may have underestimated the benefits of HAs which emphasised management as well as detection of chronic disease risk factors.[69]

Certain target populations may benefit from HAs more than others. The inclusion criteria for the Cochrane review by Krogsbøll et al. specifically excluded older people, children, and those studies looking specifically at risk factors (such as hypertension) or chronic disease (such as ischaemic heart disease).[69] While ethnicity was not an exclusion criteria, all the included studies were conducted in North America or Europe, and no information about the impact of HAs on subgroups including Indigenous populations was presented.[69] Clinically significant benefits from HAs have been found for certain subgroup populations. Beswick et al. conducted a systematic review and meta-analysis of community-based HAs for elderly people[198] which was of high quality according to systematic review appraisal criteria.[196] Beswick et al. found benefits from HAs through reduced nursing home admissions, reduced falls, and improved physical function.[198] Lennox et al. conducted an RCT of HAs for participants with intellectual disability and found large effect sizes for benefits for HAs through improved detection of vision impairment, improved uptake of hearing screening, immunisations, cervical cancer screening, and improved detection of new diseases.[199] Reporting of this trial suggests that it was consistent with recommended RCT appraisal criteria and likely to be of good quality.[200] The RCTs included in the systematic review by Beswick et al.[198] and the RCT authored by Lennox et al.[199] were not included in the Krogsbøll et al. Cochrane review[69] because they dealt with a specific population excluded from the review[198] or were published subsequent to the Cochrane review.[199] While neither study (Beswick et al. nor Lennox et al.) contributed information regarding mortality, they both produced evidence of benefit for clinically significant outcomes.[198,199]

I conducted a search using PubMed clinical queries for RCTs of HAs in an Aboriginal and Torres Strait Islander population using the following search terms.

> ((health assessment) OR (health check) OR (periodic health examination)) AND (oceanic ancestry group"[Mesh] OR Indigenous OR Aboriginal OR Torres Strait Islander)

This search revealed only one RCT by Calver et al.,[201] and while it should have met the inclusion criteria, it was not included in the Krogsbøll et al. Cochrane review.[69] This RCT was located in a remote community, studied a one off HA conducted at the community level, and found no difference in mortality 13 years later.[201] Calver et al. also found increased rates of hospitalisation in those who had had an HA which the authors attributed to increased contact with health services as a result of the HA.[201] While the findings of this RCT[201] regarding mortality are consistent with the Krogsbøll et al. Cochrane review findings,[69] they are not readily comparable with annual computerised HAs conducted in general practice.

In general practice settings, participants who respond to invitations for general HAs are more likely to be socioeconomically advantaged and less at risk of disease than those who do not.[202] [203] A systematic review by Si et al., published in 2014, sought to investigate the clinical effects of HAs in the general practice setting.[197] This systematic review included six RCTs, two of which were not included in the Cochrane review by Krogsbøll et al.[69] One of these two studies was published after the Krogsbøll et al. search had been conducted and the other included people at risk of cardiovascular disease which would have met the exclusion criteria of the Krogsbøll et al. review.[69,197] The Si et al. systematic review found no reduction in mortality, but found benefit for HAs in improving surrogate outcomes such as lowering total cholesterol, systolic blood pressure, diastolic blood pressure and body mass index (BMI).[197] Surrogate outcomes predict important clinical outcomes such as morbidity and mortality, and are used in clinical trials because changes in their status occur over a much shorter timeframe than endpoints such as disease progression or mortality.[204] However, trial results depending on surrogate outcomes need to be treated with caution. Interventions affecting surrogate outcomes may also affect important clinical outcomes such as mortality through unanticipated negative pathways that do not involve the surrogate outcome, and ultimately neutralise the intervention's benefit or cause harm.[204] Si et al. question their own findings regarding mortality. They suggested that their systematic review was underpowered to measure mortality, included studies that did not include mortality as their primary outcome, and there may have been contamination of control groups in included studies.[197] While this latest 2014 systematic review by Si et al. of HAs including RCTs conducted in general practice does not find benefit for morbidity and mortality,[87] it does cast doubt on the sweepingly negative Krogsbøll et al. Cochrane review findings based mainly on trials of HAs in community settings.[69,197]

In summary, recent systematic reviews of RCTs show that community-based HAs for well adults in non-vulnerable populations are unlikely to be clinically beneficial. Moreover, the one RCT looking at HAs for an Aboriginal and Torres Strait Islander community also found no mortality benefit.[201] However, this was one RCT reporting findings of a one-off HA in one community setting.[201] There is robust systematic review evidence that HAs conducted in the general practice setting improve surrogate clinical outcomes.[197] Repeated, annual HAs, conducted in general practice, may be more likely to result in health benefit for vulnerable populations including HAs funded for Aboriginal and Torres Strait Islander peoples through the MBS. Further RCTs of HAs for Indigenous populations conducted in general practice would help make confident conclusions about the effects of Aboriginal and Torres Strait Islander HAs on mortality.

2.5.3 Aboriginal and Torres Strait Islander health assessments in primary care

In response to calls from NACCHO for the introduction of adult and child Aboriginal and Torres Strait Islander HAs,[183] Australia appears to be the only country where publicly funded Indigenous HAs are available across the lifespan. The Taiwanese government publicly funds preventive HAs for Indigenous people aged over 55 years. Using internet searching and conversations with international colleagues, I was unable to find another country which publicly funds Indigenous HAs.

The content of Aboriginal and Torres Strait Islander HAs is influenced by Medicare requirements, evidence-based guidelines, and general practitioner (GP) preferences. To receive public funding for Aboriginal and Torres Strait Islander HAs, Australian GPs need to follow MBS guidelines regarding HA content.[205] Additionally, NACCHO and the Royal Australian College of General Practitioners (RACGP) published evidence-based recommendations for Aboriginal and Torres Strait Islander HAs.[206] Individual GPs and services such as the IIHS may further customise their Aboriginal and Torres Strait Islander HAs.

Criticism of the introduction of Aboriginal and Torres Strait Islander HAs in Australia centres on three main areas; low uptake, poor follow up of identified problems, and concern about clinical benefit in line with the contested systematic review evidence presented above. In 2009-2010, only 12.7% of Aboriginal and Torres Strait Islander peoples had received an HA, leading to concerns that this low uptake signified that the Australian Government's funding of these assessments through the MBS was a failed policy.[207] Uptake of adult HAs was lowest for Aboriginal and Torres Strait Islander peoples living in urban areas at 2.6% in 2007-2008.[207] However, national uptake of Aboriginal and Torres Strait Islander HAs was 12.1% in 2011 and has been slowly increasing since that time.[208] By way of comparison, 752 people (46%) of 1628 adults attending the IIHS in 2011 had had a computerised Aboriginal and Torres Strait Islander HA in the preceding 12 months. By 2014, national uptake of Aboriginal and Torres Strait Islander HAs had increased to 23%.[208]

Despite improvements in uptake, concern persists regarding the follow up of health problems detected during the conduct of an HA.[207,209] However, one research paper, published in 2015, conducted in a regional Aboriginal community controlled health service found that many of the problems identified by clinicians conducting Aboriginal and Torres Strait Islander HAs in primary care were either fully (26%) or partially (49%) resolved six months later.[170] The authors considered health problems to be resolved when referrals, immunisations, review of growth, and follow up investigations were attended to.[170] This study provides evidence to suggest that HAs can help identify and facilitate the appropriate management and follow up of various health concerns.[170]

Few studies have been carried out regarding the clinical benefits of HAs conducted in general practice for Aboriginal and Torres Strait Islander peoples living in urban areas. Many of the diseases and chronic disease risk factors which contribute to high mortality rates for Aboriginal and Torres Strait Islander peoples have been shown to be modifiable by preventive health interventions in primary care.[206] These diseases include ischaemic heart disease, cervical cancer, breast cancer, depression, pneumonia and diabetes.[210] At the IIHS, we conducted cross-sectional studies using adult[48] and child[49] Aboriginal and Torres Strait Islander HA data. We found that by conducting HAs, GPs were able to detect biomedical risk factors, diagnose previously undetected health conditions, and facilitate preventive health interventions such as cervical screening and smoking cessation advice.[48,49] In summary, while the clinical benefits of Aboriginal and Torres Strait Islander HAs have not yet been proven, they are likely to be achieving some of the aims proposed by NACCHO through the detection of chronic disease risk factors and instigation of preventive health activities.[183]

2.6 Research using Aboriginal and Torres Strait Islander health assessments

In addition to using HAs for clinical benefit, the staff at the IIHS have sought to use the routinely collected clinical data from these assessments for research purposes. Our experience with research involving paper-based HAs included investigator led, cross-sectional, epidemiological investigations of obesity in children[211], the self-rated health of adults[212], middle ear disease in children[109,213], and stressful events in children.[113] However, outside the IIHS, research based on Aboriginal and Torres Strait Islander HAs appears sparse. To confirm this sparsity, I conducted a PubMed search for health research conducted using on Aboriginal and Torres Strait Islander HA data using the following search terms.

> (health assessment OR health check OR periodic health evaluation) AND (Indigenous[ti] OR Aboriginal[ti] OR Torres Strait Islander[ti]) AND Australia

Outside of the IIHS, this search yielded only two studies, both in the same remote Northern Territory Australian Aboriginal community.[214,215] One study used HA data to respond to a traditional land-owner's request for an investigation of links between "caring for country" and health.[214] In this study, caring for country was defined as "Indigenous participation in interrelated activities with the objective of promoting ecological and human health".[216(p1)] Caring for country was positively associated with a number of health parameters measured by HAs including nutrition, physical activity, and other chronic disease risk factors.[214] The other study investigated cardiovascular risk factors at the time of HA, and one year later. One year after the HA, participants were found to have improvements in cardiovascular risk detection and management, which the authors attributed to the HA as an intervention.[215] These benefits of HAs are based on a historical rather than a parallel control group, so these findings need to be treated with some caution as there may have been a cohort effect operating in the community to improve cardiovascular risk management.[215]

I was unable to find any other research papers based on HA data either in Australia or internationally for Indigenous peoples. However, HA data have been used in large research projects in a number of countries including the United Kingdom[217], South Korea[218], and Japan[219] covering a wide range of health-related topics including cardiovascular disease, metabolic syndrome, and headaches.[217-219] Consistent with my findings regarding research in urban areas for Aboriginal and Torres Strait Islander peoples, research data based on HAs for Indigenous peoples are sparse.

2.7 Future research directions in Aboriginal and Torres Strait Islander health

In this chapter, I have described health research with Aboriginal and Torres Strait Islander peoples, the role of non-Indigenous researchers, the evidence-base for Aboriginal and Torres Strait Islander HAs, and shown that research based on Aboriginal and Torres Strait Islander HAs is sparse. Importantly for this doctoral research, I have confirmed the need for research in urban Aboriginal and Torres Strait Islander communities. Responding to this research need requires a vision for the health research required to meaningfully engage with Aboriginal and Torres Strait Islander communities.

The NHMRC and the Lowitja Institute have both responded to calls by Aboriginal and Torres Strait Islander peoples for health research which benefits Aboriginal and Torres Strait Islander communities. The NHMRC and the Lowitja Institute made significant efforts to consult with community key informants around Australia regarding the future needs and directions of health research for Aboriginal and Torres Strait Islander peoples. For the NHMRC, this consultation process resulted in their first Road Map published in 2002 which aimed to improve Aboriginal and Torres Strait Islander Health through research.[220] This initial Road Map produced six research themes including: descriptive research on health risk, disease, and death; research focussing on resilience; health services research; how policy and programs outside the health sector can impact on health; engaging previously under-researched Aboriginal and Torres Strait Islander communities; and developing Aboriginal and Torres Strait Islander health research capacity.[220] These themes were superseded by the health action areas contained in Road Map II, published in 2010, with the new objective of closing the gap in life expectancy between Aboriginal and Torres Strait Islander peoples and the overall Australian population.[57] Similarly, in 2012 and 2013, the Lowitja Institute held workshops around Australia with Aboriginal and Torres Strait Islander peoples to find out what future relevant health research will be needed by the health sector.[82] These workshops called for greater integration of health services, policy and research, and had a strong emphasis on the social determinants of health.[82]

2.7.1 Need for research involving community

The NHMRC Road Map II reported that community consultation was crucial to improving the relevance of health research, and needed to occur early in the research process.[57] Without this consultation and involvement of Aboriginal and Torres Strait Islander communities, research risks privileging outcomes of minimal relevance, and not focussing on outcomes that are of importance to Aboriginal and Torres Strait Islander peoples.[180] Furthermore, Yu argued that while governments control data collection and analysis, perceptions of Aboriginal and Torres Strait Islander peoples will continue to be about deficit and dysfunction.[221] Similar to NHMRC findings, the workshop participants involved in the Lowitja Institute consultation also emphasised the need for researchers to conduct research in partnership with Aboriginal and Torres Strait Islander communities and organisations, and to feed research findings back to communities.[82] In addition to consulting with Aboriginal and Torres Strait Islander peoples about research form and conduct, Bainbridge et al. argue researchers need to consider what benefit their research will bring and to view research benefit from the varying perspectives of Aboriginal and Torres Strait Islander peoples participating in research.[79] In summary, to serve Aboriginal and Torres Strait Islander peoples best, health research should be community-driven, community-led, or at least needs to involve early and ongoing community consultation which includes feedback of research findings. This process helps direct researchers to the outcomes most likely to result in community benefit.

2.7.2 Importance of mixed methods

To better involve community members in health research, workshop participants with the Lowitja Institute recommended that researchers develop the skills necessary to respond to stakeholder-driven research priorities including multi-disciplinary and collaborative mixed methods research.[82] In addition to becoming skilled in both qualitative and quantitative methods, workshop participants were also interested in maximising the value of data sources using technological advances including data linkage of routinely collected data sources in health services, other parts of the health system, and in non-health specific sectors.[82] Thus, researchers intent on producing research findings which maximise available research databases and reflect community aspirations and priorities should be prepared to engage with mixed methods including both qualitative and quantitative research approaches as appropriate for the research question.

2.7.3 Importance of social, cultural, and environmental determinants of health

In accord with NHMRC Road Map II recommendations produced by a community consultation process, the Lowitja Institute reported an urgent need to address social determinants of health.[57,82] Specifically, workshop participants were concerned about poverty, homelessness, child and maternal health, education, and incarceration rates. Workshop participants were also concerned about cultural determinants such as recognition of country, intergenerational trauma, identity, and racism.[82] The importance of SCEDH in health research was also reported by Biddle as a data gap.[180] Furthermore, Bainbridge specifically identified social and cultural determinants as an important area where research findings need to be translated into policy action.[79]

2.7.4 What data are required?

Outside urban areas, Aboriginal and Torres Strait Islander peoples may be one of the most researched groups in the world, and this research has mostly been conducted by non-Indigenous researchers.[1-3] Non-Indigenous researchers have often failed to adequately involve Aboriginal and Torres Strait Islander participants, and have failed to adequately engage with Aboriginal and Torres Strait Islander realities, worldviews, experiences, and needs.[1-3] Despite this large corpus of research, Biddle argued that data are often not available at the local level which could be used by Aboriginal and Torres Strait Islander community organisations, service providers, and government.[180]

Local level data are useful because social and geographical groupings of Aboriginal and Torres Strait Islander peoples do not always align with administrative groupings of data commonly produced by governments, and then used by researchers.[180] National and state level data collections often dichotomise ethnicity into non-Indigenous and Aboriginal and Torres Strait Islander groupings which Walter and Andersen argue is a “statistical convenience” [222(p38)] rather than reflective of the diversity of Aboriginal and Torres Strait Islander peoples.[222] Biddle argues that high quality local level data, with an emphasis on socioeconomic outcomes would be particularly valuable.[180] Furthermore, Biddle suggests analysing these data by socially meaningful groupings including age and gender, so that these data could help describe community characteristics, plan activities, develop programs, and evaluate changes in community needs over time.[180] Additionally, analysis of local level research data, fed back to community organisations at grass roots level, can help empower Aboriginal and Torres Strait Islander peoples tell their own stories, and advocate for the programs and activities that are most relevant, important, and beneficial.[82,180] Walter and Andersen argue that statistical portraits reflecting Aboriginal and Torres Strait Islander priorities can be powerful in influencing policy given the high value policy-makers place on the evidence produced by quantitative research methods.[222]

Aboriginal and Torres Strait Islander health research would also benefit from more longitudinal data, data linkage of datasets including those produced at the community or health service level, and less burdensome data collection methods.[7,180] Longitudinal data are useful for policy makers because they help establish causal pathways as changes in control variables and outcomes can be measured at more than one point in time.[180] Repeated, cross-linked, cross-sectional data collections may be cheaper, and yet still measure changes in outcomes over time, and are less prone to data attrition than longitudinal studies.[82,180] Cross-linked, cross-sectional data collections also have limitations. For example, it could be difficult to interpret changes over time given that at least some of the participants at each time point, unlike in cohort studies, are likely to be different.[223] These future directions for Aboriginal and Torres Strait Islander health research helped inform the research questions in this thesis relevant to the use of computerised HA data for research purposes.

2.8 Summary

In this Chapter, I have described the history and current state of Aboriginal and Torres Strait Islander health research, the clinical and research roles of Aboriginal and Torres Strait Islander HAs, and future directions for research. While there has been a great deal of Aboriginal and Torres Strait Islander health research, this research has often been of unclear benefit or has been damaging to Aboriginal and Torres Strait Islander peoples. Moreover, there remains a clear deficiency in the quantity of health research conducted to inform strategies to improve the health of Aboriginal and Torres Strait Islander peoples living in urban areas. To gain health benefits from further research, non-Indigenous researchers are advised to conduct collaborative research in consultation and partnership with Aboriginal and Torres Strait Islander communities. In addition to concentrating on urban areas, future research with Aboriginal and Torres Strait Islander peoples should be responsive to community priorities, involve an emphasis on SCEDH, conduct research which minimises participant burden, and conduct research at a community level which would be useful for community organisations, clinicians, and policy makers. These findings inform the research questions I present next in Chapter 3.

Chapter 3 Research Questions

In Chapters 1 and 2, I described the need for Aboriginal and Torres Strait Islander health research in urban areas that involved consultation with Aboriginal and Torres Strait Islander communities.

The aim of this chapter is to describe the research questions which have been developed based on the research needs identified by my analysis of the literature presented in Chapter 2. I hypothesise that converting paper-based HAs to computerised HAs at the IIHS will create a database that will facilitate not only cross-sectional research, but also longitudinal analysis. As I discussed in Chapters 1 and 2, research with Aboriginal and Torres Strait Islander peoples has a history of being problematic especially when conducted by non-Indigenous Australians. Privileging Aboriginal and Torres Strait Island voices is central to discovering the community's health priorities regarding research based on computerised HA data.

This chapter starts with the overarching research question for the doctoral research, and is followed by five research questions which build on each previous research question in contributing to a coherent response to the overarching thesis research question.

Overarching thesis research question

What is the validity and applicability of computerised Aboriginal and Torres Strait Islander HAs to health research in urban Aboriginal and Torres Strait Islander primary health care?

Research question 1.

Is it feasible to implement computerised Aboriginal and Torres Strait Islander HAs in Aboriginal and Torres Strait Islander primary health care which are designed to be used for both clinical and research purposes?

This question is addressed in Chapter 5 where I describe the implementation of computerised HAs and the process evaluation that determined their feasibility. After finding that the implementation of computerised HAs was feasible, I could move on to evaluate computerised HA data for research purposes.

Research question 2.

Do computerised Aboriginal and Torres Strait Islander HAs produce data which are sufficiently complete, reliable, valid, and representative of the local Aboriginal and Torres Strait Islander community to be used for research purposes?

This question is addressed in Chapter 6 where I present the evaluation of data from computerised HAs to determine their credibility for research purposes. After finding that computerised HA data produced credible data for research purposes, I wanted to know what the Aboriginal and Torres Strait Islander community's health priorities were for computerised HA research.

Research question 3.

What are the important health issues covered by computerised HAs for the Inala Aboriginal and Torres Strait Islander community?

Research question 4.

Which health research questions are priorities for research based on computerised Aboriginal and Torres Strait Islander HA data?

Research questions three and four are addressed in Chapter 7 where I consulted key informants in the Inala Aboriginal and Torres Strait Islander community regarding their health priorities with respect to HA content. Following the community consultation process described in Chapter 7, key informants in the Inala Aboriginal and Torres Strait Islander community articulated a holistic view of health concerned about a complex cycle of interrelated SCEDH. Findings from Chapter 7 support an HA research agenda concentrating on SCEDH which is pursued in Chapter 8.

Research question 5.

What is the overall distribution of SCEDH measured by computerised HAs in adult patients attending the IIHS, and between different age, sex, and ethnic groups?

Research question 5 is addressed in Chapter 8 and findings indicate that SCEDH varied for different age and sex groupings. Chapters 5 and 6 address the validity component of the overarching research question. Chapters 7 and 8 address the applicability component of the overarching research question. The nature of these research questions indicates the need for a combination of qualitative and quantitative methodologies. In Chapter 4, I will explain and justify my approach to answering these research questions which includes the use of mixed methods.

Chapter 4 Methodology

4.1 Introduction

In Chapter 3, I formulated and presented research questions regarding the use of computerised HA data for research purposes in a way that is responsive to community priorities based on the literature review presented in Chapter 2. The aim of this chapter is to describe the methodology relevant to answering these research questions. Firstly, I express how my epistemological positioning contributes to my metaphysical worldview drawing on both postpositivist and critical theory paradigms. Next, I describe the integration of two different ways of knowing using CCM situated in the transformative paradigm. Finally, I will show how a mixed methods approach can respond to concerns regarding research conducted with Aboriginal and Torres Strait Islander peoples, and is the most appropriate approach for answering the research questions posed in Chapter 3.

4.2 Positioning the researcher

As acknowledged in the introduction, Chapter 1, the methodology of a program of inquiry such as this thesis will be influenced by the metaphysics, or set of beliefs, that a researcher brings to their work.[224] The researcher's beliefs about the nature of reality, or ontology, leads to their beliefs about how knowledge can be acquired, their epistemology.[225] Together the researcher's stance on ontology, epistemology and methodology make up the paradigm within which the researcher works. One cannot definitively show that one paradigm is better than another because they are human constructions built on belief.[224] However, researchers using different paradigmatic stances are likely to formulate different research questions, and use different methodological approaches when addressing social phenomena.[226]

If I had taken a solely postpositivist stance for this research, I would have risked reproducing the findings of past medical research which has little value and potentially harms Indigenous peoples. In this research, I use both a postpositivist paradigmatic stance in developing computerised HAs in Chapters 5 and 6, and a critical theory or transformative paradigmatic stance for the community consultation research described in Chapter 7, and this informs the epidemiological investigation of SCEDH described in Chapter 8.

4.2.1 Positivism: a brief critique

The ontological positioning for positivism is that reality exists in the world, and it can be observed, measured, and understood.[224] Knowledge of this reality, or epistemology, is best attained using the scientific method in order to establish the truth about reality.[227] Positivism and the importance it places on objectivity pre-supposes that scientific knowledge is value neutral.[227] My medical training, a strong influence on my worldview formation, privileged objectivity and reason as important paths to getting the diagnosis right and instituting correct management for the people I am responsible for as their GP. This training taught me to believe that I could act as a neutral, objective knower in medical consultations consistent with a positivist epistemological position.[224] This idea of value-neutral science has been criticised by many including Kuhn and Habermas who argue that scientific observations are inevitably shaped by our human experiences.[228,229] Value-neutral science involves researchers who must remain objective and apart from participants. Attempting to set researchers apart leads to research on the researched as objects rather than with the researched as fellow subjects.[230]

4.2.2 Postpositivism: more appropriate but still insufficient

A more satisfactory approach than positivism involves embracing postpositivism, a paradigm which accepts that while there is likely to be a true reality, humans are unable to fully comprehend it owing to our fallibilities, and because our experience is socially and culturally constructed.[224] In a research context, postpositivism also means accepting that effects and outcomes may have a number of complex causative factors, and scientific research produces evidence which helps establish the probability that a finding is true rather than truth itself.[224] Regarding their epistemological positioning, unlike positivists, postpositivists accept that researchers are unlikely to be able to be objective inquirers.[224] However, objectivity is still an idealised goal to be approached through the use of a critical community of editors, referees, and peer reviewers.[224] Unlike positivism, for postpositivists, both qualitative and quantitative methods are legitimate, and the choice of method is guided by the type of research question.[224,227]

4.2.3 My approach to the development of computerised health assessment research: grounded in postpositivism

My motivation to conduct computerised HA research came from seeing potential to produce useful research outcomes from the wide range of health information collected by HAs, and wanting to overcome the practical barriers for researchers posed by paper-based HAs. Thus, the first two research chapters of this thesis, Chapters 5 and 6, are about determining whether it was feasible to implement computerised HAs in Aboriginal and Torres Strait Islander primary health care (Chapter 5), and if the data produced by computerised HAs were sufficiently representative, complete, reliable, and valid to be used for research purposes (Chapter 6). I uncritically conducted the research for these chapters situated in the postpositivist paradigm. Once I had demonstrated that computerised HAs could be feasibly implemented at the IIHS, and I had shown that the data could be used for research, the next step was to ask what research questions should be posed which could be interrogated using computerised HA data. Should investigator-driven HA-based research continue, or was there another approach? In responding to this question, I started by looking at myself as investigator.

4.2.4 Whiteness and the critical theory or transformative paradigm

I accept that the researcher and the researched are inherently linked, and that the values of each will inevitably influence the outcome of the inquiry consistent with the critical theory paradigm.[224] This paradigm takes the ontological position that reality has been shaped by multiple social and political factors.[224] Thus, these factors also shape the values of researchers, and these values in turn influence the relationship between researcher and researched, and the outcomes of any research inquiry.[224] Regarding researcher values, Moreton-Robinson notes that whiteness, referring to a set of values associated with white people, arrived in Australia with the British colonisers in the 18th Century. British colonial values became normalised in Australia, and included whiteness as an important marker of superiority.[54] In the early 20th Century, white hegemony was reinforced at Australia's Federation and by the White Australia Policy which formalised citizenship, voting, property, and immigration rights. These rights were not afforded to non-white people in Australia in the same way they were afforded to white people. Today, the sense of white superiority embodied in British colonial values continues to influence our everyday lives including the conduct of research.[54] Moreton-Robinson argued for the importance of naming and disrupting whiteness, so as to make it visible, and such that the power structures embedded in our identities may be examined and critiqued.[54]

4.3 Approaches to different ways of knowing

As a white researcher seeking to conduct research collaboratively with Aboriginal and Torres Strait Islander peoples, I needed to employ a methodology which maximised the benefit to participants and avoided the risks of participant exploitation. The theory of communicative action, proposed by Habermas, provides an emancipatory framework, like the Yolŋu Ganma metaphor described in Chapter 1, whereby two different groups may reach shared understanding through rational discussion in a way that transcends notions of power and domination.[62] Critique of communicative action centres on concern that dialogue between two different groups such as non-Indigenous researchers and Aboriginal and Torres Strait Islander communities can never be truly free of issues of power and domination.[231] While acknowledging that issues of power and domination are still likely to be present, Habermas argued that communicative action creates a space where the primary goal of communication is consensus and mutual understanding rather than always being about domination and control.[232] In a research context, I have operationalised an emancipatory dialogue between two groups with different ways of knowing by employing CCM situated in the transformative paradigm.

4.3.1 Critical communicative methodology

CCM is based on Habermas' theory of communicative action, and it informs the mixed methods approach I use to answer the third, fourth, and fifth research questions posed in Chapter 3. CCM is an approach to inquiry or research grounded in the assumption that dialogue or communication can be emancipatory as described by Habermas.[233] Consistent with the ontology of the critical theory paradigm, reality for CCM is constructed by social interactions, and does not exist independently from the subjects who experience this reality.[233] In CCM, the critical is based on the assumption that parties to social interactions bring their own value systems, but also have reflective capacity which can lead to action that can transform the social reality of the participants.[231] Reminiscent of the Yolŋu Ganma metaphor and communicative action theory, the epistemological position of CCM is that knowledge production is the result of dialogue or communication between two groups.[231] Rather than the rivers in the discourse of the Yolŋu Ganma metaphor, the two groups in CCM discourse are conceptualised as systems and lifeworld perspectives. From a social sciences research viewpoint, the system perspective would represent the academic community with their knowledge of pre-existing research and theories, and the lifeworld perspective consists of the opinions and interpretations of people experiencing their day to day lives.[230,233]

CCM seeks to include, privilege, and value the lifeworld voices of those groups who have previously been silenced by research.[233] By valuing these voices, the lifeworld is incorporated in the research process, potentially challenging the views and assumptions of researchers.[233] Puigvert, a CCM proponent, argued that methodologies which do not seek to incorporate lifeworld voices in the research process often disregard, silence, use in a decontextualised way, or misunderstand the lifeworld views of oppressed groups.[231] The problematic positioning by some research methodologies of the researcher as the knower has previously been described with respect to research conducted on indigenous peoples.[1,53,54] Egalitarianism is important to proponents of CCM such that research participants from both the system and lifeworld are positioned as knowers and their knowledge is equally valued.[230,231]

In addition to egalitarianism, another important component of CCM is its transformative potential. CCM aims to identify for oppressed groups the barriers to social participation, and the transformative enablers to overcome these barriers.[233] Thus, CCM is not just about describing social phenomena, but strives to identify alternatives, based on the lifeworld knowledge learnt through dialogue, which can improve and overcome problematic social situations.[231,233] Ultimately, CCM is driven by a transformative commitment to change policy and the social world through research which informs policy and other social actions.[231]

While CCM has transformative potential, and intends for researchers to hear lifeworld voices, there are tensions arising from the use of dialogue in collaborative research using CCM. There may be tension for the researcher in finding a strategic direction out of a plurality of lifeworld voices.[234] For example, I experienced this tension in setting the research direction after hearing varying community key informant voices described in Chapter 7. Additionally, as a non-Indigenous doctor and researcher, my medical and research training had given me a health perspective that was different to the perspective of community key informants. After grappling with these tensions in discussions with my research advisors, I decided to conduct the epidemiological investigation described in Chapter 8, and this decision was endorsed by the Inala Community Jury for Aboriginal and Torres Strait Islander Health Research (ICJ).[132] Research using CCM may produce results that do not satisfy lifeworld participants or systems world participants. The latter may be conflicted by their need to be accountable to their institutions through publications and other outputs.[85,234] It may also be difficult for researchers to create the right space in which to hear lifeworld voices while minimalising the power imbalance between researcher and researched.[234] I attempted to reduce the power differential between myself as interviewer and medical practitioner as described in Chapter 7, and lifeworld key informants from the Inala community. These tensions may be eased through researcher reflexivity, and a willingness to explore the different strands of thought produced by privileging lifeworld voices.[234]

4.3.2 The transformative paradigm

Conducting research with a view to improving the social world is consistent with the transformative paradigm proposed by Mertens.[235] Other motivations for conducting research include increasing scientific knowledge for its own sake, securing funding, and publishing papers in peer reviewed journals. The transformative paradigm shares similar ontological, epistemological, and methodological stances with the critical theory paradigm.[235] Like the critical theory paradigm, research conducted in the transformative paradigm is based on the assumption that knowledge reflects power and social relationships within society.[236] Whereas the goal of social change is sometimes implicit in the critical theory paradigm, it is always explicit in the transformative paradigm.[237] Consistent with CCM, the transformative paradigm is interested in privileging oppressed peoples' voices, knowledges and experiences rather than silencing or overlooking them.[236]

4.4 Mixed methods

In situating the research of Chapters 7 and 8 in the transformative paradigm, using CCM, I needed to use qualitative methods to hear and privilege the voices of the Aboriginal and Torres Strait Islander community in Inala. Given the research program of this thesis also involves the quantitative data produced by computerised HAs, a mixed methods approach is required. Tashakorri and Cresswell define mixed methods as:

> "research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry".[238(p4)]

There is still debate about this definition. For example, Morse defines mixed methods as only occurring within a single study, and multiple methods where different methods are used within a program of inquiry involving separate studies with distinct research questions.[239] Cresswell acknowledges the term multiple methods, but only as it is used within the pragmatic paradigm. Within this paradigm the research questions and the research outcomes are more important than considerations of the underlying worldview informing different methods.[240] Consistent with Tashakorri and Cresswell's definition above,[238] I consider this research containing quantitative and qualitative studies within the one program of enquiry to be mixed methods.

The first two research questions stated in Chapter 3 are connected to the development of computerised HAs at the IIHS and the evaluation of computerised HA data, and are best answered using quantitative methods consistent with the postpositivist paradigm. The third and fourth questions stated in Chapter 3 are posed with the objective of hearing the lifeworld voices of Aboriginal and Torres Strait Islander community key informants regarding their health priorities, and are best answered using qualitative methods consistent with CCM situated in the transformative paradigm. The fifth and final thesis research question posed in Chapter 3 responds to these lifeworld stories. The response to this fifth question is best answered using a quantitative epidemiological investigation of SCEDH measured using data from computerised HAs.

The employment of a mixed methods program of inquiry acknowledges that one data source may not be sufficient with the implication that a combination of both qualitative and quantitative methods will strengthen research outcomes.[240] One advantage of following qualitative findings with an epidemiological investigation of SCEDH is that quantitative findings may be generalisable to other populations because they are based on larger more diverse populations.[225] Moreover, the quantitative findings of the epidemiological investigation can serve to reinforce or, to use postpositivist language, validate or triangulate the findings of the qualitative study.[225] Alternatively, rather than quantitative findings simply reinforcing qualitative findings, the analysis of qualitative and quantitative findings within a research program such as this thesis can be seen as a dialectical process where the findings of both are analysed for agreements and disagreements and how together the findings contribute to a better understanding of social or health phenomena.[226]

4.4.1 Mixed methods research involving Aboriginal and Torres Strait Islander peoples

Of the 84 studies, identified in Chapter 2, conducted exclusively in urban areas (2011 to 2016), 10 (12%) used mixed methods with a qualitative component involving Aboriginal and Torres Strait Islander peoples' voices. Many of these studies were consistent with the transformative paradigm as they sought to improve the social world for Aboriginal and Torres Strait Islander peoples through health service evaluation,[131,146,153,155,160] access to health services,[156,158] or evaluation of an intervention.[159] Other studies used mixed methods to explore social phenomena likely to be priorities for Aboriginal and Torres Strait Islander peoples including smoking cessation,[154] teenage pregnancy,[161] and cardiovascular chronic disease management in primary care.[157] One study, described in Chapter 2, used qualitative methods to explore Aboriginal and Torres Strait Islander peoples' priorities, and then used quantitative methods to respond to these priorities.[241]

Consistent with the transformative paradigm, Burgess found Aboriginal people living in a remote community had better health outcomes when they participated in activities consistent with “caring for country”.[214] This finding provided empirical support for Aboriginal peoples’ assertion that “caring for country” should be considered a health promoting activity.[214] In summary, mixed methods have not been commonly used in urban communities, but where they have been employed they have been used for transformative purposes.

4.4.2 Criticism of mixed methods approaches

Much criticism of mixed methods centres on concern that research studies conducted in differing paradigms are incompatible, and that these differences are irresolvable.[242,243] Moreover, as described above, there is a concern that mixed methods research uses qualitative data to reinforce the primacy of positivist methodological approaches using quantitative data.[225] For example, qualitative research methods may be used to validate or illustrate quantitative results which reinforces the hegemony of quantitative approaches.[225,227] Qualitative methods are therefore marginalised to an auxiliary role and researchers using mixed methods may fail to use qualitative methods in a truly interpretive way.[244] This means that researchers attempt to interpret their qualitative findings in a way that suits the next quantitative phase of their research agenda situated in a positivist or postpositivist paradigm rather than interpreting qualitative results for their intrinsic meanings. These criticisms are relevant for this research as there was always a danger of bending qualitative findings presented in Chapter 7 to suit an epidemiological investigation of researcher interest based on computerised HA data. For example, for the qualitative research presented in Chapter 7, I asked community key informants about their health priorities using an interview guide with many of the biomedical prompts inherent in Aboriginal and Torres Strait Islander HAs. While key informants were primarily concerned about SCEDH, they could hardly avoid talking about the biomedical elements of health that I had included in the interview schedule. Thus, it may have suited me to focus solely on the biomedical elements and ignored some of the responses pertinent to SCEDH. I sought to avoid this outcome through reflexivity, involving Aboriginal people in my research, listening to my advisory team, and checking my interpretation of research findings with community members.

4.5 Conclusion

The research questions posed in Chapter 3 could be answered in several different ways depending on the paradigm or worldview within which I situate this research, my epistemological positioning, and the methodology I employ. I have acknowledged the values I bring to this research, and having implemented and evaluated computerised HAs, I acknowledge the importance of situating Chapters 7 and 8 in the transformative paradigm where lifeworld Aboriginal and Torres Strait Islander voices can be heard. In the transformative paradigm, the overarching goal of the research is to improve the social world of the researched.

Conducting research in the transformative paradigm required a dialogue between myself, as a non-Indigenous researcher from the systems world, and members of the Aboriginal and Torres Strait Islander community from the lifeworld, consistent with the discourse of the Yolŋu Ganma metaphor and CCM founded on Habermas' philosophy of communicative action. To achieve this dialogue, I used a mixed methods approach. Before seeking lifeworld voices, I sought to evaluate the feasibility of computerised HA implementation (Chapter 5), and evaluate the credibility of computerised HA data (Chapter 6).

Chapter 5 Implementing and evaluating the value of computerised Aboriginal and Torres Strait Islander Health Assessments in primary care for clinical care and research: a process evaluation

5.1 Introduction

In Chapter 3, I presented the research questions informed by the literature review including research question number one which I will respond to in this chapter:

> Is it feasible to implement computerised Aboriginal and Torres Strait Islander HAs in Aboriginal and Torres Strait Islander primary health care which are designed to be used for both clinical and research purposes?

In Chapter 4, I described how a mixed methods approach is best suited to answering the research questions proposed in Chapter 3. The research described in this chapter, Chapter 5, expands on the published research paper[122] attached in Appendix 2. This research is situated in the postpositivist paradigm, and aims to describe and evaluate the implementation of computerised HAs, the quantitative data collection tool central to this doctoral research.

5.1.1 Paper-based health assessments at the Inala Indigenous Health Service

As described in Chapter 1, when the Australian Government introduced the Aboriginal and Torres Strait Islander HA for adults aged 55 years and over, adults aged 15 to 55 years, and then children aged 0 to 14 years, the IIHS developed a paper-based template for use in the clinic environment. Additionally, for patients with diabetes, clinical staff at the IIHS aimed to deliver the annual diabetic cycle of care (ADC) for patients with diabetes, recorded using a paper-based template, as per the national guidelines produced by Diabetes Australia and the RACGP.[245]

In 2006, researchers at the IIHS saw newly introduced paper-based child and adult HAs as a source of routinely collected clinical data for research projects. Initially, research staff obtained ethical approval to evaluate paper-based HA data from a cohort of adult and child HAs. As described in Chapters 1 and 2, research involving these two datasets resulted in cross-sectional studies describing findings from adult[48] and child[49] HAs, and five other research papers using these two datasets.[109,113,211-213]

Limitations of paper-based HAs were experienced for both clinical work and research. Clinical limitations of the paper-based HA used at the IIHS included problems with legibility, non-standardised responses, paper consumption, and the extra administrative work associated with manually scanning the HAs into the patients' medical record. Research limitations of paper-based HAs included the need to employ a research assistant to transfer paper-based HA data into the computerised spreadsheet which was time-consuming and error-prone.

5.1.2 Moving to computerised health assessments

Owing to the limitations of paper-based medical record systems, many primary health care services including the IIHS in high income countries have transferred to computerised medical record systems in the 25 years from 1990 to 2015.[246,247] I hypothesised that changing from a paper-based to a computer-based health information technology (IT) system would address many of the limitations associated with paper-based HAs for both clinical care and research. Supporting this hypothesis are studies which find clinical benefit for computerised medical records through improvements in data quality and patient care. Computerised medical record systems are less likely to result in missing clinical data than paper-based systems[248] which has been associated with fewer adverse events in Australian general practice.[249] Fewer missing data are also likely to improve the quality of research information derived from clinic data. Furthermore, computerised medical records have been shown to enhance patient care through better adherence to preventive care guidelines and evidence-based decision-making.[250-252]

There are a number of barriers to the implementation of computerised medical record systems which refers to computerised systems collecting, storing and displaying individual patient information.[253] The primary barriers to computerised medical record implementation reported by a systematic review about physician acceptance of computerised medical records included concerns about technical issues, cost, and time.[253] Regarding the 41 research papers dealing with technical issues, this systematic review revealed physician concerns about system complexity, their computer hardware, compatibility with other systems, and the quantity of training required.[253] Regarding the 33 included research papers dealing with cost, physicians were concerned about start-up costs, implementation costs, staff training costs, and ongoing costs of running the system. Regarding the 28 included research papers dealing with time, physicians were concerned about the time required to select and implement the system, the time taken to learn the new system, the time to input data, and any extra time taken per patient. Additional secondary barriers identified by physicians that were relevant to the implementation of computerised HAs included privacy and security concerns and support from other clinicians.[253]

Countering physicians' financial concerns are the results of cost-effectiveness analyses which found that benefits following the implementation of other computerised health information systems in clinical settings were likely to outweigh investment costs, though savings could take from between 3 to 13 years to be realised.[254] The other primary and secondary concerns of physicians were considered during the implementation of computerised HAs at the IIHS.

5.2 Aims, objectives, and research question

The aim of the research in this chapter is to evaluate the feasibility of implementing computerised HAs at the IIHS.

The objective of the research in this chapter is to describe and evaluate the implementation of computerised HAs at the IIHS regarding user satisfaction, uptake, and utility for research purposes.

5.3 Methods

5.3.1 Setting and participants

The suburb of Inala and the IIHS where this research is situated have been described in detail in Chapter 1. Child, adult, diabetes, and antenatal computerised HAs were introduced at the IIHS in September 2010. The antenatal computerised HA, introduced with the other computerised HAs in 2010, had no paper-based antecedent, and did not attract a Medicare payment, but was introduced with the aim of improving antenatal care. Evaluations of computerised HAs were conducted three and 12 months later in 2011.

While many participants live close to the IIHS, an unpublished 2014 audit of adult Aboriginal and Torres Strait Islander HAs at the IIHS, found that 36% of participants came from the 4077 postcode area (Inala and Richlands). Remaining participants were distributed among 57 other postcodes across Queensland and Northern New South Wales.

5.3.2 Development of computerised health assessments at the Inala Indigenous Health Service

The IIHS is managed and funded by Queensland Health, the health sector of the Queensland Government. Queensland Health IT experts built computerised HA templates within ERIC (not an acronym nor abbreviation) which is a Queensland State government computerised health record information management system already being used in the hospital and community sector of Queensland Health's Metro South health district where Inala is situated. ERIC is separate to the general practice software (Best Practice) used at the IIHS.

To facilitate the implementation of HAs in the service, the IIHS employed a Queensland Health project manager for six months to coordinate the change management process. The project manager's role was to oversee the design of computerised HAs templates, liaise with the Queensland Health IT team regarding the implementation of computerised HAs at the IIHS, support staff training to use the ERIC IT platform, survey staff regarding their satisfaction with the changes, and produce a final report. The total cost to the IIHS of the six month project including salaries for part-time project officer, IT staff, and training was $83,000.

The development of adult and child computerised HA content was informed by Medicare requirements,[68] the National guide to a preventive HA for Aboriginal and Torres Strait Islander peoples,[206] meetings with relevant clinical and community IIHS staff, and our experience at the IIHS with the paper-based HA templates. Aboriginal and Torres Strait Islander HA templates are age-specific, and are divided into child (0-4 years, 5-14 years) and adult (15-54 years, 55+ years) groupings. All Aboriginal and Torres Strait Islander HAs included information on demographic details, protective factors, health risk factors, socioeconomic factors, examination findings, and health interventions.[48,49] Additional questionnaires embedded within adult computerised HAs included the Fagerstrom test for nicotine dependence,[255] the alcohol use disorders identification test (AUDIT) screening tool for hazardous alcohol use,[256] and the ten point Kessler psychological distress scale (K10).[257]

The antenatal template for pregnant women, newly developed by the IIHS team, was designed to be commenced at the first antenatal visit, added to during the pregnancy, and completed at the first postnatal visit. Antenatal computerised HAs were developed according to the Mater Mothers' Hospital antenatal shared care guidelines for GPs.[258] This template included demographic details, pregnancy details, obstetric history, details of each antenatal visit, and a summary of important clinical information at the first postnatal visit including delivery details, the baby's birth weight, and maternal health parameters.

The computerised HA template for patients with diabetes mellitus is completed annually, and attracts government funding through the MBS as the ADC. The computerised diabetes HA template is usually conducted in conjunction with the annual Aboriginal and Torres Strait Islander HA, and a retinal photo to screen for diabetic retinopathy. The computerised diabetes HA template was designed to cover all the important components relevant to monitoring and managing diabetes mellitus in primary care, and includes glycaemic index, blood pressure, BMI, albumin-creatinine ratio, medications, and referrals. A computerised retinal photo reporting form is usually completed at the same time, and has become standard practice for patients with diabetes after researchers at the IIHS conducted a study demonstrating the value of retinal photography for diabetic retinopathy screening in Aboriginal and Torres Strait Islander primary care.[259]

During the development of computerised HA templates, I attempted to take advantage of the benefits of computerisation to advance both the clinical and research interests of computerised HAs. For example, many variables in the computerised HAs are constrained by predetermined parameters including radio buttons, tick boxes, integers, or numbers with defined decimal places. Additionally, a small number of fields, such as BMI, cardiovascular risk, and expected date of delivery, are automatically calculated from other fields within the computerised template. Furthermore, each computerised HA also takes important clinical findings from HA responses and automatically collates the responses in a self-populating HA summary. For example, when a computerised HA item response indicates a health issue, explanatory text, such as "Self-rated health is Fair" is programmed to appear in a "Health Check Summary" text box towards the end of the template. These processes are only possible with computerisation, and are designed to improve the accuracy, reliability, efficiency, and usefulness of inputted data.

Patient attendance for computerised HAs at the IIHS is facilitated by recall, reminder, and alert systems. In this way, clinical staff aimed to deliver Aboriginal and Torres Strait Islander HAs and ADCs to all regular, eligible patients each year. When regular Aboriginal and Torres Strait Islander patients present to the IIHS, nursing staff initiate computerised HAs in ERIC, medical staff complete them, and administration staff attach the completed computerised HA to the patient's medical record in the clinic's general practice software as a file in portable document format (PDF). These measures would ideally lead to a complete, consecutive census of consenting participants in computerised HA research at the IIHS.

Development of an ethical framework for research using data from computerised health assessments

Given the ERIC system at the IIHS can generate an Excel spreadsheet collating all patient level data from a given computerised HA template for any given time period, several measures were required before these data could be used for ethical research purposes. Firstly, Queensland Health IT staff supporting the ERIC system made the web-based, password-protected system containing computerised HAs available only to the IIHS clinical user group to protect patient confidentiality. Secondly, the unspecified consent process for participation in computerised HA research was developed. NHMRC guidelines on ethical conduct in human research describe “unspecified” consent as referring to situations where participants consent to the use of their data in any further research.[59] In their National Statement on Ethical Conduct in Human Research, the NHMRC advises that when researchers obtain informed, but unspecified consent to potential research participants at the start of involvement in long-standing studies, they must explain the unspecified and extended nature of that consent.[59] The statement also counsels that unspecified consent may have to be re-negotiated, for example, when children transition to adulthood. When patients present to the IIHS and are eligible for a computerised HA, they are invited to give unspecified consent to the ongoing use of their computerised HA data for research purposes. If they agree to participate, patients (or carers of assenting children aged 15 years and younger) are asked to sign the paper-based consent form, the research consent box in the computerised HA is checked “Yes” and this populates the relevant “research consent” field in the data extract. Consenting patients and carers do not have to re-sign the consent form when they return for an HA but must give verbal consent each time they present for an episode of care involving a computerised HA. Children returning for a computerised HA at age 15 years are eligible for their first adult HA, and need to sign a new consent form. Patients who refuse consent are re-invited to participate at subsequent visits. All information regarding patients who have not given research consent is removed from the data extract prior to any research analysis. Participants who do consent to the use of their computerised HA data for research purposes are not consenting to a particular project. Additional ethical approval is required for each research project using these data.

In December 2010, this process for informed consent was part of the ethics approval for the use of computerised HA data for research purposes granted by the Metro South Human Research Ethics Committee (HREC) (HREC reference number: HREC/10/QPAH/242) (see Appendix 3). The ethics application was supported by the Inala Elders. The Inala Elders is a community organisation located in Inala, run by Aboriginal and Torres Strait Islander peoples, which provides community support, mentoring programs, and programs for older Aboriginal and Torres Strait Islander people.[260] Prior to the formation of the ICJ in 2011, the IIHS sought the support of the Inala Elders for research conducted at the IIHS. Researchers, both internal and external to the IIHS, can apply to conduct research using computerised HA data by completing a brief statement of research intent and clearly outlining exactly what data are required. It is expected that the research team will involve an IIHS staff member and ideally an Aboriginal or Torres Strait Islander person.

Between 2011 and 2017, eight research papers involving IIHS HA data have been published,[49,109,113,116,121,122,213,261] and all bar one[121] have included at least one Aboriginal person on the research team. Proposals are assessed by the IIHS research committee based on project feasibility, relevance, and cultural safety considerations. If approved by the IIHS research committee, the proposal proceeds to the ICJ. The proposal is discussed with the ICJ by the lead investigator. If the proposal obtains ICJ support, the project must then receive appropriate ethical approval from the Metro South HREC.

The 14 member ICJ consists of some self-nominated members, some representatives of local organisations such as the local Elders, and some community members chosen to ensure an appropriate spread of ages, gender and ethnicity. The ICJ, which meets approximately every three months, was set up in 2011 by the IIHS research committee with terms of reference designed to improve community involvement in decisions surrounding research at the IIHS.[132] Through the ICJ, the IIHS responds to the principles of community involvement in well communicated ethical research outlined in the Australian NHMRC's Road Map for improving Aboriginal and Torres Strait Islander health through research.[220]

Once approved, the research database containing coded re-identifiable data with identifying information removed is released to the research investigators. Research results are reported back to the ICJ in an oral presentation and in written report which is made available to the Inala Aboriginal and Torres Strait Islander community.

5.3.3 Evaluation of computerised health assessment introduction at the Inala Indigenous Health Service

The evaluation of computerised HAs included a survey of staff satisfaction, measures of the completeness of transition from paper-based to computerised HAs, and measures of computerised HA uptake. I also evaluated indices relevant to research including the number of people consenting for their computerised HA data to be used for research purposes, and research projects conducted using computerised HA data.

In January 2011, nurses, doctors, and administrative staff were invited via email to participate anonymously in a brief, post-implementation, on-line questionnaire. This survey was developed and conducted by the IT department at Queensland Health, and is an indicative rather than definitive study. This survey included questions about satisfaction with training, IT support, ease of template use, the value of the HAs, and overall satisfaction with the newly introduced computerised HAs. Responses were measured on a scale from one to ten, where ten is most satisfied.

In January 2011, the proportion of HAs completed using computerised forms was calculated three months post launch. Additionally, the number of computerised HAs completed after 12 months (20th September 2010 to 19th September 2011) was extracted from ERIC, and compared with the number of paper-based HAs from the preceding year as a proportion of the regular IIHS practice patients for each year. Data were imported into specialist statistical software package Stata version 10.0 (StataCorp, College Station, Tex, USA) for analysis. Results of these comparative analyses are reported as point estimate risk difference (RD) with 95% confidence intervals (CIs), using the computerised HA data as the reference. An α=5% level was used to define statistical significance, and all reported p-values were derived from Fisher’s exact test.

5.4 Results

5.4.1 First 3 months of computerised health assessments: initial staff evaluation

The staff survey at three months received 14 responses from 20 eligible staff (70% response rate). For most measures including overall satisfaction, staff (administrative, nursing and medical users) gave the recently introduced system of computerised HAs a median mark of 8 out of 10 (Table 5.1).

Table 5.1. Satisfaction with implementation and introduction of computerised health assessments (HAs) at the Inala Indigenous Health Service on a scale of 1 to 10 where 1 represents extremely dissatisfied and 10 represents extremely satisfied.

Satisfaction survey items	Median	Range
Satisfaction with:		
consultation during implementation	8	5 to 10
training	8	1 to 9
IT support	8	5 to 10
value of computerised HAs to your work	8	4 to 10
process of entering information	7.5	4 to 10
Overall satisfaction	8	5 to 9

5.4.2 Computerised health assessment uptake

Three months following the September 2010 commencement of computerised HAs, 378 (99.5%) of 380 HAs were completed using computerised forms, and two were completed using paper forms. The total number of patients receiving a computerised HA completed after 12 months (September 2010 to September 2011) compared with paper-based HAs from the preceding year are presented in Table 5.2. In their first year of use, the overall number of completed computerised HAs, as a proportion of regular patients, was not significantly different to the number of paper-based HAs in the preceding year. There was a reduction in the proportion of child computerised HAs, diabetes, and retinal photo reporting forms compared to paper-based HAs and an increase in the proportion of adult computerised HAs compared to paper-based HAs (see Table 5.2).

The lack of integration between the computerised HA platform and IIHS general practice software led to some computerised HAs being started by nursing staff, but not being completed by medical staff because nursing staff no longer physically handed the paper HA to medical staff for completion. Nursing staff now alert medical staff to the presence of a new computerised HA using bright pink text in the patient's progress notes, and this appears to have resolved the communication breakdown.

Table 5.2 Uptake of computerised health assessments (HAs) in September 2010-2011 compared to the preceding year of paper-based HAs using summary statistics of risk difference (RD) and 95% confidence interval (CI).

	September 2009-2010 Paper HAs			September 2010-2011 Computerised HAs			RD (95% CI)
	N*	n	(%)	N*	n	(%)	
Child HA 0-14 years	831	296	(36)	862	215	(25)	-0.19 (-0.22, -0.15)
Adult HA 15-54 years	1467	419	(29)	1628	752	(46)	0.25 (0.20, 0.30)
Older persons HA 55+ years	317	99	(31)	362	132	(36)	0.06 (-0.02, 0.14)
Annual Diabetic Cycle of Care	232	129	(56)	296	138	(47)	-0.09 (0.00, 0.17)
Retinal Photo Reporting Form	232	118	(51)	296	115	(39)	-0.12 (0.03, 0.21)
Total	3079	1061	(34)	3444	1352	(39)	1.55 (-0.81, 3.91)
Antenatal HA	Not applicable			84	52	(62)	

*Regular eligible patients

5.4.3 Research and computerised health assessments

In the first 12 months following the introduction of computerised HAs in September 2010, approximately 97% of adult patients and 96% of children's parents provided consent for their data to be used in research projects. There were no significant differences between age categories (p=0.8), ethnicity (p=0.7), or sex (p=0.8) for those who consented and those who did not.

