# Indigenous Australians are under-represented in longitudinal ageing studies

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## Abstract

***Objective:*** Evidence-based policy depends on the availability of high-quality research that is relevant to the population. This study aimed to identify the available data on the health of older Indigenous Australians in population-based longitudinal studies of ageing.

***Approach*:** Evaluation of the Dynamic Analyses to Optimise Ageing Project (DYNOPTA) dataset that has pooled nine Australian longitudinal ageing studies, six of which were analysed here.

***Main outcome measures***: Proportions of the DYNOPTA sample identified as Indigenous.

***Results:*** Indigenous participants made up 0.7% of males and 0.5% of females in the weighted sample, compared with 0.8% of both sexes in the Australian population. Indigenous under-representation is greater at ages 45-54 than at older ages, despite overall greater participation in this age range.

***Conclusions and implications:*** Within the existing Australian longitudinal ageing studies, Indigenous Australians are under-represented. This means there is a significant gap in the evidence base relating to the health of older Indigenous Australians. Research approaches specifically designed to address the health and wellbeing of older Indigenous Australians are urgently required.

***Key words:*** DYNOPTA, Indigenous, Aboriginal and Torres Strait Islander, longitudinal, ageing, older

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It is well-known that a large gap exists between Indigenous and non-Indigenous health and life expectancy in Australia.[1,2] Closing this gap is a key focus of current Australian Government health policy.[3] However, accurately measuring the gap is problematic because data are lacking or unreliable. Of particular concern is the lack of longitudinal and detailed data about the health status of older Indigenous Australians. Currently, one of the best overviews is provided by the cross-sectional National Aboriginal and Torres Strait Islander Health Survey.[4]

Without adequate population-based data about the health of older Indigenous Australians it will be difficult to fully understand the needs of this group or to plan appropriate health services. Longitudinal research is especially important for enabling trajectories of health, disease and risk factors to be documented.[5] The omission of Indigenous status on official health records has been shown to result in inaccurate

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estimates of Indigenous life expectancy[6] and it is likely that this problem affects other health estimates. Hence, the development of policy relating to Indigenous health is hindered by the lack of research data available to provide the evidence base. Moreover, with the focus of concern on negative health outcomes for Indigenous Australians, there is a risk of overlooking measures of wellbeing and indicators of 'good health' among Indigenous communities. Studies of healthy ageing and survival among Indigenous Australians can provide rich information for designing strategies that promote ageing well. Another motivation for research that provides information on optimising the health of older Indigenous Australians is the acknowledgement of the crucial role they play in creating healthy communities and ensuring the health and wellbeing of Indigenous children.

Data about older Indigenous Australians are potentially available from large-scale population-based longitudinal studies of ageing. Recent developments in population research methods involve the pooling of large cohort studies to create datasets that are large enough to permit the analysis of subgroups. Pooled datasets may, therefore, provide a greater opportunity to gain an understanding of ageing among older Indigenous Australians, even if each contributing study contains few individuals identifying as Indigenous. In this paper we aim to evaluate the volume and value of longitudinal data about the health of older Indigenous Australians available through a large collaborative project called DYNOPTA.[7]

## Research design and methods

The Dynamic Analyses to Optimise Ageing Project (DYNOPTA) is a unique dataset created through the harmonisation and pooling of data across nine separate Australian longitudinal studies of ageing collected between 1990 and 2007 (n=50,652). The design and methodology of the DYNOPTA project have been previously described.[7] The DYNOPTA baseline dataset consists of the first wave of the nine studies, individual study baselines occurred between the years 1992 and 2001. Participants included in the DYNOPTA dataset were aged 45 to 103 (M = 61.73; SD = 12.43) at baseline, were predominantly female (77.2%), reported mostly good or excellent self-rated health (69%), and reported a mode of four observations (M = 3.1; SD = 1.51) over a period of up to 12 years. The domains of variables included in the pooled dataset include demographic, cognitive, mental health, social networks, functional impairment, sensory function, mental health and mortality, and psychosocial data measures and are described elsewhere.[7]

