INDIGENOUS WOMEN AND CERVICAL SCREENING IN QUEENSLAND

The first comprehensive study on Indigenous Australian women’s inequalities in cervical screening; a Queensland record-linkage study

by

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A thesis submitted for the degree of

Doctor of Philosophy

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DECLARATION

I hereby declare that the work herein, now submitted as a thesis for the degree of Doctor of Philosophy of the Charles Darwin University, is the result of my own investigations, and all references to ideas and work of other researchers have been specifically acknowledged. I hereby certify that the work embodied in this thesis has not already been accepted in substance for any degree, and is not being currently submitted in candidature for any other degree.

I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying, and online via the University’s Open Access repository eSpace.

Lisa J Whop (7th March 2016)
STATEMENT OF CONTRIBUTION AND FINANCIAL ASSISTANCE

Contribution

This PhD was part of the National Indigenous Cervical Screening Project (NICSP) led by Professor John Condon (principal investigator) from the Menzies School of Health Research. I began my candidature in March 2012 and also served as the national project manager from January 2013 to May 2014. I was involved in the conception and study design, ethics applications, data acquisition (including data custodian approvals and record-linkage group approvals), database design and analysis plan of the NICSP. Due to significant delays in obtaining data, only Queensland data were used for the thesis. All work, except for the ethics approval from Queensland Health, which was obtained in November 2011, was performed entirely during my candidature, March 2012 to March 2016.

The thesis is presented in the format of a series of journal manuscripts, which have been published or accepted for publication in scientific journals. I performed all analyses for the research entailed in this thesis and wrote all the manuscripts, with assistance from co-authors. My PhD supervisors (Professor John Condon, Associate Professor Gail Garvey, Professor Peter Baade and Dr Kamalini Lokuge), the NICSP’s chief and associate investigators (Professor Joan Cunningham, Dr Julia Brotherton, Professor Karen Canfell, Associate Professor Patricia Valery, Professor Dianne O’Connell, Professor David Roder, Professor Dorota Gertig and my PhD supervisors) and others provided their respective expertise and guidance on several parts of the project. The contributions of all involved have been detailed at the start of each chapter. Dr Katharine Evans professionally proofread and copyedited the thesis in accordance with parts D and E of the Australian Standards for Editing Practice and the Charles Darwin University guidelines for the presentation of a thesis.
Funding

The NICSP received project funding from the National Health and Medical Research Council (NHMRC; project grant #104559) commencing in 2013. The NICSP is also part of an NHMRC Centre of Research Excellence (CRE) in Discovering Indigenous Strategies to improve Cancer Outcomes via Engagement, Research Translation and Training (DISCOVER-TT CRE; CRE #1041111) and Cancer Council New South Wales Strategic Research Partnership to Improve Cancer Control for Indigenous Australians (STREP CaClIndA; #SRP13-01). In 2012, I received a Sidney Myer Health Scholarship to fund my position as a PhD candidate in the NICSP. I also received additional funding throughout my candidature from the Menzies Enhanced Living Top-up Scholarship and a student scholarship funded by the Lowitja Institute, Australia’s National Institute for Aboriginal and Torres Strait Islander Health Research.
ABSTRACT

Since the introduction of the Australian National Cervical Screening Program (NCSP) in 1991, cervical cancer incidence and mortality in Australia have decreased by over 50%. However, incidence and mortality for Indigenous women are two and four times higher respectively than for non-Indigenous women. The NCSP is unable to report on program performance indicators for Indigenous women because Indigenous status is not routinely collected by Pap Smear Registers (PSRs).

This thesis linked data from the Queensland PSR with hospital inpatient and cancer registry data to investigate cervical screening participation, prevalence of cervical abnormalities and time to clinical investigation following a high-grade abnormality for Indigenous compared with non-Indigenous women.

The main findings were:

1. Linking PSR to inpatient data was a feasible means to achieve reliable (but not perfect) identification of Indigenous women in cervical screening data.

2. Screening participation was considerably lower for Indigenous than non-Indigenous women in all categories of age-group, remoteness and socioeconomic disadvantage and has not improved over time. There was a large decline in participation among young Indigenous women.

3. Among screened women, Indigenous women had markedly higher prevalence of both cytology- and histology-confirmed cervical abnormalities than non-Indigenous women. The prevalence of cytology-detected high-grade abnormalities appeared to be increasing over time among Indigenous women only.
4. Indigenous women with a cytology-detected high-grade abnormality were less likely to receive clinical investigation within the recommended time frame of two months, but did eventually receive follow-up.

This thesis reports the first population-based findings for Indigenous women in Queensland, highlighting the importance of including Indigenous status in administrative datasets. These findings are timely given the announcement of the Renewed NCSP to be introduced in 2017. These results can inform policy and practice in the prevention of cervical cancer amongst Indigenous women.
ACKNOWLEDGEMENTS


I am Lisa Whop a descendent of the Wagedagam tribe of the Gumulgal people of Mabuiag Island in the Torres Strait.

Thanamun kunakan ia wakai waian a apasin mura Aboriginal a Torres Strait Islander au ipikazil a thanamun buail, koi mabaigal thanamun gogait nu. Ngalpunika kunakan aa kukatal danalaig poiban.

I would like to pay my respects to my elders past and present for their resilience and strength, and pay my respects to all Aboriginal and Torres Strait Islander women, their families, elders and communities; may we live long, healthy, strong and empowered lives.

There are so many people to thank who have helped to make this PhD project possible and I am grateful to each and every one of you. First, thank you to my supervisors, who together provided much support and advice to me over the last few years.

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To my friends and family who encouraged me along the way and forgave me for all the neglect they have endured, thank you. Special thanks to:

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- My niece and nephew, Lilly and William, for their unconditional support and for understanding my absence when they did not need to.
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My deepest thanks to my incredible parents, John Whop and Meg Davis, whose passion for education and social equity (and their understanding as academics) are awe inspiring:

- Big Eso to my Dad for his willingness to share his sacred knowledge with me, his unwavering support and excitement in my life, but most of all for his ability to remind me that the guidance, connection and spirit of my ancestors lives within me—this provided so much strength to me in times of doubt and uncertainty.
- My heartfelt thanks to my Mum, who is undoubtedly the most dedicated, true, free-spirited advocate for human equity. Her work ethic, fight for equality and passion for making sure that those who are silenced in the community have a voice and are heard, has and will inspire me forever. Thank you for your warmth, understanding,
encouragement and expectation, but most of all for providing so many opportunities in my life. You are the reason this has been possible.

And finally, to my dear Nanny, Eileen Davis, who was an incredible woman. She would have been so relieved to see me finish and, more than anyone, would have rightly understood that this is just as much my mother’s achievement as mine.

For you Nanny, I dedicate this thesis.
**PUBLICATIONS**

**Chapter 2: Whop LJ, Cunningham J, Condon JR.** How well is the National Cervical Screening Program performing for Indigenous Australian women? Why we don't really know, and what we can and should do about it. *Eur J Cancer Care* 2014; 23(6): 716–20.


# TABLE OF CONTENTS

DECLARATION ........................................................................................................................... 3

STATEMENT OF CONTRIBUTION AND FINANCIAL ASSISTANCE ......................... 5

ABSTRACT ................................................................................................................................. 7

ACKNOWLEDGEMENTS ........................................................................................................... 9

PUBLICATIONS ....................................................................................................................... 13

TABLE OF CONTENTS ............................................................................................................ 15

FIGURES AND TABLES .......................................................................................................... 19

ABBREVIATIONS .................................................................................................................... 23

1 INTRODUCTION ................................................................................................................ 27

1.1 BACKGROUND .............................................................................................................. 29

1.1.1 Australian Indigenous population .......................................................................... 31

1.1.2 Queensland Indigenous population ...................................................................... 33

1.1.3 Cancer among Indigenous Australians ................................................................... 34

1.1.4 Availability of cancer related data for Indigenous Australians ............................. 37

1.1.5 Summary .................................................................................................................. 39

1.2 CANCER OF THE CERVIX ......................................................................................... 39

1.2.1 Anatomy and physiology of the cervix ................................................................. 40

1.2.2 Epidemiologic risk factors for developing cervical cancer ................................. 41

1.2.3 HPV and cervical abnormalities .......................................................................... 43

1.3 CERVICAL CANCER PREVENTION ....................................................................... 44

1.3.1 Cervical screening ............................................................................................... 44

1.3.2 HPV vaccines ....................................................................................................... 46

1.3.3 Epidemiology of cervical cancer worldwide ...................................................... 47
1.3.4 Summary of cervical cancer and screening among Indigenous populations in New Zealand, Canada and the United States ................................................................. 48

1.4 CERVICAL SCREENING IN AUSTRALIA .............................................................................. 49
1.4.1 Management guidelines of the NCSP ........................................................................ 51
1.4.2 Performance measures of the NCSP ......................................................................... 53
1.4.3 Cervical screening in Queensland ........................................................................... 54
1.4.4 Evidence for the effectiveness of the Australian program ..................................... 55
1.4.5 Evidence for the effectiveness in Queensland ......................................................... 59

1.5 CERVICAL CANCER AND CERVICAL SCREENING AMONG INDIGENOUS AUSTRALIAN WOMEN 61
1.5.1 Epidemiology of cervical cancer among Indigenous Australian women ........... 61
1.5.2 Cervical cancer risk factors among Indigenous Australians .............................. 65
1.5.3 Cervical screening among Indigenous Australian women ................................. 68

1.6 THESIS AIMS AND OUTLINE .............................................................................................. 71
1.7 REFERENCES .......................................................................................................................... 74

2 HOW WELL IS THE NATIONAL CERVICAL SCREENING PROGRAM PERFORMING FOR INDIGENOUS AUSTRALIAN WOMEN? WHY WE DON’T REALLY KNOW, AND WHAT WE CAN AND SHOULD DO ABOUT IT .................. 91

2.1 PREFACE ................................................................................................................................. 93
2.2 STATEMENT OF AUTHORSHIP ......................................................................................... 93
2.3 AUTHOR CONTRIBUTIONS ............................................................................................... 93
2.4 PUBLISHED ARTICLE ......................................................................................................... 93

3 USING PROBABILISTIC RECORD-LINKAGE METHODS TO IDENTIFY AUSTRALIAN INDIGENOUS WOMEN ON THE QUEENSLAND PAP SMEAR REGISTER: THE NATIONAL INDIGENOUS CERVICAL SCREENING PROJECT .... 99

3.1 PREFACE ............................................................................................................................... 101
3.2 STATEMENT OF AUTHORSHIP ......................................................................................... 101
3.3 AUTHOR CONTRIBUTIONS ............................................................................................... 101
THE FIRST COMPREHENSIVE REPORT ON INDIGENOUS AUSTRALIAN WOMEN’S INEQUALITIES IN CERVICAL SCREENING: A RETROSPECTIVE
REGISTRY COHORT STUDY IN QUEENSLAND, AUSTRALIA, 2000–2011

CERVICAL ABNORMALITIES ARE MORE COMMON AMONG INDIGENOUS THAN OTHER AUSTRALIAN WOMEN: A RETROSPECTIVE
RECORD-LINKAGE STUDY, 2000–2011

TIME TO CLINICAL INVESTIGATION AFTER A HIGH-GRADE ABNORMAL PAP SMEAR BETWEEN INDIGENOUS WOMEN AND NON-INDIGENOUS WOMEN IN QUEENSLAND, 2000–2009

DISCUSSION, RECOMMENDATIONS AND CONCLUDING REMARKS
7.5 CERVICAL ABNORMALITIES ....................................................................................... 174
7.6 TIME TO CLINICAL INVESTIGATION ............................................................................ 176
7.7 CHANGES TO CERVICAL SCREENING IN AUSTRALIA .................................................. 176
   7.7.1 The National HPV Vaccination Program ............................................................. 177
   7.7.2 The renewed NCSP .............................................................................................. 177
   7.7.3 The renewed NCSP and Indigenous women ........................................................ 178
7.8 CONCLUDING REMARKS ............................................................................................ 180
7.9 REFERENCES .............................................................................................................. 181

8 APPENDIX: KNOWLEDGE DISSEMINATION .................................................................... 183
FIGURES AND TABLES

Figure 1.1 Distribution of Indigenous Australian population, 2011 (sourced from the Australian Institute of Health and Welfare [AIHW] 2011 census data) ........................................ 32

Figure 1.2 Age structure of Queensland population, by Indigenous status, 2011 (sourced from the Australian Bureau of Statistics [ABS] 2011 census)22 ............................................................ 33

Figure 1.3 Indigenous peoples by remoteness area, Queensland, 201122 .......................................... 34

Figure 1.4 Incidence of selected cancers where the Indigenous incidence is higher than non-Indigenous cancers by Indigenous status, New South Wales, Queensland, Western Australia and the Northern Territory, 2005-2009. .......................................................................................... 36

Figure 1.5 Uterus and cervix of a woman of reproductive age, reprinted from the WHO’s Comprehensive cervical cancer control: a guide to essential practice, second edition47 ...... 40

Figure 1.6 A schematic diagram of the transformation zone, reproduced with permission from Colposcopy and Treatment of Cervical Intraepithelial Neoplasia: A Beginners’ Manual (Chapter 1)48 ............................................................................................................................................... 41

Figure 1.7 Worldwide incidence of cervical cancer by age group in less and more developed countries94 ........................................................................................................................................... 48

Figure 1.8 Age-standardised cervical cancer incidence and mortality rates by year, Australia115 .................................................................................................................................................. 56

Figure 1.9 Participation of women aged 20–69 in cervical screening, 1996–1997 to 2012–20133 ............................................................ ........................................................................................................................................... 58

Figure 1.10 Age-standardised two-year cervical screening participation in Queensland and Australia (women aged 20–69 years), 1996–1997 to 2012-2013 ................................................................. 60

Figure 1.11 Age-standardised cervical cancer incidence among Indigenous women aged 20–69 for New South Wales, Western Australia, Queensland and the Northern Territory, by Indigenous status (2005–2009)109 ................................................................................................................................................ 62
Figure 1.12 Age-standardised cervical cancer mortality in women aged 20–69 for New South Wales, Western Australia, Queensland, South Australia and the Northern Territory, by Indigenous status (2007–2011) 109

Figure 3.1 Queensland record linkage process, QLD, Queensland; QRLG, Queensland Record Linkage Group 106

Figure 3.2 Proportion of women at first Pap smear during 2007-2011 who were identified as Indigenous using different algorithms by age-group 108

Figure 3.3 Proportion of women at first Pap smear during 2007-2011 who were identified as Indigenous using different algorithms by remoteness 109

Figure 3.8 Supplementary File 1. Outcomes of potential pairs identified through probabilistic linkage 113

Figure 4.1 Two-year participation rates of women aged 20 to 69 years for cervical screening by Indigenous status, 2000-2001 to 2010-2011, in Queensland, Australia 123

Figure 4.2 Age-specific 2-year participation rates by Indigenous status, 2000-2001 to 2010-2011, in Queensland, Australia 123

Figure 4.3 Age-standardised proportions of screened women aged 20 to 69 years by remoteness category and Indigenous status, 2010-2011, in Queensland, Australia 125

Figure 5.1 Prevalence of histologically confirmed high-grade abnormalities per 1000 women screened, by age-group and Indigenous status, 2000–2011 141

Figure 6.1 Cumulative percentage of women having clinical investigation after a HGA Pap smear, Queensland residents aged 20-68 in 2000-2009 157

Figure 6.2 Incidence rate ratios of Indigenous women compared with non-Indigenous women investigated after a high-grade abnormal Pap smear in the first two-month period, Queensland residents aged 20-68 in 2000-2009 160
Table 1.1 NCSP performance indicators ........................................................................................................ 53

Table 3.1 Indigenous status algorithms derives from applying Queensland Health Admitted Patient Data Collection’s Indigenous status to the Queensland Pap Smear Register, 1999-2011 ........................................................................................................................................ 108

Table 4.1 Demographic characteristics of women at first recorded Pap smear in the Queensland Pap Smear Register and corresponding proportions of women in the estimated resident population, 2000–2011 .................................................................................................................. 122

Table 4.2 Age-standardised participation rates of women aged 20-69 years over time, by Indigenous status, 2000-2001 to 2010-2011, Queensland .................................................................................................................. 122

Table 4.3 Two-year participation in cervical screening by place of residence and Indigenous status, 2000-2001 to 2010-2011 .................................................................................................................. 124

Table 4.4 Two-year participation in cervical screening by area-level disadvantage and Indigenous status, 2000-2001 to 2010-2011 .................................................................................................................. 124

Table 4.5 Comparison of methods to calculate five-year participation in cervical screening, by Indigenous status, 2007-2011 .................................................................................................................. 125

Table 4.6 Multivariable analysis of two-year participation, Queensland 2000-2001 to 2010-2011 .................................................................................................................. 126

Table 5.1 Characteristics of Indigenous and non-Indigenous women at their first recorded Pap smear .................................................................................................................. 136

Table 5.2 Demographic characteristics of Indigenous and non-Indigenous women’s Pap smears by abnormality, 2000–2011 .................................................................................................................. 137

Table 5.3 Association of Indigenous status, calendar period, place of residence, area-level disadvantage and age with risk of cytology detected low-grade abnormalities and cytological and histological high-grade abnormalities including cervical cancer .................................................................................................................. 138

Table 5.4 Time trends in prevalence of cytology low-grade and histologically confirmed high-grade abnormalities by age-group, 2000-2011 .................................................................................................................. 140
Table 6.1 Demographic characteristics of women at their first high grade abnormal Pap smear, Queensland residents aged 20-68 in 2000 – 2009………………………………….150

Table 6.2 Interval-specific rate\(^1\) (per person month) of eligible\(^2\) women investigated after a high-grade abnormal Pap smear in two-month periods after the index smear, Queensland residents aged 20-68 in 2000-2009…………………………………………………………..152

Table 6.3 Clinical investigation of a high-grade abnormality by time since Pap smear for Indigenous women compared with non-Indigenous women, aged 20-68 years, 2000-2009………………………………………………………………………………….……..133
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>AATSIHS</td>
<td>Aboriginal and Torres Strait Islander Health Survey</td>
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<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<tr>
<td>ACD</td>
<td>Australian Cancer Database</td>
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<tr>
<td>ACIR</td>
<td>Australian Childhood Immunisation Record</td>
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<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>ARIA+</td>
<td>Accessibility/Remoteness Index of Australia</td>
</tr>
<tr>
<td>cHGA</td>
<td>Cytology-detected high-grade abnormality</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence interval</td>
</tr>
<tr>
<td>CIN</td>
<td>Cervical intraepithelial neoplasia</td>
</tr>
<tr>
<td>cLGA</td>
<td>Cytology-detected low-grade abnormality</td>
</tr>
<tr>
<td>CRE</td>
<td>Centre for Research Excellence</td>
</tr>
<tr>
<td>DISCOVER-TT</td>
<td>Discovering Indigenous Strategies to improve Cancer Outcomes via Engagement, Research Translation and Training</td>
</tr>
<tr>
<td>DNA</td>
<td>Deoxyribonucleic acid</td>
</tr>
<tr>
<td>ERP</td>
<td>Estimated resident population</td>
</tr>
<tr>
<td>HGA</td>
<td>High-grade abnormality</td>
</tr>
<tr>
<td>hHGA</td>
<td>Histologically-confirmed high-grade abnormality</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<tr>
<td>HPV</td>
<td>Human papillomavirus</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<td>-------------</td>
<td>------------------------------------------------------------------</td>
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<tr>
<td>HR</td>
<td>Hazard ratio</td>
</tr>
<tr>
<td>HREC</td>
<td>Human research ethics committee</td>
</tr>
<tr>
<td>HSDA</td>
<td>Health service delivery area</td>
</tr>
<tr>
<td>IARC</td>
<td>International Agency for Research on Cancer</td>
</tr>
<tr>
<td>IQR</td>
<td>Interquartile range</td>
</tr>
<tr>
<td>IRR</td>
<td>Incidence rate ratio</td>
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<tr>
<td>IRSAD</td>
<td>Index of Relative Socioeconomic Advantage and Disadvantage</td>
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<tr>
<td>LEEP</td>
<td>Loop electro-excisional procedure</td>
</tr>
<tr>
<td>LGA</td>
<td>Low-grade abnormality</td>
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<tr>
<td>MSAC</td>
<td>Medical Services Advisory Committee</td>
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<tr>
<td>NCSP</td>
<td>National Cervical Screening Program</td>
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<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<td>NICSP</td>
<td>National Indigenous Cervical Screening Project</td>
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<td>NMD</td>
<td>National Mortality Database</td>
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<td>NT</td>
<td>Northern Territory</td>
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<tr>
<td>OR</td>
<td>Odds ratio</td>
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<tr>
<td>PSR</td>
<td>Pap Smear Register</td>
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<td>PTR</td>
<td>Pap Test Register</td>
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<tr>
<td>QCR</td>
<td>Queensland Cancer Registry</td>
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<tr>
<td>QCSP</td>
<td>Queensland Cervical Screening Program</td>
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<td>QHAPDC</td>
<td>Queensland Hospital Admitted Patient Data Collection</td>
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<td>Acronym</td>
<td>Description</td>
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<tr>
<td>QPSR</td>
<td>Queensland Pap Smear Register</td>
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<td>QRLG</td>
<td>Queensland Record Linkage Group</td>
</tr>
<tr>
<td>SCJ</td>
<td>Squamocolumnar junction</td>
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<tr>
<td>SEIFA</td>
<td>Socioeconomic indexes for areas</td>
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<tr>
<td>SLA</td>
<td>Statistical local area</td>
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<tr>
<td>STREP Ca-CIndA</td>
<td>Strategic Research Partnership to improve Cancer Control for Indigenous Australians</td>
</tr>
<tr>
<td>UPS</td>
<td>Unknown primary site</td>
</tr>
<tr>
<td>VCS</td>
<td>Victorian Cytology Service</td>
</tr>
<tr>
<td>WHINURS</td>
<td>Women’s HPV Indigenous Non-Indigenous Urban Rural Study</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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1 INTRODUCTION
1.1 Background

Cervical cancer is the fourth most common cancer affecting women around the globe, with the highest burden falling on the poorest and most socially disadvantaged women. In high-income countries with organised routine cervical screening programs, cervical cancer incidence and mortality have decreased considerably over the past 40 years, but not as much for socially disadvantaged women compared with other women.

Cervical cancer incidence and mortality in Australia is amongst the lowest in the world. This is largely attributed to the introduction of the Australian National Cervical Screening Program (NCSP) in 1991. Since then, there has been a 50% reduction in cervical cancer incidence and mortality in Australian women. The NCSP is responsible for Pap Smear Register (PSRs) in each of the six states and two territories in Australia. A core function of the PSRs is to provide a recall and reminder function to women and their health care providers and to collect information regarding the participation and screening results of women in order to assess the program’s ongoing effectiveness.

Unfortunately, not all Australian women have benefitted equally from these improvements. Aboriginal and Torres Strait Islander women (referred to hereafter respectfully as Indigenous Australian women) have incidence and mortality rates two and four times higher respectively than non-Indigenous Australian women. Long standing data deficiencies in the collection of Indigenous status by PSRs have resulted in little understanding about how effective the NCSP is for Indigenous Australian women. The primary reason for the lack of information regarding Indigenous Australian women is that most pathology report forms (the main data source for PSRs) do not record Indigenous status. Without such data, it is impossible to know if Indigenous women’s participation has improved over time or differs by place of residence or socioeconomic status; if abnormal Pap smear results are more

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1Indigenous is used to refer to Australian Aboriginal and Torres Strait Islander people, described by the ‘Commonwealth working definition’ as:

1. a person of Aboriginal or Torres Strait Islander descent,
2. who identifies as being of Aboriginal or Torres Strait Islander origin and
3. who is accepted as such by the community with which the person associates.
common for Indigenous than other women; or if those with abnormal Pap smears receive timely clinical investigation and treatment.

Several small localised studies have indicated that participation in cervical screening is much lower for Indigenous Australian women compared to non-Indigenous women. These studies have been important in demonstrating that the NCSP is not as effective as it should be in at least some Indigenous communities. After 25 years, the NCSP is still unable to provide comprehensive information about Indigenous women’s screening participation, abnormalities and outcomes, or time trends.