By September 2011, one year after computerised HAs were introduced to the IIHS, two research projects using computerised HA data had received approval from the ICJ and Metro South HREC to commence. One of these projects explored characteristics of the first antenatal visit and lessons that can be learnt from these presentations at the IIHS.[121] The other explored the characteristics of children being referred to the paediatrician for behavioural or developmental problems.[116]

5.5 Discussion

Overall, I have demonstrated that the implementation of a health IT system using practice based computerised HAs is feasible and acceptable to clinical staff in an Aboriginal and Torres Strait Islander primary health care service. The number of HAs conducted at the IIHS as a proportion of regular patients remained unchanged following the introduction of computerised HAs indicating a degree of clinician usability and acceptance comparable to paper-based HAs. However, the profile of completed HAs changed with increases in the proportions of adult HAs being conducted, and decreases in the proportions of child HAs, diabetes HAs, and retinal reporting forms being conducted. The shorter form and other benefits of computerisation including constrained answers, and a summary self-populating problem list appears to have mitigated some of the challenges posed by the introduction of a new IT system. Relatively high staff satisfaction levels were helped by the expertise of the project manager that facilitated ERIC training for staff and the change management process. Boonstra et al. identified a number of other physician concerns regarding organisational barriers to computerisation of health information.[253] These barriers included small organisational size, lack of customisability, and lack of organisational leadership. However, these were not barriers for this project which was conducted within Queensland Health, a large, State-funded health organisation with a ready-made, available, customisable IT platform for computerised medical records (ERIC), and IIHS leadership support.

5.5.1 Patient care and computerised health assessments

The implementation of computerised HAs in Aboriginal and Torres Strait Islander primary health care offer several potential benefits for patient care. The computerised HAs at the IIHS collate important findings in a self-populating problem list which is a useful summary for clinicians. Computerised HAs use information regarding age, sex, blood pressure, cholesterol, and diabetes to automatically calculate cardiovascular risk. Computerised HAs also contain referral prompts. These types of minimally intrusive point of care reminders have been shown to improve practice quality in other office-based clinical settings.[262] In the future, wireless functionality could enable computerised HA deployment in the home or other clinic settings using mobile technologies, and has demonstrated value in hospital settings.[263]

The implementation of computerised Aboriginal and Torres Strait Islander HAs at the IIHS was not without challenges. Issues of confidentiality, trust, and respect needed to be worked through with the creation of computerised forms and databases, and are particularly important to manage in a culturally appropriate way in Aboriginal and Torres Strait Islander communities. Furthermore, in our first year of implementing computerised Aboriginal and Torres Strait Islander HAs at the IIHS, it was concerning that clinicians completed relatively fewer child HAs. The lower uptake of child HAs may have been caused by high staff turnover among child health nurses at the IIHS, or lack of space for conducting child HAs. Moreover, findings from community consultation key informant interviews presented in Chapter 7 suggest that computerised HAs, including child assessments, are overly long. A limitation of this feasibility study is that it did not evaluate computerised HAs from the perspective of Aboriginal and Torres Strait Islander patients.

Finally, the challenge of having computerised HAs on ERIC, and not part of the clinic's general practice software remains because the vendors of general practice software systems are, so far, unwilling to incorporate customisable computerised HAs.

5.5.2 Research with computerised health assessments

For research, the introduction of computerised HAs sitting within ERIC has facilitated the generation of a large clinical dataset at minimal extra inconvenience to patients and clinical staff which can be used for research purposes. This dataset will also help researchers at the IIHS respond to calls for research at the community level which informs strategies to address the health needs of Aboriginal and Torres Strait Islander peoples living in urban areas in Australia.[4,180] The use of routinely collected clinical data for research purposes is expanding, and has been seen as an innovative, efficient, and cost-effective way to conduct health services research which can inform policy.[264] Over time, this dataset will help build a longitudinal profile of the Aboriginal and Torres Strait Islander people attending the health service.

I did not find any studies which have used computerised Aboriginal and Torres Strait Islander HA data for research purposes which suggests this is an Australian first. To look for research based on computerised HA data, I conducted a PubMed search in 2016, with no date restrictions, using the following terms;

> (health assessment OR health check OR periodic health evaluation) AND (Indigenous[ti] OR Aboriginal[ti] OR Torres Strait Islander[ti]) AND Australia

Out of 406 hits, the only two published research papers based on computerised HA data were the previously mentioned studies conducted at the IIHS.[116,121]

Limitations exist for research based on consecutive samples where participation is influenced by both patient and clinic factors. Encouragingly, in other clinical settings, such as the emergency department, selection bias associated with consecutive samples has been described as being of low clinical relevance.[265] Another potential limitation for computerised HA research which I investigate in the next chapter, Chapter 6, is that clinic-based populations may be systematically different to the community which will affect the external validity and generalisability of research results.[266]

5.6 Conclusions

Since their introduction to the IIHS in 2010, computerised HAs are likely to have contributed to improvements in patient care owing to benefits of legibility, completeness, security, and decision support. Relatively high staff satisfaction with computerised HAs was in part due to the resources available to a large organisation like Queensland Health with its own IT department and project management expertise to facilitate staff training and change management. In Chapter 6, I evaluate the data produced by computerised HAs for research purposes.

Chapter 6 Analysis of the data representativeness, completeness, reliability, and validity of computerised health assessment

6.1 Introduction

In 2010, the IIHS transitioned from paper-based Aboriginal and Torres Strait Islander HAs to computerised HAs as described in Chapter 5. By 2013, three years after the introduction of computerised HAs, over 1,500 computerised HAs had been conducted each year for children, adults, pregnant women, and people with diabetes. The use of routinely collected clinical data from computerised HAs for research purposes has the advantage of building a database of sufficient statistical power for research purposes over a relatively short period. However, these data have not been collected primarily for research purposes, and they need to be evaluated for representativeness of their population, completeness, potential bias in missing data, data reliability, and data validity.[267] In this chapter, situated in the postpositivist paradigm described in Chapter 4, I start by describing the concepts of missing data, data representativeness, data completeness, data reliability, and data validity. To evaluate data validity, I also introduce the One21Seventy database which I used as an independent reference criterion.

6.1.1 Missing data

Missing data are a major concern with observational, routinely collected clinical data, and this concern is often beyond the control of the researcher.[264] Missing data may occur at the person or variable level. Data missing at the person level will be considered as data representativeness. Missing data from variables within HAs will be considered as data completeness.

Data representativeness

Computerised HA data may be influenced by selection bias as patient and clinic factors lead to eligible patients not receiving a computerised HA. For example, patients may be too sick or too busy to have time for a computerised HA. Additionally, the clinic may be too busy at certain times to offer a computerised HA. Furthermore, during this doctoral research, all the nursing staff who initiated computerised HAs were women which may have positively or negatively influenced the uptake of computerised HAs. Thus, it is important to evaluate the differences between those who have had a computerised HA and those who have not, and to ascertain any systematic and important biases should they exist.[268,269]

Data completeness

Missing data at the variable level is often found in research datasets, and is also a risk for computerised HA based research.[250,266] Missing data may lead to bias because while the sample may be representative, the distribution of values within a variable may not be. There is no consensus on what constitutes a large amount of missing data.[270] Some have suggested that a predictor variable only needs to be deleted from an analysis when more than 40% of values are missing.[271] A ≤10% level of missing data has been considered as being acceptable,[272] while some consider ≤5% missing as being negligible.[273] Thus, in this chapter, I analysed variables for data completeness thresholds of 5% and 40%.

Levels of missing values within datasets typically vary for different variables. The computerised HA dataset is likely to be no exception as these data are primarily collected for clinical purposes rather than for research purposes. When item responses are missing, it is problematic because these missing data lead to reduced sample size, statistical power, and accuracy of outcome measures.[274] Moreover, analysis of an incomplete dataset threatens both the internal and external validity of the results for commonly employed statistical analyses which rely on complete cases. For example, multivariable logistic regression analyses on commonly used statistical software packages, such as Stata (StataCorp, College Station, Tex, USA), default to complete case datasets using only valid, non-missing data for each variable. Even if only one variable had a relatively high degree of missing data, then the number of cases utilised in the analysis will be restricted if this variable is utilised in the statistical model as only complete cases are included. In this way, missing data may lead to biased multivariable logistic regression analyses, especially if data are not missing in a random way.

Missing data may be missing at random (MAR), where the missing data are ignorable because there is no patterning of the distribution of missing data, or missing not at random (MNAR). Variables with MNAR value distributions can result in biased statistical findings, affecting the validity of any results.[269] Therefore, it is important to assess the pattern of missing data within the variables of interest.

6.1.2 Data reliability and validity

To have confidence in the accuracy of computerised HA research data, it is important to evaluate their reliability and validity in the context of the IIHS. Reliability refers to an assessment of measurement error or the reproducibility of results. Validity refers to how accurately computerised HAs allow conclusions to be drawn about the presence and degree of an attribute for an individual.[275] To evaluate reliability and validity, it is necessary to compare computerised HA data with a criterion, or reference standard, that is known or believed to be close to the truth,[266] consistent with postpositivist thinking.[224]

6.1.3 Choice of comparators

The ideal criterion for testing the reliability and validity of computerised HAs would be a survey tool validated in Aboriginal and Torres Strait Islander health services using clinical questions designed to make inferences about individuals' health status conducted at the same time as the computerised HA in the same patient population groups. As mentioned in Chapter 1, the design and implementation of this type of criterion is beyond the scope of this doctoral research. However, a proxy criterion, One21seventy audits, already exists. I also compare computerised HA data with paper-based HA data for data completeness.

One21seventy project

The One21seventy project, commenced at the IIHS in 2010 prior to the introduction of computerised HAs, and ceased being used at the IIHS at the end of 2013 when the validation evaluation described in this chapter occurred. The name 'One21seventy' reflects a commitment to increasing life expectancy for Aboriginal and Torres Strait Islander peoples beyond one year in infancy, 21 years in youth, and 70 years in the lifespan.[276] The One21seventy project builds on the previous CQI processes developed for Australian Aboriginal and Torres Strait Islander primary care, and uses audit tools validated in Aboriginal populations by its predecessor, the ABCD (Audit and Best practice for Chronic Disease) project.[277] The ABCD national research partnership began in 2002, and was a Menzies' School of Health research project funded by the NHMRC with additional funding from the Lowitja Institute. The ABCD project aimed to enhance primary health care services, using CQI processes and action research methods to improve the prevention and management of chronic disease in Aboriginal and Torres Strait Islander primary health care.[277] By 2009, ABCD CQI tools were employed by 120 health centres across Australia.[276]

One21seventy audits were deployed annually at the IIHS by a specially trained, experienced, chronic disease nurse employed by Queensland Health as CQI coordinator. The One21seventy audits used a random sample of between 30 and 100 regular practice patients to evaluate child health using 165 variables, adults without chronic disease aged 15-54 years using 86 variables, adults with chronic disease aged 15+ years using 130 variables, and antenatal care using 190 variables. The CQI coordinator conducted a manual audit of IIHS general practice software data that was de-identified (but re-identifiable), and then entered these data on a web-based program for the One21seventy project.

I chose to use the One21seventy audit data as the criterion for evaluating computerised HA reliability and validity in this thesis because it fulfilled many of the characteristics of the ideal criterion. Firstly, One21seventy audits were conducted concurrently with computerised HAs. Secondly, One21seventy audits covered similar patient groups to computerised HAs as described in Table 6.1. Thirdly, One21seventy audits have been previously tested for repeatability and both intra and inter-auditor reliability.[277] Furthermore, a search of Australian HealthInfoNet, Google Scholar, and PubMed using the terms, "audit tool" and ("Aboriginal" OR "Torres Strait Islander") did not reveal any other audit tools which were validated in the Australian primary care setting for Aboriginal and Torres Strait Islander children, adults, people with diabetes, and pregnant women.

Table 6.1 Computerised Aboriginal and Torres Strait Islander Health Assessment (HA) and the corresponding One21seventy audit tool.

Computerised HA	Corresponding One21seventy audit
Child (0-14 years)	Child (0-14 years)
Adult (15-54 years)	Adults without chronic disease (15-54 years)
Adult (55+ years)	No corresponding audit
Annual Diabetes Assessment	Adults with diabetes (15+ years)
Retinopathy reporting form	No corresponding audit
Antenatal assessment	Pregnant women

I used One21seventy project data for all parts of this evaluation of computerised HAs. For measures of the representativeness of computerised HA data, I considered demographic data from One21seventy audits of adults without chronic disease, diabetes, and pregnant women as a representative sample of the IIHS clinic population because One21seventy data used random samples. One limitation of this approach is that One21seventy adult audits did not include patients with chronic disease whereas adult computerised HAs included patients irrespective of whether they had a chronic disease or not. A second limitation is that the One21seventy audit for children used a random sample within narrow age strata, and was not a suitable comparator with computerised child HAs for data representativeness. For children, active child patients attending the IIHS were used as the comparator. An active patient is defined as one who had presented at least once to the

IIHS during the one year study period. Thus, active patients are defined differently to regular patients who, as defined in Chapter 1, have attended the health service at least three times in the preceding two years.

For measures of data completeness, reliability, and validity, the One21seventy audit data provided a ready-made set of independently selected variables of clinical importance which could contribute to a set of core variables. Core variables were defined as variables common to both the One21seventy audit data and computerised HA data. There were well over 2,000 computerised HA variables (the variable codebook for computerised HAs runs to 185 pages), but only 69 of these variables were common to both computerised HAs and One21seventy audit data. Of these 69 core variables, 48 contained data in both datasets that could be matched. For the 21 variables containing data which could not be matched, there were important differences regarding the way variables were defined in computerised HAs and the One21seventy audit data, or the data were completely missing from one or both datasets. The measures from the 48 matched One21seventy variables were used as the reference criterion to compare with the corresponding computerised HA measures to evaluate computerised HA data reliability and validity. The 69 core variables are presented in Table 6.2 by computerised HA, and whether they could be matched.

Table 6.2 Core variables common to both One21seventy audits and computerised health assessments (HA).

HA Template	Core variables
Adults without chronic disease (15 variables)	
	Core variables containing data that could be matched
	Age, Sex, Ethnicity, Chronic conditions, Smoking status, High risk of alcohol, Body mass index, Papanicolaou smear up to date, Was K10 used?, K10 score, Blood Pressure, Proteinuria, Blood sugar level.
	Core variables containing data that could not be matched*
	Mammogram up to date, Dyslipidaemia
Antenatal care (24 variables)	
	Core variables containing data that could be matched
	Maternal age, Gestational age at birth, Birth weight, Infant ethnicity, Type of birth, Gestational age at first visit, Folic acid supplementation, Iron supplementation, Smoking, Alcohol, Recreational drugs, Body mass index, Rhesus factor
	Core variables containing data that could not be matched*
	Maternal ethnicity, Social risk factors, Abnormal urinalysis, Glucose screening test, Ultrasounds, Postnatal visit, Anaemia, Rubella titre, Reduced foetal movements, Blood Pressure, Abnormal glucose challenge test, Social risk factors
Diabetes (17 variables)	
	Core variables containing data that could be matched
	Age, Sex, Smoking status, Monofilament test, Amputation, Retinal photo, Treatment with metformin, Treatment with other oral hypoglycaemic drugs, Treatment with insulin, glycated haemoglobin (HbA1c) result, Systolic blood pressure, Diastolic blood pressure, Body mass index
	Core variables containing data that could not be matched*
	Retinopathy, Foot ulcer, Visual acuity, Foot check
Children (13 variables)	
	Core variables containing data that could be matched
	Age, Sex, Ethnicity, Weight, Height, Head circumference, Faltering growth, Developmental delay, Concern about domestic environment
	Core variables containing data that could not be matched*
	Oral health, Body mass index, Evidence of overweight/ obesity, Housing concern

* Core variables could not be matched where the variable definitions for One21seventy audit data were not comparable with computerised health assessment data or for one of the audits there were no data to compare (100% missing data).

There were limitations of the One21seventy audits as a reference criterion for evaluating computerised HA data. Firstly, it is possible that data from computerised HAs were used in the One21seventy audit. Thus, One21seventy audit data are not completely independent of computerised HA data. This bias may inflate reliability measures and is further evaluated in this chapter. Secondly, the time between computerised HA and One21seventy CQI measures (test-retest interval) ranged from 0 to 12 months. The reliability of a test-retest procedure is likely to become lower as the time interval between testing increases.[266] The test-retest interval may have negatively affected reliability measures, especially for less stable measures such as blood pressure.

Paper-based health assessments

In this chapter, I also compare data collected using paper-based HAs with those collected using computerised HAs. It was important to ensure that moving from paper-based HAs to computerised HAs led to HAs with either the same quantity or fewer missing data. As I described in Chapter 1, paper-based Aboriginal and Torres Strait Islander HAs were introduced at the IIHS for adults in 2004 and for children in 2006. Two databases of paper-based HAs were created for research purposes; one for adults (2007 to 2008) and one for children (2007 to 2009), and they are described in more detail elsewhere.[48,49] In addition to other benefits of computerised HAs described in Chapter 5, research data collected using computerised forms may be less likely to result in item non-response compared with paper-based forms.[248]

6.2 Aims, objectives, and research question

In Chapter 5, I showed that moving from paper-based HAs to computerised HAs was feasible and could produce data for research purposes. In this chapter I aim to evaluate the uptake, representativeness, completeness, and reliability of computerised HA data collected by computerised HAs at the IIHS.

Responding to this aim, the specific objectives of this chapter follow below regarding data representativeness, completeness, reliability, and validity.

Data representativeness

To evaluate the representativeness of computerised HAs against a random sample of IIHS practice patients generated by the One21seventy project.

Data Completeness

To evaluate the extent of missing data within computerised HAs.

Patterns of missing data

To evaluate the missing data of computerised HA variables looking for patterns of missing data according to demographic factors.

Paper versus computerised health assessments

To compare the level of missing data for the same variables between computerised and paper-based HAs.

Reliability and validity

To evaluate the reliability and validity of selected computerised HA measures compared with responses to the same demographic and clinical attributes measured by the concurrent One21seventy criterion dataset.

The research question, described in Chapter 3, for this chapter is;

> Do computerised Aboriginal and Torres Strait Islander HAs produce data which are sufficiently complete, reliable, valid, and representative of the local Aboriginal and Torres Strait Islander community to be used for research purposes?

6.3 Methods

In this section, I describe the setting, participants, tools, and processes I used to evaluate the representativeness, completeness, reliability, and validity of computerised HA data.

6.3.1 Setting and participants

In 2011, the IIHS saw 2,701 Aboriginal and Torres Strait Islander adults and 1,108 Aboriginal and Torres Strait Islander children as regular patients, defined by the One21seventy project as those who have consulted with the service at least three times in the preceding two years. Within this population there were approximately 40 pregnant women at any one time and 237 patients with diabetes.

6.3.2 Computerised health assessment template information

I extracted Excel spreadsheets for the 12 month period from 7th February 2012 until 6th February 2013 for child, adult, diabetes, and antenatal computerised HA templates. This timeframe was deliberately chosen to coincide with the 12 months reporting period for the One21seventy data audit.

I then imported Excel spreadsheets for computerised HAs into Stata version 12.0 (StataCorp, College Station, Tex, USA) to compare One21seventy data, and also for the comparison with paper-based HAs.

6.3.3 Comparators

I compared computerised HA data with One21seventy data for data representativeness, measures of reliability and validity. I compared computerised HA data with paper-based HAs for missing data.

One21seventy audit data

I contacted the One21seventy office in Brisbane, and asked for the Excel spreadsheets containing de-identified IIHS data for child, adult without chronic disease, adult with chronic disease, and antenatal audits. I used these Excel spreadsheets to compare the demographic representativeness of computerised adult, diabetes, and antenatal HAs.

To measure computerised HA data reliability and validity, I constructed a new database combining computerised HA and One21seventy audit data. Firstly, I re-identified the One21seventy data using the patient key kept at the IIHS, and deleted the variables that did not match computerised HA variables. Next, I imported the resulting Excel spreadsheets for child, preventive health, chronic disease, and antenatal One21seventy audits into Stata files and conducted deterministic matching based on the patient key with the corresponding computerised HA Stata files. I created a new merged Stata file, and deleted the records of patients who did not have both a computerised HA and a One21seventy audit.

Paper-based health assessment database

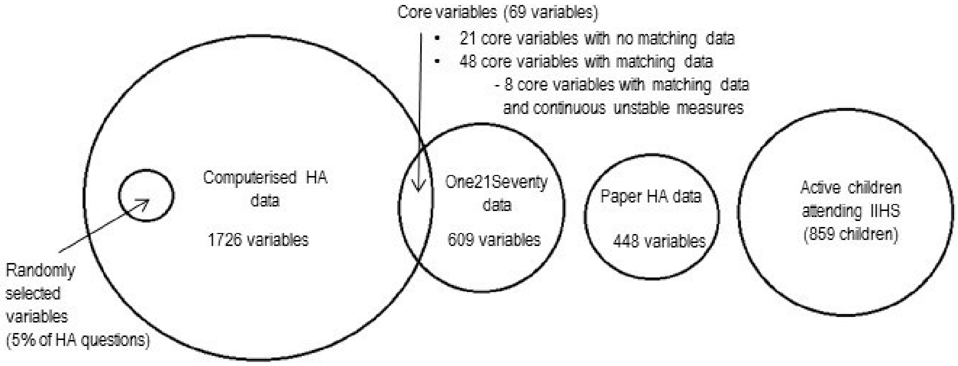
To compare the level of missing data in paper-based HAs with the newly introduced computerised HAs, I used the previously identified and defined core variables which were common to computerised HAs and One21seventy audits (Table 6.2). For adults, I used 413 paper-based adult Aboriginal and Torres Strait Islander HAs conducted at the IIHS between June 2007 and July 2008 inclusive (response rate 81%). The majority of participants identified as being Aboriginal (93%), with 4% of participants identifying as Torres Strait Islander, and 3% identified as both Aboriginal and Torres Strait Islander.[48] For children, 786 paper-based child HAs had been completed from May 2007 to December 2009. Of these, 245 (31%) represented a second HA in the same child completed within the study period. To avoid duplication, I excluded second child HAs along with 109 (20%) child HAs not accompanied by a research consent form which left 433 child HAs available for analysis. The children (54% male) were Aboriginal (91%), Torres Strait Islander (2%) or both Aboriginal and Torres Strait Islander (7%).[49] Children's ethnicity was determined by how their ethnicity was recorded in their medical record, as reported by their parent(s).

Binary outcome variables in the paper-based adult HA were all transferred to the Excel spreadsheet as either zeroes (negative response) or ones (positive response) with missing values being recorded as zeroes. This manner of data transfer limited the value of paper-based adult HAs as a comparator for missing data with computerised HAs. However, missing data were recorded in the Excel spreadsheet for paper-based HAs for categorical variables with multiple outcomes and for continuous variables. For both adult and child paper-based HAs, I imported the Excel databases into Stata for comparison with computerised HA information.

6.3.4 Data Analysis

I conducted all statistical analyses in this chapter using Stata version 12.0. I have summarised the data sources and analyses that I have used in Chapter 6 in Figure 6.1.

Figure 6.1 Summary of data sources and analyses used to evaluate computerised health assessment (HA) data at the Inala Indigenous Health Service (IIHS)



Data analysis involving computerised HA data		Computerised HAs compared with:		
	Computerised HA data	One21seventy data	Paper HA data	Active children attending IIHS
Data representativeness	Adult, diabetes, antenatal	Yes	No	No
	Child	No	No	Yes
Data completeness	Core variables	No	Yes	No
	Randomly selected variables	No	Yes	No
Data reliability and validity	All core variables with matching data	Yes	No	No
	Non-identical values of core variables with continuous, unstable measures	Yes	No	No

Data representativeness

I compared the demographic characteristics (age, sex, and ethnicity) of those adults, people with diabetes, and women receiving antenatal care who had computerised HAs with those who contributed data to One21seventy audits. For these groups the One21seventy audit used a random sample of the IIHS practice population, and therefore provided a suitable comparator to computerised HA data for evaluating the representativeness of the clinic population. For children, I compared the demographic details of children who had had a computerised HA with children who were active patients according to the practice's general practice software, and had presented at least once to the IIHS during the same period (7th February, 2012 to 6th February, 2013). Differences in the demographic characteristic proportions were expressed as relative risk (RR) with 95% CIs.

Data completeness

I calculated the proportions of missing data for core variables common to the computerised HAs and the One21seventy project. Apart from contributing to the definition of core variables, I did not use One21seventy audits for any other analysis of data completeness. I have presented analyses of missing data in computerised HAs based on cut offs of ≤5% missing data, and >40% missing data as described in the introduction.

With 1726 computerised HA variables, I wanted to randomly select an additional 5% of variables, so that I could widen my evaluation of data completeness beyond the core variables. For each of the four computerised HA templates, I used the random number generator in Excel to randomly select additional non-core variables (5% of computerised HA questions) for evaluation of data completeness. Where the randomly selected variables were part of a questionnaire and/or may have been dependent on other responses in the computerised HA, the most closely connected variable that should have been completed was chosen. For example, the Pap smear completed box was randomly selected, but was only relevant to women who had the box checked that corresponded to their Pap smear being due. Therefore, the Pap smear due box in female computerised HA templates was used rather than Pap smear completed. The full list of randomly selected variables is presented in Appendix 4.

Patterns in missing data

Where core and randomly selected computerised HA variables had >5% missing data, I conducted separate logistic regression analyses to assess whether these missing data were associated with key demographic variables: age deciles, sex, and ethnic identification (Aboriginal, Torres Strait Islander, Aboriginal and Torres Strait Islander). I conducted a Wald post-estimation x^2 test for a significant association, using an α=5% level.

Paper health assessments versus computerised health assessments

Using core variables, I compared the proportion of missing data from computerised HAs against their paper-based equivalents using the RR ratio with a 95% CI.

Analysis of reliability and validity for computerised health assessments

I compared computerised HA measures with matched patient data in the One21seventy database. The four categories of One21seventy audit tools corresponding with computerised HAs contained between 13 and 24 variables corresponding with measures in computerised HAs. Of the 69 core variables common to computerised HAs and One21seventy audits, 48 contained data that could be matched (Table 6.2). I compared the agreement or reproducibility of individual item responses from the computerised HAs with One21seventy audit data collected in the same 12 month period, and I employed the relevant statistical measures of agreement associated with test-retest reliability for continuous and categorical data, as follows.

For variables containing continuous data, I evaluated the agreement of item responses for continuous data between computerised HAs with One21seventy data using the intraclass correlation coefficient (ICC).[278] A two-way random-effects measure of variance using the absolute ICC was calculated as I was most interested in the reliability of measures based on a number of interchangeable raters.[279] These raters are the doctors and nurses at IIHS completing computerised HA forms, and the auditors gathering One21seventy data. The test-retest reliability of the actual values attributed to clinical variables by raters was the outcome of interest rather than the consistency of ratings so measures of absolute agreement were used in the analysis. For each ICC calculation, I reshaped the Stata file into long form using the continuous measure from computerised HAs and the continuous measure from One21seventy audit data. I used Cohen's values to interpret ICCs as recommended by McGraw et al. where weak correlation is less than 0.3, medium correlation is 0.31 to 0.8, and high is greater than 0.8.[280] Thus, if a continuous variable common to computerised HAs and One21seventy audits has an ICC value of 0.9, the computerised HA measurement is defined as highly reliable compared with the criterion.

All IIHS patients included in this evaluation had both a computerised HA and One21seventy audit. For many participants, the One21seventy auditor would not have included computerised HA information, and would have used other information from the participant's file. However, if computerised HA data were included in the One21seventy audit data then this would increase the agreement between the two datasets. For identical measures, it is not possible to know if One21seventy audit data represents the computerised HA data I am trying to compare it with for categorical and some continuous variables. For less stable continuous variables which would be expected to change from measurement to measurement, such as blood pressure, HbA1c, weight (measured in kilograms to the first decimal point) and BMI (measured to the first decimal point), differing values are likely to arise from independent measurements.

Thus, in addition to using and presenting the results from the complete dataset, I conducted a subsequent analysis (ICC) including only patients who had non-identical measures for unstable, continuous variables such as blood pressure. The ICC produced by this subsequent analysis measured the correlation of computerised HA and One21seventy data that were likely to be independently measured, and could then be compared with the ICC on the whole dataset. Any large discrepancies in these ICC measures would indicate bias owing to a lack of independence of One21seventy and computerised HA datasets. If the results of this subsequent analysis were consistent with the full analysis, then I could be confident that the bias associated with the lack of independence of computerised HA data and One21seventy data was small.

For comparing categorical variables between computerised HAs and One21seventy data I used the simple kappa statistic as recommended for measuring agreement between binary, non-ordinal datasets.[278] The interpretation of kappa coefficients is described in Table 6.3.[281]

Table 6.3 Kappa statistic interpretation

Kappa score	Level of agreement
≤0.2	slight agreement
0.21-0.4	fair agreement
0.41-0.6	moderate agreement
0.61-0.8	substantial agreement
0.81-1.0	almost perfect agreement

6.3.5 Ethics

I obtained ethical approval for the use of computerised HA data for research purposes from Metro South HREC in 2010. Ethical approval for the use of One21seventy audit data was obtained in 2011 from the Darling Downs Hospital and Health Service HREC. The ICJ supported this project, and the Metro South HREC approved this data evaluation study. As described in Chapter 5, individual patients consented to the use of their computerised HA information for research purposes.[122]

6.4 Results

6.4.1 Data representativeness

The proportions of adults, people with diabetes, and pregnant women who had computerised HAs at the IIHS were similar in age, sex, and ethnicity to a representative sample of regular IIHS patients determined using One21seventy audit data. There was a greater proportion of children aged 0-4 years who had had a computerised HA compared to active child patients (RR 1.3 (95% CI: 1.1,1.5)), and slightly fewer children of Aboriginal ethnicity (RR 0.9 (95% CI: 0.9, 1.0) had had a computerised HA (Table 6.4).

Table 6.4 The number, proportions, and relative risk (RR) with 95% confidence interval (CI) for children by age, sex, and ethnicity who had computerised health assessments (HA) compared to all children attending the Inala Indigenous Health Service (IIHS) as active practice patients (Feb 2012-Feb 2013).

Demographic variable		Computerised HAs (N=204)		Active IIHS patients (N=859)		Difference RR (95% CI)
		n	(%)	n	(%)	
Age (years)						
	0-4	98	(48)	326	(38)	1.3 (1.1,1.5)
	5-9	58	(28)	304	(35)	0.8 (0.6,1.0)
	10-14	48	(24)	229	(27)	0.9 (0.7.1.1)
Sex						
	Female	96	(47)	410	(48)	1.0 (0.8, 1.1)
Ethnicity		N=198		N=843		
	Aboriginal	182	(92)	812	(96)	0.9 (0.9, 1.0)
	Aboriginal and Torres Strait Islander	10	(5)	28	(3)	1.5 (0.7, 3.0)
	Torres Strait Islander	6	(3)	19	(2)	1.3 (0.5, 3.4)

For adults (Table 6.5), people with diabetes (Table 6.6), and pregnant women (Table 6.7) there were no significant differences in the demographic profile between those who had computerised HAs and regular patients identified by the One21seventy audit for age, sex, and ethnicity.

Table 6.5 The number, proportions, and relative risk (RR) with 95% confidence interval (CI) for adults by age, sex, and ethnicity who had computerised health assessments (HA) compared to randomly selected adult regular patients from the adult One21seventy audit at the Inala Indigenous Health Service (Feb 2012-Feb 2013).

Demographic variable		Computerised HA data (N=888)		One21seventy data (N=209)		Difference RR (95% CI)
		n	(%)	n	(%)	
Age (years)						
	15-24	239	(27)	61	(29)	0.9 (0.7,1.2)
	25-34	153	(17)	42	(20)	0.9 (0.6,1.2)
	35-44	183	(21)	42	(20)	1.0 (0.8, 1.4)
	45-54	162	(18)	35	(17)	1.1 (0.8, 1.5)
	55 and over	148	(17)	29	(14)	1.2 (0.8,1.7)
Sex						
	Female	466	(52)	108	(52)	1.0 (0.9, 1.2)
Ethnicity		N=870		N=208		
	Aboriginal	809	(93)	197	(95)	1.0 (0.9, 1.0)
	Aboriginal and Torres Strait Islander	34	(4)	6	(3)	1.3 (0.6, 3.1)
	Torres Strait Islander	27	(3)	5	(2)	1.3 (0.5, 3.2)

Table 6.6 The number, proportions, and relative risk (RR) with 95% confidence interval (CI) for patients with type 2 diabetes by age, sex, and ethnicity who had computerised health assessments (HA) compared to randomly selected patients with type 2 diabetes from the One21seventy audit at the Inala Indigenous Health Service (Feb 2012-Feb 2013).

Demographic variable		Computerised HA data (N=143) n	(%)	One21seventy data (N=127) n	(%)	Difference RR (95% CI)
Age (years)						
	15-24	1	(1)	1	(1)	0.9 (0.2, 3.6)
	25-34	6	(4)	8	(6)	0.8 (0.5, 1.4)
	35-44	13	(9)	21	(17)	0.7 (0.5, 1.0)
	45-54	44	(31)	40	(31)	1.0 (0.8, 1.3)
	55-64	52	(36)	40	(31)	1.1 (0.9, 1.4)
	65-74	21	(15)	12	(9)	1.2 (0.9, 1.7)
	75 and over	6	(4)	5	(4)	1.0 (0.6, 1.8)
Sex						
	Female	72	(50)	63	(50)	1.0 (0.8, 1.3)
Ethnicity				N=126		
	Aboriginal	134	(94)	123	(97)	1.0 (0.9, 1.0)
	Aboriginal and Torres Strait Islander	7	(5)	0	(0)	*
	Torres Strait Islander	2	(1)	3	(2)	0.6 (0.1, 3.4)

* unable to estimate

Table 6.7 The number, proportions and relative risk (RR) with 95% confidence interval (CI) for pregnant women by age and ethnicity that had computerised health assessments (HA) compared to randomly selected pregnant women from the One21seventy audit at the Inala Indigenous Health Service (Feb 2012-Feb 2013).

Demographic variable		Computerised HA data (N=55) n	(%)	One21seventy data (N=40) n	(%)	Difference RR (95% CI)
Age (years)						
	15-24	30	(55)	25	(63)	0.9 (0.6, 1.2)
	25-34	23	(42)	11	(28)	1.3 (0.9, 1.8)
	35-44	2	(4)	4	(10)	0.6 (0.2, 1.4)
Ethnicity		N=46				
	Aboriginal	43	(93)	36	(90)	1.0 (0.9, 1.3)
	Aboriginal and Torres Strait Islander	3	(7)	3	(8)	0.9 (0.2, 4.2)
	Torres Strait Islander	0	(0)	1	(3)	*

* unable to estimate

6.4.2 Data completeness

For adult and diabetes computerised HAs, 77% and 67% of core variables had ≤5% missing data, and 12% and 0% had >40% missing data respectively. For adult and diabetes computerised HAs, 26% and 17% of randomly selected variables had ≤5% missing data, and 5% and 26% had >40% missing values respectively (Table 6.8). Levels of missing data for child computerised HAs were high for both core and randomly selected variables at the 5% level (63% and 97% respectively), but much lower at the 40% level (3% and 5% respectively) (Table 6.8).

For antenatal computerised HAs, almost all core variables (92%) were missing more than 5% of their data, and a majority of core values were also missing more than 40% of their data. Given the findings of high proportions of core variables with large amounts of missing data in the antenatal assessment, I concluded that I had demonstrated a concern with missing data in the antenatal computerised HA, and an analysis of random variables was not warranted (Table 6.8).

Table 6.8 Proportions of variables with more than 5% and 40% missing data in computerised health assessments (HA) at the Inala Indigenous Health Service (2012-2013).

Computerised HA	Core Variables					Randomly selected variables				
	Total	>5% missing		>40% missing		Total	>5% missing		>40% missing	
	N	n	(%)	n	(%)	N	n	(%)	n	(%)
Child HA	30	19	(63)	1	(3)	39	38	(97)	2	(5)
Adult HA	26	6	(23)	3	(12)	34	25	(74)	9	(26)
Diabetes HA	9	3	(33)	0	(0)	6	5	(83)	1	(17)
Antenatal HA	24	22	(92)	13	(54)	*	*	*	*	*

* calculations for the extra 5% of randomly selected variables for antenatal HAs were not conducted owing to the large percentage of missing data for core variables

6.4.3 Patterns in item non-response

Overall, ten (6%) of 168 computerised HA variables tested contained missing data that appeared to be MNAR, with missing data associated with at least one of the demographic variables considered (Table 6.9).

Table 6.9 Numbers of computerised health assessment (HA) variables with data “missing not at random” (MNAR) according to age, sex, or ethnicity.

Computerised HA	Variables MNAR		
	N	n	(%)
Child HA (0-4 years)	25	1	(4)
Child HA (5-9 years)	22	0	(0)
Child HA (10-14)	22	0	(0)
Adult HA (15-54 years)	30	4	(13)
Adult HA (55 years and over)	30	5	(17)
Diabetes HA	15	0	(0)
Antenatal HA	24	0	(0)
Total	168	10	(6)

6.4.4 Paper health assessments versus computerised health assessments

Computerised child HA data were either less likely to be missing than for paper-based HAs or not significantly different for nine out of 16 core variables (56%) (Table 6.10). Computerised adult HA variables were either less likely to contain missing data than paper-based HAs, or not significantly different for 11 out of 14 core variables (79%) (Table 6.11).

Table 6.10 Missing data from core variables in child computerised health assessments (HA) at the Inala Indigenous Health Service (2012-2013) compared to corresponding paper-based HA data (2007-2010) using relative risk (RR) and 95% confidence interval (CI).

Variables	Computerised child HA missing data (N=204)		Paper child HA missing data (N=433)		RR (95% CI)
	n	(%)	n	(%)	
Fewer missing data in computerised HAs					
Dental problems identified	18	(9)	86	(20)	0.5 (0.3, 0.7)
Stressful events	17	(8)	78	(18)	0.5 (0.3, 0.8)
Supervision of tooth brushing	24	(12)	93	(21)	0.6 (0.4, 0.8)
Child's ethnicity	6	(3)	17	(4)	0.8 (0.4, 1.6)
No difference in missing data					
Age	0	(0)	0	(0)	*
Sex	0	(0)	9	(2)	*
Ear examination findings	28	(14)	61	(14)	1.0 (0.7, 1.4)
Number of people in the house	15	(7)	24	(6)	1.2 (0.8, 1.9)
Mental health status	46	(23)	73	(17)	1.3 (1.0, 1.7)
More missing data in computerised HAs					
Skin sores identified	36	(18)	43	(10)	1.5 (1.1, 2.0)
Immunisation status	18	(9)	18	(4)	1.6 (1.1, 2.4)
Height	21	(10)	12	(3)	2.1 (1.5, 3.0)
Domestic violence risk	66	(32)	51	(12)	2.1 (1.7, 2.7)
Weight	19	(9)	8	(2)	2.3 (1.6, 3.4)
Referral made	27	(13)	2	(0)	3.2 (2.3, 4.4)
Single parent status	42	(21)	1	(0)	3.6 (2.8, 4.7)

* CI unable to estimate

Table 6.11 Missing data from core values in adult computerised health assessments (HA) at the Inala Indigenous Health Service (2012-2013) compared to corresponding paper-based HA data (2007-2010) using relative risk (RR) and 95% confidence interval (CI)

Variables	Computerised adult HA missing data (N=740)		Paper adult HA missing data (N=442)		RR (95% CI)
	n	(%)	n	(%)	
Fewer missing data in computerised HAs					
Systolic blood pressure	1	(0)	29	(7)	0.1 (0.0, 0.1)
Overall health	8	(1)	53	(12)	0.2 (0.1, 0.3)
Employment status	9	(1)	43	(10)	0.3 (0.2, 0.4)
BMI	7	(1)	30	(7)	0.3 (0.2, 0.5)
Fagerstrom screening	425	(57)	346	(78)	0.7 (0.7, 0.8)
Visual acuity	46	(6)	47	(11)	0.8 (0.6, 0.9)
No difference in missing data					
Mammography screening required[a]	6	(2)	9	(2)	0.6 (0.4, 1.1)
Blood glucose	39	(5)	33	(7)	0.9 (0.7, 1.0)
Age	0	(0)	0	(0)	1[b]
Sex	0	(0)	0	(0)	1[b]
Audit score	442	(60)	224	(55)	1.1 (1.0, 1.2)
More missing data in computerised HAs					
Pap smear required[c]	21	*(6)*	2	*(0)*	1.5 (1.2, 2.0)
Ethnicity	13	*(2)*	0	*(0)*	1.6 (1.2, 2.2)
Total cholesterol/ HDL ratio	671	*(91)*	337	*(76)*	1.7 (1.4, 2.0)

[a] Out of 740 computerised adult HAs, 378 women (N) were eligible for mammography screening. For 442 paper-based adult HAs, 240 women (N) were eligible for mammography screening.

[b] CI unable to estimate

[c] Out of 740 computerised adult HAs, 378 women (N) were eligible for a pap smear. For 442 paper-based adult HAs, 239 women (N) were eligible for a pap smear.

6.4.5 Reliability and validity of computerised health assessment data compared to One21seventy data

When looking at all the matched information, over three quarters (77%) of computerised HA variables were in at least moderate agreement with the comparable One21seventy variable, and 46% were in high or very high agreement. Analysis of computerised HA and One21seventy variables using data that were likely to be independently measured between information sources demonstrated no significant difference from analyses using the complete data.

Reliability and validity of child computerised health assessments

For children, 45 records were matched providing adequate comparative data for most measures except for head circumference where only three records contained data that could be matched (Table 6.12).

Table 6.12 Reliability and validity of child computerised health assessment (HA) variables compared to One21seventy audit data (criterion) using kappa test for categorical variables and intraclass correlation coefficient (ICC) for continuous variables.

Variable	Number of matched records	Comparative statistic
Categorical variables		Kappa test
Fair agreement (kappa 0.21 to 0.4)		
Concern about domestic environment	18	0.31
Moderate agreement (kappa 0.41 to 0.6)		
Developmental delay	18	0.55
Substantial agreement (kappa 0.61 to 0.8)		
Ethnicity	18	0.64
Almost perfect agreement (kappa 0.81 to 1)		
Sex	45	0.91
Growth faltering	12	1
Continuous variables		ICC
Medium correlation (ICC 0.31 to 0.8)		
Head Circumference	3	0.52
High correlation (ICC >0.8)		
Age	45	0.90
Height	17	0.96
Weight	18	0.98

I conducted additional analysis on child computerised HA and One21seventy data likely to be measured independently. The values for height were different between computerised HAs and One21seventy for 9 patients (53%) with an ICC of 0.95 while the values for weight were different for 16 (89%) patients with an ICC of 0.97. For both height and weight, these ICCs were similar to the ICC conducted using all measures.

Reliability and validity of adult computerised health assessments

For adults, 82 records could be matched. Most data were in moderate agreement or better (10/13 variables) for computerised HA and One21seventy audit data (Table 6.13).

Table 6.13 Reliability and validity of adult computerised health assessment (HA) variables compared to One21seventy audit data (criterion) using kappa test for categorical variables and intraclass correlation coefficient (ICC) for continuous variables.

Variable	Number of matched records	Comparative statistic
Categorical variables		Kappa test
Slight agreement (kappa ≤0.2)		
Chronic conditions	82	0.07
Pap smear up to date	32	0.14
Fair agreement (kappa 0.21 to 0.4)		
High risk of alcohol	62	0.39
Moderate agreement (kappa 0.41 to 0.6)		
Blood pressure (elevated or not)	82	0.47
Ethnicity	82	0.48
Blood sugar level (elevated or not)	42	0.49
Substantial agreement (kappa 0.61 to 0.8)		
K10 test used	82	0.65
Almost perfect agreement (kappa >0.8)		
Smoking status	82	0.85
Proteinuria	51	0.88
Sex	82	0.98
Continuous variables		ICC
High correlation (ICC >0.8)		
BMI	78	0.99
K10 score	11	1.0
Age	82	1.0

Again, I conducted additional analysis of adult computerised HA and One21seventy data likely to be measured independently. BMI was the only continuous variable considered likely to provide different measures on different occasions. The measure for BMI was non-identical between computerised HAs and One21seventy for 7 patients (9%) with an ICC of 0.96. For BMI, the ICC conducted on non-identical measures was similar to the ICC conducted using all measures.

Reliability and validity of diabetes computerised health assessments

For people living with diabetes, 72 records could be matched. Most data were in moderate agreement or better (10/13 variables) for computerised HA and One21seventy audit data (Table 6.14).

Table 6.14 Reliability and validity of diabetes computerised health assessment (HA) variables compared to One21seventy audit data (criterion) using kappa test for categorical variables and intra-class correlation coefficient (ICC) for continuous variables.

Variable	Number of matched records	Comparative statistic
Categorical variables		Kappa test
Fair agreement (kappa 0.21 to 0.4)		
Retinal photo	64	0.21
Treatment with metformin	72	0.21
Monofilament test	25	0.28
Moderate agreement (kappa 0.41 to 0.6)		
Treatment with other oral hypoglycaemic drugs	72	0.57
Almost perfect agreement (kappa 0.81 to 1.0)		
Treatment with insulin	72	0.90
Smoking status	72	0.97
Amputation	28	1.0
Sex	72	1.0
Continuous variables		ICC
Medium correlation (ICC 0.31 to 0.8)		
Systolic blood pressure	71	0.49
Diastolic blood pressure	71	0.63
High correlation (ICC >0.8)		
HbA1c	72	0.84
BMI	72	0.99
Age	72	1.0

For diabetes computerised HAs there were a number of continuous variables that were likely to be measured independently. I considered HbA1c, BMI, systolic and diastolic blood pressure to be continuous variables most likely to provide different measures on different occasions for the diabetes computerised HA. Non-identical measures were found for HbA1c in 64 (89%) patients, for BMI in 68 (94%) patients, for systolic blood pressure in 53 (75%) patients and for diastolic blood pressure in 52 (73%) patients. The ICC conducted on non-identical measures (Table 6.15) was similar to the ICC conducted using all measures (Table 6.14).

Table 6.15 Reliability and validity of non-identical diabetes computerised health assessment (HA) variable measures compared to One21seventy audit data (criterion) using intra-class correlation coefficient (ICC).

Variable	Number of matched records	ICC
Continuous variables		
Medium correlation (ICC 0.31 to 0.8)		
Systolic blood pressure	53	0.34
Diastolic blood pressure	52	0.53
HbA1c	64	0.77
High correlation (ICC >0.8)		
BMI	68	0.99

Reliability and validity of antenatal computerised health assessments

For pregnant women, only 8 records could be matched providing limited data for analysis. Most data were in moderate agreement or better (12/14 variables) for computerised HA and One21seventy audit data (Table 6.16).

Table 6.16 Reliability and validity of antenatal computerised health assessment variables compared to One21seventy audit data (criterion) at the Inala using kappa test for categorical variables and intraclass correlation coefficient (ICC) for continuous variables.

Variable	Number of matched records	Comparative statistic
Categorical variables		Kappa test
Slight agreement (kappa ≤0.2)		
Folic acid supplementation	8	0.0
Infant ethnicity	8	0.0
Moderate agreement (kappa 0.41 to 0.6)		
Iron supplementation	7	0.5
Substantial agreement (kappa 0.61 to 0.8)		
Alcohol use	7	0.7
Almost perfect agreement (kappa 0.81 to 1.0)		
Smoking	7	1.0
Recreational drug use	8	1.0
Rhesus factor	7	1.0
Type of birth	7	1.0
Continuous variables		ICC
Medium correlation (ICC 0.31 to 0.8)		
BMI	4	0.6
Gestational age at birth	7	0.8
High correlation (ICC >0.8)		
Age	7	0.9
BMI	4	1.0
Gestational age at first visit	7	1.0
Birth weight	7	1.0

BMI was the only continuous variable considered likely to provide different measures on different occasions. Non-identical measures were found for BMI in all 4 (100%) patients so the ICC was unchanged compared to the ICC on all measures.

6.5 Discussion

Overall, I found that child, adult, and diabetes computerised HAs conducted at the IIHS produce data that are sufficiently representative, complete, reliable, and valid to be used for research purposes. Specifically, I have found that computerised HAs at the IIHS are representative of the regular IIHS patients. Additionally, for child, adult, and diabetes assessments there were generally acceptable levels of missing data. The levels of missing data for antenatal assessments are more concerning, and caution would be required in using antenatal assessment data for research purposes. Where data were missing for core and randomly selected variables they were generally MAR, and were only associated with demographic characteristics in six percent of cases (MNAR) – a rate which could be expected by chance alone (based on the α=5% level employed for these analysis). Over 80% of computerised HA data correlated moderately or highly with the matched validated One21seventy audit data used as the concurrent reference criterion in this study. For adult HAs, the core computerised HA variables were less likely to contain missing data than the same variables from the previous IIHS paper-based HA. For child HAs, the majority of core variables in computerised HAs were either less likely to be missing or missing at similar levels to those observed from paper-based HAs.

6.5.1 Strengths and limitations

This data evaluation study has several strengths. The large number of computerised HAs conducted in the 12 month study period confers confidence in the interpretation of the evaluation of data completeness and validity. Additionally, the findings are strengthened by the availability of a concurrent, validated criterion, the One21seventy audit data. Furthermore, the One21seventy project provided a list of independently selected clinical variables likely to be clinically important for patients receiving a computerised HA as well as measures with which to directly compare matched computerised HA records for data validation.

There were limitations to the approach I have used in this study. Of minor concern was that the One21seventy audits sampled children in such a way that precluded the use of this database as a comparator for analysing the demographic representativeness of computerised child HAs. Comparison with active IIHS child patients provided a satisfactory alternative. Of more concern, the analysis of the validity of antenatal computerised HA data was limited by the small number of matched computerised antenatal records with One21seventy audit data. Furthermore, the One21seventy audit data were measured over a 12 month period, and the computerised HA data come from one point within those 12 months. Therefore, comparative data could have been measured on the same day or 12 months apart and the time between test and retest (One21seventy dataset versus computerised HA dataset) was not quantifiable because the One21seventy data were not dated. This bias is likely to reduce the correlation between measures in the datasets. Conversely, One21seventy audit data were not completely independent of computerised HA data which would serve to increase the correlation between the measures in the datasets. However, most measures showed at least moderate correlation and when non-identical measures likely to be measured independently were correlated, they were not importantly different.

6.5.2 Data representativeness and completeness

The uptake of computerised HAs was, for the most part, not significantly different to the regular IIHS patient population which provides confidence that research findings from computerised HAs were generalisable to the IIHS regular patient population. Additionally, following analysis of missing data, I found that the levels of missing data were unlikely to compromise research findings for studies using child, adult, and diabetes computerised HA data. The higher levels of missing data for antenatal assessments may be a result of both the design and length of the form. It is the only computerised HA which is supposed to be active for longer than one episode of care as it is designed to be used for the whole pregnancy.

Data not missing at random

In this evaluation, only a small minority (6%) of variables with greater than 5% missing data included variables with information that appeared to be missing in a non-random manner. Variables not MAR included ear canal status in children, and lipids, sexual health status, and K10 in adults. Hence, while ear canal status in the child computerised HA was associated with ethnicity, this variable may have been missing in a patterned way owing to chance. For adults, it is plausible that lipids would be less likely to be missing with increasing age, and sexual health status more likely missing with increasing age. Missing data for men on sexual health status may occur where the female IIHS nurses felt uncomfortable asking this question. Only female nursing staff conducted computerised HAs at the IIHS during the study period. It is less clear why the K10 result would be more likely to be missing with increasing age and less likely to be missing for men. It is also not clear why the small number (five) of variables in the over 55 age group had patterns of missing data.

Missing data and future research

A number of techniques have been described to deal with missing data in clinical research.[269] Schafer and Graham describe maximum likelihood estimation and multiple imputation as the main methods of dealing with missing data, but also point to weighted regression as a possible technique.[269] In a separate IIHS study of factors contributing to middle ear disease, we used information collected from Aboriginal and Torres Strait Islander paper-based child HAs. Logistic regression analysis was conducted to determine predictors of the dependent variable, abnormal middle ear appearance using both a complete-case analysis (list wise deletion of cases with any variables missing) and a multiple imputation method. Using these two methods on paper-based HA data, obtained similar results.[122] For future research using information from computerised HAs, multiple imputation is one way of dealing with missing data in multi-variable regression analyses.

6.5.3 Data reliability and validity

Almost half of the variables included in the evaluation of computerised HAs had high levels of agreement with the data measured by the concurrent reference criterion (One21seventy data), and over three-quarters of variables showed at least moderate agreement. For continuous variables, I used the ICC which has been criticised as a single measure dependent on the range of measurement, not related to the actual scale of measurement, and which does not allow evaluation of the clinical significance of the error.[282] As an alternative, Bland and Altman suggest a limits of agreement method.[283] However, Streiner and Norman reject criticisms of the ICC, pointing out that the limits of agreement method is isomorphic with the calculation of error variance in the ICC. They conclude that the ICC is an acceptable measure of test-retest reliability for continuous variables, and that kappa tests should be used for measuring agreement between categorical variables.[275] Overall, the contribution of measurement error owing to computerised HAs appears to be reassuringly small, and compatible with the production of valid research findings in this population and setting.

6.6 Conclusions

Computerised HAs were largely representative of the regular patient population of the IIHS, and except for antenatal HAs had acceptable levels of missing data. Where data were missing, the large majority appear to be MAR, and are likely to be amenable to statistical techniques such as multiple imputation. Compared to paper-based HAs, computerised HAs have resulted in similar levels of missing data for child computerised HAs, and fewer missing data for adult computerised HAs. Over three quarters of the computerised HA data values had at least moderate agreement with values obtained using the concurrent, validated criterion (One21seventy data). Caution would be required in conducting research using computerised antenatal HA information owing to high levels of missing data. However, the computerised child, adult, and diabetes HA data could be used with more confidence. In the next chapter, Chapter 7, situated in the transformative paradigm, I describe the consultation conducted with Inala Aboriginal and Torres Strait

Islander community key informants regarding their health and research priorities for computerised HA data.

Chapter 7 "I'm not sure it paints an honest picture of where my health's at." Health assessments and research priority setting with the local Aboriginal and Torres Strait Islander community: a qualitative study

7.1 Introduction

After demonstrating the feasibility of implementing computerised HAs in Aboriginal and Torres Strait Islander primary health care in Chapter 5, I also demonstrated that computerised HAs data were sufficiently representative, complete, reliable, and valid to be useful for research purposes in Chapter 6.

In this chapter, I describe how computerised HA research at the IIHS needs to move beyond the postpositivist paradigm and into the transformative paradigm. The research described in this chapter, Chapter 7, expands on the published research paper[284] included in Appendix 5. In this research project, situated in the transformative paradigm, I privileged and heard the lifeworld voices of Aboriginal and Torres Strait Islander community members regarding the utility of HAs for research purposes. By consulting the community, a stronger, community-led research agenda within the IIHS can be implemented.

7.1.1 Past Inala Indigenous Health Service research with computerised health assessments

In the seven years since IIHS HA research commenced (2009-2016), the Western biomedical model has strongly influenced most IIHS HA research projects, and include studies investigating obesity[211], middle ear disease[109,213], and the utility of HAs to detect diseases.[48,49] The biomedical model conceives of health as being primarily about medical practitioners detecting and curing diseases in individuals.[285] These studies have been driven by medical researchers including myself with biomedical training, and involve the quantitative investigation of variables measured by HAs consistent with the postpositivist research paradigm, described in Chapter 4. Other IIHS research, not conducted by doctors, in the same period has also been investigator driven, but has not had such a disease focus. For example, one research paper-based on an analysis of child computerised HA data investigated stressful events experienced by children.[113] As I described in Chapter 1, my initial plan for this doctoral research, was to investigate oral health because I was concerned about the prevalence of dental problems, links between poorer oral health and physical health, and access barriers to dental care for patients attending the IIHS.

