A Person-Centred Approach to Performance Measurement in the Health System

David Mark BANHAM
BA (Hons), MPH

A thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy
July 2022

School of Public Health
Faculty of Health and Medical Sciences
The University of Adelaide

Table of Contents

Thesis abstract

Background

Health systems strive to improve health outcomes in the populations they serve. In Australia, a national health system performance framework supports this aim. Review of performance measures showed a focus on organisational activity rather than outcomes for people.

South Australia (SA) also set strategic targets for improved healthy life expectancy as influenced by: premature mortality; health related quality of life (HRQoL); and, potentially preventable hospitalisation (PPH). There are unmet information needs and capacity for improvement in the application of each of these measures.

Aims

This thesis aims to help inform system improvement by reorienting performance measurement toward outcomes of importance to people receiving healthcare – so called 'person-centred' measures. The thesis aims to provide empirical examples that help:

i. Reframe premature mortality measures to account for survival time from disease detection until death;

ii. Extend morbidity measurement to describe a person's self-reported state of health; and,

iii. Enhance enumeration of people experiencing PPH in emergency departments (EDs) and as admitted inpatients.

Methods

Four studies stem from the candidate's projects in SA: monitoring summary population health; piloting an advanced cancer data system; steering the first Aboriginal specific population survey; and, quantifying individuals experiencing PPH.

Study one introduces a new method that quantifies mortality related cancer burden using an example based on cancer registrations among Aboriginal and non-Aboriginal cohorts matched one-to-one on sex, year of birth, primary cancer site and year of diagnosis. Cancer burden is expressed as the PREmature Mortality to IncidencE Ratio (PREMIER), the ratio of years of life expectancy lost due to cancer against life expectancy years at risk at time of cancer diagnosis for each person.

Study two presents the first, self-reported HRQoL utility results by Aboriginal South Australians. Population weighted HRQoL was measured using SF-6D and SF-12 version 2 in face-to-face interviews. Analyses describe relationships between HRQoL and respondent characteristics, and the characteristics of interviewees completing HRQoL questions.

Studies three and four consider ED and inpatient PPH respectively. Those studies extend current reporting practices by shifting analyses from PPH as a proportion of activity, to a person-centred approach counting individuals experiencing PPH and the frequency of their events. Both studies draw on person-linked public hospital records within a period prevalence study design. Study three compares ED presentations among Refugee and Asylum Seeker Countries of birth (RASC); Aboriginal; those aged 75 years or more and all other adults. Study four determines disparities in rates, length of stay (LOS) and hospital costs of PPH for chronic conditions among Aboriginal and non-Aboriginal people.

Results

Study one included records for 777 Aboriginal people diagnosed with cancer from 1990 to 2010. Aboriginal people (n=777) had 57% (95%CI 52%-60%) more scope for improved cancer mortality outcomes two years after diagnosis compared to non-Aboriginal people of equivalent age, sex, diagnosis year and cancer site. PREMIER informs interventions by identifying people with greatest capacity to benefit from earlier detection, treatment and reduced premature mortality.

Study two showed substantial variation in self-reported HRQoL among 399 Aboriginal people in 2010/11. For example, average SF-6D results varied from 0.82 (95%CIs 0.81-0.83) among those with no chronic conditions to 0.63 (95%CIs 0.59-0.67) where 3 or more conditions were reported. Comparatively less responding to HRQoL questions was evident among people speaking Aboriginal languages, in non-urban settings, and with multi-morbidities. Further developing culturally safe, self-reporting HRQoL instruments may improve participation by vulnerable and health compromised community members.

Study three's comparisons among adult residents attending EDs in 2005–2006 to 2010–2011 showed greatest disparities in GP-Type presentations among people from RASC compared to non-Aboriginal residents aged less than 75 years (423.7 and 240.1 persons per 1,000 population respectively). Study four's inpatient PPH for chronic conditions showed Aboriginal people experienced more first-time events compared to others (11.5 and 6.2 per 1,000 persons per year respectively) and substantially longer, total length of stay (11.7 versus 9.0 days). Improved understanding of peoples' PPH informs tailored services addressing primary healthcare needs.

Conclusion

The studies assembled in this thesis help align performance measurement with outcomes for people and provide support for system improvement and health reform. While the labour-intensive collaborations necessary may limit development, current opportunities for advancing research within government agencies are discussed.

Australia's health system performance measures remain underdeveloped. This thesis contributes to addressing that need by focussing attention on the people the system exists to serve – effectively, efficiently and equitably.

Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree.

The author acknowledges that copyright of published works contained within this thesis resides with the copyright holder(s) of those works.

I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship.

Signed:

David Mark Banham

Date: 25th July 2022

Peer-reviewed journal articles resulting from this thesis

Submitted

Banham D, Karnon J, Brown A, Roder D, Lynch J. *The premature mortality to incidence ratio (PREMIER): a person-centred measure of cancer burden*. Population Health Metrics. Submitted for publication 21 March, 2019.

Population Health Metrics underwent major changes during 2019 with the appointment of a new Editor-in-Chief and Editorial Board. The finalisation of the new editorial group coincided with the outbreak of the COVID pandemic resulting in lengthy, continuing delays in the peer review process. I remain in regular contact with the Editorial Office. Pending completion of peer review the paper has been made publicly available online through medRxiv.

Published

Banham D, Karnon J, Lynch J. *Health related quality of life (HRQoL) among Aboriginal South Australians: a perspective using survey-based health utility estimates*. Health and Quality of Life Outcomes. 2019;17(1):39.

Published

Banham D, Karnon J, Densley K, Lynch J. *How much Emergency Department use by vulnerable populations is potentially preventable?: A period prevalence study of linked public hospital data in South Australia*. BMJ Open. 2019(e022845).

Published

Banham D, Chen T, Karnon J, Brown A, Lynch J. *Sociodemographic variations in the amount, duration and cost of potentially preventable hospitalisation for chronic conditions among Aboriginal and non-Aboriginal Australians: a period prevalence study of linked public hospital data*. BMJ Open. 2017;7(10).

An explanation and justification for the positioning of these publications is as follows:

I took the decision at the outset to direct all publications to Open Access journals to ensure the material would be freely available to any interested party regardless of their ability to access peer-reviewed information through traditional means of university libraries or professional associations. Specifically, it is intended to make the knowledge gained freely available to interested community members and those involved in health system evaluation.

Population Health Metrics (2021 impact factor 2.786) was chosen for the cancer metrics paper because the senior editors were instrumental in advancing the burden of disease methodology. The PREMIER metric makes a further contribution to that methodology.

Health and Quality of Life Outcomes (2021 impact factor 3.186) was the preferred journal for the HRQoL paper because the journal aims to further understanding of HRQoL, person reported measures and cultural variations which align closely with the paper's aim. The writer also published a related analysis in that journal which examined relationships between burden of disease perspectives population morbidity and self-reported HRQoL.

BMJ Open (2021 impact factor 2.692) was the preferred option for the two papers analysing public hospital records because it is a medical journal which welcomes studies in health services research, epidemiology and health economics with a focus on patients and clinicians. The journal's scope aligns well with the studies' material aimed at an audience of health providers, health service commissioners, administrators and community advocates interested in health service responses to diverse health needs in their communities.

Conference presentations resulting from this thesis

Professional conferences:

Banham D, Roder D, Brown A on behalf of the Cancer Data and Aboriginal Disparities (CanDAD) Aboriginal Community Reference Group (ACoRG). *Realising Indigenous Australians capacity to benefit from cancer care: Developing person-centred performance measures in cancer control.* World Indigenous Cancer Conference. Brisbane, 12-14 April 2016.

Banham D, Chen T. *Chronic Ambulatory Care Sensitive Conditions amongst Indigenous and non-Indigenous Australians: a cross-sectional analysis of linked data*. Oral presentation to the 9th Health Services and Policy Research Conference, Melbourne, 7–9 December 2015.

Banham D. *Vulnerable populations and Emergency Department use in the Adelaide metropolitan area: Person-centred outcomes and costs using linked, administrative data*. Oral presentation to the Population Health Congress, Hobart, 6-9 September 2015.

Banham D, Nguyen A-M T, Anastassiadis K. *Refugee & Asylum Seeker populations & Emergency Department use in the Adelaide metropolitan area: Examining outcomes & costs using linked, administrative data.* Oral presentation to the 36th Annual Australian Health Economics Society (AHES) Conference, Adelaide, 24–26 Sept 2014.

Other presentations disseminating results from this thesis

Health Translation South Australia (HTSA) forum:

Banham D. *Decision-support & continuous learning.* Workshop contribution to HTSA's forum on the role of equity-informative health economics evaluations to support service and policy decision making, Adelaide, 11 December 2019.

Banham D. *Person-centred metrics.* Workshop contribution to HTSA's forum on the role of equity-informative health economics evaluations to support service and policy decision making, Adelaide, 11 December 2019.

SA health portfolio community of practice:

Initiated in 2005, a community of practice (CoP) across South Australia's health portfolio formed as a Data and Analysis Group with the purpose of encouraging and supporting analyses of population health and health services. The CoP initially involving SA Health staff (the state government's lead health agency) then grew to include over 100 colleagues across other government agencies (state and Australian), academia, primary health networks and consumer representatives.

Banham D. (2019) *Preparing for success by counting what counts in the health system: patient/population reported outcome measures* Oral presentation to the 16th May 2019 meeting of the SA health Data & Analysis Group.

Banham D. (2019) *Preparing for success by counting what counts in the health system: cancer mortality.* Oral presentation to the 21st February 2019 meeting of the SA health Data & Analysis Group.

Banham D. (2017) *Costs & inequities in 'potentially preventable' hospital use*. Oral presentation to the 16th November 2017 meeting of the SA health Data & Analysis Group Data & Analysis Group.

Banham D. (2016) *A Person-Centred approach to performance measurement in the health system.* Data & Analysis Group 18th February, 2016.

Banham D, Haller D, Anastassiadis K. (2013) *Humanitarian arrivals & South Australian public hospital use*. Oral presentation to the 10th June 2013 meeting of the SA Health Data & Analysis Group.

Other peer-reviewed journal articles during candidature

Published

Banham D, Roder D, Keefe D, Farshid G, Eckert M, Howard N, et al. *Disparities in breast screening, stage at diagnosis, cancer treatment and the subsequent risk of cancer death: a retrospective, matched cohort of Aboriginal and non-Aboriginal women with breast cancer.* BMC Health Services Research. 2019;19.1:387.

Published

Banham D, Roder D, Eckert M, Howard NJ, Canuto K, Brown A, et al. *Cancer treatment and the risk of cancer death among Aboriginal and non-Aboriginal South Australians: Analysis of a matched cohort study.* BMC Health Services Research. 2019;19(771).

Published

Banham D, Brown A, Roder D. *Comorbidities contribute to the risk of cancer death among Aboriginal and non-Aboriginal South Australians: Analysis of a matched cohort study*. Cancer Epidemiology. 2018;52(1):75-82.

Published

Reilly R, Micklem J, Yerrell P, **Banham D**, Morey K, Stajic J, et al. *Aboriginal experiences of cancer and care coordination: Lessons from the Cancer Data and Aboriginal Disparities (CanDAD) narratives.* Health Expectations. 2018;21(5):927-36.

Published

Pule L, Buckley E, Niyonsenga T, **Banham D**, Roder D. *Developing a comorbidity index for comparing cancer outcomes in Aboriginal and non-Aboriginal Australians.* BMC Health Services Research. 2018;18(1).

Published

Banham D, Roder D, Keefe D, Farshid G, Eckert M, Cargo M, et al. *Disparities in cancer stage at diagnosis and survival of Aboriginal and non-Aboriginal South Australians.* Cancer Epidemiology. 2017;48:131-9.

Published

Brown A, Roder D, Yerrell P, Cargo M, Reilly R, **Banham D**, et al. *Cancer Data and Aboriginal Disparities Project (CanDAD) – an Overdue Cancer Control Initiative*. European Journal of Cancer Care. 2016;25(2):208-13.

Published

Yerrell PH, Roder D, Cargo M, Reilly R, **Banham D**, Micklem JM, et al. *Cancer Data and Aboriginal Disparities (CanDAD)—developing an Advanced Cancer Data System for Aboriginal people in South Australia: a mixed methods research protocol*. BMJ Open. 2016;6(12).

Published

Banham D, Hawthorne G, Goldney R, Ratcliffe J. *Health Related Quality of Life (HRQoL) changes in South Australia: A comparison of burden of disease morbidity and survey based health utility estimates.* Health and Quality of Life Outcomes. 2014;12:113.

Published

Gray J, Haji Ali Afzali H, Beilby J, Holton C, **Banham D**, Karnon J. *Practice nurse involvement in primary care depression management: an observational cost-effectiveness analysis*. BMC Family Practice. 2014;15(10).

Published

Haji Ali Afzali H, Karnon J, Beilby J, Gray J, Holton C, **Banham D**. *Practice nurse involvement in general practice clinical care: policy and funding issues need resolution.* Australian Health Review. 2014;38:301-5.

Published

Karnon J, Haji Ali Afzali H, Gray J, Holton C, **Banham D**, Beilby J. *A risk adjusted cost-effectiveness analysis of alternative models of nurse involvement in obesity management in primary care.* Obesity. 2013;21(3):472-9.

Published

Haji Ali Afzali H, Gray J, Beilby J, Holton C, **Banham D**, Karnon J. *A risk-adjusted economic evaluation of alternative models of involvement of practice nurses in management of type 2 diabetes.* Diabetic Medicine. 2013;30(7):855-63.

Submitted and in review

Banham D, Roder D, Thompson S, Bray F, Williamson A, Li M, Currow D on behalf of the Cancer and healthy aging in Aboriginal New South Wales older Generations Study (50+ years) (CHANGES) Aboriginal Advisory and Investigators' Groups. *Comorbidity among older Aboriginal and non-Aboriginal Australians with cancer in New South Wales.* Journal of Multimorbidity and Comorbidity.

Submitted and in review

Banham D, Roder D, Thompson S, Williamson A, Bray F, Currow D on behalf of the Cancer and healthy aging in Aboriginal New South Wales older Generations Study (50+ years) (CHANGES) Aboriginal Advisory and Investigators' Groups. *The effect of general practice contact on cancer stage at diagnosis in Aboriginal and non-Aboriginal residents of New South Wales*. Cancer Causes and Control.

Other conference presentations during candidature

Professional conferences:

Canuto K on behalf of **Banham D**, Roder D, O'Keefe D, Farshid G, Eckert M, Howard NJ, Brown A on behalf of the CanDAD Investigators and the CanDAD ACoRG. *Cancer treatment and the risk of cancer death among Aboriginal and non-Aboriginal South Australians: Analysis of a matched cohort study*. Oral presentation to the 2019 World Indigenous Cancer Conference, Calgary, 16-19 September 2019.

Miller S on behalf of **Banham D**, Roder D, Eckert M, Howard NJ, Canuto K, Brown A on behalf of the CanDAD Investigators and the CanDAD ACoRG. *Disparities in breast screening, stage at diagnosis, cancer treatment and the subsequent risk of cancer death: A retrospective, matched cohort of Aboriginal and non-Aboriginal women with breast cancer.* Oral presentation to the 2019 World Indigenous Cancer Conference, Calgary, 16-19 September 2019.

Banham D, Roder D, Brown A, on behalf of the Aboriginal Community Reference Group. *Establishing the capacity for Indigenous South Australians to benefit from cancer care: Developing and piloting an Advanced Cancer Data System (ACaDS).* World Indigenous Cancer Conference, Brisbane, 12-14 April 2016.

Acknowledgements

I acknowledge the Traditional Owners of the lands across South Australia (SA) and pay my respects to Aboriginal Elders, past, present and emerging. I also recognise the Ngadjuri people on whose lands I now live and write.

Many people contributed to me undertaking this thesis. Professor Melanie Wakefield first introduced me, a psychology graduate, to the melding of behavioural sciences with epidemiology. Dr Frida Cheok's innovations in epidemiology and health economics through SA Health's Health Outcomes Unit enabled my exploration of tailored interventions for comorbid depression and cardiac conditions in clinical populations. With Frida's support, and Andrew Stanley and Tony Woollacott of Strategic Policy, Research and Analysis Branch I joined with Dr Graeme Tucker to coalesce government data assets in creating summary population health measures for South Australians. Neville Hicks at the University of Adelaide challenged me to engage with the role of science in supporting health policy while Professor Robyn McDermott convinced me to bring discussion out of departmental structures and write to a wider audience after Ian Brownwood asked me for population level hospital measures. Colleagues in SA Health's Aboriginal Health team consistently questioned, encouraged and consumed any information I could develop. The SA health portfolio Data and Analysis Group John Gray, Lynley Jones and I facilitated was a high point. Our community of 100 or so members contributed valuable insights, enthusiastic soundings and a safe environment for formulating questions and nurturing responses. Executive directors Jenny Richter and Kym Piper listened to my ideas for connecting system activity to population outcomes and subsequently facilitated my joining the fledgling South Australian Health and Medical Research Institute (SAHMRI). Professor Alex Brown, Kathy Mott and Kim Morey welcomed me to the Wardliparingga Aboriginal Research Unit where Alex and Professor David Roder supported my piloting of an advanced cancer data system.

Meeting Professors John Lynch and Jon Karnon on their respective arrivals in SA was a privilege and delight. Their abilities as supervisors to elicit, inform and help refine the tasks I set myself, and to do so with minimum fuss and maximal patience are gifts I very much appreciate and continue to benefit from.

To Heather, our daughters and the sons-in-law and five "grandies" who joined us since starting the thesis, my sincere thanks and gratitude for allowing me valuable time to meet my commitments and finish what I set out to do and share.

List of abbreviations

95% CIs	95% confidence intervals
Aboriginal	Aboriginal and/or Torres Strait Islanders
ABS	Australian Bureaus of Statistics
ACaDS	Advanced Cancer Data System
ACoRG	Aboriginal Community Reference Group
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIHW	Australian Institute of Health and Welfare
AUD	Australian dollars
CALD	Culturally and Linguistically Diverse
CanDAD	Cancer Data and Aboriginal Disparities
CINSW	Cancer Institute of New South Wales
CoP	Community of Practice
ED	Emergency Department
GBD	Global Burden of Disease
HALE	Health adjusted life expectancy, also known as healthy life expectancy
HPC	Health Performance Council
HRQoL	Health related quality of life
HTA	Health Technology Assessment
HTSA	Health Translation South Australia
IHME	Institute for Health Metrics and Evaluation
LHN	Local Health Network
LYAR	Life years at risk
MADIP	Multi-Agency Data Integration Project
MIR	Mortality to Incidence Ratio
MRFF	Medical Research Future Fund
NDIS	National Disability Insurance Scheme
NHA	National Healthcare Agreement
NHS	National Health Service
NHPF	National Health Performance Framework
NHRA	National Health Reform Agreement 2020-2025
NSW	New South Wales
NSWCR	New South Wales Cancer Registry
OECD	Organisation for Economic Co-operation and Development
OR	Odds Ratio

PAF	Performance and Accountability Framework
PCCMF	Prevention and Chronic Condition Management Fund
PHN	Primary Health Network
PPH	Potentially preventable hospitalisation
PREMIER	PREmature Mortality to IncidencE Ratio calculated as YLL/LYAR for each case
$PREMIER_{cancer\ 24\text{-}months}$	PREmature Mortality to IncidencE Ratio up to 24-months after diagnosis calculated as $YLL_{cancer\ 24\text{-}months}$/LYAR for each case
$PREMIER_{cancer}$	PREmature Mortality to IncidencE Ratio calculated as YLL_{cancer}/LYAR for each case
PROM	Patient Reported Outcome Measure
PYLD	Years lived with prevalent disease and injury related disability
SA	South Australia
SAAHS	South Australian Aboriginal Health Survey
SACR	South Australian population Cancer Registry
SAPC	South Australian Productivity Commission
UK	United Kingdom
US	United States
WHO	World Health Organization
YLD	Years Lived with Disability
YLL	Years of Life Lost
$YLL_{cancer\ 24\text{-}months}$	Years of Life Lost associated with cancer death up to 24-months after diagnosis
YLL_{cancer}	Years of Life Lost associated with cancer death
YNLHN	Yorke and Northern Local Health Network

Chapter 1 Introduction

1.1 Introduction

A health system's (1) fundamental purpose is to contribute to maintaining or improving the health outcomes of the population it serves (2-5). Systems pursue this purpose by responding to a diverse array of health needs (3, 6) and delivering health related interventions to people and populations. These activities consume substantial resources and governments play an important role in administering and funding health systems. Spending on health more than doubled in real terms in the two decades to 2019 and now accounts for 9.8% of global gross domestic product (7). Around 80% of that health spending is concentrated in high income countries where governments budget for 70% or so of health expenditures. For example, recent Australian dollar (AUD) estimates of annual spending on health goods and services exceeded AUD$202 billion in 2020-21, 70% of which was contributed by the Australian Government (AUD$86 billion) and state and jurisdiction governments (AUD$56 billion collectively) (8). South Australia (SA) is one of those jurisdictions and currently budgets almost AUD$3.7 billion per annum toward health service costs (9) and does so in a highly constrained budgetary context (10). In providing these resources, governments frequently declare a commitment to a health system that is coordinated and sustainable so as to ensure the ability to meet changing health needs of the people, patients and populations who make up their constituent community (11).

1.1.1 Person-centred health systems

Many health systems have adopted the term Patient-Centred, or Person or People-Centred care (12, 13), to describe the necessity of recognising that health needs are experienced by *people*. The World Health Organization (WHO) consequently advocate for "… a fundamental shift in the way health services are funded, managed and delivered … shifting away from health systems designed around diseases and health institutions *towards health systems designed for people* (italics added)" (12, p1). This approach echoes the belief that "care is better when it recognises what patients' problems are rather than what the diagnosis is" (14, p63). The

Organisation for Economic Co-operation and Development (OECD) also advocate a person-centred approach requires greater accountability by health systems to the people using the system (13).

The US Institute of Medicine was the first to assert patient-centredness constitutes a fundamental principle of a high-quality, world-class health system (15-17). Australia adopted a similar stance in asserting a person-centred approach is a "core principle of the national health reforms" (18, p2). Patient-centred care subsequently became the subject of the Australian Commission on Safety and Quality in Health Care's (ACSQHC) first body of work (17). Adoption of this principle by Australian states and territories followed and is illustrated by SA Health, South Australia's lead health agency, commitments to transform care delivery in a person-centred manner (19).

1.1.2 Person-centred health need

If the health system's purpose and a person-centred approach means addressing a person's health needs when required, then how might "health need" be conceptualised? Health need is often referred to yet rarely defined explicitly in policy documents and funding agreements. Culyer and Wagstaff offered an initial definition whereby a person's current health status represents their need for healthcare (20). However, this overlooks the potential benefit of preventive care and the fact that not all conditions are treatable. A more widely preferred definition of need is Culyer's subsequent instrumental approach stating that the "capacity to benefit is … a condition for a need for health care to exist" (21, p148). That is, assessing whether or not need exists begins with describing the size of a health problem among people (22), then considering whether a person will be better off with a healthcare intervention than without it (23). The nature and form of healthcare intervention appropriate, or needed, will vary too. For example, the need associated with preventing disease might refer to changing the level of exposure to health determinants and risks. For instance, changed dietary practices and body mass index may be needed to prevent diabetes. A different form of care is needed where acute

conditions occur, as in the case of antibiotics and wound care for an incidence of cellulitis in a person living with diabetes. Where diabetes as a chronic condition persists, a longer-term management plan will be needed. Should diabetic neuropathy eventuate and amputation occur, the healthcare need may further develop to include rehabilitation to address functional loss. Being better off then, may refer to extending life, reducing health status deterioration, promoting health and avoiding unnecessary interventions. On this basis, "capacity to benefit could plainly … be used as a principle for allocating health care" (21, p148).

Adopting a capacity to benefit perspective to meeting health need offers a concrete, action-oriented and responsive approach. Associated with this is a general acceptance that three broad criteria should be considered when organising healthcare to meet people's needs (23, 24). Health interventions must first be *effective*. Given there will never be enough resources available to realise all health potential, decision-making demands choosing between candidate interventions (25) and makes *efficiency* a second criterion. Choices based on efficiency would suggest preferencing interventions where average cost to effectiveness ratios and the cost of achieving the next increment in health gain are acceptable. In practice though, people's capacity to benefit is unevenly or inequitably distributed within populations. This points to *equity* as a further consideration in decision-making (26). These criteria of effectiveness, efficiency and equity are useful touchstones to adopt in assessing discourse, decisions and actions within the healthcare system (23, 27, 28). While the three may often complement one another, they may also conflict. For example, occasions may arise when it is preferable to reduce inequities experienced by particular people rather than exclusively pursuing maximum health gains averaged across the wider community (23). Hence, effectiveness, efficiency and equity are also desirable dimensions of metrics used in monitoring and evaluating the performance of the healthcare system.

Person-centredness and health needs focussed care might be core principles in health systems yet the WHO acknowledges an integrated, person-centred approach represents a new field of health indicator work. This is because indicators measuring outcomes of importance to people

(29) and resulting from integrated, people-centred health services are lacking (12). For example, none of the WHO affiliations through the Global Health Observatory (30), the monitoring and evaluation frameworks for universal health coverage and the Sustainable Development Goals, or the Global Reference List of 100 Core Health Indicators (31) include person-centred measures. The WHO now proposes a body of research and developmental work on indicators tracking global progress on integrated, people-centred health services. In turn the WHO will draw together international partners to develop appropriate metrics for these critical, but less frequently measured domains of health care (12). Implementing such an approach needs monitoring. The OECD is blunt in their recent assessment on progress made in reporting that "indicators for people-centredness are still vastly insufficient" (13, p7).

In practice, the need for healthcare is very often measured empirically by ill-health because of data availability, ease of measurement and the assumption that current health status is a reasonable indicator of health need. For example, a person with poor health and a chronic illness is general accepted as being in more need of healthcare than a person with good health and no illness (2). For this reason, assessments of health system performance often begin with describing population health status (32), often using summary measures of health which enable comparisons across time and across population groups.

1.1.3 Summary measures of health status

Health adjusted life expectancy (HALE), or healthy life expectancy as it is also referred to, is one such summary measure of population health status. Healthy life expectancy describes the number of years a person can expect to live in good health, free of disease and injury (33-36). The calculation of healthy life expectancy requires two age-specific data components for a population in a given time period: mortality rates and measures of morbid health status (37, 38). The latter comprises a systematic approach to describing health states and assessing exposure to those health states (37, 39). Some expert commentators refer to HALE as the best

overall health status indicator (33) because it can be disaggregated by: quantity and quality of life; sex and age; and contributing disease related conditions and risk factors (6, 33, 40-42).

Healthy life expectancy is widely reported at global, regional and national levels (6) through the WHO (7), the OECD (43) and the Institute for Health Metrics and Evaluation (IHME) (44). The latter's principals substantially contributed to methodological and data developments through a Global Burden of Disease (GBD) framework. Australia was at the forefront of emerging national (45-48) and sub-national (41, 49-54) production of healthy life expectancy estimates using the burden of disease framework, albeit this has been sporadic due to reliance on funding across multiple government departments. South Australia adapted the national burden of disease work and established an internally consistent collection of summary health measures which could be refreshed annually using local administrative records to monitor changing healthy life expectancy (55, 56).

1.1.4 Health system performance in Australia

Health systems exist to address health need, receive large amounts of funding to do so, and warrant routine evaluation of performance. In Australia two frameworks have guided formal evaluation of health system performance: the National Health Performance Framework (NHPF) (57, 58) and the Performance and Accountability Framework (PAF) (59). The NHPF gives a structure for reporting and developing performance indicators for particular programs and/or specific population sub-groups. It does this by facilitating comparison and subsequent discussion about three domains: Health status; Health determinants; and System performance (see Figure 1.1). In practice, Australia's National Health Reform documents (4, 5) ultimately describe the NHPF's role as measuring health status.

In assessing facets of health status, the NHPF includes a health status description *'How healthy are Australians?';* encourages consideration of effective, appropriately priced interventions being available for conditions *'Where are the best opportunities for improvement?'*; and, whether opportunity exists to act on health inequities *'Is it the same for everyone?'.* That is,

the NHPF asks where there is further capacity to benefit from healthcare. In response, the Australian Institute of Health and Welfare (AIHW) and Australian Bureau of Statistics (ABS) produce a substantial literature using many health metrics. Historically, these have focussed on mortality using life expectancy trends by sex, age and level of geography (jurisdictions, area level socio-economic position and remoteness for example) with supplementary data describing the underlying causes of death.

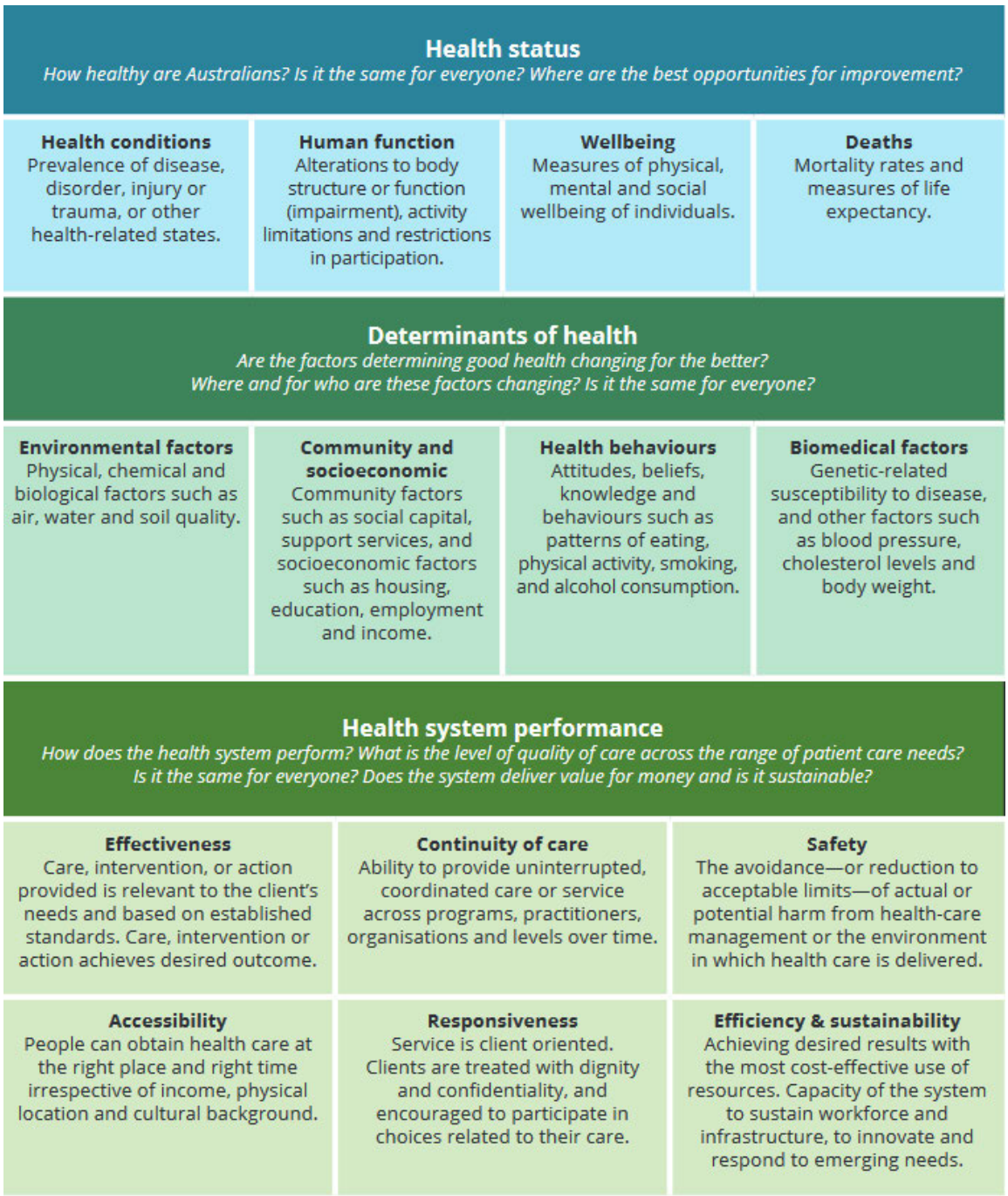


Figure 1.1: The National Health Performance Framework (2nd Edition) (57)

There is currently no routinely reported measure summarily describing disease and illness and consequent severity or morbid influence on perceived health related quality of life (HRQoL) (60) in the Australian community. Instead, a range of illness descriptions draw on: disease registries (for example, cancer and renal dialysis); population surveys (diabetes, psychological distress, and behavioural risk exposures for instance); and administrative records (such as hospitalisation as an expression of morbidity (61)). If the health system's activities are to align with continually shifting influences on peoples' quantity and quality of health outcomes, there is a clear challenge to simultaneously assess the effects of death and illness (62). While this lack of information presents a risk to informed decision-making, the burden of disease method responds to this challenge. Moreover, the latter measures are intended for use in priority setting and evaluation in response to observed needs (63). Australia has piloted used of the measures in this way (64, 65). That is, healthy life expectancy may provide a suitable, summary measure for describing the population health status domain in the NHPF.

The NHPF's second domain considers health determinants, while a third domain focusses on the health system's performance in attending to health need among patients and populations. In practice, the latter domain of assessing system performance at local levels is the remit of the PAF (59). The relationship between the two frameworks is designed to be seamless and presumably this signals the intent for directly relating health outcomes to system activities. In practice however, there are considerable methodological challenges in attributing health status change to particular policies and practices (32). These challenges include the lag between introducing a policy or treatment and observing change in mortality outcomes. For example, the time lapse between supporting smoking cessation and changes in death from lung cancer can be decades. Such distance between action and outcome discourages accountability.

Instead, the PAF and its suite of health indicators intentionally avoid describing outcomes for individuals and feature performance information at organisation levels to support comparison and choice by individual consumers. In fact, the emphasis on organisational activity and output is *so* great that a commissioned review of performance indicators on healthcare organisations,

and prepared for the National Health Performance Authority, made no reference at all to the NHPF or health status in Australia (24). In the few occasions where the PAF does report on population health outcomes, the measures are intended for Primary Health Networks (PHN). PHNs administer health programs that increase the coordination of medical services for patients in support of general practice as distinct from accounting for performance. Among Local Health Network (LHN) reports, several outcome measures are used however, these principally refer to deaths in hospital and hospital acquired infections. While valid, these measures give the impression of being defensive indicators of health maintained, or risk mitigated, rather than indicators of proactive, health restoring actions.

1.1.5 Health system performance measurement in South Australia

While fully participating in national health reporting, the South Australian government devised a comprehensive, state-wide Strategic Plan (66-68) covering many facets of community life from growing prosperity, creativity and innovation to improving wellbeing. The Plan also embraced a goal focussed approach to health outcomes throughout the population. The inaugural plan (66) targeted ambitious but achievable gains in healthy life expectancy for the whole of the South Australian population as Target 2.2 (Table 1.1). The first review of the Plan (67) retained healthy life expectancy measures and added a specific target for reducing the health expectancy inequalities between Aboriginal (new Target T2.5) and other South Australians (Target T2.4) (66). A community review of the indicators endorsed the continued use of healthy life expectancy measures (69) which were subsequently retained in the revised Plan as Targets 78 and 79 (68). This meant healthy life expectancy became embedded in the overarching framework for aligning SA Health's service activities, budgets, policy making and legislative agenda with health outcomes in the population.

Each of these areas of service activity aimed to contribute directly, or indirectly to these specific targets (70) in a logical and evidence-based manner. Monitoring and reporting on specific performance measures, or headline indicators, was also initiated to help align activities with

these strategic goals (24, 71, 72). In the case of healthy life expectancy SA Health's headline indicators included:

- Incidence of potentially avoidable and premature mortality (73);
- Prevalence and severity of illness; and
- Potentially preventable hospitalisations (PPH) for targeted diseases and conditions (70, 74).

Table 1.1 Population health targets in South Australia's Strategic Plan (SASP) 2004 (66), 2007 (67) and 2011 (68) and related health department performance measures

Strategic Objective 2: Improving wellbeing		
SASP Target:	**Healthy South Australians**	**Aboriginal healthy life expectancy**
2004 inaugural plan	Target 2.2: Increase healthy life expectancy of South Australians to lead the nation within 10 years.	Not included
2007 revised plan	Target 2.4: Increase the healthy life expectancy of South Australians by 5% for males and 3% for females by 2014[1].	Target 2.5: Lower the morbidity and mortality rates of Aboriginal South Australians.
2011 revised plan	Target 78 - Increase the healthy life expectancy of South Australians to 73.4 years (6%) for males and 77.9 years (5%) for females by 2020. [2]	Target 79 - Increase the average healthy life expectancy of Aboriginal males to 67.5 years (22%) and Aboriginal females to 72.3 years (19%) by 2020. [3]
Related headline indicators and performance measures (70, 75, 76):		
	Incidence of mortality in the South Australian population	Mortality rates of Aboriginal South Australians
	Prevalence and severity of illness (morbidity) in the South Australian population	Morbidity rates of Aboriginal South Australians
	Potentially preventable hospitalisations for targeted diseases and conditions.	Selected potentially preventable hospital admissions rate by Indigenous status (for acute, chronic and vaccine preventable diagnoses).

[1] The modified target sets a South Australian-specific level.

[2] The target was modified to be more specific. The intent of the target did not change.

[3] The target modified to be more specific and align with the National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes. The intent of the target did not change.

Subsequent commissioning of services were to refer to assessed population need in these areas and prioritising health outcomes (77) with the explicit aims of maximising health outcomes and reducing inequalities (71, 72, 78, 79). The means of trading-off, or harmonising, these two

aims was not defined but several descriptive analyses focussed on the relevant performance measures to supplement the published policy documents (56, 80-82). The objective of these analyses was to support decision-making and planning implementation by describing regional variations (56) in premature mortality observed among South Australia's Indigenous community (80, 81) and a risk profile of PPH among South Australians (82). To further support service commissioning, a systematic approach to linking effective, efficient and equitable health system activities with population healthy life outcomes was adapted and piloted for the (South) Australian context (83). The approach included an illustrative case study based on primary care management after cardiac episodes (84). This involved: accounting for population healthy life expectancy across population groups; estimating average and group specific health gains from health programs; evaluating health gains against health system costs in population subgroups; summarising relevant information about candidate intervention programs within a multi-criteria performance matrix for decision makers; reassessing outcomes (and processes) following implementation. Other related analyses: decomposed health expectancy change (85); and, identified population strata for targeting tailored, or modified, interventions (86, 87).

These analyses were generally well received and facilitated some discussion on advocacy and resource allocation to target services as hoped for in a population health approach (88, 89). Specialist audiences were particularly enthusiastic (80, 85-87, 90-94) yet there was comparative silence from within the South Australian health portfolio. In part, this suggested a reluctance to engage directly with a complex measure involving multiple underlying components, namely quantity of life and quality of life. It also highlighted a persisting limitation in systematically linking indicators and decision-making processes (95).

On one hand, strategic healthy life expectancy targets were set and these targets resonated with the wider community. Relevant, supporting headline indicators were also established from within the health portfolio. On the other hand, the strategy and its indicators remained disconnected from real-world, operational settings in which service-related planning, decision-making and delivery occurs.

A fruitful approach to resolving this tension is to identify, then act on, points of common interest. Common interests strategically *and* operationally are the people who make up the community and who are the focus of the health system and its activities. Making changed measurements in health performance more attractive to, and useable by, decision-making processes include at least two facets. Firstly, the measures must represent people's need for health services as discussed above and an ability to reflect changes in need resulting from service delivery. They must also help inform decision-making in response to current system challenges. Such challenges may include issues raised by key stakeholders while developing policies and plans, or they could be publicly acknowledged impediments to health system improvement.

Publicly identifying issues, challenges and opportunities facing the health system are part of the remit for South Australia's Health Performance Council (HPC). The HPC is an advisory body providing independent advice and formal reporting on South Australia's health system to the Minister for Health and tabling in the South Australian Parliament (96). Under South Australia's Health Care Act 2008, the HPC must formally assess the changing health outcomes of South Australians across each of its 4-yearly reports (97). The HPC examines community health status, uses NHPF domains to guide their assessment of the health system's response to health needs and emerging priorities (98), then advises the Minister on areas requiring improvement.

The HPC noted systemic failures in reaching targets set, failures which demonstrated a lack of cohesiveness in implementing then monitoring well devised plans. Consequently, HPC's 2011-2014 review (98) highlighted specific, current challenges and areas of potential improvement. Those challenges relating to health outcome assessment are summarised in Table 1.2. Each of these challenges represent, or is associated with, an unmet information need.

Table 1.2: Alignment between Health Performance Council identified health system challenges in South Australia, and their associated, unmet information needs

	Challenges for the health system	Information needs and actions
1	Reduce inequities in avoidable mortality, particularly between Aboriginal and non-Aboriginal populations;	Pursue data, analyses and valid measures informing and monitoring strategies to close gaps in potentially avoidable mortality.
2	Develop data assets and pursue analysis of clinical, administrative and population health data to inform decision-making and continuous improvement. Specifically:	Initiate surveillance methods and analyses providing valid and reliable reports on comparative health needs between and within population groups.
	a. Develop existing datasets to meet information needs, for example, improving core items on the SA population Cancer Registry (SACR);	Create new value from existing SACR holdings by linking with Australian Bureau of Statistics (ABS) Cause of Death Unit Record files and staging tumours.
	b. Bridge data gaps to better describe health outcome variations among vulnerable people and enable identification of progress or problems; and	Make fuller use of existing data holdings for reporting and monitoring outcomes for individuals and the population groups to whom they belong.
	c. Supplement SA Health data collection with purposeful sampling and reporting focussed on specific groups of people in the community;	Grow expertise in population health surveys to provide valid, reliable comparison of health needs among priority groups and wider population.
3	Increase vulnerable* people's access to and equitable gains from healthcare interventions;	Provide baseline evidence of variations in vulnerable peoples' capacity to benefit from health care interventions from which to track change over time as relevant strategies are developed and applied.
4	Provide an integrated approach to implementing and monitoring the Aboriginal Health Care Plan (72) to improve health status;	Provide valid, reliable and sustainable measurements of health status components across time and throughout the population.
5	Investigate primary and community care sector actions to reduce potentially preventable hospitalisations (PPHs) among Aboriginal and vulnerable people to meet healthcare needs at an earlier, less costly time.	Further develop information on hospital contacts (emergency and inpatient) categorised as "unnecessary" (for example, ambulatory care sensitive conditions or potentially preventable contacts).
6	Improve hospital length of stay by identifying people who can be better cared for in non-acute hospital settings;	Develop reliable baseline estimates of the number and attributes of people experiencing hospitalisations and the amount of hospital stays and costs involved with which to track change over time as relevant intervention strategies are developed and applied.

*Includes: the aged; people from culturally and linguistically diverse (CALD) communities, refugee and asylum seekers; rural and remote communities; and Aboriginal people

This introductory material identified: avoidable, premature mortality; illness prevalence and severity; and, hospital contact potentially amenable to primary and community care as outcome areas describing people's capacity to further benefit from person-centred healthcare. It also noted the gap between reporting frameworks and systematically linking organisational activity with outcomes of importance to people. Finally, it summarised contemporary areas for health system improvement and their relationship to specific people and populations.

This thesis focusses on outcome measurements relevant to healthy life expectancy as South Australia's overarching population health target and specifically, to the three headline performance areas underlying health expectancy. The thesis reorients reporting on these areas with the aim of linking healthcare activity and outcomes for the people the system serves, particularly in those areas of improvement highlighted by the HPC. A person-centred approach places the person and their experience of health need at the centre of performance reporting. Consistency between person-centred performance monitoring and person-centred practice will help align healthcare resourcing, activity and outcomes with those having the capacity to benefit from healthcare.

1.2 Thesis outline

The research in this thesis aims to improve clarity and application of system performance assessments to strategic and operational goals. This is achieved by reorienting measures toward the person receiving healthcare and outcomes of importance to them. Analyses presented relate to SA Health performance indicators underpinning targeted improvement of healthy life expectancy and current opportunities for health system improvement identified by the HPC and advised to the South Australian Minister for Health. The analyses take the form of discrete studies addressing those performance measurement opportunities by:

i. Reframing premature mortality measures to account for survival time from disease detection until death;

ii. Extending morbidity measurement to describe and value a person's self-reported state of health; and

iii. Enhancing enumeration of people experiencing potentially preventable hospital contact, firstly by way of Emergency Department (ED) presentations, then as inpatient stays.

The first study uses the example of cancer care where mortality outcomes are typically reported as the percentage of people surviving 5-years after diagnosis. The study contributes a new measure within a burden of disease framework by developing, then applying a novel person-centred measure of mortality burden. It does this by taking account of age at diagnosis and death, both of which are routinely available on cancer registries, a person-centred approach can reorient reporting to take account of opportunities for health system intervention. Such an approach will help identify people with the greatest capacity to benefit from earlier cancer detection and treatment and reducing avoidable, premature mortality. Reducing premature mortality after a cancer diagnosis measures something of fundamental importance (99) to the person at the centre of the diagnosis.

In the area of the prevalence and severity of morbid illness, estimates traditionally rely on survey participants rating their general health status on an ordinal scale in response to a single question (2). This approach is outmoded as it provides little or no detail on the most salient aspects of the condition to the person (100), how those aspects influence a person's perception of HRQoL (60), or how the quantum of illness and related experiences are changing in the community. Such information is pivotal to communication and collaboration whether in planning or delivering person-centred health care. Improved measures for surveys focussed on specific people's healthcare needs and contributors to variations in their health outcomes are required.

The second study in this thesis makes a novel contribution by including a person reported outcome measure (PROM) within South Australia's first, Aboriginal specific population survey. PROMs ask a person to assess elements of their own HRQoL (101). The results demonstrate the value of those self-reports in describing disparities in health need across groups of people and in the presence of chronic health conditions. Moreover, the survey sample is unique as respondents are drawn from some of SA's most disadvantaged communities - communities which are routinely under-represented and under-reported (98).

The final area is that of hospital contact amenable to alternative services in the community and primary care. The AIHW report publicly on population level PPH by categories of area disadvantage and geographic remoteness (102). However, the system performance measures adopted in the National Healthcare Agreement (NHA) are based on the percentage of hospital inpatient volume categorised as PPHs. This approach flows through to service performance agreements between the (SA) Department for Health and Wellbeing and local area health administrations (103-108) and illustrates one way in which performance becomes anchored against volume rather than people.

Studies three and four consider PPH in ED and inpatient settings respectively. Those studies extend current performance measurement in the system by shifting analyses from PPH as a proportion of service activity in order to demonstrate a person-centred approach. Such an approach uses data linkage to count the people experiencing PPH service contacts, and the frequency and nature of the events they experience. A person-centred approach also enables people to be grouped in new ways that are relevant to contemporary population health needs such as understanding the health and service needs of new residents from refugee and asylum-seeking backgrounds. Improving the health system's understanding on these points will inform and reorient service responses addressing unmet need for effective primary and community health care among particular people groups.

1.3 Referencing in this thesis

Chapters 2-5 include peer-reviewed manuscripts. References for those chapters are included within the reproduced manuscripts. Consistent with this, references for Chapters 1 and 6 are provided at the end of those chapters.

References

1. Arah OA, Westert GP, Hurst J, Klazinga NS. A conceptual framework for the OECD Health Care Quality Indicators Project. International Journal for Quality in Health Care. 2006;18(Suppl 1):5-13.

2. Allin S, Hernandez-Quevedo C, Massiera C. Measuring equity of access to health care. In: Smith PC, Mossialos E, Papanicolas I, Leatherman S, editors. Performance measurement for health system improvement: Experiences, challenges and prospects. Cambridge: Cambridge University Press; 2009. p. 187-221.

3. World Health Organization. The World Health Report 2000: Health systems - Improving performance. Geneva: WHO; 2000.

4. Council of Australian Governments. National Health Reform Agreement. Canberra: Australian Government; 2011.

5. Council of Australian Governments. The National Health Reform Agreement - National Partnership Agreement on Improving Public Hospital Services. Canberra: Australian Government; 2014.

6. Murray CJL, Vos T, Lozano R, Naghavi M, Flaxman AD, Michaud C, et al. Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. The Lancet. 2012;380(9859):2197-223.

7. World Health Organization. World health statistics 2022: monitoring health for the SDGs, sustainable development goals. Geneva: World Health Organization Licence: CC BY-NC-SA 3.0 IGO; 2022.

8. Australian Institute of Health and Welfare. Health expenditure Australia 2019–20. Canberra: AIHW; 2021 17 December 2021.

9. Department of Treasury and Finance. 2021–22 Budget Paper 4, Agency Statements, Volume 3. Adelaide: Government of South Australia; 2022.

10. Sustainable Budget Commission. Sustainable Budgets: Principles and Processes. Adelaide: Government of South Australia; 2009.

11. Australian Government. Australian Government 2015-16 Health Portfolio Budget Statements. Canberra: Australian Government; 2015.

12. World Health Organization. Framework on integrated, people-centred health services: Report by the Secretariat. Geneva: World Health Organization; 2016.

13. Organisation for Economic Co-operation and Development. Health for the People, by the People: Building People-centred Health Systems. Paris: OECD; 2021.

14. Starfield B. Is Patient-Centered Care the Same As Person-Focused Care? The Permanente Journal. 2011;15(2):63-9.

15. Institute of Medicine. Vital Signs: Core Metrics for Health and Health Care Progress. Washington: National Academies Press; 2015.

16. SA Health. Transforming Health: Discussion Paper. Adelaide: Government of South Australia; 2014.

17. Australian Commission on Safety and Quality in Health Care. Patient-centred care: Improving quality and safety through partnerships with patients and consumers. Sydney: ACSQHC; 2011.

18. Australian Health Ministers. Australian Health Ministers' Conference communiqué. Canberra: Australian Government; 2011.

19. SA Health. Transforming Health: Proposals Paper. Adelaide: Government of South Australia; 2015.

20. Culyer AJ, Wagstaff A. Equity and equality in health and health care. Journal of Health Economics. 1993;12(4):431-57.

21. Culyer A. Need: the idea won't do - but we still need it. In: Cookson R, Claxton K, editors. The humble economist: Tony Culyer on health, health care and social decision making: York: University of York and Office of Health Economics; 2012. p. 133-52.

22. Marshall T, Hothersall E. Needs assessment. In: Glasby J, editor. Commissioning for health and well-being: An introduction. Bristol: Policy Press; 2012. p. 43-52.

