

Rapid review of five years of Aboriginal and Torres Strait Islander health research in Australia – persisting under-representation of urban populations

Warren Jennings,^{1,2} Geoffrey Spurling,^{1,2} Brett Shannon,^{3,4} Noel Hayman,² Deborah Askew^{1,2}

Research addressing the health needs of Aboriginal and Torres Strait Islander (respectfully, hereafter, Indigenous) people is lacking, particularly for those living in urban areas, despite the majority of Indigenous people living in urban areas.^{1,2} In 2010, Eades et al. reviewed the Indigenous health research literature from 2004 to 2009 and found 555 research papers, an ‘inadequate’ 63 (11%) of which included information about Indigenous people living in urban areas.¹ The authors concluded that there were insufficient data to close the life expectancy gap between Indigenous and non-Indigenous people in urban areas, and they discussed how the phenomenon of ‘Indigenous invisibility’ in the city may contribute to this dearth of research.

At the 2016 Census, an estimated 37% of Indigenous people in Australia lived in major cities, 24% lived in inner regional areas, 20% in outer regional areas and 18% in remote and very remote areas. In total, 61% lived in major cities or inner regional centres – an increase from 53% in 2006, and 50% in 2001.² Further to this, the Indigenous population in major cities is forecast to continue increasing by 2.4–2.7% per year until 2031.³ From the prior 2011 Australian Health Survey, just over half of the burden of disease is carried by this majority of Indigenous people who live in urban areas, and their health needs may differ from those living remotely. Mental health and substance use are the biggest contributors to

Abstract

Objective: To review how published Aboriginal and Torres Strait Islander health research reflects the geographical distribution of the Indigenous population of Australia.

Methods: Rapid review using Lowitja Institute Lit.search tool for PubMed indexed Indigenous health research papers (January 2013 to January 2018). Geographic location, participant age, study type and recruitment site were identified for each paper.

Results: A total of 1,258 research papers were identified: 190 (15%) focused exclusively on Indigenous people living in urban areas; 563 (45%) in rural/remote areas; and 505 (40%) spanned urban and rural/remote areas. Despite similar burdens of disease, three times as many papers were published per 1,000 DALYs for rural/remote areas than urban areas.

Conclusions: Indigenous health research publications have more than doubled since 2010. However, research focusing on the health needs of urban Indigenous people remains low relative to disease burden and population.

Implications for public health: More research to address the health needs of Indigenous people living in urban areas is required although this should not be at the expense of research for rural and remote areas. Increased funding quarantined for Indigenous health research, coupled with self-determination of the research agenda and reporting on the geographic representativeness of research, may help address geographical inequities in research outputs.

Key words: Indigenous, Aboriginal, health research, rapid review

the health needs of Indigenous people living in urban areas; however, in remote areas, injuries comprise the highest burden.⁴

Since 2010, the National Health and Medical Research Council (NHMRC) published Roadmap 2, a strategic framework for improving the health of Indigenous people through research. Like Roadmap 1, Roadmap 2 articulated the need to address significant research gaps for urban populations, including evaluation, access and intervention research.^{5,6} However,

absent in the publication of Roadmap 3 in 2018⁷ is any mention or suggestion of reporting on the geographic distribution of research output. For research to align with community needs, considering the differing needs of geographically different communities,⁴ we argue research should also align with geographical distributions of the burden of disease and population for Indigenous peoples across the nation. Similar to Eades et al.,¹ we were interested in the equitable spread of research across

1. Primary Care Clinical Unit, The University of Queensland, Royal Brisbane and Women's Hospital, Queensland

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

3. Aboriginal and Torres Strait Islander Community Health Service, Queensland

4. LIME Medicolegal, Queensland

Correspondence to: Dr Warren Jennings, Primary Care Clinical Unit, The University of Queensland, Level 8, Health Sciences Building 16/910, Royal Brisbane and Women's Hospital, Brisbane, QLD 4029; e-mail: w.jennings@uq.edu.au

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the lifespan especially involving children. We were also interested in the contribution of the community-controlled sector to research activities and the proportion of research that was interventional versus observational.

