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Building better primary care systems for Indigenous peoples: A multimethods analysis

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MBBS (hons), MIPH, FRACGP, FARGP

JULY 2010

This thesis is submitted in fulfilment of the requirements for the degree of Doctor of Philosophy, School of Public Health, Faculty of Medicine, University of Sydney
Declaration

This thesis is submitted to the University of Sydney in fulfilment of the requirement for the Doctor of Philosophy. The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

Signature: ................................................. Date: 21/4/11
Dedication

I dedicate this thesis to two inspirational systems builders who have now passed on, Alfred W. Dhamarrandji and Ian O'Rourke. With boundless vitality both worked over several decades to provide better systems of care. I have thought of them often this last three years.
Author’s contribution

The work presented in this thesis has been carried out by the author under the supervision of Professor Alan Cass, The George Institute for International Health, University of Sydney, Associate Professor Anushka Patel, The George Institute for International Health, University of Sydney, and Professor Tarun Weeramanthri, Department of Health, Government of Western Australia. This included: planning of research, design of component studies, ethics committee submissions, the collection, management, analysis and interpretation of data, writing of manuscripts for submission to peer-reviewed journals, and the writing of the thesis. Specific author and co-author contributions are specified at the beginning of the relevant chapters and appendices.
Abstract

In this thesis I explore strategies to building better primary health care systems for Indigenous peoples with a focus on management and prevention of vascular diseases. This body of research takes a multimethods approach and is conducted in two inter-related parts.

Part A: Effectiveness of primary health care for Indigenous peoples

This stream of research examines one important aspect of health care quality—effectiveness of clinical care. I initially focus on health system monitoring by reviewing how adequately the New South Wales (NSW) Department of Health reports, by Aboriginal status, against national performance chronic disease-related indicators. I identify substantial limitations in the quality and breadth of indicators reported in NSW and propose several strategies to improve monitoring capacity. A key recommendation from this review is the need for robust data from the primary care sector. I then provide a response to this recommendation through the conduct of a case record audit in Aboriginal Medical Services (AMSs) assessing the effectiveness of primary health care for a variety of clinical measures. In addition to two other studies I have co-authored, involving mainstream Australian general practices (Appendices A and B), I demonstrate widespread under-performance in the primary care system. I then outline two studies exploring the role of point of care electronic assessment and decision support tools to improve system performance. The first describes an electronic cardiovascular disease (CVD) risk assessment program at a Māori governed Primary Health Organisation in Auckland, New Zealand. The second study describes the development, validation and mixed methods evaluation of an Australian Electronic Decision Support (EDS) system for CVD risk management which was piloted for use in both AMSs and mainstream general practices. Both studies demonstrated that electronic risk management programs can be rapidly implemented, achieve high levels of practitioner acceptability and are able to provide timely, reliable, and easy to obtain estimates of primary care system performance in the management of vascular health.
Part B: Access to health care for Indigenous peoples

In this part of the thesis I explore broader contextual factors that ought to be considered when trying to implement interventions to improve primary care system performance. To address this I conducted three studies that are closely linked to those in Part A. First, I describe a qualitative systematic review to explore the factors that influence access to health care for Indigenous peoples in Australia, New Zealand, Canada and the USA. This review was informed by the theoretical construct of 'candidacy' which describes the ways in which eligibility for health care is negotiated between individuals and health services based on both implicit and explicit criteria. I synthesise a large body of disparate literature sources to explore the utility of candidacy theory at the macro system, health service and health care encounter levels. Second, I describe the methods for a large-scale, Australian qualitative study exploring staff and community views on building better systems of care for Indigenous peoples. In addition to candidacy theory, the central Australian philosophy of kanyini was incorporated into the theoretical framework. Kanyini describes the obligation to nurture, hold and respect one another. I use these frameworks to identify key health service system features that affect access and quality of care and I discuss these findings in the context of the recent Australian governments' Indigenous health reform initiatives. Third, I conduct further analyses of the interview data involving GPs in the Australian decision support study described above in Part A. Drawing on actor-network-theory I examine GP perspectives on how the primary care network responds to a technological innovation. I assess how GPs used the tool in health care encounters, their attitudes to being advised by the tool and I explore the factors that influence their notions of best practice. The implications for implementation of EDS tools into primary care services are discussed.

The two inter-related parts of the thesis thus produce a suite of qualitative, quantitative and mixed methods studies that sequentially build a greater understanding of what is needed to build better primary care systems. By combining a deductive, hypothesis-driven component (Part A) with an inductive, exploratory component (Part B) I offer both pragmatic and complex insights to this field of inquiry. The former informs us about how well the primary care system is performing for Indigenous peoples and explores innovative interventions to improve performance. The latter recognises the contribution of broader contextual factors, occurring at multiple levels that need to be considered when implementing those interventions.
Ethical clearance

Several human research ethics committees (HRECs), health service governing bodies and institutional authorities have been involved in approval of work arising from this thesis.

Chapter 2: Robust data to close the gap: How do current vascular and maternal/newborn indicators perform as measures of progress in Aboriginal health in New South Wales?

The Clinical Excellence Commission provided written notice to the NSW Department of Health, Centre for Epidemiology and Population Health to access data.

Chapter 3: Cardiovascular disease risk management for Aboriginal and Torres Strait Islander peoples in primary health care settings: findings from the Kanyini Audit

The following institutional HRECs granted approval: Cairns & Hinterland Health Service District Ethics Committee, Princess Alexandria Hospital Health Service District, Central Australian Human Research Ethics Committee, Aboriginal Health & Medical Research Council Ethics Committee. Memoranda of Understanding were established between the George Institute for International Health and the participating Aboriginal Medical Services (AMSs) in New South Wales and Queensland. Partnership agreements were established between the Baker IDI Heart and Diabetes Institute and the participating AMSs in Central Australia.

Chapter 4: Cardiovascular risk management at a Māori-led Primary Health Organisation – findings from a cross-sectional audit

The Chairperson of the Northern X Regional Ethics Committee, Auckland reviewed the study protocol and it was determined that it did not require committee review and approval. Written permission was obtained from all health services participating in the study.
Chapter 5: An Electronic Clinical Decision Support Tool to Assist Primary Care Providers in Cardiovascular Disease Risk Management: Development and Mixed Methods Evaluation

The following institutional HRECs granted approval: Aboriginal Health and Medical Research Council Ethics Committee and the Sydney South West Area – Royal Prince Alfred Health Service Human Research Ethics Committee. Written permission was obtained from the three AMSs participating in the study. Informed written consent was obtained from all study participants.

Chapter 7: Building better systems of care for Aboriginal and Torres Strait Islander peoples: The Kanyini Qualitative Study.

The following institutional HRECs granted approval: Cairns & Hinterland Health Service District Ethics Committee, Princess Alexandria Hospital Health Service District, Central Australian Human Research Ethics Committee, Aboriginal Health & Medical Research Council Ethics Committee. Memoranda of Understanding were established between the George Institute for International Health and the participating health services in New South Wales and Queensland. Partnership agreements were established between the Baker IDI Heart and Diabetes Institute and the participating health services in Central Australia. Informed written consent was obtained from all study participants.

Chapter 8: New tools for an old trade: a sociotechnical appraisal of how electronic decision support is used by primary care practitioners

The following institutional HRECs granted approval: Aboriginal Health and Medical Research Council Ethics Committee and the Sydney South West Area – Royal Prince Alfred Health Service Human Research Ethics Committee. Written permission was obtained from the three Aboriginal Medical Services participating in the study. Informed written consent was obtained from all study participants.
Acknowledgements

The sad reality of writing a thesis is that, with the exception of my supervisors and examiners, the people most important to me are not going to read it. The few intrepid loved ones that do look at it are unlikely to go beyond this page. So given my time with you is brief I had better acknowledge you early!

Zinta Harrington, you gave me permission to be single and childless (even though I am neither) for so many nights and weekends over three years. A doctoral thesis, however monumental it may seem, pales in comparison with meeting the demands of everyday family living. Thank you, thank you, thank you. Jahan and Arun Peiris, you patiently kept yourselves busy whilst your dad fed his obsession with the laptop, squeezed in the odd teleconference and was often too distracted to watch your wondrous growth. Thanks for providing frequent, critical appraisals of my parental performance and reminding me of what was important. Maija Peiris, you arrived right at the end but were a powerful motivation to keep me writing into the wee hours. Baiba and Michael Harrington provided countless hours of childcare support, often at short notice and always cheerfully. They even did a little proof reading on the side which was gratefully appreciated. Stephen Clibborn not only let me ramble on about my research during our Sunday morning runs but then proof read the second half of the thesis with meticulous attention to detail. Daisy and Oliver Peiris looked after me when I needed to be a child again and spurred me on when I needed encouragement.

I received support from many other people and organisations for particular components of the thesis. My co-authors on each of the research papers, named at the beginning of each chapter, were vitally important to getting the job done.

The NSW Clinical Excellence Commission provided me with the inaugural Ian O’Rourke PhD scholarship in patient safety. Having had the privilege of working with Ian in Darwin and Elcho Island, this was a unique opportunity to have a personal connection with the funding body for my scholarship. I was very pleased to develop this further when the opportunity arose to work with André Jenkins and Mohammed Mohsin at the Clinical Excellence Commission for the research conducted in Chapter 2. Bruce Barraclough, Cliff
Hughes and Phil Harris were always highly supportive and I hope that my work can in some way honour Ian’s legacy.

I am grateful to several staff from the Kanyini Vascular Collaboration for assistance with the work described in Chapters 3 and 7. The Kanyini Vascular Collaboration is funded by a National Health and Medical Research Council (NHMRC) health services research grant (#402797). In particular, thanks to Maria Tchan and Hueiming Liu for being great program managers and attending to so many little things that quietly added up to be a very big thing; Alex Brown, Bernadette Rickards and Michael Howard for introducing me to the concept of kanyini and for collaborating closely on all aspects of the Kanyini Audit and Qualitative Study; and Suzanne Ingram, Jo Devries, John Brady, Barry Fewquandie and Jeannie Devitt, for so much support, wisdom and fun with implementing the studies. I also wish to thank all the Aboriginal Medical Service (AMS) partners that are participating in the Kanyini program of research. In particular, I am grateful to Darryl Wright and Tim Senior at Tharawal Aboriginal Corporation for generously opening your doors for me and seeing value in my work. I hope this thesis does some justice to the passion and commitment of the AMS sector to provide comprehensive primary care.

For Chapter 4, Tereki Stewart, Guy Naden, Jonathan Murray and Lorraine Hetarak-Stevens embraced my ideas for a cardiovascular disease risk program at Tāmaki Healthcare in Auckland. They provided me with valuable resources and encouragement to conduct the evaluation. Toshi Ninomiya and Avinesh Pillai provided statistical advice with Chapters 3 and 4. Peter Arnold gave much appreciated editorial advice for Chapters 2, 3 and Appendix D.

The electronic decision support project team (Patrick Groenestein, Ruth Webster, Rohina Joshi, Emma Heeley, Tim Usherwood, Alex Lipman, Claire Davies, Hueiming Liu, Fiona Turnbull, Anushka Patel) were critical to helping me complete the work described in Chapters 5 and 8. Ruth and Emma were also the key drivers for bringing to publication the work described in Appendices A and B respectively. Thanks also to the twenty-one General Practitioners and the three AMSs who generously participated in the pilot and to two anonymous reviewers of the research described in Chapter 8 for introducing me to the concepts of phronesis and street-level bureaucrats.
For the systematic review in Chapter 6, Jon Bleasel helped me reconcile a tempestuous relationship with the NVivo software program, spent many tedious hours searching for and retrieving articles, and assisted in intellectual wrestling with the data. Jane Parsons and Tony Ryan from the Royal Australian College of General Practitioners John Murtagh Library also provided valuable assistance with retrieving articles and generously waiving processing fees.

The final words go to my supervisors Alan Cass, Tarun Weeramanthri and Anushka Patel. You gave me great confidence to sail on this lonely voyage and make my discoveries. Your respective quantitative and qualitative skills were the perfect mix for what I was trying to achieve and I benefited greatly from your different and complementary approaches to my work. I am especially grateful to you, Alan and Anushka for making resources available at the George Institute to allow me to conduct my work, even when budgets were tight. Tarun, your enduring commitment to my qualitative work and an uncanny ability to broaden my vista with often only a handful of words was indispensable.

To all three of you, despite your furiously busy professional and personal lives, you have always made time for me when I needed it and equally you knew when to leave me alone when I needed that too. Without your expectation that my work be rigorously conducted, I would never have got to the finish line. Thank you.
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<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>A&amp;TSI HPF</td>
<td>Aboriginal and Torres Strait Islander Health Performance Framework</td>
</tr>
<tr>
<td>ABCD</td>
<td>Audit and Best Practice for Chronic Disease</td>
</tr>
<tr>
<td>ACCHS</td>
<td>Aboriginal Community Controlled Health Services</td>
</tr>
<tr>
<td>AHW</td>
<td>Aboriginal Health Worker</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>AMI</td>
<td>Acute Myocardial Infarction</td>
</tr>
<tr>
<td>AMS</td>
<td>Aboriginal Medical Services</td>
</tr>
<tr>
<td>ANZDATA</td>
<td>Australian and New Zealand Dialysis and Transplant Registry</td>
</tr>
<tr>
<td>APCC</td>
<td>Australian Primary Care Collaboratives</td>
</tr>
<tr>
<td>AusHEART</td>
<td>Australian Hypertension and Absolute Risk Study</td>
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<tr>
<td>BEACH</td>
<td>Bettering the Evaluation and Care of Health program</td>
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<tr>
<td>BMI</td>
<td>Body mass index</td>
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<tr>
<td>BP</td>
<td>Blood pressure</td>
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<tr>
<td>CASP</td>
<td>Critical Appraisal Skills Program</td>
</tr>
<tr>
<td>CDID</td>
<td>Chronic Disease Indicator Database</td>
</tr>
<tr>
<td>CDS</td>
<td>Clinical decision support</td>
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<tr>
<td>CKD</td>
<td>Chronic Kidney Disease</td>
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<tr>
<td>CTG</td>
<td>Close the Gap campaign for Indigenous Health Equality</td>
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<tr>
<td>CVD</td>
<td>Cardiovascular disease</td>
</tr>
<tr>
<td>DoHA</td>
<td>Department of Health and Ageing</td>
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<tr>
<td>EBM</td>
<td>Evidence-based medicine</td>
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<td>EDS</td>
<td>Electronic decision support</td>
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<td>EMR</td>
<td>Electronic medical record</td>
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<tr>
<td>ESKD</td>
<td>End-stage kidney disease</td>
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<tr>
<td>eGFR</td>
<td>Estimated glomerular filtration rate</td>
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<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GP NPI</td>
<td>Divisions of General Practice National Performance Indicators</td>
</tr>
<tr>
<td>HbA1C</td>
<td>Glycated hemoglobin</td>
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<tr>
<td>HDL</td>
<td>High-density lipoprotein</td>
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<td>HFL</td>
<td>Healthy for Life program</td>
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<td>HOIST</td>
<td>Health Outcomes Information Statistical Toolkit</td>
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<td>HRECS</td>
<td>Human research ethics committees</td>
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<tr>
<td>ICT</td>
<td>Information computer technology</td>
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<tr>
<td>IM</td>
<td>Information management</td>
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<td>IMPAKT</td>
<td>Improving Access to Kidney Transplants program</td>
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<td>IRF</td>
<td>Indigenous Research Fellow</td>
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<td>KQS</td>
<td>Kanyini Qualitative Study</td>
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<td>KVC</td>
<td>Kanyini Vascular Collaboration</td>
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<tr>
<td>LDL</td>
<td>Low-density lipoprotein</td>
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<td>MDC</td>
<td>Midwives Data Collection</td>
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<tr>
<td>NACCHO</td>
<td>National Aboriginal Community Controlled Health Service Organisation</td>
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<td>NATSIHS</td>
<td>National Aboriginal and Torres Strait Islander Health Survey</td>
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<tr>
<td>NGO</td>
<td>Non-government organisation</td>
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<tr>
<td>NHF</td>
<td>National Heart Foundation</td>
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<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<td>NHHRC</td>
<td>National Health and Hospitals Reform Commission</td>
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<tr>
<td>NHS</td>
<td>National Health Survey</td>
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<tr>
<td>NPDC</td>
<td>National Perinatal Data Collection</td>
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<tr>
<td>NPHS</td>
<td>National Preventive Health Strategy</td>
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<tr>
<td>NSFATSH</td>
<td>National Strategic Framework for Aboriginal and Torres Strait Islander Health</td>
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<tr>
<td>NZGG</td>
<td>New Zealand Guidelines Group</td>
</tr>
<tr>
<td>OATSIH</td>
<td>Office of Aboriginal and Torres Strait Islander Health</td>
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<td>OSCAR</td>
<td>OATSIH Services Collection Analysis and Reporting system</td>
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<td>PBS</td>
<td>Pharmaceutical Benefits Scheme</td>
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<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>PC OID</td>
<td>Productivity Commission: Overcoming Indigenous Disadvantage Report</td>
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<tr>
<td>PHO</td>
<td>Primary Health Organisation</td>
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<tr>
<td>PHS</td>
<td>Population Health Survey</td>
</tr>
<tr>
<td>PIRS</td>
<td>Patient Information Recall Systems</td>
</tr>
<tr>
<td>QI</td>
<td>Quality Improvement</td>
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<tr>
<td>RN</td>
<td>Registered Nurse</td>
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<tr>
<td>RRMA</td>
<td>Rural Remote Metropolitan Area classification</td>
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<tr>
<td>SAR</td>
<td>Service Activity Reporting</td>
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Publications arising from this thesis

Chapters 2, 3, 4 and 5, Appendices A, B and D and a number of conference abstracts (listed below) have been published in peer-reviewed journals. Chapter 8 has been accepted for publication. Appendix C has been published in a GP periodical. Abbreviated versions of Chapters 6 and 7 are currently being prepared for journal submission. A number of other outputs related to this work are listed in Appendix E.


Chapter 6: Peiris D, Weeramanthri T, Ingram S, Bleasel J, Devitt J, Cass A, What influences the accessibility of health services to Indigenous peoples in Australia, New
Zealand, Canada and USA? – A qualitative systematic review focussing on chronic illness care. An abbreviated version is planned for submission to *BMC Health Services Research*

**Chapter 7:** Peiris D, Rickards BA, Mentha R, Brady JP, Devries J, Fewquandie B, Liu H, Ingram S, Brown ADH, Devitt J, Weeramanthri T, Cass A, Building better systems of care for Aboriginal and Torres Strait Islander peoples: The Kanyini Qualitative Study. An abbreviated version is planned for submission to *BMC Health Services Research*

**Chapter 8:** Peiris D, Usherwood T, Weeramanthri T, Cass A, Patel A, New tools for an old trade: a sociotechnical appraisal of how electronic decision support is used by primary care practitioners. *Sociology of Health and Illness* in press, accepted 17/1/2011


**Published abstracts**

A number of abstracts arising from work related to this thesis have also been published.

Peiris D, Groenestein P, Heeley E, Webster R, Redfern J, Usherwood T, Patel A, HealthTracker- Decision support for primary care practitioners, National Heart Foundation


**Other publications**

Liu H, Peiris D, Hayman N, Fewquandie B, Senior T, Brown A, Cass A on behalf of the Kanyini Vascular Collaboration: Is there a safe and high quality care for Aboriginal and Torres Strait Islander peoples: A perspective from the Kanyini Vascular Collaboration Chapter 4 Windows on Safety and Quality in Health Care, Australian Commission for Safety and Quality in Health Care, 2010


Chapter 1: Introduction to a multimethods thesis

This thesis has grassroots origins. For the past twelve years I have worked as a General Practitioner (GP) in Indigenous-governed health services in Australia and New Zealand. Despite the all-consuming demands of everyday work I have witnessed a tireless energy within these services to provide care for both Indigenous and non-Indigenous peoples. As a result of working in this health care environment two questions have recurred in my professional life and consequently they constitute the research questions for this thesis. The first is seemingly straightforward but not well described: how effective is the care provided in Indigenous primary health care services? The second is broader and more complex: what is needed to build better primary care systems for Indigenous peoples?

My methodological approach to answering these questions is located within the emerging field of mixed methods research. Drawing from both quantitative and qualitative research traditions, mixed methods research has been proposed as a distinct ‘third methodological movement’. It is pragmatic in orientation, combining quantitative and qualitative methods to produce findings that go beyond what would have been obtained if these methods were conducted separately. It is a growing field and is increasingly being used in diverse disciplines including health science, psychology, sociology and education. Not all research that uses qualitative and quantitative methods is appropriate to be labelled as mixed methods research. Tashakkori and Teddlie propose that a truly mixed approach methodology incorporates multiple research strategies at all stages of the research project (i.e.: problem identification, data collection, data analysis, and final inference). Morse distinguishes mixed methods from multimethod designs. The former refers to single studies with multiple components and the latter to a series of separate studies that are interrelated and designed to address an overarching research problem, as is the case in this thesis. She established three principles to multimethod designs. The first principle is to identify the theoretical drives of the research project. These drives can broadly be characterised as inductive, characterised by exploration and discovery or deductive, characterised by testing a theory or hypothesis. The second principle is for the researcher to develop overt awareness for when the quantitative or qualitative aspect of a project is the dominant component at any given stage and to know when he or she is working...
inductively or deductively. The third principle is that when using a multimethod design each sub-project must be methodologically independent and not violate any scientific principles by drawing on methods from another sub-project. This is particularly pertinent when considering issues of sample size, types of data collected and analysis method.

Morse devised a nomenclature to schematically illustrate mixed and multimethod designs. Qualitative and quantitative are abbreviated to 'Qual' and 'Quan' respectively. The upper case notation is used to indicate the dominant method and lower case represents the supplemental component; a plus (+) sign indicates that the methods are used simultaneously; a (→) sign indicates that the methods are used sequentially. Example notations for paired methods include: (1) QUAL + quan which indicates that the qualitative method is the dominant method and a supplementary quantitative component is conducted simultaneously to add a different perspective to the inquiry. A common design scenario for this occurs when a quantitative survey of a representative sample is added to the conduct of in-depth interviews with a purposive sample to triangulate findings; (2) QUAN → qual indicates a deductively driven project in which a particular hypothesis is quantitatively tested and a subsequent qualitative component is added to further understand the quantitative findings. This design is common in clinical trials in which a qualitative process evaluation is added to make sense of the quantitative findings.

To address my broader question of what is needed to build better systems of primary care for Indigenous peoples, I take a predominantly inductive approach. Nested within this, however, are deductively driven research elements primarily directed toward the question of how effective is the care provided in Indigenous primary health care services. Using Morse’s nomenclature this thesis is a multimethod research program with a predominantly sequential design. Figure 1-1 outlines the overall schema of the thesis research elements.
In Part A, the deductive stream of the thesis, I ask three questions about the effectiveness of primary health care for Indigenous peoples:

(1) How adequately do health systems monitor the effectiveness of primary health care for Indigenous peoples?

(2) What is the extent and nature of the gaps between best practice recommendations and actual care provided in both Indigenous and mainstream primary care services in Australia?
Are electronic tools useful interventions to improve the monitoring and effectiveness of care in primary health care systems?

To provide some, but clearly not all, answers to this component I focus on vascular health care. This refers to the management and prevention of three inter-related diseases, cardiovascular diseases (CVD), chronic kidney disease (CKD) and diabetes. Chapter 2 reviews health systems monitoring of health outcomes and system performance for the vascular health of Aboriginal peoples. I use the New South Wales (NSW) health system as a case study to explore this issue. Although this chapter makes extensive use of quantitative data, the overriding thrust of this work is exploratory, seeking to understand the breadth and depth of available data for monitoring the health of Aboriginal people in NSW. Chapter 3 builds on this assessment of health systems monitoring and outlines a case record audit of the effectiveness of vascular health care in Aboriginal Medical Services. In this study I examine ‘evidence-practice gaps’ in vascular risk management for routinely attending Aboriginal and Torres Strait Islander adults. When combined with two other quantitative projects involving mainstream Australian general practices (Appendices A and B), these three studies provide a comprehensive analysis of vascular risk management in Australian primary care settings.

Chapters 4 and 5 outline a program of work exploring the ability of electronic tools to improve primary care system performance in the provision of vascular health care. Whilst maintaining a distinct focus on Indigenous health care, I also incorporate mainstream general practice perspectives in this section. Chapter 4 describes a 12 month audit evaluation of a newly implemented electronic CVD risk assessment program at a Māori-led Primary Health Organisation in Auckland, New Zealand. In Chapter 5, I explore the role of electronic decision support (EDS). I outline the development of an Australian primary care EDS tool for vascular risk management and report the findings from a mixed methods pilot evaluation conducted in both mainstream and Indigenous health services. In this study the quantitative and qualitative components are equally weighted. Together, the two studies from these chapters provide important insights on the process of implementing electronic interventions in primary care on a large scale. In particular, they shed important light on particular design features that might affect their uptake.
In Part B, the inductive stream of the thesis, I respond to my broader question of what is needed to build better systems of primary care for Indigenous peoples. I explore broader health system issues that might influence (1) the effectiveness of care and (2) the success of interventions such as those described in Chapters 4 and 5. I build my analysis at three inter-related levels: health system factors, local health service organisational issues and provider-patient factors occurring at the point of care.

In Chapter 6, I conduct a qualitative systematic review of factors affecting access to health services for Indigenous peoples in Australia, New Zealand, Canada and USA. A key feature of this review is the synthesis of disparate literature sources (grey and empirical, quantitative and qualitative, descriptive and interventional) to provide multiple perspectives. Although there is some quantitative analysis of key themes provided, the dominant method in this review involved the use of emerging qualitative synthesis techniques. I assess the utility of the theoretical construct of candidacy which is derived from a similar qualitative systematic review of access to health care for vulnerable populations in the United Kingdom. Candidacy describes the ways in which eligibility for health care is jointly negotiated between individuals and health services.

In Chapter 7, I further develop the insights from the systematic review in an empirical study, the Kanyini Qualitative Study (KQS). This large scale study also follows sequentially from the findings of the Kanyini Audit (see Figure 1-1). KQS examines community and health professional perspectives on the factors necessary to build better systems of care for Aboriginal and Torres Strait Islander peoples. There are two components to this study, a health systems assessment which combines an organisational survey with structured staff focus groups and a semi-structured interview component involving health service staff and community participants. I build on candidacy theory by locating it alongside the Central Australian concept of kanyini or ‘holding’ which describes the principle and obligations of nurturing and protecting others. I describe in detail the methods taken to conduct this study and provide an analysis of the health systems assessment component. I locate these findings in the context of the recent shifts in Australian government policy for Aboriginal and Torres Strait Islander health.
In Chapter 8, I return to EDS systems, conducting exploratory analyses of interview data collected in the study described in Chapter 5. In this chapter I take a sociological approach and use actor-network-theory to understanding the relationships between technological tools, their users and the organisational environments in which they are placed. I argue that there is an evolving dynamic between these various ‘actors’ and that understanding their relationships is critical to appreciating the impact of technological innovations on the primary care workplace.

When taken together the deductive and inductive components of this thesis provide a multidimensional analysis to building better primary care systems for Indigenous peoples. I argue the importance of developing pragmatic and well evaluated interventions. I also argue that in order to yield maximum benefit, these interventions need to occur in an environment that is responsive to the broader socio-political aspects of Indigenous primary health care.

References

PART A: HEALTH SYSTEMS MONITORING, EFFECTIVENESS OF PRIMARY CARE AND INTERVENTIONS TO IMPROVE SYSTEM PERFORMANCE
Chapter 2: Robust data to close the gap: How do current vascular and maternal/newborn indicators perform as measures of progress in Aboriginal health in New South Wales?


Author contribution: I conceived of the study, performed the literature search and analysis of the findings, wrote the first and subsequent drafts for journal submission and was the primary author for responding to reviewer comments. Dr. Mohsin assisted with extracting data from New South Wales data collections and all authors reviewed and commented on the journal manuscript drafts.

2.1 Abstract

Objective: Focussing on maternal/newborn health and vascular diseases, to review NSW Health’s reporting, by Aboriginal status, against national performance indicators relevant to preventable chronic diseases.

Methods: We reviewed seven indicator documents and the Australian Institute of Health and Welfare Chronic Disease Indicator Database to identify national indicators. We then compared six NSW Health reports with these national indicators to assess whether or not they routinely report by Aboriginal status and region.

Results: NSW Health routinely reports against six maternal/newborn and fourteen vascular-related national indicators. Five of the maternal/newborn indicators report performance by both Aboriginal status and region. Eight vascular-related indicators report by Aboriginal status and one (diabetes hospitalisations) reports by both Aboriginal status and region. We found substantial limitations in the quality and breadth of indicators. These related to under-enumeration of Aboriginal status, small or potentially unrepresentative
samples, inadequate longitudinal or regional data and a lack of indicators relevant to the performance of primary health care. Notwithstanding these limitations, we found wide and persistent disparities in outcomes for Aboriginal people for all indicators in all regions.

**Conclusions:** NSW Health reports adequately, by Aboriginal status, for maternal/newborn health monitoring (albeit constrained by under-enumeration), but provides limited information about vascular health. There is a need for a minimum national chronic disease indicator dataset against which all jurisdictions would report performance by Aboriginal status and region. Improved monitoring requires: (a) population-representative data from the primary health care sector; (b) greater coordination between hospitals and primary care; (c) improved health survey sampling with the incorporation of physical/laboratory measures; and (d) sustained efforts (especially data-linkage initiatives) to address under-enumeration.

### 2.2 Background

Federal and State governments have pledged to close the life expectancy gap of Aboriginal and Torres Strait Islander people within a generation. Accompanying this pledge has been unprecedented financial commitment by the Council of Australian Governments (COAG)\(^1\) and major health reform proposals that could substantially influence health care, both in NSW and Australia.\(^2\)-\(^5\) A key component of these reforms is the imperative to address Aboriginal and Torres Strait Islander health inequalities and to better measure the efficacy of Australia’s health care systems in achieving such gains.

A primary criterion by which health care systems are increasingly being judged is their success in improving outcomes for vulnerable populations. In establishing a framework for success, the United States Commonwealth Fund recommends monitoring by sound metrics for assessing whether or not strategic goals are being achieved.\(^6\) Identifying the most appropriate metrics and establishing mechanisms for the collection of high quality data are crucial for assessing the health care provided to Indigenous peoples. Robust mechanisms for measurement of macro-performance, which can be compared across regions and with non-Indigenous health care, have been identified as a key priority.\(^7\)
The Aboriginal and Torres Strait Islander Health Performance Framework (A&TSI HPF) is the most comprehensive attempt yet to develop such a mechanism. It was established to monitor the impact of the National Strategic Framework for Aboriginal and Torres Strait Islander Health and to influence policy analyses, planning and program implementation. Drawing from the National Health Performance Committee framework, three tiers of indicators (each with a number of sub-dimensions) are outlined: (1) health status and outcomes (health conditions, human function, life expectancy and deaths); (2) determinants of health (environmental and socio-economic factors, community capacity, health behaviours and person-related factors); and (3) health system performance (effective, appropriate, efficient, responsive, accessible, safe, continuous, capable and sustainable).

In 2007, the Clinical Excellence Commission in New South Wales (NSW) published its first ‘Chartbook’ on the quality of health care in NSW. Modelled on Commonwealth Fund reports, the Chartbook provides performance snapshots on trends in several indicators. Intended to complement the NSW Chief Health Officer’s Report and other relevant annual reports, the Chartbook aims to monitor these trends, identify areas for further investigation and to act as a resource to facilitate change. The 2008 Chartbook includes a new chapter on selected outcome indicators by Aboriginal status. Review of these indicators raise three broad questions. Which national performance indicators are routinely reported against by Aboriginal status in NSW? How reliable is this information? Given the proposed national health reforms, how well-placed is NSW to monitor the effectiveness of these reforms for Aboriginal people?

We seek here to answer these questions as they relate to one health priority area, namely preventable chronic diseases. Given there are currently over 400 indicators in the Australian Institute of Health and Welfare (AIHW) Chronic Disease Indicator Database (CDID), we focussed on two priority areas: (1) maternal/newborn health because of the importance of a ‘life-course’ approach to chronic disease and (2) vascular-related diseases (cardiovascular disease (CVD), chronic kidney disease (CKD) and diabetes) and their risk factors because these conditions make the greatest contribution to disease burden.
2.3 Methods

This review comprised three steps.

**Step 1:** A review of Federal government documents that report performance indicators by Aboriginal/Torres Strait Islander status in maternal/newborn health and vascular diseases. We focussed on ‘strategic change indicators’ which measure change in the shorter term and for which more immediate action can be taken; we therefore excluded ‘headline indicators’ related to mortality. We used a purposive sampling strategy to identify indicator documents. For inclusion, documents needed to be recent (published after 2007); national in focus; relevant to preventable chronic diseases in primary care and/or hospital settings; and have explicit indicator definitions. We took four approaches to our search: (1) A review of data sources in the A&TSI Health Performance Framework and a ‘snowballing’ search for other government and non-government documents which used these data sources; (2) consultation with content experts in health care safety and quality to identify additional documents; (3) a keyword search for Indigenous-related indicators in the AIHW CDID; and (4) a review of the proposed indicators in the discussion documents/reports relating to the proposed national health reforms. The final indicator list was reviewed by staff from the Office of Aboriginal and Torres Strait Islander Health (OATSIH).

**Step 2:** A review of NSW Health documents to identify indicators which matched those identified in Step 1. We searched the NSW Health website for routinely published reports on health performance monitoring. Staff in the Clinical Excellence Commission and the NSW Centre for Epidemiology and Population Health reviewed the retrieved reports and advised on the need to include any additional reports. For the indicators identified from these documents, we examined the quality of the data collections from which they were derived, their duration of reporting and whether or not they reported by Aboriginal status and/or any one of the following regional units (Area Health Service, Local Government Area or Accessibility/Remoteness Index of Australia (ARIA+))

**Step 3:** For those indicators identified above which do report by Aboriginal status, we sought to provide a snapshot of the routinely available types of information. We extracted and summarised data from the Health Outcomes Information Statistical Toolkit (HOIST),
from published reports and from the Australian and New Zealand Dialysis and Transplant Registry. For maternal/newborn health indicators, bi-variate (cross-tabular) analyses compared indicators with the results expressed as percentages by year, Aboriginal status and ARIA+. Information on vascular risk factors are expressed as weighted percentages for the Aboriginal and total population by urban and rural region. Hospitalisations and dialysis data are expressed as directly age standardised rates by year and Aboriginal status.

2.4 Results

Performance measures described within four Federal government, 8 15-17 and three national health reform documents 3 18 19 were reviewed. These are presented in Table 2-1. No additional indicators, not already included in these documents, were identified from the AIHW CDIC.
Table 2-1: Non-mortality maternal/newborn and vascular health indicators described in national documents that recommend reporting by Aboriginal and Torres Strait Islander status

<table>
<thead>
<tr>
<th>Indicator</th>
<th>HPF Tier</th>
<th>Reported in current documents</th>
<th>Proposed in health reform documents</th>
<th>Data sources</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Maternal/newborn health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Mean, low, premature birth weight prevalence by maternal Indigenous status (reported by various maternal &amp; birth characteristics)</td>
<td>1</td>
<td>A&amp;TSI HPF PC OID</td>
<td>NHHRC</td>
<td>NPDC</td>
</tr>
<tr>
<td>• Mean birth weight, low &amp; high birth weight by newborn Indigenous status</td>
<td>1</td>
<td>HFL</td>
<td>CTG</td>
<td>OSCAR</td>
</tr>
<tr>
<td>• Tobacco use in pregnancy</td>
<td>2</td>
<td>A&amp;TSI HPF PC OID</td>
<td>NHHRC</td>
<td>NPDC</td>
</tr>
<tr>
<td>• Smoking, alcohol consumption &amp; illicit drug use at &lt; 13 weeks pregnancy and in third trimester</td>
<td>2</td>
<td>HFL</td>
<td>CTG</td>
<td>OSCAR</td>
</tr>
<tr>
<td>• Breast feeding practices</td>
<td>2</td>
<td>A&amp;TSI HPF</td>
<td>NPDS</td>
<td>NHS NATSIHS</td>
</tr>
<tr>
<td>• Timing of first antenatal visit</td>
<td>3</td>
<td>A&amp;TSI HPF PC OID HFL</td>
<td>CTG NHHRC</td>
<td>NPDC OSCAR</td>
</tr>
<tr>
<td><strong>Vascular health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Circulatory diseases/ diabetes hospitalisations and self-reported prevalence, general practice encounters</td>
<td>1</td>
<td>A&amp;TSI HPF PC OID</td>
<td>NHHRC</td>
<td>NATSIHS NHMD BEACH</td>
</tr>
<tr>
<td>• Blood Pressure (BP) hospitalisations, self-reported prevalence, general practice encounters</td>
<td>1</td>
<td>A&amp;TSI HPF PC OID</td>
<td>NHHRC</td>
<td>NATSIHS</td>
</tr>
<tr>
<td>• End-stage renal disease- incidence, hospitalisation and treatment modality</td>
<td>1</td>
<td>A&amp;TSI HPF PC OID</td>
<td>ANZDATA</td>
<td></td>
</tr>
<tr>
<td>• Smoking prevalence</td>
<td>2</td>
<td>A&amp;TSI HPF PC OID</td>
<td>CTG NPHS</td>
<td>NHS NATSIHS</td>
</tr>
<tr>
<td>• Overweight and obesity prevalence</td>
<td>2</td>
<td>A&amp;TSI HPF PC OID</td>
<td>NPHS</td>
<td>NHS NATSIHS</td>
</tr>
<tr>
<td>• Level of physical activity</td>
<td>2</td>
<td>A&amp;TSI HPF PC OID</td>
<td>NPHS</td>
<td></td>
</tr>
<tr>
<td>• Sufficient daily fruit and vegetable intake</td>
<td>2</td>
<td>A&amp;TSI HPF PC OID</td>
<td>NPHS</td>
<td></td>
</tr>
<tr>
<td>• Hospitalisations due to tobacco</td>
<td>2</td>
<td>PC OID</td>
<td>NPHS</td>
<td></td>
</tr>
<tr>
<td>• Hospital separations attributed to obesity/tobacco</td>
<td>2</td>
<td>PC OID</td>
<td>NPHS</td>
<td></td>
</tr>
<tr>
<td>• Glycated haemoglobin recording and control for diabetics</td>
<td>3</td>
<td>A&amp;TSI HPF GPNPI HFL</td>
<td>NHHRC</td>
<td>OSCAR APCC Medicare</td>
</tr>
<tr>
<td>• Cholesterol recording and control for diabetics</td>
<td>3</td>
<td>A&amp;TSI HPF GPNPI</td>
<td>NHHRC</td>
<td>APCC Medicare</td>
</tr>
<tr>
<td>• BP recording and control for coronary heart disease/diabetes</td>
<td>3</td>
<td>A&amp;TSI HPF GPNPI</td>
<td>NHHRC</td>
<td>APCC Medicare</td>
</tr>
<tr>
<td>• Provision of chronic care plans (Medicare Items 721, 723)</td>
<td>3</td>
<td>A&amp;TSI HPF GPNPI</td>
<td>NHHRC</td>
<td>APCC Medicare</td>
</tr>
<tr>
<td>• Services with a documented chronic disease management strategy</td>
<td>3</td>
<td>A&amp;TSI HPF GPNPI</td>
<td>NHHRC</td>
<td>APCC Medicare</td>
</tr>
<tr>
<td>• Services with chronic disease registers/recall systems</td>
<td>3</td>
<td>A&amp;TSI HPF GPNPI</td>
<td>NHHRC</td>
<td>APCC Medicare</td>
</tr>
<tr>
<td>• Provision of health assessments (Medicare Items 704, 706, 708, 710)</td>
<td>3</td>
<td>A&amp;TSI HPF GPNPI</td>
<td>NHHRC</td>
<td>APCC Medicare</td>
</tr>
<tr>
<td>• Access to coronary heart disease hospital procedures</td>
<td>3</td>
<td>A&amp;TSI HPF GPNPI</td>
<td>NHHRC</td>
<td>APCC Medicare</td>
</tr>
<tr>
<td>• Ambulatory care sensitive conditions- diabetes complications &amp; angina</td>
<td>3</td>
<td>A&amp;TSI HPF GPNPI</td>
<td>NHHRC</td>
<td>APCC Medicare</td>
</tr>
<tr>
<td>Indicator</td>
<td>HPF Tier</td>
<td>Reported in current documents</td>
<td>Proposed in health reform documents</td>
<td>Data sources</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>----------</td>
<td>-------------------------------</td>
<td>-------------------------------------</td>
<td>--------------</td>
</tr>
<tr>
<td>• Provision of cardiovascular disease (CVD) risk assessments</td>
<td>3</td>
<td>Not reported</td>
<td>CTG</td>
<td>Not stated</td>
</tr>
<tr>
<td>• Access to medicine and non-medicine management for people at elevated vascular risk and/or with diabetes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Risk factor recording &amp; control for CVD, chronic kidney disease (CKD) and diabetes (includes psychosocial risk)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Brief interventions for smokers, people with overweight/obesity</td>
<td>3</td>
<td>Not reported</td>
<td>NPHS</td>
<td>Not stated</td>
</tr>
<tr>
<td>• Diabetes receipt of an annual cycle of care</td>
<td>3</td>
<td>Not reported</td>
<td>NHHRC</td>
<td>Not stated</td>
</tr>
<tr>
<td>• Specialist access for secondary prevention of chronic disease</td>
<td>3</td>
<td>Not reported</td>
<td>CTG</td>
<td>Not stated</td>
</tr>
<tr>
<td>• Reduced time to admission and guidelines implementation for CVD, diabetes, CKD.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Access to cardiac/ stroke rehabilitation, dialysis and transplantation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Waiting time at 90th percentile for cardio-thoracic surgery</td>
<td>3</td>
<td>Not reported</td>
<td>NHHRC</td>
<td>Not stated</td>
</tr>
</tbody>
</table>

**Table Abbreviations**

HPF: Health Performance Framework

**Indicator Documents**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Documents</th>
</tr>
</thead>
<tbody>
<tr>
<td>A&amp;TSI HPF</td>
<td>Aboriginal and Torres Strait Islander Health Performance Framework¹</td>
</tr>
<tr>
<td>PC OID</td>
<td>Productivity Commission: Overcoming Indigenous Disadvantage Report¹¹</td>
</tr>
<tr>
<td>GP NPI</td>
<td>Department of Health and Ageing Divisions of General Practice National Performance Indicators Program¹⁷</td>
</tr>
<tr>
<td>HFL</td>
<td>Office of Aboriginal and Torres Strait Islander Health (OATISIH): Healthy for Life Essential Indicators¹⁶</td>
</tr>
<tr>
<td>CTG</td>
<td>Steering Committee for the Close the Gap campaign for Indigenous Health Equality¹⁸</td>
</tr>
<tr>
<td>NHHRC</td>
<td>National Health &amp; Hospitals Reform Commission Interim Report¹⁹</td>
</tr>
<tr>
<td>NPHS</td>
<td>National Preventive Health Taskforce National Preventive Health Strategy³</td>
</tr>
</tbody>
</table>

**Data sources**

<table>
<thead>
<tr>
<th>Source</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPDC</td>
<td>National Perinatal Data Collection</td>
</tr>
<tr>
<td>NHMD</td>
<td>National Hospital Morbidity Database</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Survey</td>
</tr>
<tr>
<td>NATSIHS</td>
<td>National Aboriginal and Torres Strait Islander Health Survey</td>
</tr>
<tr>
<td>OSCAR</td>
<td>OATSIH Services Collection Analysis and Reporting System</td>
</tr>
<tr>
<td>SAR</td>
<td>Department of Health and Ageing Service Activity Reporting Database</td>
</tr>
<tr>
<td>BEACH</td>
<td>Bettering the Evaluation and Care of Health program</td>
</tr>
<tr>
<td>APCC</td>
<td>Australian Primary Care Collaboratives program</td>
</tr>
<tr>
<td>ANZDATA</td>
<td>Australian &amp; New Zealand Dialysis and Transplant Registry</td>
</tr>
</tbody>
</table>
Six NSW Health reports were examined for their reporting against these indicators. The data sources are primarily derived from three NSW data collections: the NSW Midwives Data Collection (MDC) 1994-2007, NSW Admitted Patient Data Collection (APDC) 1993-94 to 2006-07 and NSW Population Health Survey (PHS) 2002-05. Box 1 summarises the scope and methods used in those data collections and describes issues relating to data quality.

Text Box 2-1: Profile of three NSW data collections relevant to maternal/newborn and vascular health monitoring

**The Midwives Data Collection (MDC)**

The MDC is a population-based surveillance system covering births of at least 20 weeks gestation or 400 grams birth weight in public and private hospitals, including home births. Data are collected on maternal socio-demographic characteristics, reproductive history, pregnancy and perinatal outcomes. A validation study found that the majority of MDC data items have more than 90% inter-rater agreement and kappa coefficients above 0.70. Data on maternal Aboriginal status, but not the Aboriginal status of the baby, are routinely collected. MDC data are linked to birth registration records from the Registry of Births, Deaths and Marriages to assess enumeration of maternal Aboriginal status, in NSW this enumeration rate was estimated to be 69.3% in 2005.

**The Population Health Survey (PHS)**

The PHS is an annual computer-assisted telephone survey which commenced in 2002. It collects information about health behaviours, health status, health service use and access, and social capital. A stratified two-stage cluster sample design is used by targeting a sample of 1500 people in each AHS per year. Weighting factors are used to estimate the rates at AHS and state level. Eight hundred Aboriginal participants are estimated to be needed to detect a 5% difference in prevalence estimates. Between 2002 and 2005, 56,677 adult respondents (aged 16+) participated in the survey; 930 were Aboriginal. When compared with the 2001 census figures, Aboriginal survey respondents were more likely to be female (61.3%) and to reside in a rural area (65.6%). One report on Aboriginal adult health has been published based on these data with the next report expected in 2010.

**The Admitted Patient Data Collection (APDC)**

The APDC provides data each financial year, covering services provided by public hospitals (including psychiatric), public multi-purpose services, private hospitals and private day procedure centres for admitted patients. It includes data on interstate hospital admissions of NSW residents. From 1998, the APDC changed from reporting admissions to reporting episodes of care. This might have lead to a small increase in enumeration. A validation study found that enumeration of Aboriginal status in the APDC was 88% overall – 81% in urban, 89% in inner regional, 95% in outer regional and 100% in remote areas.
Six maternal/newborn indicators and fourteen vascular disease-related indicators identified in the national documents are routinely reported against in NSW. Table 2-2 summarises these indicators, the duration of reporting and whether or not they report by Aboriginal status and/or region. For those indicators routinely reported by Aboriginal status, key performance features are described below.
<table>
<thead>
<tr>
<th>Reports</th>
<th>Principal data collection sources</th>
<th>Indicators</th>
<th>HPF tier</th>
<th>Data reporting period</th>
<th>Data routinely reported by:</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW Mothers and Babies Report(^2)</td>
<td>Midwives Data Collection (MDC)</td>
<td>Teenage pregnancy</td>
<td>1</td>
<td>1994-2007</td>
<td>Yes</td>
</tr>
<tr>
<td>Report on child health from the NSW Population Health Survey(^2)</td>
<td></td>
<td>Tobacco use in pregnancy</td>
<td>2</td>
<td>1994-2007</td>
<td>Yes</td>
</tr>
<tr>
<td>The health of the people of NSW – Report of the Chief Health Officer (CHO)(^1)</td>
<td></td>
<td>Low birth weight prevalence</td>
<td>1</td>
<td>1994-2007</td>
<td>Yes</td>
</tr>
<tr>
<td>Two Ways Together(^4)</td>
<td></td>
<td>Premature birth prevalence</td>
<td>1</td>
<td>1994-2007</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Antenatal visit &lt;20 weeks of pregnancy</td>
<td>3</td>
<td>1994-2007</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>NSV Population Health Survey (PFS)</td>
<td>Duration of breast feeding up to 24 months</td>
<td>2</td>
<td>2002-2006</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Report on Adult Health(^2)/Report on Adult Aboriginal Health(^2) from the NSW Population Health Survey</td>
<td>NSW PHS</td>
<td>Overweight &amp; obesity prevalence</td>
<td>2</td>
<td>2002-2008</td>
<td>Yes*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Current daily &amp; occasional smoking</td>
<td>2</td>
<td>2002-2008</td>
<td>Yes*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diabetes or high blood glucose prevalence</td>
<td>1</td>
<td>2002-2008</td>
<td>Yes*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fruit and vegetable consumption</td>
<td>2</td>
<td>2002-2008</td>
<td>Yes*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Physical activity in adults</td>
<td>2</td>
<td>2002-2008</td>
<td>Yes*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cardiovascular risk factors by diabetes status</td>
<td>2</td>
<td>2006-2007</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The health of the people of NSW – Report of the CHO.</td>
<td>Admitted Patient Data Collection (APDC)</td>
<td>Cardiovascular disease hospitalisations</td>
<td>1</td>
<td>1994-2007</td>
<td>Yes</td>
</tr>
<tr>
<td>Two Ways Together</td>
<td></td>
<td>Stroke hospitalisations</td>
<td>1</td>
<td>1994-2007</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diabetes hospitalisations</td>
<td>1</td>
<td>1994-2007</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Type of ambulatory care sensitive conditions</td>
<td>3</td>
<td>1994-2007</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cardiovascular disease procedures</td>
<td>3</td>
<td>1994-2007</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diabetic amputations</td>
<td>3</td>
<td>1994-2007</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diabetic eye complications</td>
<td>3</td>
<td>2006-2007</td>
<td>No*</td>
</tr>
<tr>
<td></td>
<td>ANZDATA(^f)</td>
<td>Dialysis treatment prevalence(^a)</td>
<td>3</td>
<td>1997-2006</td>
<td>Yes</td>
</tr>
</tbody>
</table>

a. Health Performance Framework
b. 'Region' is defined as reporting by any of the following: Local Government Area, Area Health Service, Accessibility/Remoteness Index of Australia
c. Data not routinely reported by Aboriginal status due to small sample size
d. Data for overweight/obesity and diabetes from the 2004 National Aboriginal and Torres Strait Islander survey are also reported in Two Ways Together.
e. Data are reported separately for Aboriginal people based on survey respondents over the 2002-2005 period
f. Australian and New Zealand Dialysis and Transplant Registry
g. The population prevalence of maintenance dialysis provided for end-stage kidney disease (both peritoneal and haemodialysis). It includes hospital, satellite and community-based (home) dialysis
Maternal/newborn indicators

Figure 2-1 shows the trends in five indicators by Aboriginal status and area of residence. During the period 1994-2007, the prevalence of pre-term (less than 37 weeks of gestation) and low birth-weight (less than 2500 gram) babies born to Aboriginal mothers remained significantly higher than for babies born to non-Aboriginal mothers in all areas (p<0.001). Smoking prevalence in pregnancy declined for all mothers, but remained higher for Aboriginal mothers (p<0.001). A higher, stable rate of teenage pregnancies was observed among Aboriginal mothers (p<0.001). There have been improvements in access to timely antenatal care for all mothers and, although a significant difference remains (p<0.001), there has been a narrowing of the gap between Aboriginal and non-Aboriginal mothers. The proportion of NSW Aboriginal mothers starting antenatal care before 20 weeks gestation has risen from 63.0% in 1994 to 79.5% in 2007, with a notable improvement in major cities.
Figure 2-1: Maternal and newborn health indicators by Aboriginal status and region in NSW, 1993-94 to 2006-07

2-1-1: % of teenage mothers (aged < 20 years)
2-1-2: % of mothers who smoked in pregnancy
2-1-3: % of mothers with 1st antenatal care visit before 20 weeks of pregnancy
2-1-4: % of pre-term babies (born < 37 weeks gestational age)
2-1-5: % of low birth weight babies (birth weight < 2500 grams)

Data Source: The NSW Midwives data collection (MDC), 1994-2007 (HOIST) Centre for Epidemiology and Research, NSW Department of Health.
Vascular disease indicators

Table 2-3 shows the estimated prevalence of selected vascular risk factors for Aboriginal people and for the total NSW population over a similar time period. Owing to the small sample size for Aboriginal people in the PHS (n=930), the wide 95% confidence intervals around these estimates results in large imprecision.

Table 2-3: Vascular risk factor prevalence rates for persons aged 16 years and over by Aboriginal status and sex in NSW

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>Population</th>
<th>Urban Males % (95% CI)</th>
<th>Urban Females % (95% CI)</th>
<th>Rural Males % (95% CI)</th>
<th>Rural Females % (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current daily or occasional smoking</td>
<td>Aboriginal 2002-2005</td>
<td>41.3 (28.3-54.3)</td>
<td>41.1 (32.1-50.2)</td>
<td>46.7 (38.2-55.2)</td>
<td>42.2 (35.3-49.0)</td>
</tr>
<tr>
<td></td>
<td>Total NSW 2005</td>
<td>21.6 (19.4-23.8)</td>
<td>16.6 (15.0-18.2)</td>
<td>25.1 (22.7-27.6)</td>
<td>19.9 (18.2-21.6)</td>
</tr>
<tr>
<td>Diabetes or high blood glucose (as notified by a doctor or hospital – excludes gestational diabetes)</td>
<td>Aboriginal 2002-2005</td>
<td>5.1 (0.8-9.5)</td>
<td>5.8 (2.0-9.5)</td>
<td>15.3 (9.9-20.8)</td>
<td>12.4 (8.0-16.8)</td>
</tr>
<tr>
<td></td>
<td>Total NSW 2005</td>
<td>8.3 (7.0-9.5)</td>
<td>6.8 (5.8-7.7)</td>
<td>8.6 (7.4-9.8)</td>
<td>7.0 (6.0-8.0)</td>
</tr>
<tr>
<td>Overweight and obesity (Body mass index &gt;25kg/m²)</td>
<td>Aboriginal 2002-2005</td>
<td>48.9 (35.5-62.3)</td>
<td>53.2 (43.6-62.8)</td>
<td>62.1 (53.3-70.8)</td>
<td>53.3 (46.0-60.6)</td>
</tr>
<tr>
<td></td>
<td>Total NSW 2005</td>
<td>55.5 (52.9-58.1)</td>
<td>39.3 (37.2-41.4)</td>
<td>62.0 (59.4-64.6)</td>
<td>49.2 (47.1-51.3)</td>
</tr>
<tr>
<td>Adequate fruit consumption (at least 2 serves per day)</td>
<td>Aboriginal 2002-2005</td>
<td>32.0 (19.8-44.2)</td>
<td>41.7 (32.9-50.6)</td>
<td>34.5 (26.5-42.5)</td>
<td>39.9 (33.3-46.4)</td>
</tr>
<tr>
<td></td>
<td>Total NSW 2005</td>
<td>44.4 (41.9-47.0)</td>
<td>57.6 (55.5-59.7)</td>
<td>44.9 (42.2-47.5)</td>
<td>57.4 (55.3-59.5)</td>
</tr>
<tr>
<td>Adequate vegetable consumption (at least 5 serves per day)</td>
<td>Aboriginal 2002-2005</td>
<td>7.6 (2.0-13.2)</td>
<td>17.0 (9.6-24.3)</td>
<td>4.1 (1.8-6.5)</td>
<td>13.0 (8.4-17.7)</td>
</tr>
<tr>
<td></td>
<td>Total NSW 2005</td>
<td>4.0 (3.0-4.9)</td>
<td>8.9 (7.8-10.0)</td>
<td>6.4 (5.2-7.6)</td>
<td>12.7 (11.5-14.0)</td>
</tr>
<tr>
<td>Adequate physical activity (at least 150mins per week on 5 separate occasions)</td>
<td>Aboriginal 2002-2005</td>
<td>68.7 (56.6-80.9)</td>
<td>44.0 (34.9-53.2)</td>
<td>51.8 (43.3-60.3)</td>
<td>46.7 (39.9-53.6)</td>
</tr>
<tr>
<td></td>
<td>Total NSW 2005</td>
<td>57.1 (54.4-59.7)</td>
<td>48.2 (46.0-50.3)</td>
<td>55.4 (52.8-58.0)</td>
<td>45.5 (43.4-47.6)</td>
</tr>
</tbody>
</table>


Nevertheless, when compared with the total population surveyed in 2005, Aboriginal males have approximately double (p <0.01) and Aboriginal females approximately three times (p <0.001) the rate of self-reported current smoking. A significantly higher
prevalence of overweight and obesity for urban-residing Aboriginal females (approximately 1.4 times greater, p<0.05) was also noted.

Figure 2-2 shows the age-adjusted hospitalisation rates for the period 1993-94 to 2006-07 for diabetes and CVD-related conditions for the NSW population, by Aboriginal status and the age-adjusted rates of dialysis treatments for the Aboriginal and total NSW population. These data reflect the increased disease burden experienced by Aboriginal people for these three conditions.
Figure 2-2: Diabetes and Cardiovascular disease hospitalisations rates, Dialysis treatment prevalence by Aboriginal status and sex in NSW, 1993-94 to 2006-07

**Figure notes:**

1. Data Sources: NSW Admitted Patient Data Collection 1993-94 to 2006-07 (HOIST), Centre for Epidemiology and Research, NSW Department of Health, Australian and New Zealand Dialysis and Transplant Registry.

2. Data for all three graphs were age adjusted using the estimated resident population for NSW 1993-2006 as the reference population and the Australian population as at 30 June 2001 as the standard.

3. Dialysis treatment prevalence refers to the population prevalence of maintenance dialysis provided for end-stage kidney disease (both peritoneal and haemodialysis). It includes hospital, satellite and community-based (home) dialysis.
Figure 2-2: Diabetes and Cardiovascular disease hospitalisations rates, Dialysis treatment prevalence by Aboriginal status and sex in NSW, 1993-94 to 2006-07

Figure notes:
1. Data Sources: NSW Admitted Patient Data Collection 1993-94 to 2006-07 (HOIST), Centre for Epidemiology and Research, NSW Department of Health, Australian and New Zealand Dialysis and Transplant Registry.
2. Data for all three graphs were age adjusted using the estimated resident population for NSW 1993-2006 as the reference population and the Australian population as at 30 June 2001 as the standard.
3. Dialysis treatment prevalence refers to the population prevalence of maintenance dialysis provided for end-stage kidney disease (both peritoneal and haemodialysis). It includes hospital, satellite and community-based (home) dialysis.
Whilst hospitalisations of non-Aboriginal people for CVD have declined by 11% over this period, the rate amongst Aboriginal people has increased by 25%. By contrast, the diabetes hospitalisation rate has risen for all people, with Aboriginal people experiencing a 3.1 times greater rate of hospitalisations than non-Aboriginal people in 2006-07 (p<0.001). Similarly, while the rates of dialysis treatments have risen for both the Aboriginal and total NSW population, Aboriginal people experienced a 1.8 times greater rate of dialysis treatments than experienced by the total NSW population in 2007 (p<0.001).