23. Begley CE, Lairson DR, Morgan RO, Rowan PJ, Balkrishan R. Evaluating the healthcare system: Effectiveness, efficiency and equity. 4th ed. Chicago: HAP & AUPHA; 2013.

24. Hibbert P, Hannaford N, Long J, Plumb J, Braithwaite J. Final Report: Performance indicators used internationally to report publicly on healthcare organisations and local health systems. Sydney: Australian Institute of Health Innovation; 2013.

25. Drummond MF, Sculpher MJ, Torrance GW, O'Brien BJ, Stoddart GL. Methods for the Economic Evaluation of Health Care Programmes. 3rd ed. New York: Oxford University Press; 2005.

26. Braveman P. Health disparities and health equity: Concepts and measurement. Annual Review of Public Health. 2006;27:167-94.

27. Tugwell P, de Savigny D, Hawker G, Robinson V. Applying clinical epidemiological methods to health equity: the equity effectiveness loop. BMJ. 2006;332(7537):358-61.

28. Welch V, Tugwell P, Morris EB. The Equity-effectiveness Loop as a Tool for Evaluating Population Health Interventions. Revista de salud pública. 2008;10(Suppl 1).

29. Porter ME, Lee TH. The strategy that will fix health care. Harvard Business Review. 2013;91(10):50-70.

30. World Health Organization. The Global Health Observatory Geneva: WHO; 2022 [Available from: https://www.who.int/data/gho].

31. World Health Organization. 2018 Global Reference List of 100 Core Health Indicators (plus health-related SDGs). Geneva: WHO; 2018.

32. Smith PC, Papanicolas I. Health system performance comparison: an agenda for policy, information and research. Regional Office for Europe: World Health Organization; 2012.

33. Smith JN. Epic measures. New York: HarperCollins; 2015.

34. International Epidemiological Association, World Federation of Public Health Associations. Sustainable Development Goals for Health Joint Statement by the International Epidemiological Association (IEA) and World Federation of Public Health Associations (WFPHA) 2015 [Available from: http://ieaweb.org/sustainable-development-goals-for-health-joint-statement-by-the-iea-and-wfpha/].

35. Nolte E, Bain C, McKee M. Population health. In: Smith PC, Mossialos E, Papanicolas I, Leatherman S, editors. Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects. Cambridge: Cambridge University Press; 2009. p. 27-62.

36. Kyu HH, Abate D, Abate KH, Abay SM, Abbafati C, Abbasi N, et al. Global, regional, and national disability-adjusted life-years (DALYs) for 359 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. The Lancet. 2018;392(10159):1859-922.

37. Berthelot J-M. Health-adjusted life expectancy (HALE). In: Robine J-M, Jagger C, Mathers C, Crimmins EM, Suzman R, editors. Determining health expectancies. Chichester: Wiley; 2003. p. 235-46.

38. Sullivan D. A single index of mortality and morbidity. HSMHA Health reports. 1971;86(4):347-54.

39. Mathers CD, Murray CJ, Salomon JA. Methods for Measuring Healthy Life Expectancy. Health Systems Performance Assessment: Debates, Methods and Empiricism. Geneva: WHO; 2003.

40. Zhao Y, Wright J, Begg S, Guthridge S. Decomposing the Indigenous life expectancy gap by risk factors: a life table analysis. Population Health Metrics. 2013;11(1):1.

41. Begg S, Bright M, Harper C. Burden of disease and health-adjusted life expectancy in Health Service Districts of Queensland Health, 2006. Brisbane: Queensland Health; 2009.

42. Banham D, Woollacott T, Lynch J. Healthy life gains in South Australia 1999-2008: analysis of a local Burden of Disease series. Population Health Metrics. 2011;9:13.

43. Organisation for Economic Co-operation and Development. OECD Family Database Paris OECD; 2015 [Available from: http://www.oecd.org/social/family/database.htm #INDICATORS].

44. Institute for Health Metrics and Evaluation. The Global Burden of Disease: Generating Evidence, Guiding Policy. Seattle: IHME; 2013.

45. Mathers C, Vos T, Stevenson C. The Burden of Disease and Injury in Australia. Canberra: AIHW; 1999.

46. Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez AD. Burden of Disease and Injury in Australia, 2003. Canberra: AIHW; 2007. Report No.: PHE 82.

47. Australian Institute of Health and Welfare. Australian Burden of Disease Study: Fatal burden of disease 2010. Canberra: AIHW; 2015. Report No.: Cat. No. BOD 1.

48. Australian Institute of Health and Welfare. Australian Burden of Disease Study: Fatal burden of disease in Aboriginal and Torres Strait Islander people 2010. Canberra: AIHW; 2015. Report No.: Cat. No. BOD 2.

49. Department of Human Services. The Victorian Burden of Disease Study: Mortality. Melbourne: Public Health and Development Division, Department of Human Services; 1999.

50. Department of Human Services. Victorian Burden of Disease Study: Morbidity. Melbourne: Public Health and Development Division, Department of Human Services; 1999.

51. Somerford P, Katzenellenbogen J, Codde J. Burden of Disease in Western Australia: An Overview. Bulletin no. 1. Perth: Department of Health; 2004.

52. Pike A, Baade P, Harper CM, Muller S, Kennedy B. Quantifying the burden of disease and injury in Queensland 1996-1998. Information Circular. 2002;61:1-11.

53. Zhao Y, Guthridge S, Magnus A, Vos T. Burden of disease and injury in Aboriginal and non-Aboriginal populations in the Northern Territory. Med J Aust. 2004;180(10):498-502.

54. Zhao Y, You J, Guthridge S. Burden of disease and injury in the Northern Territory, 1999-2003. Darwin: Department of Health and Families; 2009.

55. Department for Health and Ageing (South Australia). South Australian Burden of Disease website Adelaide, SA: SA Health; 2010 [Available from: www.sahealth .sa.gov.au/ burdenofdisease].

56. Department of Health. Population Health in South Australia: Burden of Disease & Injury estimates 1999-2001. Adelaide: Government of South Australia; 2005.

57. National Health Information Standards and Statistics Committee. The National Health Performance Framework (2nd Edition). Canberra: AIHW; 2009.

58. National Health Performance Committee. National health performance framework report. A report to the Australian Health Ministers' Conference. Brisbane: Queensland Health; 2001.

59. National Health Performance Authority. National Health Reform: Performance and Accountability Framework. Canberra: NHPA; 2013.

60. Leidy NK, Revicki DA, Genesté B. Recommendations for Evaluating the Validity of Quality of Life Claims for Labeling and Promotion. Value in Health. 1999;2(2):113-27.

61. Taylor R. Measurement of population morbidity. In: Kerr C, Taylor R, Heard G, editors. Handbook of public health methods. Sydney: McGraw-Hill; 1998. p. 52-6.

62. Australian Institute of Health and Welfare. Australia's health 2014. Canberra: AIHW; 2014 2014. Report No.: Australia's health series no. 14. Cat. No. AUS 178.

63. Mathers C, Vos T, Lopez A, Salomon J, Ezzati M. National Burden of Disease Studies: A Practical Guide. 2.0. Global Program on Evidence for Health Policy ed. Geneva: World Health Organization; 2001.

64. Carter R, Vos T, Moodie M, Haby M, Magnus A, Mihalopoulos C. Priority setting in health: origins, description and application of the Australian Assessing Cost-Effectiveness initiative. Expert Rev Pharmacoecnomics Outcomes Res. 2008;8(6):593-617.

65. Vos T, Carter R, Barendregt J, Veerman J, Magnus A, Cobiac L, et al. The Assessing Cost-Effectiveness in Prevention (ACE-Prevention): Final Report. Brisbane, Melbourne: University of Queensland, Deakin University; 2010.

66. Department of Premier and Cabinet. South Australia's Strategic Plan. Adelaide: Government of South Australia; 2004.

67. Department of Premier and Cabinet. South Australia's Strategic Plan: the updated plan 2007. Adelaide: Government of South Australia; 2007.

68. Department of Premier and Cabinet. South Australia's Strategic Plan 2011. Adelaide: Government of South Australia; 2011.

69. Department of Premier and Cabinet. South Australia's Strategic Plan: Preliminary Community Engagement Report. Adelaide: Government of South Australia; 2006.

70. Department of Health. SA Health Strategic Plan 2008-2010: Extended to June 2014. Adelaide: Government of South Australia; 2008.

71. SA Health. Primary Prevention Plan 2011-2016. Adelaide: Government of South Australia; 2011.

72. South Australian Department of Health. Aboriginal Health Care Plan 2010-2016. Adelaide, SA: Department of Health, Statewide Service Strategy Division; 2010.

73. Public Health Information Development Unit. A Social Health Atlas of South Australia, 2010. Adelaide: PHIDU; 2010.

74. Page A, Ambrose S, Glover J, Hetzel D. Atlas of Avoidable Hospitalisations in Australia: ambulatory sensitive conditions. Adelaide: PHIDU; 2007.

75. Department of Health. SA Health Strategic Plan 2007-2009. Adelaide: Government of South Australia; 2007.

76. Department of Health. SA Health Strategic Plan 2008-2010. Adelaide: Government of South Australia; 2008.

77. Glasby J, editor. Commissioning for health and well-being: An introduction. Bristol: Policy Press; 2012.

78. O'Brien S, Policy and Commissioning Division. SA Health Clinical Commissioning Framework. Adelaide: SA Health; 2013.

79. O'Brien S, Policy and Commissioning Division. Clinical Commissioning Intentions. Adelaide: SA Health; 2013.

80. Banham D, Jury H, Woollacott T, McDermott R, Baum F. Aboriginal premature mortality within South Australia 1999-2006. Australasian Epidemiologist. 2011;18(2):59.

81. Research and Ethics Policy Unit. Aboriginal mortality in South Australia: A Profile. Adelaide: Department of Health, Government of South Australia; 2010.

82. Banham D, Woollacott T, Gray J, Humphrys B, Mihnev A, McDermott R. Recognising potential for preventing hospitalisation. Australian Health Review. 2010;34(1):116-22.

83. Banham D, Lynch J, Karnon J. An equity–effectiveness framework linking health programs and healthy life expectancy. Australian Journal of Primary Health. 2011;17(4):309-19.

84. Chew DP, Carter R, Rankin B, Boyden A, Egan H. Cost effectiveness of a general practice chronic disease management plan for coronary heart disease in Australia. Australian Health Review. 2010;34(2):162-9.

85. Banham D, Woollacott T, Lynch J. The nature and distribution of healthy life gains in South Australia 1999-2008. Australasian Epidemiologist. 2011;18(2):94.

86. Banham D, Begg S, Nguyen A-MT, Jury H, Woollacott T. Targeting health expectancy gaps in South Australia. 21st meeting of the international network on health expectancy (REVES), Copenhagen; 26-29 May 2009.

87. Banham D, Woollacott T, Barbaro B, van Zanten M. Healthy life expectancy and South Australia's Strategic Plan: A voice for health promotion. 17th National Australian Health Promotion Conference - Grass Roots to Global Action: Health Promotion in Challenging Environments, Adelaide; 1-4 May 2007.

88. Kindig D, Stoddart G. What Is Population Health? Am J Public Health. 2003;93(3):380-3.

89. Australian Healthcare and Hospital Association. Population Health. Canberra: AHHA; 2015. Report No.: 4.

90. Stiefel MC, Perla RJ, Zell BL. A Healthy Bottom Line: Healthy Life Expectancy as an Outcome Measure for Health Improvement Efforts. Milbank Quarterly. 2010;88(1):30-53.

91. Banham D, Lynch J, Karnon J. An Equity-Effectiveness Framework linking health programmes and healthy life expectancy. 7th Health Services and Policy Research Conference, Adelaide; 5-7 December 2011.

92. Banham D, Nguyen A-MT, Woollacott T, McDermott R. Potentially Preventable Admissions to South Australian public hospitals. 7th Health Services and Policy Research Conference, Adelaide; 5-7 December 2011.

93. Banham D. Development and uptake of Burden of Disease work in SA Health. Australasian Epidemiologist. 2011;18(2):29.

94. Banham D, Merlin TL, Woollacott T. Identifying multi-criteria effective strategies to address overweight/obesity in South Australia. AHPA 17th National Conference 2007: Grass Roots to Global Action: Health Promotion in Challenging Environments, Adelaide; 1-4 May 2007.

95. Veillard J, Huynh T, Ardal S, Kadandale S, Klazinga NS, Adalsteinn DB. Making Health System Performance Measurement Useful to Policy Makers: Aligning Strategies, Measurement and Local Health System Accountability in Ontario. Healthcare Policy. 2010;5(3):49-65.

96. Health Performance Council. Annual Report 2013-14. Adelaide: Health Performance Council; 2014.

97. Health Performance Council. Health Performance Council's review of the performance of South Australian health systems, the health of South Australians and changes in health outcomes over the reporting period 2015-2018. Adelaide: Government of South Australia; 2018. Report No.: 18-HPC-1947.

98. Health Performance Council. What's working, what's not: Review of the South Australian Health System Performance for 2011–2014. Adelaide: Government of South Australia; 2014.

99. Gurría A, Porter M. New York: The Huffington Post 2017. Available from: https://www.huffingtonpost.com/oecd/putting-people-at-the-cen_b_14247824.html.

100. Olsson M, Currow DC, Ekstrom MP. Exploring the most important factors related to self-perceived health among older men in Sweden: a cross-sectional study using machine learning. BMJ Open. 2022;12(6):e061242.

101. Williams K, Sansoni J, Morris D, Grootemaat P, Thompson C. Patient-reported outcome measures: Literature review. Sydney: ACSQHC; 2016.

102. Australian Institute of Health and Welfare. Admitted patient care: Australian hospital statistics 2015–16. Canberra: AIHW; 2017. Report No.: AIHW cat. no. HSE 185, Health Services Series no. 75.

103. Department for Health and Wellbeing. Service level agreement for the period of 1 July 2018 - 30 June 2019: Central Adelaide Local Health Network. Adelaide: Government of South Australia; 2018.

104. Department for Health and Wellbeing. Service level agreement for the period of 1 July 2018 - 30 June 2019: Country Health South Australia Local Health Network. Adelaide: Government of South Australia; 2018.

105. Department for Health and Wellbeing. Service level agreement for the period of 1 July 2018 - 30 June 2019: Northern Adelaide Local Health Network. Adelaide: Government of South Australia; 2018.

106. Department for Health and Wellbeing. Service level agreement for the period of 1 July 2018 - 30 June 2019: Southern Adelaide Local Health Network. Adelaide: Government of South Australia; 2018.

107. Department for Health and Wellbeing. Service level agreement for the period of 1 July 2018 - 30 June 2019: Women's and Children's Health Network. Adelaide: Government of South Australia; 2018.

108. Department for Health and Wellbeing. Yorke and Northern Local Health Network service agreement for 1 July 2019 - 30 June 2020. Adelaide: Government of South Australia; 2019.

Chapter 2 What might person-centred mortality performance measurement look like?

Publication: Banham D, Karnon J, Brown A, Roder D, Lynch J. The premature mortality to incidence ratio (PREMIER): a person-centred measure of cancer burden. Population Health Metrics. Submitted for publication 21 March, 2019.

Available online at: https://www.medrxiv.org/content/10.1101/2021.10.17.21265122v1.full

2.1 Preface to Chapter 2

I undertook analyses of premature mortality in South Australia by geographic remoteness, area level socio-economic position, Aboriginal status (1) and cause (2). The then Minister for Health, the honourable John Hill MP, subsequently facilitated a round table discussion of the sobering content with government agency leaders. That discussion made it apparent the temporal gap between potentially sentinel events and mortality outcomes make it difficult to specify where and how such events might be avoided within health service delivery.

On joining the Wardliparingga Aboriginal Health Research Unit within the newly launched South Australian Health and Medical Research Institute (SAHMRI), my role was to acquire relevant data collections to pilot an Advanced Cancer Data System (ACaDS) (Appendix A) as part of a wider Aboriginal cancer disparities project. All analysis was governed by an Aboriginal Community Reference Group (ACoRG) with much of the analysis focussing on survival after cancer diagnosis and treatment. Our monthly meetings involved much insightful questioning. Aunty Roz Weetra, a local Elder, asked "Who are you comparing us *[Aboriginal people]* to? White fellas, black fellas, Irish, Muslim … who?" A straightforward challenge on behalf of people who had survived their cancer diagnoses unlike many family members experiencing cancer and other chronic diseases. I considered options using relative survival but the necessary life tables for Aboriginal and other people groups in South Australia remain unavailable. The answer that came to me was to base an analysis on the best observed mortality rates internationally by using the Global Burden of Disease standard life table (3).

References

1. Banham D, Jury H, Woollacott T, McDermott R, Baum F. Aboriginal premature mortality within South Australia 1999-2006: a cross-sectional analysis of small area results. BMC Public Health. 2011;11(286).

2. Research and Ethics Policy Unit. Aboriginal mortality in South Australia: A Profile. Adelaide, SA: Department of Health; 2010.

3. Naghavi M, Abajobir AA, Abbafati C, Abbas KM, Abd-Allah F, Abera SF, et al. Global, regional, and national age-sex specific mortality for 264 causes of death, 1980–2016: a systematic analysis for the Global Burden of Disease Study 2016. The Lancet. 2017;390(10100):1151-210.

2.2 Statement of authorship

Title of Paper	The premature mortality to incidence ratio (PREMIER): a person-centred measure of cancer burden
Publication Status	☐ Published ☐ Accepted for Publication ☑ Submitted for Publication ☐ Unpublished and Unsubmitted w ork w ritten in manuscript style
Publication Details	**Banham D**, Karnon J, Brown A, Roder D, Lynch J. The premature mortality to incidence ratio (PREMIER): a person-centred measure of cancer burden. Population Health Metrics. Submitted for publication 21 March, 2019.

Principal Author

Name of Principal Author (Candidate)	David Mark Banham		
Contribution to the Paper	Conceptualised and initiated this paper, collated and analysed the data, wrote the manuscript and acted as correspondent author.		
Overall percentage (%)	95%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	25th July 2022

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Jonathan Karnon		
Contribution to the Paper	My contribution to this paper involved manuscript evaluation.		
Signature		Date	25th July 2022

Name of Co-Author	Alex Brown		
Contribution to the Paper	My contribution to this paper involved conceptualising and operationalizing the Cancer Data and Aboriginal Disparities project and manuscript evaluation.		
Signature		Date	25th July 2022

Name of Co-Author	David Roder		
Contribution to the Paper	My contribution to this paper involved conceptualising and operationalizing the Cancer Data and Aboriginal Disparities project and manuscript evaluation.		
Signature		Date	25th July 2022

Name of Co-Author	John Lynch		
Contribution to the Paper	My contribution to this paper involved manuscript evaluation.		
Signature		Date	25th July 2022

2.3 Publication

The premature mortality to incidence ratio (PREMIER): a person-centred measure of cancer burden.

David Banham[a b] *,

Email: david.banham@adelaide.edu.au

Jonathan Karnon[c]

Email: jonathan.karnon@flinders.edu.au

Alex Brown[b d]

Email: alex.brown@sahmri.com

David Roder[e],

Email: david.roder@unisa.edu.au

John Lynch[a]

Email: john.lynch@adelaide.edu.au

[a] *School of Public Health, University of Adelaide, North Terrace, Adelaide, South Australia, 5000, Australia.*

[b] *Wardliparingga Aboriginal Health Research, South Australian Health and Medical Research Institute, North Terrace, Adelaide, South Australia, 5000, Australia*

[c] *College of Medicine and Public Health, Flinders University, Sturt Road, Bedford Park, South Australia, 5042.*

[d] *Faculty of Health and Medical Sciences, University of Adelaide, North Terrace, Adelaide, South Australia, 5000.*

[e] *School of Health Sciences, Cancer Research Institute, University of South Australia, North Terrace, Adelaide, South Australia, 5000.*

[*] *Corresponding author at: The South Australian Health and Medical Research Institute, North Terrace, Adelaide, South Australia, 5000.*

Abstract

Background

Cancer control initiatives are informed by quantifying the capacity to reduce cancer burden through effective interventions. Burden measures using health administrative data are a sustainable way to support monitoring and evaluating of outcomes among patients and populations. The PREmature Mortality to IncidencE Ratio (PREMIER) is one such burden measure. We use data on Aboriginal and non-Aboriginal South Australians from 1990 to 2010 to show how PREMIER quantifies disparities in cancer burden: between populations; between sub-population cohorts where stage at diagnosis is available; and when follow-up is constrained to 24-months after diagnosis.

Method

$PREMIER_{cancer}$ is the ratio of years of life expectancy lost due to cancer (YLL_{cancer}) to life expectancy years at risk at time of cancer diagnosis (LYAR) for each person. The Global Burden of Disease standard life table provides referent life expectancies. $PREMIER_{cancer}$ was estimated for the population of cancer cases diagnosed in South Australia from 1990 to 2010. Cancer stage at diagnosis was also available for cancers diagnosed in Aboriginal people and a cohort of non-Aboriginal people matched by sex, year of birth, primary cancer site and year of diagnosis.

Results

Cancers diagnoses (N=144,891) included 777 among Aboriginal people. Cancer burden described by $PREMIER_{cancer}$ was higher among Aboriginal than non-Aboriginal (0.55, 95%CIs 0.52-0.59 versus 0.39, 95%CIs 0.39-0.40). Diagnoses at younger ages among Aboriginal people, 7 year higher LYAR (31.0, 95%CIs 30.0-32.0 versus 24.1, 95%CIs 24.1-24.2) and higher premature cancer mortality (YLL_{cancer}=16.3, 95%CIs 15.1-17.5 versus YLL_{cancer}=8.2, 95%CIs 8.2-8.3) influenced this. Disparities in cancer burden between the matched Aboriginal and non-Aboriginal cohorts manifested 24-months after diagnosis with $PREMIER_{cancer}$ 0.44, 95%CIs 0.40-0.47 and 0.28, 95%CIs 0.25-0.31 respectively.

Conclusion

PREMIER described disproportionately higher cancer burden among Aboriginal people in comparisons involving: all people diagnosed with cancer; the matched cohorts; and, within groups diagnosed with same staged disease. The extent of disparities were evident 24-months after diagnosis. This is evidence of Aboriginal peoples' substantial capacity to benefit from cancer control initiatives, particularly those leading to earlier detection and treatment of cancers. PREMIER's use of readily available, person-level administrative records can help evaluate health care initiatives addressing this need.

Keywords

Indigenous Australians, cancer, premature mortality, mortality to incidence ratio, disparity.

4583 words

Background

Cancer is a leading cause of death and premature death globally [1, 2]. In Australia, cancer remains the largest contributor to years of life prematurely lost (YLL) despite the age standardised burden per head of population having declined by 11% from 2003 to 2011 [3]. Average burden may mask disparate trends in outcomes between and within populations [4, 5]. In the case of Aboriginal Australians (where "Aboriginal" is respectfully used to refer to people self-identifying as Aboriginal, Torres Strait Islander, or both [6]) comparable age-adjusted YLL were initially higher (52 versus 35 YLL per 1,000 population in 2003) and further increased to 55 versus 31 YLL per 1,000 population by 2013. This higher fatal burden is influenced by comparatively greater incidence of cancers with poor survival [5, 7, 8], diagnoses at more advanced stage [9-11], lower exposure to cancer treatment [9, 12], and excess case fatality concentrated in the first two-years after diagnosis [13]. Each of these influences suggest an unmet capacity to benefit from cancer control initiatives and actions including augmented cancer screening programs and addressing variations in treatment [14-16]. Such interventions need to be accompanied by relevant performance measures; measures which ensure system accountability [17], first by articulating disparity, then quantifying the capacity to benefit from prevention, early detection and intervention.

At a macro level, performance measures for population cancer outcomes [18] usually use relative survival [7, 19]. Relative survival is the ratio of observed survival among a group of people diagnosed with cancer and the expected survival of a similar, disease free group in the general population [20]. However, that method's use can be severely limited for sub-populations of particular interest [7, 21, 22] or greatest need [22] where life tables detailing the background probabilities of death are not routinely available [23]. Such is the case with Aboriginal Australians, particularly at state and territory levels [7, 24]. An alternative is to use the Mortality to Incidence Ratio (MIR) which is the ratio of the observed cancer mortality and incidence rates in a given population in a specified time period [25, 26]. MIR is often used to illustrate disparate cancer outcomes between countries [27, 28] and the manner in which health system ranking [29] with components of cancer care such as cancer screening and treatment [28, 30-33], positively correlate with better, lower MIRs as illustrated in Figure 1 [27]. Australia's health system is ranked thirty-second by the World Health Organization and has an average MIR of approximately 0.3, which is low by international standards and reflects well on Australia's cancer control activities [34]. While less frequently used, MIR also describes cancer disparities within countries [35-37]. In this light, the favourable Australian average masks Aboriginal Australia's poorer outcome of 0.5 [38].

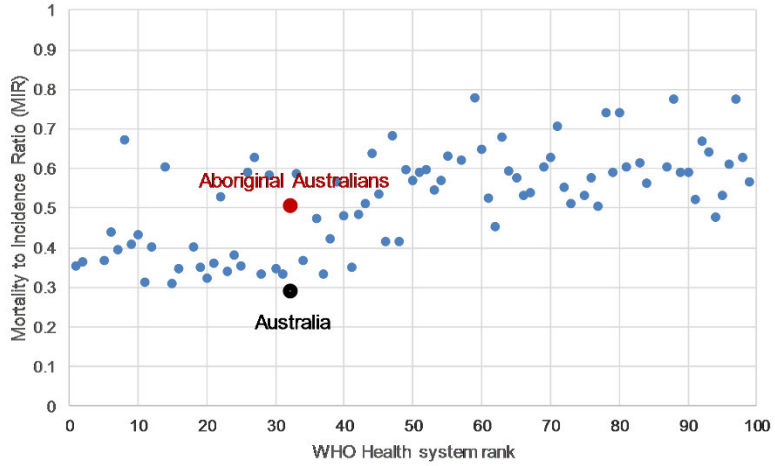


Figure 1 Mortality to Incidence Ratio (MIR) by the World Health Organization's Health System ranking (Top 100)

MIR has limited application for routine performance reporting for several reasons. As with life tables [7, 21, 22], routine and/or localised estimates for calculating population incidence and mortality rates may not be readily accessible. This is the case for Aboriginal Australians with Census estimates before 2016 labelled as 'experimental' and yearly population updates by age and smaller geographical areas not routinely published [39]. Consequently, data availability also limits the use of MIR [40] in quantifying opportunities to tailor initiatives to the needs of relevant sub-populations [41]. In addition, population [42] and cancer registrations [5, 43] available for performance monitoring often have time lags of two years or more before their release. This is sub-optimal because disparities in cancer outcome are manifest within 24-months of diagnosis [13]. Earlier signals on outcomes are needed if we are to evaluate the effects of system change in a timely manner [44, 45].

We respond to the need to further develop performance measurement in cancer control by revising MIR with the aim of increasing comparison between and within population sub-groups and without relying on infrequently available population parameters. We do so by employing a burden of disease method and measuring the time gap [46] of optimal life expectancy [47] remaining at two critical points in a person's experience of cancer: the age of a person's cancer diagnosis and death from cancer. Optimal life expectancy here refers to an international standard derived from the best observed mortality rates globally [48]. By adopting this method means we re-evaluate the MIR's underlying parameters at the person level, then aggregate results for (sub)population groups.

Consequently, we introduce the PREmature Mortality to IncidencE Ratio (PREMIER), a metric that reframes MIR within a burden of disease method. After outlining PREMIER's components and construction, we provide four analyses demonstrating its application. *Analysis One* focuses on general disparities in cancer burden existing between populations and uses cancers diagnosed among Aboriginal and non-Aboriginal Australians. Given these populations experience differences in age and primary site of cancers diagnosed [5, 8], *Analysis Two* adjusts for those confounding variables and quantifies disparity between Aboriginal people with cancer and a cohort of cancer cases drawn from the non-Aboriginal population having the same sex, year of birth, year of cancer diagnosis and primary site. *Analysis Three* enumerates differences in PREMIER within the Aboriginal and matched non-Aboriginal cohorts on the basis of cancer stage at diagnosis. To assess the extent to which disparities in cancer burden are evident soon after diagnosis, our final *Analysis Four* evaluates cancer burden between and within the matched cohorts 24-months after diagnosis. We then consider the implications and responses to observed disparities.

Methods

Study design and participants

We first provide a population context of all cancer cases [excluding non-melanoma skin cancer] diagnosed among South Australians in the period 1990 to 2010 (N=144,891). A nested retrospective, matched cohort design [9, 49] is used to compare cancers cases diagnosed among Aboriginal people (N=777) with a one-to-one random selection of cancer cases among non-Aboriginals matched on the basis of sex, year of birth, primary cancer site and year of diagnosis [8]. Follow-up time is from diagnosis date to date of death, or censoring or records at 31 December 2011, whichever occurred first.

Data sources, related measurements and definition of PREMIER

Cancer data for the South Australian population were obtained from the South Australian Cancer registry (SACR) [50] in the course of developing an advanced cancer data system within the Cancer Data and Aboriginal Disparities (CanDAD) project [51]. SACR is a

population registry collating dates of International Classification of Diseases for Oncology (ICD-O-3) [52] coded diagnoses and death (attributed as cancer or non-cancer death). Specialist clinical cancer registry staff further enhanced the nested cohort study records using diagnostic and pathology records available to SACR to include cancer stage at diagnosis using Surveillance, Epidemiology, and End Results Program methodologies [53]. Stage at diagnosis categories included: *localised* - confined to tissue of origin; *regional* - invaded adjacent tissue or regional nodes; *distant/unknown* - spread to distant lymph nodes or other organ sites; leukaemia; or insufficient staging data were available.

MIR parameters of mortality and incidence are reframed within a burden of disease framework in the following manner. Mortality among cancer cases is quantified using YLL [54, 55], the amount of life expectancy remaining at time at which death attributed to cancer occurred. Incidence is quantified using expected Life Years at Risk (LYAR) [56], that is, the amount of life expectancy remaining at time at which cancer diagnosis occurred. Both YLL and LYAR represent the years of optimal life expectancy remaining at the age a given event occurs. That optimal life expectancy, which is subsequently used as a standard against which other measures are made, was previously derived for the global burden of disease study using the lowest age-specific risk of death observed in populations greater than 5 million individuals across the world (further details are available in Appendix Table 18, p503 [54]). In the case of YLL, the relevant event is the age at death while LYAR refers to age at diagnosis.

We make three assumptions in adopting those standard life expectancy estimates. First, we assume it is fair that all people aspire to optimal life expectancy because health differentials between sub-populations are influenced through societal and environmental risk factor exposures [47, 48] rather than fixed biological determinants aside from age. Second, we assume a uniform estimate of life expectancy across time, place and circumstance facilitates fair comparisons, regardless of changing geographic or sub-population specific mortality rates. We also assume a consistent method to deriving measures facilitates comparison between those measures and such comparisons are valuable.

PREMIER represents the amount of life expectancy lost as a fraction of life expectancy remaining at the time a sentinel health event is diagnosed. In the case of premature loss of life from cancer death after cancer diagnosis ($PREMIER_{cancer}$), this is the ratio of years of life lost attributed to cancer (YLL_{cancer}) to expected life years at risk at the time of cancer diagnosis (LYAR) represented as:

$$PREMIER_{cancer} = \frac{YLL_{cancer}}{LYAR}$$

As a fraction of YLL and LYAR, PREMIER ranges from 0, where death after cancer diagnosis does not occur within the observation period, to 1, where death occurs at the same age as diagnosis. As an example, a person diagnosed with cancer at age 55 is taken as having 32.9 years of life expectancy remaining, thus LYAR is 32.9. Where death from cancer follows at age 65 the remaining life expectancy represents 23.8 years of life lost to cancer, YLL_{cancer}. $PREMIER_{cancer}$ is 23.8 / 32.9, or 0.72, indicating that 72% of life expectancy at time of diagnosis was subsequently lost.

Individual PREMIER, and its LYAR and YLL components, can be grouped across population groups, or cohorts of people diagnosed with cancer. PREMIER can refer to a variety of observation periods. For instance, populations or cohorts may be observed for: varying periods from time of diagnosis to right-censoring of observations at a given date; a fixed period after cancer diagnosis; or, a combination of the two.

Statistical analysis

Under the heading of *Risk*, we summarise the mean age at cancer diagnosis and the accompanying LYAR. Subsequent *Loss* to premature mortality describes the number and mean

age of deaths observed and attributed to cancer by SACR. Where deaths were not attributed to cancer, YLL_{cancer} is zero. The *Loss to Risk ratio*, comprises the averaged $PREMIER_{cancer}$ for individuals within each group.

Table 1 includes three groups of cancer cases: the population of cancer cases diagnosed from 1990 to 2010 among non-Aboriginal South Australians; cancer cases diagnosed among Aboriginal South Australians in the same period; and, a matched cohort of cancer cases among non-Aboriginal people. Table 2 focuses on the Aboriginal and non-Aboriginal cohorts disaggregated by stage at diagnosis. Table 3 repeats this focus while limiting observation time to a maximum of 24-months after diagnosis.

Our multivariable analysis used the matched cohorts to evaluate the relationship between: $PREMIER_{cancer}$ at 24-months after diagnosis ($PREMIER_{cancer\ 24\text{-}months}$) as the outcome with Aboriginality as the exposure and, cancer stage at diagnosis as a covariate. Interactions between Aboriginality and stage at diagnosis were also examined. We used fractional response regression [57], a quasi-likelihood estimation method available within Stata 15.1 as *fracreg* [58], and assumed a probit model for the conditional mean. This approach accommodates PREMIER's attributes as: a fraction of two continuous quantities with life expectancy lost as numerator, life expectancy at time of diagnosis as denominator; having a denominator which is also the maximum value for the numerator; and, thus having values in the range of 0 to 1 inclusive. We clustered the data by the cohorts' matched pairs and report 95% confidence intervals (95% CIs) based on robust standard errors. We report the modelled parameter coefficients which provide the sign of each covariate's effect on $PREMIER_{cancer\ 24\text{-}months}$. However, because the coefficients are difficult to interpret we also assessed the simultaneous average marginal effects of Aboriginality and stage at diagnosis on the proportion of life at risk lost in the 24-month period from diagnosis. That is, we report the change in $PREMIER_{cancer\ 24\text{-}months}$ where the cancer case involved an Aboriginal person rather than non-Aboriginal, and localised or distant stages rather than regional stage disease at diagnosis.

Results

Cancer burden between population groups

Table 1 shows SACR recorded 144,891 invasive cancer diagnoses among South Australians from 1990 to 2010. Cancer diagnoses among Aboriginal people accounted for a small number of those cases (N=777) and these are described in detail elsewhere [8]. Notably though, the latter cases were diagnosed at considerably younger age (57.7 years) compared to those among non-Aboriginal people (65.5 years). Consequently, life expectancy at risk at time of cancer diagnosis was almost 7 years higher among Aboriginal people with LYAR=31.0 (95% CIs 30.0-32.0) compared to the non-Aboriginal average of LYAR=24.1 (95%CIs 24.1-24.2). Proportionately more case fatalities, and at younger average age, were also observed among Aboriginal people with cancer. Taken together, average loss to premature mortality from cancer among Aboriginal cases was twice that of the broader group of non-Aboriginal cases (YLL_{cancer}=16.3, 95%CIs 15.1-17.5 versus YLL_{cancer}=8.2, 95%CIs 8.2-8.3). In turn, $PREMIER_{cancer}$ was markedly higher among Aboriginal compared to non-Aboriginal cases at 0.55 (95%CIs 0.52-0.59) versus 0.39 (95%CIs 0.39-0.40) respectively.

Table 1: Cancer diagnoses, premature mortality and PREMIER$_{cancer}$, South Australia 1990-2010*

		Cases among non-Aboriginal				Cases among Aboriginal				Matched cases among non-Aboriginal[#]			
		N	%	Mean	95%CIs	N	%	Mean	95%CIs	N	%	Mean	95%CIs
Risk													
	Age at diagnosis (years)	144,114	100 0%	65.5	65.4-65.6	777	100.0%	57.7	56.6-58.8	777	100.0%	58.5	57.4-59.5
	Life Years at Risk (LYAR)			24.1	24.1-24 2			31.0	30.0-32.0			30.3	29 3-31.3
Loss													
	Cancer deaths* and age (years)	62,936	43.7%	71.7	71.6-71 8	461	59.3%	61.5	60.2-62.9	340	43.8%	63.7	62.1-65.2
	Years of life lost from cancer (YLL$_{cancer}$)			8.2	8.2-8 3			16.3	15.1-17.5			11.2	10.1-12.3
Loss:Risk ra io													
	Premature mortality to incidence ratio (PREMIER$_{cancer}$)			0.39	0 39-0.40			0 55	0.52-0.59			0.40	0.37-0.44

*Among observations right-censored at 31/12/2011

[#] Randomly selected cancer cases among non-Aboriginal people matched one to one w ith cases among Aboriginal by sex, year of bir h, year of diagnosis and primary cancer site

Cancer burden between and within matched cohorts

Table 1 also compares cases among Aboriginal people compared to a randomly selected cohort of diagnoses among non-Aboriginal cases (N=777) matched by sex, year of birth, year of diagnosis and primary cancer site. LYAR among the Aboriginal and non-Aboriginal cohort are therefore equivalent because of age matching. Fewer case fatalities at comparatively older ages among the non-Aboriginal cohort led to an average YLL$_{cancer}$ at 11.2 (95% CIs 10.1-12.3) and PREMIER$_{cancer}$ at 0.40 (95% CIs 0.37-0.44) which were markedly lower than their matched Aboriginal contemporaries with PREMIER$_{cancer}$=0.55 (95%CIs 0.52-0.59). Indeed, PREMIER$_{cancer}$ for all non-Aboriginal and the subset of cases within the non-Aboriginal cohort were very similar (0.39, 95%CIs 0.39-0.40 and 0.40, 95% CIs 0.37-0.44 respectively).

Table 2 disaggregates Aboriginal and matched non-Aboriginal cohort results by stage at diagnosis. Cancers among Aboriginal people were more likely to involve distantly spread disease (n=333 or 42.8% of cases) than among non-Aboriginal people (n=255 or 32.8% of cases). Within each stage at diagnosis cancer case fatality was relatively more common among Aboriginal than non-Aboriginal people. Also, the average age at cancer death was lower among Aboriginal people than non-Aboriginal people diagnosed with regionally staged disease (58.9 versus 63.1 years) and distant staged disease (60.8 versus 63.2 years). Both factors contributed to markedly greater average YLL$_{cancer}$ in the Aboriginal cohort than the non-Aboriginal cohort with differences ranging from 2.0 (95%CIs 1.7-2.3) in localised stage to 6.2 (6.1-6.2) in regionally spread disease. For both cohorts, PREMIER$_{cancer}$ increased as cancer spread at diagnosis increased. However, PREMIER$_{cancer}$ also showed the relative amount of life at risk and subsequently lost was higher within the Aboriginal cohort at each stage of disease at diagnosis.

Cancer burden two years after diagnosis

Table 3 shows cohort outcomes up to two years after cancer diagnosis. Case fatality increased as stage at diagnosis increased from local to regional to distant stages with consistently higher loss observed among Aboriginal compared to non-Aboriginal people. Again, age at cancer death was younger among Aboriginal people than non-Aboriginal people for each stage at diagnosis. Average YLL$_{cancer}$ was also higher among Aboriginal cases at each stage of disease at diagnosis. Consequently, PREMIER$_{cancer}$ differed between cohorts 24-months after diagnosis with higher losses among Aboriginal (PREMIER$_{cancer\ 24\text{-}months}$=0.44, 95%CIs 0.40-0.47) than non-Aboriginal (PREMIER$_{cancer\ 24\text{-}months}$=0.28, 95%CIs 0.25-0.31). This difference of 0.16 in the limited 24-month follow-up period (using PREMIER$_{cancer\ 24\text{-}months}$) was very similar to the difference of 0.15 observed across the full observation period (using PREMIER$_{cancer}$).

Table 2: Cancer diagnoses, premature mortality and PREMIER$_{cancer}$ by stage at diagnosis, South Australia 1990-2010*

		Localised at diagnosis								Regional spread at diagnosis								Distant/Unknown spread at diagnosis							
		Aboriginal				Matched non-Aboriginal#				Aboriginal				Matched non-Aboriginal#				Aboriginal				Matched non-Aboriginal#			
		N	%	Mean	95%CIs	N	%	Mean	95%CIs	N	%	Mean	95%CIs	N	%	Mean	95%CIs	N	%	Mean	95%CIs	N	%	Mean	95%CIs
Risk																									
	Age at diagnosis	289	100.0%	58.4	56.5-60.3	390	100.0%	57.8	56.2-59.3	155	100.0%	55.5	53.2-57.8	132	100.0%	57.9	55.4-60.5	333	100.0%	58.1	56.4-59.8	255	100.0%	59.8	57.9-61.7
	LYAR			30.4	28.7-32.2			30.9	29.5-32.4			32.8	30.7-34.9			30.7	28.4-33.0			30.6	29.1-32.1			29.1	27.4-30.8
Loss																									
	Cancer deaths*	101	34.9%	65.9	63.0-68.9	100	25.6%	64.9	61.6-68.2	93	60.0%	58.9	56.1-61.7	59	44.7%	63.1	59.6-66.7	267	80.2%	60.8	59.1-62.6	181	71.0%	63.2	61.1-65.2
	YLL$_{cancer}$			8.3	6.7-9.9			6.3	5.0-7.6			17.8	15.1-20.6			11.6	9.0-14.2			22.5	20.8-24.3			18.5	16.6-20.4
Loss:Risk ratio																									
	PREMIER$_{cancer}$			0.30	0.25-0.35			0.22	0.18-0.26			0.56	0.49-0.64			0.41	0.33-0.49			0.77	0.73-0.81			0.68	0.62-0.73

*Among observations right-censored at 31/12/2011

Randomly selected cancer cases among non-Aboriginal people matched one to one with cases among Aboriginal by sex, year of birth, year of diagnosis and primary cancer site

PREMIER$_{cancer\ 24\text{-}months}$ also differed within cohorts and increased as stage at diagnosis increased. For example, point estimates for PREMIER$_{cancer\ 24\text{-}months}$ within the Aboriginal cohort increased from 0.17 in cases of localised disease to 0.68 where disease spread was distant or unknown, an overall change of 0.51. Overall change within the non-Aboriginal cohort was slightly less at 0.47 and ranged from 0.10 in localised disease to 0.57 in distant spread disease.

Table 3: Cancer diagnoses, premature mortality and PREMIER$_{cancer}$ at 24-months by stage at diagnosis, South Australia 1990-2010*

		All cancers								Localised at diagnosis							
		Aboriginal				Matched non-Aboriginal[#]				Aboriginal				Matched non-Aboriginal[#]			
		N	%	Mean	95%CIs	N	%	Mean	95%CIs	N	%	Mean	95%CIs	N	%	Mean	95%CIs
Risk																	
	Age at diagnosis	777	100.0%	57.7	56.6-58.8	777	100.0%	58.5	57.4-59.5	289	100.0%	58.4	56.5-60.3	390	100.0%	57.8	56.2-59.3
	LYAR			31.0	30.0-32.0			30.3	29.3-31.3			30.4	28.7-32.2			30.9	29.5-32.4
Loss																	
	Cancer deaths $_{24\text{-months}}$*																
	Age at death$_{cancer\ 24\text{-months}}$	346	44.5%	60.4	58.9-61.9	224	28.8%	63.5	61.6-65.4	51	17.6%	63.0	58.5-67.5	40	10.3%	64.4	59.3-69.4
	YLL$_{cancer\ 24\text{-months}}$			12.7	11.5-13.9			7.4	6.5-8.4			4.7	3.3-6.0			2.6	1.7-3.5
Loss:Risk ratio																	
	PREMIER$_{cancer\ 24\text{-months}}$			0.44	0.40-0.47			0.28	0.25-0.31			0.17	0.13-0.21			0.10	0.07-0.13

		Regional spread at diagnosis								Distant/Unknown spread at diagnosis							
		Aboriginal				Matched non-Aboriginal[#]				Aboriginal				Matched non-Aboriginal[#]			
		N	%	Mean	95%CIs	N	%	Mean	95%CIs	N	%	Mean	95%CIs	N	%	Mean	95%CIs
Risk																	
	Age at diagnosis	155	100.0%	55.5	53.2-57.8	132	100.0%	57.9	55.4-60.5	333	100.0%	58.1	56.4-59.8	255	100.0%	59.8	57.9-61.7
	LYAR			32.8	30.7-34.9			30.7	28.4-33.0			30.6	29.1-32.1			29.1	27.4-30.8
Loss																	
	Cancer deaths $_{24\text{-months}}$*																
	Age at death$_{cancer\ 24\text{-months}}$	67	43.2%	58.5	55.2-61.8	37	28.0%	63.4	58.4-68.3	228	68.5%	60.4	58.5-62.3	147	57.6%	63.3	61.0-65.6
	YLL$_{cancer\ 24\text{-months}}$			13.0	10.3-15.7			7.2	4.9-9.6			19.5	17.7-21.4			15.0	13.0-16.9
Loss:Risk ratio																	
	PREMIER$_{cancer\ 24\text{-months}}$			0.42	0.35-0.50			0.27	0.20-0.35			0.68	0.63-0.72			0.57	0.51-0.63

*Among observations right-censored at a maximum of 24 months after diagnosis or 31/12/2011

[#] Randomly selected cancer cases among non-Aboriginal people matched one to one with cases among Aboriginal by sex, year of birth, year of diagnosis and primary cancer site

Multivariable analysis

Table 4 shows the association between life at risk and life subsequently lost up to 24-months after cancer diagnosis in the cohorts and the concurrent effects of Aboriginality and stage at diagnosis. Both Aboriginality and advancing disease stage at diagnosis were associated with higher $PREMIER_{cancer}$. The model's marginal effects indicate Aboriginal cases experienced an average of 0.10 or 10% (95%CIs 0.06-0.14) higher $PREMIER_{cancer}$ than non-Aboriginal cohort cases diagnosed with the same stage of disease. Simultaneously, and when compared to regionally spread disease at diagnosis, localised disease was associated with 0.21 or 21% (95%CIs 0.14- 0.27) lower $PREMIER_{cancer}$ and distant/unknown spread with 0.27 or 27% (95%CIs 0.20-0.34) higher $PREMIER_{cancer}$. No further interaction of the effects of Aboriginality by stage at diagnosis was evident.

Table 4: Fractional outcome regression and average marginal effects on $PREMIER_{cancer}$ at 24-months, South Australia 1990-2010*

		Model for $PREMIER_{cancer\ 24\text{-}months}$				Average marginal effects#			
		Coef.	95% CIs	z	p>|z|	dy/dx	95% CIs	z	p>|z|
Aboriginal	No	0.00	Reference			0.00	Reference		
	Yes	0.33	0.21-0.45	5.46	<0.001	0.10	0.06-0.14	5.43	<0.001
Stage at diagnosis									
	Localised	-0.72	-0.92--0.53	-7.38	<0.001	-0.21	-0.27--0.14	-6.92	<0.001
	Regional	0.00	Reference			0.00	Reference		
	Distant/unknown	0.70	0.52-0.89	7.48	<0.001	0.27	0.20-0.34	7.81	<0.001
Constant		-0.56	0.30-0.52	-6.67	<0.001				

* Using a randomly selected cancer cases among non-Aboriginal people matched one to one with cases among Aboriginal by sex, year of birth, year of diagnosis and primary cancer site with observations right censored at a maximum of 24 months after diagnosis or at 31/12/2011

#Average marginal effects represent the change in $PREMIER_{cancer\ 24\text{-}months}$, the outcome variable, when moving from a predictor variable's reference category

Discussion

PREMIER combines life expectancy at the time of cancer diagnosis and the resultant loss of life due to cancer death in order to quantify cancer burden. This is calculated for each person diagnosed with subsequent aggregation to groups. Our first analysis demonstrated PREMIER's application in describing disparities in cancer burden for the entire population of invasive cancers diagnosed among South Australians. PREMIER described substantially higher cancer burden among the population of Aboriginal people with cancer compared to other South Australians ($PREMIER_{cancer}$ of 0.55 versus 0.39). These differences were bought about by Aboriginal South Australians with cancer having lower average age and more life expectancy (7 years) at risk of loss while also experiencing higher average premature mortality loss due to higher case fatality (59.3% versus 43.7%) and younger age at death (62 versus 72 years). Our second analysis focussed on Aboriginal and non-Aboriginal cohorts with equivalent sex, age, year of diagnosis and primary cancer site. While life expectancy at diagnosis was equivalent, PREMIER enumerated 15% more cancer burden among Aboriginal South Australians with cancer ($PREMIER_{cancer}$ of 0.55 versus 0.40). This was influenced by more frequent cancer deaths (59.3% versus 43.8%) and these deaths being at a younger age (61.5 versus 63.7 years). With the availability of stage at diagnosis for the cohorts, we then considered the variation of cancer burden within the cohorts. In both cohorts PREMIER increased as stage increased from local to regional to distant spread. In addition, PREMIER remained higher among Aboriginal people at each stage ($PREMIER_{cancer}$=0.30 versus 0.22 for localised disease; 0.56 versus 0.41 for regional spread; and, 0.77 versus 0.68 for distant spread). These disparities by stage and Aboriginality were not only apparent for the broader observation period. They were fully manifested 24-months after diagnosis and our fourth analysis showed 16% higher cancer burden among Aboriginal than non-Aboriginal contemporaries ($PREMIER_{cancer\ 24\text{-}}$

$_{months}$ of 0.44 versus 0.28 respectively). Disparity of this size then continued across longer term observations.

Our analyses align with other reports of MIR, the ratio of observed cancer mortality and incidence rates in a given population in a specified time period, which describe intra-country disparities in cancer outcomes. For example, MIR differences between Black (MIR=0.48) and White (MIR=0.40) in South Carolina are clear [35, 37], yet recent differences between Aboriginal (MIR=0.51) and Australia generally (MIR=0.30) are even more pronounced [38]. These disparate results are echoed by PREMIER within the population of South Australians diagnosed with cancer where substantially more cancer burden among Aboriginal than non-Aboriginal ($PREMIER_{cancer}$=0.55 versus 0.39 respectively) was quantified.