The research program presented in this thesis used a record-linkage approach to identify Indigenous women on the Queensland PSR and investigated participation in cervical screening, prevalence of cervical abnormalities and time to clinical investigation following a serious cervical abnormality test result.

This introductory chapter provides a brief overview of the Indigenous Australian population and a summary of cancer-related disparities, followed by an overview of cervical cancer pathology, the epidemiology of cervical cancer, and prevention programs throughout the world, in Australia and in the context of Indigenous Australian women. Finally, the chapter concludes by summarising the thesis aims.
1.1.1 **Australian Indigenous population**

Aboriginal and Torres Strait Islander people comprise the Indigenous population of Australia. Indigenous people reside on the mainland of Australia and in the Torres Strait Islands (a group of islands located between the most northern tip of Australia in Queensland and Papua New Guinea).

At June 2011, there were an estimated 669,900 Indigenous people making up 3% of the total Australian population. Torres Strait Islanders represent approximately 10% of the Indigenous population in Australia. The Indigenous population is much younger than the rest of the Australian population. The median age for Indigenous people is 21 years (similar for Aboriginal and Torres Strait Islander peoples) compared to 37 years for non-Indigenous people. The majority of Indigenous people live along the eastern sea board of Australia, similar to the rest of Australians (Figure 1.1), although a greater proportion of Indigenous people live in very remote areas compared to non-Indigenous people (13.7% versus 0.5%).
The legacy of colonisation has made lasting impressions on the health and welfare of Indigenous Australians, similar to other Indigenous populations around the world. Loss of their lands and language, traditional ways of life and disconnections with country and language has affected physical, social, emotional and mental health and wellbeing among Indigenous people. Indigenous people have largely been marginalised as the colonisers have become the dominant society. This has been reflected in poor data collection and recording of Indigenous people in a range of datasets, including health data. The available evidence suggests that Indigenous Australians continue to suffer a greater burden of illness than the rest of the population.

Life expectancy is significantly lower for Indigenous people. For Indigenous males, life expectancy is 10.6 years lower than non-Indigenous males (69.1 years versus 79.7 years) and

Figure 1.1 Distribution of Indigenous Australian population, 2011 (sourced from the Australian Institute of Health and Welfare [AIHW] 2011 census data)
for Indigenous women, 9.5 years lower than non-Indigenous women (73.7 years versus 83.1 years). Both social disadvantage and the relationship of Indigenous Australians to mainstream society have contributed to the gap in life expectancy. Factors responsible for poorer health are many and often inter-related but, compared to non-Indigenous Australians, include higher prevalence of tobacco smoking and high-risk alcohol consumption, poor nutrition, including being more overweight and obese, lower levels of education and employment rates and less access to and uptake of health services.

1.1.2 Queensland Indigenous population

The state of Queensland has the second largest Indigenous population after New South Wales. There are an estimated 189,000 Indigenous people, 4.2% of the total Queensland population. Torres Strait Islanders comprise 23% of the Indigenous population. Indigenous women in Queensland comprise 4.2% of the female population, and their median age is 22 years compared with 38 years among non-Indigenous women (Figure 1.2).

![Figure 1.2 Age structure of Queensland population, by Indigenous status, 2011 (sourced from the Australian Bureau of Statistics [ABS] 2011 census)](image)
Approximately 31% of Indigenous Queenslanders live in major cities versus 63% of non-Indigenous Queenslanders. There are a greater proportion of Indigenous people in remote areas of Queensland compared to non-Indigenous people: 19% versus 2.5%, respectively (Figure 1.3).

![Native Queenslanders Compared to Non-Native Queenslanders](image.png)

**Figure 1.3 Indigenous peoples by remoteness area, Queensland, 2011**

### 1.1.3 Cancer among Indigenous Australians

Cancer is the second leading cause of death for Indigenous Australians. Until recently, cancer was not seen as a significant health issue. Cancer was overlooked most likely because of the lower life expectancy of Indigenous people (and the association between age and cancer) and the few Indigenous people living with cancer. Cancer was also ‘overshadowed’ by the plethora of other high profile health conditions which occur at much greater rates among Indigenous than non-Indigenous people, such as diabetes, heart disease, infectious diseases, injuries and infant mortality. For example, diabetes was listed as an underlying or associated cause of death in one in every five Indigenous deaths during 2008–2012. Cancer has also been somewhat hidden because complete information has not been available from cancer registries, unlike the aforementioned conditions which have had information available for a substantial amount of time and in considerable detail.
1.1.3.1 Incidence

Reliable semi-national data for Indigenous Australians have become available in recent years from four cancer registries (Queensland, New South Wales, Western Australia and the Northern Territory) that cover 84% of the Indigenous population. Based on these data, in 2005–2009 the incidence of all cancers combined was 421 per 100,000 for Indigenous Australians and 443 per 100,000 for non-Indigenous Australians.\textsuperscript{5,24} Indigenous Australians have lower incidence of some cancers (e.g. breast, prostate, colorectal) but much higher incidence of other cancers, including many cancers amenable to prevention such as lung, cervix and liver (Figure 1.4).\textsuperscript{5} Higher prevalence of cancer risk factors such as risky alcohol consumption, tobacco smoking, poor diet, less physical activity, chronic infections, higher parity (number of children, although it can also be a protective factor) and less participation in cancer screening may be possible reasons for higher incidence of preventable cancers.\textsuperscript{23,25-28}
Notes:
1. Figure taken from the AIHW Cancer in Australia: an overview 2014 report,24 data source from the AIHW Australian Cancer Database (ACD).
2. The rates were age-standardised to the Australian population as at 30 June 2001 and based on the total number of cases over the five years from 2005–2009.
3. Some states and territories use an imputation method to determine Indigenous cancers, which may lead to differences between these data and those shown in jurisdictional cancer incidence reports.
4. UPS stands for cancer of unknown primary site.

Figure 1.4 Incidence of selected cancers where the Indigenous incidence is higher than non-Indigenous cancers by Indigenous status, New South Wales, Queensland, Western Australia and the Northern Territory, 2005-2009

1.1.3.2 Mortality
Reliable mortality data are available covering 89% of the Indigenous population from the National Mortality Database (NMD) for Queensland, New South Wales, Western Australia, South Australia and the Northern Territory. The all-cancer combined mortality rate is significantly higher for Indigenous Australians than non-Indigenous Australians (221 versus 172 per 100,000, respectively).23,24 Indigenous people with cancer died younger than non-Indigenous Australians with cancer (29% of Indigenous cancer patients died before the age of 55 years compared with 10% of non-Indigenous cancer patients), and mortality rates were higher for both Indigenous males and females than non-Indigenous males and females.23 Cancer accounted for 19% of all deaths among Indigenous Australians during 2007–2011.23
High mortality likely reflects the high incidence of high-fatality cancers among Indigenous Australians, more advanced disease at diagnosis and less treatment.

1.1.3.3 Survival

Survival from most cancers is lower for Indigenous than non-Indigenous Australians. Five-year crude survival for Indigenous people diagnosed with cancer between 1999 and 2007 using data from New South Wales, Queensland, Western Australia and the Northern Territory was 40% for all cancers combined compared with 52% for non-Indigenous Australians. The years immediately following a cancer diagnosis appear to be where the greatest disparity lies. In Queensland, it was reported that Indigenous patients had a much higher mortality rate than non-Indigenous patients in the first two years after diagnosis (50% higher in the first year, adjusted hazard ratio [HR] 1.50; 95% confidence interval [CI] 1.38–1.63), but similar mortality after the second year (HR 1.03; 95% CI 0.78–1.35 in the third year after diagnosis). Lower survival among Indigenous cancer patients may partly be explained by more advanced stage at cancer diagnosis and higher prevalence of comorbidities, reduced uptake of and less access to active treatment, remoteness of residence, and other social, cultural, environmental and economic factors.

1.1.4 Availability of cancer related data for Indigenous Australians

Statistical data about Indigenous Australians has historically been limited to administrative datasets including health-related datasets (e.g. births, deaths, hospital notifications) and demographic datasets. Reasons for this failure include a lack of an Indigenous identifier, people were not asked about their Indigenous status, Indigenous status was recorded inconsistently (asked inconsistently or recorded inconsistently) between datasets and/or over time, or because Indigenous people chose not to identify as Indigenous. However, in the
last decade or so there have been significant improvements in the quality and availability of data.\textsuperscript{39,41,42} In particular, Indigenous status in hospital admissions data has improved substantially and is now considered to be of sufficient quality for statistical reporting in every jurisdiction in Australia.\textsuperscript{42,43}

All Australian state and territory cancer registries collect Indigenous status, but only four jurisdictions (New South Wales, Western Australia, Northern Territory and Queensland), covering 84% of the Indigenous population, have sufficiently high data quality to report on cancer incidence (as described above).\textsuperscript{24} For cancer mortality, state and territory registrars of births, deaths and marriages provide the Australian Bureau of Statistics (ABS) with deaths data for the NMD, which contains information about all deaths in Australia. Indigenous status data in the NMD is of sufficient quality to report Indigenous death statistics for five jurisdictions (New South Wales, Western Australia, Northern Territory, South Australia and Queensland), that include 89% of the Indigenous population.\textsuperscript{24}

While Indigenous identification in cancer and death registers is high in these states and territories, it is not complete. Cancer incidence and mortality statistics presented in sections 1.1.3 and 1.5.1 may underestimate to a small extent the true burden of cancer in Indigenous Australians.

As previously mentioned, Indigenous status is not collected on pathology report forms and consequently the NCSP is unable to report on Indigenous women in the program.\textsuperscript{3} The issue of adding Indigenous status to pathology report forms has long been acknowledged but action to address the issue has not occurred.\textsuperscript{3,6,7} It has also been acknowledged that high quality data are needed to adequately address the cancer disparities between Indigenous and non-Indigenous Australian women.\textsuperscript{28,44,45} Adding Indigenous status to pathology report forms seems logical and simple in theory. However, in practice it may not be straightforward; key considerations include legislative changes, costs, health professional compliance and the willingness for Indigenous Australians to selfidentify.\textsuperscript{6} Even if Indigenous status were to be
added to pathology forms, it would take many years before high quality data would be available for useful reporting. An alternative is to link the PSRs with another data source that contains high-quality Indigenous status data.  

1.1.5 Summary

Overall, health disparities between Indigenous and non-Indigenous people in Australia are large, particularly in regard to life-style associated disease. In the cancer context, Indigenous Australians have higher incidence of cancers amenable to prevention. Indigenous Australian women have not had the same benefit of success from the NCSP as other Australian women and this is, in part, due to the paucity of data regarding Indigenous women on the PSRs. As a result, it has been difficult to monitor screening participation and related outcomes.

1.2 Cancer of the cervix

The World Health Organization (WHO) describes cancer as:

‘Cancer is the uncontrolled growth and spread of cells. It can affect almost any part of the body. The growths often invade surrounding tissue and can metastasize to distant sites. Many cancers can be prevented by avoiding exposure to common risk factors, such as tobacco smoke. In addition, a significant proportion of cancers can be cured, by surgery, radiotherapy or chemotherapy, especially if they are detected early.’

Cervical cancer is the uncontrolled growth of cells and tissues, which form tumours in a woman’s cervix. These tumours can invade the surrounding tissues causing similar growths in other body parts called metastases. Section 1.2 provides an overview of the aetiology of cervical cancer development including associated risk factors.
1.2.1 Anatomy and physiology of the cervix

Understanding the anatomy and physiology of a woman’s cervix is central to understanding the disease pathology of cervical cancer, in regard to both its development and prevention.

The cervix is situated in the lower part of the uterus extending through to the vagina (Figure 1.5). The lower part of the cervix is known as the extocervix and is situated within the vagina in what is known as the external orifice. Its surface is mostly stratified squamous epithelium. The endocervix is part of the cervix situated above the vagina near the opening of the uterus called the internal orifice. Its surface is columnar glandular epithelium. The cervix is a cylinder shape which can vary by age, parity and hormonal status but on average is about 3 cm long and 2.5 cm in diameter in women who are not pregnant but fertile. Unlike the endocervix, the ectocervix is visible with a speculum. The cervical canal runs through the middle of the cervix from the internal orifice to the external orifice. The ectocervix has no pain nerve endings and thus procedures involving this area are usually tolerated. The endocervix, however, has sensory nerve endings and can be painful for women during procedures involving this area.

Figure 1.5 Uterus and cervix of a woman of reproductive age, reprinted from the WHO’s Comprehensive cervical cancer control: a guide to essential practice, second edition

Chapter 1
The area where the ectocervix and endocervix meet is the squamocolumnar junction (SCJ). The SCJ can often be marked by a line of metaplasia. This line of cell change can be altered depending on the environment of the cervix. When normal physiological changes occur throughout a woman’s life (such as puberty, during menstrual cycles and menopause) the SCJ can move. It can also move for other reasons such as the use of oral contraceptives, childbirth or pregnancy status. The area between the old SCJ and the new SCJ is known as the transformation zone (Figure 1.6). The transformation zone is where most cervical cancer cells are found and where samples of cells should be taken during a Pap smear.

![Schematic diagram of the transformation zone](image)

**Figure 1.6** A schematic diagram of the transformation zone, reproduced with permission from Colposcopy and Treatment of Cervical Intraepithelial Neoplasia: A Beginners’ Manual (Chapter 1)

### 1.2.2 Epidemiologic risk factors for developing cervical cancer

The role of human papillomavirus (HPV) in cervical cancer was first demonstrated in the early 1980s by German virologist Harald zur Hausen and definitively confirmed in the mid-1990s. It is now widely accepted that HPV is necessary but not sufficient on its own to cause cervical cancer and that other risk factors are involved.
1.2.2.1 Human papillomavirus

HPV causes an estimated 5% of the total worldwide burden of cancer and has been identified in 99.7% of cervical cancer specimens. HPV is also associated with a significant proportion of other cancers including penile, vulval, anal, vaginal and head and neck cancers. The magnitude of the association of cervical cancer and HPV is greater than that of tobacco smoking and lung cancer.

There are over 150 genotypes of HPV; 40 types are capable of infecting the genital tract and 15 oncogenic types are classified ‘high-risk’ of causing disease. The 15 high-risk oncogenic HPV types are 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, 66, 68 and 70. HPV infections can trigger the development of either benign or malignant lesions. Not all HPV types cause cancer; types 6 and 11 cause genital warts and respiratory papillomatosis (where tumours grow in the air passages from the nose and mouth into the lungs). Other high-risk types can start persistent infection-causing abnormalities, which in rare cases progress to cancer. Although there is some variation of HPV genotypes around the world, HPV types 16 and 18 are the most prevalent in cervical lesions. More recently, results from an international meta-analysis indicated that HPV types 16, 18 and 45 cause nearly all cervical cancers worldwide.

HPV is a sexually transmissible virus that is common in both women and men. The estimated point prevalence of infection with HPV is 25% in young sexually active women, with a cumulative lifetime prevalence of greater than 75%. Infection with HPV usually occurs soon after onset of sexual activity among women aged 18–24 years, rapidly declines after the age of 30 but can peak again in women aged 40–50 years due to hormonal changes associated with perimenopause, before declining again.

Risk factors for the acquisition of HPV infection are sexual encounters (in particular a greater number of lifetime sexual partners), early sexual debut, behaviours of sexual partners, parity (number of births) and use of oral contraceptives.
1.2.2.2 Other risk factors

It appears that factors in addition to persistent oncogenic HPV infection contribute to the risk of cervical cancer development because most women with HPV will never develop cervical cancer. The co-risk factors which are related to HPV infection progressing to cervical cancer are not yet fully understood. Known risk factors include tobacco smoking (odds ratios [ORs] from 2 to 5), co-infection with another sexually transmitted infection, being immunocompromised, particularly with human immunodeficiency virus (HIV), the use of oral contraceptives for long periods of time; low socioeconomic status and high parity. There is also some indication that poor nutrition is associated with cervical cancer, but this has not yet been confirmed.

1.2.3 HPV and cervical abnormalities

It was believed that the progression to invasive cervical cancer occurred by progression from cervical intraepithelial neoplasia (CIN) I to CIN II to CIN III and then invasive cancer. This is now understood to be incorrect. The crucial event appears to be in the HPV deoxyribonucleic acid (DNA) infecting the proteins in cervical epithelial cells that are responsible for normal cell growth and repair. HPV causes abnormal cellular changes, most of which are mild and cellular defence mechanisms clear the infection without clinical intervention. In a small percentage of women, HPV infection persists causing mild dysplasia. However, most of these women eventually mount an adequate cell-mediated response and the lesions regress. Almost all low-grade cervical abnormalities are predictors of acute HPV infection and regress without medical intervention. Most infections are transient and are cleared in adolescent women without detection of CIN within 36 months.

If infection occurs from an oncogenic HPV type and the infection persists over time without an adequate cell-mediated immune response (to clear or control the infection), high-grade intraepithelial neoplasia and eventual invasive carcinoma can develop. While most
high-grade abnormalities also regress over time, the regression takes longer and some (less than 1%) progress to invasive cervical cancer if left untreated.\(^{49,55,77}\) The average time of high-grade lesions to cancer is approximately 10 years.\(^{49,55}\)

The majority of cervical cancers (~80–90%) originate in the squamous cells of the ectocervix part of the transformation zone.\(^{49,55}\) The remaining cervical cancers are adenocarcinomas, are less common and originate in the glandular columnar epithelium of the endocervix of the cervical canal.\(^{47,49}\)

### 1.3 Cervical cancer prevention

Cervical cancer is one of the few cancers (along with colorectal cancers) where screening can detect precancerous cells and treatment of these result in preventing invasive cancer. Over the last century, significant findings and developments have offered great insight into the understanding of cervical cancer and its prevention, including:

1. The detection of pre-cancerous lesions using the ‘Pap smear’ which has become one of the most widely adopted screening strategies in the world.\(^{81,82}\)
2. High-risk oncogenic HPV is a necessary component of cervical cancer.\(^{50,52-54}\)
3. The development of molecular methods to detect HPV (and thus improve the detection of high-grade cervical cancer precursor lesions).
4. The development of prophylactic HPV vaccines against high-risk HPV types.\(^{47,83-85}\)

#### 1.3.1 Cervical screening

The first indication that precancerous lesions could be detected by vaginal smears was discovered by George Papanicolaou in 1941, commonly known and referred to as the ‘Pap Test’ or ‘Pap smear’.\(^{82,86}\) The Pap smear has become a widely adopted and effective cervical
cancer screening tool for precancerous lesions, without any formal evaluation by a randomised control trial. Given the long interval needed for cervical cancer to develop, the Pap smear is useful as a regular screening and re-screening tool as part of a screening program. The Pap smear allows abnormalities to be detected and therefore, presents an opportunity for monitoring, further investigation and early treatment before cancer develops.

When the Pap smear is integrated into an organised screening program, it has a greater impact than opportunistic cervical screening. A large number of observational studies around the world have shown large reductions in cervical cancer incidence and mortality credited to screening programs. Population-based cervical screening has been adopted in many developed countries in North America, Western Europe and Australasia. However, the significant resources and infrastructure that are required for effective screening have prohibited population-based screening in developing countries.

The International Agency for Research on Cancer (IARC) recommends a three-yearly screening interval for women aged 25–49 years and five-yearly interval for women aged 50–64 years. The screening interval has been debated; while three years is effective, five years is also effective and more practical. As a result, there is variation in screening intervals around the world. Australia screens at a two-yearly interval, which is more frequent compared to other developed countries with effective screening programs. Finland, Ireland and the Netherlands recommend screening at five-yearly intervals, though there is much variation across Europe. The United Kingdom previously recommended a three- to five-year interval but changed to a three-year interval in line with the IARC recommendations. The United States Preventive Services Task Force recommends Pap smear screening for women aged 21–65 years every three years or screening with a combination of Pap smear and HPV testing every five years for those women aged 30–65 years who want to lengthen the screening interval. In Canada, each
province and territory recommends starting cervical screening for women at 21 years but there is some variation in the frequency of the testing and in the exit test age and requirements. The Canadian Task Force on Preventive Health Care recommends cervical screening for women aged 25-69.

There is no cervical screening (either organised or opportunistic) in most African countries (particularly in sub-Saharan Africa) due to competing health priorities, poorly-equipped health care systems, financial and workforce under-resourcing. The exception is South Africa, a much better resourced country which offers Pap smears in antenatal, postnatal, gynaecology and family planning clinics upon demand. It is the only African country to have a national cervical screening policy recommending three Pap smears for women over the age of 30 years at ten-year intervals.

The benefit of even occasional cervical screening is evident since having at least one cervical smear is associated with a reduced risk of cervical cancer, though the reduction is significantly greater for squamous cell carcinoma than for adenocarcinoma.

### 1.3.2 HPV vaccines

The development of prophylactic vaccines against HPV has been a significant accomplishment in the prevention of cervical cancer. Such vaccines hold great potential to further reduce cervical cancer incidence, especially among women who participate less in screening programs and in developing countries that lack organised screening programs and have a high burden of disease.

There are currently two vaccines that prevent infection with HPV types 16 and 18 that cause the majority of cervical cancers: Cervarix®, a bivalent vaccine and Gardasil®, a quadrivalent vaccine that also protects against HPV types 6 and 11 (the cause of most external anogenital warts). The two vaccines are highly effective in preventing persistent...
infections and HPV 16/18 associated cervical disease when given to females not infected with these HPV types. These vaccines do not protect against all types of HPV associated with cervical cancer. They do not treat HPV infection or have any effect on disease progression if the vaccine is administered to a woman with a prior or current HPV infection. Thus, vaccinated women should continue to have regular cervical screening. The WHO has stated that HPV vaccines should form part of a coordinated strategy in the prevention of cervical cancer.

1.3.3 Epidemiology of cervical cancer worldwide
Cervical cancer is the fourth most common cancer diagnosed in women in the world. Incident rates have decreased by greater than 50% in countries where screening programs have been established for a period of time. Other areas around the world have also seen some decrease in incidence, although the reason for this has not been fully explained.

The majority of the cervical cancer burden occurs in countries where cervical screening programs are not established. In 2012, an estimated 528,000 new cases of cervical cancer were diagnosed around the world. In less developed regions, age-standardised rates are greater than 30 per 100,000 women (age-standardised to the world population) Eastern Africa (42.7); Melanesia (33.3); Southern Africa (31.5); and Middle Africa (30.6). Rates in more developed countries are much lower: Sweden (7.4); United Kingdom and United States of America (6.6); Canada (6.3); Australia and New Zealand (5.5); Western Asia (4.4); and Finland (4.3). Cervical cancer is diagnosed mostly in middle-aged women. World, age-specific incidence rates are shown in Figure 1.7.
In 2012, an estimated 266,000 deaths from cervical cancer occurred worldwide; 90% of these were in the developing world. Age-standardised mortality rates range from 27.6 per 100,000 women in Eastern Africa, 22.2 in Middle Africa and 20.6 in Melanesia, to as low as 2.0 in Western Asia, Australia, New Zealand and Western Europe.

**Figure 1.7 Worldwide incidence of cervical cancer by age group in less and more developed countries**

1.3.4 Summary of cervical cancer and screening among Indigenous populations in New Zealand, Canada and the United States

Around the world, Indigenous women generally experience a higher incidence and mortality of cervical cancer. Despite their ethnic and cultural distinctiveness, Indigenous people in Australia (Aboriginal people and Torres Strait Islanders), New Zealand (Maori), Canada (First Nations/Inuit/Métis), and the United States (Native American/Alaska Native) share similarities in their historical experience, social disadvantage and health disparity. A meta-analysis including these four high-income countries showed Indigenous women from Australia, New Zealand, Canada and the United States did not have an increased risk of
dysplasia or carcinoma in situ but had elevated risk of invasive carcinoma and mortality relative to non-Indigenous people. The authors concluded that lower participation in screening programs, delayed diagnosis and inadequate care after diagnosis would most likely explain the higher incidence and mortality rates.