Increasing resource allocation to Indigenous people living in urban areas must not come at the expense of those living in rural and remote areas who still have serious social, economic and health concerns.⁸ Acknowledging this policy tension and background, and the important health needs and concerns of Indigenous peoples across all geographical locations, we considered it timely to review how published Indigenous health research reflects the geographical distribution of the Indigenous population. Our secondary aim is to understand if the volume of published research is

proportionate to the burden of disease in urban versus rural/ remote locations.

Methods

We undertook a review of five years of published Indigenous health research, using rapid review methods where systematic review steps are expedited or streamlined to produce timely, actionable evidence.^{9,10} In this rapid review, a preliminary literature search guided decisions to streamline scope (to quantity and location of research, rather than quality) and methodology (limiting the search to one database).

Literature search

Our literature search, conducted on 24 January 2018, used the validated Lowitja

Institute Lit.search tool with settings to retrieve all Aboriginal and Torres Strait Islander health research citations from the Pubmed database for the five-year period from 25 January 2013 to 24 January 2018.¹¹ Only one database was searched to streamline the review process, in recognition of the number of articles found, and for comparability to previous reviews.^{1,9,10}

Inclusion and exclusion criteria

Types of studies

Publications were included if they reported primary research (qualitative or quantitative) on Australian Indigenous peoples' health status, health access and views on health. Editorials, opinion pieces, protocols, systematic reviews, and government and institutional reports were excluded.

Informed by the 1989 holistic definition of health from the National Aboriginal Health Strategy Working Party,¹² publications relating to the wellbeing of the whole community, including health access, and Indigenous views on health and health delivery were included.

Types of participants

Publications reporting data for both Indigenous and non-Indigenous people were included if they specified Indigenous people either in the aims or methods, or Indigenous people accounted for more than 50% of the study population, and they reported separate analyses or results for Indigenous people.¹³ Similarly, international publications were included if they mentioned the Indigenous people of Australia in the aims or methods and included separate analyses or results for the Indigenous people of Australia.

Data extraction

Data extraction was performed by two researchers (WJ and BS) via manual data entry into a Microsoft Excel spreadsheet using drop-down list functions. Publications were managed in EndNote X9 software (Clarivate Analytics, Philadelphia, PA, USA). Double-checking of inclusion and extraction decisions for a subset of the papers was undertaken by another two researchers (GS and DA). The variables for data extraction are described in Table 1.

Intervention studies could be any study design that assessed a change of practice, including therapies, diagnostic interventions such as screening,¹⁴ and health system

Table 1: Outcome variables .

Year of publication
Author surname, initial
Title First five words
Journal
Age group of research participant
Child <15yo only
Adults ≥15yo only
Both
Unclear
Geographical location
Urban only (includes Major Cities and Inner Regional)
Rural/Remote only (includes Outer Regional, Remote, Very Remote)
Both, data for Indigenous people living in urban areas analysed separately
Both, no separate analysis for Indigenous people living in urban areas
Study type^a
Case study / series
Cross-sectional
Cohort
Case-control
Qualitative
Mixed Methods (study included both qualitative and quantitative methods)
Randomised Controlled Trial
Before and after
Data linkage
Evaluation and quality assurance (including continuous quality improvement)
Economic evaluation and modelling
Pre-clinical research (including genomic, genetic and microbiological studies)
Intervention^b or not
Recruitment site
Community
Primary care – Aboriginal Community Controlled Health Service, General Practices, or both
Secondary or tertiary care sites
Intersectoral
Secondary data

Notes:

a: Study type outcomes were adapted from NHMRC Keeping Research on Track report.³²

b: Intervention studies could be any study design which assessed a change of practice, including therapies, diagnostic interventions, 14 and health system interventions.

interventions such as Indigenous antenatal programs.^{13,15}

Geographical location

As per Eades et al.,¹ and using Australian Statistical Geography Standard (ASGS) Remoteness Area classifications,¹⁶ we defined urban localities as major cities (e.g. Sydney) and inner regional centres (e.g. Grafton), and rural/remote localities as outer regional, remote, and very remote areas. Study locations were determined from publications' text, author affiliations or acknowledgements, with ASGS status informed by ABS map resources.¹⁷ Where the geographical classification described by an author conflicted with our ASGS-informed categories, we used the ASGS categories for consistency.