There are notable points of difference between MIR and PREMIER though. MIR makes use of mortality and incidence rates calculated on people diagnosed or dying in any given period. Those dying may have been diagnosed in different time periods meaning different groups of people are being compared [19]. One of the consequences of this back-scattering of incident cases is to make it difficult to observe rapid changes in prognosis [19]. PREMIER however, draws directly on each individual case for both numerator (LYAR) and denominator (YLL). Because incidence and mortality are observed within the same person the need to adjust for back-scattering is avoided. This is an advantage because it enables PREMIER to provide an earlier signal on cancer outcomes. Earlier measures can inform timely evaluations of system change, particularly system change aimed at improving outcomes within 24-months of diagnosis, a time when disparities are entrenched but also able to be detected using PREMIER.

PREMIER's perspective on cancer burden is relevant to evidence-based policy development in cancer control [59] in other ways. For example, PREMIER's estimation provides absolute measures of life at risk and life lost from cancer in a manner that is useful to planning activities. This is achieved by anchoring age at diagnosis and age at cancer death against a defined, optimal outcome. By describing disparities in age at diagnosis LYAR determined the amount of life expectancy amenable to change by preventing cancer, or at least deferring cancer incidence to later ages, through reduced exposure to cancer risks. As a relative measure, PREMIER revealed disparities across stage at diagnosis where more advanced disease led to higher cancer mortality and higher PREMIER. This information can help prioritise activities leading to earlier case detection and increased participation in cancer screening activities to detect cancers at an earlier stage. PREMIER also demonstrated an ability to enumerate disparities in cancer burden associated with stage and ethnicity 24-months after cancer diagnosis, a time during which people are more likely to be receiving care through health services [45]. This becomes particularly useful in supporting activities that promote access [60], uptake and quality [15, 61] of effective and available cancer treatments. In short, PREMIER enumerates people's capacity to benefit from cancer control initiatives involving prevention, early detection and treatment and thus contributes to prioritising health system activities.

Similarly, while we report aggregated outcomes, it is important to remember PREMIER is calculated for each individually diagnosed case which become available for grouping and analysed in many configurations. We grouped observations by Aboriginality, however groups could be based on: shared area level geography; socio-economic position; or, by attending a certain service or receiving the care of particular provider. This adaptability is not only relevant to policy and planning but has further application in relating system performance to outcomes for individuals and the population groups to whom they belong [41]. PREMIER offers a robust and contemporary measure of performance with which to assess the effectiveness of early detection and treatment efforts. This is because PREMIER is free of the immediate need for background population information and time lags in reporting are reduced with counting and observations beginning as soon as diagnosis is made. This suggests the use of clinical records for reporting at patient (micro) and service (meso) levels in the first instance. As the underlying cancer and mortality records are integrated into population registries as we have used, macro level reporting for populations and

the whole of system can follow. Information at these varying levels lend themselves to continued quality improvement processes and ongoing applied research. The use of existing, routine administrative data also helps address the evaluation needs of health services and government [62] while promoting public accountability [63]. Indeed, incorporating YLL within PREMIER facilitates comparison with other health system indicators and targets around reducing avoidable and premature mortality, particularly among vulnerable populations [63].

PREMIER has other strengths. Our analyses demonstrate the feasibility of assessing PREMIER using existing, routine, administrative and/or clinical records which also suggests it is readily sustainable. Other parameters from hospital systems could inform stratification within patient groups, for example, by stage at diagnosis. As cancer mortality outcomes improve and it becomes increasingly important to assess patient morbidity, the burden of disease method also provides for health adjusting the age relevant life expectancy and incorporating this into PREMIER estimates [56, 64]. In the meantime, PREMIER responds to the call for ever-increasing comparability and granularity in reporting [64] in two ways. We showed PREMIER's comparability across populations and within small cohort groups. Further comparison with the wider Australian community, or even globally and for other time periods is quite possible because by measuring against the same, global standard. PREMIER has additional scope to generalise across conditions such as stroke or heart attack where there are definitive times of diagnosis enabling assessment of LYAR and subsequent YLL components. This would inform further comparison between and within people groups on the basis of health condition.

Limitations

PREMIER has several limitations. Interpreting relative outcome measures expressed as ratios which depend on different numerators and denominators is challenging. It is also a commonly occurring issue when considering issues of health disparity [65]. Our suggested response is to accompany PREMIER with reports of LYAR and YLL as absolute measures based on life expectancy. This raises the major limitation of PREMIER in that both LYAR and YLL are predicated on a global standard life table while local life expectancy for population groups of interest will likely be different. That is, PREMIER makes use of two biased measures and overestimates outcome disparities [66, 67] suggesting a prudent approach to its use as recommended with other survival methods [68]. The counter argument is to avoid bias by using population specific life tables [69-71]. However, life tables reflecting jurisdiction or group averages do not necessarily remedy the issue because such averages may mask considerable variation within the relevant jurisdictions or population group. For example, average life expectancy within one US county having the benefit of one of the highest observed life expectancies at birth was recently shown to subsume variations of up to 18 years among males and 15 years for females [72]. Nevertheless, when relevant life tables become available, the bias within our analysis can be approximated as done in other instances assessing the need for intra-country socio-economic position life tables [68]. Until such time though, our analysis makes use of the fall-back recommendation of using cancer specific mortality. This is justified because where health inequities exist, it is unacceptable to wait until complete information is to hand before acting. Therefore, we adopt an imperfect but well based and transparent method to quantifying health inequity by measuring against a gold standard, optimal outcome. In our case, this outcome is a standard attained by some but markedly less so by others within the same country and served by the same universal, healthcare system.

We further acknowledge our analysis of PREMIER did not account for the influence of comorbid conditions [73, 74]. In their own right, these are a major point of difference in the health status of Aboriginal and other Australians. However, PREMIER estimates for all-causes of death among people with cancer are easily calculated. Where higher risk of death from non-cancer causes are experienced [23] PREMIER estimates would increase and potentially exacerbate the disparities we documented. Other cancer survival studies do in fact report changes in the risk of death from

cancer or non-cancer causes in the five years after cancer diagnosis [23] and this issue will benefit from further investigation.

Conclusion

We demonstrated PREMIER's application in quantifying cancer burden disparities using Aboriginal and non-Aboriginal comparisons in South Australia. Cancer burden was markedly higher among Aboriginal people than non-Aboriginal in all comparisons based on: all people diagnosed with cancer; groups matched by sex, age, primary site and year of diagnosis; and, within groups experiencing similarly staged disease at diagnosis. Importantly, the extent of disparities were evident 24-months after diagnosis and persisted at similar levels thereafter. This points to a substantial capacity to benefit from improved cancer control initiatives among Aboriginal people, particularly those health system activities aimed at earlier detection and treatment of cancers. Our analyses also suggest PREMIER's use of readily available, person-level information can provide important information helping evaluate person-centred cancer care as one dimension of high-quality health care delivery addressing this need.

Abbreviations

95% CIs: 95% confidence intervals

CanDAD: Cancer Data and Aboriginal Disparities

LYAR: Life Years at Risk

MIR: Mortality to Incidence Ratio

PREMIER: PREmature Mortality to IncidencE Ratio calculated as YLL/LYAR for each case

$PREMIER_{cancer}$: PREmature Mortality to IncidencE Ratio calculated as YLL_{cancer}/LYAR for each case

$PREMIER_{cancer\ 24\text{-}months}$: PREmature Mortality to IncidencE Ratio up to 24-months after diagnosis calculated as $YLL_{cancer\ 24\text{-}months}$/LYAR for each case

PROMs: Patient Reported Outcome Measures

YLL: Years of Life Lost

YLL_{cancer}: Years of Life Lost associated with cancer death

$YLL_{cancer\ 24\text{-}months}$: Years of Life Lost associated with cancer death up to 24-months after diagnosis

SACR: South Australian Cancer Registry

Declarations

Ethics approval and consent to participate:
South Australia's Aboriginal Health Research Ethics Committee (AHREC 04-12-461) and SA Health's Human Research Ethics Committee (SA Health HREC HREC/12/SAH/35) approved the use of population cancer registry records. CanDAD's Aboriginal Community Reference Group governance ensured alignment of the study protocol with South Australian Aboriginal Health Research Accord principles [75].

Consent for publication:
Not applicable.

Availability of data and material:
The datasets generated and/or analysed during the current study are not publicly available due to privacy reasons, including the provisions of the Australian Privacy Principles. The study's data comprised of de-identified unit record administrative records and were used under privileged arrangements set out in a study specific confidentiality deed. The data cannot be accessed by another party without relevant data custodian and human research ethics approvals.

Competing interests:
The authors declare they have no competing interests.

Funding:
The CanDAD project was funded by National Health and Medical Research Council (APP1072243), Cancer Council SA's Beat Cancer Project with project partners' in-kind support. DB is supported in part by an Australian Government Research Training Program Scholarship. AB is supported by the Sylvia and Charles Viertel Senior Medical Research Fellowship. The funders were not involved in the analysis, data interpretation and writing of this manuscript.

Authors' contributions:
DB conceived the project, performed the analyses and drafted the manuscript; JL, JK, AB and DR made important contributions to operationalising this study, interpreting the statistical analysis, and revised the manuscript. All authors read and approved the final version of the manuscript.

Acknowledgements:
Dr Graeme Tucker for statistical advice and the Cancer Data and Aboriginal Disparities (CanDAD) Aboriginal Community Reference Group (ACoRG), particularly Aunty Roslyn Weetra.

References

1. Abajobir AA, Abate KH, Abbafati C, Abbas KM, Abd-Allah F, Abdulkader RS, Abdulle AM, Abebo TA, Abera SF, Aboyans V, et al: **Global, regional, and national disability-adjusted life-years (DALYs) for 333 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016.** *The Lancet* 2017, **390:**1260-1344.

2. Global Burden of Disease Cancer C: **Global, regional, and national cancer incidence, mortality, years of life lost, years lived with disability, and disability-adjusted life-years for 32 cancer groups, 1990 to 2015: A systematic analysis for the global burden of disease study.** *JAMA Oncology* 2017, **3:**524-548.

3. Australian Institute of Health and Welfare: **Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. .** Canberra: AIHW; 2016.

4. **Cancer in Aboriginal & Torres Strait Islander people of Australia** [https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians/report-editions]

5. Australian Institute of Health and Welfare: **Cancer in Aboriginal and Torres Strait Islander peoples of Australia: An overview.** Canberra: AIHW; 2013.

6. Health Performance Council Secretariat: **Monitoring the implementation of Transforming Health Indicator Report.** Adelaide: Government of South Australia; 2017.

7. Condon JR, Zhang X, Baade P, Griffiths K, Cunningham J, Roder DM, Coory M, Jelfs PL, Threlfall T: **Cancer survival for Aboriginal and Torres Strait Islander Australians: a national study of survival rates and excess mortality.** *Population Health Metrics* 2014, **12**.

8. Banham D, Roder D, Keefe D, Farshid G, Eckert M, Cargo M, Brown A, for the CanDAD Aboriginal Community Reference Group and other CanDAD investigators: **Disparities in cancer stage at diagnosis and survival of Aboriginal and non-Aboriginal South Australians.** *Cancer Epidemiology* 2017, **48:**131-139.

9. Valery P, Coory M, Stirling J, Green A: **Cancer diagnosis, treatment, and survival in Indigenous and non-Indigenous Australians: a matched cohort study.** *Lancet* 2006, **367:**1842 - 1848.

10. Condon J, Cunningham J, Barnes A, Armstrong B, Selva-Nayagam S: **Cancer diagnosis and treatment in the Northern Territory - assessing health service performance for Indigenous Australians.** *Intern Med J* 2006, **36:**498 - 505.

11. Roder D: **Comparative cancer incidence, mortality and survival in Indigenous and non-Indigenous residents of South Australia and the Northern Territory.** *Cancer Forum* 2005, **29:**7-9.

12. Condon J, Armstong B, Barnes A, Cunningham J: **Cancer in Indigenous Australians: a review.** *Cancer Causes & Control* 2003, **14:**109-121.

13. Cramb S, Garvey G, Valery P, Williamson J, Baade P: **The first year counts: cancer survival among Indigenous and non-Indigenous Queenslanders, 1997-2006.** *Med J Aust* 2012, **196:**270 - 274.

14. Adelson P, Fusco K, Karapetis C, Wattchow D, Joshi R, Price T, Sharplin G, Roder D: **Use of guideline-recommended adjuvant therapies and survival outcomes for people with colorectal cancer at tertiary referral hospitals in South Australia.** *Journal of Evaluation in Clinical Practice* 2017**:**n/a-n/a.

15. Liu JB, Ko CY: **Disparities in Rectal Cancer: Moving from Descriptions to Solutions.** *Annals of Surgical Oncology* 2017, **24:**299-301.

16. Woods LM, Rachet B, Coleman MP: **Origins of socio-economic inequalities in cancer survival: a review.** *Annals of Oncology* 2006, **17:**5-19.

17. The Lancet: **What's next for Indigenous health in Australia?** *The Lancet* 2018, **391:**632.

18. Clauser SB: **Use of Cancer Performance Measures in Population Health: A Macro-level Perspective.** *JNCI Monographs* 2004, **2004:**142-154.

19. Ellis L, Woods LM, Esteve J, Eloranta S, Coleman MP, Rachet B: **Cancer incidence, survival and mortality: explaining the concepts.** *Int J Cancer* 2014, **135:**1774-1782.

20. Ederer F, Axtell LM, Cutler SJ: **The relative survival rate: A statistical methodology.** *National Cancer Institute Monograph* 1961, **6:**101-121.

21. Mariotto AB, Noone A-M, Howlader N, Cho H, Keel GE, Garshell J, Woloshin S, Schwartz LM: **Cancer Survival: An Overview of Measures, Uses, and Interpretation.** *JNCI Monographs* 2014, **2014:**145-186.

22. Morris M, Woods LM, Rachet B: **A novel ecological methodology for constructing ethnic-majority life tables in the absence of individual ethnicity information.** *Journal of Epidemiology and Community Health* 2015, **69:**361-367.

23. He VY, Condon JR, Baade PD, Zhang X, Zhao Y: **Different survival analysis methods for measuring long-term outcomes of Indigenous and non-Indigenous Australian cancer patients in the presence and absence of competing risks.** *Popul Health Metr* 2017, **15:**1.

24. Australian Bureau of Statistics: **Life tables for Aboriginal and Torres Strait Islander Australians: 2010-2012.** Canberra: ABS; 2013.

25. Suwanrungruang K, Sriplung H, Temiyasathit S, Waisri N, Daoprasert K, Kamsa-Ard S, Tasanapitak C, McNeil E: **Appropriateness of the Standard Mortality/Incidence Ratio in Evaluation of Completeness of Population-Based Cancer Registry Data.** *Asian Pacific Journal of Cancer Prevention* 2011, **12:**3283-3288.

26. Asadzadeh Vostakolaei F, Karim-Kos HE, Janssen-Heijnen MLG, Visser O, Verbeek ALM, Kiemeney LALM: **The validity of the mortality to incidence ratio as a proxy for site-specific cancer survival.** *European Journal of Public Health* 2011, **21:**573-577.

27. Ferlay J, Soerjomataram I, Dikshit R, Eser S, Mathers C, Rebelo M, Parkin DM, Forman D, Bray F: **Cancer incidence and mortality worldwide: Sources, methods and major patterns in GLOBOCAN 2012.** *International Journal of Cancer* 2015, **136:**E359-E386.

28. Choi E, Lee S, Nhung BC, Suh M, Park B, Jun JK, Choi KS: **Cancer mortality-to-incidence ratio as an indicator of cancer management outcomes in Organization for Economic Cooperation and Development countries.** *Epidemiology and Health* 2017, **39:**e2017006.

29. World Health Organization: **The World Health Report 2000: Health systems - Improving performance.** pp. 1-177. Geneva: WHO; 2000:1-177.

30. Sunkara V, Hébert JR: **The colorectal cancer mortality-to-incidence ratio as an indicator of global cancer screening and care.** *Cancer* 2015, **121:**1563-1569.

31. Doubova SV, Pérez-Cuevas R: **Going further to measure improvements in health-care access and quality.** *The Lancet* 2018, **391:**2190-2192.

32. Fullman N, Yearwood J, Abay SM, Abbafati C, Abd-Allah F, Abdela J, Abdelalim A, Abebe Z, Abebo TA, Aboyans V, et al: **Measuring performance on the Healthcare Access and Quality Index for 195 countries and territories and selected subnational locations: a systematic analysis from the Global Burden of Disease Study 2016.** *The Lancet* 2018, **391:**2236-2271.

33. Chen S-L, Wang S-C, Ho C-J, Kao Y-L, Hsieh T-Y, Chen W-J, Chen C-J, Wu P-R, Ko J-L, Lee H, Sung W-W: **Prostate Cancer Mortality-To-Incidence Ratios Are Associated with Cancer Care Disparities in 35 Countries.** 2017, **7:**40003.

34. Cancer Australia: **National Cancer Control Indicators (NCCI) Framework.** Sydney: Cancer Australia; 2017.

35. Hébert JR, Daguise VG, Hurley DM, Wilkerson RC, Mosley CM, Adams SA, Puett R, Burch JB, Steck SE, Bolick-Aldrich SW: **Mapping Cancer Mortality-to-Incidence**

Ratios to Illustrate Racial and Sex Disparities in a High-risk Population. *Cancer* 2009, **115:**2539-2552.

36. Hashim D, Manczuk M, Holcombe R, Lucchini R, Boffetta P: **Cancer mortality disparities among New York City's Upper Manhattan neighborhoods.** *European Journal of Cancer Prevention* 2017, **26:**453-460.

37. Babatunde OA, Adams SA, Eberth JM, Wirth MD, Choi SK, Hebert JR: **Racial disparities in endometrial cancer mortality-to-incidence ratios among Blacks and Whites in South Carolina.** *Cancer Causes Control* 2016, **27:**503-511.

38. **Australian Cancer Incidence and Mortality (ACIM) books: All cancers combined** [http://www.aihw.gov.au/acim-books]

39. Australian Bureau of Statistics: **Estimates and Projections, Aboriginal and Torres Strait Islander Australians: 2001 to 2026.** Canberra: ABS; 2014.

40. Parkin D, Hakulinen T: **Analysis of survival.** In *Cancer Registration: Principles and Methods* Edited by Jensen O, Parkin D, MacLennan R, Muir C, Skeet R. Lyon: International Agency for Research on Cancer; 1991: 159-176

41. Hostetter M, Klein S: **Segmenting Populations to Tailor Services, Improve Care.** The Commonwealth Fund; 2015.

42. Australian Bureau of Statistics: **Estimates of Aboriginal and Torres Strait Islander Australians, June 2016.** Released 31 August, 2018 edition. Canberra: ABS; 2018.

43. South Australian Cancer Registry: **Cancer in South Australia 2015 - with projections to 2018.** Adelaide, SA: South Australian Department for Health and Wellbeing; 2018.

44. Canadian partnership against cancer: **Cancer Stage in Performance Measurement: A First Look.** Toronto: The Partnership; 2015.

45. Chadder J, Dewar R, Shack L, Nishri D, Niu J, Lockwood G: **A first look at relative survival by stage for colorectal and lung cancers in Canada.** *Current Oncology* 2016, **23:**119-124.

46. Murray C: **Quantifying the burden of disease: the technical basis for disability-adjusted life years.** *Bulletin of the World Health Organization* 1994, **72:**429-445.

47. Murray CJ, Acharya AK: **Understanding DALYs (disability-adjusted life years).** *J Health Econ* 1997, **16:**703-730.

48. Abajobir AA, Abbafati C, Abbas KM, Abd-Allah F, Abera SF, Aboyans V, Adetokunboh O, Afshin A, Agrawal A, Ahmadi A, et al: **Global, regional, and national age-sex specific mortality for 264 causes of death, 1980–2016: a systematic analysis for the Global Burden of Disease Study 2016.** *The Lancet* 2017, **390:**1151-1210.

49. Diaz A, Moore SP, Martin JH, Green AC, Garvey G, Valery PC: **Factors Associated With Cancer-Specific and Overall Survival Among Indigenous and Non-Indigenous Gynecologic Cancer Patients in Queensland, Australia: A Matched Cohort Study.** *International Journal of Gynecological Cancer* 2015, **25:**542-547.

50. South Australian Cancer Registry: **Cancer in South Australia 2014 - with projections to 2017.** Adelaide, SA: South Australian Department for Health and Ageing; 2017.

51. Yerrell PH, Roder D, Cargo M, Reilly R, Banham D, Micklem JM, Morey K, Stewart HB, Stajic J, Norris M, et al: **Cancer Data and Aboriginal Disparities (CanDAD)-developing an Advanced Cancer Data System for Aboriginal people in South Australia: a mixed methods research protocol.** *BMJ Open* 2016, **6:**e012505.

52. Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin D, Whelan S (Eds.): **International Classification of Diseases for Oncology**, Third Edition edition. Geneva: World Health Organization; 2000.

53. Young JJ, Roffers S, Ries L, Fritz A, Hurlbut A, National Cancer Institute (Eds.): **SEER Summary Staging Manual - 2000: Codes and Coding Instructions,**. Bethesda, MD: National Cancer Institute; 2001.

54. GBD 2016 Causes of Death Collaborators: **Global, regional, and national age-sex specific mortality for 264 causes of death, 1980–2016: a systematic analysis for the Global Burden of Disease Study 2016.** *The Lancet* 2017, **390:**1151-1210.

55. Brustugun OT, Moller B, Helland A: **Years of life lost as a measure of cancer burden on a national level.** *Br J Cancer* 2014, **111:**1014-1020.

56. Zhao Y, Malyon R: **Life Years at Risk: A Population Health Measure from a Prevention Perspective.** *International Journal of Environmental Research and Public Health* 2009, **6:**2387-2396.

57. Papke LE, Wooldridge JM: **Econometric methods for fractional response variables with an application to 401(k) plan participation rates.** *Journal of Applied Econometrics* 1996, **11:**619-632.

58. StataCorp: **Stata Statistical Software: Release 15.1.** College Station, TX: StataCorp LP; 2017.

59. Sarfati D, Garvey G, Robson B, Moore S, Cunningham R, Withrow D, Griffiths K, Caron N, Bray F: **Measuring cancer in Indigenous populations.** *Annals of Epidemiology* 2018.

60. SCRGSP (Steering Committee for the Review of Government Service Provision): **Report on Government Services 2018.** Canberra: Productivity Commission; 2018.

61. Whitehead M: **The concepts and principles of equity and health.** Copenhagen: World Health Organization; 1990.

62. Lokuge K, Thurber K, Calabria B, Davis M, McMahon K, Sartor L, Lovett R, Guthrie J, Banks E: **Indigenous health program evaluation design and methods in Australia: a systematic review of the evidence.** *Australian and New Zealand Journal of Public Health* 2017, **41:**480-482.

63. Health Performance Council: **What's working, what's not: Review of the South Australian Health System Performance for 2011–2014.** Adelaide: Health Performance Council; 2014.

64. Murray CJL, Lopez AD: **Measuring global health: motivation and evolution of the Global Burden of Disease Study.** *The Lancet* 2017, **390:**1460-1464.

65. Harper S, Lynch J: **Methods for Measuring Cancer Disparities: Using Data Relevant to Healthy People 2010 Cancer-Related Objectives. .** Bethesda, MD: National Cancer Institute; 2005.

66. Blakely T, Soeberg M, Carter K, Costilla R, Atkinson J, Sarfati D: **Bias in relative survival methods when using incorrect life-tables: Lung and bladder cancer by smoking status and ethnicity in New Zealand.** *International Journal of Cancer* 2012, **131:**E974-E982.

67. Grafféo N, Giorgi R: **Non-Matching Life Tables and Impact.** In *Satellite Symposium European Partnership for Action Against Cancer (EPAAC)*. Ispra; 2014.

68. Dickman PW, Auvinen A, Voutilainen ET, Hakulinen T: **Measuring social class differences in cancer patient survival: is it necessary to control for social class differences in general population mortality? A Finnish population-based study.** *Journal of Epidemiology and Community Health* 1998, **52:**727-734.

69. Withrow DR, Racey CS, Jamal S: **A critical review of methods for assessing cancer survival disparities in indigenous population.** *Annals of Epidemiology* 2016, **26:**579-591.

70. Withrow DR, Pole JD, Nishri ED, Tjepkema M, Marrett LD: **Choice of relative or cause-specific approach to cancer survival analysis impacts estimates differentially by cancer type, population, and application: evidence from a Canadian population-based cohort study.** *Population Health Metrics* 2017, **15:**24.

71. Howlader N, Ries LAG, Mariotto AB, Reichman ME, Ruhl J, Cronin KA: **Improved Estimates of Cancer-Specific Survival Rates From Population-Based Data.** *JNCI: Journal of the National Cancer Institute* 2010, **102:**1584-1598.

72. Dwyer-Lindgren L, Stubbs RW, Bertozzi-Villa A, Morozoff C, Callender C, Finegold SB, Shirude S, Flaxman AD, Laurent A, Kern E, et al: **Variation in life expectancy and mortality by cause among neighbourhoods in King County, WA, USA, 1990–2014: a census tract-level analysis for the Global Burden of Disease Study 2015.** *Lancet Public Health* 2017, **2:**400-410.

73. Sheppard AJ, Chiarelli AM, Marrett LD, Nishri ED, Trudeau ME: **Stage at Diagnosis and Comorbidity Influence Breast Cancer Survival in First Nations Women in Ontario, Canada.** *Cancer Epidemiology Biomarkers & Prevention* 2011, **20:**2160-2167.

74. Santorelli ML, Hirshfield KM, Steinberg MB, Lin Y, Rhoads GG, Bandera EV, Demissie K: **Racial differences in the effects of comorbidity on breast cancer-specific survival.** *Cancer Causes & Control* 2017, **28:**809-817.

75. Wardliparingga Aboriginal Research Unit: **South Australian Aboriginal Health Research Accord: Companion Document.** Adelaide: South Australian Health and Medical Research Institute; 2014.

Chapter 3 What might a person-centred illness performance measurement look like?

Publication: Banham D, Karnon J, Lynch J. Health related quality of life (HRQoL) among Aboriginal South Australians: a perspective using survey-based health utility estimates. Health and Quality of Life Outcomes. 2019;17(1):39.

Available online at: https://hqlo.biomedcentral.com/articles/10.1186/s12955-019-1107-z

3.1 Preface to Chapter 3

The burden of disease framework offered SA a health accounting system for monitoring population change in healthy life expectancy, premature mortality and morbidity. Morbidity estimates use many data sources, yet gaps remain in informing changes to key areas of mental health, dementia and hearing loss for example. Moreover, Aboriginal specific morbidity estimates were not available for healthy life expectancy calculations.

This led me to consider alternative means of monitoring morbidity in the population and I compared two perspectives on population HRQoL change. Those perspectives used burden of disease morbidity estimates from administrative data and self-reports from random and representative population surveys (1). That study's results contended that monitoring of population level HRQoL was warranted and could contribute to monitoring healthy life expectancy. No such population estimates among Aboriginal South Australians existed and a novel response was needed.

Aboriginal health colleagues in SA Health asked that I join the steering committee for the first South Australian Aboriginal Health Survey (SAAHS). With support of April Lawrie-Smith, then Director of SA Health's Aboriginal Health Branch (2) and Aboriginal Community stakeholders, I argued for SAAHS to include a generic HRQoL instrument as a vehicle for purposefully collecting Aboriginal peoples' description of their own HRQoL and morbidity.

References

1. Banham D, Hawthorne G, Goldney R, Ratcliffe J. Health Related Quality of Life (HRQoL) changes in South Australia: A comparison of burden of disease morbidity and survey based health utility estimates. Health and Quality of Life Outcomes. 2014;12:113.

2. Lawrie-Smith A. Personal correspondence: Meeting between April Lawrie-Smith and David Banham on 28 April 2015.

3.2 Statement of authorship

Title of Paper	Health related quality of life (HRQoL) among Aboriginal South Australians: a perspective using survey-based health utility estimates
Publication Status	☑ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and Unsubmitted w ork w ritten in manuscript style
Publication Details	**Banham D**, Karnon J, Lynch J. Health related quality of life (HRQoL) among Aboriginal South Australians: a perspective using survey-based health utility estimates. Health and Quality of Life Outcomes. 2019;17(1):39.

Principal Author

Name of Principal Author (Candidate)	David Mark Banham		
Contribution to the Paper	Contributed to the development and operational governance of the South Australian Aboriginal Health Survey, conceptualised and initiated this paper, analysed the data, wrote the manuscript and acted as correspondent author.		
Overall percentage (%)	95%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	25th July 2022

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Jonathan Karnon		
Contribution to the Paper	My contribution to this paper involved manuscript evaluation.		
Signature		Date	25th July 2022

Name of Co-Author	John Lynch		
Contribution to the Paper	My contribution to this paper involved manuscript evaluation.		
Signature		Date	25th July 2022

3.3 Publication

Banham et al. Health and Quality of Life Outcomes (2019) 17:39
https://doi.org/10.1186/s12955-019-1107-z

Health and Quality of Life Outcomes

RESEARCH Open Access

Health related quality of life (HRQoL) among Aboriginal South Australians: a perspective using survey-based health utility estimates

David Banham[1,2,3*], Jonathan Karnon[1] and John Lynch[1]

Abstract

Background: Australian health surveys occasionally include health utility measures in describing health related quality of life (HRQoL) across the general population. However, the HRQoL of specific population groups, such as Aboriginal and Torres Strait Islander (respectfully referred to as Aboriginal), are poorly understood. Our analysis describes HRQoL utility among Aboriginal South Australians by examining the characteristics of respondents completing HRQoL questioning, the relationship between HRQoL and respondent characteristics, then considers reported HRQoL utility in the wider population context.

Methods: Population weighted and self-reported HRQoL was measured using SF-6D, as derived from the SF-12 version 2, in the South Australian Aboriginal Health Survey's face to face interviews with 399 respondents aged 15 or more in 2010/11.

Results: Mean HRQoL utility was 0.77 (95% CIs 0.76–0.79) with marked variations by gender (females 0.03, 95% CIs 0.00–0.06 lower than males), age (with ages 55 or more 0.08, 95% CIs 0.02–0.14 lower than 15–35 years) and number of chronic health conditions (3 or more conditions 0.14, 95% CIs 0.09–0.19 lower than those with 0 conditions). A pattern of response to HRQoL questions was also evident. Response was less likely among respondents speaking Aboriginal languages at home, living in non-urban settings, and experiencing multiple chronic health conditions.

Conclusions: The SF-6D provides useful information on the HRQoL of Aboriginal South Australians. However, non-completion was pronounced among respondents speaking traditional languages and experiencing more chronic health conditions. Improved participation of vulnerable and health compromised respondents through culturally safe and relevant self-reporting HRQoL utility instruments is needed.

Keywords: Health related quality of life, Health utility, SF-6D, Patient reported outcome measures, Aboriginal health, Disparities, Health inequities

Background

Marked improvements in mortality, continued increases in the prevalence of multiple chronic conditions [1, 2], and their influence on health related quality of life (HRQoL) are contributing to growing demands for healthcare and commensurately higher costs [2]. In the face of these challenges, improving health systems' understanding of what health outcomes are produced among the people they serve, at what cost and for whom, is critical [3]. A similarly urgent need is for the knowledge developed to use appropriate metrics which reflect the perspectives of people at the centre of system activities, that is, patients and populations [4].

To meet these needs, patient reported outcomes are increasingly used for patient groups [4–7] and the broader populations to whom they belong. Patient level reports of HRQoL often make use of health utility

* Correspondence: david.banham@sahmri.com
[1]School of Public Health, University of Adelaide, North Terrace, Adelaide, South Australia5000
[2]Wardliparingga Aboriginal Health Research, South Australian Health and Medical Research Institute, North Terrace, Adelaide, South Australia5000
Full list of author information is available at the end of the article

measures which account for multiple HRQoL domains and produce a single, cardinal value describing a person's health status at a particular time [8]. Their use at a population level provides context for aggregated patient reported outcomes at disease and service levels. They also assist with evaluating healthcare treatment and service programmes' role in changing population health across time and within population sub-groups [9] for example, by facilitating group comparison by ethnicity, age and disease status.

Australia has a substantial history of using surveys to monitor population health status. In more recent times these have begun incorporating health utility measures nationally [10–12] and among state and territory jurisdictions. For example, South Australia's long standing, annual Health Omnibus Survey (HOS) series is a random and representative household survey which has administered dedicated utility measures several times since their first inclusion in 1998 [13]. The SF-36 or its abridged form SF-12, is routinely included as a multi-dimensioned and generic HRQoL measure. To enable its wider use in assessing outcomes, SF-12 results were revised to yield the SF-6D health utility measure [14]. The SF-6D has subsequently been used to describe HRQoL norms for the Australian population [15].

Despite high quality, survey based data collections, the HRQoL of many specific population groups remains largely unknown [16]. For example, the disparities in health outcomes between Australia's Aboriginal and Torres Strait Islander (herein respectfully referred to as Aboriginal) and non-Aboriginal populations is well documented in terms of: higher avoidable mortality and lower life expectancy; higher use of emergency and inpatient hospital services, particularly in areas of potentially preventable episodes of care; and the burden associated with chronic disease such as diabetes, cardiac and renal conditions.

Therefore, there is a need for supporting policy decisions and health system activities aimed at efficiently and equitably addressing peoples' needs [4] by alleviating burden and improving HRQoL. However, the latter is not included in national frameworks tracking changes to Aboriginal health outcomes [17], nor is HRQoL and health utility of Aboriginal populations widely examined within jurisdictions. This is despite the fact that health utility and aggregated patient/population reported outcomes are increasingly used to inform decisions directly affecting Aboriginal Australians on issues ranging from selecting medications for subsidy [18] through to evaluating health service performance. Some exceptions are noted in Queensland where estimates for Aboriginal health workers [19] and Aboriginal cancer patients [20] are available. In South Australia, the SF-12 [21] has been used among remote Aboriginal South Australians living with diabetes [22]. However, it has not been validated among Aboriginal South Australians [21, 23] or used to report SF-6D health utilities [21]. Nor have the health preferences of Aboriginal Australians and their conceptions of health [21, 23] been contrasted against the outcomes of the generic SF-12 instrument. The use of existing generic HRQoL measures among Indigenous populations is a challenging area. Both national [24] and international [25] experience alerts us to characteristics associated with lower participation or impeded responding within health surveys. These characteristics include poor health literacy, illness severity, language barriers and cultural biases in the relevance of questions within instruments, and are more likely to affect Indigenous populations. These challenges are important to understand and respond to because non-participation is also associated with having relatively poorer health outcomes [4].

Employing the SF-12 among a representative population sample of Aboriginal South Australians would enable assessment of participation and question completion, provide a perspective on HRQoL, and facilitate comparison against wider South Australian and Australian population norms. The South Australian Aboriginal Health Survey (SAAHS) [26] provided an opportunity to pursue this. Having received funding through the Council of Australian Governments' partnership on closing the gap in Aboriginal and non-Aboriginal health outcomes, SAAHS was commissioned to provide the first comprehensive estimates of chronic disease prevalence among Aboriginal South Australians.

This paper aims to conduct a descriptive analysis of HRQoL assessed within SAAHS using health utility as reported by Aboriginal South Australians using the SF-6D. In particular, we examine the characteristics of those completing HRQoL questions, the relationship between HRQoL and respondent characteristics, then position the HRQoL results in the wider South Australian and Australian population context.

Methods

Study design, setting and participants

The SAAHS [26] was a cross-sectional, face to face and representative survey of the Aboriginal population across metropolitan, rural and remote areas in the state of South Australia. SAAHS sampled from households within randomly selected Australian Bureaus of Statistics (ABS) 2006 Census collection districts using a stratified, multi-stage, clustered and self-weighted area design [27]. Participants were aged 15 years or more and identified as Aboriginal according to national best practice guidelines [28].

Measurements

SAAHS administered 80 health related questions sourced from other population surveys, developed by

the SAAHS Advisory committee, or previously validated instruments for population health assessment. The subset of questions available to our study included: socio-demographic characteristics of gender, age in 10-year groupings and urban, regional or remote area of residence; Aboriginal language use categorised as either English or Aboriginal/Aboriginal English as the main language at home; employment as under-employed, employed at home, or employed outside the home; yearly income as $20,000 or less. Interviewees were also asked whether a doctor had ever diagnosed them with any of the following conditions: diabetes; renal disease; hearing loss; mental health issues; asthma; or, hypertension. The number of chronic conditions reported by each respondent was summed and categorised as no conditions, 1 or 2 conditions, or 3 or more conditions.

Health utility outcomes

Health utility was estimated using the SF-6D [14, 29, 30] as based on the SF-12 version 2's 12 items [31] and used under licence. The SF-6D version 2 uses six HRQoL subscales: physical function, role limitation, social function, bodily pain, mental health and vitality. The subscales combine for an overall utility score ranging from worst possible, or death equivalent, (0.39) to full HRQoL (1.00). UK general population utility weights derived by standard gamble techniques [14] were used in estimating Australian norms [15].

Data analysis

Standard scoring algorithms were used to derive the SF-6D score for HRQoL. Where responses to SF-12 questions were missing ($n = 61$), no SF-6D score was recorded for that interview. The sample of SF-6D completed and scored (1) and not scored/missing (0) responses were compared on the basis of socio-demographic and health condition variables using logistic regression and we report the unadjusted odds ratios (OR) and their 95% confidence intervals (95%CIs). The distribution of completed SF-6D scores was negatively skewed. The distribution was improved using a cubic transformation, the results of which were used to affirm the adequacy of models reported herein. Interquartile range and arithmetic means for the untransformed scores are reported. So too are the results of ordinary least squares regression of SF-6D score against stratum within each available predictor. The reported beta coefficients and 95%CIs indicate the direction, size and strength of changing stratum levels on SF-6D score. These variables were trialled concurrently to derive the most parsimonious and best fitting model of SF-6D, the parameters of which were used to predict missing SF-6D scores. The predicted mean SF-6D scores for those originally completing/not completing SF-12 items were then compared using independent group t-tests. Age group results are contrasted against published age norms for Australia [15] and unpublished South Australian Health Omnibus [13, 32] results in 2008. All analyses were conducted with Stata version 15.1 [33].

Results

A response rate of 57.7% saw 399 interviews completed from an initial sample of 691 eligible persons. Of those, 61 respondents completed demographic questions but not sufficient SF-12 items to enable scoring of the SF-6D. This group represented 10.9% (95% CIs 8.6–12.8) of Aboriginal South Australians aged 15 or more and Table 1 compares a selection of their characteristics with those who completed SF-6D health utility scores. On average, those completing SF-6D scores were less likely to: speak Aboriginal languages or Aboriginal English at home (OR = 0.32, 95% CIs 0.16–0.63); to live in regional or remote areas (OR = 0.12, 95% CIs 0.03–0.54 and OR = 0.01, 95% CIs 0.00–0.07 respectively); or experience at least one of the six chronic health conditions listed (1 or 2 conditions OR = 0.44, 95% CIs 0.23–0.86 and 3 or more conditions OR = 0.41, 95% CIs 0.19–0.91).

Completed SF-6D scores ranged from 0.39 to 1.00 and were negatively skewed with a median of 0.82 and mean 0.77 (95% CIs 0.76–0.79) as shown in Table 2. On a bivariate level, mean scores varied across groups with females reporting lower health utility than males and age groups 35 years or more reported incrementally lower health utility compared to those aged 15 to 24 years. Speaking Aboriginal languages at home and living with chronic health conditions were also associated with lower health utility compared to those primarily speaking English at home and experiencing no chronic conditions respectively. Conversely, employment at home or outside the home was associated with comparatively better health utility than those who reported underemployment.

These characteristics contributed to a multivariable model of health utility score (Table 3). The exception was language spoken at home which did not contribute significantly in the presence of other predictor variables. Concurrent assessment of each showed that females reported average health utility 0.03 (95% CIs 0.00–0.06) lower than males, age groups 35 years and beyond reporting incrementally lower health utility than those aged 15 to 34 years and living with chronic health conditions (1 or 2 conditions $\beta = -0.07$, 95% CIs −0.12- −0.03 and 3 or more conditions $\beta = -0.14$, 95% CIs −0.19- -0.09). Employment continued to be associated with better health utility compared to underemployment by 0.05 (95% CIs 0.02–0.07). Overall, modelling gender, age, employment and chronic conditions as predictors of SF-6D scores explained 34.6% of the variance in those scores ($r^2 = 0.346$, $F(7,329) = 23.98$, $p < 0.001$).

Table 1 Respondent characteristics for completed health utility (SF-6D) estimation

Sample N=399	SF-6D not estimated n=61		SF-6D estimated n=338		OR (unadjusted) of SF-6D being estimated[#]	
	%	95% CIs	%	95% CIs		95% CIs
Total	10.9	8.6-12.8	89.1	86.2-91.4		
Sex						
Male	57.8	44.3-71.2	46.3	40.6-52.1	1.00	Reference
Female	42.2	28.8-55.7	53.7	47.9-59.4	1.59	0.87-2.89
Age (years)						
15 to 24	30.4	17.0-43.8	31.1	25.8-36.4	1.00	0.00-0.00
24 to34	21.3	9.9-32.7	21.4	16.7-26.0	0.98	0.40-2.38
35 to 44	14.5	5.8-23.3	20.9	16.5-25.3	1.41	Reference
45 to 54	15.8	6.8-24.9	14.5	9.7-19.2	0.89	0.35-2.25
55 or more	18.0	8.4-27.6	12.2	8.6-15.7	0.66	0.27-1.59
Language						
Aboriginal (mix)	27.8	16.0-39.6	11.0	7.6-14.3	**0.32**	**0.16-0.63**
English	72.2	60.4-84.0	89.0	85.7-92.4	1.00	Reference
Employment						
Under employed	40.1	26.7-53.5	35.1	29.7-40.6	1.00	Reference
Employment at home	28.2	15.6-40.9	35.6	30.1-41.1	1.44	0.68-3.04
Employed outside home	31.7	19.4-43.9	29.2	24.1-34.4	1.05	0.53-2.10
Income (yearly)						
Not stated	68.6	55.6-81.6	63.1	57.6-68.6	1.00	Reference
less than or equal $20,000	15.7	6.0-25.5	18.7	14.4-23.1	1.29	0.59-2.86
more than $20,000	15.7	4.4-27.0	18.2	13.5-22.9	1.26	0.50-3.16
Region						
Urban	7.4	-2.2-17.1	58.2	56.2-60.3	1.00	Reference
Regional	37.2	25.2-49.2	35.3	33.4-37.2	**0.12**	**0.03-0.54**
Remote	55.4	43.1-67.7	6.5	5.1-7.9	**0.01**	**0.00-0.07**
Health conditions						
Diabetes						
	71.9	60.2-83.7	86.7	82.9-90.5	1.00	Reference
	28.1	16.3-39.8	13.3	9.5-17.1	**0.39**	**0.20-0.77**
Renal						
	90.4	83.9-96.8	94.3	91.9-96.7	1.00	Reference
	9.6	3.2-16.1	5.7	3.3-8.1	0.56	0.24-1.35
Hearing loss						
	86.3	78.3-94.4	91.0	88.0-94.0	1.00	Reference
	13.7	5.6-21.7	9.0	6.0-12.0	0.62	0.29-1.37
Mental health						
	90.1	81.3-99.0	90.0	86.6-93.5	1.00	Reference
	9.9	1.0-18.7	10.0	6.5-13.4	1.01	0.35-2.95
Asthma						
	84.0	74.6-93.5	85.6	81.8-89.5	1.00	Reference
	16.0	6.5-25.4	14.4	10.5-18.2	0.88	0.41-1.91
Hypertension						
	65.6	53.3-77.8	81.8	77.3-86.4	1.00	Reference
	34.4	22.2-46.7	18.2	13.6-22.7	**0.42**	**0.23-0.79**
Comorbidities						
0 conditions	43.7	30.1-57.4	64.3	58.9-69.8	1.00	Reference
1 or 2 conditions	38.9	25.8-52.1	25.2	20.2-30.3	**0.44**	**0.23-0.86**
3 + conditions	17.3	8.3-26.3	10.4	7.1-13.8	**0.41**	**0.19-0.91**

[#]results in bold indicate stratum which differed from the Reference group in a statistically significant way (p< 0.03)

*from diabetes, renal, hearing, mental health, asthma and hypertension

Table 2 SF-6D by demographic and health conditions

	Interquartille						
	25th percentile	50th percentile	75th percentile	Mean	95% CIs	Beta (unadjusted)*	95% CIs*
Total	0.70	0.82	0.85	0.77	0.76-0.79		
Sex							
Male	0.75	0.85	0.85	0.80	0.78-0.83	0.00	Reference
Female	0.65	0.80	0.85	0.75	0.73-0.77	**-0.05**	**-0.09--0.02**
Age (years)							
15 to 24	0.80	0.85	0.86	0.824	0.80-0.85	0.00	Reference
24 to34	0.80	0.85	0.86	0.821	0.79-0.85	0.00	-0.04-0.03
35 to 44	0.66	0.82	0.85	0.755	0.72-0.78	**-0.07**	**-0.11--0.03**
45 to 54	0.58	0.72	0.80	0.694	0.64-0.75	**-0.13**	**-0.19--0.07**
55 or more	0.57	0.66	0.75	0.675	0.63-0.72	**-0.15**	**-0.20--0.10**
Language							
Aboriginal (mix)	0.59	0.68	0.86	0.71	0.66-0.77	**-0.07**	**-0.12--0.01**
English	0.72	0.82	0.85	0.78	0.76-0.80	0.00	Reference
Employment							
Under employed	0.63	0.78	0.82	0.74	0.71-0.76	0.00	Reference
Employment at home	0.70	0.85	0.85	0.79	0.76-0.82	**0.05**	**0.01-0.09**
Employed outside home	0.74	0.85	0.86	0.80	0.77-0.83	**0.06**	**0.02-0.10**
Income (yearly)							
Not stated	0.76	0.82	0.85	0.80	0.79-0.81	0.00	Reference
less than or equal $20,000	0.57	0.75	0.92	0.73	0.69-0.78	**-0.07**	**-0.11--0.02**
more than $20,000	0.58	0.72	0.86	0.72	0.66-0.77	**-0.08**	**-0.14--0.03**
Region							
Urban	0.70	0.82	0.85	0.77	0.75-0.80	0.00	Reference
Regional	0.70	0.82	0.85	0.78	0.76-0.79	0.00	-0.03-0.04
Remote	0.66	0.74	0.86	0.76	0.72-0.81	-0.01	-0.06-0.05
Health conditions							
Diabetes							
	0.72	0.82	0.85	0.78	0.77-0.80	0.00	Reference
	0.58	0.72	0.86	0.71	0.66-0.77	**-0.07**	**-0.13--0.01**
Renal							
	0.71	0.82	0.85	0.78	0.76-0.80	0.00	Reference
	0.53	0.66	0.72	0.63	0.57-0.68	**-0.15**	**-0.21--0.09**
Hearing loss							
	0.70	0.82	0.85	0.78	0.76-0.79	0.00	Reference
	0.58	0.72	0.85	0.71	0.66-0.77	**-0.06**	**-0.12--0.01**
Mental health							
	0.72	0.82	0.85	0.79	0.77-0.80	0.00	Reference
	0.55	0.62	0.72	0.63	0.58-0.68	**-0.16**	**-0.21--0.11**
Asthma							
	0.74	0.82	0.85	0.79	0.77-0.81	0.00	Reference
	0.53	0.62	0.78	0.66	0.61-0.71	**-0.13**	**-0.18--0.08**
Hypertension							
	0.75	0.82	0.85	0.80	0.78-0.81	0.00	Reference
	0.51	0.63	0.75	0.66	0.61-0.70	**-0.14**	**-0.19--0.09**
Comorbidities							
0 conditions	0.80	0.85	0.85	0.82	0.81-0.83	0.00	Reference
1 or 2 conditions	0.58	0.70	0.86	0.71	0.67-0.75	**-0.11**	**-0.15--0.07**
3 + conditions	0.53	0.62	0.72	0.63	0.59-0.67	**-0.19**	**-0.23--0.14**

*results in bold indicate stratum which differed from the Reference group in a statistically significant way (p< 0.02)

Using those parameters to predict SF-6D among missing responses resulted in that group having comparatively lower health utility at 0.75 (95% CIs 0.72–0.77), β = − 0.03 (95% CIs − 0.05- -0.00).

Health utility among Aboriginal South Australians by age is placed in the wider South Australian (n = 3014) and Australian population (N = 17,630) context within Fig. 1. Health utility decreased across age groups for each of the three population groups. However, having observed very similar utility levels among those aged 15 to 34 years, the incremental decreases in health utility observed among Aboriginal South Australians in subsequent age groups was more pronounced than those in either of the comparator populations.

Table 3 Linear regression model of relationship between SF-6D scores and respondent characteristics

	Beta	95% Confidence Intervals		t	p	r^2
		LCI	UCI			
Gender						
Male	0.00	Reference				
Female	-0.03	−0.06	−0.00	−2.22	0.027	
Age (years)						
15 to 34	0.00	Reference				
35 to 44	−0.05	−0.08	− 0.02	−3.32	0.001	
45 to 54	−0.09	−0.14	− 0.03	− 3.34	0.001	
55 +	−0.08	−0.14	− 0.02	−2.68	0.008	
Employment						
Under employed	0.00	Reference				
Employed	0.05	0.02	0.07	3.15	0.002	
Chronic health conditions						
0 conditions	0.00	Reference				
1 or 2 conditions	−0.07	−0.12	−0.03	−3.17	0.002	
3 + conditions	−0.14	−0.19	− 0.09	−5.18	< 0.001	
Constant	0.82	0.80	0.85	71.94	< 0.001	
Model fit (r^2)						0.346

Discussion

The rising prevalence of chronic disease and the risk of accumulating morbidity makes it increasingly important to monitor the HRQoL of populations. This is particularly so for groups already vulnerable to other forms of health loss through early death and the influence of widespread and pervasive social disadvantage, as is the case with Aboriginal Australians. This paper is one of few that describes HRQoL among Aboriginal Australians using a health utility measure. Having used a representative sample of randomly chosen Aboriginal adults [27] it provides a valuable comparator for reports of HRQoL within Aboriginal communities and across the broader community.

