Quantifying the cost of cancer in Australia, and the distribution of these costs by Indigenous status, remoteness, and socioeconomic disadvantage

Thesis submitted by

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Statement of Sources

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education.

Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given. Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

Nicole Bates Date

Statement of Contribution of Others

This project was made successful by a number of funding sources throughout my PhD. I was grateful to be awarded a James Cook University Postgraduate Research Scholarship, which provided a living allowance stipend during my PhD studies.

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This PhD thesis contains a number of published papers, and all persons who contributed to these articles have been included as co-authors. The co-authors for the papers in this thesis are my supervisory team. For each of the publications contained within this thesis, I conceived, designed and planned the study, and undertook the data analysis. All authors contributed to the interpretation of the data, drafting the manuscript, and approved of the final draft. Editorial assistance for this thesis was provided by my supervisors.

Statement of Ethics

This project was conducted in accordance with the National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research, 2007. The work for this thesis is part of a larger project "Quantifying Queensland cancer patients' health service use and costs", which assesses the cost to the healthcare system, and patient out-of-pocket costs, and differences in service use. The larger project received human research ethics approval from Townsville Hospital and Health Service (THHS) Human Research Ethics Committee (HREC) (HREC/16/QTHS/11), Australian Institute of Health and Welfare (AIHW) HREC (EO2017/1/343) and James Cook University (JCU) HREC (H6678). Permission to waive consent to access patient-level data was approved from Queensland Health under the Public Health Act 2005. No identifiable patient information was provided to the authors.

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Abstract

Introduction

Cancer is the leading burden of disease in Australia. Overall cancer survival has improved in the last 30 years; however, there are population groups within Australia whom experience poorer cancer survival. These population groups are Indigenous Australians, people living in remote areas, and socioeconomically disadvantaged persons.

Previous national healthcare expenditure reports, although dated, show the cost of cancer is high. There is a growing body of research estimating the cost of cancer in Australia by cancer type, or element of care; but there are limited studies regarding the national cost of cancer, or the distribution of these costs by population groups. It is important to understand the cost of cancer in order to efficiently allocate resources in a tight fiscal environment.

The objective of this PhD was to estimate the cost of cancer in Australia, with a particular focus on the distribution of these costs by Indigenous status, remoteness, and socioeconomic disadvantage. The aims were: 1) to quantify the direct costs to the public healthcare system and patient co-payments for the first 12-months following diagnosis, and to determine the distribution of these costs by Indigenous status, remoteness, and socioeconomic status; 2) to quantify the annual indirect costs due to changes in labour force participation of people with cancer; and 3) using female breast cancer as a case study, to quantify the direct costs to the public healthcare system and individual for the first three years post-diagnosis, and the distribution of these costs by Indigenous status, remoteness, and socioeconomic disadvantage.

Methodology

Two datasets were utilised in this PhD. The first was a model based on linked administrative data, *'CancerCostMod'* (addresses aims 1 and 3), and the second was the 2015 Survey of Disability, Ageing and Carers (SDAC) (addresses aim 2).

CancerCostMod

The base population for CancerCostMod is a census of all patients with a new cancer diagnoses reported to the Queensland Cancer Registry between 01JUL2011 and 30JUN2012 (n=25,553). Each individual record was then linked to the individual's Queensland Health Admitted Patient Data Collection, Emergency Department Information System, Medicare Benefits Schedule (MBS), and Pharmaceutical Benefits Scheme (PBS) records, to facilitate extraction of three full years of data following diagnoses. The base population was then weighted to represent the Australian population

of cancer patients with a new cancer diagnosis using a programmed SAS macro (GREGWT) (weighted n=123,900).

Costs were assigned to each hospital inpatient separation and emergency department presentation based upon costs reported by the Independent Hospital Pricing Authority. Costs for MBS services and PBS datasets were included in the dataset. All costs are reported in Australian dollars, and were adjusted to the 2016-17 financial year.

For aim 1, the total cost of cancer in the first 12-months following a cancer diagnosis was calculated by five cost categories: admitted and non-admitted hospital episodes, ED presentation, MBS rebate, PBS rebate, and patient co-payments. For aim 3, costs were aggregated in six-month periods from date of diagnosis to 36-months following diagnosis of breast cancer for the same cost categories, except patient co-payments were further split into MBS co-payments and PBS co-payments.

2015 SDAC

The SDAC is a national survey conducted every three years by the ABS. For this study, the dataset was limited to people of working age (25-64 years). The participants were assigned to one of three health groups: no long-term health condition (LTHC), those who identified cancer as a LTHC, and those with any other LTHC.

Results

Aim 1: Direct costs of cancer in Australia during the first 12-months post-diagnosis

The total cost to the public healthcare system was $4.8 billion and the total patient co-payments was $127 million during the first 12-months post-diagnosis. After adjusting for sex, age at diagnosis and broad cancer type, significant differences in costs were observed in relation to Indigenous status, remoteness and socio-economic status within the first year post-diagnosis. The costs of admitted and non-admitted hospital episodes were higher for people living outside of metropolitan areas, and lower for people from the least disadvantaged quintiles (Q4-5). Costs related to ED presentation were higher in Indigenous Australians. MBS rebate costs were lower among Indigenous Australians, and people living in remote areas, but higher in people living outside of the most disadvantaged quintile. PBS rebate costs were lower for Indigenous Australians, but higher for people living in remote areas, and people living outside the most disadvantaged areas. Patient co-payments were lower for Indigenous Australians and people living in regional areas, and higher in people living in areas of lower deprivation (Q4-5).

Aim 2: Annual indirect cost of cancer in Australia

The 2015 SDAC included 34,393 participants of working age (weighted N=12,387,800). Approximately half (46%) of participants with cancer were not in the labour force, resulting in an approximately $1.7 billion reduction in gross domestic product. Of people in the labour force, people with no long-term health conditions were 3.0 times more likely to be employed full-time compared to people with cancer. Amongst people with cancer, people without a tertiary qualification were 3.7 times more likely to be out of the labour force compared to people with a tertiary qualification.

Aim 3: Breast cancer case study

In Queensland, 3,080 women were diagnosed with breast cancer between July 2011 and June 2012, representing approximately 15,335 Australian women once weighted. The costs of admitted and non-admitted hospital episodes were higher for Indigenous women than non-Indigenous women, and women from the most disadvantaged quintile compared to those living in the least disadvantaged quintile. There was no consistent trend in the cost differences for hospital episodes by remoteness. For cost of ED presentations and MBS rebates paid, there were some differences, but no consistent trends in relation to remoteness, Indigenous status and socio-economic status. For PBS rebates paid, costs were lower for Indigenous women than non-Indigenous women during months 7-to-12 and 13-to-18, higher in women living in regional verse metropolitan areas during the first 12-months, and lower for women living outside the least disadvantaged quintile (Q5) during the first 12-months.

The patient co-payments for MBS services were lower for Indigenous verse non-Indigenous women during the first 12-months, and for women living in the most disadvantaged quintiles. Patient co-payments paid for PBS prescriptions were consistently lower for Indigenous women compared to non-Indigenous women, and for women living outside of the least disadvantaged quintile. There was no difference in the MBS or PBS patient co-payments paid by remoteness.

Conclusion

This is the first Australian study to describe the distribution of costs to the public healthcare system and individual by Indigenous status, remoteness, and socioeconomic disadvantage. The findings presented in this thesis demonstrate differences in both public healthcare system costs, and patient co-payment costs for these three population groups. The findings are robust because linked data from several large, population-based administrative databases were used, thereby minimising selection bias and measurement bias. These results are of particular importance for policy makers to ensure equitable allocation of healthcare resources throughout Australia. Future studies should aim to identify if there are any differences in service use and access for these population groups which are driving these differences in costs.

List of Publications

This thesis contains a number of chapters which have been published or submitted. Chapter One contains a summary of these publications, and the thesis outline. Below is a list of publications contained within this thesis, and other publications and conference abstracts accepted during the candidature.

Thesis publication details

1. Bates N, Callander E, Lindsay D, Watt K. Quantifying the hospital costs for women diagnosed with breast cancer in Australia. *Under review.* 2019.
2. Bates N, Callander E, Lindsay D, Watt K. Estimating the out-of-hospital costs for Australian women diagnosed with breast cancer. *Under review.* 2019.
3. Bates N, Callander E, Lindsay D, Watt K. Patient co-payments for women diagnosed with breast cancer in Australia. Supportive Care in Cancer. 2019. doi: https://doi.org/10.1007/s00520-019-05037-z
4. Bates N, Callander E, Lindsay D, Watt K. Correction to: CancerCostMod: a model of healthcare expenditure, patient resource use, and patient co-payment costs for Australian cancer patients. Health Economics Review. 2019; doi: 10.1186/s13561-019-0219-9
5. Bates N, Callander E, Lindsay D, Watt K. CancerCostMod: a model of healthcare expenditure, patient resource use, and patient co-payment costs for Australian cancer patients. Health Economics Review. 2018; 8:28. doi: https://doi.org/10.1186/s13561-018-0212-8
6. Bates N, Callander E, Lindsay D, Watt K. Labour force participation and the cost of lost productivity due to cancer in Australia. BMC Public Health. 2018; 18(1): 375. doi: https://dx.doi.org/10.1136/bmjopen-2016-014030

Other publications during candidature

1. Callander E, Bates N, Lindsay D, Larkins S, Preston R, Topp S, Cunningham J, Garvey G. The patient costs associated with accessing healthcare for people diagnosed with cancer: the experience of Indigenous and non-Indigenous Australians. Asia Pac J Clin Oncology. 2019; doi: 10.1111/ajco.13180
2. Callander E, Bates N, Lindsay D, Larkins S, Preston R, Topp SM, Cunningham J, Garvey G. Long-term out of pocket expenditure of people with cancer: comparing health service cost and use for Indigenous and non-Indigenous people with cancer in Australia. International Journal for Equity in Health. 2019; 18:(1) doi: https://doi.org/10.1186/s12939-019-0931-4

3. Callander E, Topp SM, Larkins S, Sabesan S, Bates N. Quantifying Queensland patients with cancer health service usage and costs: Study protocol. BMJ Open. 2017; 7(1):e014030 doi: http://dx.doi.org/10.1136/bmjopen-2016-014030
4. Turner D, Harrison S, Bates N. Sun-protective behaviours at inter-school swimming carnivals in a tropical region experiencing high ambient solar ultraviolet radiation. Frontiers in Public Health. 2016; 4: 168 doi: 10.3389/fpubh.2016.00168

Conference abstracts during candidature

1. Bates N, Callander E, Lindsay D. Estimation of the direct costs of hospital admitted cancer patients in Queensland. Australasian Tropical Health Conference; 2017; Cairns, Queensland, Australia.
2. Bates N, Callander E, Watt K, Lindsay D. Quantifying the direct costs associated with inpatient oncology services in Queensland, Australia. 12th World Congress of the International Health Economics Association; 2017; Boston, Massachusetts, USA.
3. Bates N, Emeto T, Turner D, Nikles J, Harrison S. Sun-protective behaviours of primary school students at swimming carnivals in Townsville. Townsville Health Research Week; 2016; Townsville QLD, Australia.

Table of Contents

List of Abbreviations

AATSIHS	Australian Aboriginal and Torres Strait Islander Health Survey
ABF	Activity based funding
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AR-DRG	Australian Refined Diagnostic Related Group
ARIA	Accessibility/Remoteness Index of Australia
ASGC	Australian Standard Geographic Classification
ASGS	Australian Standard Geographic Standard
AUD	Australian dollar
COSA	Clinical Oncological Society of Australia
CTG	Closing the Gap
DVA	Department of Veteran's Affairs
ED	Emergency Department
EDIS	Emergency Department Information Systems
FT	Full-time
FTE	Full-time equivalent
GDP	Gross Domestic Profit
GP	General Practitioner
HPV	Human papillomavirus
HREC	Human Research Ethics Council
NICE	National Institute for Health and Care Excellence
ICD-10-AM	International Classification of Diseases 10th Edition, Australian Modification
ICD-O3	International Classification of Diseases for Oncology, 3rd Edition

IEO	Index of Education and Occupation
IER	Index of Economic Resources
IHPA	Independent Hospital Pricing Authority
IQR	Interquartile range
IRSAD	Index of Relative Socio-Economic Advantage and Disadvantage
IRSD	Index of Socioeconomic Disadvantage
JCU	James Cook University
LFP	Labour Force Participation
LGA	Local Government Area
LTHC	Long-term health condition
MBS	Medicare Benefits Schedule
MI	Multiple Imputation
MSAC	Medical Services Advisory Committee
NBSCP	National Bowel Cancer Screening Program
NCSP	National Cervical Screening Program
NHCDC	National Hospital Cost Data Collection
NHS	National Health Survey
NILF	Not in the labour force
NSW	New South Wales
OECD	Organisation for Economic Cooperation and Development
OOP	Out-of-pocket
OOPE	Out-of-pocket expenditure
PBAC	Pharmaceutical Benefits Advisory Committee
PBS	Pharmaceutical Benefits Scheme
PHDB	Private Hospital Data Bureau

PHI	Private Health Insurance
PT	Part-time
QCR	Queensland Cancer Registry
QHAPDC	Queensland Health Admitted Patient Data Collection
SDAC	Survey of Disability, Ageing, and Carers
SEIFA	Socioeconomic Indexes for Areas
TNM	TNM Classification of Malignant Tumours
URG	Urgency Related Group

PART 1: INTRODUCTION AND LITERATURE REVIEW

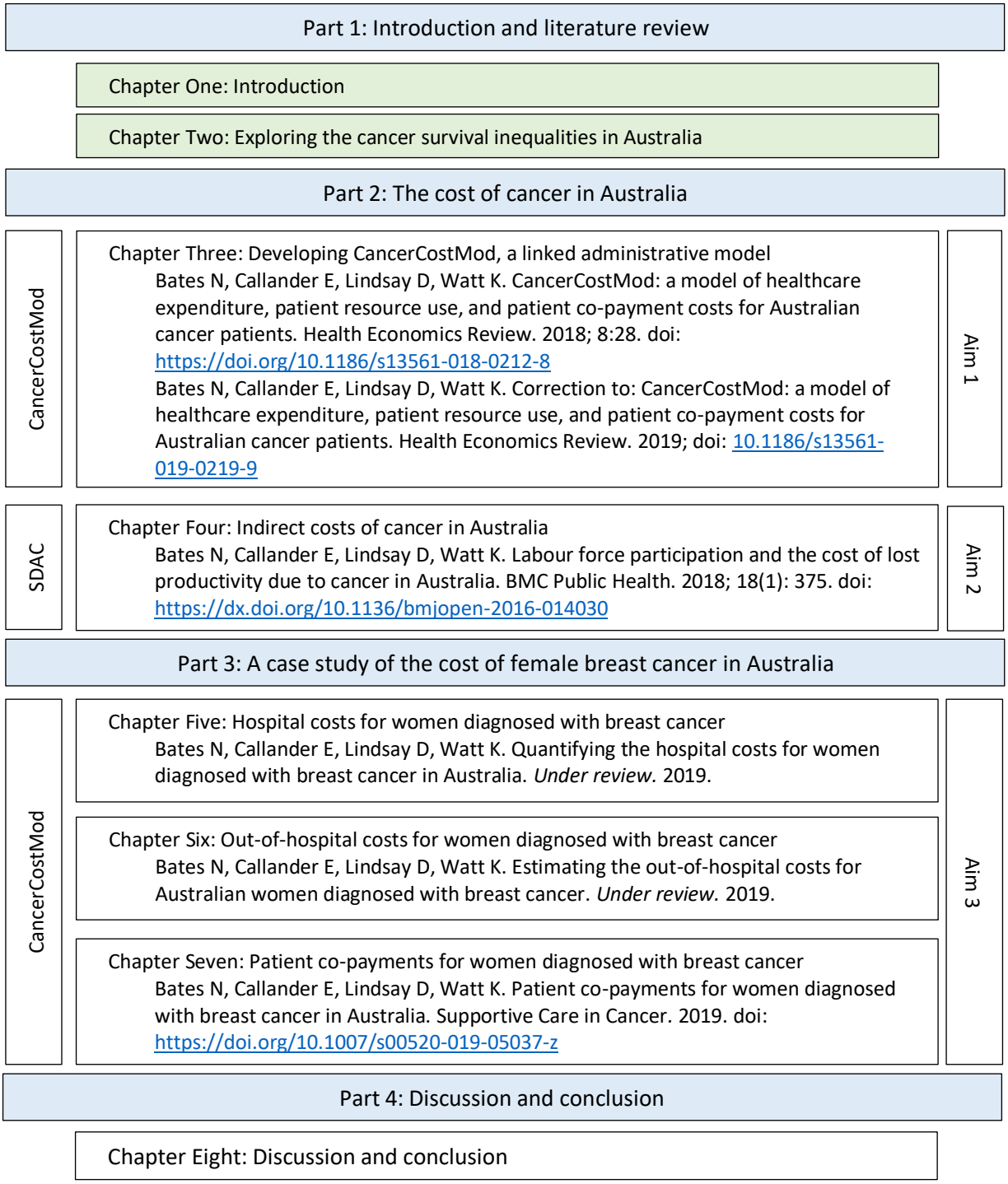

Figure 1: Thesis outline

Chapter One: Introduction

Background

Cancer was the leading contributor to the burden of disease in Australia in 2011, accounting for 19% of the total burden.[1] The majority (94%) of the burden from cancer was due to premature death.[1] In 2019, it is anticipated that an estimated 144,713 new cases will be diagnosed in Australia,[2] with prostate cancer and breast cancer the most commonly diagnosed cancers for males and females respectively.[2] The number of new cases of cancer is rising due to increasing cancer rates and an ageing population.[2, 3] Fortunately, survival following a cancer diagnosis is improving in Australia.[2, 4] The overall five-year relative survival rate has improved from 50% in 1986-1990 to 69% in 2011-2015.[2] Cancer of the testes, thyroid, and prostate had the highest five-year relative survival rates, and cancers of the pancreas, other digestive organs, and mesothelioma had the lowest five-year relative survival rates in Australia.[2] However, despite improvements in the national survival rates, it is well documented that some population groups experience poorer survival. Specifically, Aboriginal and Torres Strait Islanders (hereafter, respectfully referred to as Indigenous Australians), socioeconomically disadvantaged persons, and people living in remote and very remote areas.[2]

Reflective of this high burden of disease within Australia, the costs associated with cancer are also considerable with expenditure on cancer and other neoplasms accounting for $4,858 million to the healthcare system in 2008-09.[5] This is equivalent to 7% of total health system expenditure on chronic disease during this time.[5] Due to the increased incidence rates of cancer, as well as emerging cancer therapies and new technologies, the cost of cancer is expected to increase in the future.[6-8] In a tight fiscal environment, it is important to understand the economic burden of cancer for policy makers to efficiently allocate resources for prevention and treatment. The economic burden of cancer can be divided into direct and indirect costs. The direct costs are further divided into direct medical and direct non-medical costs, and are any costs that relate directly to the medical condition. Direct medical costs include the cost of diagnosis, treatment, and care, and direct non-medical costs include the costs of accessing this medical treatment, such as transport, relocation, etc.[9] Indirect costs consist of the lost productivity due to morbidity or premature mortality, and can include paid work, or unpaid work (such as household activities, childcare, caring for others, or volunteer work).[9-11] Although the direct cost of treating cancer is high,[5] the indirect cost of cancer may exceed the direct costs of cancer.[6, 12-16] Therefore, it is important to consider both the direct and indirect costs of cancer, which may be used to develop cost projections, and to assist policy makers in budgetary and service design planning for the future.

Within Australia the direct costs of healthcare may be incurred by the state and federal governments, individuals, private health insurers and accident and injury compensation companies. These costs are distributed in line with the structure of the Australian healthcare system. Briefly, Australia has a universal healthcare system, Medicare, which provides free medical treatment in a public hospital, and free or subsidised medical treatment outside of hospitals. Medicare is funded by the Australian government. Private health insurance is optional for individuals and families. Some medical treatment outside of hospitals are provided under the Medicare Benefits Schedule (MBS), where Medicare pays a proportion of the fee to the medical provider (known as a Medicare rebate) and individuals may incur an out-of-pocket (OOP) co-payment. These services include General Practitioner (GPs), specialist services, some imaging and pathology, optometry, and some allied health services.[17] The Pharmaceutical Benefits Scheme (PBS) provides approved medications at a subsidised rate with a valid prescription.[17] National healthcare expenditure reports commonly provide the costs for hospitalisations, out-of-hospital services, and PBS services separately.[5, 18] Many studies also use these three categories, and may also identify the costs incurred by the individual.

In this introductory thesis chapter, the costs of cancer (direct and indirect) in Australia will be described, followed by the rationale and aims of the thesis, and thesis structure. The cancer survival inequalities in Australia experienced by different sub-populations are described in Chapter Two.

Direct costs of cancer

The Australian Institute of Health and Welfare (AIHW) estimated that the direct cost of cancer to the healthcare system was $4.5 billion (excluding population screening) in 2008-09. This was an increase from $2.9 billion in 2000-01. In 2008-09, approximately 79% of the total costs was spent on hospital-admitted patient services, 9% on out-of-hospital expenditure (including general practitioner, imaging, pathology and other medical services), and 12% on prescription pharmaceuticals. The cancers with the highest expenditures were prostate cancer in males and breast cancer in females.[5] However, this report is now a decade old, and does not identify the distribution of this expenditure across population groups with known poorer outcomes.

More recently, the AIHW and Cancer Australia published a report *'Cancer in Aboriginal and Torres Strait Islander peoples of Australia: An overview'*.[18] This report estimated that the total Australian expenditure for hospitalisations where cancer was the principal diagnosis in 2010-11 was $4,021.1 million.[18] The average per person hospital expenditure for Indigenous Australians was 0.5 times lower than non-Indigenous Australians.[18] This report included only admitted patient services for both public and private hospitals, and may potentially be an underestimate of the total cost of hospitalisations. In Australia, oncology services may also include non-admitted patient services in which the patient

may receive care in the hospital as a day patient, and thus never be included in the admitted patient data collection.

Other previous Australian studies have identified the direct costs of cancer to the healthcare system for specific cancer types such as prostate cancer,[19-21] lung cancer,[22] and oesophageal cancer,[23] melanoma;[24] or limited to an element of care, such as the cost of chemotherapy,[25] or end of life care.[26] There is growing utilisation of linked administrative data to estimate the cost of cancer to the healthcare system. There have been two recent papers published, which identify the OOP costs, and Medicare rebates using linked individual-level data. Both studies included participants from a large Queensland study (QSkin Sun and Health Study), linked to the Queensland Cancer Registry (QCR), MBS and PBS claims data.[27, 28] Both of these studies included the cost to the healthcare system (for rebates paid by Medicare) and the patient co-payments paid (the patient co-payments will be discussed in more detail shortly). The first study included 452 participants from the QSkin Study who were diagnosed with one of the five most commonly diagnosed cancers in Queensland (breast, prostate, melanoma, colorectal, and lung cancer). The median Medicare rebate was $6,280 during the first two-years following diagnosis for the five cancers combined. During the first two-years from diagnosis, lung cancer accounted for the highest provider fees, followed by breast cancer.[27] The second study included 419 individuals diagnosed with one of the five major cancers (from the QSkin Study), and matched separately to 419 high GP users (individuals without cancer, but with chronic medical conditions), and 421 participants from the general population.[28] Compared to high GP users, and the general population, people with one of the five commonly diagnosed cancers had significantly higher median provider fees.[28] In addition to these studies, Goldsbury et al.[29] utilised linked administrative data from MBS, PBS, Hospital Admitted Patient Data Collection, and Emergency Department Data Collection to estimate the excess cost[1] of all cancer. The cohort for this study was Australians aged 45 years and older with cancer, matched to non-cancer controls. The authors estimated that the excess cost of cancer for people diagnosed between 2009-2013 was $6.3 billion in 2013.[29] To date, no Australian study has identified the distribution of cancer cost among those experiencing poorer health outcomes. The use of individual-level administrative data may be used to estimate the distribution of cost by patient characteristics.

In addition to the costs to the healthcare system, the cost of cancer can also be evaluated from the individual's perspective. The cost to the individual includes the direct and indirect costs.[9] Direct medical costs may include the OOP cost to the patient that directly relates to their health care, such

[1] The excess costs of a disease is estimated by calculating the difference in costs between people with a condition and people without the condition, usually matched controls

as medical services, medications, medical aids, and pathology, while direct non-medical costs may include transport, accommodation, parking, and childcare.[9] The indirect costs to the patient may include costs of lost productive time, such as lost wages, lost time completing household activities, or forgone time with friends, family and completing other activities.[9]

In Australia, the OOP fees accounted for 20% of health expenditure, which was equal to the Organisation for Economic Cooperation and Development's (OECD) average (20%) in 2015. However, this is still higher than other developed countries including France (7%), the United Kingdom (15%), New Zealand (13%), and Canada (15%).[30] A recent study showed that 21% of Australians with cancer don't access healthcare due to the cost.[31] There is growing concern that people diagnosed with cancer have high OOP costs, and are facing financial hardship.[27, 32-36] The term 'financial toxicity' was coined to describe the high costs of accessing medical care for people diagnosed with cancer.[37] Zafar and colleagues described financial toxicity as a type of adverse effect of cancer treatment.[37]

A number of Australian studies have identified the high OOP costs for cancer patients.[27, 32, 36, 38-40] However, only two studies have compared the OOP costs by geography. The first compared the OOP costs by distance travelled from home to the Townsville Hospital Cancer Centre in North Queensland, Australia. This study found that people living more than 100km away from the treatment centre had greater OOP costs compared to those living 100km away or closer.[36] The second study (conducted in Western Australia) reported that people living in a region with a Comprehensive Cancer Centre had lower OOP costs than those living outside of this region.[38] This study did not include analysis by geographical remoteness, or distance travelled, which makes it difficult to generalise to the Australian population. To the author's best knowledge, only two studies have evaluated the patient OOP costs by Indigenous status,[41, 42] and no studies have evaluated the patient OOP costs by socioeconomic status.

The majority of the studies evaluating OOP costs have relied on self-reported data through surveys.[32, 36, 38, 40] The use of self-reported data does have some inherent weaknesses. These include the accuracy of patient recall, and the recruitment of patients to the study which may potentially exclude those who have passed away, or those who are not well enough to participate in the study. The use of administrative data may overcome the limitation regarding accuracy of patient recall associated with self-reported data.[43] However, a limitation of using administrative data to capture OOP costs is that it currently only includes patient co-payments. It does not include other OOP costs, such as private medications or medical services, medical aids, travel, accommodation, and parking. To date, four Australian studies have used linked administrative data to estimate the patient co-payments by people with cancer. The two studies which evaluated the OOP cost by Indigenous status utilised the

linked administrative data and the candidate was part of the research team. Callander et al.[41] found that Indigenous Australians diagnosed with cancer had lower OOP expenditure compared to their non-Indigenous counterparts during the first three years post-diagnosis. However, Indigenous Australians also had fewer Medicare services compared to non-Indigenous Australians.[41] The second study found that Indigenous Australians had significantly lower patient co-payments in the first 6 months (61% less), and during months 7-to-12 (63% less) compared to non-Indigenous Australians. Indigenous Australians also had significantly fewer hospitalisations compared to non-Indigenous Australians.[42] Two Queensland studies were from the QSkin Study. The first study described the patient co-payments for 452 QSkin Study participant. Of the five major cancers, breast cancer conferred the highest median co-payments ($4,192; IQR: $1,165 - $7,459), followed by prostate cancer ($3,175; IQR: $971 - $3,619).[27] The second study using QSkin participants, matched to high GP users, and the general population found that the OOP costs were significantly higher for people with cancer, compared to people in the high-GP user group, and the general population group.[28]

Indirect costs of cancer

In addition to the direct costs of healthcare, there are significant indirect costs.[6, 12-15] Approximately 40% of Australians diagnosed with cancer in 2017 were of working age (25 to 64 years).[44] It is not surprising that a cancer diagnosis leads to temporary or permanent changes in labour force participation.[45] Using the 2003 Survey of Disability, Ageing and Carers (SDAC), Schofield et al.[46] reported that 49% of 45 to 64 year olds with cancer were not in the labour force.[46] Another Australian study found that of those employed prior to their diagnosis, 67% of participants reported a change in their employment, and 64% reported that their household income had reduced following a cancer diagnosis.[47] Although these changes in labour force participation have an effect on the national economic growth, there is also a significant impact to the individual and their families through lost income. The definition of financial toxicity has grown, and now encompasses the high cost of accessing care, and the impact that reduced income has on the individual and/or household.[48, 49]

Globally, there is increasing evidence of the substantial cost of lost productivity due to premature mortality.[16, 50-53] This is an emerging field of research in Australia. Carter and colleagues[54] estimated that 88,000 working years were lost due to premature deaths from cancer in 2003, accounting for approximately $4.2 billion in lost income.[54] Another report estimated that the total lifetime productivity cost for Australian adolescents and young adults diagnosed with cancer in 2016 was $508.4 million.[55] Other Australian studies have evaluated the indirect cost of individual cancers,[40, 56] or for a single state in Australia.[12]

Gaps in the literature

The cost of cancer to the healthcare system is expected to rise. A recent Lancet Oncology Commission found that health system expenditure in many countries has increased due to the rising costs of treatment (i.e. chemotherapy and radiotherapy), and an increased use and cost of imaging (such as PET and MRI scans).[6] In Australia, the national expenditure on cancer is expected to rise to $10.1 billion by 2033.[7] The PBS expenditure on anticancer drugs rose from $64.8 million in 1999-2000 to $466.3 million in 2011-12.[57] This was a 19.1% increase per year, compared to 9.0% increase for all other drugs combined.[57] Between 2000 and 2012, 23 new anticancer medications were listed on the PBS.[57] In Australia, all medications, or any revisions to medications currently on the PBS[2] must undergo a review by the Pharmaceutical Benefits Advisory Committee (PBAC) before it is listed on the PBS. The review process considers the medical condition which it is listed for, the clinical effectiveness, safety, and cost-effectiveness.[58] There are several factors which have led to the rise in PBS expenditure, including the increase in the number of PBS listings, and the high cost paid for these medications.[57] Pharmaceuticals are expected to continue to rise due to advances in targeted cancer therapy.[6, 8, 57]

Although the cost of cancer is increasing,[5-8] there are only a finite amount of resources to fund the healthcare system within Australia, necessitating choices to be made about what to fund. Furthermore, there is a paucity of studies in Australia identifying the distribution of costs by population groups experiencing poorer health outcomes, specifically Indigenous Australians compared to non-Indigenous Australians, people living in different areas of remoteness, and socioeconomically disadvantaged people. The direct and indirect costs of cancer need to be understood, in order to predict future expenditure, and to ensure equitable allocation of future resources. There are examples in Australia and internationally where costs have an important place alongside clinical effectiveness, and safety in approvals for funding recommendations for pharmaceuticals or medical services.[58-60] In Australia, the PBAC Guidelines require that applications for submission include either a full cost-effectiveness analysis or a cost minimisation economic evaluation.[58] The PBAC Guidelines include descriptions of what to include in the economic evaluation. For example, to determine the cost of medical services, the MBS scheduled fee for the item should be used, or for hospital services, the average cost weight should be applied to the Australian refined diagnostic related group (AR-DRG).[58] The Medical Services Advisory Committee (MSAC) also require applications to evaluate the cost-effectiveness of medical services.[60] Similarly, the United Kingdom's

[2] Changes may include revision of the current dose or eligible patients, changes to formulation, changes to the current listing etc

National Institute for Health and Care Excellence (NICE) guidelines evaluate evidence for both the effectiveness and cost-effectiveness to make decisions.[61]

Administrative data may be used to identify costs of cancer. Administrative data is routinely collected by a number of Government agencies throughout a person's cancer journey. Data linkage allows researchers to consolidate these various sources of data to develop a single dataset. The 2012-13 Productivity Commission's Annual Report recommended greater use of administrative data in research to evaluate policy efficacy.[62] The AIHW's Australia's Health, 2018 report identified that a number of knowledge gaps may be filled by making use of existing data, and linking data from various agencies.[63]

Thesis rationale

Improving cancer outcomes for all Australians remains a national health priority.[64] The 2015 National Aboriginal and Torres Strait Islander Cancer Framework identified seven priorities to improve quality cancer care for Indigenous Australians and thus, improving cancer outcomes.[65] One of the priorities was to "strengthen the capacity of cancer related services and systems to deliver good quality, integrated services that meet the needs of Aboriginal and Torres Strait Islander peoples"[65(p19)]. Additionally, the most recent national healthcare expenditure reports are now potentially out of date. The current Cancer Australia's Strategic Plan calls for action to ensure that 'all Australians receive accessible, best practice diagnosis and cancer care'.[66 (p15)] However, it is well known that some population groups have poorer outcomes. The AIHW Cancer in Australia reports regularly identify their key population groups as Indigenous Australians, state and territory populations, people living in different remoteness areas, and people living in different socioeconomic disadvantaged areas.[2, 44] Many factors have been identified in the literature in contributing to these poorer outcomes (discussed further in Chapter 2); however, to date, there are limited studies which have explored the distribution of cancer expenditure (as measured by costs) for these population groups. It is possible that the distribution of costs to the healthcare system and individual may contribute to the existing literature describing the inequalities in cancer outcomes by indicating poorer access to health services. In order to determine if there are any inequities in the distribution of the costs, and thus the investment in health care of patients, it is important to quantify the costs by population group. There are several benefits to using individual level administrative data. The first is that it captures all health service use for each individual and therefore may be used to identify the distribution of cost by patient characteristics. The second advantage is that it overcomes potential limitations of self-reported data from participants as outlined previously.

Research aims

The purpose of this thesis is to quantify the cost of cancer in Australia, thus providing more recent estimates of the total cost of cancer from a healthcare and individual perspective. This thesis will also be the first to describe the distribution of the costs of cancer by Indigenous status, remoteness, and socioeconomic disadvantage. If there are differences in the distribution of costs, this will be further investigated in post-doctoral work. In order to estimate the cost of cancer in Australia, linked administrative data are used in this thesis, thus meeting recommendations from the Productivity Commission and the AIHW. In this PhD, costs are calculated from different perspectives, in order to provide an estimate of the cost of cancer to the public healthcare system, society, and the individual patient.

The specific aims of this thesis are:

1. To quantify the direct costs to the Australian public healthcare system and patient co-payments for the first 12-months following diagnosis, and to determine the distribution of these costs by Indigenous status, remoteness, and socioeconomic status;
2. To quantify the annual indirect costs in Australia due to changes in labour force participation of people with cancer; and
3. Using female breast cancer as a case study, to quantify the direct costs to the Australian public healthcare system and individual for the first three years post-diagnosis, and to determine the distribution of these costs by Indigenous status, remoteness, and socioeconomic disadvantage.

Populations groups of interest

In this thesis, three population groups were identified as experiencing poorer survival, which is further detailed in the Literature Review (Chapter 2): Indigenous Australians, socioeconomically disadvantaged persons, and people living in remote and very remote areas. The terminology used in this thesis for each of these population groups is outlined below. Although other population groups experience differences in cancer outcomes, the three population groups outlined above were chosen for several reasons: 1) they are the key population groups identified in national cancer reports; 2) these population groups are identifiable using administrative data; and 3) these population groups should have suitable sample sizes for analysis.

Indigenous Australians included Australian Aboriginal and/or Torres Strait Islander persons, and was compared to non-Indigenous Australians. A common limitation in Australia is the incomplete recording of Indigenous status in health and vital registration data collections.[67, 68] The Australian

Cancer Database considers five jurisdictions to have sufficient completeness for reporting purposes, New South Wales, Victoria, Queensland, Western Australia and the Northern Territory.[44] This is important to note, as the Australian cancer statistics may underestimate the incidence of cancer for Indigenous Australians.

In Australia, there are several ways to define geographical remoteness. The Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS) commonly use the Accessibility/Remoteness Index of Australia (ARIA), Australian Standard Geographical Classification (ASGC) or Australian Standard Geographical Standard (ASGS). ARIA is a measure of remoteness based on road distance measurements to the nearest Service Centre category.[69] ARIA consists of five categories: highly accessible, accessible, moderately accessible, remote, and very remote.[70] The ASGS replaced the ASGC in 2011. The ASGS has five categories of remoteness: metropolitan, inner regional, outer regional, remote, and very remote.[71] Existing literature use a number of definitions for geographical remoteness, including collapsing the above ARIA or ASGS categories into two or three categories, for example: major cities or metropolitan areas, and areas outside of major cities or metropolitan areas.

For the main dataset used within this thesis, CancerCostMod, ASGS was chosen as the measure of remoteness as it was possible to map the postcode to the ASGS. In the development of CancerCostMod, the, postcode of residence was mapped to ASGS to provide an area of remoteness. The categories were collapsed from the five ASGS categories to three categories: metropolitan, (inner and outer) regional, and remote (and very remote) due to sample size and comparability with previous works, including the AIHW reports.

The ABS developed Socio-Economic Index for Areas (SEIFA), which is a measure of relative advantage and disadvantage.[72] SEIFA contains four indices:

- Index of Relative Socio-Economic Disadvantage (IRSD) summarises the economic and social conditions of people and households in an area. A low score indicates relative disadvantage, and a high score indicates a lack of disadvantage;[72]
- Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) summarises the economic and social conditions of people and households in an area but includes both relative advantage and disadvantage. A low score indicates the most disadvantaged, and a high score indicates the most advantaged;[72]
- Index of Education and Occupation (IEO) is a measure of the level of education and occupation, where a low score indicates relatively lower education and occupation, and a high score indicates a higher level of education and occupation;[72] and

- Index of Economic Resources (IER) uses variables relating to income and wealth, but excludes education and occupation. A low score indicates the most disadvantaged, and a high score indicates the most advantaged. [72]

During the development of the PhD proposal, it was noted that IRSD was commonly used in previous Australian studies and reports,[2, 73-76] therefore, IRSD was chosen as the measure of socioeconomic disadvantage to enable comparison to other Australian studies, and governmental reports.[2] In the development of CancerCostMod, the postcode of residence was mapped to IRSD. IRSD deciles were collapsed into quintiles, where Q1: most disadvantaged and Q5: least disadvantaged. This was due to sample size and to ensure comparability with previous works.

Thesis structure

This thesis contains four parts, and eight chapters. A brief outline of each of the parts and chapters is presented below. A number of chapters comprise peer-reviewed articles which have been published, or are currently under review. A full list of publications contained within this thesis is described previously (page viii) and in Figure 1 below (page 14).

Part 1: Introduction and literature review (Chapters One and Two)

Part 1 comprises two chapters. Chapter One provides a background on the cost of cancer in Australia, and concludes with the rationale, structure and aims of the thesis. Chapter Two is a literature review about the health inequalities, and specifically inequalities in cancer survival, observed by Indigenous status, remoteness, and socioeconomic disadvantage.

Part 2: The cost of cancer in Australia (Chapters Three and Four)

Part 2 of the thesis comprises Chapters Three and Four, and addresses aims 1 and 2. In Part 2, the focus is on all cancer types and the 12 months following diagnoses. In Chapter Three, the development of the microsimulation model, *CancerCostMod*, which is the primary dataset used in this thesis, is described. This is the first publication of the thesis. Also in this chapter, the costs to the public healthcare system in the first 12 months following diagnosis for all cancer types are quantified. This PhD is nested in a larger project, "Quantifying Queensland cancer patients' health service use and costs". The original project aimed to identify the patient OOP costs and distribution of these costs by population groups using linked administrative data. The project was expanded to include the aims of this thesis.