Indigenous women’s participation in cervical screening has also been documented as lower than their non-Indigenous counterparts. In New Zealand, where the target is 80% participation, 81.9% of European/other women had been screened compared to 62.6% of Māori women in 2011–2013. In Canada, each province and territory is responsible for its own cervical screening program and guidelines. Historically, participation rates have been lower among Aboriginal women, but more recently there is uncertainty if this is still the case. There have been varying reports of participation among Aboriginal women (First Nations/Inuit/Métis) in Canada ranging from 69% to 85%. In the United States, cervical participation rates have also been reported as considerably lower for Native American women compared to non-Hispanic white, and other ethnic groups.

1.4 Cervical screening in Australia

In the mid-1960s, opportunistic cervical screening became available in Australia though there were no formal policies or recruitment process. In 1991, Australia introduced the Organised Approach to Preventing Cancer of the Cervix, an organised, population-based cervical screening program. The program was re-named in 1995 and remains known as the National Cervical Screening Program (NCSP). The NCSP is a joint initiative and cost-shared program between the federal government and the state and territory governments. The program involves:

- Encouraging all eligible women to enter and remain in the screening program
- Ensuring optimal quality of Pap smears with training for Pap smear takers
- Ensuring optimal quality of Pap smear reading through a quality assurance program for laboratories
• Ensuring appropriate follow-up of abnormal Pap smears through management guidelines
• Providing an efficient system for notifying women of results from Pap smear providers
• Providing recall and reminder systems to ensure adequate follow-up of women with screen-detected abnormalities
• Maintaining women’s participation in the program by encouraging providers to set up reminder systems and to maintain cervical screening registers
• Reporting on national performance measures and contributing to national cancer data.

The national policy advises which women and how frequently these women should have a Pap smear. The policy was implemented in 1991 and states that, regardless whether a woman has received the HPV vaccine:

• Routine screening with Pap smears should be carried out every two years for women who have no symptoms who have ever been sexually active
• Women should start having Pap smears between the ages of 18 and 20, or one or two years after first having sexual intercourse, whichever is later
• Pap smears may cease at the age of 70 for women who have had two normal Pap smears within the past five years. Women over 70 who have never had a Pap smear, or who request a Pap smear, should be screened
• Women with abnormal smear results should be managed in accordance with the National Health and Medical Research Council’s (NHMRC) clinical management guidelines (see below).

A core infrastructure of the NCSP is the state and territory Pap Smear Registers (PSRs) which were developed as part of the program and contribute to the success of the NCSP. The PSRs are responsible for the collection of screening histories, sending reminders to women if
they are overdue for routine screening and contribute to the national data on the 
epidemiology of pre-cancerous lesions. Data are provided to the PSRs by pathology 
laboratories, who rely on pathology request forms for demographic data about screened 
women. Women are added automatically to the PSR unless they specifically asked to opt-off 
(less than 1% of screened women opt-off\textsuperscript{109,110}). Program indicators were developed by the 
Australian Institute of Health and Welfare (AIHW) and are reported annually by the NCSP 
as part of its ongoing performance monitoring.

The Australian Government announced a renewed cervical screening program to be 
introduced in May 2017\textsuperscript{111}. The renewed NCSP will reflect the best available evidence 
regarding the optimal screening age and interval, HPV vaccinated women and new 
technologies for early detection. The renewed NCSP will change from the current two year 
Pap test, to a primary HPV test every five years for women aged 25–74 years.\textsuperscript{111} There will 
also be the option of self-collection of an HPV sample for under- or never-screened women. 
Cervical screening should commence at 25 years by invitation and reminders are to be sent 
to women aged 25–69 years with exit testing up to 74 years of age.

1.4.1 Management guidelines of the NCSP

The current NHMRC 2005 management guidelines, \textit{Screening to prevent cervical cancer: 
guidelines for the management of asymptomatic women with screen detected abnormalities}, 
are based on the 2004 Australian Modified Bethesda System for classification of cervical 
abnormalities.\textsuperscript{108} The current guidelines superseded the first NHMRC guidelines, \textit{Screening 
to prevent cervical cancer: guidelines for the management of women with screen detected 
abnormalities}, which were based on the NHMRC 1994 classification of abnormalities.\textsuperscript{112} 
The purpose of the guidelines is to provide medical practitioners with evidence-based 
recommendations to manage women who have an abnormal Pap smear.
The current guidelines are being revised to accompany the renewed NCSP to be introduced in 2017. However, until 1 May 2017 the NHMRC 2005 management guidelines, *Screening to prevent cervical cancer: guidelines for the management of asymptomatic women with screen detected abnormalities* are the current and used guidelines.

1.4.1.1 *Management of low-grade abnormalities*

Prior to the current guidelines, low-grade abnormalities were intensely followed up due to their perceived seriousness. In the current guidelines, this was replaced with a ‘watch and wait’ approach due to better understanding that very few low-grade abnormalities progress to cancer within two years (the recommended screening interval) and most regress. Women with persistent low-grade abnormalities are referred to colposcopy. Women whose index Pap smear is reported as possible or definitive low-grade abnormality are recommended to have a repeat Pap smear at 12 months. Women aged over 30 who have not had a negative Pap smear in the preceding two to three years are recommended to have a repeat Pap smear in six months or immediate colposcopy.

1.4.1.2 *Management of high-grade abnormalities*

Women with high-grade abnormalities should be referred for colposcopy and a biopsy for histological confirmation. If confirmed histologically, the area of abnormal cervical tissue should be removed by excision (cone biopsy, laser, loop electro-excisional procedure [LEEP] or other diathermy techniques) or ablation (cold coagulation, radical diathermy or cryotherapy). In Australia, most treatment is done by loop excision. A hysterectomy may be recommended if a woman has a high-grade abnormal Pap smear following previous treatment, has cervical cancer, or has other coexistent gynaecological disease. After treatment of a high-grade abnormality, follow-up within four to six months is recommended.
and a repeat Pap smear and an HPV test. If two consecutive cytology and HPV typing were negative, women could return to routine two-yearly screening.

1.4.2 Performance measures of the NCSP

Annually, the AIHW provide reports on the performance of cervical screening nationally and by states and territories. The performance of the NCSP is measured using seven key performance indicators outlined in Table 1.1, using data provided by the PSRs. Indigenous women’s participation in cervical screening cannot be measured or reported nationally as stated earlier, due to Indigenous status not being included on pathology report forms, the primary data source for PSRs.

Table 1.1 NCSP performance indicators

<table>
<thead>
<tr>
<th>Performance indicators</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Participation</strong></td>
<td>The percentage of women aged 20–69 who have a Pap smear in a two-year period</td>
</tr>
<tr>
<td><strong>2 Rescreening</strong></td>
<td></td>
</tr>
<tr>
<td>2.1 Early rescreening</td>
<td>The proportion of women who have another Pap smear within 21 months of a negative Pap smear result</td>
</tr>
<tr>
<td>2.2 Rescreening after 27-month cervical screening register reminder letter</td>
<td>The proportion of women who have a Pap smear within three months of being sent a 27-month reminder letter</td>
</tr>
<tr>
<td><strong>3 Cytology</strong></td>
<td>The number of Pap smear results in each result category</td>
</tr>
<tr>
<td><strong>4 Histology</strong></td>
<td>The number of histology results in each result category (including the number of women with a high-grade histology for every 1000 women screened)</td>
</tr>
<tr>
<td><strong>5 Cytology-histology correlation</strong></td>
<td>A measure of how well cytology correlates with histology performed not more than six months after the cytology test</td>
</tr>
<tr>
<td><strong>6 Incidence</strong></td>
<td>The number of new cases of cervical cancer</td>
</tr>
<tr>
<td><strong>7 Mortality</strong></td>
<td>The number of deaths from cervical cancer</td>
</tr>
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1.4.3 Cervical screening in Queensland

The Queensland Cervical Screening Program (QCSP) is part of the NCSP, offering Pap smears in a number of settings such as mobile women’s health services in rural and remote areas, sexual health services, general practice, Aboriginal and Torres Strait Islander health services and Family Planning Queensland (now called True Relationships and Reproductive Health). The QCSP recommends cervical screening in accordance with the national policy. The Queensland Pap Smear Register (QPSR) has been in operation since 1999. The QPSR has a variable to collect Indigenous status but it is not a mandatory data item and is rarely recorded. The Queensland Public Pathology Laboratory Pap smear request form has provision to record Indigenous status (their form includes Indigenous status and their information system can record it), if it is provided by the practitioner taking the Pap smear. However, the majority of Pap smears are processed by private laboratories that do not record Indigenous status.

Since the introduction of the QCSP, there have been a number of strategies and initiatives to increase the participation rate of Indigenous women in Queensland. A state-wide Mobile Women’s Health Service was established, consisting of a network of 15 registered nurses and two Indigenous women’s health workers to provide preventative health services, including cervical screening for women in rural and remote parts of Queensland. The Healthy Women's Initiative was first set up in 1997–1998 to increase Indigenous women’s participation in cervical screening and support them to access follow-up and treatment. The initiative was a health promotion program using extensive community engagement and partnerships to explore several models of women’s health services to encourage participation in cervical screening among Indigenous women in Queensland.
1.4.4 Evidence for the effectiveness of the Australian program

The IARC recommends the following criteria for assessing the effectiveness of cervical screening:

1. Trends in mortality and incidence
2. Evaluation of operational parameters of screening (performance evaluation)

Part of IARC second recommendation states that performance indicators of participation, quality of tests, follow up and treatment are consistent with policy guidelines and program recommendations and should be evaluated, reviewed and published annually. Only criteria one and two are summarised.

1.4.4.1 Epidemiology of cervical cancer in Australia

Australia has the lowest cervical cancer incidence in the world among countries with reliable cancer incidence data. Since 1991, both incidence and mortality have decreased by approximately 50%. The age-standardised incidence rate was 14.2 per 100,000 women in 1982 and 13.3 per 100,000 women in 1991. After the introduction of the NCSP, incidence declined rapidly to approximately seven new cases per 100,000 women by 2002 and has remained fairly stable since then (Figure 1.8). Incidence of cervical cancer among women in the target age for cervical screening (20–69 years) followed a similar pattern: incidence in 1982 was 17.2 per 100,000, falling slightly to 19 per 100,000 women in 1991, before falling rapidly to 9 per 100,000 women by 2002 and plateauing thereafter (Figure 1.8). The decline in incidence seen prior to 1991 was likely the result of ad-hoc opportunistic screening and some states trialling the screening program in the 1980s. The small spike in incidence in 1994 is likely a result of increased detection in the early years of widespread organised screening rather than an actual increase in cervical cancer.
The reduction of cervical cancer incidence has been almost exclusively for squamous cell carcinomas; the incidence of adenocarcinomas has remained fairly stable, and adenocarcinomas now account for nearly 25% of cervical cancers compared to 5–10% when the NCSP was introduced. Pap smears are less effective at both sampling and identification of adenocarcinomas than squamous cell carcinomas.\textsuperscript{17,121,122}

\begin{figure}
\centering
\includegraphics[width=\textwidth]{chart.png}
\caption{Age-standardised cervical cancer incidence and mortality rates by year, Australia\textsuperscript{119}}
\end{figure}

\textit{Source: Australian Institute of Health and Welfare}

There is little geographical variation in cervical cancer incidence with two exceptions: incidence is higher in remote and very remote areas than in urban areas, but lower in areas with the highest socioeconomic status (predominantly in major cities).\textsuperscript{17}

Like incidence, mortality has decreased over time and this downward trend was evident prior to the introduction of the NCSP (Figure 1.8).\textsuperscript{3,119} The mortality rate was 7.7 per 100,000 women in 1968 compared to 1.8 in 2012 (rates age-adjusted to the Australian standard population 2001).\textsuperscript{119} In 2012, 143 of the 226 deaths (63.3%) from cervical cancer were
among women in the target age group for screening.\textsuperscript{17} Mortality increases by age group; for women under the age of 35, the rate is 1 per 100,000 and increased to 10.6 per 100,000 for women aged 85 and over.\textsuperscript{113} Mortality rates are also higher in remote and very remote areas compared with major cities and higher in the most disadvantaged areas compared with areas of least disadvantage.

1.4.4.2 \textit{Participation of Australian women in cervical screening}

According to the most recent annual report produced by the AIHW, 3,815,705 women aged 20–69 years participated in cervical screening in 2012–2013.\textsuperscript{17} This equates to an age-standardised participation rate of 57.7\% of the population (participation rate refers to the percentage of eligible women aged 20–69 years who underwent a Pap smear in the two-year period from 1 January 2012 to 31 December 2013). Nationally, participation has remained stable over recent years (Figure 1.9).
Although screening every two years is recommended in Australia, screening at longer intervals is also protective. Nationally, 70.3% of women were screened in the three-year period 2011–2013 and 83.3% in the five-year period 2008–2012. Participation (age-specific) increased by age-group, peaking at 40–45 years before declining in older age-groups. Participation decreased with increasing remoteness and increased with increasing affluence: in 2012–2013, age-standardised participation was 58.1% in major cities compared with 55.4% in very remote areas and 52.0% in the least affluent versus 63.8% in the most affluent areas.

The proportion of cytology tests that are unsatisfactory has remained steady during 2004–2012 at 2%. An unsatisfactory test occurs when the pathologist is unable to determine clearly a result. The proportion of tests reported as abnormal in 2012 was 5.8% and the proportion reported as negative (no abnormal cells present) was 92%.

Figure 1.9 Participation of women aged 20–69 in cervical screening, 1996–1997 to 2012–2013
1.4.5 Evidence for the effectiveness in Queensland

1.4.5.1 Epidemiology of cervical cancer in Queensland

In 1982, age-standardised cervical cancer incidence rates in Queensland were 18.1 per 100,000 (95% CI 15.6–20.8) women and by the beginning of the QPSR in 1999, incidence had already decreased to 11.1 per 100,000 (95% CI 9.6–12.8) women. In 2012, incidence had decreased further to 8.9 per 100,000 (95% CI 7.7–10.2). Among women in the target screening age of 20–69 years, incidence was 24.5 per 100,000 in 1982 (20.9–28.6), 15.5 per 100,000 in 1999 (95% CI 13.2–18.0) and 11.9 in 2012 (95% CI 10.2–13.8). The median age of diagnosis with cervical cancer in Queensland during 2008–2012 was 46 years (interquartile range [IQR] 35–59). Incidence was lowest in 2007 (9.5 per 100,000 among women aged 20–69 and 7.0 among all women) and has slowly increased since then.

Incidence in Queensland is 30% higher than the national cervical cancer incidence rate, but the absolute difference is small. Incidence of cervical cancer in Queensland is strongly associated with inadequate screening; about 80% of women aged 30–69 years diagnosed with a squamous cell carcinoma had not had a completed Pap smear in the four years prior to their diagnosis.

The mortality rate of cervical cancer in Queensland in 1982 was 4.4 per 100,000 women (95% CI 3.2–5.9). In 1999 rates had decreased to 2.6 (95% CI 1.9–3.5) and in 2012 to 2.0 (95% CI 1.5–2.6). For women in the target screening age, mortality rates have also decreased; 4.8 per 100,000 in 1982 (95% CI 3.2–6.8), 2.7 in 1999 (95% CI 1.8–3.9) and 1.8 in 2012 (95% CI 1.2–2.6). Mortality rates have decreased the most in women aged 80 years and over.

1.4.5.2 Participation in Queensland

The state-wide participation rate in Queensland was first recorded in the AIHW annual reports for the period 1999–2000. This was because the QPSR was the last to be introduced,
beginning in February 1999. In the most recent AIHW report for the period 2012–2013, the participation of women in Queensland aged 20–69 years was 56.4%. Queensland has consistently had one of the lowest participation rates compared to other states and territories and nationally (Figure 1.10).

Notes:

1. QPSR began operations in February 1999 and therefore Queensland data are not included in the participation or population data prior to 1999–2000 reporting period.
3. Source: AIHW analysis of state and territory cervical screening register data.

Figure 1.10 Age-standardised two-year cervical screening participation in Queensland and Australia (women aged 20–69 years), 1996–1997 to 2012-2013

In Queensland, women aged less than 30 and over the age of 60 years are less likely to have two-yearly Pap smears, along with women who are the most disadvantaged and women who live in remote areas. It has been noted that the lower participation in Queensland is likely to reflect the rapidly increasing population, geographical dispersion, workforce issues including
the availability of female providers and bulk billing services (especially in rural and remote areas).  

1.5 Cervical cancer and cervical screening among Indigenous Australian women

Cervical cancer is the seventh most commonly diagnosed cancer among Indigenous Australians compared with 22nd among the non-Indigenous population. In spite of large reductions in incidence and mortality in the non-Indigenous population, significant inequalities persist regarding the burden of cervical cancer for Indigenous Australian women.

1.5.1 Epidemiology of cervical cancer among Indigenous Australian women

1.5.1.1 Incidence and mortality

In 1998–2005, the age-standardised cervical cancer incidence rate for Indigenous women using data covering 84% of the Indigenous population was 2.7 times higher (95% CI 2.2–3.2) than that for non-Indigenous women (20 versus 7 per 100,000). Incidence for 2005–2009 among women aged 20–69 years remained significantly higher among Indigenous women than non-Indigenous women (Figure 1.11). In the Northern Territory, incidence of cervical cancer for the period 1991–2008 among Indigenous women was 28.3 per 100,000 women (95% CI 15.5–41.1) and 11.3 per 100,000 women (95% CI 4.7–18.0) among non-Indigenous women. Semi-national data (using data
from New South Wales, Queensland, Western Australia and the Northern Territory) covering 84% of the Indigenous Australian population also show a decrease in cervical cancer incidence between 1998 and 2005 by about 3% per annum (incident rate ratio 0.97 per year, 95% CI 0.83–1.13), although this was not statistically significant. The long-term trend in the Northern Territory suggests that the semi-national trend may be confirmed over a longer time period.\textsuperscript{5,124}

![Graph showing age-standardised cervical cancer incidence among Indigenous women aged 20–69 for New South Wales, Western Australia, Queensland and the Northern Territory, by Indigenous status (2005–2009)\textsuperscript{113}]

Mortality rates using data from 2007–2011 for New South Wales, South Australia, Western Australia, Queensland, South Australia and the Northern Territory indicate Indigenous women are much more likely to die from cervical cancer than non-Indigenous women (rate ratio 3.9).\textsuperscript{23} In the screening age range (20–69 years) the age standardised mortality rate was 9 per 100,000 women for Indigenous women compared with 1.9 per 100,000 for non-Indigenous women (Figure 1.12).\textsuperscript{3}
Figure 1.12 Age-standardised cervical cancer mortality in women aged 20–69 for New South Wales, Western Australia, Queensland, South Australia and the Northern Territory, by Indigenous status (2007–2011)\textsuperscript{113}

As with incidence data, long-term mortality trend data for Indigenous women are limited to the Northern Territory, where cervical cancer mortality has decreased by approximately 75% since the early 1990s. In 1991–1995, the cervical cancer mortality rate was 44.5 per 100,000 (95% CI 22.0–67.0) for Indigenous and 17.5 (95% CI 9.9–25.1) for non-Indigenous women;\textsuperscript{124} both had decreased by 2001–2006, to 10.9 (95% CI 1.4–20.5) and 1.1 (95% CI 0.1–2.1), respectively. Mortality rates were much higher for Indigenous women in remote and very remote areas (20.6, 95% CI 8.3–32.9) than in outer regional areas (2.5, 95% CI 0.0–7.4).\textsuperscript{124} Mortality rates were similar for Indigenous and non-Indigenous women in outer regional areas.\textsuperscript{124}

1.5.1.2 Survival

Survival following a cervical cancer diagnosis is lower for Indigenous than other Australian women. One-year crude survival following a diagnosis of cervical cancer for Indigenous
women is significantly lower compared with non-Indigenous women (72.7%, 95% CI 66.0–78.4 versus 85.7%, 95% CI 84.5–86.8).\textsuperscript{23} Nationally, five-year crude survival for women diagnosed in 1999–2007 was 51% compared with 67% for Indigenous and non-Indigenous women, respectively.\textsuperscript{23} Difference in survival was greatest between Indigenous and non-Indigenous women in remote and very remote areas (unadjusted survival 37.2%, 95% CI 25.2–49.1 compared with 73.8%, 95% CI 71.0–76.4) and in women 50 years and over (there were no Indigenous survivors over the age of 50).\textsuperscript{23} In the Northern Territory, five-year relative survival for women diagnosed in 1991–2006 was 38.0% (95% CI 25.3–50.9) among Indigenous women compared with 76.7% (95% CI 66.7–84.1) for non-Indigenous women.\textsuperscript{125}

Stage at cancer diagnosis is inherently associated with cancer survival. This is because the stage of the cancer reflects size of the tumour, the involvement of nodes and the spread to other sites in the body and can determine the treatment choice/outcome which impacts on survival. National data about stage at diagnosis are not available. Regional studies indicate that Indigenous women with cervical cancer have more advanced cancer at diagnosis (i.e., regional or distant spread) than non-Indigenous women.\textsuperscript{31,126} In the Northern Territory, Indigenous women diagnosed with cervical cancer in 1991–2000 were more likely to have advanced disease (Indigenous 37%, non-Indigenous 24%, \(p=0.19\)), and have lower survival (HR Indigenous: non-Indigenous 3.0, 95% CI 1.4–6.2).\textsuperscript{31} In Queensland, a matched cohort study of Indigenous compared with a random sample of non-Indigenous women (frequency-matched on year of diagnosis, cancer type, residential remoteness and age) found Indigenous women with cervical cancer had a lower proportion of localised cancers than non-Indigenous women (46% versus 69%, \(p=0.019\)).\textsuperscript{126} Among this same matched cohort, crude one-year survival was less for Indigenous compared with non-Indigenous women (crude unadjusted HR 2.46, 95% CI 1.03–5.90). However, one-year survival was not significantly different to non-Indigenous women after adjusting for stage and treatment uptake (adjusted HR 1.00, 95% CI 0.45–2.24),\textsuperscript{126} which indicates that late stage at diagnosis resulting in limited treatment options may largely be responsible for survival differentials.
1.5.1.3  Overview of cervical cancer epidemiology among Indigenous women in Queensland

The most recent incidence and mortality data about Indigenous people in Queensland (compared to a frequency-matched cohort of non-Indigenous women) is for the period 1997–2006. Cervical cancer incidence was 3.5 (95% CI 2.8–4.2) times higher for Indigenous than non-Indigenous women and mortality 7.5 (95% CI 5.5–10.1) times higher. Unadjusted five-year survival for Indigenous compared with non-Indigenous patients in Queensland (diagnosed 1998–2006) is much lower (HR 1.9, 95% CI 1.0–3.7) although not statistically significant. Unadjusted one-year survival was worse for Indigenous women compared with non-Indigenous women (HR 2.5, 95% CI 1.0–5.9), but was not different when adjusted for stage and treatment of cancer (HR 1.0, 95% CI 0.5-2.3).

1.5.2  Cervical cancer risk factors among Indigenous Australians

As outlined in section 1.2.2, there are several established risk factors for the development of cervical cancer. The following section describes the prevalence of these risk factors among Indigenous Australian women.

1.5.2.1  Human papillomavirus

Few studies have reported on the prevalence of HPV found in Pap smears among Indigenous Australian women, and even fewer on specific HPV types. A study in the Northern Territory in 1998, using tampon-collected samples, found lower prevalence of HPV infection in Indigenous than non-Indigenous women (42% versus 56%), though the analyses did not account for factors such as clinical setting, cytology results or age. Prior to the introduction of the HPV vaccination program in Australia, the Women’s HPV Indigenous Non-Indigenous Urban Rural Study (WHINURS) aimed to compare the prevalence of
cervical infection with specific HPV genotypes among Indigenous and non-Indigenous women from both remote and urban settings in Australia. Women were recruited from all states and the Northern Territory (34 sites) and permission was gained to have the participants’ Pap smear tested for HPV DNA. The results from the WHINURS study provided prevalence of HPV types by Indigenous status prior to the HPV vaccination program but, due to recruitment constraints, were not necessarily representative of all Australian women. HPV 16 was the most common genotype in both Indigenous and non-Indigenous women. The prevalence of HPV types 16 and 18 was similar for Indigenous women and non-Indigenous women in each age-group. For other HPV genotype groups (high-risk other than 16 and 18, probable high-risk and low-risk) prevalence was similar in younger age groups but higher for Indigenous women aged 31–40 years. The higher prevalence of these groups in Indigenous women was somewhat explained by smoking, a current high-grade Pap smear result or first ever Pap smear; when adjusted for these factors in multivariate analysis, the differential between Indigenous and non-Indigenous women for these groups was reduced but not eliminated. The WHINURS study found no significant differences in vaccine preventable HPV prevalence between Indigenous and non-Indigenous women with cytological abnormalities, though the authors note the study was relatively underpowered to detect a difference.