Recruitment sites

Participant recruitment sites included primary care services (including Aboriginal Community Controlled Health Services [ACCHSs] and general practices), secondary care services (hospitals and services requiring referrals such as mental health services), and community (including community events, jails, training colleges, training events and population-based surveys). Research recruiting from a combination of sites (usually secondary care, primary care and/or community) was defined as 'intersectoral'. Research using routinely collected or administrative data was classified as secondary data studies. Primary care recruitment was classified into ACCHS and non-ACCHS clinics, which encompassed mainstream private general practice but also government clinics with an Indigenous focus.¹⁸

Burden of disease and research publication output

We also compared the number of research articles focusing solely on either urban or rural/remote, with the latest published burden of disease figures for these areas (2011 Australian Burden of Disease Study).⁴ Research articles spanning urban and rural/remote locations were excluded from this analysis.

Analysis

Descriptive statistics were used to describe the various categories of publications. Fisher's exact test was used to compare independent categorical variable distributions. All analyses

were performed using Stata SE version 12.1 (StataCorp, College Station, TX, USA), and $\alpha=0.05$ defined statistical significance.

Results

A total of 3,016 abstracts were reviewed by the primary researcher (AA). Of these, 1,484 were not eligible, 1,532 full texts were reviewed, and 1,258 were included for data extraction (Figure 1, adapted from PRISMA statement¹⁹).

Of the 1,258 eligible research papers, 15% (190) focussed exclusively on urban Indigenous populations, 45% (563) on rural or remote populations and 40% (505) included both urban and rural/remote populations (Fisher's exact test, $p<0.01$, see Table 2).

Age group

A total of 187 papers (15%) reported exclusively child health research, 766 (61%) papers reported exclusively adult health research and 224 papers (18%) reported on both children and adults. A similar distribution of age groups was observed across geographic areas (Table 2).

Study design

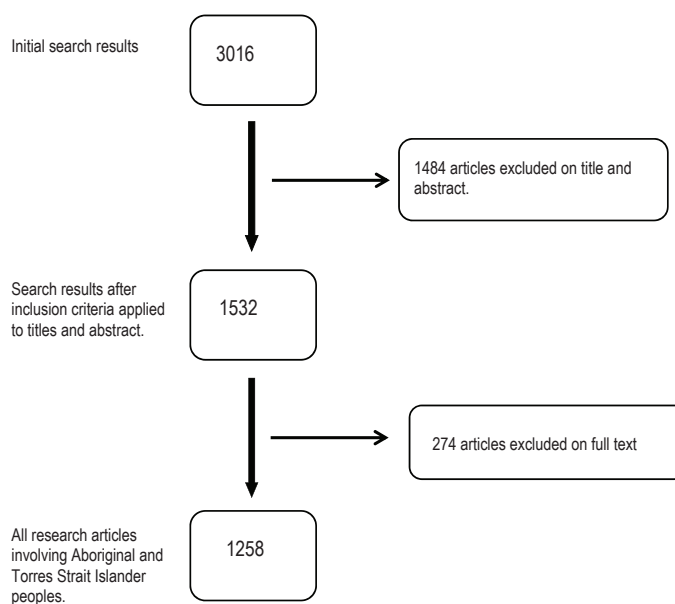
The five most common study designs (83% of all papers) were cross-sectional (480 papers, 38%), qualitative (235 papers, 19%), cohort (182 papers, 14%), mixed methods (90 papers, 7%) and data linkage (67 papers, 5%), see

Table 2. Research focussing exclusively on urban populations included the highest proportion of qualitative (33%) and mixed methods (11%) studies. Studies including both urban and rural/remote populations included the highest proportion of cross-sectional (45%) and data linkage (10%) studies ($p<0.01$). Randomised controlled trials (RCTs) were reported by 27 papers; 78% (21) of these were conducted in rural/remote areas ($p<0.01$). One in four publications reported an intervention evaluation, with similar proportions in publications focusing exclusively on urban populations only or rural/remote populations only (29% and 30%, respectively). However, fewer intervention studies were found in publications involving both urban and rural/remote populations (18%, $p<0.01$).