7.1.2 Risks with investigator-driven research

Notwithstanding my concerns about oral health, investigator-driven research, within a postpositivist research paradigm, that does not involve partnerships between researchers and Aboriginal and Torres Strait Islander communities built on self-determination and respect may lead to extension of colonial control and further trauma.[286] For example, as discussed in Chapter 1, I do not want to produce findings, however well intentioned, similar to those of Price, an American dentist. Price explained how the beauty of Aboriginal women was destroyed by dental caries through exposure to modern white man's food.[51] Price also asks us to look at an Aboriginal woman who has not been exposed to a Western lifestyle as both "primitive" and "beautiful".[51] These romanticised descriptors recall notions of the noble savage.

The noble savage was a European construction dating from the 17th Century which aimed to counter negative Hobbesian discourse about the Indigenous peoples encountered by European explorers at that time.[287] Proponents of the nobility of Indigenous peoples glorified the purity of what was considered by Europeans at the time to be "a state of nature".[287(p50)] However, the British, soon after Australia's colonisation, commonly assessed Aboriginal life as savagery of the most miserable kind with no evidence of land cultivation or "improvement".[288(p149)] Ellingson argued that debates for and against the "noble savage" tacitly accept that there was a racial hierarchy constructing Indigenous peoples as the other without problematising the word savage. Both sides of the debate assumed that humans improve their position from "living in a state of nature"[287(p50)] as savages to the superior position occupied by "civilised" Europeans.[287(p50)]

The assumption of European superiority was central to European legal notions that uncultivated land was effectively unoccupied, and so a doctrine of terra nullius could be invoked.[17] Moreton-Robinson argued that this sense of superiority is also related to the whiteness of Europeans. In the context of colonisation, the formation of white people's identity requires the existence of other lessor human beings who are primitive, savage, and can reinforce white superiority.[54] Price's references to primitive races, romanticised or otherwise, feed into a discourse promoting ongoing colonisation, including the most fundamental injustice of the dispossession of land belonging to Aboriginal and Torres Strait Islander peoples. Thus, writing without evidence of reflexivity, Price's findings exemplify the widely held concerns about research conducted by non-Indigenous people involving Indigenous peoples which perpetuate discourse consistent with imperialism and colonisation.[1] Without a collaborative research approach, the risk for non-Indigenous researchers, including myself, is that our work will be regarded as yet another example of research serving a colonising agenda.

7.1.3 Listening to lifeworld voices

To avoid research serving a colonising agenda, I sought to construct new knowledge in the spirit of the Yolŋu Ganma metaphor, described in Chapters 1 and 2. For the Yolŋu Ganma metaphor to be realised in research, there needs to be a willingness for both the researcher and the lifeworld research participants to listen and connect consistent with CCM described in Chapter 4. Moreover, health benefits from Aboriginal and Torres Strait Islander health research are more likely with community consultation and involvement.[79] Finally, in addition to listening to lifeworld voices, researchers who adopt and work within the transformative paradigm need to be willing to be transformed themselves. When Aboriginal and Torres Strait Islander perspectives on health and wellbeing have been sought, Aboriginal peoples have emphasised the importance of SCEDH consistent with the holistic Aboriginal and Torres Strait Islander definition of health.[289-291]

7.2 Aims, objectives, and research question

The aim of the research in this chapter was to develop research themes and questions that accord with the community's health priorities, and which could be meaningfully addressed using information from computerised HAs.

The objective of the research presented here in Chapter 7 is to learn what health topics covered by HAs at the IIHS are priorities for the local Aboriginal and Torres Strait Islander community, could be translated into research themes, and investigated using Aboriginal and Torres Strait Islander HA data.

The research questions, described in Chapter 3, for this chapter are:

(1) What are the important health issues covered by computerised HAs for the Inala Aboriginal and Torres Strait Islander community?

(2) Which health research questions are priorities for research based on computerised Aboriginal and Torres Strait Islander HA data?

7.3 Methods

The reporting of this qualitative study is based on the consolidated criteria for reporting qualitative research (COREQ) described by Tong et al.[292]

7.3.1 Reflexivity, a white, male, non-Indigenous doctor as interviewer

I acknowledge that my role as a white, male, non-Indigenous, GP at the IIHS and principal interviewer for this qualitative research is likely to have influenced my interview questions and interviewee responses. I was well acquainted with 17 of the 21 participants, 11 as patients. For my patients, the power difference between doctor and patient may well have been difficult to forget in the interview context. In the medical consultation, the doctor is usually seen as the one who knows and makes decisions in partnership with their patients. In this community consultation research project, my intention was to position the community stakeholder as the knower and possessor of community knowledge. To facilitate this positioning, I avoided conducting interviews in the clinical context to minimise the re-creation of the relationship dynamics that come with a medical consultation. While my community presence over ten years enabled the interviews through the trust I had built up in the community, interviews were likely to have had different outcomes had there been an Aboriginal or Torres Strait Islander interviewer, a non-medical interviewer, a female interviewer, or an interviewer who was not working at the IIHS. Some participants asked me about their medical conditions, and several participants made suggestions to improve services at the IIHS. While participants for the most part appeared comfortable discussing community health issues with a medical non-Indigenous interviewer, there were times when guardedness was evident (Box 7.1).

My male gender may also have impacted on the responses given by interviewees. Gender has been shown to produce differences in participant responses in other interview-based qualitative research. Specifically, in one study participants were anxious to avoid statements that may have offended the interviewer of another gender.[293]

My training for this research project included workshops on qualitative research and interviewing at The University of Queensland. Prior to this study, I had been a co-investigator on four research projects using qualitative research methods.

Box 7.1 Guardedness with a non-Indigenous interviewer

One participant was discussing how some non-Indigenous people would visit the service where she worked and could be surprised that only Aboriginal and Torres Strait Islander people were in charge. She then became self-conscious as she remembered that I was also a non-Indigenous, white person visiting her service:

"Sometimes even though we're a Murri centre, but they think you know, you must have a white person there. Sorry [laughs]". - *Charlotte*

It is hard to know what other conversations Charlotte and other participants suppressed because they did not trust me, did not think I would understand, or to spare my feelings and avoid potential embarrassment.

7.3.2 Co-investigators

All my co-investigators for this research project made valuable contributions to discussions relating to participant recruitment, emerging themes, coding, and data interpretation.

Dr Chelsea Bond (CB) is an Aboriginal and South Sea Islander, Inala community member, my PhD advisor, and Senior Lecturer in the Aboriginal and Torres Strait Islander studies unit at the University of Queensland, Brisbane. Dr Bond's community knowledge and expertise in qualitative research methods informed her valuable contributions to this project.

Associate Professor Deborah Askew is a white, non-Indigenous New Zealander and Australian citizen, Research Director, Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care, Brisbane and my principal PhD advisor. Associate Professor Askew's expertise in qualitative research methods and experience as research director at the IIHS informed her valuable contributions to this project.

Professor Philip Schluter is a white, non-Indigenous New Zealander, Professor at the School of Health Sciences at the University of Canterbury, Christchurch, New Zealand, and my PhD advisor. Professor Schluter's expertise in qualitative research methods informed his valuable contributions to this project.

Mr Corey Kirk (CK) is an Aboriginal, Inala community member and research officer at the IIHS. Mr Kirk was well known to many of the research participants, and was an important link between community members and myself as interviewer. His enthusiasm for the project and assistance in facilitating interviews was critical to the success of this project.

7.3.3 Positioning and methods justification

This study is situated in the transformative paradigm, described in detail in Chapter 4, with the aim of changing the social world for the better. Mertens argued that people living in circumstances associated with a greater probability of discrimination and oppression will have less access to resources and a greater probability of a lower quality of life.[236] The transformative paradigm involves expressly articulating the values of researcher and the research in the interests of social justice where justice means that research benefits accrue to those accepting the risk of participating in research.[236] The centrality of justice to the transformative paradigm is consistent with my motivations for conducting this doctoral research which are described in Chapter 1.

According to Mertens, transformative research usually requires community input in a cyclical research model involving collaborative community/ researcher determination of the research question, approach to data collection, analysis, and interpretation consistent with CCM. Research outcomes then inform the next research question, so that community members are not just spectators but part of a research cycle aimed at addressing their needs.[236]

Had I not used a CCM approach and listened to lifeworld voices, I could have simply proceeded to an investigator driven survey designed to collect a random sample of IIHS patients to rate issues covered by Indigenous computerised HAs in order of importance. Lincoln argued that this type of investigator-designed survey would produce results reinforcing academic privilege and favouring official action or systems knowledge at the expense of community or lifeworld knowledge.[233,294] In this way the pursuit of social justice is stifled and the status quo prevails.

7.3.4 Participants and setting

Co-investigators CB and CK identified participants as key informants in the community in consultation with the other investigators. We used a purposive sampling strategy of local Aboriginal and Torres Strait Islander community stakeholders. We selected key informants because they were members of community controlled or State-run organisations working in Inala to improve the health and/or social world of Aboriginal and

Torres Strait Islander community members in Inala. The community roles of key informants meant they were also likely to have knowledge about the community's health priorities and needs. Therefore, each participant fitted many if not all the characteristics of ideal key informants. These characteristics include having a community role, community knowledge, willingness to participate, and an ability to communicate.[295]

The mix of key informants was designed to include both Aboriginal and Torres Strait Islander ethnicities, male and female genders, and a range of ages working in diverse organisations with an interest in the health and wellbeing of Aboriginal and Torres Strait Islander peoples in Inala. These organisations included Inala Wangarra, a community organisation which aims to enhance the capacity of the Aboriginal and Torres Strait Islander community in Inala through sports programs, cultural programs, and employment initiatives.[296] Other organisations included the Inala Elders, Wandarra Preschool, and Centrelink. Centrelink is Australia's principle welfare agency, and is run by the Australian Government's Department of Human Services. Four participants were IIHS employees. The IIHS had already convened the 14 member ICJ whose members were chosen to represent community views on the value to the community of research being proposed at the IIHS.[132] Members of the ICJ were also considered potential interviewees, and ultimately five ICJ members participated in this study. The choice of participants was also guided by the potential for participants to be users of computerised HA based research data to improve their service delivery, and/or apply for grant funding. For example, participants may use information from the community report[297] based on this research which is attached as Appendix 1.

We expected to interview between 20 and 30 participants to achieve a spread of age, gender, ethnicity, community organisations, and to achieve data saturation. Hansen defined data saturation as the point where no substantively new ideas are coming from the interviews, and the researcher can be confident that interviewing further participants is unlikely to produce new ideas.[298]

7.3.5 Data collection

Between February and June 2013, CK or CB contacted potential participants by telephone, text, or in person. If potential participants agreed to participate, I provided information about the study, and gained informed consent. I asked CK to accompany me to interviews with a view to making participants more comfortable, having an Aboriginal person assist in interpreting participant findings, and to encourage capacity building for

CK's future research. However, after attending two interviews CK indicated that he felt uncomfortable being present at interviews, and would prefer to support the project in other ways. I conducted face-to-face semi-structured interviews regarding the role of HAs, the importance of the issues covered by HAs, and potential research priorities for computerised HA information. The semi-structured interview was chosen in this study in order to ensure that there was a focus on HAs and participant health priorities while maintaining the flexibility to cover new and unexpected topics that arose during the interview.[298] Interview questions were piloted with co-investigator CB, and the interview guide did not change following piloting (Table 7.1).

Table 7.1 Key questions for participants regarding HAs and health priorities.

1. Have you ever had a health check? When thinking about the health checks it might be helpful to take yourself back to when you last had a health check-up. What were some of the issues that you thought were important?
2. How were they important?
    - For each issue:
        - Tell me about what makes that an important issue
        - How is it important to you, your family, and the community?
        - What more would be good to know about that issue?
3. Thinking about the health checks another way, what parts of the health checks are important from the point of view of:
    - The community?
        - For each issue:
        - Tell me about what makes that an important issue
        - What more would be good to know about that issue?
    - As a family member?
        - For each issue:
        - Tell me about what makes that an important issue
        - What more would be good to know about that issue?
    - In your work?
        - For each issue:
        - Tell me about what makes that an important issue
        - What more would be good to know about that issue?
4. Looking through all the things in the table, what jumps out at you as things you want to talk about?
    - For each issue:
        - Tell me about what makes that an important issue
        - How is it important to you, your family, and the community?
        - What more would be good to know about that issue?
5. If you had to pick your top three issues from this table what would they be?
6. Are there issues that you can think of that we are not asking about but you think we should be in the health check?
7. Do you identify as Aboriginal or Torres Strait Islander or both?
    - What is your age?
    - Are you male of female?
8. How would you describe your job / role in the community in Inala?
9. Is there anything else that you would like to say about health checks or topics? Anything else that you wanted to add to what we have talked about?

Depending on participant preference, I conducted interviews in the participants' workplace, the non-clinical sector of the IIHS, and in one case in the participant's home. Interviewees were given a $25 gift voucher as a gesture of appreciation for their time. Interviews lasted between half an hour and two hours. Participants were guided by a one page summary of the topics covered by computerised HAs for children, adults, people with diabetes, and pregnant women. This summary divided HA topics into diseases, preventive health activities, social issues, lifestyle behaviours, and referrals, and included explanatory notes which described what HAs were, who they were for, and how often they were conducted (Appendix 6).

Interviews were audio taped and data were transcribed by a person with no personal or professional connection to the participants. I took field notes during each interview. Transcripts were offered to participants, and two accepted this offer. They were followed up to determine whether any corrections might be forthcoming. Neither participant returned with any corrections.

7.3.6 Interview analysis

I uploaded transcribed interview data to NVivo 9 (QSR International, Melbourne, Victoria) software to assist data coding and management. Using thematic analysis, I coded transcribed data and interview notes in NVivo, and discussed the development of categories and themes with my co-investigators at regular meetings. This process of thematic analysis is an iterative approach to qualitative data which aims to identify common themes in participant responses.[299] The broad data categories of health priorities based on HA information and attitudes to HAs were anticipated a priori. Themes were identified from participant responses.

7.3.7 Checking back with stakeholders

Results were presented back to participants in the form of informal meetings (two participants), telephone (one participant), a community seminar (nine participants) in the Inala community health centre, and the community jury (four further participants). Five participants did not respond to invitations to check results. For participants who did respond, they appeared to identify with the results, and there was no feedback suggesting the interviews had been interpreted incorrectly. At the community seminar, one Aboriginal elder said that he felt valued by the research, and one Torres Strait Islander elder was keen to know what the next steps were going to be, and how we were going to address the findings.

7.3.8 Ethics

The study was supported by the ICJ for Aboriginal and Torres Strait Islander Health Research, and approved by the Metro South HREC and the University of Queensland's

Behavioural and Social Sciences Ethical Review Committee. All participants provided written informed consent prior to being interviewed. All quotes were attributed to pseudonyms and care was taken to avoid identification of participants.

7.4 Results

7.4.1 Participants

Twelve men and nine women took part in the interviews, with five being younger than 30 years of age and seven being 50 years or older (Table 7.2). No-one who was approached to be interviewed declined. After 21 interviews, I felt data saturation had been achieved as no further obvious substantial categories or themes were emerging.

Table 7.2 Characteristics of Aboriginal and Torres Strait Islander community stakeholders (N=21)

Characteristic	Participants	(%)
Ethnicity		
Aboriginal	16	(76)
Torres Strait Islander	5	(24)
Female	12	(57)
Age group (years)		
<30	5	(23)
30-49	9	(43)
50+	7	(33)
Employed by:		
Community controlled organisation	6	(29)
Other community-based organisation	3	(14)
Inala Indigenous Health Service	4	(19)
Other State-run organisation	3	(14)
Elders	5	(24)

Three principle themes were identified in the key informant interviews: (1) complex, inter-related, intergenerational nature of health involving SCEDH; (2) ambivalence to HAs as a clinical tool; and (3) community strength.

7.4.2 Theme 1. Complex, inter-related, intergenerational nature of health involving social, cultural, and environmental determinants

Key informants talked about their health in terms of the broader conditions in which their bodies are located, and the ways in which those conditions hinder or enhance health. Key informants demonstrated an authoritative understanding, consistent with their lived experience, of the complex web of interrelated SCEDH interacting in their community. These SCEDH included poverty, racism, housing, mental health, grief, loss, education, and employment. For example, Lily was unreserved about the positive health consequences of employment for members of her family and community.

> “You give a man a job, he can afford housing, he will no doubt want to look after himself and he then changes himself as a role model for his children. The health in that is massive. Massive.” – Lily

Impact of suburb discourse

However, key informants saw employment opportunities being limited by the experience of socioeconomic disadvantage in Inala. Acknowledging the stigma sometimes attached to Inala owing to its low socioeconomic status, Emma was concerned that only negative stories were told about Inala. For example, suburbs like Inala could obtain an unjustified, unshakeably negative reputation when perhaps the reality was not as bad. This type of negative talk could lead to Inala being a difficult place to get out of for residents.

> “They don't think they're good enough to be anywhere else. You know, stuck in Inala. Everything. It just has a whole chain reaction. If they can't get a job outside of Inala and they've got to stay here and everything in the home is sort of upset. That’s how I see it.” - Emma

I have heard and been involved in many social and professional conversations, especially in medical contexts, that included a joke at the expense of people living in a low socioeconomic area. On hearing this quote and absorbing its impact, I personally resolved to always call out and refuse to join in this type of discourse. As another key informant explained, the sense of being stuck in Inala had even been codified in local discourse as not being able to get past the roundabouts at the suburb’s boundaries. Recalling the imagery of these limiting roundabouts, the majority of key informants described the inter-related SCEDH affecting health as a cycle, circle or chain.

Family breakdown

Family breakdown was mentioned by participants of all ages as an important component of this cycle which resulted in grandparents and single parents being left to look after a number of children with limited resources. Noah had been describing depression and grief before linking these elements of “the cycle” to family breakdown.

> “a lot of families I know, they’re always getting divorced, and I really find the young people, they only know one way after their parents split up, and that’s to follow” – Noah

This quote reflected Noah’s personal experience. His life had been going well until his parents split, and then the alcohol took over with its associated negative consequences.

> “around that time my parents split, so the drinking really took over my life…I really feel that’s when the depression really kicked in, and I turned to violence …getting into fights, which is no good, absolutely no good.” - Noah

Single parent

Single parent families, sometimes the product of family breakdown, were most frequently run by single mothers, and often supported by grandparents who took on disproportionately large, stressful, caring roles for their grandchildren while dealing with their own age-related chronic disease. There was a sense of fatigue and anger for Samantha as she discussed her own extended role in childcare.

> “…today, grandparents are either picking the grannies (grandchildren) up, taking them to school, get them what they want, buying them stuff, whereas the parents, they get the money, but you don’t see it. So, I don’t know what’s going to happen to them… I do find it tiring, like, I come home, pick him up, and it’s a long day for me.” – Samantha

Household crowding

Key informants described how family breakdown led to children moving in with their cousins, sharing rooms, and the resultant household crowding was associated with stress, conflict over resources, physical health problems, loss of sleep, and a lack of organisation with respect to school. Mia was worried about how children’s schooling would be affected when family breakdown led one family to move in with relatives.

> “They mightn’t get enough sleep ‘cause they’re not sleeping in their own house. The family don’t have their own family routine, so it effects the school work…” - Mia

Adolescents, peer relations, and education

As children entered high school, peer relations were supercharged by the relatively recent emergence of social media interactions and, in particular, Facebook. While some participants noted that Facebook and other social media could help maintain connections within the community and family, it was much more likely to be seen as draining self-esteem, contributing to never-ending bullying, and causing conflict. When reflecting on the changes that have occurred since his own teenage years, Luke saw social media as a significant new phenomenon that reduced physical activity for the younger generation, and meant bullying could continue beyond the school gate and late into the evening.

> "I guess this generation is more social media, stay at home, not active and just a lot of the young people I'm dealing with, they are just smoking, and drinking, and just on Facebook." - Luke

While peers could be supportive and confidence building, they could also play an influential role in perpetuating the negative aspects of "the cycle". Luke went on to tell a story about a young person he had worked with in Inala who had been doing well, but had been dragged down by her peers. He compared this situation to a bucket of crabs where any crab trying to crawl out was dragged back into the bucket.

> "… we are all in a bucket, and like you are that crab trying to get out, and that other crab is trying to pull you down. So, that's what I'm saying to them, like you want to be that crab that climbs out of the bucket." - Luke

With adolescence characterised by family breakdown, household crowding, influential peer relations, and negative social media experiences, education was often a secondary concern. Grace spoke about the intergenerational nature of "the cycle" which was characterised by limited opportunities, and perpetuated by poor life choices, and a sense of hopelessness about the future.

> "…you just see it, all these young kids going to little parties and drinking on weekend, smoking, smoking yarndi…then come Monday, they don't want to go to school 'cause they're so tired. So, then they start missing school, they fall behind, they don't finish high school, they don't have the qualifications to get a job. They're only getting Centrelink. How do they support themselves? So, they turn to crime, and then drugs, and all of that kind of stuff, and then that's where it all just starts again. Their kids are going to do the same because they don't have somebody to look up to. So, that's the cycle." - Grace

Racism

In addition to young adults facing educational and employment difficulties as part of the "cycle", men and women of all ages described their own traumatic experiences of institutional racism in their interactions with Centrelink, the Department of Housing, and the police.

> "I've been pulled over [by police] and spoken to like I'm nothing, I think that impacts especially on young people..." – Noah

Another participant talked about how this tension with the authorities is so pervasive that it contributes to the community identity of Inala. Some young Aboriginal and Torres Strait Islander men in Inala saw engaging with the criminal justice system as a rite of passage. Participants described how teenage males in particular could be tempted by peers into criminal acts, spend time in prison, and then find it very difficult to extract themselves from these peer groups later.

> "The culture of Inala…the whole thing of being an Inala boy is if you want to fit in then you go and do something bad. These kids, they think to be a man you've got to go in jail, and then you come out and they go 'Oh yeah. You've been in jail.' But yeah, that's just – that's one way." - Colin

Several participants, all over 30 years of age, felt that institutional racism had its origins in the actions of colonial authorities who had removed Aboriginal people in Inala from their natural family, culture, and language, and displaced, or *"herded"* as one participant called it, to missions and dormitory living. The loss and grief associated with this removal caused stress and further mental health problems directly contributing to intergenerational health effects. Here, Lily is discussing the very painful issues underlying a spate of suicides in young Aboriginal and Torres Strait Islander peoples living in Inala.

> "is it all tied up to the loss of land and loss of culture and loss of language, that speaking of that loss? That grief comes from those places as well." - Lily

Social and emotional wellbeing

In an environment of institutional racism, the mental health consequences for young people leaving high school without a qualification or employment were seen as bleak. In the context of his work in the community and experience with his family, Colin vividly described how young, unemployed, Aboriginal men would drink alcohol heavily from Wednesday when government benefits were paid to Sunday which was usually when the money ran out. After this drinking session, men, feeling hung over and depressed, would then return to their mother's house because they had nowhere else to go. This pattern of drinking would start again when Wednesday came around again, and the consequences for social and emotional wellbeing could be severe.

> "But then in that cycle, then you got women problems, like, your woman might have found another man, and you're drunk when you're finding out what's going on. You

> do something stupid. You're going off and a lot of fellas commit suicide, you know."
> - Colin

Key informants saw the resulting grief from premature death and especially suicide as a huge concern for the community and linked to the high levels of depression in the community. Several participants spoke about the difficulty of attending funeral after funeral. When I asked Noah what led to high levels of depression in the community he came back to his own experiences with grief.

> "I think because we are such a close community, and we do have a lot of people pass. For me, I lost three relatives in three weeks…by my third funeral I – I didn't cry, I – I couldn't cry. It was just like a normal thing for me." - Noah

I heard about the emotional impact of funerals from many participants. While I intellectually understood the emotional importance of a funeral, and all it signifies, these interviews really helped me better empathise with community members presenting in general practice who had attended a recent funeral, and sometimes more than one. Many participants were concerned that mental health issues were undiagnosed in the community, and that this untreated burden of depression would lead to unexpected suicide with devastating effect on families.

> "If I had to put one at the top of the list, it would have to be mental health because it's really a silent killer." - Steven

Grief

The resulting grief from premature death and especially suicide affected many participants' lives and was a ("frigging*"*– Olivia) huge issue for the community. The community's experience of grief exemplified the interdependent nature of SCEDH with Lily describing how grief impacted on employment and the social world for adults and children alike.

> "Well, I just see the end result of people who have lost somebody close and how it impacts their work, how it impacts them socially…and often people in the community forget about the young ones that have lost their auntie, uncle..." – Lily

7.4.3 Theme 2. Ambivalence to health assessments as a clinical tool

Most interviews commenced with a discussion of key informants' experience of Aboriginal and Torres Strait Islander HAs. Most key informants had had an HA with only two saying they had never had one. Responses were mixed as four participants gave enthusiastic, unqualified support for the capacity of HAs to detect medical problems early, and noted that HAs were an opportunity to deal with potentially shameful medical problems in a routine, less threatening manner.

> “I think the health checks are really important for Aboriginal and Torres Strait Islander people…because some people feel shame to go to the doctor, and if they leave it too long there could be a problem building in their body.” - Liam

Five key informants, mostly aged less than 30 years, commented on the time consuming nature of HAs. Another two key informants directly questioned the relevance and benefits of HAs. One of these key informants, concerned about the centrality of biomedical risk factors and illness in HAs, suggested that the health service could engage better with SCEDH. Participants’ responses suggested that their view of health and the social world was not adequately captured by HAs which measured health in a compartmentalised, biomedical way. Bradley was convinced that the health issues measured by HAs such as alcohol were often fundamentally influenced by (“deeper” – Bradley) issues that were located in the social rather than biomedical world. When I asked what these deeper issues were, Bradley pointed to identity and noted that doctors and/or HAs were unlikely to improve these aspects of health.

> GS: “Well, is there a sort of a place in there where doctors and health checks might’ve been helpful? If you think of your own journey maybe?”
>
> Bradley: “I don’t see how a doctor is going to solve an identity crisis. It’s a social thing, and even if you drag someone in here and then they talk to some sort of social PhD or whatever, that ain’t going to change the fact that when they walk back out the door and go back home to the house they just came from, that individual, they need to figure out who they are.” - Bradley

Another example of the distinction between Western biomedical views of health and how participants saw health was provided by one participant’s discussion of obesity. In a Western biomedical view of health, obesity is often narrowly conceived as a risk factor for chronic disease. However, Edward described the impact of obesity on confidence as an example of how health was defined as both a consequence of and cause of deeper social issues such as unemployment.

> “One man said, ‘I’m unemployed at the moment, all I do is sit at home and go in the cupboard and steal all my school kid’s food’...he said ‘I just can’t stop, I just snack all day’… Obviously, there’s a lot of heath related issues that come with it, diabetes

> and all of the chronic diseases. But I think if you're obese from a young age, it can affect you for the rest of your life and once your confidence goes… that limits what you can and can't do in life… you lose your ability to apply for work, stuck at home, domestic violence, you won't be as confident to undergo further study, so you can say education loses out again." - Edward

In the context of this discussion about confidence, SCEDH and health, Edward was troubled by the seemingly superficial nature of HA content which did not get to the heart of peoples' health problems.

> "I'm not sure whether it paints a really honest picture of exactly where my health's at...I think that [it] probably can go a bit more in depth." – Edward

This sentiment seemed particularly important to doctoral research about HAs, and it informed the title of this chapter and the paper[284] attached as Appendix 5.

7.4.4 Theme 3. Community strength

The personal stories told by key informants were all ones of strength as they had navigated the challenges of "the cycle" to take on meaningful, important roles within the Inala Aboriginal and Torres Strait Islander community. Key informants described how their health depended on how they negotiated the social, cultural, and environmental challenges in their youth with the support of parents, family members, and positive peer groups. After describing the negative features of "the cycle" for high school students, Grace reflected on her own schooling, and spoke of how family support had been a crucial element for the group of students in her year who had graduated.

> "We weren't rich, we weren't really wealthy, we were average … but I had that support from my family as well… that's why we graduated." - Grace

Grace stressed the importance of good role models in helping young people navigate "the cycle". Positive role models in families were also crucial for Bradley in surviving an identity crisis which stemmed from experiences of racism while growing up at school.

> "I had absolutely no idea who I was…I spent a lot of my younger days just thinking I was in some sort of weird dream, just waiting to wake up basically…Family means so much, and family ties mean so much… Now that I've got those issues intact, I've never wanted nor felt the need to pick up a drink." - Bradley

The IIHS was seen as a vital component of the community's wellbeing and self-esteem. Positive comments about the IIHS made by participants may have been more likely because I was interviewing participants as a well known doctor at this service. However, it was clear that despite the complexities of health with its social dimensions, the health service was an important, trusted part of participants' lives in the community.

> "They care. It's one of the best organisations I've been around just when I go up there. I love going up there, not because I'm sick all the time, but I love the treatment they give you." - Gregory

The community's investment and interest in the health service was evident as participants had numerous suggestions for improvements in health service delivery including increasing the number of social workers, grief counsellors, providing a dental service, better detection of mental illness, and more emphasis on the social determinants of health. One participant, concerned about single mothers, made the specific suggestion that the health service ensure it offers effective contraception to teenage women, in the form of the Implanon rod (etonogestrel implant) to help young women plan families better, gain education and employment, and then better cope with their children.

> "I just think [laughs] every girl; when they turn 13 until they're 18, put the rod in their arm [laughs]...if only that could happen, that would just help so many unplanned teen pregnancies. And then they have their whole lives ahead of them and they can finish school and they can go out and get a job then..." - Grace

Despite the challenges of socioeconomic disadvantage experienced by many people living in Inala, the Inala Aboriginal and Torres Strait Islander community was a source of strength owing to its connectedness and cultural richness. One key informant talked about how important it was that his brother, who had substance abuse problems, had a range of houses to drop into for help. Olivia expressed this community strength while recalling how a family member had survived a difficult childhood.

> "There was something strong about the community that I think was a protective factor." - Olivia

7.4.5 Research priorities

Towards the end of each interview, I asked each participant if there was one issue that they would like me to prioritise. When constructing my interview schedule this question seemed to be the most important in finding the answer to my research question regarding participant research priorities based on HA issues (Box 7.2).

Box 7.2 Extracting a single health priority

My eagerness to get a clear response was perhaps best exemplified in my efforts to pin down one of my first interviewees.

“GS: Is there one particular social issue that really gets you?

Olivia: Mmm.

GS: If I had to start where would I start?

Olivia: Because I can’t – you can’t separate them out.

GS: No. But I have to start with one of them. Or if someone was to start where would you like that person to start? Where would you start on that list?

Olivia: On this list?

GS: Yeah

Olivia: I know. Oh, far out. Okay, mental health, unemployment, housing. And the other little bits around that is drug and alcohol use and stressful events. They’re the other two things that are connected to mental health I guess. If I can sneak a few more in while I’m at it. That’s it.”

It soon became clear that many participants preferred to discuss their health priorities in an open-ended discussion about interrelated social factors, and this was reflected in many more responses to this question.

> “Yeah, I think the whole social circle, that is quite important …” - Grace

As reflected in the interview guide, HAs deal with the social world in a narrow way that emphasises individual health behaviours such as diet, exercise, alcohol and drug consumption, and their relationship with the physical body. However, key informants frequently turned to SCEDH when discussing their health priorities at the end of an interview which could cover a number of health areas. Before I asked Luke about his primary health priority, the interview had ranged over a number of diseases including diabetes, depression, heart disease, and cancer as well as his community work. However, he clearly indicated that the section of the interview guide devoted to social concerns was his priority.

> "Yeah, I think it would be this one here, social issues, depression, yeah, all of that..." - Luke

Where participants did offer a single health issue priority that I could consider as a research theme, it was often in the context of the interrelated social issues. Grief and social and emotional wellbeing were prominent.

> "…what about grief?" - Evelyn
>
> "Like I said, depression." – Noah

One participant had spent a large part of the interview discussing smoking and the social determinants which made smoking cessation difficult. However, when I asked about her main priority, she was most interested in support and services for parents with children who had learning difficulties, and were at risk of ending up in the criminal justice system.

> "The first thing that comes into my head is learning difficulties… which is interesting because if you had have asked me that before, I wouldn't have thought that that would have been a major one, but it really is." - Natasha

As mentioned previously, obesity was highlighted in the context of self-confidence and as a product of unemployment rather than as a risk factor for chronic disease.

> "So, obesity definitely" - Edward

Two participants highlighted physical health problems and again contextualised them with respect to how they impacted on social factors within "the cycle". One participant was particularly concerned about ear health.

> "I think - I'll probably change my whole thing now. The ear health one because from that being detected early and looked after early, has an impact on their entire life." – Emma

The other participant concerned about physical health problems was concerned about dental health.

> "I'm a big advocate for dental health. I just think that it's just so important… I would like for this place to really start getting more heavily involved in dental health." - Bradley

Better access to specialist care in the local community was also mentioned by three participants.

> “That’s the one I’d like to see goes through – the one for your eyes and your – well, any other appointments, if we could just have them out here.” - Samantha

Two participants were specifically concerned about access to a paediatrician to address learning and behavioural problems.

> “…we can say okay, you need to get a referral to see a paediatrician, so we can see how we can address your child’s behavioural problems, and how you can manage that at home.” - Charlotte

7.5 Discussion

Key informants gave confident, authoritative accounts of the centrality of SCEDH to the health of the community. Based on findings from my literature review from Chapter 2, this research represents the first time an Aboriginal and Torres Strait Islander community has been asked about their health and research priorities in the context of Aboriginal and Torres Strait Islander HAs. Contrary to my expectations of research priorities consistent with HA content involving diabetes, heart disease, and lifestyle risk factors, many key informants resisted giving a discrete set of ordered priorities for researchers to work through. However, this does not mean that health is not a priority. Rather, health matters in deep and profound ways that are not readily captured by HAs, but are consistent with the widely cited Aboriginal definition of health where health is not merely the provision of doctors or absence of disease, but involves all aspects of life including grief and loss, a sense of hopelessness, and being caught in the cycle of SCEDH.[291]

7.5.1 The cycle of social determinants

The “cycle” articulated by key informants in this study has similarities with the life course theory of social determinants, whereby stressors accumulate across the life course to contribute to premature health problems, disease, and death.[300,301] Adverse experiences in childhood, such as socioeconomic deprivation, exposure to violence, and infections are associated with a number of health problems in adulthood including ischaemic heart disease, liver cancer, depression, substance use, stroke, immune problems, diabetes, chronic pain, dental health, and dementia.[302-304] In addition to the accumulation of stressors over the life course, there are also critical periods when adverse experiences and stressors make a particular contribution to later health.[303] These critical vulnerable periods for the impact of social stressors involving major stage of life transitions include moving from primary to secondary school, labour market entry, establishing one's own residence, occupational change, and onset of chronic illness.[305] For Aboriginal and Torres Strait Islander peoples the life course and perpetuation of "the cycle" are fundamentally negatively influenced by the ongoing process of colonisation, associated economic deprivation, grief, loss, and the depressing effect of institutional racism.[306]

Similar to findings in this chapter, at least two studies involving interviews with Aboriginal peoples found that SCEDH were central to health. In 2012, Priest published findings from interviews with 25 care-givers of children in an urban community of eastern Australia, and aimed to explore Aboriginal perspectives of child health and wellbeing.[290] Participants in this study were concerned about the historical legacy of colonisation including the policies of the Stolen Generations and the NTNER, experiences of racism, and the difficulties for Aboriginal children maintaining their cultural identity in a predominantly white society.[290] The strong emphasis on historical and policy influences found in this study may reflect a broad overview their care-givers took when considering impacts on their children's health. In 2015, Waterworth published findings from 11 focus groups in two urban communities in Western Australia.[130] This study aimed to explore Aboriginal peoples' perspectives on factors affecting health behaviours. Participants described how culture, experiences of racism, reduced socioeconomic opportunities, family and other social connections, and personal psychological factors were important determinants of health behaviours.[130] These two studies have different emphases and motivations to the research presented in this chapter, but they both reinforce the centrality of SCEDH for Aboriginal peoples.[130,290]

7.5.2 Health assessment ambivalence

Given key informants' emphasis on interconnected SCEDH it is not surprising that a number of key informants in this Aboriginal and Torres Strait Islander community were ambivalent about HA content with its biomedical emphasis.[284] Rather than its current emphasis on diseases, the MBS item description for adult, and to a lesser extent child, Aboriginal and Torres Strait Islander HAs could have a greater emphasis on the experience of psychosocial stressors, community and cultural activity, measures of social capital, and experiences of grief and loss.[23]

Researchers from different Australian states have also stressed the importance of racism in Aboriginal and Torres Strait Islander communities.[170] [289,307] Experiences of racism were commonly reported by key informants in this study in the context of their health, but are not a recommended component of an Aboriginal and Torres Strait Islander HA. All of these SCEDH could be more comprehensively covered in the supporting information to guide the use of Aboriginal and Torres Strait Islander HAs in primary care.[68,308]

Many participant concerns regarding health priorities are situated in a social and policy world which may be beyond the scope of primary health care research. This is a common dilemma faced by the Australian primary health care sector which often recognises social determinants, but feels obliged to follow the lead of policy makers, and provide a more biomedical, service-oriented, rather than community oriented approach.[309] However, Baum reports that despite the barriers, primary health care can play an important role in addressing social determinants of health and in advocating on behalf of their clients to policy makers.[310] Interventions to address social determinants in primary care through referral to appropriate community resources have led to improvements in social and emotional wellbeing.[311,312] A closer alignment of medical understandings of health with Aboriginal and Torres Strait Islander conceptions of health is likely to result in improved health outcomes for Aboriginal and Torres Strait Islander peoples.

7.5.3 Medical misunderstandings of health priorities for Aboriginal and Torres Strait Islander peoples

The disjunction between HA content and key informants' priorities regarding SCEDH suggests that medical understandings of health are different to conceptions of health expressed by key informants in this Aboriginal and Torres Strait Islander community. Key informants gave confident accounts of how SCEDH affect the community's health which align with the previously mentioned Aboriginal definition of health where health does not just involve the individual's physical health, but also the "social, emotional, and cultural wellbeing of the whole community".[291(p.x)] Similarly, public health understandings of health acknowledge the important role of SCEDH.[313,314] Unlike Aboriginal and Torres Strait Islander and public health understandings of health, Rose argued that medical personnel have "enormous difficulty" seeing health as a population or community issue rather than a problem for individuals.[315(p432)] Furthermore, in the international context, many physicians and medical students resist addressing and receiving education regarding SCEDH.[316-318] A brief literature search looking for Australian studies investigating medical attitudes to SCEDH revealed no research articles, but there is no reason to think they would be significantly different.

After more than ten years of experience in Aboriginal and Torres Strait Islander research and general practice, I thought I had a good idea of what the main health priorities for the community would be. My biomedical training, non-Indigenous culture, maleness, and privilege all contribute to who I am as a doctor. On reflection, these attributes led me to focus on the health and wellbeing of individual body parts as important candidates for research topics, consistent with biomedical thinking.[319] My interview guide, which I handed to each participant at the beginning of each interview, was designed to constrain responses to a discussion of HA topics tapering to a focus on participants' "number one issue". Before the interviews, I thought this number one priority would be dental health or perhaps cardiovascular health, diabetes, or risk factors like smoking or alcohol. While these issues came up at times in participant responses, they were clearly secondary to concerns about the impact of a complex array of interrelated social factors on health. My general lack of appreciation for how Aboriginal and Torres Strait Islander peoples conceptualised their health was exemplified by my ignorance of the National Aboriginal Health Strategy (NAHS) Working Party document (Box 7.3).[291] Occurring more than 200 years after the start of British colonisation, the NAHS document is particularly significant because it represents the first record of a national Aboriginal health strategy.[291]

Box 7.3 Interviewer ignorance of the Aboriginal definition of health.

Interaction with a participant who was explaining the Aboriginal definition of health to me with reference to the National Aboriginal Health Strategy report.[291]

> Olivia: ...what's espoused in the NAHS report about health is life, life is health kind of stuff.
>
> GS: Sorry, which report?
>
> Olivia: The NAHS report, the Indigenous definition of health of being not just illness and disease…."

Further reflection on my failure to predict the community's health priorities after working in the community as a doctor for more than ten years, led me to find resonance in the idea of privilege as a learning disability.[320] According to Symonette,

> "One may look but still not see, listen but still not hear, touch but still not feel… Those not so situated within the power and privilege hierarchy maintain high

> consciousness nearly all the time because such consciousness enhances opportunities for access and success and more fundamentally enhances survival. Such divergent realities often manifest in persons vigorously talking past each other even when seemingly using the same words".[321(p100-101)]

I required the help of my non-medical advisors, and, in particular, my Aboriginal advisor to see clearly the themes that I identified in the research presented in this chapter. One broader implication of privilege as a learning disability is that medical personnel and medically oriented health services need to hear the community voices to respond to Aboriginal and Torres Strait Islander people's health priorities.

7.5.4 Policy misunderstandings of health priorities for Aboriginal and Torres Strait Islander peoples

Medical misunderstandings of Aboriginal and Torres Strait Islander health priorities are particularly unfortunate given the great power and significant influence medical organisations have in driving health policy agenda.[309] This research has revealed the limitations of Aboriginal and Torres Strait Islander HAs, a policy situated within the biomedical model of health.[284] Given current strategies are failing to meet their targets for health outcomes for Aboriginal and Torres Strait Islander peoples,[322] this research suggests that policy makers need to recognise the limitations of the biomedical model of health, and better account for the health priorities articulated by Aboriginal and Torres Strait Islander peoples.

7.5.5 Strengths of the transformative paradigm

In challenging my view of health, key informant interviews have in turn changed my clinical practice as a GP with the Inala Aboriginal and Torres Strait Islander community. I spend much more energy looking for and dealing with the social factors contributing to presentations. I look more carefully for mental health problems and suicidal ideation, and I have a much better sense of the impact grief has on community members. Additionally, I look for personal strengths of clients that can be built on with a view to improving confidence in dealing with health issues and risk factors, rather than victim blaming and/or unthinking advice framed in a negative way. Ultimately, I see more clearly the supportive role I can play as a GP in helping my patients negotiate the more difficult elements of social world or "the cycle" in addition to doing the best I can with respect to my traditional biomedical role.

The use of the transformative paradigm has also been central to understanding the community's health and research priorities. Involvement of Aboriginal community members (CK and CB) ensured a wide variety of Inala community key informants with varying perspectives were interviewed, and no-one declined an interview. This research, involving community consultation to identify community health and research priorities, builds on previous efforts at the IIHS to decolonise research processes including the formation of the ICJ to review IIHS research proposals.[132]

7.5.6 Limitations

Critical theorists would argue that this study would have produced different results had an Aboriginal and/or Torres Strait Islander researcher

conducted the interviews, data coding, and community feedback.[323] The study findings may have been different had there been an unstructured discussion of health and research priorities, rather than structuring the interviews around HA content. However, key informants and other community members' positive reception when results were fed back suggests concordance between our findings and key informants' beliefs and opinions.

7.5.7 Future research directions

Future HA-based IIHS research needs to value the community's knowledge regarding the importance of SCEDH, and recognise the limitations of biomedical and investigator-driven research.[284] Mixed methods research, as described in this doctoral research, can provide a more complete story when quantitative findings follow a qualitative study, which explores and defines the research direction.[240] Quantitative findings from an analysis of SCEDH can reinforce and allow further exploration of community stakeholder concerns about social factors obtained using qualitative methods. Alternatively, contradictory findings would provide opportunities for further research.[240] Quantitative analysis of the SCEDH in computerised HAs will result in a profile of SCEDH by age, sex, and ethnicity. This social profile will facilitate an assessment of the community's needs, and enable targeted interventions.

7.6 Conclusions

While HAs are important clinical tools for the early detection of physical and mental illness, HAs do not fully capture the conditions that cause or contribute to health and ill health in this community. Hence, the suggestion by one key informant that HAs do not paint an honest picture of health because HAs do not measure SCEDH to the same depth that they measure risk factors for diseases. At the IIHS, this research has supported a greater emphasis on questions regarding SCEDH in HAs consistent with the principles of comprehensive primary health care articulated by the declaration of Alma-Ata[324] and the NACCHO's definition of Aboriginal community controlled health services.[325]

Situating this research project in the transformative paradigm has contributed to changes in the researcher, HAs, and the research direction of this thesis. As a general practice researcher, I was surprised how much I had to learn about how the Aboriginal and Torres Strait Islander community in Inala conceptualised health. These research findings have changed the way I conduct consultations, and will hopefully mitigate the risk for me of perpetuating the damaging, colonising research findings of white doctors who have come before.

Future HA-based IIHS research needs to value the community's knowledge regarding the importance of SCEDH, and recognise the limitations of biomedical and investigator-driven research. In the next chapter, I use computerised HA data to explore the SCEDH discussed in this chapter that are also measured by computerised HA data.

Chapter 8 Beyond body parts: social, cultural, and environmental determinants at the Inala Indigenous Health Service

8.1 Introduction

After conducting key informant interviews described in Chapter 7, I realised that I had failed to predict or fully grasp the conceptualisation of health and health priorities for Aboriginal and Torres Strait Islander community members in Inala. As a doctor, with biomedical training, my imagining of health problems in the community where I worked centred on diseases and their biomedical risk factors. I brought to my consultations the same body part focussed approach to health that Puggy Hunter, former Chairperson of the NACCHO, lamented in his 1999 statement about funding bodies.

> "What always strikes me when our members get together and exchange information and views, is how little change there often is from year to year. Despite the Aboriginal Health Framework Agreements that have now been signed in all States and Territories, we seem to be as far away as ever from seeing the National Aboriginal Health Strategy fully implemented. We keep hearing the same old stories from our members around the country: nowhere near enough resources available to make a real difference to health and wellbeing in our Communities; continuing obstruction from State governments; and the same old bureaucratic body parts approach from the funding bodies, which makes it so hard for us to us provide proper holistic care for our people."[326]

As described in Chapter 7, rather than a body parts approach, key community informants conceptualised health in a holistic way, and were interested in how SCEDH operated in a "cycle" or complex web of interlinked determinants. Thus, in Chapter 8, rather than a biomedical emphasis, I will describe the SCEDH experienced by community members that are measured by computerised HAs.

In this introduction to Chapter 8, I start by defining, in turn, social, cultural, and environmental determinants of health before describing the centrality of SCEDH to Aboriginal and Torres Strait Islander peoples, including SCEDH specifically identified by Aboriginal and Torres Strait Islander peoples. I then discuss how SCEDH are related to morbidity and mortality, the lack of research involving SCEDH, how SCEDH were introduced to computerised HAs, and the rationale for studying SCEDH as a priority for Aboriginal and Torres Strait Islander health.

8.1.1 Social determinants of health

Marmot calls social determinants, “the causes of the causes” owing to their sometimes forgotten role in affecting health outcomes.[327(p2)] Following the rise of modern medicine over the last century, the importance of social determinants is being rediscovered by Western societies where the health focus has been on biomedicine and its role in remedying diseased body parts and the behavioural risk determinants for disease.[328] The ten social determinants originally described by Wilkinson and Marmot are low social class, stress, difficult early life, social exclusion, work, unemployment, lack of social support, addiction, food insecurity, and lack of access to transport.[329] These social determinants often overlap and interact with each other, and contribute to the many components of socioeconomic disadvantage including few family assets, poor education, insecure employment, poor housing, and low income.[313] Other commonly described social determinants that are complex and benefit from further definition include poverty, social exclusion, limited social capital, violence, and racism.

Poverty

Poverty is a recognised social determinant of poorer health though its multifaceted nature makes it difficult to measure.[330] Areas of residence have been used as a proxy measure for poverty in some models exploring links between social determinants and morbidity and mortality.[331] In this chapter, I have used the Socio Economic Indices For Areas (SEIFA) as a proxy measure for poverty, where SEIFAs are defined as,

> “People’s access to material and social resources and their ability to participate in society relative to what is commonly experienced or accepted by the wider community.”*[332(p2)]*

The Australian Bureau of Statistics uses a number of variables derived from Census data in the calculation of the SEIFA including measures of income, employment, housing, education, and car ownership.[332] SEIFA scores are a measure of relative socioeconomic advantage and disadvantage with a mean of 1,000 and standard deviation of 100 where higher scores signify relative socioeconomic advantage.[332]

Social exclusion

Often related to poverty is the idea of social exclusion which focuses on marginalisation and reduced access to societal resources. Social exclusion factors include unemployment (and/or low income), low levels of education, poor health, discrimination, and lack of integration into local community.[330]

Limited social capital

Social capital, another social determinant of health, is defined here as the ability of people to derive benefits from their social resources, social networks and the social structures that are available to them.[333] Social capital may be further thought of as bonding, bridging, and linking social capital.[334] Bonding social capital is that between close-knit groups with similar characteristics. Bridging ties are looser links that transcend ethnic or class differences through interactions in sporting clubs or other community organisations. Linking capital refers to the relationships between people that operate across formal or institutionalised power gradients.[334]

Violence

Galtung defines violence as being present for humans when the distance between their potential and actual realisations is increased, and the ability of humans to decrease this distance is impeded.[335] Violence is a multidimensional social determinant of health ranging from forms of interpersonal violence such as intimate partner violence to structural violence.[336] While interpersonal violence is violence between humans which may be physical or psychological, structural violence does not require direct actors and may result from uneven resource distribution and social injustice.[335]

Violence is an important determinant of social and emotional wellbeing for Aboriginal and Torres Strait Islander peoples, and includes State violence associated with ongoing colonisation as well as interpersonal violence. State violence, a form of structural violence, may manifest in a number of ways including the removal of Aboriginal and Torres Strait Islander children, inequitable incarceration rates, and uneven distribution of resources.[337]

Racism

Racism is an oppressive dimension in a social system in which people are divided along socially constructed racialised dimensions with power unevenly distributed (or produced) based on these dimensions.[338] Racism may be institutional or interpersonal where interpersonal racism occurs in interactions between individuals. Institutional racism occurs through economic and political systems whereby resources are unevenly distributed which disadvantages a racialised group.[339] While one group is disadvantaged, racism also involves another racialised group being unfairly advantaged based on how people in that group look.[340] Thus, Jones defines racism as;

> "a system of structuring opportunity and assigning value based on phenotype ("race"), that; unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, undermines realization of the full potential of the whole society through the waste of human resources."[340(p10)]

Research on racism in health care settings usually focuses on interpersonal racism.[125,341] However, the oppressive forces of institutionalised racism have made significant material, way of life, and symbolic changes to the culture of Aboriginal and Torres Strait Islander peoples since the arrival of British colonisers.[342]

8.1.2 Cultural determinants of health

Despite often being neglected in social determinants research, cultural determinants may even be more important than social determinants in influencing health.[343] Culture is difficult to define but can be thought of as a set of meanings that we carry into our interactions with the social and physical environment.[343] The Lowitja Institute, Australia's national institute for Aboriginal and Torres Strait Islander health research, defines culture as being about the life-giving values from which individuals, families, and communities draw strength and empowerment.[344]

Cultural determinants discourse

Discussions of cultural determinants often lead to a discourse about "the other's" culture and omits investigations of the way characteristics of the hegemonic culture produce social determinants such as socioeconomic disadvantage.[343] The hegemonic or dominant cultural group in Australia consists principally of white, non-Indigenous Australians. One way of maintaining hegemony is to control the definition of what is "the other's" culture and what is not.[343] In this way, Aboriginal and Torres Strait Islander peoples' dance, bush food, art, and lore are permitted to be seen as cultural by white Australians. Furthermore, Aboriginal and Torres Strait Islander experiences of violence and alcoholism are also explained in terms of cultural predispositions. However, the hegemonic group in Australia are unlikely to allow an investigation of how non-artistic Western cultural traits such as consumerism and individualism might produce social disadvantage and poorer health outcomes.[343] Discussions of culture should not only recognise and value Aboriginal and Torres Strait Islander peoples' cultures, but also recognise the effect of Aboriginal and

Torres Strait Islander peoples' exposure to non-Indigenous Australian cultures which has had an oppressive influence for more than 200 years.[342]

Failing to recognise the racialised thinking within cultural determinants discourse often leads to the problematic way public health research has characterised Aboriginal culture as a risk factor or problem.[345] Rather than being a barrier to health as it has been perceived through the dominant deficit discourse paradigm, culture is an enabler to health.[344] Examples of cultural determinants which enable health include freedom from discrimination, connection to Country, and protection of cultural knowledge.[344]

8.1.3 Environmental determinants of health

Environmental determinants refer to the environmental conditions which affect health outcomes. They substantially overlap with social determinants of health and include housing factors such as crowding, household amenities; injury-related factors such as work-related injury, road traffic accidents, and poisonings; and environment factors such as noise exposure, access to green space, second-hand smoke exposure at home and at work.[346] The editors of the Lancet, a leading medical journal, argued that governments have a duty to provide healthy environments especially for disadvantaged and vulnerable populations.[347] Environmental determinants are likely to be specific to their communities and have particular relevance for an epidemiological investigation at the community level.