1.5.2.2 Other risk factors

Indigenous Australians are more than twice as likely to smoke as non-Indigenous Australians (38% versus 18% in 2010). Prevalence of smoking is much higher in remote areas than more urbanised areas and young Indigenous people are significantly more likely to smoke than non-Indigenous people (18–24 year olds, 43% versus 16%). Indigenous people are also likely to be exposed to higher levels of passive smoking because of the high prevalence of smoking in the Indigenous community. However, prevalence of smoking among
Indigenous Australians has been falling (except among women living in remote areas) and there have been positive shifts in the number of cigarettes smoked per day and the number of Indigenous people who have successfully quit.\textsuperscript{135,136} In 2012–2013, 41.4% of Indigenous women aged 18 years and over were current daily smokers compared with 15.6% for non-Indigenous women.

Published information is lacking regarding hormonal contraception use among Indigenous women. In the 2004–2005 Aboriginal and Torres Strait Islander Health Survey (AATSIHS), of the Indigenous women aged 18–49 years, 14% used oral contraception, 21% used condoms, 8% used contraceptive injection, 7% used contraceptive implant, and the remaining 50% included women who used other forms of contraception, did not use contraception, or it was not known.\textsuperscript{137} Of the 14% of women who used oral contraception, the majority were from non-remote areas. Indigenous women in the WHINURS study cohort were less likely to use hormonal contraception than non-Indigenous women.\textsuperscript{130}

Earlier age at pregnancy and higher number of babies is also a risk factor for cervical cancer (due to trauma to the cervix and hormonal changes during pregnancy).\textsuperscript{76} In 1981, the average number of babies ever born to Indigenous mothers aged 40–44 was 4.55 babies. By 2011 this had fallen to 2.63 babies.\textsuperscript{17} The total fertility rate of Indigenous women is higher compared to non-Indigenous women; in 2013 the rate was 2.3 babies per Indigenous woman compared with 1.9 babies for all women.\textsuperscript{17} The median age of Indigenous women registering a birth was significantly lower than the median age of all mothers (24.9 years versus 30.8 years).\textsuperscript{17} Sexual debut has recently been reported similar to non-Indigenous Australians (median age approximately 16–17 years).\textsuperscript{133,138}

Indigenous Australians are much more likely to experience disadvantage in terms of education, health education, unemployment, inadequate housing, and infrastructure than non-Indigenous Australians.\textsuperscript{17} In Australia, socioeconomic status is measured using the Socioeconomic Indexes for Areas (SEIFA) Index, based on variables (income, education,
Chapter 1

employment etc.) collected at census. Indigenous Australians are more likely to be disadvantaged than non-Indigenous Australians. In 2011, 37% of Indigenous Australians lived in the most disadvantaged decile compared with 9% of the non-Indigenous population.

1.5.3 Cervical screening among Indigenous Australian women

As described earlier, population-based data on cervical screening participation by Indigenous Australian women is not available. Several localised studies, mostly from remote areas, have reported that participation is lower for Indigenous women than non-Indigenous women.

Reports of participation from individual communities or health services suggest varying rates of participation. Several studies reported baseline measures of participation prior to implementing an intervention in an effort to increase participation. Programs to increase screening based on specific programs within health services made large impacts on participation. In the Fitzroy Valley (a remote area of Western Australia), participation increased between two and four-fold after establishing a dedicated call-and-recall register but decreased considerably (between 29–76% decline) after a change in staff within the organisation. In one health service in Queensland, participation among their eligible clientele increased by 70.3% after implementing a specific Well Woman’s Program. Prior to the program, participation was 20.9% and this increased to 35.6% 12 months after the program completed.

Two studies, one in Queensland and one in the Northern Territory, used specific rural and remote areas where the population was made up of greater than 70% Indigenous people to estimate Indigenous women’s participation in cervical screening. In Queensland, the estimated participation for Indigenous women in these communities was 41.5%, which was lower than the rest of Queensland’s participation of 59.1%. However, within these 13
discrete Indigenous communities, there was significant variation in participation from 19.9% to 63.5%. In remote areas of the Northern Territory, participation for Indigenous women was 33.9% in 1997–1998 but increased to 44.0% in 1999–2000. Again, participation varied between communities from as low as 16.6% to as high as 75.0%.

From other available data sources, participation among Indigenous women has been reported. The AATSIHS was a cross-sectional survey where information was collected face-to-face by interview from Aboriginal and Torres Strait Islander people who were usual residents of private dwellings (6701 private dwellings, 80.2% response rate) in non-remote and remote areas of Australia. The results of the AATSIHS reported that for 2012–2013, 88% of Indigenous women aged 18 and over had at least one Pap smear in their life and 57% had a Pap smear at least every two years. However, Indigenous women were asked for permission to proceed to questions about Pap smears and it is unclear about the representativeness of these results because the proportion that declined to answer this particular question has not been reported. It is possible (perhaps likely) that women who declined were less likely to have been screened.

In 2013, national data from 180 government-funded primary health care organisations which primarily care for Indigenous people found that 32% of their eligible regular female patients aged 20–69 had a Pap smear in the preceding two years and 40% and 46% in considering the previous three years and five years, respectively. The Northern Territory is the only jurisdiction able to report in some capacity on Indigenous women’s participation. The Northern Territory report participation rates for Indigenous women only from areas where the Indigenous female population is greater than 60%, all of which are remote. Indigenous women’s participation rates in 1997–1998 were 31% and increased to 46% in 2009–2010. The participation varied greatly by health service delivery areas (HSDAs); in 2009–2010 the Top End West, East Arnhem and the Central group of HSDAs’ participation was an estimated 39–40% and in Borroloola and Katherine East
participation was 73%–74%. Borroloola serves as a good example that participation can be improved among Indigenous women and that high rates of participation are possible; in 1997–1998 participation was only 15%.124

The Victorian Cervical Cytology Register has not reported participation by Indigenous status but is actively encouraging key partners to record Indigenous status of women screened.109 In 2013, the proportion of women screened who had their Indigenous status recorded was 21.8%. Nursing practitioners were responsible for most of the recording.109

These reports have been important in documenting differences in cervical screening among Indigenous women in Australia and suggest that low participation could be the underlying cause of high cervical cancer incidence among Indigenous women. Despite the evidence they have provided, even if most reports are from small localised areas or indirect estimates, the reports have not generated real action to address the issue of low participation among Indigenous women or the failure of the NCSP to report on Indigenous women. There remains no comprehensive national reporting on cervical screening participation from the NCSP in its 25-year history.

1.5.3.1 Barriers to screening, diagnosis and treatment for Indigenous Australian women

Particular barriers exist in relation to cancer screening and cancer treatment for Indigenous Australians.36,37,147 Fatalistic views about cancer, shame, preference for traditional healing and beliefs that cancer is contagious are some of the views expressed by Indigenous people in Western Australia.147 Beliefs such as ‘screening is unnecessary in the absence of symptoms’, ‘talking about something can make it happen’, that cancer is caused from payback, or cancer is contagious are all barriers to Indigenous people accessing cancer screening and cancer treatment services.148
Barriers to cervical screening participation identified by Indigenous women in Queensland included the following:\textsuperscript{149,150}

- Lack of knowledge about cervical cancer and Pap smears
- Difficulties in communication between Indigenous women and health staff
- Inappropriate promotional material and strategies
- Lack of female doctors
- Negative association of cervical screening with treatment for sexually transmitted infections
- Fear of abnormal Pap smear results.

Additional barriers faced by Indigenous people include the large proportion of the population who live in rural and remote areas where there is decreased access to appropriate health services leading to long distances to travel. The cost of travel may impact on women participating in cervical screening and their ability to access treatment after an abnormal Pap smear.

Internationally, barriers to screening have also been reported among other Indigenous peoples and most are similar to those articulated by Australian Indigenous women. These barriers include sense of fatalism, poor communication with health professionals (including an over-reliance on medical terminology and jargon), gender of health practitioner, shame, transport issues, financial barriers, lack of screening awareness or understanding, misconceptions about risk factors and specific cultural beliefs.\textsuperscript{28}

\subsection*{1.6 Thesis aims and outline}

This thesis responds directly to several recommendations from national health policy, research and program delivery groups regarding the ability to obtain high-quality data for Indigenous women’s participation in cervical screening and/or in the advancement of cancer.
control for Indigenous people. This thesis reports on cervical screening and screening outcomes of Indigenous Australian women in the state of Queensland (which is home to the second largest proportion of Indigenous Australians). The specific methodology, ethics approvals, and funding support for each study are described within each chapter. Chapter 2 provides further background about the inadequate data collection of Indigenous status and its consequences in the NCSP and offers a suggestion for identifying Indigenous women on PSRs through record-linkage. The studies included as chapters in this thesis address the following aims:

1. To report on the process and validity of using record-linkage to identify Indigenous women on the Queensland PSR. (Chapter 3)
2. To describe the participation of Indigenous women compared with non-Indigenous women in cervical screening in Queensland. (Chapter 4)
3. To investigate and compare the prevalence of abnormal Pap smears in screened Indigenous and non-Indigenous women. (Chapter 5)
4. To assess the timeliness of investigation after a high-grade abnormal Pap smear for Indigenous women compared with non-Indigenous women in Queensland. (Chapter 6)

Finally, the thesis concludes with a discussion chapter (Chapter 7) summarising the major findings, limitations and implications of the findings for the future of cervical cancer prevention in Australia.

The thesis is organised in the form of scientific journal publications that have all been published or accepted for publication.

This thesis, the individual studies and the collective, will significantly contribute to moving the cervical cancer prevention agenda forward for Indigenous women, particularly in Australia. This is particularly so as it highlights the importance of having systems in place that are capable of identifying, monitoring and reporting on the participation of marginalised
groups such as Indigenous Australians where the overall disparities in cancer outcomes between Indigenous and non-Indigenous are so large.
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2 How well is the National Cervical Screening Program performing for Indigenous Australian women? Why we don’t really know, and what we can and should do about it
2.1  Preface

Pathology report forms do not record Indigenous status. This data deficiency and the flow-on effect to administrative databases, which use these forms as their main data source, have long been acknowledged and discussed but with little action. Chapter 2 presents a commentary on the consequences of not collecting Indigenous status (using Australia’s National Cervical Screening Program’s registers as an example) and suggests the use of record-linkage to overcome the lack of an Indigenous identifier.

Chapter 2 was an invited commentary which was part of a themed section on informatics and e-health in the *European Journal of Cancer*. The article is presented here in its entirety.

**Whop LJ, Cunningham J, Condon JR.** How well is the National Cervical Screening Program performing for Indigenous Australian women? Why we don't really know, and what we can and should do about it. *European Journal of Cancer Care* 2014; 23(6): 716–20.

2.2  Statement of authorship

All authors and their contributions are clearly outlined below. All co-authors have sent written approvals regarding their contribution towards the manuscript, their approval of the final manuscript and the inclusion of the manuscript in this thesis.

2.3  Author contributions

LJW, JC and JRC conceptualised the design and presentation of ideas. LJW drafted the initial manuscript; all authors contributed critical revisions, read and approved the final draft.

2.4  Published article
Item removed due to copyright restrictions.
3 USING PROBABILISTIC RECORD-LINKAGE
METHODS TO IDENTIFY AUSTRALIAN INDIGENOUS
WOMEN ON THE QUEENSLAND PAP SMEAR
REGISTER: THE NATIONAL INDIGENOUS
CERVICAL SCREENING PROJECT
3.1 Preface

Chapter 3 presents the methodology used to link the Queensland Pap Smear Register (QPSR), the Queensland Cancer Registry and the Queensland Health Admitted Patient Data Collections to overcome the lack of an Indigenous identifier on the QPSR, including the process for and assessment of data quality of linking these existing population-based datasets. The linked dataset is the main source of data used for subsequent analyses in chapters 4, 5 and 6. Chapter 3 has been written as a journal article of which I am the principal author and is presented here in its entirety. This article was published in *BMJ Open* and is available on the journal’s website at [http://bmjopen.bmj.com/content/6/2/e009540.full](http://bmjopen.bmj.com/content/6/2/e009540.full)


3.2 Statement of authorship

All authors and their contributions are outlined below. All authors have sent written approvals regarding their contribution towards the manuscript, the final manuscript and the inclusion of the manuscript in this thesis.

3.3 Author contributions

JRC, JC, PB, GG, PV, DO’C, JMLB, KC and LJW conceptualised the study and contributed to the development of the methodology. LJW, GG and JRC conducted the approval process and initial data acquisition. SPM, LJW, JRC and AD conducted subsequent requests for additional data, and CT conducted the linkage. LJW, AD and PB conducted the data analysis, and CT assisted in the assessment of the linkage. LJW and AD drafted the
manuscript under the guidance of PB and JRC. All authors contributed to the revision of the manuscript, and read and approved the final draft.

3.4 Published article
Using probabilistic record linkage methods to identify Australian Indigenous women on the Queensland Pap Smear Register: the National Indigenous Cervical Screening Project

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ABSTRACT
Objective: To evaluate the feasibility and reliability of record linkage of existing population-based data sets to determine Indigenous status among women receiving Pap smears. This method may allow for the first ever population measure of Australian Indigenous women’s cervical screening participation rates.

Setting/participants: A linked data set of women aged 20–66 in the Queensland Pap Smear Register (PSR, 1999–2011) and Queensland Cancer Registry (QCR, 1997–2010) formed the initial Study Cohort. Two extracts (1995–2011) were taken from Queensland public hospitals data (Queensland Hospital Admitted Patient Data Collection, QHAPDC) for women, aged 20–69, who had ever been identified as Indigenous (extract 1) and had a diagnosis or procedure code relating to cervical cancer (extract 2). The Initial Study Cohort was linked to extract 1, and women with cervical cancer in the initial cohort were linked to extract 2.

Outcome measures: The proportion of women in the Initial Cohort who linked with the extracts (true-pairs) is reported, as well as the proportion of potential pairs that required clerical review. After assigning Indigenous status from QHAPDC to the PSR, the proportion of women identified as Indigenous was calculated using 4 algorithms, and compared.

Results: There were 26,672 women (21.1%) from the Initial Study Cohort who matched to an ever Indigenous record in extract 1 (n=76,631). Women with cervical cancer in the Initial Study Cohort linked to 13,865 (71%) records in extract 2. The proportion of Indigenous women ranged from 2.0% to 2.8% when using different algorithms to define Indigenous status. The Final Study Cohort included 1,372,523 women (PSR n=3,374,402; QCR n=1,953), and 5,062,118 records.

Conclusions: Indigenous status in Queensland cervical screening data was successfully ascertained through record linkage, allowing for the crucial assessment of the current cervical screening programme for Indigenous women. Our study highlights the need to include Indigenous status on Pap smear request and report forms in any renewed and redesigned cervical screening programme in Australia.

BACKGROUND
In 1991, Australia established an organised approach to cervical screening called the National Cervical Screening Program (N CSP),1 The programme currently recommends that all women aged 20–68 years who have ever been sexually active are screened using the Pap smear test (commonly abbreviated to Pap smear or Pap test) every 2 years to detect abnormal cell changes in the cervix. Each State and Territory implemented a Pap Smear Register (PSR) to record women’s screening history and to provide a reminder function for women and their healthcare providers. Since the programme’s inception, there has
been a 50% reduction in cervical cancer incidence and mortality, resulting in one of the lowest incidence rates in the world.\(^2\)

However, Australian Aboriginal and Torres Strait Islander women (hereafter respectfully referred to as Indigenous Australians) have a disproportionately higher burden of cervical cancer, with incidence nearly three times that of non-Indigenous women and mortality over four times higher.\(^2\) It is not clear whether incidence has decreased nationally for Indigenous women in recent years. Despite their higher disease burden, cervical screening participation and outcomes are not known for Indigenous women. Two regional studies indicated that screening participation was considerably lower than national rates for Indigenous women in remote areas of Queensland and the Northern Territory,\(^3\) but information using the standard performance measures of the NCSP for Indigenous women, such as participation or adequate follow-up of abnormalities, is lacking.

These outcomes cannot be measured directly by the NCSP because pathology forms that inform the PSRs do not record Indigenous status.\(^4\) The issue of adding Indigenous status to pathology forms has been under discussion for some time, not only for the NCSP but for other areas in which pathology report forms are the main source of notification (eg, communicable diseases).\(^5\) Despite recent progress,\(^6\) change is still pending and it is likely to take many years before a change in the data collection mechanisms would provide high-quality data on Indigenous identification in PSRs.\(^6\)

Record linkage may be a feasible and more immediate solution to the lack of Indigenous status in PSRs, as has been discussed in other contexts.\(^7\) Record linkage, also referred to as data linkage, is the process of combining information within or across multiple sources relating to an individual.\(^8\) linking the PSR to a population-based data source that includes an accurate measure of Indigenous status has the potential to identify which women in the PSR are Indigenous.\(^9\) In Australia, hospital inpatient data (also known as ‘hospital separations data’) are known to be reasonably accurate sources of Indigenous status for most jurisdictions; the most recent national data quality assessment in 2011–2012 found 88% agreement between hospital records and self-report, nationally.\(^10\)

The National Indigenous Cervical Screening Project (NICSP) is utilising linkage to obtain a data set to assess participation in cervical screening and follow-up of abnormal Pap smear results among Indigenous Australian women compared with non-Indigenous women. Another aim is to examine how screening participation and follow-up of detected abnormalities are associated with survival among Indigenous and non-Indigenous Australian women diagnosed with cervical cancer.

The NICSP was designed as a national study, but due to the differing legislative and data custodian requirements across the country, the data are being obtained separately from each State and Territory. The purpose of this paper is to describe and evaluate the methods used for the Queensland component of the study (the first jurisdiction completed), which linked record in three existing Queensland Health data sets, and to compare and evaluate algorithms for defining Indigenous status.

**METHODS**

**Data sources**

The Queensland component of the NICSP involved the collection of data from three existing administrative data sets: the Queensland PSR, Queensland Cancer Registry (QCR) and the Queensland Hospital Admitted Patient Data Collection (QHAPDC).

The PSR, in operation since February 1999, collects information on Pap smears (ie, demographic details of the woman and the provider, date and results of each test) for all women who screen in Queensland (including interstate residents), and the date and results of follow-up diagnostic tests conducted after an abnormal Pap smear result. Although the PSR includes a data item for Indigenous status, these data are missing for the majority of records because they are not available from pathology reports.\(^1\)

The QCR records information on all invasive cancer cases diagnosed among Queensland residents. Cancer notification and registration in Queensland has been a statutory requirement for all public and private hospitals, nursing homes and pathology services since 1982.\(^1\) Data recorded in the QCR include date of cancer diagnosis, site and type of cancer, date and cause of death and Indigenous status. Indigenous status in the QCR is sourced from hospital notifications, death certificates and pathology when available. Completeness of Indigenous status in the QCR has been reported as 85.8%.\(^1\)

The QHAPDC contains information on hospital episodes of care for patients admitted to Queensland public and private hospitals. However, only public hospital data were included in this study as the majority of Indigenous women in Queensland (approximately 99%) seek hospital care through the public system.\(^1\) The QHAPDC does not include data on emergency department or outpatient clinic episodes. Information recorded in this collection includes clinical characteristics (eg, primary and other diagnoses, procedures occurring during the hospital admission), and demographic characteristics (eg, marital status, residential location, health insurance status and Indigenous status). The collection of Indigenous status is known to be reasonably accurate in Queensland public hospitals. In the most recent audit of Indigenous status data in 2011–2012 in Queensland, 87% (95% CI 84% to 91%) of


Chapter 3
people who self-reported as being Indigenous were recorded as Indigenous in hospital records.14

Record linkage
Specifications for extracting records from each data source were developed and tested in consultation with the relevant data managers and custodians, who then extracted the data from the PSR, QCR and QHAPDC, and provided the extractions to the Queensland Record Linkage Group (QRLG). The QRLG utilised probabilistic record linkage as implemented by the LinkageWiz Data Matching Software (LinkageWiz Inc, Adelaide) with full name, sex, date of birth and address as matching variables to identify potential matching records of women between data sets. Potential matches on each variable were allocated a ‘linkage weight’ to indicate the probability that the match was a ‘true match’. The linkage weights were predefined as the natural logarithm of the ratio of the frequency of agreement in linked pairs to the frequency of agreement in unlinked pairs. The LinkageWiz software classifies potential pairs weighted 11 and lower to be non-matches. While this can be adjusted on a study-by-study basis, the QRLG found this cut-off to be satisfactory and did not clinically review potential pairs with a weighting of 11 or under. Those with a weighting 12 and above were reviewed.

Given the number of records in each of the QHAPDC and the PSR and the resources available to the QRLG at the time, the QRLG was not able to conduct a probabilistic matching of the two complete data sets. For this reason, two specific QHAPDC extracts were used in the linkage (see figure 1, stage 1) instead of the entire QHAPDC data set. Extract 1 contained all episodes for women aged 20–69 years, within hospitals, who had ever been identified as Indigenous between 1995 and 2011 in the QHAPDC. For these women, records from hospitals where the woman never identified as Indigenous are not included. Extract 2 contained all episodes for women aged 20–69 years (regardless of Indigenous status) who were admitted to hospital between 1995 and 2011 with a diagnosis or procedure code related to cervical cancer. After these extracts were obtained, the second stage was implemented.

The second stage was to establish our Initial Study Cohort by linking records in the extracts from the PSR and the QCR (figure 1, stage 2). The Initial Study Cohort was defined as any woman aged 20–69 years who had at least one Pap smear recorded in the PSR between 1989 and 2011 and/or any woman registered in the QCR diagnosed with cervical cancer between 1997 and 2010, the latest available year at the time of record linkage. Once established, the Initial Study Cohort was linked to QHAPDC extract 1 to assign Indigenous status. We assumed women on the PSR who did not match to at least one QHAPDC record were not Indigenous and were assigned as non-Indigenous. This was then linked to extract 2 from the QHAPDC. Individual women were assigned a unique cohort identification number, consistent across data sets. Personal identifiers were removed by the QRLG before the linked data sets were sent to the research team for analysis (figure 1, stage 3).

Various components of the linked data were being utilised to achieve the objectives of the NICSP. The PSR data with Indigenous status derived from QHAPDC are being used to calculate performance indicators for cervical screening for Indigenous women. QCR and PSR data with Indigenous status assigned are being used to examine incidence and survival of cervical cancer. QHAPDC data also provides information on comorbidities recorded in the hospital records. Factors associated with screening participation/outcomes and cancer incidence/survival, such as comorbidities (derived from the QHAPDC) and remoteness and socioeconomic status (derived from information in the PSR, QCR or QHAPDC), are also being investigated.

Assessment of the linkage quality
Linkage quality was assessed initially by the QRLG which required discussions with data custodians and the research team. First, key variables were checked for authenticity (eg, plausible dates of birth, females only, dates of Pap smears, address details, etc). Possible matches were either accepted or rejected after clerical review, and the total number of possible matches accepted as true matches or rejected matches were calculated at each probability score (see online supplementary file 1a–c). We would expect to see relatively few matches between the PSR and the QCR (as cervical cancer is a relatively rare outcome for women who have Pap smears), and a high number of matches between the QCR and QHAPDC extract 2, as most of these women diagnosed with cervical cancer would have been admitted to hospital for their cancer.