Recruitment site

Community sites and primary care services were the most common recruitment sites overall (60%). Community accounted for 45% of recruitment sites in exclusively rural/remote publications (Table 2), and primary care services accounted for 45% in urban populations. Of the 273 papers (22%) recruiting participants through primary care services, recruitment exclusively through ACCHSs was reported in 135 of these papers (49%), recruitment through both ACCHSs and other primary health care settings was reported in 89 papers (33%), and recruitment through other primary health care settings

Figure 1: Flow diagram for inclusion of Aboriginal and Torres Strait Islander health research publications.



Note:
Adapted from PRISMA statement.¹⁸

was reported for 49 papers (13%). For papers set in urban-only locations using primary care recruitment, recruitment exclusively through ACCHSs accounted for 62% (53/85), compared with both urban and rural remote (43, 42%) and rural remote-only papers (39, 45%; $p=0.01$).

Burden of disease

When comparing the geographic location of published research to the latest (2011 Census) burden of disease figures (represented by disability-adjusted life years [DALY]), there were 6.3 research papers/1,000 DALYs focused exclusively on rural/remote areas compared with 2.1 papers/1,000 DALYs for exclusively urban areas, (p -value <0.01 ; Table 3). In total,

across Australia, there were seven research papers/1,000 DALYs.

Discussion

Overall, there has been more than a two-fold increase in Indigenous health research publications over the five years ending in 2018 (1,258 research papers) compared with the five years ending in 2009 (555 research papers).¹ Reflecting calls by Eades et al.¹ and the NHMRC Roadmaps 1 and 2,^{5,6} there has also been a four-fold increase in published research focussed solely towards Indigenous people in urban areas, from a low of 47 publications (9%) in the five years ending 2009¹ to the 190 publications (15%) identified

in this review. One in four publications reported an intervention evaluation, with similar proportions in publications focusing exclusively on urban populations only or rural/remote populations only.

Notwithstanding this increase in research, the proportion of research publications exclusively involving Indigenous people living in urban areas was still only 15% of all Indigenous health research publications for the five-year period ending in 2018. Despite the majority of Indigenous people living in urban areas, three times as many research papers focussed exclusively on the health of Indigenous people living in rural/remote areas compared to those living in urban areas. Given that the Indigenous population living in urban areas has burden of disease levels comparable to the population living in remote areas, and experiences different health challenges, the disparity in research output suggests calls for more health research involving Indigenous people living in urban areas is still warranted.

Strengths and limitations

Strengths of this study include the use of validated Lowitja Lit.search tool,¹¹ enabling a highly sensitive and specific search of the PubMed database. However, since this tool was published in 2014 – after the review conducted by Eades et al.¹ – use of this tool may have contributed to the four-fold increase in identified publications. Limiting the search to the PubMed database allowed comparison to Eades et al. and the efficiency of rapid review, however, publications indexed in other databases were not included. Rapid review methods^{9,10} enable a timely review of publications but do involve trade-offs compared with the methodological rigour of an in-depth systematic review. In the interest of conducting an achievable, timely and replicable review to inform current debate, we did not search grey literature and did not appraise the quality of included studies. Indigenous identification of study authors is a recommended quality variable;^{7,20,21} however, the lack of a systematic process of acknowledgement of author Indigenous status within papers made extracting this variable fraught with inaccuracies and it was not pursued in this review.

We attempted to replicate the Eades et al.¹ study from the detail provided, but made pragmatic decisions where details were

Table 2: Publications indexed in PubMed from January 2013 to January 2018 that report research involving Aboriginal and Torres Strait Islander people overall (N=1,258), and methodological characteristics partitioned by geographical location with a statistical measure of difference (Fisher's exact test).