8.1.4 Centrality of social, cultural, and environmental determinants to Aboriginal and Torres Strait Islander peoples

As part of the Declaration of Alma Ata, the World Health Organization (WHO) defined health as, "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity".[324] Under the Ottawa Charter, the WHO reaffirmed holistic conceptions of health as a resource for wellbeing.[348] The importance of a holistic approach to health which includes SCEDH as well as biomedical ones has never been in doubt for Aboriginal and Torres Strait Islander peoples.[291] It is generally assumed that the determinants influencing Aboriginal health, morbidity and mortality are complex and multidimensional.[349] NACCHO is clear that a range of SCEDH are important. For example, their definition of primary health care includes this statement,

> "Primary health care, within the holistic health provision of an Aboriginal Community Controlled Health Service, provides the sound structure to address all aspects of health care arising from social, emotional and physical determinants".[350]

As described in Chapter 7, there have also been a number of studies that involved interviews with Aboriginal and Torres Strait Islander peoples as key informants or in focus groups regarding health, and the importance of SCEDH has been the central finding.[130,290]

8.1.5 Specific social and cultural determinants identified by Aboriginal and Torres Strait Islander communities

Colonisation and decolonisation are social and cultural determinants of central importance to Aboriginal and Torres Strait Islander communities.[351] The ongoing colonisation of the Australian continent by British people is characterised by phases of invasion, frontier violence, intervention by religious and philanthropic groups, and ongoing State intrusion into Indigenous lives.[352]

Social and cultural determinants related to colonisation include acculturation, cultural genocide, and collective trauma from previous generations.[351] Acculturation refers to the social processes that bring about cultural change which occur when people from different cultures are brought together by means that include immigration or colonisation.[353] Cultural genocide refers to the destruction of one people's culture by another. In Australia, colonisation and past government acculturation policy of assimilation contributed to cultural genocide by preventing Aboriginal and Torres Strait Islander peoples practising or passing on cultural knowledge and tradition.[351] For example, the institutional removal of children from their families over many decades has been well documented, and was the subject of Prime Minister Rudd's apology to the Stolen Generation in 2008.[354]

The law, a social determinant, filters down to many aspects of policy and society to exert an influence on health. Reynolds et al. argue that where constitutional arrangements support Indigenous rights and interests, health outcomes improve.[355] Other countries with Indigenous populations that were colonised by the British have better survival rates for their Indigenous populations, and one of the complex array of determinants that may influence this difference is the more inclusive constitutional recognition of their Indigenous peoples including treaties between Indigenous and non-Indigenous peoples.[355] For example, in comparable countries to Australia such as Canada, the United States of America, and New Zealand, constitutional arrangements recognise prior rights of their Indigenous communities, and these arrangements allow for some level of constitutionally protected governance by Indigenous peoples in those communities.[355]

Country is an important cultural determinant of health for Aboriginal and Torres Strait Islander peoples.[352] Country is a term used by Aboriginal and Torres Strait Islander peoples to refer to land with which they have a deep and long-standing connection that includes the history, meanings, and spirit of the land.[356] The loss of Country since the British arrived has been particularly significant for Aboriginal and Torres Strait Islander peoples.[356] This loss of Country occurred through colonisation, and included invasion by the British and frontier violence.[351]

Decolonisation involves a range of social and cultural determinants aiming to reverse the impacts of colonisation, and involves revisiting the past to deal with the unfinished and ongoing business of colonisation.[351] Reconciliation, land, control over health, cultural survival, affirming cultural ceremony, oral history, family support and connection, spiritual and emotional wellbeing, native title, self-determination, and community control are important social and cultural determinants related to decolonisation which are likely to benefit health.[351]

Other cultural determinants important to Aboriginal and Torres Strait Islander peoples include; freedom from discrimination; collective rights; freedom from assimilation; land and culture reclamation; preservation, and promotion of language and cultural practices; protection of traditional knowledge; understanding lore, law, and traditional roles and responsibilities.[344] Like protection of traditional knowledge, cultural continuity occurs when communities take steps to preserve and rehabilitate their cultures through community and cultural activities, and these have been shown to be protective against adolescent suicide.[357] In other studies, Aboriginal community members identified important social and cultural determinants including diet, drugs and alcohol, shame, identity, social injustice, self-esteem, peer group pressure, presence of role models, government policy, family breakdown, humour, gambling, powerlessness, place, incarceration and the justice system, housing and infrastructure, access to primary care, and broken spirits.[289,349,358,359]

8.1.6 How do social, cultural, and environmental determinants relate to morbidity and mortality?

Marmot et al. established the relationship between social determinants, measured by employment grade and mortality.[314] In the Whitehall II study, Marmot et al. found that lower status jobs were more likely to be associated with health risk factors, chronic diseases, and mortality than higher status jobs.[314] Similarly, one Australian study by Turrell et al. showed in national data, at least 20% of deaths could have been avoided if all Australians had the same socioeconomic status as the most socioeconomically advantaged SEIFA quintile.[360] Australian women in this study could have avoided over 50% of deaths using the same measures.[360]

As discussed in more detail in Chapter 7, the life course theory of social determinants asserts that stressors accumulate across the life course to contribute to premature health problems, disease, and death.[300,301] There may also be critical periods when adverse experience and stressors make a particular contribution to later health.[303]

The effect of social determinants on health can also be thought of as distal, intermediate, and proximal determinants. In this framework, distal determinants are thought to have the most profound influence on health because they represent the context through which they mediate intermediate and proximal social determinants.[361] This context includes the political, economic, and social circumstances where populations are situated.[361] Intermediate social determinants are influenced by distal determinants as well as directly influencing proximal social determinants. Intermediate social determinants include the provision of services, community infrastructure, racism, and the way health, education, and criminal justice systems are set up.[362] Proximal social determinants are influenced by both distal and intermediate determinants, and have a direct impact on physical, emotional, mental, or spiritual health.[361] Examples of proximal social determinants include housing, unemployment, social stressors, education, and health related behaviours such as substance use, diet, and exercise.[362] In some cases, the distinction between distal, intermediate, and proximal social determinants can be blurred with some social determinants, such as racism, fitting into two or even all three categories.

The social determinants literature contains tensions regarding the relative importance of psychological and material pathways from distal social determinants to intermediate social determinants and then to morbidity and mortality.[363] According to one school of thought, psychological processes are the most important mediators of social determinants producing biomedical health outcomes. These psychological processes include stress in early life, the effect of social affiliations or social capital, and the effects of social status and control over one's life.[364] Social status relates to position within a social hierarchy or social gradient where those people occupying superior or dominant positions, especially in the workplace, tend to have better psychosocial health.[314,364] Those in lower socio-economic groups with lower social status may perceive their socioeconomic disadvantage and experience stress, hopelessness, poor self-esteem, hostility, as well as a lack of a sense of control.[363] However, even amongst those of lower social status, the extent of social connectedness and solidarity among societal groups may attenuate psychological stress through feelings of belonging.[363] From a biomedical health perspective, these psychosocial stressors elicit neuroendocrine and immunological responses at a cellular level which may plausibly contribute to cardiovascular disease, infections, depression, and anxiety.[313,365]

While psychological processes appear likely to play a role, others argue that the material effects of differential structural and economic investment between areas produces measurable economic differences which are directly linked to morbidity and mortality independent of psychological determinants.[363] In this way, differential material investment in the areas where ethnic minorities, such as Aboriginal and Torres Strait Islander peoples, live can lead to socioeconomic disadvantage, and increased morbidity and mortality.[366]

It is important to construct representative models which explain the links between SCEDH and morbidity and mortality given their potential to influence policy decisions regarding resource allocation.[331] For Aboriginal and Torres Strait Islander communities, models that account for social networks, culture, and the effects of racism will be more relevant than models which do not take these determinants into account.[349] For example, income based measures give an incomplete picture of socioeconomic disadvantage for Aboriginal and Torres Strait Islander peoples where even relatively income advantaged families may experience significant household crowding and high levels of negative interaction with the criminal justice system.[367] Unlike most of the literature linking higher income with greater life satisfaction, the relationship between income and life satisfaction for Aboriginal and Torres Strait Islander peoples is complex.[368,369] For Aboriginal and Torres Strait Islander men living in non-remote areas, income is associated with subjective wellbeing in a similar way to non-Indigenous Australians.[369] However, this relationship between wellbeing and income disappears for all Aboriginal and Torres Strait Islander people living in remote locations and for women in non-remote locations.[369] It may be that activities which increase income such as gaining employment result in disconnection from community and cultural activities which are important determinants of subjective wellbeing for Aboriginal and Torres Strait Islander peoples.[368] Additionally, Aboriginal and Torres Strait Islander peoples may be more likely to share income or gain resources outside the mainstream economy.[369] Alternatively, income and other forms of advantageous SCEDH such as education may not protect Aboriginal and Torres Strait Islander peoples from the harmful effects of experiences of racism.[339]

8.1.7 Lack of research into social, cultural, and environmental determinants of health

A search of the Australian Indigenous Health Infonet (2009-2015) under the topics of social determinants and social and emotional wellbeing revealed only three studies looking at social determinants at the level of the primary health care service within an Aboriginal and Torres Strait Islander community. For this search, I used the Australian Indigenous Health Infonet because it groups research papers addressing Aboriginal and Torres Strait Islander health under specific headings relevant to this doctoral research including social determinants and social and emotional wellbeing. Only one of the three identified studies used HA information, and it was conducted at the IIHS exploring the experience of stressful events by children.[113] Of the other two studies, one was concerned with caring for Country in the Northern Territory,[214] and the other explored the role of Aboriginal Medical Services in combatting discrimination.[139]

A small number of population based studies including analysis of multiple social and cultural determinants involving Aboriginal and Torres Strait Islander peoples have been conducted at the international, national, or state level.[370-375] A small number of other studies have looked at one specific SCEDH such as racism[339,374] or housing.[341,376,377]

At an international level, one longitudinal study based on Census data for Indigenous peoples from Canada, New Zealand, and Australia found that while small gains in social determinants like employment, education, and income were occurring, the relative gap with non-Indigenous peoples was rising in each country and was the worst in Australia.[370] National and state level studies of Aboriginal and Torres Strait Islander peoples in urban areas found associations between social determinants like unemployment, low education attainment, and low socioeconomic status with health outcomes such as social exclusion and psychological functioning or distress.[372,374,375,378] Both a Western Australian study of social determinants in adolescents and a Victorian study of social determinants in adults did not measure racism, but identified experiences of racism as being an important component of future research involving social determinants.[375,378] These national and international studies are valuable overviews of a select number of broad social determinants operating in Aboriginal and Torres Strait Islander communities, but are missing many SCEDH important to Aboriginal and Torres Strait Islander peoples, and therefore the information they provide policy makers is incomplete and not community specific.

The small number of studies looking at experiences of racism concerning Aboriginal and Torres Strait Islander peoples found that it is more common in urban areas where experience of racism has been reported by between 70% and 97% of participants.[338,341,376] Experiences of racism have been found to be associated with psychological distress, and have an adverse effect on mental health for Aboriginal and Torres Strait Islander peoples.[341]

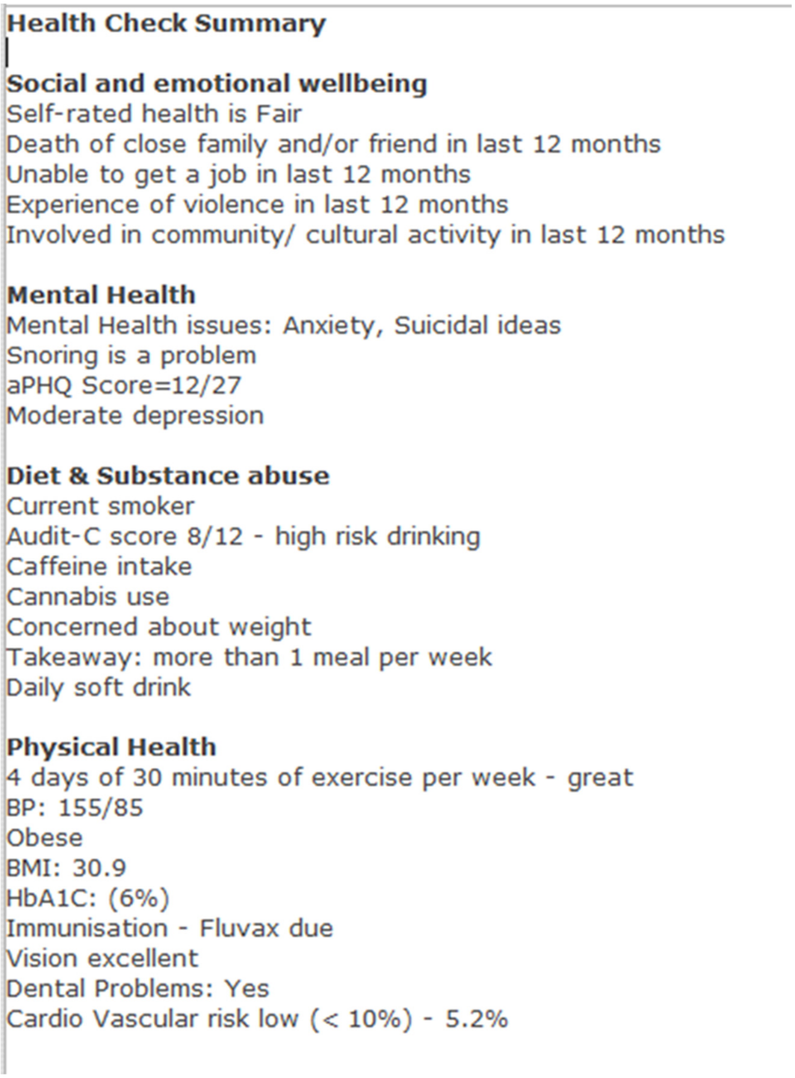
As noted in the introduction to this thesis, research data in urban contexts to inform strategies to close the gap in life expectancy for Aboriginal and Torres Strait Islander peoples is lacking.[4,5] While cross-sectional datasets exist at a national level such as Census data and the Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS) to inform Aboriginal and Torres Strait Islander health needs, health research, and policy, there is a lack of relevant data on SCEDH at the community level for Aboriginal and Torres Strait Islander communities.[180] As well as not representing specific community needs, Census data depends on Indigenous self-identification, so may not accurately represent Aboriginal and Torres Strait Islander peoples.[379] An epidemiological investigation at the community level will reflect the SCEDH specific to the community that are not captured in national or state level population studies.

8.1.8 Health assessments and social, cultural, and environmental determinants of health in the Inala Aboriginal and Torres Strait Islander community

In 2013, in recognition of the limitations of the biomedical emphasis of computerised HAs, one of my PhD advisors, CB, suggested the addition of questions addressing SCEDH to computerised HAs. Therefore, I cannot claim that the research findings from Chapter 7 were the sole inspiration for the addition of questions addressing SCEDH to computerised HAs. These newly introduced questions did not form part of HAs at the IIHS until 2014. This means that key informant responses described in Chapter 7 were not responding to computerised HAs which contained these questions.

These additional questions regarding SCEDH were designed to compare computerised HA findings at the IIHS with national data on social and emotional wellbeing, and were based on measures in the 2004-5 National Aboriginal and Torres Strait Islander Health Survey.[380] Specifically, questions addressing psychosocial stressors were introduced to computerised HAs using the Negative Life Event Scale (NLES) which includes questions about grief, violence, gambling, and experiences of racism.[371] There were also new questions regarding participation in community events, feelings of anger, and a more culturally appropriate depression screening tool, the adapted Patient Health Questionnaire 9 (aPHQ-9).[381] Single item questions regarding self-reported depression, anxiety, and suicidal thoughts were retained. Finally, additional questions also included SCEDH such as educational level, participation in community events, and housing. Involvement in cultural and community activities is a broad question, and open to interpretation by clinicians and patients, but is designed to reflect cultural continuity. All these new questions formed part of the adult computerised HAs used to measure the data analysed in Chapter 8. The 15-54 year male adult computerised HA used for this research is attached in Appendix 7. The findings from key informant interviews, described in Chapter 7, supported the addition of these types of questions into the computerised HAs. Other questions, such as a detailed diet history and a detailed illicit drug taking history, were removed to ensure that computerised HAs administration time was largely unchanged. While the additional questions relating to the social world do not change the biomedical origins of computerised HAs conducted in the clinic environment, they do serve to remind clinicians and signal to patients that the health service recognises the importance of the social world to health. The “health check summary” associated with this newly updated 15-54 year computerised HA has an updated format with inbuilt headings for social and emotional wellbeing, mental health, diet and substance abuse, and physical health (Figure 8.1). Findings from the computer HA automatically populate the “health check summary” under these headings, and clinicians can add text as desired.

Figure 8.1 Example of the updated format of the “Health Check Summary” from the new 15-54 year old computerised health assessment using a fictitious 18 year old male patient



Health Check Summary

Social and emotional wellbeing
Self-rated health is Fair
Death of close family and/or friend in last 12 months
Unable to get a job in last 12 months
Experience of violence in last 12 months
Involved in community/ cultural activity in last 12 months

Mental Health
Mental Health issues: Anxiety, Suicidal ideas
Snoring is a problem
aPHQ Score=12/27
Moderate depression

Diet & Substance abuse
Current smoker
Audit-C score 8/12 - high risk drinking
Caffeine intake
Cannabis use
Concerned about weight
Takeaway: more than 1 meal per week
Daily soft drink

Physical Health
4 days of 30 minutes of exercise per week - great
BP: 155/85
Obese
BMI: 30.9
HbA1C: (6%)
Immunisation - Fluvax due
Vision excellent
Dental Problems: Yes
Cardio Vascular risk low (< 10%) - 5.2%

8.1.9 Rationale for studying social, cultural, and environmental determinants of health as part of health assessments at the Inala Indigenous Health Service

Key informants in the Inala Aboriginal and Torres Strait Islander community and other Indigenous communities in Australia and overseas have identified SCEDH as a priority.[57,82] Therefore, it is logical to start with SCEDH when considering the direction of research and policy direction with respect to Aboriginal and Torres Strait Islander health.

The IIHS is well placed to study SCEDH as they now form a greater part of annual Indigenous computerised HAs conducted at the service. Differences in the way SCEDH are experienced by demographic variables such as age, sex, and ethnicity may represent inequities that are unjust and avoidable.[346] Furthermore, this research also provides an alternate quantitative view of the elements of health described in Chapter 7. Understanding the demographic distribution of SCEDH will also help to indicate where policy, community, and health service efforts need to be directed.

8.2 Aim, objectives, and research question

This chapter aims to describe a range of SCEDH measured by Indigenous computerised HAs at the IIHS. The objective of this epidemiological investigation is to describe the overall distribution of SCEDH measured by computerised HAs in adult patients attending the IIHS, and between different age, sex, and ethnic groups. The research question, described in Chapter 3, for this chapter is;

> What is the overall distribution of SCEDH measured by computerised HAs in adult patients attending the IIHS, and between different age, sex, and ethnic groups?

8.3 Methods

Participants were regular patients of the IIHS who had had computerised HAs, and the recruitment process for computerised HA research is described in detail in Chapter 5.

8.3.1 Data collection

This project used computerised adult Aboriginal and Torres Strait Islander HAs conducted over a one year period at the IIHS between April 2014 and March 2015 inclusive (Appendix 7). The starting date was chosen to coincide with the addition of questions regarding SCEDH to computerised HAs. Based on previous experience of computerised HA numbers at the IIHS, I expected that over the 12 month study period, approximately 1,000 adults would have HAs. Aboriginal and Torres Strait Islander HAs can be conducted at a minimum of nine months after the last HA, and I expected that approximately 100 adults would have two HAs in 12 months. For participants with two HAs included in the study period, only the first HA was used. I anticipated that a small number of potential participants would not consent to their HA data being used for research purposes. The expected sample size of 800 yields a proportion estimate with a 95% CI half-width less than 0.05. HA data are inputted for primarily clinical purposes by the clinical staff at the IIHS. The clinical staff conducting HAs during this study included nurses and GPs who were mostly non-Indigenous. The way computerised HAs are used in the clinical setting to produce research data is described in detail in Chapter 5.

8.3.2 Variables

Broadly, I describe here the variables used in this epidemiological investigation as demographic variables or SCEDH.

Demographic variables

The patient's date of birth, sex, and ethnicity are inputted by administrative staff at the IIHS when the patient is registered on their first visit to the IIHS. These data then automatically populate each new HA that each patient has at the IIHS.

Adult HAs are for Aboriginal and Torres Strait Islander peoples aged 15 years and over. Age was divided into deciles starting with 15-24 years and ending with the 65 years and over grouping. The age of the patient automatically populated the HA, and is derived from the difference in years between the patient's date of birth and the date of the patient's HA. Sex is recorded as male and female. Ethnicity is asked by reception staff when patients register on their first visit at the IIHS using the single question recommended by the RACGP, "Are you of Aboriginal or Torres Strait Islander origin?"[382] Patients may self-identify as Aboriginal, Torres Strait Islander, both, or neither. Ethnicity, as measured by Aboriginal and Torres Strait Islander HAs, does not consider the specific traditional Country or area with which Aboriginal and Torres Strait Islander peoples identify.

Social gradient and poverty

For the research described in this chapter, socioeconomic status is measured using SEIFA deciles. HAs indicate the postcode in which the individual is living, so the SEIFA for the postcode where the individual lives can be presented as an indication of the socioeconomic context where the person lives. SEIFA does not give a direct indication of that individual's socioeconomic situation.[383] As with some other demographic variables, computerised HAs automatically extract the patient's current postcode from the patient's clinical record. Reception staff are trained to enquire about and update demographic details including address at each clinic visit. The postcode automatically populates the patient's clinical record based on the last suburb inputted by reception staff (Table 8.1).

Social exclusion

In this chapter, six social exclusion factors identified in the literature[330,372] and measured by Aboriginal and Torres Strait Islander HAs are considered including unemployment, low education level, discrimination, lack of participation in community/cultural events, poor self-rated health, and homelessness. The results for social exclusion are presented as a dichotomous outcome dividing participants into those with any social exclusion factor versus those reporting no social exclusion factors (Table 8.1). Analysing social exclusion as a dichotomous outcome does not adequately capture its multidimensional nature nor should the six elements of social exclusion be considered of equal significance as social determinants of health. However, to explore all the components of social exclusion separately would greatly increase the reporting complexity without adding a great deal of useful information (Table 8.1).

Psychosocial stressors

The HAs measure 15 life stressors using the same NLES as the AIHW publication on the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples.[371] The different stressors are outlined in Table 8.1. After consulting with Aboriginal and Torres Strait Islander stakeholders, and assessing the internal logic and validity of these measures, the AIHW concluded that while some measures needed improving they should be retained for their next survey.[371] Moreover, an evaluation of the NLES in a number of remote Northern Territory Aboriginal communities found the scale performed well with respect to endorsement (missing data), discriminative ability of individual items, and reliability of the scale.[384] The outcome measure “no stressor experienced in the last 12 months” in this study is based on participants indicating they had not experienced any of the 15 NLES stressors in the preceding 12 months (Table 8.1).

Psychological distress

The HA contains single-item questions measuring self-reported depression, anxiety and suicidal thoughts. Depression, anxiety, and suicidal thoughts were considered to be present with participant self-report (Table 8.1). In 2010, when adult computerised HAs were first used they contained the K10, a validated psychological distress scale.[257] However, clinicians were concerned that this test was too long and the six point Kessler scale was introduced.[385] Despite this scale being four questions shorter, clinicians still favoured the single item depression screening question. However, ongoing concerns about the sensitivity and specificity of ultra-short depression screening questions in primary care[386] prompted the introduction to computerised HAs of the aPHQ-9 depression screening tool, developed with Aboriginal men from five different language groups.[381] It is currently being evaluated through the Getting it Right study.[387] Again, this tool was not used by all clinicians on all patients.

Alcohol, tobacco, and drug use

HAs measure current tobacco smoking and harmful alcohol use. Harmful alcohol is recorded in computerised HAs if the patient reports drinking more than two standard drinks of alcohol per day. This is consistent with NHMRC guidelines regarding alcohol use which recommend drinking no more than two standard drinks of alcohol on any day in order to avoid a life time risk of harm from alcohol.[388] High levels of missing data from the AUDIT precluded its use. Regarding the use of other substances, computerised HAs specifically measure each of recent marijuana, amphetamine, and heroin use as a dichotomous outcome (yes/no) depending on participant response (Table 8.1).

Food

The HA measures fruit and vegetable intake where adequate intake is defined as two serves of fruit and five serves of vegetables per day as per NHMRC guidelines on fruit and vegetable intake.[389] Computerised HAs do not contain questions about food security.

Exercise

The WHO recommends adults, aged 18 to 64 years, do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week, or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week, or an equivalent combination of moderate and vigorous intensity activity.[390] The relevant question in the HAs measured the number of days in the week that at least 30 minutes of vigorous exercise had occurred which does not give a ready comparison with WHO guidelines. The Australian guidelines on physical activity are based on the WHO guidelines, and start by recommending that doing any activity is better than doing none.[391] Thus, exercise has been converted into a dichotomous outcome for participants who reported vigorous exercise on at least one day per week versus otherwise (Table 8.1). In addition to physical activity, HAs measure whether participants report playing regular sport or not as a dichotomous outcome (Table 8.1).

Cultural continuity

Cultural continuity is a cultural factor which is partially measured by an HA question asking patients if they have participated in any community or cultural activity in the last 12 months (Table 8.1).

Physical environment

Standard measures of housing such as the Canadian National Occupancy Standard incorporate a number of variables to assess household crowding including an assessment of the number of bedrooms and the number of people in the house and their ages.[392] These types of measures may not be as culturally valid for populations where sleeping in a bedroom is not the only acceptable place to sleep in the house.[393] For example, the living room may be an acceptable place to sleep in traditional Japanese and Pacific South Auckland households.[393] In the Australian context, household crowding is likely to be an important factor for Aboriginal and Torres Strait Islander peoples' health.[109] However, there are other household determinants such as the quality of household infrastructure and amenities that contribute to health outcomes for Aboriginal peoples.[394] Participants' perception of household crowding as an issue in their house may be the most valid measure of household crowding as it is associated with participants' sense of how habitable their house is.[393] The HA contains a question as part of the NLES asking participants if overcrowding is an issue for them. HAs also contain a question which asks if a participant is currently homeless (Table 8.1). Quality of housing, housing tenure, access to services, and access to transport are not measured by HAs.

Table 8.1 Summary table of social, cultural, and environmental determinants measured by computerised health assessments (HA), the HA question, HA responses, and outcome analysed in this study.

Cultural or social factor	HA prompt	HA responses	Outcome analysed
Social determinants			
Poverty	Post code auto populates from patient's clinical record	Post code	Postcode is linked to socioeconomic index for area (SEIFA) and divided into deciles. Outcome is SEIFA decile one versus all other SEIFA deciles
Interaction with the criminal justice system	History of incarceration (ever)	Yes/ no	Yes
Unemployment	Current employment status	Unemployed Employed full time Employed part time Employed casually Employed on contract work Voluntary work Disability pension Other pension Home duties Study full time Study part time Carer	Unemployed versus not unemployed
Low education attainment	Highest education level obtained	Year 10 or less Year 11-12 TAFE University	Year 10 or less versus not

Table 8.1 Summary table of social, cultural, and environmental determinants measured by computerised health assessments (HA), the HA question, HA responses, and outcome analysed in this study.

Cultural or social factor	HA prompt	HA responses	Outcome analysed
Single parent	Currently single parent	Yes/ no	Yes
Negative life event scale (NLES)			
Have you experienced in the last 12 months;			
	Serious illness or disability?	Yes/ no	Yes
	Serious accident?	Yes/ no	Yes
	Death of a family member or close friend?	Yes/ no	Yes
	Divorce or separation?	Yes/ no	Yes
	Not able to get a job?	Yes/ no	Yes
	Involuntary loss of job?	Yes/ no	Yes
	Alcohol related problems?	Yes/ no	Yes
	Drug related problems?	Yes/ no	Yes
	Witness to violence?	Yes/ no	Yes
	Abuse or violent crime?	Yes/ no	Yes
	Trouble with the police?	Yes/ no	Yes
	Gambling problems?	Yes/ no	Yes
	Member of family sent to jail / currently in jail?	Yes/ no	Yes
	Overcrowding at home?	Yes/ no	Yes
	Racism or discrimination	Yes/ no	Yes
	No reported stressors?	Yes/ no	Yes
Psychological distress			
Depression	Self-reported depression	Yes/no	Yes
Anxiety	Self-reported anxiety	Yes/ no	Yes
Suicidal thoughts	Self-reported suicidal thoughts	Yes/ no	Yes
Alcohol, tobacco, drug use, diet, and exercise			
Addiction/ substance use	Harmful alcohol use (defined as more than 2 standard drinks on any given day of the week)	Yes/ no	Yes
	Smoking history	Current smoking, ex- smoker, never smoked	Current smoker versus not
	Reported recent use of marijuana	Yes/ no	Yes
	Reported recent use of amphetamines	Yes/ no	Yes
	Reported recent use of opiates including heroin	Yes/ no	Yes
Lack of healthy food/ drinks	Fruit and vegetable intake in the last 24 hours	Adequate (5 serves of vegetables and 2 of fruit), none, and suboptimal (between adequate and none)	None versus any
	Soft drink/cordial (glasses per day)	Number of glasses per day	0 glasses per day versus any
Exercise	Days of exercise per week where patients have done at least 30 minutes of exercise	Number of days per week	No days per week versus any
	Plays sport	Yes/ no	No
Social exclusion			
Social exclusion is considered present if any of the following are present:			Any social exclusion factors (Yes/ No)
Unemployment		see employment options above	Unemployed
Education to year 10 or less		see education options above	Education to year 10 or less
Poor or very poor self-rated health		Options for self-rated health include very good, good,	Poor or very poor self-rated health

Table 8.1 Summary table of social, cultural, and environmental determinants measured by computerised health assessments (HA), the HA question, HA responses, and outcome analysed in this study.

Cultural or social factor	HA prompt	HA responses	Outcome analysed
		fair, poor, or very poor	
	Experience of racism or discrimination in the last 12 months (part of the negative life event scale)	Yes/ no	Yes
	Homelessness	Yes/ no	Yes
	Involvement in community or cultural activities in the last 12 months	Yes/ no	No
Cultural determinants			
Community and cultural activity	Have you participated in a community or cultural activity within the last 12 months?	Yes/ no	No
Environmental determinants			
Homeless	Currently homeless	Yes/ no	Yes

8.3.3 Data analysis

Adult computerised HA data in Excel files were imported into the specialist statistical software package Stata version 12.0. SCEDH covered by computerised HA information are presented using frequencies and percentages. SCEDH were analysed by age group, sex, and ethnicity using bivariable logistic regression to investigate the association between each demographic variable (age, sex, and ethnicity) and the SCEDH. For bivariable logistic regression analysis, I used complete case models. Associations are presented as odds ratios (ORs) with associated 95% CIs. SCEDH were also analysed by sex within each age group using Fisher's exact test to investigate the association between each demographic variable (age, sex, and ethnicity) and the SCEDH. Statistical significance was set at the α=5% level.

Newly introduced social, cultural, and environmental determinants of health variables and data completeness

As described above in this chapter, several new SCEDH variables have been introduced to computerised HAs since computerised HA measures were analysed for missing data and the results presented in Chapter 6. These new SCEDH variables, presented in this chapter, include the NLES, participation in community and cultural activity, and highest level of educational attainment. The levels of missing data for these newly introduced variables were analysed and presented as a proportion of the total number of computerised HAs used in the analysis.

8.3.4 Ethics

This study was conducted in accordance with the NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research[56] and the NHMRC National Statement on Ethical Research in Humans.[59] Ethical approval had already been provided for the use of computerised HA information for research purposes (Appendix 3). The research has been supported by the ICJ for Aboriginal and Torres Strait Islander Health Research. This project also has ethical approval from the Metro South HREC. The process for obtaining informed consent for adult computerised HAs is described in detail in Chapter 5.

8.4 Results

During the one year study period (April 2014 to March 2015), 1103 computerised Aboriginal and Torres Strait Islander HAs were conducted at the IIHS on 922 adults. After removing the repeat assessments, there were 95 (10%) where a research consent form could not be found, and 47 (5%) where research consent was not provided, leaving 780 (85%) adults with HAs for inclusion in this epidemiological investigation.

8.4.1 Participant characteristics

Participants in this study had a similar age distribution to the national Aboriginal and Torres Strait Islander population according to Census data (Table 8.2).[395] There were approximately equal numbers of males and females and a large number of Aboriginal participants compared to Torres Strait Islander participants, and participants who identified as both Aboriginal and Torres Strait Islander (Table 8.2).

Table 8.2 Demographic characteristics of Aboriginal and Torres Strait Islander peoples who had a computerised HA at the Inala Indigenous Health Service between 1 April 2014 until the 31 March 2015 (N=780) and Census data from the Inala 4077 local government area.[a]

Demographic variables	Computerised HAs		Inala (4077) Census data[b]	
	n	(%)	n	(%)
Age (years)				
15-24	195	(25)	192	(26)
25-34	131	(17)	140	(19)
35-44	152	(19)	151	(20)
45-54	133	(17)	118	(16)
55-64	118	(15)	89	(12)
65 and over	51	(7)	55	(7)
Sex				
Female	400	(51)	411	(55)
Male	380	(49)	334	(45)
Ethnicity[c]				
Aboriginal	700	(93)	1327	(89)
Aboriginal and Torres Strait Islander	31	(4)	82	(6)
Torres Strait Islander	24	(3)	79	(5)

[a]While the postcode 4077 was most likely to be reported by participants as their residence (44%), overall 77 different postcodes were reported by participants as their place of residence.

[b]2011 Census data for age and sex are taken from the Inala community profile (4077).[383]

[c]2011 Census data for ethnicity are taken from the Inala and Richlands Queensland regional profile and include children aged 0 to 14 years.[40]

8.4.2 Missing data for newly introduced social, cultural, and environmental determinants of health

In Chapter 6, I found that for 88% of core variables in the adult HA (Table 6.2), less than 40% of their data were missing where levels of missing data over 40% were considered cause for data quality concern. For a further set of randomly selected, non-core variables, 74% of adult HA variables were missing less than 40% of their data (Table 6.8). Overall, I concluded in Chapter 6 that these levels of missing data in adult HAs were acceptable and that missing data were generally missing randomly and not in an identified pattern. Responses to questions relating to newly introduced social and cultural factors were acceptably low for NLES responses with 5% missing data. Moderate levels of data were missing for questions regarding community and cultural activity, (19% missing data) and highest level of educational attainment (21% missing data).

8.4.3 Overall proportions of social, cultural, and environmental determinants of health

As described in section 8.2, the aim of this chapter is to report SCEDH measured by computerised HAs by age, sex, and ethnic groups. The risk of this approach is that it may perpetuate a deficit discourse about Aboriginal and Torres Strait Islander peoples and the suburb of Inala. The rationale for reporting SCEDH that are challenging for the community is to show inequities that need to be addressed by policy makers through community organisations and health services. The interpretation of findings from this chapter must be considered in the context of findings from Chapter 7 regarding the strengths of the Inala Aboriginal and Torres Strait Islander community. Findings regarding SCEDH in this chapter are presented in descending order of frequency. Measures of social exclusion were the most commonly detected SCEDH followed by life stressors, and psychological distress.

Social exclusion

A large majority 463 (86%) of participants reported experiencing at least one social exclusion factor including 366 (58%) who were not involved in community or cultural activities in the last 12 months. Furthermore, almost half of participants reported attaining an education level of year 10 or less (48%) and lived in a postcode area in the lowest SEIFA decile (47%). Of the other social exclusion factors, a third reported being unemployed (33%), 13% reported experiencing racism in the last 12 months, 9% reported poor or very poor health, and a small number reported being currently homeless (4%) (Table 8.3).

Stressors

Of the stressors measured by the newly introduced NLES, 13% of participants reported no stressors at all in the last 12 months. The most common stressor experienced in the last 12 months reported by participants was death of a family member or close friend (35%) followed by being unable to get a job (27%), experiencing a serious illness (24%), and having a family member in jail (21%). Stressors that were only reported by a small number of participants included household crowding (7%), having lost a job (6%), serious accident (5%) and gambling problems (3%) (Table 8.3).

Psychological distress

Psychological distress which was reported by over a third of participants for depression (34%) and anxiety (34%). Suicidal thoughts were reported by 8% of participants. Some clinicians used the aPHQ-9 on selected patients who the clinician perceived to be at risk of mental health problems, and some clinicians did not use the aPHQ-9 at all. Owing to the large amount of missing data and the non-random quality of the missing data for aPHQ-9 outcomes (missing data dependent on the treating clinician), the results from the aPHQ-9 tool were not used in this study.

Substance use, diet, and exercise

Overall, 82% of participants did not report drinking harmful quantities of alcohol, 45% of participants did not report current tobacco smoking, and 78% of participants did not report using cannabis, amphetamines, or opiates. After current tobacco smoking, the next most commonly reported substance used was cannabis (22%), followed by harmful use of alcohol (18%). High levels of missing data from the AUDIT precluded its use. Amphetamine and opiate use were reported by small numbers of participants (Table 8.3). Playing sport was reported by 19% of participants (Table 8.3).

Table 8.3 Number (n) and percentage (%) of social, cultural, and environmental determinants reported by participants attending the Inala Indigenous Health Service for a computerised HA, 2014/2015 (N=780).

Social, cultural, and environmental determinants	N[a]	n	(%)
Social determinants			
Any social exclusion factor[b]	541	463	(86)
Year 10 education or less	613	293	(48)
Living in postcode with SEIFA in decile one	780	365	(47)
Unemployed	778	255	(33)
Single parent	435[c]	108	(25)
History of Incarceration	647	107	(17)
Negative life event scale - psychosocial stressors in last 12 months			
Death of a family member/ close friend	738	258	(35)
Unable to get a job	738	199	(27)
Serious illness	738	174	(24)
Family member in jail	738	152	(21)
Trouble with the police	738	100	(14)
Experience of racism	738	98	(13)
Witness to violence	738	96	(13)
No reported stressors	738	94	(13)
Relationship breakdown	738	91	(12)
Alcohol problems	738	87	(12)
Drug problems	738	85	(12)
Exposure to violent crime	738	80	(12)
Self-reported household crowding	738	53	(7)
Lost job	738	42	(6)
Serious accident	738	36	(5)
Gambling problems	738	23	(3)
Psychological distress			
Self-reported depression	769	262	(34)
Self-reported anxiety	750	252	(34)
Self-reported suicidal thoughts	750	59	(8)
Alcohol, tobacco, drug use, diet, and exercise			
Does not play sport	742	599	(81)
Current smoking	760	418	(55)
Inadequate fruit and vegetables	778	319	(41)
No regular exercise	762	260	(34)
Cannabis use	773	169	(22)
Harmful alcohol	712	128	(18)
Amphetamine use	758	36	(5)
Opiate use	754	28	(4)
Cultural determinants			
No community and cultural activity in last 12 months	635	366	(58)
Environmental determinants			
Homeless	453[c]	17	(4)

[a] Non-missing responses

[b] Social exclusion factors include not attending community/ cultural activities, unemployed, educational level to year 10 or less, experience of racism, homeless, and self-rated health of poor/ very poor.

[c] Homelessness and single parent status not recorded in participants aged 55 and over giving a denominator of 611

8.4.4 Bivariable measures of associations between social, cultural, and environmental determinants of health, sex, and age.

Bivariable analysis of SCEDH found associations between many SCEDH and both age and sex.

Social, cultural, and environmental determinants of health and male and female sex

Men were more likely to report challenging SCEDH. The largest difference was for a history of incarceration which was reported by 26% of men and 7% of women (Table 8.4). Measures of social exclusion were also more likely to be reported by men including attaining an education level of year 10 or less, being unemployed, and not being involved in community or cultural activity in the preceding 12 months. Men were also more likely to use cannabis, harmful levels of alcohol, opiates, and amphetamines. Psychosocial stressors measured by the NLES were also more likely to be reported by men including being unable to get a job, trouble with the police, alcohol problems and gambling problems (Table 8.4).

Women were more likely to report feeling depressed or anxious despite being more likely to report no psychosocial stressors in the preceding 12 months (Table 8.4). Social and environmental determinants reported more frequently by women included being a single parent, household crowding, and a tendency to report current homelessness. Women were less likely than men to report exercise and playing sport (Table 8.4).

Table 8.4 Odds ratio (OR) with 95% confidence interval (CI) of bivariable associations between the presence of social and cultural determinants by sex at the Inala Indigenous Health Service in 2014/2015 (N=780).

Social and cultural determinants	Female (ref) (N=400)		Male (N=380)		OR (95% CI)
	n	(%)	n	(%)	
Social determinants					
History of Incarceration	23	(7)	84	(26)	4.6 (2.8, 7.5)
Year 10 education or less	121	(40)	168	(56)	1.9 (1.4, 2.6)
Unemployed	115	(29)	140	(37)	1.5 (1.1, 2.0)
Any social exclusion factor	226	(83)	237	(88)	1.5 (0.9, 2.5)
Living in postcode with SEIFA in decile 1	188	(47)	177	(47)	1.0 (0.7, 1.3)
Single parent	81	(36)	27	(13)	0.3 (0.2, 0.4)
Psychosocial stressors – Negative Life Event Scale (last 12 months)					
Gambling problems	6	(2)	17	(5)	3.0 (1.2, 7.8)
Unable to get a job	68	(18)	131	(36)	2.6 (1.8, 3.6)
Alcohol problems	29	(8)	58	(16)	2.3 (1.4, 3.7)
Trouble with the police	37	(10)	63	(17)	1.9 (1.2, 3.0)
Lost job	16	(4)	26	(7)	1.7 (0.9, 3.3)
Drug problems	36	(10)	49	(14)	1.5 (0.9, 2.3)
Relationship breakdown	40	(11)	51	(14)	1.4 (0.9, 2.1)
Experience of racism	44	(12)	54	(15)	1.3 (0.9, 2.0)
Family member in jail	73	(19)	79	(22)	1.2 (0.8, 1.7)
Serious illness	90	(24)	84	(23)	1.0 (0.7, 1.3)
Serious accident	18	(5)	18	(5)	1.0 (0.5, 2.0)
Death of a family member/ close friend	143	(38)	115	(32)	0.8 (0.6, 1.0)
Exposure to violent crime	44	(12)	36	(11)	0.8 (0.5, 1.3)
Witness to violence	55	(15)	41	(11)	0.7 (0.5, 1.1)
Self-reported household crowding	36	(10)	17	(5)	0.5 (0.3, 0.8)
No Stressors	61	(16)	33	(9)	0.5 (0.3, 0.8)
Psychological distress					
Self-reported suicidal thoughts	34	(9)	25	(7)	0.8 (0.4, 1.3)
Self-reported depression	155	(39)	107	(29)	0.6 (0.5, 0.8)
Self-reported anxiety	153	(40)	99	(27)	0.6 (0.4, 0.8)
Alcohol, tobacco, drug use, diet, and exercise					
Cannabis use	60	(15)	109	(29)	2.3 (1.6, 3.3)
Opiate use	10	(3)	18	(5)	2.0 (0.9, 4.3)
Amphetamine use	13	(3)	23	(6)	1.7 (0.9, 3.3)
Harmful alcohol	56	(15)	72	(21)	1.5 (1.1, 2.3)
Inadequate fruit and vegetables	157	(39)	162	(43)	1.2 (0.9, 1.5)
Current smoking	218	(55)	200	(54)	0.9 (0.7, 1.2)
No regular exercise	146	(37)	114	(30)	0.7 (0.5, 1.0)
Does not play sport	317	(84)	282	(78)	0.7 (0.5, 1.0)
Cultural determinants					
No community/cultural activity in last year	174	(54)	192	(61)	1.3 (1.0, 1.9)
Environmental determinants					
Homeless	12	(5)	5	(2)	0.4 (0.1, 1.2)

A few SCEDH were not significantly different for men and women including living in a postcode with a SEIFA in decile one; the lowest 10% grouping. Of psychosocial stressors, men and women reported similar proportions of serious illness or serious accident. Men and women also reported similar proportions of tobacco smoking and self-reported suicidal thoughts (Table 8.4).

Social, cultural, and environmental determinants of health and age

Very few SCEDH did not vary significantly by age. This variability included several different patterns including a gradual increase or decrease in the frequency of reporting social and cultural determinants with age and some determinants were most frequently reported in middle age. SCEDH that were reported at similar rates across all age groups included experiences of racism, involvement in community and cultural activity, and living in a postcode area in the lowest SEIFA decile (Table 8.5).

In the youngest age decile (15-24 years), psychosocial stressors which were more commonly reported included witnessing violence (17%), trouble with the police (20%), and having a family member in jail (24%) (Table 8.5). Unemployment was also highest for 15-24 year olds (41%) and dropped significantly for people aged 55 years and over (21%). The reduction in unemployment for older age groups was associated with a corresponding rise in the number of participants who reported being on the pension. The youngest age decile was also the most likely to not eat regular fruit and vegetables (Table 8.5). Participants in the youngest age decile were the most likely to report playing sport (40%) and do exercise (80%) which were also health related behaviours less commonly reported with increasing age.

A number of SCEDH stayed at a constant frequency for age deciles up to a certain threshold when the frequency of reporting decreased. For example, tobacco smoking was reported by more than 50% of all age deciles up to 45-54 years of age when the reported rates of current tobacco smoking dropped to 24% among people age 65 years and over. Similarly, cannabis use showed an age-related threshold with more than 24% of participants in each age decile up to 45-54 years reporting use. Cannabis use dropped to 12% among 55-64 year olds and no-one among participants aged 65 years and over reported cannabis use (Table 8.5). Harmful alcohol use was reported by between 17% and 21% by participants in all age deciles between 15 years and 54 years of age before dropping to 4% among participants age 65 years and over. Amphetamines and opiate use were reported by small percentages (2% to 8%) of participants in each age decile up 45-54 years of age (Table 8.5).

For other SCEDH, there was an increase in frequency from 15-24 years to a peak in middle age and then the frequency declined with increasing age. Reporting of both depression and anxiety peaked at age 35-44 years, along with relationship breakdown, single parenthood, alcohol problems, exposure to violence, difficulty obtaining a job, and a history of incarceration (Table 8.5). Together with participants aged 45-54 years, participants aged 35-44 years were most likely to report at least one psychosocial stressor in the preceding 12 months (91%). Participants reporting suicidal thoughts gradually increased from rates of 7% in the youngest group (15-24 years) to peak at 13% in the 45-54 year age group before reducing to 0% in the 65 years and over group (Table 8.5). Of participants aged 45-54 years of age, 98% reported that they did not play sport and 45% did not do any exercise (Table 8.5).

For people aged 65 years and over, social exclusion factors tended to be more likely to be reported with increasing age such that 97% of participants in this age group reported at least one social exclusion factor. Most of this 97% could be attributed to attainment of an education level to year 10 or less which showed an increase with each age decile from 26% of 15-24 year olds up to 92% of participants aged 65 years and over (Table 8.5). Report of serious illness was also more common among participants with each increase in age decile such that 39% of participants aged 65 years and over reported serious illness as a stressor (Table 8.5).

Table 8.5 Odds ratio (OR) with 95% confidence interval (CI) of bivariable associations between social, cultural, and environmental determinants of health and age groups (15-24 yrs reference) (N=780).

SCEDH	15-24 yrs		25-34 yrs			35-44 yrs			45-54 years			55-64 years			65 + years		
	n	(%)	n	(%)	OR (95% CI)	n	(%)	OR (95% CI)	n	(%)	OR (95% CI)	n	(%)	OR (95% CI)	n	(%)	OR (95% CI)
Social determinants (not otherwise specified)																	
Any social exclusion factor	116	(81)	77	(79)	0.9 (0.5, 1.6)	90	(86)	1.4 (0.7, 2.8)	81	(93)	3.1 (1.2, 8.0)	68	(89)	2.0 (0.9, 4.6)	31	(97)	2.8 (0.9, 55.2)
Education:≤Year 10	41	(26)	34	(31)	1.3 (0.8, 2.2)	55	(45)	2.3 (1.4, 3.9)	66	(67)	5.7 (3.3, 9.9)	63	(71)	6.9 (3.9, 12.3)	34	(92)	32.3 (9.4, 111.0)
Live within SEIFA decile 1	85	(44)	65	(50)	1.3 (0.8, 2.0)	69	(45)	1.1 (0.7, 1.6)	56	(42)	0.9 (0.6, 1.5)	60	(51)	1.3 (0.8, 2.1)	30	(59)	1.8 (1.0, 3.5)
Unemployed	79	(41)	51	(39)	0.9 (0.6, 1.4)	45	(30)	0.6 (0.4, 1.0)	45	(34)	0.7 (0.5, 1.2)	25	(21)	0.4 (0.2, 0.7)	10	(20)	0.4 (0.2, 0.7)
Single parenthood	22	(15)	25	(26)	1.9 (1.0, 3.7)	39	(34)	2.8 (1.5, 5.1)	22	(27)	2.0 (1.0, 3.8)	not recorded			not recorded		
History of incarceration	16	(10)	28	(24)	2.8 (1.5, 5.5)	36	(28)	3.5 (1.8, 6.6)	20	(17)	1.9 (0.9 ,3.8)	7	(8)	0.8 (0.3, 2.1)	0	(0)	incalculable
Psychosocial stressors last 12 months (Negative Life Event Scale)																	
Death of family member	70	(39)	37	(31)	0.7 (0.4, 1.2)	57	(39)	1.0 (0.7, 1.6)	37	(30)	0.7 (0.4, 1.1)	42	(36)	0.9 (0.5, 1.4)	15	(29)	0.7 (0.3, 1.3)
Serious illness	17	(9)	15	(13)	1.4 (0.7, 2.9)	41	(28)	3.8 (2.1, 7.1)	42	(34)	5.1 (2.7, 9.5)	39	(33)	4.8 (2.6, 9.0)	20	(39)	6.3 (3.0, 13.3)
Unable to get a job	52	(29)	34	(28)	1.0 (0.6, 1.6)	49	(34)	1.3 (0.8, 2.0)	31	(25)	0.9 (0.5, 1.4)	32	(27)	0.9 (0.6, 1.6)	1	(2)	0.1 (0.0, 0.4)
Family member in jail	44	(24)	29	(24)	1.0 (0.6, 1.7)	29	(20)	0.8 (0.5, 1.3)	27	(22)	0.9 (0.5, 1.5)	21	(18)	0.7 (0.4, 1.2)	2	(4)	0.1 (0.0, 0.5)
Trouble with the police	36	(20)	24	(20)	1.0 (0.6, 1.8)	25	(17)	0.8 (0.5, 1.5)	15	(12)	0.6 (0.3, 1.1)	0	(0)	incalculable	0	(0)	incalculable
Experience of racism	21	(12)	18	(15)	1.4 (0.7, 2.7)	20	(14)	1.2 (0.6, 2.4)	18	(15)	1.3 (0.7, 2.6)	17	(14)	1.3 (0.6, 2.6)	4	(8)	0.7 (0.2, 2.0)
Witness to violence	31	(17)	17	(14)	0.8 (0.4, 1.5)	23	(16)	0.9 (0.5, 1.7)	11	(9)	0.5 (0.2, 1.0)	12	(10)	0.6 (0.3, 1.1)	2	(4)	0.2 (0.0, 0.9)
No reported stressors	33	(18)	16	(13)	0.7 (0.4, 1.3)	13	(9)	0.4 (0.2, 0.9)	11	(9)	0.4 (0.2, 0.9)	12	(10)	0.5 (0.3, 1.0)	9	(18)	1.0 (0.4, 2.2)
Alcohol problems	17	(9)	18	(15)	1.7 (0.8, 3.5)	24	(17)	1.9 (1.0, 3.7)	18	(15)	1.7 (0.8, 3.4)	9	(8)	0.8 (0.3, 1.9)	1	(2)	0.2 (0.0, 1.5)
Drug problems	17	(9)	26	(22)	2.7 (1.4, 5.2)	24	(17)	1.9 (1.0, 3.7)	15	(12)	1.4 (0.7, 2.8)	3	(3)	0.3 (0.1, 0.9)	0	(0)	incalculable
Abuse/ violent crime	23	(13)	16	(14)	1.1 (0.5, 2.1)	23	(17)	1.3 (0.7, 2.4)	8	(7)	0.5 (0.2, 1.1)	9	(8)	0.6 (0.3, 1.3)	1	(2)	0.2 (0.0, 1.1)
Household crowding	28	(15)	17	(14)	0.9 (0.5, 1.7)	15	(10)	0.6 (0.3, 1.2)	10	(8)	0.5 (0.2, 1.0)	3	(3)	0.1 (0.0, 0.5)	0	(0)	incalculable
Relationship breakdown	18	(10)	18	(15)	1.6 (0.8, 3.2)	22	(15)	1.6 (0.8, 3.2)	15	(12)	1.3 (0.6, 2.6)	14	(12)	1.2 (0.6, 2.6)	4	(8)	0.8 (0.3, 2.4)
Lost job	14	(8)	5	(4)	0.5 (0.2, 1.5)	7	(5)	0.6 (0.2, 1.6)	10	(8)	1.1 (0.5, 2.5)	6	(5)	0.6 (0.2, 1.7)	0	(0)	incalculable
Serious accident	9	(5)	7	(6)	1.2 (0.4, 3.3)	7	(5)	1.0 (0.4, 2.7)	7	(6)	1.2 (0.4, 3.2)	5	(4)	0.9 (0.3, 2.6)	1	(2)	0.4 (0.0, 3.1)
Gambling problems	7	(4)	3	(3)	0.6 (0.2, 2.5)	5	(3)	0.9 (0.3, 2.9)	5	(4)	1.1 (0.3, 3.4)	3	(3)	0.7 (0.2, 2.6)	0	(0)	incalculable
Psychological distress																	
Self-reported depression	43	(23)	50	(39)	2.2 (1.3, 3.6)	68	(46)	2.9 (1.8, 4.7)	51	(40)	2.3 (1.4, 3.7)	41	(36)	1.9 (1.1, 3.2)	9	(18)	0.7 (0.3, 1.6)
Self-reported anxiety	53	(28)	50	(40)	1.7 (1.1, 2.8)	62	(43)	1.9 (1.2, 3.0)	49	(39)	1.6 (1.0, 2.6)	31	(27)	0.9 (0.5, 1.6)	7	(14)	0.4 (0.2, 0.9)
Suicidal thoughts	13	(7)	10	(8)	1.2 (0.5, 2.8)	14	(10)	1.4 (0.6, 3.1)	16	(13)	2.0 (0.9, 4.3)	6	(5)	0.7 (0.3, 2.0)	0	(0)	incalculable
Alcohol, tobacco, drug use, diet, and exercise																	
Does not play sport	110	(60)	87	(69)	1.5 (0.9, 2.4)	129	(88)	4.8 (2.7, 8.6)	128	(98)	43.0 (10.3, 180)	98	(93)	9.4 (4.1, 21.4)	47	(94)	10.5 (3.2, 35.1)
Current smoking	100	(54)	85	(65)	1.6 (1.0, 2.6)	85	(56)	1.1 (0.7, 1.7)	82	(62)	1.4 (0.9, 2.2)	54	(47)	0.7 (0.5, 1.2)	12	(24)	0.3 (0.1, 0.5)
No fruit and vegetables	100	(51)	48	(37)	0.5 (0.3, 0.9)	56	(37)	0.6 (0.4, 0.9)	54	(41)	0.6 (0.4, 1.0)	46	(39)	0.6 (0.4, 1.0)	15	(31)	0.4 (0.2, 0.8)
No exercise	39	(20)	33	(25)	1.3 (0.8, 2.3)	56	(37)	2.3 (1.4, 3.8)	58	(45)	3.2 (1.9, 5.2)	46	(40)	2.6 (1.6, 4.3)	28	(58)	5.5 (2.8, 10.8)
Cannabis use	51	(26)	31	(24)	0.9 (0.5, 1.5)	39	(26)	1.0 (0.6, 1.6)	34	(26)	1.0 (0.6, 1.6)	14	(12)	0.4 (0.2, 0.7)	0	(0)	incalculable
Harmful alcohol	34	(20)	22	(18)	0.9 (0.5, 1.7)	26	(19)	1.0 (0.6, 1.7)	26	(21)	1.1 (0.6, 1.9)	18	(17)	0.8 (0.4, 1.5)	2	(4)	0.2 (0.0, 0.8)
Amphetamine use	14	(8)	5	(4)	0.5 (0.2, 1.5)	7	(5)	0.6 (0.2, 1.6)	10	(8)	1.1 (0.5, 2.5)	6	(5)	0.6 (0.2, 1.7)	0	(0)	incalculable
Opiate use	4	(2)	9	(7)	3.5 (1.1, 12)	9	(6)	3.0 (0.9,10.0)	6	(5)	2.2 (0.6, 8.0)	0	(0)	incalculable	0	(0)	incalculable
Cultural determinants																	
Attended community event	73	(43)	47	(43)	1.0 (0.6, 1.6)	55	(45)	1.1 (0.7, 1.7)	34	(34)	0.7 (0.4, 1.1)	44	(47)	1.2 (0.7, 2.0)	16	(40)	0.9 (0.4, 1.8)
Environmental determinants																	
Homeless	8	(6)	2	(2)	0.4 (0.1, 1.7)	3	(3)	0.5 (0.1, 1.9)	3	(3)	0.5 (0.1, 2.0)	not recorded			not recorded		

Social, cultural, and environmental determinants of health for each sex within each age decile

Analysis of SCEDH for each sex within age deciles revealed new associations not revealed in overall analyses of associations between SCEDH and sex and age. For people aged 15-24 years of age, 34 males out of 86 (40%) reported using cannabis compared with 17 females out of 109 (16%) (Table 8.6). For people aged 25-34 years, 35 males out of 72 (49%) reported being unemployed compared with 16 females out of 59 (27%) (Table 8.7). Additionally, in this age group, 16 males (25%) reported drinking alcohol in a harmful quantity compared with 6 females (11%). The proportion of females reporting smoking tobacco was highest in this age group (74%) (Table 8.7). Witness to violence was a psychological stressor which did not show a significant difference for age or sex in overall analyses apart from being less common in people aged 65 years and over (Table 8.5). However, there were 16 females out of 71 (25%) aged 35-44 years who reported witnessing violence compared to 7 males out of 81 (9%) (Table 8.8). There were 30 females (54%) in this same age group who reported being a single parent compared to 9 males (15%) (Table 8.8). Suicidal thoughts were most commonly reported in the 45-54 year age group (13%), and were reported by 9 females out of 70 (14%) and 7 males out of 63 (12%) (Table 8.9). For people aged 55-64 years, 28 males out of 56 (65%) reported not taking part in community activities in the preceding 12 months compared to 21 females out of 62 (42%) (Table 8.10). For people aged 65 years and over there were no differences for any SCEDH between males and females (Table 8.11).