The mean HRQoL utility reported among Aboriginal South Australians aged 15 or more was 0.77 (95% CIs 0.76–0.79) which is equivalent to Australian norms of 0.77 (95% CIs 0.76–0.77) using data collected in 2009–2010 [15]. Underlying those average HRQoL levels were

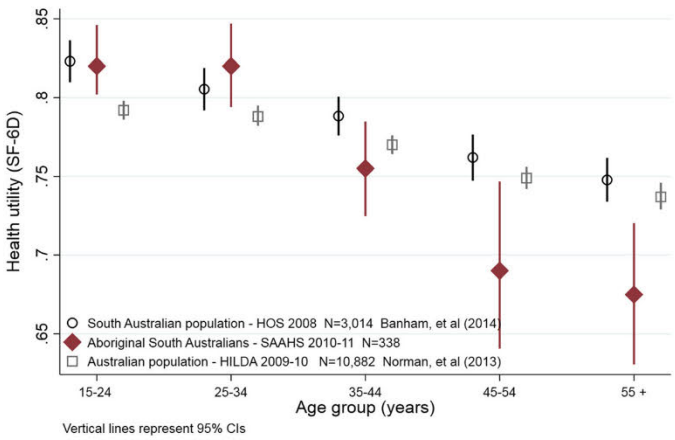


Fig. 1 Population health utility (SF-6D) by age

gender differences whereby Aboriginal females reported 5% lower HRQoL than males on average. This was consistent with the nature of gender differences observed in the wider Australian population using the SF-6D [15] and other health utility instruments such as the AQoL whether in South Australia [13] or nationally [11]. Declining HRQoL across age groups is also consistent with the general population norms [15]. However, two points of difference were notable. The average Aboriginal HRQoL at ages 15–24 was higher than that of the Australian population while the magnitude of health utility decrease into older ages within the Aboriginal community was markedly greater than those observed within the contemporary South Australian and Australian populations. This has important implications for interpreting mean health utility as each population has quite different age profiles. For example, as a consequence of high premature mortality rates, ages 45 and above are under-represented in the Aboriginal community in comparison to the non-Aboriginal population of South Australia and accounted for 17 and 41% of the respective populations [34]. Consequently, if Aboriginal South Australia had a similar age profile to that of the non-Aboriginal population, their average HRQoL utility would be lower by around 7%. Our results also provide clear evidence of pervasive self-reports of chronic health conditions and that multiple comorbid conditions are related to lower health utility. This is consistent with related population analyses. For example, the New South Wales' 45 and up study demonstrated Aboriginal respondents were comparatively more likely to report poorer self-rated health and quality of life [35] and this was further exacerbated as the number of chronic conditions increased [35]. In addition, related follow-up studies of respondents by Aboriginality [36] found response rates were lower among those reporting poorer health status and lower quality of life [36].

This latter observation resonates with a further finding of interest in our analysis. While questions enabling the description of health utility were completed by most SAAHS interview respondents, a pattern of non-responding was also apparent. Some of the predictors of not completing health utility questions (language at home and chronic health conditions) were also indicators of poorer HRQoL. Using completed responses to predict HRQoL of those missing utility scores indicated significantly lower average health utility would be expected among the latter group (by approximately 2%).

In the context of a population already reporting lower HRQoL than the wider community when age profile is considered, our findings identified a further population sub-group whose perspective on HRQoL has not been given voice. Importantly, there is reason to believe this group has further reduced health utility. The relationship observed between poor health outcomes and language is also reported in other settings. For example, a study of Aboriginal cancer patients in Australia's Northern Territory found those with an indigenous language experienced significantly poorer outcomes than those with English as their first language [37]. This suggested issues such as health literacy, depth of understanding of mainstream vernacular and difficulties in communicating within that paradigm may restrict the uptake of effective health care. The lack of engagement with SF-12 HRQoL questions may be similarly affected and the nature of questions considered too distant from, or irrelevant to, the circumstance of people whose traditional cultural connection remains strong [21, 23].

In its report to the South Australian Parliament, South Australia's Health Performance Council [16] identified the opportunity for purposefully sampling specific populations to improve awareness of unmet health needs and encourage accountable responses by the health system. The SAAHS method [27] provided some evidence in support of using a standard, generic health utility measure as a means of meeting this information need for Aboriginal South Australians. Importantly though, the results suggest cautious use because a sub-group within the target population was identified as less likely to fully participate. Those less likely to self-report health utility were also more likely to have higher levels of comorbidity and experience poorer health utility.

This raises two limitations in our analysis. The first is to recognise a probable bias in our results whereby health utility among Aboriginal South Australians is over estimated because of the omission of a vulnerable population sub-group. Secondly, if language use contributes to the exclusion of people who can reasonably be considered as having ill-described and unmet HRQoL needs, then further research is required to remedy that with suitably adapted [24], culturally relevant [21, 22, 25] and validated [23] measures.

It is imperative to pursue these improvements and build on the strengths of this study which provided evidence of variations and disparate HRQoL utility among a representative sample of randomly selected Aboriginal adults [27]. These activities will help expand existing population health assessment beyond life expectancy, an acknowledged area of considerable inequity, to include informed discussion of a population's perspective of their own HRQoL utility. Ultimately, HRQoL utility measurement could be subsumed into estimating healthy life expectancy [13, 38], a "best overall measure" p262 [39] and one widely reported internationally [40]. Healthy life expectancy helps reframe descriptions of population health disparity to include peoples' experiences of morbid illness and its severity. Health utility measurement has a special role as it makes use of self-reported outcomes in a form salient to evaluating health system activities designed to address morbid illness and improve patient/population health outcomes [41].

Conclusions

The SF-6D, as a generic health utility measure, provides useful information on the population health status of Aboriginal South Australians, albeit from a narrow and biomedically focussed perspective. However, caution is needed in its further use because the instrument's questions were less likely to be responded to by people speaking traditional language, experiencing more chronic health conditions and reporting poorer health utility. Our results therefore suggest a need for improved instruments that are salient to the Aboriginal population and which lead to improved participation and self-reporting of HRQoL and health utility.

Abbreviations

95% CIs: 95% confidence intervals; Aboriginal: Aboriginal and/or Torres Strait Islanders; ABS: Australian Bureaus of Statistics; HRQoL: health related quality of life; OR: Odds Ratio; SAAHS: South Australian Aboriginal Health Survey

Acknowledgements

The authors gratefully acknowledge SA Health and the University of Adelaide's Population Research and Outcomes Studies for collecting SAAHS data, SA Health for permitting use of those data, and Emeritus Professor Bob Goldney for permitting use of Health Omnibus Survey data. DB is supported in part by an Australian Government Research Training Program Scholarship.

Funding

Funding for the SAAHS came from the Closing the Gap National Partnership Agreement.

Availability of data and materials

The study's data comprised of de-identified survey responses. These were used under privileged arrangements set out in a study specific confidentiality deed. The data cannot be accessed by another party without relevant departmental and human research ethics approvals.

Authors' contributions

DB conceived the original research question, operationalised the study, performed data analysis, drafted and revised the manuscript. JK and JL made important contributions to interpreting the statistical analysis and revised the manuscript. All authors read and approved the final version of the manuscript.

Ethics approval and consent to participate

The SA Aboriginal Health Advisory Committee oversaw the running of the survey and provided advice on survey methods, content, instruments and questions. The Aboriginal Health Council of South Australia (04–14-553) and SA Health's Human Research Ethics Committee approved the study (HREC/14/SAH/84) and the secondary use of survey data.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Publisher's Note

Author details

[1]School of Public Health, University of Adelaide, North Terrace, Adelaide, South Australia5000. [2]Wardliparingga Aboriginal Health Research, South Australian Health and Medical Research Institute, North Terrace, Adelaide, South Australia5000. [3]Division of Health Sciences, University of South Australia, North Terrace, Adelaide, South Australia5000.

Received: 17 August 2018 Accepted: 7 February 2019
Published online: 18 February 2019

References

1. Christopher H, Joan H, Graeme M, Helena B. The prevalence of complex multimorbidity in Australia. Aust N Z J Public Health. 2016;40:239–44.
2. Puth M-T, Weckbecker K, Schmid M, Münster E. Prevalence of multimorbidity in Germany: impact of age and educational level in a cross-sectional study on 19,294 adults. BMC Public Health. 2017;17:826.
3. Porter ME, Lee TH. The strategy that will fix health care. Harv Bus Rev. 2013; 91:50–70.
4. OECD: Recommendations to OECD ministers of health from the high level reflection group on the future of health statistics: strengthening the international comparison of health system performance through patient-reported indicators. OECD; 2017.
5. Devlin NJ, Appleby J. Getting the most out of PROMs. putting health outcomes at the heart of NHS decision-making. London: The King's Fund; 2010.
6. McGrail K, Bryan S, Davis J. Let's all go to the PROM: the case for routine patient-reported outcome measurement in Canadian healthcare. HealthcarePapers. 2012;11:8–18.
7. Williams K, Sansoni J, Morris D, Grootemaat P, Thompson C. Patient-reported outcome measures: literature review. In: Sydney: Australian commission on safety and quality in health care; 2016.
8. Torrance GW. Utility approach to measuring health-related quality of life. J Chronic Dis. 1987;40:593–600.
9. Brazier J, Ratcliffe J, Salomon JA, Tsuchiya A. Measuring and valuing health benefits for economic evaluation. 2nd ed. Oxford: Oxford University Press; 2017.
10. Australian Bureau of Statistics. National Survey of mental health and wellbeing: Users' guide, 2007. Canberra: ABS; 2009.
11. Hawthorne G, Korn S, Richardson J. Population norms for the AQoL derived from the 2007 Australian National Survey of mental health and wellbeing. Aust N Z J Public Health. 2013;37:7–16.
12. Hawthorne G, Osborne R. Population norms and meaningful differences for the assessment of quality of life (AQoL) measure. Australian & New Zealand Journal of Public Health. 2005;29:136–42.
13. Banham D, Hawthorne G, Goldney R, Ratcliffe J. Health related quality of life (HRQoL) changes in South Australia: a comparison of burden of disease morbidity and survey based health utility estimates. Health Qual Life Outcomes. 2014;12:113.
14. Brazier JE, Roberts J. The estimation of a preference-based measure of health from the SF-12. Med Care. 2004;42:851–9.
15. Norman R, Church J, van den Berg B, Goodall S. Australian health-related quality of life population norms derived from the SF-6D. Aust N Z J Public Health. 2013;37:17–23.
16. Health Performance Council. What's working, what's not: review of the south Australian health system performance for 2011–2014. Adelaide: Health Performance Council; 2014.
17. Australian Health Ministers' Advisory Council. Aboriginal and Torres Strait Islander Health Performance Framework 2017 report. Canberra: AHMAC; 2017.
18. Pharmaceutical Benefits Advisory Committee. Guidelines for preparing a submission to the pharmaceutical benefits advisory Committee. Version 5.0 edition. Department of Health: Canberra; 2016.
19. Segal L, Nguyen H, Schmidt B, Wenitong M, McDermott RA. Economic evaluation of indigenous health worker management of poorly controlled type 2 diabetes in North Queensland. Med J Aust. 2016;204:1961e–1969.
20. Garvey G, Cunningham J, He VY, Janda M, Baade P, Sabesan S, Martin JH, Fay M, Adams J, Kondalsamy-Chennakesavan S, Valery PC. Health-related quality of life among indigenous Australians diagnosed with cancer. Qual Life Res. 2016:1–10.
21. Angell B, Muhunthan J, Eades A-M, Cunningham J, Garvey G, Cass A, Howard K, Ratcliffe J, Eades S, Jan S. The health-related quality of life of indigenous populations: a global systematic review. Qual Life Res. 2016;25: 2161–78.
22. Battersby MW, Ah Kit J, Prideaux C, Harvey PW, Collins JP, Mills PD. Implementing the Flinders model of self-management support with aboriginal people who have diabetes: findings from a pilot study. Australian J Primary Health. 2008;14:66–74.
23. Le Grande M, Ski CF, Thompson DR, Scuffham P, Kularatna S, Jackson AC, Brown A. Social and emotional wellbeing assessment instruments for use with indigenous Australians: a critical review. Soc Sci Med. 2017;187:164–73.

24. Brown AMR, Rowley K, Skinner T, Davy C, O'Dea K. Depression in aboriginal men in Central Australia: adaptation of the patient health questionnaire 9. BMC Psychiatry. 2013;13.271.
25. Burgard SA, Chen PV. Challenges of health measurement in studies of health disparities. Soc Sci Med. 2014;106.143–50.
26. Taylor A, Marin T, Avery J, Dal Grande E. South Australian aboriginal health survey pp. 1–223. Adelaide: Population Research and Outcome Studies; 2012. p. 1–223.
27. Marin T, Taylor AW, Grande ED, Avery J, Tucker G, Morey K. Culturally appropriate methodology in obtaining a representative sample of south Australian aboriginal adults for a cross-sectional population health study: challenges and resolutions. BMC Res Notes. 2015;8:200.
28. Australian Institute of Health and Welfare. National best practice guidelines for collecting indigenous status in health data sets. Canberra, AIHW; 2010.
29. Kharroubi SA, Brazier JE, Roberts J, O'Hagan A. Modelling SF-6D health state preference data using a nonparametric Bayesian method. J Health Econ. 2007;26:597–612.
30. McCabe C, Brazier J, Gilks P, Tsuchiya A, Roberts J, O'Hagan A, Stevens K. Using rank data to estimate health state utility models. J Health Econ. 2006; 25:418–31.
31. Ware JJ, Kosinski M, Turner-Bowker D, Gandek B. How to score version 2 of the SF-12 health survey (with a supplement documenting version 1). Quality Metric Incorporated: Lincoln, RI; 2002.
32. Goldney RD, Dunn KI, Dal Grande E, Crabb S, Taylor A. Tracking depression-related mental health literacy across South Australia: a decade of change. The Australian and New Zealand Journal of Psychiatry. 2009;43:476–83.
33. StataCorp: Stata Statistical Software: Release 15.1. College Station, TX: StataCorp LP; 2017.
34. Australian Bureau of Statistics. Experimental estimates and projections, aboriginal and Torres Strait islander Australians. Canberra: ABS; 2009.
35. Gubhaju L, Banks E, MacNiven R, McNamara BJ, Joshy G, Bauman A, Eades SJ. Physical functional limitations among aboriginal and non-aboriginal older adults: associations with socio-demographic factors and health. PLoS One. 2015;10:e0139364.
36. Gubhaju L, Banks E, MacNiven R, Joshy G, McNamara BJ, Bauman A, Eades SJ. Factors relating to participation in follow-up to the 45 and up study in aboriginal and non-aboriginal individuals. BMC Med Res Methodol. 2016;16.
37. Condon J, Cunningham J, Barnes A, Armstrong B, Selva-Nayagam S. Cancer diagnosis and treatment in the Northern Territory - assessing health service performance for indigenous Australians. Intern Med J. 2006;36:498–505.
38. The Public Health Agency of Canada Steering Committee on Health-Adjusted Life Expectancy: Health-Adjusted Life Expectancy in Canada: 2012 Report by the Public Health Agency of Canada 2013.
39. Smith JN. Epic measures. New York: HarperCollins; 2015.
40. Abajobir AA, Abate KH, Abbafati C, Abbas KM, Abd-Allah F, Abdulkader RS, Abdulle AM, Abebo TA, Abera SF, Aboyans V, et al. Global, regional, and national disability-adjusted life-years (DALYs) for 333 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990–2016: a systematic analysis for the global burden of disease study 2016. Lancet. 2017;390:1260–344.
41. Banham D, Lynch J, Kamon J. An equity–effectiveness framework linking health programs and healthy life expectancy. Australian Journal of Primary Health. 2011;17:309–19.

Chapter 4 What might a person-centred performance measure of preventable ED presentation look like?

Banham D, Karnon J, Densley K, Lynch J. How much Emergency Department use by vulnerable populations is potentially preventable?: A period prevalence study of linked public hospital data in South Australia. BMJ Open. 2019(e022845).

Available online at: https://bmjopen.bmj.com/content/9/1/e022845

4.1 Preface to Chapter 4

SA Health colleagues asked me to replicate PPH for South Australia as reported by the AIHW then extend that analysis for intra-state health regions. PPH use as a performance measure focussed on reducing the volume of PPH hospitalisation events as a percentage of total hospital events for a given hospital. This seemed a limited and unnecessarily narrow approach. Previous experiences with patient cohorts attending public hospitals clearly showed individuals often had more than one hospital event and those events could be spread across multiple hospitals (1). An initial study quantified the potential for preventing hospitalisation using person-level analysis (2). The results showed the existence of broader population patterns in hospital use and a routine performance measure was under-informed on the nature and influence of these patterns. Hospital records also provide a useful perspective on the health needs of some vulnerable populations. This was another area the health system had little insight on, yet this did not need to be the case. As a result, I initiated the PPH data linkage study (Appendix B) with the aim of adding, then routinising, a person-centred perspective on PPH within SA.

On learning of the PPH linkage study through the health portfolio's community of practice, several colleagues from policy and migrant health services asked how the project might help inform on Emergency Department contact by people with refugee and asylum seeker backgrounds. I broadened the analysis to include other potentially vulnerable population groups including Aboriginal and senior South Australians.

References

1. Cheok F, Schrader G, Banham D, Marker J, Hordacre AL Identification, course, and treatment of depression after admission for a cardiac condition: rationale and patient characteristics for the Identifying Depression As a Comorbid Condition (IDACC) project. Am Heart J 2003 Vol. 146 Issue 6 Pages 978-84.

2. Banham D, Woollacott T, Gray J, Humphrys B, Mihnev A, McDermott R. Recognising potential for preventing hospitalisation. Australian Health Review. 2010;34(1):116-22.

4.2 Statement of authorship

Title of Paper	How much Emergency Department use by vulnerable populations is potentially preventable?: A period prevalence study of linked public hospital data in South Australia
Publication Status	☑ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and Unsubmitted w ork w ritten in manuscript style
Publication Details	**Banham D**, Karnon J, Densley K, Lynch J. How much Emergency Department use by vulnerable populations is potentially preventable?: A period prevalence study of linked public hospital data in South Australia. BMJ Open. 2019(e022845).

Principal Author

Name of Principal Author (Candidate)	David Mark Banham		
Contribution to the Paper	Conceptualised and initiated the associated data linkage project. Conceptualised and initiated this paper, collated and analysed the data, wrote the manuscript and acted as correspondent author.		
Overall percentage (%)	95%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	25th July 2022

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Jonathan Karnon		
Contribution to the Paper	My contribution to this paper involved manuscript evaluation.		
Signature		Date	25th July 2022

Name of Co-Author	Kirsten Densley		
Contribution to the Paper	My contribution to this paper involved literature searching and manuscript drafting.		
Signature		Date	25th July 2022

Name of Co-Author	John Lynch		
Contribution to the Paper	My contribution to this paper involved manuscript evaluation.		
Signature		Date	25th July 2022

4.3 Publication

Open access Research

BMJ Open

How much emergency department use by vulnerable populations is potentially preventable?: A period prevalence study of linked public hospital data in South Australia

David Banham,[1,2] Jonathan Karnon,[1] Kirsten Densley,[3] John W Lynch[1]

To cite: Banham D, Karnon J, Densley K, *et al*. How much emergency department use by vulnerable populations is potentially preventable?: A period prevalence study of linked public hospital data in South Australia. *BMJ Open* 2019;**9**:e022845. doi:10.1136/bmjopen-2018-022845

► Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2018-022845).

Received 15 March 2018
Revised 11 December 2018
Accepted 13 December 2018

[1]School of Public Health, Faculty of Health and Medical Sciences, The University of Adelaide, Adelaide, South Australia, Australia
[2]Division of Health Sciences, University of South Australia, Adelaide, South Australia, Australia
[3]Flinders Medical Centre, Southern Adelaide Local Health Network, Bedford Park, South Australia, Australia

Correspondence to
Mr David Banham;
david.banham@sahmri.com

ABSTRACT

Objectives To quantify emergency department (ED) presentations by individuals within vulnerable populations compared with other adults and the extent to which these are potentially preventable.

Design Period prevalence study from 2005-2006 to 2010–2011.

Setting Person-linked, ED administrative records for public hospitals in South Australia.

Participants Adults aged 20 or more in South Australia's metropolitan area presenting to ED and categorised as Refugee and Asylum Seeker Countries of birth (RASC); Aboriginal; those aged 75 years or more; or All others.

Main outcome measures Unadjusted rates of ambulatory care sensitive condition (ACSC), general practitioner (GP)–type presentations and associated direct ED costs among mutually exclusive groups of individuals.

Results Disparity between RASC and All others was greatest for GP-type presentations (423.7 and 240.1 persons per 1000 population, respectively) with excess costs of $A106 573 (95% CI $A98 775 to $A114 371) per 1000 population. Aboriginal had highest acute ACSC presenter rates (125.8 against 51.6 per 1000 population) with twice the risk of multiple presentations and $A108 701 (95% CI $A374 to $A123 029) per 1000 excess costs. Those aged 75 or more had highest chronic ACSC presenter rates (119.7vs21.1 per 1000), threefold risk of further presentations (incidence rate ratio 3.20, 95% CI 3.14 to 3.26) and excess cost of $A385 (95% CI $A178 160 to $A184 609) per 1000 population.

Conclusions Vulnerable groups had excess ED presentations for a range of issues potentially better addressed through primary and community healthcare. The observed differences suggest inequities in the uptake of effective primary and community care and represent a source of excess cost to the public hospital system.

Strengths and limitations of this study

- This is the first study to examine variations in potentially preventable emergency department (ED) presentations and direct hospital costs among several vulnerable populations in Australia.
- The study uses person-linked public hospital records over a 6-year period from 2005 to 2006 to 2010–2011.
- The study informs health system performance measurement focused on vulnerable populations' capacity to benefit from preventative and community-based services.
- Our analysis was limited by the omission of one ED site representing approximately 10% of ED activity.
- The ED presenting diagnoses used to categorise potentially preventable presentations can be the subject of reclassification.

BACKGROUND

Australia's public hospital emergency department (ED) presentations are increasing faster[1 2] than the populations they serve.[1 3] This is an intractable concern for state and territory[4 5] health departments responsible for providing public hospital services.

Effective and efficient responses to the issue will involve the health system providing the best care at the time of first contact with a person.[6] The development of such responses will benefit from a system-wide understanding of who uses ED services and what care alternatives are needed.

We know from previous research that ED presentations for acute, chronic and vaccine-preventable conditions such as urinary tract infections, asthma and influenza are potentially suited to primary and community healthcare interventions and can be collectively quantified as ambulatory care sensitive conditions (ACSCs).[7–15] As such, ACSCs are widely used as indicators of suboptimal availability and effectiveness of primary healthcare in reducing the need for hospital care through primary prevention, early diagnosis, treatment and/or appropriate management in community settings.[16] A related measure is potentially avoidable general practice, or

general practitioner (GP)–type presentations[17 18] which comprises lower acuity ED presentations not resulting in hospitalisation. ACSC and GP-type presentations may also reflect systemic inequities in accessing relevant, effective services.[19 20] Either way, ED use is associated with financial cost to the health system and costs to individuals experiencing disruption, stress and crises, and discontinuity of care, particularly for chronic conditions. Previous analyses of administrative records have also identified several groups vulnerable to excess contact with hospitals generally. These population groups include those from Refugee and Asylum Seeker Countries (RASCs),[20–23] Aboriginal people (where 'Aboriginal' is respectfully used to refer to people self-identifying as Aboriginal, Torres Strait Islander or both[20 24]) and those aged 75 years or more.[24 25]

Descriptions of ED activity among RASC,[21 26] Aboriginal[27] and older Australians,[1 28] and the extent to which the activity is potentially preventable, are limited. In those that are available, the unit of analysis was ED presentations rather than unique individual presenters. Reframing ED activity information to describe outcomes for individuals within vulnerable populations will provide important new information. For example, understanding the number of individuals presenting to EDs, and the likelihood of their having multiple presentations, will better detail their capacity to benefit from services suiting their condition or circumstance.[29] Detailing direct service costs will then help scope the potential for redirecting resources from high cost acute environments towards preventative measures and care in community settings.

Our aim is to provide such information by quantifying the use of public hospital EDs by three vulnerable populations in comparison with the rest of the population in metropolitan South Australia. Our objectives in doing so are first to quantify the rates of public ED presentations overall, and those involving ACSC and GP-type presentations. We then quantify the comparative rates with which individuals within population groups presented to EDs once or multiple times, together with the direct, system cost of these presentations. In each instance, we stratify results for ED presentations overall to report on ACSC and GP-type presentations.

METHODS

Patient and public involvement

This study did not directly involve patients and the public in its design and conduct. Rather, the study's research questions, design and outcome measures had their genesis in a community of practice (CoP) focused on population health analyses. CoP members included service managers and policy officers who shared anecdotes of unmet need among specific population groups while also reflecting on the lack of systematic evidence on their service use, including ED, leading to gaps in supporting service planning. DB undertook to help address this information need in support of patient-focused service planning. The results have been actively disseminated through public and professional meetings including the CoP, South Australia (SA) Primary Health Networks, the Australian Health Economics Society, the Health Service Research Association of Australia and New Zealand, and Australia's Population Health Congress, while also formally offered to SA Health, the state government's lead health agency and published in a freely accessible journal.

Study design

Period prevalence study using person-linked, public hospital ED administrative records from 2005 to 2006 to 2010–2011 in Adelaide, South Australia.

Data sources

Study populations

South Australia is situated in southern, central Australia and the Adelaide metropolitan area is home to 70% of the population.[30] We used Australia's Census years in 2006 and 2011[3] to disaggregate this population into mutually exclusive categories comprising three vulnerable groups and an 'All other' comparator using the following criteria. RASC included people whose country of birth involved 50% or more of the population arriving on humanitarian visas in the decade to 2011 as reported in the Australian Government's Settlement Reporting Facility[21] (see online supplementary table A). Aboriginal included those self-identifying as such. Five-year age groupings enabled enumeration of those aged 75 years or more, and this group included any person regardless of RASC or Aboriginality. A lower age limit of 20 years was also applied, meaning the 'All others' group comprised adults aged 20 to 74 years who were not otherwise included in RASC or Aboriginal groups. Census 2011 also provided the Index of Relative Socioeconomic Disadvantage (IRSD),[31] an area-level measure of socioeconomic disadvantage. Total population were thus distributed to disadvantage quintiles of approximately equal population size[32] ranked as Quintile 1 Least disadvantage to Quintile 5 Most disadvantage.

These Census' data provided the basis of population denominators for adults aged 20 years or more. We used 'All others' as the comparison group. Separate denominators were determined for RASC aged 20 to 74 years, Aboriginal aged 20 to 74 years, those aged 75 years or more, and 'All others' (as online supplementary table B).

ED presentations for individuals

All presentations to six public hospital EDs (Royal Adelaide, The Queen Elizabeth, Lyell McEwin and Repatriation Hospitals; Flinders Medical Centre and Noarlunga Health Service) were available to the study. One further hospital was omitted having transferred between private and public administration within the observation period.

Person-level analysis was facilitated by linked project keys from SA-NT DataLink which enabled the grouping of each person's presentations across hospitals and time. We retained records for persons aged 20 years or more living

in the metropolitan area. Each individual's records took on the country of birth, Aboriginal self-identification, age and metropolitan area–level socioeconomic disadvantage quintile recorded in that person's first occurring, index presentation.

Accordingly, all individuals aged 20 years or more and presenting to EDs were categorised to one of the mutually exclusive study groups in the same manner as described for population denominators, that is, RASC aged 20 to 74 years, Aboriginal aged 20 to 74 years, those aged 75 years or more, and 'All others' with the remainder of those aged 20 to 74 years.

ED presentations type and cost

ACSC categorisation of International Statistical Classification of Diseases and Related Health Problems 10th revision (ICD-10)[33] presentation diagnoses followed the Australian standard classification for ACSC published by the Australian Institute of Health and Welfare.[34] The relevant diagnoses for ACSC categories and conditions are available as online supplementary table C. Potentially avoidable GP-type presentations were defined using Australia's National Healthcare Agreement performance indicator specification of Triage 4 or 5; excluding arrival by ambulance or police; and not subsequently admitted, transferred or deceased.[17 18]

The Australian public health system uses activity-based funding to reimburse hospitals. Each ED presentation is associated with a hospital activity Urgency Related Group (URG V.1.4) code and weighting that reflects the triage level, diagnosis and end status. The URG weighting for a presentation is multiplied by a standard, National Efficient Pricing (NEP) amount to determine the reimbursement to the ED for that presentation. We uniformly used the NEP of $A5007 for 2014–2015[35] for all presentations in our analysis. As an example, a walk-in presentation of Triage level 2 for R074 (unspecified chest pain) with a weighting of 0.2311 equates to a direct cost of $A1157. Presentations for Aboriginal people had an additional 4% loading in recognition of factors such as more frequent comorbidities which contribute to higher investigation or treatment costs. The cost of any ensuing inpatient stays were not included in this analysis.

Data analysis

We present the number of ED presentations together with the crude, unadjusted rate of presentations among each vulnerable group and the comparator group. Similarly, we report the number and rate of persons within each group who presented to EDs. The total person numbers were disaggregated by the number of ED presentations made and are reported with their associated population rates. We further describe the proportion of group members attending ED by sex, age group and area-level IRSD quintiles. The number of persons within each group who had ACSC presentations (total; acute, chronic and vaccine) or GP-type presentations are then described as a proportion of total group presenters and as a population rate. The likelihood of individuals in each vulnerable group having more than one ED presentation compared with the 'All others' group was assessed using stratified Poisson regression models and the results reported as incidence rate ratios (IRR). The cost of ED presentations (total, ACSC and its categories, and GP type) were totalled for each person presenting to EDs and the mean cost for presenters within each group was calculated. We assessed excess cost in a vulnerable group as the difference in total cost per 1000 population (the product of mean cost by number of presenters per 1000 population) in that group compared with the comparator group and provide a worked example of the relevant table as an online supplement. All analyses used Stata V.15.1.

RESULTS

Population groups

The vulnerable population groups studied made up 11.6% of the Adelaide metropolitan area total comprising RASC 0.6%, Aboriginal 1.0% and those aged 75 or more 10.0%.

Presentations and persons presenting to EDs

ED presentation rates by vulnerable groups and the characteristics of those individuals presenting are summarised in table 1. Collectively, one in five (21.6%) ED presentations involved vulnerable group members. RASC, Aboriginal and those aged 75 or more each had higher presentation rates compared with the All others group. Underlying this were both higher rates of individual persons presenting and presenting multiple times. RASC had the youngest age profile with 60% of presenters aged under 35 years and a higher likelihood of living in comparatively disadvantaged areas (61% from the most disadvantaged Quintiles 4 and 5 vs 40% of All others). Younger adults also featured among Aboriginal presenters (50% aged under 35 years) with an even higher concentration in socioeconomically disadvantaged areas (69% from Quintiles 4 and 5). Older presenters aged 75 or more were no more likely to live in disadvantaged areas than those in the All others group.

Persons presenting for ACSC and GP-type presentations

Vulnerable group members having ACSC and GP-type presentations are summarised in table 2. Each vulnerable group had markedly higher presenter rates for ACSC compared with the All others group. In particular, Aboriginal people and those aged 75 years or more had presentation rates at least twice that of the comparator group (rate ratio (RR) 2.16, 95% CI 1.62 to 2.89 and 2.88, 95% CI 2.18 to 3.80, respectively). There was more variation in the rates with which individuals in groups presented across ACSC categories. For example, in instances of acute ACSC, each of the groups had rates of individual presenters that were around twice that of the comparator group. Where chronic ACSCs were involved, however, those aged 75 years or more had fivefold higher

Table 1 Presentations and persons presenting to South Australian metropolitan public emergency departments (EDs), 2005–2006 to 2010–2011

	Refugee and Asylum Seeker Countries			Aboriginal			Aged 75 or more			All others		
	N	% of individuals presenting	Rate per 1000 population	N	% of individuals presenting	Rate per 1000 population	N	% of individuals presenting	Rate per 1000 population	N	% of individuals presenting	Rate per 1000 population
Presentations to ED	9086		1629.8	23825		2533.8	215194		2360.0	898399		1116.3
Persons presenting to ED	3749	100.0	672.5	5095	100.0	541.9	67656	100.0	742.0	346844	100.0	431.0
1 presentation	1893	50.5	339.6	2039	40.0	216.9	26541	39.2	291.1	182557	52.6	226.8
2 presentations	779	20.8	139.7	851	16.7	90.5	13561	20.0	148.7	68664	19.8	85.3
3 or 4 presentations	658	17.6	118.0	859	16.9	91.4	13781	20.4	151.1	53210	15.3	66.1
5 or more presentations	419	11.2	75.2	1346	26.4	143.1	13773	20.4	151.0	42413	12.2	52.7
Gender												
Male	2005	53.5		2461	48.3		28055	41.5		182458	52.6	
Female	1744	46.5		2634	51.7		39601	58.5		164386	47.4	
Age (years)												
20–24	1019	27.2		1179	23.1		0	0.0		58099	16.8	
25–34	1241	33.1		1368	26.8		0	0.0		73638	21.2	
35–44	857	22.9		1272	25.0		0	0.0		64831	18.7	
45–54	383	10.2		764	15.0		0	0.0		59267	17.1	
55–64	171	4.6		352	6.9		0	0.0		50982	14.7	
65–74	78	2.1		160	3.1		0	0.0		40007	11.5	
75 or more	0	0.0		0	0.0		67656	100.0		0	0.0	
2011 IRSD quintile												
Q1 Least disadvantage	215	5.7		200	3.9		12137	17.9		63007	18.2	
Q2	633	16.9		657	12.9		17021	25.2		79762	23.0	
Q	612	16.3		746	14.6		15662	23.1		66378	19.1	
Q4	1105	29.5		1383	27.1		11987	17.7		66101	19.1	
Q5 Most disadvantage	1184	31.6		2109	41.4		10849	16.0		71596	20.6	

IRSD, Index of Relative Socioeconomic Disadvantage.

Table 2 Persons presenting with ACSC and GP-type presentations to South Australian metropolitan public ED, 2005–2006 to 2010–2011

	Persons presenting (N)	% of persons within group	Persons presenting per 1000 population	Rate ratio (vulnerable group: All others) (95% CI)
ACSC presentations*				
Refugee and Asylum Seeker Countries	734	19.6	131.7	1.84 (1.37 to 2.48)
Aboriginal	1454	28.5	154.6	2.16 (1.62 to 2.89)
Aged 75 or more	18823	27.8	206.4	2.88 (2.18 to 3.80)
All others	57670	16.6	71.7	Reference
ACSC (acute)*				
Refugee and Asylum Seeker Countries	619	16.5	111.0	2.15 (1.52 to 3.03)
Aboriginal	1183	23.2	125.8	2.44 (1.74 to 3.41)
Aged 75 or more	9739	14.4	106.8	2.07 (1.46 to 2.92)
All others	41505	12.0	51.6	Reference
ACSC (chronic)*				
Refugee and Asylum Seeker Countries	105	2.8	18.8	0.89 (0.46 to 1.77)
Aboriginal	391	7.7	41.6	1.97 (1.16 to 3.56)
Aged 75 or more	10916	16.1	119.7	5.68 (3.57 to 9.57)
All others	16965	4.9	21.1	Reference
ACSC (vaccine)*				
Refugee and Asylum Seeker Countries	42	1.1	7.5	2.28 (0.53 to 13.98)
Aboriginal	34	0.7	3.6	1.09 (0.23 to 9.10)
Aged 75 or more	238	0.4	2.6	0.79 (0.11 to 4.43)
All others	2662	0.8	3.3	Reference
GP-type presentations*				
Refugee and Asylum Seeker Countries	2362	63.0	423.7	1.76 (1.50 to 2.06)
Aboriginal	2896	56.8	308.0	1.28 (1.08 to 1.53)
Aged 75 or more	15154	22.4	166.2	0.69 (0.56 to 0.85)
All others	193249	55.7	240.1	Reference

As a person may present more than one time for more than one category, the sum of persons at category level may not equal the total number of persons having presented.
*ACSC, ambulatory care sensitive condition; ED, emergency department; GP, general practitioner.

rates (RR 5.68, 95% CI 3.57 to 9.57) while rates in the Aboriginal population remained around twice that of the comparator group. RASC were relatively less represented.

GP-type presenter rates were higher than the comparator group for Aboriginal people (RR 1.28, 95% CI 1.08 to 1.53) and higher again among RASC with RR 1.76 (95% CI 1.50 to 2.08). Conversely, rates were markedly lower among those aged 75 years or more with RR 0.69 (95% CI 0.56 to 0.85). Online supplementary table D includes description for selected acute and chronic conditions.

Risk of multiple presentations

Figure 1A through 1F report the rates with which individuals had a single presentation, then those having two or more presentations. We also report the average likelihood (as an IRR) of individuals having multiple presentations compared with those in the All others group.

RASC had the highest rates of single ED presenters overall while those aged 75 or more had the highest rates of individuals with multiple presentations. Of all the groups, Aboriginal people had the highest likelihood of repeated presentations compared with All others (IRR 1.81 95% CI 1.78 to 1.83). While the rates of individuals presenting for any ACSC were highest among those aged 75 or more, Aboriginal presenters were most likely to have two or more presentations (IRR 2.22, 95% CI 2.14 to 2.30). In acute ACSC, we found Aboriginal people again had the highest likelihood of multiple presentations with IRR 2.41 (95% CI 2.31 to 2.52). They also had elevated likelihood of multiple presentations for chronic ACSC conditions; however, this category was dominated by those aged 75 or more where single *and* multiple presenter rates were highest. Indeed, those aged 75 or more had a threefold higher risk of multiple chronic ACSC presentations

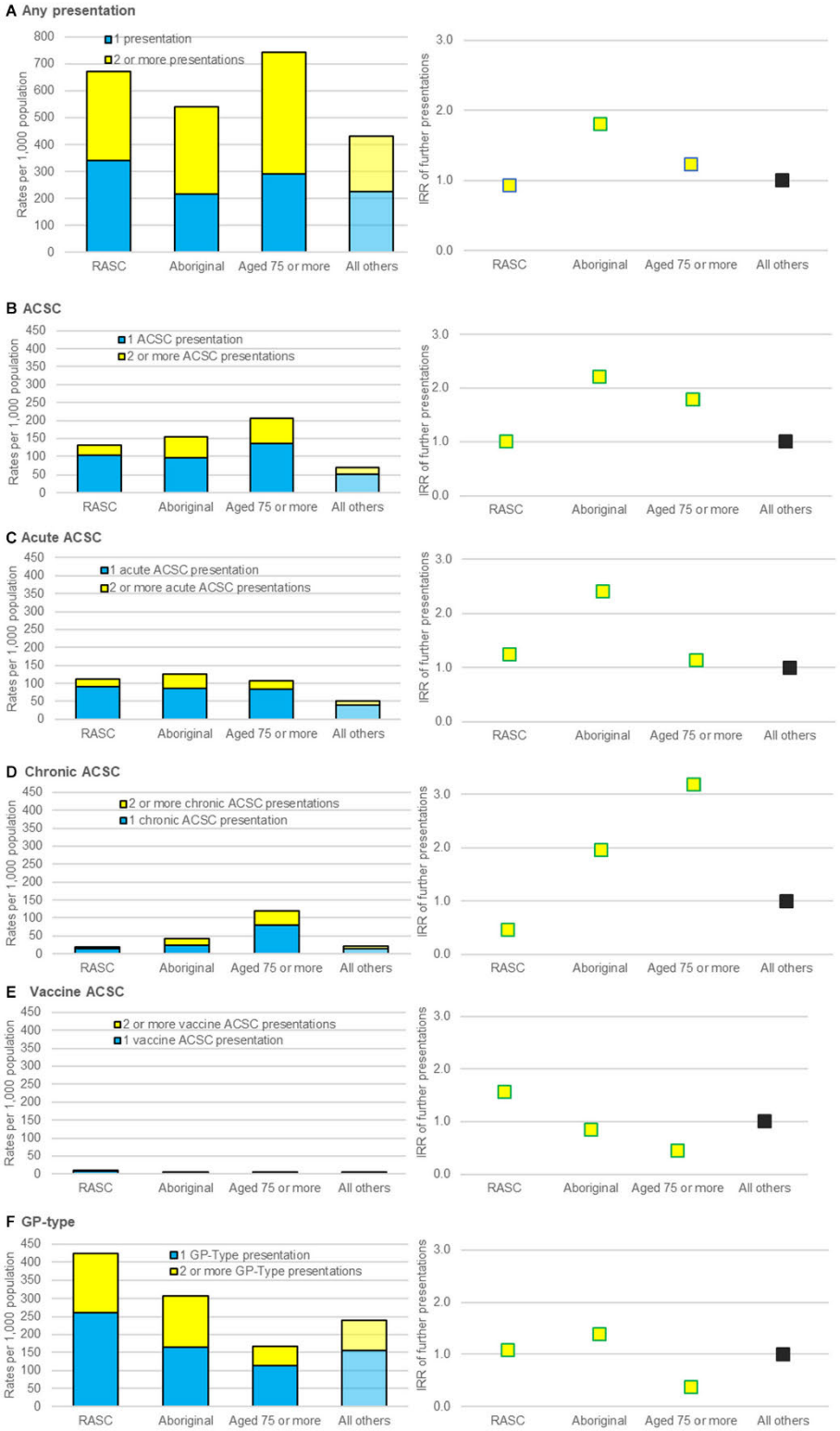


Figure 1 Rates of persons presenting to ED and the relative likelihood of subsequent presentation, South Australian public hospitals 2005–2006 to 2010–2011. ACSC, ambulatory care sensitive condition; GP, general practitioner; IRR, incidence rate ratio; RASC, Refugee and Asylum Seeker Country.

compared with All others (IRR 3.20, 95% CI 3.14 to 3.26). RASC and Aboriginal had the highest rates of individuals with two or more GP-type presentations, while Aboriginal individuals also had the greatest risk of multiple presentations, IRR 1.39 (95% CI 1.35 to 1.42).

Excess costs of ED presentations

In total, approximately $A22 million per year was associated with excess ED presentations by vulnerable groups. Table 3 contrasts observed costs among vulnerable groups per 1000 population with All others to show progressively higher excess costs for RASC, Aboriginal populations and those aged 75 or more ($A250 332, $A1 020 878 and $1 314 231, respectively). We provide a worked example of our calculations in online supplementary table E.

Excess costs attributed to potentially preventable presentations for ACSC and GP-type categories totalled $A4.2 million and $A280 000 annually. Their contribution to excess group costs also varied substantially. While individual RASC presenters accrued lower mean presentation costs, higher presenter rates led to excess costs of $A106 573 per 1000 population for GP-type presentations and $A22 524 for ACSC, the latter heavily influenced by acute conditions. Excess cost rates for Aboriginal people increased from chronic ACSC to acute ACSC to GP-type presentations. Among people aged 75 or more, ACSC costs featured more than twofold greater rates for chronic conditions than acute.

DISCUSSION

We compared the average rates which RASC, Aboriginal and older persons populations presented to EDs relative to the rest of the adult population in metropolitan South Australia. Collectively, individuals within vulnerable groups were more likely to present to EDs and to have subsequent ED attendances than members of the wider community. Average RASC and Aboriginal presenters were notably younger and more likely living in disadvantaged areas compared with other presenters.

We stratified our analysis and examination of ACSC and GP-type presentations potentially suited to alternative primary and community healthcare interventions and showed differing patterns of ED use for each vulnerable group. We discuss each group's results in turn and reflect on areas of potential primary care response.

RASC presented at twice the rate of the wider population for acute and vaccine-preventable ACSC. Also, almost two-thirds of RASC presenters had GP-type presentations, with associated excess costs exceeding $A100 000 per 1000 population in the 6-year period. This segmented understanding[36] of service use suggests newly arriving citizens have a capacity to benefit from assistance leading to improved health and health systems literacy, including health literacy on preventing infectious disease; familiarity with service alternatives[37]; and locating and accessing culturally secure primary care homes.[38] The latter point is implicated in international studies[39] and is a focus of the Australian Healthcare Homes[40] being piloted for patients with chronic and complex conditions. Our results suggest opportunities to broaden the focus of that new infrastructure by collaborating with existing Primary Health Networks to meet particular population group needs at potentially reduced cost.

Aboriginal people had comparatively higher presentation rates in all categories. They also had double the risk of multiple ED events generally, and for acute and chronic ACSC presentations. The greatest of these risks was associated with acute ACSC, the excess cost for which amounted to $A108 000 per 1000 population. A further $A53 000 per 1000 population was associated with chronic conditions. As with RASC, the findings reinforce a pervasive association of economic disadvantage[41] with stress, crisis situations and emergency responses.[42] Nevertheless and perhaps even more importantly, community healthcare centre developments which provide health-promoting and primary care services[42] can be directly informed by RASC and Aboriginal peoples' insights. Each have positive assets and cultural strengths which can help identify appropriate forms of assistance and ways of constructively engaging people receiving care.[43 44] This suggests the challenges of providing care to complex groups can be helped by improved communication among ED and hospital-based practitioners, primary care providers and the patients themselves. Two immediate actions in this regard include bringing representatives from each to meet outside the ED environment to share perspectives on preventative and alternative care strategies. Further, addressing the long-standing need for timely referral from ED to primary care practices, including copying patients into the pathway, remains a goal worth pursuing.[45]

Elevated presentation rates among older persons were influenced by acute conditions but dominated by multiple attendances for chronic ACSC. The latter accounted for one-seventh ($A181 385 per 1000 population) of excess presentation costs. Collectively, this older group continues to grow in number and proportion of population.[1] This makes the need for explicitly aligning primary care with client need[40] all the more urgent in order to manage comorbidities and prevent or defer frailty among community-living older persons.[46] Other promising intervention strategies include resourcing Local Health Networks, Primary Health Networks and general practice[47] to carry out integrated, multidisciplinary[48] care. Examples of such care include specialist review by community-based teams and even planned hospital stays to address complex needs in a controlled environment. Individuals with chronic, complex needs may also have long-term care relationships with GPs. Our method reports on the health system's willingness to increase hospital cost weightings where there is a high prevalence of comorbid conditions and the patient's needs are complex. A similar mechanism could be used in primary healthcare settings where those serving Aboriginal and older people could be incentivised to provide continuity of care, regular contact and comprehensive health checks.

Table 3 Excess emergency department (ED) costs per head of population, South Australian public hospitals 2005–2006 to 2010–2011

	Total cost per presenter ($A)	95% CIs	Cost differential (observed vs reference) ($A)	Presenters per 1000 population	Rate differential (observed vs reference)	Cost of excess presenters per 1000 population* ($A)	95% CI
ED presentations†							
Refugee and Asylum Seeker Countries	1472	$A1407 to $A1537	−244	672.5	241.5	250 332	$A211 252 to $A289 412
Aboriginal	3249	$A3068 to $A3430	1533	541.9	110.9	1 020 878	$927 241 to $1 114 516
Aged 75 or more	2785	$A2762 to $A2809	1069	742.0	311.0	1 327 018	$A1 314 231 to $A1 339 805
All others	1716	$A1706 to $A1727	Reference	431.0	Reference		
ACSC presentations†							
Refugee and Asylum Seeker Countries	800	$A722 to $A878	−916	131.7	60.0	22 524	$A13 322 to $A31 727
Aboriginal	1581	$A1451 to $A1711	−135	154.6	83.0	161 670	$A142 665 to $A180 675
Aged 75 or more	1651	$A1627 to $A1674	−65	206.4	134.8	257 950	$A254 181 to $A261 719
All others	1156	$A1141 to $A1171	Reference	71.7	Reference		
ACSC (acute)†							
Refugee and Asylum Seeker Countries	710	$A644 to $A776	−1006	111.0	59.5	33 231	$A26 485 to $A39 976
Aboriginal	1227	$A1108 to $A1345	−490	125.8	74.2	108 701	$A94 374 to $A123 029
Aged 75 or more	1135	$A1119 to $A1152	−581	106.8	55.2	75 636	$A74 458 to $A76 813
All others	884	$A873 to $A895	Reference	51.6	Reference		
ACSC (chronic)†							
Refugee and Asylum Seeker Countries	1208	$A859 to $A1557	−508	18.8	−2.2	−12 731	−$A18 461 to $A7002
Aboriginal	2129	$A1854 to $A2403	413	41.6	20.5	53 037	$A42 468 to $A63 607
Aged 75 or more	1812	$A1778 to $A1845	95	119.7	98.6	181 385	$A178 160 to $A184 609
All others	1683	$A1643 to $A1723	Reference	21.1	Reference		
ACSC (vaccine)†							
Refugee and Asylum Seeker Countries	499	$A423 to $A574	−1218	7.5	4.2	2026	$A1497 to $A2555
Aboriginal	491	$A403 to $A580	−1225	3.6	0.3	45	−$A236 to $A327
Aged 75 or more	1020	$A978 to $A1061	−696	2.6	−0.7	931	$A861 to $A1001
All others	523	$A512 to $A535	Reference	3.3	Reference		
GP-type presentations†							
Refugee and Asylum Seeker Countries	631	$A610 to $A652	−1085	423.7	183.6	106 573	$A98 775 to $A114 371

Continued

resourcing alternative care for the benefit of individual persons within vulnerable populations.

Our approach and findings have direct relevance to other jurisdictions nationally and internationally wherever vulnerable populations exist and the responsibilities of providing appropriate care is taken seriously. For example, ascertainment of RASC is challenging. While our method offers an approach for quantifying adult RASC, enumerating RASC children who are recently born in Australia will require alternative methods. Our results support calls to pursue research activities that better enumerate RASC children as an emerging vulnerable group[45] who will benefit from early, proactive interventions. Other research teams are innovating to reduce ED use by older Australians.[48] Assimilating our person-level reporting and estimation of direct costs will help inform decisions on prioritising effective interventions. Other opportunities to further develop our approach exist. These include analyses with an increased focus on individual measures of disadvantage that are amenable to change. This could involve the use of e-health records incorporating measures of health insurance status, primary care contacts and geocoded accessibility to care. Another opportunity is to take a broader view of ACSC hospitalisation by merging of ED and inpatient records. Such an approach would examine patterns of individuals' length of hospital stay across EDs and inpatient sites, together with their commensurate costs.[50]

CONCLUSION

We identified disparities in the relative frequency, nature and excess cost of ED contact by different vulnerable populations. A considerable number of ED presentations have the potential to be effectively prevented or addressed in other, lower-cost environments. This suggests inequities in the uptake of effective primary care and excess cost to the public hospital system. Enumerating vulnerable populations and service use in this way can inform person-centred care planning as a dimension of high-quality care delivery.

Acknowledgements The authors thank SA Health for administrative unit records via Statistical Linkage Project 2010-0004.

Contributors DB conceived the project, performed the analyses and drafted the manuscript. KD contributed to literature searching and manuscript preparation. JK and JWL made important contributions to operationalising this study, interpreted the statistical analysis and revised the manuscript. All authors read and approved the final version of the manuscript.

Funding DB is supported in part by an Australian Government Research Training Program Scholarship.

Competing interests None declared.