2.5 Discussion

This review of indicators routinely reported by NSW Health has assessed how adequately those measures report outcomes by Aboriginal status against national indicators in two priority areas – maternal/newborn health and vascular diseases. The major obstacles to improved monitoring relate to both the quality and breadth of indicators currently reported. NSW Health reports on a range of chronic disease-related indicators in other areas (e.g. psychosocial, respiratory and environmental health) and augments this reporting with ad hoc research and information from national data collections. We do not make any assumptions about the quality of reporting by Aboriginal status in these other areas. For the indicators examined here, the most persistent problem affecting data quality is enumeration of Aboriginal status. For the APDC, the estimated enumeration rate of 88% is reasonable and does not, therefore, preclude useful data interpretation. The MDC, however, has persistently low enumeration rates of around 70%. Data linkage using administrative datasets is a promising area, both for quantifying and improving enumeration. Using data linkage, the 2006-07 ABS Census Data Enhancement – Indigenous Mortality Quality Study estimated NSW enumeration of Indigenous status to be 87% – substantially better than previously reported.25 NSW Health has been conducting data linkage research to enhance MDC enumeration. It is expected that revised enumeration estimates will be used in future reports.

We found other important limitations in data quality and breadth. The key additional problem with both NSW and national perinatal statistics collections is that they report by Aboriginal status of the mother and not of the baby. In NSW and nationally, 36% and 28%, respectively, of registered Aboriginal births have an Aboriginal father and non-Aboriginal
mother. This leads to gaps in our understanding of health outcomes for a large proportion of Aboriginal babies. The OATSIH Healthy for Life program and a Northern Territory indicator program are now reporting data by Aboriginal status of the baby. The next NSW Health Mothers and Babies report is expected to follow suit.

For the APDC data, only two indicators (CVD and diabetes hospitalisations) are routinely reported by Aboriginal status. Although known areas of disparity, access to CVD-related procedures and rates of diabetes complications are not regularly reported by Aboriginal status or region. Only one CKD-related indicator, dialysis treatment prevalence, was identified. Figure 2 demonstrates an apparent divergence between the rapid increase in diabetes hospitalisation rates and levelling out of dialysis prevalence, especially amongst Aboriginal women. This could be explained by delays between the onset of diabetes and the manifestation of end-stage kidney disease (ESKD), or by competing mortality from premature CVD, or by poor dialysis outcomes which might reduce the increase in dialysis prevalence despite rising incidence of ESKD. Because of marked regional variation in ESKD incidence, evidence of poorer access to dialysis in rural and remote areas, and high rates of CKD risk factors in primary health care, more comprehensive monitoring with a broader range of indicators is warranted.

A limitation to the PHS data relates to sampling. Because the 2002-05 report on adult Aboriginal health did not have an a priori design, a convenience sample was gathered over three years to obtain an adequately powered sample size. There is an over-representation of females and rural respondents. Conversely, telephone-assisted data collection might lead to a substantial under-representation of Aboriginal people in remote areas, given that only 43% of Aboriginal households in remote areas and 82% in non-remote areas report having a working telephone. NSW Health currently uses ‘Bayesian smoothing techniques’ to get better estimates at small geographical levels for the total population. This method has not been tested for Aboriginal populations, however, and its limitations are not yet known. It is also likely that assessing the prevalence of health conditions based on self-report surveys produces under-estimates. Combining health surveys with physical and laboratory measures, as is done in the US National Health and Nutrition Examination Survey, would allow for more comprehensive estimates of health status. Linking data from such surveys to primary care, hospitalisations and mortality data would allow for measurement at
multiple points in the system. The NSW '45 and up' population-based cohort study of 260,000 people plans to link self-reported survey data with other datasets; specific sub-studies will include physical/laboratory measures.\textsuperscript{36} Although restricted to those aged 45 and over, 0.8\% of the sample (2,149 people) identify as Aboriginal and/or Torres Strait Islander. This, one of the largest cohorts ever assembled, should facilitate an understanding of health status, resource utilisation and outcomes for this population.

Another objective of this review was to assess preparedness to monitor progress in the proposed national health reforms. When classified using the HPF, most of the indicators regularly reported by Aboriginal status come from Tier 1 (health status) and Tier 2 (health behaviours). Many of the current Tier 3 (health system performance) indicators are derived from the primary health care sector and are traditionally considered a federal responsibility. Increased coordination between primary, secondary and acute care services, as highlighted in the NSW State Health Plan\textsuperscript{37} and in the proposed health reforms,\textsuperscript{2,4-5} are needed to enhance performance monitoring. The 'Close the Gap' Steering Committee recommends several new primary-care based Tier 3 health indicators which expand considerably on the current diabetes-focussed indicators.\textsuperscript{18} Current primary care data monitoring is poorly equipped to monitor such indicators. Accurate enumeration of Aboriginal and Torres Strait Islander status, universal uptake of electronic medical record systems, consistent and reliable data entry, electronic management and auditing tools and regular reporting mechanisms are needed to effectively monitor primary care. Recent initiatives in the Aboriginal Community Controlled Health Services (ACCHS) sector\textsuperscript{16,27,38} hold promise, but mechanisms in the non-ACCHS primary care sector are considerably under-developed. The new reporting requirements for the Divisions of General Practice\textsuperscript{17} and initiatives such as the Australian Primary Care Collaboratives\textsuperscript{39} are potential avenues for addressing this problem.

The problems of insufficient breadth and quality of indicators are not restricted to New South Wales. Extensive reviews of health system monitoring for Indigenous peoples in Canada\textsuperscript{40} and New Zealand\textsuperscript{41} highlight that the issues identified in this paper are pertinent to all three countries. It is essential, therefore that there be an appropriate, minimum chronic disease indicator dataset against which all jurisdictions can report by Aboriginal status and region. The Aboriginal and Torres Strait Islander HPF, the most advanced
national indicator framework, is a suitable reference point for developing this dataset. Several inter-related factors ought to be considered in developing such a dataset. First, although the focus of this study was vascular and maternal/infant health, there is a need to include health systems process indicators which are not condition specific. Attention to such indicators, ideally linked to health outcomes, can facilitate an early ‘diagnosis’ of health systems problems and can anticipate reasons for delays in progress on health status improvements. Second, any proposed indicator needs to be of sufficient quality to warrant inclusion. The AIHW chronic disease indicator project group considered a quality indicator to be one that was relevant, applicable across population groups, technically sound (valid, reliable, sensitive to change, robust) and feasible to collect. It also needed to be timely, marketable and lead to action. Third, Indigenous academics and representative bodies have long argued for full participation in determining how health system performance is measured. This includes the need to embrace Indigenous concepts of health into systems measurement, building local monitoring systems at the community level to complement macro-system monitoring, and making data feedback more accessible to the communities and health services whence these data originate. The Northern Territory and Queensland indicator programs, developed by the ACCHS sector, are two successful models that adhere to these principles.

With the proposed national health reforms gaining momentum and substantial funding becoming available for COAG ‘Close the Gap’ initiatives, there is renewed vigour in addressing Aboriginal and Torres Strait Islander health disparities. Despite the challenges in ensuring robust data, it is imperative that health systems are not paralysed by waiting for perfect data before taking action. The persistent and wide disparities in health outcomes, in relation to the indicators reported in this paper, substantially outweigh data quality concerns. Nevertheless, reliable measurement of progress in addressing these disparities is needed. This requires population-representative data from the primary health care sector, improved coordination between hospitals and primary care, improved health survey sampling with the incorporation of physical/laboratory measures and sustained efforts to address under-enumeration (especially data-linkage initiatives). The NSW Chief Health Officer’s Report and the Chartbook on the quality and safety of health care in NSW are useful tools for facilitating health care improvements. Through future Chartbook iterations, the Clinical Excellence Commission will monitor progress on health disparities across
individuals' life-courses and engage with key stakeholders to improve health outcomes for Aboriginal and Torres Strait Islander people.

2.6 References


Chapter 3: Cardiovascular disease risk management for Aboriginal and Torres Strait Islander peoples in primary health care settings - Findings from the Kanyini Audit

Publication details: Peiris D, Patel A, Cass A, Howard MP, Tchan ML, Brady JP, Devries J, Rickards BA, Yarnold DJ, Hayman NE, Brown ADH. Cardiovascular disease risk management for Aboriginal and Torres Strait Islander peoples in primary health care settings - findings from the Kanyini Audit, Medical Journal of Australia 2009: 191(6), 304-309

Author contribution: I co-designed the study with co-authors Patel, Cass, Brown and Howard. I coordinated ethics submissions, designed the web database, collected data and supervised others in data collection, wrote the statistical analysis plan, performed the primary analyses of the findings, wrote the first and subsequent drafts for journal submission and was the primary author for responding to reviewer comments. Co-authors Tchan, Brady, Devries, Rickards and Yarnold assisted with project management and data collection. All co-authors reviewed and commented on the journal manuscript drafts.

3.1 Abstract

Objective: To describe cardiovascular disease (CVD) risk management in Indigenous primary health care.

Design, setting and participants: Review of 1165 randomly selected case records of Indigenous Australian adults, aged ≥ 18 years, regularly attending eight health services in diverse settings in New South Wales, Queensland and Central Australia, October 2007 – May 2008.

Main outcome measure: Adherence to CVD risk screening and management guidelines, especially with respect to overall or absolute CVD risk.

Results: More than half the people in the sample (53%) were not adequately screened for CVD risk according to national recommendations. Under-screening was significantly
associated with younger age, less frequent attendance, and lower uptake of the Medicare Health Assessment. Of the sample, 9% had established CVD, and 29% of those aged ≥ 30 years were classified as high risk according to the 2004 National Heart Foundation of Australia (NHFA) adjusted Framingham equation. Of those with CVD, 40% (95% CI, 30%–50%) were not prescribed a combination of blood pressure (BP) medicines, statins and antiplatelet agents, and 56% (95% CI, 49%–62%) of high-risk individuals without CVD were not prescribed BP medicines and statins. For high-risk individuals not prescribed BP medicines or statins, 74% (95% CI, 64%–84%) and 30% (95% CI, 23%–39%) respectively, did not meet 2004 NHFA criteria for prescribing of these medications, and of those already prescribed BP medicines or statins, 41% (95% CI, 36%–47%) and 59% (95% CI, 52%–66%) did not meet respective guideline targets.

Conclusions: These management gaps are similar to those found in non-Indigenous health care settings, suggesting deficiencies across the health system. Prescribing guidelines which exclude many high-risk individuals contribute to suboptimal management. Guideline reform and improved health service capacity could substantially improve Indigenous vascular health.

3.2 Background

The lack of progress in improving health outcomes for Aboriginal and Torres Strait Islander (Indigenous) Australians has resulted in intensified efforts to close the life expectancy gap within a generation. Despite having a 2.5-fold greater total disease burden than the non-Indigenous population, Indigenous Australians substantially under-utilise primary health care consultations, pharmaceutical subsidies and specialist care. Important barriers to improved primary health care might include this inadequate access, an insufficient capacity in health service systems and dysfunctional patient-provider interactions. At least one third of the total Indigenous disease burden is due to vascular-related disease: cardiovascular disease (CVD), chronic kidney disease (CKD) and diabetes. Six risk factors (tobacco, high body mass, high cholesterol, physical inactivity, high blood pressure, low fruit and vegetable intake) explain most of this vascular disease burden. Despite the
availability of evidence-based therapies to manage these risk factors, significant evidence-practice gaps exist in both Indigenous\(^8\) and mainstream primary health care.\(^9\)

Vascular disease prevention strategies based on a person's overall or absolute cardiovascular risk maximise benefits and outperform the traditional approach which relies on management of single risk factors in isolation.\(^10\) Risk-based targeting of safe, effective drug therapies to those most likely to benefit could substantially reduce the total disease burden.\(^11\) There has been little research on the utility of absolute CVD risk-based management in Indigenous health care settings. Improved identification and management of high-risk individuals, based on adequate risk delineation, could provide a major opportunity to reduce the burden of disease in Indigenous people.

The Kanyini Vascular Collaboration is a national health services research program established to improve vascular disease outcomes for Indigenous people. The program's first study, the Kanyini Audit, aimed to describe the identification and management of CVD risk in primary health care services and to identify opportunities for improvement.

### 3.3 Methods

An audit of a random sample of health care records of Indigenous Australian adults was conducted in collaboration with eight health services in New South Wales, Queensland, and Central Australia between October 2007 and May 2008. Sites with diverse service activity, based on size, location, funding and staffing, were selected.\(^12\) According to the Rural Remote Metropolitan Area classification (RRMA),\(^13\) two services were in capital cities (RRMA 1), two in major regional centres (RRMA 2–3), two in rural locations (RRMA 4–5), and two in remote communities (RRMA 7). Seven are Aboriginal Community Controlled Health Services and one is a state government Indigenous health service.

**Sampling**

We used electronic patient information systems at each health service to produce a list of potential participants. A case record was eligible for inclusion if it identified the patient as an Aboriginal and/or Torres Strait Islander aged ≥ 18 years who had attended the service at
least twice in the preceding 2 years. Using a random number generator, 200 records were selected in each of the five larger services, while a third of the eligible records were sampled in the three smaller services. All services predominantly used electronic health records, although supplementary paper records for ancillary information were also reviewed.

The auditors were experienced health professionals familiar with the medical software. The web-based data collection form instantaneously queried apparently spurious data entries. Prescribed medicines were searched for on a pharmaceuticals database embedded within this form (using both generic and trade names). At completion, 10% of the records were reaudited to assess inter-rater reliability.

**Estimation of CVD risk**

Based on the 1991 Anderson Framingham equation, we calculated five-year CVD risk estimates for people aged ≥ 30 years (people aged < 30 years were excluded because the Anderson Framingham equation is not validated for this group). This equation uses age, sex, smoking status, blood pressure (BP), total and high-density lipoprotein (HDL) cholesterol levels, presence of diabetes, and presence of left ventricular hypertrophy to predict the risk of a first cardiovascular event (coronary heart disease, stroke, congestive heart failure and peripheral vascular disease). As the presence or absence of left ventricular hypertrophy is not reliably documented in primary care records, this was assumed to be absent.

We calculated risk using the most recent results available (including an average of the two most recent BP readings), whether or not the subjects were being treated for that risk factor. Recognising that the Framingham equation might underestimate risk for Indigenous populations, and acknowledging the absence of population-specific risk equations, the risk estimate was adjusted based on the 2004 National Heart Foundation (NHF) of Australia recommendations. People with a recorded diagnosis of coronary heart disease, cerebrovascular disease or peripheral vascular disease were assigned to the established CVD group. People with diabetes, an albumin: creatinine ratio > 3.0 mg/mmol, or an estimated glomerular filtration rate (eGFR) < 60 mL/min/1.73m², as well as those aged
≥ 75 years, were automatically assigned a 5-year CVD risk ≥ 15%. For all others, a 5% upward adjustment to the Framingham risk estimate was applied.

**Risk factor screening and management**

The ‘screening gap’ was defined as the proportion of people, recommended for screening for a particular risk factor, for whom no result of screening had been recorded at least once in the previous 2 years. Screening recommendations for our study were based on the National guide to a preventive health assessment in Aboriginal and Torres Strait Islander peoples\(^{17}\) and the Guidelines for preventive activities in general practice.\(^{18}\) Generally, these recommend screening Indigenous people for all the Framingham equation risk factors (except left ventricular hypertrophy) from the age of 18 years.\(^{17}\) Screening recommendations for proteinuria and CKD were based on Kidney Health Australia guidelines\(^{19}\) (with screening recommended for people with any one of the following: age > 50 years, systolic BP > 140 mmHg, diabetes, current smoker, body mass index ≥ 30 kg/m\(^2\)).

Two ‘prescribing gaps’ were defined: (i) the proportion of people currently not prescribed BP medicines or statins, where the NHFA guidelines, current at the time of the audit,\(^{16,20}\) recommended treatment; and (ii) the proportion of people classified as being at high cardiovascular risk who were not prescribed BP medicines, statins or antiplatelet medicines. We also used Pharmaceutical Benefits Scheme (PBS) criteria for statin subsidies to assess prescribing gaps.\(^{21}\) The ‘treatment gap’ was defined as the proportion of people, already prescribed BP medicines or statins, in whom target levels were not being reached. The study design did not allow for an assessment of adherence to medication regimens.

The provision of Medicare Health Assessments for Aboriginal and Torres Strait Islander people aged 15–54 years (Item 710) and ≥ 55 years (Items 704, 706) were recorded. These assessments mandate recording of CVD risk-factor information, along with other preventive health measures. Medicare-rebated general practice management plans (Item 721) for people with CVD, CKD or diabetes were also recorded.
Statistical analyses

Frequency distributions were reported as proportions, means or medians. Inter-rater agreement was assessed using the $\kappa$ statistic for categorical variables, and intra-class correlation coefficients for continuous variables. A pooled, overall $\kappa$ statistic was calculated using inverted variance-weighted averages. Logistic regression models (for percentage outcome variables) and linear regression models (for continuous outcome variables) were used to assess (i) age-adjusted sex differences in risk-factor characteristics and (ii) age- and sex-adjusted associations with completeness of recording of Framingham risk-factor variables. Because frequency of health care consultations was not normally distributed, the association with screening practices was analysed non-parametrically using Wilcoxon’s rank-sum test.

Ethics approval

Our study protocol was developed in collaboration with the participating Indigenous health services and approved by four regional ethics committees. A written participation agreement was signed between each health service’s governing body and the coordinating research institutes.

3.4 Results

Sample characteristics

We reviewed 1165 case records from the participating health centres. The mean age of the patients was 41.1 years (95% CI, 40.3–42.0 years); 59% were female, and 72% were ≥ 30 years. The recorded ethnicity was Aboriginal in 90%, Torres Strait Islander in 9%, and both in 1%. We re-audited 111 case records (10%) at five sites. Inter-rater agreement was high. For the categorical variables, the pooled $\kappa$ statistic was 0.91 (95% CI, 0.88–0.93). For continuous variables, the range of the intraclass correlation coefficient range was 0.87–1.00.

Screening gaps and classification of CVD risk

An overview of management practices and risk-factor screening gaps for each health centre is given in Table 3-1. Screening gaps occurred across all sites and were not related to the
remoteness of services. Major contributors to incomplete absolute risk assessments were under-screening for cholesterol and albumin: creatinine ratio levels. Table 3-2 gives the risk-factor characteristics in people with relevant information available.
Table 3-1: Care practices and screening gaps at audited health centres, by health centre location (two centres at each location)

<table>
<thead>
<tr>
<th>Patient records and consultations</th>
<th>Capital city</th>
<th>Major regional centre</th>
<th>Rural location</th>
<th>Remote community</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of records sampled</td>
<td>200</td>
<td>200</td>
<td>200</td>
<td>75</td>
<td>201</td>
</tr>
<tr>
<td>Median (range) consultations per patient in previous 2 years</td>
<td>8 (2-69)</td>
<td>8 (2-98)</td>
<td>11 (2-106)</td>
<td>8 (2-84)</td>
<td>9 (2-56)</td>
</tr>
<tr>
<td>Consultations per patient (average %) provided by:*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td>66%</td>
<td>86%</td>
<td>47%</td>
<td>62%</td>
<td>79%</td>
</tr>
<tr>
<td>Registered nurse</td>
<td>29%</td>
<td>13%</td>
<td>26%</td>
<td>11%</td>
<td>21%</td>
</tr>
<tr>
<td>Aboriginal health worker</td>
<td>4%</td>
<td>1%</td>
<td>24%</td>
<td>22%</td>
<td>0</td>
</tr>
<tr>
<td>Other staff</td>
<td>1%</td>
<td>1%</td>
<td>2%</td>
<td>5%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Medicare Health Assessment item†</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult health check (18–54 years)</td>
<td>44%</td>
<td>20%</td>
<td>11%</td>
<td>47%</td>
<td>22%</td>
</tr>
<tr>
<td>Older persons check (≥ 55 years)</td>
<td>59%</td>
<td>35%</td>
<td>30%</td>
<td>44%</td>
<td>0</td>
</tr>
<tr>
<td>GP management plan</td>
<td>49%</td>
<td>4%</td>
<td>27%</td>
<td>17%</td>
<td>61%</td>
</tr>
<tr>
<td>Risk-factor screening gap‡</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking status</td>
<td>44%</td>
<td>13%</td>
<td>20%</td>
<td>18%</td>
<td>24%</td>
</tr>
<tr>
<td>Blood pressure</td>
<td>17%</td>
<td>16%</td>
<td>1%</td>
<td>3%</td>
<td>21%</td>
</tr>
<tr>
<td>Body mass index</td>
<td>50%</td>
<td>39%</td>
<td>32%</td>
<td>28%</td>
<td>61%</td>
</tr>
<tr>
<td>Blood sugar level (without diabetes)</td>
<td>37%</td>
<td>40%</td>
<td>10%</td>
<td>18%</td>
<td>48%</td>
</tr>
<tr>
<td>Total: HDL cholesterol ratio</td>
<td>69%</td>
<td>52%</td>
<td>58%</td>
<td>32%</td>
<td>48%</td>
</tr>
<tr>
<td>eGFR§</td>
<td>46%</td>
<td>37%</td>
<td>27%</td>
<td>23%</td>
<td>34%</td>
</tr>
<tr>
<td>Albumin: creatinine ratio§</td>
<td>80%</td>
<td>78%</td>
<td>66%</td>
<td>44%</td>
<td>84%</td>
</tr>
<tr>
<td>Framingham screening gap¶</td>
<td>74%</td>
<td>44%</td>
<td>56%</td>
<td>32%</td>
<td>46%</td>
</tr>
</tbody>
</table>

Data are percentage of column totals unless otherwise stated. HDL = high-density lipoprotein. eGFR = estimated glomerular filtration rate.

* Percentages may not add to 100 because of rounding. † Proportion of patients with a Medicare Health Assessment item in previous 2 years. The denominator for adult health checks and older persons checks was the number in the specified age range. The denominator for GP management plan was patients identified as having cardiovascular disease, chronic kidney disease or diabetes. ‡ The proportion of patients recommended for screening, but a screening result had not been recorded at least once in the previous 2 years. § The denominator for eGFR testing and albumin: creatinine ratio included those with any one of the following: age, > 50 years; systolic blood pressure, > 140 mmHg; diabetes; current smoker; body mass index, ≥ 30 kg/m2. ¶ The proportion of those aged ≥ 30 years lacking information on screening for one or more Framingham risk variables. Left ventricular hypertrophy was imputed as not present.
Table 3-2: Vascular risk-factor characteristics of patients obtained from health records

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>Women (n = 693)</th>
<th>Men (n = 472)</th>
<th>P (age-adjusted sex differences)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. with</td>
<td>No. (%) or</td>
<td>No. with</td>
</tr>
<tr>
<td></td>
<td>information</td>
<td>mean (SE)</td>
<td>information available</td>
</tr>
<tr>
<td></td>
<td>available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes†</td>
<td>693</td>
<td>149 (22%)</td>
<td>472</td>
</tr>
<tr>
<td>Family history of coronary heart disease in a first-degree relative†</td>
<td>693</td>
<td>92 (13%)</td>
<td>472</td>
</tr>
<tr>
<td>Current smoker</td>
<td>483</td>
<td>226 (47%)</td>
<td>349</td>
</tr>
<tr>
<td>Body mass index, ≥ 30 kg/m²</td>
<td>384</td>
<td>182 (47%)</td>
<td>294</td>
</tr>
<tr>
<td>Mean (SE) systolic blood pressure (mmHg)</td>
<td>642</td>
<td>122.4 (0.71)</td>
<td>409</td>
</tr>
<tr>
<td>Mean (SE) cholesterol level (mmol/L)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total cholesterol</td>
<td>410</td>
<td>4.8 (0.05)</td>
<td>275</td>
</tr>
<tr>
<td>LDL cholesterol</td>
<td>323</td>
<td>2.9 (0.05)</td>
<td>203</td>
</tr>
<tr>
<td>Triglycerides</td>
<td>410</td>
<td>2.1 (0.11)</td>
<td>276</td>
</tr>
<tr>
<td>HDL cholesterol</td>
<td>334</td>
<td>1.2 (0.02)</td>
<td>222</td>
</tr>
<tr>
<td>Total: HDL cholesterol ratio</td>
<td>334</td>
<td>4.5 (0.08)</td>
<td>222</td>
</tr>
<tr>
<td>Albuminuria§</td>
<td>194</td>
<td>88 (45%)</td>
<td>144</td>
</tr>
<tr>
<td>eGFR, &lt; 60 mL/min/1.73 m²</td>
<td>407</td>
<td>45 (11%)</td>
<td>273</td>
</tr>
</tbody>
</table>

LDL = low-density lipoprotein
HDL = high-density lipoprotein
eGFR = estimated glomerular filtration rate
* Significant differences are in bold type
† If there was no mention in the record of diabetes or family history of heart disease, it was imputed as not present.
‡ Triglyceride values were log transformed for significance testing of sex differences
§ Defined as an albumin: creatinine ratio, > 3.0 mg/mmol

Fifty-three per cent of those aged ≥ 30 years lacked information on screening for one or more Framingham risk variables. When compared with the over 30 year olds for whom all Framingham risk variables had been recorded, those with insufficient recorded risk information were significantly younger (mean age, 45.4 years v 50.2 years; sex-adjusted P < 0.001), had been seen less frequently at the health service (median number of consultations, 8 v 17; P < 0.001), and were less likely to have received a Medicare Health Assessment (26% v 68%; age- and sex-adjusted P < 0.001). However, there were no
significant sex differences and no association between care-provider category and screening for all Framingham risk variables.

Nine per cent of the total sample had established CVD, and 16%, 4% and 29% of those aged ≥ 30 years had a 5-year CVD risk of low (< 10%), medium (10%-14%) and high (≥ 15%), respectively, according to the 2004 NHFA-adjusted Framingham equation.

**Prescribing and treatment gaps**

Prescribing of BP-lowering medicines and statin therapy, respectively, as measured against NHFA guidelines, are given in Figure 3-1 and Figure 3-2. For individuals currently not prescribed statins (Figure 3-2) in whom NHFA guidelines recommend their being prescribed (n = 208), only 30% would qualify for subsidised treatment under PBS criteria.

**Figure 3-1:** Blood pressure (BP) management measured against 2004 National Heart Foundation of Australia guidelines

Except where indicated, the denominator for each percentage is the number in the preceding step.

* Treatment indication was based on a consistent reading of > 130/80 mmHg for those with diabetes or chronic kidney disease, and > 140/90 mmHg for all other patients. Target BP levels were defined as: (i) ≤ 130/80 mmHg for patients with established cardiovascular disease, diabetes, chronic kidney disease, or albumin:creatinine ratio > 30 mg/mmol; and (ii) ≤ 140/90 mmHg for all other patients.
Figure 3-2: Statin prescribing measured against 2005 National Heart Foundation of Australia/Cardiac Society of Australia and New Zealand guidelines

Except where indicated, the denominator for each percentage is the number in the preceding step.

* Treatment indication was based on a low-density lipoprotein (LDL) cholesterol level > 2.5 mmol/L or any level in the presence of established cardiovascular disease. Treatment target LDL level was defined as < 2.5 mmol/L.

† Includes 27 patients in whom the serum triglyceride level was > 4.5 mmol/L and LDL level could not be calculated.

Figure 3-3 examines prescribing gaps by CVD risk category. Forty per cent of people with established CVD were not prescribed combination therapy (BP medicines, statins, antiplatelets), and over half of the high-risk individuals without CVD were not prescribed both a BP lowering medicine and a statin. When applying the 2004 NHFA guidelines for prescribing of BP- and lipid-lowering medications for individuals classified as high risk who have not yet experienced a cardiovascular event, treatment would not be recommended for 74% (95% CI, 64%–84%) and 30% (95% CI, 23%–39%), respectively, despite their high-risk status. Similarly, when applying PBS subsidy criteria for statin prescribing to this high-risk group who have not yet experienced a cardiovascular event, 30% would not qualify for the subsidy. Receipt of a Medicare preventive health check was not significantly associated with improved prescribing of BP medicines or statins for high-risk individuals.
Figure 3-3: Prescribing of major cardiovascular medication groups by absolute cardiovascular disease (CVD) risk category*

*Five-year cardiovascular disease risk was estimated using the 2004 National Heart Foundation of Australia adjustments to the 1991 Anderson Framingham equation

3.5 Discussion

This study provides a comprehensive analysis of CVD risk identification and management in Indigenous primary health care settings. While case record audits have limitations in the accuracy of data captured, we identified several issues with important implications for the effective management of cardiovascular risk.

The first of these was the large screening gaps. Although the absolute risk-based approach has theoretical benefits, its utility was limited by under-ascertainment of risk. The screening gaps were broadly similar to those found in mainstream general practice settings, and were especially large for younger, less frequent attendees. They were not related to remote location. It was encouraging that Medicare Health Assessments were associated with significantly smaller screening gaps. Point-of-care testing could be an effective strategy to ameliorate the under-performing of cholesterol and albumin: creatinine ratio tests. Although a national point-of-care program exists, lipid testing does not attract a Medicare rebate for health services participating in this program.
Substantial prescribing gaps were encountered for those at highest risk of a CVD event, although risk management compares favourably with previous Australian and New Zealand studies. Importantly, around a third of high-risk people without CVD were classified by both NHFA guidelines and PBS subsidy criteria as not qualifying for statin therapy, and almost three-quarters did not qualify for prescribing of BP medications under the 2004 NHFA guidelines; this could be considered a ‘guideline gap’. Although the changes in the 2008 NHFA guidelines will assist BP management, substantial gaps remain in recommendations for lipid-lowering drugs. This supports the findings of Chen et al that there is not only a need for improvement in guideline adherence, but for guidelines themselves to adequately identify appropriate individuals for treatment.

The barriers highlighted above are not restricted to Indigenous health care. Although the large variability in Aboriginal and Torres Strait Islander health services may mean these findings are not representative of all service settings, the similarity in findings with mainstream general practice suggests these barriers are prevalent across the primary health care system.

Based on our study’s findings, we endorse current recommendations that an absolute risk-based approach to screening be recommended for Indigenous adults, and that this be incorporated into a preventive health assessment. This check should include the Framingham risk factors (with optional assessment of left ventricular hypertrophy) — albumin: creatinine ratio, eGFR, body mass index and waist circumference, and blood glucose level for people without diabetes, and glycated haemoglobin (HbA1c) level for those with diabetes. Although it might be reasonable to assume that younger people are less likely to have a CVD event (which might partially explain the large screening gaps in younger people), the sharp rise in Indigenous CVD mortality after the age of 30 provides a strong argument for comprehensive screening from at least this age. Although a national absolute risk-based screening guideline has recently been released, a single risk-management guideline now needs to be developed to address prescribing gaps. It must avoid the assumption that all Indigenous people are at high risk, and be linked to appropriate resourcing to support its implementation. Given the evolving and uncertain evidence base, regular revision of the guideline would be essential.
Addressing guideline-related barriers alone is not sufficient. Future work in the Kanyini Vascular Collaboration will enable a better understanding of health system barriers and enablers, which can be used to develop well evaluated, novel intervention strategies in partnership with providers of Indigenous health services. If we are to close the gaps in screening, prescribing and treatment in Indigenous primary care, substantial investment in primary health care systems is needed to implement sustainable, risk-based chronic vascular disease programs that are responsive to community needs.

3.6 References


Chapter 4: Cardiovascular risk management at a Māori-led Primary Health Organisation – Findings from a cross-sectional audit


Author contribution: I designed the study, coordinated ethics submissions, co-designed the data extraction form with Jonathan Murray, supervised Doreen Scully with data collection, wrote the statistical analysis plan, performed the primary analyses of the findings, wrote the first and subsequent drafts for journal submission and was the primary author for responding to reviewer comments. All co-authors reviewed and commented on journal manuscript drafts.

4.1 Abstract

Aim: To examine the cardiovascular disease (CVD) risk profile and management for the first 12 months of an electronic risk assessment program at Tamaki Healthcare, Auckland.

Methods: An audit of risk assessment and medication data supplemented by a manual case record review.

Results: 1522 people were screened representing around 15.5% of the eligible population. Of the 1420 people with data available, 248 (17.5%) had a calculated five-year CVD risk ≥ 15% and another 177 (12.5%) had previous CVD. Māori were significantly more likely to be at high CVD risk than non-Māori (OR 2.07 (1.51–2.84); p<0.001). For Pacific peoples (mostly of Samoan, Tongan, Niuean, Fijian, or Cook Islands origin) there was no increased likelihood of high CVD risk. Medication data were available for 399 (95.5%) people at high CVD risk. Prescribing rates for this group were 78.1% for blood pressure lowering, 71.9% for lipid-lowering, 65.3% for anti-platelet, and 50.3% for all three therapies. Whilst this group may represent the better end of the management spectrum, success in achieving
treatment targets was modest. For 451 people with either diabetes or established CVD, 65.9% and 66.1% were not meeting blood pressure and lipid management recommendations respectively. There were very few disparities in prescribing rates and attainment of target levels by ethnic group.

**Conclusion:** This study has shown that a primary care electronic risk assessment program can be rapidly implemented within 12 months. Although the sample may not be representative due to a small proportion screened so far, major disparities in risk factor prevalence rates were found, particularly for Māori. Furthermore, substantial guideline-practice gaps were encountered in the appropriate prescribing of cardiovascular medicines and attainment of recommended targets. Several Tamaki Healthcare initiatives to address these findings are discussed.

### 4.2 Background

Cardiovascular disease (CVD) is the leading cause of premature death and disability in Aotearoa/New Zealand (NZ) and it remains the main reason for the widening gap in life-expectancy between Māori and non-Māori. It is well established that absolute risk-based approaches to CVD event prediction have better discriminating ability and cost-effectiveness than the traditional, single risk factor-oriented paradigm.

Although Aotearoa/NZ has been a world leader in promoting an absolute risk based guideline, its uptake has been variable and significant gaps in evidence based care remain. The recent incorporation of electronic risk assessment tools has been promising in improving uptake of the absolute risk paradigm.

The PREDICT™ decision support system, implemented in ProCare Primary Health Organisations (PHOs) in Auckland, is producing valuable information on CVD risk factor epidemiology. Such data, along with a unique national health identifier, place the country in a good position to generate population specific risk assessment tools. Moreover, with PHO funded incentives and future national CVD performance indicators, identification of at risk populations is likely to increase over the next few years.
Despite these promising initiatives important and yet unanswered questions remain. It is not clear whether risk-based screening programs lead to improved management practices. In addition to the impact on population health outcomes this has significant implications for health planners. Furthermore, given that Māori are disproportionately affected by CVD, it is critical that research is undertaken to see whether Māori are equally benefiting from absolute risk based care. This study seeks to provide further information in these areas.

4.3 Methods

In December 2006, Tamaki Healthcare Charitable Trust, a Māori-led PHO, implemented an electronic CVD-risk assessment program across twelve of its member general practices. In 2007 a further three practices joined and one practice left the PHO leaving a total enrolled population of around 42,000 people in the Auckland area.

Based on the screening recommendations by the New Zealand Guidelines Group (NZGG), practitioners were funded to perform an electronic risk assessment for the following groups:

- Māori/Pacific/Indian subcontinent groups: men ≥ 35 years, women ≥ 45 years.
- All other ethnic groups: men ≥ 45 years, women ≥ 55 years.
- People with known risk factors for CVD or diabetes: men ≥ 35 years, women ≥ 45 years.
- People with diabetes regardless of age.

Two electronic risk assessment options were available within existing practice management systems: PREDICT and the MedTech ‘Edge-CVD management’ module. Ethnicity was derived from the PHO register through a combination of self-identification and retrieval from the National Health Index. Using the NZ coding system we grouped ethnicity into five categories: NZ European/Others, Māori, Pacific peoples, Indian subcontinent, and other Asian. Thirty-six people of mainly Middle Eastern or African origin accounted for the ‘others’ in the NZ European/Others category.

NZ Deprivation Index quintiles are geographically determined using variables from census data and are a measure of socioeconomic status (one=least deprived, five=most...)
deprived). These data are supplied by the NZ Ministry of Health and, at the time of analysis, calculations were made using the 2001 census (NZDep01). (As of July 1, 2008 all PHO registers were updated using 2006 census data.)

Data were collected from:

1. A de-identified version of routinely submitted CVD risk assessment data;
2. A medication query run at each clinic to obtain the prescription history (from January 2006 to March 2008) for those who had undergone a CVD risk assessment; and
3. A manual clinic record review of patients with either a calculated or clinical five-year CVD risk of ≥ 15% was conducted by a PHO nurse to determine details of non-pharmacological management practices.

For part (3) we purposively sampled all available Māori and Pacific records and took a random sample of other ethnicities to obtain equal proportions.

Five-year risk of a fatal or non-fatal CVD event was calculated using the 1991 Anderson Framingham equation. Event endpoints include myocardial infarction, coronary heart disease, stroke or transient ischaemic attack, peripheral vascular disease, and congestive heart failure. Included in this calculation were the NZGG five percent upward adjustments for high-risk groups. These groups are based on ethnicity (Māori, Pacific, Indian subcontinent), family history of coronary heart disease, high risk diabetes (diabetes duration >10 years, albuminuria, or HbA1C>8%) or metabolic syndrome (derived from the National Cholesterol Education Program ATPIII 2001 definition). The adjustment is made only once. Recent data suggests that the five percent upward adjustment for ethnicity is a more accurate estimate of risk.

Frequency distributions were reported as proportions or means/medians. Differences in individual risk factors and treatment prescribed for ethnic groups and social deprivation quintiles were either adjusted or standardised for age and sex. Because the major CVD-risk factors are integrated in the Framingham risk equation, we did not adjust for any of these in assessing differences in overall CVD risk across ethnic and social groups.
analyses were carried out using SAS v9.1 software (Cary, NC: SAS Institute Inc, 2002-2003).

All member practices provided written consent to participate in the study and were given the opportunity to review the final manuscript. The study was also reviewed by the chairperson of the Northern X Regional Ethics Committee and under its Observational Studies Guidelines it was determined that it did not require committee review and approval.

4.4 Results

CVD risk profile

In total, 1522 people had an electronic CVD risk assessment performed over the screening period December 2006–November 2007. Clinical data were available for 1420 people (55.7% male, 44.3% female). Only 40 people (2.8%) had more than one risk assessment performed reflecting the recent implementation of this program. For these individuals we report data from the most recent assessment. Table 4-1 below gives an estimate of the proportion of patients screened at each clinic in the target risk groups.

In calculating the number of patients in the target group we were only able to extract demographic information from the PHO service utilisation records. This means that some people with the clinical criteria for screening (outlined above) who were outside the age criteria range will be excluded from this denominator. Nevertheless a marked variation in screening rates was apparent.
### Table 4-1: Estimate of the proportion of patients in target groups screened between December 2006 and November 2007, by clinic

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Number of months in the CVD program</th>
<th>Number of patients screened</th>
<th>Number of patients in target groups seen at least once</th>
<th>Coverage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>6</td>
<td>6</td>
<td>1057</td>
<td>0.6</td>
</tr>
<tr>
<td>B</td>
<td>11</td>
<td>11</td>
<td>574</td>
<td>1.9</td>
</tr>
<tr>
<td>C</td>
<td>7</td>
<td>16</td>
<td>623</td>
<td>2.6</td>
</tr>
<tr>
<td>D</td>
<td>8</td>
<td>14</td>
<td>545</td>
<td>2.6</td>
</tr>
<tr>
<td>E</td>
<td>12</td>
<td>29</td>
<td>744</td>
<td>3.9</td>
</tr>
<tr>
<td>F</td>
<td>10</td>
<td>44</td>
<td>792</td>
<td>5.6</td>
</tr>
<tr>
<td>G</td>
<td>8</td>
<td>72</td>
<td>1239</td>
<td>5.8</td>
</tr>
<tr>
<td>H</td>
<td>9</td>
<td>15</td>
<td>191</td>
<td>7.9</td>
</tr>
<tr>
<td>I</td>
<td>7</td>
<td>54</td>
<td>413</td>
<td>13.1</td>
</tr>
<tr>
<td>J</td>
<td>12</td>
<td>169</td>
<td>1139</td>
<td>14.8</td>
</tr>
<tr>
<td>K</td>
<td>9</td>
<td>53</td>
<td>155</td>
<td>34.2</td>
</tr>
<tr>
<td>L</td>
<td>10</td>
<td>277</td>
<td>644</td>
<td>43.0</td>
</tr>
<tr>
<td>M</td>
<td>12</td>
<td>375</td>
<td>853</td>
<td>44.0</td>
</tr>
<tr>
<td>N</td>
<td>12</td>
<td>387</td>
<td>864</td>
<td>44.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1522</strong></td>
<td><strong>9833</strong></td>
<td><strong>15.5</strong></td>
<td><strong>43.0</strong></td>
</tr>
</tbody>
</table>

Table 4-2 outlines the demographic and risk factor characteristics of the sample. When compared with the population eligible for screening, there was little difference in Māori representation (13.0% of those screened vs. 14.3% of those eligible). When compared with the NZ European/other group, the major disparities by ethnicity in risk factor prevalence were due to smoking (high rates amongst Māori and Pacific, and low rates amongst Indian subcontinent people) and diabetes/metabolic syndrome (high rates amongst Māori, Pacific, and Indian subcontinent groups).
Table 4-2: The demographic and risk factor characteristics of 1420 people with a CVD risk assessment performed

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Mean age (years)</th>
<th>Personal CVD history (%)</th>
<th>Current/rec current smoker (%)</th>
<th>Mean systolic BP (mmHg) (95% CI)</th>
<th>Mean TC:HDL ratio (95% CI)</th>
<th>Diabetes (%)</th>
<th>High risk diabetes (%)</th>
<th>Family history CVD (%)</th>
<th>Metabolic syndrome (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Males</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NZ European/Other</td>
<td>219</td>
<td>58.7</td>
<td>13.4</td>
<td>22.6</td>
<td>130.8 (128.6–133.0)</td>
<td>4.14 (3.97–4.30)</td>
<td>11.8</td>
<td>45.8</td>
<td>23.5</td>
<td>11.2</td>
</tr>
<tr>
<td>Māori</td>
<td>93</td>
<td>54</td>
<td>20.7</td>
<td>35.8*</td>
<td>131.2 (127.9–134.4)</td>
<td>3.95 (3.71–4.19)</td>
<td>31.7***</td>
<td>47.9</td>
<td>34.2</td>
<td>34.3***</td>
</tr>
<tr>
<td>Pacific</td>
<td>129</td>
<td>53.3</td>
<td>10</td>
<td>29.6</td>
<td>129.9 (127.1–132.6)</td>
<td>3.81 (3.61–4.02)*</td>
<td>36.7***</td>
<td>54.8</td>
<td>22.6</td>
<td>43.5***</td>
</tr>
<tr>
<td>Indian sub-continent</td>
<td>318</td>
<td>51.1</td>
<td>16.1</td>
<td>9.8***</td>
<td>125.7 (123.9–127.5)***</td>
<td>3.92 (3.79–4.06)</td>
<td>30.0***</td>
<td>40.4</td>
<td>29.5</td>
<td>26.8***</td>
</tr>
<tr>
<td>Other Asian</td>
<td>32</td>
<td>57</td>
<td>12.4</td>
<td>2.8*</td>
<td>125.7 (120.1–131.2)</td>
<td>4.00 (3.59–4.41)</td>
<td>37.1***</td>
<td>35.5</td>
<td>8.4</td>
<td>31.5**</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>791</td>
<td>54.1</td>
<td>14.8</td>
<td>19.3</td>
<td>128.8 (127.7–129.9)</td>
<td>3.94 (3.86–4.01)</td>
<td>26.6</td>
<td>45.4</td>
<td>26.4</td>
<td>26.2</td>
</tr>
<tr>
<td><strong>Females</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NZ European/Other</td>
<td>150</td>
<td>59.6</td>
<td>9.2</td>
<td>13.8</td>
<td>131.9 (129.4–134.4)</td>
<td>3.60 (3.45–3.76)</td>
<td>13.3</td>
<td>28.7</td>
<td>23.6</td>
<td>5.4</td>
</tr>
<tr>
<td>Māori</td>
<td>92</td>
<td>57.9</td>
<td>12.2</td>
<td>50.9***</td>
<td>131.6 (128.4–134.8)</td>
<td>3.67 (3.48–3.97)</td>
<td>21.4</td>
<td>60.0**</td>
<td>38.4*</td>
<td>22.8***</td>
</tr>
<tr>
<td>Pacific</td>
<td>114</td>
<td>56.8</td>
<td>6.1</td>
<td>18.3</td>
<td>128.9 (126.0–131.7)</td>
<td>3.35 (3.17–3.52)*</td>
<td>38.0***</td>
<td>64.5***</td>
<td>28.2</td>
<td>36.4***</td>
</tr>
<tr>
<td>Indian sub-continent</td>
<td>249</td>
<td>54.6</td>
<td>10.9</td>
<td>1.2***</td>
<td>126.1 (124.1–128.1)***</td>
<td>3.34 (3.21–3.46)**</td>
<td>29.2***</td>
<td>31.7</td>
<td>32.5</td>
<td>23.7*</td>
</tr>
<tr>
<td>Other Asian</td>
<td>24</td>
<td>60.6</td>
<td>0</td>
<td>5.9</td>
<td>132.8 (126.4–139.0)</td>
<td>3.45 (3.06–3.83)</td>
<td>28.6</td>
<td>23.6</td>
<td>18.8</td>
<td>16.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>629</td>
<td>56.9</td>
<td>9.4***</td>
<td>14.8*</td>
<td>128.6 (127.4–129.5)</td>
<td>3.50 (3.41–3.56)**</td>
<td>25.8</td>
<td>44.6</td>
<td>29.9</td>
<td>21.2</td>
</tr>
<tr>
<td><strong>Total assessed</strong></td>
<td>1420</td>
<td>55.4</td>
<td>12.5</td>
<td>17.1</td>
<td>128.7 (127.9–129.5)</td>
<td>3.74 (3.68–3.80)</td>
<td>26.1</td>
<td>45</td>
<td>28.1</td>
<td>23.7</td>
</tr>
</tbody>
</table>

Notes:
Ethnic sub-group means are age adjusted and prevalences are age standardised to the total population.
Total prevalence rates are age/sex standardised.
Significance testing between ethnic groups was performed for each sex using NZ European as the referent group and was age adjusted.
Significance testing for sex differences used males as the referent group and was also age adjusted.

••• p <0.001, **0.01<p>0.001, *0.05<p>0.01
Table 4-3 below shows the NZ adjusted Framingham risk profile stratified by sex. In total 425 people (30.0%) were identified to be at high CVD risk (either a clinical or calculated five-year CVD risk of ≥ 15%). Māori were significantly more likely to be at high CVD risk than non-Māori (OR 2.07 (1.51–2.84); p ≤ 0.001). For Pacific peoples, despite high smoking rates and diabetes, there was not an overall increased likelihood of high CVD risk. This can be mainly attributed to younger age and lower past CVD event rates. For NZDep01 quintiles, the Quintile 5 group was significantly more likely to be at high CVD risk than Quintile groups 1–3 (OR 1.54 [1.19–1.99]; p<0.001).

<table>
<thead>
<tr>
<th>Gender and ethnicity</th>
<th>n</th>
<th>% receiving NZ 5% adjustment</th>
<th>% with NZ adjusted Framingham Five year CVD risk</th>
<th>% with CVD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>&lt;10% 10–14% ≥ 15%</td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NZ European/Other</td>
<td>219</td>
<td>33.8</td>
<td>45.2</td>
<td>14.2</td>
</tr>
<tr>
<td>Māori</td>
<td>93</td>
<td>100</td>
<td>28</td>
<td>18.3</td>
</tr>
<tr>
<td>Pacific</td>
<td>129</td>
<td>100</td>
<td>33.3</td>
<td>27.9</td>
</tr>
<tr>
<td>Indian subcontinent</td>
<td>318</td>
<td>100</td>
<td>54.4</td>
<td>17.6</td>
</tr>
<tr>
<td>Other Asian</td>
<td>32</td>
<td>43.8</td>
<td>56.3</td>
<td>9.4</td>
</tr>
<tr>
<td>Total</td>
<td>791</td>
<td>79.4</td>
<td>45.4</td>
<td>18.1</td>
</tr>
<tr>
<td>Females</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NZ European/Other</td>
<td>150</td>
<td>26</td>
<td>63.3</td>
<td>12</td>
</tr>
<tr>
<td>Māori</td>
<td>92</td>
<td>100</td>
<td>38</td>
<td>27.2</td>
</tr>
<tr>
<td>Pacific</td>
<td>114</td>
<td>100</td>
<td>55.5</td>
<td>22.8</td>
</tr>
<tr>
<td>Indian subcontinent</td>
<td>249</td>
<td>100</td>
<td>71.9</td>
<td>13.3</td>
</tr>
<tr>
<td>Other Asian</td>
<td>24</td>
<td>29.2</td>
<td>66.7</td>
<td>20.8</td>
</tr>
<tr>
<td>Total</td>
<td>629</td>
<td>79.7</td>
<td>61.4</td>
<td>17</td>
</tr>
<tr>
<td>Total assessed</td>
<td>1420</td>
<td>79.5</td>
<td>52.5</td>
<td>17.6</td>
</tr>
</tbody>
</table>
Medical management for high-risk individuals

Prescribing patterns – Medication data were available for 1334 people (93.9%) of the sample. Figure 4-1 below shows the prescribing patterns of the three major cardiovascular medication groups by CVD risk.

Figure 4-1: Cardiovascular medication prescribing patterns by CVD risk group (n=1334)

For the vast majority of people, the prescribing patterns for all three therapies remained consistent across the 27 months of medication history. There appeared to be little impact from the risk assessment itself in stimulating new prescriptions. For high-risk groups (either a clinical or calculated 5-year CVD risk ≥ 15%), across all ethnicities, prescribing rates were 78.1% for blood pressure lowering, 71.9% for lipid lowering, 65.3% for antiplatelet, and 50.3% for all three therapies.

For patients prescribed lipid lowering therapy, 91.3% were prescribed statins, 4.9% statins and fibrates, and 3.8% fibrates alone. Exclusion of patients prescribed fibrates alone did not appreciably change the results. For blood pressure lowering therapy, both Māori (OR
3.63 [1.64–8.08]; p=0.002) and Pacific peoples (OR 2.67 [1.25–5.70]; p=0.01) were significantly more likely to be prescribed medication when compared with NZ Europeans/others after adjusting for age and sex. No significant differences were found between the two Asian ethnic groups and NZ Europeans/others.

For antiplatelet therapy, lipid lowering therapy, and combination therapy, for all three drug groups there were no significant differences in prescribing patterns across ethnic groups. Similarly, there were no significant differences in prescribing patterns across all NZDep01 quintiles for all three therapy types and combination therapy.

Adequacy of treatment – Success in achieving target thresholds (as set by the NZGG) for people with established CVD or diabetes was examined. In these groups blood pressure targets of <130/80 mmHg and lipid levels of a total cholesterol <4 mmol/L, LDL cholesterol <2.5 mmol/L, total cholesterol: HDL cholesterol ratio <4.5 are recommended. Practitioner recording of LDL cholesterol results was not mandatory in this program and so attainment of lipid targets was largely derived from total cholesterol and total cholesterol: HDL ratio results.

Figures 4-2 and 4-3 below show the gaps in reaching target thresholds for 451 people with either diabetes or established CVD.
65.9% and 66.1% of people were either not attaining target blood pressure and lipid level recommendations respectively or were not prescribed guideline indicated therapies. There were no significant ethnicity variations in achieving target blood pressure or lipid levels with one exception – Indian subcontinent people were more likely to be achieving target lipid levels (OR 3.15 [1.80–5.52]; p<0.001) than NZ Europeans/others after adjusting for age and sex. Similarly, there were no significant differences in achieving target blood pressure or lipid level recommendations across all NZDep01 quintiles.
Other medical management for high risk individuals – Records from 283 (66.6%) of the 425 high risk patients were manually reviewed. Table 4-1 lists the key findings from this final component of the audit.
Table 4-4: Non-pharmacological care practices for people at high CVD risk

<table>
<thead>
<tr>
<th>All high risk people n=283 (Māori n=73, Pacific n=70, Indian/other Asian n=72, NZ European/Other n=68)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median number of consultations in the previous two years</td>
</tr>
<tr>
<td>Mean % of consults for each patient in which the blood pressure was checked</td>
</tr>
<tr>
<td>% with at least two documented lipid checks in the previous two years</td>
</tr>
<tr>
<td>% with documentation of lifestyle assessment or advice at least once in the previous two years for:</td>
</tr>
<tr>
<td>(1) smoking</td>
</tr>
<tr>
<td>(2) nutrition</td>
</tr>
<tr>
<td>(3) alcohol</td>
</tr>
<tr>
<td>(4) physical activity</td>
</tr>
<tr>
<td>% with a green prescription recorded*</td>
</tr>
<tr>
<td>% currently enrolled in the Care Plus programme**</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>People with diabetes (n=135)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% with a documented specialist review in the previous two years</td>
</tr>
<tr>
<td>% with a documented eye review in the previous two years</td>
</tr>
<tr>
<td>% with at least two HbA1c checks in the previous two years</td>
</tr>
<tr>
<td>% with a Diabetes Get Checked review in the previous twelve months</td>
</tr>
</tbody>
</table>

Notes:
* Green prescription is a national program in which patients are provided with written advice and a support service to adopt healthy lifestyle practices.
** The Care Plus program is a NZ Ministry of Health program for chronic care management

4.5 Discussion

This study has shown that an electronic risk assessment program can be rapidly implemented in a primary care environment with 15% of an approximate 10,000 eligible population screened in less than 12 months. Aside from the usual drawbacks of clinic records based research, the variable uptake by practitioners and inconsistent screening amongst its enrolled population is clearly the major limitation to this study. We urge caution, therefore, in extrapolating these findings to the general population. As with other studies\textsuperscript{14} it is hoped that Tamaki Healthcare's electronic risk assessment program can increase overall screening rates across all clinics and reach those at highest risk of CVD.
The factors behind the variable uptake are worth exploring via a ‘systems’ approach examining issues such as workforce capacity, information systems, financial incentives, leadership, training, and support for the program. Attention to such issues was key to improvements in CVD screening rates in two recent NZ studies. Systems level audit and feedback cycles using the Wagner Chronic Care Model have also been shown to be of benefit in Australian Aboriginal health services.

Consistent with the literature, we found Māori to be at the greatest risk of CVD. The findings suggest that some of the biggest gains for Māori in CVD risk reduction lie in smoking prevention/cessation and diabetes prevention/management. Lifestyle interventions at both the primary care and population level are key components to this. The recording rates of lifestyle management practices in this study were low. This is not to say that lifestyle management is not being performed but the findings complement the Rafter et al study highlighting that CVD lifestyle management is not well documented by most primary care practitioners. Current electronic CVD risk assessment packages have little emphasis on non-pharmacological management. Integration of lifestyle assessments into the electronic assessment along with prompts to perform brief interventions, especially smoking cessation, could improve CVD outcomes.

For pharmacological management, the prescribing patterns of the three guideline indicated therapies (antiplatelet, blood pressure and lipid lowering medicines) for high risk individuals were higher than those found by Ridell et al and markedly better than those by Rafter et al. As with the Ridell study, it was encouraging to find no evidence of ethnicity or NZDep01 quintile disadvantage in prescribing patterns. There was even some evidence that blood pressure medication prescribing was better for Māori and Pacific peoples.

The stable prescribing history may mean that these high risk individuals have a better management profile than those who have not participated in the programme and so caution should again be exercised in extrapolating these findings. Even so, despite better than previously published prescribing rates, large gaps remain with only half of individuals at high risk prescribed all three indicated therapies. Furthermore, very large gaps were found
in attaining NZGG recommended targets for blood pressure and lipid levels. Two out of every three people with either diabetes or CVD were not meeting these targets.

Despite the considerable body of research that informs clinical practice, this study reflects a consistent finding that there are substantial gaps in the uptake of evidence into routine care. Studies exploring the reasons for sub-optimal implementation of clinical guidelines in general practice indicate complex and multiple barriers at the health-system, doctor and patient level. Electronic decision support is a promising initiative to address some, but clearly not all, of these barriers. Further research is needed in Aotearoa/NZ on the best implementation strategies for well described evidence. This would help broaden our knowledge of the critical contextual issues that make the uptake of evidence successful in some settings and not in others.

As a Māori-led PHO the disparities in CVD risk between Māori and non-Māori are of prime concern to Tamaki Healthcare. These disparities are not restricted to CVD. In response, the PHO is in the process of re-orienting itself toward meeting the fundamental goal of improved and equitable health outcomes for its enrolled population. A key strategy, therefore, is to effectively engage with the PHO's provider practices in the creation of integrated programs that focus on prevention and management of chronic conditions. In an environment where limited resources need to be channelled for the greatest effect, Tamaki Healthcare considers this to be one of the areas where the greatest health gains for Māori can be made. The PHO has commenced work on a Māori model for chronic conditions management and is developing strategies to promote the uptake of this model amongst its member practices. Such a model needs to complement and go beyond traditional doctor-patient oriented care.

Existing services that exemplify this include a diabetes self management and education program which is aligned with the Whare Tapa Wha model and additional clinical services that have a specific Māori focus (dietician, health psychology, child health and smoking cessation services). Several new positions (including a cardiac rehabilitation nurse, community support worker, and two lifestyle planners) have been created to support these programmes.
The PHO will also examine whether additional financial incentives to undertake CVD reviews for Māori and other vulnerable groups will result in improved screening and management of CVD risk. Whilst increased access to services and population-based initiatives are essential, a sustained commitment on the part of government to addressing ethnic and socioeconomic inequities in health is equally crucial.