Table 8.6 Social, cultural, and environmental determinants of health (SCEDH) for 15-24 year olds by sex at the Inala Indigenous Health Service in 2014/2015 (N=195).

SCEDH	Age 15-24 years (n=195)				
	Female (ref) (n=109)		Male (n=86)		Fishers exact test
	n	(%)	n	(%)	p value
Social determinants					
Any social exclusion factor	68	(85)	48	(76)	0.20
Living in postcode with SEIFA in decile 1	45	(41)	40	(47)	0.47
Unemployed	44	(41)	35	(41)	1.00
Year 10 education or less	23	(26)	18	(27)	1.00
Single parent	19	(24)	3	(5)	<0.01
History of Incarceration	5	(6)	11	(15)	0.07
Psychosocial stressors – Negative Life Event Scale (last 12 months)					
Death of a family member/ close friend	40	(39)	30	(38)	0.89
No Stressors	22	(22)	11	(14)	0.25
Unable to get a job	21	(21)	31	(39)	<0.01
Witness to violence	20	(20)	11	(14)	0.33
Family member in jail	20	(20)	24	(30)	0.12
Trouble with the police	17	(17)	19	(24)	0.26
Exposure to violent crime	14	(15)	9	(12)	0.66
Experience of racism	12	(12)	9	(11)	1.00
Self-reported household crowding	12	(12)	9	(11)	1.00
Serious illness	10	(10)	7	(9)	1.00
Relationship breakdown	9	(9)	9	(11)	0.62
Alcohol problems	8	(8)	9	(11)	0.45
Drug problems	7	(7)	10	(13)	0.21
Serious accident	6	(6)	3	(4)	0.73
Lost job	5	(5)	9	(11)	0.16
Gambling problems	0	(0)	7	(9)	<0.01
Psychological distress					
Self-reported anxiety	38	(37)	15	(18)	<0.01
Self-reported depression	30	(28)	13	(16)	0.06
Self-reported suicidal thoughts	8	(8)	5	(6)	0.78
Alcohol, tobacco, drug use, diet, and exercise					
Does not play sport	68	(67)	42	(51)	0.04
Current smoking	55	(52)	45	(56)	0.66
Inadequate fruit and vegetables	49	(45)	46	(53)	0.25
No regular exercise	25	(23)	14	(17)	0.28
Harmful alcohol	20	(20)	14	(19)	1.00
Cannabis use	17	(16)	34	(40)	<0.01
Amphetamine use	5	(5)	6	(8)	0.53
Opiate use	2	(2)	2	(3)	1.00
Cultural determinants					
No community/cultural activity in last year	54	(56)	42	(58)	0.88
Environmental determinants					
Homeless	7	(8)	1	(2)	0.14

Table 8.7 Social, cultural, and environmental determinants of health (SCEDH) for 25-34 year olds by sex at the Inala Indigenous Health Service in 2014/2015 (N=131).

SCEDH	Age 25-34 years (N=131)				
	Female (n=59)		Male (n=72)		Fishers exact test
	n	(%)	n	(%)	p value
Social determinants					
Any social exclusion factor	36	(75)	41	(82)	0.47
Living in postcode with SEIFA in decile 1	31	(53)	34	(47)	0.61
Single parent	18	(41)	7	(14)	<0.01
Year 10 education or less	15	(29)	19	(33)	0.68
Unemployed	16	(27)	35	(49)	0.02
History of Incarceration	9	(17)	19	(29)	0.19
Psychosocial stressors – Negative Life Event Scale (last 12 months)					
Death of a family member/ close friend	20	(36)	17	(26)	0.24
Family member in jail	14	(25)	15	(23)	0.83
Drug problems	12	(22)	14	(22)	1.00
Unable to get a job	10	(18)	24	(37)	0.03
Self-reported household crowding	9	(17)	4	(6)	0.25
Trouble with the police	9	(16)	15	(23)	0.49
No Stressors	9	(16)	7	(11)	0.43
Relationship breakdown	6	(11)	12	(19)	0.31
Experience of racism	6	(11)	12	(19)	0.31
Witness to violence	6	(11)	11	(17)	0.43
Exposure to violent crime	6	(11)	10	(17)	0.59
Serious illness	6	(11)	9	(14)	0.78
Alcohol problems	5	(9)	13	(20)	0.13
Lost job	3	(5)	2	(3)	0.66
Gambling problems	2	(4)	1	(2)	0.59
Serious accident	5	(9)	2	(3)	0.25
Psychological distress					
Self-reported anxiety	25	(44)	25	(37)	0.47
Self-reported depression	26	(44)	24	(35)	0.36
Self-reported suicidal thoughts	4	(7)	6	(9)	0.75
Alcohol, tobacco, drug use, diet, and exercise					
Does not play sport	42	(76)	45	(63)	0.13
Current smoking	43	(74)	42	(58)	0.07
Inadequate fruit and vegetables	19	(32)	29	(40)	0.37
No regular exercise	18	(31)	15	(21)	0.23
Cannabis use	15	(26)	16	(23)	0.68
Harmful alcohol	6	(11)	16	(25)	0.06
Opiate use	4	(7)	5	(7)	1.00
Amphetamine use	4	(7)	7	(10)	0.75
Cultural determinants					
No community/cultural activity in last year	29	(56)	33	(58)	0.85
Environmental determinants					
Homeless	1	(2)	1	(2)	1.00

Table 8.8 Social, cultural, and environmental determinants of health (SCEDH) for 35-44 year olds by sex at the Inala Indigenous Health Service in 2014/2015 (N=152).

SCEDH	Age 35-44 years (N=152)				
	Female (n=71)		Male (n=81)		Fishers exact test
	n	(%)	n	(%)	p value
Social determinants					
Any social exclusion factor	36	(77)	54	(93)	0.02
Single parent	30	(54)	9	(15)	<0.01
Living in postcode with SEIFA in decile 1	32	(45)	37	(46)	1.00
Year 10 education or less	17	(30)	38	(58)	<0.01
Unemployed	14	(20)	31	(38)	0.01
History of Incarceration	6	(11)	30	(41)	<0.01
Psychosocial stressors – Negative Life Event Scale (last 12 months)					
Death of a family member/ close friend	30	(46)	27	(34)	0.17
Serious illness	18	(27)	23	(29)	1.00
Witness to violence	16	(25)	7	(9)	0.01
Exposure to violent crime	15	(23)	8	(11)	0.07
Unable to get a job	13	(20)	36	(45)	<0.01
Alcohol problems	11	(17)	13	(16)	1.00
Family member in jail	10	(15)	19	(24)	0.30
Drug problems	10	(15)	14	(18)	0.82
Experience of racism	10	(15)	10	(13)	0.64
Relationship breakdown	8	(12)	14	(18)	0.49
No Stressors	8	(12)	5	(6)	0.25
Self-reported household crowding	7	(11)	6	(9)	0.01
Trouble with the police	6	(9)	19	(24)	0.03
Gambling problems	1	(2)	4	(5)	0.38
Serious accident	1	(2)	6	(8)	0.13
Lost job	0	(0)	7	(9)	0.02
Psychological distress					
Self-reported depression	37	(54)	31	(39)	0.10
Self-reported anxiety	36	(54)	26	(33)	0.02
Self-reported suicidal thoughts	9	(13)	5	(6)	0.17
Alcohol, tobacco, drug use, diet, and exercise					
Does not play sport	62	(87)	67	(88)	1.00
Current smoking	40	(56)	45	(56)	1.00
No regular exercise	28	(40)	28	(35)	0.50
Inadequate fruit and vegetables	24	(34)	32	(40)	0.50
Cannabis use	13	(18)	26	(33)	0.06
Harmful alcohol	10	(16)	16	(22)	0.51
Opiate use	2	(3)	7	(9)	0.18
Amphetamine use	2	(3)	7	(9)	0.17
Cultural determinants					
No community/cultural activity in last year	27	(50)	41	(59)	0.36
Environmental determinants					
Homeless	2	(4)	1	(2)	0.62

Table 8.9 Social, cultural, and environmental determinants of health (SCEDH) for 45-54 year olds by sex at the Inala Indigenous Health Service in 2014/2015 (N=133).

SCEDH	Age 45-54 years (N=133)				
	Female (n=70)		Male (n=63)		Fishers exact test
	n	(%)	n	(%)	p value
Social determinants					
Any social exclusion factor	36	(90)	45	(96)	0.41
Year 10 education or less	27	(54)	39	(80)	0.01
Living in postcode with SEIFA in decile 1	30	(43)	26	(41)	0.86
Unemployed	21	(30)	24	(38)	0.36
Single parent	14	(30)	8	(22)	0.47
History of Incarceration	2	(3)	18	(33)	<0.01
Psychosocial stressors – Negative Life Event Scale (last 12 months)					
Serious illness	25	(40)	17	(29)	0.25
Death of a family member/ close friend	21	(33)	16	(27)	0.56
Unable to get a job	12	(19)	19	(32)	0.10
Family member in jail	12	(19)	15	(25)	0.51
Relationship breakdown	8	(13)	7	(12)	1.00
No Stressors	8	(13)	3	(5)	0.21
Experience of racism	7	(11)	11	(19)	0.31
Lost job	6	(10)	4	(7)	0.75
Self-reported household crowding	6	(10)	2	(4)	0.68
Witness to violence	5	(8)	6	(10)	0.76
Trouble with the police	5	(8)	10	(17)	0.17
Drug problems	5	(8)	10	(17)	0.17
Alcohol problems	4	(6)	14	(24)	0.01
Serious accident	4	(6)	3	(5)	1.00
Exposure to violent crime	3	(5)	5	(9)	0.48
Gambling problems	3	(5)	2	(3)	1.00
Psychological distress					
Self-reported depression	30	(44)	21	(34)	0.28
Self-reported anxiety	26	(39)	23	(38)	1.00
Self-reported suicidal thoughts	9	(14)	7	(12)	0.79
Alcohol, tobacco, drug use, diet, and exercise					
Does not play sport	69	(100)	59	(97)	0.22
Current smoking	42	(61)	40	(63)	0.86
No regular exercise	32	(46)	26	(43)	0.73
Inadequate fruit and vegetables	23	(33)	31	(49)	0.08
Harmful alcohol	12	(18)	14	(24)	0.51
Cannabis use	10	(14)	24	(38)	<0.01
Opiate use	2	(3)	4	(7)	0.42
Amphetamine use	2	(3)	3	(5)	0.67
Cultural determinants					
No community/cultural activity in last year	29	(58)	38	(75)	0.10
Environmental determinants					
Homeless	1	(2)	2	(4)	1.00

Table 8.10 Social, cultural, and environmental determinants of health (SCEDH) for 55-64 year olds by sex at the Inala Indigenous Health Service in 2014/2015 (N=118).

SCEDH	Age 55-64 years (N=118)				
	Female (n=62)		Male (n=56)		Fishers exact test
	n	(%)	n	(%)	p value
Social determinants					
Any social exclusion factor	35	(85)	33	(94)	0.28
Year 10 education or less	25	(56)	38	(86)	<0.01
Living in postcode with SEIFA in decile 1	32	(52)	28	(50)	1.00
Unemployed	13	(21)	12	(21)	1.00
History of Incarceration	1	(2)	6	(14)	0.11
Psychosocial stressors – Negative Life Event Scale (last 12 months)					
Death of a family member/ close friend	23	(37)	19	(34)	0.85
Serious illness	18	(29)	21	(38)	0.43
Family member in jail	15	(24)	6	(11)	0.09
Unable to get a job	12	(19)	20	(36)	0.06
No Stressors	10	(16)	2	(4)	0.03
Experience of racism	8	(13)	9	(16)	0.79
Relationship breakdown	8	(13)	6	(11)	0.78
Witness to violence	7	(11)	5	(9)	0.77
Trouble with the police	5	(8)	3	(4)	0.72
Exposure to violent crime	3	(5)	5	(9)	1.00
Drug problems	2	(3)	1	(2)	1.00
Lost job	2	(3)	4	(7)	0.42
Serious accident	2	(3)	3	(5)	0.67
Self-reported household crowding	2	(3)	1	(2)	1.00
Alcohol problems	1	(2)	8	(14)	0.01
Gambling problems	0	(0)	3	(5)	0.10
Psychological distress					
Self-reported depression	21	(42)	16	(29)	0.12
Self-reported anxiety	22	(36)	9	(16)	0.02
Self-reported suicidal thoughts	4	(7)	2	(4)	0.68
Alcohol, tobacco, drug use, diet, and exercise					
Does not play sport	48	(91)	50	(96)	0.44
Current smoking	30	(49)	24	(44)	0.58
No regular exercise	26	(43)	20	(36)	0.57
Inadequate fruit and vegetables	20	(32)	26	(46)	0.13
Harmful alcohol	7	(11)	11	(23)	0.13
Cannabis use	5	(8)	9	(16)	0.25
Amphetamine use	0	(0)	0	(0)	1.00
Opiate use	0	(0)	0	(0)	1.00
Cultural determinants					
No community/cultural activity in last year	21	(42)	28	(65)	0.04

Table 8.11 Social, cultural, and environmental determinants of health (SCEDH) for participants aged 65 years and over by sex at the Inala Indigenous Health Service in 2014/2015 (N=51).

SCEDH	Age 65 years and over (N=51)				
	Female (n=29)		Male (n=22)		Fishers exact test
	n	(%)	n	(%)	p value
Social determinants					
Any social exclusion factor	15	(94)	16	(100)	1.00
Year 10 education or less	18	(90)	16	(94)	1.00
Living in postcode with SEIFA in decile 1	18	(62)	12	(55)	0.77
Unemployed	7	(24)	3	(14)	0.48
History of Incarceration	0	(0)	0	(0)	1.00
Psychosocial stressors – Negative Life Event Scale (last 12 months)					
Serious illness	13	(45)	7	(32)	0.40
Death of a family member/ close friend	9	(31)	6	(27)	1.00
No Stressors	4	(14)	5	(23)	0.47
Family member in jail	2	(7)	0	(0)	0.50
Exposure to violent crime	1	(4)	0	(0)	1.00
Relationship breakdown	1	(3)	3	(14)	0.30
Experience of racism	1	(3)	3	(14)	0.30
Trouble with the police	1	(3)	1	(5)	1.00
Witness to violence	1	(3)	1	(5)	1.00
Gambling problems	0	(0)	0	(0)	1.00
Unable to get a job	0	(0)	1	(2)	0.43
Lost job	0	(0)	0	(0)	1.00
Drug problems	0	(0)	0	(0)	1.00
Alcohol problems	0	(0)	1	(5)	0.43
Serious accident	0	(0)	1	(5)	0.43
Self-reported household crowding	0	(0)	0	(0)	1.00
Psychological distress					
Self-reported depression	7	(24)	2	(9)	0.27
Self-reported anxiety	6	(21)	1	(5)	0.12
Self-reported suicidal thoughts	0	(0)	0	(0)	1.00
Alcohol, tobacco, drug use, diet, and exercise					
Does not play sport	28	(97)	19	(90)	0.57
No regular exercise	17	(63)	11	(52)	0.56
Inadequate fruit and vegetables	11	(38)	4	(20)	0.22
Current smoking	8	(28)	4	(18)	0.52
Harmful alcohol	1	(3)	1	(5)	1.00
Amphetamine use	0	(0)	0	(0)	1.00
Cannabis use	0	(0)	0	(0)	1.00
Opiate use	0	(0)	0	(0)	1.00
Cultural determinants					
No community/cultural activity in last year	14	(70)	10	(50)	0.33

Ethnicity

There were small numbers of participants who identified as Torres Strait Islander and both Aboriginal and Torres Strait Islander compared to those who identified as Aboriginal. Participants who identified as both Aboriginal and Torres Strait Islander were twice as likely to identify as male as those who identified as Aboriginal. There were also significant differences in age according to ethnicity with participants identifying as Torres Strait Islander being on average more than six years older than Aboriginal participants and ten years older than participants identifying as both Aboriginal and Torres Strait Islander. The small numbers of two ethnic groups and the significant variations in age and sex make interpretation of variations in reporting of SCEDH by ethnicity difficult, and I have not presented the results of the bivariable analysis of SCEDH and ethnicity.

8.5 Discussion

Many participants in this study reported experiencing SCEDH described by key informants during the interviews reported in Chapter 7. The reporting of SCEDH by participants indicates that they are experienced in diverse ways for men and women, and vary significantly by age deciles. Men reported experiencing several interlinked SCEDH at greater frequency than women including low educational attainment, substance use, incarceration, and difficulty obtaining employment. Women also reported experiences of interlinked SCEDH at high levels, and were more likely than men to report the consequences of family breakdown including homelessness, overcrowding, and single parenthood. Women were also more likely than men to report death of a family member, anxiety, and depression.

Participants aged 35-44 years were most likely to report many psychosocial stressors along with anxiety, depression and rates of single parenthood. Reported suicidal thoughts were highest for those in the next decade of life, aged 45-54 years. Compared to older people, younger people reported higher rates of substance use, poor diet, trouble with the police, and unemployment. However, younger people were more likely to reach an education level beyond year 10 compared with older people. For those aged 45 years and older, more than half reported attaining an education level of year 10 or less. For those aged 65 years and older, very few participants reported attaining an education level beyond school year 10. As might be expected with increasing age, experience of serious illness as a psychosocial stressor increased steadily with each higher age decile.

8.5.1 Strengths and limitations

This study responds to calls to provide research data regarding SCEDH at the community level, which reduces participant burden, responds to community priorities, is useful for community organisations and health services, and is analysed by socially meaningful groupings such as age and sex.[4,57,82,180] Computerised HAs are able to generate an epidemiological profile of SCEDH with large numbers of participants in a relatively short period of time that is likely to be representative of the Aboriginal and Torres Strait Islander peoples attending the IIHS and the local community. While data on SCEDH have been collected and reported at state and national levels, this appears to be the first epidemiological investigation reporting on a range of SCEDH for adults at the community level, and is the first study reporting on these SCEDH using computerised HAs in a primary health care service.

The limitations of this approach include the large number of SCEDH, especially cultural determinants, important to Aboriginal and Torres Strait Islander peoples which are not measured by HAs, and are therefore not presented here. The failure to include these SCEDH risks not considering these cultural determinants in a discourse about health.

Clinicians collecting and inputting data on SCEDH into HAs for routinely collected clinical purposes do not have specific research training which may affect data quality. While the level of missing data for responses to the NLES was quite low (5%), there were significant quantities of missing data for some of the newly introduced SCEDH including educational level, participation in community and cultural activity, and aPHQ-9. The introduction of these items and the importance of SCEDH including psychological distress to the community had been canvassed at clinical meetings with clinical staff. Feedback from some clinical staff indicated some uncertainty and discomfort about asking about SCEDH in HAs and concern about how these questions would be received by patients. Along with the extra work of an 11 point scale, these clinician concerns appear to be the reason why so much data from the aPHQ-9 were missing that it could not be used in this analysis. Clinician resistance to non-biomedical questions are also likely to have contributed to moderate levels of missing data for other SCEDH. There will be an ongoing tension regarding data collected by computerised HAs which has the advantage of not being an extra burden for participants, but is constrained by what clinicians are willing to measure within the timeframe of a clinical consultation.

Responses to questions regarding SCEDH in this study have all been interpreted using the negative response to provide consistency of reporting, and to illustrate where the community's needs are greatest. The danger of this approach is that it may perpetuate a deficit discourse approach to Aboriginal and Torres Strait Islander health, and we forget the strength inherent in Aboriginal and Torres Strait Islander cultures and communities.[396]

Data in this study are cross-sectional, so associations may be bidirectional, and causal inferences cannot be drawn. In this sample of computerised HA data, there may have been important interactions between age and sex as independent variables on SCEDH, the dependent variables. While the sample size of this investigation precluded these analyses, future epidemiological investigation of SCEDH by age and sex with a larger sample size would benefit from an exploration of these interactions.

The validity and reliability of many HA variables were established in Chapter 6. Newly introduced questions regarding SCEDH have been evaluated for validity or reliability elsewhere and/or used in national surveys such as the NLES.[384] Some responses require further interpretation. For example, asking participants whether they participate in community or cultural activities is a question subject to interpretation by both participant and clinician in terms of what they perceive to be a community or cultural activity.

8.5.2 Strengths and weaknesses of this research compared to other studies and differences in results

Other studies looking at SCEDH for Aboriginal and Torres Strait Islander peoples are most commonly based on large national or state databases with a few select measures such as labour force statistics, education level attainment, and income.[374,375,397,398] This study is the first to focus primarily on a range of SCEDH within a health service and to use HAs as a validated data collection instrument in response to identified community priorities. Most of the SCEDH in this study focus on proximal social determinants. Thus, this study makes a relatively minor contribution to the sparse literature looking at distal SCEDH in the context of Aboriginal and Torres Strait Islander health.[351]

Social, cultural, and environmental determinants of health found at lower rates in this study

The wide variation in rates of reported racism between this study and others warrants exploration. Experience of racism in the last 12 months in this study was reported at higher rates (13%) than for Aboriginal and Torres Strait Islander peoples asked a similar question living in non-remote areas in a 2012-2013 national survey (8%).[397] However, in an urban population of Aboriginal adults aged 15 years and over in the Darwin area, 70% of participants reported experiencing at least one episode of interpersonal racism with 11-30% experiencing interpersonal racism at least some of the time.[376] In a 2014 Victorian study, 97% of Aboriginal participants reported experiencing at least one racist incident in the preceding 12 months.[341] It is possible that Aboriginal peoples are exposed to significantly more racism and discrimination in Darwin and Victoria. However, it is probably more likely that the multi-item questionnaires focusing on racism which were used in the Darwin and Victorian studies more fully detect experiences of racism than a single item question in an Aboriginal and Torres Strait Islander HA or national survey. A single-item question on racism, like that used in computerised HAs, is likely to measure experiences of overt, interpersonal racism, but is less likely to capture the impact of institutional racism. All these results suggest a problem with racism in the wider Australian community that needs to be addressed. The need to address racism and, in particular, institutional racism is also evident in Aboriginal and Torres Strait Islander peoples’ experiences of incarceration. Reported incarceration in this study was most common for men (26%), and those aged 35-44 years (28%). This is consistent with high rates of incarceration for Aboriginal and Torres Strait Islander peoples in Australia who make up 2.5% of the Australian population,[395] but a disproportionately large proportion (27%) of Australian prisoners (mainly men),[399] and this last figure is rising.[322]

In this study, reported suicidal thoughts peaked at 13% among 45-54 year olds. Level of suicidal intent has been shown to predict eventual suicide and death in non-Indigenous populations,[400] so detecting suicidal intent is important especially given suicide rates are significantly higher among Aboriginal and Torres Strait Islander peoples in Australia.[401] At the Victorian Aboriginal Health Service, 23% of 12-26 year olds reported suicidal ideation in 1997 using a health questionnaire specifically designed to ask about suicidal thoughts compared with 7% of participants aged 15-24 years reporting suicidal thoughts in this study.[181] This difference may relate to inadequate sensitivity of the single item question regarding self-reported suicidal thoughts used in this study. Alternatively, it is possible there have been improvements in mental health for young Aboriginal people in the 18 years between studies, and/or there could be protective factors working in the Inala Aboriginal and Torres Strait Islander community.

Social, cultural, and environmental determinants of health found at higher rates in this study

The higher rates of several social determinants including unemployment, educational attainment to school year 10 or less, psychological distress, and current smoking found in this study compared to other surveys of Aboriginal and Torres Strait Islander peoples living in non-remote areas also warrants exploration. One might expect rates of proximal social determinants to be higher in this study where participants are seeking health care compared with community based surveys. The IIHS is only open during office hours making access potentially more difficult for patients to attend and have HAs if they are fully employed. Alternatively, the level of disadvantage among patients attending the IIHS may be significantly better or worse than for Aboriginal and Torres Strait Islander peoples living in other parts of Australia or even Brisbane. Unemployment among participants of this study in Inala was 33% compared to 13.3% (2011 Census data) for Aboriginal and Torres Strait Islander adults aged 15-55 years living in major cities[398] and 8.7% for Aboriginal people surveyed in Victoria.[307] While Census data from 2011 indicate that the overall unemployment rate in the Inala and Richlands postcode area (4077) was 11%,[402] the unemployment rate for Aboriginal and Torres Strait Islander peoples was much higher at 29%. This unemployment rate is also significantly higher than the rate of 16% for Aboriginal and Torres Strait Islander peoples living in other postcode areas in Brisbane.[40] Similarly, 52% of Aboriginal and Torres Strait Islander peoples living in postcode area 4077 (Inala and Richlands) in 2011 attained an education level of school year 10 or less which was comparable to findings in this study (48%), and more than for Aboriginal and Torres Strait Islander peoples living in other suburbs in Brisbane (45%).[40] It appears as though low rates of educational attainment and the high unemployment rate found in this study reflect the significant disadvantage experienced by Aboriginal and Torres Strait Islander peoples in Inala rather than being an artefact of a clinic-based sample.

The level of educational attainment (school year 10 or less) amongst participants in this study varied markedly with age from 26% for 15-24 year olds up to 92% of participants aged 65 years and over, and followed a similar age-related pattern to findings for Aboriginal peoples living in major cities in New South Wales.[374] These findings are encouraging, and suggest that younger Aboriginal and Torres Strait Islander participants are much more likely to move beyond year 10 than older generations presenting to the IIHS. These findings are consistent with claims that the target of halving the gap in year 12 attainment for Aboriginal and Torres Strait Islander Australians aged 20 to 24 years of age is on track.[23]

The increased frequency of psychological distress among females and participants aged 35-44 years is similar to patterns found in Australian Health Survey data though participants reported psychological distress in this study at more than twice the rate of participants in the Australian Health Survey.[403] The Australian Health Survey claims to be “the largest and most comprehensive health survey ever conducted in Australia”.[403] Psychological distress was measured here by computerised HAs using single item questions regarding depression, anxiety, and suicidal thoughts. Other studies in varying contexts have shown inadequacies of these types of single item depression screening questions.[404-406]

Consistent with other high measures of proximal social determinants in the Inala postcode area, 54% of participants in this study (aged 15 years and over) reported current smoking compared to findings of the AATSIHS conducted in 2012 which found that 39% of Aboriginal and Torres Strait Islander adults living in non-remote areas were currently smoking tobacco.[397] As part of the Australian Health Survey, the AATSIHS is a national sample of around 13,000 Aboriginal and Torres Strait

Islander people living in remote and non-remote areas conducted between 2012 and 2013.[397] However, just as levels of educational attainment have been improving, smoking rates for adults aged 15-54 years in this 2014 study have dropped to 57% compared with age-matched tobacco smoking HA data from 2007 at the IIHS when tobacco smoking rates were reported at 67%.[48] This is still significantly higher than the overall tobacco smoking rate in Queensland which was 15% in 2011.[407] Reported cannabis and harmful alcohol use in this study are also less than their reported use in IIHS adult HA data from 2007.[48]

Social, cultural, and environmental determinants of health found at similar rates in this study compared to other studies involving Aboriginal and Torres Strait Islander peoples

Many stressors and other proximal social determinants measured in this study were reported at similar rates (within 5%) in the AATSIHS. Social determinants in this study that were reported at similar rates for AATSIHS participants in non-remote areas included death of a family member, being unable to get a job, serious illness, cannabis use, harmful alcohol, family member in jail, trouble with the police, exposure to violence, overcrowding, loss of a job in the last 12 months, serious accident, amphetamine use, opiate use, and gambling problems.[397] In this study and the AATSIHS, these stressors were reported at much higher levels than for the general Australian population. For example, only 13% of participants in this study reported experiencing no stressors in the last 12 months compared to 49% reporting no stressors in the general Australian population.[403]

Social, cultural, and environmental determinants of health experiences for other Indigenous peoples

The experience of SCEDH by Indigenous peoples in other countries is likely to be different to the SCEDH experienced by Aboriginal and Torres Strait Islander peoples owing to varying cultures, geography, and colonisation histories. However, there are also likely to be similarities in the experiences of SCEDH owing to encounters with racism and colonisation. By way of international comparison, the social and cultural determinants described in this study are similar to factors identified among Māori, the Indigenous people of New Zealand.[408] Participants in one study were clear that the disruption of whānau (immediate and wider family) and hapū (tribal or basic political unit in Māori culture) structures as a result of British colonisation were at the heart of Māori ill-health.[408] A population-based cohort study of older Māori people in New Zealand found correlations between increasing quality of life and frequency of marae (sacred gathering place of kin relations) visits and fewer experiences of discrimination.[409]

8.5.3 Implications for clinicians and the health service

HAs with more of a focus on SCEDH may help clinicians conceive of health in a more holistic way that includes the influence of these SCEDH as well as biomedical diseases and body parts. Moreover, clinicians will be in a better position to develop appropriate referral pathways to community resources and organisations helping community members deal with SCEDH. However, these referral pathways will only function for the community and health services if policy makers understand the importance of work done by community organisations, and fund them accordingly. Insecure, short term funding that does not recognise the administrative and reporting costs facing community organisations can compromise the capacity of the community sector to respond to SCEDH.[410] Health services like the IIHS, situated in the biomedical model of health favoured by policy makers,[309] could also use their resources to address SCEDH.

8.6 Conclusions

This investigation of SCEDH in the Inala Aboriginal and Torres Strait Islander community is the outcome of a research process starting with the development of computerised HAs (Chapter 5), evaluation of HA data (Chapter 6), and community consultation indicating the importance of SCEDH (Chapter 7). Computerised HAs provided information on the experience of a range of SCEDH which varied significantly according to the age and sex of participants suggesting opportunities for demographically targeted policy and local intervention. The findings in this study provide a profile of a range of SCEDH relevant to the Inala Aboriginal and Torres Strait Islander community, clinicians, and policy makers interested in improving the health of this community.

Chapter 9 Discussion

9.1 Introduction

For this doctoral research, I have been interested in how computerised HA data can be used for research which aligns with what the community says is important, and inform strategies which address the injustice of inequitable health outcomes for Aboriginal and Torres Strait Islander peoples. In this chapter, I respond to the research questions first described in Chapter 3 regarding the feasibility of producing computerised HA data, the credibility of these data for research purposes, and how these data can be used in an ethical way to address community priorities including the SCEDH. I also discuss how situating Chapter 7 in the transformative paradigm produced changes in me as a clinician and researcher, changes to computerised HAs, and changes to the direction of this doctoral research. Finally, I describe the tensions inherent in research which attempts to reconcile community priorities regarding SCEDH with the biomedical orientation of HAs and the health system more broadly. Together, these findings respond to the overarching research question regarding the validity and applicability of computerised Aboriginal and Torres Strait Islander HA based research in urban primary health care.

9.2 Feasibility of computerised health assessment implementation

In Chapter 5, I showed how computerised HAs were successfully implemented at the IIHS given the appropriate organisational structure, leadership, funding, change management process, and IT support. Compared to the pre-existing, paper-based HAs, computerised HAs produced fewer missing data, allowed for greater sample sizes, and avoided the laborious transfer of paper-based data to a computer database.

9.2.1 Computerised health assessments for primary care research

Not all the ingredients necessary to implement and maintain computerised HAs for research purposes are available to all primary health care services. As discussed in Chapter 2, there are no other examples of computerised Aboriginal and Torres Strait Islander HA based research in the recent medical literature. However, there are examples of health services research using routinely collected clinical data from computerised general practice health records in Aboriginal communities to calculate proportions of chronic diseases.[411,412] In two services these data were used to plan their activities, evaluate their effectiveness as a primary health care service, and feed these data back to the local community.[411,412] The general practice software used by both services was Communicare, and, according to the company's website, Communicare is the leading general practice software in Aboriginal and Torres Strait Islander health services.[413] As these IT systems evolve, primary health care services are likely to find it easier to develop the capacity to use routinely collected computerised health record data including HAs for research purposes, and potentially form networks with other primary health care services.[414,415] Linking routinely collected computerised HA data, using similar templates, from multiple practices would increase the sample size and generalisability of research findings while also continuing to produce data at the community level.

Once established, computerised HAs require ongoing organisational support for staff training, system maintenance, and governance structures which support Aboriginal and Torres Strait Islander oversight of how computerised HA data are used. Additionally, health services looking to produce research findings responsive to community priorities based on computerised HA data, require ongoing organisational commitment to computerised HAs, and ongoing access to the expertise required to conduct epidemiological research. Despite these requirements, routinely collected clinical data are usually cheaper to obtain than data specifically collected for research purposes, and have lower participant burden.[264,415] Research findings based on computerised HA data which inform health service delivery and enhance service reputation are likely to reinforce organisation commitment.

9.2.2 Indirect benefits of health assessments

In addition to potential direct clinical benefit, HAs benefit patients and their communities in indirect ways. For example, the Medicare income generated through the conduct of HAs can assist Aboriginal and Torres Strait Islander health services expand their services to meet community health needs. Aboriginal and Torres Strait Islander HAs have been used to help finance the model of care used by the Institute for Urban Indigenous Health (IUIH). IUIH is the umbrella organisation supporting the network of 17 community-controlled health services for Aboriginal and Torres Strait Islander peoples in South East Queensland.[416] These health services conducted approximately 12,375 Aboriginal and Torres Strait Islander HAs in 2014-2015.[416] The Medicare income derived from these HAs supports the IUIH model of care which includes the provision of allied health services, chronic disease programs, child development programs, and dental services.[416] At the IIHS, the extra Medicare income from HAs has been used to employ extra GPs, nurses, community staff, and administration staff. These extra clinical resources have led to improved access to health service delivery, reduced patient waiting times, increased patient numbers, and twice contributed to justifying the physical expansion of the IIHS to new premises since the introduction of HAs for all age groups in 2006.[43,45]

Aboriginal and Torres Strait Islander HAs can also be used as an incentive to improve access to health care. At both IIHS and IUIH services, HAs are conducted as a precondition for participants of rugby league carnivals. Using HAs in this way motivates many young people, especially men, to access health care when they may not otherwise. Furthermore, if a patient agrees to an Aboriginal and Torres Strait Islander HA, they are then eligible to up to five allied health visits which attract a Medicare rebate in the calendar year.[417]

Health assessment benefit and interest convergence

Notwithstanding the apparent direct and indirect benefits associated with HAs, the motivations of policy makers in introducing HAs are worth a brief examination. In addition to potential clinical benefits, HA revenue has supported the expansion of the State run IIHS, including clinician's salaries, to provide more primary health care services to Aboriginal and Torres Strait Islander peoples. However, many of the jobs generated by the IIHS expansion have gone to non-Indigenous workers like me. Furthermore, policy makers and medical organisations may also have been interested in the surveillance potential of HAs described in Chapter 2. Policy-makers may have agreed to introduce Aboriginal and Torres Strait Islander HAs because they could see benefits accruing to doctors and primary health care services as well as benefits for Aboriginal and Torres Strait Islander peoples. Making policy that is purported to be in the best interest of Aboriginal and Torres Strait Islander peoples, but also benefits non-Indigenous people is consistent with the principle of interest convergence. According to Bell, who was discussing racial desegregation in schools in the United States, the principle of interest convergence means that,

> "the interest of blacks in achieving racial equality will be accommodated only when it converges with the interests of whites."[418(p523)]

There may have been policy alternatives to HAs which more directly benefited Aboriginal and Torres Strait Islander peoples, but were of no immediate or obvious value to non-Indigenous people. For example, policy makers could have chosen to invest resources, allocated to HAs, in community controlled organisations specialising in employment programs for Aboriginal and Torres Strait Islander peoples. As I described in Chapters 2 and 8, levels of unemployment in Inala are high, especially for Aboriginal and Torres Strait Islander peoples. Furthermore, in Chapter 7, I found that employment was one of many interlinked SCEDH important to the community's whole of person conception of health. Moreover, rather than funding HAs, policy makers could invest these funds directly in primary health care services for Aboriginal and Torres Strait Islander peoples. This would allow these services to choose the most appropriate activities and employees to service their community rather than investing a lot of energy in the structures and staff (including doctors) required to generate income using HAs.

9.3 Computerised health assessments as a credible source of research data

Researchers using routinely collected clinical data may experience challenges regarding the representativeness of the research sample, missing data, data accuracy, and about how to interpret data that have not been specifically collected for research purposes.[264,414,415] However, as described in Chapter 5, computerised HAs at IIHS were explicitly developed for both clinical and research purposes, and the clinical staff conducting computerised HAs have been trained to enter data for dual clinical and research purposes.[122] Furthermore, in Chapter 6, I showed that computerised HA data at IIHS were sufficiently complete and accurate to be used for research purposes though caution would be required for the use of antenatal computerised HA data.

9.3.1 Sampling and computerised health assessments

One challenge for researchers using routinely collected clinical data for research purposes is that these data may be perceived as administrative data based on a convenience sample. Administrative data are data collected, often for bureaucratic purposes, that have not been designed for research purposes.[419] A convenience sample is chosen in haphazard fashion on the basis of which participants were most convenient to involve in research without concern that the data are a representative sample.[266] However, the IIHS aims to deliver Aboriginal and Torres Strait Islander HAs to all regular, eligible patients each year through a system of recalls and reminders.[122]

Ideally, the recall and reminder systems would lead to a complete, aggregated research dataset of regular, IIHS patients. However, the IIHS computerised HA research database is not complete for a number of reasons including clinic and patient factors. Patients may not respond to recall letters, may not have time for a computerised HA when they present, may decline a computerised HA, or may decline to consent for their computerised HA data to be used for research purposes. Clinicians may also not have time to complete a computerised HA when the patient presents if they are too busy. Nevertheless, in Chapters 5 and 6, I showed that, for the demographic variables investigated, participants who had computerised HAs appeared to be representative of both the IIHS practice population and Census data for the Inala Aboriginal and Torres Strait Islander population. This provides confidence in the likely external validity of research findings based on IIHS computerised HA data.

9.3.2 Sample size with computerised health assessments

A system of computerised HAs can lead to a large sample of routinely collected health research data in a relatively brief period. For example, since their introduction in 2010, the IIHS had conducted over 8,000 computerised HAs up to the end of 2015. A large sample size may improve the statistical power to identify associations.[266] By way of example, the most recent research paper accepted for publication using IIHS computerised Aboriginal and Torres Strait Islander HA data investigated oral health for 945 adults presenting to the IIHS in a two year period in 2014 and 2015.[261] The only similar study investigating the oral health of Aboriginal adults living in an urban area used a convenience sample of only 181 adults.[120] Furthermore, researchers involved with the Gudaga study, a birth cohort, have produced more research papers than any other study conducted in the five years from 2011-2016 in an urban Aboriginal population (see rapid review described in Chapter 2). The Gudaga study recruited fewer than 200 children and their care givers. Only four observational studies published between 2011-2015 involving

Aboriginal and Torres Strait Islander peoples living in urban areas recruited more than 945 patients. Three of these four studies also used routinely collected clinical data,[107,115,170] and the fourth study[119] was based on national health survey data.

9.3.3 Should epidemiological investigations of Aboriginal and Torres Strait Islander health include a non-Indigenous comparator?

By including a non-Indigenous comparator group in research about Aboriginal and Torres Strait Islander peoples, researchers claim that their findings are strengthened by showing the health disparity between Aboriginal and Torres Strait Islander peoples and non-Indigenous peoples.[119,123] Furthermore, researchers who can show these health disparities are then in a position to encourage policy makers to remedy health inequities.[114,115,119,123] As mentioned in Chapter 1, remedying health inequities is also an obligation of policy makers according to Article 24 of the United Nations declaration on the rights of Indigenous peoples.[33]

Computerised Aboriginal and Torres Strait Islander HA data do not include a non-Indigenous comparator, but this does not necessarily reduce their research utility. Researchers, who insist on a non-Indigenous population comparator, risk perpetuating a deficit discourse where the non-Indigenous population may be seen as the ideal to which Aboriginal and Torres Strait Islander peoples should aspire.[32] This approach also risks reducing Aboriginal and Torres Strait Islander peoples' health concerns to figures which need to be monitored and rectified.[32,78] In this way, the use of a non-Indigenous comparator may position Aboriginal and Torres Strait Islander peoples as “the other” who have intrinsic deficient qualities which are to blame for their ill health.[78,222] Furthermore, deficit statistics inhibit other ways of understanding, using, and portraying data about Aboriginal and Torres Strait Islander peoples which might be used for more constructive purposes such as furthering community priorities and portraying community strengths.[78,222]

The majority (71%) of observational studies that I found in my rapid review (Chapter 2), conducted between 2011-2015 involving Aboriginal and Torres Strait Islander peoples, did not use a non-Indigenous comparator. While a non-Indigenous comparator may be appropriate for some studies, researchers do not require a non-Indigenous comparator to determine the significance of health concerns for

Aboriginal and Torres Strait Islander peoples, and argue for changes at the policy, health service, or community level.

9.3.4 Health areas covered by computerised health assessments

One of my concerns when planning the community consultation research described in Chapter 7 was that key informants would not discuss any health priorities that could be adequately addressed by computerised HAs. As discussed in Chapter 5, the content of routinely collected child, adult, and diabetes computerised HAs are determined by Medicare requirements, NACCHO/ RACGP[206] and diabetes[245] guidelines, the time patients and clinicians are prepared to spend engaging with an HA, and what types of questions clinicians are prepared to ask, and patients are prepared to answer. These clinical, clinician, and patient factors limit the questions that can be asked, and means that not all research priorities identified during the community consultation process can be meaningfully addressed using computerised HA data. However, computerised HA data did permit the epidemiological investigation of SCEDH that I presented in Chapter 8. Furthermore, most of the health areas investigated by observational studies identified in the rapid review I described in Chapter 2 are measured at least in part by child, adult, antenatal, or diabetes computerised HAs. Only four of these observational studies address health topics completely outside the realm of computerised HA content. These four studies dealt with Aboriginal health liaison officers,[107] oral mucosal disease,[103] midwifery services,[126] and mental health liaison.[153] Thus, the database of computerised Aboriginal and Torres Strait Islander HAs at the IIHS represents one source of data covering a range of health topics which are relevant to community members and the primary care research community.

9.3.5 Ethics of using routinely collected data in Aboriginal and Torres Strait Islander primary health care

The pathways to accessing computerised HA data sit within an ethical framework that has led to a number of research papers supported by Metro South HREC and the ICJ.[122] Central to the credibility of computerised HA research have been security measures to ensure the confidentiality of Aboriginal and Torres Strait Islander patients' data. Computerised HAs are password protected and only available to the clinical user group at the IIHS. Completed ethics applications to the Metro South HREC include the research study protocol, a letter of support from the ICJ, and completion of a short form from the researcher explaining the nature of their project to the head of the Metro South HREC. The IIHS auspices the computerised HA database under the research committee led by the research director. Once a research project is approved by the research committee, the ICJ, and the Metro South HREC, de-identified (but re-identifiable) data are provided to researchers by me. Using this approach, four research projects have been approved. Of these projects, three research papers have been published,[116,121 261] and the fourth project is described in Chapter 8 of this thesis.

However, Nakata's concerns about large State administered databases of sensitive Aboriginal and Torres Strait Islander information remain relevant for computerised HA data at the IIHS. At present, the IIHS has an Aboriginal Clinical Director, Associate Professor Noel Hayman, and while the Research Director, Associate Professor Deborah Askew and myself as database gatekeepers are non-Indigenous, all research projects and researchers are also accountable to the ICJ.[132] However, the IIHS is a State run organisation where leadership positions inevitably change over time and recruitment is ultimately a matter for the State rather than being community controlled. No-one could guarantee that the Clinical Director role will be filled with an Aboriginal and/or Torres Strait Islander person in the future. Moreover, while the ICJ is currently an integral part of IIHS research processes, it is possible that future IIHS administrations may choose not to fund the ongoing work of the ICJ, may disregard ICJ opinion, withhold information from the ICJ, or seek to change the composition of the ICJ. The use of computerised HA data for research purposes at a State-run organisation without Aboriginal or Torres Strait Islander leadership or gatekeeping, and without community oversight would be vulnerable to criticism that computerised HA data were not being used for research purposes which were in the best interests of the community.

Consent

As described in Chapter 5, a mandatory component of Aboriginal and Torres Strait Islander HAs is consent to the HA itself. Additionally, participants in computerised HA research give unspecified written consent when they first agree to the use of their computerised HA data for research purposes. There are significant ethical questions relevant to obtaining unspecified consent from participants for undetermined, future research projects using health information from databases which are kept for lengthy periods of time. According to the NHMRC guidelines on the ethical conduct of human research, consent needs to be a voluntary choice, and based on “sufficient understanding and adequate understanding of both the proposed research and the implications of participation in it”.[59(p16)] Ideally, fresh informed consent would be obtained from each potential participant for each new research project involving participant data in accordance with the Declaration of Helsinki.[420] However, the Declaration of Helsinki (article 32) acknowledges that in some situations involving long term databases, it would be impractical to contact all potential participants, and obtain fresh consent for each research project involving data that may have been collected many years previous.[420]

Research investigators need to consider the risks and benefits of their proposals involving long term databases, and participants need to be made aware of the wide-ranging implications of giving unspecified consent.[59] These implications are described in article 12 of the World Medical Association’s Declaration of Taipei on ethical considerations regarding health databases and biobanks.[421] The Declaration of Taipei covers “the collection, storage and use of identifiable data and biological material beyond the individual care of patients”.[421] The implications of unspecified consent described by the Declaration of Taipei include concern about participant privacy, and that participant’s information be non-identifiable.[420]

Challenges to the legitimacy of unspecified consent lie in the assumption that research data from databases such as the computerised HA database can be kept secure into the future.[422] Hofmann observes that while the benefits of research based on unspecified consent accrue to the researchers, future, unpredictable risks to data security are borne by participants and their families.[422] Additionally, it may be difficult for participants to withdraw their research consent, or be aware that their data are being used in research projects.[422]

All forms of consent should be given free of coercion or pressure, and NHMRC guidelines specifically warn that “consent might reflect deference to the researcher’s perceived position of power”.[59(p17)] This concern is relevant to computerised HA research at the IIHS where consent is obtained by the treating medical practitioner. In one small, pilot survey involving Aboriginal women in the Northern Territory that investigated consent processes, most participants preferred a medical practitioner to present the information, but also wanted the presence of an Aboriginal Health Worker.[423] In other projects, trained Aboriginal research officers were preferred for obtaining individual consent.[424,425] I have trained all the GPs at the IIHS to obtain unspecified consent for computerised HA research in a non-coercive manner, cognisant of the power imbalance of a medical consultation where the doctor is positioned as the knower. Doctors obtaining consent inform potential participants of the wide-ranging implications of unspecified consent. However, while this training may mitigate some of the power imbalance, concerns about the voluntary nature of consent obtained in this context are still warranted.

In addition to individual consent, group consent of the Aboriginal and Torres Strait Islander community may also be essential, especially for a long-standing research project requiring unspecified individual consent.[426] For example, research using computerised HA data could portray Aboriginal and Torres Strait Islander people negatively which risks a deficit discourse that damages the community. I have already described Nakata's concern in Chapter 1 that research findings such as those based on computerised HA data may serve a colonial agenda that is damaging for Aboriginal and Torres Strait Islander peoples.[50] As Dodson and Williamson observe,

> "History teaches us that the pure fascination of science cannot be quarantined from its broader social implications."[426(p206)]

Potential participants are still taking a risk with potential implications for their community by participating in computerised HA research despite the lack of personal inconvenience. In the context of unspecified consent, this risk needs to be considered by participants, researchers, the ICJ, and relevant HREC.

At the IIHS, I have seen unspecified individual consent as a reasonable component of ethical computerised HA research. Unspecified consent avoids the practical difficulties of fully informed, individual, specific consent for each research project while still seeking what Hofmann terms "broad authorisation"[422(p128)] from participants to use their computerised HA data in future unspecified research projects. The unspecified consent process for computerised HA research was approved by the Inala Elders and Metro South HREC in January 2011 prior to the formation of the

ICJ. As described in Chapter 5, specific research projects using HA data required ICJ and Metro South HREC approval. In August 2016, I discussed the consent process for all routinely collected data including computerised HA data at the IIHS with the ICJ. Options of specific consent, unspecified consent, and no individual consent were canvassed with the ICJ at this meeting. The ICJ suggested that a process of unspecified consent involving discussion with their treating GP was preferred rather than with other members of the team. Specific research proposals involving computerised HA data should be presented to ICJ, and, if approved, proceed to the Metro South HREC for consideration. Therefore, the ICJ has recommended extending the existing arrangements for unspecified consent for computerised HA data to all routinely collected data at the IIHS. NHMRC guidelines state that unspecified consent "can still be sufficient and adequate for the purpose of consent".[59(p18)] Despite valid concerns about unspecified consent, the process for consent used for computerised HA research is recognised by the NHMRC, has been approved by the Metro South HREC, and is supported by the ICJ.

While informed consent is central to ethical research described by the Declaration of Helsinki,[420] future health services research involving computerised HA may not require individual consent at all. Health services research "looks at the needs and outcomes of populations in relation to health service delivery."[427(p313)] Cassell et al. argued that the Declaration of Helsinki applies more to traditional medical research because the declaration does not account for the difficulties of obtaining consent for health services research.[427] Furthermore, the requirement by ethics committees for individual consent for health services research may disadvantage the most vulnerable who may be less likely to be "signing complex consent forms and reading information sheets".[427(p316)] Thus, vulnerable groups would be less likely to benefit from the new knowledge and organisational improvements resulting from health service research.[427] Furthermore, the Queensland Public Health Act allows for the consideration of health services research without individual consent providing the data are collected by a Queensland Health clinician and anonymised in a process approved by the relevant HREC.[428] In informal discussions that I have had with Metro South HREC, this means that computerised HA data could be used for health services research including observational studies and data linkage without individual consent. This type of research would still need to be supported by the ICJ and approved by the Metro South HREC, but may be an option in the future.

Dissemination

Like consent, dissemination is an important component of ethical research. Dissemination is the active, tailored communication of research findings to a specific target audience.[429] Tailored dissemination of research findings to the academic community often takes the form of conference presentations and published journal articles.[429] During the course of this doctoral research, I have disseminated my research to the academic community in the form of five conference presentations (listed in the introductory pages of this thesis) and two research papers.[122,284]

Dissemination of research findings to the community throughout the project and at the end is also important. Community dissemination of research findings responds to the NHMRC values of responsibility, survival and protection, and spirit and integrity which are central to the ethical conduct of research with Aboriginal and Torres Strait Islander peoples.[56] Laycock et al. recommend asking the community what format they would prefer for dissemination, and provide specific suggestions for a community report.[58] In accordance with community preference and described in Chapter 7, I have presented my doctoral research findings from Chapter 7 to a community forum and the ICJ. I have also written a community report[297] based on findings from Chapters 7 and 8 which was submitted for publication just prior to the completion of this thesis and will be published in 2017 (Appendix 1). I will be presenting this report and its findings to the ICJ and in appropriate community fora such as the Inala Interagency Meeting. The Inala Interagency Meeting is a regular meeting of all the community organisations working in Inala. I will also send copies of the community report to relevant policy-makers including the State and Federal Members of Parliament representing the suburb of Inala and the Queensland Minister for Health.

9.4 Realising a transformative agenda

The use of CCM in this doctoral research situated in the transformative paradigm has provided a space for community voices to be heard which prioritised a holistic view of health interested in interlinked SCEDH. The intersection of this holistic view of health with my biomedical positioning as doctor and researcher, and the biomedical emphasis of computerised HAs resulted in changes in my perspective as clinician and researcher, changes in the content of computerised HAs, and changes in the direction of computerised HA research.

9.4.1 Changes in the researcher

The findings of Chapter 7 caused me to question my emphasis as a medical doctor on biomedical risk factors and diseases in both clinical and research contexts. As I described in Chapter 7, after working in this Aboriginal and Torres Strait Islander community for more than ten years, I was surprised and humbled that I had not predicted the strength of community concern about SCEDH. This new understanding of community priorities has changed the way I experience and conduct medical consultations, and given me more empathy for patient experiences of SCEDH. Similarly, the aggregated findings regarding SCEDH reported in Chapter 8 are not simply numbers on a page, but each data point represents community experiences of strength and difficulty. Furthermore, the findings of Chapter 7 have motivated me to improve my knowledge of community resources to address SCEDH, and prompted me to place a greater emphasis on SCEDH in teaching medical students at the IIHS and in my role as Senior Lecturer at the University of Queensland.

Perhaps my difficulties as a medical doctor in understanding the importance of the SCEDH should not be surprising given the emphasis of my training on biomedicine and diseases.[310,315] The biomedical view of health developed in Western Europe with discoveries in microbiology, anatomy and pathology to the point where “the sick in general were perceived as a unitary medium within which diseases were manifested”.[430(p235)] This emphasis on the individual in biomedicine may have facilitated its prominence given its alignment with the importance of the individual in capitalism and neoliberalism, dominant political ideologies in the 20th Century.[309] As discussed in Chapter 7, this neoliberal context may also contribute to doctors having “enormous difficulty” in seeing health holistically and as a population or community issue rather than a problem for individuals.[315(p432)] By definition, a holistic approach to health is not intended to diminish the value of biomedical understandings of health, but a closer alignment of medical understandings of health with Aboriginal and Torres Strait Islander conceptions of health is likely to result in improved health outcomes for Aboriginal and Torres Strait Islander peoples.

9.4.2 Changes to health assessments

The main change to computerised HAs that occurred during this doctoral research was the addition of questions relevant to SCEDH and mental health which were community priorities. The removal of other HA questions meant overall administration time stayed approximately the same. At no stage was the time to conduct an Aboriginal and Torres Strait Islander HA measured.