Definitions of the Indigenous status algorithms
There is national standardised method of ascertaining and recording Indigenous status so as to maintain consistency across and within administrative data sets.14 Algorithms for defining Indigenous status using linked data sets, including hospital inpatient data, have been developed by the Australian Institute of Health and Welfare (AIHW).15 Such algorithms are necessary because Indigenous status for an individual may vary across records for the same individual.11 19 Reasons for this have previously been articulated, including legitimate changes in identity, changes in reporting procedures over time and changes in perceived acceptance of identifying as an Indigenous person in mainstream institutions.20 21

We compared four algorithms to determine Indigenous status from multiple records, based on the AIHW guidelines and published evidence about the performance of different algorithms13 22 23 Ever Indigenous a woman coded as Indigenous if at least one of her QHAPDC records within the study period identifies her as Indigenous.
Figure 1  Queensland record linkage process. QLD, Queensland; QRLG, Queensland Record Linkage Group.

Most recent admission: a woman was coded as Indigenous if her most recent QHAPDC record in the study period identifies her as Indigenous.

Majority-based: a woman was coded as Indigenous if at least 50% of her QHAPDC records within the study period identify her as Indigenous.
Chapter 3

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Combination: a woman was counted as Indigenous if she was identified as Indigenous on either her most recent QHAPDC record or on at least 50% of her QHAPDC records within the study period.

Indigenous status in QHAPDC is classified as ‘Aboriginal but not Torres Strait Islander origin’, ‘Torres Strait Islander but not Aboriginal origin’, ‘both Aboriginal and Torres Strait Islander origin’, ‘neither Aboriginal nor Torres Strait Islander origin’ and ‘not stated’. Prior to June 1998 Indigenous status was recorded with a different coding system. Therefore, Indigenous status was coded as ‘Indigenous’ (defined as Aboriginal and/or Torres Strait Islander origin) and ‘non-Indigenous’ (neither Aboriginal nor Torres Strait Islander origin or not stated/unknown). Each woman in the PSR was assigned Indigenous status using each of the four algorithms. Women who did not link to extract 1 were assumed to be non-Indigenous. These variables were then merged into the PSR by cohort ID. The proportion of women identified as Indigenous on the PSR was calculated using each of these four algorithms and compared overall, and for 5-year age groups and remoteness groups based on place of residence. For context, the proportion of Indigenous women within the averaged estimated resident population (ERP) was also reported for 5-year age groups and remoteness categories. The proportion of women within our cohort identified as Indigenous was expected to be lower than the ERP regardless of algorithm use given that screening rates are not 100%. Records across all years were mapped to 2011 statistical local areas (SLAs) boundaries based on suburb and postcode. SLAs were then grouped according to level of geographic remoteness based on the Accessibility/Remoteness Index of Australia (ARIA+).

Approvals

Approvals to access and link records were obtained from the Queensland Research Linkage Group (QRLG), data custodians of the included data sets and the Director General of Queensland Health. To facilitate the calculation of time-dependent Pap smear participation rates, subsequent ethics and data custodian amendments were made to request additional information for screening history prior to age 20 for women within our cohort.

RESULTS

Approvals

From the initial ethics approval (Queensland Health) it took 19 months to obtain all relevant ethics and data custodian approvals, 5 months for the data to be extracted, and 3 months for the records to be linked and reviewed. Changes in the State government following a general election in March 2012 reduced the QRLG’s resources, which halted progress for several months and prevented linkage of the entire QHAPDC data set. Consequently, the linkage method was revised to use the two extracts. QRLG did not charge for record linkage.

Linked data set

The Initial Study Cohort was established by linking records from the PSR (n=1374 401) and the QCR (n=1955), where 1355 women existed in both the PSR and QCR data sets. There were 28 872 women (2.1%) from the Initial Study Cohort who matched to an ever Indigenous record in extract 1 (n= 76 831). Women with cervical cancer from the Initial Study Cohort were then linked to extract 2 (n=68 926), resulting in 1385 (71%) women in the Initial Study Cohort being linked to a record relating to a cervical cancer diagnosis or procedure code. Researchers received the non-identifiable Initial Study Cohort data set containing 1 374 821 women and 5 072 909 records. After receiving the linked file, further records were removed by the research team (n=10 951). There were 693 records identified with the same cohort identification number, test date, provider number and result; these were deemed to be duplicates. A further 588 records were identified with the same cohort identification number, Pap smear date and, in most cases, the same provider number but with different results. These were unable to be verified through the PSR manager or laboratory and, therefore, were all excluded. A further 1 042 records were excluded as the age at Pap smear was outside target range (20-69 years). Some women were found to have conflicting dates of birth across their records (n=8308); these were unable to be verified by the PSR and were removed. The Final Study Cohort included 1 372 823 women and 5 002 118 records.

Linkage quality

Linkage of PSR, QCR and QHAPDC

Potential matches which scored 12 or higher were deemed potential true matches and underwent clerical review by QRLG. The linking of the initial cohort (PSR to QCR) identified 47 432 potential matches of records, with 85% (n=40 449) rejected as not being a true match. The initial cohort linked to the QHAPDC extract 1 (women ever identified as Indigenous) had 102 342 potential matches of records identified; 95% were accepted as a true match. As expected, a high proportion of matches (3189 of 3249 potential matches) between women diagnosed with cervical cancer and women with cervical cancer-related diagnosis or procedure codes recorded in the QHAPDC extract 2 were accepted as true matches. The number of potential matches rejected or accepted at each weighting score for each part of the linkage is detailed in online supplementary file 1a-c.

Indigenous status algorithms

Depending on the algorithm, the proportion of Indigenous women in QHAPDC varied only slightly. There was an absolute difference of 0.08%, ranging from 2.00% (majority-based) to 2.08% (ever Indigenous;
Table 1. Indigenous status algorithms derived from applying Queensland Health Admitted Patient Data Collection’s Indigenous status to the Queensland Pap Smear Register, 1999–2011

<table>
<thead>
<tr>
<th>Algorithm</th>
<th>Indigenous*</th>
<th>Non-Indigenous†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ever Indigenous</td>
<td>26,565 (2.08%)</td>
<td>1,343,836 (67.92%)</td>
</tr>
<tr>
<td>Most recent admission</td>
<td>27,077 (2.02%)</td>
<td>1,344,726 (67.98%)</td>
</tr>
<tr>
<td>Majority-based</td>
<td>27,444 (2.00%)</td>
<td>1,344,959 (68.00%)</td>
</tr>
<tr>
<td>Combination</td>
<td>28,124 (2.05%)</td>
<td>1,344,279 (67.95%)</td>
</tr>
</tbody>
</table>

*Indigenous (defined as Aboriginal and/or Torres Strait Islander origin).
†Non-Indigenous (neither Aboriginal nor Torres Strait Islander origin or not stated/unknown).

The algorithms produced similar proportions across 5-year age groups (figure 2) and remoteness of place of residence (figure 3) for the women’s first Pap smear recorded in the past 5 years of the study period (2007–2011).

**DISCUSSION**

Cervical cancer is more common and more fatal for Australian Indigenous women than for the rest of the population.2,3,5,55 Given that it is largely preventable through cervical screening, insight into participation by Indigenous women is of paramount public health importance. This study, through the linkage of three existing public health data collections, has been able to determine, with reasonable confidence, which women in the Queensland PSR are Indigenous. This will enable statewide and regional-specific screening participation rates for Australian Indigenous women to be estimated and reported in a forthcoming paper.

In Queensland, the record linkage approach provides a cost-effective way to overcome the shortcomings of other epidemiological studies, such as small sample size, attrition and difficulty in ascertaining data for vulnerable and marginalised groups.27 To one limitation of this study was that the linkage was not ongoing, and so only provides Indigenous identification information for the cohort of women included in our study and not for subsequent cohorts of women who screen for cervical cancer. Consideration should be given to determining the feasibility of ongoing record linkage in lieu of changes to the pathology forms.

As previously discussed,30 our experience has been that the application and approval process for record linkage is complex, time consuming and often out of the researchers’ control. Despite the challenges associated with record linkage, this project is critical given two decades of national reporting of Pap smear participation rates without any measurement of the performance of the national programme for Indigenous women. The benefits of utilizing record linkage (despite complex administrative processes) have meant that: first, we were able to achieve whole of population data; and second, the individual’s anonymity was able to be truly preserved, as is also reported in other record linkage studies,27 thus overcoming the need for obtaining informed consent which was not feasible.

**Figure 2** Proportion of women at first Pap smear during 2007–2011 who were identified as Indigenous using...
The success of this project heavily relied on a high match rate between the PSR and the QHAPDC. It is likely though that some Indigenous women in the PSR have not been identified as such—either through misclassification in the hospital records, failure to link to a QHAPDC record, or because they did not attend a public hospital during the study period. Consequently, this will lead to some outcome measures (such as participation rates) being underestimated for Indigenous women.

The known, reasonably high, accuracy of the Indigenous identifier contained in the QHAPDC (87% accuracy) was a major advantage of this study. The accuracy in the QHAPDC, however, also varied by remoteness areas. The accuracy of the Indigenous identifier improved with increasing remoteness where major cities reported 72% (95% CI 62% to 80%) accuracy and remote/very remote reported 100% (95% CI 88% to 100%). This means up to 15% of Indigenous women in our cohort overall or up to 28% Indigenous women in major cities may have been incorrectly identified as non-Indigenous or of unknown Indigenous status. While we are unable to quantify the exact extent of misclassification bias in our study, sensitivity analyses using correction factors devised by the AIHW, will be performed for certain outcome measures to account for potential underidentification of Indigenous women for both overall Queensland estimates and by remoteness.

In addition, there remains some uncertainty regarding how many Indigenous women in the PSR were not identified because their PSR record failed to link to their QHAPDC record. It is impossible to quantify these false negatives, because the QRDL did not review potential matches with a weighting lower than 12, as these are deemed too low to be a true match (LinkageWiz Data Matching Software, LinkageWiz Inc, Adelaide). There were many potential pairs with weights equal to 12 which were rejected, but, as the weights increased, the number of rejections decreased. Probabilistic matching based on weighted variables coupled with clerical review has been previously reported as a robust method and, therefore, we expect minimal false-negative matches within this study.

Not all Indigenous women in the PSR would have been admitted to a public hospital during our study period and, as such, would not have been assigned Indigenous status through the record linkage process. In 2011, there was an estimated 50,189 Indigenous women who may have been eligible for inclusion in our study, but that does not include women who died, moved interstate or exclude women who may have had a hysterectomy before 2011. Extract 1 contained 76,831 Indigenous women who were resident in Queensland and aged 20-69 at any time between June 1995 and December 2011. While we cannot estimate the number of women who were eligible for screening at any time between 1995 and 2011, the large excess of women in the extract indicates that a high proportion of eligible Indigenous women were available to be included in the linkage.

The high proportion of eligible women included in extract 1 is plausible given the 15-year time frame of...
QHAPDC data. In addition, from the most recent national reports hospital separation rates are 2.3 times higher for Indigenous than non-Indigenous Australians (896 and 384 per 1000 population).\(^{28}\) Of the separations for Indigenous Australians, 58% were for women, 91% were from public hospitals, and 74% were for those aged between 15 and 64 years.\(^{29}\) Further, the hospital inpatient data collection in Western Australia, which has a statewide unique client identifier for all hospitals, includes approximately 96% of the Western Australian adult female population (personal communication, D Rosman, 2012. Record linkage Unit Manager, WA Department of Health).

The time and effort that would have been required to obtain approvals for private hospital data far outweighed the benefit of including the few Indigenous women who would have been identified through this added process. We may have missed some women from our cohort because we only collected public hospital data; however, this would be small as 96% of hospital separations for Indigenous people in Queensland occur in the public sector.\(^{28}\) Given that 70% of all women and 98% of Indigenous women who gave birth in Queensland during 2000–2009 did so in a public hospital,\(^{35,36}\) we are confident that over the 17 years of QHAPDC collected, we will have ascertainment as close to a population-based sample as possible. While we acknowledge that we may not have been able to capture all Indigenous women, we believe we have captured most using the best data and method that is currently available.

Indigenous identification using QHAPDC data, which may include multiple admission records for each patient, also relies on the algorithm used to define Indigenous status. There were minor differences in the proportion of women in the PSR who were identified as Indigenous using the different QHAPDC-based algorithms for Indigenous status (0.08% difference). Using a combination of the ‘most recent admission’ and the ‘majority-based’ algorithms, 2.05% of women in the PSR were identified as Indigenous. While this is lower than that for the Queensland Indigenous female population aged 20-49 years (2.95% of the Queensland female population aged 20-49 years\(^{21}\)), this was expected based on our hypothesis of lower participation rates for Indigenous women.\(^{7}\) Given that we may have missed some hospital records for some Indigenous women, the ‘most recent’ and ‘majority-based’ algorithms may overestimate the proportion of Indigenous women in the cohort.

It is possible that some eligible women may have been excluded from our study. For example, women who request ‘opt-off’ are deleted from the Queensland PSR and are not included here or in any population statistics derived from the PSR. The proportion of screened women who opt-off the PSR has been reported as less than 1% in other states, but has not been reported for the Queensland PSR.\(^{21,35}\) Similarly, women resident in Queensland but who had all their Pap smears during the study period outside of Queensland will not be included in this study. Queensland resident women who were screened interstate and those whose screening history was not retained in the register will be included in the population denominator but not in the numerator of women who have screened, thus resulting in an underestimate of participation. In contrast, women who are not residents, yet were screened in Queensland will be counted in the numerator but not the population denominator (eg, women who live in border towns, such as Tweed Heads), which would overestimate the screening participation rate. Consideration of how these effects impact on the outcomes will be made when reporting the final results, including assessment of relevant sensitivity analyses.

In 2014, after recommendation by the Medical Services Advisory Committee (MSAC), the Australian Government announced a renewed cervical screening programme (known as the ‘Renewed’) will be implemented by May 2017.\(^{1,38}\) The current implementation stage is concerned with, among other things, implementing a national data collection and register system. As a component of Renewal implementation the aim is to establish a national cervical screening register (real or virtual). Despite the difficulties in collecting information on Indigenous status at an individual level, we recommend that the work programme for the national screening register considers this important issue, which will ultimately facilitate better delivery of care to Indigenous women.

CONCLUSION

This study provides a proof of concept that record linkage can be used to identify Indigenous women in PSR data. The lack of an existing reliable and complete Indigenous identifier in the PSR to date has meant that the performance of the NCSP in Queensland, as in other Australian States and Territories, cannot be evaluated for Indigenous women using the PSR alone. Linkage of the PSR to the QHAPDC, which contains a reasonably accurate Indigenous identifier, does allow for such evaluation for the first time since the inception of the NCSP a quarter of a century ago. While this method can be used to produce reasonable estimates, it may not be a suitable long-term solution. Developing and implementing ongoing culturally safe and accurate ways to capture Indigenous identification in cervical screening registers must be a priority in the Renewal of the NCSP. The assessment of screening participation and outcomes for Indigenous women over the first two decades of the programme, which will be facilitated by the current linkage project, will thus provide a baseline for ongoing assessment of participation and outcomes for Indigenous women if the opportunity to consider the issues around possible collection of information on Indigenous status is implemented for the Renewed NCSP.
Acknowledgments The National Indigenous Cervical Screening Project is funded by a National Health and Medical Research Council (NHMRC) Project Grant (#1045589). This project is part of a NHMRC Centre of Research Excellence in Developing Indigenous Strategies to improve Cancer Outcomes via Engagement, Research Translation and Training (DISCOVER-IT) (the Far North Queensland Human Research Ethics Committee as of 13 March 2015. HREC/15/QCH/19-957), the joint Northern Territory Department of Health and Menzies School of Health Research (HOMER-2012-1727) and Charles Darwin University (H12093).

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

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Supplementary File 1. Outcomes of potential pairs identified through probabilistic record linkage


b) Initial Cohort linked to an extract of women ever identified as Indigenous in the Queensland Hospital Admitted Patient Data Collection, 1995-2011, 20-69 years.

c) Cervical cancer patients in the cohort linked to an extract of women with a cervical cancer diagnosis or procedure code in the Queensland Hospital Admitted Patient Data Collection, 1995-2011, 20-69 years.

NB: y-axis differ for the three figures
4 THE FIRST COMPREHENSIVE REPORT ON INDIGENOUS AUSTRALIAN WOMEN’S INEQUALITIES IN CERVICAL SCREENING: A RETROSPECTIVE REGISTRY COHORT STUDY IN QUEENSLAND, AUSTRALIA, 2000–2011
4.1 Preface

Key performance indicators regarding the participation of Indigenous Australian women in the National Cervical Screening Program (NCSP) have not been reported due to deficiencies in the collection of Indigenous status. Using linked data, as described in Chapter 3, Chapter 4 reports the participation of Indigenous women compared with non-Indigenous women in cervical screening in Queensland among 20–69 year olds from 2000–2011. Participation rates were calculated using the methodology described in the annual reports of the NCSP and presented as the proportion of the eligible screening population, standardised to the 2001 Australian population. Multivariable logistic regression was used to examine participation by Indigenous status, over time, by age-group, place of residence and area-level socioeconomic status.

This chapter has been written as a journal article of which I am the principal author. The article has been published in *Cancer* and is presented here in its entirety.


4.2 Statement of authorship

All authors and their contributions are clearly outlined below. All co-authors provided written approvals regarding their contribution towards the manuscript, their approval of the final manuscript and the inclusion of the manuscript in this thesis.
4.3 Author contributions

LJW, JRC, PB, GG, JC, PCV, DO'C, JMLB, KC, KL, DR and DG conceptualised the study and contributed to the development of the study design and methodology. LJW, GG, JRC conducted the approval process and initial data acquisition and, with SPM and AD, requested additional data. LJW analysed the data, supported by JRC, PB, JC and AD. All authors contributed to the interpretation of findings. LJW drafted the initial manuscript; all authors contributed revisions, read and approved the final draft.

4.4 Published article
Item removed due to copyright restrictions.
5 CERVICAL ABNORMALITIES ARE MORE COMMON AMONG INDIGENOUS THAN OTHER AUSTRALIAN WOMEN: A RETROSPECTIVE RECORD-LINKAGE STUDY, 2000–2011
5.1 Preface
As presented in the previous chapter, screening participation was considerably lower among Indigenous than other women in Queensland, Australia. The primary focus of Chapter 5 is to present the prevalence of cytology-detected low and high-grade cervical abnormalities and histology-confirmed high-grade cervical abnormalities of Indigenous and non-Indigenous women’s Pap smear results. Multivariable logistic regression was used to quantify the association of cervical abnormalities with Indigenous status, age-group, place of residence and area-level disadvantage.

Chapter 5 has been written as a journal article of which I am the principal author. It has been published in *PLoS One* and is presented here in its entirety.


5.2 Statement of authorship
All authors and their contributions are clearly outlined below. All co-authors have sent written approvals regarding their contribution towards the manuscript, their approval of the final manuscript and the inclusion of the manuscript in this thesis.

5.3 Author contributions
LJW, JRC, PB, GG, JC, PCV, D’O’C, JMLB, KC, KL, DR and DG conceptualised the study and contributed to the development of the study design and methodology. LJW, GG and JRC conducted the approval process and initial data acquisition along with assistance from SPM and AD in requests for additional data. LJW analysed the data with support from PB, JRC,
JC, AD and KL. All authors contributed critically to the interpretation of findings. LJW drafted the initial manuscript and all authors contributed to the revisions of the manuscript, and read and approved the final draft.

5.4 Published article

Lisa J. Whooley, Peter Baade, Gail Garvey, Joan Cunningham, Julia M. L. Brotherton, Kamalini Lokuge, Patricia C. Valery, Dianna L. O'Connell, Karen Conneility, Abbey Diaz, David Roder, Dorota M. Gertig, Suzanne P. Moore, John R. Condon

Abstract

Indigenous Australian women have much higher incidence of cervical cancer compared to non-Indigenous women. Despite an organised cervical screening program introduced 25 years ago, a paucity of Indigenous-identified data in Pap Smear Registers remains. Prevalence of cervical abnormalities detected among the screened Indigenous population has not previously been reported. We conducted a retrospective cohort study of population-based linked health records for 1,334,795 female Queensland residents aged 20–69 years who had one or more Pap smears during 2000–2011; from linked hospital records 23,463 were identified as Indigenous. Prevalence was calculated separately for Indigenous and non-Indigenous women, for cytology-detected low-grade (cLGA) and high-grade abnormalities (cHGA), and histologically confirmed high-grade abnormalities (hHGA). Odds ratios (OR) were estimated from logistic regression analysis. In 2010–2011 the prevalence of hHGA among Indigenous women (16.6 per 1000 women screened) was 95% confidence interval [CI] 14.6–18.9) was twice that of non-Indigenous women (7.6 per 1000 women screened, CI 7.3–7.7). Adjusted for age, area-level disadvantage and place of residence, Indigenous women had higher prevalence of cLGA (OR 1.4, CI 1.3–1.4), cHGA (OR 2.2, CI 2.1–2.3) and hHGA (OR 2.0, CI 1.9–2.1). Our findings show that Indigenous women recorded on the Pap Smear Register have much higher prevalence for cLGA, cHGA and hHGA compared to non-Indigenous women. The renewed cervical screening program, to be implemented in 2017, offers opportunities to reduce the burden.
of abnormalities and invasive cancer among Indigenous women and address long-standing data deficiencies.

Introduction

The Australian National Cervical Screening Program (NCSP), introduced in 1991, recommends routine two-year screening by Papanicolaou (Pap) smears for women aged 20 to 69 years who have ever been sexually active, regardless of human papillomavirus (HPV) vaccination status, ethnicity, sexual orientation or religion [1]. The major aim of the NCSP is to detect and treat cervical abnormalities prior to progression to invasive cervical cancer. A national system of state-based Pap Smear Registers (PSR) systematically records results of cervical screening, performs a recall and reminder function for women and their primary care providers, and a safety net function for follow up of screen-detected abnormalities. PSRs provide data for national reporting on screening participation, prevalence of abnormalities, outcomes after an abnormal Pap smear and other program quality indicators [2].

Low-grade abnormalities (LGA), indicated by a cytological diagnosis of a low-grade squamous intraepithelial lesion on a Pap smear, are common among young women and usually represent a cellular response to acute HPV infection [3]. Most LGAs resolve without treatment because the infection is cleared; a repeat smear after 6–12 months is currently recommended (unless a woman is aged over 30 years without a recent normal screening history), because persistent infection increases the risk of a high-grade abnormality being present [4–6]. High-grade abnormalities (HGA), as indicated by a cytological detection of a high-grade squamous intraepithelial lesion or a glandular abnormality, can indicate a true precancerous abnormality of the cervix (cervical intraepithelial neoplasia [CIN] grade 3 or adenocarcinoma in situ) or possibly a CIN grade 2 lesion, which is a diagnostic classification that includes both florid low-grade disease and grade 3 disease [7]. Since it is not possible to determine which high-grade lesions will eventually progress to cancer and which will resolve, all are investigated and treatment of confirmed high grade lesions is recommended by the current National Health and Medical Research Council guidelines (p.53) [8]. Prompt follow-up of cytology predicted HGAs by colposcopy and biopsy is required to confirm the diagnosis prior to treating the lesion [4].

Aboriginal and Torres Strait Islander women, hereafter respectfully referred to as Indigenous Australian women, have cervical cancer incidence and mortality rates two and four times higher than their non-Indigenous counterparts [9,10]. The NCSP cannot report on screening participation, abnormalities or outcomes for Indigenous women because pathology report forms (the source of information for PSRs) do not include Indigenous status [10–12].

Recently, using record-linkage methods [13], we have reported lower cervical screening participation rates among Indigenous women compared to non-Indigenous women in Queensland [14]. We report for the first time the prevalence of cervical abnormalities for Indigenous women compared to non-Indigenous women participating in cervical screening in Queensland, where 26.5% of the total Australian Indigenous population residing in this Australian state.

Methods

Data Sources

The detailed data extraction and linkage methods have been described previously [13]. Briefly, the dataset included linked records from the Queensland PSR and the Queensland Hospital
compared with non-Indigenous women had cLGA and cHGA ($p<0.001$) overall and this was consistent by age-group, area-level disadvantage and place of residence.

The odds of Indigenous women having cLGA (OR 1.7, 95% CI 1.6–1.7), cHGA (OR 2.8, CI 2.7–3.0) and hHGA (OR 2.6, CI 2.5–2.8) were higher than non-Indigenous women after adjusting only for year of Pap smear. The odds remained higher when adjusted further for area-level disadvantage, place of residence and age-group, for example, cLGA OR 1.4, CI 1.3–1.4 (Table 3).