**Table 1: Comparison of proportions Indigenous in ERP and DYNOPTA pooled[b] dataset by sex, 1996.**

| | Non-Indigenous | | | Indigenous | | | No response | |
|---|---|---|---|---|---|---|---|---|
| | ERP | DYNOPTA | | ERP | DYNOPTA | | DYNOPTA | |
| Age | % | % | (se) | % | % | (se) | % | (se) |
| Males | | | | | | | | |
| 45-49 | 98.87 | 78.32 | (1.70) | 1.13 | 0.69 | (0.28) | 20.98 | (1.71) |
| 50-54 | 98.98 | 77.94 | (1.78) | 1.02 | 0.42 | (0.21) | 21.64 | (1.79) |
| 55-59 | 99.12 | 77.98 | (1.85) | 0.88 | 0.69 | (0.27) | 21.34 | (1.83) |
| 60-64 | 99.21 | 76.40 | (2.13) | 0.79 | 0.65 | (0.28) | 22.95 | (2.08) |
| 65-69 | 99.45 | 76.09 | (2.41) | 0.55 | 1.10 | (0.51) | 22.81 | (2.40) |
| 70-74 | 99.60 | 83.62 | (1.86) | 0.40 | 0.94 | (0.55) | 15.45 | (1.75) |
| 75-79[a] | 99.61 | 79.74 | (2.54) | 0.39 | 0.16 | (0.16) | 20.09 | (2.54) |
| 80-84 | – | 80.01 | (3.32) | – | 1.40 | (1.02) | 18.59 | (3.18) |
| 85+ | – | 81.31 | (5.49) | – | 0.03 | (0.03) | 18.66 | (5.49) |
| Total | 99.19 | 78.42 | (0.88) | 0.81 | 0.68 | (0.12) | 20.88 | (0.87) |
| Females | | | | | | | | |
| 45-49 | 98.76 | 96.16 | (0.24) | 1.24 | 0.78 | (0.08) | 3.07 | (0.22) |
| 50-54 | 98.90 | 82.08 | (1.26) | 1.10 | 0.63 | (0.22) | 17.30 | (1.23) |
| 55-59 | 98.99 | 81.97 | (1.70) | 1.01 | 0.78 | (0.25) | 17.25 | (1.68) |
| 60-64 | 99.09 | 79.62 | (2.20) | 0.91 | 0.77 | (0.47) | 19.62 | (2.17) |
| 65-69 | 99.32 | 81.65 | (1.82) | 0.68 | 0.31 | (0.16) | 18.03 | (1.82) |
| 70-74 | 99.55 | 92.38 | (0.29) | 0.45 | 0.41 | (0.07) | 7.22 | (0.28) |
| 75-79[a] | 99.66 | 87.00 | (1.22) | 0.34 | 0.14 | (0.09) | 12.86 | (1.22) |
| 80-84 | – | 88.11 | (3.03) | – | 0.03 | (0.03) | 11.86 | (3.03) |
| 85+ | – | 79.32 | (5.09) | – | – | – | 20.68 | (5.09) |
| Total | 99.16 | 86.27 | (0.61) | 0.84 | 0.53 | (0.07) | 13.19 | (0.61) |

*Notes:*
*a. 75+ for ERP.*
*b. weighted to the 1996 Estimated Resident Population (ERP).*
*Source: 9,10, DYNOPTA; authors' calculations.*

Six studies were included in our analyses. The contributing studies included the Australian Longitudinal Study of Ageing (ALSA), the Australian Longitudinal Study of Women's Health (ALSWH), the Australian Diabetes, Obesity and Lifestyle Study (AusDiab), the Blue Mountains Eye Study (BMES), the PATH Through Life Project (PATH), and Household Income and Labour Dynamics in Australia (HILDA). The remaining three studies, the Canberra Longitudinal Study (CLS), the Melbourne Longitudinal Studies on Ageing (MELSHA) and the Sydney Older Persons Study (SOPS) did not ask Indigenous status; these comprised only 5.5% of the total baseline sample. Study-specific weights either existed (three studies) or were developed to adjust the sample in each study to the specific population from which it was drawn and to account for the probability of selection of each individual. These study-specific weights were combined according to their contributing sample sizes to the pooled dataset made up of the six studies with reference to sex, age group and geographical region. They were then calibrated to the 1996 Estimated Resident Population (ERP),[8] which is the mid-point for the baseline time span and is the point at which a large proportion (55%) of participants were observed. The weights for the contributing studies were combined to allow for any geographic overlap of the studies, but it should be noted that these weights do not account for the distribution of the Indigenous population at different age, sex and geographic regions.