Additional questions regarding social, cultural, and environmental determinants of health and mental health in computerised health assessments

The findings of community consultation reported in Chapter 7 and the associated research publication[284] supported the addition of more questions regarding SCEDH and mental health to HAs including the NLES. These changes have the potential to influence clinicians to better engage with the SCEDH and mental health. Despite the addition of questions regarding SCEDH and mental health to computerised HAs reflecting community concerns, HAs still have an individualistic, disease emphasis consistent with the biomedical model of health.

The biomedical rather than social emphasis of HAs is reflected in the Medicare pro forma for Aboriginal and Torres Strait Islander HAs, widely used in general practice software systems. This pro forma contains only one section titled “Environmental and living conditions” that deals with any SCEDH.[431] Furthermore, supporting information guiding the conduct of HAs produced by NACCHO and the RACGP devoted only one page to psychosocial wellbeing, and only as it applied to people aged 12 to 24 years.[206(p23)] The inclusion of more SCEDH in HAs and their supporting information may make HAs more relevant to Aboriginal and Torres Strait Islander peoples’ holistic conceptions of health.

The addition of questions regarding SCEDH and mental health to computerised HAs was met with a mixed reaction by clinical staff at the IIHS. Discussions regarding these additions occurred in clinical staff meetings and in informal corridor conversations at the IIHS. While some embraced the changes fully, others were concerned about how they would be received by patients, or were unsure about their relevance to health. Some clinicians were also concerned that the newly introduced SCEDH only served a research purpose and had minimal clinical relevance. Clinicians’ ambivalence and discomfort in asking these questions may have been reflected in the high levels of missing data for some SCEDH and especially the aPHQ-9 which was missing data for 69% for participants in the computerised HA research described in Chapter 8. The SCEDH variables of community and cultural activity (19% missing data) and highest level of educational attainment (21% missing data) were also missing more than 5% of data. By conducting a computerised HA which addresses SCEDH, clinicians are more likely to have conversations with their patients that are relevant to the patient's conception of health than in the normal course of a medical consultation.

In addition to asking questions about SCEDH and mental health, a related concern for clinical staff is how to respond if they detected SCEDH such as being unemployed or not participating in community events. In response to these concerns, I discussed with clinical staff at IIHS meetings, the relevant clinical pathways for responding to identified SCEDH including referral to the IIHS community team, psychologist, and social worker. Appropriate GP referral to appropriate community resources has been found to improve social and emotional wellbeing.[311,312] Moreover, referral by a GP to a psychologist has been shown to improve employment outcomes.[432-434] In a case series, Baum et al. described how Australian comprehensive primary health care services provided a community space for patients experiencing socioeconomic disadvantage which enhanced community connectedness, a social determinant of health.[310] Furthermore, staff at these services took an active role linking individuals with appropriate community services, and also advocated policy changes to benefit the community with which they worked.[310] At the IIHS, improved understandings of community priorities together with the additional questions regarding SCEDH in computerised HAs have contributed to conversations about how the IIHS can better address SCEDH experienced by our patients, strengthen clinical referrals to the IIHS community team, and work more closely with local community-based organisations.

9.4.3 Changes in research direction

As I discussed in Chapters 1 and 7, the initial plan for this doctoral research was to investigate oral health using computerised HA data. However, following the changes described above in myself as researcher and computerised HA content, I chose to respond to the health priorities discussed by Inala community key informants. Thus, rather than an investigation of oral health, Chapter 8 involved an investigation of interlinked SCEDH.

Future research using computerised HA data also needs to have an emphasis on SCEDH as these were the priorities indicated by community key informants. There is a recognised lack of data on SCEDH at the national level in Australia[435], a lack of data more generally at the level of primary care,[435] and a lack of data for Aboriginal and Torres Strait Islander peoples involving social determinants at the community level.[180] Future research projects including SCEDH could have a cross-sectional design such as the epidemiological investigation described in Chapter 8, or a longitudinal design. Longitudinal studies can detect and monitor changes over time, evaluate the impact of various factors in different stages of the life cycle, and evaluate interventions.[7]

Given the biomedical emphasis of Aboriginal and Torres Strait Islander HAs, there may also be opportunities in future to link data from computerised HAs with databases focusing on SCEDH. At present in Australia, data are only available on socioeconomic status at an area level.[435-437] However, socioeconomic data are available for linkage at the level of the individual in other countries like New Zealand,[438] and opportunities for data linkage are being explored for Aboriginal and Torres Strait Islander peoples.[439] Notwithstanding the currently limited opportunities for data linkage involving SCEDH, there are still opportunities to use data linkage to augment the utility of computerised HA data. For example, the AIHW hosts the national death index,[440] and data on life expectancy and cause of death could be linked with SCEDH collected using computerised HA data. Policy makers are more likely to take action on SCEDH if researchers can show a link between SCEDH and mortality.[441]

As I described in Chapter 5, all bar one[121] of the eight research papers[49,109,113,116,121,122,213,261] involving IIHS HA data published between 2011 when the ICJ was formed and 2017, have included at least one Aboriginal person on the research team. However, to adequately respond to Rigney's call for research consistent with the Indigenist Research Framework,[53] Aboriginal and Torres Strait Islander researchers should not just be participants, but leading the research agenda and projects. Ideally, future computerised HA research would be led or driven by Aboriginal and Torres Strait Islander researchers from the Inala community.

9.4.4 Challenges for the health system and policy makers

Baum argued that the prevailing neoliberal ideology in Australia not only influences doctors, but also leads to health system barriers to addressing inequitable experiences of SCEDH.[309] The neoliberal emphasis on the individual marginalises holistic conceptions of health, creating difficulties for policy makers who seek to address inequitable social determinants.[309] The medical profession, with its biomedical emphasis, adds to these difficulties by constantly calling on policy makers with limited resources to invest in the acute health care sector and fee-for-service medical funding, rather than addressing SCEDH and supporting comprehensive primary health care.[309,442,443]

By accepting an overly narrow, biomedical definition of health, policy makers risk misinterpreting health information and failing to put health issues in their proper context.[444] For example, Boddington and Raisanen argue that a Western conception of health is unlikely to accommodate the provision of programs designed to assist Aboriginal groups pass on their culture to the next generation.[444] The lack of effective policy addressing SCEDH in Australia may have contributed to the greater inequity experienced by Aboriginal and Torres Strait Islander peoples for education, income, and employment compared with the Indigenous populations of similarly developed countries like New Zealand and Canada.[370]

9.4.5 Changes for the Inala Aboriginal and Torres Strait Islander community

Findings from this doctoral research are unlikely to have directly transformative effects on community members. As described in Chapter 7, community members gave confident, knowledgeable accounts of how SCEDH affected their lives demonstrating their familiarity with holistic conceptions of health and their lived experience of SCEDH. Nevertheless, the findings of Chapters 7 and 8 may still contribute to beneficial community health outcomes. The findings of Chapter 8 regarding the frequent experience of challenging SCEDH among patients attending the IIHS support and reinforce key informant concerns reported in Chapter 7. Additionally, SCEDH reported in Chapter 8 were not evenly distributed by age and sex. Rather, I found marked variations and patterns in the distribution of SCEDH by age and sex suggesting underlying inequities in the experience of these determinants which need to be addressed by policy makers, health services, and community organisations. Without this epidemiological investigation, these patterns would remain hidden. Now identified, particular subgroups may benefit from further support and intervention. Failure of policy makers to address the inequities identified here for Aboriginal and Torres Strait Islander peoples living in Inala would represent institutionalised racism. Further to the definition I presented in Chapter 8, institutionalised racism often manifests as inaction when action is needed to remedy inequalities.[340]

As described earlier in this chapter, the findings regarding SCEDH (Chapter 8) along with findings from community consultation research (Chapter 7) have contributed to a community report[297] which I will disseminate to relevant community organisations and policy makers (Appendix 1). Compared with national or State level data, the community-level data in this report, presented by socially-meaningful groupings such as age and sex, are likely to be more useful and relevant to community organisations planning activities, health promotion, lobbying policy makers, and applying for funding.[180]

Specifically, the community report provides baseline information regarding SCEDH which is likely to be relevant to the IIHS community team which conducts men’s and women’s activities emphasising social and emotional wellbeing, physical activity, and healthy eating. These data will help Aboriginal health workers target and plan their activities according to age groups and gender. Moreover, these data on SCEDH help balance the dominant biomedical paradigm which may serve to favour clinical staff and the clinic environment over community staff when decisions about the distribution of health service resources are made.

Outside the IIHS, Inala Wangarra, a community-controlled community development organisation runs many programs including those aiming to reduce unemployment and increase participation in sport and physical activity. The Inala Elders run suicide prevention programs. For each of these community-based activities, there are community-level data in the community report[297] (Appendix 1) which are relevant to the planning, monitoring, and evaluation of these programs. I expect that staff at the

IIHS would be able to provide community reports on SCEDH at regular intervals given the ongoing nature of computerised HA data collection at the IIHS.

9.5 Benefits from this research

The benefit and overall impact of research can be difficult to measure and define.[79] Universities usually measures research impact by publications, citations, and successful grant applications. Using these measures, the academic standings of my advisors and I have already benefited owing to publications from this doctoral research.[122,284] However, these types of academic measures are unlikely to reflect improvements in the unjust and inequitable health outcomes experienced by Aboriginal and Torres Strait Islander peoples that I expressed concern about in Chapter 1.

To realise benefits, research needs to inform tangible outcomes such as improved services, an educational tool, or other health intervention.[79] This doctoral research, through its transformational agenda, may result in benefits for the Inala Aboriginal and Torres Strait Islander community through some of the changes already described in this chapter. Small benefits may be realised for the community through changes in the way I interact with patients and medical students because of this research. As discussed in Chapter 8, computerised HAs, which now better reflect community priorities, change the conversations clinicians at the IIHS have with patients, strengthen referral pathways to community organisations addressing SCEDH, and result in research which may prompt policy makers to fund measures to address inequitable experiences of SCEDH. These impacts of computerised HAs could be more wide-ranging if they become integrated into mainstream general practice software. Translating the findings of Chapters 7 and 8 into a community report (Appendix 1) increases the possibility that these research findings will be used by health services, community organisations, and policy makers to improve the lives of Aboriginal and Torres Strait Islander peoples in Inala.

Bainbridge notes that different communities may have different ideas about how they value research findings, and researchers need to

> “listen more closely to the voice of Indigenous Australians to better understand, demonstrate, and measure health research benefits”.[79(p9)]

For this research, situating Chapters 7 and 8 in the transformational paradigm and listening closely to key informants in the Inala Aboriginal and Torres Strait Islander community was central to producing research findings of potential benefit.

9.6 Research limitations

There were several limitations to this doctoral research including limits to the transformative potential of computerised HA research. This research may have had more transformative potential if the community consultation research described in Chapter 7 had occurred first. Perhaps my attributes as a white, non-Indigenous doctor impaired my ability to truly understand the concerns of the community. For example, my employment at the IIHS represents a conflict of interest when thinking critically about HAs because the IIHS and my salary are supported by revenue generated by HAs. Other limitations revealed by this research were problems with the computerised antenatal HA, the length of computerised HAs, the ongoing need for dual ERIC and general practice software systems, and threats to the internal and external validity of computerised HA research.

9.6.1 Should community consultation have been conducted first?

The research of this thesis began with evaluations of the feasibility and data quality of computerised HAs described in Chapters 5 and 6. At the beginning of this research process, this seemed a logical approach as there would be no point continuing to look at research involving computerised HA data if it was not feasible to implement computerised HAs, or the data produced by computerised HAs were not useful for research. However, an alternative approach may have been to start with the community consultation research project situated in the transformative paradigm. The advantage of starting with community consultation is that from the outset computerised HA content development, implementation, and evaluation would have proceeded with full knowledge of community priorities for computerised HA research. Full knowledge of community priorities from the outset is likely to have led to further changes to computerised HAs, and to changes in the direction of this doctoral research overall.

9.6.2 Limits to the transformative power of computerised health assessments

The important transformative components of this research come from the lifeworld voices of key informants, reported in Chapter 7, who prioritised the SCEDH. Hearing that SCEDH were central to community conceptions of health posed questions for me about whether computerised HA data with their biomedical origins and motivations were an appropriate tool for responding to key informant priorities. With my advisors, I carefully considered the advantages and disadvantages of using computerised HA data for an epidemiological investigation of SCEDH. After implementing computerised HAs and evaluating the data computerised HAs produce, it would have been a difficult decision not to use computerised HAs at all to respond to community key informant priorities. When taking the decision to proceed with the epidemiological investigation of SCEDH presented in Chapter 8, I was mindful of criticism of mixed methods research, discussed in Chapter 4. For example, there may be a tendency for mixed methods researchers to bend the findings of qualitative research to suit subsequent quantitative research.[244]

Tensions in conducting an epidemiological investigation of social, cultural, and environmental determinants of health based on community consultation findings

While the findings of the epidemiological investigation of SCEDH presented in Chapter 8 supported, reinforced, and added information to the findings of Chapter 7, these findings also produced tensions. These tensions are related to community key informants’ discussion of the holistic nature of health, the importance of cultural determinants, and the strength of the community. For example, despite the addition of questions regarding SCEDH, computerised HAs are unlikely to be able to adequately capture the SCEDH in the holistic way that health is conceptualised by Aboriginal and Torres Strait Islander community members. However, it may not be appropriate to attempt to find quantifiable elements of culture or other elements of the social world for analysis in an epidemiological investigation which purports to show how these elements might be associated with biomedical measures of ill health. This type of epidemiological investigation risks problematising and misunderstanding these cultural and social elements.[78] As discussed in Chapter 8, an epidemiological investigation of SCEDH may also reproduce a deficit discourse about Aboriginal and Torres Strait Islander peoples, and the harms of this discourse need to be considered along with the benefits of highlighting concerns about high levels of SCEDH and the inequitable experience of these SCEDH.[32,78]

Tensions, described above, related to the research described in Chapter 8 are likely to be relevant questions for other researchers conducting research involving Aboriginal and Torres Strait Islander peoples. While there may be an inadequate quantity of research papers published involving Aboriginal and Torres Strait Islander peoples[4,5] to improve health outcomes, the quality and nature of research is also important. For example, research conducted within the biomedical model of health may not be as relevant or transformative to community members as research involving SCEDH. In order to arrest the failure of current strategies to meet their targets regarding Aboriginal and Torres Strait Islander health,[445] researchers need to respond to community health priorities.

Time required to conduct computerised health assessments

As described in Chapter 7, a few key informants from the Inala Aboriginal and Torres Strait Islander community were concerned about the length of computerised HAs. Concerns about the time taken to complete computerised HAs have also been raised by clinical IIHS staff. These concerns centre on both the length of the computerised HA forms and the need to have two software systems open at the same time to conduct a computerised HA. I have claimed that using routinely collected clinical data reduces participant research burden which is an advantage of using computerised HAs. While computerised HA based research may spare participants from stand-alone research projects, the benefits of routinely collected data for dual clinical and research are attenuated if participants feel that computerised HAs are too long. To reduce the time required to conduct a computerised HA, I facilitated a process with IIHS clinicians in 2016 to critically reassess all computerised HA questions with a view to removing questions which were not Medicare pre-requisites, or were not deemed necessary for clinical or research purposes. The newly shortened adult HAs were introduced in 2016. They still contain questions about SCEDH including the NLES, but are considerably shorter than the HA used to collect data for the research described in Chapter 8 (Appendix 7). Time will tell if more computerised adult HAs are conducted with the shortened form.

An ongoing limitation of computerised HA research is that computerised HAs are situated on the ERIC platform, and are not integrated with the IIHS clinical practice software. This means clinicians completing a computerised HA need to be operating in both ERIC and the clinical practice software during the patient encounter. While the completed ERIC based computerised HA is attached to the patient's clinical software record, a fully integrated system of computerised HAs operating within the general practice software environment would be more efficient. Full integration would also improve the quality of both computerised HA data and the data contained within general practice software which is used for other purposes including CQI. As IT systems evolve, I expect that clinical practice software will be able to integrate computerised HAs in the future.

9.6.3 Non-Indigenous researcher and research with Aboriginal and Torres Strait Islander peoples

I have interpreted research findings through the lens of my non-Indigenous and white ontology, epistemology, and values. As discussed in Chapter 7, my white privilege may cause me to not hear or to misunderstand Aboriginal and Torres Strait Islander voices. To mitigate these concerns, I have attempted to take a collaborative research approach, asked for and listened to advice from my Aboriginal mentors and advisors, included Aboriginal researchers on specific research projects, situated community consultation research in the transformative paradigm, and privileged Aboriginal and Torres Strait Islander voices in my research. Furthermore, all the doctoral research presented here is accountable to the ICJ. Nevertheless, research conducted by Aboriginal and Torres Strait Islander researchers consistent with the Indigenist Research Framework using PAR may have led to findings and outcomes more aligned with community interests.[53]

9.6.4 Non-viable computerised antenatal health assessments

One significant problem which developed in 2012, two years following the introduction of computerised HAs, was the non-viability of computerised antenatal HAs. In the first year after the introduction of computerised HAs (September 2010-August 2011), 82 antenatal computerised HAs were conducted. Data on the total number of regular Aboriginal and Torres Strait Islander women presenting to the IIHS for antenatal care during that period are not readily available, but these 82 women would likely represent almost all of them. In 2012, 65 antenatal checks were conducted which decreased to 24 in 2013, five in 2014 and none in 2015.

Two factors influenced the decline in numbers of computerised antenatal HAs. The main factor was that in 2012, the Mater Mothers Hospital, the principal maternity hospital covering the Inala area, started conducting all the antenatal care for all pregnant women attending the IIHS. Therefore, after the first antenatal visit, the IIHS would not normally provide further pregnancy-related care for these women until the first postnatal visit. Another secondary factor was the length of the computerised antenatal HA. This HA was intended to be used for the entire pregnancy, and was the only computerised HA designed to remain active for more than one episode of care. For each patient, the computerised antenatal HA was commenced at pregnancy diagnosis, and then not completed until the first postnatal visit. Each episode of care during the pregnancy required input into the computerised antenatal HA. The length and need for repeated episodes of clinical data entry involved in completing computerised antenatal HAs likely contributed to the higher levels of missing data found in Chapter 6 for computerised antenatal HAs.

Notwithstanding these challenges regarding missing data, one IIHS GP led a research project using computerised antenatal HA data from 2010-2011 which found that more than 80% of pregnant women attended the IIHS in a timely manner (before 10 weeks gestation) for their first antenatal visit.[121] This study also showed low levels of sexually transmitted infections, but high levels of substance use including alcohol, tobacco, and cannabis.[121] The motivation to improve and shorten computerised antenatal HAs is lacking given the IIHS now conducts minimal antenatal care. However, the computerised antenatal HA still sits in ERIC ready for use should the situation regarding antenatal care change.

9.6.5 Threats to internal validity

In Chapter 6, threats to the internal validity of computerised HAs were evaluated. Tensions regarding the dual clinical and research motives for computerised HA questions may raise concerns for some researchers about the internal validity of computerised HA research findings. Furthermore, there were significant quantities of missing data for some computerised HA variables. These missing data compromise research findings and suggest that these variables may not be particularly clinically relevant. Regarding data validity, most computerised HA variable values showed moderate or high correlation with the external criterion, One21seventy data. However, some variable values demonstrated only fair or slight agreement. Notwithstanding the limitations of computerised HAs developed for dual clinical and research purposes, I found they have sufficient internal validity to be used for research purposes. Researchers would need to use more caution with variables showing fair or slight agreement.

9.6.6 Threats to external validity

The external validity of computerised HA data was evaluated in Chapter 6. Overall, computerised HA participants were similar for age, sex, and ethnicity to the regular IIHS patient population. Additionally, in Chapter 8, I found participants who had had a computerised adult HA were similar in age, sex, and ethnicity to Census data for postcode area 4077 (the suburbs of Inala and Richlands). However, caution must apply to claims of external validity given the diversity and heterogeneity of urban Aboriginal communities with a mobile population.[9] Furthermore, computerised HA data from the IIHS represent only one health service in one urban location, and one would need to proceed with caution in generalising findings from one Aboriginal and Torres Strait Islander health service or community to others.

9.7 Summary

In this Chapter, I have discussed how the findings of this thesis respond to the research questions described in Chapter 3. These findings demonstrate that Aboriginal and Torres Strait Islander computerised HAs can be used in primary care to produce credible research findings which respond to community priorities. However, this research has also revealed tensions. These tensions emerged because of collaborative research using mixed methods which attempted to reconcile the health priorities of community key informants situated in the social world with a research tool, setting, and researcher situated in the biomedical model of health.

Chapter 10 Implications and conclusions

10.1 Introduction

In Chapter 9, I discussed the findings, tensions, potential benefits, and limitations of this doctoral research. In Chapter 10, I draw conclusions and discuss the implications of my research findings.

10.2 Computerised health assessment research in primary health care

10.2.1 Benefits for health service delivery

As a result of this research, I have shown that it is feasible to implement a system of computerised child, adult, and diabetes HAs in Aboriginal and Torres Strait Islander primary care. In addition to research benefits, computerised HAs offer clinical benefits over paper-based HAs at the IIHS and the Aboriginal and Torres Strait Islander HA templates which come with commonly-used general practice software systems. Computerised HAs include measures that can be auto-calculated, and use clinically validated questionnaires for important clinical questions like psychosocial stressors and mental health. Moreover, computerised HAs include a health check summary where relevant HA findings are automatically collated in one structured text box at the end of the computerised HA. While there are also free text boxes in computerised HAs, the customisable, computerised form promotes consistent data input from the different clinicians conducting computerised HAs because many responses are prompted by radar buttons or constrained numerical fields. Furthermore, the capacity to customise computerised HAs allowed for the addition of questions which responded to community health priorities including several SCEDH. These questions prompt clinicians with a primarily biomedical perspective to engage with patients on the SCEDH, a known community priority, and to find appropriate referral pathways to address SCEDH.

10.2.2 Feasibility of research using computerised health assessment data

In addition to clinical advantages of customisable computerised HAs, clinical HA questions have also been designed to serve a research purpose. Research data from computerised HAs are much more useful than paper-based HA data or data from existing Aboriginal and Torres Strait Islander HAs on general practice software. Computerised HA data are less likely to be missing than paper-based HA data, and data readability is less likely to be a concern. Furthermore, the production of a research database composed of computerised HA data does not require the laborious data transfer process inherent in paper-based HA research. With technological advances, clinically captured data is more commonly used for research purposes with examples emerging from Australia[412] and internationally.[415,446]

10.2.3 Limitations to the feasibility of computerised health assessments for research purposes

The principle limitation to the widespread use of computerised Aboriginal and Torres Strait Islander HAs is that commonly used general practice software systems do not yet accommodate customisable computerised HAs which allow for extraction of non-aggregated data to facilitate analysis at the individual patient level. However, as IT systems improve and analysis of routinely collected data becomes more widespread, this capability is likely to become more widely available. Other potentially significant barriers to the implementation of computerised Aboriginal and Torres Strait Islander HAs in primary care include the length of time to conduct HAs, staff acceptance of computerised HAs, and cost of implementation. Issues of research consent, privacy, and community accountability also need to be explored. Overcoming these barriers requires committed leadership which values the clinical and research benefits of computerised HAs, and a willingness to engage with the local Aboriginal and Torres Strait Islander community.

10.2.4 Credible research findings using computerised health assessment data

I have demonstrated that the computerised Aboriginal and Torres Strait Islander HAs at the IIHS produce credible research findings. Once implemented, these computerised HAs can generate a large database, available without delay, which covers a wide range of health topics commonly investigated by researchers in this field. Importantly, researchers can also add questions to HAs which respond to community health priorities. Furthermore, I have shown that the data produced by computerised HAs are sufficiently complete, representative, reliable, and valid to be used with confidence for research purposes. Finally, research involving computerised HAs sits within an ethical framework supported by NHMRC guidelines, and the research is accountable to the community through the ICJ as well as the Metro South HREC.

10.3 Implications of situating this research in the transformative paradigm

By situating this research in the transformative paradigm, I sought the lifeworld voices of key informants in the Inala Aboriginal and Torres Strait Islander community. As reported in Chapter 7, key informants indicated that their health priorities centred on the complex, interrelated cycle of SCEDH experienced in the community consistent with the commonly accepted Aboriginal definition of health. Key informants were ambivalent about existing HA content with its biomedical emphasis. These community insights supported the addition of questions regarding SCEDH to computerised HAs, and a shift in priority from research with a biomedical emphasis to research with an emphasis on SCEDH.

10.4 Implications for research

Computerised HAs have now been conducted at the IIHS for over six years, and over 8,000 individual child, adult, diabetes, and antenatal HAs have been completed. Proposals for further cross-sectional studies based on computerised HA data to support health service delivery are already being developed, and cover areas including social and emotional wellbeing, substance use, eye health, and the health of older people. I envisage future cross-sectional studies which could cover a wide variety of health concerns which can be investigated using computerised HA data. In addition to further computerised HA research evaluating SCEDH in accordance with community priorities, investigations of associations between SCEDH and illnesses and disease would also be helpful.

With the large number of computerised HAs, researchers, including myself, will be able to construct longitudinal datasets from cohorts of participants who have had HAs. Longitudinal datasets could also be linked with external databases which may better address the SCEDH prioritised by community members. Research based on longitudinal data would allow for causal inferences to be made from associations between dependent and independent variables.

In addition to quantitative research involving computerised HA data, qualitative research exploring the effects of changes to computerised HAs would also be useful. After the qualitative research reported in Chapter 7, questions measuring SCEDH were added to computerised adult HAs, and other questions removed to shorten computerised adult HAs overall. These changes were designed to respond to community health priorities and increase computerised HA uptake. Qualitative research involving interviews with key community informants would be useful to see if the modified computerised HAs paint a more honest picture of health. From a postpositivist perspective, a randomised controlled trial of annual, computerised, Aboriginal and Torres Strait Islander HAs containing more questions measuring SCEDH would be useful. Given the doubt surrounding the clinical benefits of HAs described in Chapter 2, a systematic review of HAs for Aboriginal and Torres Strait Islander peoples, or for vulnerable groups more broadly, may help clarify the role of HAs in primary care.

Following the addition of questions regarding SCEDH, informal conversations and missing data for certain items involving SCEDH indicated a degree of discomfort for clinical staff in asking questions measuring SCEDH. Qualitative research involving interviews with clinical staff would be useful to explore their reactions to questions measuring SCEDH.

The disjunction found in this research between key informants' health priorities situated in the social world compared with the biomedical emphasis of computerised HAs also has implications for research more generally. While there may well be insufficient research data available to inform strategies to improve health outcomes for Aboriginal and Torres Strait Islander peoples living in urban areas, the quality and content of new research will be as or more important than the quantity. For example, investigator-driven research which does not respond to community priorities is likely to perpetuate the strategies and policies which have failed to improve health outcomes for Aboriginal and Torres Strait Islander peoples.

As I discussed in Chapter 9, to realise findings in the best interests of the community, transformative research is best led by Aboriginal and Torres Strait Islander researchers consistent with the Indigenist Research Framework. To this doctoral research, I brought clinical expertise as a GP, some research experience, resources from both Queensland Health and The University of Queensland, and good intentions. However, my white, privileged perspective impaired my ability to see health from an Aboriginal and Torres Strait Islander viewpoint. In Chapter 7, I described this impairment as a learning disability, and I also described the advice I required to see health more clearly from an Aboriginal and Torres Strait Islander perspective. Notwithstanding the high quality of advice that I received, my impairment is deep-seated, and linked to my identity. While there may be a role for self-reflexive non-Indigenous researchers interested in Aboriginal and Torres Strait Islander health research, it is Aboriginal and Torres Strait Islander researchers, doctors, nurses, and health workers who are likely to best understand the health stories, needs, and priorities of Aboriginal and Torres Strait Islander communities. Therefore, priority needs to be given by funding bodies and policy makers to Aboriginal and Torres Strait Islander researchers seeking the resources, training, and funding to conduct and lead health research concerning Aboriginal and Torres Strait Islander peoples.

10.5 Implications for policy

Policy makers, along with researchers and clinicians, should be concerned about the disjunction between key informant concerns regarding SCEDH and the biomedical emphasis of HAs and other health policy. Policy makers and clinicians invested in the biomedical model of health, may not find health stories revealed using qualitative research methods as convincing as a statistical portrait like that presented in Chapter 8. Aligning with community concerns about SCEDH reported in Chapter 7, the investigation of SCEDH reported in Chapter 8 revealed high rates of SCEDH which varied significantly according to the age and sex of participants. Community key informant concerns about the importance of SCEDH represent a challenge for Commonwealth and State Governments to meaningfully address the inequitable distribution of SCEDH, a form of institutional racism. Neither the key community informants described in Chapter 7 nor I have called for the abandonment of biomedicine within a holistic conception of health. However, policy makers who continue to prioritise biomedical models of health, and do not address the inequitable distribution of SCEDH risk continuing to fail to meet the policy objectives of the Closing the Gap policy framework.

10.6 Conclusions

Computerised HAs can be successfully implemented in urban Aboriginal and Torres Strait Islander primary health care for dual clinical and research purposes. I have demonstrated at the IIHS, that computerised HAs can be used for a wide range of credible cross-sectional and longitudinal research, responsive to community priorities, within an ethical framework where research accountability to the community is central. These doctoral research findings have potential to generate community benefit through changes in computerised HAs which reflect community priorities, and through feedback of computerised HA research findings to community. These doctoral research findings also encourage a policy discourse favouring action on the inequitable social, cultural, and environmental conditions in which people live.

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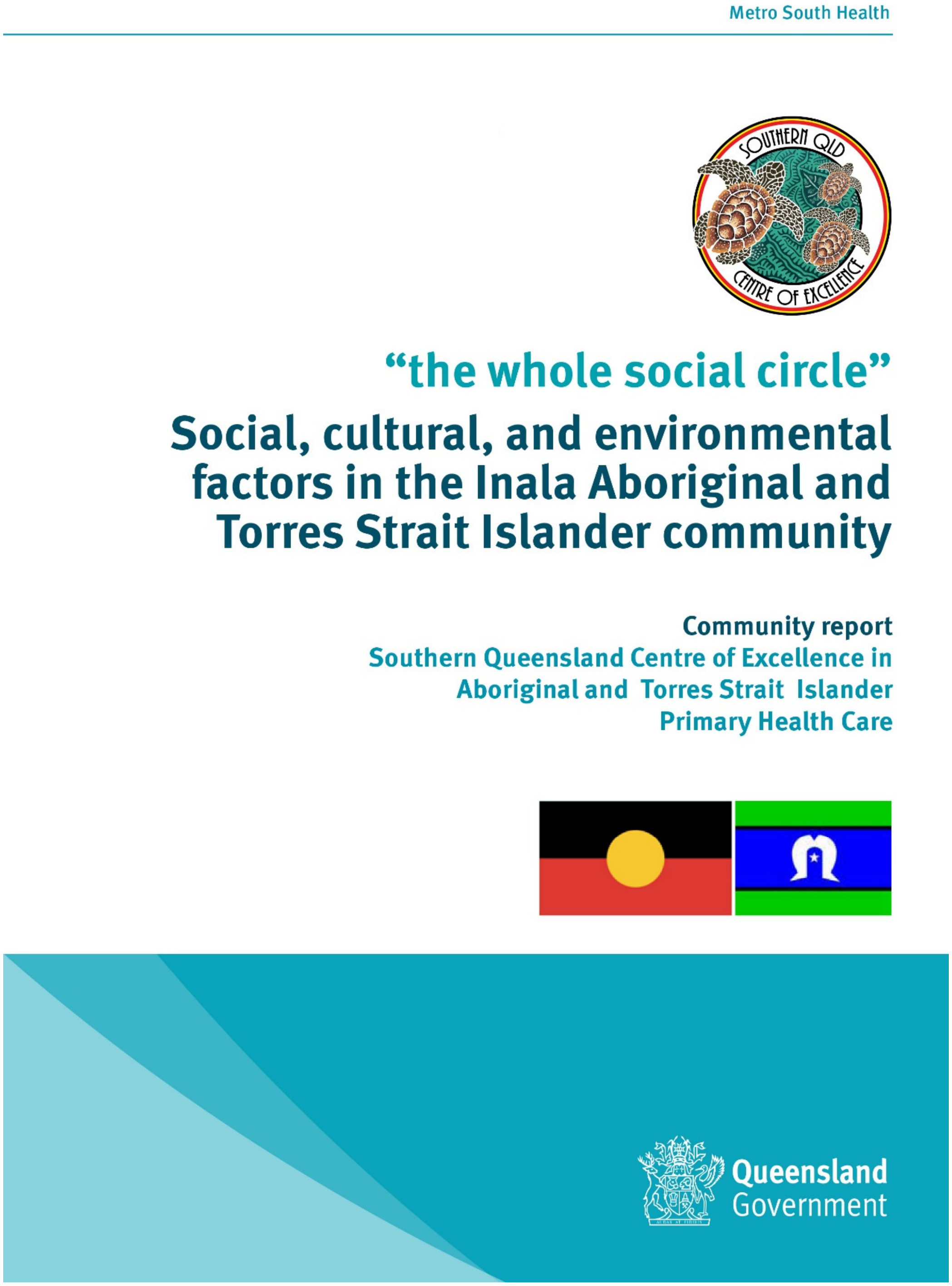
Appendices

Appendix 1 Community report



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“the whole social circle”

Social, cultural, and environmental factors in the Inala Aboriginal and Torres Strait Islander community

Community report

Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care

Queensland Government

“the whole social circle”
Social, cultural, and environmental factors in the Inala Aboriginal and Torres Strait Islander community

This community report was prepared by Dr Geoffrey Spurling, Associate Professor Deborah Askew, Dr Chelsea Bond and Professor Philip Schluter. It was supported by the Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care.

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This report is a story about the health of Aboriginal and Torres Strait Islander peoples in Inala, and has been shaped by Aboriginal and Torres Strait Islander community members of Inala. This research was conducted by a local general practitioner working at the Inala Indigenous Health Service, Dr Geoff Spurling, as part of his doctoral research and in partnership with community members. Typically, health research tells us about the medical conditions that Aboriginal and Torres Strait Islander peoples' experience. However, Dr Spurling wanted to find out the health priorities of key community stakeholders. This report combines information collected from routine health checks at the Inala Indigenous Health Service with the health stories of Aboriginal and Torres Strait Islander peoples within the community in order to reveal a more complete health story.

Community involvement

Aboriginal and Torres Strait Islander community members in Inala took part in this community consultation which aimed to find out community health priorities. We then aimed to use these priorities to plan research using Aboriginal and Torres Strait Islander health check information. Aboriginal community members, Chelsea Bond and Corey Kirk, were part of the team which analysed what community members said and helped interpret health check findings. We presented all our research to the Inala Community Jury for Aboriginal and Torres Strait Islander Health Research, and they supported our findings.[1] This research has been published in the Australian Journal of Primary Health.[2]

Permissions

Both the community consultation project and health check information project were approved at the outset by the Inala Community Jury for Aboriginal and Torres Strait Islander Health Research.[1] All community members provided written informed consent prior to being interviewed. Participants in the health check information project also provided written informed consent for their health check information to be used for research purposes. Ethical approval to proceed with both projects was given by the Metro South Human Research Ethics Committee and The University of Queensland's Behavioural and Social Sciences Ethical Review Committee.[3]

Contents

Who wrote this report?

This report is based on research conducted as part of Dr Geoffrey Spurling's doctoral research at The University of Queensland. Dr Geoffrey Spurling also works as a general practitioner at the Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care (COE), also known as the Inala Indigenous Health Service (IIHS). Associate Professor Deborah Askew is the Research Director at the COE. Associate Professor Deborah Askew, Professor Philip Schluter, and Dr Chelsea Bond are supervisors of Dr Spurling's doctoral research.

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The authors acknowledge:

- the Jagera people who are the traditional custodians of the land where this research was conducted.
- the valuable feedback provided by Karla Brady, Chief Executive Officer of Inala Wangarra, who reviewed a draft of this report and the patients attending the COE who had health checks and whose information is included in this report.
- the Royal Australian College of General Practitioners who provided funding for the community consultation research project.

Abbreviations

COE	Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care
IIHS	Inala Indigenous Health Service
NAIDOC	National Aboriginal and Islander Day Observance Committee
OR	Odds Ratio

Summary

Aboriginal and Torres Strait Islander community organisations and health services are likely to have more ideas for resolving the health concerns of their communities than they have resources available to address them. We hope that the information from the two research projects we describe in this report can help health services, community organisations, and policy makers plan activities, evaluate progress, and apply for funding for the benefit of the Inala Aboriginal and Torres Strait Islander community.

In this report, we present the results of two research projects. In the first project, we interviewed 21 members of the Inala Aboriginal and Torres Strait Islander community. We asked community members about their health priorities, so we could work out research directions for Aboriginal and Torres Strait Islander health checks conducted at the COE. Community members were worried about the social, cultural, and environmental conditions of their lives, and how these interlinked conditions were experienced as a cycle that crossed generations.

For the second research project, we used information from Aboriginal and Torres Strait Islander health checks conducted at the COE in 2014-2015 to look at the social, cultural, and environmental conditions experienced by COE patients. Overall, 780 adults consented to the use of their health check information for research. We looked at differences in how social issues were experienced for men and women and for different age groups. When reading and discussing these findings, it is important to remember both the strengths of the Inala Aboriginal and Torres Strait Islander community and the historical factors contributing to intergenerational trauma and ongoing colonisation and oppression experienced by Aboriginal and Torres Strait Islander peoples.

Some of the key findings about social issues measured by health checks are described below:

- Education levels are improving with 74% of people aged 15 to 24 years achieving greater than a Grade 10 educational level.
- Overall 34% of people who had health checks reported being employed, but 27% were unable to get a job. Unemployment was highest among young people (41%) and men (37%). 49% of young men aged 25-34 years reported being unemployed.
- 25% of people reported being single parents which was more common for women (36%). For women aged 35-44 years, 54% reported being a single parent.
- 84% of people reported that they had not spent time in jail. 26% of men reported that they had spent time in jail compared with 7% of women.
- At least one stressful event was reported by 87% of people. The most common stressful event reported by people who had a health check was the recent loss of a close relative or friend (35%).
- 34% of participants reported feeling depressed, and depression was more commonly reported by women (39%). 8% of people reported suicidal thoughts.
- While alcohol, tobacco, and other drugs were challenging social issues for some people who had health checks, 82% of people reported not drinking harmful quantities of alcohol, 45% of people reported that they did not smoke, and 88% of people reported not using marijuana, speed or heroin.
- 93% of people did not report living in overcrowded housing, but it was seen by community members as a big issue for those who did live in overcrowded houses.
- 42% of participants reported attending a community event in the last 12 months.

Many social issues were associated with positive self-rated health – even after accounting for age and sex differences between people. People who reported playing sport, doing exercise, being involved in community activities, and getting past Grade 10 at school were all more likely to report positive self-rated health. People who did not smoke tobacco or marijuana or use amphetamines were also more likely to report positive self-rated health. Additionally, people who did not report problems with gambling, exposure to violence, experiences of racism, trouble with the police, and a recent relationship separation in the last 12 months were more likely to report positive self-rated health.

The COE can provide more up-to-date health check information on a range of health matters to assist community organisations, health service delivery, and policy makers. Enquiries about health check information from the COE should be directed to Dr Geoffrey Spurling (geoffrey.spurling@health.qld.gov.au).

Introduction

This report is about and for the Aboriginal and Torres Strait Islander community in Inala and surrounding suburbs. Inala is located within the traditional lands of the Jagara people in South-East Queensland, and is located about 19km southwest of the Brisbane central business district. According to 2011 Census data, Inala and Richlands (the neighbouring suburb) have one of the highest proportions of Aboriginal and Torres Strait Islander peoples (6%) in the Brisbane area.[4] The Inala area has always had a strong sense of its community identity which is equally true for Aboriginal and Torres Strait Islander peoples.[5,6] This identity is reflected in Inala-specific songs, language, celebration of the Inala football team, and participation in the National Aboriginal and Islander Day Observance Committee (NAIDOC) week.[5,6,7]

Inala also faces social challenges. It is the only urban local government area listed in the most disadvantaged areas of Queensland in the 2015 "Dropping off the edge" report.[8] The "Dropping off the edge" report looked at people's social conditions including unemployment, time in jail, income, and internet access.[8] Community-controlled Aboriginal and Torres Strait Islander organisations, such as Inala Wangarra and the Inala Elders, work hard to address social challenges in Inala, but are limited by funding and resource shortfalls.

Two of the authors of this report (Geoffrey Spurling and Deborah Askew) work at the COE, a Queensland Government funded Aboriginal and Torres Strait Islander primary health care service, located within the suburb of Inala. In 1994, the health service began as the IIHS with 12 patients and one doctor, Associate Professor Noel Hayman and one nurse, Nola White. Noel and Nola worked with the community and went about removing barriers to primary health care. The IIHS grew to over 3000 regular patients and became the COE in 2013.[9,10]

What are Aboriginal and Torres Strait Islander health checks?

The Australian Government funds a Medicare rebate of approximately $200 to general practices for each annual comprehensive health check that general practitioners, nurses, and health workers conduct for their regular Aboriginal and Torres Strait Islander patients. These health checks are designed to pick up risk factors for diseases, and allow time for general practitioners, nurses, and health workers to talk about preventive health, and refer patients on to the services they need. At the COE, we conduct over 1000 Aboriginal and Torres Strait Islander health checks each year.[11] With patient consent, we also use the information collected by health checks for research projects that have been approved by the Inala Community Jury for Aboriginal and Torres Strait Islander Health Research and relevant ethics committees.[1]

Community consultation

We interviewed 21 community members between February and June 2013 who were members of community controlled or state-run organisations working in Inala with Aboriginal and Torres Strait Islander peoples. We aimed to include people who identified as Aboriginal and/or Torres Strait Islander, men and women, and a range of ages (Table 1).

Table 1: Characteristics of Aboriginal and Torres Strait Islander community members (N=21)

Characteristic	Participants	%
Female	12	(57)
COE Employee	4	(19)
Ethnicity		
Aboriginal	16	(76)
Torres Strait Islander	5	(24)
Age		
Less than 30 years	5	(24)
30-49 years	9	(43)
50 years and over	7	(33)

What was asked?

We asked community members about health checks and their health priorities.

Some of the specific questions we asked were:

1. Have you ever had a health check?
2. What were some of the issues that you thought were important in a health check?
3. What parts of the health check are important from the point of view of the community, as a family member, and in your work?
4. If you had to pick your top three things from the list of health issues covered by health checks, what would they be?
5. Is there anything else that you would like to say about health checks?

Interviews were recorded and lasted between half an hour and two hours. We presented what we found to the research participants and the Inala Aboriginal and Torres Strait Islander community at informal meetings, by telephone, at a community seminar, and to the Inala Community Jury for Aboriginal and Torres Strait Islander Health Research.[1]

How did we use the health check information?

After hearing community stakeholder responses to our questions about health priorities, we wanted to use health check information to look at the social, cultural, and environmental conditions of people's lives. The authors of this report are conscious of the dangers of presenting information about the Inala Aboriginal and Torres Strait Islander community that reinforce negative perceptions about Inala and/or Aboriginal and Torres Strait Islander peoples. We have attempted to not tell a story of deficit and disadvantage, but to tell of the positive outcomes of the research.

What information did we use from health checks?

As well as the 21 community members' interviews, in this report we have used information from 780 adult Aboriginal and Torres Strait Islander health checks conducted at the COE over a one year period between April 2014 and March 2015. We only used health check information where people had signed a consent form. The age, sex, and ethnicity of people who had health checks were similar to people living in the Inala area according to Census information (Table 2).[12]

Table 2: Age, sex, and ethnicity of Aboriginal and Torres Strait Islander peoples who had a computerised health check at the COE between 1 April 2014 until the 31 March 2015 (N=780) and Census data from the Inala 4077 local government area.[a]

Demographic	Health Checks		Inala (4077) Census data[b]	
	n	(%)	n	(%)
Age (years)				
15 to 24	195	(25)	192	(25)
25 to 34	131	(17)	140	(19)
35 to 44	152	(19)	151	(20)
45 to 54	133	(17)	118	(16)
55 to 64	118	(15)	89	(12)
65 and over	51	(7)	55	(7)
Sex				
Female	40	(51)	411	(55)
Male	380	(49)	334	(45)
Ethnicity[c]				
Aboriginal	700	(93)	1327	(89)
Aboriginal and Torres Strait Islander	31	(4)	82	(6)
Torres Strait Islander	24	(3)	79	(5)

[a] While 4077 was the most common place people lived (44%), overall, people who had health checks lived in 77 different postcodes.
[b] 2011 Census data for age and sex are taken from the Inala community profile (4077).[12]
[c] 2011 Census data for ethnicity are taken from the Inala and Richlands Queensland regional profile and include children aged 0 to 14 years.[4]

A cycle of social, cultural and environmental factors

Community members' responses strongly suggested a whole of person view of health which didn't just involve body parts and diseases, but also included the social, cultural, and environmental conditions that impacted on peoples' lives. The names of community members have been changed in this report to protect their privacy.

> *"Yeah, I think it would be this one here, social issues, depression, yeah, all of that..." – Luke*

From this point on, we take Luke's lead and use the term "social issues" to refer to all the social, cultural, and environmental factors discussed by community members and covered by health checks.

Education

Community stakeholders told us that education was very important and young people will struggle if they don't finish school.

> *"So then they start missing school, they fall behind, so then they don't want to go to school because they feel dumb, so they don't finish high school, they don't have the qualifications to get a job, so finding a job is hard, they're only getting Centrelink, then how do they support themselves..." - Grace*

The number of Aboriginal and Torres Strait Islander peoples getting past Grade 10 is higher for young people now than it was for their parents and grandparents.

- Over half of adults who had health checks went beyond a Grade 10 educational level (52%).
- Educational levels were higher for younger people with 74% of people aged 15 to 24 years getting to Grade 10 or beyond. This suggests improvements in education levels are being achieved for the next generation.

Education beyond Grade 10

All adults (52%)

Young people aged 15-24 years (74%)

Community involvement

Community members pointed out the strong community spirit of the Aboriginal and Torres Strait Islander community in Inala.

"…there was something strong about the community that I think was a protective factor." - Olivia

Many people who had had a health check had also been to at least one community or cultural event in the last 12 months.

- 42% of adults reported attending a community event in the last 12 months.

People attending a community event (42%)

The number of people coming to community events reflects the strong community spirit of Inala.

"Inala just gets spoken about…How we acknowledge each other in the community and how we respect each other. I think that's why there is not that much of a tension between each other's cultures and that because we do play football together, we do Stylin' Up, we do music together…even NAIDOC, you still see other non-indigenous brothers coming down and sharing the culture…So it's how we interact, and how we utilise everybody in the community to be involved in the events…" - Luke

Employment

Many community members were worried about the difficulties for people who were unemployed. Employment, especially for men, was particularly important.

> *"You give a man a job, he can afford housing, he will no doubt want to look after himself… and he then changes himself as a role model for his children. The health in that is massive. Massive." - Lily*

The percentage of people who said they were unemployed was higher than the Australian average and higher than the Inala average.[4]

- While 34% of people reported being employed, a further 27% of people reported that they had been unable to get a job in the last 12 months.
- Men (40%) were more likely to report being employed than women (29%), but men (37%) were also more likely to report unemployment than women (29%). 36% of men reported being unable to get a job compared with 18% of women.
- Young men aged 25 to 34 years were most likely to report being employed (49%). However, the same proportion of men in this age group reported being unemployed (49%). 37% of men in this age group reported that they were unable to get a job.

Employment

People reporting employment (34%)

People reporting not being able to get a job (27%)

Housing

Community members said crowding could be a big issue especially if a family lost their housing because of unemployment or recent relationship separation. This often meant families would move in with relatives who might already have money stresses. Community members were concerned about how crowding affected children in particular.

> *"...a big thing, I think, as well is crowding in houses. Because, you know, if kids are sharing a room, or two to three to a room, they don't really get much sleep at night. They go to school, they're tired, they didn't have breakfast or stayed up really late, couldn't get to sleep, too much noise. Then they don't have any energy to do work at school, struggle throughout school." - Liam*

- Most people did not report living in crowded housing (93%), but clearly this could be a big issue for the 7% who did report household crowding,
- Young people, aged 15-24 years of age, were most likely to report that they were living in crowded housing (15%) or were homeless (6%).

People who did not report overcrowding at home (93%)

Stress

Community members were worried about a number of stresses that had occurred in the last 12 months including experiences of grief.

- 35% of people who had health checks reported the passing of a relative or close friend in the last 12 months. While health checks only ask about the passing of a relative or close friend in the last 12 months, the grief may be long lasting, and can be particularly difficult if a number of close relatives or friends have passed away in a short period of time.

> *"What about grief?... Even though things might have happened 12 months, two years, three years [ago]... Like I know my family we're all still trying to deal with it." – Evelyn*

- Other stressful events people who had health checks reported in the last 12 months were having a family member in jail (21%) and trouble with the police (14%).

Stressful events

Grief (35%)

Family member in jail (21%)

Trouble with police (14%)

- 13% of people who had a health check reported experiencing racism or discrimination in the last 12 months.

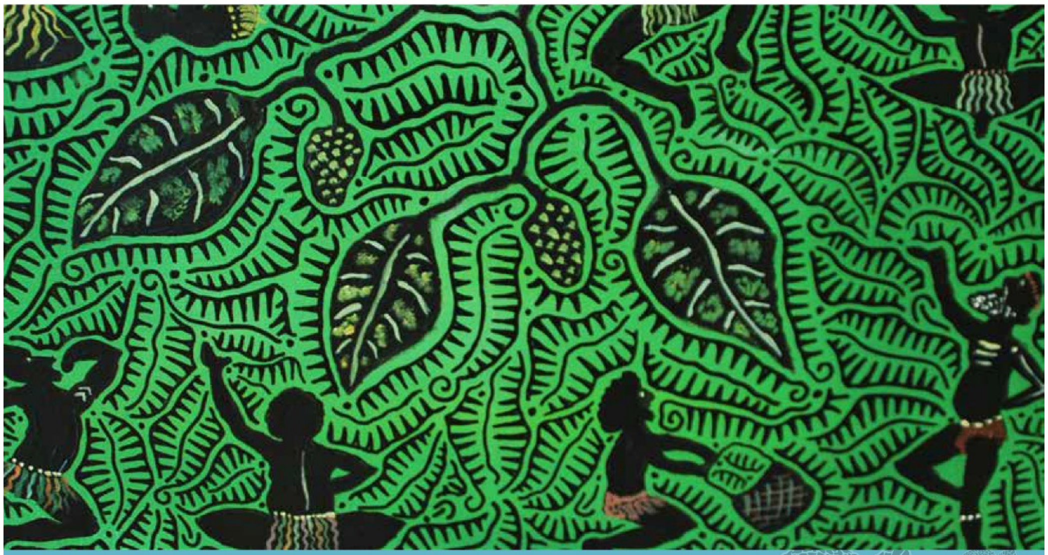
> *I experienced quite intense surveillance by the police... and I would drink quite heavily because I couldn't understand what was going on, and I was young - Olivia*

Other stressful events

Racism (13%)

Experiencing violence (13%)

Relationship separation (12%)



Number of stressful events

Stressful events did not occur in isolation, and often came on top of each other. Many people who had health checks reported experiencing more than one stressful event in the previous 12 months. While 26% of people did not report a stressful event in the last 12 months, 24% reported at least one stressful event, and half of people reported experiencing two or more stressful events in the last 12 months.

Number of stressful events experienced

No stressful events reported in last 12 months (26%)

One stressful event reported in the last 12 months (24%)

Two or more stressful events reported in the last 12 months (50%)

Family breakdown

Many people we interviewed were concerned about the effects of family breakdown on the younger generations and especially children.

> *"...around that time my parents split, so the drinking really took over – over my life...I really feel that's when the depression really kicked in, and I turned to violence ...getting into fights, which is no good, absolutely no good. - Noah*

Single parenthood

Single parenthood was most commonly reported by women.

- Single parenthood was more likely to be reported by women (36%) than men (13%).
- For women aged 35-44 years, 54% reported being a single parent.

Single parent

Women (36%)

Men (13%)

History of time in jail

The unacceptably high levels of jail time for Aboriginal and Torres Strait Islander peoples across Australia also worried community members in Inala.

> *"These kids, they think to be a man you've got to go in jail and then you come out and they go "Oh yeah. You've been in jail." But yeah, that's just - that's one way. - Colin*

- While 84% of people who had health checks did not report a history of time in jail, 16% of people reported a history of time in jail.
- Jail time was more commonly reported by men (26%) than women (7%).

People reporting time in jail

Mental health

Community members often told us how important depression, anxiety, and the devastating effects of suicide were as part of a cycle of social issues affecting the community.

> *"If I had to put one at the top of the list, it would have to be mental health because it's really a silent killer." - Steven*

- 34% of people who had a health check said they were depressed and this was more common for women (39%) than men (29%).
- People aged 35 to 44 years were the most likely to report feeling depressed (46%). Depression was least likely to be reported by people aged over 65 years (18%) and people aged 15-24 years (23%).
- 8% of people who had a health check reported suicidal thoughts, and this was most common in the 45-54 year age group (13%). Suicidal ideas were least common among people aged 65 years and over (0%), and among people aged 55-64 years (5%).

Mental health

Depression reported by women (39%)

Depression reported by men (29%)

Suicidal thoughts (8%)

Alcohol

Community members were often worried about the effects of alcohol, especially for men who did not have a job.

> *"If I was unemployed, I would know that one of my mates around here would start drinking on a Wednesday… you can drink all the way to Friday. Then you just think, all right, weekend is here. And then when the alcohol was gone, now you're hungover, you're feeling all depressed because you're going back home and you've got nothing there… a lot of these fellas just go home, they gone into a room with hardly nothing, broken down cupboards and stuff. You go and just look at the ceiling and man, what am I doing? What am I doing?" – Colin*

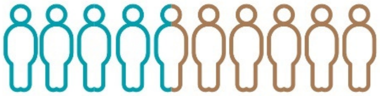
» Overall, 82% of people who had a health check did not report drinking harmful quantities of alcohol. However, men were more likely to report drinking harmful quantities of alcohol (21%) than women (15%), and this was a concern for about 20% of all people aged 15 to 64 years.

People who did not drink harmful quantities of alcohol (82%)

Smoking tobacco

Tobacco smoking rates have become less common over the last eight years. In 2007, the COE published information from adult health checks showing that 67% of people reported smoking tobacco.[13] The 2014/15 information included in this report shows tobacco smoking has reduced, and 55% of people reported smoking tobacco. Smoking tobacco was most commonly reported by young women aged 25-34 years (74%). Overall, 45% of people who had health checks reported not smoking tobacco.

People who reported not smoking (45%)



Marijuana, speed and heroin

Community members said that smoking, like alcohol and other drugs, started in teenage years.

> *"…you just see it, all these young kids going to little parties and drinking on weekend, they're probably smoking, smoking marijuana…then come Monday, they don't want to go to school 'cause they're so tired from the weekend." – Grace*

- Overall, 77% of people reported not using marijuana, speed, or heroin.
- 22% of people who had health checks reported using marijuana which was more common among young men. For men aged 15-24 years, up to 40% said they had used marijuana compared to 18% of women in the same age group.
- 5% of people who had health checks reported using speed and 4% reported using heroin.