Patient consent for publication Not required.

Ethics approval SA Health (467/08/2014) and the Aboriginal Health Council of South Australia (04-11-406) research ethics committees approved the study.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The study's data comprised de-identified unit record administrative records. These were used under privileged arrangements set out in a study-specific confidentiality deed. The data cannot be accessed by another party without relevant departmental and human research ethics approvals.

REFERENCES

1. Burkett E, Martin-Khan MG, Scott J, *et al*. Trends and predicted trends in presentations of older people to Australian emergency departments: effects of demand growth, population aging and climate change. *Aust Health Rev* 2017;41:246–53.
2. Australian Institute of Health and Welfare. *Emergency department care 2015–16: Australian hospital statistics*. Canberra: AIHW, 2016. Report No.: Health services series no. 72. Cat. no. HSE 182.
3. Australian Bureau of Statistics. *Estimates and Projections, Aboriginal and Torres Strait Islander Australians: 2001 to 2026*. Canberra: ABS, 2014. Report No.: ABS Cat. 3238.0.
4. Freed GL, Gafforini S, Carson N. Age distribution of emergency department presentations in Victoria. *Emerg Med Australas* 2015;27:102–7.
5. Stephens AS, Broome RA. Patterns of low acuity patient presentations to emergency departments in New South Wales, Australia. *Emerg Med Australas* 2017;29:283–90.
6. Health SA. *Transforming Health: Discussion Paper*, 2014.
7. Jaeger MW, Ambadwar PB, King AJ, *et al*. Emergency care of children with ambulatory care sensitive conditions in the United States. *J Emerg Med* 2015;49:729–39.
8. McWilliams A, Tapp H, Barker J, *et al*. Cost analysis of the use of emergency departments for primary care services in Charlotte, North Carolina. *N C Med J* 2011;72:265–71.
9. Johnson PJ, Ghildayal N, Ward AC, *et al*. Disparities in potentially avoidable emergency department (ED) care: ED visits for ambulatory care sensitive conditions. *Med Care* 2012;50:1020–8.
10. Carter MW, Datti B, Winters JM. ED visits by older adults for ambulatory care-sensitive and supply-sensitive conditions. *Am J Emerg Med* 2006;24:428–34.
11. Chukmaitov AS, Tang A, Carretta HJ, *et al*. Characteristics of all, occasional, and frequent emergency department visits due to ambulatory care-sensitive conditions in Florida. *J Ambul Care Manage* 2012;35:149–58.
12. Fingar K, Barrett M, Elixhauser A, *et al*. *Trends in potentially preventable inpatient hospital admissions and emergency department visits*. Rockville, MD: Agency for Healthcare Research and Quality (US), 2015.
13. Gruneir A, Bell CM, Bronskill SE, *et al*. Frequency and pattern of emergency department visits by long-term care residents--a population-based study. *J Am Geriatr Soc* 2010;58:510–7.
14. Shah MN, Wasserman EB, Gillespie SM, *et al*. High-intensity telemedicine decreases emergency department use for ambulatory care sensitive conditions by older adult senior living community residents. *J Am Med Dir Assoc* 2015;16:1077–81.
15. Brownell J, Wang J, Smith A, *et al*. Trends in emergency department visits for ambulatory care sensitive conditions by elderly nursing home residents, 2001 to 2010. *JAMA Intern Med* 2014;174:156–8.
16. Caminal J, Starfield B, Sánchez E, *et al*. The role of primary care in preventing ambulatory care sensitive conditions. *Eur J Public Health* 2004;14:246–51.
17. Bezzina AJ, Smith PB, Cromwell D, *et al*. Primary care patients in the emergency department: who are they? A review of the definition of the 'primary care patient' in the emergency department. *Emerg Med Australas* 2005;17(5-6):472–9.
18. Australian Institute of Health and Welfare. *Emergency department care 2011–12: Australian hospital statistics*. Canberra: AIHW, 2012. Report No.: Health services series no. 45. Cat. no. HSE 126.
19. Health Performance Council. *What's working, what's not: review of the South Australian Health System Performance for 2011–2014*. Adelaide: Health Performance Council, 2014.
20. Health Performance Council Secretariat. *Monitoring the implementation of Transforming Health Indicator Report*. Adelaide: Government of South Australia, 2017.
21. Correa-Velez I, Sundararajan V, Brown K, *et al*. Hospital utilisation among people born in refugee-source countries: an analysis of hospital admissions, Victoria, 1998-2004. *Med J Aust* 2007;186:577–80.

22. Correa-Velez I, Ansari Z, Sundararajan V, *et al*. A six-year descriptive analysis of hospitalisations for ambulatory care sensitive conditions among people born in refugee-source countries. *Popul Health Metr* 2007;5:1–8.
23. Hoon E, Pham C, Beilby J, *et al*. Unconnected and out-of-sight: identifying health care non-users with unmet needs. *BMC Health Serv Res* 2017;17:80.
24. Banham D, Woollacott T, Gray J, *et al*. Recognising potential for preventing hospitalisation. *Aust Health Rev* 2010;34:116–22.
25. Kirby SE, Dennis SM, Jayasinghe UW, *et al*. Patient related factors in frequent readmissions: the influence of condition, access to services and patient choice. *BMC Health Serv Res* 2010;10:216.
26. Mahmoud I, Hou XY. Immigrants and the utilization of hospital emergency departments. *World J Emerg Med* 2012;3:245–50.
27. Costa N, Sullivan M, Walker R, *et al*. Emergency department presentations of Victorian Aboriginal and Torres Straight Islander people. *Health Inf Manag* 2008;37:15–25.
28. Mazza D, Pearce C, Joe A, *et al*. Emergency department utilisation by older people in metropolitan Melbourne, 2008-12: findings from the Reducing Older Patient's Avoidable Presentations for Emergency Care Treatment (REDIRECT) study. *Aust Health Rev* 2018;42:181–8.
29. Institute of Medicine. *Crossing the quality chasm: A new health system for the 21st century*, 2001.
30. Australian Bureau of Statistics. *3238.0.55.001—Estimates of Aboriginal and Torres Strait Islander Australians*, 2013. June 2011. 30 August 2013.
31. Australian Bureau of Statistics. *Statistical Geography Volume 1—Australian Standard Geographical Classification (ASGC)*. Canberra: ABS, 2006. Report No.: Cat. no. 1216.0.
32. Australian Bureau of Statistics. *Socio-Economic Indexes for Areas (SEIFA)—Technical Paper, 2011*, 2013. Report No.: 2039.0.55.001.
33. National Casemix and Classification Centre (NCCC). *The International Statistical Classification of Diseases and Related Health Problems Australian Modification (ICD-10-AM)*. Sydney: NCCC, Australian Health Services Research Institute, University of Wollongong, 2013.
34. Australian Institute of Health and Welfare. *Australian hospital statistics 2012–13*. Canberra: AIHW, 2014. Report No.: AIHW cat. no. HSE 145 (Health Services Series no. 54).
35. Independent Hospital Pricing Authority (IHPA). *The Pricing Framework for Australian Public Hospital Services 2014–15*. Darlinghurst: IHPA, 2014.
36. Hostetter M, Klein S. Segmenting Populations to Tailor Services, Improve Care. 2015 http://www.commonwealthfund.org/publications/newsletters/quality-matters/2015/june/in-focus.
37. FitzGerald G, Toloo GS, Aitken P, *et al*. Public use and perceptions of emergency departments: a population survey. *Emerg Med Australas* 2015;27:336–42.
38. McCusker J, Roberge D, Lévesque JF, *et al*. Emergency department visits and primary care among adults with chronic conditions. *Med Care* 2010;48:972–80.
39. Ruud SE, Hjortdahl P, Natvig B. Reasons for attending a general emergency outpatient clinic versus a regular general practitioner—a survey among immigrant and native walk-in patients in Oslo, Norway. *Scand J Prim Health Care* 2017;35:35–45.
40. Jackson CL, Hambleton SJ. Australia's Health Care Homes: laying the right foundations. *Med J Aust* 2017;206:380–1.
41. Commonwealth of Australia Department of Health. *My life, my lead—opportunities for strengthening approaches to the social determinants and cultural determinants of indigenous health: report on the national consultations*, 2017. December 2017.
42. Berchet C. *Emergency care services: trends, drivers and interventions to manage the demand*: OECD, 2015. Report No. Working Paper No. 83.
43. National Academies of Sciences Engineering and Medicine. *Systems practices for the care of socially at-risk populations*. Washington, DC: The National Academies Press, 2016.
44. Blueprint for a Post-2020 National Health Agreement. *Australian Healthcare and Hospitals Association (AHHA)*: AHHA, 2017.
45. Yelland J, Riggs E, Szwarc J, *et al*. Improving the ascertainment of refugee-background people in health datasets and health services. *Aust Health Rev* 2018;42:130–3.
46. Puts MTE, Toubasi S, Andrew MK, *et al*. Interventions to prevent or reduce the level of frailty in community-dwelling older adults: a scoping review of the literature and international policies. *Age Ageing* 2017;46:383–92.
47. Productivity Commission. *Shifting the dial: 5 year productivity review*. Canberra: Productivity Commission, 2017. Report No: Report No. 84.
48. Fan L, Lukin W, Zhao J, *et al*. Interventions targeting the elderly population to reduce emergency department utilisation: a literature review. *Emerg Med J* 2015;32:738–43.
49. Banham D, Lynch J, Karnon J. An equity-effectiveness framework linking health programs and healthy life expectancy. *Aust J Prim Health* 2011;17:309–19.
50. Banham D, Chen T, Karnon J, *et al*. Sociodemographic variations in the amount, duration and cost of potentially preventable hospitalisation for chronic conditions among Aboriginal and non-Aboriginal Australians: a period prevalence study of linked public hospital data. *BMJ Open* 2017;7:e017331.

Chapter 5 What might person-centred measurement of preventable hospitalisation look like?

Publication: Banham D, Chen T, Karnon J, Brown A, Lynch J. Sociodemographic variations in the amount, duration and cost of potentially preventable hospitalisation for chronic conditions among Aboriginal and non-Aboriginal Australians: a period prevalence study of linked public hospital data. BMJ Open. 2017;7(10).

Available online at: https://bmjopen.bmj.com/content/7/10/e017331

5.1 Preface to Chapter 5

The PPH data linkage study (Appendix B) aimed to routinise a person-centred perspective on the potential for changing unnecessary or untimely hospitalisation. Traditionally, inpatient hospital records have provided valuable insights into population morbidity because of their near complete, standardised enumeration and availability (1).

Earlier analysis of premature mortality showed distinctly different patterns of health loss among Aboriginal and other South Australians (2). Within those disparities, socio-economic differences varied within levels of geographic remoteness. This raised questions of the existence of similar, concurrent patterning in peoples' experience of hospitalisation and morbidity more generally. The potentially joint effects of social, economic and geographic factors was a construct the health system had no routine population level insight into.

References

1. Taylor R. Measurement of population morbidity. In: Kerr C, Taylor R, Heard G, editors. Handbook of public health methods. Sydney: McGraw-Hill; 1998. p. 52-6.

2. Banham D, Jury H, Woollacott T, McDermott R, Baum F. Aboriginal premature mortality within South Australia 1999-2006: a cross-sectional analysis of small area results. BMC Public Health. 2011;11(286).

5.2 Statement of authorship

Title of Paper	Sociodemographic variations in the amount, duration and cost of potentially preventable hospitalisation for chronic conditions among Aboriginal and non-Aboriginal Australians: a period prevalence study of linked public hospital data
Publication Status	☑ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and Unsubmitted w ork w ritten in manuscript style
Publication Details	**Banham D**, Chen T, Karnon J, Brown A, Lynch J. Sociodemographic variations in the amount, duration and cost of potentially preventable hospitalisation for chronic conditions among Aboriginal and non-Aboriginal Australians: a period prevalence study of linked public hospital data. BMJ Open. 2017;7(10).

Principal Author

Name of Principal Author (Candidate)	David Mark Banham		
Contribution to the Paper	Conceptualised and administered the associated data linkage project. Conceptualised and initiated this paper, collated and analysed the data, wrote the manuscript and acted as correspondent author.		
Overall percentage (%)	95%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	25th July 2022

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Tenglong (Tien) Chen		
Contribution to the Paper	My contribution to this paper involved assisting with literature searching and drafting the manuscript introduction.		
Signature		Date	25th July 2022

Name of Co-Author	Jonathan Karnon		
Contribution to the Paper	My contribution to this paper involved manuscript evaluation.		
Signature		Date	25th July 2022

Name of Co-Author	Alex Brown		
Contribution to the Paper	My contribution to this paper involved conceptualising and operationalizing the Cancer Data and Aboriginal Disparities project and manuscript evaluation.		
Signature		Date	25th July 2022

Name of Co-Author	John Lynch		
Contribution to the Paper	My contribution to this paper involved manuscript evaluation.		
Signature		Date	25th July 2022

5.3 Publication

Open Access Research

BMJ Open

Sociodemographic variations in the amount, duration and cost of potentially preventable hospitalisation for chronic conditions among Aboriginal and non-Aboriginal Australians: a period prevalence study of linked public hospital data

David Banham,[1] Tenglong Chen,[2,3] Jonathan Karnon,[1] Alex Brown,[2] John Lynch[1]

To cite: Banham D, Chen T, Karnon J, *et al*. Sociodemographic variations in the amount, duration and cost of potentially preventable hospitalisation for chronic conditions among Aboriginal and non-Aboriginal Australians: a period prevalence study of linked public hospital data. *BMJ Open* 2017;**7**:e017331. doi:10.1136/bmjopen-2017-017331

► Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2017-017331).

Received 19 April 2017
Revised 5 July 2017
Accepted 26 July 2017

For numbered affiliations see end of article.

Correspondence to
David Banham;
david.banham@sahmri.com

ABSTRACT

Objectives To determine disparities in rates, length of stay (LOS) and hospital costs of potentially preventable hospitalisations (PPH) for selected chronic conditions among Aboriginal and non-Aboriginal South Australians (SA), then examine associations with area-level socioeconomic disadvantage and remoteness.

Setting Period prevalence study using linked, administrative public hospital records.

Participants Participants included all SA residents in 2005–2006 to 2010–2011. Analysis focused on those individuals experiencing chronic PPH as defined by the Australian Institute of Health and Welfare.

Primary outcome measures Number and rates (unadjusted, then adjusted for sex and age) of chronic PPH, total LOS and direct hospital costs by Aboriginality.

Results Aboriginal SAs experienced higher risk of index chronic PPH compared with non-Aboriginals (11.5 and 6.2 per 1000 persons per year, respectively) and at younger ages (median age 48 vs 70 years). Once hospitalised, Aboriginal people experienced more chronic PPH events, longer total LOS with higher costs than non-Aboriginal people (2.6 vs 1.9 PPH per person; 11.7 vs 9.0 days LOS; at $A17 928 vs $A11 515, respectively). Compared with population average LOS, the standardised rate ratio of LOS among Aboriginal people increased by 0.03 (95% CI 0.00 to 0.07) as disadvantage rank increased and 1.04 (95% CI 0.63 to 1.44) as remoteness increased. Non-Aboriginal LOS also increased as disadvantage increased but at a lower rate (0.01 (95% CI 0.01 to 0.01)). Costs of Aboriginal chronic PPH increased by 0.02 (95% CI 0.00 to 0.06) for each increase in disadvantage and 1.18 (95% CI 0.80 to 1.55) for increased remoteness. Non-Aboriginal costs also increased as disadvantage increased but at lower rates (0.01 (95% CI 0.01 to 0.01)).

Conclusion Aboriginal people's heightened risk of chronic PPH resulted in more time in hospital and greater cost. Systematic disparities in chronic PPH by Aboriginality, area disadvantage and remoteness highlight the need for improved uptake of effective primary care. Routine, regional reporting will help monitor progress in meeting these population needs.

Strengths and limitations of this study

- This is the first study to examine variations of total length of stay and direct hospital costs associated with chronic potentially preventable hospitalisations (PPH) among Aboriginal and non-Aboriginal Australians.
- The study uses a complete collection of person-linked public hospital records over a 6-year period from 2005–2006 to 2010–2011.
- The study provides a baseline for reporting of a health system performance measure focusing on individuals as well as populations experiencing chronic PPH.
- Person-linked private hospital records and death records were not available to the study.
- Hospital records for a group of the most vulnerable residents living in very remote areas and hospitalised in other jurisdictions were not included.

BACKGROUND

Chronic health conditions are increasingly important contributors to poor population health throughout the world.[1] The increased prevalence and duration of these conditions adds to the mounting pressure on health systems to respond to those needs. Hospital expenditures are a key component of these systems.[2] Australia is an example of a developed and advantaged setting where annual hospital expenditure represents the largest recurrent and growing contribution[3 4] to the average health expenditure of $6639 per person.[5]

In constrained budgetary environments, hospital performance measures are constantly scrutinised for efficiency gains. For example, inpatient length of stay (LOS) is closely associated with hospital cost[6] and reimbursements,[7] and Australia employs LOS in a suite of health system performance measures.[3 8] From a hospital's perspective, LOS indicates production of care adequate to meet clinical need while maximising bed availability and minimising treatment costs. From a patient perspective, hospital LOS means maximising quality outcomes from care while minimising risk of exposure to adverse events in hospital and time away from usual, societal roles.

Potentially preventable hospitalisations (PPHs) are another performance indicator making use of administrative data.[9–11] Under different names such as potentially avoidable hospitalisations or ambulatory care sensitive conditions, and with some variations in conditions and coding,[12–14] PPHs are widely adopted as an indicator of a community's capacity to benefit from available and effective[15–18] primary healthcare by: 'preventing the onset of an illness or condition, controlling an acute episodic illness or condition, or managing a chronic disease or condition' (p. 163).[19] Primary healthcare is the second most expensive component of Australia's health system at almost $55 billion annually.[4] Recent expert commentary argued Australia's primary health system provides around half the level of care recommended for chronic conditions that contributes to chronic PPH $2 billion annual cost to the health system.[20] Therefore, PPHs provide an important junction between two critical system components in which policy makers and health planners can consider both the technical efficiency of one sector, its effect on another sector and opportunities to adjust allocations across sectors. Efficient use of healthcare resources can maximise health outcomes in the community served.[21]

Equitable distribution of health is another challenging[21–24] but high priority[21] for contemporary health systems. PPHs result from a complex interplay of person-related,[25 26] health system, geographical[27] and socioeconomic factors[28–30] that highlight the need for directing resources towards appropriate and accessible health services.[24] Localised understanding can help inform local responses to health need.[21 31] While their underlying data do not refer to individuals, Australia's Institute of Health and Welfare (AIHW) does work towards this by reporting aggregated PPH time series by age group, sex, state/territory jurisdictions, socioeconomic disadvantage, remoteness and Aboriginal and Torres Strait Islander status (herein respectively referred to as 'Aboriginal').[32] Overall PPH rates are three times higher for the Aboriginal population compared with non-Aboriginal Australians,[32 33] which supports their designation as a disadvantaged group in terms of their use of primary health care.[34] This is consistent with indigenous population comparisons in the US,[35] Canada[36] and New Zealand.[37] Chronic PPH conditions account for much of PPH for which there is a fivefold difference in the hospitalisation rates by Aboriginality.[32 33] Australian reporting of chronic PPH conditions[9] focuses on primary diagnoses of: angina, asthma, chronic obstructive pulmonary disease (COPD), congestive cardiac failure, diabetes complications, hypertension, iron deficiency anaemia, nutritional deficiencies and rheumatic heart disease (specific diagnosis and procedural criteria for chronic PPH are listed in online supplementary table A). While the indicator could be further developed by including other conditions such as chronic kidney disease,[38] discrete chronic PPH conditions currently reported for angina, COPD,[38] congestive cardiac failure[39 40] and rheumatic heart disease[41] are each associated with disparities between Aboriginal and non-Aboriginal populations. A particularly significant area is that of PPH from diabetes complications, the most frequently reported chronic PPH among Aboriginal Australians.[32 42–45] Similar disparities in chronic PPH between Aboriginal and non-Aboriginal populations are reported across Australia's states and territories of Victoria,[45] the Northern Territory,[44] Queensland,[46] Western Australia,[47] New South Wales[48] and South Australia (SA).[49 50]

Despite considerable evidence of variations in PPH rates and LOS, relatively little is known about how the two measures covary.[51] Given the extent of disparities in chronic PPH rates by Aboriginality, this appears an opportune place from which to improve understanding of *who* in the community is more likely to experience potentially unnecessary, prolonged and costly hospitalisation. The first of only two studies that considered chronic PPH and LOS together focused on diabetes hospitalisations among older, Hawaiian people categorised as either Asian, islander or white.[52] The second Australian study considered results for individuals on the basis of Aboriginal identity.[48] The results affirmed higher chronic PPH rates among Aboriginal people compared with non-Aboriginal contemporaries of the same age, sex and living in the same geographic area. Moreover, elevated rates were accompanied by LOS that was 4% higher on average.[48] However, neither study explicitly describes the variation of chronic PPH and LOS rates within the populations studied, yet evidence in other areas point to considerable within-population heterogeneity in health outcomes. For example, analysis of premature mortality among Aboriginal South Australians showed an interaction between area level socioeconomic disadvantage and remoteness where the social gradient between disadvantage and premature mortality outcomes increased as remoteness increased.[53]

None of the recently reviewed literature on PPH and LOS analysed the costs associated with the hospital events. Such information is critical to inform complex commissioning decisions of the opportunity cost, at least from a health system perspective, of pursuing technical and allocative efficiencies while reducing the human and societal costs represented by a person's time out of role.

If health systems are to attend to the needs of people and populations, it is important to focus on individuals

and subpopulations in their localised setting. This focus will benefit from supplementing AIHW reporting, based on unlinked data, with administrative records linked to individuals and their use of services. The latter are becoming more routinely available in Australian states and territories. Using these in quantifying disproportionate hospitalisation, rehospitalisation and time spent in hospital while simultaneously describing the system resources involved can provide valuable information on which elements of the health system are working, for whom and in what context.[2 54]

This study considers the disparity between rates of PPH for chronic conditions for Aboriginal and non-Aboriginal South Australians. It examines the association between area level socioeconomic disadvantage, geographic remoteness and the frequency, length and cost of hospitalisation for chronic PPH within those populations. This paper addresses three questions: which individuals experienced chronic PPH?; how does the LOS and cost of hospitalisation for these conditions vary between Aboriginal and non-Aboriginal populations?; and what is the relationship between the ecological risk factors of area level socioeconomic position and remoteness with PPH for chronic diseases within these populations?

METHODS

Ethics approval

Research ethics committee approvals are held from SA Health (467/08/2014) and the Aboriginal Health Council of South Australia (04-11-406).

Study design

A period prevalence study using linked, public hospital administrative records.

Data sources

Hospital separations

Details of the universally available healthcare for patients admitted to public hospitals are collated at time of their discharge, or separation, from hospital then added to the Integrated South Australian Activity Collection (ISAAC) maintained by SA Health, the state government's lead health agency. The term 'separations' is used synonymously with 'admissions'[14 51 55 56] and 'hospitalisations'[12 18 25 30 40 45 48 52] reported in other research referenced by our study. Chronic PPH within ISAAC records for financial years 2005–2006 to 2010–2011 were categorised using AIHW criteria for ICD-10 primary diagnoses and relevant procedure codes.[57] ISAAC includes mandatory fields of age, Aboriginal identification and Statistical Local Area (SLA) of usual residence. Residents of the Anangu Pitjantjatjara Yankunytjatjara Lands (APY Lands) access over 95% of their hospital services in the neighbouring jurisdiction (at Alice Springs Hospital in the Northern Territory).[58] This activity is not recorded within ISAAC so any residual APY resident hospitalisations were removed from hospital and population denominator counts.

Hospital costs across the period were calculated in a uniform manner using Australia's National Efficient Price for public hospital healthcare activity in 2015–2016[7] and expressed in Australian dollars. These prices are based on each separation's Australian Refined Diagnostic Related Group (v7.0) with loadings for outlying LOS, Aboriginality (4%) and area remoteness (ranging from an additional 8% in outer regional to 22% for very remote areas).

Hospital separations for individuals

Analysis of separations for individual people was facilitated by probabilistically linked project keys from SA-NT DataLink, an organisation within Australia's data linkage network. These keys enabled grouping of each person's separations across hospitals and time. Each individual's records were assigned the last recorded age and the SLA recorded in that person's index, or first occurring, separation. Aboriginality was categorised on the basis of a person having identified as Aboriginal in *any* hospital separation during the observation period. Identification of Aboriginal status can be difficult and introduce misclassification bias.[59] Accordingly, a more stringent definition for sensitivity analyses was based on a person identifying as Aboriginal on more than 75% of records.

Population and statistical geography

South Australia is in southern, central Australia. Comprising a land area of almost 1 million square kilometres and a resident population of 1.64 million[60], 71% in the capital's metropolitan area, SA has a low population density of 1.67 persons per square kilometre. The Aboriginal population comprised 2.3% of population with one half residing in the metropolitan area.[60]

The study's population denominators were based on Australia's Census years in 2006 and 2011[61]. The relevant estimates of resident population by sex, age and Aboriginality include sex and age profiles by rurality and total population for SLAs, the smallest routinely available geographic areas for intrastate analysis.[62] The mean annual total population for each SLA was 12 584 (SD=10 029) ranging from 0 to 36 407.[63]

The Australian Bureau of Statistics (ABS) index SLAs by socioeconomic characteristics[64] and geographic remoteness. Census 2011 Index of Relative Socioeconomic Disadvantage (IRSD)[57 64 65] ranks SLAs whereby 1 is least disadvantaged and 123 the most disadvantaged area. These are further aggregated to disadvantage quintiles of approximately equal population size.[62] SLAs with nominal population and no relative IRSD rank would not contribute to the analysis and were omitted. The Accessibility/Remoteness Index of Australia (ARIA+) uses road distance to service centres[62] to allocate a continuous measure ranging from 0 (high accessibility) to 15 (high remoteness). SLAs can be collapsed into categories of major city (ARIA+ ≤0.2), regional (ARIA+ >0.2 and ≤5.92) and remote areas (ARIA+ >5.92).

Data analysis

Crude, unadjusted rates of individuals experiencing chronic PPH with respect to Aboriginality, sex, age and area level IRSD quintiles and remoteness categories were summarised using cross-tabulations. Among these individual patients, the mean number of chronic PPH separations and the associated mean, total LOS and hospital costs was determined.

LOS and cost outcomes were then placed into a broader, population context. Indirect sex and age adjustment[66] with 5-year age groupings to 75+[67] controlled for confounding from sex and age variations between Aboriginal and non-Aboriginal people experiencing chronic PPH and the population more generally. Area outcomes therefore represent the ratio of observed versus expected outcome based on South Australian totals. For example, an outcome of 1.50 for total chronic PPH LOS among a population group indicates the ratio of observed versus expected LOS across that group was one and a half times, or 50% higher, than the South Australian average after adjusting for sex and age differences.

Outcomes of LOS and hospital cost ratios observed among the population of each SLA were positively skewed and subsequently normalised using square root transformations. The relationship between transformed outcomes and the potential covariates of SLA IRSD rank and remoteness were examined using least squares regressions[68] with each SLA's contribution weighted by population size. While the focus was on chronic PPH as a group, diabetes complications are known to be nationally over-represented among Aboriginal people[69] as the largest single chronic PPH condition and up to 10 times the rate of the non-Aboriginal population. To examine any potential bias introduced by an association between diabetes complications, area disadvantage and remoteness, records were further stratified as either diabetes complications or all other chronic PPH with analyses repeated for each. The reported coefficients and 95% CIs represent the change in the standardised ratio for each one unit change in disadvantage rank and remoteness.

All analyses used Stata V.14.2.[70]

RESULTS

Crude separations

Of 1 828 846 public hospital separations involving usual SA residents, 117 127 (6.4%) were categorised as chronic PPH. Aboriginal people experienced these at 2.2 (95% CI 2.1 to 2.4) times the rate of non-Aboriginals (n=4391 at 26.7 chronic PPH per 1000 persons per year compared with n=112 736 at 12.1 per 1000 persons per year).

Demographic and diagnostic profile (person-based analysis)

Chronic PPH involved 60 208 individuals, 1892, or 3.2%, of whom were Aboriginal. Table 1 quantifies aspects of their experience showing Aboriginal people were 1.8 (95% CI 1.6 to 2.1) times more likely to be hospitalised than non-Aboriginal people. There were several marked differences in conditions responsible for hospitalisation with diabetes complications being the primary diagnosis for more than one-third of Aboriginal patients with chronic PPH compared with around one in five non-Aboriginal patients. Chronic PPH events can involve more than one diagnosed chronic condition, and this was observed more frequently among Aboriginal patients. For instance, the 2311 diagnosed chronic conditions among 1892 Aboriginal patients hospitalised averages 1.22 per patient. The comparison for non-Aboriginal patients was 1.14 comprising 66 343 chronic condition diagnoses among 58 316 patients.

Aboriginal patients experiencing chronic PPH were more likely to be female and of a much younger age compared with non-Aboriginal patients (median ages of 48 and 70 years, respectively). The proportion of individual Aboriginal patients from areas of most disadvantage (54.1% vs 26.7%) or regional and remote areas (64.2% vs 35.6%) was around double that of non-Aboriginal people.

The number of chronic PPH, associated LOS and estimated hospital costs averaged across individual patients are summarised in table 2. The dominant pattern is one of more frequent hospitalisation per Aboriginal person by sex, and across areas of residence and most age groupings. The average of 11.7 days LOS was 30% greater for Aboriginal patients with the differences peaking in the 55–74 age ranges. Hospital costs follow a similar pattern but with more pronounced differences by Aboriginality. For example, averaged hospital costs accumulated for Aboriginal patients were 56% higher than non-Aboriginal patients ($17 928 vs $11 515) with differences most prominent in the 55–74 age ranges. The absolute difference in excess of $11 500 represented an almost two-fold difference in relative terms.

Figure 1A illustrates the stark disparity in the age at which Aboriginal and non-Aboriginal people experienced a first chronic PPH. Figure 1B then illustrates the mean number of separations those individual patients experienced. Aboriginal people aged 35–44 or more not only experienced markedly higher rates of chronic PPH but having had a first event, they were increasingly likely to experience at least one more event.

Sex and age standardised LOS and costs

Figure 2 places results for individuals hospitalised into a population context by graphing sex and age standardised outcomes by Aboriginality (LOS in figure 2A and costs in figure 2B) for all areas, then disadvantage quintiles and remoteness categories. Each marker is weighted by area population as per online supplementary table B. Figure 2A illustrates the LOS rate associated with chronic PPH within the Aboriginal population was six times more than the state average after adjusting for sex and age. Chronic PPH LOS among Aboriginal and non-Aboriginal populations progressively increased across levels of area

Table 1 Demographic and diagnostic distribution of Aboriginal and non-Aboriginal patients experiencing a first chronic PPH in South Australian public hospitals, 2005–2006 to 2010–2011

	Aboriginal			Non-Aboriginal		
	n	%	Patients per 1000 population each year	n	%	Patients per 1000 population each year
Chronic PPH	1892	100.0	11.5	58316	100.0	6.2
Conditions*						
Angina	293	15.5	1.8	10587	18.2	1.1
Asthma	528	27.9	3.2	12346	21.2	1.3
COPD	341	18.0	2.1	11930	20.5	1.3
Congestive cardiac failure	221	11.7	1.4	11079	19.0	1.2
Diabetes complications	700	37.0	4.3	12574	21.6	1.3
Hypertension	79	4.2	0.5	2199	3.8	0.2
Iron deficiency anaemia	107	5.7	0.7	4974	8.5	0.5
Nutritional deficiencies	0	0.0	0.0	62	0.1	0.0
Rheumatic heart disease	42	2.2	0.3	592	1.0	0.1
Gender						
Male	860	45.5	10.6	29970	51.4	6.5
Female	1032	54.5	12.4	28346	48.6	6.0
Age						
0–4	167	8.8	8.6	4148	7.1	8.1
5–14	137	7.2	3.5	3775	6.5	3.4
15–24	92	4.9	2.7	1691	2.9	1.4
25–34	115	6.1	5.0	1531	2.6	1.3
35–44	264	14.0	13.1	2452	4.2	1.9
45–54	429	22.7	28.8	4211	7.2	3.2
55–64	355	18.8	44.2	6714	11.5	5.8
65–74	223	11.8	61.0	9583	16.4	12.7
75+	110	5.8	59.7	24211	41.5	32.8
Area disadvantage (2011 IRSD)						
Q1 least disadvantage	31	1.6	3.7	6298	10.8	3.4
Q2	128	6.8	7.7	10799	18.5	5.1
Q3	159	8.4	7.6	10918	18.7	6.6
Q4	551	29.1	11.6	17739	30.4	7.4
Q5 most disadvantage	1023	54.1	14.5	15562	26.7	8.9
Area remoteness (ARIA+)						
Major cities	677	35.8	8.0	37532	64.4	5.6
Regional	813	43.0	13.7	18329	31.4	7.7
Remote	402	21.2	19.4	2455	4.2	7.7

*Subtotals of n=2311 and 66343, respectively. Does not round to 100% as chronic PPH can include more than one condition.
ARIA+, Accessibility/Remoteness Index of Australia; COPD, chronic obstructive pulmonary disease; IRSD, Index of Relative Socioeconomic Disadvantage; PPH, potentially preventable hospitalisation.

disadvantage but change was far more pronounced within the Aboriginal population and concentrated among the relatively larger disadvantaged populations in quintiles 4 and 5. Similarly, comparison of major city with remote locations involved nearly threefold higher results from 4.2 to 12.1 times the state average. Hospital costs incurred (figure 2B) show very similar patterns with slightly higher mean differences between Aboriginal and non-Aboriginal results. Linear regression models between the two sex and age standardised outcomes of LOS and cost ratios across three levels (all chronic PPH, diabetes complications and all other chronic PPH) and the covariates of area level disadvantage and remoteness are presented for Aboriginal and non-Aboriginal populations in table 3.

Table 2 Mean number of separations, total LOS and hospital cost associated with chronic PPH in South Australian public hospitals, 2005–2006 to 2010–2011

	Number of chronic PPH				LOS for chronic PPH				Costs of chronic PPH			
	Aboriginal		Non-Aboriginal		Aboriginal		Non-Aboriginal		Aboriginal		Non-Aboriginal	
	Mean	95% CIs	Mean	95% CIs	Mean	95% CIs	Mean	95% CIs	Mean	95% CIs	Mean	95% CIs
Chronic PPH	2.6	2.4 to 2.8	1.9	1.9 to 1.9	11.7	10.6 to 12.7	9.0	8.9 to 9.2	$17 928	$16 367 to $19 490	$11 515	$11 344 to $11 686
Conditions												
Diabetes complications	2.4	2.1 to 2.6	1.8	1.8 to 1.9	13.3	11.7 to 15.0	10.0	9.7 to 10.3	$20 665	$18 253 to $23 077	$14 601	$14 172 to $15 031
Other than diabetes	2.4	2.2 to 2.6	1.8	1.8 to 1.9	9.2	8.1 to 10.3	8.3	8.1 to 8.4	$14 074	$12 416 to $15 733	$10 083	$9916 to $10 250
Gender												
Male	2.7	2.5 to 3.0	1.9	1.9 to 2.0	12.2	10.7 to 13.7	9.1	8.9 to 9.3	$18 895	$16 794 to $20 997	$11 993	$11 749 to $12 237
Female	2.5	2.3 to 2.8	1.9	1.9 to 1.9	11.2	9.7 to 12.7	9.0	8.7 to 9.2	$17 121	$14 856 to $19 386	$11 009	$10 769 to $11 249
Age												
0–4	1.5	1.3 to 1.6	1.6	1.5 to 1.6	2.9	2.3 to 3.4	2.5	2.4 to 2.6	$5000	$3743 to $6256	$4178	$4041 to $4315
5–14	2.1	1.7 to 2.5	1.9	1.8 to 1.9	4.6	3.3 to 6.0	3.7	3.4 to 3.9	$6700	$5232 to $8168	$5775	$5499 to $6051
15–24	1.9	1.2 to 2.5	2.1	1.9 to 2.2	6.3	4.0 to 8.7	4.9	4.3 to 5.5	$14 070	$8113 to $20 028	$8460	$7524 to $9396
25–34	2.4	1.5 to 3.3	1.7	1.6 to 1.8	11.0	5.8 to 16.2	4.0	3.6 to 4.4	$18 513	$9779 to $27 247	$6339	$5767 to $6910
35–44	2.2	1.9 to 2.5	1.7	1.6 to 1.9	10.1	7.9 to 12.4	6.1	4.9 to 7.3	$15 854	$12 503 to $19 206	$9220	$7878 to $10 562
45–54	2.7	2.4 to 3.1	1.7	1.7 to 1.8	12.0	9.9 to 14.1	7.3	6.6 to 7.9	$19 096	$15 989 to $22 202	$10 623	$9809 to $11 438
55–64	3.2	2.6 to 3.8	1.9	1.8 to 2.0	14.9	12.0 to 17.8	8.9	8.4 to 9.3	$24 023	$19 306 to $28 740	$12 291	$11 696 to $12 886
65–74	3.4	2.8 to 4.1	2.0	2.0 to 2.1	18.6	14.1 to 23.0	10.5	10.1 to 10.9	$25 820	$20 512 to $31 128	$13 940	$13 440 to $14 441
75+	2.8	2.1 to 3.4	2.0	2.0 to 2.0	17.1	11.7 to 22.6	11.7	11.5 to 11.9	$19 258	$13 985 to $24 532	$13 420	$13 189 to $13 651
Area disadvantage (2011 IRSD)												
Q1 least disadvantage	2.4	1.4 to 3.3	1.8	1.7 to 1.8	7.1	3.3 to 10.8	7.9	7.5 to 8.3	$12 481	$4338 to $20 624	$9908	$9474 to $10 341
Q2	2.5	2.0 to 3.1	1.8	1.8 to 1.9	10.1	7.0 to 13.2	8.8	8.4 to 9.2	$15 995	$10 932 to $21 058	$11 176	$10 728 to $11 625
Q3	2.4	1.9 to 3.0	1.9	1.9 to 2.0	12.3	7.9 to 16.8	9.5	9.1 to 9.8	$16 776	$11 410 to $22 142	$11 788	$11 389 to $12 186
Q4	2.5	2.2 to 2.8	1.9	1.9 to 1.9	10.7	9.0 to 12.5	8.9	8.6 to 9.1	$17 228	$14 710 to $19 746	$11 372	$11 053 to $11 691
Q5 most disadvantage	2.8	2.5 to 3.0	2.1	2.0 to 2.1	12.4	10.8 to 14.0	9.5	9.2 to 9.8	$18 503	$16 208 to $20 798	$12 351	$12 012 to $12 689
Area remoteness (ARIA+)												
Major cities	2.5	2.2 to 2.8	1.9	1.9 to 2.0	10.8	9.0 to 12.6	9.3	9.2 to 9.5	$16 918	$14 110 to $19 727	$11 892	$11 667 to $12 116
Regional	2.7	2.4 to 3.0	1.9	1.9 to 1.9	11.7	10.0 to 13.4	8.5	8.2 to 8.7	$16 575	$14 413 to $18 737	$10 753	$10 481 to $11 024
Remote	2.7	2.3 to 3.1	1.8	1.7 to 1.9	13.1	10.8 to 15.4	8.5	7.9 to 9.1	$21 377	$17 931 to $24 824	$11 490	$10 673 to $12 307

ARIA+, Accessibility/Remoteness Index of Australia; IRSD, Index of Relative Socioeconomic Disadvantage; LOS, length of stay; PPH, potentially preventable hospitalisations.

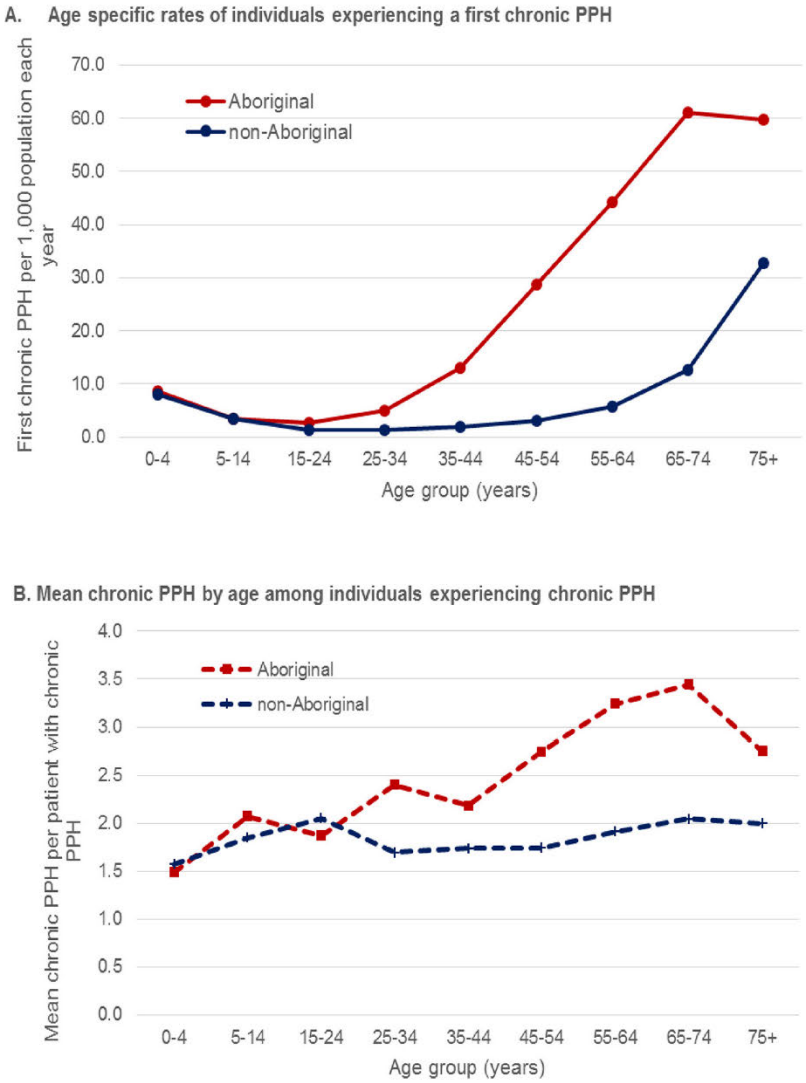


Figure 1 Rate of individuals with first chronic PPH and subsequent mean of chronic PPH by age and Aboriginality, South Australian public hospitals 2005–2006 to 2010–2011. PPH, potentially preventable hospitalisations.

After allowing for sex and age differences, Aboriginal people's LOS and cost outcomes, for each level, varied significantly across area disadvantage and remoteness. For example, within the Aboriginal population, the standardised LOS rate ratio associated with all chronic PPH was 2.09 (95% CI 0.00 to 5.83) times the state average (of one). The disparate LOS rate increased by an average of 0.03 (95% CI 0.00 to 0.07) with each change in disadvantage rank and a further 1.04 (95% CI 0.63 to 1.44) as remoteness increased. These associations of disadvantage and remoteness with LOS were consistent within stratified subgroups of diabetes complications and all other chronic PPH. However, the magnitude of change in LOS ratios was higher for diabetes complications (2.59; 95% CI 0.00 to 10.82) than for all other chronic PPH (1.86; 95% CI 0.43 to 1.21) before adjusting for the influence of area disadvantage and remoteness. The change observed in LOS for diabetes complications was around twice that for all other chronic PPH for both disadvantage (0.05; 95% CI 0.00 to 0.15 vs 0.02; 95% CI 0.00 to 0.06) and remoteness (1.62; 95% CI 0.73 to 2.51 vs 0.82; 95% CI 0.43 to 1.21). Similar variations in standardised cost ratio outcomes across levels of outcome and by disadvantage and remoteness were observed for the Aboriginal population.

Results for the non-Aboriginal population also show consistent associations between area disadvantage and each outcome and level whereby the standardised ratio increased as disadvantage increased. However, area remoteness was not associated with increased LOS or cost. Moreover, the base from which change occurred was substantially lower. For instance, the standardised LOS ratio for chronic PPH among the non-Aboriginal

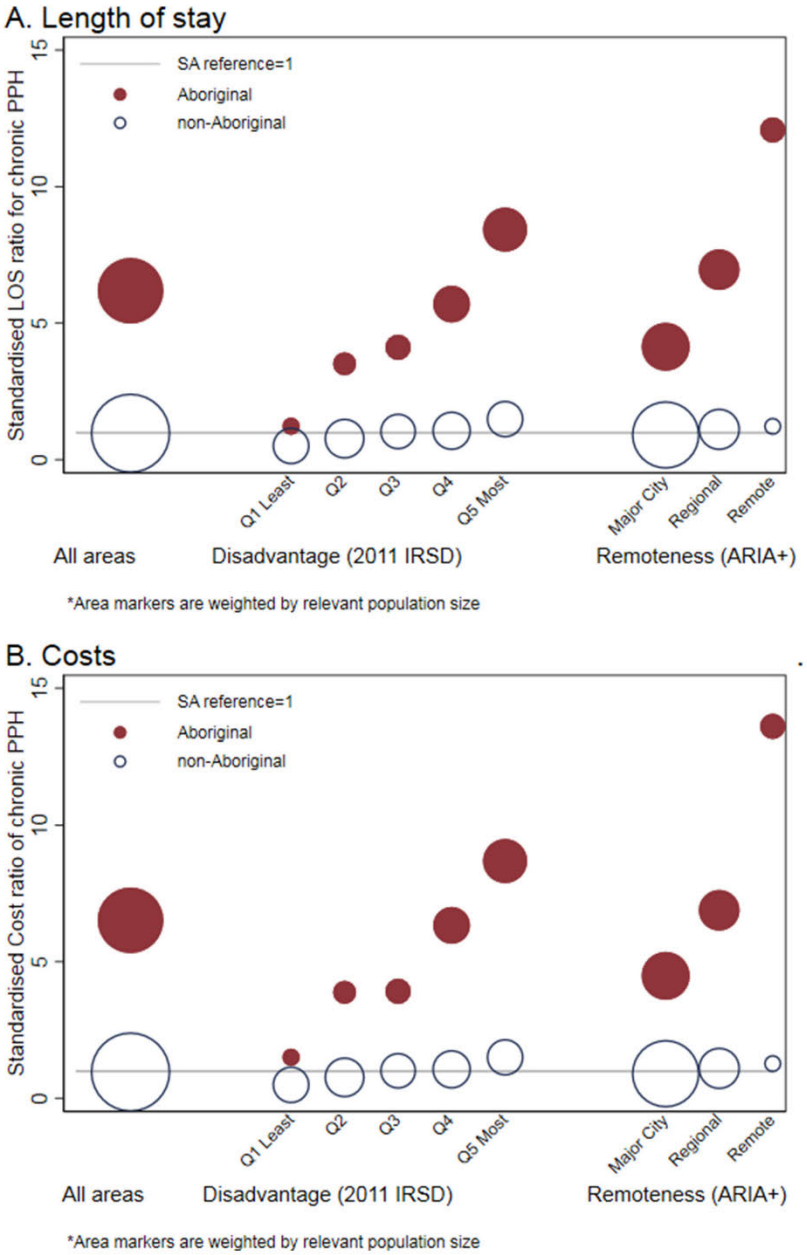


Figure 2 Ratio of sex and age adjusted public hospital LOS (panel A) and costs (panel B) for chronic PPH by Aboriginality, disadvantage and remoteness in SA, 2005–2006 to 2010–2011*. ARIA+, Accessibility/Remoteness Index of Australia; IRSD, Index of Relative Socioeconomic Disadvantage; LOS, length of stay; PPH, potentially preventable hospitalisations; SA, South Australia.

population before adjusting for disadvantage rank was less than half (95% CI 38% to 54%) of the state average.

The potential for interaction between area disadvantage and remoteness was examined without result. Sensitivity analyses using a more stringent definition of Aboriginality were also conducted but did not change our overall conclusions.[71]

DISCUSSION

This study provides evidence of stark disparities in the rates with which Aboriginal and non-Aboriginal individuals experienced PPH for chronic conditions. Aboriginal people had almost twice the risk of experiencing a chronic PPH overall compared with their non-Aboriginal contemporaries. Other disparities noted include higher chronic PPH rates among Aboriginal females and younger adults

Table 3 Relationship of SLA attributes with standardised ratios* of LOS and cost by Aboriginality, South Australian public hospitals 2005–2006 to 2010–2011

	Aboriginal				Non-Aboriginal			
LOS	Change coefficient	95% CIs	p	N (SLAs)	Change coefficient	95% CIs	p	N (SLAs)
Chronic PPH				118				119
Constant	2.09	0.00 to 5.83	<0.001		0.46	0.38 to 0.54	<0.001	
Area disadvantage rank (2011 IRSD)†	0.03	0.00 to 0.07	0.005		0.01	0.01 to 0.01	<0.001	
Area remoteness (ARIA+)‡	1.04	0.63 to 1.44	<0.001		0.02	0.00 to 0.04	0.183	
Diabetes complications PPH								
Constant	2.59	0.00 to 10.82	0.003		0.41	0.31 to 0.52	<0.001	
Area disadvantage rank (2011 IRSD)†	0.05	0.00 to 0.15	0.005		0.01	0.01 to 0.01	<0.001	
Area remoteness (ARIA+)‡	1.62	0.73 to 2.51	<0.001		0.02	0.00 to 0.05	0.225	
Other chronic PPH								
Constant	1.86	0.00 to 5.45	<0.001		0.48	0.39 to 0.56	<0.001	
Area disadvantage rank (2011 IRSD)†	0.02	0.00 to 0.06	0.004		0.01	0.01 to 0.01	<0.001	
Area remoteness (ARIA+)‡	0.82	0.43 to 1.21	<0.001		0.01	0.00 to 0.04	0.258	
Cost								
Chronic PPH								
Constant	2.44	0.00 to 5.92	<0.001		0.44	0.36 to 0.51	<0.001	
Area disadvantage rank (2011 IRSD)†	0.02	0.00 to 0.06	0.008		0.01	0.01 to 0.01	<0.001	
Area remoteness (ARIA+)‡	1.18	0.80 to 1.55	<0.001		0.02	0.00 to 0.04	0.078	
Diabetes complications PPH								
Constant	3.95	0.00 to 10.88	<0.001		0.40	0.30 to 0.50	<0.001	
Area disadvantage rank (2011 IRSD)†	0.03	0.00 to 0.12	0.006		0.01	0.01 to 0.01	<0.001	
Area remoteness (ARIA+)‡	1.43	0.68 to 2.18	<0.001		0.02	0.00 to 0.05	0.258	
Other chronic PPH								
Constant	1.74	0.77 to 5.40	<0.001		0.45	0.37 to 0.53	<0.001	
Area disadvantage rank (2011 IRSD)†	0.02	0.00 to 0.06	0.005		0.01	0.01 to 0.01	<0.001	
Area remoteness (ARIA+)‡	1.08	0.69 to 1.48	<0.001		0.02	0.00 to 0.04	0.090	

*Square root transformed.
†Change is per one unit increase in SLA disadvantage rank.
‡Change is per one unit increase in SLA ARIA +score.
ARIA+, Accessibility/Remoteness Index of Australia; IRSD, Index of Relative Socioeconomic Disadvantage; LOS, length of stay; PPH, potentially preventable hospitalisations; SLA, Statistical Local Area.

with rates steeply increasing from least to most disadvantaged quintiles and/or remote areas of South Australia. Conversely, non-Aboriginal patients were more likely to be concentrated among older adults. A social gradient across disadvantage levels was also apparent; however, the steepness of the gradient from most to least disadvantaged areas was markedly lower for non-Aboriginal people. These findings are consistent with the wider literature focused on ethnic differences in PPH[35–37] and underpin the disproportionate population rates of chronic PPH among Aboriginal South Australians.[9 57 69]

This analysis at the individual level furthers our understanding by demonstrating how, having experienced one chronic PPH event, Aboriginal patients were also more likely to endure further chronic PPH. This was associated with an increased accrual of time spent in hospital that was almost one-third higher for Aboriginal patients. Moreover, the associated hospital costs were more than 50% higher than for non-Aboriginal patients on average and more variable within the group of Aboriginal patients.