The following variables were used in this study: age, sex, contributing study, Indigenous status, and an indicator of death and non-death attrition between the first and second waves of each study. AusDiab, ALSWH and HILDA all sampled the national population and included rural and remote areas, of which ALSWH oversampled women in rural and remote areas. ALSA sampled the Adelaide metropolitan area and oversampled males and persons aged 85 years or older, PATH sampled the Australian Capital Territory and Queanbeyan, and BMES sampled Blue Mountains (see Table 2). Only the three national studies obtained Indigenous status using item wording that was consistent with national best practice guidelines: 'Are you [is the person] of Aboriginal or Torres Strait Islander origin? If the person is of both Aboriginal and Torres Strait Islander origin, mark both boxes' (1=No, 2=Aboriginal, 3=Torres Strait Islander).[9] Other studies asked "which of the following groups describes yourself", or required respondents to check a box corresponding to their 'racial group'. BMES relied on interviewer judgment of racial background and respondents were asked if interviewers were unsure.

## Results

### *Indigenous participants in DYNOPTA*

The number of participants identifying as Indigenous in the DYNOPTA baseline dataset was 297. Of these, 74 were aged 65+. Studies that sampled the national population and included younger age cohorts had a greater proportion of Indigenous participants compared to studies that sampled older aged cohorts from local, more urban areas (Table 2). There was no discernible pattern of non-response between studies conforming to best practice guidelines and

**Table 2: Contributing study sample, method of Indigenous identification and non-response rates.**

| Study | Baseline year | Age range | Geographic coverage | Population oversampled or excluded | Baseline sample size | Indigenous question[b] | Indigenous[a] (%) | Non-response (%) |
|---|---|---|---|---|---|---|---|---|
| ALSA | 1992 | 65-103 | Adelaide | Males and persons over 85 were oversampled | 2,087 | Which of the following groups describes yourself? | 0.05 | 0.24 |
| ALSWH mid | 1996 | 45-51 | National | Rural and remote were oversampled | 13,706 | Best Practice | 0.92 | 0.91 |
| ALSWH old | 1996 | 58-76 | National | Rural and remote were oversampled | 12,431 | Best Practice | 0.37 | 7.17 |
| AusDiab | 1999 | 45-95 | National | Census districts classified at 100% rural in the 1996 census or which included >10% Indigenous Australian population were excluded | 7,296 | Best Practice | 0.77 | 0.05 |
| BMES | 1992 | 45-100 | Blue Mountains | None | 3,654 | Interviewer identified | 0.16 | 0.60 |
| HILDA | 2001 | 45-90+ | National | People living in remote and sparsely populated areas were outside the coverage of the survey | 6,164 | Best Practice | 0.94 | 30.35 |
| PATH | 2001 | 60-66 | ACT and Queanbeyan | None | 2,550 | Racial Group? (check box) | 0.08 | 0.08 |

*Notes:*

a. *Small numbers prevented reporting of study specific Indigenous proportions by sex. In the ALSWHmid and ALSWHold, women from rural and remote areas were selected with twice the proportions of the Australian population.*

b. *Best practice for self-report of Indigenous identity 'Are you [is the person] of Aboriginal or Torres Strait Islander origin? If the person is of both Aboriginal and Torres Strait Islander origin, mark both boxes' (1=No, 2=Aboriginal, 3=Torres Strait Islander).9*

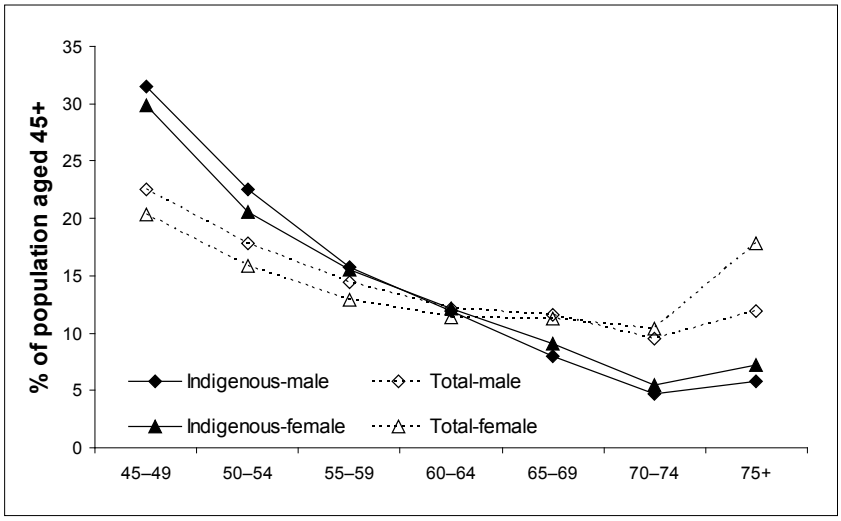


**Figure 1: Age structure of total and Indigenous populations in Australia aged 45+ by sex, 1996.**
**Source: Australian Bureau of Statistics.[10]**