	Total		Urban ^a only		Both urban & rural/remote		Rural/Remote ^b		p-value ^c
	N	(%)	n	(%)	n	(%)	n	(%)	
Overall publications	1,258	(100)	190	(15)	505	(40)	563	(45)	<0.01
Age									
Adults only	766	(61)	124	(65)	320	(63)	322	(57)	0.05
Children only	187	(15)	34	(18)	70	(14)	83	(15)	0.40
Both children and adults	224	(18)	28	(15)	89	(18)	107	(19)	0.42
Unclear	81	(6)	4	(2)	26	(5)	51	(9)	<0.01
Total	1,258	(100)	190	(100)	505	(100)	563	(100)	
Study design									
Cross-sectional	480	(38)	63	(33)	228	(45)	189	(34)	<0.01
Qualitative	235	(19)	63	(33)	89	(18)	83	(15)	<0.01
Cohort	182	(14)	23	(12)	57	(11)	102	(18)	<0.01
Mixed Methods	90	(7)	21	(11)	29	(6)	40	(7)	0.06
Data linkage	67	(5)	2	(1)	51	(10)	14	(2)	<0.01
Evaluation and quality assurance	53	(4)	4	(2)	19	(4)	30	(5)	0.14
Before and after	39	(3)	5	(3)	14	(3)	20	(4)	0.76
Economic evaluation and modelling	29	(2)	1	(1)	7	(1)	21	(4)	0.01
RCT	27	(2)	3	(2)	3	(1)	21	(4)	<0.01
Preclinical research	25	(2)	1	(1)	3	(1)	21	(4)	<0.01
Case study / series	21	(2)	2	(1)	3	(1)	16	(3)	0.01
Case-control	10	(1)	2	(1)	2	(0)	6	(1)	0.39
Total	1,258	(100)	190	(100)	505	(100)	563	(100)	
Type of study									
Interventional study	319	(25)	56	(29)	92	(18)	171	(30)	<0.01
Observational study	937	(75)	134	(71)	412	(82)	391	(70)	<0.01
Total	1,258	(100)	190	(100)	505	(100)	563	(100)	
Recruitment site									
Primary Care	273	(22)	85	(45)	102	(20)	86	(15)	<0.01
Community	473	(38)	52	(27)	168	(33)	253	(45)	<0.01
Hospital/Secondary Care	225	(18)	40	(21)	62	(12)	123	(22)	<0.01
Intersectoral	99	(8)	10	(5)	48	(10)	41	(7)	0.15
Secondary Data	188	(15)	3	(2)	125	(25)	60	(11)	<0.01
Total	1,258	(100)	190	(100)	505	(100)	563	(100)	

Notes:

a: Urban defined as Major Cities and Inner Regional ASGS categories

b: Rural/remote defined as Outer Regional, Remote and Very Remote ASGS categories

c: Fisher's exact test used to generate the p values for proportions from different geographical locations.

lacking. Definition of urban status as major cities and inner regional ASGS classifications was deduced from Eades et al.'s abstract and introduction.¹ This classification was clear, replicable, and allowed us to align our study with Eades et al.; it also enabled comparison with ABS and AIHW population and burden of disease data.⁴ These ASGS classifications are based on distance from major centres, rather than size of population, and did lead to some counterintuitive classifications. For instance, research based in regional cities such as Darwin, Townsville and Cairns, which are outer regional,¹⁶ was classified as rural/remote. Conversely, research in smaller towns such as Tamworth, in north-western New South Wales, which is inner regional because of proximity to major centres, was thus classified as urban. These ASGS-informed geographical categorisations have limitations, both for this study and more generally. More work needs to be done to understand how these remoteness classifications reflect the density and visibility of Indigenous populations.