Sex and age adjusted rates of time spent in hospital for chronic PPH and expressed as rates per capita reflect the

number of individuals and the length of time hospitalised. These standardised population outcomes showed LOS for chronic PPH among Aboriginal South Australians was six times higher than the state average. The best outcomes within the Aboriginal community were observed among the relatively few living in areas of least disadvantage, although these were still markedly higher than the state average. Diabetes complications are heavily implicated in chronic PPH for Aboriginal people. Their presence, with or without other chronic conditions, exacerbate LOS rates and hospital costs among Aboriginal people but not so within the non-Aboriginal population. Even after partitioning out diabetes-related hospitalisations, substantial differences in LOS and cost remain among other chronic PPH experienced by Aboriginal people.

The results further highlight systematic inequities between populations while also highlighting substantial within-population variation whereby a relatively small number of people experienced considerable time in hospital and away from their usual societal roles because of chronic health conditions. This is consistent with recent US literature demonstrating the role of chronic PPH, and particularly diabetes, as sustaining and even increasing disparities between African Americans and whites.[56] Similarly, it affirms other Australian research highlighting widespread Aboriginal/non-Aboriginal differences and differences within the Aboriginal population in chronic PPH generally and the pervasive, adverse results of diabetes complications across geographic areas.[48] Moreover, the results identified that increased chronic PPH were accompanied by systematically increased accrual of LOS and greater hospital costs.

The extent to which these differences are amenable to change needs further discussion. By definition, chronic PPH represent opportunities for change through exposure to primary healthcare, notwithstanding a range of individual, societal, clinical and system level factors are related to their occurrence[72 73] and may each be associated with realising this potential. This is supported by studies of risk factor exposure across levels of socioeconomic disadvantage and remoteness.[33] Whether the chronic PPH events were preventable in their immediate context is less certain. The high prevalence of diabetes complications and higher levels of chronic multimorbidities among Aboriginal patients observed in this study suggests comparatively more advanced disease for which hospitalisations, more often, for longer periods and at greater cost is an appropriate and expected result. A heightened need for preventive and early intervention through primary and community care is evident.

Authoritative reviews of the international literature found chronic PPH,[74 75] and unplanned hospitalisation more generally[76] among selected patient groups, were reduced by interventions promoting self-management support, continuity of care with a general practitioner and integration of primary and secondary care. Other interventions, such as case management, appear to reduce LOS.[74–76] However, each review was restricted by a relative lack of robust evaluation of interventions as they are introduced into health systems. Such evaluations are emerging and indicate promising primary healthcare interventions in chronic disease management and diabetes are available. Australia's largest randomised intervention in diabetes delivered positive outcomes in HbA1c levels, blood pressure, waist circumference, depression, care-plan take-up and chronic PPH in the trial group receiving each of five available quality improvement and flexible funding components.[43] Mainstream general practice services are less available for remote Aboriginal populations exhibiting greater need in terms of chronic PPH LOS and costs, yet evidence of effective intervention among Aboriginal populations is available.[77] Randomised diabetes care led by community health workers in regional and remote areas showed promising HbA1c reductions among poorly controlled type 2 diabetes patients[78] and modest net reductions in diabetes-related hospitalisation in the treatment group.[79] Nevertheless, a critical need for substantively increasing the training and supply of Aboriginal healthcare workers remains.[80] Generally negative evaluation of incremental cost-effectiveness assessments based on short-term, averaged and disease-specific results[43 79] may impede this investment.

Our description of who is more likely to experience chronic PPH, for what conditions, with what frequency and at what direct cost to the health system suggest three areas for developing incremental cost to outcome analyses. The first is to consider flow-on benefits from disease-specific interventions to other comorbid chronic conditions, especially where disparities in condition prevalence exist. Second, evaluation based on longer term accumulated hospitalisation costs for individual trial participants is warranted. Where project term constraints apply, our results provide an initial empirical base. Finally, placing individual participant results into a population context provides an information base for allocating resources that address healthcare needs for primary and community care at lower cost to individuals and acute care services.[24]

Subsequent reporting of cumulative LOS and costs at a person level adds value to system performance monitoring by making the person and patient the centre of reporting and evaluation, as well as the centre of care. Providing empirical evidence of change occurring at individual and population levels will help align system activities and monitoring with the ultimate aim of providing appropriate and effective care of patients and people, equitably and efficiently.

Limitations

The study has several limitations. First, cumulative LOS as an outcome variable is influenced by the nature of admission with interhospital transfers having longer LOS than emergency admissions.[6] Recurrent hospital events for chronic conditions among people in regional and remote settings may involve comparatively more interhospital transfers or planned admissions for treatment where

primary health interventions are scarce. Nevertheless, the observations summarised in this study represent an aspect of peoples' lived experience of contending with chronic disease. Continuing research will benefit from focusing on mode of admission to hospital and the local availability of primary care. Second, the propensity to identify as Aboriginal has increased across recent times, and any undercounting in earlier Aboriginal population denominators would affect population rates. However, this study's population estimates are drawn from the internally consistent ABS series covering 1996–2011 as based on the 2011 Census and the first available set of ABS non-experimental population denominators. Accordingly, there are no known inflation of rates due to population undercounts. Nevertheless, estimates incorporating Census 2016 will provide a valuable reliability check when used with concurrent hospital data in future analyses. Third, while public hospital care is universally available in SA and estimating rates makes appropriate use of population denominators, the omission of private hospital separations undercounts some chronic PPH, particularly among relatively advantaged citizens. Further studies will benefit from including these private hospital separations and from exploring whether chronic PPH were associated with planned care or the result of emergency presentations. Finally, the omission of the APY Lands SLA means chronic PPH outcomes associated with a very remote area and SA's most disadvantaged are not represented.[81] Subsequent research in the area will benefit from including APY Land residents hospitalised in the Northern Territory[50] to ensure results for the most remote and disadvantaged population groups are not underestimated.

CONCLUSION

The results show heightened risk of chronic PPH among Aboriginal individuals that compounds into more rehospitalisation and accumulated time in hospital at greater cost to the person, their community and the health system. At a population level, the systematic change in chronic PPH and LOS by Aboriginality and area suggests efforts to address these potentially avoidable hospitalisations will benefit from targeting specific population segments, particularly in areas of greater socioeconomic disadvantage and geographic remoteness. This analysis helps guide such actions by identifying subpopulations within the wider community who could most benefit from improved understanding of antecedent causes of hospitalisation. Routine reporting across population groups and regions will help monitor progress in meeting the underlying population health needs with earlier, and perhaps lower cost, interventions.

Author affiliations
[1]School of Public Health, Faculty of Health and Medical Sciences, The University of Adelaide, Adelaide, South Australia, Australia
[2]Wardliparingga Aboriginal Research Unit, The South Australian Health and Medical Research Institute, Adelaide, South Australia, Australia
[3]School of Medical Science, Griffith Health, Griffith University, Gold Coast, Queensland, Australia

Acknowledgements DB is supported in part by an Australian Government Research Training Program Scholarship. AB is supported by The Sylvia and Charles Viertel Senior Medical Research Fellowship. The authors would like to thank: SAHMRI and the Wardliparingga Aboriginal Health Research Unit for providing a Summer Scholarship for TC and SA Health for administrative unit records via Statistical Linkage Project 2010-0004. John Glover, Torrens University's Public Health Information Development Unit (PHIDU) and the Australian Department of Health for Aboriginal and Torres Strait Islander small area population estimates for 2006.

Contributors DB conceived the project, performed the analyses and drafted the manuscript; TC contributed to literature searching and manuscript preparation; JK, AB and JL made important contributions to operationalising this study, interpreting the statistical analysis and revised the manuscript. All authors read and approved the final version of the manuscript.

Competing interests None declared.

Ethics approval SA Health; Aboriginal Health Council of South Australia.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The study's data comprised of deidentified unit record administrative records. These were used under privileged arrangements set out in a study-specific confidentiality deed. The data cannot be accessed by another party without relevant departmental and human research ethics approvals.

REFERENCES

1. Vos T, Flaxman AD, Naghavi M, *et al*. Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet* 2012;380:2163–96.
2. Alliance for Health Policy and System Research. *Systems thinking for health systems strengthening*. Geneva: World Health Organization, 2009.
3. Victorian Auditor-General's Report. *Hospital Performance: Length of Stay*. Melbourne: Victorian Government, 2016.
4. Australian Institute of Health and Welfare. *Health expenditure Australia 2013–14: analysis by sector*. Canberra: AIHW, 2015.
5. Australian Institute of Health and Welfare. *Health expenditure Australia 2013–14*. Canberra: AIHW 2015.
6. Kulinskaya E, Kornbrot D, Gao H. Length of stay as a performance indicator: robust statistical methodology. *IMA Journal of Management Mathematics* 2005;16:369–81.
7. Independent Hospital Pricing Authority. *National Efficient Price Determination: 2015-16*. IHPA, 2015.
8. National Health Performance Authority. *Hospital Performance: Length of stay in public hospitals in 2011–12*. Sydney: NHPA 2013.
9. Australian Institute of Health and Welfare. *Australian hospital statistics 2012–13*. Canberra: AIHW 2014.
10. Australian Institute of Health and Welfare. National Healthcare Agreement: PI 18-Selected potentially preventable hospitalisations, 2013. 2013.
11. National Health Performance Authority. National Health Reform: Performance and Accountability Framework: National Health Performance Authority. 2013.
12. Katterl R, Anikeeva O, Butler C, *et al*. Potentially avoidable hospitalisations in Australia: Causes for hospitalisations and primary health care interventions. 2012.
13. Jackson G, Tobias M. Potentially avoidable hospitalisations in New Zealand, 1989-98. *Aust N Z J Public Health* 2001;25:212–21.
14. Longman JM, Passey ME, Ewald DP, *et al*. Admissions for chronic ambulatory care sensitive conditions - a useful measure of potentially preventable admission? *BMC Health Serv Res* 2015;15:472.

15. Agency for Healthcare Research and Quality. *Quality Indicator User Guide: Prevention Quality Indicators (PQI) Composite Measures Version 4.4*. Rockville: US Department of Health and Human Services 2012.
16. Rosano A, Loha CA, Falvo R, *et al*. The relationship between avoidable hospitalization and accessibility to primary care: a systematic review. *Eur J Public Health* 2013;23:356–60.
17. Niti M, Ng TP. Avoidable hospitalisation rates in Singapore, 1991-1998: assessing trends and inequities of quality in primary care. *J Epidemiol Community Health* 2003;57:17–22.
18. Ansari Z, Haider SI, Ansari H, *et al*. Patient characteristics associated with hospitalisations for ambulatory care sensitive conditions in Victoria, Australia. *BMC Health Serv Res* 2012;12:475.
19. Billings J, Zeitel L, Lukomnik J, *et al*. Impact of socioeconomic status on hospital use in New York City. *Health Aff* 1993;12:162–73.
20. Swerissen H, Duckett S, Wright J. Chronic failure in primary medical care: Grattan Institute. 2016.
21. Culyer AJ. Efficiency, equity and equality in health and health care: Centre for Health Economics, University of York. 2016.
22. Muenchberger H, Kendall E. *Determinants of avoidable hospitalization in chronic disease: Development of a predictor matrix*. Meadowbrook: Griffith University, 2008.
23. McIntyre D, Mooney G. eds. *The Economics of Health Equity*. Cambridge: Cambridge University Press, 2007.
24. Diderichsen F. *Resource allocation for Health Equity: Issues and methods*. Washington DC: The World Bank, 2004.
25. Laditka JN, Laditka SB. Race, ethnicity and hospitalization for six chronic ambulatory care sensitive conditions in the USA. *Ethn Health* 2006;11:247–63.
26. Moy E, Mau MK, Raetzman S, *et al*. Ethnic differences in potentially preventable hospitalizations among Asian Americans, Native Hawaiians, and other Pacific Islanders: implications for reducing health care disparities. *Ethn Dis* 2013;23:6–11.
27. Booth GL, Hux JE, Fang J, *et al*. Time trends and geographic disparities in acute complications of diabetes in Ontario, Canada. *Diabetes Care* 2005;28:1045–50.
28. Muenchberger H, Kendall E. Predictors of preventable hospitalization in chronic disease: priorities for change. *J Public Health Policy* 2010;31:150–63.
29. Trachtenberg AJ, Dik N, Chateau D, *et al*. Inequities in ambulatory care and the relationship between socioeconomic status and respiratory hospitalizations: a population-based study of a Canadian city. *Ann Fam Med* 2014;12:402–7.
30. Roos LL, Walld R, Uhanova J, *et al*. Physician visits, hospitalizations, and socioeconomic status: ambulatory care sensitive conditions in a Canadian setting. *Health Serv Res* 2005;40:1167–85.
31. OECD. *Geographic Variations in Health Care*. OECD Publishing, 2014.
32. Australian Institute of Health and Welfare. *Aboriginal and Torres Strait Islander Health Performance Framework 2012: detailed analyses*. Canberra: AIHW, 2013.
33. Australian Health Ministers' Advisory Council (AHMAC). *Aboriginal and Torres Strait Islander Health Performance Framework 2014 Report*. Canberra: Australian Government, Department of the Prime Minister and Cabinet, 2015.
34. Bywood PT, Katterl R, Lunnay BK. *Disparities in primary health care utilisation: Who are the disadvantaged groups? How are they disadvantaged? What interventions work? PHC RIS Policy Issue Review*. Adelaide: Primary Health Care Research & Information Service, 2011.
35. Korenbrot CC, Ehlers S, Crouch JA. Disparities in hospitalizations of rural American Indians. *Med Care* 2003;41:626–36.
36. Shah BR, Gunraj N, Hux JE. Markers of access to and quality of primary care for aboriginal people in Ontario, Canada. *Am J Public Health* 2003;93:798–802.
37. Barnett R, Malcolm L. Practice and ethnic variations in avoidable hospital admission rates in Christchurch, New Zealand. *Health Place* 2010;16:199–208.
38. Zhao Y, Connors C, Wright J, *et al*. Estimating chronic disease prevalence among the remote Aboriginal population of the Northern Territory using multiple data sources. *Aust N Z J Public Health* 2008;32:307–13.
39. Wong CX, Brooks AG, Cheng YH, *et al*. Atrial fibrillation in Indigenous and non-Indigenous Australians: a cross-sectional study. *BMJ Open* 2014;4:e006242.
40. Teng TH, Katzenellenbogen JM, Thompson SC, *et al*. Incidence of first heart failure hospitalisation and mortality in Aboriginal and non-Aboriginal patients in Western Australia, 2000-2009. *Int J Cardiol* 2014;173:110–7.
41. He VY, Condon JR, Ralph AP, *et al*. Long-Term Outcomes From Acute Rheumatic Fever and Rheumatic Heart Disease: A Data-Linkage and Survival Analysis Approach. *Circulation* 2016;134:222–32.
42. Gibson OR, Segal L, McDermott RA. A systematic review of evidence on the association between hospitalisation for chronic disease related ambulatory care sensitive conditions and primary health care resourcing. *BMC Health Serv Res* 2013;13:1–13.
43. Department of Health. *Evaluation Report of the Diabetes Care Project*. Canberra: Australian Government, 2016.
44. Sq L, Gray N, Guthridge S, *et al*. Avoidable hospitalisation in Aboriginal and non-Aboriginal people in the Northern Territory. 2009.
45. Ansari MZ, Simmons D, Hart WG, *et al*. Preventable Hospitalisations for Diabetic Complications in Rural and Urban Victoria. *Aust J Prim Health* 2000;6:261–73.
46. Anderson M, Dugdale A. Ambulatory services in an aboriginal community and a west Queensland rural area. *Aust J Rural Health* 1997;5:121–5.
47. Department of Health. *Annual Performance Management Framework 2014-2015: Activity Based Funding and Management Program*. Perth: Department of Health, 2014.
48. Harrold TC, Randall DA, Falster MO, *et al*. The contribution of geography to disparities in preventable hospitalisations between indigenous and non-indigenous Australians. *PLoS One* 2014;9:e97892.
49. Banham D, Woollacott T, Gray J, *et al*. Recognising potential for preventing hospitalisation. *Aust Health Rev* 2010;34:116.
50. Government of South Australia. *Aboriginal Health Care Plan 2010-2016*. Adelaide, SA: Department of Health, Statewide Service Strategy Division, 2010.
51. Busby J, Purdy S, Hollingworth W. A systematic review of the magnitude and cause of geographic variation in unplanned hospital admission rates and length of stay for ambulatory care sensitive conditions. *BMC Health Serv Res* 2015;15:1–15.
52. Guo MW, Ahn HJ, Juarez DT, *et al*. Length of Stay and Deaths in Diabetes-Related Preventable Hospitalizations Among Asian American, Pacific Islander, and White Older Adults on Medicare, Hawai'i, December 2006-December 2010. *Prev Chronic Dis* 2015;12:E124.
53. Banham D, Jury H, Woollacott T, *et al*. Aboriginal premature mortality within South Australia 1999-2006: a cross-sectional analysis of small area results. *BMC Public Health* 2011;11:286.
54. Pawson R, Greenhalgh J, Brennan C, *et al*. Do reviews of healthcare interventions teach us how to improve healthcare systems? *Soc Sci Med* 2014;114:129–37.
55. Busby J, Purdy S, Hollingworth W. Using geographic variation in unplanned ambulatory care sensitive condition admission rates to identify commissioning priorities: an analysis of routine data from England. *J Health Serv Res Policy* 2017;22.
56. Mukamel DB, Ladd H, Li Y, *et al*. Have Racial Disparities in Ambulatory Care Sensitive Admissions Abated Over Time? *Med Care* 2015;53:931–9.
57. Australian Institute of Health and Welfare. *Admitted patient care: Australian hospital statistics 2013–14*. Canberra: AIHW 2015.
58. Division SADoHSSS. *Aboriginal Health Care Plan 2010 – 2016*. South Australia: Dept. of Health. Statewide Service Strategy Division 2010.
59. Thompson SC, Woods JA, Katzenellenbogen JM. The quality of indigenous identification in administrative health data in Australia: insights from studies using data linkage. *BMC Med Inform Decis Mak* 2012;12:133.
60. Australian Bureau of Statistics. 3238.0.55.001 - Estimates of Aboriginal and Torres Strait Islander Australians, June 2011. 2013.
61. Australian Bureau of Statistics. *Estimates and Projections, Aboriginal and Torres Strait Islander Australians: 2001 to 2026*. Canberra: ABS 2014.
62. Australian Bureau of Statistics. *Statistical Geography Volume 1 - Australian Standard Geographical Classification (ASGC)*. Canberra: ABS, 2006.
63. Australian Bureau of Statistics. *Population Estimates by Age and Sex, Australia by Geographical Classification[ASGC 2011]*. Australian Bureau of Statistics, 2012.
64. Australian Bureau of Statistics. *An introduction to Socio-Economic Indexes for Areas (SEIFA), 2006. Information Paper*. Canberra: ABS, 2008.
65. Australian Bureau of Statistics. Socio-Economic Indexes for Areas (SEIFA) - Technical Paper *2013*. 2011.
66. Berry J, Harrison J. *A guide to statistical methods for injury surveillance. Revised ed*. Adelaide: AIHW, 2005.
67. Australian Bureau of Statistics. *National Aboriginal and Torres Strait Islander health survey 2004-05*. Canberra, ACT: Australian Bureau of Statistics, 2006.
68. Australian Bureau of Statistics. *ASGC remoteness classification: purpose and use*. Canberra: ABS, 2003.

69. Australian Institute of Health and Welfare. *Admitted patient care: Australian hospital statistics 2014–15*. Canberra: AIHW 2016.
70. Stata Statistical Software: Release 14.2 [program]. College Station, TX: StataCorp LP, 2015.
71. Delaney JA, Seeger JD, analysis S. In: Velentgas P, Dreyer N, Nourjah P, *et al*, eds. *Developing a protocol for observational comparative effectiveness research: a user's guide*. Rockville, MD: Agency for Healthcare Research and Quality, 2013.
72. Passey ME, Longman JM, Johnston JJ, *et al*. Diagnosing Potentially Preventable Hospitalisations (DaPPHne): protocol for a mixed-methods data-linkage study. *BMJ Open* 2015;5:e009879.
73. Falster MO, Jorm LR, Douglas KA, *et al*. Sociodemographic and health characteristics, rather than primary care supply, are major drivers of geographic variation in preventable hospitalizations in Australia. *Med Care* 2015;53:436–45.
74. Purdy S. Avoiding hospital admissions: What does the research evidence say?: The King's Fund. 2010.
75. Clinical Epidemiology Health Service Evaluation Unit. *Potentially preventable hospitalisations: a review of the literature and Australian policies*. Melbourne: Melbourne Health, 2009.
76. Purdy S, Paranjothy S, Huntley A, *et al*. Interventions to reduce unplanned hospital admission: a series of systematic reviews: National Institute of Health Research. 2012.
77. Gibson OR, Segal L. Limited evidence to assess the impact of primary health care system or service level attributes on health outcomes of Indigenous people with type 2 diabetes: a systematic review. *BMC Health Serv Res* 2015;15:154.
78. McDermott RA, Schmidt B, Preece C, *et al*. Community health workers improve diabetes care in remote Australian Indigenous communities: results of a pragmatic cluster randomized controlled trial. *BMC Health Serv Res* 2015;15:68.
79. Segal L, Nguyen H, Schmidt B, *et al*. Economic evaluation of Indigenous health worker management of poorly controlled type 2 diabetes in north Queensland. *Med J Aust* 2016;204:196.
80. Brown A, Kritharides L. Overcoming cardiovascular disease in Indigenous Australians. *Med J Aust* 2017;206:10–12.
81. Australian Bureau of Statistics. *Census of population and housing: Socio-Economic Indexes for Areas (SEIFA), Australia - Data only, 2011*, 2013.

Chapter 6 Discussion and conclusion

6.1 Person-centred measures address identified needs for health system information

This thesis aimed to illustrate ways to improve the clarity and application of health system performance assessments by reorienting measures toward the people receiving healthcare and their outcomes – so called 'person-centred' indicators. With reference to specific, overarching SA Health performance indicators and current opportunities for health system improvement identified by the Health Performance Council (HPC), the studies in this thesis provided examples on:

iv. Reframing premature mortality measures to account for survival time from disease detection until death;

v. Extending morbidity measurement to describe and value a person's self-reported state of health and HRQoL; and

vi. Enhancing enumeration of people experiencing potentially preventable hospital contact with EDs and as inpatients.

Having concluded those studies, this chapter now:

- Reflects on the achievement of the studies in addressing the need for person-centred, headline performance indicators while meeting information needs required to support health system improvements in South Australia specifically.
- Summarises key developments in Australian health policy occurring while the thesis studies were undertaken. Those developments include: revisions to the Health Performance Framework; the National Health Agreement's commitment to value-based health care; and, emerging quantitative tools for resource distribution within the health system.
- Examines how the developed measures and methods fit within current Australian health system reform, an emerging context in which policy and processes continue to evolve, and offers opportunities for greater awareness, understanding and applications of person-centred measures within the health system.
- Considers opportunities for continued development, application and translation of person-centred performance measures into health system practices.
- Identifies limitations in the studies completed while describing further steps to address those limitations and expand research work in support of a health system aimed at effectively, efficiently and equitably improving the health of people, patients and populations.

6.1.1. The baseline context

Person-centred performance measures have broad relevance across many countries (1) with variations in form and application. For example in the United Kingdom (2), the National Health Service (NHS) oversees localised activities of Clinical Commissioning Groups assessing performance against a shared Quality Outcomes Framework (3, 4); while Canada's universal health system is primarily funded and administered by strong provincial and territory governments (5) with less prescriptive reporting of quality outcomes. The background to this thesis outlined the Australian health system's clear intent toward maintaining or improving population health outcomes. A range of health status measures exist to support that intention. However, the accompanying health system performance framework focussed almost exclusively on organisational activity and output, thereby failing to systematically relate these activities to changes in peoples' health status. At a jurisdictional level, South Australia embraced a strategic and goal focussed approach to planning for equitable health outcome improvement and formally targeted changes in healthy life expectancy over time. The target measures accounted for widely ranging outcomes from premature mortality and quantity of life; to, the amount and severity of morbid illness, or HRQoL; and, exposure to acute hospital settings when earlier, primary care may be more appropriate. Accordingly, relevant headline indicators were established in each of those three areas. Yet there existed an unmet challenge of informing commissioning and eventual evaluation of system performance in each of these areas, and the extent to which services achieved health outcome change for the people receiving them. The HPC reinforced this challenge when they noted the health system's systemic failures to reach targets due to insufficient planning and monitoring (6). In advising South Australia's Minister for Health on remediating system response to priority health needs, the HPC identified a range of challenges, each of which was accompanied by unmet information needs.

Moreover, equitable health improvement among people is an essential part of the goal. So, it is necessary to look beyond average change across SA for instance and examine distributions of health within the population. Given the focal point of a person-centred health system is individuals, it follows that individuals become the unit of measurement. Results for individuals can then be grouped in ways that are relevant to decision-making. Such groupings may be based on disease state (cancer stage at diagnosis for instance), demography (age, gender, ethnicity), geography (remoteness) or socio-economic position (disadvantage). Information of this nature is available to meet information needs and in a person-centred way.

6.1.2 Meeting needs for headline performance indicators and system improvement

In response, the key findings of this thesis fill information gaps by reorienting the use of existing data assets and performance measures toward people with health needs and those people's health outcomes in areas of premature mortality and potentially preventable hospital use. That reorientation resulted in the first main finding, that is indicators focussed on person-level mortality, morbidity and service use outcomes *can* be constructed and support pursuit of broad, population health targets. The second main finding was that the constructed person-level measures developed knowledge which helps meet publicly reported challenges facing South Australia's health system.

On the first point, the thesis provides examples of person-centred measures relevant to state health department performance indicators and over-arching strategic targets in population health (Table 6.1). Healthy life expectancy summarises population health outcomes for a given time period using a combination of age-specific mortality and health status (7-9). The studies in this thesis provide measurements relevant to healthy life expectancy through its related headline indicators. On the headline indicator of premature mortality in the South Australian community, Chapter 2 introduced the premature mortality to incidence ratio (PREMIER), using the example of cancer outcomes among Aboriginal and non-Aboriginal people, then quantified disparities in early death from cancer and the substantial capacity for Aboriginal people to further benefit from cancer control initiatives.

Focussing on the headline indicator of illness prevalence and severity within the South Australian community, Chapter 3 demonstrated an approach to capturing the self-reported prevalence and health consequences of chronic disease among members of a vulnerable population using a health utility measure derived from a widely used HRQoL instrument. Person level perspectives on the headline indicator of potentially preventable hospitalisation were enumerated in two ways. Disparities in potentially preventable emergency department use by adult members of vulnerable populations were demonstrated in Chapter 4. That study illustrated how the number, rates and costs of Ambulatory Care Sensitive Conditions (ACSC) and General Practice (GP)-type presentations to emergency settings varied across groups of people in the community, which demonstrated the scope for influencing changes through increased uptake of effective primary and community health care. Changing the focus to potentially preventable inpatient events for chronic conditions, Chapter 5 enumerated major disparities in the number and rates of people experiencing hospitalisation for those conditions along with the accumulated time spent in hospital and the associated health system costs.

Table 6.1 Population health targets in South Australia's Strategic Plan (SASP) (10-12), related health department performance measures and thesis person-centred performance measures

SASP Targets:	Related headline indicators and performance measures (13-15):	Person-centred performance measures	Thesis chapter
Healthy South Australians Targets 2.2, 2.4 and 78: Increase healthy life expectancy of South Australians …	Incidence of premature mortality in the South Australian population	The premature mortality to incidence ratio (PREMIER): a person-centred measure of cancer burden	Chapter 2
	Prevalence and severity of illness (morbidity) in the South Australian population	Person reported health utility measure describing health related quality of life (HRQoL)	Chapter 3
Aboriginal healthy life expectancy T2.5 and 79: Increase the average healthy life expectancy of Aboriginal South Australians …	Potentially preventable hospitalisations for targeted diseases and conditions.	Number and rates of Emergency Department presentations for ambulatory care sensitive conditions (ACSC), general practitioner (GP)–type presentations and associated direct ED costs	Chapter 4
		Number and rates of potentially preventable hospitalisation for chronic conditions, total length of stay and direct hospital costs	Chapter 5

South Australia's health system faces challenges in areas where the HPC asserts data and consequent information is either non-existent, inaccessible or underused (16). Table 6.2 reiterates the unmet health information needs as reported to the Minister for Health (6, 17) and tabled in South Australia's Parliament along with the relevance of person-centred performance measures in each thesis chapter to addressing those needs in support of responding to the identified health challenges.

Table 6.2: Alignment between Health Performance Council identified health system challenges, their associated, unmet information needs and thesis chapter

	Challenges for the health system	Information needs and actions	Thesis chapter
1	Reduce inequities in avoidable mortality, particularly between Aboriginal and non-Aboriginal populations;	Pursue data, analyses and valid measures informing and monitoring strategies to close gaps in potentially avoidable mortality.	Chapter 2
2	Develop data assets and pursue analysis of clinical, administrative and population health data to inform decision-making and continuous improvement. Specifically:	Initiate surveillance methods and analyses providing valid and reliable reports on comparative health needs between and within population groups.	
	a. Develop existing datasets to meet information needs, for example, improving core items on the SACR;	Create new value from existing SACR holdings by linking with Australian Bureau of Statistics (ABS) Cause of Death Unit Record files and staging tumours.	Chapter 2
	b. Bridge data gaps to better describe health outcome variations among vulnerable* people and enable identification of progress or problems; and	Make fuller use of existing data holdings for reporting and monitoring outcomes for individuals and the population groups to whom they belong.	Chapters 2, 3, 4 and 5
	c. Supplement SA Health data collection with purposeful sampling and reporting focussed on specific groups of people in the community;	Grow expertise in population health surveys to provide valid, reliable comparison of health needs among priority groups and the wider population.	Chapter 3
3	Increase vulnerable* people's access to, and equitable gains from, healthcare interventions;	Provide baseline evidence of variations in vulnerable peoples' capacity to benefit from health care interventions from which to track change over time as relevant strategies are developed and applied.	Chapters 2, 3, 4 and 5
4	Provide an integrated approach to implementing and monitoring the Aboriginal Health Care Plan (18) to improve health status;	Provide valid, reliable and sustainable measurements of health status components across time and throughout the population.	Chapters 2, 3, 4 and 5
5	Investigate primary and community care sector actions to reduce potentially preventable hospitalisation (PPH) among Aboriginal and vulnerable* people to meet healthcare needs at an earlier, less costly time.	Further develop information on hospital contacts (emergency and inpatient) categorised as "unnecessary" (for example, ambulatory care sensitive conditions or potentially preventable contacts).	Chapters 4 and 5
6	Improve hospital length of stay by identifying people who can be better cared for in non-acute hospital settings;	Develop reliable baseline estimates of the number and attributes of people experiencing hospitalisations and the amount of hospital stays and costs involved with which to track change over time as relevant intervention strategies are developed and applied.	Chapter 5

*Includes: the aged; people from culturally and linguistically diverse (CALD) communities, refugee and asylum seekers; rural and remote communities; and Aboriginal people

The PREMIER metric in Chapter 2 is highly relevant in addressing a number of these challenges. Using cancer outcomes as an example, PREMIER demonstrates a clear ability to articulate existing inequities in avoidable mortality between Aboriginal and non-Aboriginal South Australians (Challenge 1) while doing so in a person-centred and information rich way (19) that monitors cancer control initiatives aimed at reducing inequalities. In doing so, the creation and analysis of PREMIER involved augmenting the value of existing data holdings to inform decision-making and continued improvement (Challenges 2a and b). PREMIER created new value from existing SACR holdings through improved knowledge on: Aboriginal status; cause(s) of death attributions (cancer and non-cancer) (20); summary stage of disease information (20); then, reframing cancer incidence and mortality events in terms of an international, health accounting system (21, 22). More fulsome use of existing datasets in this way promotes a sharpened focus on reporting outcomes for individuals diagnosed with cancer and the population groups to whom they belong.

In PREMIER's case, groupings of people were based on Aboriginal status and cancer stage at diagnosis. Anchoring each person's cancer outcomes against a global standard provided clear evidence of variations in Aboriginal peoples' capacity to benefit from relevant cancer control initiatives and to track change in a valid, reliable and sustainable way (Challenges 3 and 4 respectively). Capturing person-level reports of prevalent health conditions and health utility using a standard HRQoL instrument as described in Chapter 3 directly addresses the challenge of purposefully sampling and reporting outcomes of importance to vulnerable populations (Challenge 2c). The study method made additional use of existing survey data holdings (23, 24) (Challenge 2b) while contributing to the adaptation of existing population survey methods (25, 26) to provide a valid, reliable baseline measure of health utility and HRQoL, capacity to benefit from healthcare intervention and subsequent monitoring of health status change, particularly among Aboriginal people (Challenges 3 and 4). Addressing potentially preventable hospitalisation by activating earlier and effective care alternatives in community settings is outlined in Challenge 5. Successfully informing this challenge on who (numbers and rates of people) experiences what conditions (for example, chronic disease) leading to how much "unnecessary" use of which services (emergency and/or inpatient) and at what cost begins to be addressed in Chapters 4 and 5. The studies within those chapters improve description of the disparities experienced by vulnerable people by using individuals as the unit of measurement and aggregating those individual's results to enhance reporting and benchmarking for change (Challenge 3). In both studies the method derived is peer-reviewed and publicly reported to maximise the ongoing validity and reliability of results (Challenge 4).

In summary, the discrete person-centred studies within this thesis realise opportunities to further inform performance measures related to healthy life expectancy and state level strategic goals. The person-centred perspective, the methods derived and subjected to peer review, reorient performance reporting away from system activity toward people and the extent to which their health needs can be met by healthcare interventions. The studies also address an array of information needs associated with acknowledged health system challenges in South Australia. The person-centred approach can act to challenge and motivate a more responsive health system that addresses the health needs of people, patients and the populations to which they belong. Moreover, the measures can encourage the health system to consider the degree to which health need will be met by proposed interventions and which people are more/less likely to access and benefit from those interventions. This information is valuable to informing continuous quality improvement in the system and evaluating system performance.

6.2 Person-centred measures inform current health system initiatives and reform

Having responded to the health system performance requirements of one jurisdiction and epoch, a fact globally is that governments, their administrations, and health industry needs for health system performance measurement and reporting continue to change and develop (27). These changes are influenced by several areas of demand. Members of the public are increasingly adept in accessing and consuming complex information. Health information on changing population health is one facet of this complex information. Increased familiarity demands responses that ensure good governance and accountability from health service organisations and providers (28). It is also accompanied by continually developing expectations for, and availability of, services and technical innovations. This in turn increases pressures for containing costs and ensuring the sustainability of health systems (27).

The following discussion summarises those factors in the context of contemporary Australian developments in health system performance and practice. This includes an update on the health status and health service use of Australia's population; revisions to the performance framework's ability to relate health status to health service provision; and health reform initiatives intended to ensure the continued sustainability of the health system. The discussion considers how the measures developed in this thesis fit within those areas.

6.2.1 Australians' health now

After motivating state and intra-state analyses of population health measures and their relationships with health system activity (23, 29-34) and providing the genesis for developing person-centred performance measures in this thesis, formal targeting of improved healthy life expectancy and its related headline indicators within South Australia was terminated in 2018

(16). However, periodic national reporting of healthy life expectancy continues. Average healthy life expectancy in Australia continued to increase from 2011 to 2018 and reflects a dynamic equilibrium between morbidity and mortality (35). A dynamic equilibrium indicates increased survival is accompanied by increased morbidity, but time lost to morbidity remains a constant proportion of life expectancy (36). However, disaggregating national averages by socio-economic disadvantage showed health expectancy change was unevenly distributed within the population. For example, health expectancy gaps between the lowest and highest socio-economic areas increased from 2011 to 2018 (37). This was accompanied by an expansion, or proportionately more, morbidity in the lowest socioeconomic areas, and compressed morbidity in the highest socioeconomic areas (35, 38). Such movements in health expectancy not only reflect earlier jurisdiction level findings (30) but examples of negative change are also observed in other high-income nations. For instance, healthy life expectancy in England from 2010 to 2016 declined among women while the proportion of life spent with morbidity increased for both men and women (39).

Premature mortality in Australia reduced by 20% between 2003 and 2015 with age standardised rates falling from 111 to 89 years of life lost (YLL) per 1,000 population (38). Yet this is not the same for everyone. Cancers are the greatest cause of disease burden (40) and premature mortality (38) in Australia. While cancer related premature mortality decreased by an average of 10% in the period 2003 to 2011, age-adjusted loss among Aboriginal people *increased* by almost 6% in the same period (41). Thus, cancer related inequalities between Aboriginal and non-Aboriginal Australians increased (41) making timely, regular information in this area even more essential.

Burden of disease estimates indicate average population morbidity in Australia changed little between 2003 and 2018 (age adjusted Years Lived with Disability (YLD) per 1,000 persons of 97.9 and 98.1 respectively) (37). Again, this result is not consistent throughout the population and existing gaps between groups of people are further widening. For instance, morbidity among non-Aboriginal Australians decreased marginally for males (0.7 YLD per 1,000) and increased slightly in females (0.3 YLD per 1,000). Aboriginal Australians experienced comparatively higher morbidity in 2003 with male and female Aboriginal people experiencing further, sizeable increases to 2018 (by 4.4 YLD per 1,000 to 199.0 among males and by 6.9 YLD per 1,000 to 197.9 among females). Data gaps in mental health conditions, dementia, hearing loss and other high morbidity diseases limit the comprehensive assessment of changing morbidity using a burden framework (23, 37). While Australia's National Health Surveys include an alternative, albeit single generic HRQoL measure, the Short Form question of "In

general, would you say your health is: Excellent; Very good; Good; Fair; Poor", those surveys remain sporadic.

Conditions needing hospital contact provide more reliable disease related data over time (37) and hospital records remain a key information source on population morbidity (42). These records show public hospital emergency department activity continues to increase in excess of population growth. In the five years to 2020-21, age-adjusted presentation numbers increased by 3.2% each year (43) compared with population increase of 1.1% (43, 44). Similarly, inpatient hospitalisation numbers also rose by an average 3.3% each year (45), average costs per separations changed little (Table 7.1, (46)) and hospital expenditures increased by almost 4% annually to exceed AUD$83 billion in the year 2019-2020 (47, 48). The proportion of that inpatient activity considered potentially preventable increased by 8.1% in relative terms, from 25.8 to 27.9 age-adjusted hospital separations per 1,000 population in the five years to 2017-18 (49). This change included a widening in PPH rates for COPD and diabetes complications among people living in remote versus major cities areas and for COPD, gangrene and pelvic inflammatory disease in more socio-economically disadvantaged areas (50).

In short, widening inequalities in healthy life expectancy, or headline indicators of premature mortality and potentially preventable service use indicate a continuing need for monitoring and understanding influence of health system's activities on health outcomes.

6.2.2 The revised Australian Health Performance Framework

Important revisions occurred to Australia's Health Performance Framework (AHPF) (51) since commencing this thesis. The revised and re-organised framework (52) is now referred to as the Australian Health System Conceptual Framework (Figure 6.1) and retains the domains of health status, health determinants and health system performance.

Major revisions occurred in developing the logic model for health system performance. Building on the Australian Productivity Commission's models for relationships between technical efficiency, cost-effectiveness and program effectiveness (53, 54) the AHPF Health System Performance Logic Model (Figure 6.2) now supersedes the Performance and Accountability Framework (PAF) (55). A critical change is that the logic model now moves performance assessment past service inputs, processes and outputs exclusively onto outcomes and the effectiveness of addressing health status and peoples' health needs.

One further important change is the increased prominence of equity, or the minimisation of avoidable differences among people, as a domain influencing all elements of the Framework.

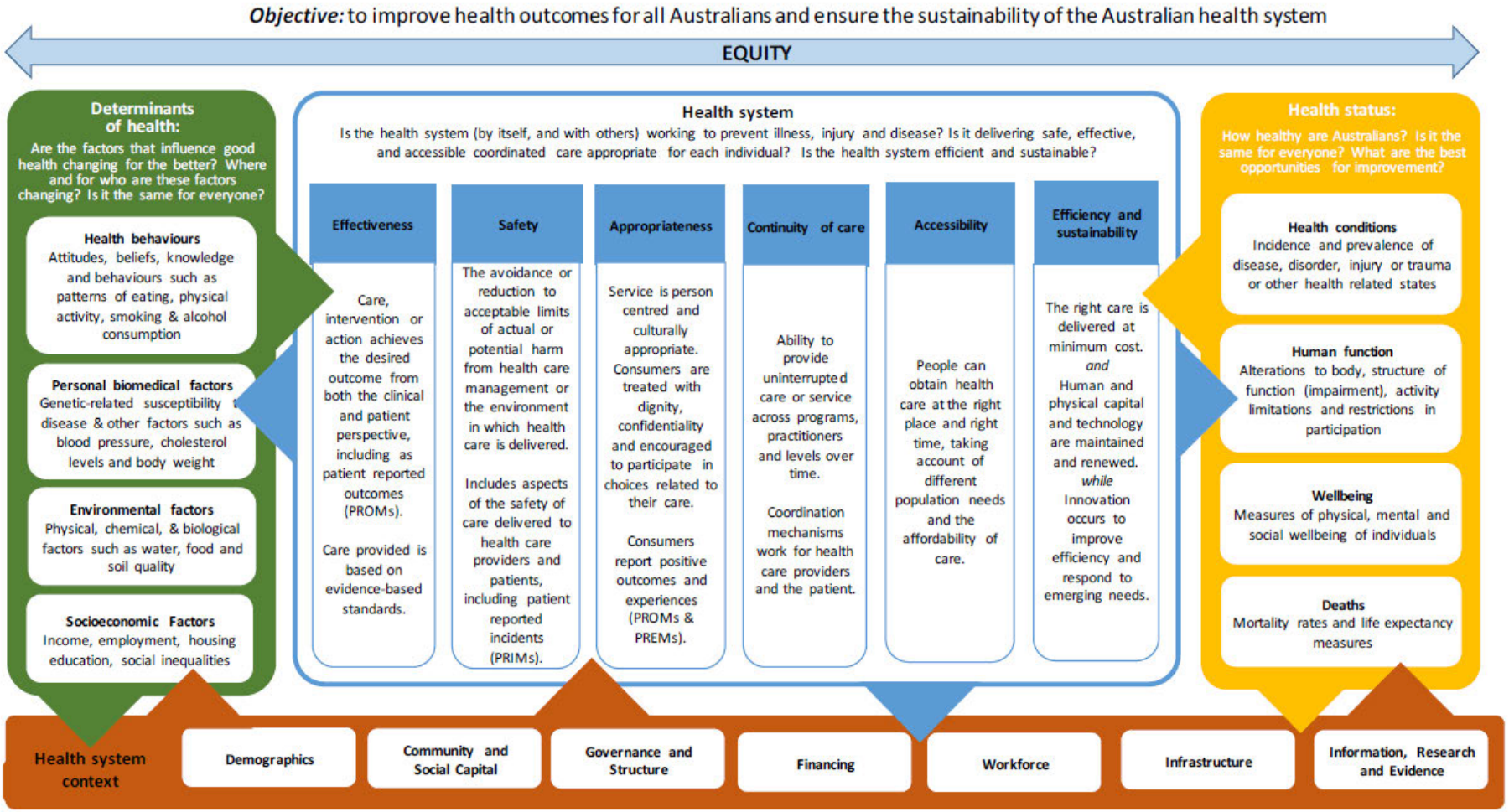


Figure 6.1 Australian Health System Conceptual Framework (52)

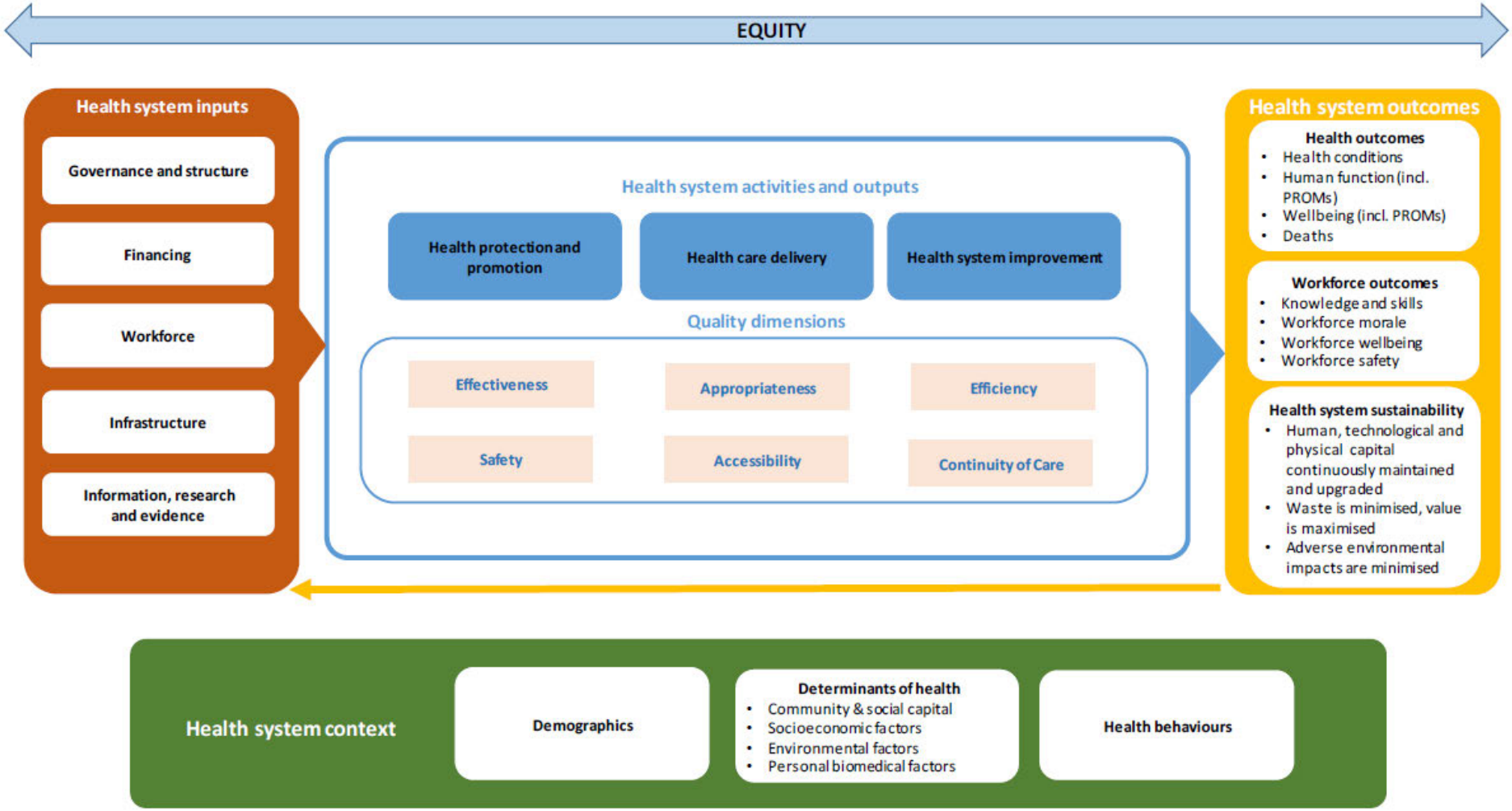


Figure 6.2 AHPF Health System Performance Logic Model (52))

The change means "… the Framework explicitly recognises the need for monitoring equity across the determinants of health, the health system and health status … through disaggregation of performance measure data" (52, p5).

The restructured, logical AHPF caters for continued use of traditional assessment indicators and inter-jurisdiction comparisons. The Framework can also further our understanding of the consequences of implementing policies and programs, then evaluating improvements gained through logically related, person-centred outcomes. Fresh potential uses include a new focus on assessing outcomes and associated costs, so called "value" in health care (56-60), as an emerging priority of health systems internationally and within Australia. At present though, existing (NHPF and PAF) indicators are retained with further review and revision to take place. Chapter 1 of this thesis noted those existing indicators focus on activity and outputs with little reference to outcomes (61), an issue the studies in this thesis sought to address.