People who reported not using marijuana, speed or heroin (77%)

Diet and exercise

Community members did not only see diet and exercise as a concern for individuals, but as part of bigger social issues like not having a job.

> *…one man said, "I'm unemployed at the moment, all I do is sit at home and go in the cupboard and steal all my school kid's food in there…I just can't stop, I just snack all day…" So obesity in general is the start of many problems. - Edward*

- Overall, 59% of people reported that they ate enough fruit and vegetables. Of the 41% of people who had health checks and reported that they didn't eat enough fruit and vegetables, this was most common for 15-24 year olds (51%). 43% of people who had health checks reported drinking soft drink every day.
- 66% of people who had health checks reported doing regular exercise, and 19% played sport.

Diet and exercise

People who reported eating enough fruit and vegetables (59%)

People who reported regular exercise (66%)

People who reported playing sport (19%)

Positive self-rated health and social issues

Many social issues were associated with positive self-rated health. We asked people who had health checks if they rated their health as very good, good, fair, poor, or very poor. People who rated their health as very good or good were considered to have positive self-rated health. Of all the social issues measured by health checks, we found 12 were statistically related with positive self-rated health after accounting for age and sex differences between people. Here we use odds ratios (ORs). If OR equals 1, then the association between social issues and self-rated health is neither positive nor negative. If OR is less than 1, then the association of social issues with self-rated health is negative, and if OR is greater than 1, then the association of social issues with self-rated health is positive. The estimated ORs for the 12 social issues associated with positive self-rated health are presented in Figure 1.

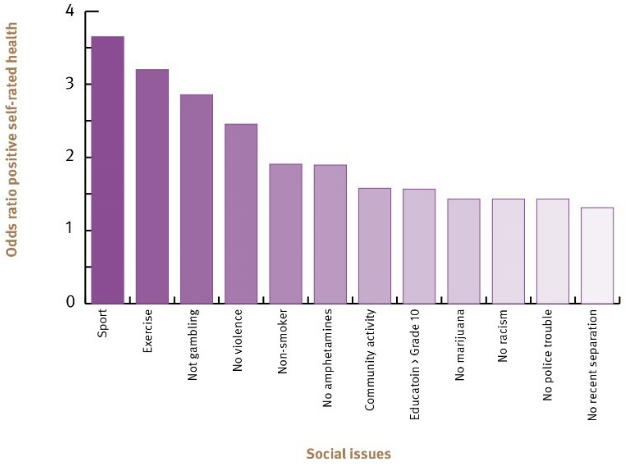


Figure 1: The chances of people rating their health as positive depending on the social issues they reported at the COE 2014/15, N=780.

People who reported playing sport (OR 3.6) and doing physical activity (OR 3.3) were more than three times as likely to report positive self-rated health than people who did not report playing sport or doing physical activity. People who did not report gambling or experiencing violence in the last 12 months were 2.9 and 2.3 times more likely to report positive self-rated health respectively than people who did report gambling or experiencing violence in the last 12 months. People who reported that they did not smoke or use amphetamines were nearly twice as likely to report positive self-rated health compared with people who reported current smoking and amphetamine use. For people participating in community activities and those who got past Grade 10 at school, they were 1.7 times more likely to report positive self-rated health than people who did not report participating in community activities and for those who got to Grade 10 or less at school. People who reported not using marijuana, not experiencing racism in the last 12 months, and not having trouble with the police in the last 12 months were 1.6 times more likely to report positive self-rated health than people who reported using marijuana, experiencing racism, and who reported having trouble with the police in the last 12 months. Finally, people who did not report a relationship separation in the past 12 months were 1.5 times more likely to report positive self-rated health than people who reported a relationship separation in the last 12 months.

Conclusion

The community members we interviewed live and work in the Inala Aboriginal and Torres Strait Islander community, and have a deep understanding of the strengths and challenges in their community. While there are significant community strengths, a large number of the people who had health checks experienced the social issues that community members were concerned about.

Social issues are experienced in different ways for men and women and for different age groups. While a little over a third of people who had health checks reported being employed, men were more likely to report being unemployed and say they had trouble getting a job. Approximately 80% of people who had health checks did not report drinking harmful quantities of alcohol, did not use marijuana, speed, or heroin, and did not report time in jail. However, men were more likely to report drinking alcohol and using marijuana, and more likely to report time in jail than women.

Women were more likely than men to report being a single parent especially in the 35-44 year age group. Women were also more likely than men to report anxiety, depression, overcrowding, and homelessness.

Social issues were also reported at different rates at different ages. People aged from 35 to 44 years who had health checks were most likely to report many major stressors along with anxiety and depression. The high rates of suicidal thoughts in all groups were concerning, and especially for those aged 45 to 54 years. Younger people (15-24 years) were significantly more likely to reach an education level beyond Grade 10, report doing exercise, and report playing sport compared with older people. However, younger people were also more likely to report using marijuana, amphetamines, or heroin, or have trouble getting a job, being in trouble with the police, and not eating adequate fruit and vegetables. The experiences of racism reported here by Aboriginal and Torres Strait Islander men and women of all ages are an ongoing challenge for policy-makers, clinicians, researchers, and Australian society as a whole.

There are many social issues important to Aboriginal and Torres Strait Islander peoples, which are not measured by health checks, and are not presented here such as knowledge of traditional customs, language, and country, history of removal from family, and satisfaction with sense of identity. In addition, social issues measured in a broad clinic-based health check may not be as accurate as surveys designed to measure individual social issues. It is also important to remember that rather than just statistics, many of the numbers presented in this report represent very challenging human experiences.

The information in this report about social issues provides a baseline for measuring and evaluating programs dealing with these issues in this community. Across Australia, this type of health information, responding to community priorities at the community level for men and women across the life span, is not readily available.[14]

The associations between positive self-rated health and many social issues reported here suggest that activities and programs which address social issues are likely to improve health. For community organisations and health services to plan, run, and monitor such programs they will need appropriate resourcing and support from policy-makers.

The COE continues to conduct health checks and collect information which may be useful for health services, community organisations, and policy makers. The types of information collected by the COE are not limited to social issues in adults, and cover a range of other mostly medical measures for children, adults, and people with diabetes. Enquiries about health check information from the COE should be directed to Dr Geoffrey Spurling (geoffrey.spurling@health.qld.gov.au).

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Appendix 2 Peer reviewed publication of Chapter 5

Hyperlink to publication:

http://bmcmedinformdecismak.biomedcentral.com/articles/10.1186/1472-6947-13-108

Accepted author manuscript

Title Page

Implementing computerised Aboriginal and Torres Strait Islander Health Checks in primary care for clinical care and research: a process evaluation

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Abstract:

Word Count: 319 (350 words max)

Background

Paper-based Aboriginal and Torres Strait Islander health checks have promoted a preventive approach to primary care and provided data to support research at the Inala Indigenous Health Service, south-west Brisbane, Australia. Concerns about the limitations of paper-based health checks prompted us to change to a computerised system to realise potential benefits for clinical services and research capability. We describe the rationale, implementation and anticipated benefits of computerised Aboriginal and Torres Strait Islander health checks in one primary health care setting.

Methods

In May 2010, the Inala Indigenous Health Service commenced a project to computerise Aboriginal and Torres Strait Islander child, adult, diabetic, and antenatal health checks. The computerised health checks were launched in September 2010 and then evaluated for staff satisfaction, research consent rate and uptake. Ethical approval for health check data to be used for research purposes was granted in December 2010.

Results

Three months after the September 2010 launch date, all but two health checks (378 out of 380, 99.5%) had been completed using the computerised system. Staff gave the system a median mark of 8 out of 10 (range 5-9), where 10 represented the highest level of overall satisfaction. By September 2011, 1099 child and adult health checks, 138 annual diabetic checks and 52 of the newly introduced antenatal checks had been completed. These numbers of computerised health checks are greater than for the previous year (2010) of paper-based health checks with a risk difference of 0.07 (95% confidence interval 0.05, 0.10). Additionally, two research projects based on computerised health check data were underway.

Discussion

The Inala Indigenous Health Service has demonstrated that moving from paper-based Aboriginal and Torres Strait Islander health checks to a system using computerised health checks is feasible and can facilitate research.

Conclusions

We expect computerised health checks will improve clinical care and continue to enable research projects using validated data, reflecting the local Aboriginal and Torres Strait Islander community’s priorities.

Keywords:

Computerised medical record systems

Aboriginal and Torres Strait Islander Health

Primary Health Care

Background

In Australia, improved clinical systems and research opportunities in urban Aboriginal and Torres Strait Islander primary health care are likely to be required to help meet the Australian Government's ambitious target to close the gap in life expectancy between Indigenous and non-Indigenous Australians within a generation [1]. Aboriginal and Torres Strait Islander peoples living in non-remote locations contribute approximately 60% of the 11 year gap in life expectancy [2], yet a systematic review published in 2010 found only 63 (11%) of 555 articles on Indigenous health published between 2004 and 2009 included information about Aboriginal and Torres Strait Islander peoples from urban areas [3].

In the effort to close the life expectancy gap, an important clinical tool for primary care is the Australian Government funded annual well-person's health check (HC) for Aboriginal and Torres Strait Islander peoples of all ages. These checks were intended to increase preventive health opportunities, detect chronic disease risk factors and reduce inequities in access to primary care for Aboriginal and Torres Strait Islander peoples [4]. At the Inala Indigenous Health Service (IIHS), we aim to deliver an Aboriginal and Torres Strait Islander HC to all regular patients each year. The evidence for this practice in vulnerable populations is lacking. A systematic review of HCs conducted in primary care settings found improved delivery of recommended clinical preventive services and the authors felt this justified their continued implementation [5]. However, a more recent systematic review published in 2012 by Krogsboll and colleagues reported that general HCs for well adults conducted in primary care or the community were not beneficial and did not reduce morbidity, mortality, nor disease specific mortality. The inclusion criteria for this review excluded older people, children and studies looking specifically at risk factors (such as hypertension) or disease (such as diabetes). Additionally, the majority of trials and patients in this systematic review were conducted in the community where participants were invited to participate which the review authors acknowledged could result in selection bias favouring the well [6]. Clinically significant benefits have been found for other groups receiving HCs such as elderly people who benefited through reduced nursing home admissions, reduced falls and improved physical function [7]. While ethnicity was not an exclusion criteria for the most recent systematic review of HCs, all the included studies were conducted in North America or Europe and no information about the impact of health checks on Indigenous populations was presented [6].

For patients with diabetes we aim to deliver the annual diabetic cycle of care for all patients as per national guidelines produced by Diabetes Australia and the Royal Australian College of General Practitioners [8]. The IIHS facilitates these aims with recall, reminder, and alert systems and we have shown that paper-based HC templates can improve our clinic-based preventive health services [9, 10]. However, clinical limitations of the paper-based HC included problems with legibility, non-standardised responses, extra administrative work associated with manually scanning the HCs into the patients' medical record and paper consumption.

Notwithstanding these limitations, we proceeded with paper-based HC research at the IIHS and obtained ethical approval to evaluate data from a cohort of adult and a cohort of child HCs. The resulting research into childhood obesity [11], stressful events in children [12], self-rated health [13], and middle ear disease [14] relied on a research assistant collating paper HCs, deciphering clinicians' handwriting and then transferring this information to a data spread sheet line by line. We hypothesised that moving from this time-consuming, error-prone, paper-based process to a computer-based health information technology system would address many of these limitations and enhance patient care through better adherence to preventive care guidelines [15].

Information technology experts built the templates within ERIC, a Queensland state government computerised health record information management system already being used in a few Brisbane hospitals and the local community health sector as an electronic medical record. At the IIHS, we made this web-based, password-protected system available only to the clinical user group at the IIHS to protect patient confidentiality. The ERIC system can generate a Microsoft Excel spreadsheet (Microsoft Corporation, Redmond, WA, USA) collating all patient level data from a given computerised HC template for any given time period. When regular Aboriginal and Torres Strait Islander patients present to the IIHS, nursing staff initiate computerised HCs in ERIC, medical staff complete them and administration staff attach the completed computerised HC to the patient's medical record in the clinic's practice software (Practix) as a PDF (portable document format). Computerised HCs were launched at the IIHS in September 2010 and consisted of child and adult Aboriginal and Torres Strait Islander HCs, the annual diabetic HC and a newly introduced antenatal HC.

The objective of this study is to describe the introduction of computerised HCs at the IIHS and evaluate their implementation in terms of user satisfaction, uptake, and utility for research purposes.

Methods

Describing the introduction of computerised HCs at the IIHS.

Setting and participants

The IIHS is situated in south-western Brisbane, Australia. In 2011, 4.8% of people living in the suburb of Inala (postcode area 4077 includes Inala and the three surrounding suburbs) identified themselves as being Aboriginal and/or Torres Strait Islander; one of the highest proportions in Brisbane [16]. Inala is in the lowest 10% of Australian postal areas for scores of socioeconomic indices [17]. In a 2007 audit of adult Aboriginal and Torres Strait Islander paper-based HCs at the IIHS, 42% of participants came from the 4077 postcode area, with remaining participants distributed among 50 other postcodes across Queensland and Northern New South Wales [10]. In 2011, the IIHS saw 1909 Aboriginal and Torres Strait Islander adults and 861 Aboriginal and Torres Strait Islander children as regular patients (defined as those who have consulted with the service at least three times in the preceding two years). Within this population there were approximately 40 pregnant women at any one time and 278 patients with diabetes. Measures taken to improve HC uptake at the IIHS such as recall, reminder and alert systems would ideally lead to a complete, consecutive sample of consenting participants in computerised HC research at the IIHS.

Computerised HC templates and ongoing template enhancement

Computerised HC content was developed according to Medicare requirements (Australia's publicly funded universal health care system), the Australian National guide to a preventive health assessment for Aboriginal and Torres Strait Islander peoples [18], meetings with relevant clinical IIHS staff and our experience with useful questions from the paper-based HC templates. Aboriginal and Torres Strait Islander HCs use age specific templates, divided into child (0 to 4 years, 5 to 14 years) and adult (15 to 54 years, 55+ years) groupings. The computerised templates used at the IIHS and described in this paper are presented as additional files. All Aboriginal and Torres Strait Islander HCs include information on demography, resilience factors, health risk factors, socioeconomic factors, examination findings, and health interventions [9, 10]. Additional questionnaires embedded within adult computerised HCs include the Fagerstrom test for nicotine dependence [19], the alcohol use disorders identification test (AUDIT) screening tool for hazardous alcohol use [20], and Kessler psychological distress scale (K10) [21].

The antenatal template for pregnant women is commenced at the first antenatal visit and is added to during the pregnancy and only completed at the first postnatal visit. This template includes demographic details, pregnancy details, obstetric history, details of each antenatal visit and a summary of important clinical information at the first postnatal visit including delivery details, the baby's birth weight, and maternal health parameters.

The computerised monitoring tool for patients with diabetes mellitus is completed annually, attracts government funding (the annual diabetic cycle of care), and is usually conducted in conjunction with the annual Aboriginal and Torres Strait Islander HC and a retinal photo to screen for diabetic retinopathy. This template is designed to cover all the important components relevant to monitoring and managing diabetes mellitus in primary care and includes glycaemic index, blood pressure, body mass index, albumin-creatinine ratio, medications and referrals. A computerised retinal photo reporting form is usually completed at the same time and has become standard practice for patients with diabetes after the IIHS conducted a study demonstrating the value of retinal photography for diabetic retinopathy screening in primary care [22].

All variables in the computerised HCs are constrained by predetermined parameters including radio buttons, tick boxes, free text, integers or numbers with defined decimal places. A small number of fields, such as body mass index and expected date of delivery, are automatically calculated from other fields within the computerised template. Each computerised HC also takes important findings and collates them in a self-populating HC summary. When a computerised HC item response indicates a health issue, explanatory text (e.g. “current smoker”) is programmed to appear in a “Health Check Summary” text box towards the end of the template.

An ongoing process of improving the clinical relevance and usefulness of the HCs occurs at the IIHS. Two years following the introduction of computerised HCs, clinic staff were asked for feedback regarding the content of computerised HCs. Using these responses, a small clinical group made recommendations for improving the templates, including the addition of a self-populating “Actions” text box and functionality to compute cardiovascular risk. These changes are being implemented by the Information Technology (IT) department of Queensland Health.

Evaluation of computerised HCs at IIHS

Staff satisfaction, three months post launch (January 2010)

Nurses, doctors and administrative staff were invited via email to participate anonymously in a brief, post-implementation, on-line questionnaire. This survey was developed and conducted by the IT department at Queensland Health and is an indicative rather than definitive study. This survey included questions about satisfaction with training, IT support, ease of template use, the value of the HCs and overall satisfaction with the newly introduced computerised HCs. Responses were measured on a scale from one to ten, where ten is most satisfied.

Computerised HC uptake

The proportion of HCs completed using computerised forms was calculated three months post launch (January 2010). The number of computerised HCs completed after 12 months (20th September 2010 to 19th September 2011) was extracted from ERIC and compared with the number of paper-based HCs from the preceding year as a proportion of the regular IIHS practice patients for each year. Data were imported into specialist statistical software package Stata version 10.0 (StataCorp, College Station, Tex, USA) for analysis. Results of these comparative analyses are reported as point estimate risk difference (RD) with 95% confidence intervals (CIs), using the computerised HC data as the reference.

Research using data from computerised HCs

Validity and missing data

At the IIHS, we have a previously validated criterion standard, the One21seventy audits, against which we will compare the data generated by computerised HCs. The One21seventy project, an annual continuous quality improvement process, commenced at the IIHS in 2010 prior to the introduction of computerised HCs [23]. The One21seventy project uses a range of evidence-based audit tools to monitor clinical practice in the prevention and management of chronic diseases, including four specific audit tools that correspond to the same four broad patient groups included in the computerised HCs at the IIHS; child health, preventive health in adults (aged 15-54 years), patients with diabetes, and pregnant women. For each computerised HC, there are between 14 and 25 variables that correspond with variables from the One21seventy audits and will be used in to validate computerised HC data.

Missing data may occur for computerised HC data collected primarily for clinical purposes and may reduce statistical power and study validity. We will evaluate missing computerised HC data and compare missing data from computerised HCs with missing data from paper-based HCs.

Ethical computerised HC research of relevance to the community

In their National Statement on Ethical Conduct in Human Research, the National Health and Medical Research Council (NHMRC) advises that informed consent at the commencement of involvement in long-standing studies must explain the unspecified and extended nature of that consent [24]. The statement also counsels that consent may have to be re-negotiated, for example when children transition to adulthood. The consent process described here for the use of these computerised HC data for research purposes was supported by the local Inala Elders and approved with full ethical approval to proceed in December 2010 by the Queensland Health Metro South Human Research Ethics Committee at the Princess Alexandra Hospital (PAH HREC) in Brisbane which covers the IIHS (HREC reference number: HREC/10/QPAH/242).

When patients present to the IIHS and are eligible for a computerised HC, they are invited to consent to the ongoing use of their computerised HC data for research purposes. If they agree to participate, patients (or carers of assenting children aged 15 years and younger) are asked to sign the paper based consent form, the research consent box in the computerised HC is checked “Yes” and this populates the relevant “research consent” field in the data extract. Consenting patients and carers do not have to re-sign the consent form when they return for an HC but must give verbal consent each time they present for an episode of care involving a computerised HC. Children returning for a computerised HC at age 15 years will be eligible for their first adult HC and will need to sign a new consent form. Patients who refuse consent are re-invited to participate at subsequent visits. All information regarding patients who have not given research consent is removed from the data extract prior to any research analysis. Participants who do consent to the use of their computerised HC data for research purposes are not, however, consenting to a particular project and while further written consent is unlikely to be required, additional ethical approval is required for each research project using these data.

Researchers, both internal and external to IIHS, can apply to conduct research using computerised HC data by completing a brief statement of research intent and clearly outlining exactly what data are required. It is expected that the research team will involve an IIHS staff member and ideally an Aboriginal or Torres Strait Islander person. Proposals are assessed by the IIHS research committee based on project feasibility, relevance and cultural safety considerations. If approved by the IIHS research committee, the proposal proceeds to the community jury.

The 14 member Inala Aboriginal and Torres Strait Islander Community Jury for Health Research consists of some self-nominated members, some representatives of local organisations such as the local Elders, and some community members chosen to ensure an appropriate spread of ages, gender and ethnicity. The jury, which meets approximately every three months, was set up in 2011 by the IIHS research committee with terms of reference designed to improve community involvement in decisions surrounding research at the IIHS. Through the jury, the IIHS responds to the principles of community involvement in well communicated ethical research outlined in the Australian NHMRC’s Road Map for improving Aboriginal and Torres Strait Islander health through research [25]. The proposal is discussed with the jury by the lead investigator in plain English. If the proposal obtains jury support, the project must then receive appropriate ethical approval from the PAH HREC. Once approved, the research database containing coded re-identifiable data with identifying information removed is released to the research investigators. Research results are reported back to the jury in an oral presentation and in written report which is made available to the Inala Aboriginal and Torres Strait Islander community.

To improve the relevance of computerised HC research to the local Aboriginal and Torres Strait Islander community we will conduct key informant interviews with jury members and other stakeholders working in the Inala Aboriginal and Torres Strait Islander community regarding issues covered by computerised HCs that are of concern or interest to them. The primary outcome of this research will be the identification of the community's health research priorities which will inform the research agenda of the IIHS into the future.

Results

First 3 months: initial staff evaluation

The staff survey at three months received 14 responses (70% response rate). For most measures including overall satisfaction, staff (administrative, nursing and medical users) gave the recently introduced system of computerised HCs a median mark of 8 out of 10 (Table 1). Administrative staff noted that attaching the computerised PDF to the patient's practice software was significantly easier than scanning in multiple pages of a paper-based HC.

First 3 months: computerised HC uptake

Three months following the September 2010 launch of computerised HCs, two HCs had been completed using paper forms and 378 using computerised forms out of 380 HCs (99.5% uptake of computerised forms). The lack of integration between the computerised HC platform and IIHS primary health care practice software led to some computerised HCs not being completed as nursing staff no longer physically handed the paper HC to medical staff for completion. Nursing staff now alert medical staff to the presence of a new computerised HC using bright pink text in the patient's progress notes and this appears to have resolved the communication breakdown.

First 12 months: computerised HC research consent rate, uptake and evaluation
Approximately 3% of adult patients and 4% of children's parents did not provide consent for their data to be used in research projects. There were no significant differences between age categories (p=0.8), ethnicity (p=0.7) and gender (p=0.8) of those who consented and those who did not. The total number of patients receiving a computerised HC completed after 12 months (September 2010 to September 2011) compared with paper-based HCs from the preceding year are presented in Table 2. There was a reduction in the proportion of child computerised HCs compared to paper-based HCs and an increase in the proportion of adult computerised HCs compared to paper-based HCs. The overall number of completed computerised HCs as a proportion of regular patients in their first year at the IIHS increased compared to the overall number of paper-based HCs in the preceding year with a risk difference of 0.07 (95% CI; 0.05, 0.10) (Table 2).

Research using computerised HCs

By September 2011, two research projects had received approval from the community jury and PAH HREC to commence using computerised HC data. One of these projects explores characteristics of the first antenatal visit and lessons that can be learnt from these presentations at the IIHS [26].

Discussion

The issues of confidentiality, trust and respect that arise with the creation of computerised forms and databases are particularly important to manage in a culturally appropriate way in Aboriginal and Torres Strait Islander communities. We have demonstrated that the implementation of a health information technology system using practice based computerised HCs is feasible in Aboriginal and Torres Strait Islander primary health care.

The number of HCs conducted at the IIHS as a proportion of regular patients increased following the introduction of computerised HCs indicating at least similar clinician usability and acceptance compared to paper-based HCs. We suppose that the shorter form and other benefits of the computerised form such as constrained answers and a summary self-populating problem list have outweighed the challenge posed by a new information technology system. There are a number of clinical advantages to incorporating computerised HCs in primary care. Using computerised

Aboriginal and Torres Strait Islander HCs as data collection tools, as far as we know an Australian first, means they represent a clinical intervention with no increased inconvenience for patients. Additionally, fully computerised medical records are less likely to result in missing clinical data than paper-based systems [27]. Reductions in missing clinical data have been associated with a reduction in adverse events in Australian general practice [28] and are likely to improve the quality of research information derived from these clinic data. Cost-effectiveness analysis following the implementation of other computerised health information systems in clinical settings found benefits were likely to outweigh investment costs, though this could take from between 3 to 13 years [29].

The computerised HCs at IIHS collate important findings in a self-populating problem list which is a useful summary for clinicians. Computerised HCs have the potential to use decision support in domains including cardiovascular risk calculation and referral prompts. These types of minimally intrusive point of care reminders have been shown to improve practice quality in other office-based clinical settings [30]. In the future, wireless functionality could enable computerised HC deployment in the home or other clinic settings using mobile technologies and has demonstrated value in hospital settings [31].

For research, the introduction of this health information technology system has facilitated the generation of a large clinical dataset at minimal extra inconvenience to patients. The primary health care setting has the potential to conduct large numbers of computerised HCs over time which will help us respond to calls for research which informs strategies to address the health needs of Aboriginal and Torres Strait Islander peoples living in urban areas in Australia [3].

Limitations exist for research based on consecutive samples where participation is influenced by both patient and clinic factors. In other clinical settings, such as the emergency department, selection bias associated with consecutive samples has been described as being of low clinical relevance [32]. In our first year of implementing computerised Aboriginal and Torres Strait Islander HCs at the IIHS, it is of concern that relatively fewer child HCs were completed. This may have been a result of high staff turnover among child health nurses at the IIHS, lack of room for carrying out child HCs or perhaps the computerised form for children was too long.

Future evaluations of computerised HCs would benefit from asking patients as well as clinical staff about the experiences of having a HC. As the clinical services of the IIHS move into a new, larger building in 2013 we expect the capacity to conduct computerised HCs will be greatly enhanced. We also expect developments in our general practice software will lead to better integration of computerised HCs and the patient's medical record within the one information technology system. Clinic-based populations are likely to be systematically different to the community which will affect the external validity and generalizability of research results [33].

Conclusions

We expect improvements in patient care owing to the benefits of legibility, completeness, security and decision support for computerised HCs over paper HCs. Future objectives include the integration of computerised HCs within general practice clinical software for use in multiple sites. The research potential of computerised HCs will be further enhanced by data validation and community consultation processes designed to enable credible research relevant to the community.

List of abbreviations

IIHS: Inala Indigenous Health Service

HC: Health Check

PDF: Portable Document Format

PA HREC: Princess Alexandra Human Research Ethics Committee

NHMRC: National Health and Medical Research Council

NACCHO: National Aboriginal Community Controlled Health Organisation

Competing interests

GS, DA and NH are all Queensland Health employees. GS and NH are clinicians and researchers using the new computerised templates in this primary health care setting.

Authors' contributions

GS conceived of the project, helped design the templates, obtained ethical approval and wrote the article; DA provided advice at all stages of project implementation and provided advice on template design, ethical matters, research planning and helped draft the final manuscript; PS provided advice on ethical matters, data storage/ security, research planning and helped draft the final manuscript; NH helped design the templates, provided advice on ethical approval and future research directions. All authors read and approved the final manuscript.

Acknowledgements

District Technology Services for facilitating the implementation project which led to computerised HC templates being used at the IIHS. Queensland Health funded publication of the study.

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Table 1.

Satisfaction with implementation and introduction of computerised health checks at the Inala Indigenous Health Service (IIHS) on a scale of 1 to 10 where 1 represents extremely dissatisfied and 10 represents extremely satisfied.

Survey items	Median	(Min., Max.)
Satisfaction with:		
consultation during implementation	8	(5, 10)
training	8	(1, 9)
IT support	8	(5, 10)
value of computerised health checks to your work	8	(4, 10)
process of entering information	7.5	(4, 10)
Overall satisfaction	8	(5, 9)

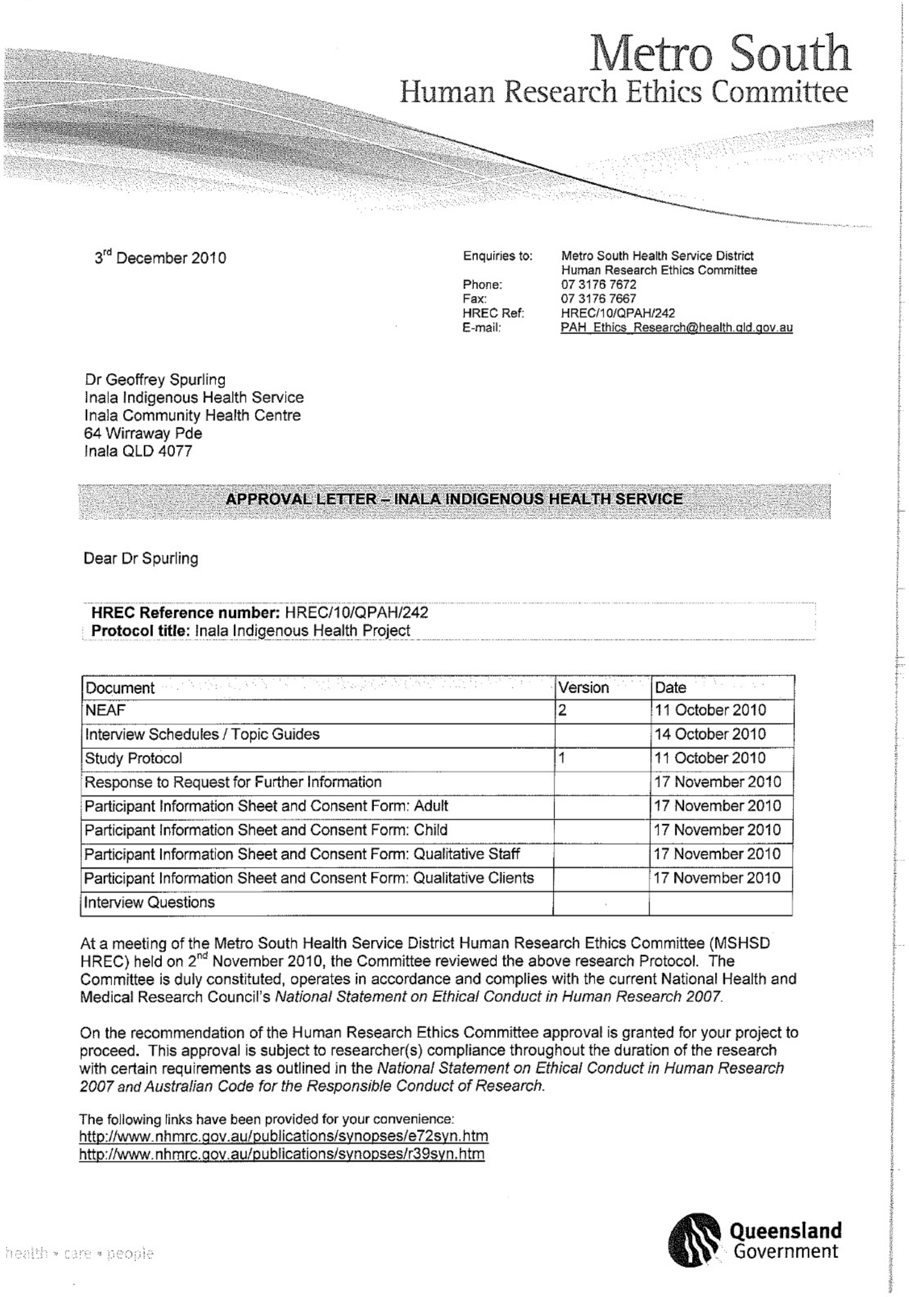
Table 2.

Uptake of computerised health checks (HC) in September 2010-2011 compared to the preceding year of paper-based HCs.

	September 2009-2010 Paper HCs			September 2010-2011 Computerised HCs			Risk Difference (95% CI)
	n	*(%)*	N*	n	*%*	N*	
Child HC 0-14 years	296	*36*	831	215	*25*	861	-0.13 (-0.18, -0.07)
Adult HC 15-54 years	419	*29*	1467	752	*47*	1588	0.20 (0.16, 0.24)
Older persons HC 55+ years	99	*31*	317	132	*41*	321	0.11 (0.03, 0.19)
Annual Diabetic Cycle of Care	129	*51*	255	138	*50*	278	-0.01 (-0.09, 0.08)
Retinal Photo Reporting Form	118	*46*	255	115	*41*	278	-0.05 (-0.14, 0.04)
Total	1061	*34*	3125	1352	*41*	3326	0.07 (0.05, 0.10)
Antenatal HC	N/A			52	62	84	

*Regular patients

Appendix 3 Ethical approval for computerised health assessments to be used for research purposes



Metro South
Human Research Ethics Committee

3rd December 2010

Enquiries to:	Metro South Health Service District Human Research Ethics Committee
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Dr Geoffrey Spurling
Inala Indigenous Health Service
Inala Community Health Centre
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APPROVAL LETTER – INALA INDIGENOUS HEALTH SERVICE

Dear Dr Spurling

HREC Reference number: HREC/10/QPAH/242
Protocol title: Inala Indigenous Health Project

Document	Version	Date
NEAF	2	11 October 2010
Interview Schedules / Topic Guides		14 October 2010
Study Protocol	1	11 October 2010
Response to Request for Further Information		17 November 2010
Participant Information Sheet and Consent Form: Adult		17 November 2010
Participant Information Sheet and Consent Form: Child		17 November 2010
Participant Information Sheet and Consent Form: Qualitative Staff		17 November 2010
Participant Information Sheet and Consent Form: Qualitative Clients		17 November 2010
Interview Questions		

At a meeting of the Metro South Health Service District Human Research Ethics Committee (MSHSD HREC) held on 2nd November 2010, the Committee reviewed the above research Protocol. The Committee is duly constituted, operates in accordance and complies with the current National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research 2007.*

On the recommendation of the Human Research Ethics Committee approval is granted for your project to proceed. This approval is subject to researcher(s) compliance throughout the duration of the research with certain requirements as outlined in the *National Statement on Ethical Conduct in Human Research 2007* and *Australian Code for the Responsible Conduct of Research.*

The following links have been provided for your convenience:
http://www.nhmrc.gov.au/publications/synopses/e72syn.htm
http://www.nhmrc.gov.au/publications/synopses/r39syn.htm

health • care • people

Queensland Government

Some requirements are briefly outlined below. Please ensure that you communicate with the HREC on the following:

- ***Protocol Changes:*** Substantial changes made to the protocol require HREC approval http://www.health.qld.gov.au/pahospital/research/amendments.asp
- ***Problems and SAEs:*** The HREC must be informed of any problems that arise during the course of the study which may have ethical implications. Serious adverse events must be notified to the HREC as soon as possible http://www.health.qld.gov.au/pahospital/research/adverse_events.asp
- ***Lapsed Approval:*** If the study has not commenced within twelve months approval will lapse requiring resubmission of the study to the HREC.
- ***Annual Reviews:*** All studies are required by the NHMRC to be reviewed annually. To assist with reporting obligations an Annual Report template is available on the MSHSD HREC website. This form is required to be completed and returned to the HREC within the 12 month reviewing period http://www.health.qld.gov.au/pahospital/research/monitoring.asp

As this research involves the recruitment of patients from the Metro South Health Service District (MSHSD), it is my responsibility to remind you of your ongoing duty of care for all people recruited into projects or clinical trials whilst public patients. All conditions and requirements regarding confidentiality of public information and patient privacy apply. You are required to comply at all times with any application requirements of Australian and Queensland Laws including the Health Services Act, the Privacy Act, Public Health Act (2005) and other relevant legislation, ethics obligations and guidelines which may be applicable to the MSHSD from time to time including, without limitation, any requirement in respect of the maintenance, preservation or destruction of patient records.

When the study involves patient contact, it is your responsibility as the principal investigator to notify the relevant consultant and request their approval.

Should you have any problems, please liaise directly with the Chair of the HREC early in the program.

A copy of this letter should be presented when required as official confirmation of the approval of the Metro South Health Service District Human Research Ethics Committee.

We wish you every success in undertaking this research.

Yours sincerely,

David Theile

Dr David E. Theile Snr
DISTRICT CHIEF EXECUTIVE OFFICER
METRO SOUTH

14/12/10

Appendix 4 Extra randomly selected variables from each computerised health assessment (5% of computerised health assessment questions)

Child HA
- Have the child's ears been checked?
- Is the child's teeth brushing supervised
- Does the child have a single parent?
- Does the child have a foster parent?
- Has the child experienced any stressful life events?
- Did the mother use recreational drugs while pregnant?
- What is the child's immunisation status?
- Are there skin problems?
- Was there a neonatal hearing screen?
- Does the child have mental health issues?
- Does the child drink water?
- Is there a past medical history of recurrent chest infections?
- Was there a referral from the health assessment?

Adult HA
- Is there a mental health issue?
- Employment status
- Is there evidence of hearing loss?
- Were there any concerns about men's sexual function?
- What was the urinary urobilinogen?
- What was the audit score?
- Were other substances consumed?
- What was the Fagerstrom score?
- What was the visual acuity?
- Self-rated health status?
- Were there skin problems?
- Was the tetanus vaccination up to date?
- Was the patient referred to a dietitian?
- Was there a change in bowel habit?
- Was contraception required?
- Were there any sexual health concerns?

Diabetes HA
- Is the patient taking blood pressure lowering medication?
- How many cigarettes is the patient smoking per day?
- Were glasses used in the visual acuity test?
- What stage of renal failure is the patient?
- What was the patient's ankle brachial index on the right side?
- Is there a history of peripheral vascular disease?

Appendix 5 Peer reviewed publication of Chapter 7

Hyperlink to publication:

http://www.publish.csiro.au/py/PY16131

Accepted author manuscript.

Title

"I'm not sure it paints an honest picture of where my health's at." Identifying community health and research priorities based on health assessments within an Aboriginal and Torres Strait Islander community: a qualitative study.

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Abstract

Aboriginal and Torres Strait Islander health assessments are conducted annually in Australian primary care to detect risk factors, chronic diseases, and implement preventive health measures. At the Inala Indigenous Health Service, health assessment data have also been used for research purposes. This research has been investigator-driven, which risks misinterpreting or ignoring community priorities compared to community-led research. The objective of this research was to learn the Aboriginal and Torres Strait Islander community's health priorities which could be translated into research themes, and investigated using health assessment data. We conducted thematic analysis of data from 21 semi-structured interviews with purposively selected key informants from an urban Aboriginal and Torres Strait Islander community. Key informants articulated an authoritative understanding of how interrelated, inter-generational, social, cultural, and environmental determinants operated in a "cycle" to influence the community's health. Key informant views supported the inclusion of these determinants in health assessments, reinforced the importance of comprehensive primary health care, and strengthened referral pathways to community resources. Some key informants were ambivalent about Aboriginal and Torres Strait Islander health assessments because of their biomedical emphasis. This research also revealed limitations of health assessment based research and the biomedical emphasis of the health system more broadly.

Summary statements

What is known about the topic?

- The majority of research involving Aboriginal and Torres Strait Islander health assessment data has been investigator-driven which risks misinterpreting community priorities.

What does this paper add?

- Asking key community informants about their health priorities demonstrated the importance of social, cultural, and environmental determinants of health, and revealed limitations of health assessments, health assessment based research, and the biomedical emphasis of the health system more broadly.

Introduction

Current national strategies to improve health outcomes including life expectancy for Aboriginal and Torres Strait Islander peoples are failing to meet their targets (Australian Government 2016). This failure may be due, in part, to the lack of research to inform strategies to improve health in urban areas (Eades *et al.* 2010), the setting where the majority of Aboriginal and Torres Strait Islander people live (Australian Bureau of Statistics 2013) and where most disease burden is experienced (Australian Institute of Health and Welfare 2016). High quality, community level research data are required to inform program delivery and advocacy (Biddle 2014).

One way to address the lack of research data is to use computerised Aboriginal and Torres Strait Islander health assessment (HA) data designed for dual clinical and research purposes (Spurling *et al.* 2013). Investigator-driven HA-based published research papers at the Inala Indigenous Health Service (IIHS) have reflected investigator inclinations and the biomedical emphasis of HAs (Spurling *et al.* 2013). The biomedical model conceives of health as primarily about medical practitioners detecting and curing diseases in individuals (Lewis 2005). However, rather than a preoccupation with diseases and their risk factors, the National Aboriginal Health Strategy Working Party emphasised the importance of social and cultural determinants in its holistic definition of health for Aboriginal and Torres Strait Islander peoples (National Aboriginal Health Strategy Working Party 1989). Investigator-driven research, not conducted in consultation with the community, may waste resources, misinterpret priorities, or worse, represent an extension of colonial control causing further trauma (Monk *et al.* 2009). This research aimed to identify the priority health issues of the Inala Aboriginal and Torres Strait Islander community, and which of these might be translated into research questions answerable using computerised HA data.

Methods

We situated this research in the transformative paradigm which assumes that knowledge reflects power and social relationships within society, and seeks to improve the social world by privileging oppressed peoples' voices rather than silencing or overlooking them (Mertens 2009).

Participants and data collection

CK and CB used their community links to identify key informants with knowledge of the community's health concerns. Key informants included members of community controlled or State-run organisations working in Inala to improve the health and/or social world of Aboriginal and Torres Strait Islander community members in Inala, and respected local Aboriginal and Torres Strait Islander elders. Purposeful sampling of key informants was designed to include a mix of both Aboriginal and Torres Strait Islander ethnicities, male and female genders, and a range of ages working in diverse organisations with an interest in the health and well-being of Aboriginal and Torres Strait Islander peoples in Inala. We aimed to interview sufficient key informants to achieve data saturation such that we could be reasonably confident that the inclusion of additional key informants was unlikely to produce new themes (Guest *et al.* 2006).

Between February and June 2013, CK contacted potential participants by telephone, text, or in person. GS, a non-Indigenous medical doctor who has worked at the IIHS for over ten years conducted face-to-face semi-structured interviews with consenting participants as part of his doctoral research. Care was taken to not replicate the power structures of a medical consultation by conducting interviews away from the clinical setting. Depending on participant preference, interviews were conducted in the participants' workplace, the non-clinical sectors of the IIHS, and in one case in the participant's home. An interview guide and one page summary of health categories contained in HAs for children, adults, people with diabetes, and pregnant women was used to facilitate discussion regarding the role of HAs, and key informants' health priorities for research using HA information. Consistent with semi-structured interview methods, some participants used the interview guide to prompt their thinking, and others spoke about their health priorities without reference to the guide. Interviews lasted between 30 minutes and two hours, were audiotaped, transcribed, and interview notes were taken. Interviewees received $A25 gift vouchers for participating.

Analysis

Transcribed interview data were uploaded to NVivo 9 (QSR International, Melbourne, Victoria) software which was used to assist data management. One investigator (GS) used thematic analysis (Braun and Clarke 2006) to code and categorise transcribed data and interview notes, and discussed the identification and development of themes with the other authors at regular meetings. The broad categories of health priorities based on HA information and attitudes to HAs were anticipated *a priori*. Our interpretation of the data was fed back to key informants and other community members at informal meetings, by telephone, at a community seminar, and to the Inala Community Jury for Aboriginal and Torres Strait Islander Health Research (ICJ) (Bond *et al.* 2016). Community members' responses, comments, and questions at these feedback sessions supported our interpretation of interview responses.

Ethics approval and community oversight

The study was supported by the ICJ and approved by the Queensland Health Metro South Human Research Ethics Committee at the Princess Alexandra Hospital and the University of Queensland's Behavioural and Social Sciences Ethical Review Committee. All participants provided written informed consent prior to being interviewed. All quotes were attributed to pseudonyms and care was taken to avoid identification of participants.

Results

Twelve men and nine women took part in the interviews, with a range of ages (Table 1). No-one who was approached to be interviewed declined. After 21 interviews, we felt data saturation had been achieved. The task of identifying a list of discrete health research priorities from the HAs was not achieved. Rather, deeper understandings of health and illness beyond HA content were elicited from participants. The three central themes that emerged included: (1) *Complex, inter-related, intergenerational* *nature of health involving social, cultural, and environmental determinants of health (SCEDH)*; (2) *Ambivalence to HAs; and* (3) *Community strength*

Complex, inter-related, intergenerational nature of health involving SCEDH. Male and female key informants of all ages, demonstrated an authoritative understanding, consistent with their lived experience, of the complex cycle of interrelated SCEDH interacting in their community. For example, Lily was unreserved about the positive health consequences of employment for members of her family and community.

> *"You give a man a job, he can afford housing, he will no doubt want to look after himself, and he then changes himself as a role model for his children. The health in that is massive. Massive." – Lily*

Employment was just one important SCEDH operating in an interrelated cycle, circle or chain to influence health. Key informants described how family breakdown led to children moving in with their cousins, sharing rooms, and the resultant household crowding was associated with stress, conflict over resources, and physical health problems. Mia was worried about how children's schooling would be affected when family breakdown led one family to move in with relatives.

> *"They mightn't get enough sleep 'cause they're not sleeping in their own house. The family don't have their own family routine, so it effects the school work…" - Mia*

In adolescence, key informants also spoke of how peer influences, and negative social media experiences frequently combined to impede young people's educational potential. Grace described the resulting hopelessness and intergenerational nature of "the cycle."

> *"…you just see it, all these young kids going to little parties and drinking on weekend… they start missing school, they fall behind, they don't finish high school, they don't have the qualifications to get a job…So they turn to crime, and then drugs…and their kids are going to do the same because they don't have somebody to look up to. So that's the cycle." – Grace*

In addition to educational and employment difficulties, participants of male and female genders and all ages described disempowering and traumatic experiences of institutional racism in their interactions with social services and the police.

> *"I've been pulled over [by police] and spoken to like I'm nothing, I think that impacts especially on young people..." – Noah*

In this environment of institutional racism, the mental health consequences for young people leaving high school without a qualification or employment were bleak. *Many key informants were concerned that mental health issues were undiagnosed in the community, and that this untreated burden of depression would lead to unexpected suicide with devastating, community-wide effects.*

> *"If I had to put one at the top of the list, it would have to be mental health because it's really a silent killer." – Steven*

The resulting grief from premature death and especially suicide was seen as a huge issue for the community. This concern was more likely to be expressed by female key informants.

> *"Well, I just see the end result of people who have lost somebody close and how it impacts their work, how it impacts them socially…and often people in the community forget about the young ones that have lost their auntie, uncle..." – Lily*

Female key informants were also more likely than males to suggest that more support was required to assist community members navigate challenging elements of the cycle like grief, single parenthood, unemployment, and household crowding.

Ambivalence towards HAs.

Most key informants had had a HA with only two saying they had never had one. Key informants' experience of Aboriginal and Torres Strait Islander HAs were mixed as four key informants gave unqualified support for the capacity of HAs to detect medical problems early.

"I think the health checks are really important for Aboriginal and Torres Strait Islander people…because some people feel shame to go to the doctor, and if they leave it too long there could be a problem building in their body." -Liam

However, a similar number of mostly younger key informants commented on the time consuming nature of HAs. Another key informant was concerned about the centrality of chronic disease risk factors and illness in HAs, and suggested that the health service could engage better with SCEDH. In the context of a discussion about the impact of confidence and SCEDH, Edward felt that HA content was superficial, and did not get to the heart of peoples' health problems.

> *"I'm not sure whether it paints a really honest picture of exactly where my health's at...I think that [it] probably can go a bit more in depth."* – *Edward*

Participants' responses suggested that their view of health and the social world was not adequately covered by HAs which measured health in a compartmentalised, disease focused way. For example, Bradley felt doctors and HAs were unlikely to help with his past concerns about identity, a social issue central to his health.

> *"I don't see how a doctor is going to solve an identity crisis. It's a social thing…"* – *Bradley*

Community strength

The personal stories told by participants were all ones of strength as they continued to navigate the challenges of "the cycle" to take on meaningful, important roles within the Inala Aboriginal and Torres Strait Islander community. Participants described how their health depended on the support of parents, family members, and positive peer groups. After describing the negative features of "the cycle" for high school students, Grace talked about how family support had been a crucial element for the group of students in her year who had graduated.

> *"We weren't rich, we weren't really wealthy, we were average … but I had that support from my family as well… that's why we graduated."* – *Grace*

Not only was support crucial at home and in the family, participants expressed positivity about the connectedness and cultural richness of the Inala Aboriginal and Torres Strait Islander community.

> *"There was something strong about the community that I think was a protective factor."* – *Olivia*

The IIHS was also seen as an important component of the community's well-being and self-esteem. Positive comments about the IIHS made by participants may have been more likely because the interviewer was a well-known doctor at this service.

However, the health service was clearly an important, trusted part of participants' lives in the community.

> *"They care. [The IIHS] is one of the best organisations I've been around… I love the treatment they give you."* - Gregory

Discussion

Key informants gave confident, authoritative accounts of the centrality of SCEDH to the health of the community. These accounts were consistent with the holistic Aboriginal definition of health which is not merely the provision of doctors or absence of disease, but involves all aspects of life including grief and loss, a sense of hopelessness, and being caught in the cycle of SCEDH (National Aboriginal Health Strategy Working Party 1989). Other studies involving interviews with Aboriginal peoples also found SCEDH were central to health including the historical legacy of colonisation, experiences of racism, and reduced socio-economic opportunities (Priest *et al.* 2012, Waterworth *et al.* 2016).

The "cycle" articulated by key informants in this study has similarities with the life course theory of social determinants, whereby stressors accumulate across the life course at critical, vulnerable, life transitions (Blane 2006). Adverse experiences in childhood, such as socioeconomic deprivation, are associated with a number of health problems in adulthood including ischaemic heart disease, depression, substance use, diabetes, and premature death (Finch and Crimmins 2004, Power *et al.* 2013). For Aboriginal and Torres Strait Islander peoples, the life course and "the cycle" are negatively influenced by ongoing colonisation and institutional racism (Carson *et al.* 2007).

Key informants' ambivalence towards HAs implies a disjunction between the risk factor and disease emphasis of HAs and the complex cycle of interrelated SCEDH lived by key informants. This disjunction suggests limitations for policies informed by the biomedical model of health especially given current strategies are failing to meet their targets for health outcomes for Aboriginal and Torres Strait Islander peoples

(Australian Government 2016). For researchers, in addition to an inadequate quantity of health research addressing the health needs of Aboriginal and Torres Strait Islander peoples in urban areas (Eades *et al.* 2010), this disjunction suggests that research needs to have a greater emphasis on the SCEDH reflecting key informant priorities.

While participant concerns were largely situated in a social and policy world which some may argue is beyond the scope of primary health care, this sector can play an important role in addressing social determinants of health (Baum *et al.* 2013). At the IIHS, this research has supported inclusion of additional questions regarding SCEDH in HAs, consistent with the principles of comprehensive primary health care articulated by the declaration of Alma-Ata (World Health Organization 1978). One of the authors of this paper, CB, an Aboriginal community member, suggested the addition of these questions prior to the conduct of the interviews described here, but these questions did not form part of HAs at the IIHS until after the interviews had been concluded. The additional questions regarding SCEDH are likely to better identify patient health concerns, reinforce the importance of multi-disciplinary comprehensive primary health care which includes social workers and community-based health promotion, and prompt referral to appropriate community resources which has been found to improve social and emotional wellbeing (Grant *et al.* 2000).Better understandings of community priorities from this community consultation research together with the additional questions regarding SCEDH in HAs have contributed to conversations within the IIHS about how the service can better address SCEDH experienced by our patients, strengthen clinical referrals to the IIHS community team, and work more closely with local community-based organisations.

The involvement of Aboriginal community members (CK and CB) ensured a wide variety of Inala community key informants with varying perspectives were interviewed, and no-one declined an interview. However, critical theorists would argue that this study would have produced different results with an Aboriginal and/or Torres Strait Islander researcher conducting the interviews, data coding, and community feedback (Mathison 1997). The study findings may also have been different had there been an unstructured discussion of health and research priorities, rather than structuring the interviews around HA content. However, the positive reception at community feedback sessions suggests concordance between our findings and key informants' beliefs and opinions.

Conclusions

While HAs have a role in individual, preventive health, they may be less useful in responding to the complex, interrelated SCEDH important to key community informants' conception of health. Future HA-based IIHS research needs to value the community's authoritative knowledge regarding the importance of SCEDH, and recognise the limitations of biomedical and investigator-driven research. The importance of a holistic conception of health including SCEDH is not limited to Aboriginal and Torres Strait Islander peoples in Inala. By conducting a computerised HA which includes more questions about SCEDH, clinicians in a wide range of primary health care settings are more likely to have conversations with their Aboriginal and Torres Strait Islander patients which are relevant to their patients' conception of health. In turn, these conversations are likely to lead to the management plan and referrals required to help resolve patient health concerns. These findings also represent a challenge for policy makers to meaningfully address SCEDH as part of a health system which purports to meet the health needs of Aboriginal and Torres Strait Islander peoples, but continues to prioritise biomedical models of health and health care.

Competing interests

The first author, GS, conducted this study as part of his doctoral research.

Tables

Table 1 Characteristics of Aboriginal and Torres Strait Islander community stakeholders (N=21)

Characteristic	Participants	(%)
Ethnicity		
Aboriginal	16	(76)
Torres Strait Islander	5	(24)
Female	12	(57)
Age group (years)		
<30	5	(23)
30-49	9	(43)
50+	7	(33)
Employed by:		
Community controlled organisation	6	(29)
Other community-based organisation	3	(14)
Inala Indigenous Health Service	4	(19)
Other state-run organisation	3	(14)
Elders	5	(24)

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Appendix 6 Community consultation: health assessment issues and interview schedule

Issues covered by health checks

Who?	Issues for this group	Preventing problems	Social issues	Health behaviours	Illnesses and Conditions	Referrals
Child Health Check	Stressful Events Breastfeeding Development - growth - social - language Ear Health Skin Health Behaviour problems Learning problems	Immunisations Accidents and Injuries	Unemployment Education Single parent Housing Crowding Domestic Violence Depression - Family - Conflict - Anxiety - relationship problems	Smoking Drug and alcohol use Physical Activity Nutrition	Teeth Mental Health Overweight and Obesity	Dental Psychologist Social worker Dietician Optometrist Medical Specialists
Adult Health Check	Diabetes prevention Hepatitis C	Pap smears Mammograms Looking for diabetes Vision and hearing Sexual health screening Reducing heart attacks - Cholesterol - Blood pressure				
Antenatal Health Check	Preterm birth	Folic acid tablets (reduces spina bifida) Iron tablets (reduces anaemia)				
Diabetes Health Check	Sugar control	Eye disease Foot risks Kidney health				

Interview Guide

Checklist

Note book, pen, voice recorder, consent forms, gift card, iphone

Before

Discuss interest in the research
Offer Interview schedule to peruse
Ask if recording is ok
Offer PICF to read and sign consent form

Explanatory Statements regarding the health checks:

The child and adult health checks are offered each year to Aboriginal and Torres Strait Islander children and adults attending the Inala Indigenous Health Service. They are meant to cover all the important health issues, pick up problems early and give the doctors and nurses a chance to provide advice and make changes to improve health.

The antenatal check is started on all women who present to the Inala Indigenous Health Service with a pregnancy. The check is added to each time the woman comes in and is meant to help nurses and doctors provide the best possible care for women through their pregnancy. It is finished at the women's first visit after delivery.