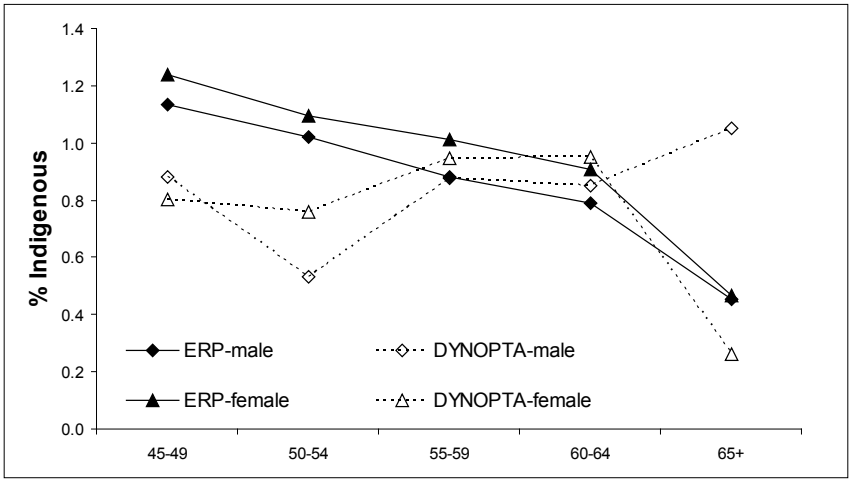


**Figure 2: Comparison of proportions Indigenous Australians by age in the ERP and DYNOPTA dataset* with non-responses excluded from weighted estimates, 1996. (* Weighted to the 1996 Estimated Resident Population [ERP]).**

studies that used less-rigorous approaches to identifying Indigenous participants, although this may be confounded with study differences in sample characteristics. The attrition rate between the first and second waves for the Indigenous sub-sample was 30%, compared with 19% for the non-Indigenous sub-sample, and the number of Indigenous participants included in wave 2 was reduced to 207.

Among the Australian population in 1996, 0.8% of both males and females aged 45 years and older were identified as Indigenous (Table 1).[10] In comparison, in the weighted DYNOPTA data 0.7% of males and 0.5% of females were identified as Indigenous.

Several factors contribute to this under-representation of the Indigenous population, including the difference at the national population level in the age distributions of the Indigenous and total populations aged 45+ (Figure 1). Though over-sampling of the oldest age groups occurred in some DYNOPTA studies, the number of Indigenous participants at these ages remains very small as a consequence of their small numbers in the total Australian population and the focus of contributing studies on urban areas (Table 2).[11] It is also possible that the high rates of non-response to the question on Indigenous status have contributed to the lower than expected percentage of participants who were Indigenous: 20.9% of males and 13.2% of females did not respond to the question on Indigenous status (Table 1). If non-responses are removed from the data, a direct comparison can be made between the ERP and DYNOPTA with respect to the percentage of participants identified as Indigenous at different ages.* Figure 2 indicates that when non-responses are excluded from weighted estimates in DYNOPTA, there is greater under-representation of Indigenous Australians ages 45-54 than at older ages, despite higher participation in absolute numbers. For males, this may have been in part due to the exclusion criteria of the AusDiab and HILDA studies (see Table 2). Further investigation was precluded by the small number of Indigenous participants.