While the AHPF is yet to identify new indicators for assessing health outcomes, it does outline features of good performance measures (52) against which new indicators will be assessed (62, 63). Table 6.3 summarises the alignments between those features and the studies of person-centred performance measures. Each of the studies in the thesis exhibit most, if not all, of the features of good performance measures. Such strong alignment is not unexpected as each study began with a performance area closely aligned with healthy life expectancy, a thoroughly researched summary population health measure (64) with considerable pedigree and use internationally (65). Healthy life expectancy and each of the associated headline indicators were the subject of extensive discussion and review in the South Australian Strategic Plan consultations internally to government (66) and publicly (67). Each of the studies in the thesis focussed on those headline indicators with the further intention of relating health service exposures to outcomes for people. A further strength came from testing the studies through oral presentations at scientific conferences (68-71) before subjecting each study to the peer review process. While the result of latter process is not known at the time of writing for the study detailed in Chapter 2, the approach naturally highlights the alignment between the measures and desirable features conforming to accepted, objective scientific writing practices. Presenting the measures for peer review showcased the way in which subject measures were meaningfully explained and contextualised, aims were adequately measured using well documented data sources, and methods were appropriate. Each of the study results show the measures' capacity for descriptive comparisons within and between groups of people and discerning important variations. Moreover, the face validity and acceptability of the measures to wide-ranging audiences is apparent. For instance, the PREMIER was first derived in consultation with an Aboriginal Community Reference Group who further engaged with translating the knowledge

Table 6.3 Alignment between Australian Health Performance Framework (52) good performance measurements and person-centred measures in this thesis

Good performance measures		Thesis' person-centred performance measures			
Feature	**Description**	**Premature mortality**	**Morbidity**	**Potentially preventable hospitalisation**	
				Emergency department	**Inpatient**
Meaningful and understandable	Accurately describes progress towards, and the achievement of, agreed outcomes	✓	✓	✓	✓
	Provides a good indication of success	✓	?	✓	✓
	Aids public understanding of government achievement	✓	✓	✓	✓
Measurable	Outcome is quantifiable	✓	✓	✓	✓
Comparable and hierarchical	Allows for comparisons:				
	over time	✓	✓	✓	✓
	between jurisdictions and/or geographical groupings	✓	✓	✓	✓
	between target groups	✓	✓	✓	✓
	across similar programs or initiatives	✓	✓	✓	✓
Documentation	What is being measured is clear	✓	✓	✓	✓
	Data definitions explain:				
	what the measure shows and why it is important	✓	✓	✓	✓
	data source(s)	✓	✓	✓	✓
	collection arrangements	✓	✓	✓	✓
	measurement frequency	✓	✓	✓	✓
	statistical techniques for calculating outcome	✓	✓	✓	✓
	data limitations, including those outside the control of government.	✓	✓	✓	✓
	If survey used, the following are documented:	Not applicable		Not applicable	Not applicable
	the method used for selecting the sample		✓		
	the sample size		✓		
	response rates		✓		
	uncertainty margins in reported performance		✓		
Accurate	Sufficiently accurate to promote community confidence in conclusions drawn	✓	Unclear	✓	✓
Simple, cost-effective administration	Data collection cost are known	✓	Unclear	✓	✓
Use of existing data	Existing data sets considered for measuring the impact of the output group	✓	New data	✓	✓
Timely	Relevant data collection agencies and working groups consulted on existing data	✓		✓	✓
	Other measures are known to be more cost effective?	No	Unclear	No	No
	Any significant delay in collecting and collating data?	No	Unclear	No	No

*adapted from (52), page 12, Table 1

gained into action plans (72). Variations in health utility across chronic disease informed the evaluation of health needs in South Australia's Aboriginal Chronic Disease Consortium Road Map 2017-2021 (72). The Emergency Department presentation method informed the business case for philanthropic ventures providing ongoing care for vulnerable citizens (73); and, totalled length of stay for PPH has been adopted in other jurisdictions (74).

Morbidity was an area of comparably less alignment between measurement and desirable features. Unlike the other studies' use of existing administrative datasets, HRQoL and health utility measurement required the purposeful collection of new survey data. New collections incur a cost and resource use, two factors which may affect their sustainability. The constructs of morbidity, HRQoL and utility overlap but have points of difference too and represent a dynamic area of continued research aimed at adequately measuring health status in evaluation and economic evaluation (75, 76). These definitional and data capture challenges are not unique to this thesis and are evident internationally at OECD level (77, 78), and country level in the UK (79, 80) and Canada (81) for example. Chapter 3 contributes to addressing these challenges by: showing the value of purposefully collecting survey data from members of a vulnerable population; demonstrating the relationships between self-reported health utility outcomes and disease prevalence within that population; then, positioning this information in a broader South Australian and Australian population context. By investing time and resources in asking people about their health, the survey results also revealed patterns among incomplete responses by people who could reasonably be expected to experience poorer HRQoL. The analysis of the SAAHS carried out in Chapter 3 informs further research into HRQoL instrument design for vulnerable populations as with the "What Matters 2 Adults" project (82). This information is an important and timely input to Australia's health performance landscape (79, 80, 83).

Australia, like many other high-income countries (77) is attending to the regular collection of HRQoL and utility measures as examples of Person/ patient/ population Reported Outcome Measures (PROMs) (52, 84, 85). PROMs focus on outcomes that are important for a person and which result from interactions with the health system. This makes PROMs particularly significant given that contemporary healthcare is dominated by chronic conditions and associated morbidity needing management over longer periods of time (81). Reviews for Australia's Council on Safety and Quality in Health Care (ACSQHC) (83, 86) concluded that PROMs are not widely available at local levels but make up some of the key data gaps:

- Contributing to more person-centred views of health system performance;

- Leading to improved quality, safety and effectiveness of different interventions; and,
- Enhancing interactions between patients and clinicians.

The revised AHPF is intended to provide an environment suitable for increased use of PROMs and more systematic assessment of value for people from health care (52, 83, 86). Chapter 3 illustrates a widely used, generic PROM at a population level while underscoring opportunities for improved validity of such a PROM for vulnerable people. These opportunities include consideration of health domains outside of traditional measures, for example social, community and cultural domains (87).

In summary, Australia's framework and logic for assessing health system performance has undergone substantial revision but the revision of actual performance indicators is lagging. This research studies in this thesis offer indicators which demonstrate desirable features relevant to the AHPF in areas of mortality (Chapter 2) and potentially preventable service use (Chapters 4 and 5). On the challenging topic of morbidity, Chapter 3 makes a valuable contribution by highlighting the population use of a PROM to enumerate disparate health needs within a vulnerable population.

6.2.3 Australia's National Health Reform Agreement 2020-2025

Australia's Commonwealth, State and Territory governments share the intention of improving health outcomes that matter to people. They all agree Australia's health system should be shaped on responding to the health needs of individuals, their families and communities while ensuring the system works effectively and efficiently to eliminate differences in health status (84). The collective of governments have committed to act on their intentions and acknowledge that existing health system practices, information and funding are currently organised around system activity rather than outcomes. Through the National Health Reform Agreement 2020-2025 (NHRA) (84) governments have outlined their health reform agenda leading to a clear focus on achieving health outcomes for people by transitioning to person-centred care.

Person-centred reforms need support from person-centred information. Afterall, "the system cannot claim to be 'patient centred' if it is not as informed as it could be about patients' … outcomes" (17, p3). The NHPF provides the framework for information that will "improve accountability and performance reporting on the health system" (84, p7), yet the necessary supporting national performance indicators have not been determined. Earlier discussion showed this thesis contributes relevant examples of well featured, person-centred indicators.

This section outlines seven NHRA reform areas and how this thesis' person-centred performance measures may contribute to each (Table 6.4). The vision of paying for value and outcomes (Reform area 1) in response to individual and community need "means maximising patient outcomes, improving population health and high quality, evidence-based clinical care, relative to the cost of delivery" (84, p96). Meaningful metrics are one of the prerequisites for supporting the implementation of value-based care (88). For example, measures of outcomes and costs are essential to any flexible funding response moving resources from low to higher value care (59) using suitable interventions. Chapters 4 and 5 illustrated the change potential for outcomes in areas of emergency presentations and inpatient stays along with the direct system costs involved. This information would complement evidence of an intervention's expected effects as well as monitoring change before and after intervention in a real-world context. Chapter 2's inquiry into early cancer death measured the scope for health outcome change associated with cancer (89) and bowel cancer (68) among a vulnerable population. That information can support other research inquiring into the costs and effectiveness of tailoring screening interventions for earlier cancer detection among those populations (90).

Paying for outcomes according to need involves a fundamental shift in health financing. This provides the opportunity for an example of how person-centric measures might contribute to actions informing resource allocation efficiently and equitably according to peoples' need (91). Two relevant actions are: developing health funding and payments frameworks; and, informing flexible funding methodologies within public hospital funding models. The Health Outcome Resource Standard (HORSt) (93) is a contemporary quantitative tool for informing both aspects of resource distribution within Australia. The HORSt is a population needs-based tool aiming to distribute funding from state jurisdictions to intra-state, Local Health Network (LHN) geographies (93). HORSt uses age-standardised PPH as a proxy for population health outcomes and establishes benchmarks of desirably low PPH levels for small population areas. HORSt seeks to explain variations in PPH with reference to each populations' social determinants of health as measured by ABS Socio-Economic Indexes For Areas (94, 95). These explanations are used to estimate the potential for PPH change which then informs the share of funding for each area.

Table 6.4 National Health Reform Agreement long-term health reforms (91)

Reform area	1. Paying for value and outcomes	2. Prevention and wellbeing	3. Joint planning and funding at a local level	4. Interfaces between health, disability and aged care systems	5. Nationally cohesive Health Technology Assessment	6. Empowering people through health literacy	7. Enhanced health data
Vision	Health system financing supports contemporary, value-based care focussed on individual and community needs	People live healthier lives, maintaining good health with fewer living with preventable chronic illness. Our health system more equitable and focussed on those with greatest need while acting on social and economic causes	Better-integrated, patient-centred care supports equitable access and improved outcomes. Integrated planning and funding at local levels supports providers to collaborate and coordinate patients' treatment	Better coordination between health, primary care, aged care, and disability systems ensuring people access services meeting their complex needs and improving outcomes	Improved decision-making delivers safe, effective, efficient and equitable care improving population health and is financially viable	People manage health and choices, avoid illness, engage effectively with services, achieving better outcomes	Integrated data supports better decisions which improve health outcomes and save lives. Richer, accessible information helps deliver targeted, person-centred and value-based care.
Key activities include:	Describe population health need with input from Australian Health Performance Framework (AHPF). Develop a national health funding and payments framework.	Further knowledge of current and future population health challenges. Develop financing mechanisms for scaling primary prevention.	Reform barriers to AHPF needs assessment, funding and commissioning Trial, evaluate and rescale joint planning and funding		Prioritise interventions and evidence. Develop a federated framework informing (dis)investment and implementation	Develop and communicate measures of system and service performance with input from AHPF	Grow person linked data and analytics workforce. Capitalise on existing projects. Pilot local interventions, review, then scale up.

… continued

Table 6.4 continued …

Reform area	1. Paying for value and outcomes	2. Prevention and wellbeing	3. Joint planning and funding at a local level	4. Interfaces between health, disability and aged care systems	5. Nationally cohesive Health Technology Assessment	6. Empowering people through health literacy	7. Enhanced health data
Outcomes include:	Core principles for consistent outcome focussed, value based health measures. Flexible funding supporting effective, efficient and equitable resource allocation focussed on patient outcomes. Reduced inefficient health care practice, e.g. avoidable hospital contact.	Social determinants of health are addressed. Priority populations have less chronic disease and hospitalisation	National principles for local level commissioning supporting collaboration between primary, community and acute care More local level initiatives causing improved health outcomes.	New indicators and data collection. Reduced avoidable hospital presentation and time hospitalised.	Improved public awareness, understanding and trust of HTA processes.	People access and engage reliable, appropriate information. Increased innovations involving researchers, providers and people.	Use of best practice health data and analytics, with linked data and patient reported measures. Better evidence of service use and informed health care planning and delivery.
Thesis contribution	Take account of prevention and include peoples' outcomes (e.g. avoiding disease) Person-centred and equitable outcomes are two relevant principles. Provide an example of paying for value and outcomes.	Scope potential for change in mortality, morbidity and potentially preventable service use through addressing social determinants of health	Scope potential for change from hospital to primary care settings	In part, better use of existing, administrative data (e.g. link disability, immigration, Centrelink to enhanced hospital	Local population need and outcomes inform HTA.	Health system culture changes	Transforming organisational focus away from disease areas toward the health and health care path (diverse groups) of people will facilitate reform (92). Thesis provides examples of a key development area.

Person-centred measurements will support continuing development and expansion of HORSt in two ways, the first of which is by advancing HORSt's measures beyond coarse aggregations toward detailed enumeration for individuals and population groups. Chapters 4 and 5 demonstrate enumeration can be based on area remoteness and socio-economic position, age, socio-demographic background, or some combination of each. More granular information of this kind allows more flexibility in aggregating groups of people. Improved flexibility, for example by calculating age-specific rates across population groups can reduce the potential for biasing equity considerations when using age-standardisation (96). Secondly, HORSt's measures can broaden in scope, past the counting of events, to include time, or dose, of hospitalisation experienced by individuals within groups (97, 98). This action will add flexibility to inputs and outputs within the HORSt, and enable resource allocation based on shared personal characteristics, for example ethnicity and age as the studies in this thesis demonstrate, rather than relying on hospitalisation numbers grouped in ways which may be ecologically fallacious (94).

Further reforms to prevent disease and illness and promote wellbeing (Reform area 2) require a baseline describing peoples' current experience of disease prevalence, its severity and consequential health service use. To achieve the vision equitably also requires that baseline information for priority populations be disaggregated by age, ethnicity and social determinants of health. Using a person-centred approach, Chapter 2 contributes an example of secondary disease prevention by scoping change and mortality benefits from earlier detection of cancer as. Chapter 3 provides a baseline on the amount and comparative severity of chronic illness in terms of HRQoL and health utility as experienced by Aboriginal people in South Australia. Chapters 4 and 5 estimate the potential for moving from hospital to community-based care among people of different socio-economic positioning and demographic backgrounds.

Joint planning and funding at a local level (Reform area 3) supports the vision of better-integrated, co-ordinated and patient-centred care providing equitable, improvement in outcomes. This is actioned by incentivising local collaborations between health sectors (99) to effect positive change for people in the community (97). For example, PPH among people is a shared responsibility of LHNs and Primary Health Networks (PHNs), or acute and primary and community health sectors involving state and Commonwealth government funding. Both share a role in innovating and experimenting to tailor community specific solutions for preventing and better managing chronic conditions (99, 100). Chapters 4 and 5 provide information relevant to joint planning of preventing unnecessary hospital use at local levels by enumerating the number and nature of persons experiencing these hospital services and the associated costs

to the health system. Localised, intra-state level data provide baseline information for decisions on appropriate interventions, then monitoring changes to health and inequalities (16).

Moving reform beyond health organisations and onto Reform area 4's better coordinated interfaces between health, disability and aged care systems envisages the ability for people with complex needs successfully accessing relevant, effective services that improve outcomes. Chapter 3 contributes to this area by describing part of the increasing complexity of need among people (101), for example needs associated with multimorbidity as a new and increasingly normal feature of health status (102). It does this by enumerating the prevalence of chronic disease (97, 103) and its effects on health utility (103). Chapters 4 and 5 take this further by illustrating the results of inequitable and complex needs that result in avoidable hospital presentations and increased time spent in hospital.

Evidence-based decision-making delivering safe, effective, efficient and equitable care that results in improved population health at sustainable cost is the vision associated with reformed, nationally cohesive Health Technology Assessment (HTA) (Reform area 5). Capitalising on the contribution to local level planning and evaluation of real-world effectiveness by the person-centred measures in this thesis will help create an evidence base for further iterations in decision making and HTA. The measures achieve this by providing a baseline on outcomes that are important to people across dimensions ranging from early mortality, to disease and its influence on HRQoL, and exposure to hospital services that may be amenable to change. Compiling publicly available, locally relevant and person-centred information can help make HTA processes more meaningful and trusted by communities (104).

Raising awareness of, and access to, evidence derived from their own local experiences (105) can assist with empowering people through health literacy (Reform area 6). An improved line of sight from health need to service delivery and changed outcomes may motivate people to manage their health more actively, avoid illness, engage effectively with services, and ultimately achieve better outcomes. Where health inequities exist, metrics helping quantify their magnitude and change over time in a publicly accountable way are desirable (106). The development and exploration of measures within this thesis deliberately sought to take up the latter point of public accountability. In the case of Chapter 2's PREMIER metric, the initiation and construction of the measure came from discussion with Aboriginal Community representatives and, as with each of the metrics studied, was the subject of public and professional presentations, then made freely available.

Each of the abovementioned reform areas rely on enhanced health data (Reform area 7) which, when integrated, can support better decisions, inform interventions leading to improved health outcomes and the saving of lives.

To summarise, the measures in this thesis make a valuable contribution to health reform in Australia. They do this by demonstrating the advantages of enhanced, longitudinal (107) person-linked data that bring a clear focus on measurements relevant to people and their health outcomes where such indicators are lacking. Further, they demonstrate the measures' value to the health system's public accountability and continued performance. Those person-centred measures focus squarely on the people the health system exists to serve – effectively, efficiently and equitably.

6.3 Advancing person-centred health system performance measurement

This thesis had its genesis in research initiatives within a state government health agency in response to the challenge of better linking health system activity with population outcomes. The studies use the people at the centre of those activities as the unit of analysis and flexibly aggregate results from that base. The person-centred approach in the thesis studies met a range of information needs identified in a state jurisdiction, they align closely with well-featured indicators helping evaluate health system performance and areas of health reform in Australia. That being the case, it is appropriate to consider how person-centred performance measures might develop further to inform health system performance and support system reform. One approach involves collaborating with other researchers and disciplines to raise awareness of the possibilities for translating research to better support health system decision-making. The studies in this thesis contributed to one such public forum organised by the writer in conjunction with Health Translation SA (HTSA), an organisation bringing together a network of researchers, clinicians, educators, policy makers, consumers and the community to advance healthcare practice and policy in South Australia. The forum focussed on the role of equity-informative health economics evaluations to support service and policy decision making and is summarised in Appendix C.

Two current yet contrasting examples for furthering relevant research and development within government agencies are now discussed to describe issues relating to the process of implementing person-centred measures. These examples are based on continuing experiences with the Cancer Institute of New South Wales (CINSW) and the Yorke and Northern Local Health Network (YNLHN). The examples cover issues of addressing data gaps; measurement development; analysis infrastructure; strategic policy framework; resourcing; normalisation through cultural change; and, the active involvement of people and community. A further reflection considers the relevance of person-centred measurement beyond the health system and onto broader strategy and governance across other publicly resourced sectors in Australia.

6.3.1 The Cancer Institute of New South Wales (CINSW)

Since its establishment as a distinct entity within the New South Wales (NSW) health portfolio in 2003, CINSW has led cancer control initiatives with a particular focus on preventing cancer and improving outcomes through information, research and education. A 10-year program of reporting for better cancer outcomes (108) at whole of state, regional networks and service levels have matured CINSW as a data user and knowledge provider. The recently updated CINSW Strategic Plan (109) (Appendix D) is directed by principles of person-centredness, equity and collaboration. CINSW recognises the risks of developing cancer, accessing quality care and surviving are influenced by many factors outside of health services, factors such as education, socioeconomic status, cultural background and place of residence. Having observed inequities in many of these issues and identifying potential for improved outcomes, opportunities exist for fresh research innovations.

An existing CINSW master linked dataset comprises cancer registry and screening information, private/public hospital records, PBS, MBS and a growing number of clinical collections. Yet gaps remain in the data needed to better understand the social, demographic and economic influences on cancer diagnosis, treatment and outcomes. Those gaps are now being remedied through the linking of the New South Wales Cancer Registry (NSWCR) with the ABS Multi-Agency Data Integration Project (MADIP) which includes whole of population census records (110, 111). Information gleaned from those enhanced data can contribute to person-centred measures of vulnerability to poorer outcomes. Such measures may focus on discrete social, demographic (for example, disability or proficiency in English) and economic variables (for example, education or income). Alternatively, existing area indexes of socio-economic position could be reoriented toward a person-centred socio-economic index by building on principal components analysis trials within the ABS (112). Those measures may lead to better enumeration of the cancer care pathway from upstream influences of social determinants of health, to the quantity and quality of healthy life expectancy after cancer diagnosis. Appendix E shows the writer's conceptual map for structuring a data system across that pathway. Within the pathway, critical junctures can be enumerated too. For example in the 12-months before diagnosis, patient complexity in terms of pre-existing health conditions (113) and primary care exposure influencing earlier detection of cancer (114) are important. After diagnosis, measures can quantify a person's fact of treatment; time to treatment; time in treatment; and, completeness of treatment (115, 116). Ultimately, better measurement across a person's cancer care pathway can account for the complexity of a person's circumstance to inform improved, more tailored delivery of health care and outcomes (117).

Existing analytic infrastructure, strategic framework and culture all contribute to CINSW treating research as a part of their normal business. This environment allows for piloting inquiries as described above then reviewing them with peers before potentially useful information products are refined for areas of data delivery, coding, production and public reporting. However, the current Cancer Plan's explicit adoption of person-centredness, equity and collaboration principles offer the opportunity for "normal business" and culture to develop further, for example by broadening a distinct clinical service focus toward a wider societal perspective. This is because "success … requires commitment beyond NSW Health – there must be effective collaboration across all parts of our community, including individuals, government agencies, non-government and community organisations, and the private sector" (109, p3).

6.3.2 South Australia's Yorke and Northern Local Health Network (YNLHN)

Stark contrasts exist between the CINSW and South Australia's Yorke and Northern Local Health Network (YNLHN). Local Health Networks were established under South Australia's Health Care Act 2008 (118) and included a Country Health SA LHN. The latter devolved into six regional networks which became operational in July 2019 and included YNLHN (119). Like their metropolitan contemporaries, regional LHNs have responsibility for delivering public hospital services. While regional LHNs are smaller in scale they involve complexities not experienced in metropolitan settings, the first of which is a heavy reliance on general practitioners providing medical services at hospital sites. An extra complexity is that business as usual in YNLHN includes responsibilities for delivering residential and home-based aged care and National Disability Insurance Scheme (NDIS) services.

While YNLHN core activities involve service delivery, there exists a longstanding neglect of fit for purpose data and information infrastructure. This is publicly illustrated by continued use of CHIRON as a patient administration system (120, 121). CHIRON is an MS-DOS platform installed in the 1990s and licenced "as is, where is" with no technical development or support provided (122, p1). The scantness of electronic data systems is accompanied by nominal data analytic capability and structure. Nonetheless, in establishing a strategic plan and framework for action (123) (Appendix F), YNLHN have committed to delivering quality, equitable, seamless and integrated care that is accountable to the LHN community and acknowledge this demands continuous learning. In other words, YNLHN has considerable opportunity for putting a learning approach into practice by: developing a digital platform integrating data across the breadth of service areas; growing the necessary analytic capabilities; while, nurturing organisational culture, skills and workforce focussed on accountably and which "achieves an

effective balance between local decision-making in relation to incorporated hospitals and health system-planning, integration and management" (119, p2).

A person-centred approach is entirely consistent with YNLHN commitments in service delivery and accountability. Data development can build on the experiences of other organisations and perhaps be carried out collaboratively with other regional LHNs to provide scale for routine geographic comparisons and aggregation for specific groups of people. The breadth of services provided strongly suggests a need for developing the knowledge base of disability and/or age/ and/or medical complexity. A suggested starting point for a relevant data system enumerating people's use of hospital services is outlined in Appendix G. That system melds the writer's conceptual map for CINSW data (Appendix E) and the initial PPH project (124) (Appendix B). The metrics developed in Chapters 4 and 5 are immediately relevant to that system but so too are fresh quality measures on fact of treatment received and timeliness of that treatment. Adequately resourcing the data infrastructure, analytics and reporting is an issue which must be addressed in earnest given their current state. Taking into account the close involvement of primary care providers and hospital services, a regional LHN presents further opportunity for piloting a Prevention and Chronic Condition Management Fund (PCCMF) as recommended by Australia's Productivity Commission (99). The LHN decides how and where to spend those funds but must do so in a publicly accountable way. In the case of the YNLHN that means a manner consistent with their consumer and community engagement strategy (125). To accompany this with a clear, person-centred focus while adopting a learning culture from the outset takes advantage of a near 'greenfield' opportunity for innovation.

A general framework accounting for the health needs of people and populations; assessing intervention effectiveness, efficiency and equity; applying the knowledge gained to decision-making and implementation; then, monitoring and evaluating services may be relevant to the LHN. An equity-effectiveness framework linking health programs and healthy life expectancy has been piloted by the writer in the South Australian context (31). The pilot used the example of coronary heart disease management in general practice, associated costs, estimated benefits to healthy life expectancy outcomes to develop a multi-criteria performance matrix in support of decision-making focussed on prioritising intervention programs. The pilot demonstrated healthy life expectancy outcomes were difficult to engage with because of its perceived complexity and detachment from day-to-day service delivery. The person-centred measures in this thesis address those difficulties because they are indicators related to healthy life expectancy and to health service delivery. That is, candidate interventions could be appraised on their ability to influence premature mortality, HRQoL, PPH, or a combination of each.

Accordingly, the equity-effectiveness framework aligns with the strategic objectives of YNLHN and provides a natural environment for adopting current and emerging person-centred performance measures.

6.3.3 Australian government

This thesis focused on performance measurement in the health system and the role that person-centred measures offer in better aligning system activity with healthy life expectancy outcomes among those the system serves. Another way to advance person-centred approaches to performance measurement is through adopting the perspective in support of other strategic goals in publicly resourced sectors.

Motivation for the examples provided in this thesis stem from strategic goals set within a whole of community initiative in the South Australian context. The current Australian budget strategy now includes the explicit commitment of aligning allocations to dimensions of well-being that are important to the community (126). Accompanying this is the further pledge of initiating "a conversation about how to measure what matters to Australians." (126, p119). The conversation will be guided and informed by the OECD Framework for Measuring Well-being and Progress (127), a framework which includes indicators of life expectancy and self-reported health status. Indicators and goals will follow in other domains.

As the South Australian experience and the studies in this thesis demonstrate however, strategic goals are one thing but developing a line of sight from resourced activity to outcomes in complex operational settings is challenging, but possible. Drawing on these experiences can help inform national work. If the principle directing budgetary processes in Australia is that "the economy is supposed to serve the people, not the people the economy" (128) strategic indicators will be necessary but not sufficient. Further measures closer to operational settings will also be necessary. Adopting a person-centred focus for those measures may support the achievement of strategic goals beyond health and deliver outcomes for people and their communities in other domains such as education and skills, work and life and social connectedness.

6.4 Limitations

Limitations of each paper comprising this thesis are presented in the relevant chapters. There are other limitations to the thesis as a whole.

The first general limitation is that these studies were conducted in on Australian jurisdiction and so may be constrained in scope as they explicitly address to issues in the South Australian community and health system. As a result, the studies and metrics may not be widely generalisable. On the other hand, the measures studied were valid and well-informed responses

to one government's strategic policy and health system challenges in a high-income setting. Having established the measures' validity in that setting, the subsequent discussion sections describe the measures relevance to current health system reform in Australia. The subsequent discussion outlines concrete ways the person-centred approach to performance measurement may be advanced and assist health systems to provide better information on the needs of people experiencing cancer as a particular disease and members of a particular regional country setting.

The second general limitation of the thesis was the considerable time lag between initiating the associated research projects, then receiving and analysing the relevant data. Developing the measures and carrying out the analyses has been a labour-intensive process and one which is suited to undertaking a thesis but appears unsustainable in the-frames dictated by health system organisations in the 'real world'. Peak international health organisations such as the WHO (129) and OECD (1) point to the need for dedicated work on person-centred indicators. Acknowledgement of the need is also implicit in the AHPF. The WHO, OECD and Australia's National Health Information and Performance Principal Committee (52) also acknowledge the labour-intensive processes involved which implies an understanding of the need to resource the work. Concrete examples addressing this need are broached in the context of two organisations.

A general limitation experienced by many studies using administrative records is the potential for incompleteness on key personal characteristics, particularly those relating to vulnerabilities under study. Even using high standard registry level records as in Chapter 2 there existed the potential for a bias from misclassifying Aboriginality. Accordingly, some false categorisation of Aboriginal cases and non-Aboriginal was expected (20). However, the number of such cases would comprise a very small proportion other non-Aboriginal group and would therefore cause little bias or attenuation of disparities observed (130). Similar comments are relevant to Chapter 5's analysis of inpatient hospital records. In that particular case, formal sensitivity analyses based on a person identifying as Aboriginal in at least 75% of hospital events (in lieu of any such identification) did not substantially change reported results. The emergency department records used in Chapter 4 are acknowledged as less complete and misclassification individuals is more likely. The extent to which this occurred was not examinable within this thesis and is a source of caution when using the findings. The matter of data completion and integrity one of continuing importance for data validation in subsequent data linkages. Advances can be made by cross-matching records on important characteristics across organisations, for example, where community and migrant health records become integrated with hospital collections.

The issue of time lag from policy introduction to changes in outcomes, and indeed the responsiveness of performance measures to change, was broached in the thesis' introduction. The studies within this thesis provide a baseline against which change might be evaluated in the future and the ability to quantify change over time was beyond the scope of this work. However, the measures presented may reasonably be expected to reduce time lags in reporting on population outcomes because of their construction. For example, calculation of PREMIER (Chapter 2) requires date of birth, diagnosis and death (or censoring) for each individual. There is no need to wait for updated population numbers or life tables and this can accelerate reporting. Similarly, HRQoL measures using PROMs (Chapter 3) are reliant only on capturing self-reports by individuals arranged into patient, community or population groups (31). Repeated measures can be sought at suitable, predetermined intervals after intervention without necessarily relying on further data becoming available. Finally, people experiencing PPH (Chapters 4 and 5) need only be counted once at baseline at which the exposure among any given population segment is enumerated. Flags can be recorded for any further contacts during a predetermined observation period by that person and added to counts of contact, length of stay and costs. The remaining, limiting factor is the availability of relevant population parameters existing at baseline, that is the numbers within particular population segments at baseline by sex, age and group status.

More broadly though, health service research linking system activity with person-centred outcomes associated performance measures could be considered by Australia's Medical Research Future Fund (MRFF) such as through their 'data infrastructure' programs but these are so far of relatively small scale and directed at specific areas of unmet need. A relative strength of the thesis studies was their emergence from grounded, real-world collaborations between researchers, policy officers, service planners and community members. Together we explored variations in health care services on health outcomes and *who* stands to gain *how much* from interventions, an issue rarely considered in the evaluation literature or efficacy trials (131). MRFF applications demand collaboration and the ability for translation into real work environments. Enabling more analyses demonstrated in this thesis can help address this area of ongoing need.

A straightforward example of this enabling would involve YNLHN partnering with other country area LHNs to construct a data system which enumerates people's use of hospital services as outlined in Appendix G. Adopting staged approach would begin with organising an enduring data linkage of SA held data assets for public ED and inpatient hospital events. Updating baseline measures of people using hospital services by replicating the studies in Chapters 4 and 5 will introduce analysts, clinical and planning support staff to the method and

metrics while informing community engagement activities in local settings (125). A second stage would set about expanding data assets to include private hospital records within SA and nationally held, person-linked MBS and PBS records. The resulting, expanded platform will facilitate new insights into patterns of service provision where clinicians often work across private practice and (country) hospital settings. Analyses would contrast GP service provision with PPH experienced by people and examine the potential for particular people groups to "receive more health care, but of worse quality and insufficient quantity to meet their additional needs" (132, p828). Enumerating inequities of this kind can serve to inform plans for effective and efficient interventions which meet local peoples' needs. Those analyses could support clinicians in providing personalised, comprehensive care (133) as well as extending the analyses in this thesis by informing adjustment for the presence of multi-morbid conditions using hospital and PBS records. A third stage enhance the data platform with new, person specific linkages of NDIS and aged care service data. Those enhancements will more completely reflect the vulnerabilities among people for whom the LNHs provide services. The subsequent insights can support continued learning, decision-making and health resource distribution at local levels (134) in pursuing equitable health gains among those the system exists to serve.

6.5 Conclusion

This thesis identified the opportunity for health performance measures to become more person-centred. In response, the studies in the thesis provided baseline examples of what those measures can look like in a setting where the health system commits to equitably improving the healthy life expectancy of community members it serves. The person-centred perspective, the methods derived and subjected to peer review, reoriented performance reporting away from system activity toward people and the extent to which their health needs can be met by healthcare interventions. Importantly though, the person-centred approach demonstrated how using individuals as the foundation for measurement allows a flexible approach to grouping people and quantifying health inequities in a range of ways. The results can not only challenge the health system to respond in new ways to peoples' disparate health needs but can inform and monitor remedial activities by the health system. The studies also addressed an array of information needs associated with acknowledged health system challenges at the time the thesis was formulated. Subsequent analysis of current initiatives in health performance evaluation and system reform showed a clear and continuing role for cultivating person-centred performance measurement in support of continued, equitable health outcome improvement.

Data linkage infrastructures, performance frameworks, policy commitments and the potential for culture change in support of a person-centred approach to healthcare performance exist, yet

relevant indicators in the toolkit are lacking. This thesis contributes to addressing that need. In doing so, it focusses squarely on the people the system exists to serve – effectively, efficiently and equitably.

References

1. Organisation for Economic Co-operation and Development. Health for the People, by the People: Building People-centred Health Systems. Paris: OECD; 2021.

2. Thorlby R. England. New York: Commonwealth Fund; 2020.

3. Lester H. The UK quality and outcomes framework. BMJ. 2008;337:a2095.

4. Population Health Clinical Audit and Specialist Care Team NHS Digital. NHS Outcomes Framework Indicators - March 2022 release. Richmond: NHS Digital; 2022 [Available from: https://digital.nhs.uk/data-and-information/publications/statistical/nhs-outcomes -framework/march-2022#chapter-index].

5. Allin S, Marchildon G, Peckham A. Canada. New York: Commonwealth Fund; 2020.

6. Health Performance Council. What's working, what's not: Review of the South Australian Health System Performance for 2011–2014. Adelaide: Government of South Australia; 2014.

7. Sullivan D. A single index of mortality and morbidity. HSMHA Health reports. 1971;86(4):347-54.

8. Berthelot J-M. Health-adjusted life expectancy (HALE). In: Robine J-M, Jagger C, Mathers C, Crimmins EM, Suzman R, editors. Determining health expectancies. Chichester: Wiley; 2003. p. 235-46.

9. Mathers CD, Murray CJ, Salomon JA. Methods for Measuring Healthy Life Expectancy. Health Systems Performance Assessment: Debates, Methods and Empiricism. Geneva: WHO; 2003.

10. Department of Premier and Cabinet. South Australia's Strategic Plan. Adelaide: Government of South Australia; 2004.

11. Department of Premier and Cabinet. South Australia's Strategic Plan: the updated plan 2007. Adelaide: Government of South Australia; 2007.

12. Department of Premier and Cabinet. South Australia's Strategic Plan 2011. Adelaide: Government of South Australia; 2011.

13. Department of Health. SA Health Strategic Plan 2007-2009. Adelaide: Government of South Australia; 2007.

14. Department of Health. SA Health Strategic Plan 2008-2010. Adelaide: Government of South Australia; 2008.

15. Department of Health. SA Health Strategic Plan 2008-2010: Extended to June 2014. Adelaide: Government of South Australia; 2008.

16. Smith M. Ex-premier Mike Rann's vision for South Australia purged after 14 years by new ruling Liberals. Sunday Mail (SA). 9 June 2018.

17. Health Performance Council. Health Performance Council's review of the performance of South Australian health systems, the health of South Australians and changes in health outcomes over the reporting period 2015-2018. Adelaide: Government of South Australia; 2018. Report No.: 18-HPC-1947.

18. South Australian Department of Health. Aboriginal Health Care Plan 2010-2016. Adelaide, SA: Department of Health, Statewide Service Strategy Division; 2010.

19. Knaul FM, Garcia PJ, Gospodarowicz M, Essue BM, Lee N, Horton R. The Lancet Commission on cancer and health systems: harnessing synergies to achieve solutions. The Lancet. 2021;398(10306):1114-6.

20. Banham D, Roder D, Keefe D, Farshid G, Eckert M, Cargo M, et al. Disparities in cancer stage at diagnosis and survival of Aboriginal and non-Aboriginal South Australians. Cancer Epidemiology. 2017;48:131-9.

21. GBD 2016 Causes of Death Collaborators. Global, regional, and national age-sex specific mortality for 264 causes of death, 1980–2016: a systematic analysis for the Global Burden of Disease Study 2016. The Lancet. 2017;390(10100):1151-210.

22. Brustugun OT, Moller B, Helland A. Years of life lost as a measure of cancer burden on a national level. Br J Cancer. 2014;111(5):1014-20.

23. Banham D, Hawthorne G, Goldney R, Ratcliffe J. Health Related Quality of Life (HRQoL) changes in South Australia: A comparison of burden of disease morbidity and survey based health utility estimates. Health and Quality of Life Outcomes. 2014;12:113.

24. Norman R, Church J, van den Berg B, Goodall S. Australian health-related quality of life population norms derived from the SF-6D. Australian and New Zealand Journal of Public Health. 2013;37(1):17-23.

25. Harrison Health Research. Health Omnibus Survey: a prospectus. Adelaide: South Australian Health Commission; 1996.

26. Taylor A, Marin T, Avery J, Dal Grande E. South Australian Aboriginal Health Survey Survey. Adelaide: Population Research and Outcome Studies; 2012.

27. Smith PC, Mossialos E, Papanicolas I, Leatherman S, editors. Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects. Cambridge: Cambridge University Press; 2009.

28. Smith PC, Mossialos E, Papanicolas I. Performance measurement for health system improvement: experiences, challenges and prospects. Copenhagen: World Health Organization

and World Health Organization, on behalf of the European Observatory on Health Systems and Policies; 2008.

29. Department of Health. Population Health in South Australia: Burden of Disease & Injury estimates 1999-2001. Adelaide: Government of South Australia; 2005.

30. Banham D, Woollacott T, Lynch J. Healthy life gains in South Australia 1999-2008: analysis of a local Burden of Disease series. Population Health Metrics. 2011;9:13.

31. Banham D, Lynch J, Karnon J. An equity–effectiveness framework linking health programs and healthy life expectancy. Australian Journal of Primary Health. 2011;17(4):309-19.

32. Banham D, Woollacott T, Gray J, Humphrys B, Mihnev A, McDermott R. Recognising potential for preventing hospitalisation. Australian Health Review. 2010;34(1):116-22.

33. Research and Ethics Policy Unit. Aboriginal mortality in South Australia: A Profile. Adelaide: Department of Health, Government of South Australia; 2010.

34. Banham D, Jury H, Woollacott T, McDermott R, Baum F. Aboriginal premature mortality within South Australia 1999-2006: a cross-sectional analysis of small area results. BMC Public Health. 2011;11(286).

35. Australian Institute of Health and Welfare. Australia's health 2020 - data insights. Canberra: AIHW; 2020. Report No.: Australia's health series no. 17. Cat. No. AUS 231.

36. Nusselder WJ. Compression of morbidity. In: Robine J, Jagger C, Mathers C, Crimmins E, Suzman R, editors. Determining Health Expectancies. Chichester: Wiley; 2003. p. 35-58.

37. Australian Institute of Health and Welfare. Australian Burden of Disease Study 2018: Impact and causes of illness and death in Australia. Canberra: AIHW; 2021. Report No.: Cat. No: BOD 29.

38. Australian Institute of Health and Welfare. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2015 Canberra: AIHW; 2019. Report No.: Australian Burden of Disease Study series no. 19. Cat. No. BOD 22.

39. Marmot M, Allen J, Boyce T, Goldblatt P, Morrison J. Health equity in England: The Marmot Review 10 years on. London: Institute of Health Equity; 2020.

40. Australian Institute of Health and Welfare. Burden of cancer in Australia: Australian Burden of Disease Study 2011. Canberra: AIHW; 2017. Report No.: Australian Burden of Disease Study series no. 12. Cat. no. BOD 13.

41. Australian Institute of Health and Welfare. Australian Burden of Disease Study: Impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2011. Canberra: AIHW; 2016. Report No.: Australian Burden of Disease Study series no. 6. Cat. No. BOD 7.

42. Taylor R. Measurement of population morbidity. In: Kerr C, Taylor R, Heard G, editors. Handbook of public health methods. Sydney: McGraw-Hill; 1998. p. 52-6.

43. Australian Institute of Health and Welfare. Emergency department care. Canberra: AIHW; 2022 [Available from: https://www.aihw.gov.au/reports-data/myhospitals/sectors/emergency-department-care].

44. Australian Institute of Health and Welfare. Emergency department care. Canberra: AIHW; 2019 [Available from: https://www.aihw.gov.au/reports-data/myhospitals/sectors/emergency-department-care].

45. Australian Institute of Health and Welfare. Hospital activity. Canberra: AIHW; 2020 [Available from: https://www.aihw.gov.au/reports-data/myhospitals/themes/hospital-activity].

46. Australian Institute of Health and Welfare. Australian hospital statistics 2018-19: Admitted patient care Canberra: AIHW; 2019 [Available from: https://www.aihw.gov.au /reports-data/myhospitals /sectors/admitted-patients].

47. Australian Institute of Health and Welfare. Spending on hospitals. Canberra: AIHW; 2021 [Available from: https://www.aihw.gov.au/reports-data/myhospitals/themes/spending-on-hospitals].

48. Australian Institute of Health and Welfare. Health expenditure Australia 2018–19. Canberra: AIHW; 2020 06 November 2020. Report No.: Health and welfare expenditure series no. 66. Cat. No. HWE 80.

49. Australian Institue of Health and Welfare. Australia's Health Performance Framework: Selected Potentially Preventable Hospitalsations Canberra: AIHW; 2020 [Available from: https://www.aihw.gov.au/reports-data/australias-health-performance/australias-health-performance-framework/national/all-australia/effectiveness/effectiveness?tab=2.1.4].

50. Australian Institute of Health and Welfare. Disparities in potentially preventable hospitalisations across Australia, 2012–13 to 2017–18. Canberra: AIHW; 2020.

51. National Health Information Standards and Statistics Committee. The National Health Performance Framework. 2nd Ed. Canberra: AIHW; 2009.

52. The National Health Information and Performance Principal Committee. The Australian Health Performance Framework. 2017.

53. Productivity Commission. On efficiency and effectiveness: some definitions. Canberra: Australian Government; 2013.

54. Steering Committee for the Review of Government Service Provision. Report on Government Services 2005. Canberra: Productivity Commission, Australian Government; 2005.

55. National Health Performance Authority. National Health Reform: Performance and Accountability Framework. Canberra: NHPA; 2013.

56. Porter ME, Lee TH. The strategy that will fix health care. Harvard Business Review. 2013;91(10):50-70.

57. Woolcock K. Value Based Health Care: Setting the scene for Australia. Canberra: Deeble Institute for Health Policy Research; 2019. Report No.: 31.

58. McCaughey D, McGhan G, Bele S, Sharma N, Ludlow NC. The Quest for Value in Canadian Healthcare: The Applied Value in Healthcare Framework. HealthcarePapers. 2019;18(4):48-57.

59. Duckett S. Value-Based Healthcare: Fad or Fabulous? HealthcarePapers. 2019;18(3):15-21.

60. Hans Olav M. Value in Health: How It Is Defined and Used in Priority Setting and Pricing in Norway. HealthcarePapers. 2019;18(3):22-8.

61. Hibbert P, Hannaford N, Long J, Plumb J, Braithwaite J. Final Report: Performance indicators used internationally to report publicly on healthcare organisations and local health systems. Sydney: Australian Institute of Health Innovation; 2013.

62. Australian Institute of Health and Welfare. National Primary Health Care Data Asset Data Development Plan: Exposure draft for consultation v1. Canberra: AIHW; 2019.

63. Australian Institute of Health and Welfare. Developing a National Primary Health Care Data Asset: consultation report. Canberra: AIHW; 2019. Report No.: Cat. no. PHC 1.

64. Robine J, Jagger C, Mathers C, Crimmins E, Suzman R, editors. Determining Health Expectancies. Chichester: Wiley; 2003.

65. Smith JN. Epic measures. New York: HarperCollins; 2015.

66. South Australia's Strategic Plan Audit Committee. South Australia's Strategic Plan Progress Report 2006. Adelaide: Government of South Ausrtralia; 2006.

67. Department of Premier and Cabinet. South Australia's Strategic Plan: Preliminary Community Engagement Report. Adelaide: Government of South Australia; 2006.

68. Banham D, Roder D, Brown A, on behalf of the CanDAD Aboriginal Community Reference Group. Realising Indigenous Australians capacity to benefit from cancer care: Developing person-centred performance measures in cancer control. World Indigenous Cancer Conference, Brisbane; 12-14 April 2016.

69. Banham D, Chen T. Chronic Ambulatory Care Sensitive Conditions amongst Indigenous and non-Indigenous Australians: a cross-sectional analysis of linked data. 9th Health Services and Policy Research Conference, Melbourne; 12-14 April 2015.

70. Banham D. Vulnerable populations and Emergency Department use in the Adelaide metropolitan area: Person-centred outcomes and costs using linked, administrative data. Population Health Congress, Hobart; 6-9 September 2015.

71. Banham D, Nguyen A-MT, Anastassiadis K. Refugee & Asylum Seeker populations & Emergency Department use in the Adelaide metropolitan area: Examining outcomes & costs using linked, administrative data. Australian Health Economics Society (AHES) Conference, Hobart; 24-–26 Sept 2014.

72. Keech W, Mckivett A, Morey K, Stewart H, Clinch D, Saltmarsh A, et al. South Australian Chronic Disease Consortium Road Map 2017-2021. Adelaide: SAHMRI; 2017.

73. Snelling J. Personal correspondence: Meeting between Jack Snelling of Baptist Care and David Banham on avoidable emergency department use by vulnerable people on 3 July 2019. 2019.

74. Bell J, Lingam R, Wakefield CE, Fardell JE, Zeltzer J, Hu N, et al. Prevalence, hospital admissions and costs of child chronic conditions: A population-based study. Journal of Paediatrics and Child Health. 2020;56(9):1365-70.

75. Brazier J, Ratcliffe J, Salomon JA, Tsuchiya A. Measuring and valuing health benefits for economic evaluation. First ed. Oxford: Oxford University Press; 2007.

76. Brazier J, Ratcliffe J, Salomon JA, Tsuchiya A. Measuring and valuing health benefits for economic evaluation. Second ed. Oxford: Oxford University Press; 2017.

77. Organisation for Economic Co-operation and Development. Recommendations to OECD Ministers of Health from the high level reflection group on the future of health statistics: Strengthening the international comparison of health system performance through patient-reported indicators. Paris: OECD; 2017.

78. Organisation for Economic Co-operation and Development. PaRIS: Patient – Reported Indicators Survey The next generation of OECD health statistics. Paris: OECD; 2017.

79. Maynard A. Let's visit the PROM's. Nursing Standard. 2009;21(9):28.

80. Devlin NJ, Appleby J. Getting the most out of PROMs: Putting health outcomes at the heart of NHS decision-making. London: The King's Fund; 2010.

81. McGrail K, Bryan S, Davis J. Let's All Go to the PROM: The Case for Routine Patient-Reported Outcome Measurement in Canadian Healthcare. HealthcarePapers. 2012;11(4):8-18.

82. Garvey G, Anderson K, Gall A, Butler TL, Cunningham J, Whop LJ, et al. What Matters 2 Adults (WM2Adults): Understanding the Foundations of Aboriginal and Torres Strait Islander Wellbeing. International Journal of Environmental Research and Public Health. 2021;18(12):6193.

83. Williams K, Sansoni J, Morris D, Grootemaat P, Thompson C. Patient-reported outcome measures: Literature review. Sydney: ACSQHC; 2016.

84. Council on Federal Financial Relations. Addendum to National Health Reform Agreement 2020-2025. Canberra: Australian Government; 2020.

85. Commission on Excellence and Innovation in Health. Strategy for 2020-2023: Draft for consultation. Adelaide: Government of South Australia; 2020.

86. Thompson C, Sansoni J, Morris D, Capell J, Williams K. Patient-reported outcome measures: An environmental scan of the Australian healthcare sector. Sydney: ACSQHC; 2016.

87. Angell B, Muhunthan J, Eades A-M, Cunningham J, Garvey G, Cass A, et al. The health-related quality of life of Indigenous populations: a global systematic review. Quality of Life Research. 2016;25(9):2161-78.

88. Rees Daniel J, Bates V, Thomas Roderick A, Brooks Simon B, Laing H, Davies Gareth H, et al. Collaborating to deliver value in health care: exploring conditions required for successful healthcare and life science sector collaboration. Transforming Government: People, Process and Policy. 2020;15(1):169-90.

89. Banham D, Karnon J, Brown A, Roder D, Lynch J. The premature mortality to incidence ratio (PREMIER): a person-centred measure of cancer burden. Population Health Metrics. Submitted.

90. Lew J-B, Feletto E, Worthington J, Roder D, Canuto K, Miller C, et al. The potential for tailored screening to reduce bowel cancer mortality for Aboriginal and Torres Strait Islander peoples in Australia: Modelling study. Journal of Cancer Policy. 2022;32:100325.

91. Australian Health Ministers. National Health Reform Agreement (NHRA) – Long-term health reforms roadmap. Canberra: Australian Government; 2021.

92. Wade-Grey L. Putting data, digital and tech at the heart of transforming the NHS. London: NHS Digital; 2021.

93. Slater J. A Health Outcomes Resource Standard (HORSt) for Australian State Public Health Funding Distributions. Wollongong: University of Wollongong; 2019.

94. Kennedy B, Firman D. Indigenous SEIFA – revealing the ecological fallacy. 12th Biennial Conference of the Australian Population Association, Canberra; 15-17 September 2004.

95. Australian Bureau of Statistics. Socio-Economic Indexes for Areas (SEIFA) - Technical Paper, 2016. 2018. Report No.: 2033.0.55.001.

96. Robson B, Purdie G, Cram F, Simmonds S. Age standardisation - an indigenous standard? Emerg Themes Epidemiol. 2007;4:3.

97. Banham D, Chen T, Karnon J, Brown A, Lynch J. Sociodemographic variations in the amount, duration and cost of potentially preventable hospitalisation for chronic conditions among Aboriginal and non-Aboriginal Australians: a period prevalence study of linked public hospital data. BMJ Open. 2017;7(10).

98. Banham D, Karnon J, Densley K, Lynch J. How much Emergency Department use by vulnerable populations is potentially preventable?: A period prevalence study of linked public hospital data in South Australia. BMJ Open. 2019(e022845).

99. Productivity Commission. Shifting the Dial: 5 Year Productivity Review. Canberra: Australian Government; 2017. Report No.: 84.

100. Verhoven A. Value-based care: why it matters so much now. The Health Advocate. Canberra: AHHA; 2020.

101. Maree P, Hughes R, Radford J, Stankovich J, Van Dam PJ. Integrating patient complexity into health policy: a conceptual framework. Australian Health Review. 2020;45(2):199-206.

102. Weller D, Mercer S. Multimorbidity in Cancer Patients: the 'New Normal'. Clinical Oncology. 2020;32(9):551-2.

103. Banham D, Karnon J, Lynch J. Health related quality of life (HRQoL) among Aboriginal South Australians: a perspective using survey-based health utility estimates. Health and Quality of Life Outcomes. 2019;17(1):39.

104. Drummond M, Torbica A, Tarricone R. Should health technology assessment be more patient centric? If so, how? Eur J Health Econ. 2020;21(8):1117-20.

105. Digirolamo R. High cost of hospital strain. The (Adelaide) Advertiser: News Limited; 22 April 2019.

106. Cookson R, Mirelman AJ. Equity in HTA: what doesn't get measured, gets marginalised. Israel Journal of Health Policy Research. 2017;6:38.

107. Cookson RA, Asaria M, Ali S, Ferguson B, Fleetcroft R, Goddard M, et al. Health Equity Indicators for the English NHS: a longitudinal whole-population study at the small-area level. Health Services and Delivery Research. 2016;4(26).

108. Cancer Institute NSW. Cancer control in New South Wales: Statewide report 2020. Sydney: Government of NSW; 2021.

109. Cancer Institute NSW. The NSW Cancer Plan: A plan for NSW to lessen the impact of cancers 2022-2026. Sydney: Government of NSW; 2021.

110. Australian Bureau of Statistics. Multi-Agency Data Integration Project (MADIP) Canberra: ABS; 2022 [Available from: https://www.abs.gov.au/about/data-services/data-integration/integrated-data/multi-agency-data-integration-project-madip].

111. Australian Bureau of Statistics. MADIP research projects Canberra: ABS; 2022 [Available from: https://www.abs.gov.au/websitedbs/d3310114.nsf/home/statistical+data+integration+-+madip+research+projects].

112. Australian Bureau of Statistics. Building on SEIFA: Finer Levels of Socio-Economic Summary Measures. Canberra: ABS; 2013. Report No.: Cat. No. 1352.0.55.135.

113. Banham D, Roder D, Thompson S, Bray F, Williamson A, Li M, et al. Comorbidity among older Aboriginal and non-Aboriginal Australians with cancer in New South Wales. Journal of Multimorbidity and Comorbidity. In review.

114. Banham D, Roder D, Thompson S, Williamson A, Bray F, Currow D. The influence of comorbid conditions and general practice contact on cancer stage at diagnosis: A comparison of older Aboriginal and non-Aboriginal cohorts in New South Wales from 2003to 2016. Cancer causes and control. In review.

115. Banham D, Roder D, Norsa E, Vinod S, Currow D. Timeliness of adjunct chemotherapy after surgery for stage III colon cancer in Aboriginal and non-Aboriginal Australians: Piloting a retrospective cohort analysis of first diagnoses among older NSW residents, 2003 to 2016. Sydney: CINSW; 2021.

116. Banham D, Roder D, Clarke S, Currow D. Time to radiotherapy in Aboriginal and non-Aboriginal people experiencing non-small cell lung cancer: Piloting a retrospective cohort analysis of first diagnoses among older NSW residents, 2003 to 2016. Sydney: CINSW; 2021.

117. Nicolaus S, Crelier B, Donzé JD, Aubert CE. Definition of patient complexity in adults: A narrative review. Journal of Multimorbidity and Comorbidity. 2022;12: 26335565221081288.

118. Parliament of South Australia. Health Care Act 2008. Adelaide: Parliament of South Australia; 2008. Report No.: Version: 23.8.2021.

119. Parliament of South Australa. Health Care (governance) Amendment Act 2018. Adelaide: Parliament of South Australia; 2018. Report No.: No 8 of 2018 assented to 2.8.2018.

120. Donnellan A. Software legal battle could put SA patients' safety at risk, Government outlines in court documents2016. Available from: https://www.abc.net.au/news/2016-06-18/software-legal-battle-could-put-sa-patients-safety/7522934.

121. Scopelianos S. South Australia to pay $5m to continue using old patient records system. 2016. Available from: https://www.abc.net.au/news/2016-08-05/sa-to-pay-5m-to-continue-using-old-patient-records-system/7693992.

122. Global Health. SA Health extends PAS licence to 31-March 2022: Notice to the Australian Stock Exchange. Melbourne: GLH; 2020.

123. Yorke and Northern Local Health Network. Yorke and Northern Local Health Network Strategic Plan 2020-2025. Port Pirie: YNLHN; 2021.

124. Banham D, Nguyen A-MT. Potentially Preventable Admissions to South Australian public hospital services: analysis using statistically linked administrative data. Adelaide: Research and Ethics Policy Unit, SA Health; 2011.

125. Yorke and Northern Local Health Network. Consumer and Community Engagement Strategy 2020-2025. Port Pirie: YNLHN; 2021.

126. Commonwealth of Australia, Treasury. Budget October 2022-23: Budget strategy and outlook Budget Paper No. 1. In: Treasury, editor. Canberra: Commonwealth of Australia; 2022.

127. Organisation for Economic Co-operation and Development. Compendium of OECD Well-being indicators. Paris: OECD; 2011.

128. 7.30 Report. Joseph E. Stiglitz Australian Speaking Tour [television broadcast]. Sydney: ABC; 2022. [Available from: https://www.youtube.com/watch?v=tqXuaJ1U5UY].

129. World Health Organization. Framework on integrated, people-centred health services: Report by the Secretariat. Geneva: World Health Organization; 2016.

130. Rothman K, Greenland S, Lash T. Modern Epidemiology, Third Edition: Philadelphia: Lippincott; 2008.

131. Sogaard R, Lindholt JS. Assessment of inequality alongside policy-oriented trials: An empirical framework based on the case of screening. Epidemiology. 2019;30:706-12.

132. Cookson R, Doran T, Asaria M, Gupta I, Mujica FP. The inverse care law re-examined: a global perspective. The Lancet. 2021;397(10276):828-38.

133. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. The Lancet. 2012;380(9836):37-43.

134. Searles A, Piper D, Jorm C, Reeves P, Gleeson M, Karnon J, et al. Embedding an economist in regional and rural health services to add value and reduce waste by improving local-level decision-making: protocol for the 'embedded Economist' program and evaluation. BMC Health Serv Res. 2021;21(1):201.

Appendices

Appendix A

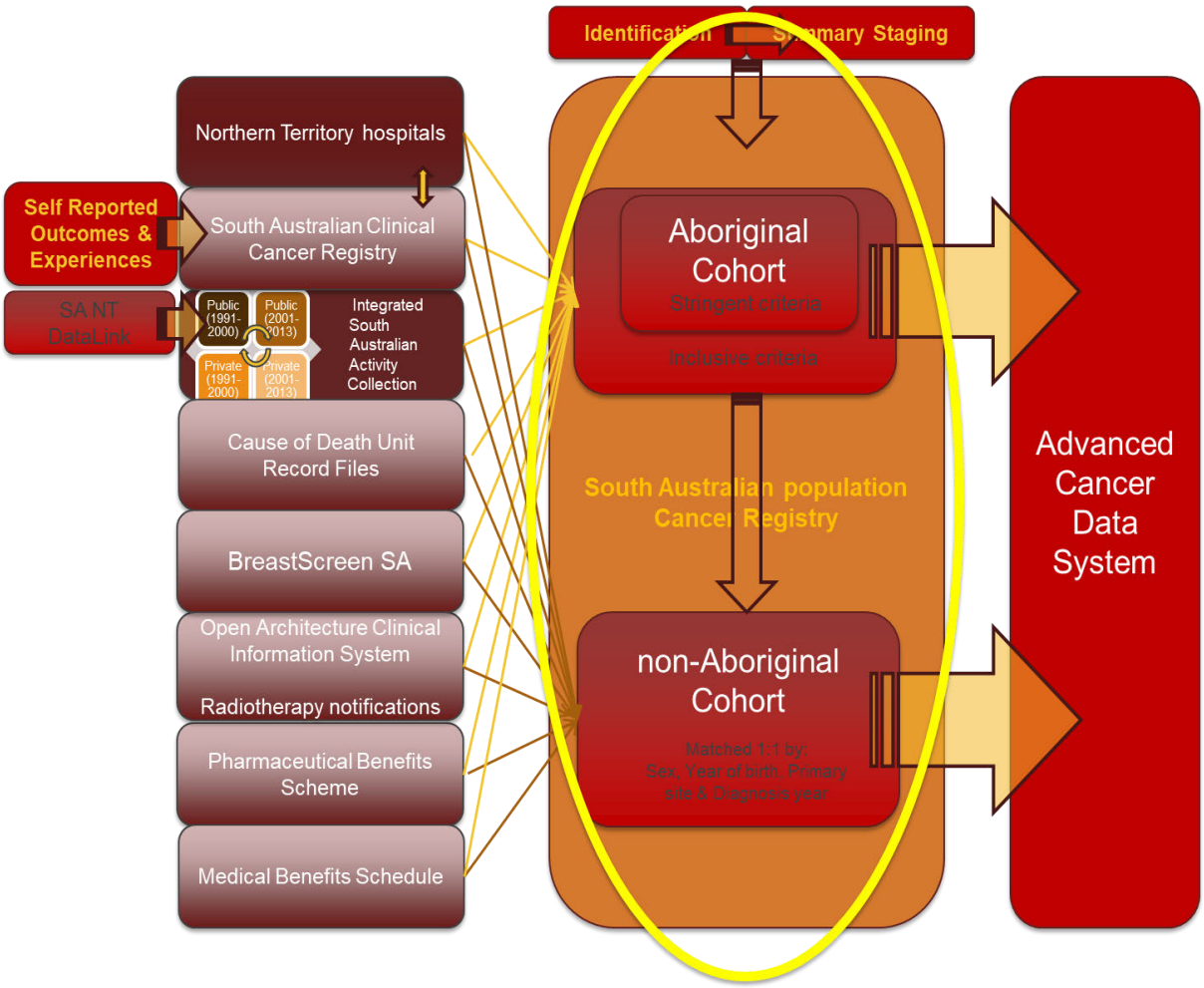


Figure A1 The Advanced Cancer Data System Pilot (ACaDS) and its data components

Appendix B

Potentially Preventable Hospital use in South Australia

Potentially Preventable Hospital contacts (PPHs) indicate hospital presentations and stays which might be avoided if appropriate, necessary and timely health care is available elsewhere. Most analyses of PPH look at volume of hospital services. Person linked administrative records provide an alternative perspective focussing on the people experiencing hospital contact. Focussing on individuals and groups within the community will help inform and monitor person-centred care.

This project asks:

1. How many people experience **inpatient** stays in South Australian hospitals?

2. How many people experience PPHs in South Australian hospitals?

3. What proportion of people experience multiple, or more frequent, PPHs and total length of stay?

4. What are the demographic characteristics of people experiencing more frequent PPH?

5. What hospital resources associated with PPHs?

6. What is the geographic relationship between the area of usual residence of people experiencing PPHs, local primary health services and acute care facilities?

In some community sections there is a relationship between **Emergency Department** (ED) services and PPHs. So the study will also ask:

7. How many people access EDs in South Australian hospitals and how many of these are potentially preventable?

8. How many of the people attending public hospital EDs subsequently experience PPHs as inpatients of South Australian hospitals?

The addition of **death** records to the linked dataset will allow further questions such as:

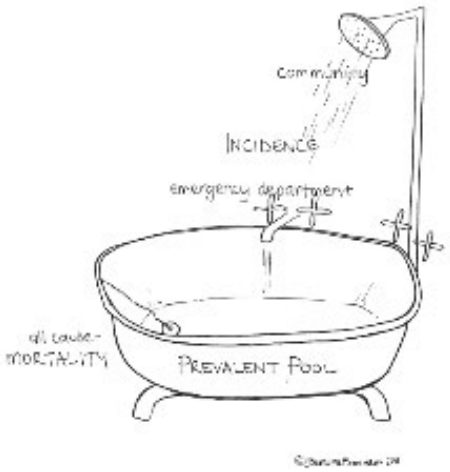
9. How many people in the wider community have ever experienced PPAs and how many exit the prevalent pool because of death each year?

10. Following a PPA event, what changes to mortality risk occur over time? For example, has 12 month survival after a first PPA admission changed from 2010 to 2019?

Questions 1 to 7 deal with **incident** PPA events. Questions 7 and 8 focus on patient **pathway** to hospitalisation. Questions 9 and 10 will help provide information about **prevalence**, case **fatality** and duration associated with PPAs.

Answering these questions will help:

- Monitor changing trends in the distribution of PPAs within the community. For example, for aggregate PPAs and/or underlying conditions by sex, age and area;
- Identify gaps in the spatial distribution of people experiencing PPAs, the provision of primary health services and acute care services;
- Inform discussions about the potential for reallocating resources toward associated primary care and preventive activities;
- Evaluate population health outcomes that result from relevant resource, service and practice changes in a continuous improvement framework;
- Inform further developments of SA Health and Wellbeing performance indicators;
- Inform discussions about the association between hospital ED and inpatient services and the relationship with primary care and preventive activities;
- Inform discussions about patient outcomes following PPA separations.



For more information contact:
David Banham
Phone: 0423 202 562
Email: david.banham@sa.gov.au

Figure B1 Flier for statistical linkage project

Appendix C

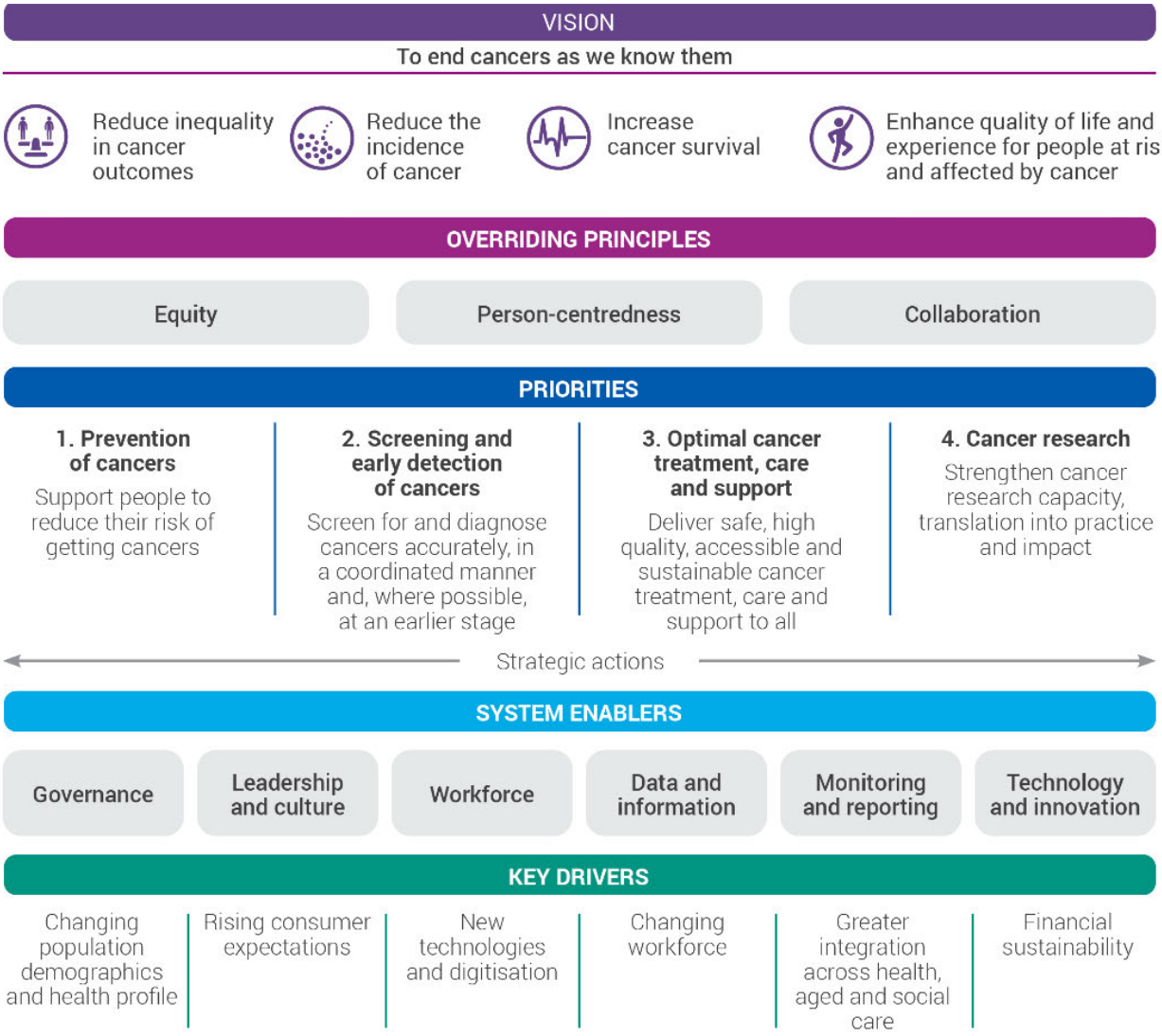


Figure D1 The NSW Cancer Plan 2022-2026 on one-page

Appendix D

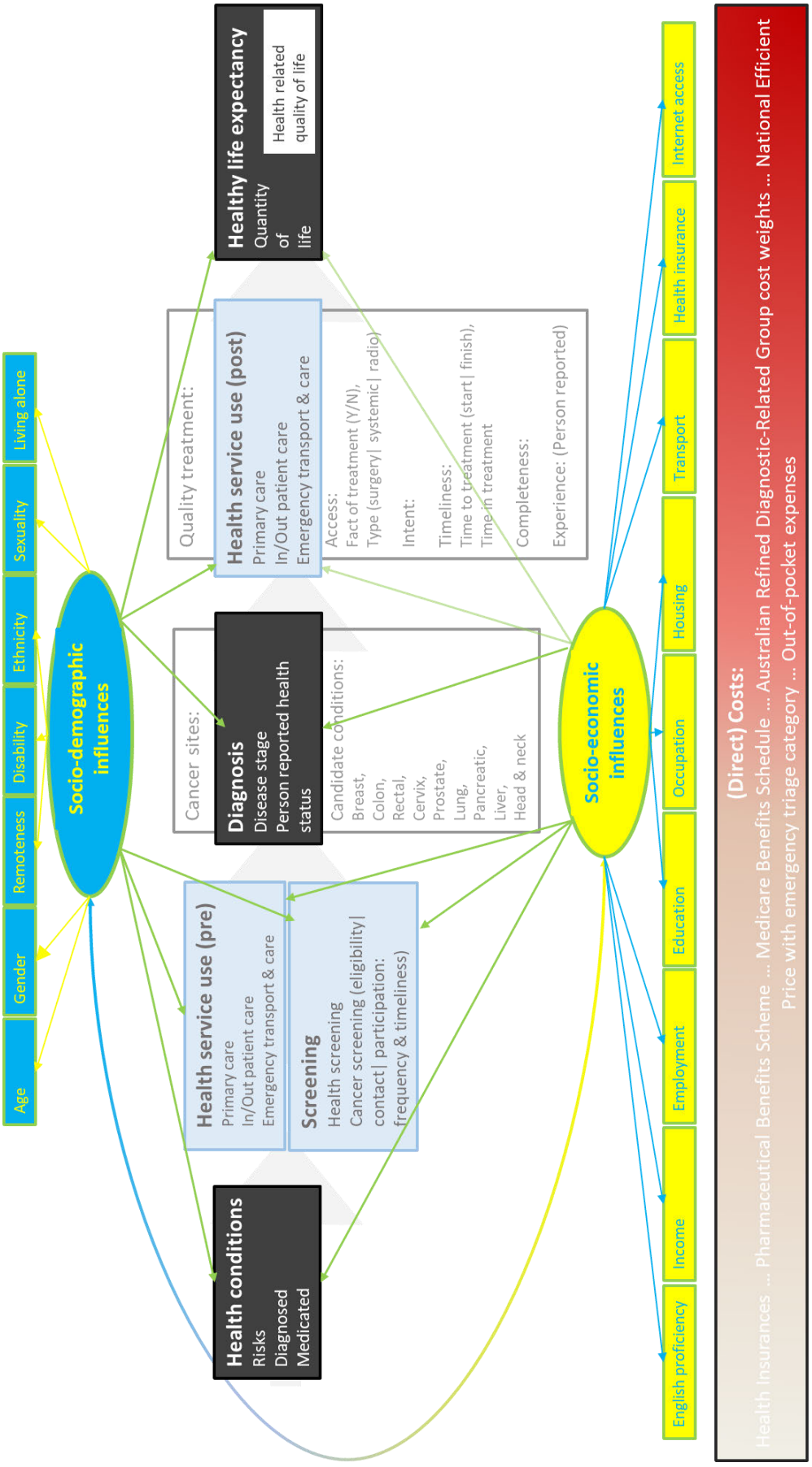


Figure E1 A conceptual map for structuring a data system across the cancer care pathway

Appendix E

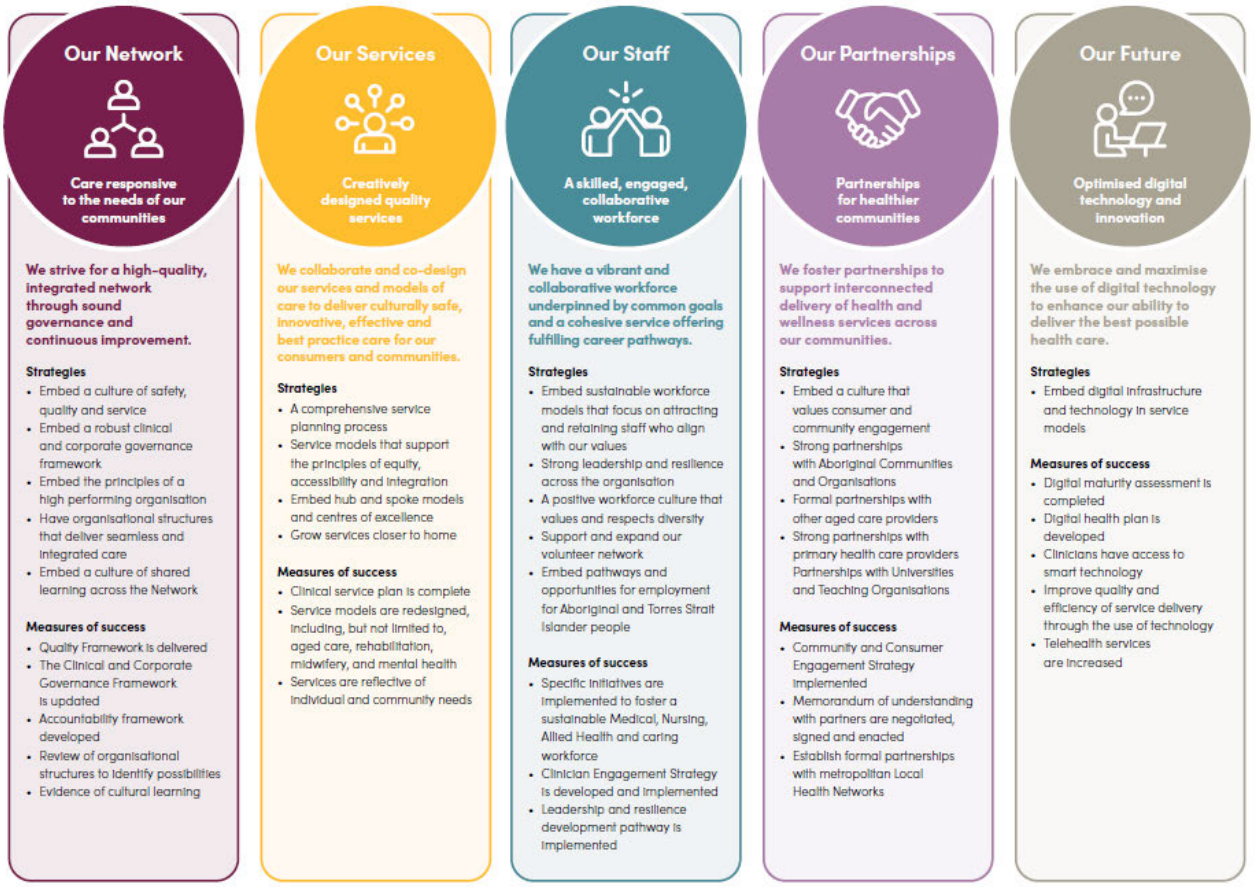


Figure F1 The YNLHN Strategic Plan 2020-2025 on one-page

Appendix F

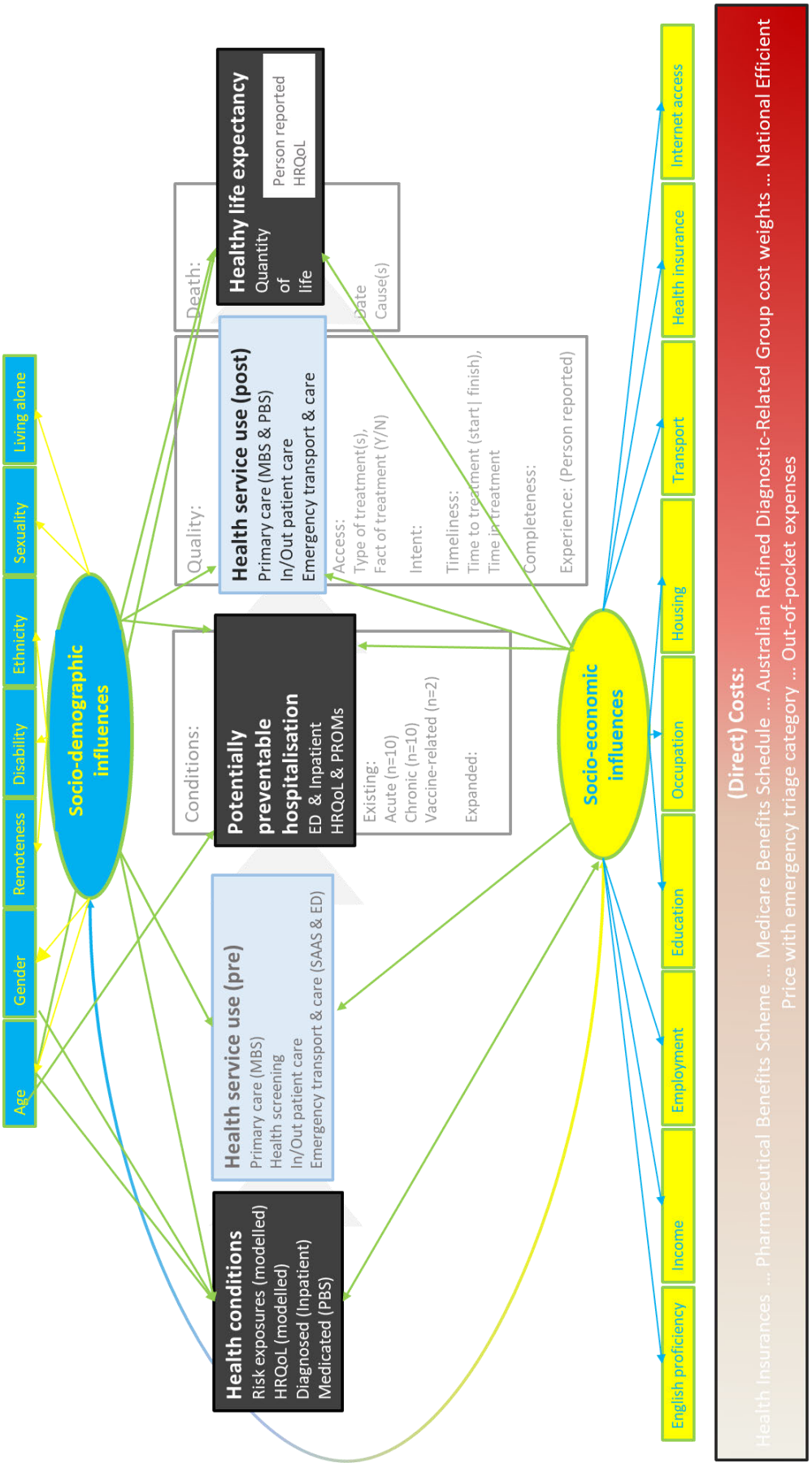


Figure G1 A conceptual map for structuring a data system focussed hospital service use

Appendix G

11 December 2019

Working Towards Equity in Health in South Australia: *Challenges and opportunities from the forum on 'The role of equity-informative health economics evaluations to support service and policy decision making'.* Executive Summary

Aims and objectives:

Research into health systems and services aims to inform answers to important questions for decision-makers in support of improved policies, practices and ultimately, improved outcomes among patients and populations. Three important and inter-related aspects of this information are: effectiveness; efficiency and, equity. Our forum focussed on the special role of equity within health and economic evaluation in South Australia. This involved:

- introducing the nature, role and application of equity-informative economic evaluation;
- highlighting the importance of health equity to the South Australian context;
- identifying challenges and opportunities for equity-informed economic evaluation; and,
- identifying some of the existing key research assets available to take some of these opportunities.

Method, Participation and Outcomes:

A keynote talk to 70 participants offered **three methods in equity-informative economic evaluation**:

1. Effectiveness analyses are equity informing when they describe: average intervention effects for population groups in disadvantaged areas; differential effects for more/less disadvantaged groups; and, effects at different parts of the outcome distribution (not just averages);
2. Distributional cost-effectiveness analyses move beyond standard cost-effectiveness analyses to inform on the distributions of outcomes and opportunity costs;
3. Analysis of equitable quality improvement provides valuable information by unpacking averaged results among organisations, sub-populations and across time.

Applied work in this area demands careful, open consideration of related ethical issues.

Health equity is important for South Australia because persisting, unnecessary variations exist in peoples' health outcomes and their access, uptake and participation in quality health services.

A facilitated panel conversation began **identifying equity related challenges and opportunities** for partnerships among decision makers, services providers and the community. These included:

- Understanding the nature of community need and preferences in allocating resources;
- Monitoring and evaluating person-centric service use, experiences, costs and outcomes across clinical; and population groups; and,
- Developing relevant questions, methods, data platforms, and research capacity.

Presentations and discussion in a subsequent workshop then **identified key research and contextual assets** for addressing those challenges and taking opportunities before us. To guide further actions in this area, excerpts from the workshop content are related to two critical issues:

1. What questions must an equity-informed health economics research agenda answer?
2. How will we enable equity-informative economic research supporting decision-making?

Conclusion:

Our forum summary provides items for continued discussion and action. Using these as a guide, by further collaborating, and using our existing assets as a base we can take the next steps in equity informing economic research. Our research will translate into action and improved health outcomes overall while reducing differences in outcomes among people. A key research objective is to inform health system reform through continuous equitable, effective and efficient innovation.

Introduction

Uncle Frank Wangutya Wanganeen gave a warm welcome to participants in the forum co-hosted by Health Translation SA and SAHMRI's Aboriginal Health Equity theme on 11th December 2019. In doing so, Uncle Frank shared from Kaurna culture and language while also highlighting the ongoing need for health research and practice that make a difference to him, his family and community.

Research into health systems and services aims to provide information that answers important questions for decision makers. Collectively, the information must support continuing improvement of policies, practices and ultimately, improved outcomes among the patients and populations served. Three important aspects of this information are: effectiveness (e.g. quality and benefits); efficiency (e.g. costs); and, equity (e.g. distributional issues).

With a focus on the special role of equity, the forum explored the role of equity-informative health economic evaluation in supporting service and policy decision making in South Australia (SA). Outcome and economic evaluation research is more the exception than the norm across SA's health portfolio, so we covered a broad range of related domains and topics. These included: describing the nature, role and application of equity-informative economic evaluation; highlighting the importance of health equity for SA; identifying some of the challenges and opportunities before us; and identifying some of the key research assets available to address these challenges and realise opportunities for growing the use of equity-informed economic evaluation.

In approaching an underdeveloped area in this way, we pursued two of Health Translation SA's priorities in: encouraging the mobilisation of leadership and collaboration to strengthen research translation; and, building expertise and capacity in research translation. Around 70 participants demonstrated their willingness to explore this topic and bought diverse organisational backgrounds from: state government departments; non-government organisations; consumer and advocacy groups; universities; and, health services. They also bought wide-ranging disciplinary expertise in economics, epidemiology, ethics, community engagement, metrology, computer science, business administration and health service research at clinical and population levels.

This summary is less concerned with reiterating presentations and more about compiling challenges and opportunities, and, recognising research assets which could help inform our responses. This is aimed at prioritising ways to nurture equity informing research that supports policy and practice, and continuous learning in each. By inviting further collaboration and making use of existing assets, we can take the next steps in realising our potential for conducting equity informing research that translates into action. Hence, some forum content is editorialised, and specific presentation content arranged into themes. Participants' review and comment on the result is welcomed.

Summary of Proceedings

Professor Richard Cookson, a health economist with the University of York UK, shared an overview of his research **on the nature, role and application of equity-informative economic enquiry**. Richard reinforced the importance of tracking averaged results in the health system, then drew out the extra value of detailing variations: who gains and who loses. Where this is done, inequality and equity related gradients and gaps may become apparent. Decision makers need further information on the effects of service and policy options on those gradients and gaps. He put forward three methods addressing this need:

1. Effectiveness analysis using randomised control trials and quasi-experimental methods are equity informative when they describe: average effect for population groups in disadvantaged areas; and, differential effects for more/less disadvantaged groups. While many studies are underpowered for such sub-group analysis, careful focus on critical data items can successfully prepare for subsequent, pooled meta-analyses.

2. *Distributional cost-effectiveness analysis (DCEA)* moves past standard, averaged cost-effectiveness analysis to inform on the variations, or distributions, around average outcomes and opportunity costs. The method considers: baseline prevalence of a condition as an indication of "need"; receipt or uptake of a health intervention(s) being considered; completion of follow-up and treatment; the observed capacity to benefit from that intervention; and, the opportunity costs involved.

3. *Analysis of equitable quality improvement* unpacks averaged indicator results and enables comparison between organisations servicing similarly profiled populations.

Richard reminded participants that equity is a complicated subject. It requires careful, ethical consideration in selecting and using equity-related metrics, while maintaining respectful processes and treatment of people.

Mary Patetsos of the Northern Adelaide Local Health Network board and SA's Health Performance Council used the latter's "State of our health" report to describe **the importance of health equity for South Australia**. Mary identified persisting trends within SA's health system involving varying and unmet needs for services (e.g. in dentistry and among CALD and other potentially vulnerable populations) with related pressures on costs and workforce. Promising system responses are apparent in areas of sustained focus on patient safety; place based-preventive actions; addressing of access difficulties; improved communication in transferring care from hospital to community; and development of information platforms on CALD and other vulnerable populations.

Wendy Keech (HTSA) facilitated a **panel conversation** between Richard, Mary, John Slater (SA Health), Julie Ratcliffe (Flinders University) and the audience which **began identifying health equity economic challenges and opportunities** for SA in:

- Efficiently allocating resources to hospitals, LHNs and PHNs to close equity gaps in areas such as potentially preventable hospital contact;
- Commissioning service delivery based of need rather than historical allocation;
- Positively influencing decisions taking account of social health determinants and health equity;
- Mandating consumer involvement in all stages of research (e.g. as per the UK's NIHR);
- Developing longitudinal cohort data platforms enabling analysis across the entire life course;
- Funding for policy informing methodological research (e.g. deriving community preferences for redistributing health benefits and resources); and
- (Re)generating relevant workforces and capacity (e.g. GP workforce and health economists).

The forum's afternoon **workshop** featured presentations on key research that is directly involved in **developing and applying equity-informative evaluations** in SA.

Professor John Lynch of the Better Start team (University of Adelaide) introduced an exemplar, intelligent data system focussed on early childhood. Better Start's analyses show variations in risk exposure among children which identified opportunities to tailor responses toward universal services and/or providing intensive supports. With partnerships across government, this research is informing

evaluation of care models, and re-alignment of resources with areas of need. Analyses also informs purposeful gathering of data on components of service activity, therapeutic contact and referrals.

Associate Professor Maria Inacio (SAHMRI and University of South Australia) introduced **the Registry Of Senior Australians (ROSA)** platform which follows senior Australians entering the aged-care sector. ROSA's Outcome Monitoring System (OMS) monitors, then benchmarks 12 safety and quality indicators to detect unwarranted variations to inform evidence-based quality improvement initiatives among its government and industry partners. ROSA's research includes epidemiological, health service, comparative effectiveness studies and economic evaluations. The latter includes: assessing transition and costs from community to residential care; health care utilisation and costs of wait times to community-based aged care programs; and, the effects of frailty on service utilisation.

Professor Stephen McDonald (ANZDATA, University of Adelaide, SAHMRI and SA Health) oriented us to the Australia and New Zealand Dialysis and Transplant (ANZDATA), a long-standing, clinical quality platform tracking variations and trends in end-stage kidney disease incidence, treatment uptake and transplantation. ANZDATA analyses and exemplar public reporting identified variations by socio-economic position and Indigenous status. Recent reporting informed wide-ranging discussion on inequalities in organ transplant and named relevant barriers and facilitators. The resulting 35 recommendations for change resulted in funding to pilot programs to meet peoples' capacity to benefit. Allocating limited organs among many potential recipients demands an equitable, principled approach to transplant allocation (e.g. understand community and/or health professional perspectives), valid decision support algorithms, then implementing and auditing results. Allocation issues are not confined within disease areas, they also extend across diseases.

Professor Jon Karnon (Flinders University) illustrated the use of **distributional cost-effectiveness analysis** in the Australian health system. Averaged cost-effective analyses assess costs per quality adjusted life year (QALY) in assessing pharmaceutical and medical services. Public health and health care interventions, where equity is often an issue, have no such processes. Using the example of cardiovascular disease prevention among Indigenous Australians, Jon illustrated how to weight QALYs gained to reflect equity values across cost, disease and recipient characteristics. An equity perspective might also estimate multiplier effects, that is, the consequences of investing in people and goods within SA communities in contrast to purchasing goods off-shore, as is the case with pharmaceuticals.

David Banham (University of Adelaide and University of South Australia) shared a **decision-support and continuous learning framework** for linking health system activity with healthy life expectancy and disability-adjusted life years (DALY) outcomes across socio-economic groupings. An example focussed on coronary heart disease (CHD) management in general practice to describe variations in population need, intervention effect and costs, then showed the varying effects of resource allocation methods.
After critiquing the above outcome measures, discussion turned to examples of complementary, **person-centred outcome measures** which offer timelier information on mortality, health-related quality of life (HRQoL) and morbidity metrics. Mortality examples drew on the Advanced Cancer Data System (ACaDS) within the Cancer Data and Aboriginal Disparities (CanDAD) project. HRQoL examples drew on self-reports in SA population surveys. Morbidity items use administrative records on emergency department presentations and inpatient length of stay for potentially preventable or ambulatory care sensitive conditions. These metrics were also related to the contemporary Australian policy context, particularly the objectives within the Health Performance Agreement: 2020-2025.

Each presentation provided clear evidence of inequities and unwanted variation in the distribution of wide-ranging outcomes within the community. However, most presentations did not explicitly focus on **economic** evaluation in support of service and policy decision making. The subsequent gap in research coverage represents an area of unmet information need affecting government and non-government organisations alike with consequences for the wider community. Meeting this information need presents a positive challenge for the research community to inform innovation and reform. As with attendees to the forum, "community" includes: government (Commonwealth and state) and their agencies; non-government and private enterprises; consumer or citizen groups; as well as, academic research, teaching and knowledge translation organisations.

Our research challenges and opportunities

The following draws on the forum's proceedings to formulate a research agenda relevant to addressing unmet information needs. To do this, a vision statement commensurate with the national health reform objectives is proposed. The relevant information needs and key assets identified in the forum are then arranged under two broad challenges focussed on people, programming their research, and enabling sustained collaboration to address information needs.

Vision statement. *We will contribute research leading to improved health outcomes overall while reducing differences in outcomes among people. Our research will inform health system reform through continuous equitable, effective and efficient innovations.*

Challenge 1. *What questions must an equity-informed health economics research agenda address?*

1.1. How can we identify, inform, then translate learning, insights and processes into health organisations for reforming and innovating strategy, planning, delivery and evaluation?

Comment: Attendance at the forum, the nature and breadth of presentations, and subsequent discussion demonstrated a clear interest in the role of equity-informative health economics evaluations. Moreover, conversations were quite clearly focussed on practical issues needing relevant information and evidence, evidence to apply to system reform and innovation which improves outcomes and experiences equitably across the community.

Having needs for, and interest in, equity-informed health economic evaluation but relatively little history in systematically carrying out such evaluations presents SA with a "green field" to cultivate in this area.

Key assets: South Australia's population size and relative stability is a great asset as is the growing familiarity of forum participants and their wider networks with each other. SA Health is embedding health economic functions in several areas including Wellbeing SA and the Commission on Excellence and Innovation. This indicates a growing demand for answers to the questions raised in the forum and opportunity for research informing those topics. We have a small cadre of health economists will considerable expertise in the highly relevant areas of health technology assessment, economic modelling, eliciting health-state preferences and stakeholder engagement. Importantly, those experts are willing and able to apply their knowledge by working with decision-makers and developing workforce capacity.

Key Action: Identify a group of people who could get together and develop some proposals on how to incorporate equity considerations into current policy, practice and quality improvement areas, then offer support to: SA Health (central office) in the first instance; Local Health Network boards; the primary health care system; and, community members.

Include proposals for specific opportunities to develop appropriate methods and applications of distributional cost-effectiveness analyses (DCEA). For example:

- Articulate formal processes to review options for public health interventions and delivery;
- Elicit (South) Australian norms and preferences for adjusting DCEA benefits;
- Adjust cost differences for population groups on the basis of: Indigenous, culturally and linguistically diverse, or other background; socioeconomic positioning; and/or geographic distance (urban/regional/remote);
- Articulate multiplier effects from interventions; and,
- Articulate methods for handling uncertainty around costs and effects in decision-making.

Further proposals may include responses to the following questions which reflect topics of discussion during the forum.

1.2. How might we define, target, then monitor equitable health improvement?

Comment: A creative challenge is to know what we mean by equitable change: in relative or absolute terms, or some combination of both; and, for whom in what circumstances.

Key assets: An equity monitor is now part of SA Health's developing business plan to drive change. Governance of the public hospital system has also broadened to shared responsibilities for localised decision-making through ten local health networks and their boards.

Research into equity-informing indicators has a rolling start through:

- ROSA and partners' 12 key performance indicators (KPI) of value to clients and service providers involved in aged care. Each KPI can describe variations in averaged results; and,
- Instigation of person-centred performance measures describing outcomes among people groups.

Also, South Australia has considerable experience in building and learning from high quality population and clinical registries and other advanced, person-centred data systems.

Actions: 1. Identify some equity indicators and work to track them over time and across population groups. For example, hospital acquired complications and avoidable readmissions are ongoing areas of interest.

2. Add value to existing information by adding an equity component such as equity weighted, avoidable readmissions.

3. Include methodological development in proposals aimed at answering practical reform and innovation challenges.

1.3. How do we best capture community preferences for equitable change?

Comment: Weighting decisions in health is the domain of the decision-taker. Citizens will also have views on if, and how to, take account of equity in weighting decisions. For example, forum participants discussed to what extent inequality aversions exist and the development of methods necessary to assess preferred trade-offs between equity and total population health. Eliciting community preferences is critical, must involve citizens in developing the methods and topic areas with the resultant views being available to decision-makers.

Key assets: South Australian researchers have existing vignettes of varying intervention effects and costs across population groups and experience in conducting citizen juries with which to gauge community views on decision weighting.

South Australia has well developed and organised consumer networks who indicated a clear expectation and willingness to contribute to informing equitable quality improvement. For example, consumer alliance representatives reminded the forum of housebound people who may have particular (unmet) need but a lower likelihood of receiving or participating in care, or of being counted using administrative records.

Action: Include community and consumer representation in the formulating and carrying out all proposals.

1.4. What are identifiable and measurable issues people can do something about? What components are amenable to change through health intervention and how are they distributed in the community? How might we monitor performance after decisions to intervene are taken?

Comment: Often we don't really know how to improve things, so it may be helpful to reframe this activity as learning and information for quality improvement. This will take time and could involve normalising the collection of relevant data items, building a history, and learning from our experience in doing so.

Key assets: Research into equity-informing indicators has a rolling start. Relevant indicator areas include: early cancer detection rates; emergency department presentation rates; and avoidable admissions to hospital (ambulatory care sensitive conditions, or potentially preventable hospitalisation). A general equity-effectiveness framework with which to arrange our learning and informing of quality improvement activities is available.

Action: Confer with key informants (communities and decision-makers) about elements of care, outcome and experience that are sensitive to health care decisions and amenable to change.

Establish a team, set about monitoring selected items for a time, then advance further as our learning matures. Compare results between people groups (e.g. by area, socio-economic position, or ethnicity). Benchmark results against other health services serving similar populations, or the national average; or, an organisation against itself over time.

Share granular results with communities, clinicians, their peers, and decision-makers alike.

1.5. How can we develop equity perspectives in local evidence from randomised trials and observational studies to inform commissioning, continuous learning and quality improvement?

Comment: Localised governance of SA's public hospital system carries responsibilities in meeting the varying and changing health needs of their diverse communities. This increases the need for quality, localised information on health outcomes and the magnitude and distribution

of health change occurring within communities, for example, by targeting interventions among homeless people.

Key assets: SA has expert skills and experiences in some methodological areas relevant to this question. Local applications are less developed however, the service commissioning and contracting environment continues to mature to include a defined health economics component, development of new business models, and new demand for this information.

Action: Develop equity perspectives in randomised trials and observational studies by describing effect (sizes) among population groups before transferring them into an equity-effectiveness framework for decision makers.

Start this process by providing a baseline picture of existing system performance indicators of outcomes and experience and their distribution among people.

Challenge 2. *What will enable our collaborative, equity-informed health economics research agenda?*

2.1. Who are necessary collaborators on equity-informed health economics research?

Comment: A community of practitioners will benefit from: the grounding voice of citizens and consumers; partners across government, particularly central government; and, perspectives from disciplines of economics, ethics, psychology, biostatistics, epidemiology and health informatics.

Key assets: The number of forum participants, their organisational and disciplinary diversity shows SA already has a collective of interested and able people with a shared interest in health equity.

Action: Using the forum attendee list as a guide, approach, then invite delegates to a facilitated meeting to take the next steps in a strategic work program (refer 2.2 below).

2.2. What is the strategic work program for our collaboration?

Comment: Research questions cover many facets and specific projects will cover an array of disease and population topics. A strategic approach can ensure that, as well as focussing on disease and population need, we recognise and prioritise ongoing development of the skills, knowledge and abilities required to realise our vision into the future.

Key assets: Forum presentations and discussion provided concrete starting points for projects addressing variations in health need across organisations (e.g. aged care), clinical specialties (e.g. renal care and organ transplant), health outcome areas (e.g. mortality, health status and morbidity related service use).

Action: Facilitate a meeting of interested individuals, work groups and organisations to review the overarching vision suggested and clarify shared goals. At that meeting, set about developing a supportive structure including a five-year plan focussed on headline inequality targets together with smaller, achievable supporting stepping stones. Examples of target areas include early cancer detection rates, avoidable hospitalisation, child vaccinations rates and medication (mis)use.

2.3. What will inform answers to the research questions now and into the future?

Comment: One critical enabler is person-centred, linked data which is accessible, valid, reliable, and preferably longitudinal across the entire life course. Such data holdings must also continue to develop along with the questions they aim to answer.

Key assets: Forum presentations drawing on digital platforms within Better Start, ROSA, ANZDATA and ACaDS showed quality, longitudinal data collections across the life course exist with the support of SANT DataLink, a data integrating authority, who successfully support collaborations between their partner organisations (government and academia) and wider community. The presentations also reinforced priorities in developing: data coverage by incorporating private hospital records (see Appendices A and B); and, data content by routinising information on patient living arrangements, CALD status, and first/preferred language. Improved shared understanding of the nature and purpose of data collected will improve the validity and reliability of monitoring, analysis and evaluation, and better informed decisions.

Action: Within the strategic planning phase, discuss the development of a purposeful, master-linked data asset. This data repository would support the diverse, but clearly visioned research agenda supporting system reform and innovation.

2.4. How will the research be resourced?

Comment: Tensions exist between service provider's need to balance budgets and seek efficiencies while optimising outcomes. Resourcing new (cost-effective) technologies is often limited to reallocating an existing program budget. A wider, system perspective is possible.

Seed funding is required to draw on existing momentum across far-ranging interests, expertise and activities. The momentum could be directed into shaping a shared, purposeful and applied research plan which coalesces with health portfolio and community goals. The Medical Research Future Fund (MRFF) has key potential for resourcing equity-informing economic research. An essential MRFF criteria demands researchers partner with health services and focus on impact.

Key assets: Longstanding collaborations within the broader SA health portfolio exist. For example, shared interests in actioning equity in health bought people to the forum. Participants' interest and demonstrated commitment is an important asset. Focussing this active involvement onto areas of reform and innovation committed to by Commonwealth and state/territory government and captured as priorities in the planning process is a critical opportunity.

Actions: Investigate alternatives in (existing) allocations across sectors (organisations, work units and disease groupings) according to population need and capacity to benefit from health interventions. Equity considerations could be embedded within this.

Further articulate shared goals and reform areas in the strategic planning exercise, mapping each to the strategic priorities guiding national health reform objectives.

Identify and explore short-term funding for that planning exercise and other priority reform issues. For example, equitable integrated and appropriate care between acute, primary and community-based settings is a broad area directly aligning with all strategic priorities and Objectives 5, 7(a, b, c, f, g, h and i).

Investigate the scope for system wide resource distribution and potentials for increased productivity in the health system aimed at addressing health needs.

2.5. What will sustain the collaboration's people and their program of work?

Comment: South Australia currently has a small health economic workforce with limited capacity for taking on new ventures. The need for a medium to long-term perspective, and limited resourcing immediately highlights the challenge of beginning, then sustaining equity-informed economic research into the future.

Key assets: Training opportunities are available to grow the workforce and skill base, for example through the University of Adelaide's Graduate Certificate/Graduate Diploma and Masters in *Health Economics and Policy.* Other existing segments within the collaboration have a larger scale with skills and capacity to help to nurture and provide supplementary training.

Action: Confirm the availability of the University of Adelaide's coursework and the prospects of internships within collaborating organisations. Given Professor Cookson's offer of support for our research enterprise generally, a further action is to explore student-staff placement with the University of York.