Coordinated and well resourced strategies could maximise the impact of CVD programs and ultimately enhance primary health care’s contribution to better health outcomes.

4.6 References


Chapter 5: An Electronic Clinical Decision Support Tool to Assist Primary Care Providers in Cardiovascular Disease Risk Management – Development and Mixed Methods Evaluation


Author contribution: I co-designed the pilot evaluation of the decision support tool with co-authors Joshi, Usherwood and Patel. I coordinated ethics submissions, designed the data collection forms and the interview guide with Rohina Joshi. I supervised the research assistants for data collection, conducted the interview evaluation, performed the statistical analyses, coded the interview data and co-interpreted the qualitative findings with Tim Usherwood. I wrote the first and subsequent drafts for journal submission and was the primary author for responding to reviewer comments. Co-authors Webster, Groenestein, Usherwood and Patel were responsible for initial development of the decision support tool. All co-authors reviewed and commented on the journal manuscript drafts.

5.1 Abstract

Background: Challenges remain in translating the well-established evidence for management of cardiovascular disease (CVD) risk into clinical practice. Although electronic clinical decision support (CDS) systems are known to improve practitioner performance, their development in Australian primary health care settings is limited.

Objectives: Study aims were to (1) develop a valid CDS tool that assists Australian general practitioners (GPs) in global CVD risk management, and (2) preliminarily evaluate its acceptability to GPs as a point-of-care resource for both general and underserved populations.
Methods: CVD risk estimation (based on Framingham algorithms) and risk-based management advice (using recommendations from six Australian guidelines) were programmed into a software package. Tool validation: Data from 137 patients attending a physician’s clinic were analysed to compare the tool’s risk scores with those obtained from an independently programmed algorithm in a separate statistics package. The tool’s management advice was compared with a physician’s recommendations based on a manual review of the guidelines. Field test: The tool was then tested with 21 GPs from eight general practices and three Aboriginal Medical Services. Customized CDS-based recommendations were generated for 200 routinely attending patients (33% Aboriginal) using information extracted from the health record by a research assistant. GPs reviewed these recommendations during each consultation. Changes in CVD risk factor measurement and management were recorded. In-depth interviews with GPs were conducted.

Results: Validation testing: The tool’s risk assessment algorithm correlated very highly with the independently programmed version in the separate statistics package (intraclass correlation coefficient 0.999). For management advice, there were only two cases of disagreement between the tool and the physician. Field test: GPs found 77% (153/200) of patient outputs easy to understand and agreed with screening and prescribing recommendations in 72% and 64% of outputs, respectively; 26% of patients had their CVD risk factor history updated; 73% had at least one CVD risk factor measured or tests ordered. For people assessed at high CVD risk (n = 82), 10% and 9%, respectively, had lipid-lowering and BP-lowering medications commenced or dose adjustments made, while 7% newly commenced anti-platelet medications. Three key qualitative findings emerged: (1) GPs found the tool enabled a systematic approach to care; (2) the tool greatly influenced CVD risk communication; (3) successful implementation into routine care would require integration with practice software, minimal data entry, regular revision with updated guidelines, and a self-auditing feature. There were no substantive differences in study findings for Aboriginal Medical Services GPs, and the tool was generally considered appropriate for use with Aboriginal patients.
Conclusion: A fully-integrated, self-populating, and potentially Internet-based CDS tool could contribute to improved global CVD risk management in Australian primary health care. The findings from this study will inform a large-scale trial intervention.

5.2 Background

Cardiovascular disease (CVD) accounts for 18% of the total disease burden and 11.2% of health system expenditure in Australia. Australian Aboriginal peoples experience around five times greater CVD burden than other Australians. Despite recent gains, CVD remains Australia’s biggest killer, accounting for 46,134 deaths and disability in around 1.4 million Australians in 2005. Although effective preventive therapies are available for people at high risk of a first and subsequent CVD event, substantial challenges remain in translating this evidence into clinical practice. Our recent studies of CVD risk management in mainstream Australian general practice and indigenous health service settings found around half of routinely attending adults did not have sufficient information collected to comprehensively screen for CVD risk. For those identified at high CVD risk, only a minority (31% in mainstream general practice settings and 40% in indigenous health services) were prescribed guideline-indicated medications.

The reasons for suboptimal implementation of clinical guidelines include complex and multiple barriers at the health system, doctor, and patient level. For a time-constrained general practitioner (GP), consolidating numerous guidelines to make clinical decisions is challenging. This is particularly true for CVD, where overall or absolute risk assessment is recommended and simultaneous management of multiple risk factors is required. Despite guideline endorsement of the absolute risk-based approach, few Australian GPs use cardiovascular risk assessment tools to guide management.

Clinical decision support (CDS) – in Australia also commonly called electronic decision support (EDS) – is one of the most promising interventions to improve uptake of guideline-based recommendations in clinical practice. In two systematic reviews on the effectiveness of CDS, around two-thirds of studies demonstrated improvement in practitioner performance. Key features of successful interventions included instantaneous output
generation for use at the point-of-care, minimal data entry, provision of automatic prompting for GPs, and a requirement that GPs actively respond to recommendations.

A number of controlled evaluations of CDS systems that are integrated with electronic medical records (EMRs) have been conducted in the areas of CVD risk and diabetes. They have shown variable improvements in risk factor screening/documentation and overall processes of care. Beyond trial settings, several countries have successfully implemented large-scale CDS systems for CVD risk in primary care settings. In the United Kingdom, an electronic CVD risk assessment (but not decision support) package is being integrated into one of the most commonly used GP software systems. In the United States, the ATHENA decision support system is able to be integrated with a variety of primary care software platforms to promote guideline-based management of blood pressure (BP). In New Zealand (NZ), an Internet-based CVD risk management system based on the New Zealand Guidelines Group recommendations has been fully integrated into the country’s most popular medical software platform. This system has demonstrated improvements in uptake of CVD risk assessments. Although there have been attempts in Australia to consolidate evidence about CVD management into a point-of-care paper chart tool, GPs would prefer decision support in an electronic format.

Here we outline our methods for the development of a CDS tool and present the findings of a preliminary evaluation of its use in primary care settings. This forms the first stage of a broader research and development program that will lead to the implementation and controlled evaluation of a tool that is fully integrated into Australian primary care software systems.

5.3 Methods

Development of the CDS tool

For risk assessment, an algorithm was written based on the 1991 Framingham risk equation to predict five-year risk of a first CVD event (coronary heart disease, stroke, congestive heart failure, peripheral vascular disease). Recognizing that this equation might underestimate risk for certain clinical conditions and for specific ethnic groups, adjustments were made using recommendations from the New Zealand Guidelines Group.
and guidelines from the National Heart Foundation (NHF) of Australia.\textsuperscript{26,27} The risk factor variables and adjustments are summarized in Textbox 5-1.

**Textbox 5-1: Framingham risk equation variables and adjustments used for calculation of 5-year CVD risk in the Clinical Decision Support tool**

**Framingham risk factor variables:**
- Age
- Sex
- Smoking status
- Blood pressure (BP)
- Total and high-density lipoprotein cholesterol levels
- Presence of diabetes
- Presence of left ventricular hypertrophy

A 5\% increase to the baseline risk score is made once only if any of the following are present:
- History of premature CVD in a first-degree relative
- Body mass index $\geq$ 30 kg/m$^2$
- Total cholesterol $> 8$ mmol/L
- Systolic BP $> 170$ mmHg
- Diastolic BP $> 100$ mmHg
- Diabetes duration $> 10$ years
- Glycated hemoglobin (HbA1C) $> 8\%$ for the last 12 months
- High-risk ethnic background (Aboriginal, Torres Strait Islander, Māori, Pacific peoples, South Asian)

Age $\geq 75$ years and calculated 5-year risk $< 15\%$, then risk is adjusted to 15\%.

If the following high-risk conditions are present and calculated 5-year risk is $< 20\%$, then risk is adjusted to 20\%:
- Established CVD (coronary artery disease, ischemic cerebrovascular disease, peripheral vascular disease)
- Left ventricular hypertrophy
- Genetic dyslipidemias
- Diabetes and chronic kidney disease (estimated glomerular filtration rate [eGFR] $< 60$ mL/min/1.73 m$^2$)
- Proteinuria (defined as either albumin to creatinine ratio $\geq 30$ mg/mmol or proteinuria $> 1$ g/day)

To define the risk management outputs of the tool, pharmacological treatment recommendations from six Australian CVD-related guidelines current in 2007 were consolidated into a single algorithm.\textsuperscript{26,28-31} The thresholds and treatment targets for BP, lipid, and anti-platelet management are summarized in Textbox 5-2.
Text Box 5-2: Indications and target levels for CVD medication management programmed into the Clinical Decision Support tool

1. **Anti-platelet medication indications:**
   - Established coronary heart disease
   - Diabetes
   - Ischemic cerebrovascular disease

2. **BP medication**

   Indications for commencing treatment:
   - BP > 125/75 mmHg for the following:
     - Diabetes and proteinuria (defined as either albumin to creatinine ratio > 30 mg/mmol or proteinuria > 1 g/day)
     - Diabetes and chronic kidney disease (defined as eGFR < 60 mL/min/1.73 m²)
   - BP > 130/80 mmHg for all others with diabetes or isolated proteinuria
   - BP > 140/90 mmHg and any one of the following:
     - Established CVD
     - Chronic kidney disease (eGFR < 60 mL/min/1.73 m²)
     - Aboriginal, Torres Strait Islander, Pacific Islander, Maori, South Asian background
     - Adjusted 5-year CVD risk > 10% (assuming lifestyle advice given for 3-6 months)
   - BP > 150/95 mmHg and adjusted 5-year CVD risk < 10% (assuming lifestyle advice given for 3-6 months)

   **Target treatment levels:**
   - BP < 125/75 mmHg for those with diabetes and proteinuria
   - BP < 130/80 mmHg for:
     - All others with diabetes
     - Chronic kidney disease
     - Isolated proteinuria
     - Age < 65 years
   - < 140/90 mmHg for all others

3. **Lipid medication**

   Indications for commencing treatment:
   - Established CVD at any level
   - Genetic lipid disorders at any level
   - Diabetes and serum triglycerides > 2 mmol/L
   - Low-density lipoprotein cholesterol > 2.5 mmol/L and any of the following:
     - Diabetes
     - Aboriginal or Torres Strait Islander
     - Adjusted 5-year CVD risk > 15%

   **Target treatment levels:**
   - Low-density lipoprotein cholesterol < 2.5 mmol/L

The risk assessment and management algorithms were programmed into a stand-alone software package (Igor Pro 6, WaveMetrics Inc, Portland, OR, USA) that produced a single-page output. If there was complete risk factor information available, a risk score was generated and plotted along a colour spectrum bar and treatment recommendations were
provided. If information required for absolute risk assessment was absent, the output identified the variables missing and the colour bar was changed to greyscale. Because many Australian guidelines are not exclusively risk based, some treatment recommendations could still be made despite incomplete risk factor information. Examples of these two types of output are shown in Figure 5-1 and Figure 5-2.
Figure 5-1: Sample Clinical Decision Support output with complete information and color bar

Risk assessment inputs:

- **Age:** 63
- **Sex:** Female
- **Left-ventricular hypertrophy:** No
- **Current (last 12 months) smoking:** Yes
- **Total-Cholesterol:** 4.8
- **Triglycerides:** 1.0
- **HDL-Cholesterol:** 1.3
- **LDL-Cholesterol:** 3.0
- **Systolic BP:** 142
- **Diastolic BP:** 86
- **Creatinine:** 105 µM
- **Proteinuria:** No
- **Diabetes:** Yes
- **Diabetes for more than 10y:** No (Rx 2005)
- **HbA1c >8% more than 1 year:** No
- **History of cardiovascular disease (CVD):** No
- **Genetic dyslipidemia:** No
- **Family history of CVD:** No
- **Higher risk ethnicity:** No
- **Body mass index:** 28.7 kg/m^2
- **Lipid therapy:** No
- **Blood pressure therapy:** No
- **Antiplatelet therapy:** Yes

Estimated 5-year risk: 21% (high)

### Consider the assessment, treatment and target levels of:

- **Absolute risk assessment** is recommended because age is ≥ 50, and elevated BP, elevated lipids, diabetes, and chronic kidney disease are present.
- **Diabetes monitoring** is recommended.
- **Lipid evaluation** is recommended at age ≥ 45, diabetes, CVD, smoking, and elevated BP are present.
- **BP monitoring** is recommended as age is over 18 years, urate elevated blood pressure present.
- **Smoking cessation or reduction** is recommended for multiple health benefits.
- **Lipid modifying therapy** is recommended as diabetes and elevated lipids, and elevated risk are present.
- **BP lowering therapy** is recommended as multiple indications are present.
- **Antiplatelet therapy** is recommended as diabetes is present.
- **Blood pressure lowering therapy** is not meeting target as diabetes is present and BP > 130/85mmHg.
Figure 5-2: Sample Clinical Decision Support output with incomplete information and greyscale bar
Validation testing of the tool

De-identified data from all consecutive patients with complete risk factor information attending a specialist vascular clinic over a 3-month period (May to August 2008, n = 137) were entered into the tool by a trained research assistant to generate CDS outputs. The validity of these outputs was assessed in two parts. First, a researcher who was not involved with the algorithm development programmed the Framingham risk equation and adjustments into a second statistical software package, STATA version 9.2 (Stata Corporation, College Station, TX, USA). Correlation between risk scores generated from the CDS tool and the STATA program were assessed. Second, an experienced physician, blinded to the CDS tool management recommendations, reviewed the risk assessment data for each patient. She then performed a manual review of the guidelines and assessed whether anti-platelet, BP-lowering, and lipid-lowering medications were indicated or whether targets were being met for those patients already prescribed BP-lowering and lipid-lowering drugs. Agreement between the CDS tool and the physician’s recommendations was assessed.

Field testing in primary health care

The tool was field tested in two different Australian primary health care settings: eight teaching general practices in Sydney and three Aboriginal Medical Services (AMSS) in New South Wales. Sampling was purposive and sought GPs interested in research and training who might critically appraise the tool and provide recommendations for its future development. A diversity sample in terms of GP age, gender, and size of practice was sought. Consecutive, routinely attending patients (Aboriginal ≥ 35 years, non-Aboriginal ≥ 45 years) were invited from the waiting room to participate. The patient age range is based on Australian guideline recommendations for absolute risk assessment screening. Each GP had outputs generated for around 10 patients. This number was considered sufficient to allow (1) adequate exposure to a variety of tool outputs, (2) an appreciation of the tool’s application in a typical working day, and (3) minimal administrative burden to the GP or the practice. Figure 5-3 provides a schema for how the study was conducted. Because the pilot version of the tool was built using stand-alone software, it lacked the ability to pre-populate with demographic and clinical data already existing in the EMR. Thus, the key role of the research assistant was to act as a proxy for this pre-populating feature by
accessing the relevant risk factor information from the patient's EMR. In essence, this simulated the situation that might occur if the tool was built into the GP's practice software system. The resultant output was given to GPs prior to the consultation for review with their patients.

Figure 5-3: Study schema for evaluation of the Clinical Decision Support tool

Clinic staff inform potentially eligible participants (Aboriginal clients aged >35 years, non-Aboriginal > 45 years) irrespective of the reason for their visit

Step 1
Research Assistant (RA) obtains informed consent from participant to access his/her health record

Step 2
RA obtains available data from practice software and paper files and enters data into EDS software on own laptop. The EDS output is generated by the tool and the RA prints this.

Step 3
RA gives doctor the printed EDS output prior to the consultation. Doctor completes a brief questionnaire evaluating the output at the end of the consultation

Repeat Steps 1-3 for 10 consecutive participants

End of study
Doctor completes a separate end of study questionnaire & participates in an interview evaluation
Evaluation and analyses

A mixed methods evaluation was conducted following the methods outlined by Tashakkori and Teddlie. Specifically, the quantitative and qualitative components were equally weighted and combined simultaneously to obtain an understanding of the effectiveness (quantitative), acceptability (quantitative and qualitative), and feasibility (qualitative) of a CDS tool for CVD risk management in primary care settings.

At the end of each consultation, GPs completed a short survey on their attitudes about the tool and management provided. At study completion, GPs completed a second survey on their practice characteristics. This survey adapted some questions from a previously published instrument. GPs then participated in an in-depth interview evaluation. Interviews were semi-structured and conducted by a GP researcher who had a practical working knowledge of the tool in clinical settings. Interviews covered three domains: (1) general attitudes about the tool and its impact on the consultation; (2) a review of specific tool outputs; (3) recommendations for future tool development. Full details of the survey instruments and interview guide are provided in Attachments 1-3.

Descriptive statistics and quantitative analyses were conducted using SAS version 9.1 (SAS Institute Inc, Cary, NC, USA). Management decisions were assessed as to whether GPs acted on recommendations from the tool output. Interview recordings were professionally transcribed, and thematic content analysis was performed drawing on the methods outlined by Patton. Interview transcripts were initially reviewed in their entirety to become familiar with the data. They were then open coded to core thematic categories and these analyses were conducted contemporaneously with data collection. At the end of study, the investigator team met on several occasions to determine how these open-coded categories would be relationally grouped to determine the final major themes. NVivo 8 (QSR International, Melbourne, Victoria, Australia) was used to help organize the data through this analysis process.

The study was approved by both the Sydney South West Area Health Service and Aboriginal Health and Medical Research Council ethics committees. Patients and GPs gave written informed consent to participate in the study. Signed agreements were obtained from the three participating AMSs.
5.4 Results

Validation of the tool

The tool’s risk assessment algorithm showed near perfect correlation with the independently programmed algorithm used in STATA (intraclass correlation coefficient 0.999). The variation was wholly explained by different rounding methods used in each software program. For prescribing recommendations, agreement between the tool and the physician’s recommendations for initiation of anti-platelet and lipid treatment was 100%. Agreement on meeting guideline targets for those already prescribed BP- and lipid-lowering treatments was also 100%. Agreement on initiation of BP treatment was 97% (kappa 0.95). In both cases of disagreement, the BP was < 125/75 mmHg and the physician judged that treatment was not indicated, while the tool recommended that treatment could not be determined due to missing information on proteinuria.

Field testing – Quantitative evaluation

Twenty-one GPs participated in the study. Practices varied greatly in size, ranging from a solo GP practice with minimal administrative support to a large practice with 23 GPs and 15 nurses. Table 5-1 outlines GP characteristics and their use of electronic practice management features. Table 5-2 shows the risk factor characteristics of the patient population by Aboriginal status and prescribing rates of preventive CVD medications.
Table 5-1: Characteristics of the 21 participating GPs in the Clinical Decision Support pilot study

<table>
<thead>
<tr>
<th>Feature</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>12</td>
<td>57</td>
</tr>
<tr>
<td>Age group (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>30-39</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>40-49</td>
<td>11</td>
<td>52</td>
</tr>
<tr>
<td>50+</td>
<td>6</td>
<td>29</td>
</tr>
<tr>
<td>Postgraduate qualifications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fellowship of the Royal Australian College of GPs</td>
<td>15</td>
<td>71</td>
</tr>
<tr>
<td>Diploma (e.g. obstetrics, child health)</td>
<td>11</td>
<td>52</td>
</tr>
<tr>
<td>Master (e.g. public health)</td>
<td>4</td>
<td>19</td>
</tr>
<tr>
<td>Participate in research sometimes or often</td>
<td>19</td>
<td>90</td>
</tr>
<tr>
<td>Use of Internet at least once daily</td>
<td>19</td>
<td>90</td>
</tr>
<tr>
<td>Electronic practice software features always used</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication prescribing</td>
<td>20</td>
<td>95</td>
</tr>
<tr>
<td>Automated pathology results downloaded</td>
<td>19</td>
<td>90</td>
</tr>
<tr>
<td>Online billing</td>
<td>14</td>
<td>67</td>
</tr>
<tr>
<td>Electronic patient recalls</td>
<td>13</td>
<td>62</td>
</tr>
<tr>
<td>Scanning of paper documents</td>
<td>12</td>
<td>57</td>
</tr>
<tr>
<td>Electronic care plans</td>
<td>12</td>
<td>57</td>
</tr>
<tr>
<td>Disease registers</td>
<td>7</td>
<td>33</td>
</tr>
<tr>
<td>Frequency of performing cardiovascular risk assessments for Aboriginal 35+ years, non-Aboriginal 45+ years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>Less than 50% of the time</td>
<td>16</td>
<td>76</td>
</tr>
<tr>
<td>Greater than 50% of the time</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Preferred method of assessing risk</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Zealand guidelines color charts</td>
<td>15</td>
<td>71</td>
</tr>
<tr>
<td>Calculators within medical software</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Other methods (e.g. downloaded calculator)</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Risk assessment never performed</td>
<td>3</td>
<td>14</td>
</tr>
</tbody>
</table>
Table 5-2: Baseline risk assessment characteristics of 200 patients attending their GP

<table>
<thead>
<tr>
<th></th>
<th>Non-Aboriginal (n = 134)</th>
<th>Aboriginal (n = 66)</th>
<th>Total (n = 200)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years (mean ± SD)</td>
<td>51.5 ± 29.8</td>
<td>50.1 ± 10.62</td>
<td>51.1 ± 25.1</td>
</tr>
<tr>
<td>Female</td>
<td>79 (59%)</td>
<td>45 (68%)</td>
<td>124 (62%)</td>
</tr>
<tr>
<td>Recorded diabetes</td>
<td>37 (28%)</td>
<td>30 (46%)</td>
<td>68 (34%)</td>
</tr>
<tr>
<td>Current smokerb</td>
<td>36 (27%)</td>
<td>33 (50%)</td>
<td>69 (35%)</td>
</tr>
<tr>
<td>5-year adjusted CVD risk</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low risk (&lt;10%)</td>
<td>28 (21%)</td>
<td>16 (24%)</td>
<td>44 (22%)</td>
</tr>
<tr>
<td>Moderate risk (10-15%)</td>
<td>12 (9%)</td>
<td>9 (14%)</td>
<td>21 (11%)</td>
</tr>
<tr>
<td>High risk (&gt;15%), excluding established CVD</td>
<td>28 (21%)</td>
<td>11 (17%)</td>
<td>39 (20%)</td>
</tr>
<tr>
<td>Established CVD</td>
<td>30 (22%)</td>
<td>13 (20%)</td>
<td>43 (22%)</td>
</tr>
<tr>
<td>Unable to estimate risk due to missing information</td>
<td>36 (27%)</td>
<td>17 (26%)</td>
<td>53 (27%)</td>
</tr>
<tr>
<td>Medication prescribed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lipid-lowering</td>
<td>67 (50%)</td>
<td>31 (47%)</td>
<td>98 (49%)</td>
</tr>
<tr>
<td>Anti-platelet</td>
<td>50 (37%)</td>
<td>20 (30%)</td>
<td>70 (35%)</td>
</tr>
<tr>
<td>BP-lowering</td>
<td>85 (63%)</td>
<td>37 (56%)</td>
<td>122 (61%)</td>
</tr>
</tbody>
</table>

* Reported as no. (%) unless otherwise indicated. Percentages may not add to 100% due to rounding.

b Current smoker or quit within past 12 months.

For the 200 CDS outputs generated for review, GPs agreed or strongly agreed that the output was easy to understand (77% of outputs), that screening and prescribing recommendations were appropriate (72% and 64% of outputs, respectively), and that recommendations on treatment targets were appropriate (70% of outputs). Fifty-two (26%) patient records were updated with CVD-related information, most commonly family history, past history of CVD, and smoking status. Figure 5-4 highlights the changes in risk factor screening and management following the consultation. Ninety-five (48%) patients received changes to their management, of whom 49 (52%) received lifestyle advice on CVD risk factors. For people assessed at high CVD risk (n = 82), 10% and 9%, respectively, had lipid-lowering and BP-lowering medications commenced or dose adjustments made, while 7% newly commenced anti-platelet therapy.
Figure 5-4: CVD management practices before and after a consultation involving the Clinical Decision Support tool

5-4-1: Risk factor recording rates

- Urinary albumin creatinine ratio
- Blood pressure (BP)
- Cholesterol (including HDL)
- Body mass index
- Estimated glomerular filtration rate
- Smoking status

% of total sample (n=200)

- Previously performed & not updated
- Previously performed & updated
- Not previously performed & newly checked
- Not previously performed & not checked

5-4-2: Prescribing of CVD medicines for those at high CVD risk (5 year CVD risk >15% or established CVD) (n=83)

- Anti-platelet + BP + Lipid lowering
- BP + Lipid lowering
- Anti-platelet medicines
- Lipid lowering medicines
- BP lowering medicines

% of high risk individuals

- Already prescribed
- Newly prescribed
- Not prescribed

5-4-3: Attainment of guideline targets for individuals at high CVD risk already prescribed CVD medicines

- BP lowering treatment (n=66)
- Lipid lowering treatment (n=54) (Missing information for n=1)

% at high risk already prescribed CVD medicines

- Already reaching target
- Not reaching target & treatment changed
- Not reaching target & no change to treatment
Field Testing – Qualitative Evaluation

All GPs participated in the interview evaluation, with interviews ranging from approximately 30 to 60 minutes duration. One interview was conducted with a pair of participants, two interviews were conducted over the telephone, and the remainder were individual face-to-face interviews. Three major themes arose from the interview content analysis that will be reported here. A fourth substantive theme was identified that related to how tools are used in general practice and the role of evidence-based medicine in decision making. As this issue extends beyond factors related to the CDS tool and was not a specific objective of the study, an in-depth analysis of this theme will be conducted separately.

Theme 1: Systematic provision of care

Most GPs felt that the tool was effective in providing comprehensive support in CVD risk management, both at the point-of-care and as an adjunct to reviewing their clinical performance.

Oh well it does help, because it’s your data there ... and you look at it and you think ‘Oh gee, that’s not there. I haven’t put that in’ or ‘Well yeah, they are not to target there’ ... So it’s just a reminder that you might think you’re doing okay, but there’s nothing like seeing the actual figures to make you realize that ‘Okay, there’s room for improvement here.’ [Interview 7: Male GP over 60 years]

I think it was quite a good thing because you would finish the consultation about whatever that was about and then you’d almost have a separate time set for looking at cardiovascular risk ... Otherwise, I would think about doing it through the consultation, but you just seem to forget and then you would think ‘Oh damn it, I should have done that.’ So having that piece of paper there gave you that conversation: ‘Well now we’ve finished everything, let’s look at this.’ [Interview 12: Male GP 40-49 years]

I think it’s useful to us ... It’s basically like a mini audit. So anything that makes you look a little bit deeper at the person sitting in front of you is always worthwhile ... [Interview 19: Male AMS GP 40-49 years]

Importantly, however, recommendations based on single risk factor readings, out-of-date, or even false readings undermined the full benefit of such a tool. GPs sought clarification on the underlying assumptions in how risk was calculated and management recommendations were made. For the few GPs who were dissatisfied with the tool’s recommendations, these issues accounted for much of that dissatisfaction.
It gives information which, as it's blandly presented, you go, 'How did you get that?' I got a couple of people where I got a 20% number and you go, 'Oh that's madness, that's not you,' and often because it's based on single digit information ... like a single blood pressure. [Interview 11: Male GP 50-59 years]

The other issue I have with this data which came up is it uses the last available input ... I think what would be really good is something that came up and said, 'This is the risk, but we've used data that's three years out of date ... You need to be doing it again.' ... just a reminder to say, 'Ah, I should be thinking about that for everyone.' I think that would be really useful. [Interview 17: Female AMS GP 20-29 years]

GPs further highlighted the need for ongoing revision as guidelines are updated.

We're used to every month getting a download of the new drug file, the new program data ... with therapeutic guidelines ... There's a little button that says, this is emerging guidelines or these are the things that have just been incorporated within it ... You don't really want to be working on guidelines that are too old. [Interview 11: Male GP 50-59 years]

**Theme 2: Risk communication**

Despite only brief exposure to the tool, many GPs commented on its role in risk communication. The synthesis of multiple risk factor information onto a single page appeared to promote a beneficial dialogue with patients. The need for an evaluation from the patient perspective was highlighted.

I think the biggest impact is that it changed the way I talked about what I was doing with patients, in that it made it a much more slick, neat package to describe the normal screening that you do for risk management. And so I felt it was easier to deliver some description of where they're at now. And from their point of view, I mean it's hard to know, but they seemed to understand that it was a multifactorial thing, rather than just being one of those single disease problems ... The thing that I don't really know, that I guess would be useful, is what they think when they walk out the door, what they actually understand of what I've said. [Interview 2: Female AMS GP 40-49 years]

Most noteworthy was the prominence of the color bar (see Figure 5-1) in promoting discussions about risk management.

I like this one [referring to the color bar] ... I mean, everyone knows that red means danger, so if they're heading towards this one, it's a lot more visual, the impact ... [Interview 15: Female AMS GP 30-39 years]

I could see the potential for using it to discuss with the patient ... I like the fact that it had that nice bar with the color gradations because my other previous use of trying to describe risk has been using that one from the New Zealand calculator, and it's very
complicated. It’s too complicated. And I find it really, you know, very pretty, but difficult for the patient to really get much sense out of. So I liked that single bar. I thought that was much more useful for people. [Interview 9: Female GP 50-59 years]

Yeah, and even the colored diagram is really helpful in seeing and being able to say, ‘Look, this is going into orange – this says high in red.’ And there’s almost an emotional response to the colors that come back there that is actually really useful compared to me saying, ‘Look, people with diabetes have heart attacks and strokes.’ [Interview 4: Male AMS GP 30-39 years]

Additionally, some GPs considered that interactively changing the risk factor profile and resulting risk score (including color category) would facilitate conversations about the relative contributions of individual risk factors to overall risk.

I could think on the absolute risk bar, if you’ve got an arrow for where they sit now, potentially you could have an arrow for if you were to modify what was modifiable and where could you get. ‘You [the patient] could ultimately work your way down to here,’ and it might be a way of saying, ‘Well, there is the gap,’ and that might be helpful as a motivator. [Interview 8: Male GP 30-39 years]

So that gets me thinking about talking to the patient about the relative merits of putting them on drugs compared to smoking, and I think as an interactive thing I could bring up this thing and change her smoking or change her BMI … and say, ‘This is a much simpler way of dramatically changing your absolute risk.’ [Interview 16: Male AMS GP 50-59 years]

**Theme 3: Challenges for implementation in routine care**

While GPs felt that it was appropriate and feasible to incorporate CVD risk management into routine care, the time pressures in doing so were highlighted. A major potential constraint identified would be the time required for data entry. A common view expressed was that a tool integrated with practice software would need to be pre-populated with as much risk factor information as possible.

I think it depends on the patient. The ones where I think it takes most time are those where it’s not been brought up and it turns out that the risk is high. So where you feel the stakes are higher … and it’s not really been on your radar and it’s certainly not been on the patient’s radar. There aren’t that many of those. For most of the patients where the risk is high, you’re already aware that their risk is high … In that context, it isn’t that much extra work. [Interview 4: Male AMS GP 30-39 years]

I’m not sure how you can do it, because some are from pathology reports coming back, some things you have to measure, and then some people don’t put it in the right boxes. They just type in. So if you don’t put it in the right place, then the software won’t be able to pick it up. If I have to go enter [data] into this thing, then I’m pretty
sure very few people are going to do it ... just like the New Zealand one ... But, if you could extract it automatically, or maybe I fill in the occasional one ... then that’s fine. [Interview 10: Male GP 50-59 years]

One of my rules in general practice is ‘every 30 seconds counts,’ so if it becomes something that slows the program down, if it becomes something that blocks your progress on doing what you want to do ... they’re the things that would make it less usable ... rather than becoming distracted by this thing because you are stuck with closing boxes and pop-ups and forced to put data in ... What I like about this [the CDS tool], it pulls information together for you so you don’t have to look through 7, 8 different places ... [Interview 11: Male GP 50-59 years]

This was considered particularly germane to GPs who are less comfortable with EMR use and where information may not be stored in an extractable format.

Less-computer-literate doctors will find it less useful because they don’t have the information there ... So, if people put garbage in, you will get garbage out, and I don’t think that is going to change ... I can’t imagine a paper file doctor wanting to use the tool in the first place. So I think your target is only likely to be people who are more computer savvy. [Interview 8: Male GP 30-39 years]

Some GPs advised of the need for a more graphically oriented layout and innovative prompting mechanisms that avoid contributing to the already congested number of ‘pop-up’ prompts present in their systems. Additionally, some GPs felt that the screening (as opposed to management) recommendations offered little additional value and, in their time-poor context, may distract from the recommendations about indicated preventive therapies.

I find it all too wordy ... I can’t read those words while I’m sitting there with a patient. I still have to sit there and think, ‘What does that sentence actually mean?’ So, it needs to be very graphic, where it says the same thing to you graphically. [Interview 2: Female AMS GP 40-49 years]

[The tool was] almost too busy ... I’ve only got a minute to glance at it ... People normally wait about four, six weeks to come and see me, and so they’ve got a lot of stuff they want to see me about ... I don’t need to know that lipids evaluation is recommended for those aged over 50. What you want is the real necessary stuff ... those first four things (the screening recommendations) actually weren’t necessary ... You’ve got 15 minutes at most and ... if you don’t have that information in the first two lines, people won’t read it. [Interview 14: Female GP 40-49 years]
5.5 Discussion

This preliminary evaluation demonstrates that a valid decision support tool for CVD risk management can be successfully developed and that such a tool was favorably received by GPs working in two distinct primary health care settings. The baseline prescribing patterns of CVD medications to high-risk individuals were broadly similar to those reported in our previous Australian audit studies. The improvements in risk factor screening and the intensification of existing therapies were promising signs of the tool’s ability to promote absolute risk-based care. It was also encouraging that despite, or perhaps because of, the high rates of Aboriginal CVD burden, the tool was viewed positively by AMS care providers. A large-scale controlled evaluation would clearly be needed to substantiate these preliminary study findings.

The evaluation identified key aspects of both the tool’s scientific design and functionality that are likely to be crucial for successful wider implementation. Our findings support the systematic review evidence that CDS tool features associated with improved performance include factors such as integration with routine workflow, provision of automated decision support, and provision of recommendations rather than simply assessments. Perhaps the most fundamental finding from this study is that CDS tools need to be effectively incorporated into routine care and avoid being viewed as an optional, additional burden to the workload. Integration within existing medical software systems and maximal use of information contained in other parts of the EMR would reduce data entry and increase the tool’s use. Although the uptake of EMRs in the Australian primary care system is widespread for prescribing medications and pathology services, their routine use for other purposes is more variable. This poses both challenges and opportunities for CDS tools. In this pilot, the research assistant accessed health information from disparate parts of the EMR, including free-text information. The ability to automatically ‘push’ data into a CDS tool and limit burdensome data entry is dependent on the extent to which information exists in an extractable format. If the amount of extractable information is scant, this could pose a major barrier to use of CDS tools. The tool itself, however, can be utilized as a strategy to overcome this problem. If the information that is entered directly into the tool can be ‘pulled’ back into the appropriate parts of the EMR, then there is a dual purpose being served – that of performing a clinically relevant task at the point-of-care and a data
cleaning process. In practical terms, this would mean that the CDS output would either be automatically generated based on existing data or prompt the practitioner for any missing data. This missing data could then be entered directly into the tool and written back to the appropriate part of the health record, avoiding the need for double data entry. This makes future risk assessments easier to perform, affords extraction of more reliable data for auditing and quality improvement purposes, and supports the use of shared electronic health records across multiple service providers. Full EMR integration is also a key consideration in supporting other components of chronic disease management such as chronic care plans, well person’s health assessments, and audit cycles of care (all of which attract Australian government-funded rebates). This could ensure that the tool facilitates existing care, rather than competes with it.

The NZ Web-based decision support system for CVD risk has been purposefully designed to be ‘agnostic’ to the EMR environment and is capable of pushing and pulling data with a variety of commercial products. As a centrally deployed system, there is also a mechanism for rapid implementation of updates as subsequent guidelines evolve (already a priority issue in Australia given that three new CVD-related guidelines have been released since initial programming of this tool). In order to meet these specification requirements in the Australian context, adequate resourcing and a close collaboration between researchers and EMR vendors are needed. The Medical Software Industry of Australia, which is the peak representative body for all EMR providers, the Australian Health Information Council, and the Australian government’s National E-Health Transition Authority are key stakeholders that can assist with establishing industry standards on CDS tools. Furthermore, endorsement of these tools by the peak national bodies responsible for generating and disseminating guidelines could further increase GP confidence in their validity.

An important consideration for future development of the tool is to more fully understand its impact on communication of CVD risk between care provider and patient. This study confirms previous findings that GPs use these tools to facilitate the provider–patient interaction. Of particular note was the role of the color spectrum bar in communicating risk information and the desire to interactively change this based on different risk scenarios. While this tool examined decision support for the care provider, further work examining how best to provide decision support for the patient is needed. This includes
identifying acceptable formats for conveying risk information, evaluating the impact of decision support on health care interactions, and exploring its potential for use outside the clinical consultation (e.g. self-management programs and personal eHealth records).

**Limitations**

A limitation of this preliminary evaluation was that changes in care provider practices were based on a single consultation, reducing the ability to assess the potential impact of the CDS tool over time. A second potential limitation was the sampling method. Rather than seek a representative sample, we sought GPs who might actively contribute to the future development of the tool. AMSs were considered important settings to assess whether the tool was acceptable for use in a population with high levels of health disadvantage. Despite this purposive sampling, the types of medical software used, the electronic features used within those software systems, and the rates of performing absolute risk assessments were broadly similar to those reported in the Australian literature.12,36

**Future Implications**

The implications of a CDS tool for CVD risk management extend well beyond being a point-of-care clinical resource. Data from UK CVD risk programs have allowed for the generation of population-specific risk prediction equations that outperform Framingham-based algorithms.20 The NZ decision support system, combined with linkage to mortality and hospital databases, is similarly allowing for rapid advances in CVD risk factor epidemiology. The combination of a centrally managed Internet-based system with local management of program specifics by primary health organizations allows for a ‘ground up’ approach to incorporating population health aspects into such systems. Along with epidemiological advances, both the UK and NZ systems allow for the use of large-scale primary care data to monitor health system performance. In Australia, such systems will play an integral role in the broader eHealth strategies being proposed to reform the health care system.37-39 Performance measures in CVD risk management are integral to the UK Quality and Outcomes Framework and are allowing for large-scale analyses of regional variation and progress in reducing health inequalities.40 In Australia, this is especially pertinent to addressing Aboriginal health inequities where specific indicators for the measurement and reduction of CVD risk are proposed.41 Awareness of these broader issues
and incorporation of the major study findings into the next phase of the project will
provide a strong foundation to develop, implement, and evaluate an integrated CVD risk
management system in Australian primary health care.

5.6 References


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   pressure-lowering regimen among 6105 individuals with previous stroke or transient

   of pravastatin on mortality in patients with and without coronary heart disease across

7. The Heart Outcomes Prevention Evaluation Study Investigators. Effects of an
   angiotensin-converting enzyme inhibitor, ramipril, on cardiovascular events in high-

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9. Webster RJ, Heeley EL, Peiris DP, Bayram C, Cass A, Patel AA. Identifying the


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5.7 Attachments

Attachment 1: GP questionnaire completed at the end of each patient consultation

Attachment 2: GP questionnaire completed at the end of the study

Attachment 3: GP interview guide
Attachment 1: GP questionnaire completed at the end of each patient consultation

Electronic Decision Support Feasibility Study
End of consultation questions

Patient ID: [______] Sex (F/M): [__]  

We are collecting this information to evaluate the EDS tool and develop it further. This is an untested tool; please use your clinical judgment to manage your patient. Your assistance is appreciated.

Please note that the questions below apply for this patient only.

<table>
<thead>
<tr>
<th>Please indicate whether you agree or disagree with the statement below</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Don't know or not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The EDS printout was easy to understand</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The screening/monitoring recommendations were appropriate</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The treatment recommendations were appropriate</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>For patients already taking BP or cholesterol medicines, the recommendations on meeting targets were appropriate</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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</tr>
</tbody>
</table>

2. Did you update your clinical records based on the recommendations of the EDS tool?  
   If yes, which of the following did you add or update?  
   Yes No

   ☐ Family history of cardiovascular disease
   ☐ Past history of cardiovascular disease
   ☐ Smoking status
   ☐ Genetic dyslipidaemia/ Familial Hypercholesterolaemia
   ☐ Diabetes status
   ☐ Other cardiovascular disease related information (please specify):

3. Did you order or perform any of the following for your patient in this consultation?  
   If yes, please tick as many as apply.  
   Yes No

   ☐ Blood pressure
   ☐ Total cholesterol
   ☐ Fasting Blood glucose/GTT
   ☐ Height & weight
   ☐ HDL
   ☐ Serum creatinine/eGFR
   ☐ Waist circumference
   ☐ LDL
   ☐ Urinary Albumin:Creatinine Ratio
   ☐ Urinalysis
   ☐ Triglycerides
   ☐ HbA1c
   ☐ ECG
   ☐ Electrolytes
   ☐ Other tests (please specify):

4. Did you change the treatment plan for your patient?  
   If yes, which of the following did you change or add?  
   Yes No

   ☐ Blood pressure lowering therapy
   ☐ Blood glucose lowering therapy
   ☐ Lipid lowering therapy
   ☐ Anti-platelet therapy (aspirin, clopidogrel, dipyridamole etc.)
   ☐ Lifestyle modification advice (either Smoking, Nutritional, Alcohol or Physical Activity advice)
   ☐ Other treatments (please specify)
Attachment 2: GP questionnaire completed at the end of the study

Electronic Decision Support
Feasibility Study
End of study GP questionnaire

We are collecting this information to evaluate the Electronic Decision Support tool and develop it further. Because this is an untested tool we are interested to know your opinions about its feasibility for use in General Practice. Your responses to the questions below will give us important background information about you and your practice and will take about 15 minutes to complete. All responses are private and confidential. Your assistance is greatly appreciated.

Section 1: Your Background

1.1 What is your age?
- [ ] 20-29
- [ ] 30-39
- [ ] 40-49
- [ ] 50-59
- [ ] 60 or over

1.2 What is your gender?
- [ ] Male
- [ ] Female

1.3 What is the primary language you speak at home?

1.4 What country were you born in?

1.5 From which university did you obtain your medical degree?

1.6 Please list up to four of your post-graduate medical qualifications below:

<table>
<thead>
<tr>
<th>Qualification</th>
<th>Institution</th>
<th>Year awarded</th>
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<tbody>
<tr>
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</tbody>
</table>

1.7 Are you vocationally registered?
- [ ] Yes
- [ ] No

1.8 How many sessions per week do you work at this practice?

1.9 How many sessions per week do you work elsewhere?

1.10 How often do you participate in research?

<table>
<thead>
<tr>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

1.11 How often do you conduct your own research?

<table>
<thead>
<tr>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>
### Section 2: Practice Characteristics

**2.1** How many of each category of the following staff are employed in this practice? (If none then please write '0'):

<table>
<thead>
<tr>
<th>Staff Category</th>
<th>Doctors</th>
<th>Nurses</th>
<th>Aboriginal Health Workers</th>
<th>Practice Managers</th>
<th>Other administrative staff</th>
<th>Allied Health professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Nurses</td>
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<tr>
<td>Aboriginal Health Workers</td>
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<tr>
<td>Practice Managers</td>
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<tr>
<td>Other administrative staff</td>
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<tr>
<td>Allied Health professionals</td>
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</tbody>
</table>

**2.2** Which of the following best describes access to bulk-billing at your practice? (please choose one)

- Exclusively bulk-billing
- Selective bulk-billing (e.g., children, seniors, concession card holders)
- No bulk-billing
- Other billing arrangements (please specify):

**2.3** Is your practice accredited?

- [ ] Yes
- [ ] No

If so what year was the practice first accredited? (please leave blank if you don’t know): __________

**2.4** Please indicate your agreement or disagreement with the following statements about your practice.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I consider this practice to be innovative.</td>
<td></td>
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</tr>
<tr>
<td>We are actively doing things to improve quality of care.</td>
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<tr>
<td>After we make changes to improve quality, we evaluate their effectiveness.</td>
<td></td>
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<tr>
<td>We have quality problems in our practice.</td>
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<tr>
<td>Our procedures and systems are good at preventing errors from occurring.</td>
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</tbody>
</table>

2
### Section 3: Use of Information Technology

#### 3.1 How often do you use the Internet for personal and/or professional use, including e-mail from home, work, or another location?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>□</th>
<th>□</th>
<th>□</th>
<th>□</th>
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</thead>
<tbody>
<tr>
<td>Several times a day</td>
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<tr>
<td>Daily</td>
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<td>Weekly</td>
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<tr>
<td>Monthly</td>
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<tr>
<td>Less than monthly or not at all</td>
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</tbody>
</table>

#### 3.2 Which practice software system do you currently use at your practice?

- Medical Director
- MedTech
- Best Practice
- Practix
- Other (please specify):

#### 3.3 Overall how satisfied are you with the computer systems at your practice?

- Very Unsatisfied
- Ununsatisfied
- Neutral
- Satisfied
- Very Satisfied

#### 3.4 Please indicate which of the following features you use in your practice.

<table>
<thead>
<tr>
<th>Feature</th>
<th>Not available at this practice</th>
<th>Available but I do not use it</th>
<th>I use some of the time</th>
<th>I use most or all of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic medication prescribing</td>
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<td></td>
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<tr>
<td>Electronic pathology ordering</td>
<td></td>
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<tr>
<td>Electronic downloads of pathology results</td>
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<tr>
<td>Electronic care plans</td>
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<tr>
<td>Electronic disease registers (e.g. diabetes)</td>
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<tr>
<td>Electronically generated recalls (e.g. immunizations, pap smears)</td>
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<tr>
<td>Electronic on-line billing</td>
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<tr>
<td>Scanning of paper documents into practice software (e.g. specialist letters)</td>
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</tr>
</tbody>
</table>
3.5 How much of a barrier is each of the following to successful implementation of computer systems at your practice?

<table>
<thead>
<tr>
<th>Area</th>
<th>Not a barrier</th>
<th>Minor barrier</th>
<th>Major barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff training</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Privacy/ Security concerns</td>
<td></td>
<td></td>
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<tr>
<td>Medical software limitations</td>
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<td></td>
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<tr>
<td>Technical limitations (e.g. slow response time of computers, poor technical support)</td>
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</tbody>
</table>

3.6 Please indicate how positive the impact of computer systems has been for each of the areas below.

<table>
<thead>
<tr>
<th>Area</th>
<th>Very negative</th>
<th>Somewhat negative</th>
<th>No effect</th>
<th>Somewhat positive</th>
<th>Very positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>The practice of evidence based medicine</td>
<td></td>
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<tr>
<td>Patient-doctor communication</td>
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<tr>
<td>Patient privacy</td>
<td></td>
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<tr>
<td>Practice cost efficiencies</td>
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<tr>
<td>Overall patient safety (e.g. reduction in medication errors)</td>
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</tr>
</tbody>
</table>

**Section 4: Access to medical information**

4.1 Please indicate how influential the following sources of medical information are in your practice.

<table>
<thead>
<tr>
<th>Source</th>
<th>Not influential</th>
<th>Somewhat influential</th>
<th>Very influential</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation and discussion with GP colleagues</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Correspondence with specialists</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Pharmaceutical company representatives</td>
<td></td>
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<tr>
<td>Drug product information within clinical software (e.g. MIMS)</td>
<td></td>
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<tr>
<td>Continuing Medical Education (CME) events</td>
<td></td>
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<tr>
<td>Conferences</td>
<td></td>
<td></td>
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<tr>
<td>Australian Medicines Handbook</td>
<td></td>
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<tr>
<td>Medical newspapers (e.g. Medical Observer/ Australian Doctor)</td>
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<tr>
<td>Australian Family Physician</td>
<td></td>
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<tr>
<td>Peer-reviewed journals</td>
<td></td>
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<tr>
<td>Evidence Based Medicine guides (eg. Up to Date)</td>
<td></td>
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<tr>
<td>Personal Internet searches (Google, PubMed etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical guidelines from professional organisations</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
4.2 Please indicate how influential the following clinical guidelines are on your clinical practice.

<table>
<thead>
<tr>
<th>Guideline</th>
<th>I am not aware of this guideline</th>
<th>Not influential</th>
<th>Somewhat influential</th>
<th>Very influential</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Heart Foundation &quot;Hypertension Management Guide for Doctors&quot;</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>National Heart Foundation and Cardiac Society of Australia and New Zealand &quot;Position Statement on Lipid Management&quot;</td>
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</tr>
<tr>
<td>National Heart Foundation &quot;Reducing Risk in Heart Disease&quot;</td>
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<tr>
<td>The RACGP &quot;Red Book&quot;- &quot;Guidelines for Preventive activities in General Practice&quot;</td>
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<td>Diabetes Australia and RACGP &quot;Diabetes Management in General Practice&quot;</td>
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<td>Kidney Health Australia- &quot;Chronic Kidney Disease Management in General Practice&quot;</td>
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<td>Therapeutic Guidelines- Cardiovascular</td>
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<tr>
<td>The Pharmaceutical Benefits Scheme criteria for lipid lowering therapies</td>
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</table>
### Section 5: Use of cardiovascular risk assessments

For patients over 45 years (or over 35 years for indigenous patients), on average how often would you calculate cardiovascular risk?

<table>
<thead>
<tr>
<th>Always</th>
<th>More than 50% of the time</th>
<th>Less than 50% of time</th>
<th>Never</th>
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</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

If you do calculate your patients' cardiovascular risk which of the following resources do you use?

- Paper colour charts (e.g. NPS, Heart Foundation, New Zealand)
- Risk calculators within your medical software
- On-line or downloaded risk calculators
- Other risk calculation methods: *(please specify)*

Thank you for your participation!
Attachment 3: GP interview guide

Department of General Practice, Westmead Hospital

Electronic Decision Support Feasibility Study End of study Evaluation Interview guide

Part 1: General overview of the EDS tool
The aim of the EDS tool is to assist GPs through the provision of decision support for the management of cardiovascular risk. I'd like to start by talking about your personal experience of the EDS tool, and then go on to ask your views about its applicability in general practice more generally.

a. Overall, what do you think was the impact of the EDS tool on the quality of care you were able to provide for your patients?

b. How useful was the EDS tool in supporting communication with your patients?

c. How effective was the EDS tool in assisting you to practise according to national guidelines for cardiovascular risk management?

Part 2: The EDS output
I'd now like to show you some sample printouts from patients enrolled in the study at your practice.

a. What did you find useful about the EDS printout?

b. What information was not helpful in the EDS printout?

c. Was there anything confusing about the printout?

d. How could we improve the printout?

Part 3: Implementation of the EDS in General Practice
Our future plans are to integrate the EDS into the commonly used medical software in General Practice.

a. If we do this, what do you see as its potential benefits?

b. Would you anticipate any disadvantages?

c. What barriers do you think we would face? [Probe: practical/ technical/ other]

d. How do you think we could improve it?

e. Would you personally consider using it in your practice? [Probe: why/ why not?]

Part 4: Wrap up
a. Are there any other issues not covered that you would like to talk about?
PART B: EXPLORING THE CONTEXTUAL FACTORS THAT INFLUENCE HEALTH CARE ACCESS AND QUALITY FOR INDIGENOUS PEOPLES
Chapter 6: What influences access to health services for Indigenous peoples in Australia, New Zealand, Canada and USA? A qualitative systematic review utilising candidacy theory and focusing on chronic illness care

Planned publication details: Peiris D, Weeramanthri T, Ingram S, Bleasel J, Devitt J, Cass A, What influences the accessibility of health services to Indigenous peoples in Australia, New Zealand, Canada and USA? – A qualitative systematic review utilising candidacy theory and focussing on chronic illness care. An abbreviated version is currently being prepared for submission to BMC Health Services Research

Author contribution: I designed the study, conducted the literature searches, was the primary reviewer of the documents retrieved, coded half of the documents retrieved and supervised Jonathan Bleasel to code the remainder. In consultation with the co-authors I conducted the thematic analyses, wrote the first and subsequent drafts of the chapter and am the primary author responsible for progressing this to journal submission. Co-authors Weeramanthri, Ingram, Bleasel and Devitt assisted with the critical appraisal of the qualitative studies. All co-authors reviewed and commented on chapter drafts.

6.1 Abstract

Background: Despite extensive literature documenting inequities in access to health care for Indigenous peoples in Australia, New Zealand, Canada and USA, there have been limited reviews of the literature to understand why this occurs. The recent construct of ‘candidacy’ was developed to analyse health care access for vulnerable populations. It describes the ways in which eligibility for health care is jointly negotiated between individuals and health services. It recognises that both parties have explicit and implicit criteria for whether health care is sought or provided. In this study we assess the utility of ‘candidacy’ theory, building a theoretical framework for identifying the factors integral to improving Indigenous peoples’ access to health care.
Methods: A qualitative systematic review was conducted drawing principally on three synthesis methods, meta-ethnography, critical interpretive synthesis and thematic synthesis. We analysed 394 empirical and grey literature documents from Australia, New Zealand, Canada and the USA, written between 1990 and 2007, which were retrieved via a combination of database searches and purposive sampling.

Results: Four interrelated thematic domains were identified that affect Indigenous peoples' candidacy to health care: (1) authoritarian discourses characterised by oppressive practices of the State and disease-dominated, biomedicalised care; (2) Indigenous discourses characterised by the right to self-govern health services and to promote alternate models of care; (3) health service organisational structures that are easy to navigate especially through the availability of Indigenous staff, adequate resources and a focus on quality improvement; and (4) health care encounters built on the trustworthiness of care providers, awareness of broader contextual factors which affect the acceptance and refusal of care, and adequate attention to communication dynamics (both the medium and message). A fifth theme, prevalent across all domains, was related to constructions of cultural difference and cultural safety as barriers/enablers to candidacy.

Conclusions: Candidacy is a useful construct for understanding access issues at the organisational and health care encounter levels. There are, however, broader systemic issues at play in which care is negotiated between (1) a predominantly non-Indigenous State that adjudicates through its institutions how care is offered and (2) a predominantly Indigenous counter-movement that seeks to maximise participation in shaping those institutions. Complex interventions that synergistically enhance candidacy at multiple levels (health care encounters, organisations and macro systems) are therefore needed to improve service accessibility for Indigenous peoples.

6.2 Background

There is extensive literature documenting inequitable access to health care for Indigenous peoples in Australia, New Zealand, Canada and USA. Despite this ample evidence there have been few attempts to systematically review the literature for the underlying reasons. In this review we synthesise the literature to better understand how Indigenous peoples’
accessibility to health services is conceived and talked about. There are contested definitions of 'access'. For this review we take a broad view drawing on Pechansky and Thomas' concept of access as 'the degree of fit between clients and the health care system'. Guilford et al. suggests that access is a multi-dimensional concept that is not merely about service availability but also incorporates broader factors related to utilisation, acceptability and affordability, relevance, effectiveness (with a focus on beneficial health outcomes) and equity. This broader notion of 'access', therefore aligns it closely to 'quality' of care, particularly Donabedian's original notion of 'maximalist' quality which is the level and type of care that provides the greatest improvement in health regardless of cost. Indeed amongst the many dimensions of quality, access is usually one major component alongside others (effectiveness, efficiency, safety, equity, appropriateness, timeliness, acceptability, patient responsiveness, satisfaction, health improvement and continuity). Rather than attempting to disentangle access from these other dimensions, we have embraced this ambiguity in our appraisal of the literature.

Our theoretical approach is based on Dixon-Woods and colleagues' 'critical interpretive synthesis' of literature related to health care access for vulnerable groups in the United Kingdom. Authors of this review, similarly, took a much broader view of access than merely service utilisation. The emphasis was on an inductive synthesis of the literature rather than a more traditional aggregative review. It included a diverse body of literature rather than exclusive reliance on empirical research. From this review a core synthetic construct termed candidacy was developed. Candidacy describes the ways in which eligibility for medical attention and intervention is jointly negotiated between individuals and health services. It examines the dynamic interplay between users and providers of a service to understand barriers and recognises that both parties may have explicit or implicit criteria for whether health care is sought or provided. Three sub-themes within the theory are particularly pertinent to this review: (1) Navigation and permeability of services. This refers to the routes taken by people to gain a point of entry to health services. It requires an awareness of where to go and the mobilisation of personal, social and practical resources in order to gain access. Permeable services require little negotiation for entry and a minimal level of understanding of how the system works; (2) Presentations, adjudications and offers. This describes the circumstances under which people appear, are invited or coerced into health care. It also refers to health professional judgements about eligibility for care,
the processes by which care is offered and patient decisions to accept, refuse or resist care; and (3) Tractability. This refers to the policies, structural developments, resource allocations and interventions undertaken by services to address inequity in access to health care.5

Dixon-Woods and colleagues' review found that health service users in vulnerable groups must work hard to promote their candidacy to health care and that the depth and complexity of this effort can evolve into insurmountable obstacles. Health services are frequently poorly equipped to identify and overcome these obstacles. The candidacy construct provides a useful lens to identify the weaknesses, obstacles and fractures in health care systems and their effects on accessibility for disadvantaged groups. In this review we apply this lens to determine its utility in the Indigenous health care context for the four countries in question and we seek to identify factors that might be integral to improving Indigenous peoples’ access to health care.

6.3 Methods

The overall conduct of the review was guided by recommendations from the Evidence for Policy and Practice Information and Co-ordinating Centre.6 A review team was assembled comprising Indigenous and non-Indigenous people from diverse research disciplines (anthropology, health policy, primary health care, health services research, and health communication). The following review question was proposed: what influences the accessibility of health services for Indigenous peoples in Australia, New Zealand, Canada and USA? To narrow the scope somewhat we examined accessibility to chronic illness care and prevention with a particular focus on three inter-related chronic conditions: cardiovascular diseases (CVD), chronic kidney disease (CKD) and diabetes. The concepts underlying the candidacy constructs were then reviewed and critiqued before commencing document searches.