The prevalence of cLGA decreased after 2005; was lower for older than younger women, but was not associated with area-level disadvantage. Compared to women in inner regional areas, women living in all other areas had a higher prevalence of cLGA. For all women, cLGA prevalence significantly decreased over time in all age-groups (Table 4). The prevalence of cHGA increased over time, was lower in the most affluent area, and for older women, but was higher in outer regional, remote and very remote areas (Table 3).

The prevalence of hHGA was higher among Indigenous (16.5 per 1000 women screened, CI 13.9–19.5) than non-Indigenous women (7.3 per 1000 women screened, CI 7.1–7.6), in 2000–2001 and remained relatively constant in both groups up to 2010–2011 (16.6 per 1000 women screened, CI 14.6–18.9 and 7.5 per 1000 women screened, CI 7.3–7.7, respectively). Prevalence was higher for Indigenous women in each age-group (Fig 1). In the 20–29 year age-group, prevalence of hHGA increased over time for Indigenous women only and multivariable analysis confirmed this was a statistically significant trend (Table 4). There were no significant changes in prevalence of hHGA over time for other age-groups among Indigenous women. Among non-Indigenous women, hHGA prevalence decreased significantly in 40–69 year olds.
Admitted Patient Data Collections (QHAPDC). The Queensland PSR was used to identify women resident in Queensland aged 20–69 years (at the time of testing) who had a Pap smear between February 1999 (the start of the Queensland PSR) and December 2011, and had not opted to be excluded from the Queensland PSR. Variables obtained from the Queensland PSR included: date of birth (mm/yyy); place of residence (suburb and postcode); test date; type (cytology or histology); and result. An Indigenous identifier was assigned to the PSR cohort by linking to a QHAPDC extract of women aged 20–69 years who had ever been identified as Indigenous when admitted to a Queensland public hospital during 1995–2011. The QHAPDC has reasonably high accuracy of Indigenous status in 2011/12, 87% (95% CI 84–91) of Indigenous inpatients were correctly identified as Indigenous in hospital records (compared to self-identification) [15]. Women who linked to at least one QHAPDC record were identified as Indigenous if at least 50% of their QHAPDC records identified them as such [13,16]. Those who did not match to at least one QHAPDC extract record, or had fewer than 50% of their QHAPDC records identified as Indigenous, were assumed to be non-Indigenous. Women were excluded from the study if they had insufficient details to determine the statistical local area (SLA) of residence within Queensland for at least one Pap smear.

Outcome Measures
Abnormal Pap smear results were categorised according to the Australian Modified Bethesda System 2004 as: low-grade abnormality (LGA: possible or definitive low-grade squamous intraepithelial lesion detected at cytology (includes previous terminology of atypical squamous cells of undetermined significance)); or high-grade abnormality (HGA: prediction of CIN 2 or higher, adenocarcinoma in situ, or invasive cancers (includes previous terminology of atypical squamous cells, possible high-grade lesion)), consistent with current national reporting [4]. Cytology-detected LGA and HGA are hereafter referred to as cLGA and cHGA, respectively, to distinguish them from histologically confirmed HGA (hHGA). We categorised women as having an hHGA if there was a record of hHGA within six months after the date of a Pap smear. Women with an HGA histology report who had not had a cytology test within the previous six months were excluded because these tests may have resulted from investigations other than cervical screening.

Location of residence based on suburb and postcode at the time of Pap smear was mapped to the 2011 SLA boundaries. If the address information for a specific Pap smear was insufficient to determine SLA, then information from the closest adjacent record for the same woman was used. SLAs were grouped into five categories from major city to very remote [17]. We assigned an area-based measure of socioeconomic disadvantage to each woman based on the SLA of place of residence using the Index of Relative Socio-Economic Advantage and Disadvantage, with Queensland population-based quintiles from most disadvantaged to most affluent [18].

Statistical analyses. Demographic characteristics are presented as medians (with inter-quartile ranges [IQR]) for non-normally distributed continuous variables and as frequencies and percentages for categorical variables. Proportions for different groups of women were compared using chi-squared tests. Prevalence of hHGA was determined by dividing the number of hHGA in each two-year calendar period (2000–2001 to 2010–2011) by the number of women who were screened in the corresponding two-year period and directly age-standardised based on the 2001 Australian Estimated Resident Population and expressed per 1000 women [19]. Simple linear regression was used to graphically present the association of age-standardised hHGA prevalence and time period stratified by Indigenous status. Logistic regression was used to quantify the association (as odds ratios) between independent variables of interest and the prevalence of each of cLGA, cHGA and hHGA. The regression
models for each outcome included five a priori independent categorical variables of interest (the 'main effects' model): Indigenous status; age at time of test; in age groups of 20–29, 30–39, 40–49 (reference category), 50–59 and 60–69 years; two-year calendar periods from 2000–2001 (reference category) to 2010–2011; place of residence (inner regional as the reference category); and disadvantage quintiles (quintile 3 as the reference category). An interaction between each independent variable and Indigenous status was assessed, but these were not included in the final models because inclusion of the individual interaction terms did not change the estimates for the other a priori variables substantially. To examine if prevalence of abnormalities within each age-group was changing over time, we fitted separate logistic models for each age-group for cLGA and hHGA, including two-year calendar periods as an ordinal variable and Indigenous status, area-level disadvantage and place of residence. We assessed if temporal trends differed by Indigenous status by fitting an interaction term.

To assess whether hHGA was more common for women who had not previously had a Pap smear, we selected women aged 30–69 years who had a Pap smear in 2010–2011 and dichotomised their screening history into 'yes previous screen' or 'no previous screen' using a ten-year look-back period (2000–2009). Of these women, we determined how many had an hHGA up to six months after their Pap smear in 2010–2011.

Given the non-independence of multiple tests carried out for each woman, we accounted for clustering (i.e. treating each woman as a cluster) in the logistic models and assessed the overall model fit. Because the likelihood ratio test was not appropriate when accounting for clustering, we used the Wald chi-squared test to determine overall significance of each covariate and interaction term. Joint chi-squared tests were used to assess the contribution of each variable to model fit, and the Z test to assess the significance of individual coefficients within the logistic model.

All analyses were conducted using Stata (Version 14.0, Stata Corporation, College Station, TX) [20].

The Human Research Ethics Committees (HREC) of Queensland Health (Far North Queensland HREC HREC/15/QCH/19-957), the Northern Territory Department of Health & Menzies School of Health Research (HOMER-2012-1737) and Charles Darwin University (H12993) approved the study along with the Queensland Research Linkage Group, data custodians, and director general of Queensland Health to access and link records. The research team received a de-identified linked dataset and therefore was unable to obtain individual consent from participants. This process was approved by the aforementioned ethics committees.

Results

We excluded 1545 women with conflicting dates of birth, 3174 women with missing address details (a total of 11,072 Pap tests) and 518 women with hHGA only. Our final cohort included 1,334,795 women with 4,565,250 Pap smears from 2000–2011. There were 26,829 Indigenous women (2.0%) identified in the PSR cohort with 87,372 Pap smears. The median number of Pap smears per woman was similar for Indigenous and non-Indigenous women (3, IQR 1–5). Similar proportions of Indigenous and non-Indigenous women had only one (26.9% vs 26.6%), two or three (35.4% vs 30.9%) and four or more (37.7% vs 42.4%) Pap smears during the study period. The demographic details of women at their first recorded Pap smear are summarised in Table 1. Indigenous women compared to non-Indigenous women were more likely to be younger (median age 34, IQR 27–43 vs 40, IQR 30–50), live outside major cities and live in less affluent areas.

The proportions of abnormal tests by socio-demographic variables for Indigenous and non-Indigenous women are shown in Table 2. Greater proportions of tests for Indigenous women
### Table 2. Demographic characteristics of Indigenous and non-Indigenous women’s Pap smears by abnormality, 2009–2011.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Indigenous</th>
<th></th>
<th></th>
<th>Non-Indigenous</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>% cLGA</td>
<td>% cHGA</td>
<td>N</td>
<td>% cLGA</td>
<td>% cHGA</td>
</tr>
<tr>
<td>No. Pap smears</td>
<td>67,372</td>
<td>5.6</td>
<td>3.2</td>
<td>4,777,876</td>
<td>4.3</td>
<td>1.2</td>
</tr>
<tr>
<td>Age group (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>20–24</td>
<td>15,465</td>
<td>13.4</td>
<td>5.7</td>
<td>481,149</td>
<td>10.9</td>
<td>2.3</td>
</tr>
<tr>
<td>25–29</td>
<td>15,897</td>
<td>8.5</td>
<td>5.2</td>
<td>554,668</td>
<td>6.8</td>
<td>2.2</td>
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<tr>
<td>30–39</td>
<td>26,654</td>
<td>6.0</td>
<td>3.1</td>
<td>1,193,327</td>
<td>4.3</td>
<td>1.4</td>
</tr>
<tr>
<td>40–49</td>
<td>16,659</td>
<td>4.7</td>
<td>2.1</td>
<td>1,080,806</td>
<td>3.7</td>
<td>0.7</td>
</tr>
<tr>
<td>50–59</td>
<td>8619</td>
<td>3.4</td>
<td>1.3</td>
<td>765,180</td>
<td>2.8</td>
<td>0.5</td>
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<td>60–69</td>
<td>3,826</td>
<td>3.4</td>
<td>1.5</td>
<td>402,748</td>
<td>2.0</td>
<td>0.5</td>
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<tr>
<td>Area-level disadvantage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q1</td>
<td>24,546</td>
<td>7.2</td>
<td>3.6</td>
<td>501,561</td>
<td>4.5</td>
<td>1.2</td>
</tr>
<tr>
<td>Q2</td>
<td>30,114</td>
<td>7.0</td>
<td>3.7</td>
<td>996,147</td>
<td>4.6</td>
<td>1.3</td>
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<tr>
<td>Q3</td>
<td>15,363</td>
<td>7.2</td>
<td>3.3</td>
<td>1,042,366</td>
<td>4.6</td>
<td>1.2</td>
</tr>
<tr>
<td>Q4</td>
<td>13,164</td>
<td>7.4</td>
<td>3.6</td>
<td>1,080,243</td>
<td>4.8</td>
<td>1.2</td>
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<tr>
<td>Q5 (most affluent)</td>
<td>4,185</td>
<td>6.9</td>
<td>2.7</td>
<td>857,561</td>
<td>4.8</td>
<td>1.1</td>
</tr>
<tr>
<td>Place of residence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major cities</td>
<td>21,324</td>
<td>7.0</td>
<td>3.1</td>
<td>2,745,136</td>
<td>4.8</td>
<td>1.1</td>
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<tr>
<td>Inner regional</td>
<td>13,503</td>
<td>7.1</td>
<td>3.4</td>
<td>895,540</td>
<td>4.2</td>
<td>1.2</td>
</tr>
<tr>
<td>Outer regional</td>
<td>35,000</td>
<td>7.0</td>
<td>3.7</td>
<td>761,111</td>
<td>4.9</td>
<td>1.3</td>
</tr>
<tr>
<td>Remote</td>
<td>6609</td>
<td>8.4</td>
<td>4.4</td>
<td>46,932</td>
<td>5.0</td>
<td>1.6</td>
</tr>
<tr>
<td>Very remote</td>
<td>10,806</td>
<td>7.0</td>
<td>3.3</td>
<td>29,158</td>
<td>4.9</td>
<td>1.7</td>
</tr>
</tbody>
</table>

Notes:
1. Table 2 shows the proportion of abnormal results from the total number of tests by Indigenous status (excluding tests that were taken in the same year with the same result).
2. cLGA: Cytology detected low-grade abnormality; cHGA: cytology detected high-grade abnormality.

* Statistically significant chi-squared test for association, p<0.001 comparing the proportion of abnormal Pap smears among Indigenous women and the proportion of abnormal Pap smears among non-Indigenous women.

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In 2010–2011, 348,549 women aged 30–69 years had a Pap smear, of whom 1.6% were Indigenous. hHGA was more common among women without a Pap smear history (unadjusted prevalence Indigenous: 36.6 per 1000 women without and 11.3 per 1000 with screening history; non-Indigenous: 10.7 per 1000 without and 4.5 per 1000 with screening history).

We carried out a sensitivity analysis by re-running all models and estimating hHGA prevalence by excluding cervical cancer in the definition of the outcome variable; there were no differences in these and the main results for the prevalence of hHGA (comparison data not shown). We also calculated a histology detection rate, based on the number of HGAs reported by histology, using the method as reported by the Australian Institute of Health and Welfare [21]: the detection rate was 23 and 9 per 1000 women screened in 2011 for Indigenous women and non-Indigenous women, respectively.

**Discussion**

Indigenous women had markedly higher prevalence of cytology-detected and histology-confirmed cervical abnormalities than non-Indigenous women. The prevalence of cHGA increased over time for Indigenous women only. Prevalence of cLGA decreased over time for both groups of women.
Table 3. Association of Indigenous status, calendar period, place of residence, area-level disadvantage and age with risk of cytology detected low-grade abnormalities and cytological and histological high-grade abnormalities including cervical cancer.

<table>
<thead>
<tr>
<th>Variables</th>
<th>cLGA Adjusted ORs (95% CI)</th>
<th>cHGA Adjusted ORs (95% CI)</th>
<th>HhHGA Adjusted ORs (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indigenous women</td>
<td>1.38 (1.33–1.43)</td>
<td>2.16 (2.05–2.27)</td>
<td>1.98 (1.87–2.10)</td>
</tr>
<tr>
<td>Year</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000–2001</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>2002–2003</td>
<td>0.99 (0.98–1.01)</td>
<td>1.04 (1.00–1.07)</td>
<td>1.07 (1.03–1.11)</td>
</tr>
<tr>
<td>2004–2005</td>
<td>0.99 (0.97–1.00)</td>
<td>1.19 (1.15–1.23)</td>
<td>0.98 (0.94–1.01)</td>
</tr>
<tr>
<td>2006–2007</td>
<td>0.82 (0.80–0.83)</td>
<td>1.23 (1.19–1.28)</td>
<td>0.92 (0.88–0.96)</td>
</tr>
<tr>
<td>2008–2009</td>
<td>0.83 (0.84–0.86)</td>
<td>1.19 (1.15–1.23)</td>
<td>0.94 (0.91–0.98)</td>
</tr>
<tr>
<td>2010–2011</td>
<td>0.52 (0.57–0.59)</td>
<td>1.25 (1.25–1.33)</td>
<td>1.02 (0.98–1.06)</td>
</tr>
<tr>
<td>Area-level disadvantage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q1</td>
<td>1.00 (0.98–1.02)</td>
<td>1.06 (1.02–1.10)</td>
<td>1.04 (1.00–1.09)</td>
</tr>
<tr>
<td>Q2</td>
<td>1.01 (0.99–1.03)</td>
<td>1.06 (1.03–1.09)</td>
<td>1.08 (1.04–1.12)</td>
</tr>
<tr>
<td>Q3</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Q4</td>
<td>1.01 (0.99–1.03)</td>
<td>1.02 (0.99–1.06)</td>
<td>0.97 (0.94–1.00)</td>
</tr>
<tr>
<td>Q5 (most affluent)</td>
<td>1.00 (0.98–1.02)</td>
<td>0.98 (0.97–0.99)</td>
<td>0.91 (0.89–1.02)</td>
</tr>
<tr>
<td>Place of residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major city</td>
<td>1.09 (1.06–1.11)</td>
<td>0.99 (0.96–1.02)</td>
<td>1.02 (0.98–1.05)</td>
</tr>
<tr>
<td>Inner regional</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Outer regional</td>
<td>1.12 (1.10–1.14)</td>
<td>1.09 (1.05–1.12)</td>
<td>1.07 (1.03–1.11)</td>
</tr>
<tr>
<td>Remote</td>
<td>1.12 (1.08–1.16)</td>
<td>1.24 (1.15–1.34)</td>
<td>1.18 (1.08–1.30)</td>
</tr>
<tr>
<td>Very remote</td>
<td>1.05 (1.04–1.16)</td>
<td>1.11 (1.02–1.22)</td>
<td>1.04 (0.93–1.16)</td>
</tr>
<tr>
<td>Age group (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20–29</td>
<td>2.53 (2.50–2.57)</td>
<td>3.15 (3.05–2.27)</td>
<td>4.20 (4.05–4.36)</td>
</tr>
<tr>
<td>30–39</td>
<td>1.18 (1.16–1.20)</td>
<td>1.87 (1.81–1.92)</td>
<td>2.30 (2.21–2.39)</td>
</tr>
<tr>
<td>40–49</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>50–59</td>
<td>0.75 (0.74–0.77)</td>
<td>0.70 (0.67–0.73)</td>
<td>0.53 (0.50–0.56)</td>
</tr>
<tr>
<td>60–66</td>
<td>0.52 (0.50–0.53)</td>
<td>0.50 (0.48–0.53)</td>
<td>0.42 (0.39–0.46)</td>
</tr>
</tbody>
</table>

Notes:
1. Binary logistic regression model comparing odds of having an abnormality adjusted for all a priori variables in the table. Clustering of Pap smear for women was accounted for in each model.
2. Table 3 presents OR, Odd Ratios: 95% CI, 95% Confidence Intervals
3. Each independent variable in the table had overall p<0.001 and each outcome variable (type of abnormality) p<0.001.

doi:10.1371/journal.pone.0150473.t003

We were able to identify Indigenous women in the PSR only if women had been a public hospital inpatient between 1995 and 2011 [13]. Women admitted to hospital may differ from those who were not. Indirect evidence suggests that almost all Indigenous women in the age-range for our study would have been admitted to a public hospital over the 17 year period that we used to identify Indigenous women [13], so it is likely that our results apply to almost all screening women. Queensland has the second highest proportion of Indigenous people in its population and they have widely varied geographic and socioeconomic characteristics. Therefore, it is probable that the results for Queensland be applicable to the broader Australian Indigenous population.

The availability of individual-level PSR data facilitated a more precise method for estimating the prevalence of hHGA than reported previously [21]. This previous method calculated hHGA...
prevalence from aggregated data supplied by PSRs: number of hHGAs (excluding cancer) divided by the number of women screened. We calculated hHGA prevalence directly for screened women (i.e. including only hHGA/cervical cancer if there was a record of a recent Pap smear) using individual-level data. This increased precision in estimating hHGA prevalence in screened women provides greater validity of our study findings. Differences in estimation methods mean comparisons with previously published estimates requires some caution [22].

Participation in cervical screening of Indigenous women is significantly less than that of non-Indigenous women in Queensland, a known risk factor for cervical cancer [11]. Increasing screening among Indigenous women would likely reduce HGAs. We did not have data about other risk factors such as persistent HPV infection, lower individual-level socio-economic status, lower education level, smoking, possible dietary deficiencies, oral contraception, age at first intercourse and early and higher parity [23–27]. The prevalence of HPV types 16 and 18 has previously been reported to be similar for Indigenous and non-Indigenous women and more recently similar age at sexual debut has been reported [28,29]. Some evidence indicates that Indigenous women have lower prevalence of other oncogenic HPV types in the 36–40 year age-group [29]. Indigenous women in this cohort had much higher prevalence of LGAs—a known marker of productive HPV infection—and hHGAs, of which 50–60% are caused by HPV types 16 and 18 [3,39]. This suggests that a difference in HPV infection patterns may exist. Young Indigenous women have higher smoking rates [2], lower age at parity and higher fertility rates [31], less oral contraceptive use [29] and are more likely to live in areas of disadvantage [3]. It is crucial to understand the possible role of these factors in the increased risk of HGAs developing (or not regressing) among Indigenous women.

The Australian Government has announced changes to the current NCSP which will shift to a new program (the 'Renewal') in May 2017 using primary HPV testing every five years for women aged 25–74 years [32,33]. Starting screening at age 25 is consistent with international reports showing that screening and treatment of HGAs below the age of 25 is not effective at preventing cancer [34], and will occur in the context of the significant decline in high-grade lesions in 20–24 year olds following the 2007 introduction of the national HPV vaccination program in Australia [10,35]. Given our findings it is timely and important that the Renewal helps address the needs of Indigenous women. High prevalence of HGAs among Indigenous women has previously been reported among Indigenous women in remote areas [22]. Increasing the uptake of HPV vaccination for Indigenous children must be a priority. Although some evidence indicates coverage and/or dose completion rates for Indigenous female adolescents

Table 4. Time trends in prevalence of cytology low-grade and histologically confirmed high-grade abnormalities by age-group, 2000–2011.

<table>
<thead>
<tr>
<th>Age-group*</th>
<th>cLGA All women†</th>
<th>Indigenous</th>
<th>Non-Indigenous</th>
</tr>
</thead>
<tbody>
<tr>
<td>20–29</td>
<td>0.94 (0.94–0.94)</td>
<td>1.07 (1.02–1.12)</td>
<td>1.00 (0.99–1.01)</td>
</tr>
<tr>
<td>30–39</td>
<td>0.99 (0.99–0.99)</td>
<td>0.99 (0.95–1.05)</td>
<td>0.99 (0.98–1.01)</td>
</tr>
<tr>
<td>40–49</td>
<td>0.84 (0.84–0.85)</td>
<td>1.03 (0.93–1.14)</td>
<td>0.96 (0.94–0.98)</td>
</tr>
<tr>
<td>50–59</td>
<td>0.81 (0.81–0.82)</td>
<td>0.92 (0.76–1.12)</td>
<td>0.94 (0.91–0.97)</td>
</tr>
<tr>
<td>60–69</td>
<td>0.81 (0.80–0.82)</td>
<td>0.84 (0.69–1.02)</td>
<td>0.81 (0.77–0.86)</td>
</tr>
</tbody>
</table>

Notes:
1. Table 4 reports OR (Odd Ratios) for a two-year increase in time; followed by 95% CI (Confidence Intervals).
2. cLGA: Cytology detected low-grade abnormality; hHGA: cytology detected high-grade abnormality.
*each model included indigenous status, area-level disadvantage and place of residence and an interaction term for Indigenous status and year.
†ORs were similar for Indigenous and non-Indigenous women for cLGAs over time and therefore have been presented for all women combined.

doi:10.1371/journal.pone.0150473.t004
Fig 1. Prevalence of histologically confirmed high-grade abnormalities per 1000 women screened, by age-group and Indigenous status, 2000–2011.

doi:10.1371/journal.pone.0150473.g001
during the catch-up phase were lower than for non-Indigenous female adolescents [36], reassuringly, early vaccination program outcomes in terms of falls in presentations for anogenital warts (caused by HPV types also included in the vaccine) have been similar for 15–25 year old Indigenous and non-Indigenous females [37]. Over the longer term, it is hoped that current school-based routine HPV vaccination, which now includes boys as well as girls, will encourage relatively high ongoing coverage overall and that this mode of delivery will reduce inequalities in outcomes for Indigenous women.

The Renewal will provide the option of self-collection of HPV samples for under-screened and never-screened women, which is supported by international evidence that self-collection can increase screening among these groups [38]. Other opportunities to increase screening include an invitation to commence screening at a woman’s 25th birthday using a call-and-recall system inviting women to rescreen, rather than the current reminder-based screening system. Possible mediums of invitations could be considered such as using SMS or email or letter and the inclusion of educational resources and information.

Evidence suggests that there has been some reduction in the incidence of cervical cancer over time among Indigenous women [9,10,39], indicating that efforts to reduce the burden of cervical cancer for Indigenous women have been somewhat effective. For over two decades the NCSP has been unable to report on the impacts of the program for Indigenous Australian women on a wide range of outcomes [11,12,21]. The Renewal program must take the critical opportunity to ensure that Indigenous women are able to be recorded in the proposed national registry. Our study provides benchmark measures giving an opportunity to develop and assess the effectiveness of interventions designed to increase the number of women who are followed up for a serious abnormality and reduce the severity of those outcomes.