The fourth chapter consists of the second publication of the thesis, which is an examination of the labour force participation rates of people with cancer to measure the annual indirect costs of all

cancer types in Australia. This chapter only addresses a small part of the indirect costs of cancer, specifically the cost of lost productivity due to morbidity using the 2015 SDAC. This nationally representative survey was chosen as it had the potential to identify labour force participation rates for people with cancer, which could then be used to measure the annual indirect costs due to morbidity. Conducting a full study on the indirect costs of cancer, including lost productivity costs due to morbidity and mortality were beyond the scope of this PhD.

Part 3: A case study of the cost of female breast cancer in Australia (Chapters Five, Six, and Seven)

The third part of the thesis comprises three chapters (each chapter is a separate manuscript, these are currently under review or published), and addresses aim 3. The focus is on female breast cancer as a case study, and costs in the 36-months following diagnoses are examined in greater depth. Breast cancer is the most commonly diagnosed cancer for women worldwide,[77] and in Australia.[2] Accordingly, it was chosen as the case study for the remainder of this thesis. Although males can develop breast cancer, the proportion is much lower, and thus all analyses in this part of thesis are limited to female breast cancer only. The public healthcare system expenditure for hospital presentations are examined in Chapter Five, and for MBS and PBS Government rebates in Chapter Six. Chapter Seven is an investigation of the patient co-payments for MBS services and PBS prescriptions.

Part 4: Discussion and conclusion (Chapter Eight)

The final part of the thesis presents a synthesis of the main findings of the thesis in the context of relevant literature and the strengths and limitations of the overall programme of research. Recommendations for policy, practice and research are provided.

List of publications

Five of the chapters within this thesis comprise published works, or works under review. For each of the papers contained within this thesis, I am the primary author. Details of the publications are summarised in the diagram below of the thesis structure. For chapters which comprise of or contain a published article, the original article has been inserted into the chapter as published, thereby retaining the formatting and referencing of the journal. These chapters contain a brief introduction and conclusion to contextualise the research in this thesis.

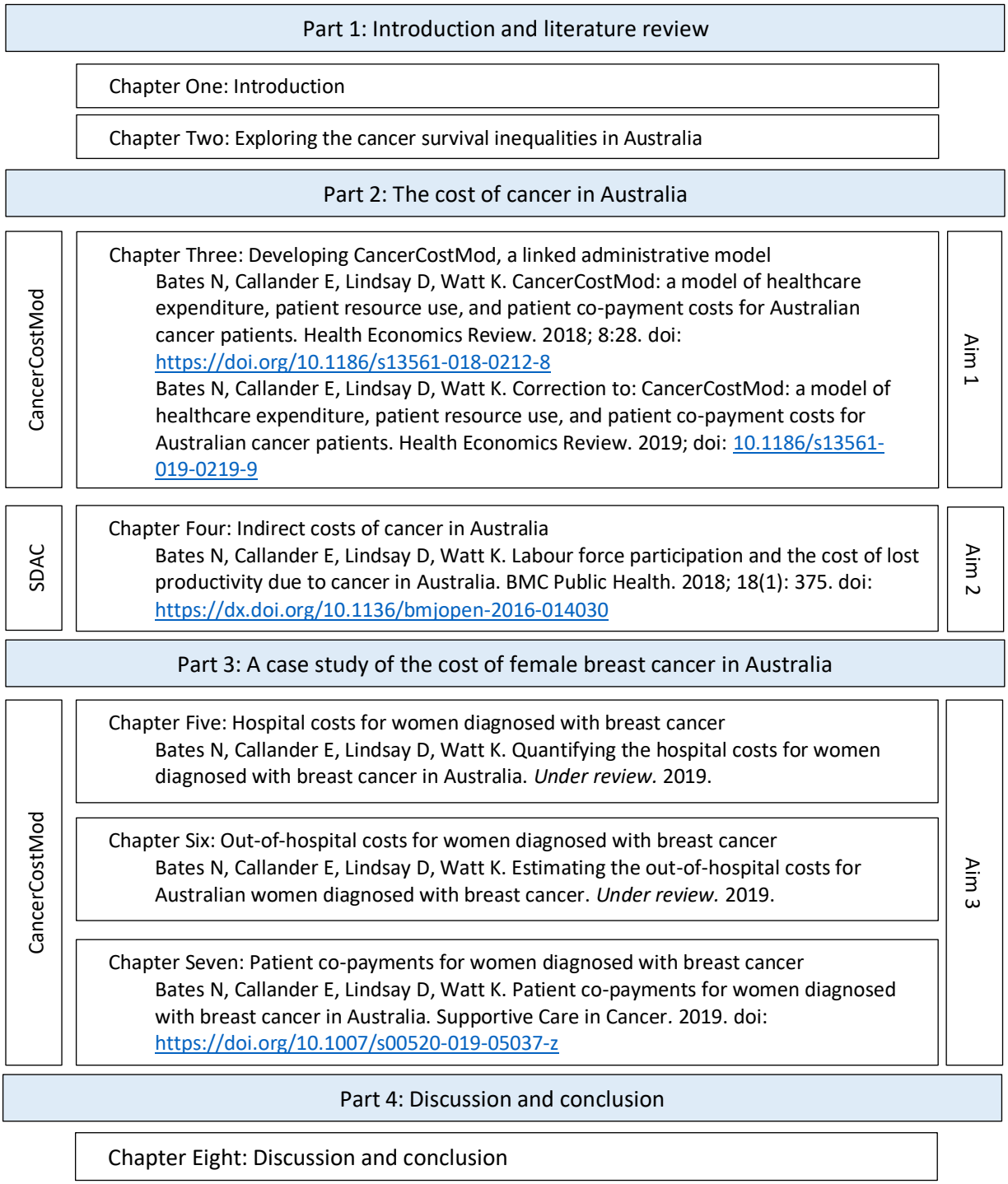

Figure 1: Thesis outline

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Chapter Two: Exploring the cancer survival inequalities in Australia

Introduction

According to the Australian Institute of Health and Welfare (AIHW), one in two Australians will be diagnosed with cancer in their lifetime.[1] In 2019, this was anticipated to translate to approximately 144,713 new cases of cancer,[1] with breast cancer, prostate cancer, colorectal cancer, melanoma of the skin, and lung cancer the most commonly diagnosed.[1] In 2011, cancer accounted for 19% of the total burden of disease, ranking it ahead of cardiovascular diseases (15%).[2] The majority (94%) of the burden of cancer is due to premature mortality.[2] Three in ten deaths in Australia were due to cancer in 2016;[1] most commonly from lung cancer, colorectal cancer, prostate cancer, breast cancer, and pancreatic cancer.[1]

Cancer survival in Australia has improved over the last 30 years.[1, 3] The five-year survival rate for all cancers combined improved from 47% during the period 1982-1987 to 69% between 2011-2015.[1] Despite these improvements, Aboriginal and Torres Strait Islander Australians, hereafter, respectfully referred to as Indigenous Australians (approximately 3% of the population[4]), people living in remote areas, and socioeconomically disadvantaged persons experience poorer cancer survival.[1, 5-20] To add to the complexity, these three population groups often overlap. For example, a greater proportion of Indigenous Australians reside in remote and very remote areas compared to non-Indigenous Australians (an estimated 18.4% vs 1.4% respectively in 2016).[21] In addition, a greater proportion of Indigenous Australians, and people living in rural and remote areas experience disadvantage with respect to education, employment, and access to goods and services.[22, 23]

The aim of this review is to describe the differences in cancer outcomes for Indigenous Australians, people living in remote areas, and socioeconomically disadvantaged people in Australia. The general inequalities in health status will be explored, followed by a description of the differences in risk factors and cancer screening participation; incidence and mortality; and access to healthcare and treatment for these different population groups, thus highlighting the need to assess the distribution of costs by these characteristics when describing expenditure on cancer.

Methods

Indigenous Australians, socioeconomically disadvantaged persons, and people living in remote and very remote areas are three population groups identified in this thesis as experiencing poorer

survival. The research question for this review was broad, and sought to describe the health inequalities, and the inequalities in cancer incidence, mortality, and survival by Indigenous status, remoteness, and socioeconomic disadvantage. A narrative literature review was chosen.

A search of Medline (Ovid), Cinahl, and Scopus databases was completed. The search strategy was based on keywords and subject headings. Search terms included 1) neoplasm or cancer; 2) diagnosis, incidence, survival, mortality; 3) inequality or inequity, social determinants of health, socioeconomic or disadvantage, rural or remote or geography, Indigenous or Aboriginal; and 4) Australia, Australian Capital Territory, New South Wales, Northern Territory, Queensland, South Australia, Tasmania, Western Australia. These categories were then combined using 'AND'. Reference lists of the included articles were also screened to identify any other eligible studies. All study designs were included in the review, but only articles that compared inequalities between the population group of interest and its comparator (ie Indigenous vs non-Indigenous Australian, or urban vs non-urban). A grey literature search of Australian and international organisations was conducted to find reports that include disparities between population groups, and national cancer reports. For example, the AIHW, Cancer Australia, Cancer Council, and World Health Organization (WHO).

Health inequalities

The differences in health status between population groups are labelled health inequalities. If these differences in health status are unfair and potentially avoidable, they are defined as health inequities. Health inequities can be described by the social determinants of health, which are 'the conditions in which people are born, grow, live, work and age'.[24] The social determinants of health include social gradient, stress, early life, social exclusion, work, employment, social support, addiction, food, and transport.[24, 25] The social gradient describes the social and economic factors which includes income, family assets, education, employment status and position, housing, and other circumstances.[24, 25] People who are lower on the social gradient (i.e. more disadvantaged) experience poorer health and reduced life expectancies compared to those who are higher on the social gradient.[24-30]

The Australian burden of disease studies by the Australian Institute of Health and Welfare measure the burden of disease using disability-adjusted life years, which combines premature mortality and morbidity.[2, 31, 32] These studies can be used to monitor population health and can be used to compare diseases and population groups.[31] In Australia in 2011, a total of 4.5 million years were lost due to premature mortality and morbidity.[31] However, the proportion of this burden was not equal across all population groups. The age-standardised rate of burden in very remote areas was 1.7 times the rate for major cities.[31] Using the Index of Socioeconomic Disadvantage (IRSD), the most recent Australian burden of disease study reported that people from the lowest socioeconomic quintile bore

a greater proportion of the total burden than people from the highest socioeconomic quintile (23.6% compared to 15.7%).[31] In 2011, the burden of disease was 2.3 times greater for Indigenous Australians than non-Indigenous Australians.[32]

It has been estimated that one third (31%) of the total burden of disease in Australia is due to modifiable risk factors, and is therefore preventable.[31] These modifiable risk factors that contribute to the burden included tobacco use (9.0%), high body mass index (5.5%), alcohol use (5.1%), physical inactivity (5.0%), and high blood pressure (4.9%).[31] Amongst Indigenous Australians, modifiable risk factors account for an even greater proportion (37%) of the total burden.[32] Tobacco use is the highest modifiable risk factor for Indigenous Australians, contributing to 12% of their total burden.[32] Approximately half (51%) of the gap in disease burden between Indigenous Australians and non-Indigenous Australians is attributable to modifiable risk factors.[32]

Studies have found that there is an association between socioeconomic disadvantage and poor health behaviours such as tobacco use, alcohol consumption, diet and exercise.[26, 33-35] The Whitehall II Study found that tobacco use was highest in the lowest employment grade and decreased with increasing employment grade.[26] Poor health behaviours have been also associated with lower education attainment.[33, 36] People living in the most disadvantaged quintile were more likely to smoke daily compared to those living in the least disadvantaged quintile (21.4% vs 8.0).[37] According to the 2014-15 National Health Survey (NHS), smoking rates were highest in outer regional and remote areas of Australia (20.9%) and lowest in major cities (13.0%). Although the smoking prevalence has declined over the last 20 years for both Indigenous and non-Indigenous Australians, Indigenous Australians are still more likely to be smokers compared with their non-Indigenous counterparts (45% compared to 16% in 2014-15).[38] Indigenous Australians living in remote areas are more likely to be smokers (56%) compared to those living in non-remote areas (42%).[38]

The 2014-15 NHS also reported that women living in socioeconomically disadvantaged areas were more likely to be overweight and obese (61.1%) compared to those living in the least disadvantaged areas (47.8%); however, there was no differences observed in males. Adults living in inner regional (69.2%) or outer regional/remote areas (69.2%) were more likely to be overweight compared to adults living in major cities (61.1%).[37] In 2012-13, Indigenous Australians were 1.5 times more likely to be obese than non-Australians. The rates of overweight and obese Indigenous Australians were highest in non-remote areas (67%) compared to remote areas (61%).[39]

Risk factors and cancer screening participation

Risk factors

The 2011 Australian Burden of Disease Study reported that 17 risk factors accounted for 44% of the burden of cancer. The largest contributing risk factor was tobacco use, which accounted for 22% of the total burden of cancer. In total, tobacco use was attributable to 11 types of cancer.[2] Whiteman et al.[40] estimated that 32% of all cancers diagnosed in Australia in 2010 were attributable to 13 modifiable risk factors. The leading risk factors contributing to the population attributable fraction were tobacco smoke, solar radiation, inadequate diet, and being overweight or obese.[40] Other risk factors for cancer include but are not limited to: alcohol consumption, certain infections (such as Hepatitis B virus and human papillomavirus (HPV)), reproductive and hormonal factors, family history, genetics, dietary factors, being overweight, physical inactivity, and ultraviolet radiation exposure.[41] The increased risk factors reported between the population group of interest and its comparator (ie Indigenous vs non-Indigenous Australian, or metropolitan vs non-metropolitan, or most disadvantaged vs least disadvantaged) may in part describe the increased incidence of cancers for which exposure to these risk factors are known to be causally related.

Participation in cancer screening

Australia has three national cancer screening programs, which provide population-based screening targeting a specific population to reduce morbidity and mortality through early detection.[1] These three programs are: BreastScreen Australia, National Cervical Screening Program (NCSP), and National Bowel Cancer Screening Program (NBCSP). There are some reported differences in participation rates in these programs between the three population groups of interest in this thesis. However, national participation rates for the NCSP and NBCSP are not available for Indigenous Australians, as Indigenous status is not routinely collected on pathology forms.[42, 43]

Breast Cancer Screening

BreastScreen Australia provides free mammograms for women aged 40 years and older every two years. The target age range is women aged 50 to 74 years. In 2014-15, the national average participation rate for the target age group was 54%. Indigenous women had lower participation rates than non-Indigenous women (37% verse 53%). Women living in outer regional areas had the highest participation rate (57.2%), and the lowest participation rate was in very remote areas (46.6%). Participation was similar for women from all socioeconomic groups.[44]

Cervical Cancer Screening

The NCSP was introduced in 1991, and until 2017, the NCSP recommended a Papanicolaou smear (Pap test) every two years for women. The NCSP was revised in December 2017 due to the success of

the National HPV Vaccination Program.[45] Persistent HPV infections are a known precursor for developing cervical cancer.[46] In 2007, Australia introduced the National HPV Vaccination Program for adolescent girls and young women. In 2013, the program was extended to include boys as well.[47] The new guidelines recommend a Cervical Screening Test every five years.[45] Although more research is required to determine the effect that the HPV vaccine has had on cervical cancer incidence and mortality, recent studies have reported a reduction in the prevalence of HPV-types that are included in the vaccination.[48, 49]

Prior to the changes to the NCSP, differences in screening participation rates were reported by Indigenous status, remoteness and socioeconomic disadvantage. In 2015-16, the age-standardised national screening participation rate was 56% for women aged 20-69 years.[45] Women living in very remote areas had the lowest participation rates (46.3%), and women living in major cities and inner regional areas had the highest participation rates (56.4% and 56.6% respectively).[45] Participation rates were highest for women from the highest socioeconomic group (62.1%) compared to women from the lowest socioeconomic group (50.4%).[45]

A recent Queensland study using linked administrative data found that the two-year participation rates in the NCSP in 2010-11 was approximately 20% less for Indigenous women than non-Indigenous women.[50] In this study, the highest participation rates for both Indigenous and non-Indigenous women were in outer regional, and the lowest in very remote areas; and rates improved with increasing advantage; however, participation rates were lower in Indigenous women than non-Indigenous women in all areas of remoteness and advantage.[50] Similar findings were reported in the Northern Territory, with participation rates for Indigenous women approximately 18-19% lower than national Australian participation rates during 1999-2000, and 2003-2004.[51] In contrast, the AIHW (using the 2012-13 Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS)) did not report any geographical variance in participation rates.[52] The lower participation rates for NCSP are thought to be factors for increased cervical cancer mortality rates for Indigenous women.[9, 50, 51]

Bowel Cancer Screening

The target population for the NBCSP are aged 50-74 years. The national participation rate was 41% in 2015-16.[53] Differences in participation rates were reported for socioeconomic advantage, with the highest rates reported in the most advantaged areas (43%) and lowest rates in the least advantaged areas (39%).[53] The rates were also highest in inner regional areas (44%), and lowest in very remote areas (28%).[53] The 2018 NBCSP report estimated that the 2015-16 participation rates for Indigenous Australians was 19.5% compared to an estimated 42.7% participation rate for non-Indigenous Australians.[53] The Aboriginal and Torres Strait Islander Health Performance Framework 2014 Report

(using the 2012-13 AATSIHS) found that 18% of eligible Indigenous males and 11% of eligible Indigenous females reported participating in bowel cancer screening.[54] The 2017 Aboriginal and Torres Strait Islander Health Performance Framework Report did not contain any more recent data.[23]

Incidence and mortality

The most recently published national statistics reports that for the period 2010-14, the age-standardised incidence rate for all cancers combined was highest for people in the two lowest IRSD areas, and lowest for people living in the two highest socioeconomic areas.[1] During this same time period, the highest age-standardised incidence rates for all cancers combined occurred in people living in inner regional areas (513 cases per 100,000 persons), and rates were lowest among people living in very remote areas (445 cases per 100,000 persons).[1]

People living in the lowest socioeconomic areas had higher age-standardised mortality rates for all cancers combined compared to those living in the highest socioeconomic areas during the period 2012-16 (187 vs 136 per 100,000 persons).[1] The highest age-standardised mortality rate for all cancers combined (195 per 100,000) occurred in people living in very remote areas, and people living in major cities had the lowest rates (157 per 100,000).[1]

Differences in incidence and mortality by geographical location have been consistently reported in the literature. Cancer atlases, which identify geographical variation in incidence and survival for multiple cancers, have been published in Queensland (2011)[14] and South Australia (2012).[15] The Queensland Atlas presented cancer incidence and cancer survival between 1996 and 2007. [14] In general, compared to the average survival, people who lived in more rural or disadvantaged areas had lower survival.[14] A Queensland study recently compared survival of individuals diagnosed with one of the major five cancers between 1997-2004 and 2005-12, and found that although cancer survival has improved, there are still differences in survival by geographical location.[19]Recently, an interactive online 'Australian Cancer Atlas' was launched by Cancer Council Queensland, with the support of Queensland University of Technology, and FrontierSI.[16] The Australian Cancer Atlas provides a summary of cancer diagnoses (2010-14) and excess deaths (2006-14) for all cancers combined, and a number of individual cancer types.[16] Other studies have also found differences in survival by area by geographical location for specific cancer types.[17, 18] For example, in men diagnosed with prostate cancer, although the five-year survival rate improved in Australia between 1982 to 2004, the survival gap widened between urban and rural areas.[17] The risk of dying from rectal cancer increased with increasing distance from a radiotherapy facility.[18]

A recent study reported that the gap in survival from cancer has increased by level of socioeconomic disadvantage in New South Wales (NSW) between 1980 and 2008, and that this difference remains after adjusting for stage of disease.[5] Another NSW study found that 13.4% of cancer deaths were attributable to socioeconomic inequality.[6] Tervonen et al.[13] analysed all new cancer cases in NSW diagnosed between 1980 and 2009. The authors reported that compared to people living in the least disadvantaged areas, those living in more disadvantaged areas had higher odds of being diagnosed with a distant staged disease. This association was stronger for the most recent period, 2000-09. This study also found that compared to people living in major cities, people living in either inner or outer regional areas were less likely to be diagnosed with a distant staged disease.[13]

In March 2019, the AIHW released a new Cancer in Australia 2019 report. However, due to available data sources, the age-standardised rates of cancer were not reported.[1] Thus, the following information is from the Cancer in Australia, 2017 report.[20] The current national statistics regarding the incidence of cancer in Indigenous Australians published by the Australian Institute of Health and Welfare contains information from five (of eight) jurisdictions in Australia.[20] This was because these jurisdictions are deemed to have 'sufficient completeness' on Indigenous status.[20] The age-standardised incidence rate for all cancers combined was 484 per 100,000 for Indigenous Australians compared to 439 per 100,000 for non-Indigenous Australians between 2008 and 2012, and the age-standardised mortality rate for all cancers combined was also higher in Indigenous Australians than non-Indigenous Australians between 2010-14.[20]

In Queensland, the incidence of cancer in Indigenous Australians between 1997-2006 was 21% lower than in the total Queensland population; however, the mortality rate was 36% higher.[7] A national study found that cancer survival was lower for Indigenous Australians compared to non-Indigenous Australians at one year (63.8% vs 83.4%) and five years (46.7% vs 70.0%) following diagnosis. Cancer mortality rates were 65% higher for Indigenous persons in very remote areas compared to metropolitan areas, but only 23% higher for non-Indigenous people.[8] A recent Queensland study found that although the five-year survival was lower in Indigenous Australians compared to non-Indigenous Australians, the first year after diagnoses accounted for 50% of the excess mortality. In this study, survival did not vary by geographical location or socioeconomic disadvantage.[10] A separate study found that after the first year of diagnosis, the survival ratios were relatively constant for most cancers; however, the survival inequality continued to widen for liver cancer, breast cancer and head and neck cancers.[12]

Access to healthcare services

Although Australia's universal healthcare system aims to provide equal access to medical services,[55] there are several barriers to accessing healthcare services. These barriers include but are not limited to physical access, access to culturally appropriate services, and patient costs.[22] Before these barriers are discussed, it is important to introduce Australia's universal healthcare system, Medicare. Medicare provides free treatment at public hospitals, and free or subsidised medical care outside of public hospitals. The Medicare Benefits Schedule (MBS) contains a list of services which receive a rebate from the Commonwealth Government through Medicare. If there is a gap between the total charged by the provider and the rebate, the patient will be charged a co-payment.[55] In some cases, the service provider may choose to 'bulk-bill' the patient, or accept the rebate as the full fee for the service. Access to subsidised approved prescription pharmaceuticals are provided under the Pharmaceutical Benefits Scheme (PBS). In contrast to the MBS co-payments, for approved prescriptions, patients will be charged any amount up to the total patient co-payment (in 2018, the general co-payment was $39.50, and $6.40 with a valid concession card).[56] In other words, the patient will only pay a maximum of the patient co-payment, and if the cost of the prescription pharmaceutical is greater than the co-payment, the Commonwealth Government will pay the remainder of the cost of the medication.[55, 56]

The sheer size of Australia's landmass provides challenges in physically accessing healthcare services. Access to healthcare services reduces with increasing remoteness.[22, 57] In 2015, there were 442 full-time equivalent (FTE) medical practitioners per 100,000 population in major cities, and 263 FTE per 100,000 population in remote/very remote areas.[58] The availability of cancer services also varies according to remoteness.[59] In 2006, the Clinical Oncological Society of Australia (COSA) published results of rural and regional oncology services in Australia. They found that in 2003-04, of the 1,304 Australian public and private hospitals surveyed, only 157 regional hospitals administered chemotherapy, 11 had access to radiation units of which less than half were fully staffed, and only five had surgical oncology services. The accessibility of specialist medical practitioners or cancer support staff were also much lower in rural and regional areas.[59] Therefore, many patients who live outside metropolitan areas will be required to travel from their homes to access treatment, and stay away from their homes for the duration of their treatment.[59] Travel and accommodation incurs a substantial economic burden for people with cancer,[60-66] which may be a barrier to accessing care. An additional barrier for rural patients is spending time away from family and friends, and on-going employment requirements.[61, 64, 66]

Telehealth is an emerging model of care, which is being used to provide healthcare services, including oncology services to areas lacking physical access to specialists. The Townsville Cancer Centre introduced tele-oncology in 2007 to provide medical oncological services to regional North Queensland.[67, 68] This model of care enables patients to receive chemotherapy treatment at rural hospitals (for example Mt Isa, approximately 900km from Townsville), with the consultant medical oncologist being located in Townsville, and a senior doctor, chemotherapy-competent nurses, and allied health workers being located at the rural hospital.[68] However, telehealth may not be appropriate or available for all patients. For example, patients requiring radiotherapy or haematology treatment are still required to travel.

Indigenous Australians face additional barriers to accessing healthcare. The Aboriginal and Torres Strait Islander Health Performance Framework 2017 report[23] identified several barriers including transport and distance to the health provider, waiting too long, availability of culturally appropriate services, and cost.[23] The number of Indigenous Australians working in the health workforce is low.[23] Increasing the number of Indigenous Australians working in the health workforce has been identified as essential to achieve equitable outcomes.[69] There are also different cultural beliefs surrounding health, healthcare, and cancer, which may influence health seeking behaviours.[70-72]

Although Australia has a universal healthcare system, individual OOP costs are a potential barrier in accessing healthcare. The out-of-pocket costs of health care in Australia have received attention from the Australian Government in recent years. In 2018, the Ministerial Advisory Committee on OOP costs was established to provide advice on reforms in OOP costs for health care.[73] The 2017-18 ABS Patient Experiences Survey reported that only 4% of people who needed to see a GP delayed or did not go due to cost.[74]This could reflect the fact that during 2016-17, 86% of non-referred GP services were bulk-billed (all-time high).[75] However, as this is a household survey, there is potentially selection bias. A higher proportion of people delayed or skipped seeing a medical specialist, dentist, or delayed or did not get their prescribed medication due to cost.[74] According to a recent AIHW report on OOP costs for out-of-hospital Medicare services, almost half of all patients incurred an OOP cost in 2016-17.[76] The amount varied by Primary Health Network area, state, and type of service. For example, the highest OOP costs were for specialist and obstetric services.[76]

The term financial toxicity has been coined to describe the high OOP expenditure associated with cancer treatment,[77] and is a growing concern in Australia and internationally.[60, 62, 63, 78] A recent study of Australians with chronic health conditions found that 21% of Australians with cancer reported that they had skipped treatment due to the costs.[79] Another study found that 63% of participants reported a level of financial burden due to obtaining medications prescribed in relation to their cancer.[80] These

OOP costs may be a greater financial barrier to accessing care for those with greater socioeconomic disadvantage. To date, some studies have identified that people living further away from a treatment centre incur higher OOP costs for travel and accommodation.[60-66] However, to date, no study has identified the distribution of OOP costs by Indigenous status, or socioeconomic status.

Variation in cancer treatment

Following a cancer diagnosis, there have been a number of differences reported in the treatment received by patients based upon their Indigenous status, geographical location, and socioeconomic disadvantage. Clinical factors, such as cancer type, stage of disease at diagnosis, and co-morbidities may impact the recommended treatment options. As discussed previously, variation in the stage of disease at diagnosis has been reported in different population groups. Indigenous Australians with cancer are also more likely to have more co-morbidities than their non-Indigenous counterparts.[13, 81-83]

In a recent systematic review of variations in outcomes for Indigenous women with breast cancer in Australia, Dasgputa et al. (2017)[84] identified five studies in which clinical management by Indigenous status was examined.[82, 85-88] Differences between Indigenous and non-Indigenous women were reported in two[82, 88] out of the five studies.[84] For women diagnosed with breast cancer in New South Wales between 2001 and 2007, after adjusting for age, year of diagnosis, and stage, Indigenous women were less likely to receive surgical treatment than non-Indigenous women (odds ratio 0.50, confidence interval: 0.33-0.78, p=0.003).[82] Of those who received surgery, Indigenous women were more likely to have a mastectomy than non-Indigenous women.[82] The second study was a national study of 50-69 year old women who had participated in BreastScreen during the period of 1996-2005.[88] This study reported, that of women screened, Indigenous women were more likely to undergo mastectomy surgery rather than local excision.[88] Differences in uptake of treatment by Indigenous status has also been reported for other cancer types.[81, 83, 89] A Queensland matched cohort study of adults diagnosed with cancer between 1998 and 2004 found that Indigenous Australians were less likely to receive any treatment compared to non-Indigenous Australians.[83] Similar findings of reduced treatment have also been reported for Indigenous Australians diagnosed with lung cancer.[89]

Reduced physical access to healthcare services is a factor when considering variation in treatment. Several studies have reported lower rates of surgical intervention between people living in rural areas.[17, 86, 90-94] Men diagnosed with prostate cancer in regional or rural areas had lower rates of radical prostatectomy compared to men living in urban areas.[17] Lower rates of breast conserving surgery and higher rates of mastectomy have been reported for women living outside of urban areas.[91, 93, 94]

There is also evidence of reduced uptake of radiotherapy for people living further away from radiotherapy centres.[66, 91, 95] Spatial differences have also been reported in women's intention to choose adjuvant therapy (radiotherapy, chemotherapy, and hormone therapy), with women living close to a treatment centre more likely to intend to use adjuvant therapy.[95] For some rural women diagnosed with breast cancer, having to travel in order to receive radiotherapy was a reason in choosing not to have radiotherapy, and instead choosing a mastectomy.[66] Hegney et al.[64] explored the experiences of 17 people diagnosed with cancer who had to travel 150km to receive radiotherapy. The authors identified five major themes in the study: the burden of travel, accommodation, financial burden, being away from family and friends, and the burden placed on their family and friends.

Conclusion

Inequalities in health status still exist in Australia, despite improvements in health.[22] It is well documented that Indigenous Australians, people living in remote areas, and socioeconomically disadvantaged persons experience inequalities in health status, and more specifically,[22] for cancer outcomes compared to the overall Australian population.[1] This review explored a number of factors which contribute to this difference in cancer survival. These factors include increased exposure to risk factors, differences in screening participation, variation in incidence and mortality, differences in stage of disease at diagnosis, barriers to accessing healthcare services, and more specifically, variation in cancer treatment.

As highlighted in Chapter One, the cost of cancer is substantial. In 2008-09, the cost of cancer to the Australian healthcare system was $4.5 billion. The majority of this was spent on hospital services (79%), followed by prescription pharmaceuticals (12%), and out-of-hospital expenditure (9%).[96] The cost of cancer is expected to rise.[96-99] However, little is known about the distribution of these costs by Indigenous status, remoteness, or socio-economic disadvantage. The current literature identifies inequalities in cancer survival. Many factors have been identified which contributes to these differences in cancer survival, including variation in access to, and treatment of cancer by these characteristics, therefore it is reasonable to expect that the cost of cancer differs between these population groups. This thesis seeks to provide a more recent estimation of the cost of cancer in Australia, and the distribution of these costs by population group. Understanding the economic burden to the public healthcare system, society, and the patient will be the first step to help policy makers ensure that there is equitable access to treatment for all population groups.

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PART 2: THE COST OF CANCER IN AUSTRALIA

This part of the thesis addresses the first two aims of the thesis and contains two published papers. In Chapter Three, the methodology used to develop the model, CancerCostMod is described, and the cost of cancer in Australia for the first 12-months following a cancer diagnosis for all cancer types is presented. The distribution of these costs by population group are also modelled. In Chapter Four, the indirect costs due to changes in labour force participation for people with cancer are quantified.

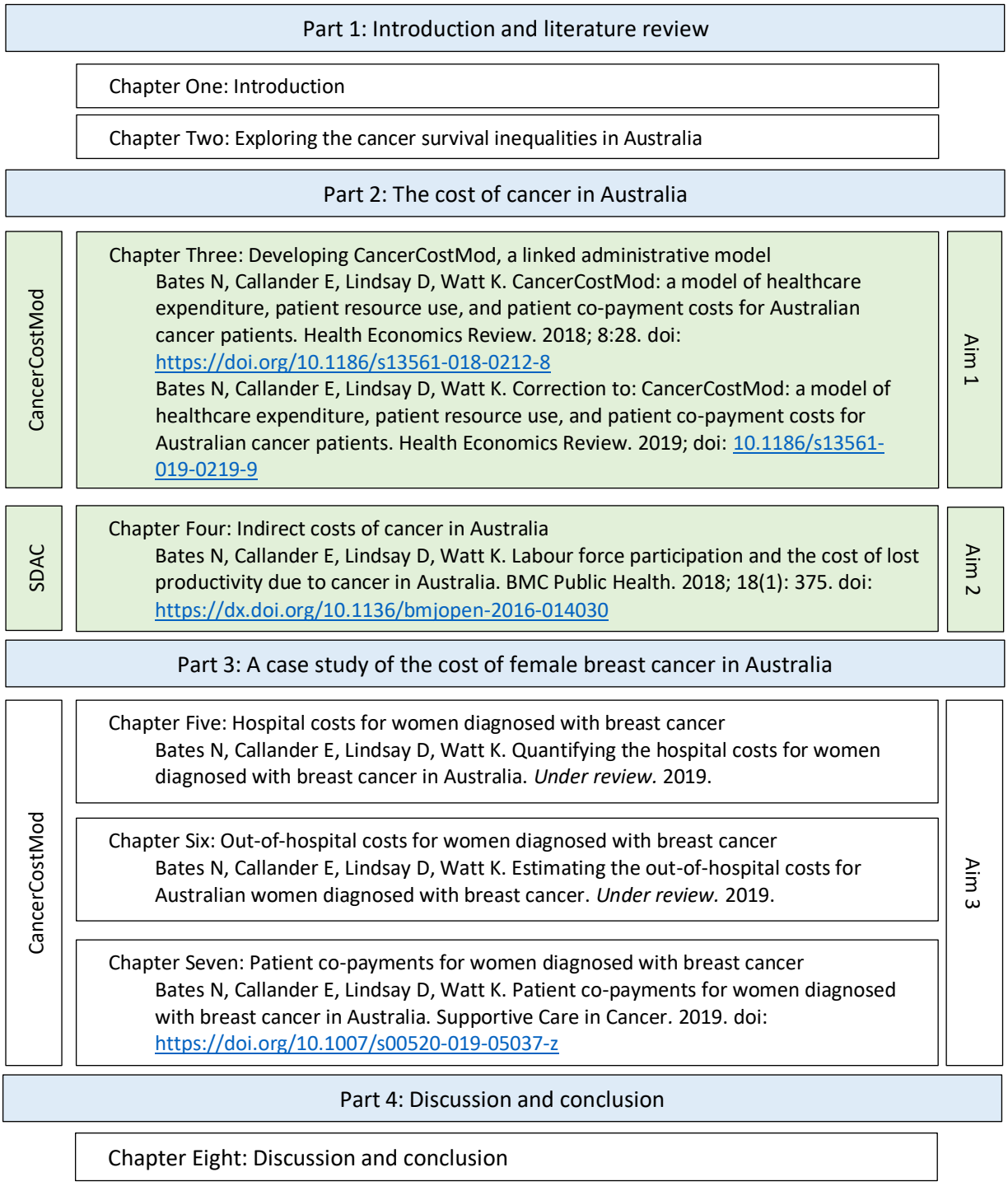

Figure 1: Thesis outline

Chapter Three: Developing CancerCostMod, a linked administrative model

Introduction

This chapter comprises the first publication for the thesis, which describes the methodology used to develop the model, *CancerCostMod*. The cost of cancer in Australia for the first year following a cancer diagnosis for all cancer types are also presented in this chapter, thus addressing the first aim of the thesis. In brief, CancerCostMod used administrative data which is routinely collected throughout a person's cancer journey, from diagnosis to three years following diagnosis. Administrative data is becoming more widely used to assess patient outcomes, health care service use, and disparities.

The development of CancerCostMod includes a census of all individuals diagnosed with cancer between July 2011 and June 2012. The data were then linked to administrative health records between July 2011 and June 2015. The original dates of data extraction for CancerCostMod were chosen due to completeness of data available at the time of commencement, and to allow for all participants to have at least three years of follow up data.

This aim of this paper was to 1) describe the development of our dataset, *CancerCostMod*; 2) to describe the total costs of cancer in Australia during the first 12-months post-diagnosis; and 3) to describe the distribution of the cost of cancer in Australia during the first 12-months post-diagnosis by population group.

This chapter is inserted as published in the *Health Economics Review*:

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Health Economics Review

RESEARCH Open Access

CancerCostMod: a model of the healthcare expenditure, patient resource use, and patient co-payment costs for Australian cancer patients

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Abstract

Although cancer survival in general has improved in Australia over the past 30 years, Indigenous Australians, socioeconomically disadvantaged persons, and people living in remote areas still experience poorer health outcomes. This paper aims to describe the development of CancerCostMod, and to present the healthcare expenditure and patient co-payments for the first 12-months post-diagnosis. The base population is a census of all cancer diagnoses (excluding non-melanoma skin cancer) in Queensland, Australia between 1 July 2011 and 30 June 2012 ($N = 25,553$). Each individual record was linked to their Queensland Health Admitted Patient Data Collection, Emergency Department Information System, Medicare Benefits Schedule, and Pharmaceutical Benefits Scheme records from 1 July 2011 to 30 June 2015. Indigenous status was recorded for 87% of participants in our base population. Multiple imputation was used to assign Indigenous status to records where Indigenous status was missing. This base population was then weighted, using a programmed SAS macro (GREGWT) to be representative of the Australian population. We adopted a national healthcare perspective to estimate the cost of cancer for hospital episodes, ED presentations, primary healthcare, and prescription pharmaceuticals. We also adopted an individual perspective, to estimate the primary healthcare and prescription pharmaceutical patient co-payments. Once weighted, our sample represents approximately 123,900 Australians (1.7% Indigenous Australians). The total healthcare system cost of all cancers during the first 12-months post diagnosis was $4.3 billion, and patient co-payments costs were $127 million. After adjusting for sex, age at diagnosis, Indigenous status, rurality, socioeconomic status, and broad cancer type, significant differences in costs were observed for population groups of interest within the first year post-diagnosis. This paper provides a more recent national estimate of the cost of cancer, and addresses current research gaps by highlighting the distribution of healthcare and individual costs by Indigenous status, rurality, and socioeconomic status.

Keywords: CancerCostMod, Cancer, Economic burden, Cost, Healthcare system, Patient co-payment

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Introduction

In Australia, the overall cancer mortality rate decreased by 23% between 1982 and 2017 [1]. However, three population groups experience poorer cancer outcomes compared to the general Australian population: Australian Aboriginal and/or Torres Strait Islander people (hereafter respectfully referred to as Indigenous people), socioeconomically disadvantaged persons, and people living in remote areas [1]. To add to the complexity of this issue, these population groups often overlap. Indigenous people more often live in remote and very remote areas [2], and a greater proportion of people living in rural and remote areas experience socioeconomic disadvantage [3]. A recent study found that the socioeconomic disparities in cancer survival appear to have worsened over the past 30 years. The gap remained after accounting for diagnosis stage, and cancer site [4].