Persisting gap for research in urban areas

The persisting gap in research publications in urban compared with rural/remote Indigenous populations and burden of disease figures suggests that the problem of Indigenous invisibility in the city remains. This gap traces its origins to racist assumptions and stereotypes of what constitutes a 'real' Indigenous person or community, worsened by the poorer identification of Indigenous people in urban settings, particularly in the health context.²²⁻²⁵ Identity-policing of what is considered authentically Indigenous may structurally play out in what Indigenous health research is deemed important and worthy of resourcing. Additionally, concerns persist that increasing resources for Indigenous people living in urban areas may come at the cost of resources for those living in rural and remote areas who do have serious social, economic and health concerns.⁸ Our comparison of papers to burden of disease figures is an attempt to demonstrate where health research attention is needed.

Strength of community control and self-determination

Consistent with NHMRC Roadmap 3 recommendations for researchers to develop relationships and partnerships with Indigenous organisations,⁷ the community

Table 3. Indigenous health research publications indexed in Pubmed from January 2013 to January 2018, by 2011 burden of disease measured using Disability Adjusted Life Years (DALY) for Indigenous peoples living in urban and rural/remote localities (excluding research conducted in both urban and rural/remote locations).

	Urban ^a only		Rural/Remote ^b only		p-value ^c
	n	(%)	n	(%)	
Total research papers	190	(25)	563	(75)	–
Burden of Disease (DALY Disability Adjusted Life Years) ⁴	90,549	(50)	89,193	(50)	–
Research papers /1000 DALY	2.1		6.3		<0.01

Notes:

a: Urban defined as Major Cities and Inner Regional ASGS categories

b: Rural/remote defined as Outer Regional, Remote and Very Remote ASGS categories

c: Fisher's exact test used to calculate p-value

controlled sector continues as a significant facilitator to closing the urban research gap, with ACCHSs being the largest recruiters in urban publications. This is despite the policy challenges to ACCHS funding of 'mainstreaming', where early Closing The Gap funding and attention was directed at mainstream general practice,²⁶ and funding shortfalls to community organisations following the Indigenous Advancement Program.²⁷ ACCHSs are uniquely placed to consider the whole-of-person context, work from a strengths-based approach with a foundation of trust and create a flow between research and sustainable outcomes.²⁶ The continued support of ACCHSs in leading urban Indigenous research and embedding this within their comprehensive primary health care service delivery model is recommended.

Policy context for increase in research papers

The four-fold increase in research papers since 2010 may reflect policy changes that commenced in 2008 with the Australian Government's Closing The Gap initiatives.²⁸ Unfortunately, the Government's 2020 report card on Closing the Gap progress showed that life expectancy for Indigenous people, and the Indigenous life expectancy gap, have improved only slightly, and outcomes lag behind targets.²⁸ Strong Indigenous voices are concerned that increased research funding and volume alone will not address this disparity without a corresponding broadening of intellectual investment in Indigenous health. This intellectual investment involves a shift in focus to self-determination, Indigenous-led research, community consultation, and research into the actual causes of ill-health, including racism and other social determinants of health.^{7,29,30}

Where to from here

NHMRC Reporting on Roadmap 3³¹ has begun to address this intellectual shift, and the focus on Indigenous-led research grants is promising. Guides to the critical appraisal of the quality of Indigenous health research also reflect these shifts, and provide guidance for future reviews;^{20,21} however, more systematic documentation of Indigenous identification of research authors will be required. Indigenous people and communities are the best placed to drive the research agenda that addresses their health needs, including the differing needs of geographically different communities. This is important, for we argue that if research is to align with community needs,⁴ it must also align with the geographical distribution, including the 61% of Indigenous peoples living in urban areas.² We argue for the inclusion of geographic representativeness of Indigenous health research in future national planning and reporting.

Implications for public health

While the overall quantity and proportion of publications reporting urban Indigenous health research have increased since the previous review, the under-representation of urban health research compared to population and burden of disease remains, and calls for more health research involving Indigenous people living in urban areas is still warranted. These calls should not be at the expense of remote areas still experiencing compelling health, social and economic concerns.⁸ Rather, these findings should be used in planning and prioritisation processes, and highlight an area where there has been significant neglect for urban Indigenous populations.

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