Literature search strategy

We took a broad and inclusive search strategy in the initial stages using the three core elements of the review question as our search terms: (1) Indigenous peoples from Australia, New Zealand, Canada, USA (2) health care services; and (3) chronic illness care
and prevention. The search period was 1990-2007 inclusive. The international databases examined included: Medline, EMBASE, the Cochrane library, PsycINFO, ERIC, Science Citation and Social Science Citation Indexes via the Web of Science, CINAHL, BiblioMap and HealthPromise. The electronic database search was then augmented by purposive sampling with a specific focus on capturing grey literature sources. The grey literature was considered key in determining perspectives that are not traditionally represented in academic journals—especially Indigenous perspectives. The views of health care consumers, community groups, clinicians, health service managers, Indigenous representative bodies, government and non-government organisations were sought. To access this grey literature we conducted searches within government and non-government websites, general searches using ‘Google’ and ‘Google scholar’, a number of Australasian databases (AMI, APAIS-Health, ATSImhealth, Health and Society, RURAL, Meditext) via Informit and the Australian Indigenous Health Infonet and recommendations from personal contacts with experts in the field. As we gained more familiarity with the content, forward and backward citation tracking from key articles and hand searching of themed issues in specific journals was also conducted.

**Exclusion criteria**

Although the themes from the candidacy constructs were helpful in reviewing which documents to include, these were not exclusively relied upon when making decisions on which documents were included for review. We performed an initial scoping exercise based on a cursory review of the types of literature that had arisen from the various searches. This allowed us to iteratively refine our exclusion criteria. Four main areas of exclusion were identified: (1) empirical studies that quantified disparities in health status, risk factors and health service utilisation between Indigenous and non-Indigenous peoples were excluded as we were exploring the reasons for these disparities rather than their magnitude; (2) documents with a health focus beyond the domain of health services, particularly community-based health promotion, workforce education issues and research methods were considered outside the review scope; (3) documents focussed on clinical management and treatment guidelines were considered not relevant; and (4) disease specific documents not pertaining to the inter-related cluster of CVD, CKD and diabetes were excluded unless reviewers considered they addressed health service issues applicable.
to any health conditions. Documents included for analysis were categorised into primary descriptive studies (sub-classified by study design), interventions and program descriptions/evaluations, and other sources not based on primary data (sub-classified into reviews, reports, opinion pieces, editorials/letters and other grey literature sources). The full search and exclusion process is shown in Figure 6-1.

**Data management**

Citations, including abstracts or complete references where available, were exported to Endnote X (Thompson Reuters Carlsbad, CA) from each database search and then merged to produce a single dataset. Duplicates and irrelevant sources were then removed. Additional references found from purposive sampling were then added. This dataset was then exported and tabulated in Microsoft Excel. Sources that met the exclusion criteria were classified by the reason for exclusion and removed. Full text documents were mainly obtained via electronic downloads and where this was not possible, print versions were procured from a professional librarian service and electronically scanned. The final dataset of included documents was then imported into NVivo (QSR International Melbourne, Vic) and managed for analysis.

**Synthesis methods**

We explored and were influenced by a variety of synthesis techniques, particularly those of meta-ethnography, critical interpretive synthesis and thematic synthesis. Our approach was pragmatic and intuitively driven rather than strictly adhering to any one method. The analysis process was conducted in three stages.

First, commencing with the qualitative studies, we sought to gain an initial impression of the types of themes talked about in the literature. A quality appraisal process was conducted for these studies using the National Health Service Critical Appraisal Skills Program (CASP) tool. We were aware of the controversies surrounding quality appraisal checklists and took an exploratory approach to this activity. This initially involved four team members in the appraisal of a small sample of qualitative studies. Each reviewer rated his/her level of agreement with the ten CASP statements on a 3 point scale (0=disagree, 1=neutral, 2=agree). The form we used is shown in Attachment 1. At a subsequent meeting
each reviewer discussed his/her rationale for the scores assigned to each of these studies. Following this, two reviewers then conducted a quality appraisal for all qualitative studies in the dataset using the CASP tool.

Second, full text documents within each classification group were read and coded line by line in NVivo using the methods outlined by Thomas and Harden. This allowed us to obtain a descriptive map of the emergent themes. This process was done iteratively, initially by the whole review team, to develop preliminary themes and then continued by two reviewers for the remainder of the data. These two reviewers remained in constant discussion about themes emerging from their respective readings. Modifications to the themes and their definitions were carried out. In this process we were influenced by Noblitt and Hare's notion of \textit{reciprocal translation} in which key concepts in each source were identified and an attempt was made to translate these concepts into subsequent readings of other sources. This was initially a highly dynamic process where ways of explaining the data were postulated, contested and subsequently revised or discarded. It was facilitated by regular informal discussion with the broader review team. The descriptive mapping allowed us to appreciate dialectical relationships between particular themes. Drawing on Noblitt and Hare's concept of \textit{refutational synthesis} and Dixon-Woods and colleagues emphasis on the \textit{critical} analysis of contrary evidence, this allowed us to explore ambiguities and tensions in the evidence. This process of identifying thematic consistency and tension was conducted both within and across the various document types. As the analysis progressed this interactive development and mapping of themes became less vigorous and a certain level of stasis was attained somewhat akin to the notion of saturation in qualitative empirical work.

Third, following the quality appraisal and descriptive mapping stage, we developed more conceptually complex analyses of the key themes within the principal domains identified in the descriptive map. A feature common to all qualitative synthesis techniques is the development of 'third order' interpretations that maintain a clear connection to the primary data but go beyond a mere summative analysis of major themes. Noblitt and Hare refer to this as \textit{lines-of-argument synthesis}. Although we were open to generating new synthetic constructs, we were particularly interested in examining consistency with and divergence from the synthetic constructs already developed within candidacy theory. Consequently,
there was a further critical analysis process that involved going back and forth from the candidacy constructs to the thematic domains developed in the descriptive mapping phase. At frequent moments in this process we returned to the coded data and conducted repeat readings of particular documents to ensure our overall synthesising arguments remained salient. As much as possible, we heavily referenced the source data so as to provide some degree of transparency in how these synthesising arguments were developed.

6.4 Findings

Data extraction and classification of the sources

Figure 6-1 below illustrates the data extraction process using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses format.\(^\text{13}\)
Figure 6-1: Data extraction, exclusion process and classification of documents

International databases searched (1391 references retrieved)

Merged data set (1282)

Full text documents analysed in NVivo (354)

Excluded articles (888 references removed)
- Disparities in health status & health service utilisation (182)
- Not of specific relevance to health services (eg. community based health promotion) (218)
- Focus on other diseases- mental illness (126), maternal & child health (54), cancer (41), other (42)
- Research methods and approaches (36)
- Health professional training and education (89)
- Disease management guidelines (14)
- Full text source unable to be obtained (24)
- Miscellaneous reasons (27)

Primary descriptive research (134)
- Health service audits (12)
- Surveys (42)
- Qualitative studies (80)
- Evaluation discussed (30)
- Quantitative (21)
- Qualitative (5)
- Mixed (6)

Interventions/projects (65)
- No evaluation discussed (25)
- Explicit search strategy (5)
- No explicit search strategy (61)

Review Articles & Reports (78)
- Government/NGO reports (12)
- Opinion pieces (79)
- Letters/editorials/commentaries (29)

"Grey" literature (127)
- Other (eg. conference proceedings, speeches, interviews) (19)
Qualitative studies – critical appraisal

Four members of the review team conducted a detailed appraisal and analysis of five qualitative studies. The appraisal scores using the CASP tool are shown in Table 6-1 and demonstrate considerable variation in the scores assigned by each reviewer.

Table 6-1: Quality appraisal scores for five qualitative studies using the Critical Appraisal Skills Program (CASP) Tool

<table>
<thead>
<tr>
<th>Study</th>
<th>Reviewer 1</th>
<th>Reviewer 2</th>
<th>Reviewer 3</th>
<th>Reviewer 4</th>
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<td>Bartz 1999</td>
<td>10</td>
<td>19</td>
<td>16</td>
<td>15</td>
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<tr>
<td>Browne 2001</td>
<td>17</td>
<td>19</td>
<td>14</td>
<td>18</td>
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<tr>
<td>Cram 2003</td>
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<td>18</td>
<td>16</td>
<td>16</td>
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<tr>
<td>Ritchie 2001</td>
<td>14</td>
<td>6</td>
<td>11</td>
<td>15</td>
</tr>
<tr>
<td>Towle 2006</td>
<td>12</td>
<td>19</td>
<td>18</td>
<td>19</td>
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</table>

*For each of the 10 CASP tool questions reviewers were asked to rate their agreement with the statement (0 = disagree, 1 = neutral, 2 = agree) up to a maximum total score of 20. See Appendix 1 for details.

The key explanation for the disparity appeared to be each reviewer’s *gestalt* opinion on the inherent appeal of the study. This related to factors beyond the tool questions and was especially influenced by the reviewer’s background and experience. For example, the ethical conduct of the research was of prime importance to one reviewer, for another the use of inappropriate jargon in the methods affected his reading of one study and for two reviewers with extensive qualitative research experience the ability to shed new light on a topic was key. There was, however, much greater agreement amongst the team on the key themes arising from each paper. With this caveat in mind two reviewers then appraised all 80 qualitative studies using the CASP tool. A marked variation in the quality of the studies was noted. Fourteen studies scored below ten; nineteen studies scored between ten and fourteen; twenty-three studies scored between fifteen and seventeen; and twenty-four studies scored greater than seventeen. Appraisal scores for the 80 studies are available in Attachment 2.
Thematic syntheses

Seventeen substantive themes were identified from the 394 full text sources reviewed. Table 6-2 highlights the density of themes by document type. We grouped these themes into five inter-related domains (represented diagrammatically in Figure 6-2) and these are discussed in detail below.
<table>
<thead>
<tr>
<th>Theme</th>
<th>Audits</th>
<th>Surveys</th>
<th>Qualitative Studies</th>
<th>Evaluated Programs/Interventions</th>
<th>Program Descriptions</th>
<th>Reviews and reports</th>
<th>Opinion pieces</th>
<th>Letters/Conferences</th>
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<tr>
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<td>The role of the State</td>
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<td>4</td>
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<td>34</td>
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<td>13</td>
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<td>10</td>
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<td>Patient-centred care &amp; the provider-patient relationship</td>
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<td>31</td>
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</tbody>
</table>

* The numbers in each cell represent the number of documents in which the coded theme was considered to be a substantive feature.
Figure 6-2: Descriptive map of seventeen key themes identified from the review of 394 full text documents*

- Authoritarian discourses
  - Role of the State (114)

- Biomedicalisation (74)
  - Biomedical health information (63)

- Health Service Structure, Function & Organisation
  - Health professional relationships/ roles (56)
  - Importance of Indigenous health staff (88)
  - Navigation & permeability of health services (71)
  - Resource constraints (68)
  - Quality improvement strategies (50)

- Indigenous discourses & de-colonising influences
  - Self-determination (86)
  - Sociocentrism (62)
  - Indigenous knowledges (88)

- Health care interactions
  - Patient centred care (48)/ provider-patient relationship (82)
  - Communication (73), Language & literacy (22)

- Role of 'culture' in healthcare (119)

* The number of documents in which a particular theme was identified as a substantive feature is shown in parenthesis next to that theme.
**Domain 1: Authoritarian discourses**

**The role of the State**

The perception that the State perpetuates colonising practices was a substantive theme in around one quarter of documents and was prevalent across all four countries. The effects of inter-personal and institutional oppression, historical trauma and dispossession of land, identity and community were strongly voiced in qualitative studies, surveys, reviews, and a large number of opinion pieces/editorials – the majority from Indigenous commentators. Of particular note, the enduring and often inter-generational effects of oppressive practices, such as forced separation of children from their families, were remarked on in many interview accounts. These broader societal practices are not merely colonial remnants. Some documents suggest that the construction of Indigenous people as ‘dissolute, neglectful and irresponsible’ and their communities as riddled by violence, sexual abuse and alcohol excess has permitted the State to create a discursive frame for Indigenous people as discredited medical subjects in need of rectification. A coerced candidacy, unilaterally devised by the State under the guise of science and public health, then becomes justified. It allows for levered social change in the name of health improvement. Mutual obligation agreements are an example where the State determines eligibility for services and resources on condition that certain social and health commitments are made. In this way such agreements are framed as inclusive and participatory rather than punitive.

Whilst it is clear that the State is not merely an authoritarian actor, the density of responses encountered in this review highlights the challenges faced by the State in its attempts to foster a post-colonial society in which Indigenous/non-Indigenous relations can develop differently. The State has at times responded to these challenges in ways that might perpetuate oppositional stances. This was reflected in a critical discourse analysis of Australian ministerial and prime ministerial speeches on Aboriginal affairs over the last three decades. In these leaders’ speeches a number of continuous discourses emerged around the competence and capacity of Indigenous people, issues of control and responsibility and Indigenous people and circumstances as a ‘problem’. This was also affirmed in an opinion piece where contemporary parliamentarians were noted to view Indigenous people as hopeless and helpless, lacking desire to improve their situation.
Such discourses firmly position the non-Indigenous State against the Indigenous Other and reflect the State’s struggles to imagine any alternative. It creates a confused policy environment founded on governmental instability about what to do and how to do it.\(^50\) Several commentators noted the role of treaties and the obligations of governments to honour these agreements as an important mechanism for addressing this propensity for confused policy. These treaties, present to varying degrees in all countries except Australia, are heavily influential in the way health systems have developed, are supported and the breadth and type of care they provide.\(^70-74\) Despite a certain amount of structural protection afforded by such treaties, a number of commentators noted that they remain contested and vulnerable to being undermined.\(^75-77\) There was little discussion about the role of international agreements. However, in one Australian document analysis, authors concluded that international agreements pertaining to the rights of Indigenous peoples, as long as they remain unratified, are highly constrained in their ability to affect ‘rights-based’ health system changes.\(^70\)

### Biomedicalisation and biomedical health information

Illich’s classic work on medicalisation discussed how the medical institution appropriated aspects of the social and cultural world to the medical dominion.\(^78\) The expansionism of medical jurisdiction, authority and practices into new realms is a global phenomenon that escalated post World War II. Clarke and colleagues argue that in more recent times there has arisen a new expansionist movement of ‘biomedicalisation’ in which the biological aspects of medicine come to dominate. Biomedicalisation is characterised by technological and scientific advances, the use of epidemiology to elaborate on risk and surveillance and transformations in how biomedical knowledges are produced and consumed.\(^79\) A large proportion of excluded articles in this review was related to epidemiological descriptions of Indigenous peoples’ (ill)-health. These studies frequently have obligatory opening sentences that serve to identify Indigenous peoples as first and foremost people of poor health status and disadvantage. The adverse consequences of implicitly constructing Indigenous peoples as diseased was emphasised in several documents.\(^42\ 44\ 67\ 80-85\)

Interviews with Indigenous participants highlighted how health professionals use epidemiology to fuel negative stereotypes.\(^86\) Furthermore, by invoking public health practices around infectious disease containment the same process is taken through the
deployment of expert outsiders to manage chronic diseases.\textsuperscript{87} This domination of disease management, a body parts approach, and poor recognition of and attention to other dimensions of health was voiced in several documents.\textsuperscript{21-22 39 44 58 62 66 88-96} This can lead to unbridgeable gaps in the clinical encounter and may re-ignite colonial tensions. In one opinion piece, rigid enactments of the biomedical role were viewed as a mechanism of control and ‘white efficiency’.\textsuperscript{97} In one qualitative study, rather than becoming defined by diabetes, this disease was re-framed as a colonising force (the ‘Coca-colonisation’ of the food supply) requiring adaptive responses to ensure survival.\textsuperscript{98}

Health professional attitudes to the disease-dominated approach were diverse. In some qualitative studies participants had a tendency to frame cultural identity on the basis of disease epidemiology profiles \textsuperscript{14 86 99} whilst in others doctors were aware of the potential harms in biomedicalising the health care encounter.\textsuperscript{14 100-101} In two studies health professionals expressed frustration when biomedical causation was usurped by Indigenous causation, with some viewing this as a tactic to avoid taking responsibility.\textsuperscript{102-103} In one revealing case study, a doctor actively avoided validating stress as a factor in her patients with diabetes because this was seen as non-medical ‘stuff’ and a distraction from the ‘important’ issues of diet, weight, physical activity and taking medicines.\textsuperscript{14} The nursing literature revealed interesting tensions with nurses viewing themselves as disempowered or ill-equipped agents of a biomedicalist discourse that traditionally appointed doctors as its principal advocates.\textsuperscript{17 104-106}

Indigenous peoples’ apparent lack of awareness of biomedical information including specific diseases, risk factors, clinical effects, and optimal management were voiced in qualitative studies,\textsuperscript{107-109} one survey,\textsuperscript{110} reviews,\textsuperscript{111-113} opinion pieces,\textsuperscript{114-115} and a program evaluation.\textsuperscript{116} A few studies acknowledged that narrow conceptions of knowledge about diseases were problematic\textsuperscript{117-119} highlighting that issues such as discordant views of causation \textsuperscript{21 120-122} may be an important reason for an apparent poor knowledge uptake. Two opinion pieces examined non-Indigenous views on how to make biomedical education more accessible through the use of Indigenous language concepts and learning styles.\textsuperscript{123-124} There may, however, be unintended consequences to such approaches with one anthropologist arguing that the use of such resources has the potential to decontextualise the body and affirm a pedagogic power over the seemingly unknowing
subject. Thus, in general, documents relating to biomedical knowledges tended to be superficial and assume that greater education and heightened awareness would lead to increased action on personal health issues. One Indigenous commentator strongly refutes this assumption, asserting that didactic biomedical education has, on balance, served to disempower, framing people as vacant in understanding their bodies and what is good for them.

Biomedicalisation is therefore an important discursive lens for understanding Indigenous peoples’ candidacy for health care. Although there were exceptions in the literature proposing alternate frames, it remains the primary mode in which health professionals identify candidacy and make adjudications on the kind of care that should be offered. This offer of candidacy is conditional. Indigenous peoples are eligible for care if willing to take responsibility for their diseases and risk factors. Whilst this may be a feature of any Western health care encounter, unique to this context is the way in which biomedicalism is enacted on a stage with a colonial backdrop. Health care providers may be cast as agents of an oppressive State that perpetrates harm in the name of biomedicine. There is limited scope in the candidacy construct to incorporate these broader societal level discourses despite their apparent profound impact on Indigenous peoples’ candidacy for health care.

Domain 2: Indigenous discourses and de-colonising influences

Three inter-related and predominantly Indigenous driven discourses were identified that contrast with the authoritarian discourses described above. The dialectical relationships between Indigenous and non-Indigenous discourses have a substantial impact on candidacy for health care.

Self-determination

One of the most important, commonly voiced themes in this review is the right to full participation in how societal institutions such as health are shaped. This participation is intimately connected with broader self-determination discourses around nationhood. Indigenous governed organisations are a key example of how the principles of self-determination (characterised by self-empowerment, resistance to State control and expression of Indigenous ideologies) are incorporated into the structure and function of
health services. There were many examples in the literature of how these principles are enacted in practical terms. By aligning health services according to these principles they become vehicles for procedural justice. Not merely providers of services, they serve as symbolic markers of achievement and appear to greatly enhance candidacy for health care.

In all four countries there has been growing recognition of the role of Indigenous governed health services. In the USA, self-governance is becoming an increasingly prominent feature within the Indian Health Service. In Canada the majority of health services in First Nations areas are now self-governed. In New Zealand there are now over 200 Māori health providers. In Australia the Aboriginal Community Controlled Health Services (ACCHSs) began as small-scale, grassroots movements to now comprise around 150 facilities delivering comprehensive primary care services across the country. Despite the size of this movement there are ongoing debates about the adequacy of support for such initiatives. One international review of funding arrangements to self-governed organisations in Canada, New Zealand and Australia has been conducted. It concluded that when these organisations are recognised by the State as the sole legitimate provider rather than having to compete with multiple providers, administrative and financial barriers are lessened and services appear to be more comprehensive.

Despite strong endorsement for community self-governance within descriptive research and the grey literature, few quantitative studies examined their role in improving service delivery and quality of care. One exception was a New Zealand study, which found that community-governed not-for-profit organizations were more likely to charge lower fees, employ a higher number of Indigenous staff, have written policies on quality management, and a greater degree of community based services (eg health promotion services).

Self-governed services tend to challenge the conventional power dynamics in the health system. As much as they are providers of health care, they are also community organisations providing services in a variety of areas that may have only indirect links to health. Tsey describes a pyramidal organisational structure to ACCHSs with Indigenous managers at the top, mainly non-Indigenous clinicians occupying the middle layer and Indigenous community health workers at the base. Whilst there were some accounts of
how non-Indigenous health care practitioners may embrace Indigenous self-governance,\textsuperscript{61} one qualitative study suggested this position became more ambivalent if it threatened their scientific hegemony through competition for resources.\textsuperscript{120} Kowal highlights substantial tension on the part of non-Indigenous health professionals between a ‘universalist’ position in which there is a moral obligation to intervene in the face of poor health outcomes and the ‘particularity’ of honouring Indigenous self-determination which may be undermined by such interventions.\textsuperscript{144} This dilemma of when to intervene was revealed in a poignant exchange between a non-Indigenous and an Indigenous primary care physician.\textsuperscript{145} The former publicly wrote about concerns of violence and neglect toward children in the community she had worked in for over ten years and the latter discussed the implications of such uni-lateral exchanges where discussions between Aboriginal people, communities and their care providers are not mutually developed and understood. By contrast, such tensions were taken to the opposite extreme by non-Indigenous interviewees in one qualitative study who advocated complete withdrawal of non-Indigenous involvement in health services even if this meant a worsening of health outcomes in the short term.\textsuperscript{17} In other studies, however, a more balanced view prevailed where community control did not signify an undermining of the technical and political roles played by non-Indigenous staff and organizations and these roles were seen as critical to create enabling environments to address complex issues.\textsuperscript{146}

\textbf{Sociocentric care}

Whilst cognisant of the debates around individualism-sociocentrism dichotomies, we encountered many qualitative studies,\textsuperscript{35, 58, 83, 147-148} one survey,\textsuperscript{149} one review\textsuperscript{150} and several opinion pieces\textsuperscript{43, 54, 55, 151-153} in which health and health care was mediated by social context. Family-based social structures were a source of practical and emotional support for health care needs and motivation to change health behaviours.\textsuperscript{22, 60, 147, 154-156} Looking after one’s health was also seen as important in order to maintain responsibilities to family.\textsuperscript{62, 82, 107-108} Caring for family members could also be a reciprocal phenomenon and bring about changes in health choices for the carer as well.\textsuperscript{154} Worry for family well-being and the experience of chronic illness in other family members was a notable concern in two qualitative studies.\textsuperscript{62, 155} Dislocation from family and country was a poignant factor amongst the considerable challenges of accessing health care away from home.\textsuperscript{107, 127, 157-158}
Whilst family generally constituted a substantial support mechanism, in some documents family was also noted as a barrier to implementing healthy lifestyle choices.\textsuperscript{22 154 159}

Candidacy appears to be greatly enhanced when health services embrace sociocentric principles. Such services are vibrant social spaces, often marked by a blurred distinction between staff and patients. Several studies remarked on how such services convey a sense of belonging to their users.\textsuperscript{29 97 99 108 158 160-161} Health care interventions and programs that incorporated sociocentric perspectives were generally considered highly acceptable forms of health care.\textsuperscript{30 98 152 160 162-163} There were several examples highlighting how conventional health services, especially hospitals, are poorly equipped to embrace such perspectives. Issues such as allowing access to visitors, involving family in making treatment decisions, obtaining informed consent and knowing who to communicate key messages to about an individual’s health care were cited as instances where health system practices were discordant with the expectations of its users.\textsuperscript{23 164-166} This is made more challenging when health practitioners have little awareness of complex kinship structures\textsuperscript{167} and other contextual factors that may easily be misinterpreted as obstruction or disinterest in care recommendations.\textsuperscript{19} By contrast Indigenous-governed health services are more likely to face the opposite situation where challenges are posed due to a high degree of intimacy between those working in the service and those using it. These intimate relationships may challenge conventional management structures. They are continually negotiated and factored into a broader dynamic of reciprocal obligations and relationships (e.g. kinship, gender, ceremonial status, age). In one qualitative study involving Indigenous managers these issues were prominent when considering the different layers of accountability both to the community and government funding bodies. These accountabilities were perceived to extend far beyond those required for non-Indigenous managers and were viewed as a core feature of their job role.\textsuperscript{59}

**Indigenous knowledges**

Closely related to self-determination discourses was the importance of Indigenous knowledge generation as a counter-point to biomedicalisation. Durie asserts that Indigenous knowledges are epistemologically distinct from those derived from biomedicine – the former derives understanding from a synthesis of components based on
a wider context whilst the latter constructs knowledge from observation of smaller and smaller components of particular phenomena. Smylie notes further that this synthesis involves combining everyday pragmatism with metaphysical and symbolic realities. These dynamic and differently expressed knowledges are inextricably intertwined with ethics and values systems that constitute the fabric of societies. They are an integral part of the physical and social environment and a collective good.

Knowledges that stemmed from connection to land and natural environments; ceremony, stories and spiritual practice; access to traditional foods; and the role of elders in knowledge formation were strongly voiced. The importance of traditional healing and healers was particularly apparent in many qualitative studies, one survey, reviews, and opinion pieces. Four surveys found that use of traditional healers was prominent in many US jurisdictions and in one First Nations community in Canada. Contrasts with Western biomedical healing systems were explored in one New Zealand qualitative study that examined the different approach to diagnosis taken by Māori traditional healers. It highlighted a less linear approach in which healing and diagnosis may happen contemporaneously and where context and spiritual/supernatural elements were integrated into the ontology of identifying, naming and treating illness. A detailed project exploring the role of diagnosis amongst Navajo healers and patients, similarly highlighted complex processes involved in diagnosis. Although there were ample accounts of these different systems of healing, some authors cautioned against artificial reification of these knowledges given the great diversity within and across Indigenous groups and the degree of connectedness to non-Indigenous knowledge paradigms. Several qualitative studies highlighted that healing frameworks were not simply polarised into Indigenous and non-Indigenous frames and the ability to move freely between these differently constructed frames of healing was important when seeking health care.

There were several accounts of how State-sanctioned biomedicine resists these knowledges. We encountered few interventions and programs that focussed on the incorporation of Indigenous knowledge systems and principles into health service structures (see the Kaupapa Service – Whanaungatanga Model of Care and the Native American Patient Advocate program for exceptions). Several documents commented on
how Indigenous concepts of health and healing systems are frequently subjugated. In one qualitative study authors concluded that health professionals considered traditional healing practices to not be of intrinsic interest but were tolerated as long as they did no harm. In another, respect for traditional practices was apparent at a surface level only and primarily judged against an a priori validity of the Western scientific paradigm. This subjugation of Indigenous knowledges can result in feelings of degradation and secrecy on the part of its proponents. Even when Indigenous knowledge systems are acknowledged they tend to be incorporated in a reductionist manner with many elements de-contextualised and ‘scientifically’ appropriated. This further emphasises the importance of a societal level candidacy in which broader discourses influence the provision and receipt of care.

**Domain 3: Health service structure, function and organisation**

**Navigation and permeability of health services**

Many features that promote the navigability and permeability of health services described in the Dixon-Woods et al. review were similarly encountered here. They included proximity of health services and availability of transport, minimal or no out-of-pocket costs for attendance and treatments, after-hours access, and outreach services/mobile clinics. Welcoming physical spaces and Indigenous staff as the point of first contact were also frequently highlighted. The ability of a health service to go beyond its health care functions and to serve as a social space was viewed favourably. This included the promotion of community activities, child care facilities, and social networking opportunities. Making health services more permeable also had adverse consequences. The availability of social facilities, the establishment of open door-policies, walk-in clinics and flexibility to see anyone no matter what their circumstances could lead to overcrowding, increased waiting times and concerns about privacy. Although there were a number of interventions and programs with elements that addressed navigation and permeability barriers, very few were rigorously evaluated with some exceptions (see Gruen et al. for an extensively evaluated program on specialist outreach services).
Tractability of health services (1): the roles of non-Indigenous and Indigenous health staff

Tractable health services have detailed policies and service developments that are oriented toward improving access.\textsuperscript{5} One of the most influential factors on the tractability of services in this review was health staff roles, responsibilities and interactions. Health professionals frequently commented on their broader population health and managerial roles.\textsuperscript{34 97 211-213} They involve balancing acute care demands with managing broader programs,\textsuperscript{97 127 214-216} negotiating tensions between robust recall and reminder systems and respect for patient autonomy,\textsuperscript{158} understanding and working within Indigenous governance structures\textsuperscript{136 217-218} and collaborating with other agencies to implement sustainable programs.\textsuperscript{138 219} Whilst these roles were clearly a major source of job satisfaction, they are often roles for which staff may not be well equipped. The construction of these challenges as formidable, frontier medicine can impart a sense of heroic zeal in staff that choose to work under such demanding circumstances.\textsuperscript{36} Several such accounts were observed in contemporary opinion pieces in this review.\textsuperscript{220-225} Alongside resource constraints (discussed below), the inability to accommodate these challenges results in high staff turnover, loss of corporate memory and gaps in basic service provision.\textsuperscript{138 216}

A second important workforce element that affects the tractability of services is the roles taken by Indigenous staff. In several qualitative studies both patients and care providers acknowledged Indigenous participation in the health professional workforce as being of fundamental importance.\textsuperscript{86 99 127 177 226} Similar sentiments were voiced in reviews,\textsuperscript{35 38 77 94 227 228} opinion pieces/editorials\textsuperscript{76 130 229-231} and one comprehensive review of community health worker training.\textsuperscript{232} Indigenous staff influence candidacy through their multifarious roles. These include working as clinicians and health promoters,\textsuperscript{97 133 265 233-238} brokering better delivery of health information,\textsuperscript{61 111 157 165 198 208 219 239-241} fulfilling responsibilities to patients as friends and family whilst maintaining professionalism and avoiding nepotism,\textsuperscript{29 59 127 160-161 242-243} and representation in managerial positions.\textsuperscript{35 59 72} Balancing community expectations and workplace responsibilities was a source of both stress and satisfaction, particularly for managers.\textsuperscript{59} The level of training opportunities and professional support was perceived in several documents to be incommensurate with the considerable demands exacted from these roles.\textsuperscript{19 34 244-246}
Although there was substantial endorsement of the roles played by Indigenous community health workers, non-Indigenous health staff did not always appreciate what these roles were, the degree of overlap with their own roles and how to best develop congruence across the respective roles.\textsuperscript{17} \textsuperscript{19} \textsuperscript{133} \textsuperscript{206} \textsuperscript{242-243} \textsuperscript{247} Although there were few empirical studies focussing on Indigenous doctor and nurse perspectives, their presence as leaders in health service organisation, delivery and policy was readily apparent in more recent opinion pieces.\textsuperscript{27} \textsuperscript{49} \textsuperscript{53} \textsuperscript{75} \textsuperscript{128-129} \textsuperscript{187} \textsuperscript{213} \textsuperscript{218} \textsuperscript{248-251} In general, evaluations of the role of Indigenous staff in interventions/projects were superficial and yielded little additional insights to those gained from other literature sources.

**Tractability of health services (2): Resource constraints**

A second dominating influence on the tractability of services was the issue of resource constraints. Problems with insufficient personnel, high staff turnover and inadequate infrastructure or funding were frequently voiced.\textsuperscript{14} \textsuperscript{17} \textsuperscript{104-105} \textsuperscript{111-112} \textsuperscript{126} \textsuperscript{134} \textsuperscript{158} \textsuperscript{160} \textsuperscript{197} \textsuperscript{201} \textsuperscript{215} \textsuperscript{243} \textsuperscript{252-254}

One review and one program description noted that Australian governments were not fulfilling their obligations to provide essential services in remote areas.\textsuperscript{26} \textsuperscript{216} Conversely in the USA, people residing in urban areas receive minimal funding through the Indian Health Service compared to those residing on rural reservations.\textsuperscript{215} \textsuperscript{255} Siloed funding streams and multiple accountability processes,\textsuperscript{97} \textsuperscript{136-137} \textsuperscript{256} ill-defined resource allocation processes and unrealistic expectations from funding bodies,\textsuperscript{146} prioritising medical care over preventive activities,\textsuperscript{140} dependency on alternate funding sources to cover shortfalls,\textsuperscript{77} inadequate resources to write funding submissions \textsuperscript{136} and lack of flexibility in funding structures\textsuperscript{138} \textsuperscript{253} all contribute to health service vulnerabilities in meeting health care demand. The different patterns of service provision in Indigenous health settings where more time may be required and more complex health issues are managed were perceived to not be well recognised by funding bodies.\textsuperscript{151} Two program evaluations found a deterioration in clinical outcomes following hand over of specialist chronic disease programs to the primary care service. Both concluded that competition with other primary care programs for the limited resources available were key contributors to the worsening of outcomes.\textsuperscript{257-258}
Tractability of health services (3): Quality improvement in health services

A number of audits and interventions were focussed on reviews of clinical data to assess effectiveness of care. Most interventions involved the development of indicators, measuring and feedback of performance, and health service actions to improve quality. These interventions utilised well-established quality improvement methods such as increased access to clinical guidelines, improved computerisation and recall systems, and feedback cycles of care. A program based on the use of Chronic Care Model has had wide uptake in Australia and shown modest improvement in processes of care, links between Aboriginal Health Workers and improved diabetes care and associations between improved system development and quality of diabetes care. The competing demand of acute care services, resource constraints and a lack of clear delineation of staff roles were noted in two opinion pieces and one program evaluation as major barriers to sustainable quality improvement initiatives. There was also substantial tension in the literature between the use of health service information for local quality improvement purposes and its use for performance management by external funding bodies. Experiences where unrealistic expectations of improvements in health status measures are placed on health services as a condition of funding highlighted the problems with ‘top down’ approaches to performance management. In three detailed reviews of Canadian, Australian and New Zealand Indigenous health performance measurement systems authors argue that the development of macro-system measures, usually based on physical and disease variables, often take precedence over the development and use of locally specific health indicators. These locally developed measures of service delivery may be difficult to quantify, not specifically focussed on health status and outcomes, and reflect alternate philosophies and values that are not amenable for use as performance measures in the classical sense. Despite this, such measures may be very meaningful gauges of quality. Involvement of Indigenous advisory groups in the development of health system indicators; clear, focussed goals that are committed to by local health service boards and administrative bodies; and the use of Indigenous health worker managed programs were highlighted as important ingredients for quality improvement initiatives. Also highlighted was the need for indicators that monitor governments’ performance rather than just that of the health service. The candidacy
framework has limited scope to incorporate these issues of macro-system monitoring for quality of care.

There was little discussion on the role of complaints mechanisms and this does not appear in the candidacy framework as a feature of tractable organisations. This was surprising given the substantial role played by patient complaints in improving quality and safety of care. We found few accounts of patient experiences of making complaints and only cursory discussions on the presence or absence of complaints policies. One New Zealand survey found that community-governed non-profit health services (which included, but was not restricted to Māori health providers) were more likely to have written policies on complaints processes than for-profit services.142 At the macro-system level, despite recommendations that hospital complaint frequency and availability of complaints mechanisms be incorporated into national Indigenous indicator frameworks,275 this does not appear to be nationally monitored in any of the four countries.

Domain 4: Health care interactions

The health care encounter is the crucible in which the above domains exert their influence. Within the candidacy construct the sub-theme of ‘presentations, adjudications and offers’ is particularly salient here. This theme describes the circumstances by which people present for care; adjudications or judgements on the part of care providers on whether care ought to be offered (e.g. moral deservingness or perceived benefit); and decisions by patients to accept or refuse these offers. Of particular relevance is the idea that health services rely on an ‘ideal user’ who is equipped with exactly the right set of competencies and demands that health services are designed to meet.5 We identified three substantive areas which impact on these presentations, adjudications and offers: (1) the care provider-patient relationship and patient centred care; (2) communication, language and literacy; and (3) the role of gender and the body in care.

Care provider-patient relationship and patient centred care

The core components of patient-centred care feature strongly as enablers of effective patient-provider interactions. Acknowledgement of the patient’s worldview, validation of his or her agenda, affirmation of individuality and autonomy, and empowerment in the
clinical encounter play a pivotal role in enhancing acceptance of care. In particular, the inter-related issues of (in-)sufficient time and (dis)-trust in care encounters were important components affecting the quality of the care provider-patient relationship. In one qualitative analysis of why patients take their own leave from hospital, distrust of the care provider was found to have enduring effects on individuals' and their families' decisions to present for care for years to come. Towle and colleagues found that insufficient time and distrust were also closely connected to historical oppression. These factors contrast with health services' ideal users who do not take up too much time and have implicit trust in the system and its workers.

A number of other documents highlighted that the decisions people make about their health and presentations to care are contextually mediated. The (in)-ability of care providers to be perceptive of this was noted to be a key element in how the care provider-patient relationship manifests. For care providers this poses tensions between the utilitarian agenda of ‘knowing’ a person to adjudicate on the management of illness and recognition of alternate and potentially unknowable processes that may manifest as refusals to accept care (e.g. alternate knowledge and healing systems, consensus based decision-making processes that exceed personal autonomy, and apparent ‘unhealthy’ choices driven by difficult social circumstances and minimal institutional support). Once again the ideal user should present to the health care encounter with no contextual baggage and health services would not need to validate such baggage as being important. Only a few qualitative studies explored care provider perspectives on refusals to accept care. These tended to be restricted to a superficial examination of issues related to personal responsibility. One in depth qualitative study, however, did explore in detail care provider attitudes about patient ‘compliance’ to management recommendations. Rather than considering it a ‘problem’ related to ‘patient behaviours’, authors conclude that it ought to be considered as the ‘material consequences of particular models and practices of health service provision, undertaken within particular institutional, political, social and cultural contexts’. When viewed in this way ‘compliance’ fits well with the underlying premise of candidacy, namely that eligibility for care is jointly negotiated between individuals and health service. However, it goes further to suggest that this negotiation process is mediated by broader societal parameters.
Gender and the body

Although less frequent than other themes, some studies identified sensitivities around the way bodies are treated in health care interactions that may contribute significantly to acceptance or refusal of care. There were accounts of a patient’s body being viewed as dirty and handled disrespectfully by a care provider in one study, adjudications by care providers of perceived dirty or unhygienic lifestyles due to a lack of washing and circumstances in which traumatic experiences in residential schools rendered some women feeling very vulnerable in physical examinations. In this latter example the body becomes a locus for oppressive medical practices whose antecedents were laid in the colonial era. Feelings of vulnerability for women undergoing invasive procedures were also voiced in a qualitative study involving American Indian women. One participant in this study, however, considered that having invasive physical procedures was an important and acceptable part of taking care of oneself. There were few documents examining health provider and organisational responses to these issues. In one New Zealand qualitative study of non-Māori care providers, there was a brief mention by some participants of the need to obey protocols in asking permission to touch or examine a person. Similarly, there were only cursory explorations of specific gendered responses to health care provision which focussed mainly on issues of gender discordance between provider and patient, different patterns of presentation by males to care providers, different responses to health information and conflicts between health advice and notions of ideal body types.

Communication, language and literacy

The role of communication dynamics, language and literacy in patient-provider interactions was a frequently occurring theme that appears to profoundly influence presentations, adjudications and offers of care. The most commonly discussed problems were: a lack of understanding of written or spoken health professional advice, too much, too little or too rapidly delivered information, dissonance in the primary languages spoken by care providers and patients, and the lack of interpreter services and ineffective use of these services when they were available. Pervasive miscommunication (often unrecognised by both care providers and patients) and failure to achieve a shared understanding of key, usually biomedical concepts
was encountered in one Australian study of health care interactions in the renal dialysis setting. These issues highlight again the orientation of health services around the ideal user who is able to attain a satisfactory level of comprehension from the information the system provides.

Patient sensitivity to care providers' non-verbal communication, (particularly subtle nuances in tone, gestures, body positioning) were also noted as influential factors in the acceptability of care. By contrast, however, Towle and colleagues' qualitative study of doctor-patient communication found participants talked very little about the importance of non-verbal communication despite being vigilant for these issues. Nevertheless, the use of communication devices such as indirect story telling, prioritising the nurturing of the relationship over management of the health problem, the use of silence, metaphor and seemingly circular language featured prominently. Health professionals' inattention to the use of these devices may lead to false adjudications of passivity or unwillingness to engage. This may be an especially pertinent issue in health care encounters with elders. This is not to say that patients do not actively refuse to provide information. For one participant in a qualitative study, the withholding of information represented a resilience strategy in response to perceived past injustices where one's stories were frequently manipulated. Consequently there are a range of complex communication dynamics and devices at play that may impact on offers, acceptances and refusals of care.

In parallel with issues related to the communication medium, was discussion around the message, especially biomedically oriented messages. It was common to find in the concluding recommendations to many studies that more 'appropriate' resources are needed to address information gaps. In particular, it was frequently recommended that care providers need to deliver messages consistent with the worldview of the patient or that information needs to be simplified in order to make it more accessible. Lea questions the value of simplifying information when such information may be underpinned by complex epistemologies of westernised good health. By contrast, Durie argues that perceived knowledge divides and disparate worldviews are bridged frequently and comfortably by Indigenous peoples. Interestingly, in two qualitative studies, despite perceived lack of information and discordant knowledge being common, this did not necessarily diminish the acceptability of health care. This suggests that
acceptable communication encounters are not just about bridging different ontological perspectives. They are intimately connected to the processes by which messages are constructed and delivered. Smylie’s review of Indigenous health literacy asserts that proper attention to these processes can become part of a broader act of self-determination. 41

There were few examples from programs and interventions specifically related to enhancing communication encounters. Some strategies considered to be effective (but generally not evaluated) include information delivered by peers who had experience of diabetes, 109 introducing information through mechanisms such as talking circles 98 and the generation of knowledge products that paid attention to the source, presentation and dissemination of such products. 148 Strategies such as language revitalisation programs were commented on in one qualitative study to be an especially useful way to engage with young Māori on health issues. 61 Two studies broadened communication with individuals to that of the network. Energising these networks ensures messages are more coherent and this plays a key role in the sustainability of health programs. 21 138 Consistent with a socio-centric approach, two studies concluded that important health messages needed to be communicated to social/family networks to allow for effective decision-making processes. 165 167 Thus attention to broader communication processes can uncover creative opportunities in communication dynamics rather than it being viewed merely as a contest of competing agencies. 284

Domain 5: The role of ‘culture’

An intersecting theme across all the above domains was the role played by culture and cultural difference in candidacy for health care. Different attitudes to food, the role of shame, different clothes, different gender and avoidance protocols, different social obligations, different spiritual and healing beliefs, different use of time, differences in ‘traditional’ compared to ‘non-traditional’ peoples, different levels of passivity and shyness were frequently mentioned as potential barriers to accessing care. There are many references to such differences. 18-21 29 48 92 111 119 124 167 209 212 214 277 284-289 This leads to the assertion that cultural difference is a root cause for diminished candidacy. If cultural differences are constructed as potential barriers it is assumed, therefore, that better health professional awareness of and sensitivity to these issues may improve candidacy. Several
A common health system response is to package an understanding of cultural differences into staff cross-cultural awareness courses. One opinion piece provides an especially poignant example where a series of tables are presented in a staff education handbook to contrast the difference between ‘American Indians’ and ‘Euro-Americans’. The key issue here is not to debate whether these differences exist but to recognise the potential consequences that may result from essentialising Indigenous cultural identities. Such culturalist approaches construct highly stylised, imaginary conceptions of cultural difference where particular essences are reified and either upheld as noble or denigrated as problem behaviours. Moreover they assume a homogenous mono-cultural identity to care providers, placing the cross-cultural gaze on the Indigenous Other from a supposed neutral (White) platform. This is ironic given the multiple cultural identities of health professionals in the four countries studied.

By contrast, there is an alternative voice in the literature that critiques culturalism. Cultural safety, a term originally proposed by Māori nurses, shifts the role of culture away from a check-list approach based on a person’s ethnic background and toward a critical examination of the power imbalances in health care encounters. Drawing on the mainstream movement of quality and safety in health care it is built on principles of minimising risk and reducing error. Reflecting its origins, the use of this term is most commonly encountered in the nursing literature and there are several references to cultural safety and security in the documents we reviewed. It builds on a realisation that sensitivity and awareness have done little to serve the interests of Indigenous peoples’ access to better health care. Cultural safety, therefore, is a reflexive process that shifts the lens back to the self. It is a method of decolonisation, allowing health services to re-orient themselves to better meet the needs of vulnerable groups, irrespective of their cultural identity. Examples include, shifts from awareness training to anti-racism training; developing tools that critically examine notions of culture, race and oppression and avoid essentialising and stereotyping; organisational audits for compliance with treaty principles; and making explicit the differences between cultural phenomena and those related to socio-economic inequity. Such interventions are intended to increase the tractability of whole institutions and
strengthen candidacy for care through enhanced navigation (by making services more permeable), increased presentations (by making people more comfortable to claim eligibility for care) and fairer adjudications (by making staff more cognisant of how they make judgements).

6.5 Discussion

This review of documents from Australia, Canada, New Zealand and the USA, over the period 1990-2007, has sought to elaborate on the factors that influence Indigenous peoples’ accessibility to health care with a focus on chronic illnesses. We applied the candidacy construct as a theoretical framework upon which to understand access. Although developed with reference to a number of vulnerable populations in the United Kingdom, we found the synthetic constructs derived from candidacy theory to be highly useful in this context. As a general organising theory, its greatest contribution is the ability for it to be intricately woven into several inter-related aspects of the health system, especially at the levels of organisational structures, workforce, and health care encounters.

There are important implications for Indigenous health services research and approaches to system change. A key finding was the scant evaluation of programs and a dearth of research interventions that address candidacy. Aside from quality improvement studies, which are mainly focussed on effectiveness of care, there is an insufficiently developed body of knowledge with which to be able to test whether interventions in our principal thematic areas enhance candidacy. Based on our findings, it is likely that interventions to improve access need to be complex and multifaceted, simultaneously enhancing candidacy at a number of levels. Quantitative studies must overcome the challenges of developing validated measures of candidacy. Although empirical qualitative studies have potential to provide valuable insights, as seen in this review, it is important that they be rigorously conducted in order to provide sufficient depth to understand what works and how. We therefore would recommend that research interventions and programs incorporate a mixed methods approach to their design and evaluation and that the very conduct of such research be cognisant of the candidacy issues raised in this paper.
The most important limitation to candidacy theory that we encountered was a restricted scope in incorporating macro-system issues. Within all five interpretative domains in this review, we found that access to health services is influenced by broader societal discourses of power. Many participants in qualitative studies and commentators in reviews and opinion pieces perceived the State to be a perpetrator of past and contemporary oppressive practices. In the health care arena this manifests most strongly through the biomedicalisation of care and endorsement of culturalist agendas. Indigenous peoples' resistance to these agendas was palpable and underscores a movement to re-shape health institutions that are predicated on an inappropriate ideal user. Political struggles for self-determination and validation of alternate knowledge systems and approaches to care were amply expressed. Whilst these factors may not be unique to the Indigenous health context, their enactment in the context of non-Indigenous/Indigenous post-colonial power relations affords them specific meanings. Thus these broader discourses of power have a profound impact on candidacy and its sub-themes. We consider, therefore, the need to incorporate a 'societal candidacy' in which eligibility for care is negotiated in arenas beyond the health care space. Societal candidacy is characterised by a dialectical relationship between a non-Indigenous State that adjudicates through its institutions how care is offered and a predominantly Indigenous counter-movement that seeks to maximise participation in shaping those institutions. Greater appreciation of this dynamic and contested space, in which neo-colonial and decolonising discourses are enacted, not only helps explain why systems of care break down but it can foster different approaches to enhancing candidacy.

There are potential limitations to how we conducted this review. Our attempt to include a diversity of voices resulted in a labyrinthine mix of qualitative studies, audits and surveys, programs with at best cursory evaluations, quality improvement interventions, mainly non-systematic topic reviews and a plethora of opinion pieces. Whilst we considered the incorporation of non-traditional document sources essential for ensuring a balanced representation, we could be criticised for putting undue emphasis on untested views. Table 2, however, highlights a similar breadth of themes encountered in opinion pieces to the qualitative empirical studies and thus we believe it constitutes a rich data source with which to triangulate findings. Despite this, there are important limitations in how we sampled these opinion piece documents. By mainly focussing on database searches our
grey literature may not adequately capture Indigenous perspectives from non-scientific sources. A more expansive search of non-health and non-print media would have been a useful adjunct. This would, however, have made the scale of the project prohibitively large.

Another limitation is that by drawing on a variety of synthesis methods (meta-ethnography, critical interpretive synthesis and thematic synthesis) we may be criticised for not sufficiently adhering to any one method. We contend, however, that these synthesis methods remain emergent and as such pragmatism is an appropriate strategy to explore their utility. At the earlier stages, thematic synthesis was especially useful in developing a descriptive map of what was most talked about in the literature. The critical aspect of the critical interpretive synthesis approach was most helpful at the later stages of the analysis in which the principal thematic domains and tensions highlighted within and across them were brought together. The meta-ethnographic technique of reciprocal translation worked reasonably well across qualitative studies, reviews and opinion pieces. We were less successful, however in translating themes to the quantitative empirical studies and programs and interventions. Consequently themes such as ‘quality improvement’ derived mainly from audit studies and interventions tended not to translate well into other areas.

Although the principal of refutational synthesis was appealing we did not discretely apply this method. Rather it was in the critical analysis stage of our overall synthesising arguments that certain refutations like the cultural awareness-cultural safety divide became apparent.

Our quality appraisal process for the qualitative studies emphasises the inherently subjective nature of qualitative research. The high degree of inter-rater variability in the use of the CASP tool raised concerns about its validity. Our findings support those of others that quality appraisal checklists tend to be overridden by overall judgement. To this end, however, a strength of our review process was the differing epistemological influences of our team. This allowed us to interpret the data in different ways and develop syntheses that reflected this diversity. Involvement of researchers with disparate backgrounds who each have a key stake in the relevance of the findings was a useful way to gauge the quality of documents and the subsequent synthesis of the findings. Further, for
all aspects of our synthesis, we have sought to make explicit our reflexivity in the analysis by exhaustively referencing our interpretations.

In our attempt to synthesise findings across countries we run the risk of being reductionist. Much of the literature we analysed is locally specific, small in scale, variable in quality and there were few existing international reviews to guide our analyses. This makes national and international extrapolation difficult. Inattention to context, oversimplification of themes and artificially constructing dichotomies, when these are expressed differently at the local level, are all potential pitfalls in such an exercise. All of the themes reported in this review were widely prevalent across all four countries and whilst they were certainly expressed differently there appeared to be sufficient points of similarity to enable an adequate synthesising argument. Also, by examining constructs and counter-constructs, such as the State authoritarian – Indigenous decolonising discourses, we were able to identify patterns of dissent across particular themes. These conflicts and points of tension tended not to be restricted to any one country. Although we could never do justice to the importance of locally specific analyses, we hope that the provision of detailed references makes our interpretations transparent and can allow others to use these analyses to explore local issues in more depth.

Addressing inequitable access to health care is a major focus of all four countries' health systems and features prominently in current health reform agendas. Candidacy frameworks help explain why the 'many barriers' approach to conceptualising access is not helpful. Barriers are mediated by complex institutional environments and thus their removal is rarely a straightforward process. Candidacy theory highlights the need to apply multiple, synergistic approaches at different levels. For this reason, it is unlikely that implementing 'candidacy checklists' would be an effective way of improving care. Organisational audits framed around candidacy, however, could be an appealing way of identifying strategies to improve access. Such audits would need to be collaboratively developed by system planners, service managers, care providers and community users. They could be equally pertinent to macro systems as they are to local health care organisations. By focussing on organisational culture there is an increased prospect of embedding integrated interventions into health care systems, rather than focussing on specific barriers in isolation. Culturally 'aware' personnel cannot meaningfully enhance Indigenous peoples' candidacy in the
absence of whole of organisation initiatives to make services safer and more tractable. Indigenous staff that are poorly remunerated and given access to limited training opportunities are unlikely to support the sociocentric function of health services. Improving health care provider communication styles and making more effective resources available will not necessarily enhance candidacy if there is inadequate health service governance and poor infrastructural supports.

Candidacy theory, especially if broadened to incorporate societal and macro-level issues, can assist in embracing systemic and inter-personal aspects of health care. Although the development of successful strategies to enhance Indigenous peoples' candidacy for care remains a challenge, this review outlines for care providers, policy makers and health service researchers a range of factors at multiple levels that warrant consideration.

6.6 References


71. Lavoie JG. Indigenous Primary Health Care Services in Australia, Canada and New Zealand. Winipeg, Canada: Centre for Aboriginal Health Research, 2003.


205. Virani S, Strong D, Tennant M, Greve M, Young H, Shade S, et al. Rationale and implementation of the SLICK project: Screening for Limb, I-Eye, Cardiovascular


### 6.7 Attachments

**Attachment 1: Screening questions for appraising qualitative literature using the Critical Skills Appraisal Toolkit**

#### General

1. **Was there a clear statement of the aims of the research?**
   
   **Consider:**
   
   - what the goal of the research was
   - why it is important
   - its relevance

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<th>Neutral</th>
<th>Disagree</th>
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2. **Was a qualitative methodology appropriate?**
   
   **Consider:**
   
   - if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

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#### Study Design

3. **Was the research design appropriate to address the aims of the research?**
   
   **Consider:**
   
   - if the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)

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<th>Disagree</th>
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4. **Was the recruitment strategy appropriate to the aims of the research?**
   
   **Consider:**
   
   - if the researcher has explained how the participants were selected
   - if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
   - if there are any discussions around recruitment (e.g. why some people chose not to take part)

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#### Data Collection

5. **Were the data collected in a way that addressed the research issue?**
   
   **Consider:**
   
   - if the setting for data collection was justified
   - if it is clear how data were collected (e.g. focus group, semi-structured interview etc)
   - if the researcher has justified the methods chosen
   - if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they used a topic guide?)
   - if methods were modified during the study. If so, has the researcher explained how and why?
   - if the form of data is clear (e.g. tape recordings, video material, notes etc)
   - if the researcher has discussed saturation of data

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<th>Disagree</th>
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**Reflexivity and Ethics**

6. Has the relationship between researcher and participants been adequately considered?

*Consider whether it is clear:*
- if the researcher critically examined their own role, potential bias and influence during formulation of research questions
- how data were collected, including sample recruitment and choice of location
- how the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?

*Consider:*
- if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- if the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- if approval has been sought from the ethics committee

**Data Analysis**

8. Was the data analysis sufficiently rigorous?

*Consider:*
- if there is an in-depth description of the analysis process
- if thematic analysis is used. If so, is it clear how the categories/themes were derived?
- whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- if sufficient data are presented to support the findings
- to what extent contradictory data are taken into account
- whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?

*Consider:*
- if the findings are explicit
- if there is adequate discussion of the evidence both for and against the researcher’s arguments
- if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)
- if the findings are discussed in relation to the original research questions

**Value of the Research**

10. How valuable is the research?

*Consider:*
- if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
- if they identify new areas where research is necessary
- if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used
## Attachment 2: Table of quality appraisal scores for 80 qualitative studies

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<th>Year</th>
<th>Reference</th>
<th>Country</th>
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<td>Barr, D. A.</td>
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<td>Bartlett, J. G.</td>
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Chapter 7: Building better systems of care for Aboriginal and Torres Strait Islander peoples: The Kanyini Qualitative Study

Planned publication details: Peiris D, Rickards BA, Mentha R, Brady JP, Devries J, Fewquandie B, Liu H, Ingram S, Brown ADH, Devitt J, Weeramanthri T, Cass A, Building better systems of care for Aboriginal and Torres Strait Islander peoples: The Kanyini Qualitative Study. An abbreviated version of this paper is currently being prepared for submission to BMC Health Services Research

Author contribution: I co-designed the study with co-authors Brown, Cass, Rickards and Devitt. I wrote the study protocol, coordinated ethics submissions, and co-designed the attachments to this paper with Michael Howard and Bernadette Rickards. I supported and trained co-authors Brady, Devries, Fewquandie in conducting interviews and data analysis. I coordinated all aspects of data management. I coded and performed the primary analyses of the health systems assessments interview data, wrote the first and subsequent drafts of this chapter and will be the primary author responsible for progressing this chapter to journal submission.

7.1 Abstract

Background: Aboriginal and Torres Strait Islander peoples experience inequitable access to health care. The Kanyini Vascular Collaboration (KVC) is a health services research program involving Aboriginal Medical Services (AMSs) with its principal aims being to understand and overcome gaps in health care access and quality. This paper has two components: (1) A detailed account of the methods used in one KVC study, the Kanyini Qualitative Study (KQS); and (2) presentation of the findings from the first part of the KQS, the ‘health systems assessment’.

Objectives: (1) To understand community and health professional views on barriers and enablers to optimal primary, specialist and hospital care; (2) to determine which organisational components affect accessibility and quality of care; (3) to situate findings
within the context of the recent Council of Australian Governments (COAG) ‘Close the Gap’ Indigenous health policy initiatives.

Methods: The study was iteratively designed by a multi-disciplinary team, including six Indigenous researchers with extensive AMS experience. Two theoretical frameworks were used: the candidacy construct, described in Chapter 6, and the Central Australian concept of kanyini, or ‘holding’ which describes the principle and obligations of nurturing and protecting others. There were two study components: (1) Health systems assessments involving staff focus groups at seven AMS sites participating in the Kanyini audit (see Chapter 3); and (2) semi-structured interviews involving community (n=108) and staff (n=96). For both study components, a purposive, maximum diversity sample was sought. We interviewed regular AMS users (with and without vascular diseases), non-users of the AMS, health professionals, managers and external service providers. Site-specific and central thematic analyses were conducted involving the whole research team. Data management was supported by NVivo 8.

Results from the health systems assessment: 37 staff participated in seven health systems assessments. Staff emphasised that AMS health care was distinct to mainstream services. Community governance and leadership, community representation on staff (especially Aboriginal Health Workers), and commitment to community development were important organisational features to ‘hold’ people. In accordance with candidacy theory, these features allow an organisation to be more ‘tractable’ to vulnerable populations. The responsibility to ‘hold’ people, however, was undermined by considerable insecurity in whether government supports the AMS sector. Grossly inadequate staff capacity and poor information systems were the most cited barriers to quality improvement. By contrast on-site specialist services, managed by AMS staff, were a strong enabler of comprehensive and coordinated support. Staff described several patient experiences of discrimination in hospitals that required considerable effort on their part to reinstate care. This suggests that hospitals still construct Indigenous peoples as ‘non-ideal users’ whom they are unwilling to properly ‘hold’.