A number of factors have been identified in contributing to these survival inequalities, including but not limited to differences in risk factors [1, 5], being diagnosed at a later stage [5, 6], differences in access to oncology services [7, 8], a greater number of comorbidities [6], and differences in treatment [6, 9–11]. High patient out-of-pocket expenditure (OOPE) may also impact a person's decision to access care, with one study finding 21% of people with cancer skipping healthcare due to the cost [12], and another study found that 11% of patients found that prescriptions relating to their oncology treatment caused financial burden [13]. A recent study reported that the median total cost to the patient for provider fees during the first 2 years was over $20,000 for people diagnosed with lung or breast cancer [14]. Studies using self-reported costs, have found that OOPE is higher for those who have to travel to receive treatment, due to travel and accommodation costs [15, 16].

The healthcare system expenditure for cancer is also high [17–19]. A commissioned report estimated that the lifetime costs of cancer for a patient diagnosed in New South Wales (NSW), Australia, in 2005 was $3.9 billion [17]. These costs are expected to rise with new technologies, new pharmacotherapies, and population changes [20]. This predicted increase in costs has already been seen with the annual Pharmaceutical Benefits Scheme (PBS) expenditure on anticancer drugs increasing by approximately $400 million between 1999 and 2000 and 2010–11. This was an average increase of 19% compared to 9% for all other drugs combined [21]. The Australian Institute of Health and Welfare (AIHW) reported that cancer cost approximately $4.5 billion in 2008–09 (excluding screening). The majority of these costs were due to hospital admitted patient services (79%), followed by prescription pharmaceuticals (12%), and out-of-hospital costs, such as general practitioner, specialists, pathology, and imaging (9%) [18]. However, these reports are now a decade old, and do not look at the distribution of costs by population group. To the author's best knowledge, only one report has compared the cost of hospital expenditure by Indigenous status. The AIHW and Cancer Australia reported that in 2010–11, the per person hospital expenditure for all cancers combined for Indigenous Australians was half of that for non-Indigenous Australians [19].

CancerCostMod is Australia's first model of health service use, healthcare expenditure, and patient co-payments for people diagnosed with cancer in Australia. This model has several objectives:

1. To quantify the current health system use, and healthcare expenditure for people with cancer, and to determine any inequalities by Indigenous status, socioeconomic status, and remoteness;
2. To quantify the patient co-payment for people with cancer, and to determine any inequalities by Indigenous status, socioeconomic status, and remoteness;
3. To estimate the costs to government and individuals of "optimal service use" - if all patients received the maximum access of care.

This paper aims to 1) describe the development of our model, CancerCostMod; 2) to describe the total costs of cancer in Australia during the first 12-months post-diagnosis; and 3) to describe the distribution of the cost of cancer in Australia during the first 12-months post-diagnosis by population group.

Methods

Base population – Linked administrative data

The protocol describing the data linkages that were undertaken to create this dataset has been described previously [22]. Briefly, the base population for this model was a census of all patients diagnosed with cancer in Queensland between 1 July 2011 and 30 June 2012, as recorded by the Queensland Cancer Registry (QCR) ($N = 25,553$ patients). Each individual's QCR record was linked to their Queensland Health Admitted Patient Data Collection (QHAPDC) records (243,034 separations for 21,944 patients), and Queensland Health Emergency Department Information Systems (EDIS) (46,455 presentations from 12,825 patients) from 1 July 2011 to 30 June 2015. This linkage was conducted by the Queensland Health Statistical Services Branch using deterministic and probabilistic methods. Each participant's record was then linked to their individual Medicare Benefits Schedule (MBS) (6,058,380 services) and Pharmaceutical Benefits Scheme (PBS) (2,619,712 prescriptions) records from 1 July 2011 to 30 June 2015 by the Data Linkage Unit at the AIHW using probabilistic

linkage. Overall, 99.4% of cohort members were matched to the Medicare enrolments register.

The QCR dataset contained date of diagnosis, International Classification of Diseases for Oncology (ICD-O) morphological code, ICD-O topographical code, differentiation code, behaviour status, as well as date and cause of death if applicable. The stage at diagnosis is not routinely collected by the QCR. Other variables included sociodemographic information, such as date of birth, sex, Indigenous status, and postcode at diagnosis.

The QHAPDC records contained information on all separations from a private or public hospital in Queensland. Facility number, patient residential postcode, admission and separation date, length of stay, hospital insurance status, and the Australian Refined Diagnostic-Related Group (AR-DRG) was recorded for each separation. The AR-DRG is a classification system, where episodes of care are coded using the ICD-10-Australian Modification (ICD-10-AM) and Australian Classification of Health Interventions, which is used to code procedures and interventions [23]. The EDIS dataset contained all emergency department (ED) presentations, including information such as date of presentation, facility number, patient postcode at time of presentation, triage category (Australasian Triage Scale for treatment prioritisation), discharge destination, and ICD-10-AM code.

MBS data include individual patient identifier, patient postcode, date of service, provider postcode, MBS item code, fee charged, benefit paid (by MBS), patient co-payment costs, and hospital flag. MBS claims data exclude Department of Veteran's Affairs beneficiaries. PBS data includes individual patient identifier, patient postcode, date of supply, PBS item, patient category (concession or general), patient co-payment costs, benefit amount, pharmacy postcode. PBS data excludes private prescriptions, over-the-counter medications, under co-payment prescriptions, Repatriation Pharmaceutical Benefits Scheme prescriptions, and any medications dispensed under special arrangements.

Development of CancerCostMod

Cancer classification

Using the ICD-O 3rd Edition [24] and the Cancer Council Queensland methods website [25], the type of cancer was grouped into 18 broad cancer categories: head and neck; digestive organs; colorectal cancer; female genital organs; breast cancer; prostate cancer; male genital organs excluding prostate; urinary tract; eye, brain and other parts of the central nervous system (CNS); mesothelioma, Kaposi sarcoma and soft tissue; thyroid and other endocrine organs; other thoracic and respiratory organs; bone; tracheal, bronchus and lung cancer; other skin; melanoma; blood and lymphatic system; other or ill-defined cancers.

Socioeconomic status and rurality

The patient's postcode at diagnosis was mapped to the Australian Bureau of Statistics (ABS) Index of Relative Socio-Economic Disadvantage (IRSD), and Australian Statistical Geography Standard (ASGS) [26]. IRSD is a summary of the economic and social conditions of an area, and is a measure of relative disadvantage only, where decile 1 was the most disadvantaged, and decile 10 was the least disadvantaged. ASGS has five categories 'metropolitan', 'inner regional' 'outer regional', and 'remote' and 'very remote'. There were 151 records with 'unknown or not stated' postcodes at diagnosis, which could not be mapped to IRSD or rurality. We have categorised these records as 'unknown or not recorded' for IRSD and rurality. For our analyses, we collapsed rurality into three categories ('metropolitan', 'regional', and 'remote') and IRSD into quintiles (Q1: most disadvantaged and Q5: least disadvantaged).

Indigenous status

A common data limitation in Australia is that Indigenous status may be incompletely recorded in health and vital registration data collections [27]. The Australian Cancer Database considers five (of eight) jurisdictions to have sufficient completeness for reporting purposes, NSW, Victoria, Queensland, Western Australia and the Northern Territory [1]. A 2011–12 audit found that Indigenous status in Queensland Health hospital admission records had 87% weighted completeness (CI 84–91%) [27].

Indigenous status was recorded for 87% of participants in our original cohort from the QCR dataset. We used a number of methods to assign Indigenous identification to the 13% of records for which there was missing data or 'unknown' Indigenous status recorded ($n = 3316$). Initially, records with missing or unknown Indigenous identification on the QCR dataset were assigned to be 'Indigenous' if they resided in a local government area (LGA) that had greater than or equal to 75% of the population identified as Indigenous, as reported by the ABS' estimated resident Indigenous Australian and non-Indigenous Australian populations in each Queensland LGA for 2011 [28]. Seventy-five percent was chosen as a conservative cut-off, reflecting the definition by the ABS of a 'Discrete Indigenous Community' as one that has greater than half of the population identifying as Aboriginal and/or Torres Strait Islander [29].

We then used multiple imputation (MI) to impute the remaining missing values for Indigenous status ($n = 3297$). We used the MI procedure in SAS 9.4 (SAS Institute Inc., Cary, NC, USA), which has three distinct phases [30]. We used logistic regression to develop the imputation model for multiple imputation, as the variable of interest was dichotomous (Indigenous or not-Indigenous). Covariates

used were similar to those used by Morell et al. [31], and included sex, 5-year age group, 12-month survival, country of birth (Australia, not Australia, or not stated/unknown), broad cancer group (18 categories), rurality (5 categories), and IRSD deciles. We used PROC MI with a monotone logistic statement, with 20 imputations, followed by PROC LOGISTIC, and finally PROC MIANALYZE to produce inferential results.

Weighting to the Australian population

In order to provide results that are representative to the Australian population, we used the programmed SAS macro GREGWT to weight our dataset to the Australian population. GREGWT is a generalised regression reweighting algorithm which was developed by the ABS and is commonly used to weight their household surveys against known benchmarks [32]. The mathematical techniques underlying GREGWT have been described elsewhere [33, 34]. In the current study, data were benchmarked against the 2012 Australian Cancer Database [35]. This database provides Australia-wide cancer incidence rates stratified by cancer type, age group and gender. Cancer incidence rates for 2012 were extracted from this database and used as the benchmark for the calculation of weights in the current study.

Defining costs

We developed CancerCostMod to allow analyses of costs from different perspectives. We adopted a national healthcare perspective, to estimate the direct cost of cancer to the healthcare system for hospital, primary healthcare and prescription pharmaceuticals. We also adopted an individual perspective, to estimate the patient co-payments for primary healthcare and prescription pharmaceuticals.

All costs were calculated monthly for each individual from the date of diagnosis ($t = 0$) for 36 months. If an individual had no health services for the month, the cost was recorded as $0. All costs are reported in Australian dollars (AUD), and were adjusted to the 2016–17 financial year using the Reserve Bank of Australia inflation calculator [36].

Hospital costs

Within Australia, public hospitals are run by the State and Territory governments, and are jointly funded by the state and national governments through either activity-based funding (ABF) or block funding [37]. The ABF model pays hospitals for the number and mix of services provided, and accounts for patients that may be more complicated. The Independent Hospital Pricing Authority (IHPA) was established as part of the National Reform Act 2011, and is responsible for the implementation of the ABF for public hospitals. The IHPA produces an annual National Hospital Cost Data Collection (NHCDC), which includes the voluntary submission of cost data for each AR-DRG from public and private hospitals. This information is then used to develop the National Efficient Price, which determines the federal contribution to the ABF system, and the National Efficient Cost, which determines the federal contribution to block funding. Each State and Territory is then responsible for distributing the federal and state funding to their public hospitals. The annual NHCDC reports are available online [38–41]. Private hospitals are owned and operated by private institutions but must still comply with national standards. Private hospitals receive funding from patient charges, private insurance, and Medicare rebates [42].

The cost attributed to each AR-DRG for public hospital separations was assigned using the actual cost as reported by the NHCDC Report (available online) [38–41] for the relevant year. To reflect possible variations in the costs of delivering healthcare to some individuals, we included the adjustment for certain patient demographics produced by the IHPA (pediatric, patient remoteness and/or Indigenous person, and private patient service and accommodation) [43–45]. As there were no adjustments published for the 2011–12 financial year, we used the adjustment for the 2012–13 period. The cost attributed to each AR-DRG for private hospital separations was assigned for the relevant year using the average charge per separation reported by the Private Hospital Data Bureau Annual Reports (available online) [46].

In Australia, some patients may receive treatment as a non-admitted (out-) patient at a hospital location, but are not formally 'admitted', and are therefore not captured in the QHAPDC dataset. In order to capture these non-admitted hospital services, we included MBS items which related to services or procedures performed in a hospital setting. This method has been used in previous Australian studies [47, 48]. We identified these MBS items by conducting a keyword search of the MBS item descriptions to identify hospital items: 'hospital' (excluding codes which specified it was in a place 'other than a hospital'), 'theatre', 'emergency department', and 'prior to discharge'. Item codes relating to chemotherapy and radiotherapy were also identified through consultation with staff from the Townsville Hospital and Health Service, Townsville Cancer Centre. The rebate paid by Medicare for MBS codes for these 'hospital' items were included in the hospital costs. Hereafter, admitted and non-admitted hospital episodes will be referred to as 'hospital episodes'.

The ED classification system, Urgency Disposition Groups, and Urgency Related Group (URG), was originally developed in Western Australia [49] to group patient presentations into categories. The IHPA implemented this system nationally in 2012, and it has since undergone several revisions commissioned by the IHPA [50]. Each ED presentation was coded to a URG using the triage category, discharge destination and the primary reason for attending the ED (ICD-10-AM). The cost attributed to each URG for each ED presentations was assigned using the

average cost per presentation as reported by the NHCDC Report (available online) [38–41] for the relevant year.

MBS and PBS costs

Briefly, Australia's universal healthcare system (Medicare), provides free and subsidized medical services under MBS and PBS. For services covered by MBS, if there is a gap between the rebate paid by Medicare and the amount charged by the service provider, the individual will incur an out-of-pocket co-payment. In some cases, the service provider may 'bulk-bill' a patient, or charge the amount equal to the Medicare rebate, resulting in no individual co-payment. For prescription pharmaceuticals, the individual will be charged up to the set patient co-payment for concession (low income card holders) and general patients. Australia has several safety net arrangements for individuals and family groups with high OOPE (two Medicare Safety Nets, and one PBS Safety Net). Once an individual or family group reaches a given amount on co-payments for a calendar year, they will receive a higher government subsidy, resulting in reduced patient co-payments [51]. Furthermore, Indigenous Australians living with, or at risk of chronic disease may also be eligible to receive prescription pharmaceuticals at reduced cost through the Closing the Gap (CTG) PBS Co-payment Programme [52]. However, hospital prescriptions are excluded from this programme [52].

The MBS and PBS data includes date of service/dispensing, MBS/PBS item number, patient postcode, provider/pharmacy postcode, and total fee charged, rebate paid, and patient co-payment.

Statistical analysis

Initially, descriptive analysis was undertaken to describe the social and demographic characteristics of the sample, and weighted sample. Then the total cost for the first 12-months post-diagnosis for the five types of healthcare expenditure: hospital episodes, ED presentations, MBS items, PBS items, and patient co-payments are presented for the broad type of cancer, and the population groups of interest. We also present the average total healthcare cost per person (to the Australian healthcare system), and the average patient co-payment per person during the first 12-months following a diagnosis. We chose to include the standard deviation, as in many cases, the standard deviation was greater than the mean, indicating a wide dispersion of the costs.

Finally, the total cost of cancer for the first 12-months following diagnosis for each of the five types of healthcare were modelled with a generalized linear model using a gamma distribution, with a log link function. This included the number of months the patient survived as an offset to the model. The analysis was limited to include adults (≥ 18 years at diagnosis), and only to those who had costs for the healthcare type used in the model. Independent variables included in the analysis were sex, age at diagnosis, Indigenous status (reference group = non-Indigenous Australians), rurality (three categories; reference group = metropolitan), IRSD quintiles (reference group = Q1 (most disadvantaged)) and broad cancer type (18 categories; reference group = tracheal, bronchus and lung cancer).

All analyses were undertaken using SAS V9.4 (SAS Institute Inc., Cary, NC, USA). Weighted estimates are presented, unless otherwise stated.

Human Research Ethics approval was obtained from the Townsville Health and Hospital Service Human Research Ethics Committee (HREC) (HREC/16/QTHS/11), AIHW (EO2017/1/343) and James Cook University HREC (H6678). Permission to waive consent was approved from Queensland Health under the Public Health Act 2005. No identifiable information was provided to the authors.

Results

CancerCostMod cancer incidence

In total, 25,553 individuals were diagnosed with a new cancer in Queensland between July 2011 and June 2012. Once weighted, this represents 123,900 Australians. Table 1 reports the demographic characteristics of our model for all cancers, and for the five most commonly diagnosed cancers in Australia. Our original QCR dataset had complete Indigenous status for 87% of our records, which matches an audit of Queensland Health hospital admission records in 2011–12 [27]. After imputation, we estimated that 2129 of our model were Indigenous Australians.

Table 2 reports the age-standardised incidence rates for our weighted model, compared to the national age-standardised incidence rates for new cases diagnosed in 2012. The CancerCostMod age-standardised incidence rate for the five most commonly diagnosed cancers in Australia are similar to the national age-standardised incidence rate for new cases in 2012.

Cost of cancer during the first 12-months post-diagnosis by broad cancer type

The total initial cost associated with newly diagnosed cancer for the healthcare system was $4.3 billion, and total patient co-payment was $127.7 million. Hospital episodes accounted for 77% of the healthcare expenditure, followed by PBS (14%) and MBS 6%. Table 3 shows the total cost of cancer for the first 12-months following diagnosis for all cancers combined, and for each broad cancer type (excluding 'bone' and 'other thoracic and respiratory organs' cancers due to sample size). The most expensive cancers to the healthcare system were cancers of the blood and lymphatic

Table 1 Demographic characteristics of CancerCostMod for all cancers combined, and most commonly diagnosed cancers[a]

	All cancers	Breast cancer	Prostate cancer	Colorectal cancer	Tracheal, bronchus and lung cancer	Melanoma of the skin
Actual n	25,600	3100	4200	2900	2100	3300
Weighted N (%)	123,900	15,400 (12.5)	20,700 (16.7)	14,800 (11.9)	11,100 (9.0)	12,300 (9.9)
Died within 12-months post-diagnosis (%)	25,100 (20.2)	700 (4.2)	1000 (4.6)	2400 (16.3)	6400 (57.7)	400 (3.1)
Age group						
≤ 17 (%)	1000 (0.8)	–	–	–	–	–
18 to 44 (%)	9300 (7.5)	1800 (12.0)	100 (0.6)	700 (4.7)	200 (1.6)	1800 (14.6)
45 to 64 (%)	42,700 (34.5)	7600 (49.1)	7800 (37.7)	4100 (27.7)	2900 (26.3)	4500 (36.4)
≥ 65 (%)	70,900 (57.2)	6000 (38.9)	12,800 (61.8)	10,000 (27.6)	8000 (72.1)	6000 (48.7)
Sex						
Male (%)	69,300 (55.9)	100 (0.7)	20,700 (100)	8100 (54.9)	6500 (58.4)	7200 (58.4)
Female (%)	54,600 (44.1)	15,300 (99.3)	n/a	6700 (45.1)	4600 (41.6)	5100 (41.6)
Indigenous status						
Non-Indigenous Australian (%)	121,800 (98.3)	15,200 (98.4)	20,500 (99.0)	14,600 (99.1)	10,800 (97.3)	12,100 (98.8)
Indigenous Australian (%)	2100 (1.7)	300 (1.6)	200 (1.0)	100 (0.9)	300 (2.7)	100 (1.2)
Rurality[b]						
Metropolitan (%)	58,500 (47.5)	7800 (50.5)	9100 (44.1)	6700 (45.9)	5000 (45.2)	6100 (49.7)
Regional (%)	54,500 (44.2)	6400 (41.7)	9600 (46.5)	6600 (45.1)	5100 (45.8)	5300 (43.7)
Remote (%)	10,200 (8.3)	1200 (7.8)	1900 (9.4)	1300 (9.1)	1000 (9.0)	800 (6.7)
IRSD[c] Quintiles[b]						
Q1 (Most disadvantaged) (%)	11,300 (9.2)	1100 (7.2)	2100 (10.2)	1400 (9.8)	1300 (11.6)	1000 (8.2)
Q2 (%)	5700 (4.7)	800 (5.0)	900 (4.3)	700 (4.6)	600 (5.3)	500 (4.3)
Q3 (%)	19,900 (16.2)	2500 (16.3)	3400 (16.5)	2500 (16.7)	1900 (17.5)	1800 (14.7)
Q4 (%)	56,000 (45.5)	6700 (43.7)	9300 (45.2)	6700 (45.7)	4900 (44.5)	5900 (47.9)
Q5 (Least disadvantaged) (%)	30,200 (24.5)	4300 (27.8)	4900 (23.8)	3400 (23.1)	2300 (21.1)	3000 (24.9)

[a] Weighted results reported (except in the first row), and rounded to the nearest 100. Weighted values less than 100 are not reported
[b] Excluding individuals with missing postcodes
[c] Index of Relative Socio-Economic Disadvantage

system, followed by colorectal cancer and breast cancer. Colorectal cancer was the most expensive cancer in regards to hospital episodes, and cancers of the blood and lymphatic system had the highest MBS and PBS rebate costs. During the first 12-months, cancers of the eye, brain and other parts of the central nervous system (CNS) accounted for the highest average cost per person to the Australian healthcare system, followed by cancers of the blood and lymphatic system. The most expensive cancers in regards to patient co-payments were cancers of the blood and lymphatic system, followed by breast cancer and colorectal cancer. The average patient co-payment costs per person were highest for cancers of the blood and lymphatic system, followed by cancers of the eye, brain and other parts of the central nervous system (CNS).

Table 2 Australian and CancerCostMod Cancer Incidence

Broad cancer group	National new cases, 2012	National incidence rate (a)	CancerCostMod cases	CancerCostMod incidence rate (a)
All cancers	121,693	482.85	123,915	492.75
Breast cancer (female only)	15,337	120.42	15,335	120.56
Prostate cancer (male only)	20,687	168.25	20,687	168.37
Colorectal cancer	14,793	58.46	14,774	58.54
Tracheal, bronchus and lung cancer	11,114	43.78	11,104	43.52
Melanoma of the skin	12,250	49.51	12,250	49.42

[(a)] Incidence rates are standardised to the Australian population as at 30 June 2001 and are expressed per 100,000 population

Table 3 Total cost of cancer during the first 12-months post-diagnosis by cancer type[a]

	N[b]	Cost To The Australian Healthcare System (AUD)						Patient co-payment[e] (AUD)	
		Hospital episodes[c]	ED presentations	MBS rebate[d]	PBS rebate	Total cost to the healthcare system	Average healthcare cost per person (SD)	Total	Average per person (SD)
All cancers combined	123,900	3,302,933,000	88,103,100	263,243,600	631,804,300	4,286,083,900	34,600 (41300)	127,673,700	1000 (2000)
Prostate cancer	20,700	279,788,000	6,416,200	36,828, 600	38,650,600	361,683,300	17,500 (17,300)	16,324,000	800 (1200)
Breast cancer	15,400	266,860,700	6,744,700	36,690, 600	170,956,200	481,252,200	31,200 (29,700)	21,040, 900	1400 (1500)
Colorectal cancer	14,800	581,675,500	11,849,400	30,563,000	71,878,900	695,966,800	47,100 (38,200)	16,979,500	1100 (1800)
Blood and lymphatic system	13,300	564,265,300	13,286,600	40,503,100	176,947,100	795,002000	59,800 (70,800)	24,655,400	1900 (4100)
Melanoma of the skin	12,300	53,047,300	1,575,700	23,174,800	12,506,700	90,304,500	7400 (12600)	4,945,100	400 (500)
Tracheal, bronchus and lung cancer	11,100	396,063,600	15,618,400	24,164,600	45,331,000	481,177,600	43,300 (34,700)	10,168,700	900 (1700)
Digestive organs	10,100	394,784,900	12,668,100	20,303,100	31,119,600	458,875,800	45,500 (36,800)	11,273,000	1100 (2000)
Cancers of the urinary tract	6200	181,697,200	5,022300	10,703,000	17,623,000	215,045,500	34,700 (31800)	4,816,000	800 (1100)
Gynaecological cancers	5200	138,156,900	3,121,600	10,475,000	16,774,700	168,528,200	32,300 (31500)	5,171,800	1000 (1600)
Head and neck	4000	118,588,400	2,478,200	10,264,700	9,019,700	140,351,100	34,900 (45,500)	2,374,400	600 (1200)
Other or ill-defined cancers	2700	67,701,500	2,316,900	4,295,300	6,051400	80,365,200	29,600 (29,700)	2,239,700	800 (1700)
Thyroid and other endocrine glands	2600	48,531,700	799,400	4,195,500	3,631,300	57,157,900	22,000 (34,400)	1,180,600	500 (600)
Eye, brain and CNS	1900	101,300,100	3,113,900	3,324,700	17,342,800	125,081500	64,700 (70,400)	2,830,000	1500 (2300)
Mesothelioma, Kaposi Sarcoma, and soft tissue	1600	62,604,600	1,882,200	3,245,200	9,187,200	76,919,200	47,100 (46100)	2,080,100	1300 (2200)
Male genital organs, exc prostate	900	17,921,400	678,900	2,190,200	2,267,400	23,057, 900	25,000 (30,400)	643,200	700 (1200)
Other skin cancer	800	11,920,400	283,300	1,749,400	1,456,800	15,409,900	18,600 (28100)	541,900	700 (1100)

[a] Weighted results reported, and rounded to the nearest 100
[b] Excluding broad cancer types with less than 500 individuals ('bone', and 'other thoracic and respiratory organs')
[c] Admitted and non-admitted hospital episodes
[d] MBS rebate, excluding items included as non-admitted hospital episodes
[e] MBS and PBS patient co-payment

Cost of cancer during the first 12-months post-diagnosis by population group

We then aimed to describe the cost of cancer for the first 12-months post-diagnosis by Indigenous status, rurality, and socioeconomic disadvantage, as shown in Table 4. The average total healthcare cost per person was greater for Indigenous people diagnosed with cancer in the first 12-months, compared to non-Indigenous people diagnosed with cancer. However, the average patient co-payment was greater for non-Indigenous people diagnosed with cancer, compared to Indigenous people diagnosed with cancer. Table 4 also shows that the average total healthcare cost per person was greater for people from the most disadvantaged quintile (Q1), and the lowest for people in the least disadvantaged quintile (Q5). Conversely, the average patient co-payment was greatest for people in the least disadvantaged quintile (Q5), and lowest for people in the most disadvantaged quintile (Q1).

Finally, we conducted five generalized linear models to predict costs, limiting our analyses to adults only (≥ 18 years), adjusting for sex, Indigenous status, rurality, IRSD quintile, age at diagnosis, and broad cancer type (co-efficients not shown). Table 5 shows the abbreviated output for the five types of cost: hospital episodes, ED presentations, MBS rebates (excluding hospital items), PBS rebates, and patient co-payments. Indigenous Australians had significantly higher costs for hospital episodes (22% higher) and ED presentations (23% higher), but significantly lower costs for MBS rebates (8% lower), PBS rebates (18% lower), and patient co-payments (61% lower) compared to

Table 4 Total cost of cancer for the first 12-months post-diagnosis, by population groups[1]

		Cost To The Australian Healthcare System (AUD)						Patient co-payment[4] (AUD)	
	n	Hospital episodes[2]	ED presentations	MBS rebate[3]	PBS rebate	Total cost to the healthcare system	Average healthcare cost per person (SD)	Total	Average per person (SD)
Weighted total	123,900	3,302,933,000	88,103,100	263,243,600	631,804,300	4,286,083,900	34,600 (41300)	127,673,700	1000 (2000)
Indigenous status									
Non-Indigenous Australian	121,800	3,233,868,900	85,643,100	259,009,200	623,618,600	4,202,139,700	34,500 (41100)	126,913,100	1000 (2000)
Indigenous Australian	2100	69,064100	2,459,900	4,234,500	8,185,700	83,944,200	40,100 (48100)	760,600	400 (800)
Rurality[5]									
Metropolitan	58,500	1,485,140,700	38,505,200	125,884,200	306,909,000	1,956,439,200	33,500 (38,200)	65,570,600	1100 (1900)
Regional	54,500	1,495,270,400	42,165,900	116,837,100	270,755,900	1,925,029300	35,300 (42300)	52,061400	1000 (1900)
Remote	10,200	311,295,100	6,805,500	19,718,200	52,844,900	390,663,700	38,200 (51900)	9,831,600	1000 (2500)
IRSD[6] Quintiles[5]									
Q1 (Most disadvantaged)	11,300	349,061100	11,248,900	21,232,900	47,295,500	428,838,500	38,000 (43000)	9,226,300	800 (1900)
Q2	5700	160,726,000	3,180,500	11,653,000	28,801,500	204,361,000	35,700 (42300)	4900,200	900 (1800)
Q3	19,900	554,607,600	14,727,500	41,726,900	102,484,100	713,546,100	35,900 (46,800)	17,757,000	1100 (1800)
Q4	56,000	1,469,376,800	42,010,300	128,352,200	288,661,500	1,928,400,700	34,400 (40,400)	59,401,200	1100 (1800)
Q5 (Least disadvantaged)	30,200	757,934,600	16,309,300	59,474,600	163,267,300	996,985,900	33,000 (38,300)	36,179,100	1200 (2000)

[1] Weighted results reported, and rounded to the nearest 100
[2] Admitted and non-admitted hospital episodes
[3] MBS rebate, excluding items included as non-admitted hospital episodes
[4] MBS and PBS patient co-payment
[5] Excluding individuals with missing postcodes
[6] Index of Relative Socio-Economic Disadvantage

non-Indigenous Australians. The costs for hospital episodes had significantly higher costs in the first 12-months post-diagnosis with increasing remoteness, 6% for people living in inner and outer regional areas, and 15% higher for people living in remote and very remote areas compared to those living in metropolitan areas. People living in remote and very remote areas had 10% lower costs for MBS rebates and 10% higher PBS rebate costs. Compared to those living in the most disadvantaged areas (IRSD Q1), those in quintiles 3–4 had decreasing costs associated with hospital episodes. There were no differences in the costs of ED presentations for IRSD quintiles. The costs incurred for MBS and PBS rebates and also patient co-payments increased as the IRSD quintile increased (moved towards the least disadvantaged).

Discussion

The use of administrative health data is growing in Australia and is supported by a number of Australian Government agencies [53]. There are many advantages of using administrative data for research, including being non-intrusive to the target population, no (or low) cost for data collection (but there may be a cost-recovery charge), and the ability to capture a large population. Administrative data has advantages over sample data, which relies on self-reported information from patients, and also excludes patients who have passed away. There are a growing number of international studies which have used linked administrative data to describe the patterns and cost of cancer. For example, recent international studies have used administrative data to describe the excess cost of cancer in New Zealand [54], Canada [55], and England [56]. Our model, CancerCostMod does not seek to describe the excess cost of cancer compared to the general population, but rather, describe the distribution of costs for population groups experiencing poorer health outcomes. This paper aimed to 1) describe the development of our model, CancerCostMod; 2) to describe the total costs of cancer in Australia during the first 12-months post-diagnosis; and 3) to describe the distribution of the cost of cancer in Australia during the first 12-months post-diagnosis by population group.

We estimated that the total cost to the Australian healthcare system was $4.3 billion. Hospital episodes accounted the majority (77%) of the costs to the healthcare system. This is similar to the AIHW national

Table 5 Five generalized linear models of the cost of cancer for the first 12-months[1]

	Hospital episodes[2]		ED presentations		MBS rebate[3]		PBS rebates		Patient co-payment[4]	
	Ratio	Estimate (SE)	Ratio	Estimate (SE)	Ratio	Estimate (SE)	Ratio	Estimate (SE)	Ratio	Estimate (SE)
Intercept	–	8.4819 (0.0526) ***	–	5.4363 (0.0728) ***	–	5.7499 (0.0382) ***	–	6.8536 (0.0721) ***	–	4.7398 (0.0593) ***
Age	1.01	0.0073 (0.0005) ***	1.01	0.0103 (0.0008) ***	1.00	−0.0021 (0.0004) ***	0.99	−0.0109 (0.0008) ***	1.00	0.0033 (0.0006) ***
Female	0.89	−0.1177 (0.0186) ***	0.95	−0.0537 (0.0262) *	0.95	−0.0551 (0.0129) ***	0.85	−0.1597 (0.0234) ***	0.98	−0.0214 (0.0192)
Indigenous Australians	1.22	0.1978 (0.0605) **	1.23	0.2095 (0.0752) **	0.92	−0.0888 (0.0402) *	0.82	−0.1928 (0.0735) **	0.39	−0.9315 (0.0619) ***
Inner and outer regional area	1.06	0.0557 (0.0182) **	1.02	0.0196 (0.0275)	0.99	−0.0138 (0.0126)	1.04	0.0366 (0.0231)	0.94	−0.0571 (0.0189) **
Remote and very remote area	1.15	0.1401 (0.0296) ***	1.03	0.0322 (0.0454)	0.90	−0.1092 (0.0207) ***	1.10	0.0912 (0.0381) *	0.98	−0.0219 (0.0311)
IRSD[5] Q2	1.01	0.0091 (0.0415)	1.00	0.0004 (0.0626)	1.07	0.0675 (0.0289) *	1.05	0.0474 (0.0519)	1.00	−0.0026 (0.0432)
IRSD[5] Q3	0.94	−0.0619 (0.0309) *	1.01	0.0097 (0.0420)	1.08	0.0805 (0.0216) ***	1.11	0.1053 (0.0389) **	1.00	−0.0020 (0.0324)
IRSD[5] Q4	0.90	−0.1042 (0.0275) ***	0.98	−0.0215 (0.0368)	1.18	0.1642 (0.0193) ***	1.17	0.1582 (0.0348) ***	1.23	0.2033 (0.0289) ***
IRSD[5] Q5 (least disadvantaged)	0.88	−0.1297 (0.0323) ***	0.94	−0.0603 (0.0467)	1.00	0.0016 (0.0226)	1.19	0.1703 (0.0411) ***	1.32	0.2746 (0.0338) ***

* p-value < 0.05
** *p*-value < 0.01
*** p-value < 0.001
[1] Adjusted for age at diagnosis, sex, Indigenous status, rurality, IRSD quintiles, and broad cancer type
[2] Admitted and non-admitted hospital episodes
[3] MBS rebate, excluding items included as non-admitted hospital episodes
[4] MBS and PBS co-payment is the cost to the patient
[5] Index of Relative Socio-Economic Disadvantage

report, which estimated that hospital admitted patient services accounted for 79% of the national healthcare system expenditure in 2008–09 [18]. Likewise, in other countries, admitted hospital services have been reported as contributing to the greatest proportion of cancer-related costs [55, 57, 58]. Initially, we described the total costs to the healthcare system, and the average costs per person to the healthcare system by cancer type, and population group. This initial analysis showed the average costs per person to the healthcare system were higher for each of our population groups of interest, compared to their reference group – Indigenous Australians, people living in remote areas, and people from the most disadvantaged quintile. We found that the total cost of cancer during the first 12-months post-diagnosis was significantly different for Indigenous Australians, people living in remote and very remote areas, and people living in areas of greater disadvantage. These differences in costs could be due to differences in health system use, which we will examine in future studies.

We estimated that the individual patient co-payment costs were $127 million in the first 12-months following diagnosis. The initial analysis found that the average co-payment costs were lower for Indigenous Australians, and people from the most disadvantaged quintile. After adjusting for age, sex, Indigenous status, rurality, IRSD quintiles, and broad cancer type, we found that the patient co-payment costs were lower for Indigenous Australians compared to non-Indigenous Australians, for people in inner and outer regional areas compared to metropolitan, and patient co-payment costs were greater for people from IRSD quintiles 4 and 5. These findings may be due to Australia's universal healthcare system, and policies in place, such as the Medicare Safety Nets, the PBS Safety Net, and the CTG PBS Co-payment Programme to protect vulnerable population groups and people with higher healthcare co-payments. We will examine the differences in patient co-payments in more detail in future studies.

To our knowledge, this is the first study in Australia to use individual-level data to estimate the cost of cancer for Indigenous Australians. A previous report by AIHW and Cancer Australia reported that the average per person hospital expenditure for Indigenous Australians was half of that for non-Indigenous Australians [19]. However, this report used population-level data and only included hospitalizations for which cancer was the primary cause [19]. The advantage of using individual-level data allows us to

determine if there are differences in health system use, and cost between Indigenous and non-Indigenous people. Further studies using CancerCostMod will examine these differences in more detail.

This is the first model in Australia, which aims to describe the healthcare system costs and patient co-payment costs for these population groups experiencing inequalities. Previous Australian studies have reported higher OOPE for rural patients with cancer [15, 16]. Recently, Newton et al. (2018) reported that the highest OOPE was due to surgery (23%), tests (20%), and accommodation (12%) [16]. Whereas, Gordon et al. (2009) reported travel costs accounting for the greatest proportion of patient OOPE (71%), followed by medical appointments (10%), and PBS co-payments (9%) [15]. Although CancerCostMod only estimates the patient co-payments for primary health care and prescription pharmaceuticals, it has the advantage of using administrative data, and thus is not subject to selection bias (recruitment and loss-to follow-up), or recall bias in recalling healthcare expenditure.

A strength of this study is that the base population includes everyone diagnosed with cancer in Queensland, and 3 years of follow-up data were obtained using linked administrative data. Our data have then been weighted to the Australian population to allow us to estimate the healthcare expenditure of cancer to the Australian healthcare system, and the patient co-payments for Australians diagnosed with cancer.

A common limitation of Australian health studies, is the completeness of Indigenous status on health records. We used multiple imputation to assign Indigenous status to missing records in our original QCR cohort. As reported, once weighted, our model included 2129 Indigenous Australians. There are currently no reliable data on the number of new cancer cases for Indigenous Australians for each jurisdiction in Australia. The most recent national AIHW data reports that in 2012, approximately 1343 new cancer cases were diagnosed in Indigenous Australians [59]. However, this estimate is based on five (of eight) jurisdictions only, in which the majority (90%) of Indigenous Australians live [59]. There is also varying levels of completeness of Indigenous status for each jurisdiction (from 2% unknown, to 18% unknown) [59]. Therefore, this national estimate may be underestimating the true incidence of cancer in Indigenous Australians [59]. One of the 2015 National Aboriginal and Torres Strait Islander Cancer Framework priorities is to "strengthen the capacity of cancer related services and systems to deliver good quality, integrates services that meet the needs of Aboriginal and Torres Strait Islander people" [60], and calls for improved recording of Indigenous status, and recommends the use of linked administrative data to look at patterns of care for Indigenous Australians in order to meet one of their priorities [60]. CancerCostMod uses individual-level data, which allows us to evaluate the service use and to quantify the cost of care for Indigenous Australians.

Administrative data have inherent weaknesses, primarily that the data are not collected for the purpose of research. For example, we were unable to estimate the cost of cancer by clinical staging, as this is not routinely collected by the QCR. The QCR does not collect individual or household financial information, therefore, we used aggregated area-level data to classify an individual's level of socioeconomic disadvantage. We were also unable to analyze individual physiological, biological or clinical factors, which are considered by the treating specialist and may alter the suitability of different treatment options. The patient co-payment costs will be limited to costs incurred for MBS and PBS items, which excludes patient co-payment costs for private or non-prescription pharmaceuticals, private health insurance premiums, or hospital excess, or travel/accommodation costs. Finally, we sought to describe the cost of ED presentations for people with cancer. The IHPA first used the ED Classification System in the National Efficient Price Determination in 2012–13 [45]. The IHPA NHCDC annual reports include the average cost of each ED presentation from 2011, however, there have been several changes to the ED URG classification system and we have included the estimation of the costs of ED presentations separately to the hospital episodes.

Conclusions

These findings are of interest to policy makers and healthcare providers, as they provide an evaluation of the total cost of cancer. To ensure an equitable healthcare system, it is first important to determine if there are any inequalities in relation to healthcare service use and expenditure amongst population groups whom experience poorer health outcomes. This paper describes the development of CancerCostMod, Australia's first model of health service use, healthcare expenditure, and patient co-payment expenditure for people with cancer. CancerCostMod can be used to fill the gap by quantifying the current health system use, healthcare expenditure and patient co-payment costs for population groups experiencing poorer health outcomes - Indigenous people, people living in rural and remote areas, and socioeconomically disadvantaged persons. We found significant differences in healthcare expenditure and patient co-payments for the first 12-months following a cancer diagnosis for each of these population groups. CancerCostMod can be used to look at the cost from different perspectives for the first 3 years, with the potential to increase the cohort enrolment period and study period.

Abbreviations

ABF: Activity based funding; ABS: Australian Bureau of Statistics; AIHW: Australian Institute of Health and Welfare; AR-DRG: Australian Refined Diagnostic-Related Group; ASGS: Australian Statistical Geography Standard; ED: Emergency department; EDIS: Emergency Department Information System; ICD-10-AM: International Classification of Diseases 10th Edition, Australian Modification; ICD-O: International Classification of Diseases for Oncology; IHPA: Independent Hospital Pricing Authority; IRSD: Index of Relative Socio-Economic Disadvantage; LGA: Local government area; MBS: Medicare Benefits Schedule; MI: Multiple imputation; NHCDC: National Hospital Cost Data Collection; NSW: New South Wales; OOPE: Out-of-pocket expenditure; PBS: Pharmaceutical Benefits Scheme; QCR: Queensland Cancer Registry; QHAPDC: Queensland Health Admitted Patient Data Collection

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Availability of data and materials

The datasets used during the current study are not publicly available due to privacy constraints associated with our ethics approval that explicitly prohibits the sharing of data.

Authors' contributions

NB conceived, designed and planned the study, and undertook the data analysis. All authors contributed to the interpretation of the data, drafting the manuscript, and approved of the final draft.

Competing interests

The authors declare that they have no competing interests.

Publisher's Note

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Shortly after publishing this paper, an error in the SAS syntax was identified. This resulted in an underestimation of the cost of (admitted and non-admitted) hospital episodes. A correction was requested (November) and approved (December) by the Editor-in-Chief of Health Economics Review. The correction was available online on the 19th of January 2019. The original paper and the correction are presented in this thesis. When referring to the results from this chapter elsewhere in the thesis, the correct results are used.

Health Economics Review

CORRECTION Open Access

Correction to: CancerCostMod: a model of the healthcare expenditure, patient resource use, and patient co-payment costs for Australian cancer patients

Nicole Bates[1,2*], Emily Callander[2], Daniel Lindsay[1] and Kerrianne Watt[1]

Correction to: Health Economics Review (2018) 8:28 https://doi.org/10.1186/s13561-018-0212-8

Correction

Following publication of the original article [1], the authors reported errors on their article.

In Tables 3 and 4 of this manuscript, the costs presented in the "hospital episodes", "total cost to the health care system" and "average health care cost per person" columns were incorrect. Consequently, the numbers in the "Ratios" and "standard errors" columns related to the Hospital Episodes section of Table 5 were incorrect. The corrected Tables are shown below.

Subsequently, the following sentences needed to be corrected. Corrected content is shown in bold:

Abstract, Results, Discussion

The total initial cost associated with newly diagnosed cancer for the healthcare system is **$4.8** billion. Hospital episodes accounted for **80%** of the healthcare expenditure, followed by PBS (**13%**) and MBS (**5%**).

Results, subheading "Results of Cost of cancer during the first 12-months post-diagnosis by population group", 2nd paragraph:

Indigenous Australians had significantly higher costs for ED presentations (23% higher), but significantly lower costs for MBS rebates (8% lower), PBS rebates (18% lower), and patient co-payments (61% lower) compared to non-Indigenous Australians. [**The words "for hospital episodes (22%)" have been removed from the sentence**].

The costs for hospital episodes were significantly higher in the first 12-months post-diagnosis with increasing remoteness, **4%** for people living in inner and outer regional areas, and **10%** higher for people living in remote and very remote areas compared to those living in metropolitan areas. [**these percents were previously reported as 6% and 15% higher, respectively**].

Compared to those living in the most disadvantaged areas (IRSD Q1), those in **quintiles 4–5** had decreasing costs associated with hospital episodes [**quintiles 3–4 were previously reported**].

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Reference

1. Bates N, Callander E, Lindsay D, et al. CancerCostMod: a model of the healthcare expenditure, patient resource use, and patient co-payment costs for Australian cancer patients. Health Econ Rev. 2018;8:–28. https://doi.org/10.1186/s13561-018-0212-8.

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Table 3 Total cost of cancer during the first 12-months post-diagnosis by cancer type[1]

		COST TO THE AUSTRALIAN HEALTHCARE SYSTEM (AUD)						Patient co-payment[5] (AUD)	
	N[2]	Hospital episodes[3]	ED presentations	MBS rebate[4]	PBS rebate	Total cost to the healthcare system	Average healthcare cost per person (SD)	Total	Average per person (SD)
All cancers combined	123,900	3,824,163,400	88,103,100	263,243,600	631,804,300	4,807,314,400	38,800 (42,900)	127,673,700	1000 (2000)
Prostate cancer	20,700	374,172,600	6,416,200	36,828, 600	38,650,600	456,068,000	22,000 (18,700)	16,324,000	800 (1200)
Breast cancer	15,400	377,396,200	6,744,700	36,690, 600	170,956,200	591,787,700	38,300 (31,300)	21,040, 900	1400 (1500)
Colorectal cancer	14,800	643,503,400	11,849,400	30,563,000	71,878,900	757,794,700	51,300 (39,800)	16,979,500	1100 (1800)
Blood and lymphatic system	13,300	616,132,000	13,286,600	40,503,100	176,947,100	846,868,700	63,600 (73,600)	24,655,400	1900 (4100)
Melanoma of the skin	12,300	70,844,800	1,575,700	23,174,800	12,506,700	108,102,000	8800 (13,400)	4,945,100	400 (500)
Tracheal, bronchus and lung cancer	11,100	434,675,600	15,618,400	24,164,600	45,331,000	519,789,700	46,800 (35,700)	10,168,700	900 (1700)
Digestive organs	10,100	433,725,600	12,668,100	20,303,100	31,119,600	497,816,400	49,400 (38,400)	11,273,000	1100 (2000)
Cancers of the urinary tract	6200	202,334,900	5,022,300	10,703,000	17,623,000	235,683,200	38,000 (32,600)	4,816,000	800 (1100)
Gynaecological cancers	5200	159,616,700	3,121,600	10,475,000	16,774,700	189,988,000	36,400 (32,700)	5,171,800	1000 (1600)
Head and neck	4000	141,306,700	2,478,200	10,264,700	9,019,700	163,069,400	40,500 (47,200)	2,374,400	600 (1200)
Other or ill-defined cancers	2700	76,240,900	2,316,900	4,295,300	6,051,400	88,904,500	32,800 (31,500)	2,239,700	800 (1700)
Thyroid and other endocrine glands	2600	55,221,900	799,400	4,195,500	3,631,300	63,848,200	24,600 (35,800)	1,180,600	500 (600)
Eye, brain and CNS	1900	114,903,700	3,113,900	3,324,700	17,342,800	138,685,000	71,800 (73,200)	2,830,000	1500 (2300)
Mesothelioma, Kaposi Sarcoma, and soft tissue	1600	69,741,200	1,882,200	3,245,200	9,187,200	84,055,900	51,500 (47,800)	2,080,100	1300 (2200)
Male genital organs, exc prostate	900	19,635,700	678,900	2,190,200	2,267,400	24,772,300	26,800 (30,900)	643,200	700 (1200)
Other skin cancer	800	15,355,100	283,300	1,749,400	1,456,800	18,844,600	22,700 (30,200)	541,900	700 (1100)

[1]Weighted results reported, and rounded to the nearest 100
[2]Excluding broad cancer types with less than 500 individuals ('bone', and 'other thoracic and respiratory organs')
[3]Admitted and non-admitted hospital episodes
[4]MBS rebate, excluding items included as non-admitted hospital episodes
[5]MBS and PBS patient co-payment

Table 4 Total cost of cancer for the first 12-months post-diagnosis, by population groups[1]

		COST TO THE AUSTRALIAN HEALTHCARE SYSTEM (AUD)						Patient co-payment[4] (AUD)	
	n	Hospital episodes[2]	ED presentations	MBS rebate[3]	PBS rebate	Total cost to the healthcare system	Average healthcare cost per person (SD)	Total	Average per person (SD)
Weighted total	123,900	3,824,163,400	88,103,100	263,243,600	631,804,300	4,807,314,400	38,800 (42,900)	127,673,700	1000 (2000)
Indigenous status									
Non-Indigenous Australian	121,800	3,749,654,000	85,643,100	259,009,200	623,618,600	4,717,924,900	38,700 (42,800)	126,913,100	1000 (2000)
Indigenous Australian	2100	74,509,400	2,459,900	4,234,500	8,185,700	89,389,500	42,700 (48,800)	760,600	400 (800)
Rurality[5]									
Metropolitan	58,500	1,738,821,800	38,505,200	125,884,200	306,909,000	2,210,120,300	37,800 (39,900)	65,570,600	1100 (1900)
Regional	54,500	1,721,146,800	42,165,900	116,837,100	270,755,900	2,150,905,700	39,500 (43,800)	52,061,400	1000 (1900)
Remote	10,200	352,165,600	6,805,500	19,718,200	52,844,900	431,534,200	42,200 (53,800)	9,831,600	1000 (2500)
IRSD[6] Quintiles[5]									
Q1 (Most disadvantaged)	11,300	387,822,900	11,248,900	21,232,900	47,295,500	467,600,300	41,400 (44,100)	9,226,300	800 (1900)
Q2	5700	183,953,200	3,180,500	11,653,000	28,801,500	227,588,200	39,800 (43,700)	4,900,200	900 (1800)
Q3	19,900	635,646,500	14,727,500	41,726,900	102,484,100	794,585,000	39,900 (48,500)	17,757,000	1100 (1800)
Q4	56,000	1,715,299,900	42,010,300	128,352,200	288,661,500	2,174,323,900	38,800 (42,000)	59,401,200	1100 (1800)
Q5 (Least disadvantaged)	30,200	889,411,700	16,309,300	59,474,600	163,267,300	1,128,462,900	37,300 (40,200)	36,179,100	1200 (2000)

[1]Weighted results reported, and rounded to the nearest 100
[2]Admitted and non-admitted hospital episodes
[3]MBS rebate, excluding items included as non-admitted hospital episodes
[4]MBS and PBS patient co-payment
[5]Excluding individuals with missing postcodes
[6]Index of Relative Socio-Economic Disadvantage

Table 5 Five generalized linear models of the cost of cancer for the first 12-months[1]

	Hospital episodes[2]		ED presentations		MBS rebate[3]		PBS rebates		Patient co-payment[4]	
	Ratio	Estimate (SE)	Ratio	Estimate (SE)	Ratio	Estimate (SE)	Ratio	Estimate (SE)	Ratio	Estimate (SE)
Intercept		8.5519 **(0.0483) *** **	–	**5.4363 (0.0728) *** **	–	**5.7499 (0.0382) *** **	–	**6.8536 (0.0721) *** **	–	**4.7398 (0.0593) *** **
Age	1.01	0.0062 (0.0005) ***	1.01	**0.0103 (0.0008) *** **	1.00	**−0.0021 (0.0004) *** **	0.99	**−0.0109 (0.0008) *** **	1.00	**0.0033 (0.0006) *** **
Female	0.88	−0.1267 (0.0167) ***	0.95	**−0.0537 (0.0262) ***	0.95	**−0.0551 (0.0129) *** **	0.85	**−0.1597 (0.0234) *** **	0.98	**−0.0214 (0.0192)**
Indigenous Australians	1.02	0.0220 (0.0525)	1.23	**0.2095 (0.0752) ** **	0.92	**−0.0888 (0.0402) ***	0.82	**−0.1928 (0.0735) ** **	0.39	**−0.9315 (0.0619) *** **
Inner and outer regional area	1.04	0.0364 (0.0165) *	1.02	**0.0196 (0.0275)**	0.99	**−0.0138 (0.0126)**	1.04	**0.0366 (0.0231)**	0.94	**−0.0571 (0.0189) ** **
Remote and very remote area	1.10	0.0947 (0.0268) ***	1.03	**0.0322 (0.0454)**	0.90	**−0.1092 (0.0207) *** **	1.10	**0.0912 (0.0381) ***	0.98	**−0.0219 (0.0311)**
IRSD[5] Q2	1.02	0.0214 (0.0373)	1.00	**0.0004 (0.0626)**	1.07	**0.0675 (0.0289) ***	1.05	**0.0474 (0.0519)**	1.00	**−0.0026 (0.0432)**
IRSD[5] Q3	0.98	−0.0232 (0.0279)	1.01	**0.0097 (0.0420)**	1.08	**0.0805 (0.0216) *** **	1.11	**0.1053 (0.0389) ** **	1.00	**−0.0020 (0.0324)**
IRSD[5] Q4	0.95	−0.0510 (0.0250) *	0.98	**−0.0215 (0.0368)**	1.18	**0.1642 (0.0193) *** **	1.17	**0.1582 (0.0348) *** **	1.23	**0.2033 (0.0289) *** **
IRSD[5] Q5 (least disadvantaged)	0.93	−0.0700 (0.0293) *	0.94	**−0.0603 (0.0467)**	1.00	**0.0016 (0.0226)**	1.19	**0.1703 (0.0411) *** **	1.32	**0.2746 (0.0338) *** **

*p-value < 0.05
**p-value < 0.01
***p-value < 0.001
[1]Adjusted for age at diagnosis, sex, Indigenous status, rurality, IRSD quintiles, and broad cancer type
[2]Admitted and non-admitted hospital episodes
[3]MBS rebate, excluding items included as non-admitted hospital episodes
[4]MBS and PBS co-payment is the cost to the patient
[5]Index of Relative Socio-Economic Disadvantage

Summary

The total cost of cancer to the Australian public healthcare system estimated in this study was AU$4.8 billion for the first twelve months, and the total patient co-payments incurred was $127.7 million. The costs to the public healthcare system were presented separately for admitted and non-admitted hospital episodes, ED presentations, MBS rebates, and PBS rebates.

In addition to estimating the total costs, this is the first Australian study where costs have been reported separately for those within the population known to experience poorer outcomes following a cancer diagnosis (specifically, remoteness, socio-economic status and Indigenous status). After adjusting for age, sex, Indigenous status, remoteness, socioeconomic disadvantage, and broad type of cancer, there were significant differences for each of the cost categories analysed:

- Hospital episodes: costs increased with increasing remoteness, costs were significantly lower for people living in the least disadvantaged quintiles (Q4-5), but there was no significant difference by Indigenous status;
- ED presentations: costs were significantly greater for Indigenous Australians compared to non-Indigenous Australians, but there was no difference by remoteness or socioeconomic disadvantage;
- MBS rebates: costs were significantly lower for Indigenous Australians and people living in remote and very remote areas, and costs were significantly higher for people living in IRSD Q2-4;
- PBS rebates: costs were significantly lower for Indigenous Australians, but costs were significantly higher for people living in remote and very remote areas, and for people living in IRSD Q3-5; and
- Patient co-payments were significantly lower for Indigenous Australians and for people living in regional and remote areas, and significantly higher with decreasing socioeconomic disadvantage.

In addition to the limitations discussed in the published article, another limitation is that the data may not capture any changes in treatment and funding policies. The census of all cancer diagnoses in Queensland between July 2011 and June 2012, is now up to eight years old. The research team plan to build upon this original dataset, and increase the date range for all cancer diagnosis, and the date ranges for the data linkage. This will allow the sample size to be increased, and will allow the date range for the follow-up of costs to be increased as well. The administrative data did not include pre-

existing medical conditions, as described in the published protocol,[3] we describe that the cost for all health service use was included, regardless of whether it is directly attributable to cancer or not. Furthermore, the OOP patient co-payments were limited to patient co-payments included in the MBS or PBS datasets. As such, it did not include all OOP costs, such as private health insurance, private medications, private medical services, travel, accommodation, parking etc. These costs are known to be high, particularly travel costs for rural patients and thus the patient co-payments are an underestimation of the total patient OOP expenditure.

This study had several purposes. To describe the development of CancerCostMod, which was the primary dataset used in this thesis; to estimate the cost of cancer during the first 12-months post-diagnosis, and to describe the distribution of these costs by remoteness, Indigenous status, and socioeconomic disadvantage. In fulfilling these purposes, the first aim of the thesis was addressed.

[3] Callander E, Topp SM, Larkins S, Sabesan S, Bates N. Quantifying Queensland patients with cancer health service usage and costs: Study protocol. BMJ Open. 2017; 7(1):e014030 doi: http://dx.doi.org/10.1136/bmjopen-2016-014030

Chapter Four: Indirect costs of cancer in Australia

Introduction

Many people who are diagnosed with cancer are of working age. Furthermore, due to changes in the age of retirement in Australia, it is important to consider the impact cancer will have on the working population. In this chapter, the second aim of the thesis is addressed: to quantify the annual indirect costs due to changes in labour force participation of people with cancer.

The aims of this study were to determine the labour force participation characteristics of people with cancer, to estimate the indirect costs of cancer due to lost productivity, and to identify any inequality in the distribution of labour force absence in Australia.

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Labour force participation and the cost of lost productivity due to cancer in Australia

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Abstract

Background: In Australia, 40% of people diagnosed with cancer will be of working age (25–64 years). A cancer diagnosis may lead to temporary or permanent changes in a person's labour force participation, which has an economic impact on both the individual and the economy. However, little is known about this economic impact of cancer due to lost productivity in Australia. This paper aims to determine the labour force participation characteristics of people with cancer, to estimate the indirect cost due to lost productivity, and to identify any inequality in the distribution of labour force absence in Australia.

Methods: This study used national cross-sectional data from the 2015 Survey of Disability, Ageing and Carers, conducted by the Australian Bureau of Statistics (ABS). The ABS weighted each component of the survey to ensure the sample represented the population distribution of Australia. The analysis was limited to people aged 25–64 years. Participants were assigned to one of three health condition groups: 'no health condition', 'cancer', and 'any other long-term health condition'. A series of logistic regression models were constructed to determine the association between health condition and labour force participation.

Results: A total of 34,393 participants surveyed were aged 25–64 years, representing approximately 12,387,800 Australians. Almost half (46%) of people with cancer were not in the labour force, resulting in a reduction of $1.7 billion to the Australian gross domestic product (GDP). Amongst those in the labour force, people with no health condition were 3.00 times more likely to be employed full-time compared to people with cancer (95% CI 1.96–4.57) , after adjusting for age, sex, educational attainment and rurality. Amongst those with cancer, people without a tertiary qualification were 3.73 times more likely to be out of the labour force (95% CI 1.97–7.07).

Conclusions: This paper is the first in Australia to estimate the national labour force participation rates of people with cancer. People with cancer were less likely to be in the labour force, resulting in a reduction in Australia's GDP. Cancer survivors, especially those without a tertiary qualification may benefit from support to return to work after a diagnosis.

Keywords: Cancer, Oncology, Costs, Health economics, Productivity

Background

Cancer is the leading burden of disease in Australia [1] and internationally [2]. In 2017, an estimated 134,174 Australians will be diagnosed with cancer, of which 40% will be of working age (25–64 years) [3]. Using the 2003 Survey of Disability, Ageing and Carers, Schofield et al. [4] found that half (49%) of older Australians (aged 45–64 years) with cancer were not in the labour force. In a more recent Australian study of 255 cancer patients, 67% reported changes to their employment [5]. A systematic literature review of employment and work-related issues in cancer survivors included 64 international studies and found that over a six-year period after a cancer diagnosis, 26–53% of cancer survivors were out of work (lost their job or quit) [6]. Similarly, a recent meta-analysis of international studies found that compared to healthy control participants, cancer survivors were 1.4 times more likely to be unemployed [7]. These studies focus on the individual perspective, and highlight the important financial distress faced by individual cancer patients and their

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families due to being out of the labour force [5, 8–12]. However, to date there has been minimal focus on the societal perspective in Australia, and the consideration of the aggregate costs of these changes in workforce participation; nor has there been consideration of the distribution of the costs of labour force absence, looking at the population groups most likely to be affected. Such information could be more useful to policy makers, concerned with maximising welfare to the whole of society.

Health economic evaluations routinely evaluate the direct cost of illness; however, the indirect cost of lost productivity due to morbidity and premature mortality may exceed the direct costs of cancer [13–17]. In Europe, the estimated cost of lost productivity from cancer in 2009 was 42%, a further 18% was attributed to the cost of informal care, and only 41% of costs were attributed to direct health care [18]. The National Institute of Health estimated that in 2010, the cost of lost productivity in the United States accounted for 61% of the total cost of cancer, compared to 39% for the direct costs [15]. In Korea, the estimated morbidity and premature mortality costs accounted for 55% of the total cost of cancer, compared to 28% for medical care in 2009 [17]. In New South Wales, Australia in 2005, lost productivity accounted for 54% of the total lifetime cost of cancer, compared to the direct costs which accounted for 29% of the total lifetime costs [13]. However, this report was from a single state in Australia. Carter, Schofield and Shrestha [19] recently estimated that approximately 88,000 working years were lost, due to premature deaths from cancer in 2003 in Australia, which cost $4.2 billion in present value of lifetime income. Lung and colorectal cancers accounted for 30% of the total loss of income. This study provides a national perspective of the cost of cancer due to premature mortality; however, there is currently limited work on the productivity cost for people with cancer who are out of the labour force.

This paper will contribute to the growing body of research on the indirect costs of cancer. The aims of this research conducted within an Australian context are to: 1) determine whether people with cancer have different labour force participation characteristics to people with no health conditions, or any other long term health conditions, 2) estimate the cost of cancer due to lost productivity (limited to the context of paid work) and 3) identify any inequality in the distribution of labour force absence amongst those with cancer.

Methods

Data

The primary data source accessed for this data was the 2015 Survey of Disability, Ageing and Carers (SDAC). This is a national survey conducted every 3 years by the Australian Bureau of Statistics (ABS). The SDAC sample was a randomly selected sample of the Australian population, regardless of health condition or disability status and included participants from both household and cared-accommodation, but excluded those residing in prisons/correctional institutes, religious and/or educational institutes; very remote areas, and discrete Indigenous communities. The sample frame comprised approximately 25,500 private dwellings, 250 self-care retirement, and a further 1000 cared-accommodation facilities. To adjust for any potential bias in survey participants, the ABS weight the survey data against known population benchmarks. Briefly, the weight value indicates how many of the population unit each sample unit represents. The two components were weighted separately, the household component was benchmarked to the estimated resident population in each jurisdiction, and the cared accommodation component was benchmarked to the census population counts of this component as described in detail by the ABS [20]. Weighting allows an inference of results to the general Australian population.

The survey included questions on demographics (such as age, sex, highest level of education achievement, and geographical remoteness), labour force participation, and long-term health conditions (LTHC). LTHC's were defined by the SDAC as a condition lasting, or was likely to last 6 months or more, or symptoms in the previous 12 months for an episodic condition (ie asthma or epilepsy) and coded by the ABS based upon the ICD-10 [20]. Although the original survey included answers for specific medical conditions, the ABS regrouped some conditions for data release. For example, the types of cancer were grouped by the ABS: skin cancer (ICD C43–44), breast cancer (ICD C50), prostate cancer (C61), bowel/colorectal cancers (C18–21) and any other neoplasm (including benign tumours).

Statistical analysis

Analyses were limited to people aged 25–64 years. Excluding survey respondents under the age of 25 allowed those most likely to be participating in higher education to be excluded; and those over the age of 65 were excluded, as the traditional retirement in Australia in 2015 was 65 years. Participants were categorised into one of three health condition groups: 'no LTHC' included those who did not report any LTHC, 'cancer' included those who reported having cancer (skin, breast, prostate, bowel/colorectal or any other neoplasm) as a LTHC, and 'any other LTHC' included those who reported any other LTHC. Labour force participation (LFP) was recorded as employed full-time (FT), employed part-time (PT), unemployed but looking for FT and/or PT work, and not in the labour force (NILF).[1] Educational attainment was recoded into a dichotomous variable (tertiary vs non-tertiary education); as was rurality (major cities and other), and age (25–44 years and 45–64 years).

Aim 1: Labour force participation of people with cancer

A series of logistic regression models were constructed to determine the association between cancer and LFP. Initially, the analysis was limited to include those in the labour force only. A logistic regression model was constructed to estimate the odds of being employed full-time for people with cancer, LTHC, and no health condition (respectively), after adjusting for age, sex, educational attainment and rurality. A second logistic regression model was constructed to estimate the odds of being out of the labour force for people with cancer, LTHC, and no health condition (respectively), after adjusting for age, sex, educational attainment and rurality.

Aim 2: Cost of labour force absence associated with cancer

Using the same approach as other Australian studies [21–25], the financial impact to Australia's gross domestic product (GDP) due to people with cancer being out of the labour force was estimated using the Australian Treasury's formula [26]:

$$\mathrm{GDP} = (\mathrm{GDP}/\mathrm{H})\ \mathrm{x}\ (\mathrm{H}/\mathrm{EMP})\ \mathrm{x}\ (\mathrm{EMP}/\mathrm{LF})\ \mathrm{x}\ (\mathrm{LF}/\mathrm{Pop15+})\ \mathrm{x}\ \mathrm{Pop15+}$$

where GDP = gross domestic product; H = total hours worked; EMP = total number of persons employed; LF = total labour force; and Pop15+ = population aged 15 years and over [26].

This method has been previously used in other studies [21–25], and differs from the friction cost method, which argues that people who leave the labour force due will be replaced by other workers (including those who were previously unemployed) thus limiting the cost of workers leaving the labour force [27]. Australia has a very low unemployment rate (6.3% in July 2015) [28] and significant labour shortages in some industries [29], furthermore, the Australian Treasury's aim to make Australia's financial position more sustainable by promoting productivity, population growth and labour force participation [30], recognising the signficiant cost labour force exit has on the Australian economy.

Aim 3: Inequality in the distribution of labour force absence amongst those with cancer

A concentration index was initially used to determine whether there was any inequality in the distribution of labour force absence amongst people with cancer. The concentration index is normally used as a measure of health inequality, and assesses the distribution of health outcomes across socioeconomic groups in a population. The concentration index reflects the cumulative proportion of health held by the cumulative proportion of the population, ranked by a measure of socioeconomic status. The measure of socioeconomic status used was the highest level of education attainment achieved, as reported in the survey (7 ordinal categories: Year 8 or below, Year 10, Year11/12, Certificate, Diploma, Bachelor, Post-graduate). The concentration index ranges from − 1 to 1, with a value of 0 denoting perfect equality in the distribution of labour force absence, a negative value denoting a distribution skewed towards people of lower socioeconomic status, and a positive value denoting a distribution skewed towards people of higher socioeconomic status. The concentration index (CI), and it's associated 95% confidence intervals, were computed as follows:

$$2\sigma_R^2\left(\frac{y_i}{\mu}\right) = \alpha + \beta R_i + \varepsilon_i$$

Where σ_R^2 is the variance of R_i (the individual's rank), y_i is the labour force status of each individual (i = 1, 2, 3….N), α is the intercept, ε_i is the error terms, and β is the CI [1]. Finally, among only people with cancer, a multivariate logistic regression model was constructed to estimate the odds of being not in the labour force, after accounting for age, sex, educational attainment, and rurality.

All analyses were undertaken using SAS V9.4 (SAS Institute Inc., Cary, NC, USA). Weighted estimates are presented, unless stated otherwise. GDP figures are presented in 2015 Australian dollars.

Results

Within the 2015 SDAC, a total of 34,393 participants were of working age (25–64 years), which represented approximately 12,387,800 people when weighted. Of the participants in this age group, there were 7,287,100 with no health conditions, 108,900 people with a type of cancer, and 4,991,800 with some other LTHC. Table 1 shows the demographic characteristics for each of the health condition categories (no LTHC, cancer, and any other LTHC).

Aim 1: Labour force participation of people with cancer

Table 2 shows the employment status for people with no health condition, people with cancer, and people with any other LTHC. Almost half (46%) of people with cancer were not in the labour force, compared to approximately a quarter (27%) of people with any other LTHC, and only 12% of people with no health condition.

Firstly, the analyses were limited to people who were in the labour force. Of those with cancer who were employed, 47% were employed full time, compared with 68% of those with any other LTHC, and 74% of those with no health condition. Amongst those in the labour force, after adjusting for age, sex, educational attainment and rurality, those with no health condition had 3.00

Table 1 SDAC sample demographic characteristics of Australian adults of working age, 25–64 years (using weighted totals, rounded to the nearest 100)

	Long-term health condition		
	No LTHC Total (%)	Cancer Total (%)	Any other LTHC Total (%)
Total			
Survey Participants	18,990	355	15,048
Weighted Population estimate	7,287,100	108,900	4,991,800
Sex (weighted)			
Male	3,641,800 50%	46,600 43%	2,420,400 48%
Female	3,645,300 50%	62,300 57%	2,571,500 52%
Age (weighted)			
25–44 years	4,615,600 63%	18,500 17%	1,960,200 39%
45–64 years	2,671,500 37%	90,400 83%	3,031,700 61%
Educational attainment (weighted)			
Non-tertiary	4,429,000 62%	75,500 71%	3,526,200 73%
Tertiary	2,702,000 38%	30,100 29%	1,336,700 27%
Rurality (weighted)			
Major cities	5,610,800 77%	74,500 68%	3,425,500 69%
Other areas	1,676,200 23%	34,400 32%	1,566,300 31%

LTHC long-term health condition

times the odds of being employed full-time than people with cancer (95% CI 1.96–4.57; $p < 0.0001$). Similarly, those with any other LTHC had 2.15 times the odds of being employed full-time (95% CI 1.41–3.28; $p = 0.0004$) than those with cancer.

Secondly, the odds of being out of the labour force were calculated. Table 3 shows that after adjusting for age, sex, educational attainment and rurality, those with no health condition, and those with any other long-term health condition had lower odds of being out of the labour force compared to adults with cancer.

Table 2 Labour force participation of participants (weighted)[a]

Health condition	Employed FT Number (%)	Employed PT Number (%)	NILF Number (%)	Total weighted population estimate
No LTHC	4,585,900 62.9%	1,589,700 21.8%	887,100 12.2%	7,287,000
Cancer	27,300 25.3%	30,400 28.1%	50,100 46.4%	108,100
Any other LTHC	2,328,700 46.8%	1,104,900 22.2%	1,344,100 27.0%	4,975,900

LTHC long-term health condition, *FT* full-time, *PT* part-time, *NILF* not in the labour force, have not looked for work in the last 4 weeks, and do not intend to work or look for work in the future

[a]The number and percentage of people who were 'unemployed' were not presented due to low unemployment rate in Australia, and hence the low sample number of unemployed people

Table 3 Logistic regression model of being not in the labour force

Parameter	*Estimate*	*Standard Error*	*P-Value*
Intercept	−2.49	0.16	< 0.001
Male	0.97	0.35	< 0.001
Aged 25–44	0.35	0.03	< 0.001
Tertiary education attainment	0.70	0.04	< 0.001
Lives in major city	0.04	0.04	0.2255
No LTHC	−1.68	0.14	< 0.001
Any other LTHC	−0.81	0.14	< 0.001
Odds of being out of the labour force			
	Odds Ratio[a]	95% CI	*P*-value
Cancer	Reference		
No LTHC	0.19	0.14–0.25	< 0.001
Any other LTHC	0.45	0.34–0.58	< 0.001

LTHC long-term health condition

[a]adjusted OR = adjusted for age, sex, educational attainment, and rurality

Aim 2: Cost of labour force absence associated with cancer

An estimated 50,100 Australian adults of working age (25–64 years) with cancer were not in the labour force in 2015, thereby reducing Australia's GDP by approximately $1.7 billion (Table 4).

Table 4 The proportion of people out of the labour force, and the financial impact on Australia's GDP amongst people with cancer (weighted)

	Estimated number NILF	Total people with cancer	% NILF/total people with cancer	Difference in GDP AU$ million
Total				
	50,100	108,900	46%	$1738 million
Sex				
Male	19900[a]	46,600	43%	$690 million
Female	30300[a]	62,300	49%	$1051 million
Age				
25–44 years	6900	18,500	37%	$239 million
45–64 years	43,200	90,400	48%	$1499 million
Educational attainment				
Non-tertiary	42,100	75,500	56%	$1460 million
Tertiary	7500	30,100	25%	$260 million
Rurality				
Major cities	32,100	74,500	43%	$1114 million
Other areas	18,000	34,400	52%	$624 million

[a]rounded up

Aim 3: Inequality in the distribution of labour force absence amongst those with cancer

The concentration index showing level of inequality in the distribution of labour force absence amongst people with cancer was calculated to be − 0.20 (95% CI -0.26 to − 0.13), which indicates that having cancer and being not in the labour force is unequally skewed towards those with a low educational attainment.

Amongst people with cancer, those without a tertiary qualification were 3.73 times more likely to be out of the labour force (95% CI 1.97–7.07; $p < 0.0001$), than people with tertiary education. Sex, age, and rurality were not associated with being out of the labour force ($p = 0.0818$, $p = 0.3723$, $p = 0.1869$ respectively).

Discussion

The results of this paper have shown that in 2015, almost half (46%) of adults of working age (25 to 64 years) with cancer were not in the labour force. Of those in the labour force, adults with no health conditions had 3 times the odds of being employed full-time than adults with cancer. Other studies have supported our findings that following a cancer diagnosis, many patients report a temporary or permanent change to their labour force participation, including a reduction in work hours and stopping work [5, 6, 8, 9, 11, 31–34].

Amongst people with cancer, a greater proportion of older people (45–64 years) were not in the labour force, however, this appears to be explained by other demographic factors. Amongst people with cancer, those without a tertiary qualification had nearly four times the odds of being out of the labour force; age, sex, and rurality were not associated with a greater risk. Higher education attainment has been identified as a positive factor in returning to work [6, 35], which also supports our findings that labour force absence amongst those with cancer is unequally skewed towards those with lower levels of education attainment. Other factors which may affect returning to work include jobs that require manual labour, and those with less flexible working arrangements [6, 8, 10, 32, 33]. The type of cancer and treatment factors may also negatively impact returning to work [6, 7, 10, 35]. For example, Clarke et al. [35] found that colorectal and lung cancer survivors had greater difficulties performing daily activities, and colorectal, lung, and bladder cancer survivors were more likely to have functional limitations, which may impact work ability.

This paper looked at distribution of people being out of the labour force for any reason, with some people potentially being out of the labour force directly as a result of cancer, while others may have chosen early retirement [11] due to a reassessment of their priorities following a health shock. In Australia, employees (excluding casual employees) are entitled to paid sick leave (10 days each year for full-time employees), and unpaid leave for up to 3 months [36]. While the Australian retirement age in 2015 was 65 years, at which time individuals may be eligible to access a government 'age pension', individuals may have access to their superannuation from age 55. However, previous work has found that despite these sources of financial support, early retirement due to LTHC has a significant negative impact on an individual's income and wealth [22, 25]. As such cancer survivors may benefit from additional support by the Government, employers and medical professionals to facilitate returning to work if they choose to. Previous studies have shown that many cancer survivors will return to work after treatment, from 40% at six-months to 89% at 24-months following a cancer diagnosis [6].

A key strength of this paper is that it used the 2015 SDAC, which is a national survey weighted to the Australian population. Participants who identified as having cancer as a long-term health condition represented 0.9% of the weighted population. It was estimated that around 1.5% of the Australian population had cancer in 2011–12 [37]. However, we limited our analyses to people of working age only (25–64 years), which excluded people over 75 years, who had the highest rate of developing cancers (11.1% for men and 4.4% for women) [37]. Therefore, this study was representative of the Australian population of working age.

However, the use of the SDAC also has several limitations. This survey did not include information about the time since diagnosis, which may be a factor in labour force participation [8, 9, 12]. Secondly, although the main types of cancer in Australia (skin, breast, prostate, and colorectal cancer) are identified in the SDAC, the number of participants in each type was small, and therefore, disaggregated analysis by type of cancer was not possible. Finally, it is possible that some types of cancers, which may have minimal impacts on returning to work, may have been over-estimated, particularly if someone recently had the lesion removed. For example, non-melanoma skin cancers are the most common type of cancer in Australia, and in some cases, the cancer is completely removed with a biopsy, or removed by surgical excision [38, 39]. We only included LTHC in our analyses, which was defined in the survey as conditions lasting or expected to last 6-months [20], which should exclude cases in which the only treatment received was complete removal of the lesion.

This paper provides an insight into the economic burden of cancer due to labour force participation, and builds upon the growing body of literature. However, we acknowledge that this is only a small part of the larger burden of cancer, and are currently conducting a larger study on the cost of cancer to the healthcare system and the individual [40]. Future research also should look at

the distribution of labour force participation rates across the different types of cancer to ensure equitable access and allocation of resources.

Conclusion

A large proportion of Australians diagnosed with cancer are of working age, and in general cancer survival rates are improving [3]. Furthermore, in light of the increase of the Australian retirement age, from the current 65 to 67 years by 2023 (increasing by 6 months every 2 years commencing July 2017 [41]), it is reasonable to expect that the cost of lost productivity may increase in the coming years. There is a call for support systems to facilitate return to work for cancer survivors who want to work [42]. For some survivors, returning to work after a cancer diagnosis is an important milestone, both financially and emotionally [33, 43]. Cancer survivors without a tertiary qualification may benefit from additional support. This paper is the first in Australia to estimate the national labour force participation rates of adults of working age with cancer, and the indirect cost of cancer due to lost productivity. This information is valuable when considering how cancer affects patients and society.

Endnote

[1]Not in the Labour Force defined as not in the labour force, and have not looked for work in the last 4 weeks, and do not intend on working or looking for work in the future.

Abbreviations

ABS: Australian Bureau of Statistics; CI: Concentration index; FT: Full-time; GDP: Gross domestic profit; LFP: Labour force participation; LTHC: Long-term health condition; NILF: Not in the labour force; PT: Part-time; SDAC: Survey of Disability, Ageing and Carers

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Availability of data and materials

The data that support the findings of this study are available upon request from the Australian Bureau of Statistics.

Authors' contributions

NB and EC conceived the study, participated in study design, performed the analyses, contributed to the interpretation, and writing the manuscript. DL participated in interpreting the results, and writing the manuscript. KW participated in the design of the study and writing of the manuscript. All authors have read and approved the final manuscript.

Ethics approval and consent to participate

The dataset for this study is from publicly, de-identified available data, with permission from the Australian Bureau of Statistics.

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests.

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Summary

A cancer diagnosis may result in changes in an individual's labour force participation. At the time of the 2015 SDAC, almost half (46%) of people of working age (25 to 64 years) with cancer were not in the labour force, resulting in an annual reduction of $1.7 billion to the Australian gross domestic product (GDP). After limiting the analysis to people with cancer, people without a tertiary qualification were more likely to be out of the labour force. There was no significant differences in labour force participation by age, sex, and rurality. Employment policies should support the individual's decision to return to work if they wish to. Amongst those with cancer, some people may require additional assistance in returning to the workforce.

In addition to the limitations discussed in the published article, there are some additional limitations relating to the aims of this thesis. Specifically, this thesis aimed to describe the labour force participation and indirect costs by Indigenous status, remoteness, and socioeconomic status. Due to the limitations of the dataset, it was not possible to analyse the labour force participation and indirect costs by Indigenous status or socioeconomic status. In addition to this, due to the sample size in the dataset, the remoteness categories were collapsed into 'major cities Australia, and 'those living in other areas'. Therefore, the analysis was unable to identify any differences in labour force participation between metropolitan, regional, and remote.

Future studies should identify if there are any differences in labour force participation between population groups. Due to the limitations of the SDAC as outlined, it may be necessary to recruit people diagnosed with cancer and obtain information directly from these participants and their families. The information from future studies may then be used to identify people who require additional support in returning to the workforce following a cancer diagnosis.

PART 3: A CASE STUDY OF THE COST OF FEMALE BREAST CANCER IN AUSTRALIA

In Part 2 of the thesis, the direct and indirect costs of all cancers were estimated, and the distribution of these costs by groups known to experience poorer outcomes from cancer were investigated (remoteness, Indigenous status, socioeconomic disadvantage). Part 3 of the thesis focuses specifically on female breast cancer, and a longer timeframe is included (three years following diagnoses) to allow a more detailed examination of relevant costs. The first three years post-diagnosis was chosen for several reasons. Logistically, at the time of commencement, data was available until June 2015. Each individual had at least three years of follow-up data, unless the individual passed away prior to this date. Additionally, previous literature has shown the highest costs are accrued during the first 12-months following diagnosis, and final 12-months of life; however, there from limited research in Australia. Therefore, including the immediate three years post-diagnosis enabled the costs to be estimated for both the public healthcare system, and individual to determine how these costs change over this time period. Future research will seek to extend both the cohort enrolment dates, and the follow-up period.

Female breast cancer was chosen as it is the most commonly diagnosed cancer in Australia. In addition to this, it was selected to overcome a common data limitation in the dataset. All cancer diagnoses (excluding non-melanoma skin cancers) are reported to the jurisdiction's cancer registry. However, the stage at diagnosis is not routinely reported. Additional information is collected by the Queensland Cancer Registry (QCR), such as tumour size, and evidence of lymph node involvement. As described in the following papers, using methods described from previous Queensland studies, breast cancer stage was categorised as early, advanced, and unknown.

Part 3 of the thesis comprises three separate chapters (each a peer-reviewed manuscript), and addresses the third aim of the thesis: to quantify the direct costs to the public healthcare system and individual for the first three years following a female breast cancer diagnosis, and to determine the distribution of these costs by Indigenous status, remoteness, and socioeconomic disadvantage. Chapters Five and Six focus on the cost to the public healthcare system, and Chapter Seven focuses on the costs to the individual.

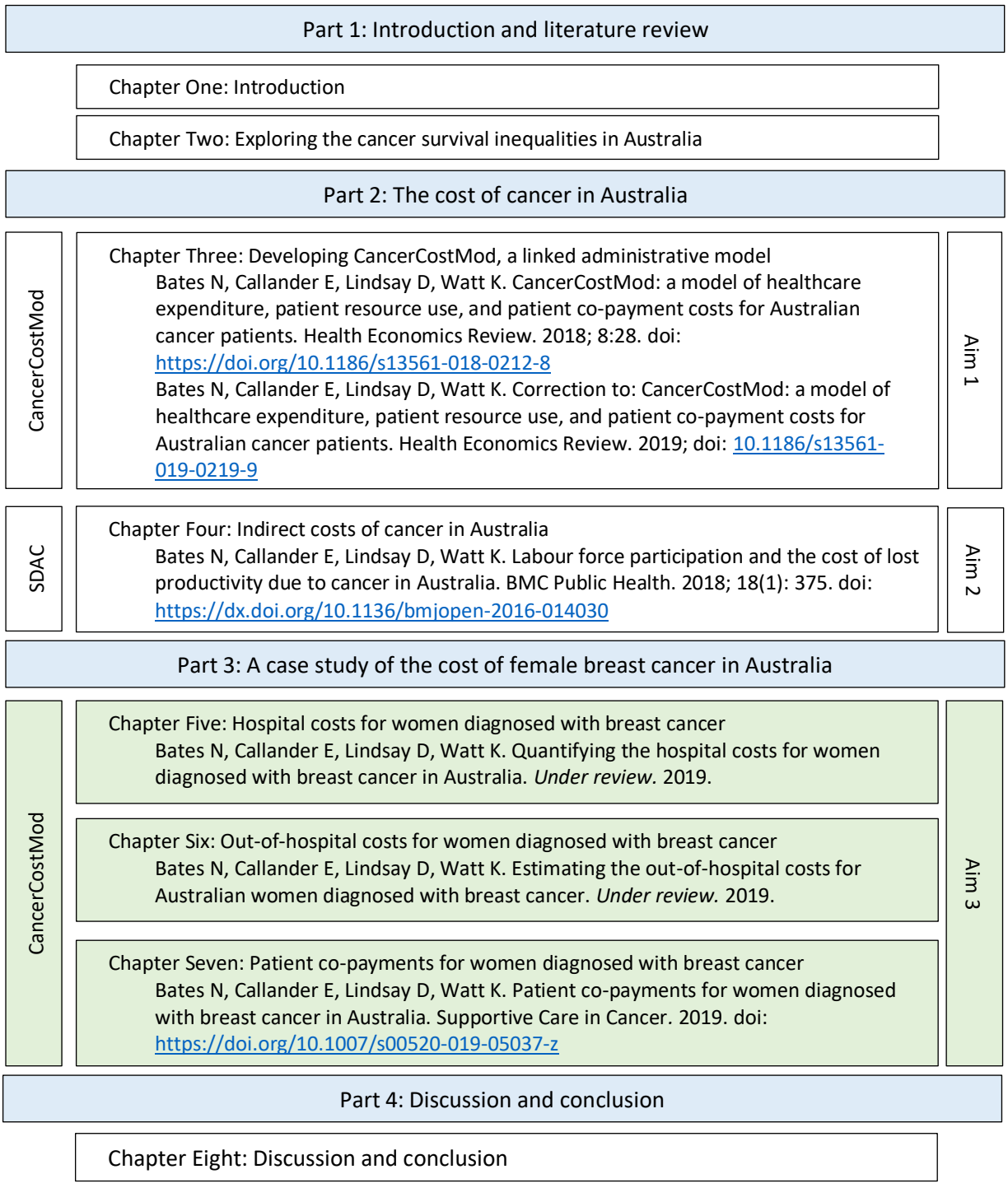

Figure 1: Thesis outline

Chapter Five: Hospital costs for women diagnosed with breast cancer

Introduction

In this chapter, CancerCostMod was used to identify the hospital expenditure associated with female breast cancer for the first three-years following diagnosis, and to determine the distribution of these costs by Indigenous status, geographical remoteness, and socioeconomic status. CancerCostMod was limited to women diagnosed with breast cancer (ICD-O C50).

At the time of thesis submission, this chapter is under review. It is presented in the thesis in the format required by the journal:

> Bates N, Callander E, Lindsay D, Watt K. 2019. Quantifying the hospital costs for women diagnosed with breast cancer in Australia, using CancerCostMod – a population-based data linkage study. *Under Review*

Quantifying the hospital costs for women diagnosed with breast cancer in Australia, using CancerCostMod – a population-based data linkage study

Running title: Australian hospital costs for female breast cancer

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Abstract

Background: Breast cancer is the most commonly diagnosed cancer in women in Australia. Indigenous women, women living in rural and remote areas, and socioeconomically disadvantaged women experience poorer survival following a breast cancer diagnosis. We sought to describe the cost of female breast cancer for hospital episodes and emergency department presentations in Australia, and whether the distribution of costs varied by these characteristics.

Methods: We used a linked administrative dataset, CancerCostMod. The base population for this dataset was all cancer diagnoses in Queensland, Australia between 1JUL2011 and 30JUN2012, as recorded by the Queensland Cancer Registry. Each record was then linked to Queensland Health Admitted Patient Data Collection, Emergency Department Information Systems, Medicare Benefits Schedule, and Pharmaceutical Benefits Scheme between 1JUL2011 and 30JUN2015. The dataset was then weighted to be representative of the Australian population. For this study, CancerCostMod was limited to female breast cancer diagnoses only. The cost of (admitted and non-admitted) hospital episodes and emergency department (ED) presentations were determined. The mean cost per patient for each six-month time period from diagnosis to three years were then modelled.

Results: Between 1JUL2011 and 30JUN2012, 3,079 Queensland women were diagnosed with breast cancer – representing 15,335 Australian women once weighted. The total cost of hospital episodes was $558.4 million during the first three-years, and an additional 12.8 million for ED presentations. The cost of hospital episodes were consistently greater across the three-year study period for Indigenous women compared to non-Indigenous women, and for women living in the most socioeconomically disadvantaged quintile, compared to those living in the least socioeconomically disadvantaged quintile. Some differences in costs of hospital episodes were observed by remoteness, but these were not consistent. Although there were some differences in the average cost for ED presentations, there were no consistent differences across the three-year period for the groups of interest.

Conclusions: This is the first study in Australia to quantify the cost of hospital episodes and ED presentations of Breast Cancer in such detail, and also to describe the distribution of costs by Indigenous status, remoteness, and socio-economic status. These findings have important policy implications

Background

Breast cancer is the most commonly diagnosed cancer in women, and is one of the leading causes of cancer mortality and morbidity in women worldwide.[1] In Australia, the incidence of breast cancer is increasing, and was projected to be the second leading cause of cancer death in females in 2017.[2] Despite improved national survival rates, it is well documented that Aboriginal and/or Torres Strait Islander women (hereafter, respectfully referred to as Indigenous women), women living in rural and remote areas, and socioeconomically disadvantaged women experience poorer survival rates.[3-5] Similar inequalities by ethnicity, socioeconomic status and remoteness for female breast cancer survival have been reported within other high income countries.[6-8]

Reflective of the high burden of breast cancer, the costs of breast cancer in Australia accounted for the highest total expenditure on cancer for females in 2008-09 (11.4%, AU$235 million), mostly attributable to hospital services (62%).[9] A New South Wales (NSW) report estimated that breast cancer was the third most costly cancer, accounting for 7% (AU$76.7 million) of the total health system cost of cancer in NSW in 2005.[10] These reports highlight the relative high investment in breast cancer health services within the Australian healthcare system, but are now nearly a decade old and do not consider other groups with known inequalities.

In 2010-11, the total Australian healthcare expenditure on hospitalizations where the primary diagnosis was female breast cancer was approximately $162.9 million.[11] A report by the Australian Institute of Health and Welfare in 2013 identified that the average per person hospital expenditure for Indigenous women with breast cancer was 0.6 times lower than non-Indigenous women.[11] To the authors' best knowledge, this is the only documented evidence regarding the healthcare expenditure of cancer by Indigenous status; however, only hospital costs where cancer was the principal diagnosis were included in this report.

Previously published estimates of cancer costs rely on aggregated data, which has several limitations that may be overcome by individual-level data. For example, individual-level data allows us to identify individual patient characteristics, such as stage of disease, Indigenous status, remoteness, and socioeconomic status, which may contribute to differences in costs. In recent years, the use of individual level data in Australian costing studies is growing. Of the two studies that included breast cancer, one identified costs for patients undergoing chemotherapy in New South Wales, [12] and one identified the excess costs associated with people over the age

of 45 diagnosed cancer.[13] The first study reported that inpatient hospital care accounted for the highest proportion of average costs for metastatic breast cancer (44%), and 20% for adjuvant breast cancer.[12] The second study found that for people diagnosed with breast cancer, hospitalizations accounted for the greatest proportion of costs during both the first 12-months following a diagnosis (44%), and the last 12-months of life (65%).[13]

The aim of the present study was to identify hospital expenditure for women diagnosed with breast cancer for the first three years post-diagnosis, and to determine the distribution of this expenditure by Indigenous status, remoteness, and socioeconomic status, using linked administrative data. It is the first time whole of population data linkage has been utilized in Australia to estimate costs associated with cancer. This population-based data linkage study adopted a national health system perspective, in which we looked at the cost to the healthcare system for hospital episodes (admitted and non-admitted) and emergency department (ED) presentations.

Methods

Study design and study population

The population for this study was nested in a larger dataset, 'CancerCostMod'.[14] The methodology for the development of 'CancerCostMod' is described in detail elsewhere.[15] Briefly, the base population for 'CancerCostMod' is a census of all cancer diagnoses (excluding non-melanoma skin cancer) in Queensland (1 July 2011 and 30 June 2012), as recorded by the Queensland Cancer Registry (QCR) (N=25,553 patients). Each individual's QCR record was linked to their records in: Queensland Health Admitted Patient Data Collection (QHAPDC); Queensland Health Emergency Department Information Systems (EDIS) by the Queensland Health Statistical Services Branch; Medicare Benefits Schedule (MBS); and Pharmaceutical Benefits Scheme (PBS) by the Australian Institute of Health and Welfare (AIHW), from 1 July 2011 and 30 June 2015, so that there were three full years of data for each individual, post-diagnosis. This dataset was then weighted to the Australian population with cancer, using a programmed SAS macro called GREGWT (N=123,900).[15] For this study, we limited 'CancerCostMod' to include records of female breast cancer (ICD-O C50), aged 18 years or greater at the time of diagnoses.

The QCR database includes sociodemographic determinants at time of diagnosis such as age, sex, Indigenous status and residential postcode. Postcode was mapped to Index of Relative Socio-Economic Disadvantage (IRSD

- a summary of the economic and social conditions of an area, and collapsed into quintiles: Q1=most disadvantaged, Q5=least disadvantaged), and Australian Statistical Geography Standard (ASGS - a measure of remoteness; categorised into metropolitan, regional (inner and outer), and remote (remote and very remote). Postcodes were missing records; these were not mapped to IRSD or remoteness. Indigenous status was recorded for 87% of our original QCR dataset; multiple imputation was used to impute missing Indigenous status, as described previously.[15]

The QCR does not routinely collect detailed breast cancer staging, however, it does collect information on the tumour size and evidence of lymph node involvement. Using methods from previous Queensland studies,[4, 16] we categorized breast cancer stage as:

- 'Early', where tumour size was ≤ 20mm, and no evidence of lymph node involvement;
- 'Advanced', where tumour size was > 20mm, or if there was any evidence of lymph node involvement regardless of tumour size, or if the diagnosis was because of metastatic disease;
- 'Unknown', where lymph node involvement or tumour size was unknown.

Assigning costs for hospital episodes and ED presentations

Australia has a universal healthcare system, Medicare, which provides free public hospital services, and free or subsidized primary health care outside of hospitals. Private health insurance is optional. Funding of Australian hospitals are a mixture of the Australian Government, State/Territory Government, individual out-of-pocket payments, Department of Veteran's Affairs (DVA), Private Health Insurance and other. In 2011-12, approximately 89% of funding for public hospitals were from the Australian and State Governments, compared to 32% for private hospitals. Private hospitals received 44% of their funding from PHI, and 11% from individuals.[17] The QHAPDC and EDIS datasets contained all separations and ED presentations at a Queensland hospital, which included both public and private hospitals.The methods used to assign cost are described in detail elsewhere.[15]

In brief, the cost of each public hospital admitted episode of care was attributed to the Australian Refined Diagnostic-Related Group (AR-DRG) using the cost as reported by the National Hospital Data Collection (NHCDC) report (available online)[18] for the AR-DRG for the relevant year. To reflect possible variations in costs of delivering healthcare to some participants, we included an adjustment for certain patient demographics.[19] The cost

attributed to each AR-DRG for private hospital separations was assigned for the relevant year using the average charge per separation reported by the Private Hospital Data Bureau (PHDB) Annual Reports (available online) for each AR-DRG.[20]

In Australia, some oncology patients may receive treatment at a hospital as a non-admitted (out-) patient, and are therefore not captured in the QHAPDC dataset, however these services are often funded under the MBS and so are captured on the MBS claims records. In order to include these costs, we identified hospital items from the MBS dataset.[15] The benefit paid under the MBS was used to assign a cost to each service. Hereafter, admitted and non-admitted hospital episodes will be referred to as 'hospital episodes'.

Each Emergency Department (ED) presentation was coded to the ED classification system Urgency Related Group (URG) using the triage category, discharge destination and the primary reason for attending the ED (ICD-10-AM). The cost attributed to each URG for each ED presentation was assigned using the average cost per presentation as reported by the NHCDC Report (available online)[18] for the relevant year.

We analyzed and presented the results of hospital episodes and ED presentations separately, as the ED classification system is relatively new. It was first used in costing information from the NHCDC Round 14 (2009-2010) and in the national price determination from 2012-13.[21]

The cost of hospital episodes and ED presentations were calculated for each month for each individual from the date of diagnosis (t=0) to 36 months post-diagnosis. If an individual had no health services for the month, the cost was recorded as $0. If an individual passed away during the study period, there was no cost recorded for subsequent months following death. All costs are reported in Australian dollars (AUD), and adjusted to the 2016-17 financial year, using the Reserve Bank of Australia inflation calculator.[22]

Statistical analysis

Descriptive analysis was undertaken to identify the demographic characteristics of the weighted sample. The costs were then aggregated into six-month time periods to quantify the total cost within each 6-month time period of hospital episodes and ED presentations for all participants, and then separately by age group (18-44 years, 45-64 years, and 65 years and older), breast cancer stage, Indigenous status, remoteness, and

socioeconomic status. As there were a large number of records with no health service utilized during each period, the dataset was limited to those who had at least one hospital episode or ED presentation before calculating the average number and average cost of health services during each time period.

Finally, the mean costs per patient for each six-month time period following diagnosis were modelled with generalized linear models using a gamma distribution, and a log link function. This included the number of months the patient survived as an offset to the model. Independent variables included in the analysis were Indigenous status (reference group=non-Indigenous women), age group (reference group=18-44 years), remoteness (reference group=metropolitan), socioeconomic disadvantage (reference group=IRSD Q5 (least disadvantaged)), breast cancer stage (reference=early), number of services during the time period analysed, and death during the time period (binary).

All analyses were undertaken using SAS V9.4 (SAS Institute Inc., Cary, NC, USA). Human Research Ethics approval was obtained from the Townsville Hospital and Health Service Human Research Ethics Committee (HREC) (HREC/16/QTHS/11), AIHW HREC (EO2017/1/343) and James Cook University HREC (H6678). Permission to waive consent was approved from Queensland Health under the Public Health Act 2005. No identifiable information was provided to the authors.

Results

Between 1 July 2011 and 30 June 2012, 3,079 women over the age of 18 were diagnosed with breast cancer in Queensland. Once weighted for the Australian population, this represented 15,335 women. Demographic characteristics at diagnosis of women diagnosed with breast cancer are shown in Table 1. The mean age at diagnosis was 61 years (SD: 14 years).

Table 1: Demographic characteristics at diagnosis of Australian female breast cancer patients, diagnosed between 1 July 2011 and 30 June 2012 (weighted)

	N
N	3,079
N (weighted)	15,335
Age group	
18-44 years (%)	1,848 (12.1)
45-64 years (%)	7,536 (49.1)
65 years and above (%)	5,951 (38.8)
12-month mortality	646 (4.2)
Indigenous status	
Indigenous women (%)	248 (1.6)
Non-Indigenous women (%)	15,087 (98.4)
Remoteness *	
Metropolitan (%)	7,712 (50.6)
Regional (%)	6,359 (41.7)
Remote (%)	1,180 (7.7)
Index of Relative Socio-Economic Disadvantage *	
Quintile 1 (most disadvantaged) (%)	1,095 (7.2)
Quintile 2 (%)	767 (5.0)
Quintile 3 (%)	2,483 (16.3)
Quintile 4 (%)	6,669 (43.7)
Quintile 5 (least disadvantaged) (%)	4,236 (27.8)
Breast cancer stage	
Early (%)	6,695 (43.6)
Advanced (%)	7,174 (46.8)
Unknown (%)	1,466 (9.6)

* Those with missing postcode data at diagnosis were excluded (weighted n=85)

The total cost of admitted and non-admitted hospital episodes over the three years post-diagnosis was AU$558.4 million (Table 2). The first six-months following diagnosis contributed to around half (50.1%) of the total costs for hospital episodes in this cohort (AU$279.5 million), with a total of 758,594 hospital episodes. The average cost of hospital episodes during the first three years post diagnosis was $36,675 per person (SD 36,488). The average number of hospital episodes over the three-year study period was 124 (SD 109). The first six-months following diagnosis also had the highest average number of hospitalizations per patient (50 episodes), and highest average cost per patient ($18,377). In all but the first six-months, the standard deviation was larger than the mean, indicating a wide dispersion of both the average number of hospital episodes and average costs between individuals.

Table 2: Costs to the health system for hospital episodes of female breast cancer in Australia, for women diagnosed between 1 July 2011 and 30 June 2012 (weighted)

Time since diagnosis	Number of patients	Total hospital episodes		Average per patient who had a hospital episode	
		Number of hospital episodes	Total cost ($)	Number of hospital episodes (SD)	Cost of hospital episodes ($) (SD)
0-6 months	15,211	758,594	279,524,527	50 (39)	18,377 (15,896)
7-12 months	14,520	431,607	95,526,937	30 (33)	6,579 (11,589)
13-18 months	14,240	195,401	46,225,336	14 (20)	3,246 (8,046)
19-24 months	13,916	170,698	44,299,437	12 (24)	3,183 (8,306)
25-30 months	13,715	169,598	49,751,793	12 (29)	3,628 (13,196)
31-36 months	13,345	154,685	43,072,866	12 (26)	3,228 (9,477)

Table 3 shows the cost of ED presentations for female breast cancer patients in Australia for women diagnosed between 1 July 2011 and 30 June 2012. The total cost for ED presentations was $12.8 million, and there were 17,403 ED presentations across the three years. The first six-months following diagnosis contributed $4.9 million (38.4%) of the total costs. The average cost of ED presentations during the first three years per person was $2,077 (SD: 2,360) and the average number of ED presentations was 3 (SD: 3). The average cost per patient was also highest in the first six-months following diagnosis ($1,429). During each of the six-month periods, the standard deviation shows less variance from the mean than hospital episodes for both the average number of ED presentations and the average total cost of ED presentations.

Table 3: Costs to the health system for ED presentations of female breast cancer in Australia, for women diagnosed between 1 July 2011 and 30 June 2012 (weighted)

Time since diagnosis	Number of patients	All ED presentations for cohort (15,335 individuals)		Average per patient who had an ED presentation	
		Number of ED presentations	Cost	Number of ED presentations (SD)	Cost of ED presentations ($) (SD)
0-6 months	3,445	6,594	4,922,775	2 (1)	1,429 (1,122)
7-12 months	1,566	2,377	1,794,763	2 (1)	1,146 (897)
13-18 months	1,394	2,250	1,565,506	2 (2)	1,123 (870)
19-24 months	1,269	1,942	1,409,814	2 (2)	1,111 (987)
25-30 months	1,324	2,123	1,577,551	2 (2)	1,191 (1,032)
31-36 months	1,366	2,117	1,551,278	2 (1)	1,136 (1,027)

Figure 1 shows the average cost per patient for hospital episodes and ED presentations by age group (A and B), breast cancer stage (C and D), Indigenous status (E and F), remoteness (G and H), and socioeconomic disadvantage (I and J) by six-month time periods. There are some small differences in the average cost per patient by age group for both hospital episodes and ED presentations. The average cost per patient for hospital episodes (C) was greater for women diagnosed with advanced stage disease during the first six-months, and 7-to-12 months following diagnosis; however, women diagnosed with unknown stage disease had greater average ED presentations during these time periods. The average cost per patient was higher for Indigenous women than non-Indigenous women for both hospital episodes (E) and ED presentations (F) across all time points for the three-year study period. In terms of remoteness, there was little difference in the average cost per patient for hospital episodes (G); but some cost differences were observed for ED presentations (H) – specifically, women living in remote areas had slightly higher costs compared to women living in metropolitan or regional areas, and there was an increase in the average cost of ED presentations for women living in remote areas during months 12-to-18. The average cost per patient for hospital episodes was similar by IRSD quintiles (I); and there were some inconsistent differences for the average cost per patient for ED presentations (J).

Figure 1: Average cost per patient for Hospital Episodes and ED Presentations by age group, breast cancer stage, Indigenous status, remoteness, and socioeconomic disadvantage. Average costs per patient were calculated for each six-month period from diagnosis to 3-years. The figures on the left present the unadjusted average costs for admitted and not-admitted hospital episodes, and on the right present the unadjusted average cost for ED presentations by characteristics of interest.

Table 4 shows the parameter estimates produced by the six generalised linear models, estimating the mean admitted and non-admitted hospital episode cost per patient for each six-month time period for hospital episodes, adjusting for Indigenous status, remoteness, socioeconomic status, age group at diagnosis, stage of disease at diagnosis, number of hospital episodes during time period being analysed, and death during time period being analysed. Costs were significantly greater for Indigenous than non-Indigenous women in all but one of the time periods analysed (13-to-18 months). There were some differences in the mean cost per patient by remoteness, but this was not consistent across all time periods. Compared to women living in the least disadvantaged area (Q5), costs were significantly greater for women from the most disadvantaged area (Q1) for all but the final six-month period, and for women living in the second most disadvantaged area (Q2) during 25-to-30 months and 31-to-36 months.

Finally, we examined the mean cost per patient for each six-month time period for ED presentations, adjusting for Indigenous status, remoteness, socioeconomic status, age group at diagnosis, stage of disease at diagnosis, number of ED presentations during time period being analysed and death during time period being analysed (Table 5). Compared to non-Indigenous women, costs for Indigenous women were 1.41 times greater during 25-to-30 months post-diagnosis. Women living in remote areas had significantly lower costs during 13-to-18 months, 25-to-30 months, and 31-to-36 months compared to women living in metropolitan areas. There were no significant differences across the socioeconomic quintiles.

Table 4: Parameter estimates of independent variables in generalised linear regression model of the costs for hospital episodes for women diagnosed with breast cancer between 1 July 2011 and 30 June 2012, Australia (Weighted data)

		0-6 months		7-12 months		13-18 months		19-24 months		25-30 months		31-36 months
	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)
Intercept		8.3246 (0.0662) ***		5.8759 (0.1223) ***		5.0887 (0.1322) ***		4.9019 (0.1450) ***		4.7931 (0.1467) ***		4.0776 (0.1569) ***
Indigenous women	1.47	0.3857 (0.1011) ***	1.59	0.4645 (0.1844) *	1.29	0.2509 (0.1884)	1.93	0.6580 (0.2187) **	2.51	0.9198 (0.2328) ***	2.50	0.9163 (0.2351) ***
Regional	1.05	0.0516 (0.0299)	1.06	0.0624 (0.0530)	1.02	0.0214 (0.0589)	0.95	-0.0482 (0.0630)	0.91	-0.0947 (0.0675)	1.15	0.1370 (0.0688) *
Remote	1.06	0.0604 (0.0495)	0.84	-0.1770 (0.0910)	0.78	-0.2484 (0.0979) *	1.29	0.2543 (0.1068) *	1.15	0.1406 (0.1102)	0.98	-0.0187 (0.1136)
IRSD Q1	1.17	0.1609 (0.0573) **	1.36	0.3097 (0.1027) **	1.76	0.5660 (0.1108) ***	1.72	0.5421 (0.1192) ***	1.64	0.4917 (0.1287) ***	1.26	0.2327 (0.1300)
IRSD Q2	1.06	0.0573 (0.0640)	0.82	-0.2032 (0.1142)	1.25	0.2260 (0.1243)	1.22	0.1982 (0.1345)	1.70	0.5310 (0.1416) ***	1.39	0.3294 (0.1455) *
IRSD Q3	0.95	-0.0467 (0.0409)	1.01	0.0070 (0.0720)	0.83	-0.1888 (0.0788) *	0.78	-0.2493 (0.0857) **	0.96	-0.0393 (0.0915)	0.87	-0.1390 (0.0920)
IRSD Q4	1.04	0.0386 (0.0318)	1.27	0.2389 (0.0568) ***	1.00	-0.0035 (0.0632)	0.86	-0.1535 (0.0680) *	1.04	0.0381 (0.0718)	1.03	0.0303 (0.0741)
Age 45-64 years	1.00	-0.0049 (0.0388)	0.73	-0.3093 (0.0692) ***	0.68	-0.3876 (0.0749) ***	0.61	-0.4862 (0.0814) ***	0.54	-0.6138 (0.0862) ***	0.80	-0.2277 (0.0854) **
Age ≥ 65 years	0.92	-0.0861 (0.0400) *	0.91	-0.0948 (0.0731)	0.74	-0.3043 (0.0777) ***	0.75	-0.2866 (0.0846) ***	0.61	-0.4950 (0.0900) ***	1.04	0.0422 (0.0884)
Advanced stage	1.27	0.2354 (0.0253) ***	1.45	0.3690 (0.0469) ***	1.23	0.2049 (0.0497) ***	1.19	0.1749 (0.0533) ***	1.23	0.2083 (0.0565) ***	1.46	0.3753 (0.0566) ***
Unknown stage	0.84	-0.1725 (0.0501) ***	1.30	0.2653 (0.0907) **	1.06	0.0581 (0.1001)	0.92	-0.0873 (0.1108)	1.27	0.2374 (0.1219)	1.09	0.0848 (0.1267)
Number of hospital episodes during period analysed	1.01	0.0053 (0.0003) ***	1.03	0.0306 (0.0010) ***	1.07	0.0654 (0.0024) ***	1.07	0.0647 (0.0029) ***	1.06	0.0590 (0.0029) ***	1.06	0.0599 (0.0029) ***
Death during period analysed	0.48	-0.7279 (0.0456) ***	0.34	-1.0740 (0.0903) ***	0.33	-0.1226 (0.0993) ***	0.36	-1.0221 (0.1103) ***	0.38	-0.9773 (0.1077) ***	0.37	-0.9914 (0.1174) ***

* p-value < 0.05; ** p-value < 0.01; *** p-value < 0.001

Table 5: Parameter estimates of independent variables in generalised linear regression model of the costs for ED presentations for women diagnosed with breast cancer between 1 July 2011 and 30 June 2012, Australia (weighted data).

		0-6 months		7-12 months		13-18 months		19-24 months		25-30 months		31-36 months
	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)
Intercept		4.9887 (0.1672) ***		3.6519 (0.2344) ***		3.5262 (0.1462) ***		3.5033 (0.1427) ***		3.0024 (0.1303) ***		2.7180 (0.1550) ***
Indigenous women	1.04	0.0391 (0.1750)	1.11	0.1081 (0.2864)	1.12	0.1109 (0.1830)	1.11	0.1051 (0.1476)	1.41	0.3418 (0.1448) *	1.10	0.0926 (0.1341)
Regional	0.92	-0.0820 (0.0790)	1.03	0.0270 (0.1118)	0.86	-0.1476 (0.0780)	0.98	-0.0228 (0.0773)	0.89	-0.1206 (0.0711)	0.85	-0.1602 (0.0704) *
Remote	1.02	0.0214 (0.1398)	0.93	-0.0729 (0.2101)	0.72	-0.3250 (0.1581) *	0.85	-0.1683 (0.1230)	0.80	-0.2243 (0.1113) *	0.70	-0.3627 (0.1059) ***
IRSD Q1	1.08	0.0766 (0.1367)	0.88	-0.1282 (0.1974)	1.29	0.2521 (0.1334)	0.90	-0.1109 (0.1263)	0.98	-0.0159 (0.1157)	1.02	0.0189 (0.1244)
IRSD Q2	1.18	0.1631 (0.1797)	1.25	0.2197 (0.2964)	1.21	0.1886 (0.1894)	1.10	0.0945 (0.1646)	0.96	-0.0392 (0.1423)	1.20	0.1804 (0.1362)
IRSD Q3	1.15	0.1400 (0.1210)	1.03	0.0330 (0.1824)	1.23	0.2102 (0.1189)	1.01	0.0107 (0.1055)	1.10	0.0961 (0.1088)	1.13	0.1190 (0.1111)
IRSD Q4	1.12	0.1093 (0.0953)	1.12	0.1101 (0.1414)	1.14	0.1296 (0.0913)	0.89	-0.1149 (0.0876)	1.09	0.0816 (0.0764)	1.05	0.0527 (0.0894)
Age 45-64 years	1.01	0.0138 (0.0964)	1.11	0.1063 (0.1463)	1.07	0.0695 (0.0993)	1.02	0.0205 (0.1002)	1.09	0.0899 (0.0935)	0.99	-0.0060 (0.0949)
Age ≥ 65 years	0.98	-0.0249 (0.1020)	1.24	0.2157 (0.1477)	1.24	0.2147 (0.0988) *	1.12	0.1145 (0.1006)	1.27	0.2373 (0.0939) *	1.18	0.1618 (0.0959)
Advanced stage	1.01	0.0118 (0.0739)	1.13	0.1197 (0.1063)	1.07	0.0709 (0.0712)	0.92	-0.0819 (0.0671)	1.07	0.0698 (0.0620)	1.19	0.1728 (0.0631) **
Unknown stage	1.28	0.2495 (0.1411)	1.04	0.0387 (0.1808)	0.96	-0.0362 (0.1249)	0.95	-0.0470 (0.1227)	1.11	0.1028 (0.1317)	1.02	0.0235 (0.1185)
Number of ED presentations during period analysed	1.47	0.3847 (0.0290) ***	1.65	0.4991 (0.0566) ***	1.36	0.3061 (0.0278) ***	1.39	0.3320 (0.0317) ***	1.39	0.3315 (0.0253) ***	1.47	0.3884 (0.0293) ***
Death during period analysed	0.62	-0.4840 (0.0931) ***	0.75	-0.2813 (0.0957) **	0.79	-0.2334 (0.0602) ***	0.77	-0.2633 (0.0666) ***	0.83	-0.1832 (0.0566) **	0.86	-0.1487 (0.0538) **

* p-value < 0.05; ** p-value < 0.01; *** p-value < 0.001

Discussion

This is the first Australian study to use whole of population linked administrative data to estimate the cost of admitted and non-admitted hospital episodes and ED presentations for women diagnosed with breast cancer. The total cost of hospital episodes was $558.4 million, and the total cost of ED presentations was $12.8 million for the first 36-months following diagnosis. The first six-months post-diagnosis accounted for the highest proportion of the costs for hospital episodes (50%) and ED presentations (38%).

The AIHW estimated that the cost of hospital admissions for female breast cancer was $146.33 million in 2008-09.[9] More recently, the AIHW and Cancer Australia estimated that the total expenditure for hospital admissions for female breast cancer was $162.9 million in 2010-11.[11] However, both reports only include admitted hospital episodes where the principal diagnosis was female breast cancer. These reports also exclude non-admitted patient services. It is difficult to directly compare our results to these reports, as we sought to estimate the cost for admitted and non-admitted hospital episodes. We also estimated the total cost of all hospital episodes, irrespective of primary diagnosis for women diagnosed with breast cancer between 1 July 2011 and 30 June 2012.

A key aim of this study was to look at the distribution of costs amongst groups who are known to experience poorer health outcomes. After adjusting for age, remoteness, socioeconomic status, stage of disease, number of hospital episodes, and death during period analyzed, we found that the mean cost per patient for hospital episodes was significantly greater for Indigenous women compared to non-Indigenous women throughout almost all of the first three years post-diagnosis. This could be due to Indigenous women potentially having more comorbidities,[23, 24] which may add to the complexity of treatment, thereby increasing hospital costs. Although we found some differences in costs when comparing remoteness, this was not consistent. We found consistently higher costs for women living in the most disadvantaged area compared to those living in the least disadvantaged area.

Previous Australian studies have identified differences in treatment following a breast cancer diagnosis.[23, 25-28] For example, there is evidence that women living in outer regional and remote areas have lower rates of breast conserving surgery, and higher rates of mastectomy compared to cities.[25, 26] Higher rates of mastectomy have

also been observed in women from more disadvantaged areas,[26] those who lived further away from a radiation facility,[26] and Indigenous women.[23] These differences in treatment may explain some of the differences in costs that we observed in our study. Further analysis is required to determine if these differences are driving the differences in cost in this cohort.

We found no significant differences by remoteness, socio-economic status or Indigenous status in the average cost per patient for ED presentations during the first 12-months post-diagnosis. Women living in remote areas had significantly lower costs during 13-to-18 months, and 25-to-30 months post-diagnosis. Women living in regional or remote areas had lower costs during 31-to-36 months post-diagnosis. We found no significant differences in any time period when comparing socioeconomic disadvantage. Future work should focus on determining if there are differences in the reasons for ED presentations in this cohort.

The key strength of this study is the use of population-based data linkage to estimate total costs and costs by patient characteristics. The use of individual level administrative data overcomes potential measurement bias (recall, self-report, interviewer, etc), and is advantageous over using population-level data or aggregated data. However, the use of administrative data also has inherent weaknesses. Notably, the QCR does not routinely collect stage of disease at diagnosis, therefore we identified the stage as 'early', 'advanced', and 'unknown'. We used aggregated area-level data to classify an individual's level of socioeconomic disadvantage, as individual or household financial information is not routinely collected by the QCR.

We quantified the cost to the Australian healthcare system for hospital admissions and ED presentations for women diagnosed with breast cancer. We identified that the mean hospital episode cost and ED presentation cost differs for the population groups of interest. This paper is the first in Australia to identify the inequalities in healthcare expenditure by remoteness, Indigenous status and socio-economic status. This has important implications for health policy and health service planning in relation to breast cancer prevention, such as improving participation in the national screening program for these population groups. Planned future studies will look at service use and drivers of costs for hospital episodes and ED presentations amongst these sub-populations whom experience poorer health outcomes.

Declarations

Ethics approval and consent to participate

Human Research Ethics approval was obtained from the Townsville Hospital and Health Service Human Research Ethics Committee (HREC) (HREC/16/QTHS/11), Australian Institute of Health and Welfare (AIHW) HREC (EO2017/1/343) and James Cook University HREC (H6678). Permission to waive consent was approved from Queensland Health under the Public Health Act 2005. No identifiable information was provided to the authors.

Consent for publication

Not applicable.

Availability of data and materials

The datasets used during the current study are not publicly available due to privacy constraints associated with our ethics approval that explicitly prohibits the sharing of data.

Competing interests

The authors declare no competing interests.

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Author contributions

NB conceived, designed and planned the study, and undertook the data analysis. All authors contributed to the interpretation of the data, drafting the manuscript, and approved of the final draft.

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Table 1: Additional descriptive costs to the health system for hospital episodes and ED presentations, for women diagnosed between 1 July 2011 and 30 June 2012 (weighted)

	Hospital episodes				ED presentations			
Time since diagnosis (months)	Mean ±SD	Median	IQR	Max	Mean ±SD	Median	IQR	Max
0-6	183,767 ± 15,896	15,891	11,054	314,875	1,429 ± 1,122	1,146	1,303	6,724
7-12	6,579 ± 11,589	2,608	8,626	274,412	1,146 ± 897	979	809	6,286
13-18	3,246 ± 8,046	505	2,710	171,443	1,123 ± 870	975	609	6,611
19-24	3,183 ± 8,306	392	1,766	125,954	1,111 ± 987	955	608	10,650
25-30	3,628 ± 13,196	377	1,854	418,178	1,191 ± 1,032	987	780	8,401
31-36	3,228 ± 9,477	366	1,616	209,459	1,136 ± 1,027	982	767	8,300
TOTAL	**36,675 ± 36,488**	**27,832**	**28,441**	**807,422**	**2,077 ± 2,360**	**1,346**	**1674**	**30,950**

Summary

This study estimated the direct costs to the public healthcare system for admitted and non-admitted hospital episodes and ED presentations during the first three-years following a breast cancer diagnosis. For women diagnosed with breast cancer, Indigenous status and socioeconomic disadvantage were associated with significantly higher costs for admitted and non-admitted hospital episodes, after adjusting for relevant confounders (remoteness, age, stage, number of hospital episodes, death). Specifically, costs were significantly higher in Indigenous women and women living in the most disadvantaged quintile for admitted and non-admitted hospital episodes. There were no consistent differences in the costs for ED presentations.

The findings of this study should be considered in the context of several unavoidable limitations inherent to the administrative data used. Firstly, the QCR does not include stage of disease at diagnosis, therefore, stage was categorised into early, advanced, and unknown. Secondly, remoteness and socioeconomic status were categorised using aggregated area-level data. Thirdly, non-admitted hospital services were not captured in the QHAPDC dataset. As described, hospital-related MBS items were included in the hospital analysis, which may have over-estimated hospital services. Finally, co-morbidities were not included in the dataset, and the analysis did not include the impact of co-morbidities on the cost.

This study addressed part of the third aim of the thesis: to quantify the direct costs to the public healthcare system and individual for the first three years following a female breast cancer diagnosis, and to determine the distribution of these costs by Indigenous status, remoteness, and socioeconomic disadvantage. Future studies should consider 1) the drivers of the costs to the hospital system and the distribution of these costs, 2) the impact of co-morbidities on the costs, and 3) extend the timeframes to provide a continuous analysis of the costs and changes of costs across time.

Chapter Six: Out-of-hospital costs for women diagnosed with breast cancer

Introduction

In the previous chapter, the direct costs to the public healthcare system for admitted and non-admitted hospital episodes and ED presentations during the first three-years following a breast cancer diagnosis in women were presented. In this chapter (Chapter Six), the focus remains on costs to the public healthcare system, but the emphasis is now on the total cost of MBS services and PBS prescriptions for these women.

At the time of thesis submission, this chapter is under review. It is presented in the thesis in the format required by the journal:

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Estimating the out-of-hospital costs for Australian women diagnosed with breast cancer – using CancerCostMod, a linked administrative model

Running title: Out-of-hospital costs - breast cancer

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Contributors

NB conceived, designed and planned the study, and undertook the data analysis. All authors contributed to the interpretation of the data, drafting the manuscript, and approved of the final draft.

Abstract

Introduction: Breast cancer is the most commonly diagnosed cancer in women in Australia. Although survival has improved, there are variations in outcomes by Indigenous status, remoteness, and socioeconomic status. This study estimate the cost to the Australian Government for out-of-hospital medical services and prescription pharmaceuticals for women diagnosed with breast cancer during the first 36-months post-diagnosis; and to determine the distribution of these costs by Indigenous status, remoteness, and socioeconomic status.

Methods: We identified women diagnosed with breast cancer from a larger study, CancerCostMod. The base population of CancerCostMod included all cancer diagnoses (01JUL2011-30JUN2012), which was then linked to administrative health records (01JUL2011-30JUN2015), and weighted to be representative of the Australian population. Our analysis was limited to include costs of out-of-hospital medical services identified through the Medicare Benefits Schedule (MBS), and prescription pharmaceuticals (Pharmaceutical Benefits Scheme (PBS)). We calculated these costs for MBS and PBS for each 6-month period post-diagnosis, and then modelled the mean cost per patient for each period.

Results: 3,079 women were diagnosed with breast cancer, representing 15,335 Australian women after weighting. The total cost for MBS services during the first three years post-diagnosis was $73.7 million, and an addition $239.2 million for PBS prescriptions. We found no consistent difference in the average cost for MBS services by remoteness, Indigenous status or socio-economic status. There were consistent differences in the average cost of PBS prescriptions by these characteristics.

Conclusions: This unique study quantified the total healthcare expenditure for out-of-hospital medical services and pharmaceutical prescriptions.

Introduction

Breast cancer is the most commonly diagnosed cancer in women in Australia.[1] In 2017, an estimated 17,586 women were diagnosed with breast cancer,[1] and the incidence is expected to rise.[2] Survival rates for female breast cancer have improved, and are currently at 90%.[1] However, there are some women who experience poorer survival, including Aboriginal and Torres Strait Islander women (hereafter respectfully referred to as Indigenous women), women living outside of metropolitan areas, and socioeconomically disadvantaged women.

Treatment options for female breast cancer include surgery, radiotherapy, chemotherapy, and hormonal therapy; or a combination of these. There are many factors to consider when deciding on the best treatment, including the type and stage of cancer, hormone status, lymph node status, patient history, and the woman's preference.[3] While initially, many of the treatment options may be in a hospital setting, women may also need to access some medical services outside of the hospital setting, such as General Practitioner (GP) visits, pathology and imaging services, allied health services, and pharmacy. Amongst the treatment options is also the choice to be treated within either the private or the public healthcare system.

Australia has a mixed payment system, where the individual may choose to be treated in the private and/or public health system. Australia's universal health insurance scheme, Medicare, provides free treatment at a public hospital. If an individual chooses to be treated at a private hospital, Medicare may cover a proportion of fees.[4] Medicare also contributes a rebate (proportion of the fee) for services listed on the Medicare Benefits Schedule (MBS) for services conducted outside of hospitals.[4] The MBS includes GP visits, some allied health services, pathology, imaging and optometry. For MBS services, if the fee charged is greater than the Medicare rebate, than the patient pays a co-payment. If the fee charged is equal to the Medicare rebate, than the patient is 'bulk-billed', resulting in no co-payment.[4]

The Pharmaceuticals Benefits Scheme (PBS) provides rebates for listed prescription drugs, with the patient paying a co-payment, and the Federal government paying the remainder of the charge.[4]

To date, there are limited recent studies quantifying the out-of-hospital costs to the Australian healthcare system for women diagnosed with breast cancer. Goldsbury et al.[5] estimated the excess cost of cancer (including breast cancer) in Australia for people aged 45 years and older, compared to matched cancer-free controls. Another study estimated the average cost of cancer (including breast) for people undergoing chemotherapy in New South Wales.[6] However, to the authors' best knowledge, no Australian study has identified the distribution of costs for out-of-hospital medical services and prescription, by remoteness, Indigenous status or socio-economic status.

The most recent Government expenditure report estimated that female breast cancer accounted for the greatest healthcare expenditure in females, approximately $235million, however this was for 2008-09. Out-of-hospital services accounted for approximately $29million, and an additional $60million for prescription pharmaceuticals.[7] This national report used aggregated data related only to specific cancer services, which may underestimate the total costs, and does not allow estimates to be stratified for different population groups. The use of individual-level administrative data may overcome these limitations. Furthermore, this report is now potentially out-of-date due to increased incidence of breast cancer, changes to treatment protocols, and any new additions to the PBS. For example, between 2000 and 2012, 23 new anticancer drugs were added to the PBS, including three for the treatment of breast cancer.[8] The expenditure for anticancer drugs listed on the PBS rose from $64.8 in 1999-2000 to $466.3 million in 2011-12.[8]

This study used CancerCostMod, a model developed to estimate the healthcare expenditure of people diagnosed with cancer using linked administrative data.[9,10] We adopted a national healthcare system perspective, to 1) estimate the total cost of MBS services and PBS prescriptions for women diagnosed

with breast cancer during the first three years following diagnosis; and 2) determine the distribution of these costs by Indigenous status, remoteness, and socioeconomic status.

Methods

Study population

The population for this study was sourced from a larger study, 'CancerCostMod', described in detail elsewhere.[9,10] Briefly, the base population was a census of all cancer diagnoses (excluding non-melanoma skin cancer) recorded by the Queensland Cancer Registry (QCR), Australia between 1JUL2011 and 30JUN2012 (n=25,553 patients). All new cases of cancer in Australia, except for non-melanoma skin cancer, are required to be reported to the jurisdiction's cancer registry.[1,11] The QCR records were then linked to Queensland Health Admitted Patient Data Collection (QHAPDC) and Queensland Health Emergency Department Information Systems (EDIS) by the Queensland Health Statistical Services Branch before being linked to MBS and Pharmaceutical Benefits Scheme (PBS) records by the Australian Institute of Health and Welfare (AIHW) from 1JUL2011 to 30JUN2015. The authors then weighted this base population to the Australian population with cancer, using GREGWT, a programmed SAS macro (weighted N=123,900). For this paper, we limited 'CancerCostMod' to include records of female breast cancer (ICD-O C50).

Demographics

Sociodemographic characteristics at the time of diagnosis, such as age, sex, Indigenous status, and residential postcode were included in the QCR dataset. The authors mapped the patient postcode at diagnosis to the Index of Relative Socio-Economic Disadvantage (IRSD), which is a summary of the economic and social conditions of an area, and is a measure of relative socioeconomic disadvantage.[12] IRSD was collapsed into quintiles (Q1=most disadvantaged, and Q5=least disadvantaged). Postcode was also mapped to the Australian Statistical Geography Standard (ASGS), a measure of remoteness,[13]

then categorised into 'metropolitan', 'regional' (inner and outer), and 'remote (remote and very remote'). Records with missing postcodes were unable to be mapped to IRSD or remoteness. As described previously,[9] Indigenous status was recorded for 87% of our original QCR dataset. We used multiple imputation to impute missing Indigenous status.[9]

Breast cancer staging

The stage at diagnosis is not routinely collected by the QCR, however, using methods published in previous Queensland studies,[14,15] breast cancer stage was categorised as:

- 'Early': tumour size ≤ 20mm, and no evidence of lymph node involvement;
- 'Advanced': tumour size > 20mm, or any evidence of lymph node involvement regardless of tumour size, or if the diagnosis was because of metastatic disease;
- 'Unknown': lymph node involvement or tumour size unknown.

Assigning costs to MBS services and PBS prescriptions

For this study, we limited CancerCostMod to out-of-hospital MBS services (i.e., excluding item codes included in the hospital, which have been described previously[9]), and PBS prescriptions. The variables related to MBS services included information on the date of service/prescription, patient postcode, provider postcode, item code, full charge, Government rebate, and patient co-payment. This dataset excluded any services or items not covered by MBS or PBS; items claimed through the Department of Veteran Affairs; and prescriptions distributed under alternative arrangements.

Monthly rebate amounts were calculated separately for MBS services and PBS prescriptions for each individual from the date of diagnosis (time=0), to 36-months following diagnosis. The rebate amount is the amount paid by the Federal Government per service. From hereafter this will be referred to as 'cost' for readability. If an individual died during the first three years following diagnosis, no costs were

recorded for subsequent months. All costs are reported in Australian dollars (AUD), adjusted to the 2016-17 financial year using the Reserve Bank of Australia inflation calculator.[16]

Statistical analysis

Descriptive analyses were undertaken to ascertain the demographic characteristics of women diagnosed with breast cancer. We aggregated the costs into six-month time periods from date of diagnosis (t=0) to 36 months post-diagnosis for MBS services and PBS prescriptions. The dataset was limited to those who had at least one MBS service or PBS prescription at each time period to calculate the average number and average cost during each of these time periods.

Finally, we used generalized linear models with a gamma distribution and a log link function to model the mean costs per patient for each six-month time period. This included the number of months the patient survived as an offset to the model. Independent variables were: Indigenous identification (reference group=non-Indigenous women), age group (reference group=18-44 years), remoteness (reference group=metropolitan), socioeconomic disadvantage (reference group=IRSD Q5 (least disadvantaged)), breast cancer stage (reference=early), number of MBS services or PBS prescriptions during the time period being modelled (continuous), and death during the time period being modelled.

All analyses were undertaken using SAS V9.4 (SAS Institute Inc., Cary, NC, USA). Human Research Ethics approval was obtained from the Townsville Hospital and Health Service Human Research Ethics Committee (HREC) (HREC/16/QTHS/11), AIHW HREC (EO2017/1/343) and James Cook University HREC (H6678). Permission to waive consent was approved from Queensland Health under the Public Health Act 2005. No identifiable information was provided to the authors.

Results

In Queensland, 3,079 women were diagnosed with breast cancer between 01JUL2011 and 30JUN2012, representing 15,335 Australian women once weighted. Table 1 shows the demographic characteristics

at diagnosis of women diagnosed with breast cancer. The average age at diagnosis was 61 years (SD: 14 years).

Table 1: Demographic characteristics at diagnosis of Australian women diagnosed with breast cancer (weighted)

	N
N	3,079
N (weighted)	15,335
Age group (years)	
18-44 (%)	1,848 (12.1)
45-64 (%)	7,536 (49.1)
≥65 (%)	5,951 (38.8)
12-month mortality	646 (4.2)
Indigenous status	
Indigenous women (%)	248 (1.6)
Non-Indigenous women (%)	15,087 (98.4)
Remoteness*	
Metropolitan (%)	7,712 (50.6)
Regional (%)	6,359 (41.7)
Remote (%)	1,180 (7.7)
Index of Relative Socio-Economic Disadvantage*	
Q1 (most disadvantaged) (%)	1,095 (7.2)
Q2 (%)	767 (5.0)
Q3 (%)	2,483 (16.3)
Q4 (%)	6,669 (43.7)
Q5 (least disadvantaged) (%)	4,236 (27.8)
Breast cancer stage	
Early (%)	6,695 (43.6)
Advanced (%)	7,174 (46.8)
Unknown (%)	1,466 (9.6)

*Those with missing postcode data at diagnosis were excluded (weighted n=85)

During the first three years after diagnosis, the total MBS costs were $73.7 million (Table 2). The first six-months following diagnosis incurred the greatest total number of MBS services (429,278), and the greatest total MBS costs of approximately $25 million. The average total cost per person during the first three years was $4,911 (SD: 3,199), with an average of 107 MBS services during this time.

Table 2: MBS services for women diagnosed with breast cancer in Australia (weighted)

Time since diagnosis (months)	N (participants)	Total		Average per patient	
		Number of MBS services	Total costs (AU$)	Number of MBS services (SD)	Costs (AU$) (SD)
0-6	14,884	429,278	25,001,241	29 (21)	1,680 (1,200)
7-12	14,022	271,654	11,437,954	19 (16)	816 (874)
13-18	13,991	248,924	11,099,762	18 (15)	793 (776)
19-24	13,488	223,412	8,748,235	17 (15)	649 (707)
25-30	13,499	226,000	9,222,178	17 (14)	683 (646)
31-36	12,947	209,753	8,199,681	16 (14)	633 (622)

The total number of PBS prescriptions for women diagnosed with breast cancer was 1,447,350 prescriptions, which totalled approximately $239.2 million (Table 3). The average cost of PBS prescriptions during the first three-years following diagnosis was $16,404 (SD: 21,761) and the average number of PBS prescriptions was 99 (SD: 90).

Table 3: PBS prescriptions for women diagnosed with breast cancer in Australia (weighted)

Time since diagnosis (months)	N (participants)	Total		Average per patient	
		Number of PBS prescriptions	Total costs (AU$)	Number of PBS prescriptions (SD)	Cost (AU$) (SD)
0-6	14,034	355,884	105,927,632	25 (19)	7,548 (9,921)
7-12	13,421	246,277	63,063,993	18 (17)	4,699 (9,299)
13-18	12,852	223,778	33,743,789	17 (17)	2,626 (5,985)
19-24	12,360	211,787	13,817,867	17 (17)	1,118 (2,353)
25-30	11,918	208,215	12,273,637	17 (17)	1,030 (2,697)
31-36	11,515	201,408	10,383,381	17 (17)	902 (2,057)

Figure 1 shows the average cost for MBS and PBS by age group (A and B), stage of disease (C and D), Indigenous status (E and F), remoteness (G and H), and socioeconomic disadvantage (I and J). The first six-months accounted for a greater average cost per person for each of the characteristics presented in Figure 1. Interestingly, there was little variation in average costs per person in each of the six-month time periods, in relation to Indigenous status, remoteness, and socio-economic status. There were

some differences in average cost per person by age-group; costs were higher in younger women for both MBS services and PBS prescriptions than women aged 45-64 years, and 65 years and older. There were also differences in the average cost per person for MBS services and PBS prescriptions by cancer stage. MBS rebates in the first 6-months were greater in women diagnosed with advanced stage disease, and PBS prescriptions were also higher in this group in both the first 6-months, and 7-to-12 months following diagnosis.

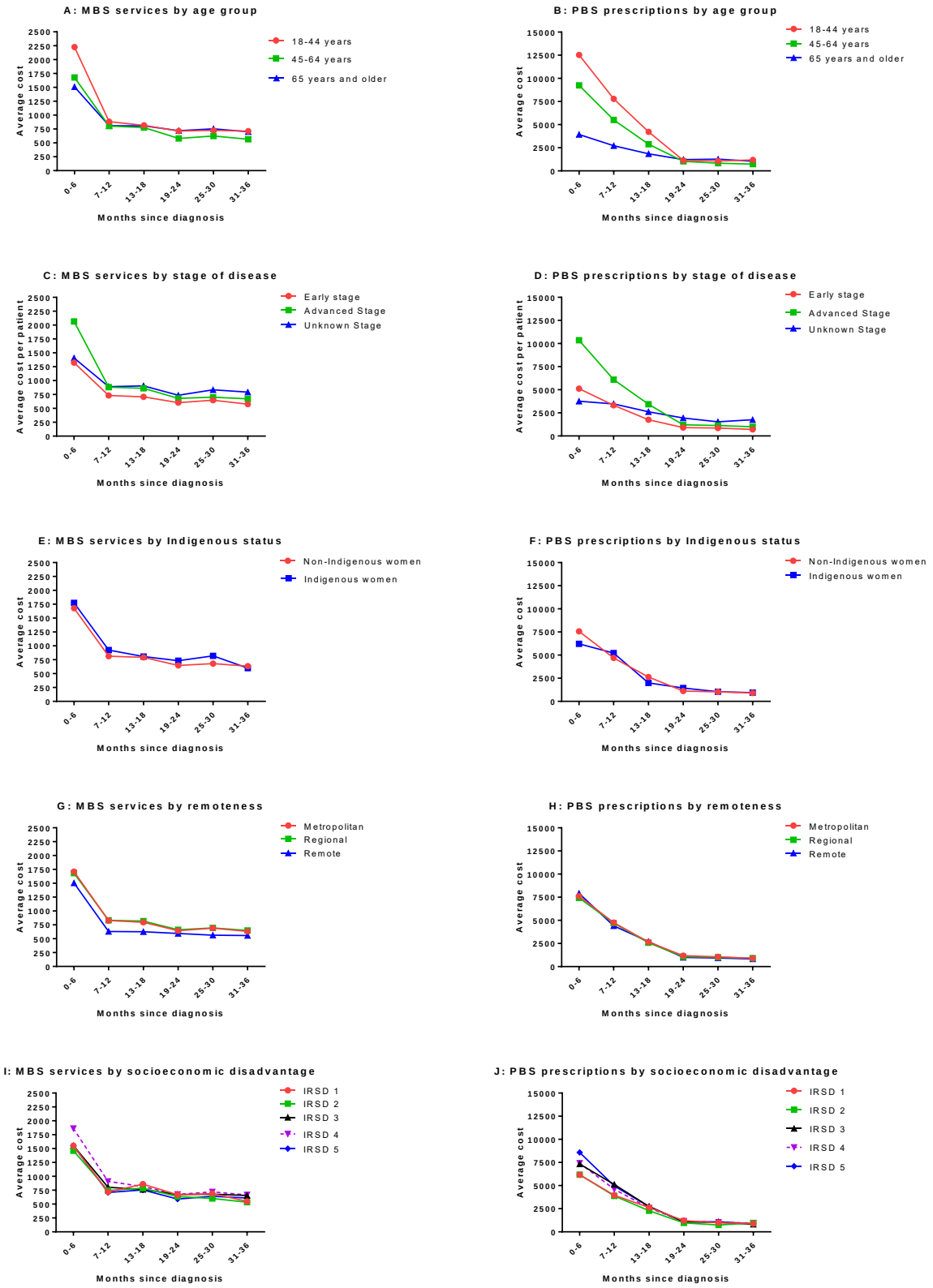

Figure 1: Average cost per patient for MBS services and PBS prescriptions by age group, breast cancer stage, Indigenous status, remoteness, and socioeconomic disadvantage. Average costs per patient were calculated for each six-month period from diagnosis to 3-years. The figures on the left present the unadjusted average costs for MBS services, and on the right present the unadjusted average cost for PBS prescriptions by characteristics of interest.

Table 4 shows the parameter estimates produced by the six generalised linear models, estimating the mean costs for MBS services per patient for each six-month time period, adjusting for Indigenous status, remoteness, IRSD quintile, age group at diagnosis, stage of disease at diagnosis, and death during time period being analysed. There was no significant difference in the average MBS costs by Indigenous status across each of the time periods. Costs were 10% higher among women living in regional areas than those living in metropolitan areas during the 19-to-24 month period. Compared to women in the least disadvantaged quintile (Q5), costs were 10% higher in women living in Q4 during the first six-months post-diagnosis, and 15% lower for women living in Q2 (2nd most disadvantaged) during the period of 13-to-18 months. Compared to women in the age group 18 to 44 years, costs were consistently lower among women in the older two age groups for each of the six-month periods analysed. Women diagnosed with advanced stage disease had significantly higher costs during the first three six-month periods analysed, and for the 31-to-36 months period; however, there was no consistent difference for women diagnosed with 'unknown stage'.

Table 4: Parameter estimates of independent variables in generalised linear regression model of the MBS costs for women diagnosed with breast cancer (weighted data).

		0-6 months		7-12 months		13-18 months		19-24 months		25-30 months		31-36 months
	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)
Intercept		5.2289 (0.0611)***		3.3421 (0.0853)***		2.8540 (0.0765)***		2.6413 (0.0871)***		2.3729 (0.0727)***		1.9668 (0.0880)***
Indigenous women	0.94	-0.0623 (0.0918)	1.04	0.0417 (0.1180)	1.11	0.1010 (0.1081)	1.04	0.0356 (0.1237)	0.98	-0.0168 (0.1112)	0.99	-0.0099 (0.1273)
Regional	0.98	-0.0233 (0.0276)	0.99	-0.0064 (0.0352)	1.01	0.0110 (0.0321)	1.10	0.0961 (0.0366)**	1.01	0.0112 (0.0322)	1.00	-0.0049 (0.0368)
Remote	0.97	-0.0298 (0.0464)	0.91	-0.0915 (0.0604)	0.96	-0.0431 (0.0548)	1.09	0.0838 (0.0614)	0.93	-0.0743 (0.0546)	1.02	0.0172 (0.0621)
IRSD Q1 (most disadvantaged)	1.10	0.0991 (0.0529)	1.05	0.0496 (0.0679)	1.02	0.0153 (0.0621)	0.92	-0.0801 (0.0696)	1.00	-0.0026 (0.0619)	0.90	-0.1063 (0.0701)
IRSD Q2	0.95	-0.0541 (0.0596)	0.97	-0.0305 (0.0774)	0.85	-0.1606 (0.0689)*	0.93	-0.0751 (0.0788)	0.97	-0.0305 (0.0682)	0.87	-0.1374 (0.0790)
IRSD Q3	1.02	0.0170 (0.0380)	1.06	0.0599 (0.0481)	0.96	-0.0359 (0.0438)	0.97	-0.0310 (0.0497)	1.01	0.0125 (0.0438)	1.00	0.0020 (0.0504)
IRSD Q4	1.10	0.0961 (0.0296)**	1.04	0.0389 (0.0384)	1.00	-0.0008 (0.0341)	0.94	-0.0590 (0.0393)	1.02	0.0239 (0.0346)	0.97	-0.0339 (0.0393)
Age(45-64)	0.82	-0.1975 (0.0361)***	0.82	-0.1937 (0.0464)***	0.97	-0.0330 (0.0416)	0.82	-0.2010 (0.0472)***	0.83	-0.1878 (0.0416)***	0.88	-0.1250 (0.0472)**
Age(≥65)	0.70	-0.3552 (0.0374)***	0.68	-0.3800 (0.0485)***	0.76	-0.2787 (0.0436)***	0.75	-0.2852 (0.0492)***	0.75	-0.2837 (0.0439)***	0.83	-0.1905 (0.0496)***
Advanced stage	1.33	0.2829 (0.0239)***	1.07	0.0649 (0.0305)*	1.15	0.1408 (0.0272)***	1.04	0.0401 (0.0309)	1.00	-0.0003 (0.0270)	1.08	0.0784 (0.0309)*
Unknown stage	1.03	0.0329 (0.0457)	1.07	0.0717 (0.0607)	1.09	0.0858 (0.0559)	1.08	0.0803 (0.0638)	0.99	-0.0112 (0.0596)	1.25	0.2238 (0.0684)**
Number of services	1.02	0.0232 (0.0007)***	1.05	0.0442 (0.0012)***	1.05	0.0447 (0.0012)***	1.05	0.0517 (0.0014)***	1.05	0.0451 (0.0012)***	1.05	0.0502 (0.0014)***
Death during period analysed	0.72	-0.3246 (0.0424)***	1.00	0.0005 (0.0640)	1.03	0.0273 (0.0584)	0.78	-0.2466 (0.0676)***	1.02	0.0206 (0.0541)	1.01	0.0105 (0.0671)

The ratio presented are relative to the reference group: Indigenous status (reference=non-Indigenous women), age group (reference=18-44 years), remoteness (reference=metropolitan), socioeconomic disadvantage (reference=IRSD Q5 (least disadvantaged)), breast cancer stage (reference=early), number of services accessed during the period analysed, and death during the time period being modelled.

*p-value: *<0.05; **<0.01; ***<0.001

Finally, we examined the cost per patient for each six-month time period for PBS prescriptions, adjusting for Indigenous status, remoteness, IRSD quintile, age group at diagnosis, stage of disease at diagnosis, and death during time period being analysed (Table 5). Costs were significantly lower among Indigenous for PBS items during 7-to-12 months (65% less), and 13-to-18 months (63% less) compared to their non-Indigenous counterparts. Compared to women living in metropolitan areas, women living in regional areas had 12% higher costs in the first six-months, and 24% higher costs during months 7-to-12. Compared to women living in the least disadvantaged quintile (Q5), women living in the first, third, and fourth quintiles had significantly lower costs for PBS prescriptions during the first 12 months, but women living in the first and fourth quintiles had significantly higher costs.

Table 5: Parameter estimates of independent variables in generalised linear regression model of the costs for PBS prescriptions for women diagnosed with breast cancer. Weighted data presented.

		0-6 months		7-12 months		13-18 months		19-24 months		25-30 months		31-36 months
	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)	Ratio	Co-efficient (SE)
Intercept		6.3458 (0.1208)***		5.0244 (0.1578)***		4.4974 (0.1690)***		2.8209 (0.1402)***		2.6121 (0.1431)***		2.4591 (0.1643)***
Indigenous women	0.90	-0.1045 (0.1865)	0.65	-0.4367 (0.2132)*	0.63	-0.4639 (0.2306)*	0.79	-0.2380 (0.2084)	0.66	-0.4220 (0.2249)	0.71	-0.3450 (0.2485)
Regional	1.12	0.1132 (0.0547)*	1.24	0.2163 (0.0648)***	1.14	0.1290 (0.0695)	0.94	-0.0609 (0.0602)	1.06	0.0554 (0.0667)	1.09	0.0817 (0.0722)
Remote	1.17	0.1572 (0.0925)	1.08	0.0804 (0.1110)	1.24	0.2117 (0.1238)	0.92	-0.0823 (0.1007)	1.16	0.1467 (0.1134)	1.06	0.0576 (0.1207)
IRSD Q1 (most disadvantaged)	0.78	-0.2538 (0.1062)*	0.64	-0.4414 (0.1246)***	0.81	-0.2053 (0.1342)	1.34	0.2926 (0.1136)**	1.08	0.0751 (0.1262)	0.92	-0.0871 (0.1356)
IRSD Q2	0.85	-0.1647 (0.1171)	0.93	-0.0704 (0.1399)	0.92	-0.0859 (0.1519)	0.93	-0.0724 (0.1262)	0.68	-0.3813 (0.1381)**	0.78	-0.2507 (0.1497)
IRSD Q3	0.82	-0.1980 (0.0756)**	0.81	-0.2074 (0.0908)*	0.95	-0.0467 (0.0969)	1.08	0.0764 (0.0815)	0.88	-0.1227 (0.0911)	0.84	-0.1773 (0.0982)
IRSD Q4	0.85	-0.1617 (0.0587)**	0.85	-0.1617 (0.0686)*	0.91	-0.0933 (0.0754)	1.21	0.1880 (0.0654)***	0.91	-0.0971 (0.0717)	0.94	-0.0664 (0.0765)
Age(45-64)	0.71	-0.3428 (0.0719)***	0.60	-0.5085 (0.0861)***	0.67	-0.4041 (0.0945)***	0.90	-0.1058 (0.0809)	0.72	-0.3340 (0.0896)***	0.63	-0.4663 (0.0961)***
Age(≥65)	0.18	-1.7032 (0.0751)***	0.18	-1.7316 (0.0923)***	0.29	-1.2328 (0.1019)***	0.70	-0.3628 (0.0853)***	0.69	-0.3662 (0.0930)***	0.56	-0.5823 (0.1000)***
Advanced stage	1.60	0.4692 (0.0468)***	1.62	0.4843 (0.0549)***	1.73	0.5488 (0.0599)***	1.28	0.2507 (0.0505)***	1.22	0.1997 (0.0544)***	1.24	0.2169 (0.0587)***
Unknown stage	0.87	-0.1450 (0.0931)	1.03	0.0302 (0.1112)	1.30	0.2630 (0.1219)*	1.60	0.4702 (0.1053)***	1.14	0.1352 (0.1162)	1.97	0.6755 (0.1317)***
Number of prescriptions	1.05	0.0516 (0.0017)***	1.06	0.0538 (0.0025)***	1.04	0.0359 (0.0024)***	1.05	0.0445 (0.0019)***	1.05	0.0513 (0.0021)***	1.05	0.0473 (0.0023)***
Death during period analysed	0.76	-0.2791 (0.0848)***	1.46	0.3775 (0.1114)***	1.08	0.0733 (0.1246)	0.98	-0.0183 (0.1037)	0.95	-0.0468 (0.1020)	1.02	0.0173 (0.1173)

The ratio presented are relative to the reference group: Indigenous status (reference=non-Indigenous women), age group (reference=18-44 years), remoteness (reference=metropolitan), socioeconomic disadvantage (reference=IRSD Q5 (least disadvantaged)), breast cancer stage (reference=early), number of services accessed during the period analysed, and death during the time period being modelled.

*p-value <0.05; **p-value <0.01; ***p-value <0.001

Discussion

This novel study is the first in Australia to use individual-level linked administrative data to quantify the out-of-hospital healthcare costs to the Federal Government for women diagnosed with breast cancer. We estimate that the total costs to Medicare for MBS services during three years post-diagnosis was $73.7 million, and $239.2 million for PBS prescriptions. The average cost per patient over the study period was $4,911 for MBS services, and $16,404 for PBS prescriptions.

We estimated that the first six-months accounted for the highest costs during the study period following a female breast cancer diagnosis. This is similar to other studies which analyzed the cost of breast cancer by phase of care that have reported that the initial phase (defined by authors as the first 3-months, 6-months, or 12-months) and the terminal phase (last 12-months of life) have the highest costs.[5,17-19] At this time, we were unable to estimate the cost of breast cancer by phase of care, due to the relatively short study period. This may be possible in future studies, if the study period for CancerCostMod is expanded.

Our study found that during the first year post-diagnosis, MBS services accounted for approximately $36 million, and PBS prescriptions accounted for approximately $169 million. These findings are greater than that reported in the AIHW report, which estimated the cost of breast cancer to be $29 million for out-of-hospital, and $60 million for prescription pharmaceuticals in 2008-09.[7] Our study found a large increase in pharmaceuticals compared to the 2008-09 report, and there may be several possible reasons, including the listing of new anticancer medications on the PBS. In Australia, the Pharmaceutical Benefits Advisory Committee reviews all submissions for new medications or changes to current medications to be listed on the PBS. Karikios et al.[8] reported three new breast cancer medications listed on the PBS between 2000 and 2012 (Trastuzumab 2007, Lapatinib 2008, and nab-Paclitaxel 2009). Our findings seem to confirm that the cost of cancer to the PBS has increased for female breast cancer.

Previous studies have identified differences in clinical management of female breast cancer for the population groups covered in this study.[20-23] However, the majority of these other studies focused on surgical and radiotherapy treatment following diagnosis, which would be accessed through a hospital setting, and thus excluded from the analysis in this study. Our study found no significant difference in the average cost of MBS services between Indigenous and non-Indigenous women diagnosed with breast cancer. Although there were some six-month periods with significant differences in the average cost of MBS services by remoteness, or socioeconomic status, we did not observe a consistent difference.

These findings are interesting, as it is well documented that there are many barriers in accessing primary health care for Indigenous Australians, people living in remote areas, and socioeconomically disadvantaged persons.[11,24-26] Barriers include reduced physical access to health services outside of urban areas,[24] and availability of culturally appropriate services.[25] The out-of-pocket (OOP) costs are also a potential barrier to accessing services, which may be more acutely felt by these population groups.[11,25,26] The Medicare Safety Net is a policy to reduce high OOP costs, in which once an individual or family group reach a threshold, they will receive a higher proportion of rebate paid by Medicare, reducing their co-payment.[4] The lack of differences in average cost of rebates paid, may mean that these policies are supporting equitable access to services, but this study did not compare the number or type of services accessed by this cohort. It is possible that there were differences in the type of MBS services accessed, and the number of times these services were accessed. Due to potential OOP fees associated with medical services, it is possible that some individuals may choose to access services which incur little or no OOP fee (ie bulk-billed services, or free public hospital treatment). For example, GP bulk-billing rates have been increasing in Australia, and in 2016-17, 86% of GP attendances were bulk-billed.[11] This may be of particular interest for population groups who may be at greater risk of financial hardship. Future studies should examine if there are any differences in the number and type of MBS services accessed by population group.

In contrast to the findings for MBS services, we did find significant differences in the average cost of PBS prescriptions by Indigenous status, remoteness, and socioeconomic disadvantage. Costs were significantly lower among Indigenous women diagnosed with breast cancer during months 7-to-12 and 13-to-18. Compared to women living in the least disadvantaged quintile (Q5), women living in Q1 and Q3-4 had significantly lower costs during the 0-to-6 months, and 7-to-12 months post-diagnosis. Whereas, women from regional areas had greater costs than their metropolitan counterparts during the first 6-months and 7-to-12 months. Future research should investigate if there are differences in prescribing and uptake of recommended treatment in this cohort.

This main strength of this paper is that the base population was a census of all women diagnosed with breast cancer in Queensland, which we then weighted to be representative of the Australian population. The use of administrative data allowed us to include all out-of-hospital MBS services, and PBS prescriptions that were reimbursed by the Australian Government. There are also weaknesses associated with administrative data. For example, the stage of disease at diagnosis is not routinely collected in Australia, therefore we categorized the stage of disease as 'early', 'advanced', and 'unknown'. Our dataset did not contain individual or household income, and we therefore used the ABS area-level data to map postcode to socioeconomic disadvantage. The use of area-based socioeconomic measures may not reflect a person's actual socioeconomic position as it is an area-based measure. Another limitation of our study was that our dataset excluded any services or items not covered by MBS or PBS, as outlined in the methods.

For the first time in Australia, this study identified the total healthcare expenditure for MBS services and PBS prescriptions adjusting for patient demographics. In the future, we plan to expand the population of CancerCostMod to include cancer diagnoses past the end of our current range, and to increase the years of linked administrative data. As this will increase both our sample size and study period, this will allow us to identify the costs by phase of disease (initial, continuing, and terminal phases) stratified by demographics, and allow us to examine the increasing expenditure for newly

listed PBS medications. Future studies should also determine if there are any differences in the access of MBS services and PBS prescriptions.

The cost to Medicare for MBS services and PBS rebates for women diagnosed with breast cancer is substantial. This is the first of its kind in Australia to used linked administrative to estimate these costs for population groups experiencing poorer health outcomes following a breast cancer diagnosis. Although we found some differences in the cost for MBS services, there was not a consistent pattern across the first three-years following diagnosis. We did find more significant differences in the average cost for PBS prescriptions by Indigenous status, remoteness and socio-economic status.

Additional information

Ethics approval and consent to participate

Human Research Ethics approval was obtained from the Townsville Hospital and Health Service Human Research Ethics Committee (HREC) (HREC/16/QTHS/11), AIHW HREC (EO2017/1/343) and James Cook University HREC (H6678). Permission to waive consent was approved from Queensland Health under the Public Health Act 2005. No identifiable information was provided to the authors.

Declaration of interests

The authors declare no competing interests.

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Table 2: Additional descriptive costs to the health system for MBS services and PBS prescriptions, for women diagnosed between 1 July 2011 and 30 June 2012 (weighted)

	MBS services				PBS prescriptions			
Time since diagnosis (months)	Mean ±SD	Median	IQR	Max	Mean ±SD	Median	IQR	Max
0-6	16,80 ± 1,200	1,472	1,633	9,105	7,548 ± 9,921	2,026	11,480	62,048
7-12	816 ± 874	545	800	6,054	4,699 ± 9,299	1,082	2,700	51,641
13-18	793 ± 776	548	745	8,730	2,626 ± 5,985	750	1,282	62,553
19-24	649 ± 707	428	659	8,686	1,118 ± 2,353	616	984	31,327
25-30	683 ± 646	488	649	6,341	1,030 ± 2,697	529	897	45,801
31-36	633 ± 622	445	675	5,643	902 ± 2,057	468	778	29,221
TOTAL	**4,911 ± 3,199**	**4,266**	**3,733**	**26,340**	**16,404 ± 21,761**	**8,756**	**16,240**	**139,168**

Summary

This study found a large increase in the rebates paid for both PBS prescriptions and MBS services compared to the 2008-09 national expenditure report for cancers and other neoplasms, confirming the rising costs in both of these areas. After adjusting for relevant confounders (age group, stage, number of services, and death), there were no consistent differences in the MBS rebates paid as a function of Indigenous status, remoteness, or socio-economic disadvantage. However, there were differences in the PBS rebates paid by the Australian Government on these characteristics. Specifically, costs were significantly higher in Indigenous women during months 7-to-12 and 13-to-18, women living in regional areas during the first 12-months, and women living in most disadvantaged quintile (Q1), Q3-4 during the first 12-months.

The same dataset was used in chapter 6 as in chapter 5, hence the limitations inherent to the dataset are the same. These limitations included limited data on stage of disease at diagnosis, using aggregated area-level data for socioeconomic status and remoteness, and that the impact of co-morbidities were not included in the analysis. Furthermore, the PBS dataset did not include items dispensed to public patients in public hospitals, or medications dispensed under alternative funding schemes. As such, not all chemotherapy medications would be included in the dataset, and would underestimate the expenditure associated with pharmaceutical use.

This study addressed part of the third aim of the thesis: to quantify the direct costs to the public healthcare system and individual for the first three years following a female breast cancer diagnosis, and to determine the distribution of these costs by Indigenous status, remoteness, and socioeconomic disadvantage. This study did find differences in costs for Indigenous women during months 7-to-12 and 13-to-18, however, it was outside the scope of the study to conduct an in-depth exploration of these differences in relation to treatment options and pathways. Future studies are planned to consider 1) the drivers of out-of-hospital costs, specifically in relation to treatment options and pathways for Indigenous breast cancer patients and Indigenous patients with any type of cancer, 2) the impact of co-morbidities on the costs, and 3) extend the timeframes to provide a continuous analysis of the costs and changes of costs across time.

Chapter Seven: Patient co-payments for women diagnosed with breast cancer

Introduction

Chapters Five and Six of this thesis presented the health service costs associated with breast cancer among women in the three years following diagnosis, using CancerCostMod. In this chapter, the focus is on costs to the individual. Specifically, CancerCostMod is used to estimate the total patient co-payments for MBS services and PBS prescriptions, and to determine the distribution of these co-payment costs by Indigenous status, remoteness, and socioeconomic status.

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ORIGINAL ARTICLE

Patient co-payments for women diagnosed with breast cancer in Australia

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Abstract

Purpose Among Australian women, breast cancer is the most commonly diagnosed cancer. The out-of-pocket cost to the patient is substantial. This study estimates the total patient co-payments for Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) for women diagnosed with breast cancer and determined the distribution of these costs by Indigenous status, remoteness, and socioeconomic status.

Methods Data on women diagnosed with breast cancer in Queensland between 01 July 2011 and 30 June 2012 were obtained from the Queensland Cancer Registry and linked with hospital and Emergency Department Admissions, and MBS and PBS records for the 3 years post-diagnosis. The data were then weighted to be representative of the Australian population. The co-payment charged for MBS services and PBS prescriptions was summed. We modelled the mean co-payment per patient during each 6-month time period for MBS services and PBS prescriptions.

Results A total of 3079 women were diagnosed with breast cancer in Queensland during the 12-month study period, representing 15,335 Australian women after weighting. In the first 3 years post-diagnosis, the median co-payment for MBS services was AU$ 748 (IQR, AU$87–2121; maximum AU$32,249), and for PBS prescriptions was AU$ 835 (IQR, AU$480–1289; maximum AU$5390). There were significant differences in the co-payments for MBS services and PBS prescriptions by Indigenous status and socioeconomic disadvantage, but none for remoteness.

Conclusions Women incur high patient co-payments in the first 3 years post-diagnosis. These costs vary greatly by patient. Potential costs should be discussed with women throughout their treatment, to allow women greater choice in the most appropriate care for their situation.

Keywords Breast cancer · Patient co-payment · Financial toxicity · Australia

Introduction

In 2018, it was anticipated that an estimated 18,087 women would be diagnosed with breast cancer, which is the most commonly diagnosed cancer in women within Australia [1]. Most recent estimates suggest that 5-year survival for women diagnosed with breast cancer in Australia is 90% [1]. However, improvements in treatment and survival come at a cost to both the healthcare system and the patient. Recent Australian studies have highlighted that women diagnosed with breast cancer will face significant out-of-pocket (OOP) costs [2–4]. These high OOP costs may result in people diagnosed with cancer delaying or forgoing healthcare [5–7]. This financial burden placed on individuals and their families due to a cancer diagnosis is known as 'financial toxicity' [8].

Australia has a universal healthcare system, Medicare, which has three parts: hospital, medical, and prescription pharmaceutical. Individuals receive free treatment at public hospitals and free or subsidized medical services outside of public hospitals. The Medicare Benefits Schedule (MBS) includes medical services such as attendances by medical doctors, tests and scans, most procedures performed by doctors, optometrists, and some allied health services. For items listed

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on the MBS, Medicare pays a rebate (proportion of the fee) to the service provider. If the fee charged is equal to the rebate, the patient incurs no co-payment (the service is 'bulk-billed'); however, if the fee charged by the service provider is greater than the rebate, the patient will be charged an OOP co-payment [9]. Medical service providers in Australia may set their own fees, resulting in unregulated OOP fees for patient [10].

The Pharmaceutical Benefits Scheme (PBS) is a list of approved prescription pharmaceuticals, for which the patient is charged a co-payment, and the Australian Government funds the remainder of the fee [9]. There are also a number of policies in place to protect individuals and family groups from spending a high amount on patient co-payments during the year. Individuals and families with a concession card or health care card may be eligible to obtain medications and health services at a lower cost. In addition to this, the respective Medicare and PBS Safety Nets have a number of thresholds which depend on the individual or family group circumstances, such as concessional cardholders. Once an individual or family group reach the threshold, they will have a higher proportion of their service/prescription subsidized for the remainder of the year [9]. In 2010, the Closing the Gap (CTG) PBS prescriptions were introduced, which allowed Indigenous Australians to have access to PBS medicines at a lower cost or for free [11].

There is growing concern regarding the high OOP expenditure associated with a breast cancer diagnosis. A recent report commissioned by the Breast Cancer Network Australia indicated that the median OOP for women was $4809 in the first 5 years post-diagnosis (interquartile range (IQR), $1510 and $17,200) [4]. Although similar OOP costs for women living in urban and non-urban areas were reported, women living in non-urban areas were found to access fewer services. Women living in non-urban areas were also reported to spend more on accommodation costs compared with women from urban areas [4]. In a recent Queensland study using administrative data to estimate the OOP costs of major cancers, the median co-payment for women diagnosed with breast cancer was $4192 (IQR, 1165–7459) during the first 2 years following diagnosis [3]. However, the sample was relatively small (84 women diagnosed with breast cancer), and the study did not compare costs by sub-populations such as Indigenous status, remoteness, or socioeconomic status. A longitudinal study of 287 Queensland women diagnosed with breast cancer found that the greatest total costs (direct and indirect) were during the first 6 months post-diagnosis, followed by a gradual decline over the next 18 months [2]. Costs were higher for women diagnosed with positive lymph nodes and for younger women (≤ 50 years) [2]. In a study of people diagnosed with cancer and being treated at The Townsville Hospital (Queensland), travel expenses accounted for the greatest OOP costs (71%), followed by medical services (10%) and medications (9%) [12]. Costs were highest for people living further away from the hospital and for people receiving radiotherapy [12]. The two latter studies relied on self-reported costs, which have some limitations associated with recall. The use of linked administrative data may overcome this shortcoming.

A linked administrative data model (CancerCostMod) was used in the present study to estimate the patient co-payments for women diagnosed with breast cancer. For this study, we adopted an individual perspective to (1) estimate the total patient co-payments for MBS services and PBS prescriptions for women diagnosed with breast cancer during the first 3 years following diagnosis and (2) determine the distribution of these co-payment costs by Indigenous status, remoteness, and socioeconomic status.

Methods

Study population

The methodology for 'CancerCostMod' has been previously described [13]. Briefly, this dataset comprises all cancer diagnoses (excluding non-melanoma skin cancer) in the Queensland Cancer Registry (QCR) between 01 July 2011 and 30 June 2012 ($N = 25,553$ patients), which were then linked with data on hospital admissions (Queensland Health Admitted Patient Data Collection (QHAPDC)) ED presentations (Emergency Department Information Systems (EDIS)), MBS, and PBS from 01 July 2011 and 30 June 2015. The Queensland Health Statistical Services Branch completed the linkage of QCR, QHAPDC, and EDIS, and then the Australian Institute of Health and Welfare (AIHW) linked this dataset to MBS and PBS. The base population was weighted by the authors to the Australian population to be representative of the Australian population. The authors used a programmed SAS macro, GREGWT (weighted $N = 123,900$) [13]. The 2012 Australian Cancer Database was used as the benchmark for the weighting [14]. For this study, we extracted from 'CancerCostMod' records of female breast cancer (ICD-O C50) in those aged 18 years or greater at the time of diagnosis.

Sociodemographic characteristics

Sociodemographic variables obtained in the QCR dataset at the time of diagnosis were age, sex, Indigenous status, and residential postcode. Postcode was mapped to the Index of Relative Socio-Economic Disadvantage (IRSD) and collapsed into quintiles (Q1 = most disadvantaged, and Q5 = least disadvantaged). The IRSD is a summary of the economic and social conditions of an area and is a measure of relative socioeconomic disadvantage [15]. Postcode was also mapped to the

Australian Statistical Geography Standard [16] to obtain a measure of remoteness: metropolitan, regional (inner and outer), and remote (remote and very remote). The original QCR dataset had 151 records with missing postcodes were unable to be mapped to IRSD or remoteness. Indigenous status was recorded for 87% of the sample obtained from the QCR. The authors imputed records with missing Indigenous status. Briefly, records of patients with missing Indigenous status who lived in a local government area where ≥ 75% of the population were Indigenous Australian were assigned to be 'Indigenous.' We then used multiple imputation to impute the remaining records with missing Indigenous status. These methods have been described in more detail previously [13].

Breast cancer staging

The stage at diagnosis is not routinely collected by jurisdictional cancer registries in Australia. As such, we categorized stages into 'early' (tumour size ≤ 20 mm with no evidence of lymph node involvement), 'advanced' (tumour size > 20 mm, or if any lymph node involvement regardless of size, or if there was metastatic disease), and 'unknown' (tumour size or lymph node involvement was unknown) using similar methods published in previous Queensland studies [17, 18].

Assigning patient co-payments to MBS services and PBS prescriptions

The MBS and PBS datasets used in developing CancerCostMod included information on the date of service/prescription, patient postcode, provider postcode, item code, full charge, Government rebate, and patient co-payment. The patient co-payment was summed monthly for MBS services and PBS prescriptions from the date of diagnosis (time = 0) for 36 months following diagnosis. If an individual died during the first 3 years following diagnosis, no costs were recorded for subsequent months following death. All co-payments were adjusted to the 2016–2017 financial year using the Reserve Bank of Australia inflation calculator [19]. All costs are reported in Australian dollars (AUD).

The MBS and PBS datasets include all MBS services and PBS prescriptions, which includes oncology and non-oncology medical services and prescriptions. This study excluded any costs associated with treatment that was not covered by Medicare, such as some medical services, over-the-counter, or private prescriptions. Other OOP costs such as private health insurance, hospital excess or charges, travel, accommodation, food, or indirect costs due to changes in labour force participation for the patient (and their caregiver/s) were also excluded. Patient comorbidities were also excluded from the dataset and, therefore, not adjusted for in the analysis.

Statistical analysis

Descriptive analyses were conducted to determine the characteristics of women diagnosed with breast cancer. To describe the total co-payment costs for this sample, we aggregated the co-payments for MBS and PBS separately into 6-month time periods from the date of diagnosis ($t = 0$) to 36 months post-diagnosis. We report the total and average patient co-payment separately for MBS services and PBS prescriptions during each of the time periods analysed (limited to those who accessed at least one health event).

Finally, we modelled the mean patient co-payment during each 6-month time period using generalized linear models, using a negative binomial regression, and a log link function. There were six separate models (one for each 6-month period) for MBS co-payments and 6 separate models for PBS co-payments. Covariates included in these analyses were Indigenous status (reference = non-Indigenous women), age group (reference = 18–44 years), remoteness (reference = metropolitan), socioeconomic disadvantage (reference = IRSD Q5 (least disadvantaged)), breast cancer stage (reference = early), number of medical services accessed during the period analysed, and death during the time period being modelled. These are variables that may have influenced treatment and therefore costs associated with treatment. The models also included the number of months the individual survived as an offset to the model. All analyses were undertaken using SAS V9.4 (SAS Institute Inc., Cary, NC, USA).

Human Research Ethics approval was obtained from the Townsville Hospital and Health Service Human Research Ethics Committee (HREC) (HREC/16/QTHS/11), AIHW HREC (EO2017/1/343), and James Cook University HREC (H6678). Permission to waive consent was approved from Queensland Health under the Public Health Act 2005. No identifiable information was provided to the authors.

Results

Between 1 July 2011 and 30 June 2012, 3079 women were diagnosed with breast cancer in Queensland. This represents 15,335 Australian women once weighted. Demographic characteristics at diagnosis are shown in Table 1. The mean age for this cohort was 61 years (SD, 14 years). Demographic characteristics were similar for the weighted and unweighted sample.

During the first 12 months following diagnosis, 646 women passed away. Of this, 44% lived in metropolitan areas, 36% lived in regional areas, and 11% lived in remote areas (please note that due to missing postcode data, this does not add to 100%). Of those who passed away during the first 12 months following diagnosis, 7% lived in the most disadvantaged areas

Table 1 Demographic characteristics at diagnosis of Australian women diagnosed with breast cancer between 1 July 2011 and 30 June 2012 (weighted)

	N
N	3079
N (weighted)	15,335
Age group	
18–44 years (%)	1848 (12.1)
45–64 years (%)	7536 (49.1)
≥ 64 years (%)	5951 (38.8)
12-month mortality	646 (4.2)
Indigenous status	
Indigenous women (%)	248 (1.6)
Non-Indigenous women (%)	15,087 (98.4)
Remoteness*	
Metropolitan (%)	7712 (50.6)
Regional (%)	6359 (41.7)
Remote (%)	1180 (7.7)
Index of Relative Socio-Economic Disadvantage*	
Quintile 1 (most disadvantaged) (%)	1095 (7.2)
Quintile 2 (%)	767 (5.0)
Quintile 3 (%)	2483 (16.3)
Quintile 4 (%)	6669 (43.7)
Quintile 5 (least disadvantaged) (%)	4236 (27.8)
Breast cancer stage	
Early (%)	6695 (43.6)
Advanced (%)	7174 (46.8)
Unknown (%)	1466 (9.6)

*Those with missing postcode data at diagnosis were excluded (weighted $n = 85$)

(IRSD Q1), 3% lived in Q2, 16% lived in Q3, 46% lived in Q4, and 20% lived in Q5 (least disadvantaged). Table 2 describes the stages of disease at diagnosis for Australian women diagnosed with breast cancer by Indigenous status, remoteness, and socioeconomic status.

Table 3 describes the number of MBS services and PBS prescriptions accessed by women diagnosed with breast cancer during the first 3 years post-diagnosis. On average, each woman accessed 233 services MBS services (SD, 144) during the first 3 years following a breast cancer diagnosis and an average of 99 PBS prescriptions (SD, 90).

A summary of the patient co-payments for MBS services and PBS prescriptions over the first 3 years following diagnosis is reported in Table 4. During the first 3 years post-diagnosis, the average co-payments for MBS services was AU$1440 (SD, $1946). For MBS patient co-payments, the standard deviation was larger than the mean in each of the 6-month periods, indicating a wide dispersion in the average patient co-payment between individuals. This was not observed for PBS prescriptions. During the first 3 years post-diagnosis, the average co-payments for PBS prescriptions was AU$974 (SD, $707).

The average patient co-payments for MBS services and PBS prescriptions are shown in Fig. 1 by age group (panels a and b), stage of disease (panels c and d), Indigenous status (panels e and f), remoteness (panels g and h), and socioeconomic disadvantage (panels i and j). In most of the panels, the first 6 months following diagnosis accounted for a higher proportion of patient co-payments. There is some variation in the average co-payment for MBS services during the 0–6 and 7–12 months post-diagnosis by age group and stage of disease, but after 12 months, there is little to no variation. There is some variation in the average co-payment for PBS prescriptions over the first 6 months by age group and stage of disease. Indigenous women have lower average patient co-payments for both MBS services and PBS prescriptions across all time periods. There was some variation observed in the average patient co-payment for MBS services when

Table 2 Stages of disease at diagnosis of Australian women diagnosed with breast cancer between 1 July 2011 and 30 June 2012 (weighted)

	Early	Advanced	Unknown
Indigenous Australian (%)	75 (30)	123 (50)	50 (20)
Non-Indigenous Australian women (%)	6620 (44)	7052 (47)	1415 (9)
Remoteness**			
Major city (%)	3424 (44)	3567 (46)	721 (9)
Regional (%)	2757 (43)	3066 (48)	536 (8)
Remote (%)	514 (44)	537 (46)	129 (11)
Index of Relative Socio-Economic Disadvantage**			
Quintile 1 (most disadvantaged) (%)	439 (40)	557 (51)	99 (9)
Quintile 2 (%)	368 (48)	351 (46)	49 (6)
Quintile 3 (%)	1085 (44)	1188 (48)	210 (9)
Quintile 4 (%)	3018 (45)	3078 (46)	573 (9)
Quintile 5 (least disadvantaged) (%)	1786 (42)	1995 (47)	455 (11)

**Those with missing postcode data at diagnosis were excluded (weighted $n = 85$)

Table 3 Number of MBS services and PBS prescriptions for women diagnosed with breast cancer in Australia (weighted)

Time since diagnosis (months)	MBS services Mean ± SD	PBS prescriptions Mean ± SD
0–6	75 ± 45	25 ± 19
7–12	47 ± 39	18 ± 17
13–18	30 ± 27	17 ± 17
19–24	28 ± 31	17 ± 17
25–30	28 ± 34	17 ± 17
31–36	26 ± 31	17 ± 17

comparing by remoteness and socioeconomic disadvantage. Women living in metropolitan areas appear to have slightly higher co-payments for MBS services throughout the first 3 years compared with women living in regional and remote areas. Women living in the least disadvantaged quintiles (Q4 and Q5) had higher patient co-payments for MBS services compared with those living in quintiles 1–3. There was very little variation in the patient co-payment for PBS prescriptions by remoteness or socioeconomic disadvantage.

Table 5 shows the parameter estimates produced by the six generalized linear models, estimating the mean patient co-payment per patient for each 6-month time period for MBS services, adjusting for Indigenous status, remoteness, socioeconomic status, age group at diagnosis, stage of disease at diagnosis, number of MBS services during period analysed, and death during time period being analysed. For MBS services, co-payments were 82% lower in Indigenous women during 0–6 months and 79% lower during the 7–12 months post-diagnosis compared with those in non-Indigenous women. There were no consistent differences between areas of remoteness. Compared with women living in the least disadvantaged area (Q5), women living in Q1, Q2, and Q3 had significantly lower costs for 0–6 months and 7–12 months.

Finally, we examined the mean co-payment per patient for each 6-month time period for PBS services, adjusting for indigenous status, remoteness, socioeconomic status, age group at diagnosis, stage of disease at diagnosis, number of PBS services during the period analysed, and death during the time period being analysed (Table 6). Co-payments were significantly lower for Indigenous women during each of the 6-month periods analysed compared with those for non-Indigenous women (ranging from 41% less during months 7–12, to 30% less during 19–24 months). There were no significant differences by remoteness in any of the 6-month periods analysed. Compared with women living in the least disadvantaged quintile (Q5), patient co-payments reduced with increasing disadvantage in the first 6 months post-diagnosis (Q1, 21% fewer; Q4, 13% fewer). Women from the most disadvantaged quintile also had 18% fewer costs during 13–18 months, 15% fewer costs during 19–24 months, 19% fewer costs during 25–30 months, and 16% fewer costs during 31–36 months.

Discussion

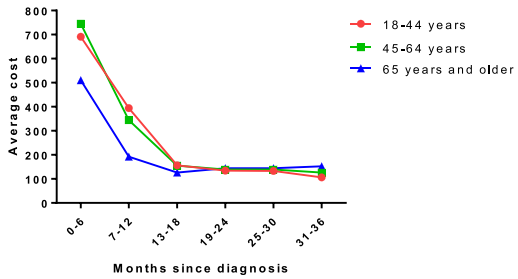
The total patient co-payments for the first 3 years for women diagnosed with breast cancer was approximately $21.7 million for MBS services and $14.2 million for PBS prescriptions. The average patient co-payment for MBS services during the first 3 years was $1440, with some women paying a maximum of $32,249. In addition, the average co-payments paid per patient for PBS prescriptions during the first 3 years post-diagnosis was $974, with a maximum of $5390.

We presented the costs for patient co-payments for MBS services and PBS prescriptions. A recent Queensland study estimated the median patient co-payments for all services and prescriptions billed through Medicare during the first 2 years post-diagnosis was $4192 [3]. These results are also comparable to other reports of high OOP costs in Australia following a breast cancer diagnosis [2, 4]. Both of these other studies include direct and indirect costs following a breast cancer diagnosis. Our data set did not include costs which did not incur a rebate paid by Medicare. However, our study is unique

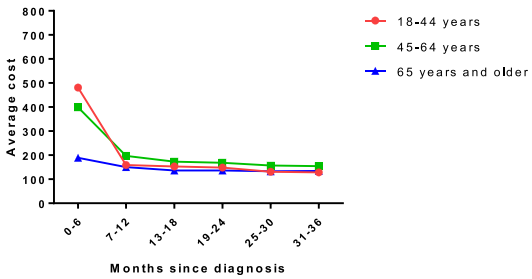
Table 4 Patient co-payments of MBS services and PBS prescriptions for women diagnosed with breast cancer in Australia (weighted)

Time since diagnosis (months)	MBS services				PBS prescriptions			
	Mean ± SD (AU$)	Median (AU$)	Interquartile range (AU$)	Maximum (AU$)	Mean ± SD (AU$)	Median (AU$)	Interquartile range (AU$)	Maximum (AU$)
0–6	649 ± 845	229	1–1121	6620	326 ± 322	205	105–451	2137
7–12	294 ± 605	61	0–253	9404	175 ± 148	141	77–222	1759
13–18	145 ± 314	54	0–164	5901	156 ± 131	121	72–216	1282
19–24	140 ± 390	49	0–149	10,193	153 ± 127	115	73–219	1192
25–30	140 ± 423	54	0–145	9899	145 ± 124	112	61–193	1536
31–36	133 ± 407	44	0–138	10,745	143 ± 118	116	61–192	1203
TOTAL	1440 ± 1946	748	87–2121	32,249	974 ± 707	835	480–1289	5390

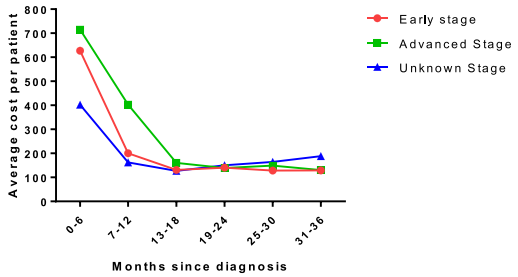
Panel A: MBS services by age group



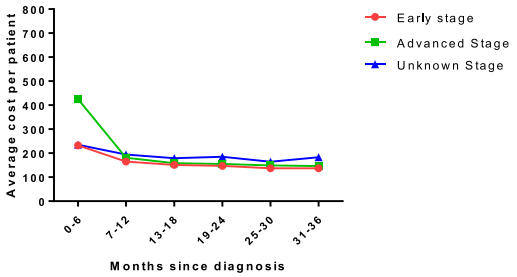
Panel B: PBS prescriptions by age group



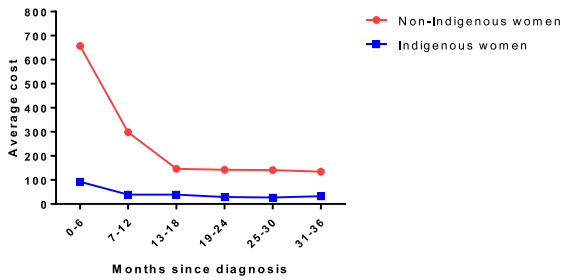
Panel C: MBS services by stage of disease



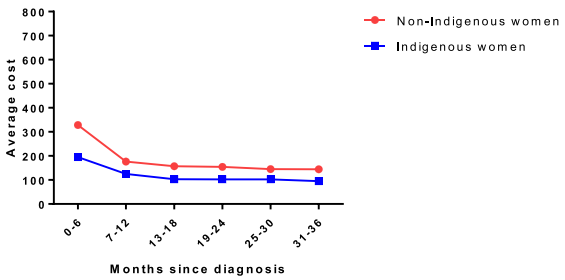
Panel D: PBS prescriptions by stage of disease



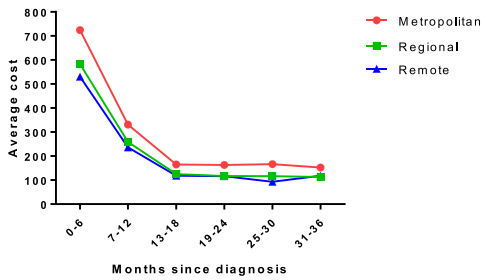
Panel E: MBS services by Indigenous status



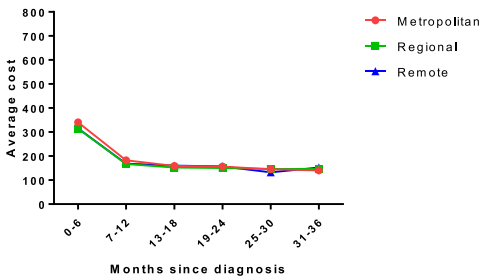
Panel F: PBS prescriptions by Indigenous status



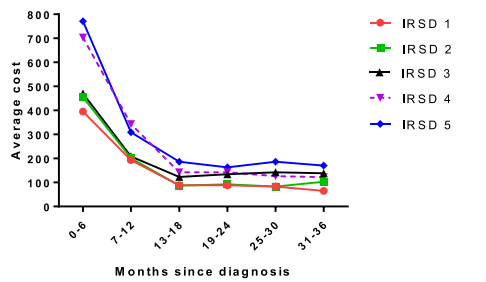
Panel G: MBS services by remoteness



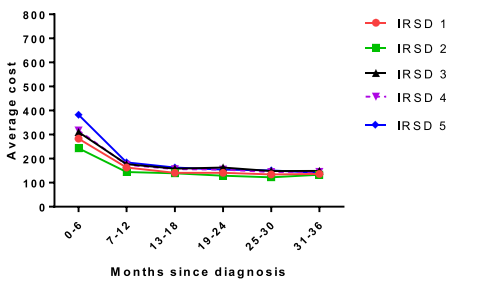
Panel H: PBS prescriptions by remoteness



Panel I: MBS services by socioeconomic disadvantage



Panel J: PBS prescriptions by socioeconomic disadvantage



◀ **Fig. 1** Average patient co-payments for MBS services and PBS prescriptions by age group (**a**, **b**), breast cancer stage (**c**, **d**), Indigenous status (**e**, **f**), remoteness (**g**, **h**), and socioeconomic disadvantage (**i**, **j**). Average costs per patient were calculated for each 6-month period from diagnosis to 3 years. The figures on the left present the unadjusted average patient co-payments for MBS services, and on the right present the unadjusted average patient co-payments for PBS prescriptions by characteristics of interest

in that it describes the distribution of patient co-payments by Indigenous status, remoteness, and socioeconomic status.

We found that Indigenous women and women living in areas of socioeconomic disadvantage had significantly lower patient co-payments for MBS services during the 12 months following diagnosis, even after adjusting for the number of services used during this time. These findings may indicate that the policies in place to protect individuals and family groups from spending a high amount on patient co-payments during the year are working. These policies include lower payments for eligible Concession Card holders, as well as the Medicare and Extended Medicare Safety Nets. Once an individual or family group patient reaches the threshold set for that calendar year, then they may receive a greater proportion of Medicare rebate for out-of-hospital services [9].

In Australia, the rebate paid by Medicare is set in the Schedule (a listing of all Medicare services subsidized by the Government); however, health practitioners are able to set the fee charged for the service provided, resulting in unregulated patient co-payments. Some MBS service providers may also choose to bulk-bill patients, resulting in no patient co-payment. Some un-referred services may be eligible for bulk-bill incentives from the government [20]. In 2015, OOP expenditure in Australia was 20%, which was equal to the Organisation for Economic Cooperation and Development average (20%), but higher than the average paid in the UK (15%), New Zealand (13%), and Canada (15%) [21]. This is of concern, as it is known that people may delay or forgo healthcare due to costs [5, 7]. Previous work by some of the authors found that 21% of Australian adults with cancer skipped care due to the costs [5]. In a survey of people with cancer, 10.9% indicated that the cost of treatment influenced their decision about cancer treatment [7]. A recent study using CancerCostMod identified that on average, Indigenous Australians with cancer had lower patient co-payments for MBS services and PBS prescriptions combined compared with non-Indigenous Australians with cancer. There were also differences in the number and type of MBS services accessed between Indigenous Australians and non-Indigenous Australians [22]. Future studies should identify if there are differences in the type and number of MBS services and PBS prescriptions for women diagnosed with breast cancer.

In relation to PBS prescriptions, we found that after adjusting for the number of prescriptions, patient co-payments were significantly lower in Indigenous women and in women living in areas of socioeconomic disadvantage (Q1–4). Again, these findings may indicate that the prescriptions dispensed under the CTG scheme for Indigenous Australians, lower co-payments for people with eligible Concession Cards, and the PBS Safety Net may be protecting individuals and family groups from paying excessive patient co-payments for their prescriptions. In contrast to unregulated patient co-payments for MBS services, patients will pay up to the patient co-payment for approved PBS medications (2018 general patient, $39.50; and concession card holder $6.40) [23]. However, previous studies have found that cost is a barrier in obtaining the prescription [6, 24]. In a survey of people with cancer, 11% indicated that medications prescribed for their cancer treatment caused financial burden. Those who had a reduced income following their diagnosis reported greater financial burden due to prescribed cancer medications. Almost 12% of participants indicated that they used an alternative (over-the-counter, medication already at home, medicines from someone else) to their prescribed cancer-related medications [6].

Our study found no consistent difference in the patient co-payments paid for MBS services or PBS prescriptions by remoteness. In comparison, previous studies have reported higher patient OOP expenditure for people living outside of urban areas. A recent Western Australia study reported that of people diagnosed with one of the four most common cancers, total OOP expenditure was higher in participants residing outside of the South West region, who had private health insurance and were under the age of 65 years. This study included direct and indirect costs. The categories which accounted for the greatest proportion of expenditure were surgery, tests, accommodation, and fuel [25]. These results were similar to a Queensland study, which reported travel expenses accounting for the greatest proportion (71%) of total costs for cancer patients [12]. OOP costs were greatest for people living more than 100 km from the hospital in which they received care, compared with those who lived within 100 km from this hospital [12]. Our study was unable to estimate indirect costs, as these were not covered by Medicare.

This study has several strengths, primarily due to the use of population-based linked administrative data. We included the patient co-payment costs of all MBS services and PBS prescriptions from date of diagnosis to 36 months post-diagnosis for women diagnosed with breast cancer. The data was weighted to be representative of the Australian population. We have previously calculated that the age-standardized incidence rate of women diagnosed with breast cancer for CancerCostMod was 120.56 per 100,000, compared with the national age-standardized incidence rate of 120.42 per 100,000 for women diagnosed with breast cancer in 2012 [13]. Administrative data also overcomes potential measurement bias (poor recall, self-report, interviewer, etc.). However, administrative data also has several weaknesses. For example,

Table 5 Parameter estimates of independent variables in generalized linear regression model of the co-payments for MBS services for women diagnosed with breast cancer between 1 July 2011 and 30 June 2012, Australia (weighted data presented)

	0–6 months		7–12 months		13–18 months		19–24 months		25–30 months		31–36 months	
	Ratio	Coefficient (SE)	Ratio	Coefficient (SE)	Ratio	Coefficient (SE)	Ratio	Coefficient (SE)	Ratio	Coefficient (SE)	Ratio	Coefficient (SE)
Intercept		3.2038 (0.1917)***		1.8748 (0.2348)***		2.0679 (0.1605)***		1.9362 (0.1263)***		1.7002 (0.1209)***		1.3809 (0.1364)***
Indigenous women	0.18	− 1.7388 (0.2791)***	0.21	− 1.5685 (0.3202)***	0.99	− 0.0139 (0.2673)	0.82	− 0.1972 (0.2623)	0.65	− 0.4288 (0.2730)	1.06	0.0556 (0.3063)
Regional	1.05	0.0443 (0.0835)	1.02	0.0226 (0.0968)	0.99	− 0.0083 (0.0484)	0.95	− 0.0557 (0.0472)	1.09	0.0896 (0.0454)*	0.99	− 0.0136 (0.0501)
Remote	1.27	0.2370 (0.1440)	1.04	0.0360 (0.1671)	1.01	0.0079 (0.0839)	0.91	− 0.0926 (0.0780)	1.03	0.0264 (0.0781)	0.92	− 0.0816 (0.0853)
IRSD Q1	0.59	− 0.5337 (0.1591)***	0.62	− 0.4783 (0.1860)*	0.74	− 0.3064 (0.0957)**	0.97	− 0.0350 (0.0933)	0.72	− 0.3236 (0.0921)***	0.76	− 0.2694 (0.0985)**
IRSD Q2	0.64	− 0.4427 (0.1797)*	0.49	− 0.7087 (0.2095)***	0.72	− 0.3322 (0.1062)**	0.90	− 0.1021 (0.1021)	0.73	− 0.3095 (0.0978)**	0.83	−0.1923 (0.1070)
IRSD Q3	0.58	− 0.5499 (0.1176)***	0.59	− 0.5270 (0.1348)***	0.86	− 0.1470 (0.0692)	0.94	− 0.0594 (0.0677)	0.78	− 0.2450 (0.0648)***	1.01	0.0079 (0.0714)
IRSD Q4	0.89	− 0.1129 (0.0879)	0.90	− 0.1107 (0.1025)	0.84	− 0.1773 (0.0502)***	0.92	− 0.0799 (0.0478)	0.81	− 0.2084 (0.0468)***	0.88	− 0.1256 (0.0513)*
Age 45–64 years	1.06	0.0604 (0.1090)	1.02	0.0168 (0.1268)	0.92	− 0.0869 (0.0623)	0.98	− 0.0215 (0.0582)	0.95	− 0.0506 (0.0584)	1.10	0.0909 (0.0626)
Age ≥ 65 years	0.71	− 0.3448 (0.1129)**	0.60	− 0.5067 (0.1318)***	0.63	− 0.4545 (0.0662)***	0.73	− 0.3089 (0.0622)***	0.73	− 0.3120 (0.0626)***	0.89	− 0.1214 (0.0677)
Advanced stage	0.73	− 0.3197 (0.0718)***	1.08	0.0801 (0.0876)	1.02	0.0168 (0.0409)	1.03	0.0276 (0.0387)	0.98	− 0.0169 (0.0383)	0.96	− 0.0405 (0.0417)
Unknown stage	0.58	− 0.5402 (0.1365)***	0.63	− 0.4689 (0.1672)**	0.95	− 0.0472 (0.0948)	1.07	0.0655 (0.1003)	1.09	0.0896 (0.1022)	0.81	− 0.2159 (0.1149)
Number of MBS services during period analysed	1.03	0.0260 (0.0011)***	1.03	0.0261 (0.0014)***	1.02	0.0207 (0.0009)***	1.02	0.0188 (0.0007)***	1.02	0.0182 (0.0007)***	1.02	0.0200 (0.0009)***
Death during period analysed	0.62	− 0.4778 (0.1269)***	0.92	− 0.0790 (0.1768)	0.87	− 0.1349 (0.1419)	0.65	− 0.4251 (0.1035)***	0.71	− 0.3416 (0.1000)***	0.72	− 0.3334 (0.1155)**

The ratios presented are relative to the reference group: Indigenous status (reference = non-Indigenous women), age group (reference = 18–44 years), remoteness (reference = metropolitan), socioeconomic disadvantage (reference = IRSD Q5 (least disadvantaged)), breast cancer stage (reference = early), number of medical services accessed during the period analysed, and death during the time period being modelled

*p value < 0.05, **p value < 0.01, ***p value < 0.001

Table 6 Parameter estimates of independent variables in generalized linear regression model of the co-payments for PBS prescriptions for women diagnosed with breast cancer between 1 July 2011 and 30 June 2012, Australia (weighted data presented)

	0–6 months		7–12 months		13–18 months		19–24 months		25–30 months		31–36 months	
	Ratio	Coefficient (SE)	Ratio	Coefficient (SE)	Ratio	Coefficient (SE)	Ratio	Coefficient (SE)	Ratio	Coefficient (SE)	Ratio	Coefficient (SE)
Intercept		3.9211 (0.0765)***		2.3079 (0.0779)***		2.0292 (0.0844)***		1.7807 (0.0829)***		1.3308 (0.0802)***		0.9763 (0.0892)***
Indigenous women	0.61	− 0.4926 (0.1191)***	0.59	− 0.5234 (0.1125)***	0.61	− 0.4973 (0.1206)***	0.70	− 0.3632 (0.1345)**	0.63	− 0.4557 (0.1299)***	0.68	− 0.3855 (0.1419)**
Regional	1.01	0.0059 (0.0347)	0.96	− 0.0382 (0.0338)	1.02	0.0174 (0.0356)	1.01	0.0105 (0.0354)	1.08	0.0742 (0.0364)	1.07	0.0648 (0.0386)
Remote	1.09	0.0816 (0.0583)	0.99	− 0.0081 (0.0574)	1.10	0.0935 (0.0609)	1.06	0.0536 (0.0603)	0.99	− 0.0088 (0.0619)	1.09	0.0826 (0.0658)
IRSD Q1	0.79	− 0.2370 (0.0672)***	0.91	− 0.0971 (0.0654)	0.82	− 0.1955 (0.0681)**	0.85	− 0.1580 (0.0674)*	0.81	− 0.2156 (0.0701)**	0.84	− 0.1776 (0.0735)*
IRSD Q2	0.75	− 0.2850 (0.0742)***	0.83	− 0.1845 (0.0732)*	0.84	− 0.1718 (0.0762)*	0.87	− 0.1394 (0.0756)	0.78	− 0.2486 (0.0770)**	0.83	− 0.1923 (0.0819)*
IRSD Q3	0.83	− 0.1870 (0.0479)***	0.93	− 0.0748 (0.0468)	0.92	− 0.0798 (0.0492)	0.96	− 0.0459 (0.0492)	0.90	− 0.1085 (0.0505)*	0.95	− 0.0533 (0.0535)
IRSD Q4	0.87	− 0.1405 (0.0372)***	0.95	− 0.0527 (0.0361)	0.93	− 0.0707 (0.0381)	0.96	− 0.0388 (0.0380)	0.90	− 0.1102 (0.0389)**	0.96	− 0.0422 (0.0414)
Age 45–64 years	0.87	− 0.1406 (0.0456)**	1.19	0.1725 (0.0446)***	1.08	0.0784 (0.0477)	1.11	0.1065 (0.0481)*	1.18	0.1633 (0.0498)***	1.18	0.1631 (0.0529)**
Age ≥ 65 years	0.37	− 0.9955 (0.0477)***	0.70	− 0.3612 (0.0487)***	0.66	− 0.4123 (0.0518)***	0.68	− 0.3875 (0.0525)***	0.77	− 0.2604 (0.0539)***	0.80	− 0.2206 (0.0572)***
Advanced stage	1.35	0.2996 (0.0309)***	1.03	0.0253 (0.0288)	1.02	0.0214 (0.0300)	1.04	0.0417 (0.0299)	1.08	0.0746 (0.0308)*	1.05	0.0468 (0.0323)
Unknown stage	1.09	0.0821 (0.0589)	1.07	0.0685 (0.0583)	1.13	0.1234 (0.0613)*	1.21	0.1887 (0.0620)**	1.17	0.1556 (0.0667)*	1.51	0.4111 (0.0735)***
Number of PBS services during period analysed	1.03	0.0251 (0.0010)***	1.02	0.0207 (0.0011)***	1.02	0.0179 (0.0011)***	1.02	0.0186 (0.0011)***	1.02	0.0181 (0.0011)***	1.02	0.0173 (0.0012)***
Death during period analysed	0.74	− 0.3063 (0.0536)***	1.07	0.0696 (0.0574)	0.96	− 0.0411 (0.0650)	0.85	− 0.1670 (0.0630)**	0.95	− 0.0537 (0.0607)	1.07	0.0719 (0.0648)

The ratios presented are relative to the reference group: Indigenous status (reference = non-Indigenous women), age group (reference = 18–44 years), remoteness (reference = metropolitan), socioeconomic disadvantage (reference = IRSD Q5 (least disadvantaged)), breast cancer stage (reference = early), number of PBS services accessed during the period analysed, and death during the time period being modelled

*p value < 0.05, **p value < 0.01, ***p value < 0.001

the QCR does not routinely collect stage of disease at diagnosis, or breast cancer type, or socioeconomic status of individuals. Therefore, we identified the stage as 'early', 'advanced', and 'unknown' and used aggregated area-level data to identify socioeconomic disadvantage and remoteness. We were unable to estimate patient OOP costs which were not covered by Medicare, such as some medical services, over-the-counter medications, private prescriptions, private health insurance (including premiums and excess), travel, accommodation, food, or indirect costs due to changes in labour force participation for the patient (and their caregiver/s). These indirect costs are known to account for a high proportion of the costs to the patient [2, 12, 25]. Patient comorbidities were also excluded from the dataset and, therefore, not adjusted for in the analysis.