## Discussion

Our study has quantified the sparseness of available information about the health of older Indigenous Australians in existing longitudinal studies contributing to the DYNOPTA project. The level of coverage of the Indigenous population is less than optimal, particularly for females, reducing the usefulness of the DYNOPTA dataset for research on Indigenous ageing. In addition to the very small number of Indigenous participants overall, the lack of participants in the older age groups is particularly noteworthy. The relatively young Indigenous population age structure stems from

* **Footnote:** At all ages, 0.9% of male and 0.6% of female participants who responded to the question about Indigenous status identified as Indigenous.

lower Indigenous life expectancy, as well as past migration and fertility patterns in the non-Indigenous population. It is, therefore, necessary to design studies that focus on the Indigenous population, rather than rely on studies that address the general population. Such studies require a range of methodologies that capture the social, environmental and community aspects of health. Although there are health and cultural issues specific to Indigenous Australians, design of new data collections may benefit from the expertise gained in other countries where epidemiological studies have been specifically designed to measure the health of Indigenous peoples.[12] For example, the *Te Hoe Nuku Roa*[13] study is a longitudinal study of adult Māori health, and the New Zealand Health Work and Retirement Study has a special focus on Māori health and includes 3,117 Māori participants.[14]

Another approach to obtaining information about the health of any population group is through analysis of administrative datasets. However, linking survey data with administrative data is limited by the response bias in the existing surveys documented here. This approach may also raise issues relating to informed consent and would require appropriate community consultation. Finally, the diversity of health services used by Indigenous Australians may not be captured well through linking to administrative datasets.

Our evaluation of the DYNOPTA dataset highlights an enormous gap in research on older Indigenous Australians, namely the lack of reliable longitudinal evidence about Indigenous health and ageing. The few cross-sectional studies that have been conducted on the prevalence of conditions among older Indigenous Australians show that while infectious disease is decreasing, chronic conditions are increasing and may be more prevalent than in the non-Indigenous population. For example, studies show that rates of dementia are 5.2 times higher in an Indigenous community in the Kimberly region than in the overall Australian population.[15] Rates of vascular dementia are particularly elevated in Indigenous communities.[16]

A national longitudinal study of older Indigenous Australians would provide valuable new knowledge about the health and ageing of this section of the population. Such a study could be informed by the Longitudinal Study of Indigenous Children, funded by Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), which is designed to explore how Aboriginal and Torres Strait Islander children develop resilience longitudinally, and to recognise links between early childhood experiences and later life outcomes (www.fahcsia.gov.au/sa/Indigenous/progserv/families/lsic/Pages/default.aspx).

This study involves widespread prior community-based consultation, Indigenous leadership and balanced participation in the study steering committee. Data collection is conducted by Indigenous research officers located at 11 sites across Australia. Having Indigenous interviewers creates positive communication, rapport and trust with Indigenous families and communities. Interviewers also provide critical input to questionnaire development on behalf of communities and participants.

However, before instigating such intensive targeted research, it is essential to seek Indigenous leadership and guidance and undertake wide community-based consultation. It is also valuable to identify other available sources of information through previous investment in medical research and population-based datasets. In addition to evaluating the DYNOPTA dataset we conducted a brief review of the literature that identified only 13 articles reporting on prospective studies including older Indigenous Australians. Of these, only the NSW 45+ Study, which now includes 266,000 people, had sufficient numbers of Indigenous people for detailed analyses.[17] However, even where sufficient data about Indigenous Australians are available from studies of the wider population, careful consideration must be given to the analysis and representation of these data.[18]

Importantly, studies included in DYNOPTA were sampled from the total population and made no special provision for the inclusion of the Indigenous population. Although the scope for individuals to identify as Indigenous was part of the methodology of most surveys, only three used best practice for the self-reporting of Indigenous identity. These studies tended to be more recent and nationally representative. The NHMRC protocols for conduct of research with Indigenous Australians were published subsequent to the commencement of the contributing DYNOPTA studies.[18] New longitudinal studies would have the benefit of being designed and conducted under these protocols. Any proposal for such a study would also need to be reviewed by Aboriginal Health and Medical Research Council and appropriate procedures for the involvement of Indigenous Australians in the research would need to be followed.

We conclude that there is an urgent need to develop an evidence base for public health research into the health of adult Indigenous Australians, particularly older adults. While the overall research effort needs to include a mixture of qualitative and quantitative methods, a longitudinal study of adult Indigenous health that is carefully designed to sample relevant remote, rural and urban areas, and which focuses on culturally relevant health issues would contribute significantly to addressing the lack of population-based data about adult Australian Indigenous health.

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All studies would like to thank the participants for volunteering their time to be involved in the respective studies. Details of all studies contributing data to DYNOPTA, including individual study

leaders and funding sources, are available on the DYNOPTA website (http://DYNOPTA.anu.edu.au).The findings and views reported in this paper are those of the author(s) and not those of the original studies or their respective funding agencies.

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