The diabetes health check is offered to everyone attending the Inala Indigenous Health Service who has diabetes each year. It is meant to pick up problems early and help the doctors and nurses care for people with diabetes.

One thing research can do is to tell us whether there are relationships between the issues in this table

As examples:

- we have already found that one of the most important relationships with ear problems is crowding at home.
- we have also found that referral to a paediatrician is related to the mental health of the mother, child snoring and crowding at home
- we have found that people feel better about their health if they are employed, not overweight and not depressed.

Research might also tell us how big an issue is, more about an issue or if the issue is getting better or worse. This can help us know what to do about it.

- For example, research into eye disease for diabetes helped us get a special eye camera and helped us make the case to get an eye specialist to visit the clinic.

This interview is to try and help us at the Inala Indigenous Health Service work out what we should be focussing our research on. We want to know what you think are the important areas for us to look at.

Record

This is interview CC **x** , taking place at **y** on **date**.

1. Have you ever had a health check? When thinking about the health checks it might be helpful to take yourself back to when you last had a health check-up. What were some of the issues that you thought were important?

   How were they important?
      i. For each issue:
         1. Tell me about what makes that an important issue
         2. How is it important to you, your family, the community?
         3. What more would be good to know about that issue?

2. Thinking about the health checks another way, what parts of the health checks are important from the point of view of:
   a. The community?
      i. For each issue:
         1. Tell me about what makes that an important issue
         2. What more would be good to know about that issue?
   b. As a family member?
      i. For each issue:
         1. Tell me about what makes that an important issue
         2. What more would be good to know about that issue?
   c. In your work?
      i. For each issue:
         1. Tell me about what makes that an important issue
         2. What more would be good to know about that issue?

3. Looking through all the things in the table, what jumps out at you as things you want to talk about?
   a. For each issue:
      i. Tell me about what makes that an important issue
      ii. How is it important to you, your family, the community?
      iii. What more would be good to know about that issue?

4. If you had to pick your top three issues from this table what would they be?

5. Are there issues that you can think of that we are not asking about but you think we should be in the health check?

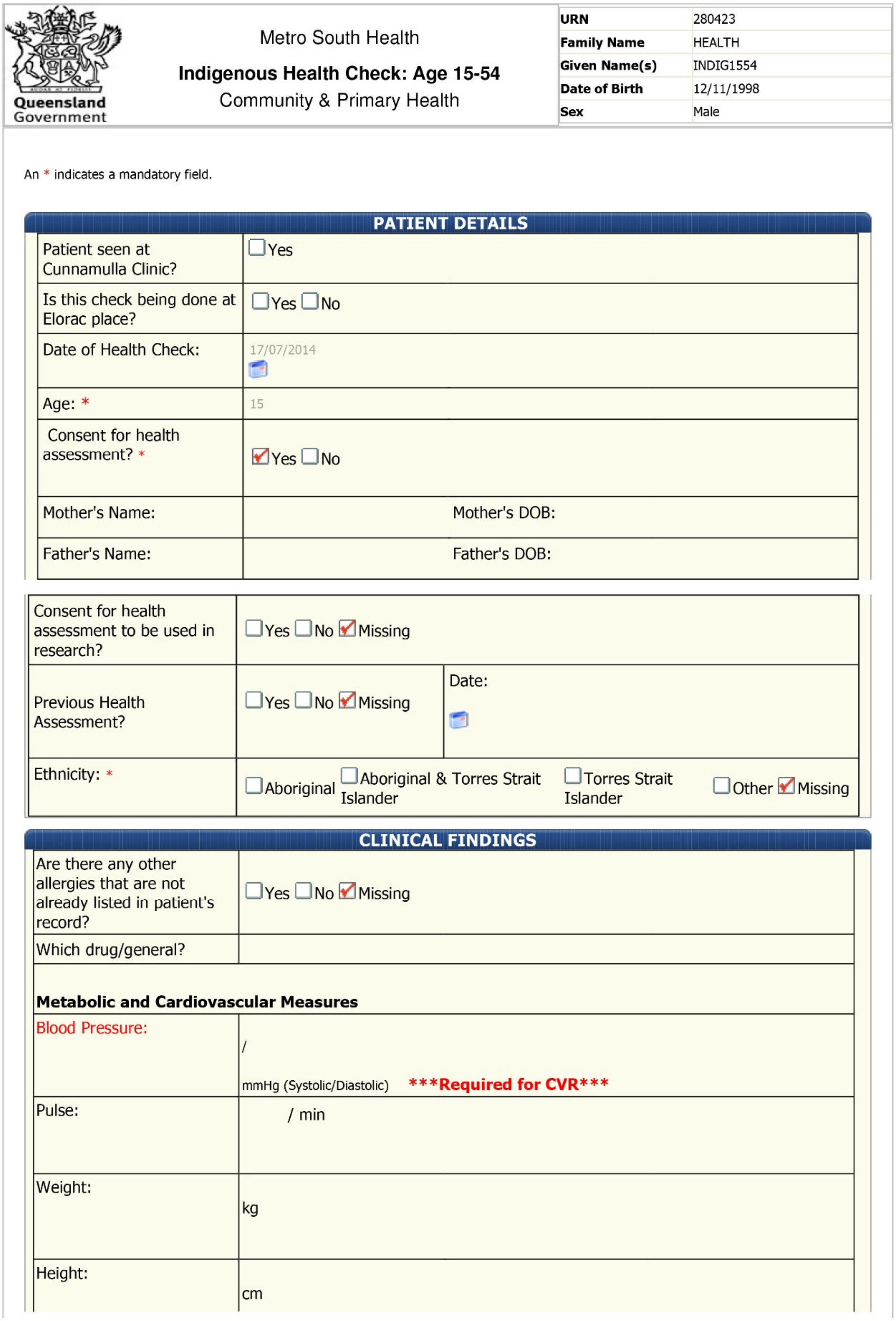
6. Do you identify as Aboriginal or Torres Strait Islander or both?

   Age
   Male/ Female
   How would you describe your job / role in the community in Inala?

7. Is there anything else that you would like to say about health checks or topics? Anything else that you wanted to add to what we have talked about?

STOP RECORDING

Appendix 7 The 15-54 year computerised adult HA template introduced in 2014, and used for the research described in Chapter 8



Queensland Government

Metro South Health

Indigenous Health Check: Age 15-54

Community & Primary Health

URN	280423
Family Name	HEALTH
Given Name(s)	INDIG1554
Date of Birth	12/11/1998
Sex	Male

An * indicates a mandatory field.

PATIENT DETAILS

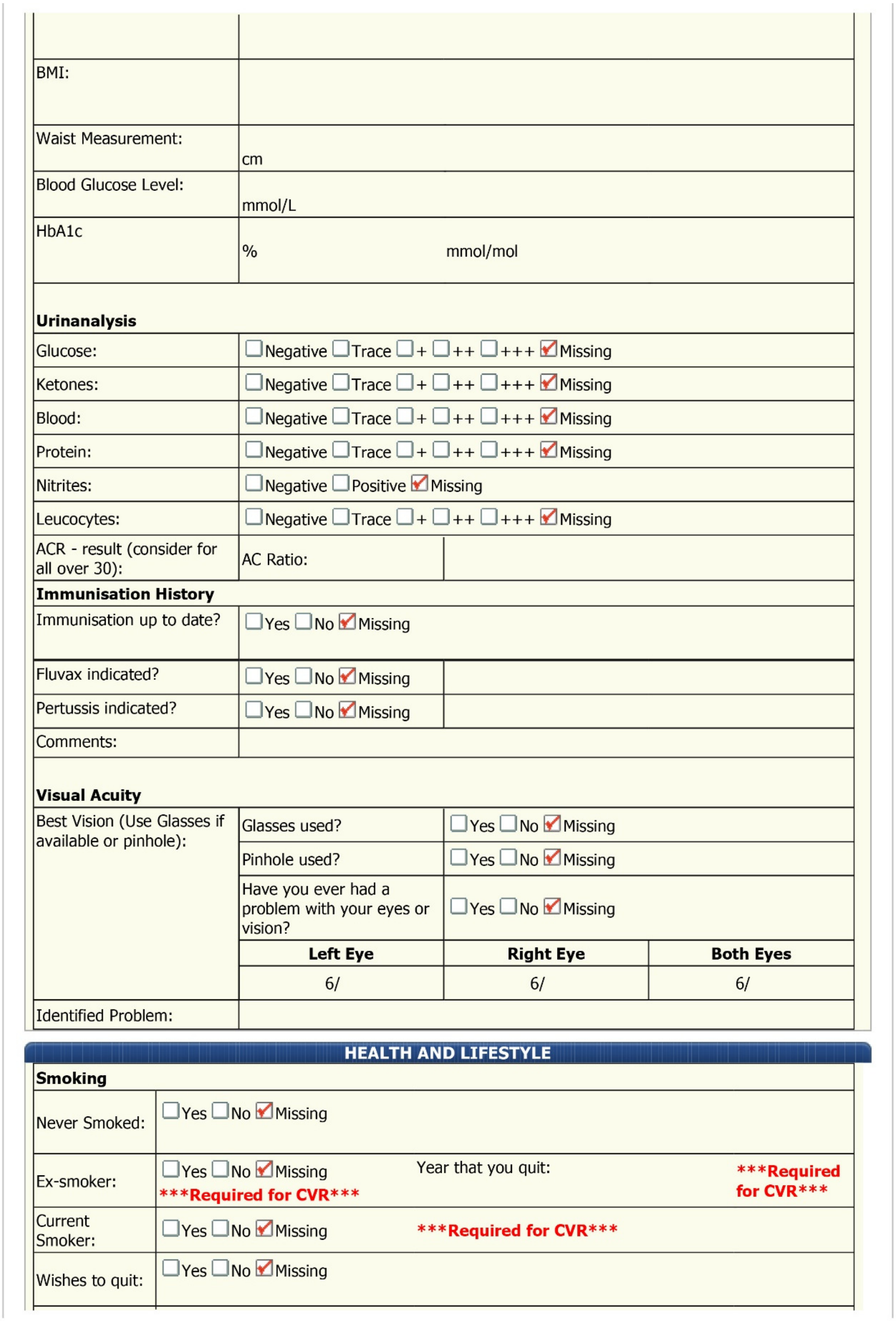
Patient seen at Cunnamulla Clinic?	☐ Yes		
Is this check being done at Elorac place?	☐ Yes ☐ No		
Date of Health Check:	17/07/2014		
Age: *	15		
Consent for health assessment? *	☑ Yes ☐ No		
Mother's Name:		Mother's DOB:	
Father's Name:		Father's DOB:	

Consent for health assessment to be used in research?	☐ Yes ☐ No ☑ Missing	
Previous Health Assessment?	☐ Yes ☐ No ☑ Missing	Date:
Ethnicity: *	☐ Aboriginal ☐ Aboriginal & Torres Strait Islander ☐ Torres Strait Islander ☐ Other ☑ Missing	

CLINICAL FINDINGS

Are there any other allergies that are not already listed in patient's record?	☐ Yes ☐ No ☑ Missing
Which drug/general?	
Metabolic and Cardiovascular Measures	
Blood Pressure:	/ mmHg (Systolic/Diastolic) *****Required for CVR*****
Pulse:	/ min
Weight:	kg
Height:	cm

Page 1 of 11 printed from ERIC - Not for scanning

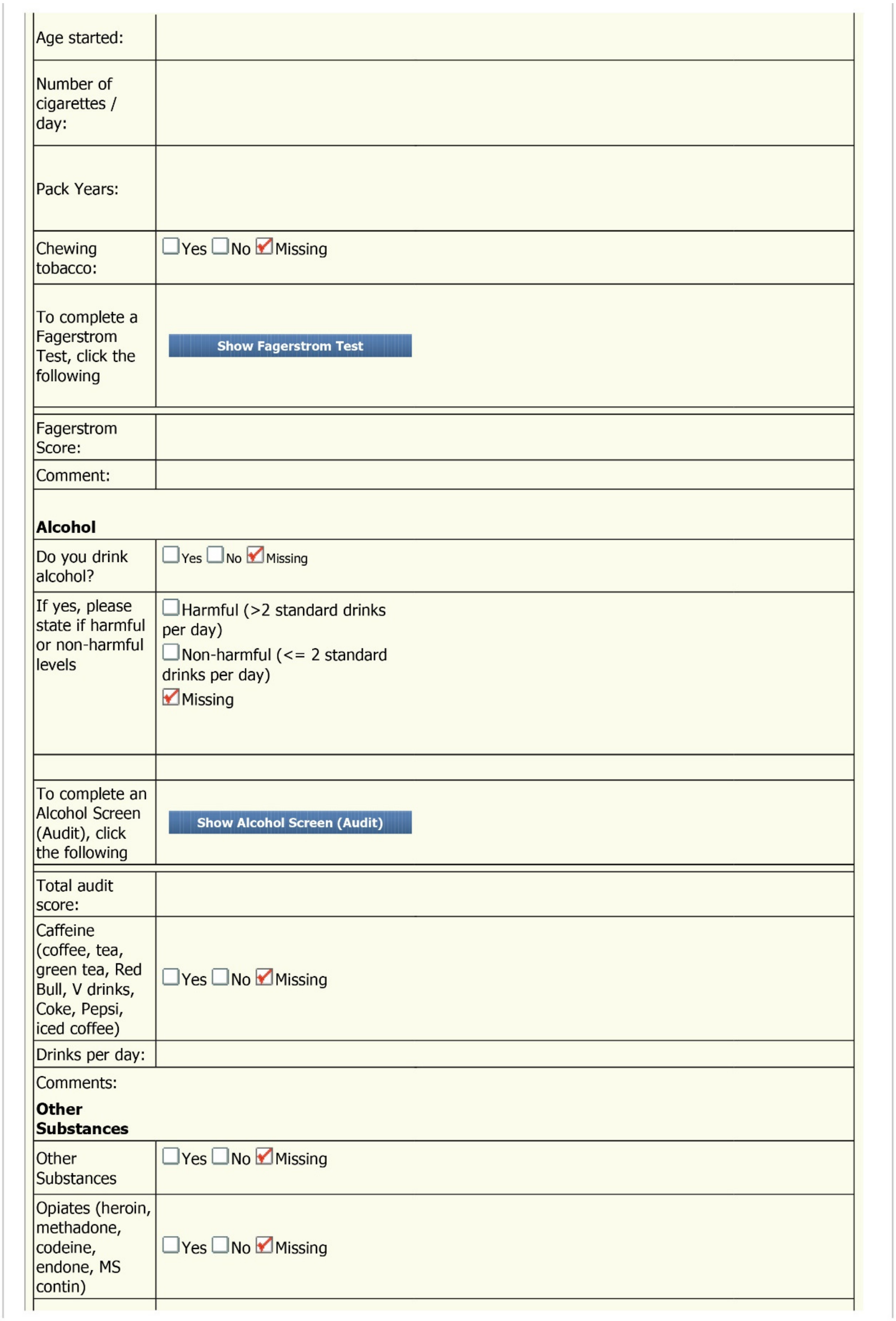


BMI:			
Waist Measurement:	cm		
Blood Glucose Level:	mmol/L		
HbA1c	%	mmol/mol	
Urinanalysis			
Glucose:	☐Negative ☐Trace ☐+ ☐++ ☐+++ ☑Missing		
Ketones:	☐Negative ☐Trace ☐+ ☐++ ☐+++ ☑Missing		
Blood:	☐Negative ☐Trace ☐+ ☐++ ☐+++ ☑Missing		
Protein:	☐Negative ☐Trace ☐+ ☐++ ☐+++ ☑Missing		
Nitrites:	☐Negative ☐Positive ☑Missing		
Leucocytes:	☐Negative ☐Trace ☐+ ☐++ ☐+++ ☑Missing		
ACR - result (consider for all over 30):	AC Ratio:		
Immunisation History			
Immunisation up to date?	☐Yes ☐No ☑Missing		
Fluvax indicated?	☐Yes ☐No ☑Missing		
Pertussis indicated?	☐Yes ☐No ☑Missing		
Comments:			
Visual Acuity			
Best Vision (Use Glasses if available or pinhole):	Glasses used?	☐Yes ☐No ☑Missing	
	Pinhole used?	☐Yes ☐No ☑Missing	
	Have you ever had a problem with your eyes or vision?	☐Yes ☐No ☑Missing	
	Left Eye	**Right Eye**	**Both Eyes**
	6/	6/	6/
Identified Problem:			

HEALTH AND LIFESTYLE

Smoking			
Never Smoked:	☐Yes ☐No ☑Missing		
Ex-smoker:	☐Yes ☐No ☑Missing ***Required for CVR***	Year that you quit:	***Required for CVR***
Current Smoker:	☐Yes ☐No ☑Missing	***Required for CVR***	
Wishes to quit:	☐Yes ☐No ☑Missing		

Page 2 of 11 printed from ERIC - Not for scanning



Age started:	
Number of cigarettes / day:	
Pack Years:	
Chewing tobacco:	☐Yes ☐No ☑Missing
To complete a Fagerstrom Test, click the following	Show Fagerstrom Test
Fagerstrom Score:	
Comment:	
Alcohol	
Do you drink alcohol?	☐Yes ☐No ☑Missing
If yes, please state if harmful or non-harmful levels	☐Harmful (>2 standard drinks per day) ☐Non-harmful (<= 2 standard drinks per day) ☑Missing
To complete an Alcohol Screen (Audit), click the following	Show Alcohol Screen (Audit)
Total audit score:	
Caffeine (coffee, tea, green tea, Red Bull, V drinks, Coke, Pepsi, iced coffee)	☐Yes ☐No ☑Missing
Drinks per day:	
Comments: **Other Substances**	
Other Substances	☐Yes ☐No ☑Missing
Opiates (heroin, methadone, codeine, endone, MS contin)	☐Yes ☐No ☑Missing

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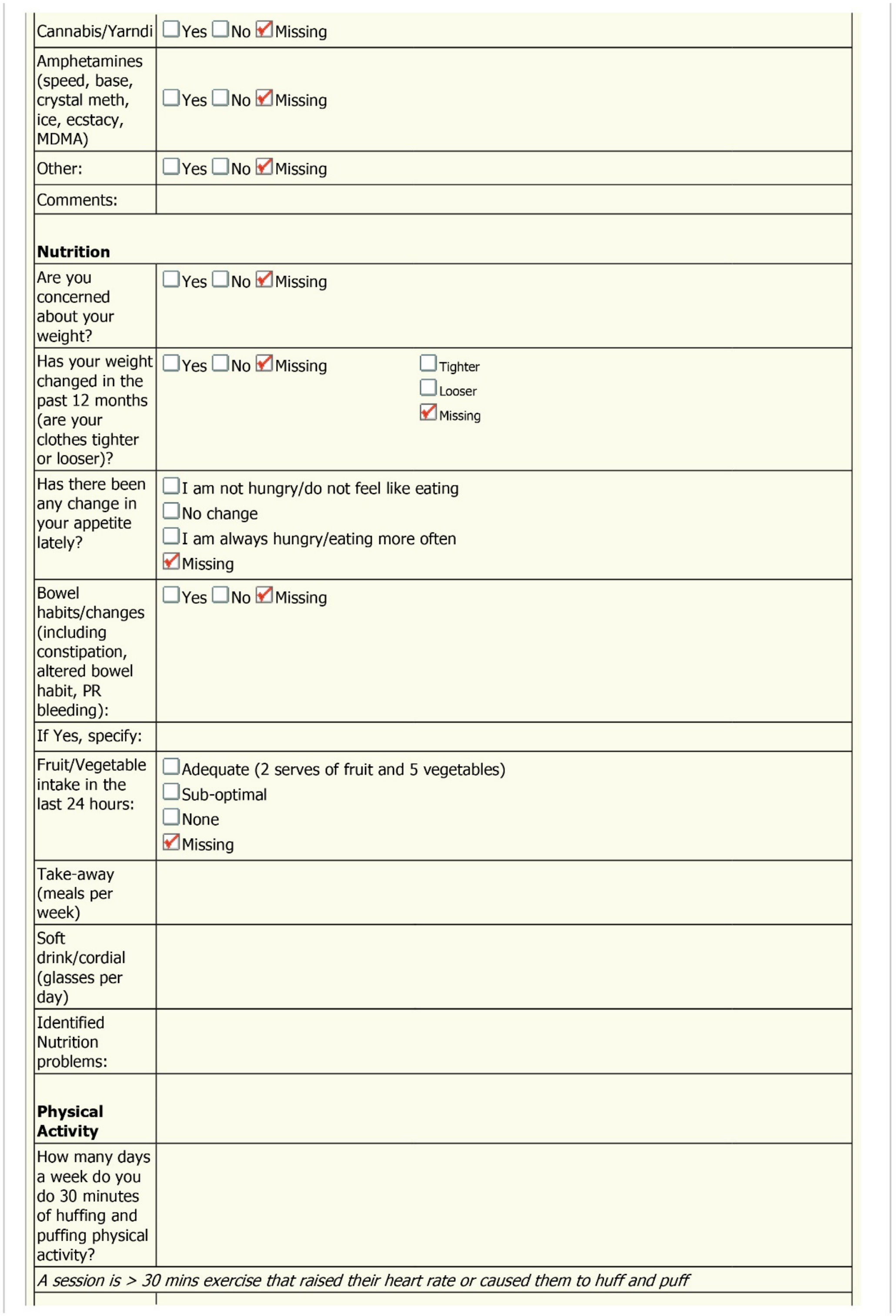
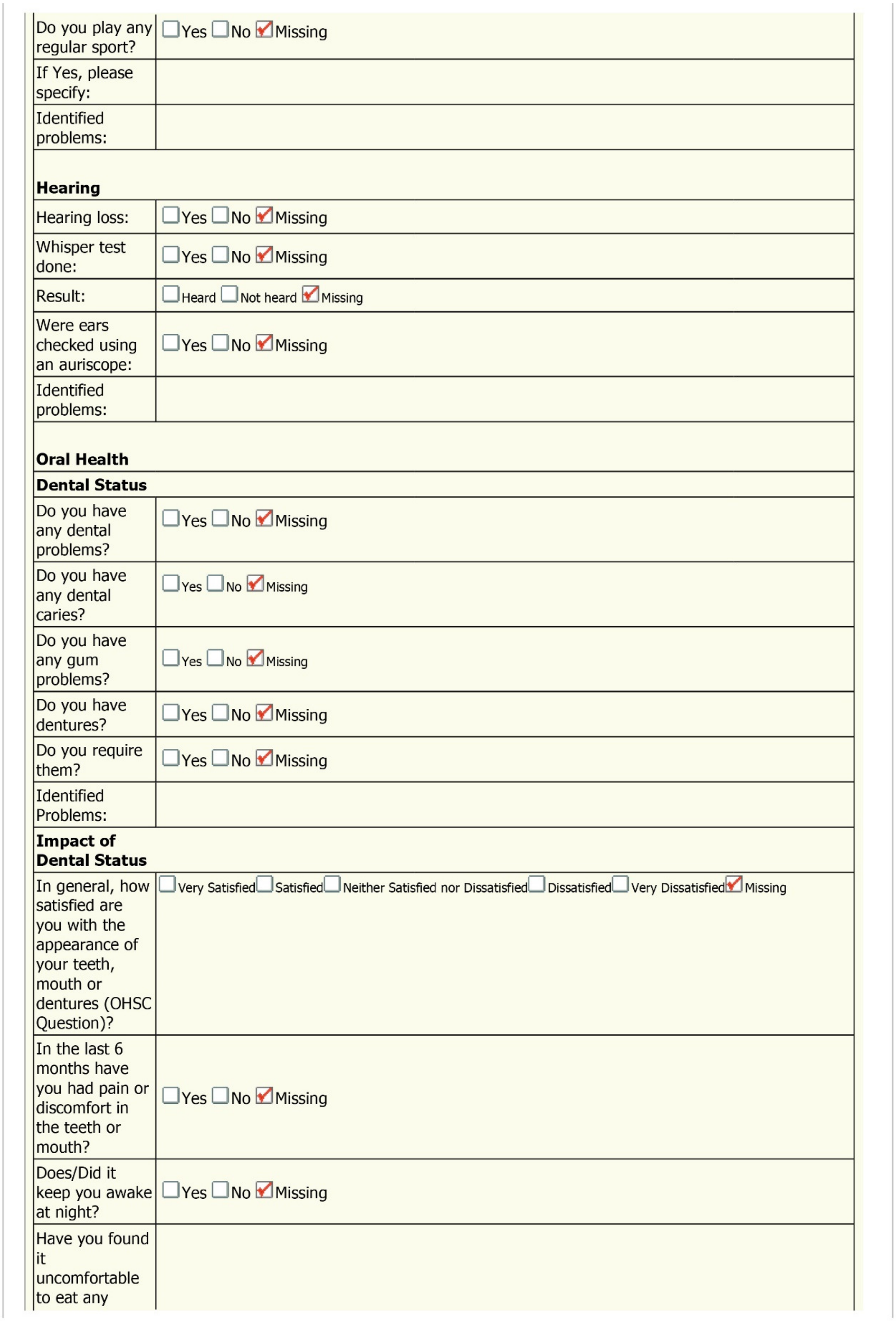
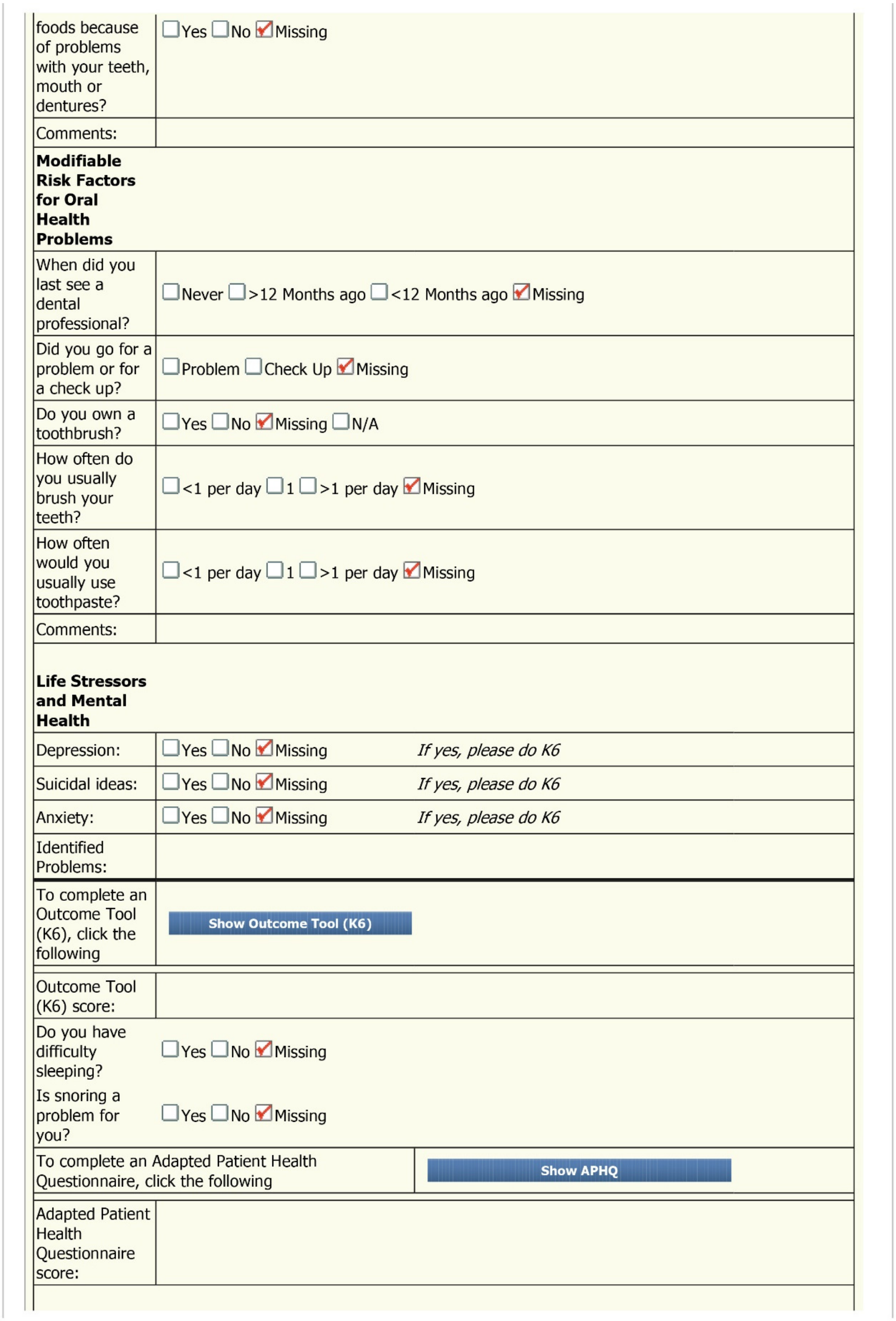


Cannabis/Yarndi	☐Yes ☐No ☑Missing
Amphetamines (speed, base, crystal meth, ice, ecstacy, MDMA)	☐Yes ☐No ☑Missing
Other:	☐Yes ☐No ☑Missing
Comments:	
Nutrition	
Are you concerned about your weight?	☐Yes ☐No ☑Missing
Has your weight changed in the past 12 months (are your clothes tighter or looser)?	☐Yes ☐No ☑Missing ☐Tighter ☐Looser ☑Missing
Has there been any change in your appetite lately?	☐I am not hungry/do not feel like eating ☐No change ☐I am always hungry/eating more often ☑Missing
Bowel habits/changes (including constipation, altered bowel habit, PR bleeding):	☐Yes ☐No ☑Missing
If Yes, specify:	
Fruit/Vegetable intake in the last 24 hours:	☐Adequate (2 serves of fruit and 5 vegetables) ☐Sub-optimal ☐None ☑Missing
Take-away (meals per week)	
Soft drink/cordial (glasses per day)	
Identified Nutrition problems:	
Physical Activity	
How many days a week do you do 30 minutes of huffing and puffing physical activity?	
A session is > 30 mins exercise that raised their heart rate or caused them to huff and puff	



Do you play any regular sport?	☐Yes ☐No ☑Missing
If Yes, please specify:	
Identified problems:	
Hearing	
Hearing loss:	☐Yes ☐No ☑Missing
Whisper test done:	☐Yes ☐No ☑Missing
Result:	☐Heard ☐Not heard ☑Missing
Were ears checked using an auriscope:	☐Yes ☐No ☑Missing
Identified problems:	
Oral Health	
Dental Status	
Do you have any dental problems?	☐Yes ☐No ☑Missing
Do you have any dental caries?	☐Yes ☐No ☑Missing
Do you have any gum problems?	☐Yes ☐No ☑Missing
Do you have dentures?	☐Yes ☐No ☑Missing
Do you require them?	☐Yes ☐No ☑Missing
Identified Problems:	
Impact of Dental Status	
In general, how satisfied are you with the appearance of your teeth, mouth or dentures (OHSC Question)?	☐Very Satisfied☐Satisfied☐Neither Satisfied nor Dissatisfied☐Dissatisfied☐Very Dissatisfied☑Missing
In the last 6 months have you had pain or discomfort in the teeth or mouth?	☐Yes ☐No ☑Missing
Does/Did it keep you awake at night?	☐Yes ☐No ☑Missing
Have you found it uncomfortable to eat any	



foods because of problems with your teeth, mouth or dentures?	☐Yes ☐No ☑Missing	
Comments:		
Modifiable Risk Factors for Oral Health Problems		
When did you last see a dental professional?	☐Never ☐>12 Months ago ☐<12 Months ago ☑Missing	
Did you go for a problem or for a check up?	☐Problem ☐Check Up ☑Missing	
Do you own a toothbrush?	☐Yes ☐No ☑Missing ☐N/A	
How often do you usually brush your teeth?	☐<1 per day ☐1 ☐>1 per day ☑Missing	
How often would you usually use toothpaste?	☐<1 per day ☐1 ☐>1 per day ☑Missing	
Comments:		
Life Stressors and Mental Health		
Depression:	☐Yes ☐No ☑Missing	*If yes, please do K6*
Suicidal ideas:	☐Yes ☐No ☑Missing	*If yes, please do K6*
Anxiety:	☐Yes ☐No ☑Missing	*If yes, please do K6*
Identified Problems:		
To complete an Outcome Tool (K6), click the following	Show Outcome Tool (K6)	
Outcome Tool (K6) score:		
Do you have difficulty sleeping?	☐Yes ☐No ☑Missing	
Is snoring a problem for you?	☐Yes ☐No ☑Missing	
To complete an Adapted Patient Health Questionnaire, click the following	Show APHQ	
Adapted Patient Health Questionnaire score:		

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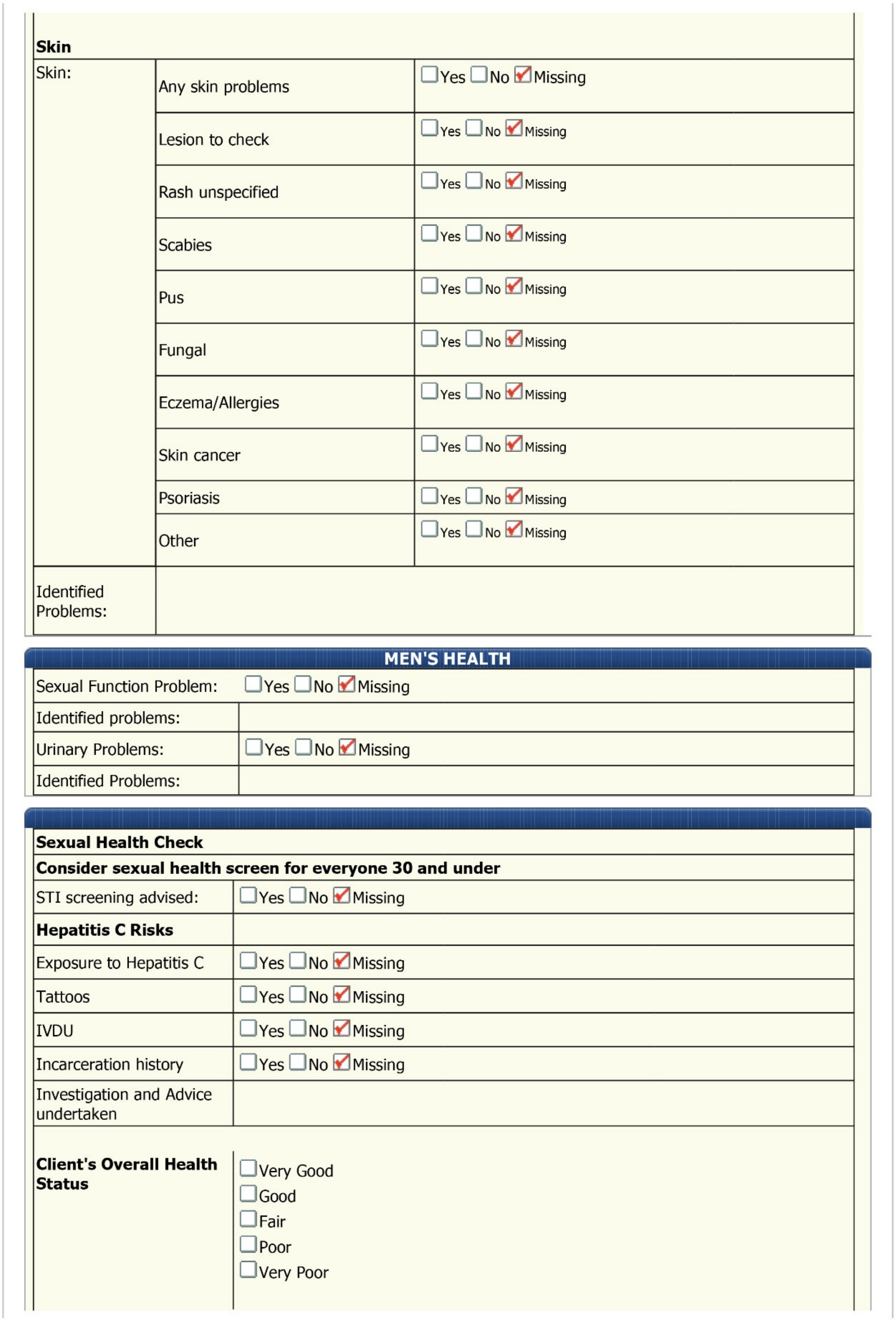
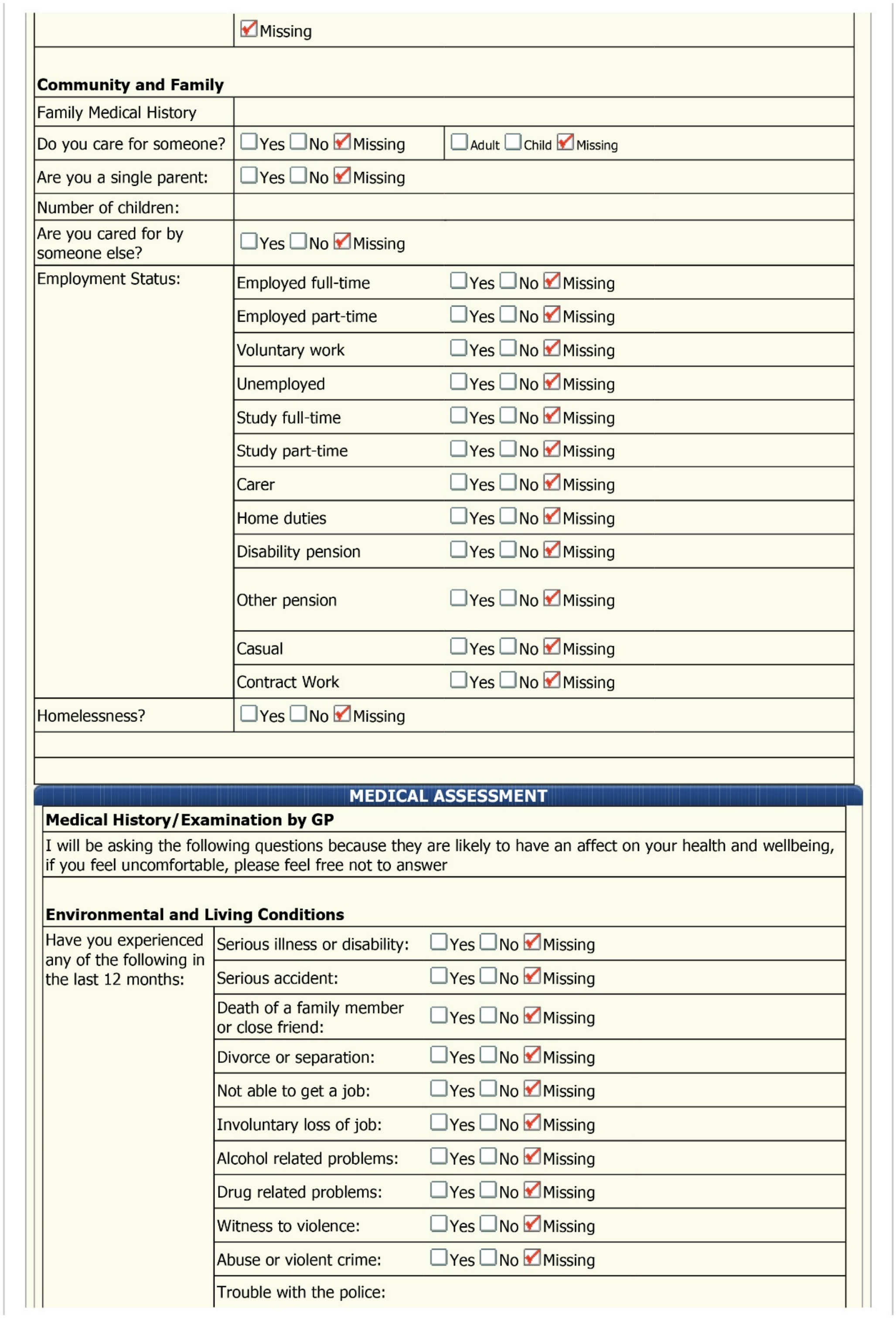


Skin		
Skin:	Any skin problems	☐Yes ☐No ☑Missing
	Lesion to check	☐Yes ☐No ☑Missing
	Rash unspecified	☐Yes ☐No ☑Missing
	Scabies	☐Yes ☐No ☑Missing
	Pus	☐Yes ☐No ☑Missing
	Fungal	☐Yes ☐No ☑Missing
	Eczema/Allergies	☐Yes ☐No ☑Missing
	Skin cancer	☐Yes ☐No ☑Missing
	Psoriasis	☐Yes ☐No ☑Missing
	Other	☐Yes ☐No ☑Missing
Identified Problems:		

MEN'S HEALTH

Sexual Function Problem:	☐Yes ☐No ☑Missing
Identified problems:	
Urinary Problems:	☐Yes ☐No ☑Missing
Identified Problems:	

Sexual Health Check	
Consider sexual health screen for everyone 30 and under	
STI screening advised:	☐Yes ☐No ☑Missing
Hepatitis C Risks	
Exposure to Hepatitis C	☐Yes ☐No ☑Missing
Tattoos	☐Yes ☐No ☑Missing
IVDU	☐Yes ☐No ☑Missing
Incarceration history	☐Yes ☐No ☑Missing
Investigation and Advice undertaken	
Client's Overall Health Status	☐Very Good ☐Good ☐Fair ☐Poor ☐Very Poor



	☑Missing

Community and Family

Family Medical History		
Do you care for someone?	☐Yes ☐No ☑Missing	☐Adult ☐Child ☑Missing
Are you a single parent:	☐Yes ☐No ☑Missing	
Number of children:		
Are you cared for by someone else?	☐Yes ☐No ☑Missing	
Employment Status:	Employed full-time	☐Yes ☐No ☑Missing
	Employed part-time	☐Yes ☐No ☑Missing
	Voluntary work	☐Yes ☐No ☑Missing
	Unemployed	☐Yes ☐No ☑Missing
	Study full-time	☐Yes ☐No ☑Missing
	Study part-time	☐Yes ☐No ☑Missing
	Carer	☐Yes ☐No ☑Missing
	Home duties	☐Yes ☐No ☑Missing
	Disability pension	☐Yes ☐No ☑Missing
	Other pension	☐Yes ☐No ☑Missing
	Casual	☐Yes ☐No ☑Missing
	Contract Work	☐Yes ☐No ☑Missing
Homelessness?	☐Yes ☐No ☑Missing	

MEDICAL ASSESSMENT

Medical History/Examination by GP

I will be asking the following questions because they are likely to have an affect on your health and wellbeing, if you feel uncomfortable, please feel free not to answer

Environmental and Living Conditions

Have you experienced any of the following in the last 12 months:	Serious illness or disability:	☐Yes ☐No ☑Missing
	Serious accident:	☐Yes ☐No ☑Missing
	Death of a family member or close friend:	☐Yes ☐No ☑Missing
	Divorce or separation:	☐Yes ☐No ☑Missing
	Not able to get a job:	☐Yes ☐No ☑Missing
	Involuntary loss of job:	☐Yes ☐No ☑Missing
	Alcohol related problems:	☐Yes ☐No ☑Missing
	Drug related problems:	☐Yes ☐No ☑Missing
	Witness to violence:	☐Yes ☐No ☑Missing
	Abuse or violent crime:	☐Yes ☐No ☑Missing
	Trouble with the police:	

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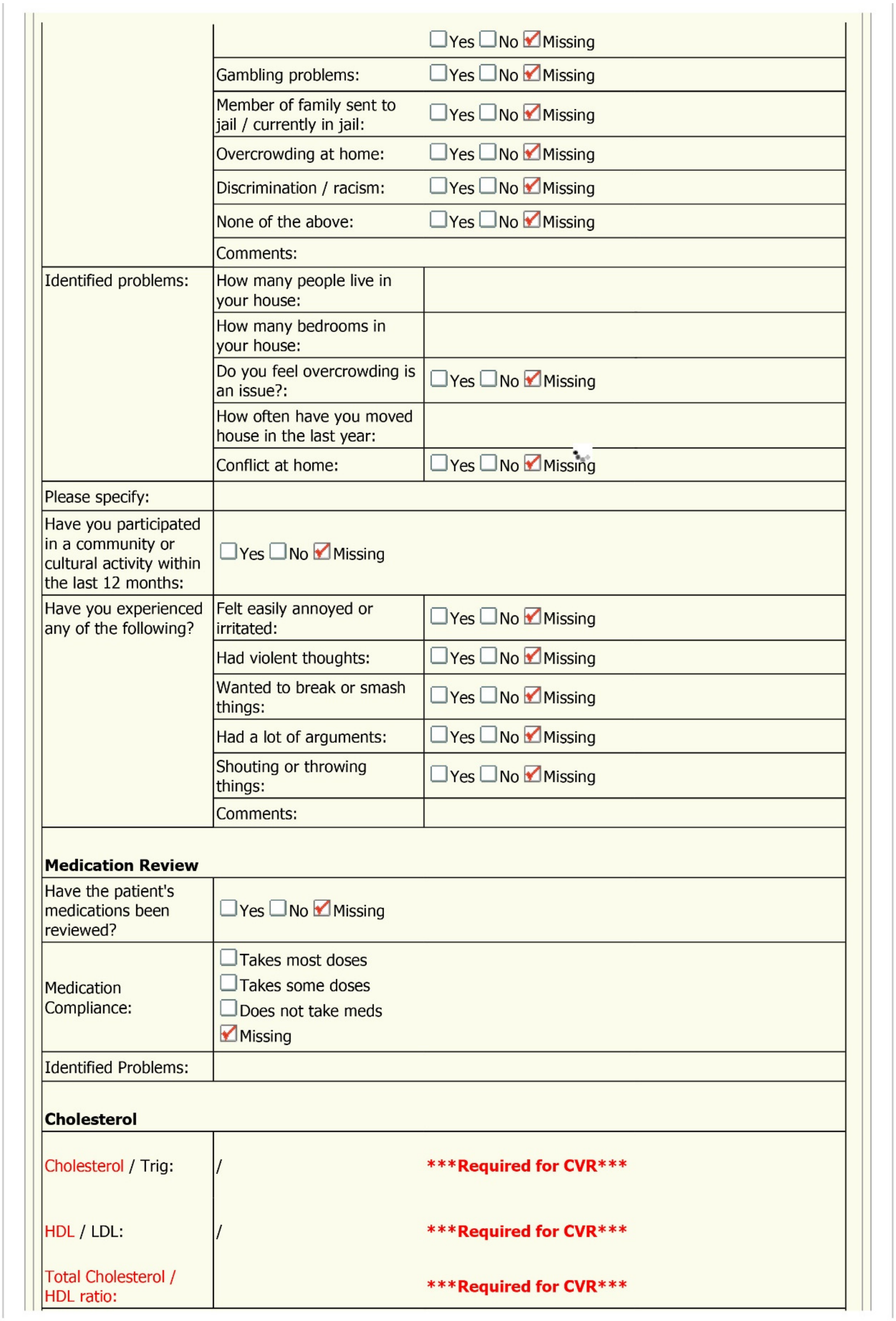

		☐Yes ☐No ☑Missing
	Gambling problems:	☐Yes ☐No ☑Missing
	Member of family sent to jail / currently in jail:	☐Yes ☐No ☑Missing
	Overcrowding at home:	☐Yes ☐No ☑Missing
	Discrimination / racism:	☐Yes ☐No ☑Missing
	None of the above:	☐Yes ☐No ☑Missing
	Comments:	
Identified problems:	How many people live in your house:	
	How many bedrooms in your house:	
	Do you feel overcrowding is an issue?:	☐Yes ☐No ☑Missing
	How often have you moved house in the last year:	
	Conflict at home:	☐Yes ☐No ☑Missing
Please specify:		
Have you participated in a community or cultural activity within the last 12 months:	☐Yes ☐No ☑Missing	
Have you experienced any of the following?	Felt easily annoyed or irritated:	☐Yes ☐No ☑Missing
	Had violent thoughts:	☐Yes ☐No ☑Missing
	Wanted to break or smash things:	☐Yes ☐No ☑Missing
	Had a lot of arguments:	☐Yes ☐No ☑Missing
	Shouting or throwing things:	☐Yes ☐No ☑Missing
	Comments:	
Medication Review		
Have the patient's medications been reviewed?	☐Yes ☐No ☑Missing	
Medication Compliance:	☐Takes most doses ☐Takes some doses ☐Does not take meds ☑Missing	
Identified Problems:		
Cholesterol		
Cholesterol / Trig:	/	*****Required for CVR*****
HDL / LDL:	/	*****Required for CVR*****
Total Cholesterol / HDL ratio:		*****Required for CVR*****

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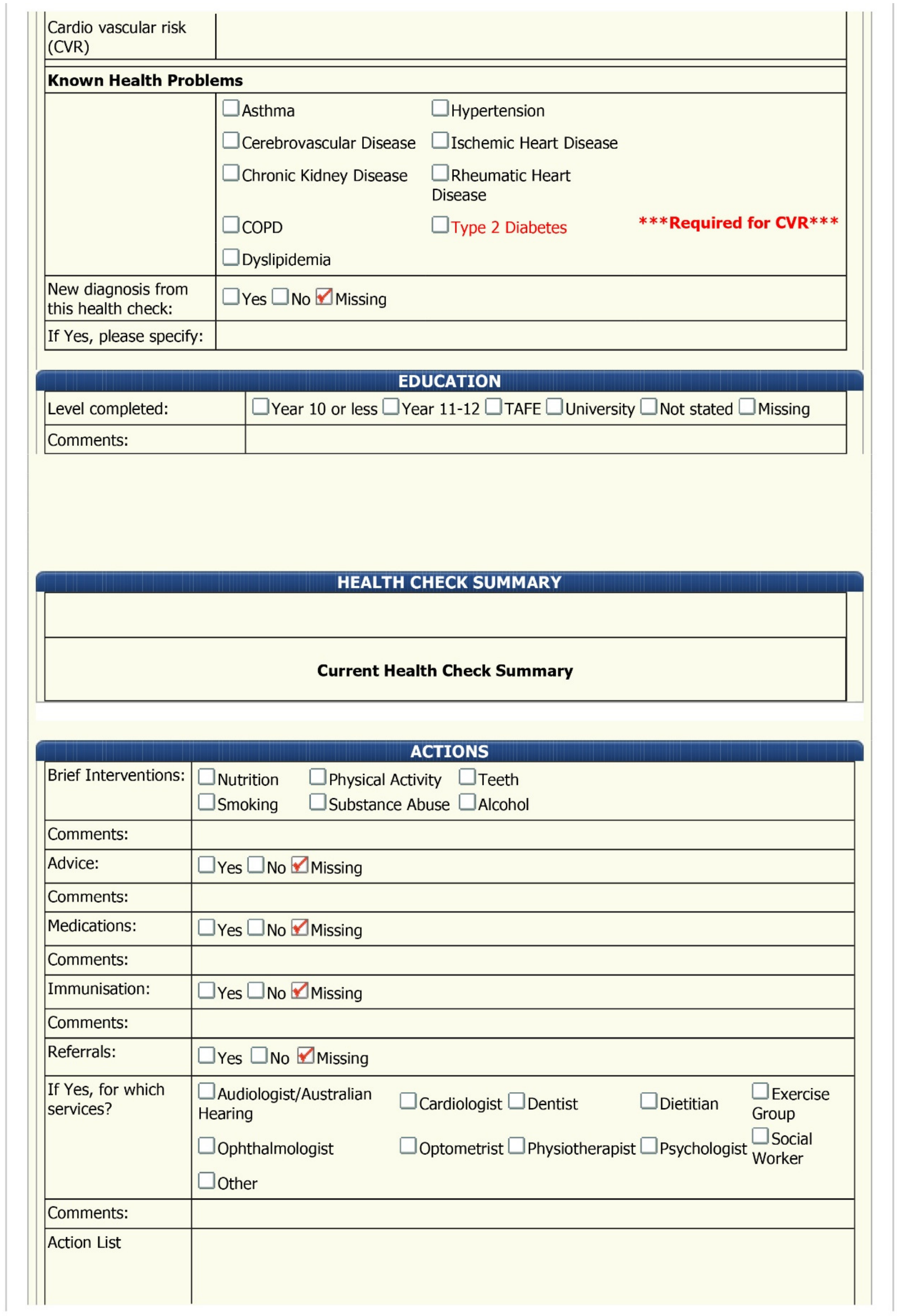

Cardio vascular risk (CVR)	

Known Health Problems

	☐Asthma ☐Hypertension ☐Cerebrovascular Disease ☐Ischemic Heart Disease ☐Chronic Kidney Disease ☐Rheumatic Heart Disease ☐COPD ☐Type 2 Diabetes *****Required for CVR***** ☐Dyslipidemia
New diagnosis from this health check:	☐Yes ☐No ☑Missing
If Yes, please specify:	

EDUCATION

Level completed:	☐Year 10 or less ☐Year 11-12 ☐TAFE ☐University ☐Not stated ☐Missing
Comments:	

HEALTH CHECK SUMMARY

Current Health Check Summary

ACTIONS

Brief Interventions:	☐Nutrition ☐Physical Activity ☐Teeth ☐Smoking ☐Substance Abuse ☐Alcohol
Comments:	
Advice:	☐Yes ☐No ☑Missing
Comments:	
Medications:	☐Yes ☐No ☑Missing
Comments:	
Immunisation:	☐Yes ☐No ☑Missing
Comments:	
Referrals:	☐Yes ☐No ☑Missing
If Yes, for which services?	☐Audiologist/Australian Hearing ☐Cardiologist ☐Dentist ☐Dietitian ☐Exercise Group ☐Ophthalmologist ☐Optometrist ☐Physiotherapist ☐Psychologist ☐Social Worker ☐Other
Comments:	
Action List	

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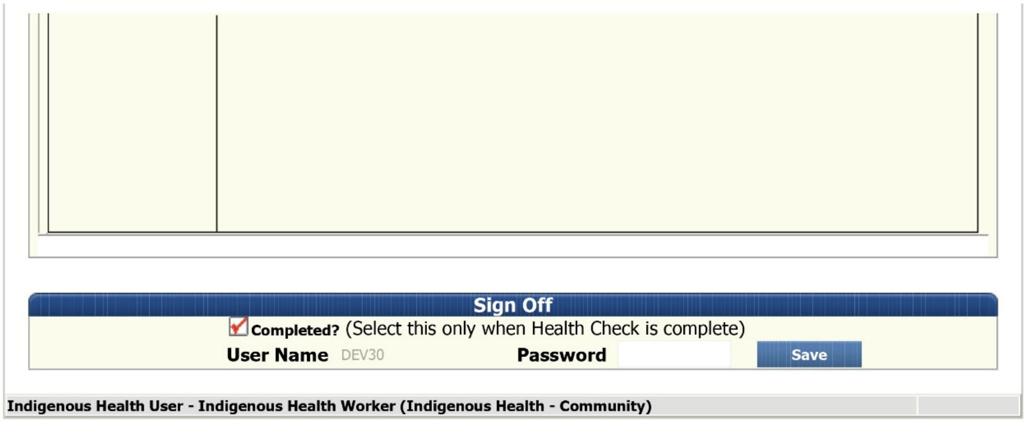

Sign Off

☑ **Completed?** (Select this only when Health Check is complete)

User Name DEV30 **Password**

Indigenous Health User - Indigenous Health Worker (Indigenous Health - Community)