Discussion: Kanyini and candidacy are promising theories for conceptualising issues affecting health care access and quality. Some COAG initiatives (workforce capacity
strengthening, improving chronic care delivery systems and increasing access to specialist services) are well placed to address barriers cited here. However, there are few initiatives that capitalise on the unique mechanisms by which AMSs ‘hold’ their users and enhance their candidacy to health care. Further, the COAG emphasis on improving access to mainstream services may contribute to AMS sector insecurity and resistance to collaborate. Forthcoming analyses of KQS data will further develop the insights gained here.

7.2 Background

In the previous chapter we explored candidacy as a theoretical construct to understand how the contemporary literature frames issues of access to health care for Indigenous peoples in Australia, New Zealand, Canada and USA. Our synthesis of both empirical and grey literature sources identified a number of thematic domains that influence access to health care. At the broadest level we identified a dialectical relationship in which non-Indigenous State sponsored health institutions are juxtaposed alongside an Indigenous counter-movement that seeks greater participation in the governance of those institutions. This relationship is historically informed by the colonial encounter and permeates many aspects of the delivery and receipt of health care.

Although candidacy theory was somewhat limited in incorporating these societal level issues, we found it apposite for understanding access barriers and enablers at the level of health care organisations. Three sub-themes to the theory were particularly relevant. (1) Tractability refers to the policies, structural developments, resource allocations and interventions undertaken by services to address inequity in access to health care. Our review found that Indigenous staff employment, adequate resources and a commitment to quality improvement were key features of a ‘tractable’ health service. (2) Navigation and permeability of services refers to the routes taken by people to gain a point of entry to health services with permeable services requiring little negotiation for entry and a minimal level of understanding of how the system works. Here also, Indigenous staff played a key role in making services more permeable. Transport services, flexible appointment structures, minimal out-of-pocket expenses, and welcoming physical spaces that conveyed a sense of belonging to the service were also important features of a permeable service. (3) Presentations, adjudications and offers which describes the circumstances under which
people appear, are invited or are coerced into health care. The notion that health services are frequently designed to only meet the needs of an 'ideal user' who has a particular set of competencies and demands is particularly pertinent here. We identified the care provider-patient relationship; communication, language and literacy; and the importance of gender and the body to be three key areas that influence presentations, adjudications and offers of care.

In this paper we develop these insights further through an empirical qualitative study, the Kanyini Qualitative Study (KQS). Study aims are to: (1) understand community, clinician, health service manager and external service provider perspectives on the barriers and enablers to good health care; (2) determine organisational factors that affect health care access and quality; (3) explore whether barriers and enablers to care manifest differently in primary care, specialist and hospital settings; (4) situate findings within a policy relevant framework, identifying strategies for potential improvement of care.

We locate our analysis in the context of recent shifts in Australian government policy for Aboriginal and Torres Strait Islander health. In November 2008 the Council of Australian Governments established a National Partnership Agreement on 'Closing the Gap' in Indigenous health outcomes (henceforth the COAG NPA). In addition to other agreements on housing and employment, the COAG NPA, budgeted at $1.6 billion over four years, has created unprecedented levels of funding for health service initiatives. The $800 million Commonwealth component is focused on improving outcomes for chronic diseases. The package is divided into three areas: (1) 'tackling chronic disease risk factors' focuses on reducing smoking prevalence, the creation of an Indigenous tobacco and lifestyle workforce, and use of social marketing campaigns to promote better health; (2) 'improving chronic disease management and follow-up care' focuses on improved access to medicines, incentives to care providers to improve chronic care management, improved care coordination and access to specialist services, and monitoring and evaluation of all these initiatives; and (3) 'workforce expansion' focuses on increasing primary care workforce capacity, the use of Indigenous outreach workers to broker health services, additional nursing and general practitioner (GP) training placements and promotion of guideline-based care. The COAG NPA is directly relevant to enhancing candidacy to
health care. We therefore seek to use our study findings to help inform this emerging policy environment and to identify factors that might be key to successful implementation.

**The Kanyini Vascular Collaboration**

The Kanyini Vascular Collaboration (KVC) is a five year health services research program established in late 2006 and funded by the Australian National Health and Medical Research Council. The primary aim of the collaboration has been to work with Aboriginal Medical Services (AMSs) to increase access to high quality care for Aboriginal and Torres Strait Islander peoples. Participating AMSs are based in New South Wales (NSW), Queensland and Central Australia covering urban, rural and remote locations. KVC is multi-disciplinary in nature bringing together researchers, health service managers, clinical and non-clinical health staff and policy-makers. Its objectives are to better understand gaps in health care access and quality for Aboriginal and Torres Strait Islander people with a focus on management and prevention of vascular diseases; to collaborate with AMSs to develop and test strategies to overcome system barriers; to improve research and service delivery capacity within AMSs; and to use study findings to better inform policy directions.

A series of discrete but inter-related studies are incorporated into the program. Studies include (1) the Kanyini Audit of prevention and management practices relating to chronic diseases in the community-controlled primary care sector (described in Chapter 3); (2) the KQS – the subject of this paper; (3) the Kanyini-GAP randomised controlled trial of a polypill based strategy to maximise access to evidence-based, long-term treatments among individuals at high vascular risk; and (4) a series of innovative quality improvement projects to improve the prevention and management of vascular diseases within primary health care services.

**Theoretical framework**

Starting with candidacy theory and its sub-themes, the research team held a series of workshops, teleconferences and face-to-face meetings over a six month period in 2007 to critique these themes and assess their applicability and relevance to the participating AMSs. This process occurred concurrently with the systematic review of the literature.
described in Chapter 6. Given the pressing need to promote Indigenous-specific models of care we also explored Central Australian philosophical concepts relevant to health care access. In particular we focussed on the concept of *kanyini*. This term is used by a number of language groups in Central Australia, including Pitjantjatjara, Pintubi and Luritja.

*Kanyini* represents one of the four foundations of Aboriginal life in Central Australia: *Tjukurpa* (Law, Dreaming); *Walytja* (Family); *Ngurra* (Land, Country) and *Kanyini*. In essence, *kanyini* describes the principle and primacy of caring for others — an obligation to nurture, protect and care for other people, family, country and the law.  

2 Myers’ ethnography describes Pintubi concepts of *kanyini*:

The metaphor of ‘holding’ (*kanyininpa*) is rooted in a powerful experience: it derives from a linguistic expression describing how a small child is held in one’s arm against the breast (*kanyimu yampungka*). The image of security, protection and nourishment is immediate. Extension of this usage characterises a wide range of relationships as variants of this mixture of authority and succour. An older woman who oversees and looks after the younger girls and women in the single women’s camp is said to ‘hold’ them. Most fully, the concept designates a central core of senior persons around whom juniors aggregate and by whom they are ‘held’. (p.212)

Similarly McCoy highlights how *kanyirninpa* is expressed in relationships that involve teaching and learning, and how it is viewed as an essential ingredient for social and emotional wellbeing.  

4 Randall defined *kanyini* as an unconditional love and responsibility to all things.  

Although rooted in Central Australian life there are related concepts described in health services research from other regions such as Yolngu concepts of *djäka* (caring) and *gungayun* (assisting).  

6 The use of the term *kanyini* for the name of our collaboration (KVC) was discussed with health service partners. Despite being specific to Central Australia it had inherent appeal across all sites and there was interest in exploring its relevance to health services research. In this way we inductively merged theories from the broader literature with Aboriginal philosophies, resulting in a conceptual framework centred around *candidacy* and *kanyini*.

### 7.3 Methods

#### Design and planning

There are two components to the KQS study design: (1) Health Systems Assessments involving structured AMS staff focus groups; and (2) semi-structured interviews with
community and health professionals. Figure 7-1 below outlines the study schema and its relationship to the Kanyini Audit. The rest of this paper describes in detail the methods used to develop both components and presents an analysis of data from the first component, the Health Systems Assessment.

Figure 7-1: Kanyini Qualitative Study – Study Schema

The KQS was strongly informed by the Improving Access to Kidney Transplants (IMPAKT) project. This inter-disciplinary health services research program examined, using a patient journey approach, the obstacles encountered in accessing dialysis and transplant services for Aboriginal and Torres Strait Islander peoples. The IMPAKT project was large. The team spoke with 241 Indigenous and non-Indigenous patients, 95 renal related staff and 28 other key informants across 26 urban, regional and remote dialysis and transplant centres in every Australian state and territory. There were clear synergies with KQS. Involving health services in the design and conduct of the project, the use of in-depth
qualitative research methods on a large multi-site scale, and the shared objective of identifying system level barriers/enablers which could inform future policy are similar features to the two projects. Three researchers from IMPAKT played a core role in the KQS which allowed us to adapt a range of scientific and operational methods from this program.

**Research team**

Two research institutes, based in Sydney and Alice Springs, coordinated the project. Kanyini chief investigators provided research guidance to the project and played an active role in all aspects of the study. Project staff consisted of two program managers at each institute, a research officer with several years experience as a remote area nurse and a senior research fellow who was a practising AMS GP with detailed knowledge of quality improvement programs in AMS settings. Although the study was implemented at several sites in two Australian states and one territory, a strong local focus was also maintained. This acknowledges that personal contacts with key stakeholders, recognition of local differences and forming local relationships are critical. Central to this local focus was a commitment to build local research capacity within AMSs through the employment of Indigenous Research Fellows (IRFs). Five positions were created – one in Central Australia, three in Queensland and one in New South Wales. These staff had considerable experience in AMSs having worked as Aboriginal Health Workers (AHWs), program coordinators, researchers and project officers. All were employees of the participating AMSs with the exception of the Central Australian IRF who was employed directly by the coordinating research institute. The IRFs drew on their past professional experience, community networks and relationships within the health service to guide the conduct of the study. In the initial phases of the project they coordinated the formation of community site reference groups comprising key local Aboriginal and Torres Strait Islander stakeholders (agencies or individuals). These groups reviewed the study procedures and provided guidance on how best to implement the study at each site (see Attachment 1 for the terms of reference).
Health Systems Assessment

Design

The transition point between the Kanyini Audit and Qualitative Study was a qualitative assessment of the health systems in place at each AMS (see Figure 7-1). In this study component we were influenced by the Audit and Best Practice for Chronic Disease (ABCD) research program which has taken a systems level approach to quality improvement in several AMSs. In ABCD a series of cross sectional clinical audits are coupled with a structured systems assessment in which staff are guided by a facilitator to assess the quality of their systems. The methodology and resources are adapted from the Assessment of Chronic Illness Care survey instruments and are based on the Chronic Care Model (CCM) developed by the US Improving Chronic Illness Care program. This survey was in turn modelled on an instrument developed by the US Indian Health Service for evaluating diabetes care. The ABCD systems assessment is intended for use by health services to: (1) identify areas for improvement in care for chronic illness before beginning quality improvement work; and (2) evaluate the level and nature of improvements made in response to quality improvement interventions. Assessments are made along six CCM components—community resources, health organisation, self-management support, delivery system design, decision support and clinical information systems. The ABCD team has integrated this tool into an assessment, planning and action cycle. This approach has demonstrated modest improvements in process outcomes (improved delivery of scheduled services) and clinical endpoints (diabetes control and cholesterol reductions).

Based on the experience of the ABCD and IMPAKT projects, when health service staff met to collectively discuss and determine responses to a structured health systems assessment (ABCD) or a review of processes of care (IMPAKT), important discussions were generated. Drawing on these two studies, we used the Kanyini Audit findings to explore staff perspectives on health systems issues that impact on access to quality health care. The purpose of this exercise was descriptive and exploratory rather than as part of a quality improvement methodology. A structured assessment form was developed to guide discussions with staff. Four principal domains of inquiry were developed. These were informed by our review of candidacy theory; concepts of kanyini; the findings from
IMPAKT and ABCD projects; and informal observations of health service systems that were made during the conduct of the Kanyini Audit. These domains covered the following: (1) Health service governance and cultural safety; (2) workforce issues and professional standards; (3) experiences of quality improvement activities and supports; and (4) navigation of care including access to hospital and specialist services. A series of structured questions were developed around these domains. A sample of the Health Systems Assessment form and the accompanying facilitator guide is shown in Attachments 2.1 and 2.2.

Sampling

We invited the eight participating AMSs in the Kanyini Audit to participate. These sites were selected on the basis of interest in participating and reflected diverse governance, funding arrangements, service activity and staffing mix. According to the Australian Standard Geographical Classification, two AMSs are urban, one is inner regional, two are outer regional, one is remote and two are very remote. According to National Aboriginal Community Controlled Health Service Organisation (NACCHO) definitions seven services are Aboriginal Community Controlled Health Services (ACCHSs) and one is a state government run AMS. Each assessment involved one staff focus group per site with three to seven participants and two research facilitators per group. We purposively sampled to ensure a diverse range of clinical, administrative and managerial staff participated.

Focus group conduct

Each session lasted approximately two hours. The first hour involved a brief presentation by the research facilitator and review of a site-specific feedback report on the key findings from the Kanyini Audit (see Figure 7-1). A sample feedback report is shown in Attachment 3. Discussion of audit findings was unstructured and served as an 'ice-breaker' for focusing on the systems assessment. In the second hour the structured focus group was conducted covering the questions in the systems assessment form. Each group was facilitated by one researcher and the program manager from one of the two coordinating research institutes. All facilitators had detailed experience of working in AMSs and specific appreciation of local context having been involved in data collection for the Kanyini Audit. Staff were encouraged to give expansive explanations of their views and
these sessions were digitally recorded and professionally transcribed. Specific survey responses will be correlated with the findings from the Kanyini audit as part of a quantitative systems modelling exercise. For the KQS, however, our focus was oriented toward the conversations generated around these domains rather than answers to specific questions. Analysis of these health systems focus group data was conducted concurrently with analysis of the semi-structured interview data (see 7.3.7 below).

**Semi-structured interviews**

**Design**

Following the Health Systems Assessment we progressed to semi-structured interviews with health professionals and the community. From the conceptual frameworks of *Kanyini* and candidacy we developed five inter-related domains of inquiry which guided the conduct of the individual interviews: (1) how people engage with care; (2) staff and community experiences of care; (3) what people (staff and community) consider to be the features of proper care; (4) specific barriers and enablers to receiving and providing proper care; and (5) approaches needed to build better systems of care. From these broad domains of inquiry interview questions and accompanying probes were iteratively developed by the research team. The exhaustive list of suggested primary questions and potential probing questions is shown in Attachment 4.1 (community interviews) and Attachment 5.1 (health professional interviews). These sample questions were then further refined over the next 3 months following pilot testing at each health service site. In this phase interviewers were encouraged to adapt the questions to make them applicable to local context and suitable to their interview style. This led to refinements in the type, phrasing and order of questions asked. IRFs were given direct supervision and training to assist with conducting interviews. Two-weekly teleconferences and four-monthly face-to-face site specific training workshops were provided to support each research team member to gain confidence in conducting semi-structured interviews.

**Sampling**

The eight AMSs partner sites from the Kanyini Audit, as well as one additional, outer regional ACCHS that had newly joined the collaboration were the organising hubs for the semi-structured interviews. In addition to working with these AMSs, interviews were
conducted with staff from a range of specialist, allied health and hospital services based on recommendations at each site. We used a purposive, maximum variation sampling strategy to guide the selection of interview participants. Three groups of community participants were sought: people with chronic diseases who regularly used the AMS for their routine health care; people without chronic conditions that regularly used the AMS; and where possible we drew on local networks to invite people who never use or irregularly use their local AMS to participate. Across these categories a balance between male and female participants and an even distribution of ages was sought. For staff interviews we sought views from Indigenous and non-Indigenous health staff. This includes clinical staff (doctors, nurses, Aboriginal Health Workers and allied health staff), non-clinical administrative staff (receptionists, transport workers, other administrative officers), visiting health professionals, health service managers and directors on local boards of management. Where possible we also sought views from key informant hospital and government community service health professionals. A sampling matrix spreadsheet was developed at each site for both community and health professional staff with these broad characteristics. Interviewers regularly updated this sheet and this was used to guide future people to sample. This was useful to prevent over- and under-sampling of particular groups. These sampling matrices were locally maintained by IRFs and aggregated centrally at the two coordinating research institutes at frequent intervals to oversee sampling progress across all sites.

**Interview conduct**

We drew on the rich, multidisciplinary nature of our research team to conduct the semi-structured interviews. IRFs provided guidance on who to talk to, the appropriate setting and who might be the best person to conduct the interview. We adopted three different strategies to interviewing: (1) For many interviews we used a peer to peer interviewing strategy (e.g. a GP researcher spoke with a GP, an IRF spoke with Aboriginal Health Workers and community members). This allowed health professional participants to have a collegial level discussion and was particularly helpful for senior staff and medical staff where there were limited opportunities for interviewing. For community participants this was also helpful in establishing rapport, communicating the purpose of the study and giving participants a known person to whom post-interview issues could be referred. (2)
Whilst peer-to-peer interviewing has obvious strengths there were a number of times where we departed from this in favour of an ‘outsider’ approach where an external researcher conducted the interview. This was particularly helpful for health professional interviews where sensitive workplace issues might arise and for community interviews where participants had a close relationship to the IRF. (3) For several interviews we also took an ‘insider-outsider’ approach where two people (one internal and one external to the organisation) interviewed together. This combination allowed the outsider to ask ‘naïve’ questions and clarify assumed contextual factors whilst the insider was able to draw on deeper understandings of community and workplace issues to enrich discussions further.

Individual interviews were conducted using a narrative (open-ended question) approach. The approach was informal, flexible and respectful, with the primary motivation being to encourage participants to articulate their experiences and views in the five domains of inquiry. Interviews were conducted in a variety of settings including the AMS and other non-government Indigenous organisations such as elders’ associations, participants’ homes, hospitals and community health centres. Unless the participant had any objections, interviews were digitally recorded and professional transcribed (see data management process below).

We also conducted interviews in languages other than English. Rather than interpreter-guided interviews we employed a similar strategy to IMPAKT in which researchers who were fluent speakers of the participants’ primary languages conducted the interviews. We were fortunate that one IRF team member was a fluent Kriol speaker. For Central Australian interviews a non-Aboriginal anthropologist, fluent in a number of regional languages, was sub-contracted to conduct a small number of interviews. Following completion of the interview in the person’s primary language, another research team member conducted a ‘second order’ interview with this anthropologist in English. This interview would generate a conversation around the key issues raised by the participant and this was digitally recorded and professionally transcribed as usual. This transcript and any relevant field notes were then reviewed at the analysis stage.
**Data management**

Basic demographic details for participants in both the Health Systems Assessment and the semi-structured interviews were collected on a record of interview form (see Attachment 4.2 for community and Attachment 5.2 for staff versions). This form was also used by the interviewer to record any relevant field notes and observations made during the interview. Alternatively, interviewers used the digital voice recorder to make any additional comments about the interview and these were transcribed and appended as field notes to the interview transcript.

Because of the multi-site nature of this study, there needed to be clear processes in how we managed the data. This process is outlined in Attachment 8. Each site maintained a study log which ensured that essential interview data were managed appropriately and various tasks were completed post-interview. This included recording the interview participant details from the record of interview form into the study log; emailing the interview audio recording to the relevant coordinating research institute for professional transcription; recording details in the sampling matrix; and returning the transcribed interview to the participant if requested and responding to any recommended changes. Upon completion of these steps the interview transcript was ready for importing into NVivo 8 (QSR International, Vic) for coding and analysis. Periodically all site specific study logs were merged to produce an overall study log. This allowed us to assess progress on interviews conducted across all sites. Summary tables of interview data were reviewed at study meetings and this guided decisions on when to stop conducting further interviews. The local NVivo files were also periodically merged to produce a single file with all coded interview data.

**Ethical considerations**

This study seeks to provide an in-depth analysis of the journeys made by patients and their care providers when seeking and providing health care. It was important to our team that the principles of *kanyini* be applied not only to understanding the delivery of health care but to the conduct of our research. In so doing we were strongly aware of our responsibilities and obligations to participants and our partner health services. Consent material comprised of a written information sheet about the study and an informed consent
form to participate. Separate versions were developed for community and health professional participants. Samples are provided in Attachments 6.1-6.4. Whilst for many the opportunity to voice their stories was welcomed, there was the potential for this to cause distress. A locally developed distress protocol was used at each site in order to guide interview staff on the appropriate actions to be taken in these situations. These protocols were reviewed by ethics committees and community reference groups. A sample distress protocol is provided in Attachment 7.

Privacy of data was also an important consideration, particularly where staff were providing details about their workplace. Participants were asked where they would like their interview information stored and who was allowed access to this information. In some instances this meant that information was held off site and research staff who were employees of the health service did not have access to the data. At other times staff and community participants welcomed full participation from local research staff in analysis and interpretation of the data and in these cases password protected interview data were stored locally and only accessible by designated research staff. Five site specific ethics committees, including one Aboriginal committee, reviewed and approved the study protocol. Memoranda of understanding and/or partnership agreements were established between the coordination research institutes and the respective governing bodies at each health service. These covered all components of the KVC program. Job descriptions, professional development plans, formal and informal support to Kanyini IRFs were included as attachments to these documents.

**Analysis process**

Thematic analyses were conducted contemporaneously with data collection, following the methods outlined by Patton. We developed a single coding and analysis framework for both the health systems assessment interview data and the semi-structured interviews. There were four discrete stages to its development.

**Stage 1: October 2008 to March 2009**

Responses to the Health Systems Assessment form were tabulated and reviewed by the research team. Two researchers at each of the coordinating institutes conducted repeat
readings of the focus group transcripts. At this stage these interviews were used to get a broad sense of the systems issues raised by staff. Using this as background context, we then focussed our attention on analysis of the semi-structured interviews. Team members involved in interviews at each site selected two interview transcripts (usually one staff and one community participant) and these were circulated and read by eight team members. A half-day video conference was then convened in which these interviews were discussed in depth. One of the interviewers would inform us of any relevant contextual factors and provide a brief summary of the key issues arising from the interview. A pre-assigned discussant, usually based at another site, then provided detailed comments based on his/her reading of the transcript. All team members then participated in an open discussion to clarify the themes. The process was repeated for six interviews in total and a summary of the emerging themes was produced. This summary was refined in subsequent teleconferences and interviewers were able to use the outcomes from this early stage analysis to inform subsequent interviews.

Stage 2: April to August 2009

A similar process was conducted with a further four interviews analysed in a face to face meeting. The summary of themes developed in Stage 1 was further refined and the major findings thus far were presented at the annual Kanyini investigator meeting. This meeting had around 30 attendees from health service partners, study chief investigators, research staff and other key government and non-government stakeholders. The discussions arising from this meeting further refined our analysis process. Following this meeting, one or two new interview transcripts were similarly discussed at our fortnightly teleconferences.

Stage 3: August 2009

By the end of this preliminary analysis process we commenced the coding of interviews. The team met for a two-day face to face workshop with the aim of further developing our skills in coding interview transcripts. This was facilitated by an experienced qualitative researcher who had played a mentorship role throughout the development of the study. Various exercises were conducted to critique study objectives and conduct line by line coding of selected transcripts. Training in the use of NVivo was also provided. Several important issues arose from this workshop that shaped our approach to analysis. There was
a strong need to maintain the integrity of interview participant accounts and to recognise that thematic analyses had the potential to be overly reductive in aggregating selected transcript excerpts from multiple participants. Each of us had unique approaches to interpreting and perceiving the data particularly in relation to our health professional and cultural background. This required the analysis process to be handled sensitively and democratically. Another important aspect that aided this process was the personal insights from research team members who were employees of partner health services. Awareness of organisational history, governance, operational management, program development and staff workforce issues provided important context to interpretation of the data. Similarly the experienced researchers on our team played a key role in situating findings within the broader historical and contemporary health systems context. Their insights from other related qualitative work also contributed greatly to this.

Stage 4: October 2009 to March 2010

With some guiding principles to coding established we then created the coding framework with which to analyse the interviews. Four new interview transcripts (two health professional and two community) from four sites and the seven health systems assessments interview transcripts were then coded line by line in NVivo. Despite having already reviewed several interviews, we sought to open code these interviews without referring to the provisional themes that had been developed. Where possible, all research staff coded their own interview data, usually in teams of two or three people. This resulted in four NVivo files (one for Central Australia, two for Queensland and one for New South Wales) which were then merged to a single central file. The locally generated codes were grouped into clusters and these were critically reviewed in a fourth workshop conducted over two days. Overlapping codes from each site were collapsed together, whilst in other instances site specific codes were maintained. A complete draft coding framework with accompanying definitions was then agreed upon and this was then used to code the remainder of the data collected. Periodic revisions were needed to this coding framework as new codes emerged from subsequent interviews. These were discussed in the fortnightly teleconferences and the recommended changes were incorporated into the coding framework. The use of multiple NVivo files with the identical coding framework allowed up to nine researchers at different sites to code data. This made it possible to conduct site
specific analyses whilst at the same time ensuring some harmony to interview coding across all sites.

**Communication of study progress and findings**

Using study findings to inform policy agenda is a central KVC objective and therefore an effective communication strategy is important. Health service partners and other interested stakeholders are informed of the study’s progress via a quarterly newsletter, website updates and annual investigators’ meetings. Those services in which an IRF is based receive additional updates via internal staff meetings. Project staff at the two co-ordinating institutes also have a regular presence at each AMS site, conducting two monthly face-to-face visits and regular telephone meetings. For most sites this has occurred for over three years.

A structured dissemination strategy will be implemented over 2010 and has been budgeted accordingly. Feedback will consist of three components. (1) A preliminary site specific analysis will be presented at each AMS to allow sites to reflect on the interpretation of their local data. This feedback will be used as a type of ‘member checking’ process to determine the salience of the findings and to guide us on the need for additional analyses. We will draw on our feedback experience with the Kanyini Audit in which a series of meetings were held with AMS boards of directors, management staff and clinical staff. Open community forums are also planned. (2) As our analyses develop further a second feedback activity centred on the study’s overall findings will then be conducted at each site. (3) Study findings will then be communicated to a wider audience via conference presentations, publications and a series of policy stakeholder forums in which key government and non-government agencies will be invited to discuss study findings.

**7.4 Results**

Seven Health Systems Assessments involving 37 staff were conducted between May and July 2008, soon after completion of the Kanyini Audit. Table 7-1 provides a profile of the services and professional categories of the participating staff. Due to a range of competing priorities one of the remote services that participated in the Kanyini Audit was unable to participate.
Table 7-1: Health service characteristics for the health systems assessment

<table>
<thead>
<tr>
<th>Service</th>
<th>Urban 1</th>
<th>Urban 2</th>
<th>Regional 1</th>
<th>Regional 2</th>
<th>Regional 3</th>
<th>Remote 1</th>
<th>Remote 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service population (% regular clients)</td>
<td>3444 (63%)</td>
<td>2882 (76%)</td>
<td>504 (63%)</td>
<td>748 (76%)</td>
<td>11740 (70%)</td>
<td>780 (72%)</td>
<td>1100 (91%)</td>
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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Workforce total (Indigenous)</td>
<td>26 (9)</td>
<td>42 (23)</td>
<td>6 (5)</td>
<td>9 (4)</td>
<td>133 (103)</td>
<td>7 (2)</td>
<td>12 (6)</td>
</tr>
<tr>
<td>General Practitioners (Indigenous)</td>
<td>4 (1)</td>
<td>6</td>
<td>1b</td>
<td>2 (1)</td>
<td>8</td>
<td>1</td>
<td>1*</td>
</tr>
<tr>
<td>Registered Nurses (Indigenous)</td>
<td>9 (1)</td>
<td>1</td>
<td>2 (1)</td>
<td>14 (2)</td>
<td>4</td>
<td>3</td>
<td></td>
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<td>2</td>
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<td>0</td>
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<tr>
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<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
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Systems

<table>
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<tr>
<th>Electronic record system</th>
<th>Practix</th>
<th>MDC</th>
<th>Ferret/MDC</th>
<th>MDC</th>
<th>MDC</th>
<th>Communicare</th>
<th>Communicare</th>
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<tbody>
<tr>
<td>Automated pathology</td>
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<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td></td>
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<tr>
<td>Disease register system</td>
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<td>Home medicines review</td>
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On-site specialist services

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<tr>
<th>General physician</th>
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<th>monthly</th>
<th>weekly</th>
<th>2 monthly</th>
<th>yearly</th>
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</thead>
<tbody>
<tr>
<td>Cardiologist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6 monthly</td>
<td>yearly</td>
</tr>
<tr>
<td>Service</td>
<td>Urban 1</td>
<td>Urban 2</td>
<td>Regional 1</td>
<td>Regional 2</td>
<td>Regional 3</td>
<td>Remote 1</td>
</tr>
<tr>
<td>----------------------</td>
<td>---------</td>
<td>---------</td>
<td>------------</td>
<td>------------</td>
<td>------------</td>
<td>----------</td>
</tr>
<tr>
<td>Nephrologist</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Ophthalmologist</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<td>-</td>
<td>monthly</td>
<td>daily</td>
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</tr>
<tr>
<td>Dentist</td>
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<td>daily</td>
<td>-</td>
<td>-</td>
<td>daily</td>
<td>2 monthly</td>
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<td></td>
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<td>No</td>
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<td>Yes</td>
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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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</tbody>
</table>

**Table Notes**

- a. Focus group participants
  - Urban 1: Clinical director, GPs (x2), Chronic disease RN, AHW project officers (x2), Aboriginal liaison manager
  - Urban 2: Board member, GP, AHWs (x2), RN, Finance manager
  - Regional 1: Chief Executive Officer, GP, RN, Driver, Receptionist
  - Regional 2: GP (x2), RN, AHW (x2), Receptionist
  - Regional 3: GP, Chronic disease AHW, Cardiac Rehabilitation AHW, Programs Coordinator
  - Remote 1: GP, RN (x2)
  - Remote 2: RN (x3)
- b. Part-time locum only
- c. Medical Director
For the semi-structured interviews we spoke with 108 community members and 96 staff over a 14 month period from October 2008 to December 2009. Analyses of these semi-structured interview data will be reported in subsequent papers not contained in this thesis.

**Qualitative themes from the Health Systems Assessment**

Five core themes from the staff focus group discussions on their health systems are discussed here. They are: (1) AMSs are different to the mainstream; (2) AMSs are under threat; (3) Workforce roles and capacity; (4) Commitment to quality improvement; and (5) Challenges in access to hospital and specialist care.

**Theme 1: AMSs are different to the mainstream**

At all sites staff emphasised the unique aspects of AMS service delivery when compared with the mainstream. In particular, engagement with local Aboriginal and Torres Strait Islander communities was repeatedly affirmed as the main difference. Staff viewed the type of care they provided to be comprehensive, responsive to community expectations and patient, rather than business-oriented.

> They (clients) get such a marvellous wide ranging preventive health service. Aboriginal people only come when they’re sick, so you’ve got to seize that moment and address all the other issues, like diabetes, or hypertension, or kidney disease. And so, with this sort of organization, you can’t solve all those problems, but you can attempt to address them. In a normal general practice, or in a mainstream setting, that would never happen. So I think they’re wonderful organizations for preventive health. (CEO Regional AMS)

By contrast, private general practice was viewed as focussing on maximising business revenue and providing reactive rather than preventive health care. It was also felt to inadequately acknowledge the particular needs of Aboriginal and Torres Strait Islander peoples.

> I suppose, as an Indigenous doctor, you often get (patients saying) ‘I’m happy to talk to you about this, but I wouldn’t really want to talk to the GP down the road about it ... If it’s something to do with emotional, cultural, spiritual stuff, then that really does need to be addressed. But, you know, mainstream practices might not see it as ‘true’ medicine. (GP regional AMS)
Although community linkages are known to be an important component to chronic care, the depth of community connection in AMSs goes beyond this. Even for the only non-community governed health service, staff stressed the importance of ensuring community input and that this is usually not appreciated in mainstream services.

Even though we’re a mainstream health service we do work really strongly with the community and I think that’s probably a big plus for us. There’s nothing more important than having local people (on staff) ... that liaise between the community and us ... We still have that strong contact, especially with the elders ... Normally mainstream health services never venture out in Indigenous health to actually work with the community and not many (patients) come to them. (Clinical director urban AMS)

Consistent with our theoretical understandings of kanyini, staff frequently commented on the obligations they felt to reach people and act in their best interests. This need to hold and nurture people was most profoundly felt by Aboriginal Health Workers.

Not only do we work here but we live in the community. So a lot of the clients that come are our relatives or a relative of our relatives ... So our work doesn’t just stop when we finish work, it continues after work as well. (AHW/Programs coordinator regional AMS)

These obligations constitute a powerful mechanism for enhancing the candidacy of Indigenous communities for health care. For AHWs there was an unconditional quality to the care provided, subtly blending the well-demarcated work responsibilities with diffuse personal obligations in the community. Whilst these obligations may manifest quite differently for non-Indigenous staff a similar dedication beyond the ordinary was apparent.

... we go in on the weekend to see people in hospital, on our weekends off ... It is an absolute necessity that it’s done but nurses are having to pick up the burden of the social aspects of the clinic and (they are) doing them in their own time. (Registered nurse remote AMS)

This duty to reach people also helps explain why health promotion constitutes a key part of service activity. Bridging clinical services with activities that develop community capacity are central to health service function.

Daniel (pseudonym for an Indigenous project officer) works on a shared responsibility agreement with the football club. It’s brought in an investment of a few hundred
thousand dollars to the community and has been used here to engage health promotion initiatives ... I think that is a really good example of delivering health in a very different way and engaging the community's strengths. Rugby league is a huge factor for a man and it shows in figures that men attending the clinic are still under represented ... So the work that's been undertaken has seen an investment of infrastructure in the community sector as well as furthering this clinic. (Aboriginal health promotion officer urban AMS)

In order for an AMS to 'hold' and nurture its community, this engagement is needed at all levels of the organisation, not just with the governing board. Only when local staff are employed across a variety of positions can this hold be consolidated. This workforce affirms community linkages and the consequent legitimacy of the organisation.

Being a community controlled service you not only have it (community control) at the board level but it should be reflected in the organisational structure right through to even the groundsmen ... it gives the staff themselves a sense of belonging and knowing that it is owned by the community. We all live in this community so we're a part of the organisation and we're working for it, showing to the wider community that we are able to work at all these different levels. (AHW regional AMS)

One health system feature that strongly reflects kanyini is the availability of transport services. This was universally acknowledged as a critical component to good health care rather than merely an ancillary support. Staff from all professional backgrounds commented that the level of care provided is heavily influenced by the availability of transport and that its absence 'defeats the purpose of us being here'. For one urban service that is not funded to provide transport, clinical managers frequently bent rules to ensure patients attended appointments. Similarly for the two remote services, transport was critically important. One service provided daily visits to homelands, transporting people either back to the clinic or to the major referral centre if acute or specialist care was needed. Substantial monetary and human resources were allocated to maintain this service. For the other remote site airplane transport services were especially dire with long wait times and patients having to travel alone to attend appointments. This left many feeling vulnerable when 'stuck' without family in the referral centre. For some people this impacted greatly on future decisions to seek specialist care. Thus transport is a key mechanism by which people are 'held' by their health service and supported to navigate the system.
Theme 2: AMSs under threat

Despite the primary importance of firm connections to community, several AMSs felt that their community governance structures were under threat. These perceived threats manifest at a number of levels. For several of the ACCHSs, relationships with their principal funding body, the Office of Aboriginal and Torres Strait Islander Health, were a frequent source of tension. Many staff commented on the challenges of having to compromise community needs and expectations in order to satisfy external expectations, particularly complex reporting to funding bodies. A robust governing board was considered critical to balancing these tensions.

The Board are better equipped and better able to run the health service because they’re from the community, they know what the community need. To me it’s a best practice approach, it’s an evidence based approach because we are the community. We know what we want. We don’t always have to be told ‘you need this, you need that’, or ‘you should be doing this’. (AHW regional AMS)

For the two services under the auspices of ACCHSs from other regions, staff felt the fundamental principle of community governance was being undermined. Relationships with the auspicing body were volatile and for one service, the continual lack of progress toward becoming an independent health service left many staff feeling despondent.

There’s probably to some extent a fundamental flaw in that we aren’t as community controlled as we’d like to be. We’re controlled by a different community, which just doesn’t make sense. (The local Board is) a bit of a toothless tiger unfortunately ... About five years ago, it was really strong ... and (names people) were working really hard towards us becoming independent. But there’s only so many times you can get kicked in the teeth before you stop going back there to get another one. (GP regional AMS)

This volatile relationship often resulted in confusion amongst staff about who are the decision makers and what are the appropriate lines of management. At one service it left staff feeling that directives were made in a top heavy manner with little consideration of their opinions.

Well, the biggest problem at the minute is that there’s too many chefs in the kitchen ... And the big picture seems to get lost ... and this has to be put back on track ... And when you’ve got fifty thousand different opinions it gets very muddled. (Nurse regional AMS)
By contrast, one large and experienced AMS considered it had a duty to support new AMSs in the region and its experience in auspicing several fledgling health services were recounted positively. These arrangements were always intended to be temporary with the view to supporting the health service to become independent.

There are five or six of them (auspiced services) around here and the AMS has played an important part in setting them up and then handing them over to people in those communities that run those affairs. And that speaks volumes about their approach to doing business. (AHW regional AMS)

Another frequently perceived threat is that mainstream health service providers do not consider that AMSs provide adequate services, thereby legitimising increased external involvement. In this poignant interaction between an AMS board member (P1) and AHW (P2) both felt there was a hidden agenda to eliminate AMSs altogether, replacing them with poor quality ‘mainstream’ health care.

P1: They (government community health services) shouldn’t think that they are far superior to the AMS team. That sort of an attitude, they should cut it out.

P2: Oh that attitude will stay around for a long time until somebody, until the boss of this organisation says something to them ... I’ve seen it happen ever since this partnership agreement first started.

P1: But they say that we need their services too but that doesn’t mean they should come and tell you to do this, do this, do this. Low grade services ... they try to bung it onto us.

P2: They have been for quite some time though.

P1: Still trying...If we look a little bit further down the track, say five, ten years time there won’t be any more AMSs in New South Wales. They will become all mainstream.

P2: That’s a plan of the minister ... low grade services.

P1: That’s where we’re heading, towards mainstream.

Despite these fears of being consumed by the mainstream, there were examples of successful partnerships between AMSs, government and other non-government agencies. One Aboriginal Health Worker argued for a ‘co-operative self-determination’ where government agencies practise non-interference whilst still maintaining support to AMSs to self-direct the delivery of health care. At one health service site the establishment of an
inter-agency forum over 14 years ago has allowed government and non-government organisations (NGOs) to have equal representation and complete several collaborative projects. Indigenous project officers from the health centre have played a central coordinating role for this forum and have supported a number of small Indigenous NGOs to expand their community development capacity. This appears to have been successful in implementing a ‘co-operative self-determination’ model.

**Theme 3: Workforce roles and capacity**

*Lack of staff*

Several people interviewed felt chronic staff shortages curtailed the quality of care they provided. This was the major contributor to staff burn out. In particular, insufficient staff to meet acute care needs was considered a critical barrier to developing sustainable chronic disease services.

> In the past, patients would have a preventive health check but this has stopped because there’s been an influx in acute care ... That leaves the doctors no time to manage chronic needs and help patients to self-manage ... So I think we need to look at how are we as an organisation going to tackle acute care. And then by reducing that, I think it would then have an impact on the chronic disease because a lot of the acute care is manifesting as chronic disease later. (GP regional AMS)

These comments are supported by the Kanyini Audit findings in which over 40% of routinely attending adults aged 30 and over were at high risk of vascular diseases or already had these diseases. It highlights that patient care cannot be easily dichotomised into acute and chronic care. Chronic care is likely to be everyone’s business, whether in the specialised or general clinic setting. The sequelae of this are that adequate resources are essential in order to provide comprehensive chronic care services to routinely attending patients, regardless of the reason for the encounter.

*Role of Aboriginal health workers*

In candidacy theory, ‘tractability’ refers to organisational policies that are specifically geared toward increasing access for vulnerable populations. AHWs appear to be one of the key mechanisms to making AMSs more tractable. Many staff commented on their ability to expand the type of care provided and that their unique skills to engage with community
members is a critical adjunct to conventional medical services. This was not merely an issue of their identification as an Aboriginal and/or Torres Strait Islander person. One Aboriginal GP commented that AHWs added value in ways that he could not.

An Aboriginal health worker is a key person that community members will feel more comfortable talking to about stuff than even with me ... When Tanya (pseudonym) was working as a health worker, it was just a different place to work altogether. If I was struggling to chase someone up for weeks, I might just mention it to her and she’d say, ‘Oh look, today they’re probably down here’, and go and get them. One of the things that helps me out as the GP is having that true feedback from the community as to what’s really going on. Because sometimes people tell me stuff, and it’s not quite what everyone else is talking about ... So, it puts you on the right foot to initiate what you believe to be appropriate treatments. (GP regional AMS)

The diverse roles fulfilled by AHWs were evident in this study. In several sites a more traditional AMS model was in operation where the AHW works at the ‘frontline’ of clinical care providing the first point of contact for triage and health screening. Brokerage roles such as making health information more accessible are a key part of this role.

I like working with my own people ... It’s great that I’m the clinical health worker because I break down the barriers ... Doctors tend to talk big words and a lot of the community don’t understand that. So I’ll break it down into our jargon and I put it straight to them. (AHW urban AMS)

Juxtaposed with these traditional clinical and brokerage roles is an increasing emphasis on health promotion and community development roles. For one project officer the delivery of ‘strengths based health promotion’ was closely aligned with asserting Indigenous concepts of health.

I’ve always struggled with the role of the Indigenous health worker and where we sit in the structure ... I think there’s a lot of uncertainty and health workers work in very different environments ... And I guess where I feel most comfortable is around community-based health promotion and delivering health from an Indigenous perspective of health. So not just thinking about food and exercising but thinking about community wellbeing. That’s my agenda and what I see as important as an Indigenous person in the health profession. (Indigenous project officer urban AMS)

In one remote service, registered nurses felt AHW staff had a nominal presence in the health service only, suggesting they served no useful function at all, acting rather as ‘pin-ups’. Competing priorities with family responsibilities branded them as unreliable and
because they were not of sufficient standing in the community they lacked the respect of the people they served.

They (AHWs) are terrific to use as go-getters and liaisons and communicators and things like that, but they don’t want to do health work ... There’s a lot of issues because for both of our health workers there’s family groups that they won’t go near ... And I just think that being a health worker here is a position that doesn’t have any credence or respect in the community ... Ideally the health worker here would be someone who’s indigenous and knowledgeable with the people, but who’s not from here, who is impartial to all the different groups of people here. (Nurse remote AMS)

Such comments stand in stark contrast to the preceding ones in which AHWs play an expansive role as the nexus between service and community, broker of services, coordinator of health promotion activities and embodiment of a community governance model. They emphasise a more narrow view of AHWs as medical assistants. These apparent weaknesses of over-familiarity with the community can constitute a substantial asset to the health service if supported appropriately. The level of organisational support for these roles is therefore a critical factor in maximising the contribution of the AHW workforce to improved care.

Workplace orientation and professional development support

Although access to professional development opportunities seemed well supported, few sites had any formal orientation to prepare staff for working in AMSs. Only the state-run service has obligatory cultural awareness training workshops for new staff and many commented that this course was tokenistic, poorly preparing staff for the realities of their work on the ground. Similarly staff who attended state government run clinical orientation training workshops considered them to be ‘just a piece of paper’ bearing little relevance to what was actually needed. Despite this limited orientation, staff commented on a wide variety of informal measures through which they gained experience and support to carry out their job roles. In particular, guidance from senior Indigenous people was highly valued. In some services consultation with elders (either as patients or at community education events) was used to get advice on appropriate professional conduct. Senior Aboriginal clinical staff also played a critical role. One GP commented on how he would seek advice from an Aboriginal nurse manager for difficult management issues. This support allowed him to feel his work practices were safe. In another service doctors
received ad hoc ‘corridor’ training from the senior doctor. This doctor’s multiple perspectives as an Aboriginal person, respected clinical manager and medically qualified health professional enabled him to support a variety of staff on a breadth of issues. Fulfilling these roles, however, placed great demands on him.

It’s very refreshing and very exciting having one of the other doctors who is Indigenous because it just helps keep everything in a better balance ... I think Jason (pseudonym) was an incredible person ... Everybody wanted him because he’s confident, affable and smart. The difficulty was that although it was fantastic having him in that role, it was also very difficult for him to actually perform the role adequately because he had so many other responsibilities ... I think that must always be a tension for people in that position. (GP regional AMS)

Theme 4: Commitment to Quality improvement (QI)

Three components of the CCM were most talked about in relation to effective quality improvement strategies. These were related to organisational influence (especially leadership), information systems, and delivery system design (especially care planning and follow-up).

Organisational influence and leadership

Interest and capacity at the highest levels of management appear key to establishing satisfactory QI systems in AMSs. At one service, three senior positions (executive officer, medical director and a dedicated systems manager) take responsibility for QI activities. Of particular importance is the link between the medical director and the executive. For many years this relationship had been extremely productive and QI activities thrived. In recent times with the medical director position becoming vacant and high turnover in the systems manager position, this leadership structure has become more tenuous and QI activities are noticeably less robust. At another site, staff felt that managers were out of touch with their needs and made decisions that were ill-informed or cost-driven rather that patient care driven.

To provide good chronic disease management you need great systems and at the moment we’ve had problems with that ... From experience, systems are always forced upon us by higher management ... systems we don’t want. (Clinical director AMS)
Delivery systems and care planning

The issues of sufficient numbers of adequately trained staff for quality improvement activities was extensively discussed. There was a variety of approaches as to how staff should take responsibility for recall systems and chronic care planning. In two services nurses had the primary responsibility to manage recall systems whilst at another service, AHW program coordinators managed disease specific programs such as diabetes and cardiac rehabilitation. These approaches contrast with another service’s experience where chronic care coordination was provided as a part of a joint state and federal funded initiative conducted in partnership with three AMSs and other regional health providers. Under this program externally funded ‘care units’, based at the AMS, initiated health assessments and care plans. Additional funding was also available to assist patients to access specialist services under this scheme. Whilst care coordination is inherently appealing and has been trialled successfully elsewhere, the AMS staff we interviewed felt that the program was overly driven by the external stakeholders and that this actually hindered effective care coordination. These external managers of the program were considered to be overly focused on data collection for statistical reports and less committed to actual coordination of care.

There were mixed views about the role of Medicare health assessments and care plans as a component to chronic care delivery systems. For one service an upfront investment in nursing staff to manage these Medicare items proved to be a successful business strategy as the income generated was able to ostensibly fund these positions. At another service, however, the chief executive officer cautioned that when this became the end rather than a means to quality patient care it could compromise the integrity of the service.

You can spend all your time chasing Medicare dollars ... you can do health assessments just for the sake of doing health assessments and not actually help the patients ... It’s not necessarily the great pot of gold ... it’s not going to solve all your problems ... And chasing a handful of dollars, sometimes you don’t pursue the right directions, and your directions should be primarily improving the health of the community that you’re working with. (CEO regional AMS)

Information Computer Technology/Information Management (ICT/IM)

Many staff felt their ICT/IM infrastructure was sub-standard. This constitutes a major barrier to supporting a culture of quality improvement in chronic care. Whilst there were
simple problems such as not enough computers, the most common and serious concern was that systems had frequent outages and that support services were inadequate to troubleshoot problems when they arose. Staff were concerned about inadequate data backups, unsystematic processing and potential loss of important information, and fears that outages of paperless systems could substantially compromise patient safety. We witnessed several outages at a number of services during data collection for the Kanyini Audit. On one occasion this was so severe that managers closed the clinic and many patients who had already completed screening procedures were turned away.

Dissatisfaction with Patient Information Recall Systems (PIRS) was equally important. Of the various systems used there appeared to be strengths and weaknesses with each of them with no one system being an ideal fit.

I would really love to marry Ferret, Communicare and Medical Director all into one. That would be the best program because I think they all have something within them that’s so good and then there’s a part of them that is so crap... We all need different bits out of it so the doctors need the clinical side, health workers need the management side and the Board and management need all the data for their reports, for funding purposes. So we all need something out of it, but one program never gives all of it ... I think the person who comes up with this program is going to be a national icon!

(AHW regional AMS)

This again emphasises the unique needs of AMSs where different PIRS components are needed for a wide range of purposes. Equally important was the lack of staff training to fully reap the benefits of whichever system was being used. Staff felt that even after several years of use they were still discovering new things.

I think we’re done a disservice because we’re not oriented properly to Medical Director when we start here. So it takes you a year or two to actually learn how to use it properly ... And my argument with this organisation which was saying, ‘Let’s bring in Ferret’, was ‘Let’s use Medical Director properly and make the recall system work properly.’ Sure, you don’t have exactly the population data that you do with Ferret but if we did the best job we could with Medical Director, we would actually be doing a pretty good job. (GP regional AMS)

Thus despite the varied QI strategies in place, a common theme was the need for high level leadership with a strong investment in nursing and/or AHW staff. Adequate information
systems are desperately needed with barriers operating at the level of users (poor training and support), the environment (poor infrastructure) and unsuitable software systems.

Theme 5: Challenges in access to hospital and specialised care

Another key CCM component of good delivery systems design is the degree of coordination between primary care and specialist services. There were again mixed views on satisfaction with hospital and specialist services. Staff identified several barriers related to poor hospital communication, experiences of discrimination and difficulty in navigating specialist services.

Hospital communication

There were mixed accounts regarding satisfaction with the care provided by hospitals. Generally in the urban and larger regional centres staff were satisfied with service provided and the level of communication. At the smaller rural and remote sites, however, AMS staff felt that communication processes were often poor, particularly at the time of hospital discharge. At one regional site successful communication appeared to be ‘hit and miss’ depending on whether there were conscientious staff working there at the time. At one remote site, staff commented that it was common to be completely unaware of an episode of hospital care with it only coming to their attention when the patient subsequently attended the AMS requesting medication. At the other extreme, information would be faxed for people that the AMS did not provide care to and this would create burdensome work ensuring that other health services were notified. As one remote GP commented, ‘The fax just seems to spit stuff out at us all day long’.

Discrimination

Experiences of discrimination in the hospital and specialist care systems were pervasive in all settings. There were abundant stories of hospital staff displaying hostile attitudes to patients. These were often fuelled by stereotypical assumptions about Aboriginal people.

We had a young Aboriginal fella, he went to the hospital, presented at A&E, and the nurse asked him ‘when was the last time you had a bath?’ (The person then walked out). And I heard about this young fella over the weekend and Monday morning, we went looking for him. We brought him in to see the doctor. It turned out he had an
abscess on his lung which was really serious and he had to be hospitalised straight away. (AHW regional AMS)

Such discriminatory attitudes emphasise that Aboriginal and Torres Strait Islander people may be viewed *apriori* as non-ideal users and treated hostily by the hospital system. Patients may have little recourse to address this hostility other than to leave. The hospital system’s preference for the ideal user makes it highly intractable. Although patient complaints may be responded to appropriately, at one site staff commented that this did not seem to change the way the system functioned.

I have asked patients to write letters of complaint … And then we’ve got really nice letters back saying there are taxi vouchers for them and everything. And then it happens again. (GP regional AMS)

The volume of accounts of discrimination experienced by patients means that AMS staff are frequently intervening on the patient’s behalf to restore access rights. Doctors in particular use their power to soften hardline stances taken by hospital and specialist staff.

Interviewer: Have you heard of discriminatory practices in the hospital sector and how do you deal with that?

Participant: A lot of advocating from me … ringing and cutting through the crap, the resistance and the verbal ‘rolling of the eyes’ and just keeping on pushing until the appointment happens. And apologising on the patient’s behalf and explaining why certain appointments haven’t been attended and ‘could we please now have it happen?’ (GP urban AMS)

Specialised care

Access to specialist services in remote areas was a substantial problem in the two services we interviewed. Consistent with the ideal user concept, remote area specialist services appear to struggle with the need to adapt systems to circumstances that are quite different from those in the city.

One of the issues is that people at the end of the line are so busy that they don’t actually think, ‘Gee this person comes from a 1000 km away, so we actually have to think differently about this person’. Yes, we need to do what we would do for everybody else but hey, we can’t send them back and get them back next week. (GP remote AMS)
In one service this led to devastating consequences where a patient with suspected coronary heart disease was asked to travel back to her community to await coronary angiography at a major referral centre. During this waiting period she had a fatal heart attack.

In regional and urban areas specialist availability was also a challenge. AMSs in those areas are continually cultivating networks of specialists whom they know are favourably disposed toward providing care to Aboriginal and Torres Strait Islander people. Personal connections and feedback from patients are the most important mechanisms for gauging if these services are suitable. Eliminating financial barriers through the availability of bulk-billing specialists is a key consideration for determining suitable specialists to which to refer. Although these specialist networks tend to develop in an ad hoc manner, there were several examples of highly successful partnerships that are improving access to specialised services. The primary ingredient in these partnerships was the enhancement of on-site service provision. At one AMS a cardiac rehabilitation service was established through formal agreements with the hospital. Local AMS staff managed the program and external hospital staff would provide on-site services. There has been a dramatic increase in attendance since commencing this program. Central to the program’s early success has been management by an AHW who has himself experienced a heart attack. In this way a specialist service can be delivered by trusted local staff on site, thus facilitating access to the full range of other AMS services such as transport, dental care, social and emotional well-being services and general primary care.

Other innovative strategies to improve access to on-site specialist services included partnerships with endocrine and ophthalmology services to up skill local GPs in diabetic retinal screening and intensive insulin management; research partnerships with universities and institutes that had dedicated service provision components; and establishment of interagency agreements with other service delivery organisations to ensure harmonisation of care and more efficient distribution of resources.
7.5 Discussion

This analysis of AMS health systems forms the first component of the KQS. It provides a useful snapshot into staff perceptions of barriers and enablers to health care access and quality for Aboriginal and Torres Strait Islander peoples. Two theoretical constructs, *kanyini* and *candidacy*, developed from very different epistemological positions, guided our analyses. Consistent with the systematic review findings in Chapter 6, *candidacy* prevails as a useful way of describing and understanding access issues. The sub-constructs of *tractability* and *navigation* of health services are particularly helpful. Tractable and navigable health services have good governance structures, sound leadership, systems that welcome the 'non-ideal user', and a well-supported workforce with a strong Indigenous staff component. The relevance of *kanyini* was different from but complementary to *candidacy*. It provides an important frame with which to understand the distinct features of the way care is provided in AMS settings. *Kanyini* is rooted in powerful emotional, spiritual and culturally specific dimensions. This does not mean, however, that its underlying epistemologies are irrelevant to health care systems and the individuals working within them. McCoy uses *kanyini* concepts to explain the excellent educational outcomes that were achieved in one Central Australian school. The way in which this institution 'held' people, honouring its obligations to nurture and 'grow' its students could be viewed as a systems approach. Similarly, the multiple strategies that AMSs take to ensure community governance, community representation on staff, and strengths based health promotion activities are all features of this obligation to hold people from childhood to old age. The degree to which a person, family or community feel held may be a fundamental driver of whether care is viewed as 'proper' and this will be a key part of forthcoming analyses of the semi-structured interview component of this study.

This duty felt by AMSs to properly 'hold' people is undermined by a substantial fear about the viability of the AMS sector. Despite the ACCHS sector having a stronger national presence than ever before, staff remain suspicious of government intentions. The COAG NPA has had mixed responses from the ACCHS sector. Many ACCHS advocates are concerned that these initiatives are primarily targeted toward improving Aboriginal people's access to mainstream general practice services, and that they are neglecting the substantial role played by this sector. Although the focus groups in this study pre-date the
COAG NPA, it is quite likely that these new initiatives would further compound rather than allay the feeling of being under threat. For organisations that are under auspicing arrangements with OATSIH there are particular policy challenges. Where there is a clear commitment to hand over governance to the local AMS, then the auspicing arrangements appear satisfactory. Where relationships with the auspicing body are such that there is little scope for local governance or where the auspicing body itself is experiencing difficulties then good governance and sound operations management appear untenable. From a funding body perspective it is clear that fledgling organisations with limited capacity to function independently pose a high risk of not remaining viable. Further, there are substantial gains to be made from shared infrastructure, especially IT and human resource support, and financial management. OATSIH conducts regular risk assessment reviews as a part of their funding agreements with health services. Whilst auspicing arrangements are clearly a useful strategy for mitigating risk, this study highlights that a better balance may be needed between upholding community engagement principles and provision of external support to ensure viability of the AMS.

Consistent again with the systematic review findings in the previous chapter, the employment and support of Indigenous staff is a critical component to enhancing tractability of AMSs. AHWs make a vital contribution to ensuring that people are properly held. These findings are pertinent to the workforce expansion component of the COAG NPA in which several hundred new Indigenous workforce positions will be created including tobacco workers, lifestyle workers, outreach workers and self-management workers. Whilst such a large workforce commitment may be a sound investment there are cautionary aspects to this policy. The ability of an AMS to ‘hold’ its community is equally applicable to its staff, especially its Indigenous staff. Given a large proportion of these new workforce positions will be based in Divisions of General Practice there is potential to shift existing AHWs away from the AMS sector into organisational environments that are isolating for Indigenous staff. Further, there are important supports needed for the professional development of the AHW workforce. Despite a national workforce strategic framework being developed in 2002, progress on implementation has been slow and barriers to improving workforce standards remain. There are, however, promising initiatives currently being implemented. The recently launched National Aboriginal and Torres Strait Islander Health Worker Association may help to address this with the creation
of national registration and accreditation standards. It is hoped that this agency will provide professional development opportunities that are flexibly delivered and that recognise the diverse roles played by AHWs. Institutional supports such as these are vital mechanisms to better ‘holding’ this workforce.

A recent systematic review found that interventions in a number of CCM components (delivery system design, self-management and clinical information systems/decision support) led to small to moderate improvements in diabetes care. Staff in this study identified a number of barriers and enablers to successful delivery system models. Of particular relevance to the COAG NPA is the use of Medicare incentives to promote better systems of chronic care. Financial incentives will be provided to AMSs and private general practices for registering and providing a minimum number of Medicare services to Aboriginal and Torres Strait Islander peoples with or at risk of a chronic disease. Low uptake of these Indigenous specific Medicare items has been well documented in both the Kanyini Audit and elsewhere. We identified several system issues that might contribute to this, especially poor information management and inadequate staff resources. Perhaps more important, however, were the mixed views of the value of these Medicare items for patient care. Whilst the larger sites felt incentives could assist in providing comprehensive care and additional business revenue, at the smaller sites the additional bureaucratic hurdles they created were viewed as distractions from good health care. ACCHS advocates have voiced similar concerns that the use of Medicare incentives in the COAG NPA will create an ‘inverse care’ situation where those that need the least care will be more likely to receive these Medicare services and ACCHSs with the least capacity and those patients with more complex care needs will miss out. Close monitoring will be needed to identify if such uptake patterns do indeed emerge.

The information barriers we encountered are highly consistent with a recent OATSIH review of health service views on reporting requirements. The Aboriginal Health and Medical Research Council has also recently conducted a series of organisational audits on ICT/IM capacity in NSW ACCHSs. This review found a considerable shortfall in budget allocation toward information systems, low levels of ICT/IM governance within ACCHSs, and poor computer literacy amongst staff members. These issues are again consistent with our study findings and warrant urgent attention. The COAG NPA includes a component for
the monitoring and evaluation of package initiatives at 32 sentinel sites, however there are no specific initiatives to address infrastructure barriers and staff support. NACCHO and its ACCHS state affiliate organisations are, however, developing ICT/IM strategies and two state affiliates have successfully implemented performance indicator programs. Whilst this progress is encouraging, the scale of these barriers is so large that substantial commitment will be needed to improve ICT/IM capacity nationally.

Whilst there were relatively minor frustrations about hospital systems (especially communication processes), the most concerning issue was the repeated accounts of perceived discrimination experienced by patients. In one NSW and Qld survey, discrimination in everyday life was experienced by 43% of Indigenous respondents compared with approximately 25% of those who were not from an Indigenous background. Dealing with these negative experiences appears to be a regular component of AMS health professionals' work. Discussion of institutional and interpersonal discrimination in hospitals is beyond the scope of this paper, but it seems likely that conventional cultural awareness training workshops do little to address such a complex and highly pervasive issue. Some potentially instructive alternative strategies include anti-racism training and the development of tools that critically examine notions of culture, race and oppression. At an institutional level, New Zealand Māori advocates have called for organisational audits for compliance with Treaty of Waitangi principles. In addition, several New Zealand district health boards have policies outlining tikanga best practice guidelines for respecting Māori principles in relation to hospital care. In Australia, the Victorian Health Promotion Foundation has conducted extensive reviews of the literature and surveys of community attitudes to discrimination. This organisation is currently developing a range of workforce and organisational development strategies, although hospital based interventions are not currently a major focus.

On-site specialist outreach clinics appear to be a beneficial strategy to enhance the proper holding of people. Our findings complement those found in the evaluation of the Northern Territory Specialist Outreach Program. Although such services are likely to meet the chronic care needs of a minority of clients, there are delivery systems benefits beyond making services more permeable and navigable. On-site services foster sound collaborating relationships between AMSs, government and private agencies. They support
AMSs to more comprehensively ‘hold’ clients by better coordinating primary and specialist service delivery. The use of adequately supported and trained AHW coordinators can impart a strong nurturing component to these services. At a systems level, on-site services can enhance professional development opportunities for local staff (e.g. via case conferences, journal clubs, and training in technical procedures) and there are clear advantages with using local PIRS systems for information management. The federally funded Medical Specialist Outreach Assistance Program complements state and territory outreach specialist programs in rural and remote communities. Within the COAG NPA, increased funding will be provided to expand this program. Our study findings support this policy decision and, if adequately financed, it has the potential to make an important contribution to improving the navigation of specialist care in the bush.

An important finding from this study is that whilst the barriers may manifest differently, improved access to specialist services is not exclusively an issue of geographical isolation. In 2006-7 non-recurrent funding was provided for five brokerage services to make specialist access more navigable, particularly in urban settings. One of the Kanyini sites is participating in this initiative, but unfortunately has encountered major difficulties with poor governance arrangements between the key stakeholders. Some COAG NPA funding has been allocated to enhancing specialist access in urban areas, however, there is little detail on how this will be implemented. Recommendations from the National Hospitals and Health Reform Commission to develop a single funding authority for all Aboriginal and Torres Strait Islander health services is another promising initiative to address navigational barriers between the primary and specialist care settings. Similar to the Australian Department of Veteran Affairs model, eligible patients would receive universal entitlements to particular services. This would allow the patient to be the arbiter of which services to access and care providers would be able to claim benefits from this funding authority. Given the substantial restriction in choice of specialist provider and the accompanying financial and transport barriers discussed in this study, innovative models should be explored. This is needed not only in regional and remote areas, where chronic under-supply predominates, but also in urban settings, where access challenges prevail despite specialist supply being less of an issue.
Although analysis of the KQS data is ongoing, we are making steady progress to developing a detailed understanding of the issues affecting health care access and quality for Aboriginal and Torres Strait Islander peoples. The critical next step is to assess whether these findings are pertinent in our interviews with community participants. Analyses of individual staff interviews will also provide important corroborating data to determine whether our findings are consistent. Based on the health systems assessment findings, the frameworks of kanyini and candidacy are useful theoretical foundations. They hold promise in providing important policy relevant insights for enhancing AMS sector capacity and may be of value in other health service contexts that provide care for underserved populations. With federal and state governments embarking on major health reforms for all Australians, large scale qualitative work of this nature can play a key role in determining strategies that will lead to better systems of care.

7.6 References


7.7 Attachments

Attachment 1: Local Reference Group Terms of Reference
Attachment 2.1: Health Systems Assessment form
Attachment 2.2: Health Systems Assessment facilitators guide
Attachment 3: Sample Kanyini audit feedback report
Attachment 4.1: Community interview guide and suggested probes sample
Attachment 4.2: Record of interview form for community participants
Attachment 5.1: Health professional interview guide and suggested probes sample
Attachment 5.2: Record of interview form for health professional participants
Attachment 6.1: Sample study information sheet for community participants
Attachment 6.2: Sample study information sheet for health professional participants
Attachment 6.3: Sample consent forms for community participants
Attachment 6.4: Sample consent forms for health professional participants
Attachment 7: Participant distress protocol sample
Attachment 8: Interview process and data management flow chart
Mission Statement:

The Local Reference Group will guide the research and ensure transparency and accountability in dealing with critical issues relevant to their local Aboriginal and Torres Strait Islander community and organisations.

Overview of the Kanyini Vascular Collaboration:

The Kanyini Vascular Collaboration is the coming together of a committed group of Indigenous and non-Indigenous researchers, Aboriginal Medical Services (AMSs), a government primary health care service, community members and policy-makers. The research will be conducted Australia-wide across several sites in NSW, Qld and Central Australia.

The two main co-ordinating bodies are The George Institute for International Health in Sydney and the Baker Heart Research Institute in Alice Springs.

This program will help us know why Aboriginal people are missing out on best practice care and help us to work out how to keep people healthy. Our goal is to improve health outcomes for Aboriginal people at risk of vascular disease (especially heart and kidney disease and diabetes). We want to:

- Understand health system and health service barriers;
- Develop, implement and evaluate appropriate models of care; and
- Engage Aboriginal and Torres Strait Islander communities and policy makers.

The research program is comprised of four separate yet inter-related projects;

i. the Kanyini Audit Study,
ii. the Kanyini Interview Study,
iii. the Kanyini Documentary project,
iv. the Kanyini Polypill Study.

A representative from the George Institute will provide further information about each of the component studies.

Timeframe:

- The Kanyini Vascular Collaboration commenced in August 2006 and is approximately 5 years duration
- Once established the Local Reference Group will guide the research program to completion of the program.
Role of the Local Reference Group:

The role of the Local Reference Group is as follows:

i. To ensure that Indigenous community perspectives are asserted in the overall governance of the program.

ii. To ensure that local and external research staff are conducting the Kanyini studies in a professional and competent manner that serves the interests of the community.

iii. To determine the best ways to conduct community consultation and feedback processes.

iv. To provide advice as needed on the Kanyini component studies.

Examples of this include:
1. Reviewing processes for conducting interviews.
2. Specific advice on the appropriateness of interview questions.
3. Identifying appropriate members of the community for participation in the Kanyini studies.
4. Strategies for involving the local community in the Kanyini clinical intervention studies.

Further details will be given in advance relating to specific input required.

Members of the Local Reference Group:

These will be comprised of Aboriginal and Torres Strait Islander members across the following:

- Indigenous Research Fellow (IRF) — Chair
- Aboriginal and Torres Strait Islander representatives from government and non-government sector.
- Representatives from ACCHS and/or Indigenous specific primary care services.
- Health service attendees.

There will be consistent representation by the established membership listed in Attachment 1 (a proxy member may be nominated by the established member to attend a meeting if required).

Meetings:

The LRG will meet 4 times a year. The key aspects of these meetings are the following:

- Chair: The meetings will be chaired by the Indigenous Research Fellow. Meetings should not proceed without the Chair.
- Attendance: Meetings will only proceed if there are **** members present (half + 1). A representative from The George Institute is expected to attend these meetings unless otherwise requested by the Chair.
- Location: Meetings will be at a location and date agreed upon by the group. The Chair will notify members of this and circulate an agenda in advance.
- Duration: Approx. 1 – 1 ½ hours.
- Minutes will be taken by an established member of the LRG.

Reimbursement for time:

Sitting fees will be negotiated with members and the George Institute representative at the first meeting of the Local Reference Group. This will be documented in the Terms of Reference for each Local Reference Group.

Members:

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Position Title</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Attachment 2.1: Kanyini Health Systems Assessment Form

### Kanyini Health Systems Assessment Form

**AMS code**: 
**Date of interview**: 
**Interviewers**: 

### Focus group members:

<table>
<thead>
<tr>
<th>Name</th>
<th>Name</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Service characteristics

<table>
<thead>
<tr>
<th>Estimated total service population:</th>
<th>Total staff:</th>
<th>Number Indigenous:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GPs:</td>
<td>Number Indigenous:</td>
</tr>
<tr>
<td></td>
<td>RNs:</td>
<td>Number Indigenous:</td>
</tr>
<tr>
<td>Estimated number regular clients:</td>
<td>Allied Health staff:</td>
<td>Number Indigenous:</td>
</tr>
<tr>
<td>Estimated number visitors/ irregular clients:</td>
<td>Male AHWs:</td>
<td>Number Indigenous:</td>
</tr>
<tr>
<td>Total budget:</td>
<td>Female AHW:</td>
<td>Number Indigenous:</td>
</tr>
<tr>
<td>% budget allocated for chronic disease:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Community ownership and accessibility - Can you describe how the health service involves the community in health care delivery?

- Indigenous governing board:  
- Indigenous manager:  
- Orientation to community provided to new staff:  
- Client transport services available: 

### Cultural safety - Can you describe how the health service approaches cultural issues in health care?

<table>
<thead>
<tr>
<th>Cultural awareness programs available</th>
<th>Cultural leave provided</th>
<th>Use /support of Ngangkari/ traditional healing</th>
<th>Funded Ngangkari/ traditional healing services</th>
<th>Availability of separate male and female spaces</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>

### Quality of care - Can you describe the quality improvement strategies that you have or have had in place?

<table>
<thead>
<tr>
<th>Routine Quality Improvement activities conducted</th>
<th>Dedicated Quality Improvement staff</th>
<th>Chronic disease coordinator</th>
<th>Clinical service orientation</th>
<th>Professional development support</th>
<th>Guidelines for chronic disease management</th>
<th>Guideline training provided to staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>
### Models of care - Can you describe any systems in place to support chronic care?

<table>
<thead>
<tr>
<th>Service</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outreach clinics conducted</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Chronic disease prevention programs</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Chronic disease case management</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Onsite pharmacist</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Access to Section 100</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Home medicines review available</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Adherence monitoring available</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Computerised record system</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Automated pathology available</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Routine population data</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Recall system in place</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Chronic disease register available</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

### Hospital care - How adequate is the continuity of care with the hospital system?

<table>
<thead>
<tr>
<th>Service</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital liaison staff available</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Care planning includes hospital staff</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Quality of communication: Admission notification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outpatient department/ Specialist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discharge notification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consistency in management between hospital and health service</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Regional Services - What access do you have to the following regional specialist services?

#### Cardiology Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiologist available</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Hospital clinics</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Hospital outpatient clinics</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Cardiac rehabilitation services available</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Echocardiography service available</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Stress tests available</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Angiography services available</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

#### Renal Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nephrologist available</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Hospital clinics</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Hospital outpatient clinics</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Dialysis services available</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Transplant services available</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

#### Diabetes Services based at the AMS

<table>
<thead>
<tr>
<th>Service</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Ophthalmology</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Podiatry</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Dietician</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>
Kanyini Systems Assessment Tool – Facilitator Guide

**ACCHS code**
Aboriginal Community Controlled Health Service (ACCHS) identifier, unique number allocated to each ACCHS involved in the research project. Numerical 4 digit identifier

**Date of Interview**
Record date Systems Assessment interview conducted. [DD/MM/YY]

**Interviewer**
Record the initials of the individual conducting the Systems Assessment interview.

**Focus group members**
Record the initials of each individual participating in the Systems Assessment interview.

**Service characteristics**

**Estimated service population**
Record the total number of clients registered as attendees to the health service.

**Estimated number of regular clients**
Record the number of regular clients attending the health service (who routinely receive PHC at the health service).

**Estimated number of visitors/irregular clients**
Record the number of visiting clients that attend the health service (A visitor is someone who does not live within the catchment area, but that has previously attended the health service).

**Total operating budget**
Record the total operating budget of the health service. NB: Answering this question is optional

**Proportion for CD**
Record the proportion of the budget that is specifically identified for the delivery of chronic disease care or programs. NB: Answering this question is optional

**Total staff**
Record the total number of staff employed by the health service (including clinical, administration, and ancillary staff)

**General Practitioners**
Record the number of GPs currently employed within the health service. Record the number of GPs who are indigenous.

**Registered Nurses**
Record the number of RNs currently employed within the health service. Record the number of RNs who are indigenous.

**Male Aboriginal Health Workers**
Record the number of male AHWs currently employed within the health service.

**Female Aboriginal Health Workers**
Record the number of female AHWs currently employed within the health service.

**Allied Health staff**
Record the number of Allied Health persons currently employed. List each Allied Health position(s).
Community ownership and accessibility

Indigenous governing board
Is the ACCHS governed by a completely or majority indigenous governing board?

Indigenous manager
Is the Manager (or ‘CEO’, ‘Administrator’, ‘Director’ etc) of the health service indigenous?

Community orientation
Does the health service provide an orientation to the community for staff on commencement? What form does this orientation take?

Client transport service
Does the health service provide a transport service to its clients to attend the health service and/or other services/regional hospital? [Can you describe what transport is provided for?]

Cultural congruence

Cultural Awareness Program
Do health service staff undertake cultural awareness training programs when commencing work at the service?

Cultural leave provision
Does the health service have provision for indigenous staff to take cultural leave for funerals etc.?

Use/support of Ngangkari/ traditional healing
Does the health service use and support the use of Ngangkari/Traditional Healers?

Funded Ngangkari/ traditional healing services
Are Ngangkari/Traditional Healers paid by the health service for consultations?

Separate Men’s and Women’s space
Does the health service have designated women’s/ men’s areas within the service?

Quality of care

Routine quality improvement activities conducted
Does the health service have a systematic Quality Improvement (QI) process in place? Can you describe the QI initiatives that are in place?

Dedicated quality improvement staff
Does the health service have an identified position responsible for developing, maintaining and coordinating Quality Improvement processes within the health service?

Chronic disease coordinator
Does the health service have an identified position responsible for coordinating chronic disease care? What are the responsibilities of this position?

Clinical service orientation
Does the health service have a formal clinical orientation programme for new clinical staff on commencement of employment? Can you describe what this programme consists of?

Professional development support
Does the health service encourage and provide support for staff to attend PD activities?
Does the health service have a formal Professional Development programme for staff? Can you describe what this programme consists of?

Guidelines for chronic disease management
Does the health service have accessible, user friendly guidelines available and encouraged/mandated for use by all practitioners with respect to the identification and management of chronic disease? [E.g. CARPA, NHFA, CARI, NHMRC].
**Guideline training provided to staff**
Does the health service provide training to staff, in the use of these guidelines? Can you describe what the training consists of?

**Models of care**

**Outreach clinics**
Does the health service provide outreach primary care services? Can you describe these services?

**Chronic disease case management**
Does the health service use a case management model for clients with an identified CD? Can you describe the model used?
Case management refers to planning, coordinating, managing and reviewing the care of an individual patient. This may involve, assigning each person a 'case manager' who is responsible for assessing patients’ needs; developing a care plan, arranging suitable care; monitoring the quality of care; and maintaining contact with the patient and their family.

**Chronic disease prevention programmes**
Does the health service have any chronic disease prevention initiatives in place? Can you describe the initiatives that are in place?

**Onsite Pharmacist**
Is there an onsite pharmacist?

**Access to Section 100**
Does the health service have access to Section 100 arrangements for the supply of pharmaceutical goods?

**Home medicines review process**
Is there a process in place for conducting Home Medication Reviews and claiming the available Medicare rebate?

**Monitoring adherence**
Is there a process for monitoring adherence? Describe

**Computerised record system**
Is there a computerised Patient Information and Recall System (PIRS) in use?

**Automated pathology**
Is there an automated system for receiving pathology results?

**Routine population data**
Is there a formalised mechanism for providing regular population health data to the community and health service staff?

**Recall system**
Is there a client recall system in place that supports the delivery of or 'recalls' individuals to receive scheduled services?

**Chronic disease register**
Is there a register of all clients with chronic disease?

**Hospital care**

**Hospital Liaison**
Record if the health service employs a hospital liaison officer.

**Care planning includes hospital staff**
Record if hospital staff are included in the development of Team Care Arrangements [EPC 723 or equivalent].

**Communication, Accessibility and Consistency of Hospital Based Services.**
The following questions seek to build consensus among focus group participants, by considering the usual process and barriers to care and ease of communication between primary care staff and hospital staff when arranging [or
attempting to arrange admission, referral, assessment and management by specialists within hospitals, and this occurs following a patient's discharge from hospital.

<table>
<thead>
<tr>
<th>Admission:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Describe the ease of communicating with and accessibility of hospital services when attempting to arrange the admission of a patient for assessment or management?</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
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<tr>
<td>3</td>
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<tr>
<td>4</td>
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<tr>
<td>5</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>OPD/Specialist:</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you describe the ease of communicating with and accessibility of hospital outpatient or specialist services?</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
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<tr>
<td>5</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Discharge:</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you describe the flow of information, patient results and care requirements following a hospital admission?</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consistency in management between hospital and PHC: To what degree are management practices, medications and follow-up similar between hospital and PHC services with relation to CD care?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
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<tr>
<td>5</td>
</tr>
</tbody>
</table>
Regional Services

**Cardiologist services**
Does a cardiologist visit the health service to provide clinical care? If so, how often?
Is there a cardiologist at the hospital accessed by health service clients or referred to by the health service?

**Cardiac Rehabilitation services**
Do health services clients have access to cardiac rehabilitation services or programmes? If so, are they run by the health service or external agencies/providers?

**Echocardiography service**
Are echocardiography services available for health service clients? [Local, Regional, Distant Tertiary Referral]. If so, are there any difficulties for clients accessing them?

**Stress tests available**
Are Exercise Stress Testing services available for health service clients? [Local, Regional, Distant Tertiary Referral]. If so, are there any difficulties for clients accessing them?

**Angiography services**
Are angiography services available for health service clients? [Local, Regional, Distant Tertiary Referral]. If so, are there any difficulties for clients accessing them?

**Renal services**
Does a Nephrologist visit the health service to provide clinical care? If so, how often?
Is there a nephrologist at the hospital accessed by health service clients or referred to by the health service?

**Dialysis**
Are renal dialysis services available for health service clients? [Local, Regional, Distant Tertiary Referral]. If so, are there any difficulties for clients accessing them?

**Transplant**
Are kidney transplant services available for health service clients? [Local, Regional, Distant Tertiary Referral]. If so, are there any difficulties for clients accessing them?

**Diabetes services at the AMS**
Does a physician visit the health service to provide clinical care? If so, how often?

**Ophthalmologist**
Does an ophthalmologist visit the health service to provide clinical care? If so, how often?

**Podiatry**
Does a podiatrist visit the health service? If so, how often?

**Dietician**
Does a dietician visit the health service? If so, how often?
## Attachment 3: Sample Kanyini Audit Study Feedback Report

### XYZ Health Service
- Records audited: 200
- Mean age: 42.9
- % Male: 43.5%
- % Female: 56.5%

### National
- Records audited: 1165
- Mean age: 41.1
- % Male: 40.5%
- % Female: 59.5%

### Comment:
These specific recorded conditions were looked for in this audit. The results do not reflect all recorded conditions found in the case record.

### Smoking status

<table>
<thead>
<tr>
<th>Category</th>
<th>National</th>
<th>XYZ Health Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current</td>
<td>30%</td>
<td>35%</td>
</tr>
<tr>
<td>Ex-smoker</td>
<td>20%</td>
<td>25%</td>
</tr>
<tr>
<td>Never</td>
<td>30%</td>
<td>20%</td>
</tr>
<tr>
<td>Not recorded</td>
<td>10%</td>
<td>10%</td>
</tr>
</tbody>
</table>

### Body Mass Index

<table>
<thead>
<tr>
<th>Category</th>
<th>National</th>
<th>XYZ Health Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;18</td>
<td>5%</td>
<td>10%</td>
</tr>
<tr>
<td>18-24</td>
<td>30%</td>
<td>25%</td>
</tr>
<tr>
<td>25-29</td>
<td>40%</td>
<td>30%</td>
</tr>
<tr>
<td>30-34</td>
<td>15%</td>
<td>10%</td>
</tr>
<tr>
<td>35-39</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>≥40</td>
<td>5%</td>
<td>10%</td>
</tr>
<tr>
<td>Not recorded</td>
<td>5%</td>
<td>10%</td>
</tr>
</tbody>
</table>

### Albuminuria

<table>
<thead>
<tr>
<th>Category</th>
<th>National</th>
<th>XYZ Health Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal</td>
<td>50%</td>
<td>40%</td>
</tr>
<tr>
<td>Microalbuminuria</td>
<td>25%</td>
<td>30%</td>
</tr>
<tr>
<td>Macroalbuminuria</td>
<td>15%</td>
<td>20%</td>
</tr>
<tr>
<td>Not recorded</td>
<td>10%</td>
<td>5%</td>
</tr>
</tbody>
</table>

### Chronic Kidney Disease

<table>
<thead>
<tr>
<th>Category</th>
<th>National</th>
<th>XYZ Health Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>10%</td>
<td>15%</td>
</tr>
<tr>
<td>Stage 2</td>
<td>20%</td>
<td>15%</td>
</tr>
<tr>
<td>Stage 3</td>
<td>30%</td>
<td>20%</td>
</tr>
<tr>
<td>Stage 4</td>
<td>20%</td>
<td>15%</td>
</tr>
<tr>
<td>Stage 5</td>
<td>10%</td>
<td>5%</td>
</tr>
<tr>
<td>Not recorded</td>
<td>5%</td>
<td>5%</td>
</tr>
</tbody>
</table>

(Data available: National n=120, XYZ Health Service n=131)
### Risk factor recorded

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>XYZ Health (n=39)</th>
<th>National (n=1165)</th>
<th>Comment:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood Pressure</td>
<td>98.5%</td>
<td>90.2%</td>
<td>People at risk of Chronic Kidney Disease (CKD)* is based on Kidney Health Australia guidelines and includes any one of the following:</td>
</tr>
<tr>
<td>Blood glucose</td>
<td>91.5%</td>
<td>78.9%</td>
<td>- Age&gt;50 years</td>
</tr>
<tr>
<td>Smoking status</td>
<td>80.0%</td>
<td>71.4%</td>
<td>- BP &gt;140/90 mmHg</td>
</tr>
<tr>
<td>Lipids</td>
<td>67.0%</td>
<td>58.9%</td>
<td>- Diabetes</td>
</tr>
<tr>
<td>eGFR</td>
<td>65.5%</td>
<td>57.4%</td>
<td>- Current smoker</td>
</tr>
<tr>
<td>Body Mass Index (BMI)</td>
<td>59%</td>
<td>55.7%</td>
<td>- BMI≥30 kg/m²</td>
</tr>
<tr>
<td>Albumin Creatine Ratio (ACR)</td>
<td>26.0%</td>
<td>29.0%</td>
<td></td>
</tr>
<tr>
<td>ACR and eGFR for at risk CKD*</td>
<td>32.5%</td>
<td>31.8%</td>
<td></td>
</tr>
</tbody>
</table>

* n=151 for XYZ, n=851 for National

### Comment:

Comment:

- People at risk of Chronic Kidney Disease (CKD) is based on Kidney Health Australia guidelines and includes any one of the following:
  - Age>50 years
  - BP >140/90 mmHg
  - Diabetes
  - Current smoker
  - BMI≥30 kg/m²

Comment:

Only 36 of 55 people with diabetes had sufficient data to record albuminuria

Comment:

Cardiovascular risk is calculated using the Framingham based New Zealand Cardiovascular Guidelines. This includes a 5% addition to the risk calculation for Indigenous populations.

The risk assessment algorithm is not validated for under 30 year olds.
Comment:
Lifestyle assessment was recorded as present if there was any evidence in the clinical record of discussion with the client about smoking, nutrition, physical activity or alcohol in the past 2 years.

Comment:
EPC items were recorded as complete if there was evidence in the record of a complete assessment and/or evidence of billing for that item. If there was evidence of an unclaimed or partially filled assessment it was recorded as incomplete.
<table>
<thead>
<tr>
<th>Medications</th>
<th>Total Sample</th>
<th>Clients with Diabetes*</th>
<th>Clients with CVD*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>XYZ n=200</td>
<td>National n=1165</td>
<td>XYZ n=55</td>
</tr>
<tr>
<td></td>
<td>National n=249</td>
<td></td>
<td>National n=27</td>
</tr>
<tr>
<td></td>
<td>National n=101</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood pressure lowering</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Cholesterol lowering</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Antiplatelet medication</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>BP + Statin + Antiplatelet</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
</tbody>
</table>

**Blood pressure management - prescribing patterns**

**Comment:**

Treatment thresholds were based on the average of the two most recent systolic blood pressure recorded values

Treatment indications and target values were measured against the National Heart Foundation guidelines.
Lipid management - prescribing patterns

**Comment:**

Treatment thresholds were based on the most recent cholesterol results. Treatment indications and target values were measured against the 2007 Pharmaceutical Benefits Scheme indications for Aboriginal and Torres Strait Islander people.
Attachment 4.1: Community interview guide and suggested probes sample

Kanyini Qualitative Study Interview Guide- Community Participants

Introductions:

1. What does ‘being well’ or ‘being healthy’ mean to you?
2. Do you think of yourself as a well/healthy person?
3. What do you do to stay well/healthy?
   Possible Prompts:
   - Are there any things you do that you think help you stay healthy?
   - What help do you get to stay well?
   - Where do you get help from?
4. Can you tell me about the last time that you felt unwell?
   Possible Prompts:
   - What happened?
   - Were you unwell enough that you needed to get help from family, community, clinic, hospital?
5. When you have been unwell, have people looked after you properly?
   Possible prompts around Family-community based ‘proper care’ context:
   - What does it mean to you, to be looked after properly when you are unwell?
   - Have family ever cared for you when you were unwell? What kinds of things did they do to look after you?
   - How do you want to be looked after, when you are unwell? What do you need?
   Possible prompts around Clinical ‘proper care’ context:
   - What sorts of things make a nurse a ‘good’ nurse?
   - What do you think makes a ‘good’ doctor?
   - When you are unwell at the clinic, what should happen for you to feel properly looked after?
   - If you’re unwell in the hospital, what should staff do to look after you properly?
   - Are there some places where you’ve felt properly cared for/looked after each time you go there?
   - Why did you feel properly looked after in those places?
   - Are there some places where you’ve gone to get help/care when you’ve been unwell, but people have not looked after you properly? What happened there?
6. What makes it easier for you to get care when you are unwell?
   Possible prompts:
   - When you have been unwell, what things have made it easier for you to get the care that you need to get better?
   - What makes getting the care you need at (AMS, community clinic) easier for people?
   - What things make it easier for you and your family to get looked after properly in hospital?
7. Can you tell me about any problems you’ve had trying to get care when you’ve been unwell?
   Possible prompts:
   - What things can make it hard for you to get care/get looked after properly when you are unwell?
   - What things make getting the care you need at (AMS, community clinic) hard sometimes?
   - What things make getting care at the hospital hard for you and your family?
8. Do you know someone in your community or family who has an illness like diabetes, heart disease or kidney disease?
   Possible Prompts:
   - Can you tell me their story about having an illness like (diabetes, heart disease or kidney disease)?
   - What things happened to them when they started to get unwell?
   - Where did they go for help? Why go there? [talk to someone in family, go to community clinic/AMS, go to hospital...]
9. Do you have an illness like diabetes, heart disease, or kidney disease?

If 'NO' to this question try these probes/prompts and then GO TO QUESTION 12

- How do you know you don’t have these kinds of illness?
- Do you think that you might get diabetes, heart disease, or kidney disease one day? Why/why not?
- Do you think there are some things that people do in their everyday lives that can affect their health? What are some of these things do you think?
- What kinds of things might help someone to avoid/stop them from getting illnesses like these?

If 'YES' to this question GO TO QUESTION 10 & 11

10. What happened when you found out you were unwell with (diabetes, heart or kidney disease)?

Possible prompts:
- What did you do when you found out you were unwell with (diabetes, heart or kidney disease)?
- How were you feeling when you first got unwell with (diabetes, CHD, or CKD)?
- Were there some signs/feelings that made you realize that you were unwell? What were they? [Insert disease-specific symptoms as prompts if required]
- What happened next? Did you talk to someone? What did they say?
- Did you go some place to get help for this illness? Where did you go? [family, Ngangkari, Community AMS/clinic, hospital...]
- Why go to this person/place for help?
- What did they do to help you? Did you get the help/care that you needed from them?
- Did people help you understand about this illness? How did they do this?
- Did people help you to manage this illness and teach you how to look after yourself?

11. How has having this illness changed your life?

Possible Prompts:
- How has it affected you?
- Do you feel unwell having this disease? Why/why not?
- How has it affected your family?
- Did you have a job before you got unwell? Were you able to keep working after getting unwell?
- Have there been changes to your life now because you are unwell like [more clinic visits, need more medicines/treatments, need new/more tests to be done, need to travel to appointments in town, see other doctors, sometimes feel so unwell you need to go to hospital...]
- Are these things hard to get, or hard to do for you and your family?
- Do you need family to help you manage your illness? [getting the medicines that you need, getting the follow-up care, getting to appointments...]

12. How can things be made better for you and your family to get the care you need when you are unwell

Possible prompts:
- How can things be made better at your (AMS, community clinic)?
- How can things be made better in hospitals for you and your family when they get unwell?
- If you could change anything in the health service what would it be?
- [E.g. better follow-up care for people when they first get sick, more help with management and supply of medicines, access to practical and realistic dietary advice...Ask specific questions if they have diabetes, heart disease, kidney disease?]
## Attachment 4.2: Record of interview form for community participants

<table>
<thead>
<tr>
<th>Interview Date</th>
<th>Site</th>
<th>Interview type</th>
<th>Interviewer(s)</th>
<th>Study ID No</th>
</tr>
</thead>
</table>

Please answer the following:

- **What is your age?**
- **What is your postcode?**
- **Gender**: Male □  Female □
- **Ethnicity**: Aboriginal □  Torres Strait Islander □  Both Aboriginal and Torres Strait Islander □  Other (please specify): □
- **What language(s) do you speak at home?**
- **Where are you currently living?**: Own home/ flat □  A home/flat owned by family □  A rented home/flat □  A friend’s house/flat □  A hostel/ other temporary accommodation □  Other (please specify): □
- **What is your current relationship status?**: Married □  Divorced/ Separated □  Widowed □  De facto/ long term partner □  Single □  Other relationship (please specify): □
- **What is your highest level of school education?** (Year 1 to Year 12)
- **What is your employment status?** (tick as many as apply): Full-time work □  Part-time/ Casual work □  Full or part-time study □  Unpaid/ Volunteer work □  Unemployed □  Other (please specify): □
- **Do you have regular access to the following:**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phone □  □</td>
<td></td>
</tr>
<tr>
<td>Car □  □</td>
<td></td>
</tr>
<tr>
<td>Computer □  □</td>
<td></td>
</tr>
<tr>
<td>Internet □  □</td>
<td></td>
</tr>
</tbody>
</table>
Introductions......

1. What is your role/job in this Health Service?

2. What do you think influences Aboriginal peoples’ decisions to seek care from your Health Service?
   Probe
   • What issues do you think influence how Aboriginal people engage with care from your HS?
   • What things about your Health Service encourage engagement?

3. What challenges do Aboriginal people have to overcome to get care from your HS?

4. What does ‘caring well’ for your patients involve?
   Probes
   • What do you need to do in your job to feel that you’ve cared for someone well/properly?
   • Can you tell me about a ‘good’ experience you’ve had of caring for an Aboriginal patient with chronic disease?
   • Can you tell me about an experience that was ‘bad’ or unsuccessful in your view?
   • What makes a ‘good’ doctor/a ‘good’ nurse/ a good team?
   • Do your Aboriginal patients sometimes have needs that you can’t provide?
   • Do you see any difference between these kinds of issues and those that affect non-Aboriginal patients?

5. What is your experience of the role of family in caring for Aboriginal people?
   Probes
   • What is the role of family in caring for an Aboriginal person who becomes ill with a chronic disease (diabetes, heart or kidney disease)?
   • Does the health service you’re working in include the families of Aboriginal patients? How do they do this?

6. Are you aware of any other types of care that your Aboriginal patients may have sought before they come to this HS for care?
   Probes
   • Have your patients accessed care such as: Ngangkari, lay person, AHW living in their community, family?
   • What kind of care is provided in these settings?

7. During your time working in Aboriginal health have you changed your practice in any way?
   Probes
   • Have you changed anything about the way you approach your job, to better meet the needs of your Aboriginal patients? If so, what sorts of things
8. What is needed to provide better care for Aboriginal people with chronic disease?

Probes
- If we were able to redesign this Health Service to make it able to care well for people with chronic disease - what would it look like?
- What would you change about your Health Service if you could?
- Are there factors outside your control/your health service that impact upon care for your patients?
- What do you need from 'the system' in order to look after Aboriginal people with chronic disease properly?
## Attachment 5.2: Record of interview form for health professional participants

<table>
<thead>
<tr>
<th>RECORD OF INTERVIEW - Health Professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview Date</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

Please answer the following:

What is your age?

<table>
<thead>
<tr>
<th>Gender</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
</table>

Ethnicity
(tick as many as apply to you)

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Aboriginal</th>
<th>Torres Strait Islander</th>
<th>Both Aboriginal &amp; Torres Strait Islander</th>
<th>Other (please specify):</th>
</tr>
</thead>
</table>

What language(s) do you speak at home?

<table>
<thead>
<tr>
<th>Language(s)</th>
</tr>
</thead>
</table>

Were you born in Australia?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If you were born overseas please specify your country of birth and the year you arrived in Australia.

Country of birth:

Year first arrived:

What is your job title?

(If you have more than one job please include the one where you are most involved in working with Aboriginal/ Torres Strait Islander people)

<table>
<thead>
<tr>
<th>Job Title</th>
</tr>
</thead>
</table>

How long have you been working in this position?

<table>
<thead>
<tr>
<th>Years</th>
</tr>
</thead>
</table>

How long have you been involved in working with Indigenous communities? (either in Australia or overseas)

<table>
<thead>
<tr>
<th>Years</th>
</tr>
</thead>
</table>

What is your highest level of school education?

(Year 1 to Year 12)

<table>
<thead>
<tr>
<th>Education Level</th>
</tr>
</thead>
</table>

Do you have any post-school qualifications?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If you ticked 'yes' please list your qualifications. (Tick as many as apply. Please also write the year you obtained the most recent qualification in each category)

<table>
<thead>
<tr>
<th>Qualifications</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>TAFE/ VET or equivalent certificates</td>
<td></td>
</tr>
<tr>
<td>Diplomas</td>
<td></td>
</tr>
<tr>
<td>Bachelor degrees</td>
<td></td>
</tr>
<tr>
<td>Post-Graduate Certificates/ Diplomas</td>
<td></td>
</tr>
<tr>
<td>Masters Degree/PhD</td>
<td></td>
</tr>
<tr>
<td>Other qualifications (eg Nurses boards, RACGP)</td>
<td></td>
</tr>
</tbody>
</table>

Do you have membership with any professional organisations or elected committees? (eg. CATSIN, CRANA, Nursing Union/ RCNA, AIDA, GP/Specialist colleges, Public Health Association, AMA)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If yes please list the organisations you belong to:
We invite you to participate in the Kanyini Interview study
- Participant Information Sheet -

What is the Kanyini interview study?
The study is about talking with Aboriginal patients living with heart disease, kidney disease and diabetes. We would like to understand your stories of using health services, both in the community and hospital and to hear what you have to say about the difficulties in getting the care you need. We will also talk separately to health centre staff and other people working in Aboriginal health.

The Kanyini Interview study is part of a larger program which is looking at why Aboriginal people are missing out on the best care and to help us to work out how to keep people healthy. There are four studies in the program which will help us to develop information to overcome these barriers so that you can get the better care.

Why are we doing this study?
Aboriginal people have too much heart disease, diabetes and kidney disease. These sicknesses are causing too many deaths across the country. We know that there are treatments that work to keep people well, but Aboriginal people are less likely to get them. This study will help us to know why this happens and help us to work out better ways to keep people healthy.

How will we do the study?
We will be talking to patients, health workers, staff and doctors in several health centres across NSW, Qld and the NT. We will come and meet with you at a time and place that is best for you. We would like you to feel comfortable so you can choose how you would like to be interviewed; whether in a small group or one-on-one. We can arrange an interpreter if you like.

Who are the people doing this research?
The research will be conducted Australia-wide across several sites in NSW, Qld and the NT. Some key people in the research team include:

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Alan Cass</td>
<td>The George Institute For International Health, Sydney</td>
</tr>
<tr>
<td>Dr Noel Hayman</td>
<td>Inala Indigenous Health Service, Brisbane</td>
</tr>
<tr>
<td>Prof Sandra Eades</td>
<td>The Sax Institute, Sydney</td>
</tr>
<tr>
<td>Dr Alex Brown</td>
<td>Baker Heart Research Institute, Alice Springs</td>
</tr>
</tbody>
</table>

What will it mean if you take part in the Kanyini Qualitative study?
A study team member would talk to you about your health and what you think about using health services. You may wish to share both positive and negative experiences in using health services. If there are any difficult or upsetting experiences that you prefer not to talk about we will always respect that. You can stop the interview at anytime. If you wish we will also try to get help for you to deal with any specific problems you may be having.
There are no medical tests or treatments as part of this study. No money will be paid to you if you decide to participate in the study.

What will happen to the information collected?
We would like to tape your interviews and will provide you with either a paper copy or audio copy after the interview. We would like you to listen/read the interview transcript and give us feedback on its contents by:

- Giving your consent that the transcript is a satisfactory representation of your views,
- Making changes to the existing transcript,
- Asking us for a repeat interview to expand on or change things that you said, or
- Withdrawing your data and consent to participate in the study.

All information will be kept private. All study information will be securely stored in a locked file at the George Institute for International Health in Sydney and only accessed by study team members. Nothing written in reports will link you personally to the study.

What benefits can come from this study?
The study will benefit Aboriginal people with heart disease, kidney disease and diabetes or people at risk of getting any of these diseases. The information from this study will give a better understanding of the barriers to finding these diseases early and help to work out how to keep people healthy.

We know that patients are often not listened to when it comes to telling their stories about trying to get the right health care. This study gives you the chance to speak out and let us know what you think. The information you give will help the people who plan and organise health services to improve them and give Aboriginal people better care.

Does the study have ethical approval?
This study has been reviewed and approved by the Princess Alexandra Hospital Human Research Ethics Committee. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make an independent complaint, you can contact the Ethics Manager, Princess Alexandra Hospital Human Research Ethics Committee on telephone (07) 3240 5856 or email PAH_Ethics_Research@health.qld.gov.au.

Contact details:
If you have any complaints or questions regarding this research project please contact:

Dr Alan Cass  (02) 9993 4553  The George Institute For International Health
Maria Tchan  (02) 9993 4505  Level 10, King George V Building
David Peliris  (02) 9993 4513  Missenden Rd Camperdown NSW 2050

Page 2 of 2
What is the Kanyini Qualitative study?

The Kanyini Qualitative study is a qualitative evaluation of knowledge, attitudes, practices and perceived needs of patients, communities, health care providers and policy makers with respect to the prevention and management of chronic disease. We would like to hear your stories as a health professional about systemic barriers to health care for Aboriginal people with cardiovascular and chronic kidney diseases (CVD and CKD) and diabetes.

The Qualitative study is part of a larger program which aims to look at why Aboriginal people are missing out on best practice care and to help us to work out how to keep people healthy. There are four component studies within the collaboration. The first two studies are aimed at identifying barriers to optimal chronic disease care and based on the information found in these studies two further studies will look at trialling interventions to overcome these barriers.

How will we do the Kanyini Qualitative study?

The Kanyini Qualitative study will be conducted Australia-wide across several sites in NSW, Qld and the NT. We aim to Interview around 180 patients and 120 health related staff; health care providers (such as Aboriginal health workers, doctors, nurses) and senior health organisation leaders, bureaucrats, managers and policy makers from the Aboriginal Community Controlled Health Services (ACCHS’s), hospital and government sector.

The interview process is informal and flexible as our main aim is to encourage study participants to articulate their experiences and views. The interviews can take place in small groups or one-on-one. Please let us know if you have a preference.

Who is involved in this research?

The Kanyini Vascular Collaboration is made up of an experienced team of Indigenous and non-Indigenous health service and clinical researchers, policy-makers, health economists, clinicians, and communities. Some key people involved in this study include:

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Alan Cass</td>
<td>The George Institute For International Health, Sydney</td>
</tr>
<tr>
<td>Dr Noel Hayman</td>
<td>Inala Indigenous Health Service, Brisbane</td>
</tr>
<tr>
<td>Prof Sandra Eades</td>
<td>The Sax Institute, Sydney</td>
</tr>
<tr>
<td>Ms Cilla freeze</td>
<td>W/Chopperan Health Service, Cairns</td>
</tr>
<tr>
<td>Dr Alex Brown</td>
<td>Baker Heart Research Institute, Alice Springs</td>
</tr>
</tbody>
</table>
What will it mean if you participate in this study?

If you participate in this study you will be interviewed by a study team member who is skilled in this type of research. The focus of the interview will depend on your area of expertise. Our aim is to hear your experiences and views about the barriers to health services for Aboriginal people.

What will happen once we've collected your information?

We would like to tape your interviews and will provide you with either a paper copy or audio copy after the interview. We would like you to listen/read the interview transcript and give us feedback on its contents by either;

- Giving your consent that the transcript is a satisfactory representation of your views,
- Asking for minor changes to be made to the existing transcript,
- Asking us for a repeat interview to expand on or change things that you said, or
- Withdrawing your data and consent to participate in the study.

All information will remain confidential. Study information will be stored in a securely locked file at the George Institute for International Health and will be accessed only by study team members. Nothing written in reports will link you personally to the study.

What benefits can come from this study?

This study seeks to understand the personal perspective of staff working within the Aboriginal health sector at a variety of levels. Through this process we hope to provide a better understanding of what are the systemic barriers to providing best practice chronic disease care for Aboriginal people. We will use this knowledge to develop, implement and evaluate innovative best-practice models, developed in partnership with, and specifically for, Aboriginal people. The information gained from this study will be regularly fed back and formally integrated into a series of policy forums with the view to stimulating productive dialogue on ways forward in chronic disease care.

Does the study have ethical approval?

This study has been reviewed and approved by the Princess Alexandra Hospital Human Research Ethics Committee. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make an independent complaint, you can contact the Ethics Manager, Princess Alexandra Hospital Human Research Ethics Committee on telephone (07) 3240 5866 or email PAH_Ethics_Research@health.qld.gov.au

Contact details: If you have any complaints or questions please contact:

Dr Alan Case 02 9993 4553 The George Institute For International Health
Dr David Peiris 02 9993 4513 Level 10, King George V Building
Ms Maria Tchan 02 9993 4505 Missenden Rd Camperdown 2050 NSW
Attachment 6.3: Sample consent form for community participants

Participant Consent Form
Kanyini Interview Study

Before you sign this form please be sure that you understand what it means to be part of the study. Please read (or have read to you) the Information Sheet. Please ask the study team member to answer any questions you have.

It is important to understand:
- You do not have to take part in this study if you do not wish to.
- You can stop taking part at any time.
- You may decide not to take part in the study. This will not affect your treatment or health care.
- Information you give will be used only for this study. It will be stored in a secure place. Only study team members will have access.
- Your name and details will not be made public. Nothing written in reports will link you personally to the study.

1. I have a copy of the study information sheet and have had an opportunity to ask questions about the study. □ yes □ no
2. I agree to take part in an interview for the study. □ yes □ no
3. Do you agree that the interview be taped? □ yes □ no
4. Do you wish to have an interpreter present at the interview? □ yes □ no
5. Would you like a (written) copy of your interview? □ yes □ no
6. Do you wish to check the interview as described in the information sheet? □ yes □ no
7. Do you agree that some of your words (not your name) be used in the study reports? □ yes □ no
8. At the end of the study do you wish our interview record to be destroyed? □ yes □ no
9. Do you understand that you have the right to withdraw your consent and cease involvement in the study at any time without penalty, either financial or personal? □ yes □ no

Participant to complete:
__________ hereby consent to take part in this study.

Signature: Date:

Witness to complete:
__________ hereby consent to take part in this study.

Signature: Date:
Investigator to complete:

Name: ____________________________ Role in Project: ____________________________

I have explained the nature and purpose of the study to the above participant and have answered their questions.

Signature: ____________________________ Date: ____________________________

Ethical Approval:

This study has been reviewed and approved by the Princess Alexandra Hospital Human Research Ethics Committee. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make an independent complaint, you can contact the Ethics Manager, Princess Alexandra Hospital Human Research Ethics Committee on telephone (07) 3240 5656 or email PAH_Ethics_Research@health.qld.gov.au.

Contact details:

Dr Alix Cass (02) 9993 4563 The George Institute For International Health
Maria Tohan (02) 9993 4505 Level 10, King George V Building
Dr David Peiris (02) 9993 4513 Missenden Rd

Camperdown 2050 NSW
Health Professional Consent Form
Kanyini Interview Study

Before you sign this form please be sure that you understand what it means to be part of the study. Please read (or have read to you) the Information Sheet. Please ask the study team member to answer any questions you have.

It is important to understand:
- You do not have to take part in this study if you do not wish to.
- You can stop taking part at any time.
- You may decide not to take part in the study.
- Information you give will be used only for this study. It will be stored in a secure place. Only study team members will have access.
- Your name and details will not be made public. Nothing written in reports will link you personally to the study.

1. I have a copy of the study information sheet and have had an opportunity to ask questions about the study. yes □ no □
2. I agree to take part in an interview for the study yes □ no □
3. Do you agree that the interview be taped? yes □ no □
4. Would you like a (written) copy of your interview? yes □ no □
5. Do you wish to check the interview as described in the information sheet? yes □ no □
6. Do you agree that some of your words (not your name) be used in the study reports? yes □ no □
7. Do you have any objections to the interview record being kept at the end of the study? yes □ no □
8. Do you understand that you have the right to withdraw your consent and cease involvement in the study at any time without penalty, either financial or personal. yes □ no □

Participant to complete:
I ___________________________________________ Name) hereby consent to take part in this study.

Signature: _______________________________ Date: _______________________________

Witness to complete:
I ___________________________________________ Name) hereby consent to take part in this study.

Signature: _______________________________ Date: _______________________________
Investigator to complete:

Name: Role in Project:

I have explained the nature and purpose of the study to the above participant and have answered their questions.

Signature: Date:

---

Ethical Approval:

This study has been reviewed and approved by the Princess Alexandra Hospital Human Research Ethics Committee. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make an independent complaint, you can contact the Ethics Manager, Princess Alexandra Hospital Human Research Ethics Committee on telephone (07) 3240 5856 or email PAH_Ethics_Research@health.qld.gov.au.

---

Contact details:

Dr Alan Cass (02) 9993 4553 The George Institute For International Health
Maria Tchan (02) 9993 4505 Level 10, King George V Building
David Peiris (02) 9993 4513 Missenden Rd Camperdown NSW 2050
Attachment 7: Participant distress protocol sample

Kanyini Vascular Collaboration - Qualitative Study
Process for management of participant distress

The Kanyini Qualitative study aims to provide an in depth analysis of the journeys that patients and their care providers make when dealing with chronic diseases. This study is primarily oriented to respectfully and authentically documenting participant reflections on these journeys. The welfare of participants is of prime importance in this study and at all times takes precedence over data collection. This includes both the welfare of individual patients and their health services as organisations. It is vital that this be respected in all phases of the study conduct. Whilst for many participants the opportunity to voice these stories may be welcomed, interviewers need to be sensitive to any potential distress that may arise from such a process. It is recommended that the following points are addressed at each interview site to provide an effective and sensitive process for interviewers to follow in the event of participants becoming distressed.

The Kanyini Vascular Collaboration (KVC) must ensure that these site-specific processes to manage distress are established before any local interviews occur.

Prior to interviews:

1. At each health service the KVC will work with a Local Reference Group (LRG) comprising key local stakeholders, the Indigenous Research Fellow and a designated community advocate (agency or individual).
2. The KVC and the LRG will work together to develop a site specific procedure for reporting and managing participant distress. Together they will:
   - Create a notification of distress form (see sample attached)
   - Identify suitable counselling/ other support services that can be referred to if needed.
   - Ensure that these services are willing and have the capacity to provide support.
   - Ensure all interview staff are familiar with the local distress management procedure and that due care is taken in the conduct of any interviews.
   - Review any significant issues of concern that are occurring as a result of this study.

At the time of the interview:

As a part of the informed consent process participants will be made aware of their right to withdraw from the study at any time. Interviewers will be trained appropriately to be sensitive to any signs of distress that may arise during an interview. Prior to commencing the interview each participant will be informed of the nominated support person whom they can contact if need be after the interview process.

In collaboration with the participant they may be required to take any of the following actions:

1. Breaking off the interview prematurely;
2. Agreeing to leave the distressing topic;
3. Referral for additional support to the participant. This may involve:
   a. Arranging a clinical visit with the participant’s usual care provider to address the problem or;
   b. Arranging for counselling support.
   c. Other appropriate support mechanisms as determined by the LRG

Post interview:

If referral for additional support is needed then the interviewer will complete a notification form and submit to the referral service for review. The referral service will then be responsible for reviewing the case and arranging to talk with the participant. The referral service will provide brief documentation of the actions taken and the referral form will be retained in the confidential client record.
Kanyini Vascular Collaboration - Qualitative Study

Reporting of participant distress

(To be completed by the interviewer)
Participant is seeking further support: YES NO

Name of participant: __________________________________________
Date of reporting: _____________________________
Study site: __________________________________________
Interviewer: __________________________________________
Date of interview: _____________________________

Name of support person/ service referred to: __________________________________________

Actions the interviewer has taken in responding to the distress.

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

Name of interviewer: __________________________________________
Signature: __________________________________________
Date: __________________________________________

(To be completed by the nominated support person/ services)

Details of follow up action taken by the support person/services:

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

Name of referral person: __________________________________________
Signature: __________________________________________
Date: __________________________________________
Chapter 8: New tools for an old trade – A sociotechnical appraisal of how electronic decision support is used by primary care practitioners


Author contribution: I designed the study, coordinated ethics submissions, conducted the interviews, performed the primary analyses of the findings, worked with co-authors Usherwood, Weeramanthri and Cass in interpreting the findings and wrote the first and subsequent drafts for journal submission. I was the primary author for responding to reviewer comments. All co-authors reviewed and commented on journal manuscript drafts.

8.1 Abstract

This article explores Australian general practitioners’ (GPs) views on a novel electronic decision support (EDS) tool being developed for cardiovascular disease management. We use Timmerman and Berg’s technology-in-practice approach to examine how technologies influence and are influenced by the social networks in which they are placed. In all 21 general practitioners who piloted the tool were interviewed. The tool occupied an ill-defined middle ground in a dialectical relationship between GPs’ routine care and factors promoting best practice. Drawing on Lipsky’s concept of ‘street-level bureaucrats’, the tool’s ability to process workloads expeditiously was of greatest appeal to GPs. In doing so, the tool has potential to alter the structure, process and content of health-care encounters. The credibility of EDS tools appears to be mediated by fluid notions of best practice, based on an expert scrutiny of the evidence, synthesis via authoritative guidelines and dissemination through trusted and often informal networks. Balanced against this is the importance of ‘soft’ forms of knowledge such as intuition and timing in everyday decision-making. This resonates with Aristotle’s theory of phronesis (practical wisdom) and may render EDS tools inconsequential if they merely process biomedical data. While EDS tools show promise in improving health practitioner performance, the socio-technical dimensions of their implementation warrant careful consideration.
8.2 Background

Systematic reviews have shown that electronic decision support (EDS) systems may improve practitioner performance in health care (Garg et al. 2005, Kawamoto et al. 2005, Shojania et al. 2009). Despite the rapid proliferation of such systems and their appeal to health-systems planners there has been limited sociological inquiry into their impact. This is needed because a narrow focus on effectiveness, as gauged by practitioner performance, will not assess their influence on other dimensions of health-care quality. Further, the demonstration of their efficacy in trial settings is likely to understate many of the real world contingencies that will impact on uptake of these technologies.

Timmermans and Berg (2003) have outlined three contrasting theoretical approaches to understanding how medical technologies influence health-care practices: (i) technological determinism, in which innovation acts as an instrument of power imposed as part of 'a medico-industrial complex' onto doctors and patients who have limited agency in the process; (ii) social essentialism, in which social and political realities preferentially select particular technologies to suit their purposes and the technologies themselves are blank slates absorbing and reflecting these prevailing paradigms; and (iii) technology-in-practice, which assumes a dialectical relationship between the technologies and their users. This last approach draws on actor-network theory (Latour 2005) and views technologies as one of many actors neither devoid of ability to influence nor assuming a 'super agency' with extraordinary power over other actors.

Marc Berg has written extensively about the ways in which technologies such as decision support systems (Berg, 1997b), patient care information systems (Berg 2001), clinical protocols (Berg 1997a), guidelines (Berg et al. 2000) and even the medical record itself (Berg and Harterink, 2004) function as non-human actors in the health-care context. Drawing mainly from ethnomethodological studies, this work allows us to appreciate how these technologies influence the ways in which organisations deliver healthcare and how human actors (doctors, nurses, patients and others) respond. By following the interactions created by these human and non-human actors we can begin to appreciate their sociological effects. Latour (2005: 12) states:
you have ‘to follow the actors themselves’, that is try to catch up with their often wild innovations in order to learn from them what the collective existence has become in their hands, which methods they have elaborated to make it fit together, which accounts could best define the new associations that they have been forced to establish.

Health professionals’ core business of delivering quality patient care is characterised by complex knowledge processes that are not amenable to a simple process of behaviour change. While guidelines and protocols have appeal in providing professional transparency about decision-making processes, they tend to presuppose medical action as a logical sequence of steps toward a perceived, single optimum code of practice (Berg 1997a). Greatbatch et al.’s (2005) ethnographic work shows that rule-based expert systems capture only part of what experts do. Health professionals are constantly sidelining rules based on their expertise, practical limitations and judgements about their patients’ expectations and capabilities (Summerskill and Pope, 2002). Berg found that decision support systems were frequently modified once implemented, often compromising substantially the original ‘scientific’ thought processes that went into their algorithms (Berg 1997b). Appreciation of these factors is important in explaining the known limited effectiveness of protocols and guidelines (Grimshaw et al. 2004).

The role of technologies as non-human actors in the health-care encounter can pose epistemological challenges. Alongside traditional doctor-centred and emerging patient-centred agencies such as shared decision-making, culturally competent care and self-management, are third party actors with regulatory authority (May et al. 2006). One such actor is the evidence-based medicine (EBM) movement in which predominantly clinical trial and population-based evidence has come to define appropriate care. EBM is asserted to be the guiding principle by which the profession defines and regulates appropriate conduct (Armstrong 2002). The core dilemma faced by EBM is overcoming the challenge of applying population-based findings to individual health-care encounters in which doctor and patient agencies prevail (May et al. 2006). Hence, new technologies such as point-of-care decision support are viewed optimistically by health system planners because of their potential to narrow ‘evidence-practice gaps’, bringing epidemiological and clinical trial evidence into everyday practice.
This convergence of human and non-human actors in the health-care encounter produces a symbolic drama (May et al. 2006) whose effects are not well elaborated. In this article we draw on the technology-in-practice approach (Timmermans and Berg 2003) to develop an understanding of the ways in which EDS tools function as actors in the social context of primary care. This forms part of a broader research programme to develop an EDS tool in Australian primary care settings, described below. A previously published pilot evaluation (Peiris et al. 2009a), focused on tool design and the modifications needed to allow for its routine use by general practitioners. The motivation for this sub-study arose from a dedicated part of the interview evaluation in which general practitioners (GPs) were encouraged to give a more expansive account of the implications of the future implementation of the tool in practice. It was in this part of the interview that important data emerged relating to the dialectical relationship between routine care provided by GPs and the promotion of best practice, in particular the role of evidence, guidelines and technological tools. In this article we more thoroughly explore this relationship by examining the actors and social settings in which EDS tools are placed.

Development of an Australian EDS tool for cardiovascular disease risk management

EDS systems are relatively underdeveloped in Australian primary care settings. In 2005 researchers at The George Institute, in partnership with several collaborators, established a research programme to develop and implement a suite of EDS tools for use in primary health care. A specific objective of this programme is ensuring these tools are suitable for use in private general practices and community-governed Aboriginal medical services (AMS). The first major project in this programme focuses on CVD. CVD is a collective term to include diseases such as coronary heart disease, stroke and peripheral vascular diseases. Despite major advances over the last two decades in CVD epidemiology and a plethora of clinical trials establishing the efficacy and safety of various therapeutic interventions there has been variable translation of this knowledge into practice. Multiple, complex guidelines and inadequate resources to implement them at the point of care are contributing factors to the low uptake of best practice recommendations in Australia (Peiris et al. 2009b’ Webster et al. 2009). To help address this, an EDS tool was developed that synthesises recommendations from several Australian guidelines into a single CVD management algorithm to provide point-of-care recommendations.
8.3 Methods

In the pilot implementation a stand-alone version of the tool was field tested with 21 GPs working in eight private, teaching general practices and three AMSs. Sampling was purposive. We sought GPs interested in research, medical education and the provision of services to Aboriginal people. It was considered that GPs with these interests might subject the tool to vigorous scrutiny and provide recommendations for its future development. Prior to study commencement, research staff provided GPs with an orientation to the tool and interpretation of the output. In all 200 routinely attending adult patients (33% Aboriginal, 67% non-Aboriginal) within the age ranges recommended for CVD risk assessment were invited from the waiting room to participate in the study. A research assistant accessed the patient’s electronic health record and entered data into the EDS tool, thus simulating the automated data entry that would occur if the tool was fully integrated in the GP’s software system. The resultant output was printed and given directly to GPs to review during their consultation with the patient. A sample annotated output is shown in Figure 8-1. The manner in which GPs used the tool in the consultation was at their discretion, including whether or not to show the tool output to the patient. Each GP had outputs generated for up to 10 patients, a big enough number with which to gain an appreciation of the tool’s application in a typical working day.
At the study completion, the GPs participated in an in-depth interview evaluation and completed a survey about their professional background and attitudes to electronic information. The interviews were conducted by the lead author, a practising GP who had a working knowledge of the tool but was not involved in its development. Two interviews were conducted by phone with the remainder in the GPs’ consulting rooms. This not only created a comfortable setting but it provided contextual information about the setting in which routine health-care encounters occur. It also allowed for easy access to computer records for patients seen in the study. The interviews were generally conducted on the day or within a few days of use of the tool and ranged from 30 to 60 minutes’ duration. The interview was semi-structured and was conducted in three parts. The interview guide is provided in Chapter 5, Attachment 3. The first part involved an initial discussion about attitudes to the tool and its impact on the health-care consultation. In the second part, sample tool outputs were selected in order to stimulate a collegial discussion about actual clinical scenarios and the rationale for particular management decisions. This allowed GPs
to recount the 'story' of the health-care encounter (Greenhalgh and Hurwitz 1999) in much the same way as cases are discussed for management purposes with colleagues and for medical education. During these discussions GPs frequently reviewed the patients’ electronic health records to elucidate the decisions made. The third and final component of the interview involved discussing recommendations for the future implementation of the tool in routine general practice.

Interview recordings were professionally transcribed and thematic content analysis was conducted following the methods outlined by Patton (2002). Analyses were conducted contemporaneously with data collection and used to inform subsequent interviews. As we began to identify the socio-technical aspects of tools to be a substantive issue, more weight was given to this in subsequent interviews. Upon completion of all interviews repeat readings of interview transcripts were conducted and the findings were then provisionally categorised by theme. These themes were jointly discussed by the research team over a series of meetings and the major thematic groupings were refined. The team comprised the lead author; a senior GP academic who has provided strategic advice on tool development from an early stage of the project; two health service researchers not involved in the project, who offered an outsider perspective to the analyses; and the project leader, who has been responsible for the broader EDS research and development programme since its inception. This insider-outsider team composition was especially useful for challenging and justifying particular thematic interpretations, and mitigating any bias arising from a single interviewer being used.

NVivo 8 (QSR International, Melbourne, Victoria) was used to assist with organising the data. Principal study findings were fed back to the participating GPs and AMS managers as a written report and oral presentations. The study was approved by both the Sydney South West Area Health Service and Aboriginal Health and Medical Research Council ethics committees. Patients and GPs gave their written consent to participate and signed agreements were obtained from the governing bodies for the three participating AMSs.
8.4 Findings and interpretation

A total of 12 male GPs and nine female GPs participated. Nine GPs worked in AMSs and the remainder in urban, teaching, private general practices. The practice size varied greatly, ranging from solo operators to a large multidisciplinary service with 20 GPs. Four GPs were under 40-years old, 11 were 40–49-years old and six were over 50-years old. All spoke English as their primary language. Eighteen were Australian university graduates. High levels of professional training were attained. Fifteen held fellowship status with the Royal Australian College of General Practitioners, 11 held postgraduate diplomas and four held Master’s degrees. All but two participants regularly conducted or participated in research projects. Overall 19 participants reported use of the Internet at least once daily.

Table 8-1 provides the survey results. Although there are limitations to self-reported data, the participants recorded a high uptake of electronic practice software features and positive attitudes to the role of computers in general practice.

**Table 8-1: Survey responses on attitudes to computers and sources of medical information for the 21 participating GPs**

<table>
<thead>
<tr>
<th>Electronic practice software features used</th>
<th>Always used</th>
<th>Sometimes used</th>
<th>Not used or not available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication prescribing</td>
<td>20</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Automated pathology results</td>
<td>19</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>On-line billing</td>
<td>14</td>
<td>–</td>
<td>7</td>
</tr>
<tr>
<td>Electronic patient recalls</td>
<td>13</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Scanning of paper documents</td>
<td>12</td>
<td>–</td>
<td>9</td>
</tr>
<tr>
<td>Electronic care plans</td>
<td>12</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Chronic disease patient registers</td>
<td>7</td>
<td>10</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Effect of computers on the following</th>
<th>Positive/very positive</th>
<th>No effect</th>
<th>Negative/very negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient safety</td>
<td>18</td>
<td>3</td>
<td>–</td>
</tr>
<tr>
<td>Practice of evidenced based medicine</td>
<td>17</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Practice cost efficiencies</td>
<td>14</td>
<td>7</td>
<td>–</td>
</tr>
<tr>
<td>Patient privacy</td>
<td>11</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>Patient/doctor communication</td>
<td>10</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Source of medical information</td>
<td>Very influential</td>
<td>Somewhat influential</td>
<td>Not influential</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>------------------</td>
<td>----------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Specialists*</td>
<td>14</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td>Clinical guidelines from professional organisations</td>
<td>13</td>
<td>8</td>
<td>-</td>
</tr>
<tr>
<td>Continuing medical education events</td>
<td>11</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Pharmaceutical product information in medical software</td>
<td>10</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>GP colleagues</td>
<td>9</td>
<td>12</td>
<td>-</td>
</tr>
<tr>
<td>Electronic text books</td>
<td>9</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>Personal internet searches</td>
<td>8</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>Peer-reviewed journals</td>
<td>8</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Conferences**</td>
<td>7</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Medical newspapers</td>
<td>2</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>Pharmaceutical representatives</td>
<td>-</td>
<td>7</td>
<td>14</td>
</tr>
</tbody>
</table>

* 1 missing response
** 2 missing responses

Five principal themes and their resonances with particular studies are discussed here. Two themes relate to how and why the tool might influence the routine care provided by GPs. They include ‘GPs as street-level bureaucrats’ and ‘communication influences’. Three further themes relate to the role of the tool in notions of best practice care. They include ‘technogovernance’, ‘mindlines’ and ‘phronesis’.

**GPs as street-level bureaucrats**

Checkland (2004) used Lipsky’s concept of ‘street-level bureaucrats’ (Lipsky 1980) to better understand the impact of normative codes of practice such as clinical guidelines on the work of GPs. Framing GPs as street-level bureaucrats recognises their role as powerful, semi-autonomous workers directly engaging with a demanding public and having to process voluminous data to make rapid, safe and effective decisions (Lipsky 1980). The pressures of processing information efficiently were noted in this study. Despite guideline recommendations to perform regular CVD risk assessments, nearly all 19 participants reported performing these infrequently or not at all in their routine practice. A major
barrier was that the most commonly used paper chart version was not practical to implement:

Interviewer: Are you a prior user of the New Zealand [paper] risk chart calculator?

Participant: Look I’ve seen it and I haven’t used it simply because where do I put it? I mean there’s enough junk on my desk and around this room already. So unless it’s in the software it’s not useful. (Interview 7: Private practice male GP 60+ years)

In this way GPs indicated that the most supportive function of an EDS tool was if it enabled access to resources and guidelines during the health-care encounter. On reflecting why she didn’t use guidelines more often at the point of care, one GP said:

I think that’s really been the reason why I haven’t used them more routinely because yeah I know the guidelines but I have them in another place. So it’s been an issue in terms of first of all getting [access to them] and then applying it … and all that time that’s involved with that. So I think it can only be a bonus the fact that it’s immediately there. (Interview 5: AMS female GP 30-39 years)

Similarly, rather than actively not implementing evidence, GPs are more likely to be simply distracted from certain management actions by the routine pressures of the health-care encounter:

I think that there is the scenario that [for] the people you know well you often overlook things. And it is very useful to have a tool that actually brings you back to basics again. You know, sometimes you are just so focused on things and you forget. (Interview 3: AMS female GP 40-49 years)

Juxtaposed against this appreciation for being brought back to the basics, one GP expressed irritation when the tool failed to acknowledge previously performed work and made blanket or seemingly obvious recommendations:

She’s [already] had her cholesterol done and then it says ‘cholesterol evaluation is recommended …’ They’re telling us to suck eggs repeatedly, and I don’t like it. (Interview 15: Private practice female GP 40-49 years)

GPs also frequently commented on the failure of on-screen prompts to effectively integrate with the natural workflow of the clinical consultation. They cautioned against EDS tools adding to the already burdensome prompts to perform various clinical tasks.
I mean there are already a lot of pop-up windows... and adding another one isn’t going to get anyone very excited ... Imagine how much better the software would be if it tracks the way you use a consultation. (Interview 4: AMS male GP 30-39 years)

**Communication influences**

The tool exerted additional important influences beyond expeditious processing. In these instances the tool punctuated conversations about CVD risk in new ways. For one GP the tool created quarantined discussions around cardiovascular risk management:

I think it was quite a good thing because you would finish the consultation about whatever that was about and then you’d almost have a separate time set for looking at cardiovascular risk ... So having that piece of paper [the tool output] there gave you that conversation: ‘well now we’ve finished everything, let’s look at this.’ (Interview 13: Private practice male GP 40-49 years)

Another GP forewarned of dangers if the tool distorted priorities in the health-care encounter. By eliciting particular types of information related to cardiovascular risk this may come at the expense of other, potentially more patient-focused information:

One of the dangers I would see with this is the encouragement of game playing ... So an electronic decision support module that is only related to cardiovascular disease ... could lead you to focus on getting cholesterol and things done and perhaps forget immunisations or pap smears or the housing forms because that’s what the computer is flashing up at you. (Interview 4: AMS male GP 30-39 years)

While some of the above observations are informed conjecture based on how GPs may implement the tool in routine care, they demonstrate how innovative technologies have the potential to synchronise the solicitation and delivery of particular types of information (Greatbatch *et al.* 2001). Such technologies have the capacity to focus GPs’ attention and produce particular kinds of conversations with patients, potentially displacing others. A number of GPs described how the tool not only created space for these conversations but shaped the content of their talk, broadening the existing communication devices that are deployed to discuss CVD risk management. One GP found this changed her overall communication package:

I think the biggest impact is that it changed the way I talked about what I was doing with them, in that it made it a much more slick, neat package to describe the normal
screening that you do for risk management. And so I felt it was easier to deliver some description of where they’re at now. (Interview 2: AMS female GP 40-49 years)

Several GPs commented on how they used the classification of the person’s risk on the colour spectrum bar to influence discussions (see Figure 8-1). For one GP the graphic representation of risk coupled with the unquestionable authority of the computer became a device for the delivery of routine messages about adopting healthy lifestyles:

Yeah and even a coloured diagram is really helpful in being able to say, ‘look, the computer says it’s true. This isn’t just me making up words around diabetes. Look, this is going into orange – this says ‘high’ in red’. And there’s almost an emotional response to the colours that come back that is actually really useful compared to me saying, ‘look people with diabetes have heart attacks and strokes’. (Interview 4: AMS male GP 30-39 years)

In this way the tool output, and in particular the use of colour, can be viewed as a boundary object (Star and Griesemer 1989); an entity that establishes coherency between the disparate world-views of researchers, clinicians and patients but may be used differently by each of these actors. It is not merely a means of representing categories of risk on the basis of inputs to the tool algorithm. Rather, it can become an influential entry point for how health professionals frame risk and advise on actions to mitigate risk, and how patients interpret risk.

Technogovernance

May et al. (2006) describe a process of ‘technogovernance’ in which technological innovation is used to create a differently distributed accountability from that seen in the traditional doctor–patient dyad. Non-human actors, such as EDS tools, can change the structure and direction of decision-making processes. By actively bringing guidelines into the consultation, these tools become a third epistemological authority (alongside the doctor’s and patient’s) bringing about new practices of governance.

We encountered diverse views from GPs about these technogovernance issues. A number of GPs expressed being at ease with this third presence. Although we cannot know how this may have manifested in actual practice, some of the more experienced GPs welcomed
being made aware of an ideal and potentially unachievable management scenario for their patients:

I’m comfortable in that if I don’t meet a target and I’ve made a conscious decision about that I’m comfortable to live with that, I’ve been making those decisions for 20 odd years. But I’m comfortable that the guidelines are there now, I feel much safer. (Interview 17: AMS male GP 50-59 years)

I don’t have a problem with seeing that that’s where this person ought to be ... It’s a goal and you can explain that to the patient by saying ‘Look this will move, if we do this, but the choice is really yours’. There’s lifestyle, there’s enjoyment of life, there’s the ideal situation and we’ll come to some consensus. (Interview 7: Private practice male GP 60+ years)

Two GPs, however, were challenged by the tool’s perceived external authority and its agency was palpable in their accounts. For one GP the tool took on a threatening and vexatious quality ‘embarrassing’ him into better practice.

They [patients] come for condition X and the machine is tapping me on the shoulder and saying, ‘by the way, look at this’. Well I suppose one thing that crosses my mind is embarrassment. If it was so bad that you’d missed it and it said, ‘hey you need to prescribe this like now’, I would be thinking ‘who’s running the show, the machine or me?’ ... Somewhere in my past I’ve always wanted to make sure that the doctor is the one who is making the decisions. (Interview 11: Private practice male GP 50-59 years)

Another GP perceived that the tool changed the direction of engagement when her patient reviewed the recommendations and suggested to her that a medication be prescribed:

Interviewer: What about the prompts around meeting targets? I think you did in fact make changes to his blood pressure and cholesterol medicines.

GP: You made me do that! You see...[laughing], the older my patients get the less I like to interfere ... So your tool has made me do an intervention which I’m not sure if it’s okay or not actually ... John [pseudonym] himself wanted to see this ... so that’s partly what made me change his stuff ... Once a patient sees this ... like you and I, we can intellectualise about it and recognise it’s just a tool, but for a patient it’s very real and they would often in fact want treatment. (Interview 14: Private practice female GP 40-49 years)

This GP also raised concerns about the tool’s potential for use by health system bureaucracies as a mechanism to assess performance and outcome payments:
This tool ... what I'd hate to see is if we ever get to outcome payments ... because this hasn't been performed within six months - maybe for some very valid reasons and because of other issues with the patient. So I'd hate that. (Interview 14: Private practice female GP 40-49 years)

**Mindlines**

Related to the technogovernance issues were broader discussions about how GPs relate to evidence in practice. Gabbay and Le May’s ethnographic study found that participating GPs rarely ‘accessed, appraised and used explicit evidence directly from research or other formal sources’ (2004: 3). Rather, they relied on mindlines - tacit guidelines informed by brief readings of guidelines but, more importantly, collectively mediated through various informal networks (colleagues, opinion leaders and even their patients). Despite the limitations of self-reported data, Table 1 indicates that the most influential sources of medical information for participating GPs were specialists, professional guidelines and continuing medical education activities. More direct sources of evidence, such as peer-reviewed journals, were less influential. Although these GPs had high levels of postgraduate training and a predisposition to research, they seemed to indicate that evidence needs to be validated through trusted networks, especially colleagues and professional organisations. This was particularly important when GPs considered incorporating new evidence into practice:

> There's an element of consensus around what peers are doing. So an example would be, say, using ACE inhibitors and A2 antagonists [two blood pressure medicines]... The recommendations were to use both [in combination] and then the evidence came out that it doesn't seem to be any more effective. My feeling is that I don't really want to be using both of them. But I haven’t got a feel for what my peers are doing yet ... and what the specialists are doing. So I'm in that discomfort zone where I'm actually fairly comfortable with what the evidence shows, but I'm not sure what's being recommended by everyone else yet. (Interview 4: AMS male GP, 30-39-years old)

Thus, new and emerging evidence was often greeted cautiously. Until this evidence becomes embedded in particular mindlines its utility is of questionable relevance. Guidelines from trusted organisations constitute an important component to these mindlines even if they are out of date or conflict with emerging evidence:

> From a GP's point of view, you just want the guidelines. You don't want to know about what's coming up because what's coming up may or may not change. You can get one trial that's says this is a great thing and then a few years later you might get
another trial that’s effectively the opposite. ... As a GP you can’t know about all the little bits and pieces of everything that’s not going to lead to a change in management. (Interview 12: private practice male GP, 40–49-years old)

There was also concern that premature adoption of research-based recommendations had the potential to damage the credibility of the profession. The example of delayed findings of increased risks associated with hormone replacement therapy (HRT) was cited:

I think if it’s not proven to be a guideline we’re going to look like we did with HRT. You’ve got to be pretty sure before you put it in a guideline. I imagine it’s got to be as solid as it can be. (Interview 16: private practice female GP, 40–49-years old)

If decision support tools challenge established and trusted networks they may create inconsistencies with these mindlines. The existence of multiple, sometimes conflicting and out-of-date guidelines for CVD in Australia could exacerbate these inconsistencies. One GP commented on the confusion that could occur if the authors of EDS tools became alternative expert actors who proposed recommendations that were different from those of existing experts:

It could get confusing, because I think you’d end up having the programmers or the decision-makers around the computer system becoming experts ... and then there would be all sorts of quotes from professors or medical newspapers saying, ‘Well, that’s not the recommendation and we shouldn’t be doing that’. It leads to confusing messages because there isn’t actually the consensus around something until it hits the guidelines. (Interview 4: AMS male GP, 30–39-years old)

**Phronesis**

While evidence, guidelines and protocol implementations were important factors in how decisions are made, the participating GPs made a number of references to the role of wisdom, intuition and timing as being of prime importance. Their comments resonate with Aristotle’s theory of phronesis, often translated as ‘prudence’ or ‘practical wisdom’ (Flyvbjerg 2001). One GP questioned the value of CVD-related tools and felt that assessing a patient’s risk was an intuitive process that came with experience:

In general practice [tools are] not that important. ... I think most of us, we really treat on empirical grounds. We have a feeling that this person is at higher risk, and we just treat them. ... I don’t seem to have many slip through my fingers, because I see them
a couple of times a year for coughs and colds etcetera. (Interview 10: private practice male GP, 50–59-years old)

In particular, the fact that management is implemented over a series of consultations can take precedence over point-of-care decision support:

I think that’s where continuity of care and the art of general practice really comes to the fore . . . that you actually try to meet the patient’s and the doctor’s agenda. But you know, ‘the longitudinal consultation’, I think that’s the important thing . . . . What I would love is a tool to show the effectiveness of continuity of care. Like, John, for instance, I’ve seen him for 25 years. There is no tool like that. Continuity of care is probably . . . his biggest [contributor to] improvement in health. (Interview 14: private practice female GP, 40–49-years old)

Even for the few, mainly younger, GPs who performed CVD risk assessments regularly, the skill of applying the process in a meaningful way took on more prominence than the results of the assessment itself:

It takes a long time to do it [CVD risk assessments] properly . . . and to make people understand them. The more I did it actually, the less that I used it after . . . the more I realised it was an art. I think it’s great having the numbers but it’s how you apply that number to that person sitting there, is my real feeling. (Interview 19: AMS female GP, 20–29-years old)

Phronesis is characterised by an openness to change through reflection both in action during the health-care encounter and ‘on-action’ after the encounter (Schon 1983). This reflective process was described by one AMS GP for whom awareness of population data on risk factors and inequitable health outcomes for Aboriginal peoples was influencing his previously conservative approach to treatment decisions:

My practice is changing . . . . I’ve come from a practice where I was saying ‘let’s see how it goes’ because patients are unwilling to take a new medication or increase the dose. . . . Whereas out here, I think you’ve just got to do it. They [Aboriginal people] are a really at-risk group. . . . And if you say, ‘Wait, that’s okay’ you’re sending a message that you’re not that comfortable starting them on something. (Interview 17: AMS male GP, 50–59-years old)

Thus much of the decision-making process for GPs is not merely scientifically based. It is equally bounded by the social and moral values that influence the interaction between doctors and patients. As Dew et al. (2010) state, ‘the delivery of a diagnosis and a
treatment plan is an interactionally complex matter that does not lend itself to the rigid following of a protocol’. Technologies that privilege ‘hard’, coded data may therefore be ineffective in influencing ‘soft’, value-laden decision-making processes.

8.5 Discussion and Conclusion

This exploratory study of Australian GP attitudes to a novel EDS tool for CVD risk management provides some insights into how EDS tools might function in the primary care workplace. Our findings suggest that EDS occupies an ill-defined middle ground in a dialectical relationship between the routine care provided by GPs and a range of interrelated actors promoting best practice.

EDS tools have the potential to offer practical support to GPs for the more efficient conduct of routine care. The concept of street-level bureaucrats is helpful in understanding why care may be perceived to be enhanced. Lipsky (1980: xii) wrote: ‘The decisions of street-level bureaucrats, the routines they establish, and the devices they invent to cope with uncertainty and work pressures, effectively become the public policies they carry out’. Factors that influence the adoption of particular policies include consistency with personal vision and professional values, harmony with local practices, adequate resources and lack of competing priorities. There were several accounts in this study where GPs saw the potential for the EDS tool to support their public policies, especially through the expeditious processing of workloads. This helps explain the findings from meta-analyses of trial data in which issues such as incorporation of tools in routine work flow and availability at the time and the location of decision-making are associated with improved practitioner performance (Kawamoto et al. 2005).

Although we did not analyse the real-time use of the tool the interview accounts also indicated that GPs fashioned the tool in particular ways to make it relevant in the clinical encounter. Heath et al. (2003) suggest that technological tools are artefacts ‘made at home’ in the workplace and necessarily undergo a process of transformation according to a tacit body of practice and reasoning. Participating GPs talked of using the tool as a device to punctuate particular discussions, particularly focusing on risks of developing CVD. In this pilot the tool output came pre-prepared for use in the health-care encounter. The future,
practice-ready version of the tool will allow for real-time changing of input data during the consultation. This may alter how GPs and patients use the tool to direct the timing and flow of the clinical encounter when compared with the pilot version. Greatbatch et al. (2001) found that the computer creates structured conversational boundaries by focusing patients’ and doctors’ gaze on the screen and directing conversations via the populating of particular screen fields. We found GPs alluded to such conversational boundaries, particularly when using the tool’s risk score and colour category to explain the patient’s current and projected state of health. Consistent with the notion of the tool as a boundary object (Star and Griesemer, 1989), it may be deployed and interpreted differently by the various actors that are engaging with it. Importantly, it does not necessarily privilege GP agency over that of the patient. In this study there was a striking account where a patient initiated treatment decisions based on the tool outputs, thus altering the GP’s preferred management recommendations.

Alongside the tool’s ability to support and influence routine care, we identified competing elements that can render EDS tools inconsequential. The theory of phronesis helps to appreciate the role of soft knowledge construction when GPs make decisions in practice. The notion of time as an important factor in decision-making was emphasised in this study, particularly the way in which decisions are distributed over a series of encounters between GPs and their patients (Rapley 2008). These encounters constitute a narrative that is intuitively ‘read’ by doctors (Greenhalgh and Hurwitz 1999). This narrative is not linear. The journey made between doctor and patient is marked by ‘advances and reversals, vectored progress and cyclic repetition, bursts of change and lulls of sameness’ (Charon 2000: 64). Greenhalgh and Hurwitz (1999) highlight four distinct texts that are operating in this journey: the experiential text of the patient’s life outside the health-care encounter, the narrative text constructed by the doctor about the patient’s illness, the physical or perceptual text derived from physical examination and the instrumental text derived from tests and machines. Decision support, when derived primarily from the latter two texts, can be of secondary interest. The development of patient-specific interfaces and access to data outside of the health-care encounter may, therefore, be effective strategies to better incorporate these broader narrative and experiential texts.
In addition to the tool’s potential to support routine care was a range of views on how it might represent a vehicle for best practice. We found that decision support tools interact with a variety of other agents of best practice, particularly EBM, guidelines and professional organisations. The participating GPs viewed best practice as a fluid process where evidence is scrutinised by trusted experts, distilled into guidelines and disseminated through trusted networks. Gabbay and le May’s (2004) conception of a non-linear incorporation of EBM along tacit mindline networks appears germane. EDS tools that are inconsistent with these mindlines may be viewed as irrelevant and potentially even untrustworthy.

Rather than a form of technological determinism (Timmermans and Berg 2003), we found that GPs actively engaged with this tool, being neither subsumed under its force nor inert to its potential influences. Most GPs did not perceive the tool as challenging their epistemological position in any meaningful way. Of note, however, the tool’s authoritarian agency was salient for two participants, one of whom expressed fear of the potential use of such tools to rate performance. It is conceivable that as these tools become organisationally embedded and promoted through national programmes their potential to influence the agency of the GP could grow. Ethnographic studies examining the implementation of the UK’s Quality and Outcomes Framework pay-for-performance programme have found that the collection of biomedical data is being prioritised over other dimensions of health-care quality in order to meet indicator targets (Checkland et al. 2007; Grant et al. 2009). While pay-for-performance programmes may be viewed suspiciously, peak professional bodies, by contrast, appear to be perceived as trusted technogovernors. Endorsement and dissemination of tools by these organisations might be expected to enhance their credibility and diminish any sense of authoritarian agency. However, from Gabbay’s work, we see that the energising of informal networks, particularly personal accounts from other professional colleagues, is likely to be an influential factor in uptake.

Limitations

Our study sample clearly has bearing on the findings presented here and their implications. The participating GPs were highly trained and generally demonstrated favourable attitudes to the role of information technology in general practice. Resistance to uptake of decision
support tools may be greater among GPs who are less research- and education-oriented and less embracing of technological innovation. Alternatively, GPs with less interest in this area may be less likely to question the veracity of recommendations and be more reliant on such tools. Post hoc interviews, using a peer-to-peer method of data collection, afforded us some advantages by engaging GPs in collegial conversations but this may have predisposed GPs to reflect their ideals rather than their practice. Further, our interpretation of the tool’s influence on communication might have been different if we were able to witness actual health-care encounters. Moreover, had we explored patients’ views different interpretations of the key themes may well have arisen. For example, while we found little difference in opinions for GPs working in Aboriginal health settings compared with those in mainstream general practice, a patient-focused enquiry might have produced quite different findings in these two settings.

Implementation in a broader range of primary care settings, involvement of the patient perspective and the use of ethnomethodology are key areas to focus on for future work in this area. In the next phase of this project the tool will be integrated into primary care software systems and there will be a specific patient interface for use both within and outside the health-care encounter. It will be trialled over a 12-month period in a larger number of settings to those studied here. This will allow us to enlist a combination of methods, including ethnography, to understand in more detail whether and how these tools become embedded both in the workplace and the community.

The context of general practice has shifted from the surgery, in which discrete illnesses episodes are treated, to a complex environment where health, illness and risks are more diffusely located between the consultation room and the community (Armstrong 2004). The application of EDS tools is becoming equally complex. Other human actors (such as specialists, non-GP health professionals, lay peer supporters and families), non-human technological actors (for example, personal e-health records, mobile phones, cloud computing, personal and shared e-health records) and technogovernors (for example, e-health regulators, professional standards bodies and pay-for-performance programmes) are all shaping health care in new and potentially profound ways. It will be important to follow these actors carefully as our current appreciation of their roles and influence is limited. While it is apparent that EDS tools and related technologies have the potential to improve
health system performance, our gaze should not be limited to only this aspect of healthcare quality. It is only through appreciation of the socio-technical dimensions of these tools that we will be able to understand their broader implications.

8.6 References


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Chapter 9: Discussion and Conclusions

In this thesis I have adopted a multimethods research design to address two inter-related questions. How effective is the care provided in Indigenous primary health care services and what is needed to build better primary care systems for Indigenous peoples? At the commencement of this body of work, I expected to identify barriers and enablers in the health system that impacted on Indigenous peoples' health care. Based on my inductive stream of work, mainly derived from Part B of the thesis, I have learnt that a 'many barriers/enablers' approach is not helpful in bringing about health system improvements. Their mere identification fails to recognise the interactive and multiplicative manner in which they operate. Overcoming barriers and enhancing enablers is thus, rarely, a straightforward process. If interventions are too narrowly focussed at the individual level or on organisational diffusion they are unlikely to make much of an impact. This has important implications for my deductive stream of work (Part A) in which I identify widespread system under-performance and explore electronic tools as a strategy to address this. Such strategies, however promising, can be undermined by complex socio-political factors when translated into practice. The central challenge, therefore, is to develop and implement complementary interventions in such a manner that they are responsive to complex environments. I have sought to elaborate a nuanced understanding of some of the contextual factors that contribute to this complexity in the field of Indigenous health. These factors are operating at the levels of the macro health system, health services and health care encounters.

9.1 Macro health systems

Gauging effectiveness of care and system performance requires robust monitoring. In Chapter Two, I address the first question in my deductive stream of the thesis: How adequately do health systems monitor the effectiveness of primary health care for Indigenous peoples? I used a case study of vascular and maternal/newborn health monitoring by Aboriginal status in the New South Wales (NSW) health system to illustrate deficiencies in both the breadth and depth of indicators that are currently reported. A particular limitation was the lack of reporting on primary care performance for vascular health indicators. Whilst my analysis focussed on only two aspects of health systems
monitoring in one Australian state jurisdiction, other literature (discussed in Chapter 2) suggests that these issues are pertinent to other health systems both in Australia and elsewhere. Whilst these issues remain, macro level monitoring of health system performance, at least in the area of vascular health care, is limited in informing progress on effectiveness of care for Indigenous peoples. I made a number of recommendations on strategies to improve system monitoring. These include the need for population-representative data from the primary health care sector; greater coordination between hospitals and primary care; improved health survey sampling with the incorporation of physical and laboratory measures; and sustained efforts to address under-enumeration of Indigenous status.

In Chapter 6, I build on this analysis of health systems in a different way by qualitatively reviewing the issues that influence access to health care for Indigenous peoples in Australia, New Zealand, Canada and the USA. For this review I took a broad definition of health care ‘access’ which incorporates many dimensions beyond service utilisation including acceptability and affordability, relevance, effectiveness and equity. I drew my analysis from a diverse body of empirical and grey literature sources over the last twenty years to assess this. At the core of my enquiry was a critical examination of the construct of candidacy to health care. Whilst candidacy theory was able to be applied well at the level of health care services and encounters between providers and patients, there were limitations to its utility at the macro systems level. Through the synthesis of these literature sources I identified that systems of care for Indigenous peoples evolve from a dialectical relationship between a non-Indigenous State that adjudicates through its institutions how care is offered and a predominantly Indigenous counter-movement that seeks to maximise participation in shaping those institutions. I termed this a ‘societal candidacy’ in which eligibility for care is negotiated in socio-political arenas beyond the health care space. These negotiations are historically informed and have currency in broader political movements, particularly assimilation and self-determination. These societal level factors fundamentally shape the way in which health systems have evolved in the four countries. Further, they are not merely remnants of the colonial encounter. The Kanyini Qualitative Study analysis in Chapter 7 identified that both Aboriginal and non-Aboriginal staff, working in community governed Aboriginal Medical Services (AMSs), feel the very
existence of these services to be under threat because of changing policy directions of the State.

I concluded, therefore that strategies designed to enhance candidacy at this societal level can heavily influence how health institutions are shaped and the type of care that is negotiated between them and the community. These strategies are necessarily complex. Establishing legally binding treaties and implementing rights-based frameworks require paradigmatic shifts in government policy and therefore can remain elusive. However, where such frameworks already exist, their principles could be more firmly embedded into health systems structures. Although the challenges are clearly greater if there is resistance to addressing these societal factors, the health system can still be proactive in enhancing candidacy. In Chapter 6, I raise the possibility of candidacy organisational audits in which institutions are reviewed against multi-level criteria which are drivers for enhanced candidacy. Similar to Māori advocacy for Treaty of Waitangi audits (see discussion Chapter 6), candidacy audits could provide service wide recognition of particular principles that need to be adhered to in order to enhance accessibility and quality of health care. The methodological approach to developing such audits would need itself to be cognisant of the issues of candidacy and maximise involvement from a range of Indigenous and non-Indigenous stakeholders.

9.2 Health services

In Chapter 3 and Appendices A and B, I address the second question in my deductive stream of research: what is the extent and nature of the gaps between best practice recommendations and actual care provided in both Aboriginal and mainstream primary care services in Australia? In combination, the case record audit in AMSs (Kanyini Audit), and two cross-sectional studies of mainstream primary care for almost exclusively non-Aboriginal patients (the Bettering the Evaluation and Care of Health (BEACH) program and the Australian Hypertension and Absolute Risk Study (AusHEART)) provide one of the most comprehensive pictures to date of primary care performance for the prevention and management of vascular diseases in Australia. In all three studies substantial gaps on a range of clinical indicators related to effectiveness of care were found. In the Kanyini Audit (Chapter 3) and BEACH studies (Appendix A), around one half of routinely
attending adults (aged 30+ years) lacked sufficient information with which to make a comprehensive vascular risk assessment. In all three studies, for those who were identified at high risk of vascular diseases, a large proportion was not receiving guideline recommended treatments. Figure 9-1 shows the prescribing rates of guideline indicated medicines for people with established vascular diseases (aspirin, statins and blood pressure medicines) and those at high risk of those diseases (blood pressure and statins) for all three studies. It highlights that many people are missing out on appropriate prescription of these medicines.

Figure 9-1: Prescribing rates of guideline indicated medicines for people at high risk of cardiovascular diseases – A comparison of three studies

Although the methods for each study were different, this figure demonstrates some encouraging signs that performance in the Kanyini AMS sites is at least comparable and possibly even better than in the mainstream general practices involved in the other two studies. Despite this, there are system wide issues across all settings that need to be addressed to close these and related performance gaps.

I used the inductive stream of work to elaborate on these systems issues for Indigenous peoples’ health care. In Chapter 6, the qualitative literature synthesis identified the utility
of a number of candidacy sub-constructs to better understand health care access and quality. In particular, the constructs of navigation/permeability (e.g. transport, friendly reception staff, welcoming spaces, flexible appointments) and tractability (especially the role of Indigenous staff, resource limitations and commitment to quality improvement activities) were useful ways in which to frame the contextual factors that might affect access and quality at the health service level. In Chapter 7, I used findings from the Kanyini Qualitative Study to explore local systems at AMSs. I continued to apply candidacy theory but also introduced the central Australian concept of kanyini as a companion theoretical framework to understanding how care is delivered in AMS settings. From this study I conclude that the type of care provided in AMSs is different from that in mainstream services. Consistent with the underlying philosophy of kanyini, this different care is characterised by a deep emotional connection to local communities. AMS care providers feel a strong obligation to nurture and protect the communities they service. The Health Systems Assessment findings from Chapter 7 suggest that the principles to maximise this holding are based on good governance, a good workforce and good systems design. Although these principles may be equally pertinent to non-AMS organisations, they manifest uniquely within this broader context of kanyini. Concordant with the findings in the literature review, the presence of Indigenous staff represented at all levels of the organisation was critical to enable the ‘holding’ responsibility of services to be properly fulfilled. Such sociocentric models of care need substantial support and generally staff felt that despite persistent advocacy for such a model, Australian government authorities frequently failed to acknowledge its importance. Many health service organisational features identified in this study were aligned with the Chronic Care Model and in particular were related to leadership, information systems and delivery system design. Noteworthy features include the role of care planning, navigable specialist services and receptive hospital environments. There were ample accounts of where systems became vulnerable if these factors were not simultaneously operating well. Multifaceted and well-resourced interventions that address factors at the levels of health service governance, workforce and delivery design features are therefore needed to enable AMSs to provide better systems of care.
9.3 Health care encounters

Having identified limitations to the effectiveness of vascular health care in both AMSs and mainstream general practices, Chapters 4 and 5 examined the role of point of care electronic tools in improving clinical practice. Although both of these projects were early in their inception, the findings demonstrate that these tools were both acceptable and feasible to use for primary care practitioners in both Indigenous health services and mainstream general practice in Australia and New Zealand. There were also preliminary signs that widespread implementation of such tools could play an important role in enhancing effectiveness of care, but clearly further work is needed to substantiate this claim. A further important application is the capacity for electronic clinical tools to provide good quality primary care data for monitoring performance both within and across health services. As highlighted in Chapter 2, this is essential for monitoring health system responsiveness to reducing inequities in health care and outcomes for Indigenous peoples. The New Zealand CVD risk assessment program at Tamaki Health care provided reliable and easy to obtain data on a large number of patients. These data showed that despite large variations in risk factor prevalence by ethnicity, there was little variation in prescribing of guideline-indicated medicines for different ethnic sub-populations. Information of this nature can be of immense value to health systems planners, regional providers of primary care services and care providers themselves.

In Chapter 5 I explored the role of electronic decision support (EDS) for CVD risk management in Australian primary care. This pilot study demonstrated that general practitioners (GPs) considered the EDS tool acceptable for use in both mainstream general practice and AMS settings. There are, however, key design feature elements that require attention if such tools are to be used as a part of routine care. These findings are now being used to inform subsequent development of a system that is fully integrated with two of the most commonly used primary care software platforms in Australia. A large scale cluster randomised controlled trial with a qualitative process evaluation involving both AMSs and mainstream general practices is planned for mid-2011.

Although systematic review evidence suggests that EDS tools are effective in improving performance, the effect size is highly variable. In addition to specific design features, this
suggests there are contextual factors that influence their uptake and effectiveness. The inductive stream of this thesis has been instructive in appreciating some of these factors. Health care encounter level factors such as communication, patient centred care, adherence to cultural safety principles, and the roles played by Indigenous community workers were identified in both Chapters 6 and 7 as being important influences on the type of care provided.

Specific to electronic tool interventions, Chapter 8 explores the role of factors related to organisational culture and attitudes of health practitioners. I took a sociological perspective to explore these factors by conducting further analyses of interview data from the pilot study described in Chapter 5. In this study I sought to better understand the relationship between electronic tools, their users and the organisational environments in which they are placed. Although less familiar to clinicians and health service researchers, the sociological literature provided useful theoretical insights to interpret the findings. GPs’ personal values and professional standards play a critical role in attitudes to technological tools. Further, there are both internal (e.g. the ability to process patient care efficiently) and external organisational factors (e.g. the role played by professional bodies) that affect the way in which health care decisions are made. Of note, there were few substantive differences in the findings for GPs working in AMSs compared with those working in non-AMSs. I conclude from this work that technological innovation using decision support has potential to make a major impact on how primary health care is delivered. Given the pilot nature of the project and limited exposure that GPs had to the EDS tool, it is too early to determine the extent of this impact. For the proposed cluster trial in 2011, intervention sites (AMS and mainstream general practice) will receive the EDS system for 12 months. A mixed methods evaluation is again planned and the qualitative component will explore the implications for health services and the degree to which the EDS system becomes embedded into organisational culture. By involving AMS and non-AMS sites there will be further opportunities to review the effect of the EDS system in different organisational environments.
9.4 Limitations

There are a number of limitations to each component study in this thesis and these are discussed in each chapter. There are also broader issues to the way this thesis was conducted that are of relevance to the findings. With the exception of Chapters 4 and 6 the bulk of this thesis has focussed on issues of access and effectiveness of care for Australian Aboriginal and Torres Strait Islander peoples. Although Chapters 4 and 6 suggest the findings are of relevance to Indigenous health care in other regions, there is a danger of over-extrapolating findings and ignoring the role played by the specific context of Australian health care systems.

For my deductive stream (Part A) I focussed mainly on measures of effective clinical care for vascular health care. Although many of these measures are strongly associated with improved health outcomes they remain process oriented. Cohort study designs that assessed the associations between clinical process of care and patient outcomes would be needed to address this. Further, by focussing mainly on effectiveness of care the thesis has not quantitatively examined other patient focussed indicators of health care quality, in particular satisfaction, acceptability, timeliness, efficiency, and safety. Although the inductive stream (Part B) offers a number of important insights into these areas, empirical studies specifically targeting the patient experience are needed to explore these other domains of quality in health care. A related limitation in relation to the evaluation of electronic tools was scant understanding of patient perspectives. The degree to which these tools are acceptable, easy to interpret and able to empower patients to make health care decisions was not explored and is a vital area for further enquiry. This is of particular relevance as there is now emerging interest in developing EDS tools to assist with self-management of chronic diseases.

Similarly, from the inductive stream of work, my analysis of how to build better systems of care often came from the perspective of health professionals. The semi-structured interview component of the Kanyini Qualitative Study in which over one hundred community participants were involved will provide critical insights into patient perspectives. It will allow us to triangulate the findings from the Health Systems
Assessment and open up new areas of inquiry. Analysis of these data has commenced and the reporting of findings is expected to commence in late 2010.

9.5 Concluding remarks

Three years ago I commenced this work to make more sense of my own workplace and habits and to explore ways of improving the quality of my work and that provided in Aboriginal Medical Services. Through this thesis I have sought to progress a series of qualitative, quantitative and mixed methods studies to sequentially build a greater understanding of what is needed to build better primary care systems. Whilst the focus of this work was specific to Indigenous health, the findings could be of relevance to other populations that experience difficulties in health care access and quality. Being a multimethods research program, an important requirement is that it produces a body of work that is more than the sum of its parts. By combining an inductive, exploratory component with a deductive, hypothesis-driven component I offer both pragmatic and complex insights to this field of inquiry. As a clinician it has been important for me to incorporate medically oriented elements that may assist with the everyday demands of providing health care. Equally important, however, has been the need to expand my clinical gaze further to include a sociological dimension. By progressively building on these clinical and sociological perspectives I have come to appreciate their complementary roles in contributing to improved primary health care for Indigenous peoples.
Appendix A: Gaps in cardiovascular disease risk management in Australian general practice


Author contribution: Authors Webster, Bayram and Patel designed the study, coordinated ethics submissions and data collection. I verified the statistical analyses on this paper, revised the results and discussion section and assisted with responding to reviewer comments.
Gaps in cardiovascular disease risk management in Australian general practice

Ruth J Webster, Emma L Healey, David P Peiris, Clare Bayram, Alan Cass and Anushka A Patel

ABSTRACT

Objective: To evaluate the management of cardiovascular disease (CVD) risk in Australian general practice.

Design, setting and participants: National cross-sectional survey of 99 Australian general practitioners participating in the Bettering the Evaluation and Care of Health (BEACH) program. Data on 2618 consecutive adult patients presenting to the participating GPs over a 5-week period from September to October 2006 were analysed.

Main outcome measures: Proportions of patients screened, treated and reaching targets according to (1) current Australian CVD risk guidelines and (2) overall or absolute CVD risk.

Results: Blood pressure (BP) had not been recorded for 13% of the sample. Of 1400 patients not prescribed antihypertensive medication, treatment was indicated for 8%. Of 821 patients already prescribed antihypertensive medication, 59% were achieving target BP. Data on low-density lipoprotein (LDL) cholesterol levels were not available for 53% of the 2175 patients who should have had lipid screening according to the guidelines. Of 624 patients not prescribed a statin, treatment was indicated for 41%. Of 368 patients already prescribed a statin, 62% were achieving target LDL cholesterol levels. Sufficient data for calculation of absolute risk had been recorded for 74% of the 1736 patients for whom such calculation was recommended by the guidelines. The remaining 26% either had at least one required variable unmeasured (20%) or missing from the data collection (6%). For those at high absolute CVD risk (without established disease) and those with established CVD, 23% and 53%, respectively, had been prescribed both antihypertensive medication and a statin.

Conclusions: Gaps between guideline recommendations and practice in recording and managing BP were relatively low compared with gaps for lipids. When stratified by absolute risk, patients at high risk of a cardiovascular event were found to be substantially undertreated.

Data for our study were collected as a Supplementary Analysis of Nominated Data (SAND) study of the BEACH program from a random sample of 99 GPs over a 5-week period from September to October 2006. In each study area, the GP, in discussion with the patient and using information from the patients record, records information about aspects of the patient’s health and uses the BEACH outcome data. The full methodology of these studies is described elsewhere.12

In our study, GPs recorded, for a subsample of 30 of the 100 consecutive encounters (if the patient was aged 18 years or over), the presence, measurement and levels of CVD risk factors and relevant medication use (Box 1). All parameters used for calculation of CVD risk, estimation of indications for treatment and target levels for risk factors
1 Questions asked of general practitioners

Which best describes the patient's smoking status? 

- Current smoker
- Quit < 12 months ago
- Quit ≥ 12 months ago
- Never smoked

- Does the patient have...?

- (yes/no) don't know
- Coronary heart disease
- Cerebrovascular disease
- Peripheral vascular disease
- Overweight/obesity

- Family history of heart disease
- Protonuria
- Diabetes

- Is the patient currently taking...?

- (yes/no) don't know
- Statin
- Angiotensin-converting enzyme
- Other antihypertensive agent
- ACE inhibitor
- Blood pressure, HDL cholesterol, triglycerides

- What was the patient's most recent BP reading?

- Systolic/BP, diastolic BP

- What was the patient's most recent test for total cholesterol/HDL cholesterol/triglycerides?

- < 4.1 mmol/L, don't know

- The patient's most recent test for each of total cholesterol/HDL cholesterol/triglycerides were

- < 12 months ago
- ≥ 12 months ago

- ACE = angiotensin-converting enzyme, BP = blood pressure, HDL = high-density lipoprotein.

were taken from Australian guidelines current at the time of data collection.7,14,15

Estimation of cardiovascular disease risk

Because CVD risk assessment tools are validated only for people aged 30 years and over, patients under 30 years were excluded from the calculation of risk. For eligible patients for whom there were sufficient data, the estimated 5-year risk of a cardiovascular event was calculated using the Framingham equation.4 As data on left ventricular hypertrophy were not collected, this was assumed to be absent in all patients.

National Heart Foundation of Australia (NHF) guidelines were followed in applying adjustments to the Framingham equation.4 For patients with diabetes and for patients aged ≥ 75 years and over, the estimated 5-year risk was adjusted to a minimum of 15%. The estimated risk was increased by 5% in the presence of a family history of coronary heart disease, identification as Aboriginal or Torres Strait Islander, systolic blood pressure (BP) > 170 mmHg, diastolic BP > 100 mmHg, or total cholesterol level > 8 mmol/L. This 5% increment was applied only once for any individual patient. Patients with established coronary heart disease, cerebrovascular disease or peripheral vascular disease were categorised in a separate high-risk group — those with "established CVD".

Patients for whom the GP had indicated "don't know" for at least one risk factor required for calculation of absolute risk were put in the category of "data not measured/known". A further category "data missing", encompassed patients about whom at least one risk factor required for calculating absolute risk had not been provided by the GP and "don't know" had not been selected.

Patients whose data were "missing" or for whom the GP had indicated "don't know" for variables indicating clinical conditions (eg, protonuria, diabetes) were assumed not to have the clinical condition.

Determination of indicators for measuring blood pressure, lipid levels and absolute risk

NHF guidelines recommend BP measurement for all people aged 18 years and over. Thus, all patients in our study should have had their BP measured.7

For lipid screening, NHF guidelines recommend measurement for people who have established CVD, BP > 140/90 mmHg, diabetes, chronic renal failure, proteinuria or a family history of coronary heart disease; or who are current smokers, obese, of Aboriginal or Torres Strait Islander descent, or aged ≥ 45 years.8,9

For absolute risk screening, various guidelines recommend measurement for people who are of Aboriginal or Torres Strait Islander descent or aged ≥ 50 years, or who have established CVD, BP > 140/90 mmHg, low-density lipoprotein (LDL) cholesterol level > 2.5 mmol/L, triglyceride level > 2 mmol/L, diabetes or estimated glomerular filtration rate < 60 mL/min/1.73m².7,16,17 Because of space limitations on the BEACH form, we could not ask GPs to indicate whether they had actually calculated absolute risk.

Determination of indications for pharmacological treatment

For patients currently not prescribed statins or antihypertensive medication, indications for treatment were determined for those for whom data were available.7,14-17 In addition, for these patients, we determined whether the 2004 Pharmaceutical Benefits Scheme (PBS) criteria (which were current for the period of data collection) for subsidised prescription of statin therapy were met.

Ascertainment of target levels for patients already prescribed medication

For patients already taking a statin or antihypertensive medication, we assessed the attainment of NHF-recommended BP and lipid (LDL cholesterol < 2.5 mmol/L) targets.8

Statistical analyses

Data are presented as means (SDs) or proportions, as appropriate. The difference in mean age between participating GPs and all Australian GPs was assessed using a paired t test. χ² tests were used to compare the age and sex distribution of GPs in our study with the 17,628 Australian GPs (defined as vocational registrars and GPs and GP registrars) who claimed at least 375 general practice items of service in the comparable 3-month Medicare data period. Statistical analyses were carried out using SAS software, version 9.1 (SAS Institute, Cary, NC, USA).

Ethics approval

Ethics approval was obtained from the Ethics Committee of the Australian Institute of Health and Welfare.

RESULTS

Ninety-nine GPs' provided data for 2618 patients aged 18 years and over. GPs agreeing to participate in the BEACH program have previously been shown to be generally representative of the current GP workforce, apart from having a higher mean age.10 Our sample had fewer GPs aged under 45 years than the broader GP workforce (13.3% v 34%; χ² = 20.5; P < 0.001),10 but was representative with regard to the proportion of male GPs (59% v 65%, respectively; F = 0.61).
### Health Care

#### 2 Patient characteristics*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Men (n = 1034)</th>
<th>Woman (n = 1571)</th>
<th>Total (n = 2618)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (SD)</td>
<td>54.7 (18.7)</td>
<td>52.5 (20.2)</td>
<td>53.3 (19.6)</td>
</tr>
<tr>
<td>Location of practice*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>720 (70%)</td>
<td>1094 (70%)</td>
<td>1820 (70%)</td>
</tr>
<tr>
<td>Rural or remote</td>
<td>295 (29%)</td>
<td>448 (29%)</td>
<td>743 (28%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>19 (2%)</td>
<td>29 (2%)</td>
<td>55 (2%)</td>
</tr>
<tr>
<td>Reported diabetes</td>
<td>125 (12%)</td>
<td>127 (8%)</td>
<td>253 (10%)</td>
</tr>
<tr>
<td>Current smoker</td>
<td>1254 (25%)</td>
<td>280 (18%)</td>
<td>537 (21%)</td>
</tr>
<tr>
<td>Risk of CVD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Established CVD</td>
<td>225 (22%)</td>
<td>203 (13%)</td>
<td>428 (16%)</td>
</tr>
<tr>
<td>High risk (&gt; 15%) (excluding patients with established CVD)</td>
<td>150 (15%)</td>
<td>229 (15%)</td>
<td>380 (15%)</td>
</tr>
<tr>
<td>Moderate risk (10%–15%)</td>
<td>49 (5%)</td>
<td>25 (2%)</td>
<td>74 (3%)</td>
</tr>
<tr>
<td>Low risk (&lt;10%)</td>
<td>138 (13%)</td>
<td>327 (21%)</td>
<td>465 (18%)</td>
</tr>
<tr>
<td>Unable to estimate risk:</td>
<td>472 (44%)</td>
<td>787 (50%)</td>
<td>1271 (47%)</td>
</tr>
<tr>
<td>At least one variable not measured by/unknown to GP</td>
<td>304 (29%)</td>
<td>280 (18%)</td>
<td>577 (21%)</td>
</tr>
<tr>
<td>At least one variable missing in data collection</td>
<td>472 (46%)</td>
<td>787 (50%)</td>
<td>1259 (48%)</td>
</tr>
<tr>
<td>Age &lt; 30 years</td>
<td>123 (12%)</td>
<td>265 (19%)</td>
<td>388 (14%)</td>
</tr>
<tr>
<td>Medication use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statin</td>
<td>247 (24%)</td>
<td>264 (17%)</td>
<td>511 (20%)</td>
</tr>
<tr>
<td>Antiplatelet therapy</td>
<td>225 (22%)</td>
<td>222 (14%)</td>
<td>449 (17%)</td>
</tr>
<tr>
<td>Antihypertensive therapy</td>
<td>385 (37%)</td>
<td>460 (29%)</td>
<td>849 (32%)</td>
</tr>
</tbody>
</table>

CVD = cardiovascular disease. GP = general practitioner. *Figures are number (% of patients, except where otherwise specified. † Data on sex were missing for 13 patients. ▲ Data on sex were missing for six patients in metropolitan areas and seven patients in "unknown" areas. ▷ Percentages may not add up to 100% due to rounding. § Current smoker or quit within past 12 months.

#### 3 Distribution of patients with data on antihypertensive therapy (AHT), and management gap*

<table>
<thead>
<tr>
<th>BP information recorded</th>
<th>n = 2282 (87%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BP information not measured</td>
<td>n = 282 (11%)</td>
</tr>
<tr>
<td>Missing n = 54 (2%)</td>
<td></td>
</tr>
<tr>
<td>Total sample n = 2618</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>AHT information missing</th>
<th>n = 61 (5%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not prescribed AHT n = 1400 (61%)</td>
<td></td>
</tr>
<tr>
<td>Treatment not indicated n = 1288 (92%)</td>
<td></td>
</tr>
<tr>
<td>Treatment indicated n = 112 (8%)</td>
<td></td>
</tr>
<tr>
<td>Prescribed AHT n = 921 (36%)</td>
<td></td>
</tr>
<tr>
<td>Not attaining target BP n = 329 (41%)</td>
<td></td>
</tr>
<tr>
<td>Achieving target BP n = 486 (50%)</td>
<td></td>
</tr>
</tbody>
</table>

BP = blood pressure. * Treatment indication was determined according to National Heart Foundation of Australia guidelines for the management of hypertension. Target BP levels are defined as ≤125/75 mmHg for patients with diabetes and proteinuria; ≤130/80 mmHg for patients with diabetes without proteinuria; and ≤140/90 mmHg for all other patients.  

#### Missing data

Proportions of missing data for each variable were small (1%-6%).

#### Patient characteristics

Patient characteristics are shown in Box 2. The sex distribution and location (rural/metropolitan) of respondents were similar to the distributions for all BEACH encounters.

#### Blood pressure management

Gaps relating to antihypertensive treatment are shown in Box 3. Of patients not being treated, 112 (8%) qualified for treatment according to the 2004 NHF hypertension management guidelines. When the data were re-analysed using the recommendations of the updated 2008 NHF hypertension guidelines, this figure rose to 482 (34%).

#### Lipid management

Of the 2618 patients, 2175 (83%) should, according to NHF guidelines, have had their lipid levels measured. Gaps in lipid management are summarised in Box 4. A total cholesterol value had been recorded for 1444 patients (66%). Sufficient information to determine all lipid fractions (high-density lipoprotein cholesterol, LDL cholesterol and triglycerides) was available for 1029 patients (47%). The number of participants with LDL information was used as the basis for...
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4 Distribution of patients with data on statin treatment, and management gap*

- LDL = low-density lipoprotein.
- *Treatment indication was determined according to National Heart Foundation of Australia/Cardiac Society of Australia and New Zealand guidelines on lipid management. Target LDL cholesterol level is defined as <2.5 mmol/L.

<table>
<thead>
<tr>
<th>Risk category</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Established CVD</td>
<td>426 (25%)</td>
</tr>
<tr>
<td>High risk (excluding patients with established CVD)</td>
<td>373 (22%)</td>
</tr>
<tr>
<td>Medium risk</td>
<td>74 (4%)</td>
</tr>
<tr>
<td>Low risk</td>
<td>416 (24%)</td>
</tr>
<tr>
<td>Unable to estimate risk</td>
<td>348 (20%)</td>
</tr>
<tr>
<td>Diabetes status</td>
<td>31 (2%)</td>
</tr>
<tr>
<td>Smoking status</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Sex</td>
<td>0</td>
</tr>
<tr>
<td>Blood pressure</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Unable to estimate risk (at least one variable missing)</td>
<td>99 (5%)</td>
</tr>
</tbody>
</table>

5 Distribution of risk and missing data in patients who should have had absolute risk of CVD measured* (n = 1736)

<table>
<thead>
<tr>
<th>Risk category</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Established CVD</td>
<td>426 (25%)</td>
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<td>Diabetes status</td>
<td>31 (2%)</td>
</tr>
<tr>
<td>Smoking status</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Sex</td>
<td>0</td>
</tr>
<tr>
<td>Blood pressure</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Unable to estimate risk (at least one variable missing)</td>
<td>99 (5%)</td>
</tr>
</tbody>
</table>

The flowchart in Box 4, as this is the key variable in determining NHF treatment recommendations. Of the 624 patients not prescribed a statin, 254 (41%) qualified for treatment under NHF criteria. Applying the then-current PBS criteria, 64 (25%) of these 254 would have been eligible for cost-subsidised statin treatments. Applying the current PBS criteria would increase those eligible to 139 (55%).

Absolute risk
According to the guidelines, absolute risk should have been calculated for 1736 patients (56% of the sample), all of whom were aged 30 years or over. Sufficient information was available to calculate this risk in 1282 patients (74%); the necessary data were not measured/unknown for 348 patients (20%); and data were missing for the remaining 99 patients (6%). The distribution of risk for the 1736 patients for whom absolute risk should have been calculated is shown in Box 5. More than a fifth of these patients (22%) were at high risk for CVD.

Treatment stratified by risk category
The proportions of patients in each risk category who were prescribed various cardiovascular medications are summarised in Box 6. Sixty-five per cent of high-risk participants were prescribed at least one medication (a statin, antihypertensive agent or antplatelet drug). Fifty-three per cent of patients with established CVD and 23% of those at high risk of CVD (without established CVD) were prescribed a combination of an antihypertensive medication and a statin.

DISCUSSION
Our survey reveals significant gaps in CVD risk screening and management in Australian general practice. This has been documented previously for people with established disease. We assessed management gaps in the context of the relatively new clinical paradigm of prevention of CVD according to absolute risk. It was not our

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Among patients for whom absolute risk of CVD should have been estimated, the proportions of patients receiving antihypertensive therapy (AHT), a statin or antiplatelet therapy (APT), by CVD risk category.

- Established CVD
- High risk
- Medium risk
- Low risk

CVD = cardiovascular disease. * According to the guidelines. † Number of patients in each risk category: established CVD (628), high risk (213), medium risk (24), low risk (416). Any treatment refers to at least one of a statin or antihypertensive or antiplatelet medication.

aim to assess the appropriateness of guideline recommendations for the calculation or adjustment of absolute risk. These issues require debate in other forums. Instead, we sought to quantify guideline adherence and the extent of absolute-risk-based prescribing.

In terms of individual risk factor guidelines, BP was managed reasonably well according to the guidelines current at the time. However, 71% of patients eligible for lipid screening were either not recognised as needing to be screened, or were not prescribed appropriate medicines or, once prescribed, were not attaining recommended targets.

When patients were stratified by absolute risk, the management gaps were more striking. Fewer than half of those with established CVD — arguably those at highest risk — were being prescribed the universally recommended combination of antihypertensive, statin and antiplatelet medications. 5,12,21 For those at high risk who had not yet experienced a cardiovascular event, about a third were taking no medications to modify their risk, and fewer than a quarter were prescribed the combination of antihypertensive and statin medications.

We uncovered several factors that may explain these low prescribing rates. First, relevant data were available for fewer than half (47%) of the patients for whom lipid screening was indicated. Having appropriate data is an essential first step in assessing and managing risk. For 20% of patients for whom absolute risk should have been calculated, GPs lacked the data to do so, primarily because lipid levels had not been measured.

Second, treatment generally appears to be based on levels of individual risk factors rather than on absolute risk. This is supported by the guidelines' focus on risk factor levels as targets rather than on treatment to lower absolute risk. Although in our study we were unable to directly assess how frequently GPs performed absolute risk assessment, other studies have shown that most GPs do not routinely calculate absolute risk. 23,24

Third, under the guidelines current at the time of our study, statins and antihypertensive medications would not have been recommended for some high-risk individuals. It has been shown that guideline recommendations do not always accurately target those at highest risk of CVD. 25-28 Our data support this contention. The move in the 2008 NHF hypertension management guidelines towards risk-based prescribing recommendations (with antihypertensive treatment recommended for all high-risk patients) is a promising initiative. However, the differing approaches between the NHF hypertension and lipid guidelines (including slightly different definitions of patients at high risk, and recommendations for prescribing lipid-modifying therapy in certain high-risk groups being based primarily on LDL cholesterol levels rather than level of CVD risk) could lead to confusion or failure to follow the recommendations.

Fourth, GPs are restricted by PBS prescribing criteria. We found marked differences in recommendations between the NHF lipid guidelines and the 2006 PBS criteria for prescribing statins, although the latest PBS criteria are an improvement.

Our study did not assess non-pharmacological measures of control. Furthermore, we only collected single measurements of BP and lipid levels. In general practice, before prescribing medications, a trial of lifestyle modification and monitoring of risk factors over time is commonly undertaken. In this context, these aspects of study design might have led to an overestimation of management gaps. However, in relation to patients at highest risk, who require pharmacological therapy, this is unlikely to significantly affect our findings.

In addition to non-pharmacological approaches, the use of statins and antihypertensive and antiplatelet medications is the established evidence-based strategy for reducing CVD risk. Clinical practice guidelines help clinicians discern "best-practice medicine". Having multiple, sometimes conflicting, single-risk-factor guidelines confuses time-poor GPs, who are expected to apply different guidelines concurrently. The separate updating of each guideline makes additional demands on GPs' time. Furthermore, CVD risk management, although important, is only one aspect of a GP's workload and can often be provided only opportunistically during consultations, usually about other problems.

The substantial undertreatment of high-risk patients demonstrated in our study suggests that synthesis of current multiple risk factor management guidelines into a single CVD risk management guideline is urgently required. Essential components of such a guideline would be the endorsement of absolute-risk-based screening and the integration of risk assessment with multifactorial recommendations on management. Such a guideline should comply with National Health and Medical Research Council (NHMRC) recommendations and be endorsed nationally by all relevant peak
REFERENCES

Appendix B: Cardiovascular risk perception and the evidence-practice gap in Australian general practice (the AusHEART study)


Author contribution: Emma Heeley was the primary author responsible for all aspects of this study. I assisted in the design of the study and was the principal General Practitioner on the study advisory committee. I revised the results and discussion section and assisted with responding to reviewer comments. All co-authors contributed to manuscript drafts.
Cardiovascular risk perception and evidence–practice gaps in Australian general practice (the AusHEART study)

Emma L Heeley, David P Peiris, Anushka A Patel, Alan Cass, Andrew Weekes, Claire Morgan, Craig S Anderson and John P Chalmers

Cardiovascular disease (CVD) is the leading cause of death and disability worldwide.1 In 2005, CVD was responsible for 35% of deaths in Australia and an estimated 1.4 million Australians (6.9% of the population) were living with a CVD-related disability.2 Ninety percent of Australian adults have at least one modifiable CVD risk factor and 25% have three or more modifiable risk factors.3 Because around 85% of Australians visit a general practitioner every year,4 primary care is the ideal setting for CVD prevention. The federal government has targeted CVD as a priority area in its proposed National Primary Health Care Strategy5 and has set specific performance benchmarks for the management of CVD risk and for the prevention of CVD.6 As vascular health checks in primary care have been shown to be highly cost-effective, improving the performance of these checks could reduce the rising costs of acute hospital care.7,8

Despite evidence that CVD management and prevention should be based on an individual's overall or absolute risk, there has been little analysis on how extensively this evidence is being implemented in primary health care. One qualitative study demonstrated that GPs do not routinely perform absolute CVD risk assessments.9 Barriers identified include lack of understanding of the difference between absolute and relative risk, poor understanding of how to use CVD risk tools in clinical management, and lack of incorporation of risk tools into practice software. Several recently published studies have revealed substantial gaps in CVD risk management.10-13 Potential barriers that have been identified include guidelines for single diseases and conflicts with the criteria for prescribing subsidised medications within the Pharmaceutical Benefits Scheme (PBS).

New guidelines for the assessment of absolute CVD risk were published by the National Vascular Disease Prevention Alliance (NVDPA) in March 2009.14 In this study, we sought to describe the distribution of CVD risk according to various guidelines, to ascertain GPs' perceptions of their patients' CVD risks and to determine the proportion of patients whose CVD risk is being managed according to current Australian evidence-based guidelines.

METHODS
The Australian Hypertension and Absolute Risk Study (AusHEART) was a nationally representative, cluster-stratified, cross-sectional survey of 322 general practitioners. Each GP was asked to collect data on CVD risk factors and their management in 15-20 consecutive patients aged ≥55 years who presented between April and June 2008, and to estimate each patient's absolute risk of a cardiovascular event in the next 5 years.

Main outcome measures: Estimated 5-year risk of a cardiovascular event, proportion of patients receiving appropriate treatment.

Results: Among 5293 patients, 29% (1548) had established CVD. A further 22% (1149), when categorised according to the 2009 National Vascular Disease Prevention Alliance guideline, to 42% (2211), when categorised according to National Heart Foundation (NHF) 2004 guideline, had a high (>15%) 5-year risk of a cardiovascular event. Of the 1548 patients with established CVD, 50% were prescribed a combination of a blood pressure (BP)-lowering medication, a statin and an antiplatelet agent, and 9% were prescribed a BP-lowering medication and a statin but not an antiplatelet agent. Among high-risk patients without established CVD, categorised using NHF 2004 adjustments, 34% were prescribed a combination of a BP-lowering medication and a statin. GPs estimated 60% of patients with established CVD as having a risk of less than 15%. The GPs' estimates of risk among patients without established CVD agreed with the centrally calculated estimate (according to the NHF 2004 guideline) in 48% of instances (κ = 0.21).

Conclusions: These data confirm substantial undertreatment of patients who are at high risk of a cardiovascular event. We recommend that GPs assess absolute risk for older patients and ensure that high-risk patients receive evidence-based pharmacotherapy.
For each patient who was recruited, GPs completed a one-page questionnaire on CVD risk factors and currently prescribed medications. Included in this was a request to repeat tests for fasting blood lipids, fasting blood glucose and estimated glomerular filtration rate, if these had not been performed within the guideline-recommended time frame. Urinary dipsticks were supplied to assess albumin to creatinine ratio (ACR).

Ninety percent of participating GPs were already using electronic blood pressure (BP) monitors or were provided with one, for use in this study, through the High Blood Pressure Research Council of Australia Better Blood Pressure Measurement Initiative. GPs also provided their estimate of each patient’s absolute risk of having a cardiovascular event within the next 5 years. This was requested without specifying how the GP should come to this determination. Data were collected prospectively between April and June 2008. GPs were contacted to resolve illegible or missing information on the questionnaires. In cases where missing or unknown values were not resolved, we assumed, when calculating CVD risk, that the patient did not have the risk factor.

Estimation of absolute CVD risk
Following data collection, estimation of absolute 5-year risk of a cardiovascular event was calculated centrally (by one of us (E.L.H.), using available data) for each patient without established CVD, using the 1991 Framingham risk equations. This is based on age, sex, smoking status, BP, total and high-density lipoprotein cholesterol levels, diabetes and left ventricular hypertrophy to predict a first CVD event.

Adjustments to the Framingham risk calculation were made according to three guidelines — the National Heart Foundation (NHF) Hypertension management guide for doctors 2004 (the prevailing guideline at the time of data collection), the NHF Guide to management of hypertension 2008, and the NVDPA Guidelines for the assessment of absolute cardiovascular disease risk (published in 2009). The adjustment criteria are summarised in Box 1. The NVDPA 2009 guideline also states that the Framingham method is likely to underestimate absolute risk in certain patients (Aboriginal and Torres Strait Islander patients, patients with diabetes who are younger than 60 years and do not have microalbuminuria, overweight or obese patients, and patients aged 75 years or older), for whom clinical judgement is required. However, we did not make any further automatic adjustments to the Framingham method of calculating risk in response to the NVDPA suggestion of groups in whom risk might be underestimated.

Unadjusted and adjusted 5-year risks of a cardiovascular event were then classified into low (<10%), moderate (10% to <15%) and high (≥15%) categories, as specified in the NHF 2004, NHF 2008 and NVDPA 2009 guidelines. Patients with established CVD (defined as previous myocardial infarction, stroke, peripheral arterial disease, revascularisation, transient ischaemic attack or angina) were classified into a separate category.

Statistical analyses
Differences between data on participating GPs and data on the GP workforce were tested using the χ² test. Sex differences were tested using the χ² test for categorical variables and the independent t test for differences between means. Agreement between GP estimates of risk and centrally calculated estimates of risk was evaluated using κ statistics. Data entry and manipulations were carried out using SAS version 9.1 (SAS Institute, Cary, NC, USA). Statistical analyses were conducted using STATA version 9.2 (Stata Corporation, College Station, Tex, USA).

Ethics approval
The study was approved by the Royal Australian College of General Practitioners (RACGP) National Research and Evaluation Ethics Committee. All patients gave written informed consent to participate in the study.

RESULTS
NP characteristics and completion of questionnaires
A total of 1416 GPs expressed interest in participating in the AusHEART study, of whom 534 were selected to participate. Of those selected, 322 GPs (60%), provided data for an average of 16 patients each; the remaining 212 did not contribute data or withdrew before contributing data. Characteristics of the actively participating GPs, compared with non-participating GPs and the Australian GP workforce, are shown in Box 2. When compared with the Australian GP workforce, the actively participating GPs were more likely to be older and located in a rural area.

At the time of data lock on 28 November 2008, less than 5% of data were missing for most variables on questionnaires completed by GPs. Variables with greater than 5% missing data (ie, data field not completed or indicated as “unknown”) were: first degree relative with CVD at <60 years (9%), left ventricular hypertrophy (6%), hypertensive retinopathy (7%), ultrasound or radiological evidence of atherosclerotic plaque (13%) and estimate of cardiovascular risk in the next 5 years (11%).
Patient characteristics and risk distribution

Data were obtained from 5293 patients whose sex was recorded and who were aged 55 or older, of whom 3462 (65%) consented to participate in the longitudinal follow-up component of the study. Their demographic and CVD risk factor details are summarised in Box 3. Box 4 shows the distribution of risk categories using Framingham-based risk estimates alone, as well as the distribution using adjustments from the three different Australian guidelines. Using the NHF 2004, NHF 2008 and NVDPA 2009 guideline adjustments, 2211 (42%), 2465 (47%) and 3145 (22%) patients, respectively, were classified as high risk. The NVDPA guideline did, however, state that risk might be underestimated in 793 of the 2026 low-risk patients (39%) and 241 of the 458 moderate-risk patients (53%). If these patients were all categorised as high risk, this would result in a similar risk distribution to that resulting from NHF 2004 adjustments.

### 2 Characteristics of general practitioners in the AusHEART study compared with the Australian GP workforce

<table>
<thead>
<tr>
<th>Category</th>
<th>Australian GP workforce (n=24,903)</th>
<th>Total (n=14,116)</th>
<th>Non-participating GPs (n=212)</th>
<th>Participating GPs (n=322)</th>
<th>χ²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.59</td>
</tr>
<tr>
<td>Age (years)†</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>&lt;35</td>
<td>2370 (10%)</td>
<td></td>
<td>57 (4%)</td>
<td>11 (5%)</td>
<td>9 (3%)</td>
</tr>
<tr>
<td>35-44</td>
<td>6080 (24%)</td>
<td></td>
<td>232 (18%)</td>
<td>39 (18%)</td>
<td>57 (18%)</td>
</tr>
<tr>
<td>45-54</td>
<td>8076 (32%)</td>
<td></td>
<td>506 (39%)</td>
<td>72 (34%)</td>
<td>138 (43%)</td>
</tr>
<tr>
<td>≥55</td>
<td>8377 (34%)</td>
<td></td>
<td>574 (41%)</td>
<td>88 (42%)</td>
<td>112 (35%)</td>
</tr>
<tr>
<td>State</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.66</td>
</tr>
<tr>
<td>Australian Capital Territory</td>
<td>383 (2%)</td>
<td></td>
<td>28 (2%)</td>
<td>2 (1%)</td>
<td>7 (2%)</td>
</tr>
<tr>
<td>New South Wales</td>
<td>7948 (32%)</td>
<td></td>
<td>528 (37%)</td>
<td>67 (32%)</td>
<td>113 (35%)</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>345 (1%)</td>
<td></td>
<td>8 (0.6%)</td>
<td>3 (1%)</td>
<td>2 (0.6%)</td>
</tr>
<tr>
<td>Queensland</td>
<td>5051 (20%)</td>
<td></td>
<td>271 (19%)</td>
<td>41 (19%)</td>
<td>61 (19%)</td>
</tr>
<tr>
<td>South Australia</td>
<td>2100 (8%)</td>
<td></td>
<td>100 (7%)</td>
<td>20 (9%)</td>
<td>21 (7%)</td>
</tr>
<tr>
<td>Tasmania</td>
<td>660 (3%)</td>
<td></td>
<td>31 (2%)</td>
<td>5 (2%)</td>
<td>8 (2%)</td>
</tr>
<tr>
<td>Victoria</td>
<td>6057 (24%)</td>
<td></td>
<td>311 (22%)</td>
<td>51 (24%)</td>
<td>81 (25%)</td>
</tr>
<tr>
<td>Western Australia</td>
<td>2359 (9%)</td>
<td></td>
<td>139 (10%)</td>
<td>23 (11%)</td>
<td>29 (9%)</td>
</tr>
<tr>
<td>Practice in rural area</td>
<td>7097 (29%)</td>
<td></td>
<td>335 (24%)</td>
<td>68 (32%)</td>
<td>115 (36%)</td>
</tr>
<tr>
<td>Practice uses computerised records</td>
<td>na</td>
<td></td>
<td>1138 (80%)</td>
<td>185 (87%)</td>
<td>260 (81%)</td>
</tr>
<tr>
<td>Cardiovascular risk calculators used§</td>
<td>na</td>
<td></td>
<td>885 (63%)</td>
<td>137 (65%)</td>
<td>209 (65%)</td>
</tr>
<tr>
<td>Paper risk charts</td>
<td>na</td>
<td></td>
<td>554 (39%)</td>
<td>135 (42%)</td>
<td>83 (39%)</td>
</tr>
<tr>
<td>Online or downloaded calculators</td>
<td>na</td>
<td></td>
<td>73 (5%)</td>
<td>22 (7%)</td>
<td>10 (5%)</td>
</tr>
<tr>
<td>Calculators within electronic record system</td>
<td>na</td>
<td></td>
<td>420 (30%)</td>
<td>96 (30%)</td>
<td>68 (32%)</td>
</tr>
</tbody>
</table>

* Number of GPs for 2007-08 financial year, and data from the Australian Government Department of Health and Ageing. † P values represent χ² test comparing actively participating GPs with Australian GP workforce. ‡ P values for age and state data represent tests for differences in distribution in age and state categories, respectively. § Some GPs did not declare their age. Appendix 8 - 4 includes practices in remote areas. ¶ Some GPs used more than one calculator; na = not available.

**GP perception of risk**

Of 1548 patients with established CVD, GPs provided an estimated 5-year risk of a cardiovascular event for 1345 patients (87%). For this group, the mean 5-year risk was estimated to be 17%. However, GPs categorised 805 patients with established CVD (60%) as having a 5-year risk of less than 15%.

For the 3745 patients without established CVD, GPs estimated the 5-year risk of a cardiovascular event for 3364 (90%) of patients. Comparison of GP estimates of risk category with centrally calculated estimates showed 48% agreement with estimates calculated using the NHF 2004 guideline (κ = 0.21), 47% agreement with estimates calculated using the NHF 2008 guideline (κ = 0.20), and 58% agreement with estimates calculated using the NVDPA 2009 guideline (κ = 0.31). GP risk categorisation had the strongest agreement with risk calculated using the unadjusted Framingham risk calculation — 60% agreement (κ = 0.33). By comparison with NHF and NVDPA guideline-based estimation of risk, GPs tended to underestimate their patients' risks.

**Prescribing gaps**

Box 5 shows prescribing patterns for major cardiovascular medication groups stratified by categories of risk estimated using NHF 2004 guideline adjustments. Of the 1548 patients with established CVD, 780 (50%) were prescribed a combination of a BP-lowering medication, a statin and an antiplatelet agent, and 143 (9%) were prescribed a BP-lowering medication and a statin without an antiplatelet agent. Using unadjusted Framingham risk estimates as well as estimates calculated using the NHF 2004, NHF 2008 and NVDPA 2009 guideline adjustments, 39%, 34%, 32% and 42%, respectively, of patients at high risk of a cardiovascular event in the next 5 years (but without established CVD) were prescribed a combination of a BP-lowering medication and a statin (with or without an antiplatelet...
agent). When applying the criteria for PBS subsidy for high-risk patients without established CVD (using NHF 2004 guideline adjustments), treatment would not be recommended to 1537 of 2211 patients (70%) despite being at high risk. An estimated 64% (420 of 674 patients) of high-risk patients eligible for a statin subsidy under the PBS were prescribed a statin.

Of the 1799 patients with and without CVD not prescribed at least one BP-lowering medication, treatment was indicated for 802 (45%), according to the NHF 2004 guidelines. Statin treatment was indicated for 892 (34%) of the 2597 patients not prescribed a statin, according to the 2005 NHF and Cardiac Society of Australia and New Zealand guidelines.41

Achieving target levels of cholesterol and blood pressure

Of the 2364 patients with and without established CVD who were prescribed a statin, 1250 (53%) were not achieving target low-density lipoprotein cholesterol levels (defined as <2.5 mmol/l for all others). Among the 3342 patients with and without established CVD who were prescribed a BP-lowering agent, 1956 (59%) were not achieving target BP levels (defined as <125/75 mmHg for patients with proteinuria, ≤ 130/85 mmHg for those with coronary heart disease, diabetes, stroke, transient ischaemic attack, macroalbuminuria or known chronic kidney disease, or ≤ 140/90 mmHg for all others).

DISCUSSION

The AusHEART study shows that large evidence-practice gaps exist in primary and secondary prevention of CVD for older Australians. Our findings are similar to those of our previous cross-sectional studies involving younger adults in mainstream and indigent health settings,10,13 and are consistent with recent findings by other investigators.11,12 The consistency of outcomes suggests that these gaps are entrenched in primary care.

A clear outcome of this study is that uptake of the paradigm for care based on absolute risk is limited. The infrequent use of absolute risk assessments to guide care was shown in three distinct ways. First, about 60% of participating GPs reported using CVD risk calculators. Second, there was substantial disagreement between patients' risks as perceived by GPs and as derived from Framingham-based algorithms. This discordance was prevalent, regardless of which guideline adjustment method was used, and GPs tended to substantially underestimate their patients' absolute risks. Third, when stratified by absolute risk category, among two-thirds of patients at high risk of a first CVD event were not prescribed a combination of a BP-lowering medication and a statin.

These evidence–practice gaps are not only related to low uptake of absolute risk-based care. Around half of the patients with established CVD, for whom the evidence for benefits of BP-lowering, statin, and anti-platelet therapy are well established, were not prescribed this combination. Given that the risk of a subsequent CVD event is very high in patients with established CVD, there are substantial health gains to be made by specifically targeting improved management in this group of patients alone. With around one-third of the sample having established CVD and up to a further 40% assessed as being at high risk of a first CVD event, as well as evidence of substantial gaps, prevention efforts targeted to patients at highest risk might prove highly cost-effective.

It is possible that this study is not fully representative of the evidence–practice gaps in general practice. Some study factors suggest that the actual gaps might be wider. First, although the sampling method was random, the final group of GPs who participated might represent those more likely to have a specific interest in CVD risk management. Second, the study design prompted the measurement of risk factors if these had not been assessed recently. Such additional measurements might not otherwise have occurred in routine clinical care. Other study factors suggest that the actual gaps might be narrower. First, GPs participating in this study were older than the broader GP workforce and more likely to be practising in a rural area. Second, prescribing pattern assessments were based on a single consultation and therefore did not include new prescriptions provided at subsequent consultations. The planned 5-year follow-up of a large proportion of the cohort will address this limitation and provide data on patients' use of prescribed medications throughout the follow-up period.
### 4 Distribution of CVD risk categories for patients in the AusHEART study (n = 5293), calculated using Framingham risk equations and different guideline adjustments

<table>
<thead>
<tr>
<th>Risk Category</th>
<th>Percentage of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low risk (&lt;10%)</td>
<td>40%</td>
</tr>
<tr>
<td>Moderate risk (10% to &lt;15%)</td>
<td>45%</td>
</tr>
<tr>
<td>High risk (≥15%)</td>
<td>15%</td>
</tr>
</tbody>
</table>

**Risk calculation method**
- CVD = cardiovascular disease
- NHF = National Heart Foundation
- NVOPA = National Vascular Disease Prevention Alliance

### 5 Prescription of major cardiovascular medication groups by CVD risk category, calculated using NHF 2004 guidelines, for patients in the AusHEART study (n = 5293)

<table>
<thead>
<tr>
<th>Medication Class</th>
<th>Low risk (&lt;10%)</th>
<th>Moderate risk (10% to &lt;15%)</th>
<th>High risk (≥15%)</th>
<th>Established CVD</th>
</tr>
</thead>
<tbody>
<tr>
<td>BP-lowering mediation</td>
<td>60%</td>
<td>70%</td>
<td>75%</td>
<td>10%</td>
</tr>
<tr>
<td>Statin</td>
<td>70%</td>
<td>80%</td>
<td>70%</td>
<td>20%</td>
</tr>
<tr>
<td>Antiplatelet agent</td>
<td>50%</td>
<td>60%</td>
<td>60%</td>
<td>20%</td>
</tr>
<tr>
<td>BP-lowering medication + statin</td>
<td>40%</td>
<td>50%</td>
<td>40%</td>
<td>10%</td>
</tr>
<tr>
<td>BP-lowering medication + antiplatelet agent</td>
<td>20%</td>
<td>30%</td>
<td>20%</td>
<td>10%</td>
</tr>
</tbody>
</table>

**Medication classes**
- CVD = cardiovascular disease
- NHF = National Heart Foundation
- BP = blood pressure

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The evidence–practice gaps found in this study are not only the domain of individual clinicians, they also relate to system failure. A stronger effort to rationalise the many guidelines for assessment and management of CVD risk factors is needed. The NHFPA guideline for CVD risk assessment and future plans for an accompanying management guideline are important advances in creating a standardised approach in primary health care. In addition, the NVOPA is aiming to raise awareness about CVD risk assessment in the general population by providing a simple online risk calculator. A departure from the many existing guidelines for individual diseases might also simplify management options. Harmonisation of guidelines with the PBS is a key accompanying step. The development of point-of-care decision support tools might be another way to increase the use of guidelines. Practice nurses and other non-GP care providers could also play a role in supporting CVD risk management. This survey highlighted that most patients aged 55 or older who attend GPs are at high risk of CVD. It also revealed significant evidence–practice gaps and, in light of the availability of known and effective therapies to reduce risk, we should give priority to strategies for improving CVD risk management in primary care. We recommend that GPs assess the absolute CVD risk of their older patients and ensure that high-risk patients receive evidence-based pharmacotherapy.

**ACKNOWLEDGEMENTS**

We thank the 532 GP investigators who participated in the study. Those who submitted data for 15 or more patients were eligible for 40 Category 1 points for RACGP continuing professional development program. Dr Peter Arnold helped draft the manuscript. Data were collected and initially analysed by Statistical Revelations, Melbourne. We also thank Catherine Devlin for help with collating data and Ruth Webster for help with interpreting the guidelines.

The study was supported by an unrestricted educational grant from Servier Australia. David Pairs is supported by a scholarship from the Clinical Excellence Commission. Anushka Patel is a recipient of an NHF Career Development Fellowship.

Craig Anderson is a Principal Research Fellow of the National Health and Medical Research Council (NHMRC). Alan Cass is a recipient of a Senior Research Fellowship from the NHMRC.

**COMPETING INTERESTS**

The AusHEART study was conducted as a collaborative project between the George Institute for International Health and Servier Australia. Emma Healey received a travel grant from Servier to present AusHEART findings at the European Stroke Conference. Anushka Patel has received speaker fees and travel assistance from Servier. Alan Cass has received an honorarium for speaking at a national education meeting sponsored by Servier. Andrew Weekes and Claire Morgan are employed by Servier Australia and collaborated with the George Institute investigators in the study design and review of the submitted article. Craig Anderson has received speaker fees and educational grants from Boehringer Ingelheim, Servier, Pfizer and Genzyme, and travel assistance to attend meetings from Sanofi-Aventis, Boehringer Ingelheim, Mayo Clinic and the Korean Stroke Society. John Chalmers has received research grants from Servier for the Perindopril Protection Against Recurrent Stroke Study (PROGRESS), the Action in Diabetes and Vascular Disease Preterax and Diamicron MR Controlled Evaluation (ADVANCE) and the AusHEART study, and has received lecture fees for speaking at scientific meetings from Servier.

**AUTHOR DETAILS**

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Andrew Cass, MB BS, FRACP, PhD, Director, Renal Division³
Andrew Weekes, BMedSci, BMBS, Head⁴

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Appendix B - 6
REFERENCES


(RECEIVED 9 APR 2009, ACCITED 13 SEP 2009)
Appendix C: Development of a resource for cardiovascular risk assessment for Australian general practitioners


Author contribution: This was a commissioned piece in which Anushka Patel was the primary author responsible for the concept and writing of this paper. I wrote the sections on General Practitioner guidelines and one of the case studies. I commented on all draft revisions of the paper.
Cardiovascular risk assessment

Background

Despite a consistent decline in cardiovascular death rates since the 1970s, cardiovascular diseases remain the leading cause of death and disability in Australia. In 2013 more than 30,000 deaths and 300,000 hospital admissions were attributable to coronary, stroke or vascular disease.

In addition, more than one million Australians were estimated to have a disabling condition as a result of these diseases, with considerable evidence that a disproportionate burden of cardiovascular conditions is experienced by socioeconomically disadvantaged groups within the population.

The direct health costs of cardiovascular diseases in 2009 were $7.6 billion, representing 11% of all recurrent health expenditure. This is projected to rise to $13.5 billion by 2011. Clearly, much of this expenditure is related to encounters in primary healthcare, with cardiovascular disease being the most common problem managed by GPs in 2009/10, representing about 11% of all consultations.

Therefore the prevention of cardiovascular events remains a major national priority and must include a rational approach to identifying and targeting preventive interventions towards individuals at highest cardiovascular risk in the community.

Patients who already have established cardiovascular disease (e.g., previous MI, known angina, previous stroke or TIA, established aortic or peripheral vascular disease) have a substantially increased risk of a future cardiovascular event. For example, asymptomatic survivors of MI who are interested in current preventive therapies have an annual risk of death of at least 3%, and this excess risk persists and is cumulative over many years. These patients constitute about 10% of the population but contribute about 40% of cardiovascular deaths in the community.

Clearly those are very high-risk patients who should be prioritised and treated most aggressively with preventive therapies. Such individuals are mostly identified through their clinical histories. For patients who complain of symptoms suggestive of manifest cardiovascular disease (e.g., chest discomfort, breathlessness, etc.) or have new relevant signs (e.g., carotid bruit), investigations to determine whether acute treatment is necessary should be the priority.

This review therefore focuses on identifying and estimating cardiovascular risk among asymptomatic patients who have not yet developed overt cardiovascular disease. About 60% of all cardiovascular deaths occur in this group of people.
Absolute risk approach to prevention of cardiovascular disease

DURING the past decade there has been a fundamental shift in the clinical para-
digm for cardiovascular dis-
ease prevention — away from an approach based on defining and managing
single risk-factor abnormalities
(e.g., hypercholesterolemia) and
then basing the need for, and intensity of, risk-factor
management on an evalua-
tion of a person's future risk of
experiencing a cardiovascular
event (figure 1).

This 'absolute risk' approach is rooted in an
understanding of the nature of
the association between key modifiable risk factors
such as blood pressure and
cholesterol and the inci-
dence of vascular events. In a
category of diseases and
indicators, these associations
have been shown to be
proportionate, such that no ob-
vious threshold value can be
identified that clearly defines
abnormal levels of blood pressure or
cholesterol (i.e., 'hyperten-
sion threshold') or cholesterol
levels ('hypercholesterolemic
threshold').

Furthermore, these con-
clusions maintain that the
relative benefits from a
given reduction in blood pressure or
cholesterol are likely to be
regardless of the initial level of
these risk factors.

For example, in the case of
cholesterol, there is evidence to
guarantee that among those at
highest risk, the relative risk of a
particular cardiovascular event,
rather than necessarily in those with the high-

est initial level of a particu-
lar risk factor.

So, for example, one might expect that a 45-year-
old smoking male with dia-
betes and a systolic blood
pressure of 135mmHg will benefit more, in absolute
terms, from being started on a
blood-pressure-lowering drug that a 50-year-old non-
smoking, non-diabetic woman with a systolic blood
pressure of 145mmHg (figure 2).

These epidemiological
observations have been sup-
ported by evidence from clin-
cial trials that have shown
greater relative benefits from
more severe intensive lowering of blood pressure and
LDL cholesterol, as well as
subgroup analyses show-
ning that the relative effects of
treatment are similar regard-
less of initial levels of blood
pressure or cholesterol (in
the case of trials at baseline risk or trials at blood-pressure lowering) or LDL cholesterol
in the case of trials at target
therapy.)

How can cardiovascular risk be assessed?

BASED on the evidence supporting the 'absolute risk' approach to the
prevention of cardiovascular events, the
American Heart Association has been increasingly incorpo-
rating absolute risk assessment into
its guidelines. This involves using
formulas to estimate a person's
future risk of cardiovascular disease.

Formal risk-assessment tools are based on statistical
predictive models derived from cohort studies
in which individuals are followed for
many years to determine whether or not they develop car-
diovascular disease. Many such tools are
available but the ones most commonly
recommended in Australia are
those derived from the Framingham Heart Study.

A number of Framingham-based risk
charts are also available,
which are included in the
Australian guidelines for the
assessment of absolute cardio-
avascular disease risk, published in
March 2009 (see box, page 33).

The most commonly used clinical
predictive model derived from
this study includes only six major predic-
tors of cardiovascular disease:

- Age
- Sex
- Current smoking status
- Presence or absence of diabetes
- Systolic blood pressure
- Total to HDL cholesterol (TC to HDL-C ratio)

The Framingham risk equations have
been translated into complex
statistical formulae into various for-
mulas more appropriate for the
clinical setting. These formulae include
specific categories based on the
clinical setting (figure 3), as well as
on-adult computer desktop,
calculators, or calculators
available on the Internet. Use of
such charts requires the essential
first step that the relevant risk factors are
measured and available.

The RACGP's Guidelines for Pre-
ventive Activities in General Practice
(the 'Red Book') sixth edition (2001)
states that:

- All adults aged over 18 who have
their blood pressure checked at least
over two years, and if they are at
elavated vascular risk should be
checked every 6-12 months.

- All adults aged over 45 who have
diabetes should have their lipoprotein profile checked at
least every five years, and every 12-24 months
if they are at elevated vascular
risk.

- All adults aged over 55 who
smoke for at least five years and
have diabetes should be screen for
diabetes.

- The Framingham risk equations
have been translated from complex
statistical formulae into various for-
mulas more appropriate for the
clinical setting. These formulae include
categories based on the
clinical setting, as well as
on-adult computer desktop,
calculators, or calculators
available on the Internet. Use of
such charts requires the essential
first step that the relevant risk factors are
measured and available.

The RACGP's Guidelines for Pre-
ventive Activities in General Practice

Figure 1: Patient A shows the close correlation between systolic blood pressure (SBP) (horizontal axis) and the future risk of a cardiovascular event. The different risk groups are represented as different lines. Although the relative risk is the same for both low and high baseline risk, there is a declining absolute risk over 10 years as the baseline risk increases. This implies that other factors, such as lifestyle, may be more important in determining the risk for the individual patient.

Figure 2: Patient B with the higher blood pressure will usually be prescribed blood pressure-lowering treatment (at is appropriate). However, people such as Patient C will often modify risk factors (e.g. smoking, diet, exercise) and achieve similar reduction in vascular risk.
### Figure 3: Australian cardiovascular risk charts (available online — see above resources, page 35)

**Risk level for 5-year cardiovascular disease**

1. **High risk**
   - Age: 65 years or older
   - Total cholesterol: 5.0 mmol/L or more
   - HDL cholesterol: less than 1.0 mmol/L
   - Diabetes

2. **Moderate risk**
   - Any two of the above factors present

3. **Low risk**
   - No risk factors present

**How to use the risk charts**

1. Identify the start point relating to the patient’s sex, diabetes status, smoking status and total cholesterol.
2. Follow the risk charts based on the patient’s age, total cholesterol, HDL cholesterol and diabetes status.

**Using clinical judgment when assessing cardiovascular risk**

- While the charts provide a broad assessment of risk, it is important to consider individual clinical and genetic factors.
- A patient with diabetes and hypertension may be at increased risk even if their other risk factors are low.

**Role of additional tests for evaluating cardiovascular risk**

**SEVERAL tests have recently become available that may have a role in further refining cardiovascular risk assessment.** Generally, these tests are most useful when they are **negative** (i.e., suggestive of low risk), but their utility in higher-risk cases is less clear.

**Table 3: Parameters relevant for assessing cardiovascular risk**

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>10-year cardiovascular risk score based on age, sex, smoking history, total cholesterol, HDL cholesterol and diabetes status.</td>
</tr>
<tr>
<td>Smokers</td>
<td>Smoking status (current, ex-smoker, never-smoker).</td>
</tr>
<tr>
<td>Blood pressure</td>
<td>Blood pressure level (systolic and diastolic).</td>
</tr>
<tr>
<td>Total cholesterol</td>
<td>Total cholesterol level.</td>
</tr>
<tr>
<td>HDL cholesterol</td>
<td>HDL cholesterol level.</td>
</tr>
<tr>
<td>Diabetes status</td>
<td>Presence or absence of diabetes.</td>
</tr>
</tbody>
</table>

*Information on these variables is relevant for the calculation of Framingham risk scores. Additional information may be required for higher-risk categories.*
Linking cardiovascular risk assessment with treatment

There is no single Australian guideline for assessing and managing cardiovascular risk, although efforts are being made to address multiple risk factors such as hypertension. Currently, there is no single risk assessment tool that can provide consistent, and the following qualitative descriptors of risk to help define treatment strategies.

- Low risk: <10% estimated five-year probability of a cardiovascular event.
- Moderate risk: 10–15% estimated five-year probability of a cardiovascular event.
- High risk: >15% estimated five-year probability of a cardiovascular event.

An Australian Health Foundation position statement (www.healthfound.org) on the use of low-dose aspirin for preventing cardiovascular events unequivocally confirms that the benefits of low-dose aspirin outweigh the bleeding risks in patients with established atherosclerotic cardiovascular disease (myocardial infarction or other cardiovascular disease, including stroke, peripheral vascular disease). Therefore, it is recommended that the use of low-dose aspirin be considered for patients with a five-year coronary heart disease risk of >7.5% (possibly equivalent to a five-year cardiovascular disease risk of >10%).

Authors’ case studies

Present and future cardiovascular risk in a relatively young patient with several risk factors

Mr LR, 46, only occasionally attends his practice for medical complaints. He emigrated to Australia from India 10 years ago and has lived in the area for 3 years. He is right-handed and does a lot of manual work. He is not currently taking any medications and refers to himself as being in relatively good health. He has a brief dilatation and aortic stenosis and has a history of hypertension.

He referred for a cholesterol level of 5.5 mmol/L, LDL cholesterol 4.4 mmol/L, and HDL cholesterol 1.0 mmol/L. He completed his physical examination and decided to see the colour chart to explain LR’s vascular risk to him.

Step 1. Does the patient have a history of established cardiovascular disease?

There are no features in his history or examination to assume he has established disease.

Step 2. What is LR’s cardiovascular risk based on the Framingham risk chart?

Based on the information and using the Australian risk charts, his calculated five-year risk of a cardiovascular event is low, at 5.9%.

Step 3. Is there any other clinical information that would influence this assessment of his cardiovascular risk?

Because of his Indian ethnic background, consideration should be made to adjust his risk. Furthermore, his family history for coronary artery disease (particularly because it occurred in a first degree relative at a young age), his diabetes family history and his obesity are all influential factors that may mean his risk is underestimated.

For these reasons it would be reasonable to make an upward adjustment of 5% to his risk estimate. After doing this his current five-year risk estimate moves into the moderate (10–15%) range. Because the strongest predictor of a cardiovascular event is age LR’s risk will substantially increase over time.

Step 4. Should I order any additional tests to refine my assessment of his cardiovascular risk?

Given the history of high blood pressure readings, perform an ECG may be useful to assess for left ventricular hypertrophy. Screening for chronic kidney disease with an eGFR and a urinary albumin/creatinine ratio (best taken on a early morning spot urine sample) may also assess for any additional risk beyond that estimated with the Framingham risk tool.

Coronary calcium scores might be a useful assessment tool. It might help to classify him into a higher risk category (where pharmaceutical as well as lifestyle interventions may be necessary) or a lower risk category (where a sole focus on lifestyle management may continue).

References

from the previous page information to the 55-64-year-old chart, it is easy to demonstrate that his risk will increase up to 16.19% 'high' range over the next 15 years if there are no other changes to his current lifestyle. If he develops diabetes over this period and his blood pressure starts to rise, his risk escalates to the 25-29% range.

While there are many complex issues at play in how risk is communicated, this approach can be helpful in discussing the importance of lifestyle and pharmacological management of cardiovascular risk factors.

**Cardiovascular risk in an overweight ex-smoker with high BP**

Mrs BG, a 50-year-old accountant, is planning to travel to Thailand on a holiday and is seeking advice on any immunisation requirements. She mentions that a first cousin, a male aged 68, has recently undergone angiography. She is a former smoker. Her family history suggests that her father died suddenly at age 74. She has one older brother aged 54 and her mother is currently 76, neither of whom have any known vascular disease. She is not taking any medications at present. She says she has lost 1 kg in body weight since she last saw you, but engages in little physical exercise.

On examination you note that her BMI is 26 kg/m² with a waist circumference of 95 cm. Her blood pressure today is 162/84 mmHg. She does not have any vascular bruits. Fast ing blood tests performed at her last visit showed a blood glucose level of 4.9mmol/L, total cholesterol of 5.8 mmol/L and HDL cholesterol of 1.2 mmol/L. The serum creatinine and eGFR levels were within the laboratory reference range for normal.

**Step 1. Does the patient have a history of established cardiovascular disease?**

Based on Mrs BG's history and the absence of clinical signs suggesting over vascular disease, it is reasonable to assume the absence of major vascular disease.

**Step 2. What is her cardiovascular risk based on the Framingham risk charts?**

Based on this information, her calculated five-year risk of a cardiovascular event is 5-9% using the New Australian risk charts. This assumes absence of diabetes (based on the fasting blood glucose level) and current non-smoking status.

**Step 3. In the absence of any additional clinical information that would influence this assessment of her cardiovascular risk?**

Her family history would not be considered strongly suggestive of premature vascular disease. She is currently a non-smoker and has only recently abstained. She is overweight and does not exercise.

**Step 4. Should I order any additional tests to refine my assessment of her cardiovascular risk?**

Performing an ECG (and an echocardiogram, if accessible, or if the ECG indicates left ventricular hypertrophy by blood pressure criteria) would be useful, as would be testing for microalbuminuria. Presence of either of these characteristics would suggest that Mrs BG's long-term risk of a cardiovascular event is higher than estimated with the Framingham risk tool.

**Step 5. How should this cardiovascular risk assessment influence drug treatment recommendations I make?**

In the absence of a single vascular risk-management guideline, separate guidelines or position statements would need to be considered.

**BP lowering (National Heart Foundation of Australia)**

BP lowering (National Heart Foundation of Australia Guide to Management of Hypertension 2008). If there are no other risk factors uncovered that would reclassify Mrs BG's five-year cardiovascular risk estimate to >10%, current guidelines suggest that she is at the borderline for initiating drug therapy if lifestyle measures fail to persistently reduce her systolic blood pressure to below 150 mmHg and her diastolic blood pressure to below 90 mmHg.

However, it is important to note that her cardiovascular risk will progressively increase as she ages. If she has any additional risks (eg, left ventricular hypertrophy on ECG), current guidelines recommend immediate initiation of drug treatment.

Cholesterol lowering (National Heart Foundation of Australia/Cardiac Society of Australia and New Zealand Position Statement on Lipid Management 2003). Statin therapy would not be currently recommended for Mrs BG unless the five-year cardiovascular risk is estimated to be 15%, or 10-15% with the presence of the metabolic syndrome or a significant family history of premature cardiovascular disease.
Case study
DAVID, 58, is an electrician who has been visiting the practice for about 10 years. He has been well, apart from treatment of some benign skin lesions and osteoarthritis of his right knee, and over the years has seen different GPs in the practice.

Periodically he has had his lipids checked. His total cholesterol has ranged from 5.0 to 6.5 mmol/L on different occasions over the last few years. David has no history of cardiovascular disease or diabetes, does not smoke and has no significant family history of illness.

I saw him recently when he came in to review lipid results from a few days earlier and to obtain a repeat script for rosvastatin 5mg daily, which he had been started on about a month earlier by another GP. The recent results after a month of rosvastatin were total cholesterol 5.4 mmol/L, triglycerides 0.9 mmol/L, HDL cholesterol 1.5 mmol/L and LDL cholesterol 3.5 mmol/L.

On examination blood pressure was 126/70mmHg, weight 65kg, height 1.73m, BMI 22kg/m². His lipids before starting rosvastatin were total cholesterol 6.4 mmol/L, triglycerides 1.7 mmol/L, HDL cholesterol 1.3 mmol/L and LDL cholesterol 4.2 mmol/L.

On reviewing the situation it became apparent that David did not qualify for PBS-subsidised statin treatment. I discussed this with him and explained that he could continue on rosvastatin but would have to pay the full cost of therapy. He was not in a position to afford this at present.

Questions for the author
How could cardiovascular risk assessment help in managing this patient?
Assuming the absence of any modifying factors (e.g., chronic kidney disease), David's estimated five-year risk of a cardiovascular event before treatment with statins, is 5-10%. Prolonged statin therapy might be expected to reduce this risk by about 20%, so that the probability of such an event occurring over a five-year period would be about 4-8%.

This type of cardiovascular risk assessment would allow David to better understand the extent of the likely benefits of statin therapy to him at the present time — it suggests the current potential benefits of statin treatment for him are real, but quantitatively modest because of his relatively low initial risk.

The risk charts would also help show how the situation would change if his blood pressure levels rise or he is diagnosed with diabetes, which might reinforce any messages about maintaining healthy lifestyle behaviours. Of course, simply ageing will have the greatest effect on his estimated risk, which will increase to the "moderate risk" category of 10-15% in 10 years time with no change in other risk factors, and current PBS criteria will still not permit subsidised statin therapy.

The reality is that there is a disconnect between guideline recommendations and PBS subsidy criteria, although this gap reduced substantially with the latest revisions to the PBS.

Dr Sailyot Vagholkar
Prairiewood, NSW
One of the advantages of the absolute risk approach is that it provides a rationale for targeting risk factors that are not necessarily the most abnormal, but may still provide significant benefit.

How to Treat Quiz

Cardiovascular risk assessment
— 10 April 2009

1. Which TWO statements about absolute cardiovascular risk assessment are correct?
   a) Patients with established cardiovascular disease (CVD) do not require further risk assessment or need for preventive treatments.
   b) Most adults over 75 should be considered to have a five-year absolute risk of <10%.
   c) The Australian cardiovascular risk assessment guidelines recommend review of an individual’s risk estimate every two years at a minimum risk.

2. Which TWO statements about the modification of ASCVD guidelines for Preventive Activities in General Practice (FAME) are correct?
   a) All adults aged 45 should have their lipid profile measured at least once every two years.
   b) All adults aged 45 should have their lipid profile measured at least once every two years.
   c) FAME guidelines should aim at age 45 in same individuals and age 35 in high-risk ethnic groups.

3. Which THREE statements about use of Framingham-based risk assessment tools are correct?
   a) Framingham-based risk tools have been validated in adults of all ages.
   b) These risk tools provide a broad estimation of a patient’s risk that should be combined with clinical judgment.
   c) For people with severe elevations of blood pressure or cholesterol, the tools are likely to underestimate risk.

4. Which THREE statements about assessment of absolute cardiovascular risk in people with diabetes are correct?
   a) Some guidelines consider diabetes confer a similar risk to that of established CVD, and so do not recommend further risk stratification in people with diabetes.
   b) Specific risk tools are available to use in people with diabetes.
   c) The Australian cardiovascular risk assessment guidelines recommend use of Framingham-based risk tools in people under 65 with diabetes.

5. Karen’s BP is 140/90mmHg. She has no signs of vascular disease. Her fasting glucose level is 5.3mmol/L, total cholesterol is 6.1mmol/L, HDL cholesterol 1.2mmol/L, and triglycerides 3.4mmol/L. Using the Australian charts, what is Karen’s five-year CVD risk?

6. Which THREE of the following statements are correct?
   a) Diabetic blood pressure
   b) Body mass index
   c) Diabetes status
   d) Total cholesterol to HDL cholesterol ratio (TC/HDL cholesterol ratio)
   e) Non-smoking
   f) Use of aspirin

7. Karen’s BP is 140/90mmHg. She has no signs of vascular disease. Her fasting glucose level is 5.3mmol/L, total cholesterol is 6.1mmol/L, HDL cholesterol 1.2mmol/L, and triglycerides 3.4mmol/L. Using the Australian charts, what is Karen’s five-year CVD risk?

8. Which THREE of the following statements are correct?
   a) It would be useful to ask Karen about any family history of premature vascular disease.
   b) Her weight, height and waist circumference should be measured and BMI calculated.
   c) An ECG is the best means for assessing whether a patient has left ventricular hypertrophy (LVH).
   d) An APGVR should be used to assess for atrial fibrillation.
   e) An ECG is the best means for assessing whether a patient has left ventricular hypertrophy (LVH).

9. Which THREE of the following statements are correct?
   a) Use of high-sensitivity C-reactive protein (hsCRP) with low levels of high-density lipoprotein cholesterol
   b) Measurements of coronary artery calcium scores may be helpful in patients with intermediate risk.
   c) A carotid intima-media thickness of >1.5 is associated with a 15% risk of a cardiovascular event in the next five years.

10. Which TWO of the following statements are correct?
    a) If Karen continues to smoke, provided there are no changes to her other risk factors, in 10 years her five-year CVD risk will be >20%.
    b) If Karen stops smoking now, provided there are no changes to her other risk factors, in 10 years her five-year CVD risk will be >20%.
    c) If Karen develops diabetes, provided there are no changes to her other risk factors, in 10 years her five-year CVD risk will be >20%.
    d) If Karen develops diabetes, provided there are no changes to her other risk factors, in 10 years her five-year CVD risk will be >20%.

How to Treat Quiz 

Appendix C – 8
Appendix D: Addressing inequities in access to quality health care for Indigenous people


Author contribution: This was an invited editorial for an original research article. I conceived of the paper, and used the preliminary findings from the literature review in Chapter 6 to write the first and subsequent drafts. Co-authors Cass and Brown commented on manuscript drafts.
Addressing inequities in access to quality health care for indigenous people

David Peiris MBBS MIPH, Alex Brown BMed MPH, Alan Cass MBBS PhD

Key points

- Inequities in access to necessary health care are unacceptable and contribute to gaps in health status between indigenous and non-indigenous people.
- Access barriers exist in patient-provider interactions, health services and health systems.
- Indigenous perspectives on access barriers are poorly represented and undervalued in the scientific literature.
- Consider moving toward the concept of "cultural safety" rather than a checklist approach.

Any issues influence access to quality health care for indigenous people. In this issue of CMAJ, Gao and colleagues describe inequities in access to health care and service utilization among Canadian Aboriginal people with chronic kidney disease. Similar findings have been reported in Australia, New Zealand and the United States. Although well-conducted studies that quantify the extent of the disparity and trends in health care access are needed, addressing the underlying causes of this disparity is a priority — not merely because such disparities are unacceptable but because disparities in access contribute to major and avoidable ill health.

One key contextual barrier to accessing health care that has been described in the literature from Australia, Canada, New Zealand and the US is the continuing impact of colonization. The Canadian Royal Commission on Aboriginal Peoples and the Australian Royal Commission on Aboriginal Deaths in Custody comprehensively documented the contemporary effects of past discriminatory policies on indigenous people. Although few empirical studies have examined the health effects of discriminatory policies, a well-conducted cohort study in Australia reported that the forced removal of Aboriginal children from their families affected health for generations. By engendering distrust in government agencies, policies such as these contribute to high levels of stress among indigenous people. Psychosocial stress, a phenomenon common to many vulnerable populations, is an important barrier to accessing health care and has been consistently associated with adverse health outcomes for indigenous people.

Health care systems and health care services are not immune from this historical policy context. Studies, predominantly with qualitative designs, have shown that indigenous people are sensitive to power imbalances in their interactions with health care services. This is intimately linked with the dominance of the biomedical paradigm and the view that noncompliant behaviours by indigenous people are the cause of poor health outcomes. By contrast, when care providers promote a non biomedical approach to health care interactions, through trust, reciprocity and shared decision-making, they can empower recipients and more effectively deliver interventions to reduce the gap in health outcomes. Much work focuses on miscommunication as an access barrier. Relevant factors include communication dynamics and sharing of health information, language and literacy. In health care for indigenous people, the power dynamic directly affects communication.

A related, complex area is the attribution of cultural factors as both barriers to and facilitators of health care. There is a clear need to abandon stereotypical concepts of indigenous cultures and the simplistic embrace of particular culture-based ingredients as means of transforming services into becoming "appropriate," "aware," "sensitive" or "competent" — terms that are often poorly defined. The more dynamic concept of "cultural safety," originally developed by Maori nurses, is quite different. Cultural safety shifts the role of culture away from a check-list approach based on a person's ethnic background and toward a critical examination of the power imbalances in health care encounters between indigenous patients and non-indigenous health care providers. When viewed in this way, culturally safe health care becomes a core principle for the reorientation of health services to better meet the needs of vulnerable groups, irrespective of their ethnic background.

We need to move beyond patient–provider interactions in developing a policy-informing agenda on access. Known facilitators of access are the establishment of community-governed health services, a robust indigenous managerial and clinical workforce and the ability to deliver models of care that embrace indigenous knowledge systems. The interpretive synthesis of the literature about the barriers to access for vulnerable groups by Dixon-Woods and colleagues has led to the development of the useful concepts of "navigation" and "permeability." Navigation requires an awareness of the available services and the mobilization of personal and health service resources to provide access, such as transport, minimal out-of-pocket cost and flexible hours. Permeable services require little negotiation for entry and a minimal level of understanding of how the system works. These services may include having welcoming physical spaces, open-door policies and reception staff who are known to the community.

Measures of health system performance are increasingly used to improve access and quality of care. The US Indian Health Service has invested substantially in information tech-
nology to support macrosystem monitoring of quality measures. The Australian government is developing quality indicator programs for Aboriginal health services. Although these approaches are valuable, caution is needed in their application. In a review of indigenous health performance measurement systems, Smylie and colleagues argue that the development of these macrosystem measures, which are usually based on physical and disease variables, often come at the expense of developing locally specific health indicators for indigenous populations. The article by Gao and colleagues exemplifies the problem discussed by Anderson and colleagues in the classification of ethnicity, particularly for people of mixed descent. The classification of non-status First Nations and Metis people as non-Aboriginal is epidemiologically expedient, but it raises concerns about equity. Support for local measurement systems responsive to indigenous people and to their health service priorities can complement conventional performance measures and ensure valid interpretation of those measurements.

Our list of barriers and facilitators is not exhaustive. A key consideration is the need for greater clarity in how we conceptualize barriers, their defining characteristics and their causes. Closely related is the need to move beyond explanatory models, which focus on deficiencies in individuals and services, and toward a better understanding of existing facilitators to improved access and quality. The research on which to base policy is a labyrinthine mix of qualitative studies, audits and surveys, program evaluations, advocacy, quality improvement projects, nonsystematic topic reviews and opinion pieces. Opinion pieces are often key sources of indigenous perspectives but are poorly represented and under-valued in the scientific literature. Much of this disparate literature is locally specific, small in scale and is often not amenable to the reductionism of conventional systematic reviews. This makes national and international extrapolation difficult and poses dilemmas for the development of evidence-based policy.

In Canada, Australia, New Zealand and the US, inequities in access to health care and outcomes for indigenous people have been well-characterized. To close these gaps, we need to document disparities and understand their causes more precisely and make collaborative changes. Such changes are often resisted by institutional, political, structural, social and cultural forces. As indicated by an Aboriginal man with end-stage kidney disease interviewed for the Improving Access to Kidney Transplants study when discussing communication with his kidney specialist: "You don't go knocking on their door, [that's the] 'danger one.' The door is locked. They sit behind closed doors." If we are able to open these doors, our health care systems may perform better for the most vulnerable.

**Competing interests:** None declared.

**Contributors:** Each of the authors contributed to the content of the article, revised it critically and approved the final version for publication.

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**REFERENCES**


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Appendix E: Other outputs during my doctoral studies

Awards

2008 Early in Career Public Health Award, Public Health Association of Australia

2009 Cross Cultural Public Health Research Award, Faculty of Medicine, University of Sydney

Invited presentations

- Aboriginal Health Research Conference Plenary Session Sydney – Working effectively with communities, April 2008
- Aboriginal Health & Medical Research Council GP update forum, Sydney. ‘Cardiovascular risk management in Aboriginal Medical Services’ June 2008
- Aboriginal Drug and Alcohol Network Conference, Tamworth. ‘Chronic Diseases in Aboriginal Health – Closing treatment gaps’ July 2008
- Aboriginal Health & Medical Research Council GP update forum, Sydney. ‘Research in an Aboriginal Community Controlled context ‘ May 2009
- Aboriginal Health & Medical Research Council Action for Health Conference Plenary Session, Sydney ‘Monitoring and Clinical Systems in Primary Care’ September 2009
- Wentwest Division of General Practice annual GP Expo – One day workshop on CVD risk management and prevention in primary care. Sydney, May 2010

Media appearances

The findings from the Kanyini Audit (Chapter 2) and the ‘Identifying the Gaps in Cardiovascular Risk Management’ paper (Appendix A) received widespread media attention. I appeared in 25 national TV, radio and newspaper sources during the last week of September. I also demonstrated the electronic CVD decision support system, described in Chapter 5, to Dr Norman Swan on the ABC Catalyst program on October 1, 2009

Appendix E – 1
Committee appointments

• Royal Australian College of General Practitioners Faculty of Aboriginal and Torres Strait Islander Health

• Aboriginal Health & Medical Research Council Information Computer Technology/Information Management Reference Group

• Technical Reference Group member advising the Department of Health and Ageing on Pharmaceutical Benefits Scheme Measures for the Council of Australian Governments National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes

• Technical Reference Group member advising the Department of Health and Ageing on the development of a Primary Health Care Resource for the Council of Australian Governments National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes

• Baker IDI NHMRC diabetes management guidelines implementation working group
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