Internationally, Australia has been at the forefront of cervical cancer prevention. However, below the surface of this success, Indigenous Australian women carry a disproportionate burden of disease, comparable to many countries without the resources available in Australia. The Renewal of the cervical screening program provides the opportunity to overcome long standing data deficiencies and should consider the Indigenous-specific patterns and trends identified in our study. It is imperative that any major changes to current screening practices prioritise Indigenous women. Failure to do so will result in further disenfranchisement and disadvantage of Indigenous women, their families and their communities.

Acknowledgments

We would like to acknowledge the staff and registrars from the Queensland Pap Smear Register, the Queensland Cancer Registry and the Queensland Health Admitted Patient Data Collections for their assistance in providing the data, and the Queensland Research Linkage-Group for linking the data. We gratefully acknowledge Tegan Harris for a range of contributions, including building and designing the database.

Author Contributions

Conceived and designed the experiments: LJW JRC PB GG JC PCV DO JMLB KC KL DR DG. Analyzed the data: LJW. Wrote the paper: LJW JRC PB GG JC PCV DO JMLB KC KL DR DG SPM AD. Contributed critically to the interpretation of study findings: LJW JRC PB GG JC PCV DO JMLB KC KL DR DG SPM AD. Conducted the approval process and data acquisition: LJW GG JRC AD SPM. Provided data analysis support: PB JRC JC AD KL.

References


32. MSAC (Medical Services Advisory Committee) (2014) MSAC application no. 1276: National Cervical Screening Program renewal. Canberra: MSAC.


6 Time to clinical investigation after a high-grade abnormal Pap smear between Indigenous women and non-Indigenous women in Queensland, 2000–2009
6.1 Preface
As demonstrated in the previous chapter, high-grade abnormal Pap smears are more common for Indigenous than non-Indigenous women. Chapter 6 investigates the timeliness of clinical investigation for Indigenous (compared with non-Indigenous) women after a high-grade abnormal result. Overall probability of receiving follow-up within 12 months was calculated using the Kaplan-Meier method and Cox proportion hazards regression was used to assess if Indigenous status, area-level disadvantage, place of residence and age-group were associated with time to clinical investigation.

Chapter 6 has been accepted for publication by the Medical Journal of Australia. The manuscript is presented here in its entirety.


6.2 Statement of authorship
All authors and their contributions are clearly outlined below. All co-authors have sent written approvals regarding their contribution towards the manuscript, their approval of the final manuscript and the inclusion of the manuscript in this thesis.

6.3 Author contributions
LJW, JRC, PB, GG, JC, PCV, DO’C, JMLB, KC, KL, DR and DG conceptualised the study and contributed to the development of the overall study design and methodology. LJW, GG and JRC conducted the approval process and initial data acquisition along with assistance.
from SPM and AD in requests for additional data. LJW, PB and JRC devised the analysis plan and LJW analysed the data with support from PB and JRC. All authors contributed critically to the interpretation of findings. LJW drafted the initial manuscript and all authors contributed to the revisions of the manuscript, and read and approved the final draft.

### 6.4 Accepted article
ABSTRACT

Objectives: To investigate time to follow-up for clinical investigation after a high-grade abnormality (HGA) detected by Pap smear for Indigenous and non-Indigenous women in Queensland.

Design/setting/participants: Population-based retrospective cohort study using linked data from the Queensland Pap Smear Register (PSR), cancer registry and hospital admitted patient data. 34,980 women aged 20–68 years (1,592 Indigenous) with their first HGA Pap smear recorded on the PSR (index smear) during 2000–2009 were included and followed to 2010.

Main outcome measures: Time (in days) from the HGA index smear to clinical investigation (histology test or cancer diagnosis date). The follow-up time was censored at 12 months.

Results: The percentage of women who had a clinical investigation within two months after a HGA was lower for Indigenous (34.1%, 95% CI 31.8-36.4) than non-Indigenous (46.5%, 46.0-47.0) women (unadjusted incidence rate ratio [IRR] =0.65, 0.60–0.71). A differential remained after adjusting for place of residence, area-level disadvantage and age-group (adjusted IRR 0.74, 0.68-0.81). However, after the initial two months, Indigenous women who had not been followed up already were more likely to have a clinical investigation than non-Indigenous women (adjusted IRR for 2–4 month interval 1.18, 1.05-1.33); by six months a similar percentage of Indigenous (62.2%, 59.8-64.6) and non-Indigenous (62.8%, 62.2-63.3) women had been followed up.

Conclusions: Follow-up within two months needs to improve for Indigenous women, but slow follow-up is a small contributor (at most) to their higher cervical cancer incidence and mortality, compared to low screening participation.
SUMMARY BOX

**The known:**

- The burden of cervical cancer is greater for Indigenous than non-Indigenous women.
- Cervical screening participation is significantly lower and prevalence of cervical abnormalities is significantly higher among Indigenous women compared with non-Indigenous women in Queensland.

**The new:**

- Indigenous women are less likely to receive clinical investigation after a high-grade abnormal Pap smear within the recommended two months, however by the six months follow-up was similar for Indigenous women.

**The implications:**

- Improving timeliness of follow-up and increasing participation in cervical cancer prevention is important to reduce inequalities among Indigenous women, which could be addressed in the Renewed National Cervical Screening Program beginning May 2017.
BACKGROUND

For most Australian women, cervical cancer control efforts have been a success. Cervical cancer incidence and mortality have decreased by over 50% since the introduction of the National Cervical Screening Program (NCSP) in 1991. The NCSP currently recommends women aged 18-69 years who have ever been sexually active have a Pap smear every two-years to detect and treat cervical abnormalities before they progress to cervical cancer. Current guidelines recommend clinical investigation by a specialist within two months of a high-grade abnormal (HGA) Pap smear as it is these abnormalities which in some women progress to cervical cancer. Investigation typically involves a colposcopy to examine the cervix and biopsy the affected area to confirm the diagnosis histologically.

Cervical cancer incidence and mortality are two and four times higher respectively for Aboriginal and Torres Strait Islander (hereafter referred to respectfully as Indigenous) than non-Indigenous women. The recent decreases in cervical cancer incidence among Indigenous women in the Northern Territory and suggestive evidence of a decrease nationally indicate that efforts to prevent cervical cancer in Indigenous women may have been partially effective. However, in the absence of routine screening data for Indigenous women, how this has been achieved and what gaps remain cannot be assessed.

We recently reported Indigenous women’s cervical screening participation was 20 percentage points lower than, and their prevalence of HGAs twice as high as, non-Indigenous women in Queensland. Here, we report on the adequacy of follow-up for clinical investigation among Indigenous and non-Indigenous women after a HGA Pap smear.

1, 2, 3, 4, 5, 6, 7, 8
METHODS

We conducted a record-linkage study using data from the Queensland Pap Smear Register (PSR), the Queensland Hospital Admitted Patient Data Collections (QHAPDC) and the Queensland Cancer Registry (QCR). All three datasets include Indigenous status, but the PSR Indigenous status data are unreliable and incomplete. The data extraction and record linkage process have been described elsewhere. Briefly, the PSR was used to identify Queensland resident women aged 20–69 who had a Pap smear between 8 February 1999 (the start of the PSR) and 31 December 2011. We linked the PSR to hospital inpatient records of women aged 20-69 who had ever been identified as Indigenous at a hospital admission between 1995 and 2011. The QHAPDC has high accuracy of Indigenous status (87%, 95% CI 84-91). Women were classified as Indigenous if they linked to at least one QHAPDC record and if ≥50% of their records were reported as Indigenous. All other women were classified as non-Indigenous. The linked analysis dataset contained date of birth, residence (suburb/postcode), test date, test type (cytology or histology) and test result from the PSR; Indigenous status determined using QHAPDC data; and, where relevant, cervical cancer diagnosis date from the QCR. Women were excluded if their address details were insufficient to determine Queensland residency. There were no missing data across variables used in this analysis.

Study population

Women aged 20-69 years from the Queensland PSR entered the study on the date of their first HGA Pap smear (the ‘index smear’) between 1 January 2000 and 31 December 2009, with clinical follow-up information (biopsy histology result or cancer diagnosis date) available until 31 December 2010. HGA included all Pap smears coded (based on the national cytology coding system) as possible or definitive cervical intraepithelial neoplasia grade 2 or worse, adenocarcinoma in situ, and invasive cancers. Only women with a Queensland address and aged 20-68 at the index smear were included. Women aged 69 at
the time of Pap smear were excluded to ensure 12 months follow-up was available. Clinical investigation was defined by a histology test or cancer diagnosis (data up to 31 Dec 2010) following the index smear. Women who had a clinical investigation before or on the index smear date were excluded because the investigation was likely in response to gynaecological symptoms.

**Geographical areas**

Location of residence at the time of the index smear was mapped to 2011 Statistical Local Area (SLA) boundaries. SLAs were grouped according to geographic remoteness based on the Accessibility/Remoteness Index of Australia (ARIA+). Area-level disadvantage was measured by quintiles using the Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD).

**Outcome measures**

The main outcome measure reported is time to clinical investigation following a HGA Pap smear, calculated as days from the index smear to the first recorded clinical investigation (histology test or cancer diagnosis date). The PSR does not record colposcopies, but colposcopists are required to perform a biopsy in more than 95% of women with high grade cytological abnormalities who are not pregnant. Follow-up time was censored at 12 months from the index smear date. Since the PSR does not systematically include information about deaths or interstate migration, we assumed ongoing residence in Queensland for 12 months following the index smear.

**Statistical analyses**

Medians were reported for non-normally distributed variables and compared using the Mann-Whitney test. Trend for ordinal variables was assessed using the chi-squared test from bivariate logistic regression model. The Kaplan-Meier method was used to estimate the failure function \(1-S(t)\), which is the probability that the event (clinical investigation) has
occurred by time t (expressed in months following the index Pap smear). We reported this probability separately for Indigenous and non-Indigenous women. Cox proportional hazards regression was used for multivariable analysis of factors associated with time to investigation; the model included terms for remoteness of residence, area-level disadvantage, age-group (in five-year age-groups) and Indigenous status. Interactions between Indigenous status and covariates, and between time since index smear and covariates, were considered. There was a significant interaction between Indigenous status and time to clinical investigation, which indicated a violation of the proportional hazard assumption. Therefore, interval-specific follow-up rates were calculated using two-monthly intervals (expressed per person month) and interval-specific hazard ratios (interpreted and reported as incidence rate ratios (IRR)). Two-month intervals were used to incorporate the current recommendation of receiving clinical investigation within two months from the HGA Pap smear and have consistent time intervals over a full 12 month period. We assessed temporal trends of clinical investigation in the first two months for Indigenous women compared with non-Indigenous women using the margins and lincom commands in Stata.

For all analyses, an association was statistically significant if the p-value was less than 0.05. Stata version 14.0 was used for analysis. (StataCorp, College Station, Texas, USA)

Ethical approval

The study was approved by Human Research Ethics Committees of Queensland Health (HREC/15/QCH/19-957), the Northern Territory Department of Health and Menzies School of Health Research (HOMER-2012-1737) and Charles Darwin University (H12093). Data access and linkage was approved by the director general of Queensland Health, data custodians and the Queensland Research Linkage Group.

RESULTS
The Queensland PSR contained records of 1,219,034 women aged 20–69 years and resident in Queensland who had a Pap smear during 2000–2009. After excluding 215 women (whose index smear was either on the same date as a cancer diagnosis or histology, preceded by cancer or taken at age 69), the study cohort consisted of 34,980 women with a HGA Pap smear, 1,592 (4.6%) of whom were classified as Indigenous after linkage to hospital records. 790 women with a HGA Pap smear had a record of invasive cervical cancer recorded on the QCR (of a total of 1352 cancer diagnoses recorded on the QCR between 2000-2009). Indigenous women were younger than non-Indigenous women at their index smear (median age 28 years [interquartile range, IQR 23, 36] and 31 years [IQR 25, 40], respectively; z=11.3, p<0.001); and more likely to live in less affluent and more remote areas (Table 1).
Table 1 Demographic characteristics of women at their first high grade abnormal Pap smear, Queensland residents aged 20-68 in 2000–2009

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Indigenous</th>
<th>Non-Indigenous</th>
<th>( \chi^2 ) (df)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age group (years)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-24</td>
<td>31.1</td>
<td>21.1</td>
<td>( \chi^2=108.9 ) (1)</td>
<td></td>
</tr>
<tr>
<td>25-29</td>
<td>24.8</td>
<td>22.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-34</td>
<td>15.9</td>
<td>18.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35-39</td>
<td>11.5</td>
<td>12.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40-44</td>
<td>7.2</td>
<td>8.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>45-49</td>
<td>4.2</td>
<td>6.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-54</td>
<td>2.3</td>
<td>4.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-59</td>
<td>1.4</td>
<td>3.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-64</td>
<td>0.9</td>
<td>2.0</td>
<td>( \chi^2=603.0 ) (1)</td>
<td></td>
</tr>
<tr>
<td>65-68</td>
<td>0.9</td>
<td>1.2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| **Area-level disadvantage** | \( \chi^2 \) (df) | p value |
| Q1 (most disadvantaged)    | 28.5       | 11.4             |         |
| Q2                        | 34.7       | 22.7             |         |
| Q3                        | 18.0       | 23.0             |         |
| Q4                        | 15.0       | 25.1             |         |
| Q5 (most affluent)         | 3.0        | 17.8             |         |

| **Place of residence** | \( \chi^2 \) (df) | p value |
| Major city               | 22.6       | 60.5             |         |
| Inner regional           | 14.6       | 18.9             |         |
| Outer regional           | 42.0       | 18.4             |         |
| Remote                   | 9.4        | 1.4              |         |
| Very remote              | 11.4       | 0.8              |         |

* \( \chi^2 \), chi-squared test for ordinal trend from bivariate logistic regression model; df, degrees of freedom; p, p value

Using simple proportions, a greater proportion of Indigenous than non-Indigenous women had a record of a clinical investigation within 12 months: 70.8% versus 66.6% (p<0.001).

However, median follow-up time was longer for Indigenous (100 days, 95% CI 91-112) than non-Indigenous women (69 days, 68-70). The cumulative percent of women who had a clinical investigation up to six months after the index smear was lower for Indigenous than non-Indigenous women, but higher for Indigenous women thereafter (Figure 1). The
interval-specific follow-up rates are shown in Table 2; Indigenous women’s follow-up rate was lower in the first two months than non-Indigenous women, but higher thereafter.

![Cumulative percentage of women having clinical investigation after a HGA Pap smear, Queensland residents aged 20-68 in 2000-2009.](image)

<table>
<thead>
<tr>
<th></th>
<th>&lt;2 months</th>
<th>&lt;4 months</th>
<th>&lt;6 months</th>
<th>&lt;8 months</th>
<th>&lt;10 months</th>
<th>&lt;12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-Indigenous</strong></td>
<td>15,510</td>
<td>4,223</td>
<td>1,170</td>
<td>617</td>
<td>380</td>
<td>336</td>
</tr>
<tr>
<td>No. women with clinical investigation</td>
<td>46.5% (46.0-47.0)</td>
<td>59.2% (58.5-59.7)</td>
<td>62.8% (62.2-63.3)</td>
<td>64.5% (64.0-65.1)</td>
<td>65.7% (65.2-66.2)</td>
<td>66.6% (66.1-67.1)</td>
</tr>
<tr>
<td><strong>Indigenous</strong></td>
<td>542</td>
<td>304</td>
<td>143</td>
<td>64</td>
<td>43</td>
<td>31</td>
</tr>
<tr>
<td>No. women with clinical investigation</td>
<td>34.1% (31.8-36.4)</td>
<td>54.0% (51.5-56.4)</td>
<td>62.2% (59.8-64.6)</td>
<td>66.1% (63.8-68.5)</td>
<td>68.9% (66.6-71.2)</td>
<td>70.7% (68.5-73.0)</td>
</tr>
</tbody>
</table>

Figure 1 Cumulative percentage of women having clinical investigation after a HGA Pap smear, Queensland residents aged 20-68 in 2000-2009.
Table 2 Interval-specific rate\(^1\) (per person month) of eligible\(^2\) women investigated after a high-grade abnormal Pap smear in two-month periods after the index smear, Queensland residents aged 20-68 in 2000-2009

<table>
<thead>
<tr>
<th>Time (months)</th>
<th>Indigenous</th>
<th>Non-Indigenous</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(95% CI)</td>
<td>(95% CI)</td>
</tr>
<tr>
<td>0-2</td>
<td>0.20 (0.19-0.22)</td>
<td>0.31 (0.30-0.31)</td>
</tr>
<tr>
<td>2-4</td>
<td>0.19 (0.17-0.21)</td>
<td>0.14 (0.14-0.14)</td>
</tr>
<tr>
<td>4-6</td>
<td>0.10 (0.08-0.12)</td>
<td>0.05 (0.04-0.05)</td>
</tr>
<tr>
<td>6-8</td>
<td>0.06 (0.04-0.07)</td>
<td>0.02 (0.02-0.03)</td>
</tr>
<tr>
<td>8-10</td>
<td>0.04 (0.03-0.06)</td>
<td>0.02 (0.02-0.02)</td>
</tr>
<tr>
<td>10-12</td>
<td>0.03 (0.02-0.04)</td>
<td>0.01 (0.01-0.02)</td>
</tr>
</tbody>
</table>

\(^1\) Interval-specific follow-up rate per person month with 95% confidence interval of women who had a clinical investigation during this period  
\(^2\) eligible women are those women who did not have a clinical investigation in the preceding intervals

The interval-specific incidence rate of clinical investigation was also lower for Indigenous than non-Indigenous women (IRR < 1.0) in the first two months after the index smear, but higher thereafter (Table 3). After adjusting for area-level disadvantage, place of residence and age-group and including time-varying interactions, Indigenous women remained less likely to have a clinical investigation in the first two months (adjusted IRR 0.74, 0.68–0.81) than non-Indigenous women (Table 3). IRRs of clinical investigation in the first two months for Indigenous women compared with non-Indigenous women were less than one in all years between 2000 and 2009 with no apparent improvement over time (Figure 2).
Table 3 Clinical investigation of a high-grade abnormality by time since Pap smear for Indigenous women compared with non-Indigenous women, aged 20-68 years, 2000-2009

<table>
<thead>
<tr>
<th>Time (months)</th>
<th>Incidence rate ratio(^1)</th>
<th>Unadjusted</th>
<th>Adjusted(^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2</td>
<td>0.65 (0.60-0.71)</td>
<td>0.74 (0.68-0.81)</td>
<td></td>
</tr>
<tr>
<td>2-4</td>
<td>1.32 (1.18-1.48)</td>
<td>1.18 (1.05-1.33)</td>
<td></td>
</tr>
<tr>
<td>4-6</td>
<td>2.16 (1.80-2.59)</td>
<td>1.67 (1.39-2.01)</td>
<td></td>
</tr>
<tr>
<td>6-8</td>
<td>2.28 (1.75-2.95)</td>
<td>1.62 (1.24-2.10)</td>
<td></td>
</tr>
<tr>
<td>8-10</td>
<td>2.53 (1.86-3.46)</td>
<td>1.69 (1.23-2.32)</td>
<td></td>
</tr>
<tr>
<td>10-12</td>
<td>2.32 (1.59-3.37)</td>
<td>1.47 (1.01-2.15)</td>
<td></td>
</tr>
</tbody>
</table>

\(^1\) Indigenous:non-Indigenous, (95% confidence interval)
\(^2\) Adjusted for age-group, place of residence, area-level disadvantage
Figure 2 Incidence rate ratios of Indigenous women compared with non-Indigenous women investigated after a high-grade abnormal Pap smear in the first two-month period, Queensland residents aged 20-68 years in 2000-2009.

There were 34,764 women with a possible or definitive HGA / cancer *insitu* recorded on their Pap (excluding women with invasive cancer on their Pap); of these, 674 (1.9%) had an invasive lesion recorded at clinical investigation.

**DISCUSSION**

Indigenous women were less likely to receive clinical investigation after a HGA Pap smear within the recommended two month interval, regardless of which year the HGA smear occurred. However, six months after the index smear, follow-up was similar and thereafter higher for Indigenous women. By 12 months, a greater proportion of Indigenous women had
clinical investigation than non-Indigenous women. We are unable to report, using data from this study, why 30% of women have not had clinical investigation. It is possible that some of these women had a repeat Pap smear which would not have been counted as clinical investigation or did not have a biopsy at colposcopy visit (this would be rare as discussed below).

A successful cervical cancer prevention program depends on the adequate assessment, treatment, and follow-up of women who have cervical abnormalities. The NCSP has been unable to report on program indicators for Indigenous women and, consequently, much has remained unknown regarding how Indigenous women interact with cervical screening. Our findings show that most women eventually are followed up, but that Indigenous women are less likely to have clinical investigation within the two-month period recommended in current NHMRC guidelines. Significant delays in clinical investigation could result in progression of HGAs.

Possible reasons for the delay in follow-up among Indigenous women may include factors relating to health systems, health practitioners and individuals. From the health system perspective, cost, access and cultural appropriateness of services would likely influence women’s decision-making about attending diagnostic follow-up of a cytology abnormality. Although Medicare pays a rebate for private outpatient services, additional payment is usually required.

Indigenous Australians are more likely to use the public hospital system compared to other Australians (90% of hospital separations versus 57% are from a public hospital), where wait times for dysplasia clinics may be several months long. In Queensland more than half of the Indigenous population live in outer regional, remote or very remote areas. While access to services in these areas is limited and long distance travel may act as a barrier to timely follow-up, our study found the Indigenous differential remained after adjusting for remoteness and area disadvantage, suggesting the impact of additional factors.
Mainstream health care settings can be culturally uninviting. This, combined with a history of marginalisation, can create feelings of alienation, isolation, fear and mistrust towards the healthcare system and health practitioners. Ineffective communication from health practitioners can compound these issues. Cultural understandings of cancer may also lead to delays in seeking diagnostic or curative treatment; from an Indigenous perspective cancer could be seen as a death sentence or retribution for a past wrong, and mainstream cancer treatment may be seen as a loss of traditional lifestyle.

Our findings are similar to those for BreastScreen Australia, where Indigenous women were less likely to attend post-screening assessment within the recommended time following mammography. In New Zealand, the proportion of women receiving follow-up after a HGA Pap test (as indicated by a report of cervical histology) was lower for Maori than European/other women at 90 days (81.0% compared with 83.6%) and 180 days (87.5% compared with 89.2%), although the differences were small.

The strengths of our study include near complete population-based data about cervical screening and clinical investigation from the Queensland PSR (including a 12 month follow-up period), and a reliable data source (QHAPDC) to identify Indigenous women on the PSR. We have previously reported in detail possible reasons why our record-linkage methodology may not have identified all Indigenous women. Briefly, accuracy of Indigenous status in Queensland hospital records is not perfect (accuracy estimated at 87% in 2011, and more accurate in regional and remote than metropolitan areas), but has improved over time. It is possible that not all Indigenous women had a public hospital record available for linkage, though this is likely to be uncommon.

Our follow-up classification was reliant on a histology test record or cancer diagnosis date. Therefore, women who had a colposcopy without a biopsy would incorrectly be classified as not having had any follow-up. It is not possible to quantify the number of Indigenous or non-Indigenous women in this category because of the lack of comprehensive colposcopy data in

Chapter 6
the current PSR. However, we expect this number to be small, given that the current NHMRC guidelines\(^2\) and The Colposcopy Quality Improvement Program\(^14\) recommend that a biopsy is taken except in unusual circumstances (e.g. if a woman is pregnant). Also we determined the time to clinical investigation by the pathology date, which may introduce error if a delay occurred between the colposcopy and pathology assessment.

We are unable to report on the number of Queensland resident women who were followed-up interstate (e.g. border populations like Tweed Heads), thus, our estimates of women investigated may be slightly underestimated. This may explain in part why Queensland has reported a lower proportion of women who were-followed up than in Victoria in 2013 which recorded 89% of women who had a HGA reported on one or more of their Pap tests were followed-up within six to nine months of the HGA Pap smear (by colposcopy and/or biopsy).\(^23\) Prior to 2006, the then guidelines recommended women to return for annual cytology to confirm absence of abnormalities, following HGAs. Therefore, for a very small number of women included in the study, index Pap smears identified prior to 2006 may have been for test-of-cure, and it is uncertain whether these woman would be more or less compliant with follow-up than women receiving first ever HGA result. We cannot determine which women this applies to, so we cannot exclude or adjust for these women in our analysis. There is a possibility that including these women underestimates or overestimates time to follow-up for both Indigenous and non-Indigenous women.