The sample of women diagnosed with breast cancer that was used in this manuscript was obtained from a larger dataset, CancerCostMod. The original data included had indigenous status recorded for 87% of the records [13]. In the development of this dataset, Indigenous status was imputed for records with missing or unknown Indigenous status. Missing Indigenous status is a common data limitation in Australian health studies [26]. Previously, Australian national cancer statistics have included data from five (of eight) jurisdictions only, as these jurisdictions are considered to have sufficient completeness of Indigenous status for reporting [1]. It is possible that the national statistics underestimate the true incidence of cancer in Indigenous Australians [27]; it is also possible that we have overestimated the number of new cases of cancer for Indigenous Australians.

Conclusion

This study supports previous findings of high OOP co-payments following a breast cancer diagnosis. We also found significant differences in the patient co-payments for women diagnosed with breast cancer in Australia by Indigenous status and socioeconomic disadvantage. Although it may be difficult to predict all of the patient co-payments throughout their cancer journey, there is a call for greater transparency for patient co-payments. As costs are a potential barrier to accessing treatment, health professionals should be aware of potential co-payments which may be incurred and discuss these with the patient throughout their cancer journey.

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Authors' contribution NB conceived, designed, and planned the study and undertook the data analysis. All authors contributed to the interpretation of the data and drafting the manuscript and approved of the final draft.

Compliance with ethical standards

Conflict of interest The authors declare that they have no competing interests.

Ethics approval and consent to participate Human Research Ethics approval was obtained from the Townsville Hospital and Health Service Human Research Ethics Committee (HREC) (HREC/16/QTHS/11), AIHW HREC (EO2017/1/343), and James Cook University HREC (H6678). Permission to waive consent was approved from Queensland Health under the Public Health Act 2005. No identifiable information was provided to the authors.

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Summary

This chapter represents the final chapter of Part 3, which focused on the costs associated with women diagnosed with breast cancer for the three years following diagnoses. Chapters Five and Six presented costs to the health care system, but this chapter specifically focused on the costs to the individual. This study found that Indigenous women paid significantly lower patient co-payments than their non-Indigenous counterparts for MBS services and PBS prescriptions during the first year post-diagnosis. Patient co-payments for MBS services were significantly lower during the first 12-months post diagnosis in women living in the most disadvantaged areas (Q1-3), compared to women living in the least socioeconomically disadvantaged areas (Q5), and patient co-payments for PBS prescriptions were significantly lower in the first six-months following diagnosis. MBS and PBS co-payments were consistently lower in women living in the more disadvantaged quintiles throughout the three-year follow-up period. There were no differences in co-payments for MBS or PBS services by remoteness.

The same dataset was used in this study as for the previous two chapters, thus there are the same limitations inherent to the dataset. In addition to these limitations, the patient OOP costs included in this study are limited to patient co-payments only. It was not possible to include costs that were not captured in the MBS and PBS datasets, as such, costs for travel, accommodation, parking, child care, private health insurance, private prescriptions/health services etc were not included in the analysis.

This study addressed part of the third aim of the thesis: to quantify the direct costs to the public healthcare system and individual for the first three years following a female breast cancer diagnosis, and to determine the distribution of these costs by Indigenous status, remoteness, and socioeconomic disadvantage. Future studies should consider 1) the drivers of high OOP co-payments and the distribution of these costs, 2) the impact of co-morbidities on the costs, and 3) extend the timeframes to provide a continuous analysis of the costs and changes of costs across time. Finally, future studies should consider other types of OOP costs that were not captured in this chapter, and the distribution of these costs by population group.

In Part 4 of the thesis, the findings presented in Chapters Three to Seven are synthesised in the context of relevant literature, strengths and limitations. Finally, recommendations and conclusions are provided.

PART 4: DISCUSSION AND CONCLUSION

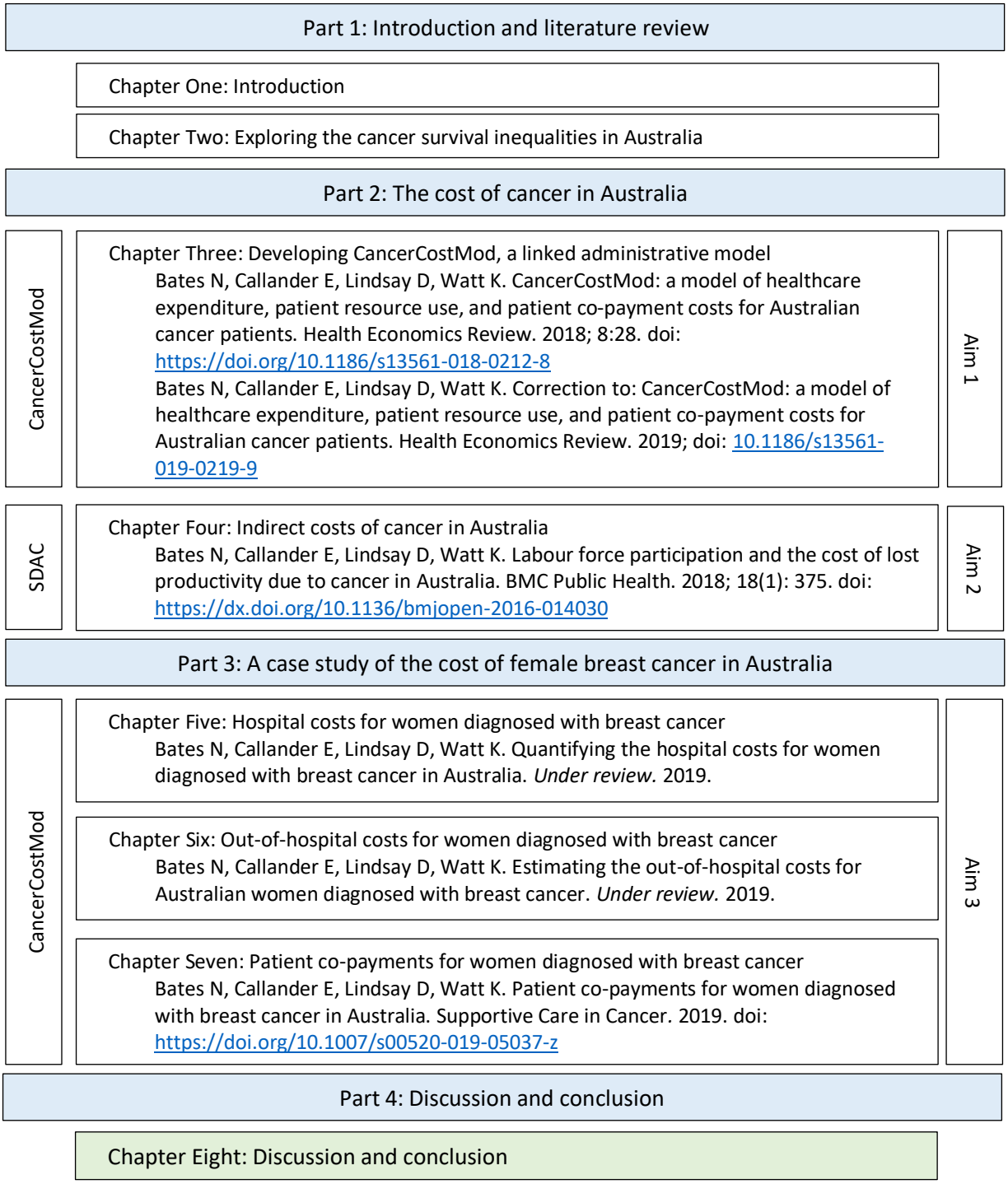

Figure 1: Thesis outline

Chapter Eight: Discussion and Conclusion

Cancer is the leading burden of disease in Australia,[1] and imparts a significant economic burden on the public healthcare system, society, and the individual. The overall objective of this thesis was to describe the cost of cancer in Australia, with a particular focus on identifying the distribution of this cost by those groups within the population known to experience poorer outcomes following diagnosis. Indigenous Australians, people living in remote areas, and socioeconomically disadvantaged people experience inequalities in cancer survival. In this final chapter of the thesis, the results presented in Chapters Three to Seven are summarised and synthesised to better understand the cost of cancer in Australia, and the distribution of these costs by the mentioned characteristics (Indigenous status, remoteness, socioeconomic disadvantage). Policy and practice implications, as well as strengths and limitations of the overall programme of research are discussed, and areas for future research are highlighted. The findings of this thesis need to be considered in the context of the Australian policy at the time of data collection, and publication of findings.

Summary of the key findings

This thesis is comprised of four Parts. Part 1 of this thesis contained the introduction and literature review, which contextualised this body of work. Part 2 comprised two chapters, which described the direct and indirect costs for all cancers in a 12-month time period (Chapters Three and Four respectively). Chapter Three described the development of *CancerCostMod*, a model based on linked administrative data that was used for the majority of the thesis. Also identified in Chapter Three was the cost of cancer in Australia for the first 12-months post-diagnosis – this was an estimated $4.8 billion to the public healthcare system, and an additional $127.7 million to the individual.

Results from this study showed that during the first 12-months following a cancer diagnosis, there were significant differences in the costs to the public healthcare system and individual by Indigenous status, remoteness and socioeconomic disadvantage. The costs to the public healthcare system were categorised as: admitted and non-admitted hospital episodes, ED presentations, MBS rebates, and PBS rebates. For admitted and non-admitted hospital episodes, compared to people living in metropolitan areas, costs were 4% higher for people living in inner/outer regional areas, and 10% higher for people living in remote/very remote areas. Costs were significantly lower for people living areas of lower disadvantage (Q4 = 5% lower, and Q5 = 7% lower) compared to people living in the most disadvantaged area (Q1). There was no significant difference in the costs for hospital episodes between Indigenous and non-Indigenous people diagnosed with cancer. For ED presentations, costs were 23% higher among Indigenous Australians compared to non-Indigenous Australians. No

differences in cost for ED presentations were observed by remoteness or socioeconomic disadvantage.

The cost for out-of-hospital medical services were calculated using MBS rebates paid by Medicare. During the first 12-months following a cancer diagnosis, rebates paid were 8% lower in Indigenous Australians compared to non-Indigenous Australians. Using people living in metropolitan areas as the reference, rebates paid for the healthcare of people living in remote and very remote areas were 10% lower, but there was no difference for people living in regional areas. Compared to people living in the most disadvantaged area (Q1), the rebates paid for the healthcare of people living in areas of lower disadvantage (Q2-Q4) were significantly higher (Q2=7%, Q3=8%, and Q4=18%).

The cost to the public healthcare system for PBS prescriptions was captured using the rebates paid for PBS approved prescriptions. During the first 12-months, the PBS rebates paid were 18% lower for Indigenous Australians compared to non-Indigenous Australians. People living in remote/very remote areas had 10% greater rebates paid for PBS prescriptions compared to people living in metropolitan areas, and compared to those living in the most disadvantaged quintile, people living in Q3-Q5 had significantly higher PBS rebates (Q3=11%, Q4=17%, and Q5=19%).

The patient co-payments for MBS services and PBS prescriptions were combined to provide the total co-payments paid during the first 12-months. Patient co-payments were 61% lower in Indigenous Australians compared to non-Indigenous Australians. Compared to people living in metropolitan areas, patient co-payments were 6% lower for people living in inner/outer regional areas. Higher co-payments were observed in people living in the two least disadvantaged quintiles compared to people living in the most disadvantaged quintile (Q4=23% and Q5=32%).

In Chapter Four, the annual indirect cost associated with labour force absence for all cancer types in Australia was examined, using the 2015 Survey of Disability, Ageing and Carers (SDAC). This study identified that at the time of the 2015 SDAC, 46% of people of working age with cancer (aged 25-64 years) were not in the labour force, resulting in $1.7 billion reduction in Australia's GDP. Of people with cancer, those without a tertiary qualification (which was used as a proxy measure of socioeconomic status) were more likely to be out of the labour force. However, there were no differences between people living in major cities and those living outside of major cities in terms of labour force participation. Indigenous status was not available in the dataset, and was thus not included in the analysis.

Part 3 of the thesis focused on female breast cancer, but a longer timeframe was examined (three years following diagnoses) to facilitate a more thorough investigation of relevant costs. The cost of

female breast cancer to the public healthcare system (Chapters Five and Six), and the individual (Chapter Seven) during the first three years following diagnosis were presented in these three chapters. Female breast cancer was chosen as a case study in this thesis, as it is the most commonly diagnosed cancer in Australia.[2]

Chapter Five identified the hospital costs for women diagnosed with breast cancer and Chapter Six quantified the rebates paid by the Australian government for MBS services and PBS prescriptions. Results presented in Chapter Five indicate that the average cost per person for admitted and non-admitted hospital episodes was higher for Indigenous women compared to non-Indigenous women, and women living in the most disadvantaged quintile compared to women living in the least disadvantaged area. There were little to no differences in the average cost of ED presentations during the first two-years, but in the third year post-diagnosis, costs were lower in women living in remote areas than those living in metropolitan areas.

In Chapter Six, little to no consistent differences were identified in the average rebates paid by Medicare for MBS services by remoteness, Indigenous status or socio-economic disadvantage. However, there were differences in the average rebate paid by Medicare for PBS prescriptions throughout the three-year study period for Indigenous women (lower costs during months 7-to-12 and 13-to-18) compared to non-Indigenous women, regional (higher costs during the first 12 months) compared to metropolitan, and for women living outside of the least disadvantaged quintile (lower costs during the first 12-months).

Chapter Seven identified the high patient co-payments for MBS services and PBS prescriptions incurred by women following a breast cancer diagnosis. These findings support previous Australian studies which have identified high out-of-pocket (OOP) costs borne by women diagnosed with breast cancer.[3-5] The cost of healthcare is a known barrier for people accessing cancer treatment.[6, 7] Significant differences were observed in the co-payments paid by Indigenous status, remoteness, and socioeconomic status. Specifically, for MBS services, Indigenous women incurred 82% lower co-payments during the first 6-months, and 79% lower co-payments during months 7-to-12 compared to non-Indigenous women. Socioeconomic disadvantage was a strong predictor for patient co-payments paid for MBS services across the three year study period. Compared to women living in the least socioeconomically disadvantaged quintile (Q5), co-payments were significantly lower in women living in the most socioeconomically disadvantaged quintile (Q1) for all but one 6-month time period during the first three-years post diagnosis. Co-payments were significantly lower among women living in Q2 in four of the six time periods analysed. Remoteness was not a significant predictor of patient co-payments incurred.

A similar trend was seen for patient co-payments incurred for PBS prescriptions. Compared with non-Indigenous women, Indigenous women diagnosed with breast cancer had significantly lower patient co-payments throughout the three-year study period. Socioeconomic disadvantage was associated with PBS co-payments incurred by individuals. Costs were significantly lower for women living in the two most disadvantaged quintiles (Q1 and Q2) compared to women living in the least disadvantaged quintile (Q5), for all but one of the six time periods analysed.

Implications for practice and policy

Direct costs and service delivery

In Chapter Three, differences were identified in the direct cost to the public healthcare system and the individual for adults diagnosed with cancer. These differences may be due to several factors, including differences in stage of disease at diagnosis; differences in accessing care, either due to barriers or personal choice; and differences in treatment, as reported in Australian studies.[8-21] Stage of disease is not routinely collected by the QCR, therefore it was not possible to adjust for stage of disease in the analyses. However, in Chapters Five to Seven, breast cancer stage was categorised by the author using information on breast tumour size, and evidence of lymph node involvement (categorised as early, advanced, or unknown). While the findings presented in Chapters Five to Seven relate specifically to breast cancer, the findings from these chapters support the findings from Chapter Three. The differences in the direct costs remain for women diagnosed with breast cancer even after adjusting for stage of disease at diagnosis.

Cancer staging is important, as this gives an indication of the extent or spread of the cancer. This information may be used to estimate chances of survival, and to determine the appropriate treatment options available. The most commonly used staging system is the Tumour, Node, Metastasis (TNM) staging system, which contains information on the size and extent of the main tumour, lymph nodes, and if the cancer has metastasized.[22, 23] The limited information on cancer stage at diagnosis is a recognised limitation of cancer data in Australia.[2, 24] Cancer Australia is currently working on projects to improve national data on the stage of disease at diagnosis for the five most commonly diagnosed cancers.[24] The AIHW Cancer in Australia 2019[25] report included a chapter regarding cancer stage at diagnosis for the five most commonly diagnosed cancers in Australia. The availability of staging information in the future will enable stage of disease to be considered in future analyses.

In this thesis, differences were found in the cost of admitted and non-admitted hospital episodes by remoteness, socioeconomic disadvantage and Indigenous status. Although no significant difference in the cost of admitted and non-admitted hospital episodes by Indigenous status in Chapter Three,

differences were found in Chapter Five. Indigenous women diagnosed with breast cancer had higher costs for hospital episodes, even after adjusting for stage of disease, and number of hospital episodes. The higher costs for hospital episodes found in the breast cancer case study could be due to differences in the type of treatment following diagnosis. Previous studies have identified that compared to non-Indigenous women, Indigenous women have higher rates of mastectomy and lower rates of breast conserving therapy.[8, 10, 26] The differences identified in the hospital costs between Indigenous and non-Indigenous women may partially be due to possible differences in treatment. The study presented in this thesis aimed to identify the hospital expenditure for women diagnosed with breast cancer, and to determine the distribution of costs by patient characteristics. Future studies could consider the costs for different clinical treatment pathways in more detail.

Improving cancer outcomes for Indigenous Australians remains a national concern. Providing "culturally safe services and a culturally competent workforce"[27(p 15)] have been identified as one of several recommendations in the National Aboriginal and Torres Strait Islander Cancer Framework to improve cancer outcomes for Indigenous Australians.[27] Cancer care involves a multi-disciplinary team which includes doctors, nurses, and allied health staff. All staff should receive ongoing cultural safety training to ensure care are provided with culturally appropriate care. A recent study of cancer services found that having Indigenous staff members and specific Indigenous staff roles were beneficial to engage with Indigenous people with cancer.[28] Culturally appropriate services and workforce must be a priority for all aspects of cancer and healthcare, and must commence at prevention and screening. Although prevention and screening were not the focus of this thesis, any changes in health policy must consider funding for prevention and not just treating the disease. Providing culturally appropriate services has been identified as a fundamental component to improve cancer outcomes for Indigenous Australians.[27]

In Chapter Three, higher costs were identified for hospital episodes for people living outside of metropolitan areas (4% higher for people living in regional areas, and 10% higher for people living in remote areas). In contrast, no consistent trends were observed by remoteness in the female breast cancer study. The differences identified in Chapter Three could be due to differences in accessing services by area of remoteness. Differences in clinical management by remoteness have been reported in Australia; however, the majority of evidence is for breast and prostate cancers.[13-19] A recent systematic review reported limited evidence regarding differences in clinical management by remoteness.[29] Physical access to oncology services reduces with increasing remoteness.[30] Thereby, some patients may need to travel or relocate to receive care.[31, 32] Eligible patients may be able to apply for assistance in their state if they are required to travel. Queensland Health offers the Patient Travel Subsidy Scheme (PTSS) to assist patients who are referred for specialist medical services not

offered at their local public facility.[33] Patients will still incur out-of-pocket costs, as the PTSS is not intended to cover all costs associated with travel or accommodation.[34] The costs associated with travel and accommodation are substantial for people diagnosed with cancer who live outside metropolitan or major regional centres,[4, 21, 35-39] and thus may be a barrier in accessing treatment.

One strategy to help overcome the geographical distance in Australia has been the introduction of tele-oncology. The tele-oncology model of care enables patients to receive chemotherapy at rural hospitals.[40, 41] However, this may not be appropriate for all patients or for all cancer types, as some patients will still be required to travel to receive care. The Townsville Cancer Centre has used this model of care since 2007 to provide medical oncology services in North Queensland.[40, 41] The model of care has been shown to safely deliver chemotherapy,[42] improve timely access to medical oncology services,[43] and has been found to be acceptable for patients and health workers.[44, 45] There has also been one study which evaluated the cost-savings of this model of care compared to the usual model of care in North Queensland (Townsville Cancer Centre and six rural sites). The study reported savings due to a reduction in travel costs to the healthcare system.[46] To date, this is the only study to evaluate the costs of tele-oncology in Australia. Future studies should evaluate the cost-savings of tele-oncology to the Australian healthcare system on a wider scale in Australia, as well as the potential cost-savings to the patient due to a reduction in travel and accommodation costs.

In regards to ED presentations, Chapter Three found higher costs for Indigenous Australians, however, there was no difference by remoteness or socioeconomic disadvantage. In contrast, the findings from Chapter Five (breast cancer study) showed that, after adjusting for Indigenous status, socioeconomic disadvantage, remoteness, age, stage, number of ED presentations, and death there was little difference in the costs for ED presentations for female breast cancer patients. A recent commissioned review found that disease-related factors, treatment-related factors (e.g., adverse drug reactions and complications), and patient related factors (e.g., demographics, comorbidities, and Indigenous status) increased ED presentations in New South Wales for cancer patients.[47] Adverse reactions following chemotherapy account for a large proportion of unplanned hospitalisations.[48-50] ED presentations are not only costly to the healthcare system,[51] but also a cause of distress for the patient and their family, therefore, any interventions to reduce potentially avoidable ED presentations would be beneficial to the patient and the healthcare system. Future studies should identify if there are a difference in the number of ED presentations in this cohort, and if these presentations are potentially avoidable. This information may be used to develop targeted interventions to educate and manage symptoms if possible for patients, their families, and their primary health care provider. For example McKenzie et al.[48] proposed the need for coordinated multi-disciplinary care between cancer center staff and primary care providers.

The differences observed in the rebates paid by Medicare for MBS services and PBS prescriptions (Chapter Six) may in part be linked to the patient co-payments incurred. The MBS contains a list of approved items, which Medicare will pay a rebate to the service provider. However, medical service providers may set their own fees, resulting in unregulated OOP fees for patients.[52] Some service providers may choose to charge the amount equal to the rebate, and thereby 'bulk-bill' the patient, resulting in no patient co-payment. The findings from Chapter Three may partially be described by differences in the number of MBS services accessed, or PBS prescriptions dispensed. The findings from Part 4 (Chapters Five to Seven, the female breast cancer case study) found that there was no trend in the differences rebates paid for MBS services by remoteness, Indigenous status, or socioeconomic disadvantage after adjusting for number of MBS services in each time period. However, there were differences identified in the rebates paid for PBS services by these characteristics despite adjusting for number of PBS prescriptions dispensed.

The OOP fees have been reported to be high for cancer patients. The financial toxicity associated with high OOP costs of cancer is a growing concern.[4, 35, 37, 53] The Medicare Safety Net and PBS Safety Net are two policies which are designed to protect individuals and/or family groups from high patient co-payments throughout the calendar year. Once an individual and/or family group reach the threshold for the safety net they are eligible to have their medical services or prescriptions subsidised at a higher rate for the remainder of the year.[54] In addition to this, Indigenous Australians are able to access eligible prescription pharmaceuticals at a lower cost, or free under the Closing the Gap (CTG) PBS prescription program.[55] The CTG Prescription programme excludes hospital prescriptions.[55] This is of particular importance for cancer treatment, where most of the oncology services are offered through the hospital as either an admitted patient or non-admitted patient. It is not uncommon for hospital prescriptions to be dispensed outside of the hospital (in other words, dispensed at a community pharmacy). There are many reasons, including, but not limited to the medication not being stocked at the hospital pharmacy, discharge medications, repeats or ongoing medication, and patient choice. Therefore, if these prescriptions are dispensed at a community pharmacy, the prescription is not eligible to be dispensed under the CTG programme. The Society of Hospital Pharmacists of Australia reported that hospital staff are facilitating access to medication by liaising with the GPs, which was administratively burdensome.[56] The exclusion of hospital prescriptions from the programme should be re-considered for Indigenous Australians receiving care, which is primarily in a hospital setting.

The findings from Chapter Three and Seven indicate that these policies are working, as even after adjusting for co-variates, co-payments were lower for people living in the most disadvantaged areas and Indigenous Australians compared to their comparison groups. In Chapter Three, MBS and PBS

patient co-payments were combined, whereas, patient co-payment for MBS and PBS were analysed separately in Chapter Seven. Chapter Three identified some differences in total patient co-payments by remoteness, but there was no significant difference by remoteness in the female breast cancer study for patient co-payments for MBS services or PBS prescriptions (Chapter Seven).

In Chapter Seven, large variation was observed in the mean patient co-payments paid by women with breast cancer for MBS services during each of the six-month periods. In contrast, there was little variation in the mean PBS co-payments paid. This may be because the patient pays *up to* the patient co-payment for PBS prescriptions, and although there may be variation in the amount paid if the item is under the patient co-payment, this is 'minimal' compared to the possible variation in MBS services.

As a result of the variation in fees charged for MBS services, it may be possible that some patients may choose to visit a medical provider who bulk-bills over a specialist with an unknown, but potentially greater OOP co-payment. A recent study using CancerCostMod found that Indigenous Australians had a greater ratio of MBS services for non-referred attendances for enhanced primary care, other, and practice nurse items; but had less than half the number of specialist attendances.[57] The proportion of bulk-billed GP services has increased, and was 86% in 2016-17.[58] Medicare have incentive payments for bulk-billing on eligible un-referred services.[59] It is possible that there are differences in the type of MBS services accessed due to cost.

There is a growing call for medical professionals to discuss the potential patient OOP costs with the patient.[60-62] This may allow potential costs to be considered when choosing the best treatment pathway. The high OOP costs in Australia have received attention in recent years, and in 2018 and 2019, a number of published reports have made recommendations for addressing these high OOP costs. A common theme in these reports was increased fee transparency, by having published fees on websites.[60-62] The Consumers Health Forum of Australia and the University of Melbourne also recommend improving informed financial consent for consumers.[62] The report identified the responsibility of improving informed financial consent falls on all health professionals.[62] Although the report identified that GPs may be the gatekeeper for referrals to specialists, there were many challenges to GPs providing accurate information on fees for specialists or other health practitioners.[62] Therefore, all health professionals should be responsible for openly discussing out-of-pocket fees with individuals.

In addition to these recommendations, all patients and their families should be offered individualised support to help navigate possible schemes and policies available to them. Although there is information about the Safety Nets, and PTSS available online or on request, this may be confusing, or difficult to access for patients, especially during a stressful time following a cancer diagnosis. For

example, information on the PBS Safety Net is available online, or through the pharmacy on request. However, if patients (and their family) use different pharmacies, they must keep track of their expenditure on a Prescription Record Form (available on request from the pharmacy). As a pharmacist, I would discuss the safety net with patients where possible and recommend that individuals and families keep a Prescription Record Form throughout the year. As discussed previously, eligible patients may apply for travel assistance; however, patients must apply for this before travelling. Therefore, medical professionals should be aware of and discuss the state's relevant travel assistance scheme when referring patients to hospitals for specialist services.

Labour force participation and indirect costs

Workforce participation changes are not uncommon following a cancer diagnosis.[63-66] A systematic review reported that an average of 62% of cancer survivors returned to work at 12-months, and an average of 89% of individuals returned to work within 24 months post- diagnosis.[63] In Australia, full-time employees are entitled to 10 days of paid sick leave, and up to three months of unpaid leave.[67] However, in some cases, people may need to take more time off, which must be negotiated with their employers. Although there was no evidence from Chapter Four in this thesis that labour force participation was associated with remoteness for people with cancer, people living in areas of increasing remoteness may have additional difficulties in balancing work, as they may be required to travel, or relocate to access cancer treatment.[31, 32] In a recent Queensland qualitative study, 45 patients diagnosed with haematological cancers were interviewed. The study identified that farmers and rural property owners reported additional responsibilities of maintaining their property during their treatment.[32]

Changes in workforce participation following a cancer diagnosis can also contribute to financial hardship for an individual and their family.[64, 68-71] This is also a concern for carers, who may be required to take extended leave to assist their loved one. Changes in workforce participation, which may result in a reduction of household income may contribute to increased financial hardship.[7, 72] The financial hardship is a concern, as the OOP cost of cancer is known to be high,[4, 35, 37, 53] and is a potential barrier in accessing care.[6, 64, 73] These changes in workforce, and the resulting changes in income should be considered by health professionals when discussing the potential OOP costs with individuals. For many survivors, returning to work is an important milestone.[68, 69] Survivors wishing to return to work should discuss this with their health professional team and their employers. Some individuals may require additional assistance to enable their return to work.

Strengths and limitations

This thesis used two main datasets: 1) CancerCostMod, a model based on linked administrative data, and 2) the 2015 Survey of Disability, Ageing, and Carers (SDAC). The strengths and limitations of the use of these two datasets in this thesis will be described separately.

CancerCostMod

CancerCostMod was developed using individual-level administrative data from multiple sources. There are many strengths in using a dataset such as the one developed for the thesis. The base population for CancerCostMod was a census of all individuals diagnosed with cancer in Queensland between 1 July 2011 to 30 June 2012. In Australia, cancer is a notifiable disease, and all diagnoses (excluding non-melanoma skin cancer) are reported to the jurisdiction's cancer registry. A census from the Queensland Cancer Registry ensured that all cancer diagnoses in Queensland were included in the base population, and minimised potential selection bias. Using weighted data, this thesis was able to estimate the costs for the Australian population. The use of individual level administrative data ensures that the dataset was not subject to measurement bias (including but not limited to memory, self-report, interviewer, etc.), and allows analysis to be conducted at an individual level.

Both the 2015 National Aboriginal and Torres Strait Islander Cancer Framework[27] and the current Cancer Australia's Strategic Plan call for action to ensure equitable health service delivery of cancer services for all Australians.[74] The individual level analysis enabled the distribution of costs by patient characteristics to be analysed. Therefore, the findings from this thesis may be of interest to policy makers to strengthen cancer related services for all Australians. The use of linked administrative data allowed data from several sources (QCR, Queensland Health Admitted Patient Data Collection, Queensland Health Emergency Department Information System, MBS, and PBS) to be consolidated into a single dataset. As such, the data used in this thesis met recommendations from the Productivity Commission and the AIHW.[58, 75]

However, there are inherent limitations of using administrative data. For example, the QCR does not collect information on the stage of disease at diagnosis, individual or household income, or other comorbidities. The individual's postcode at diagnosis was used to map to the Australian Bureau of Statistics' Index of Relative Socio-Economic Disadvantage (IRSD). This is a measure of the economic and social conditions of an area.[76] IRSD is an aggregated area-level measure of socioeconomic disadvantage, and therefore may not accurately represent all individuals living in the area.

The original QCR dataset recorded Indigenous status for 87% of the individuals. Indigenous status was an important part of the analysis for the thesis, thus, several steps were undertaken to assign

Indigenous status to those with missing records. These have been discussed in Chapter Three. The first step assigned Indigenous status if individuals resided in a Local Government Area that had greater than or equal to 75% of the population identified as Indigenous. The ABS define a Discrete Indigenous Community as a community in which half of the individuals identify as Indigenous Australian.[77] The 75% used in developing CancerCostMod was chosen as a conservative cut-off. For those remaining records, multiple imputation was used to assign Indigenous status. The multiple imputation methods used in CancerCostMod were similar to those used in a previous New South Wales cancer study.[78] There are potential limitations to this approach: firstly, it was assumed that Indigenous status was correctly recorded in the original QCR dataset; secondly, the steps taken to assign Indigenous status for those with missing records may have incorrectly assigned Indigenous status.

The base population was weighted to be representative of the Australian population, however, this has some inherent limitations. The Queensland cancer cohort was benchmarked to the Australian cancer incidence by cancer type, age, and sex. It was not possible to weight for additional characteristics (Indigenous status, remoteness and socioeconomic status), as such, there may be inherent variations which could not be captured in the CancerCostMod dataset. This means that if Queensland is different to other states in regards to Indigeneity, remoteness, and socioeconomic status, then it is not possible to be perfectly representative to the Australian population, as the base population is still Queensland.Cancer stage at diagnosis is not routinely collected by QCR. Therefore, cancer stage was not adjusted in the analysis in Chapter Three. For Part 3, the female breast cancer case study, the stage was categorised into early, advanced, or unknown stage. The methods used in categorising these stages were identified from previous Queensland studies[79, 80] and have been described in each of the studies in Part 3 (Chapters Five to Seven).

Non-admitted hospital services were not captured in QHAPDC, however, in Australia, some oncology patients may receive treatment as a day patient, or as a non-admitted patient. As described in Chapter Three, the MBS dataset was used to capture these out-patient hospital services. The PBS dataset did not include items dispensed to public patients in public hospitals, or medications dispensed under alternative funding schemes, thus the cost of PBS items to the public healthcare system would be an underestimation of the true costs. In regards to patient OOP costs, the MBS and PBS datasets did not capture private medical services, over-the counter medications, or private prescription pharmaceuticals, and thus these OOP costs were unable to be estimated. Furthermore, other OOP costs incurred by patients and their families which were not captured in the administrative data included private health insurance, accommodation, travel, childcare, lost wages, etc. OOP costs

incurred for travel and accommodation are known to be high for cancer patients and their families.[4, 21, 35-39]

2015 SDAC

There were many strengths in using the 2015 SDAC to address the indirect cost of cancer due to lost productivity from morbidity. The 2015 survey was the eighth (and most recent) SDAC conducted by the Australian Bureau of Statistics (ABS).[81] This survey was chosen for the thesis because it provided a national cross-section of labour force participation for people with long-term health conditions, including cancer. The ABS weights the survey, which allows the results to be generalised to the Australian population.[81] This study was also the first in Australia to quantify the cost of lost productivity due to cancer for adults of working age.

However, the use of an existing survey does have several limitations. These include that the SDAC was a cross-section only, therefore selection bias is unavoidable. The SDAC did not include information on the time since diagnosis. Due to a small sample size (of people with cancer), it was not possible to provide analysis by the main type of cancer.[82] The SDAC categorised remoteness as 'Major cities Australia', 'inner regional Australia', and 'other areas' using the Accessibility and Remoteness Index of Australia (ARIA).[81] In the thesis, due to sample size, 'inner regional Australia' and 'other areas' were collapsed into one category. Therefore, this study was only able to identify if there was any difference in labour force participation between people living in major cities and those living in other areas.

In addition to these limitations, there were additional limitations in using the 2015 SDAC in identifying any differences in labour force participation or indirect costs by the characteristics of interest in this thesis. Specifically, it was not possible for this study to identify differences in the distribution of labour force participation by Indigenous status or socioeconomic disadvantage. To the author's best knowledge, no study has identified if there are differences in employment following a cancer diagnosis for Indigenous Australians. The findings from Chapter Four show that of those with cancer, people without a tertiary qualification were significantly more likely to be out of the labour force. The proportion of Indigenous Australians attending tertiary education are lower than that of non-Indigenous Australians.[83] Therefore, Indigenous Australians diagnosed with cancer who do not have a tertiary qualification may also be more likely to be out of the workforce.

Directions for future research

The cost of cancer is increasing, and will continue to increase.[84-86] In order to allocate finite resources equitably, it is essential that these costs are monitored. This thesis quantified the cost of cancer in

Australia, and described the costs by characteristics known to result in poorer outcomes (Indigenous status, remoteness, socioeconomic disadvantage). The development of CancerCostMod, a model based on linked administrative data which uses individual-level data, confers many possibilities for future research.

Future research should build upon the initial results from the first study in this thesis (Chapter Three), which quantified the cost of cancer during the first 12-months post-diagnosis, and found that there are differences in costs to the public healthcare system and the individual by remoteness, Indigenous status, and socioeconomic disadvantage. The use of individual level data may be used to model the costs for different treatment pathways. This could be used to identify areas which may benefit from additional funding. The use of administrative data may also allow determine if there are any differences in the clinical treatment pathways by patient characteristics, and to quantify the costs associated with these differences. Previous literature in Australia has identified that there are differences in uptake of treatment options,[8-21] but administrative data could be used to monitor these differences.

Female breast cancer was chosen as the case study in this thesis, as it is the most commonly diagnosed cancer. Future research using CancerCostMod will consider other cancer sites. Increasing the cohort population past July 2012, would increase the sample size, thus allowing the costs to be examined for less common cancer types. This will also allow analysis of cancer types, which have known inequalities for population groups, such as lung cancer, or cervical cancer. This may help allocation of resources, or funding to particular types of cancer for prevention, treatment, or research for treatment.

Another direction for future research would be to increase the cohort of CancerCostMod by including diagnoses past June 2012, and by increasing the follow-up period. If CancerCostMod is expanded, it may be possible to include the costs of cancer in Australia for the maintenance phase, and terminal phase (last 12-months of life). A number of international studies have used linked administrative data to identify the cost of cancer by phase (initial, maintenance, and terminal).[87-92] These studies have identified that the initial and terminal phases have higher costs.[87-91] However, no study has evaluated the distribution of these costs by characteristics known to result in poorer outcomes such as those examined in this thesis (Indigenous status, remoteness, socioeconomic disadvantage). The inclusion of these phases by these characteristics may highlight distinct phases which have greater disparity between costs, and thus benefit from a more in-depth examination.

In addition to this, future studies should focus on the distribution of other areas of OOP costs to the individual and their family, such as travel, accommodation, parking, and private medical expenses. In

order to obtain OOP costs not captured in this thesis, direct patient data collection will be required. Administrative data can be used in combination with patient surveys to confirm the costs to the patient. No identifiable patient information was provided to the authors, therefore, the dataset used in this thesis will not be able to identify other areas of OOP costs.

Conclusion

This thesis represents a novel body of work which determined the distribution of cost of cancer in Australia to both the public healthcare system and individual by Indigenous status, remoteness, and socioeconomic disadvantage. During the first 12 months following diagnosis, this was an estimated $4.8 billion to the public healthcare system, and an additional $127.7 million to the individual. The findings confirm that there are differences in costs to the public healthcare system and the individual by these characteristics. The lower patient co-payments paid by Indigenous Australians and those living outside of the least disadvantaged areas indicates that the policies protecting individuals from high co-payments appear to be working.

These results are of particular importance for policy makers to ensure equitable allocation of healthcare resources throughout Australia. Future studies should identify if there are any differences in service use and access for these population groups which are driving these differences in costs. Linked administrative data has many advantages, primarily that selection and measurement bias are limited. Importantly for this thesis, the use of linked individual-level data enabled the analysis of the costs by characteristics of interest (Indigenous status, remoteness, and socioeconomic disadvantage). Health service research and cost-of-illness studies are of particular importance and may contribute to reducing the survival inequalities identified for Indigenous Australians, people living in remote and very remote areas, and socioeconomically disadvantaged persons. Continuous monitoring and evaluation of these survival inequalities are required to ensure that all Australians have equitable access to cancer care across the continuum to improve survival for all Australians.

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