Ultimately, these findings are reflective of follow-up among screened women in Queensland, and similar analyses in other jurisdictions are warranted given the potential importance of this clinical and health service delivery information.

**CONCLUSIONS**

The Australian NCSP will introduce major changes from May 2017 shifting from a two-year Pap test to a five-year HPV test for women aged 25–74 years.\(^24\) In preparation for this new program new draft clinical management guidelines have been released and the pertinent
screening result in the renewed program will no longer be HGA cytology but will move to HPV16/18 positive or other high risk HPV with a cytology-triage-positive result. Our findings will continue to be of relevance in assessing time to clinical investigation for Indigenous women, even though the screening process (and trigger for colposcopy referral) will change.\textsuperscript{25}

Our finding that Indigenous women with HGAs are less likely to receive clinical follow-up within the recommended two monthly interval is concerning. Reasons behind the initial delay need to be identified and addressed. While our study findings regarding clinical investigation are important to address, increasing participation in cervical cancer prevention programs, both screening and HPV vaccination, remain critical to close the gap in cervical cancer for Indigenous women.
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7 DISCUSSION, RECOMMENDATIONS AND CONCLUDING REMARKS
7.1 Introduction

Prior to this work, several small localised studies provided an indication that Indigenous Australian women participated less in routine cervical screening than other Australian women but no comprehensive population-based data were available about cervical screening for Indigenous women.\textsuperscript{1,2} The NCSP has been operating for 25 years but has not been able to report specifically on Indigenous women despite their cervical cancer incidence and mortality being significantly greater than the rest of the population.\textsuperscript{3} It has not previously been known how Indigenous women participate in cervical screening, whether participation has improved over time or varies by age-group, place of residence or socioeconomic status, what the results of their Pap smears are, or the time taken to clinical investigation following a high-grade smear abnormal result and how these compare to non-Indigenous women.

The gap in comprehensive population-based data regarding Indigenous women has made it difficult to implement strategic programs to improve screening participation (and reduce cervical cancer incidence) of Indigenous women, measure outcomes of such programs, assess the effectiveness of current policy or make recommendations for future policy, and implement practice improvements for Indigenous women.

The research presented in my thesis provides the first comprehensive, population-based data about cervical screening for Indigenous women covering the entire Queensland Indigenous population. While there are some limitations to the study particularly regarding completeness of Indigenous identification (see below), my results clearly demonstrate that cervical screening participation is much lower for Indigenous than other Queensland women and has not improved since the Queensland Pap Smear Register (PSR) began in 1999. The prevalence of high-grade cervical abnormalities is higher for Indigenous women; and that investigation and treatment is slower for Indigenous women after a high-grade abnormal Pap smear. The NCSP is not performing as effectively for Indigenous women as it could be and its performance is not improving. While similar comprehensive data are not yet...
available for other states, the localised studies that have been previously published indicate that the situation in Queensland is not unique.

7.2 Limitations

Limitations specific to each study have been described in detail within the respective chapters. Here, the focus is to first discuss the overarching limitations which are critical to the interpretation of the main message of the thesis and then discuss these limitations in the context of what remains unknown.

It is unlikely that the linkage between the PSR and hospital inpatient data identified all Indigenous women in the PSR. This would have particularly biased participation rates for Indigenous women which would be underestimated to a small extent (discussed in Chapter 3). This underestimate is likely to be consistent over time but greater in urban (by up to four percentage points in ‘major cities’) than remote areas (little or no underestimate in ‘very remote’ areas; Chapter 4). There would be minimal overestimation of non-Indigenous participation. However, the plausible extent of this underestimation is much smaller than the very large difference in participation rates between Indigenous and non-Indigenous women (Chapter 4).

The prevalence of abnormalities (Chapter 5) and time to follow-up after a high-grade abnormality (Chapter 6) would not have been affected by underidentification of Indigenous women to the same extent as participation rates. Prevalence of abnormalities and time to follow-up were measured among those women who were identified as Indigenous and there is strong evidence that the large majority of Indigenous women recorded in the PSR were correctly classified as Indigenous. These two outcome measures would only be biased if the small proportion of screened Indigenous women who were misclassified as non-Indigenous had different prevalence of abnormalities or time to follow-up to the large majority of correctly classified Indigenous women. The direction of such potential bias is unknown but its magnitude would be small, if any, because the misclassified women are a small proportion of the correctly classified women.
No data were available about the prevalence of hysterectomy among Indigenous women. If the prevalence of hysterectomy among Indigenous women is different to the total Australian prevalence (either higher or lower) that we used to calculate the denominator of both Indigenous and non-Indigenous participation rates, the Indigenous participation rates reported above will be biased to a small extent. However, the potential magnitude of this possible bias appears to be small; sensitivity analysis found a small effect on differences between Indigenous and non-Indigenous participation rates for women aged 25–40 years (where less than 5% of the population have had a hysterectomy) compared with all women aged 20–69 years. If there was a considerable difference in the prevalence of hysterectomy among Indigenous women, we would have expected a large difference in the 20–69 year rates verses the 25–40 year rates because of the large proportion (approximately 30%) of women 40 years and older who have had a hysterectomy.

### 7.3 Identification of Indigenous women in PSRs

By using record-linkage methods, we were able to achieve whole-of-population data at an individual-level and report population estimates for Indigenous women’s participation, prevalence of abnormalities, and time to clinical investigation. This is a significant milestone and something the NCSP has not been able to achieve in any state or territory in its 25-year history.

The consequences of not collecting Indigenous status on pathology request forms have long been recognised. An Australian Institute of Health and Welfare (AIHW) report published in 2013 summarised the importance of data on Indigenous people: ‘Accurate identification of Aboriginal and Torres Strait Islander people is vital for understanding trends and disparities in health status. This data is important for planning and improving health services to meet the needs of Indigenous Australians.’ Adding Indigenous status to pathology request forms would require a number of changes to be made including, legislative changes (required in Queensland and at the time of the AIHW 2013 report changes were being sought), system changes including laboratory IT systems, compliance of health practitioners to obtain Indigenous status and willingness of Indigenous women
to self-identify. The process would require funding to support these system and process changes. Adding Indigenous status to pathology forms is not the only option to obtain Indigenous status, as demonstrated by what we have achieved through record-linkage. However, the complex, time consuming and resource intensive process of the record-linkage method would prove a difficult undertaking unless the process was more accessible and streamlined, especially if it were to be a national and cross-jurisdictional process. Two alternative linkage options would be to intermittently link or permanently link the PSR to hospital data. The first of these options would require the PSR being added to the master linkage key of the state-based linkage groups within a jurisdiction if available. The latter permanent option has been done recently in the Northern Territory (NT) where they have linked the PSR to the hospital record number (a unique client identifier used in all NT public hospitals). Of course, any changes would need to be considered in light of the proposed national cervical screening register (see below).

### 7.4 Participation

Participation in cervical screening was much lower among Indigenous women than non-Indigenous women and there has been no improvement over time. Indigenous women who do screen appear to screen as regularly as their non-Indigenous counterparts; over 90% of both Indigenous and non-Indigenous women who had a Pap test in 2010–2011 had a history of a Pap test in 2000–2009.

The real problem appears to be the high proportion of Indigenous women who rarely or never screen. This is where public health efforts need to be placed. It is possible to achieve both high levels of participation and increase participation rates among Indigenous women. In 2006, Binns and Condon reported very low participation by Indigenous women in Central Australia; by the next reporting period there was a considerable increase in participation from 32% in 2005–2006 to 44% in 2007–2008. High levels of screening participation among Indigenous women in particular areas have been achieved where the participation rate was greater than the national rate. In Borroloola (in the NT), participation increased among Indigenous women from 15% in 1997–1998 to approximately 73% in
2009–2010,\textsuperscript{7} demonstrating that improving participation rates for Indigenous women is possible to levels that exceed national expectation. Small area analysis is urgently needed because it provides information about individual communities and health services. This information is important to enable investigation of what these services are doing in order to reach high participation and use these strategies to improve screening elsewhere. This type of analysis can also provide information about the types of services where Indigenous women are more likely to be screened (e.g. Aboriginal community-controlled health service, family planning clinic, or mainstream practice).

Participation decreased among young Indigenous and non-Indigenous women over the study period but more so for young Indigenous women. We are unsure if this is a study design artefact or an impact of the introduction of the HPV vaccine. It is possible that the decreasing participation rate in young Indigenous women was an artefact because women who turned 20 during the study period would have had less time to have a hospital admission during the study period and thus be less likely to have hospital inpatient data available to link to the PSR. Consequently, these women may have been more likely to be misclassified as non-Indigenous. It could be possible to validate this finding by linking the PSR to another data source that has reliable Indigenous status for young people such as data from the Australian Childhood Immunisation Register (ACIR).

It is also plausible that the decreasing participation of young women was not a study design artefact but a real decrease among human papillomavirus (HPV) vaccinated women no longer presenting for cervical screening. HPV vaccinated women have been found to be less likely than unvaccinated women to participate in cervical screening but this has not been reported specifically for Indigenous women.\textsuperscript{8} An investigation into HPV vaccination and screening among Indigenous women should be done and could be done by linking PSR data to the HPV Vaccination Register and the ACIR.

It is also possible that there are misconceptions among women that a Pap smear is no longer needed if they have been vaccinated. It is important that knowledge level and understanding about HPV, cervical screening, and HPV vaccination are investigated among Indigenous girls and women. The
findings from such investigations could underpin education and health promotion campaigns that are relevant to Indigenous women.

7.5 Cervical abnormalities
Among women screened in our study, Indigenous women had markedly higher prevalence of cytology-detected low- and high-grade abnormalities and histology-confirmed high-grade abnormalities. This finding is consistent with previous reports for Indigenous women in remote areas.\(^7\) We also found that the prevalence of cytology-detected high-grade abnormalities increased among young Indigenous women but not among young non-Indigenous women. We do not know why abnormalities are higher, particularly since Indigenous women who were screened, screened as regularly as non-Indigenous women. Higher prevalence of risk factors (other than HPV) among Indigenous people is well documented such as higher prevalence of smoking, higher fertility and younger age at first pregnancy, and greater likelihood of living in areas of disadvantage.\(^9,10\) The higher prevalence of cervical abnormalities is likely, at least in part, to be caused by these factors. The higher prevalence of risk factors reinforces the critical need for Indigenous women to regularly participate in cervical screening.

We are also unable to explain why the prevalence of high-grade abnormalities detected by Pap smears is increasing in young Indigenous women only. We expected that abnormalities would have decreased in this group as a result of HPV vaccination, although we did not know the HPV vaccination status of women in our study. Substantial decreases in cervical abnormalities among women receiving any dose of the quadrivalent HPV vaccine have been observed but not specifically reported for Indigenous women.\(^11,12\) National data about HPV vaccine coverage for Indigenous girls are not available. Coverage and/or dose completion rates among Indigenous female adolescents during the catch-up phase were lower than non-Indigenous female adolescents.\(^13\) Available data from Queensland and the NT show that HPV vaccination coverage among girls identified as Indigenous aged 12–17 years in the catch-up program was approximately 15 percentage points lower than non-Indigenous girls. More
recently, an ecological study reported that there has been a reduction in hospital admissions regarding a diagnosis of genital warts in the first four years after the introduction of the National HPV Vaccination Program and that this was similar for Indigenous and non-Indigenous women.\textsuperscript{14} This recent study suggests that benefits of HPV vaccination have not discriminated. However, given our finding of increasing prevalence of high-grade abnormalities among Indigenous women, we recommend specific data regarding cervical abnormalities are important for ongoing monitoring of program effectiveness and to detect possible implications due to the lower vaccine coverage and abnormality trends among Indigenous women.

An alternative hypothesis for why prevalence of high-grade abnormalities among young Indigenous women is increasing is that screening behaviour among these women has changed. When calculating the prevalence of abnormalities, the at-risk population includes only those who have screened within the time period. As such, patterns in screening behaviour will manifest in the prevalence of abnormality. The results of this study demonstrate an increase in high-grade abnormalities occurring concurrently with a decrease in screening participation among young Indigenous women. If the women who continue to participate in cervical screening are those who have not received or completed HPV vaccination, as previous studies suggest,\textsuperscript{8} then the screened population, used to calculate prevalence of high-grade abnormalities, are at higher risk of abnormalities than the general young Indigenous female population. This then increases the proportion of screened women who have a cytology-detected high-grade abnormality, while the actual risk of high-grade abnormalities among all young Indigenous women may remain unchanged. It remains unclear though why this would be occurring only among the Indigenous population when the general population have reported less screening by vaccinated women\textsuperscript{8} but a decrease in cervical abnormalities since the introduction of HPV vaccination.\textsuperscript{12,15}
7.6 Time to clinical investigation

Fewer Indigenous than non-Indigenous women with high-grade abnormal Pap smears were investigated and treated within the recommended two-month period. However by six months, follow-up for Indigenous women was comparable to that for non-Indigenous women (and slightly higher thereafter). This delay in clinical investigation in the initial two months occurred throughout the study period. One possible explanation for the delay in follow-up could be a higher proportion of Indigenous women living more remotely and having to travel into more urbanised areas for access to specialists. However, we accounted for place of residence in the multivariate analyses and the differential in the two-month period persisted. More detailed small area analyses could include investigation of whether the initial lag is caused by intrinsic factors associated with remoteness including issues of access, disadvantage and road distance. Although lack of participation is a major contributor to higher incidence, delay in clinical investigation is also an indicator of health service disparities that are contributing to Indigenous ill health.

7.7 Changes to cervical screening in Australia

The National Cervical Screening Program (NCPS) underwent a review of its policies and operations in 2011, known as the ‘Renewal’. The Renewal proposed major changes to cervical screening in Australia, largely as a response to major scientific advances in understanding the aetiology of cervical cancer and technological developments in preventing and screening for it. These include the role of the HPV in disease causation, the introduction of HPV vaccination, and the development of HPV testing as a primary screening tool (including the possibility of self-administered screening tests). On 1 May 2017, the NCSP will change from a two-yearly Pap test to a five-yearly HPV test for women 25–74 years of age. The Renewal is a major change in national policy and practice. Implementation of the recommendations from the Renewal requires changes to legislation, new clinical and laboratory practices, major public and professional education programs, and major re-organisation of how the program operates (including a new national screening register). These changes provide a rare
opportunity to address the long-standing deficiencies of the national program for Indigenous women that are apparent in the results presented in this thesis.

7.7.1 The National HPV Vaccination Program

There are currently two licensed available vaccines: Gardasil (CSL Biotherapies Pty Ltd, Victoria, Australia), a quadrivalent vaccine preventing HPV types 6, 11, 16, and 18 and Cervarix (GlaxoSmithKline Australia Pty Ltd, Victoria, Australia), a bivalent vaccine preventing HPV types 16 and 18. These vaccines are now included on the National Immunisation Program. In 2007, Australia was the first country around the world to offer the vaccine free to girls aged 12 years and a catch-up program for women up to 26 years of age during 2007–2009. The school-based vaccination program continues to vaccinate girls (and from 2014, has also included boys) aged 12–13 years with the quadrivalent vaccine.

7.7.2 The renewed NCSP

In 2011 the Australian Department of Health announced there would be a ‘Renewal’ of the NCSP. The announcement of the Renewal was to ensure that the screening program reflected the best available evidence and respond to changes that would occur because of the HPV vaccine, and the availability of new technologies. In April 2014, the Australian Medical Services Advisory Committee (MSAC) made several recommendations for a renewed cervical screening program for both vaccinated and unvaccinated women. These recommendations were accepted and the renewed NCSP will be implemented on 1 May 2017. The NCSP will change from the current two-yearly Pap test to a primary HPV test every five years for women 25–74 years. There will also be the option of self-collection of an HPV sample for under- or never-screened women. Cervical screening should commence at 25 years by invitation and reminders will be sent to women aged 25–69 years with exit testing up to 74 years of age. The renewed NCSP also aims to establish a national cervical screening register where it is anticipated that there will be improved data collection about Indigenous status,
identification of culturally and linguistically diverse women, and a colposcopy results (rather than only biopsy results).  

7.7.3 The renewed NCSP and Indigenous women

Major changes to the NCSP have been proposed and endorsed without any real evidence about Indigenous women in the existing program. The findings of this thesis provide information that highlights gaps in the current and future NCSP. The renewed NCSP will begin May 1 2017 and there is still time to consult with and work with Indigenous women, Aboriginal community-controlled health services, and Indigenous leaders (particularly women) to ensure that the renewed NCSP critically addresses the needs of Indigenous women in its delivery.

To date, the details of how the renewed NCSP will improve data collection for Indigenous women remain vague. What is known is that the new national register will aim to have a single record per person nationally (instead of separate state-based records at present) and a more streamlined reporting system for participants and health professionals. The Australian Government has devoted funding in the 2015–2016 Federal Budget to the recommendations made in the Renewal including the national register. However, there are no specific details available regarding how the register will improve the collection of Indigenous status. We would expect these details to be forthcoming and the complexity of record-linkage as outlined in chapters 2 and 3 is considered, particularly if national linkage is to take place.

Specific strategies to prioritise and reduce the burden of disease among Indigenous women are also unclear. Reductions in cervical cancer incidence and mortality rates by 15–22% in the total population are expected from using HPV testing.  

Self-sampling will also be offered to women who are under-screened or never screened and based on our study, we can assume this will be particularly applicable to Indigenous women. However, the further reductions anticipated and the self-sampling option will only occur if women are actually participating in cervical screening—which our findings confirm is considerably less for Indigenous women.
The most significant issue to address is recruiting Indigenous women into the program. Recruitment of Indigenous women into cervical screening is particularly important for the renewed NCSP to urgently address as we found that over a five-year screening period, there was an even wider gap in participation between Indigenous and non-Indigenous women. There is a lack of evidence about how to achieve high screening participation for Indigenous women. Talking with Indigenous women is an important next step in better understanding why Indigenous women do and do not participate in cervical screening. Such information is critical in creating strategies to improve cervical screening participation and screening for other cancers among Indigenous Australians.

The renewed NCSP does provide some opportunities to improve screening among Indigenous women. For example, the letter of invitation sent out to women on their 25th birthday could be tailored and include educational material that is culturally appropriate to Indigenous women and should be developed in consultation with Indigenous women. Furthermore, primary care providers will be able to offer self-sampling to women who are under-screened or never-screened; self-sampling has been shown to improve screening among these hard to reach women.19

From the few published reports, it is imperative that the renewed NCSP explores, sooner than later, communities and their primary care services that already have high participation among Indigenous women such as Borroloola in the NT. Understanding what has already been successful and applying or adapting successful strategies and practices elsewhere is an obvious means for the NCSP to improve its performance for Indigenous women. Although this may be challenging, it is the responsibility of the NCSP to investigate how high levels of participation are already achieved in some communities and this should be occurring now as part of the renewal process.

The need to engage with Indigenous women and Indigenous communities is paramount to the success of the renewed NCSP for Indigenous women. A series of consultative meetings with Indigenous communities, Aboriginal and Torres Strait Islander women, and health services are critical to better understand the barriers and to put into place processes to address them.
We have delivered a series of presentations and meetings with key stakeholders in Queensland to disseminate the findings of this thesis which include Queensland Health and key Aboriginal health organisation groups. These are listed in Appendix 1.

7.8 Concluding remarks
This thesis contains the results of concerted efforts to obtain population-based data that allowed for the analysis and reporting of key performance indicators of cervical screening for Indigenous women in Queensland for the first time. We have reported rates of participation, prevalence of abnormalities, and time to clinical investigation of high-grade abnormalities using a record-linkage method to identify Indigenous women on the PSR. The studies within this thesis have provided benchmark estimates and an important assessment of cervical screening for Indigenous women in Queensland with implications for Indigenous women throughout Australia. The results in this thesis can be used to provide an evidence-base for an Indigenous-focused cancer screening strategy. This thesis has also identified areas in cervical screening that still need to be addressed including targeted strategies to increase participation of Indigenous women in cervical screening.

Cervical cancer is a devastating disease for women, their families and communities, made more so by how easily preventable it is. It is a sad truth that such inequity can be so evident in a developed and resource-rich country like Australia. The true success of this work is what happens next. It is imperative that the renewed cervical screening program addresses the serious data deficiencies in collecting and reporting Indigenous status and investigates strategies that improve screening participation among Indigenous women. Cervical cancer prevention is rapidly evolving in Australia and the results from this thesis will give a voice to Indigenous women for the first time and provide critical evidence to help address the significant burden of this disease among this population.
7.9 References


5. Acumen Alliance. Aboriginal & Torres strait islander identifier on pathology forms: feasibility study into increasing the completeness of the Aboriginal and Torres Strait Islander identifier in ACT government registries. Canberra, ACT: ACT Health, 2007.


8 APPENDIX: KNOWLEDGE DISSEMINATION
This appendix provides an overview of related activities undertaken by me throughout my candidature.

**Stakeholder meetings**

Several meetings were organised with key stakeholder groups in Queensland to share the findings of this thesis. At each meeting, I presented an overview of each of the study findings and contributed to discussions regarding the implications for the particular stakeholder group. Meetings were held with staff from the following groups:

- Queensland Government, Queensland Health, Aboriginal and Torres Strait Islander Health Branch
- Queensland Government, Queensland Health, Queensland Cervical Screening Program
- The Institute of Urban Indigenous Health
- Queensland Aboriginal and Islander Health Council.

We have also produced in partnership with the Queensland Health groups, a ministerial brief for the Queensland Minister of Health. Another very important process I have been involved in is being a voting member of the multidisciplinary clinical working party for the development of the clinical management guidelines to accompany the renewed NCSP. The draft guidelines are now undergoing public consultation. I have been a co-lead of several sections for the guidelines including the Aboriginal and Torres Strait Islander screening section. This has been an important process in informing the committee of the particular patterns of screening for Indigenous women.

**Related presentations**

I have also presented at several conferences and large national meetings about the National Indigenous Cervical Screening Project and/or about my PhD. They include:
1. 2015 Plenary at the Preventing Cervical Cancer Conference, Melbourne.
   Presentation title ‘Cervical screening for Aboriginal and Torres Strait Islander women.’ This was an invited talk, presented by Professor John Condon and I.

2. 2015 Invited speaker, Queensland Health Data Linkage Symposium ‘National Indigenous Cervical Screening Project: a data linkage study.’ Brisbane. I presented on the overall methodology of my PhD, providing insights into undertaking a linked project, including the many challenges and enablers.

3. 2014 Invited speaker, Clinical Oncological Society of Australia Annual Conference, Melbourne. This was a specific cancer policy session, in which I presented how Indigenous status could be achieved on the Pap Smear Registers, and the information such data would provide.


5. 2013 Invited speaker at the Menzies Foundation Data Linkage Workshop, ‘National Indigenous Cervical Screening Project: a data linkage study’, Melbourne. This workshop included several researchers in Australia, key policy advisors and people from the public sector. I provided an overview of how data linkage could help overcome Indigenous under-identification in administrative datasets using the NCSP as the example. A report was published shortly after by the Menzies Foundation to summarise the key points discussed at the meeting and can be found here:

6. 2013 Invited speaker at the National Indigenous Cancer Network Roundtable, Brisbane where I presented a brief overview of the NICSP.
7. 2013 Invited speaker at the Better Health through Research hosted by Menzies School of Health Research, Melbourne and Sydney. This talk was to an audience of a high profile corporate and philanthropic audience. Some highlights of the talk can be found here: https://youtu.be/PdHsDK2MhJs

**Contribution to National Indigenous Cervical Screening Project**

I was employed for one day a week as the national project manager for the National Indigenous Cervical Screening Project for about 14 months during the candidature. During this time I applied for nine ethics applications for several states and territories (New South Wales, Northern Territory, Western Australia, Victoria and Australian Capital Territory). I also coordinated the applications and requests for data from data custodians and the linkage application with the linkage group of each jurisdiction. I co-wrote the first data dictionary for the database developed to store the data.

**Related publications**

The following list of publications were worked on and published during my candidature:

