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Transformation of mortality in a remote Australian Aboriginal community: a retrospective observational study

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3 **Transformation of mortality in a remote Australian Aboriginal community: a retrospective**
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Abstract

Objectives To describe trends in ages and causes of deaths in a remote-living Australian Aboriginal group over a recent 50 year period.

Design A retrospective observational study, from 1960 to 2010, of deaths and people starting dialysis, using data from local clinic, parish, dialysis and birthweight registers.

Setting A remote island community in the Top End of Australia's Northern Territory, where a Catholic Mission was established in 1911. The estimated Aboriginal population was about 800 in 1960 and 2,260 in 2011.

Participants All Aboriginal residents of this community whose deaths had been recorded.

Outcome measures Annual frequencies and rates of terminal events (deaths and dialysis starts) by age-group and cause of death.

Results In all, and against a background of high rates of low birthweight, 223 deaths in infants and children and 934 deaths in adults (age ≥ 15 years) were recorded; 88% were of natural causes. Most deaths in the 1960s were in infants and children. However, these fell dramatically, across the birthweight spectrum, while adult deaths progressively increased. The leading causes of adult natural deaths were chronic lung disease, cardiovascular disease and, more recently, renal failure, and rates were increased two-fold in those of low birthweight. However, rates of natural adult deaths have been falling briskly since 1986, most markedly among people of age 45+ years. The population is increasing and its age structure is maturing.

Conclusions The changes in death profiles, the expression of the Barker hypothesis and the ongoing increases in adult life expectancy, reflect epidemiologic and health transitions of astonishing rapidity. These probably flow from advances in public health policy and health care delivery, as well as improved inter-sectoral services, which are all to be celebrated. Other remote communities in Australia are experiencing the same phenomena, and similar events are well advanced in many developing countries.

Strengths and limitations of this study

- The broad sweep and historical depth of this study, the unique data sources and the integration of clinical and demographic information have allowed delineation of the profound and recent transformation of mortality not previously appreciated in the Australian Aboriginal setting.
- Although the failure to have captured some deaths is inevitable, it has probably resulted in understatement of the magnitude of this transition.

Introduction

Recent literature describes a rapid shift in patterns and causes of death in most countries and regions. Infant and childhood deaths have decreased, life expectancy has increased,¹ and more deaths in adults are associated with non-communicable chronic diseases.² Here we describe such a transition in a remote-living Aboriginal Australian group over the last 51 years.

The Tiwi people live in three major communities (and several smaller ones) on Bathurst and Melville Islands off the coast of the Northern Territory (NT), about 90 km by sea from Darwin (Figure 1). They lived in relative isolation for perhaps 7,000 to 15,000 years, and consider themselves distinct from mainland Aboriginal people, with their own unique origins, language, and customs.³

In 1911, a Catholic mission was established by the Missionaries of the Sacred Heart (MSC), led by Father Francis Xavier Gsell.⁴ Changes followed in lifestyle (from nomadic hunter gatherers to living in fixed dwellings), in diet (from food from the bush and sea to depot supplies of less perishable, high caloric density food, of flour, fat, meat and sugar), in family and community structures (from polygamy and networks of carers within extended families to monogamy), and in the establishment of dormitories, schools and clinics. Transition has been especially accelerated since World War 2. Cigarettes were widely introduced around this time. The 1967 referendum formally recognised Aboriginal people in Australia,⁵ and they were thenceforth included as residents in the national census. Legal access to alcohol began around that time. The first social club, serving alcohol, was opened in the largest Tiwi community in 1967.

Some early insights into remote-living Aboriginal people in the NT are provided by Ellen Kettle, the first Rural Survey Sister in the NT, who pioneered mobile health work in isolated areas and established health records for individuals, and by Dr John Hargrave, the first Aboriginal Health Officer, who personally examined members of many communities in 1957/1958. Both advanced understanding of Aboriginal health and development of services and policy. They described endemic conditions (yaws, malaria, infestations, trachoma), imported conditions like leprosy, syphilis (arguably), tuberculosis, measles, small pox and influenza. They documented florid malnutrition and frank starvation, high infant and maternal mortality and conspicuously low birthweight. They then described, over time, dramatic reductions in infant mortality, the appearance of alcohol related disorders, and of occasional overweight and obesity, as well as the emergence of non-communicable chronic diseases.^{6,7}

These phenomena occurred against a background of continuous improvements in remote Aboriginal health services, including management of infections and infestations, immunisations, better obstetric services, better maternal and child care, and cancer surveillance. Chronic non-communicable diseases, predominantly type 2 diabetes,

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3 cardiovascular disease, chronic lung disease and chronic kidney disease now dominate the
4 adult health profile and are the focus of most of health service provision for remote-living
5 Australian Aboriginal adults.⁸
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8 Clinical services were established by the mission, starting as first aid facilities on the beach
9 at Nguuu (now Wurrumiyanga) on Bathurst Island. These eventually evolved into a clinic and
10 local hospital, run by the Sisters of the Order of Our Lady of Sacred Heart (OLSH), with
11 additional clinics in the Melville Island communities of Milikapiti and Pirlangimpi. Medical
12 records were established for individuals, along with clinic-based registers for births and
13 deaths. Doctors from Darwin eventually provided backup support. More recently, there
14 have been resident doctors for intermittent periods. Local hospital beds were closed in the
15 early 1990s, and all persons needing hospital admission were thenceforth streamed to the
16 Royal Darwin Hospital, transported by small plane. Responsibility for clinical services was
17 transferred from the mission to the NT government in the early/mid-1990s.
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22 Anthropologist Charles Hart enumerated a Tiwi population of 1,062 in 1928.³ Dr John
23 Hargrave estimated the Tiwi population at about 800 to 900 in 1957, compatible with a
24 1954 Commonwealth Government estimate of 920.^{9,10} Regular government census
25 estimates have been published every five years since 1986.
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29 Traditionally, Tiwi people have only occasionally transmigrated, usually for purposes of
30 intermarriage according to tribal edicts. The destinations of people who travel, and the
31 movements and locations of community members, are known by all. Deaths of people who
32 die out of community (usually in Darwin or while visiting other communities) are
33 documented in their medical records on in their “home” community clinic and added to the
34 death register.
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38 Death rates in the Tiwi community, along with those in Aboriginal people in Arnhem Land,
39 have among been the highest in Australia: in the 1990s, with age-standardisation, they were
40 six times those of the Australian mainstream.¹¹ Cases of kidney failure began to attract
41 attention in the 1980s;¹² for several decades Tiwi people had the highest rates of renal
42 failure yet described, and the first hemodialysis unit in a remote Aboriginal location was
43 established in Wurrumiyanga on Bathurst Island in the late 1990s. We have previously
44 described the high rates of low birthweight in this community and the risk exacerbations for
45 natural deaths in infants, children and young adults associated with low birthweight.^{13,14}
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49 **Methods**

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51 Data sources were the written logs of deaths maintained by the clinics, dialysis unit records
52 of NT Renal Services, and in this staunchly Catholic community, records maintained by the
53 parish priests of all funerals and burials. We report recorded deaths over the 51 year period
54 from 1960 to 2010, beginning when clinic recording of details of death (age, date and
55 explanation) was becoming more systematic.
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3 Starting in the 1980s, maintenance dialysis has been available to Tiwi persons with end-
4 stage renal disease; numbers of patients starting treatment increased steadily until
5 apparently stabilising at about 6 persons a year in the early 2000s. In this study, initiation of
6 dialysis is considered a natural (renal) death, occurring when dialysis began, because
7 without that treatment all participants would have died shortly thereafter.
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10 Description of cause of death became more detailed over time. In the early years the only
11 discrimination for some deaths was of natural versus unnatural causes, while, in later years,
12 there was more detailed narrative on cause(s) and associations of death. In the early years,
13 deaths in people over 60 years of age often received a causal assignment of “old age” or
14 “debility”, but with time “disease or organ-specific” assignments increased for them as well.
15 In the context of sometimes sparse clinical detail, and conforming to the methodology for
16 the Global Burden of Disease study, we derived and assigned a principal cause of death only.
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20 Unnatural deaths, or deaths of misadventure, included those due to accidents, drownings,
21 fire (burns and smoke inhalation), homicide, suicide, poisonings, jelly fish stings, crocodile
22 and shark attacks etc. We defined the main categories of natural deaths as cardiovascular
23 (heart attack, congestive heart failure, ischemic heart disease, coronary artery disease and
24 stroke), respiratory (chronic lung disease, chronic obstructive airways disease, chronic
25 bronchitis, bronchiectasis, pneumonia), renal (death with terminal renal failure, and also,
26 after 1985, institution of dialysis in people with terminal renal failure), various other causes
27 (eg sepsis, liver failure, lupus, cancer etc.), and debility or old age. When there was
28 uncertainty about deaths or persons, data were checked with several senior community
29 members, who had lived through much of the study interval and had known most
30 community members.
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36 Analyses were conducted using Stata 14 (StataCorp. 2015. *Stata Statistical Software:
37 Release 14*. College Station, TX: StataCorp LP). Numbers and rates of deaths were calculated
38 by age-group and cause of death. Five-year moving averages were created using the
39 tssmooth package. Mortality rates, per 100,000 population, could be calculated only since
40 1986, the first year of the subsequent quinquennial national census that specifically
41 enumerated Aboriginal Tiwi people. Total population estimates were also taken from census
42 figures.¹⁵
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47 **Patient involvement**

48 This study has retrospectively reviewed combined records of forerunning studies. There was
49 no direct contact with patients or individuals. No patients were involved in setting the
50 research questions or the outcome measures, nor were they involved in developing plans
51 for recruitment, design, or implementation of the study. No patients were asked to advise
52 on interpretation or writing up of results.
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Results

1,190 deaths were recorded, and age was documented or age group could be inferred in 1,156 (97.1%) of these (for 95.0% of deaths in the first two decades, and 98.6% of deaths in the last three decades).

Of these 1,156 deaths, 222 were in infants and children (<1 years and 1 to <15 years respectively), and 934 (78.5%) were deaths of adults (at ages ≥ 15 years). Twenty-five (11.3%) deaths of infants and children were deaths of misadventure and 197 (88.7%) were of natural causes. Among adults, 114 (12.2%) of deaths were due to misadventure and 820 (87.8%) were natural deaths.

Figure 2 shows deaths by age-group and interval. Early on, most deaths were in infants and children. These fell rapidly at first, then more slowly. The main categories of death in infants and children were diarrhoea, respiratory disease and failure to thrive, with some cases of sudden infant death, and a few congenital abnormalities.¹³ In 1973, a house fire killed six siblings, making a major contribution to deaths due misadventure in this group.

As infant and childhood deaths fell, numbers of deaths of adults increased. Many of these have been among young adults (ages 15 to <49 years) with high numbers of both natural death and deaths of misadventure. The latter include motor vehicle accidents, drownings, homicide, and suicide; there were 50 suicides between 1985 and 2010, of which 47 (94%) were among males.

Most deaths are now in people of ≥ 45 years, and most of these are of natural causes. The numbers have not perceptibly increased since the early 1990s. Only 2.6% of these older adult deaths were due to misadventure.

Figure 3 shows the trends in natural deaths in adults over time, by primary causal assignment. Numbers peaked in the later 1980s but have since had an indeterminate or falling trend. Through the mid-1980s there were substantial numbers of natural deaths with no further details and deaths with assignments of "old age" or debility", but there have been more "organ-system" assignments since the early 1990s. Among specific assignments, cardiovascular deaths, and cancer/liver/other deaths were represented over the continuum, while pulmonary (respiratory) deaths became prominent but more recently have been decreasing. Renal deaths become prominent in the 1980s; there were 25 renal deaths in the 1980s, 42 in the 1990s and 52 from 2000 to 2009, constituting 14.7, 24.1 and 31.7% of all natural deaths in those intervals.

Figures 4 A-C show the smoothed estimated rates of natural deaths by age-group since 1986.¹⁵ Rates of death in infants and children have fallen remarkably. There was an early increase in death rates among young adults, followed by a progressive decline since the early 1990s. Death rates of people age ≥ 45 years have markedly declined, at least until the

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3 last few years of the observation interval. The net effect of all these changes is a decrease
4 overall death rates of the entire population.
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6 These trends are further summarised in Table 1, which shows the rates of natural deaths by
7 age-group in the first and last 5-year blocks of the observation interval. Death rates of
8 infants and children fell by 89.5%, those of young adults fell by 23.5%, while of people age
9 ≥ 45 years fell by 65.1%. For the population as a whole, rates of natural death fell by 52.2%.
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12 Figures 5 A-D show that the population age structure has changed over <40 years to include
13 higher numbers and proportions of young and middle age adults.^{15,16} In addition, the size of
14 the total population has increased by 85%.
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17 Discussion

18 This is the most complete description of deaths in any indigenous Australian community. It
19 shows a profound change in patterns, rates and causes of death over a 51 year interval.
20 Infant and childhood deaths have fallen dramatically; now most people die as adults (≥ 15
21 years), and of natural causes. Furthermore, in the last 25 years, rates of natural deaths of
22 adults have been falling. The population is increasing and is progressively ageing.
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25 With continued improvements in prevention and treatment of infectious diseases, adult
26 deaths are increasingly due to non-communicable diseases, with chronic lung disease,
27 cardiovascular disease and renal disease making the greatest contribution. These chronic
28 diseases have usually overlapped and been co-contributors to death, although this is
29 obscured by our use of mutually exclusive categories of primary cause of adult death.
30 Among specific assignments, cardiovascular deaths, and cancer/liver/other deaths etc. have
31 been represented over several decades, while pulmonary deaths became prominent in the
32 1970s, but have decreased since the early 1990s. Kidney failure has become prominent
33 since the 1980s, and is now the single leading assignment.
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36 The improving but still excessive rates of natural deaths are, in large part, the
37 representation of the "Barker hypothesis".¹⁷ We have shown that the dramatic reductions in
38 early life mortality have been experienced across the birthweight spectrum, so that, against
39 a background of seriously low birthweights, large cohorts of underweight infants, who were
40 previously at greatest risk for early death, have now survived to adult life. As adults, they
41 have enhanced susceptibility to chronic disease, as the hypothesis proposes and as we have
42 demonstrated.^{13,18,19} Through 2010, rates of natural adult deaths before the age of 41 years
43 in the Tiwi populations was twice that of those with higher birthweights, with the greatest
44 accentuation of risk being for pulmonary deaths, a 6-fold increase (Med J Aust, submitted
45 Jan 2017).¹⁴
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48 The continued evolution of the chronic disease rates and patterns and rates over time is
49 probably influenced by improving birthweights, changing age structure among adults,
50 improved prevention, screening and management of chronic disease and changes in
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3 competing causes of deaths. With reductions in deaths from pulmonary disease and
4 postponement of cardiovascular deaths, flowing from a secular increase in birthweights,¹³
5 and from better medical management, coexisting nephropathy has more opportunity to
6 pursue its more leisurely course to renal failure.²⁰
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10 Availability and use of the clinic-based death records and the supporting parish burial
11 records sets this study apart. The NT-wide government register of deaths dates only back to
12 the mid-1980s, and in that register, community assignment has sometimes been
13 incomplete. Moreover, government records do not capture the full burden of renal failure,
14 due to deficient documentation of a renal cause of death, both in people receiving renal
15 replacement therapy (RRT), and in those dying of renal failure without receiving RRT.^{21,22}
16 Our composite definition of “renal deaths” as the start of RRT and a renal death without RRT
17 more fully reveals the burden of renal failure disease. That approach is necessary for
18 monitoring, prevention and intervention strategies, especially in the context of the burden
19 and costs of RRT.^{23,24} Furthermore, it is the only way that kidney failure rates can be
20 compared with populations in other countries for whom RRT is not widely available.
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25 Our data also reveal an excess of deaths by misadventure in young adults in more recent
26 years. Such deaths, often alcohol or drug-fuelled, are prominent among young Aboriginal
27 adults nationwide, and are of grave concern.^{25,26}
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31 Limitations include the fact that some Tiwi deaths were probably not captured in our data
32 sources. This is more likely in the earlier years, so that that the earlier numbers and rates of
33 deaths, as well as the subsequent fall in deaths, have probably been understated.
34 Moreover, from 1985 to 2009, the government agencies recorded 18% fewer deaths for the
35 Tiwi community than we have recorded, with under-identification varying from 10 to 30%
36 over five consecutive 5 years intervals (In an email from Y Zhao, (yuejen.zhao@nt.gov.au)
37 2016 Oct 24). An additional limitation is assignment of a single category of cause of death,
38 whereas natural deaths in adults have multiple causes and associated conditions; the
39 coexistence of cardiovascular risk and lung disease, and of renal disease with cardiovascular
40 disease are well recognised. However, the use of a single underlying cause of death is
41 dictated by the detail of the source data. It is also the approach employed until recently for
42 the mortality component of the study of Global Burden of Disease.
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48 Is it credible that about half the deaths in Tiwi people in the 1960s were in subjects less than
49 15 years of age? The World Health Organization estimated that, in 1955, fully 40% of global
50 deaths were in children age <5 years, so presumably an even greater proportion were
51 deaths of people <15 year old).²⁷ Furthermore, analyses of skeletal remains of some
52 premodern cultures have suggested that up to 68% of deaths occurred people <15 years old
53 (Chamberlain cited in Roser, 2006).^{1,28} Hart’s comment that, around 1928, five of 15
54 bestowed wives (females promised in marriage to specific Tiwi community members), died
55 before puberty, supports a high childhood mortality.³
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3 Other Aboriginal groups in remote areas of Australia over the same intervals have
4 undoubtedly experienced similar transitions. NT government agencies have described
5 similar trends in early life mortality since 1967, and improvements in natural death rates
6 overall since the late 1980s (Figures 6 and 7).²⁹ In the Shire of Broome, Western Australia,
7 Gracey et al. described excessive levels of Aboriginal infant and childhood infection and
8 under-nutrition in the 1970s and 1980s and increasing deaths by misadventure in young
9 Aboriginal adults between 1971 and 1994.³⁰ Our findings are also consistent with events in
10 many other countries and regions. Figure 8 shows the fall in early life mortality since 1960,
11 which is most dramatic in disadvantaged populations like Yemen, Afghanistan, Bangladesh
12 and Nepal,³¹ while Figure 9 shows the simultaneous increase in life expectancy at birth,
13 again most marked in disadvantaged settings.³² Our Tiwi data show that the improvement in
14 life expectancy is a function of reduced early life mortality as well as increasing adult
15 longevity.
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22 These changes represent triumphs of inter-sectoral improvements, public health policy and
23 health care more broadly, which are to be celebrated. This is especially welcome news for
24 the Tiwi Aboriginal people, whose mortality rates have been the worst in Australia,¹¹ and for
25 remote-living Aboriginal people more broadly. It is also comforting for health care providers
26 and policy makers to see such large scale progress demonstrated through an historical
27 perspective, and should support resolve to stay the course in ongoing improvements.⁸ More
28 broadly, this information should moderate the negative discourse which has pervaded the
29 Aboriginal health literature.
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33 Encouraging as these trends are, further improvement in adult death rates can still be
34 anticipated. Birthweights continue to improve, so that accentuated chronic disease risk from
35 that source should decline; adult health services continue to improve, especially in
36 prevention, screening and management of chronic disease,⁸ and rates of smoking are
37 falling.³³ Continuing challenges, however, include high rates of obesity,³⁴ poor diet,
38 especially sugar excess,³⁵ drug use, alcohol abuse, and foetal alcohol syndrome.⁷
39 Interpersonal violence, especially high rates of suicide and accidents, remain serious
40 challenges. Efforts to improve education, skills training, employment opportunities,
41 empowerment and socioeconomic status must be unflagging and be robustly supported.
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19 Contributors: WH conceived and designed this work, collected data, directed data analyses,
20 interpreted the findings and wrote the manuscript. BMcL conducted field work, and
21 performed data collection and data preparation. SM prepared data, performed analyses and
22 contributed to interpretation, produced figures and tables, and coordinated preparation
23 and editing of the manuscript. All authors had full access to all of the data in the study and
24 can take responsibility for the integrity of the data and the accuracy of the data analysis. All
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50 Transparency: The lead author affirms that the manuscript is an honest, accurate, and
51 transparent account of the study being reported; that no important aspects of the study
52 have been omitted; and that any discrepancies from the study as planned have been
53 explained.
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Table

Table 1. Mean (95%CI) natural death rate per 100,000 population by five-year intervals and age-group

Time interval	<15 years	15-44 years	45+ years	All ages
1986-1990	547.4 (406, 689)	426.3 (240, 613)	8065.4 (6778, 9353)	1480.7 (1240,1721)
2006-2010	60.5 (-81, 202)	326.3 (140, 513)	2815.2 (1528, 4103)	716.8 (476,957)

Note: The mean of aggregate natural deaths over years 2001-2010 is used for deaths of those <15 years of age.

Sources: 1986-2011 census data, Australian Bureau of Statistics (Catalogues: 1987, #2460.0; 2012,#2002.0).¹⁵

Legend of Figures

Figure 1. The Tiwi Islands, Northern Territory, Australia

Note: Wurrumiyanga was formerly named Nguuu.

Source: Adapted from Google Map data. The Tiwi Islands. Google; ©2017 [cited 2017 Jan 10]. Available from: <https://www.google.com.au/maps/@-12.2087082,130.7314414,8.75z>

Figure 2. Numbers of Tiwi deaths by age-group and broad cause of death, 1960-2010

Note: A five-year rolling average of frequencies is presented; people who have started dialysis are included among natural deaths.

Figure 3. Numbers of Tiwi natural adult deaths by age-group and cause of death, 1960-2010

Note: A five-year rolling average of frequencies is presented; people who have started dialysis are included among renal deaths.

Figures 4 A-C. Tiwi natural death rates by age-group, 1986-2010

Note: A five-year rolling average of rates is presented; population data derivation: 1986-2010 from quinquennial Census estimates (Australian Bureau of Statistics Catalogues: 1987, #2460.0; 1993, #2730.7; 2000, #70609; 2007, #2001.0; 2002, #2002.0; 2012, #2002.0);¹⁵ people who started dialysis are included among natural deaths; the low rates of death depicted for those <15 years from 2003 to 2010 are each based upon the average of the very small number of events (four) that occurred between 2001 and 2010.

Figures 5 A-D. Age distribution of the Tiwi population at four time-points, by sex, 1971-2011

Sources: 1971 data was cited in Peterson, 1988;¹⁶ 1986-2011 census data, Australian Bureau of Statistics (Catalogues: 1987, #2460.0; 2000, #70609; 2012, #2002.0).¹⁵

Note for figure formatting – please enter the text given below in the top left of each graph for Figure 5 A-D:

A. 1971

Total population: 1,221

B. 1986

Total population: 1,806

C. 1996

Total population: 2,023

D. 2011

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3 **Total population: 2,263**
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5 Figure 6. Infant mortality, Northern Territory and Australia, 1967-2007
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7 Source: Northern Territory Department of Health, 2011.²⁹
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10 Figure 7. Leading causes of death in the Aboriginal population of the Northern Territory:
11 1985-2006
12

13 Source: Northern Territory Department of Health, 2011.²⁹
14

15 Figure 8. Under-five mortality rates for selected countries, 1960-2015
16

17 Source: adapted from UNICEF Global Database, 2015.³¹
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19 Figure 9. Life expectancy at birth for selected countries, 1960-2013
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21 Source: adapted from The World Bank, 2016.³²
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24 Source notes: Derived from male and female life expectancy at birth from sources such as:
25 United Nations Population Division; World Population Prospects; United Nations Statistical
26 Division. Population and Vital Statistics Report (various years); Census reports and other
27 statistical publications from national statistical offices; Eurostat: Demographic Statistics;
28 Secretariat of the Pacific Community: Statistics and Demography Programme; and U.S.
29 Census Bureau: International Database.
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Figure 1. The Tiwi Islands, Northern Territory, Australia

Note: Wurrumiyanga was formerly named Nguui.

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Source: Adapted from Google Map data. The Tiwi Islands. Google; ©2017 [cited 2017 Jan 10]. Available from: <https://www.google.com.au/maps/@-12.2087082,130.7314414,8.75z>

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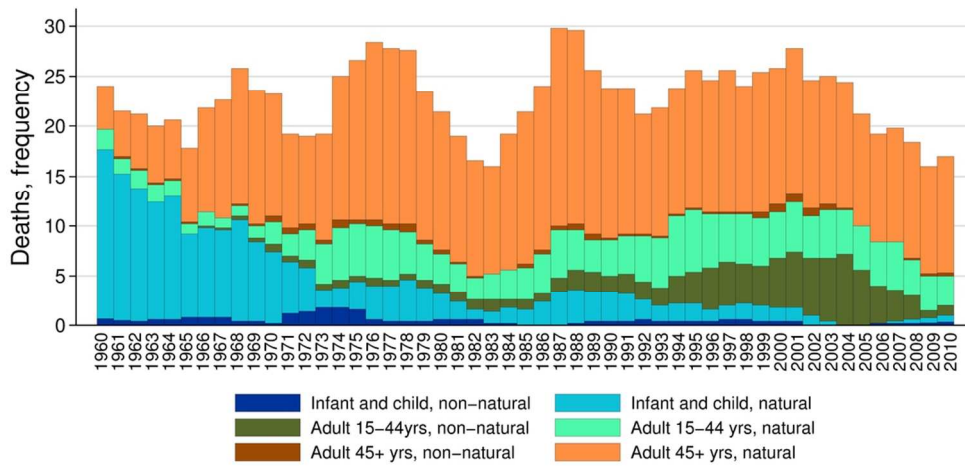


Figure 2. Numbers of Tiwi deaths by age-group and broad cause of death, 1960-2010
 Note: A five-year rolling average of frequencies is presented; people who have started dialysis are included among natural deaths.

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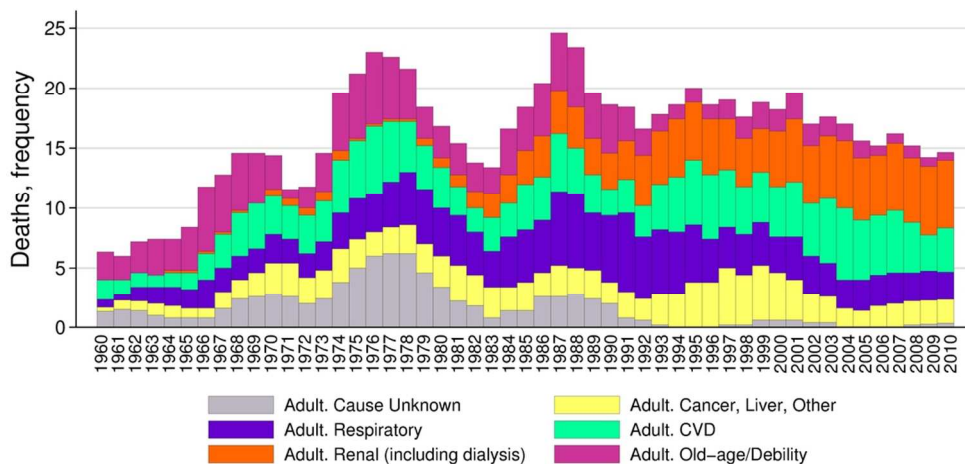
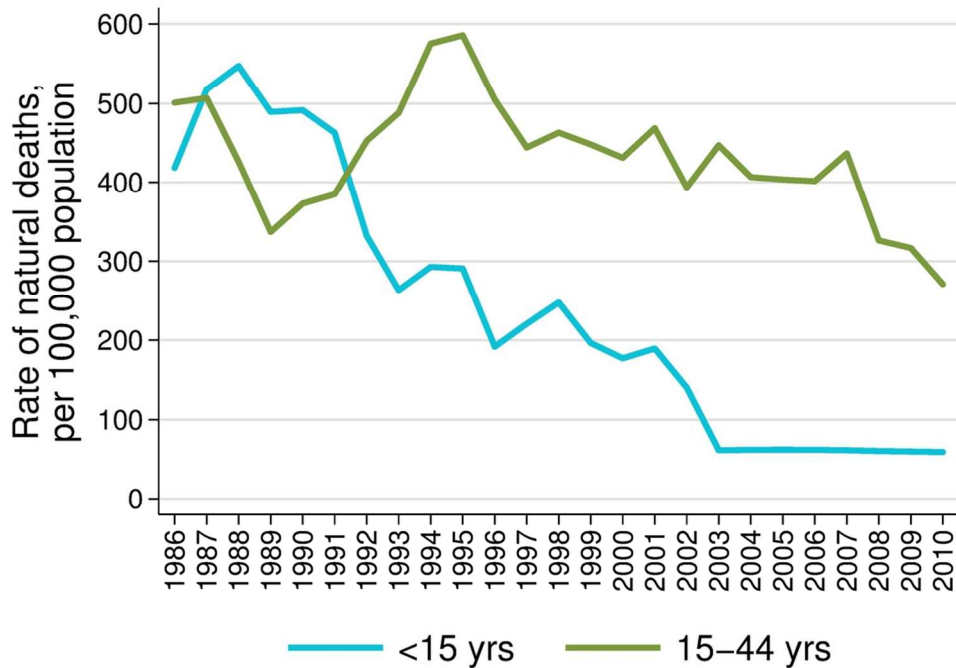


Figure 3. Numbers of Tiwi natural adult deaths by age-group and cause of death, 1960-2010
 Note: A five-year rolling average of frequencies is presented; people who have started dialysis are included among renal deaths.

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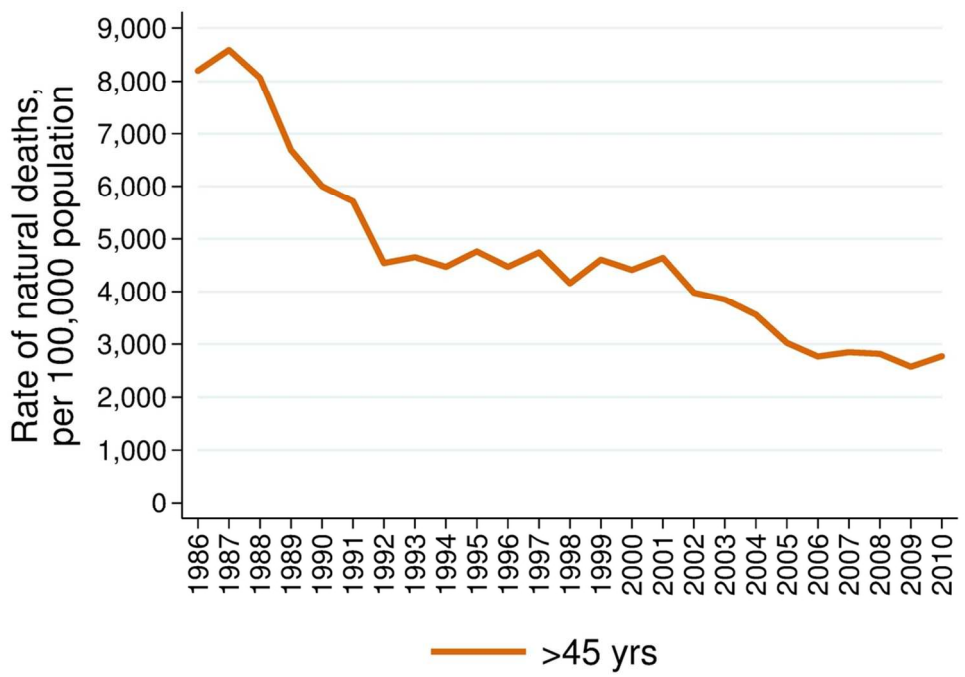
Figures 4 A-C. Tiwi natural death rates by age-group, 1986-2010

Note: A five-year rolling average of rates is presented; population data derivation: 1986-2010 from quinquennial Census estimates (Australian Bureau of Statistics Catalogues: 1987, #2460.0; 1993, #2730.7; 2000, #70609; 2007, #2001.0; 2002, #2002.0; 2012, #2002.0); 15 people who started dialysis are included among natural deaths; the low rates of death depicted for those <15 years from 2003 to 2010 are each based upon the average of the very small number of events (four) that occurred between 2001 and 2010.

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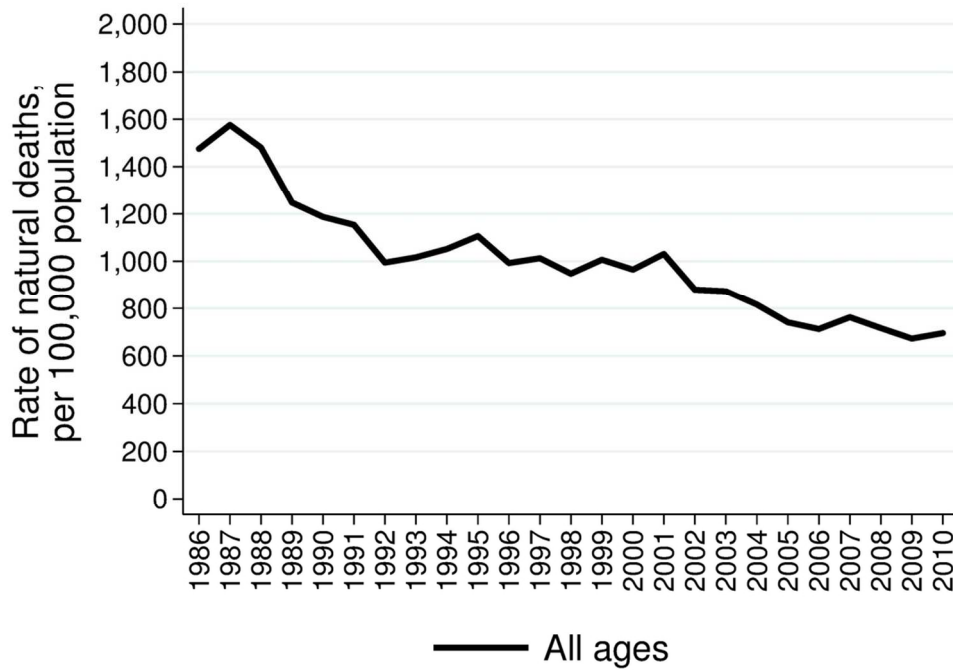


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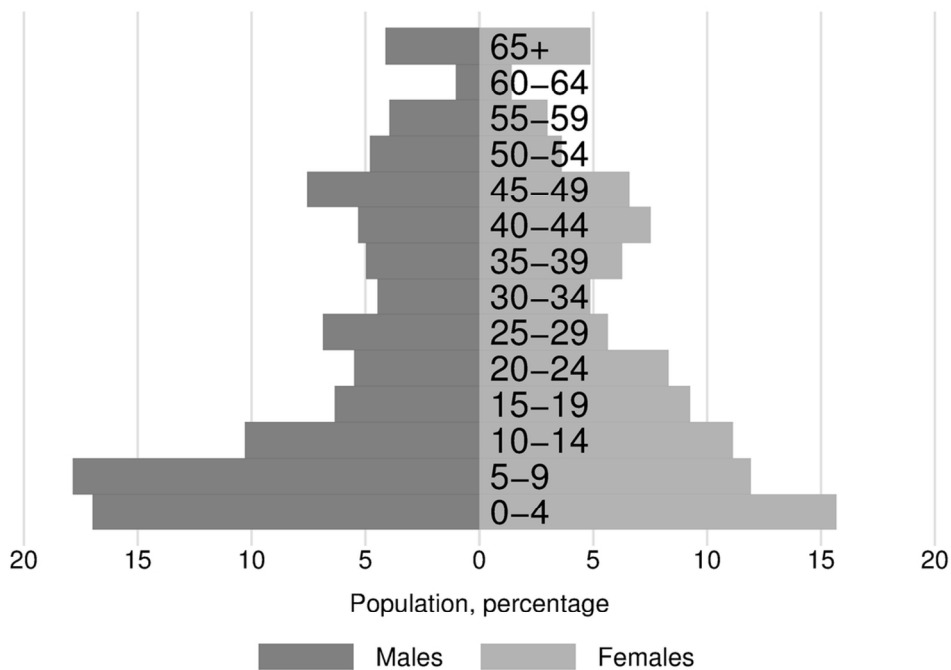
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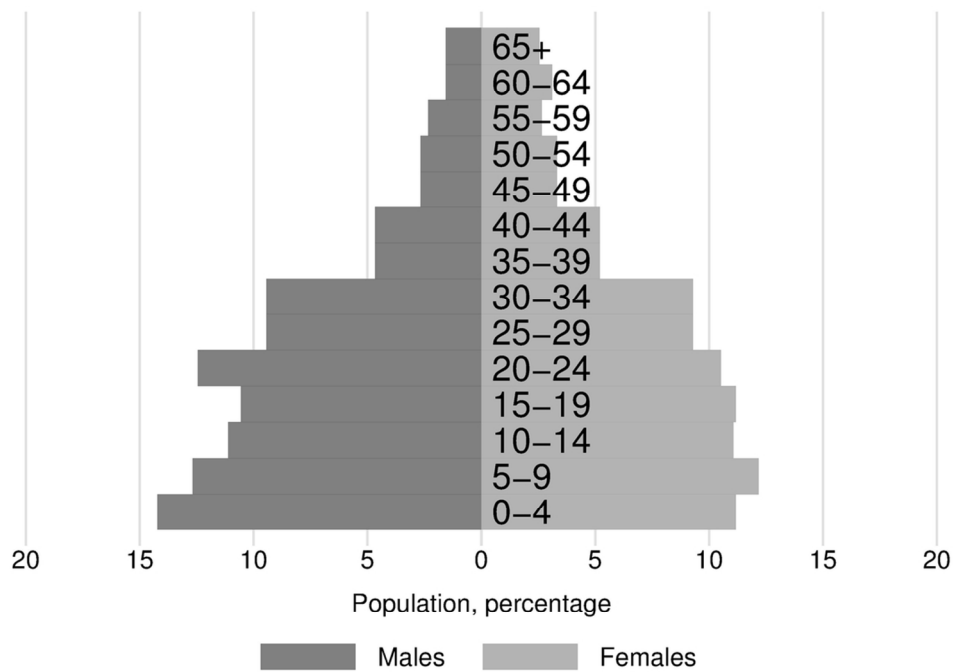


Figures 5 A-D. Age distribution of the Tiwi population at four time-points, by sex, 1971-2011
Sources: 1971 data was cited in Peterson, 1988; 16 1986-2011 census data, Australian Bureau of Statistics
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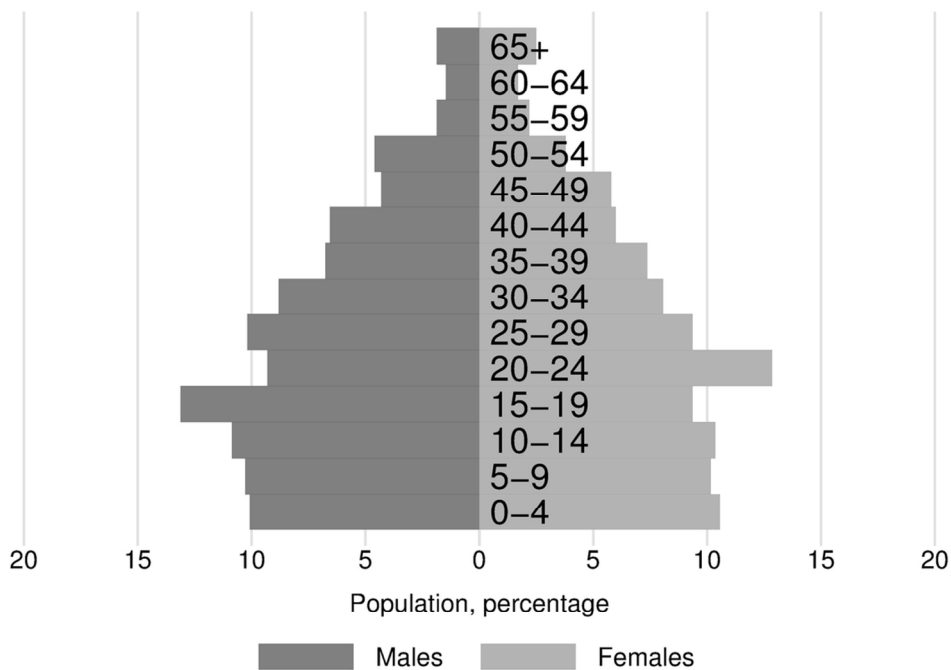


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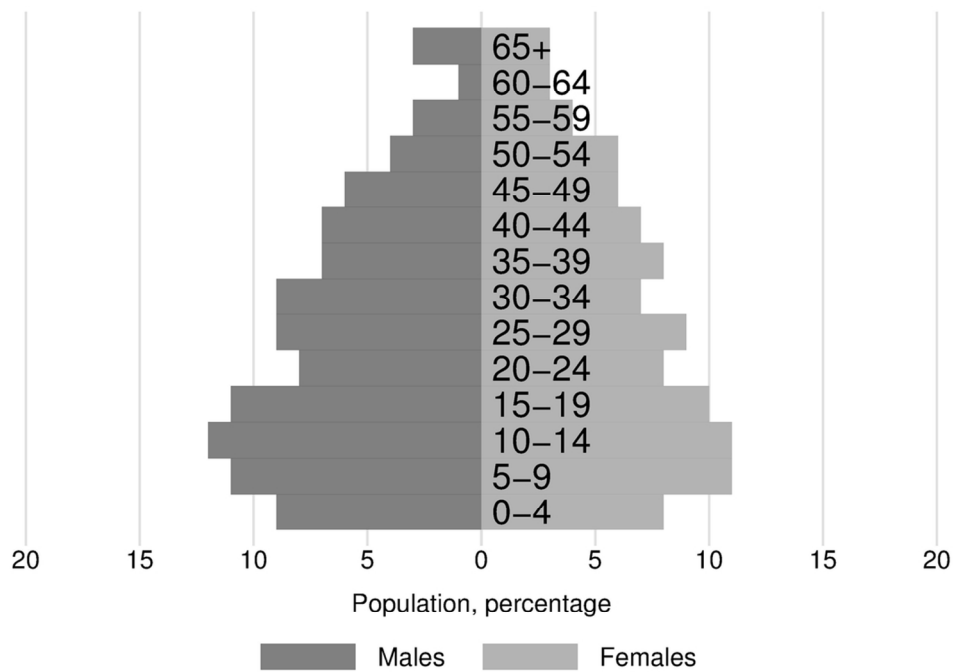


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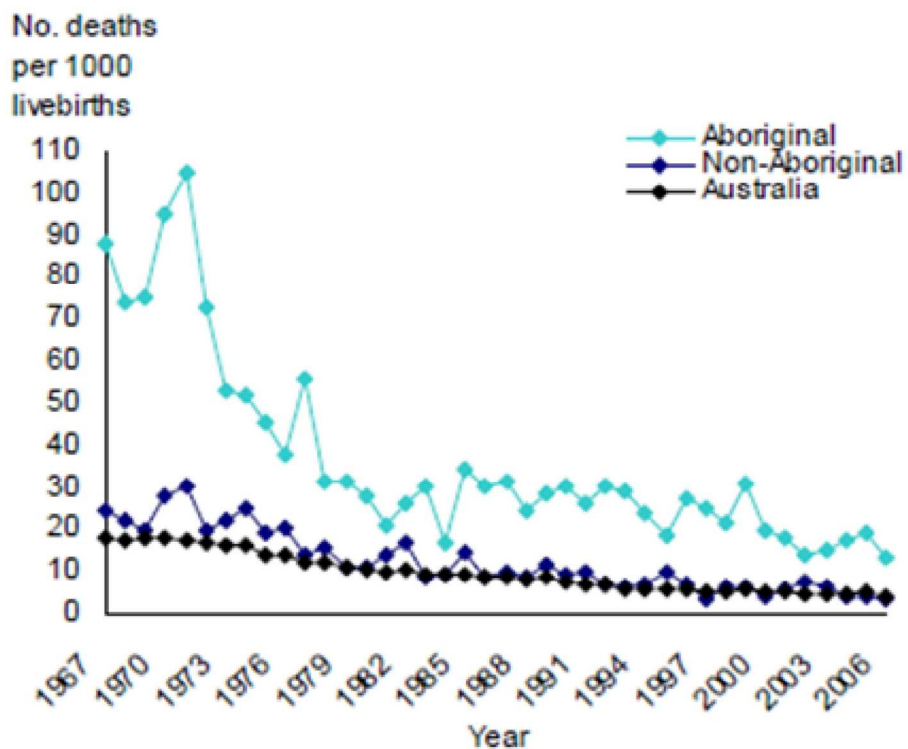


Figure 6. Infant mortality, Northern Territory and Australia, 1967-2007
 Source: Northern Territory Department of Health, 2011.29

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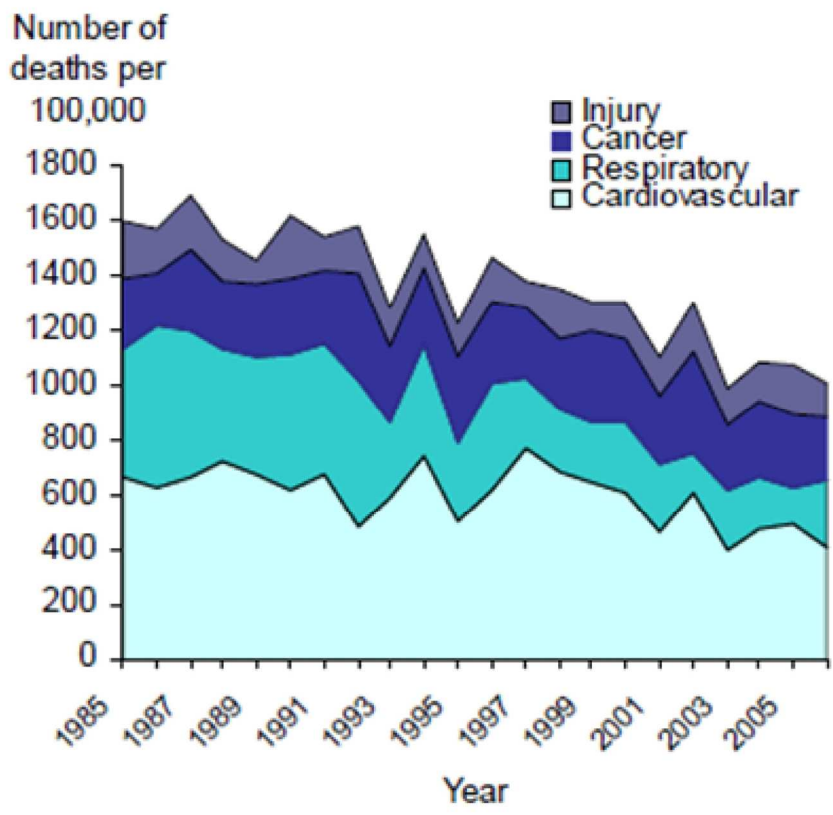


Figure 7. Leading causes of death in the Aboriginal population of the Northern Territory: 1985-2006
 Source: Northern Territory Department of Health, 2011.29

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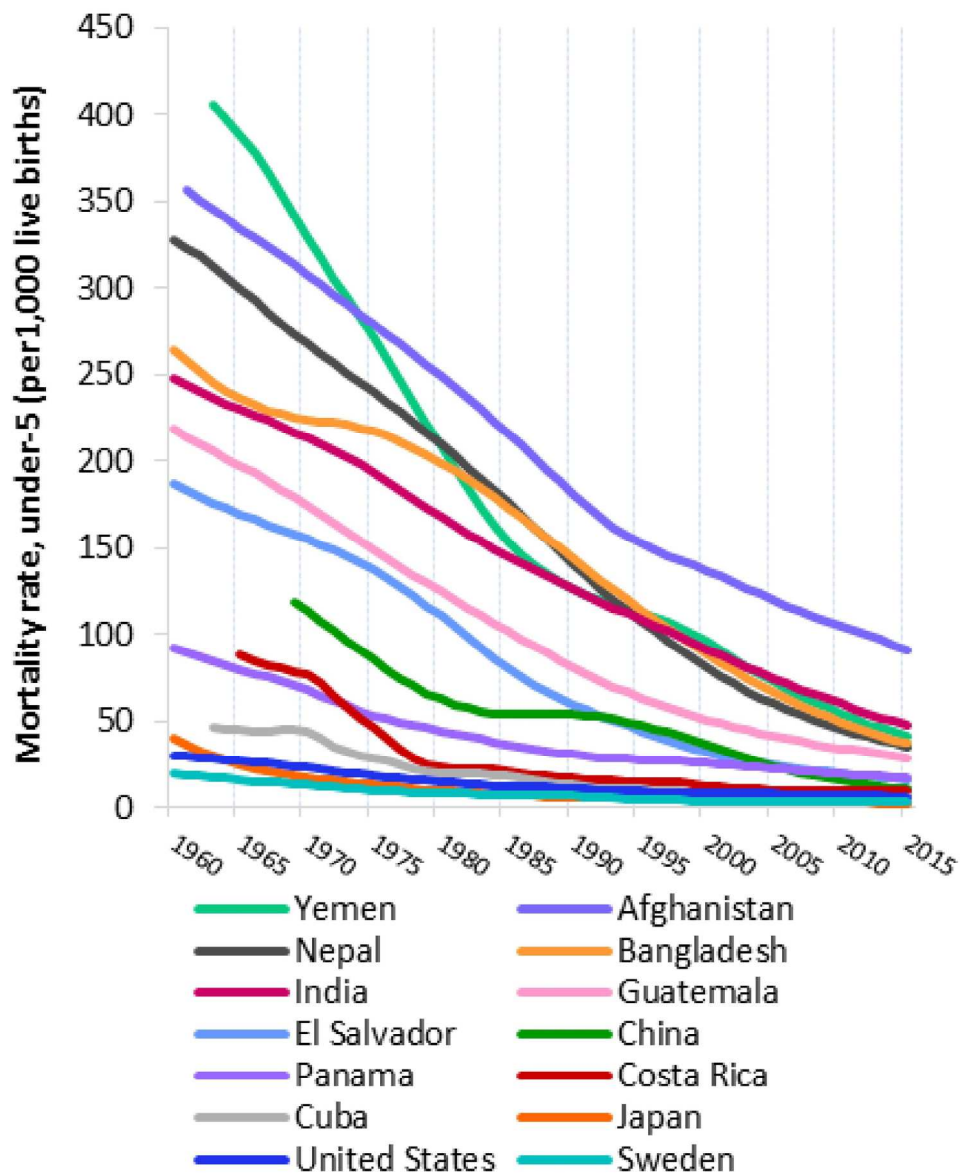


Figure 8. Under-five mortality rates for selected countries, 1960-2015
 Source: adapted from UNICEF Global Database, 2015.³¹

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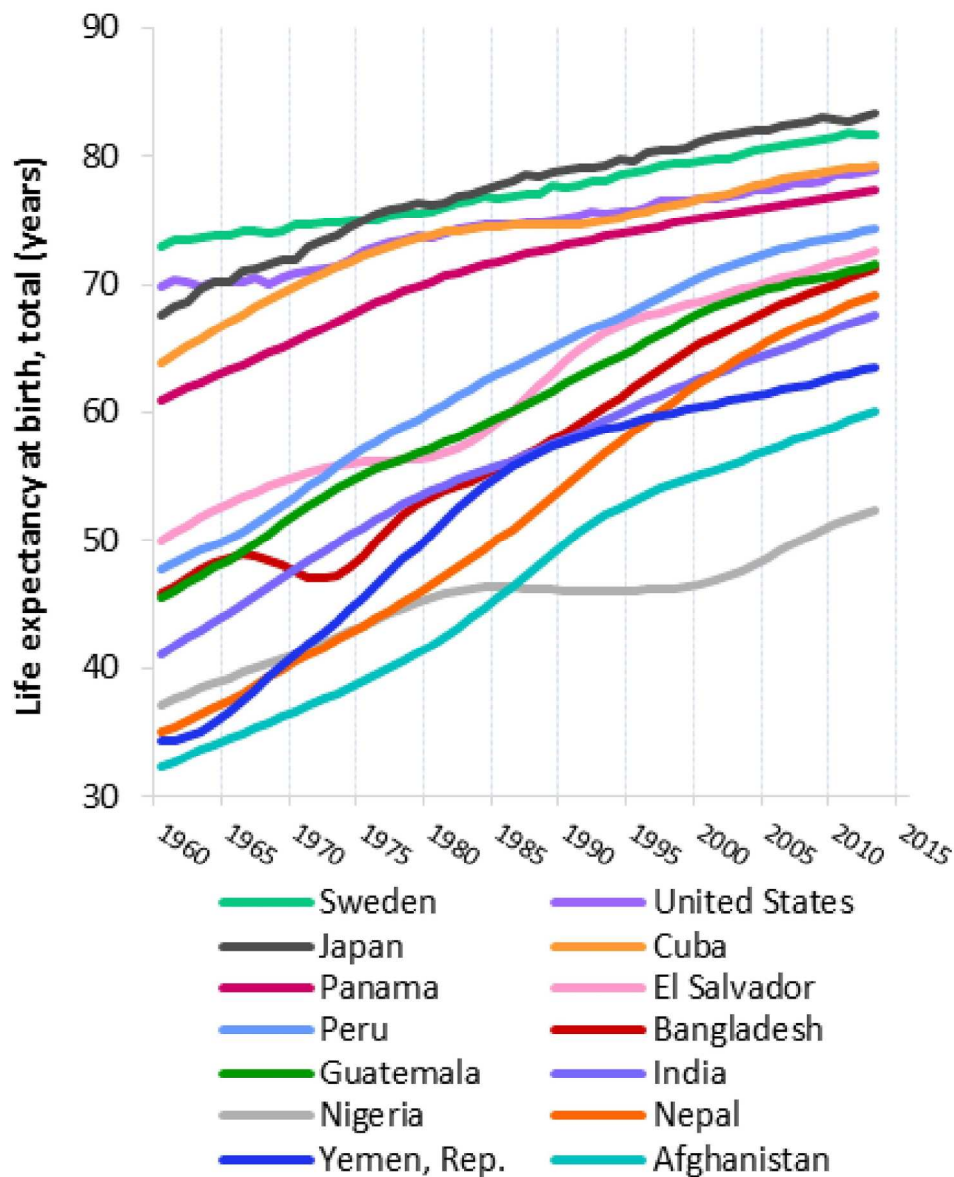


Figure 9. Life expectancy at birth for selected countries, 1960-2013

Source: adapted from The World Bank, 2016.³²

Source notes: Derived from male and female life expectancy at birth from sources such as: United Nations Population Division; World Population Prospects; United Nations Statistical Division. Population and Vital Statistics Report (various years); Census reports and other statistical publications from national statistical offices; Eurostat: Demographic Statistics; Secretariat of the Pacific Community: Statistics and Demography Programme; and U.S. Census Bureau: International Database.

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Note for figure 5A-D formatting

– please enter the text given below in the top left of each graph for Figure 5 A-D:

A. 1971

Total population: 1,221

B. 1986

Total population: 1,806

C. 1996

Total population: 2,023

D. 2011

Total population: 2,263

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page No.(s) [Paragraph No.(s)]
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3[1-9]
Objectives	3	State specific objectives, including any prespecified hypotheses	3[1]
Methods			
Study design	4	Present key elements of study design early in the paper	4[6]-5[5]
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4[6]-5[5]
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	4[4] 5[5]
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	-
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	4[5]-5[4]
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4[5]-5[4]
Bias	9	Describe any efforts to address potential sources of bias	5[1-3] 7[3-4] 8[1,3]
Study size	10	Explain how the study size was arrived at	4[5]-5[3]
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4[5]-5[4]
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	5[3]
		(b) Describe any methods used to examine subgroups and interactions	5[4]
		(c) Explain how missing data were addressed We believe that the ascertainment of deaths overall is as good as it can be. We have accessed the original sources for this information (4[5]). There are no published government estimates prior to 1985. From 1985, our ascertainment compares favourably with that of government agencies (8[3]). Subjects included are those with available death data, plus age at death or age-group and natural or unnatural cause of death classification.	

As a more detailed description of the cause of death was not consistently documented until after 1985 we restricted analyses by cause of death to 1985-2010. Additionally, as census data also became available from that time, death rates were calculated in the same time period.

(d) *Cohort study*—If applicable, explain how loss to follow-up was addressed

Case-control study—If applicable, explain how matching of cases and controls was addressed

Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy

(e) Describe any sensitivity analyses

Continued on next page

Results		Page No.(s) [Paragraph No.(s)]	
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	6[1-2]
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	6[1-5] Figures 1 & 2
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time <i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	7[3]-8[2]
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	8[3]
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	8[4]-9[3]

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Generalisability	21	Discuss the generalisability (external validity) of the study results	9[1]
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Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	11[3]
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*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Transformation of mortality in a remote Australian Aboriginal community: a retrospective observational study

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5 **observational study**
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Abstract

Objectives To describe trends in ages and causes of deaths in a remote-living Australian Aboriginal group over a recent 50 year period.

Design A retrospective observational study, from 1960 to 2010, of deaths and people starting dialysis, using data from local clinic, parish, dialysis and birthweight registers.

Setting A remote island community in the Top End of Australia's Northern Territory, where a Catholic Mission was established in 1911. The estimated Aboriginal population was about 800 in 1960 and 2,260 in 2011.

Participants All Aboriginal residents of this community whose deaths had been recorded.

Outcome measures Annual frequencies and rates of terminal events (deaths and dialysis starts) by age-group and cause of death.

Results In all, and against a background of high rates of low birthweight, 223 deaths in infants and children and 934 deaths in adults (age ≥ 15 years) were recorded; 88% were of natural causes. Most deaths in the 1960s were in infants and children. However, these fell dramatically, across the birthweight spectrum, while adult deaths progressively increased. The leading causes of adult natural deaths were chronic lung disease, cardiovascular disease and, more recently, renal failure, and rates were increased two-fold in those of low birthweight. However, rates of natural adult deaths have been falling briskly since 1986, most markedly among people of age 45+ years. The population is increasing and its age structure is maturing.

Conclusions The changes in death profiles, the expression of the Barker hypothesis and the ongoing increases in adult life expectancy, reflect epidemiologic and health transitions of astonishing rapidity. These probably flow from advances in public health policy and health care delivery, as well as improved inter-sectoral services, which are all to be celebrated. Other remote communities in Australia are experiencing the same phenomena, and similar events are well advanced in many developing countries.

Strengths and limitations of this study

- The broad sweep and historical depth of this study, the unique data sources and the integration of clinical and demographic information have allowed delineation of the profound and recent transformation of mortality not previously appreciated in the Australian Aboriginal setting.
- It is inevitable that we have failed to capture some deaths in the past, which probably resulted in understatement of the magnitude of this transition. In some recorded natural deaths the assignments were approximate and the contribution of multiple causes was underestimated.

Aims and objectives

To describe trends in mortality over more than fifty years in a remote Aboriginal community in the Northern Territory (NT) of Australia.

Background

Recent literature describes a rapid shift in patterns and causes of death in most countries and regions. Infant and childhood deaths have decreased, life expectancy has increased,¹ and more deaths in adults are associated with non-communicable chronic diseases.² Here we describe such a transition in a remote-living Aboriginal Australian group over the last 51 years.

The Tiwi people live in three major communities (and several smaller ones) on Bathurst and Melville Islands off the coast of the Northern Territory, about 90 km by sea from Darwin (Figure 1). They lived in relative isolation for perhaps 7,000 to 15,000 years, and consider themselves distinct from mainland Aboriginal people, with their own unique origins, language, and customs.³

In 1911, a Catholic mission was established by the Missionaries of the Sacred Heart (MSC), led by Father Francis Xavier Gsell.⁴ Changes followed in lifestyle (from nomadic hunter gatherers to living in fixed dwellings), in diet (from food from the bush and sea to depot supplies of less perishable, high caloric density food, of flour, fat, meat and sugar), in family and community structures (from polygamy and networks of carers within extended families to monogamy), and in the establishment of dormitories, schools and clinics. Transition has been especially accelerated since World War 2. Cigarettes were widely introduced around this time (anecdotal evidence). The 1967 referendum formally recognised Aboriginal people in Australia⁵ and they were thenceforth included as residents in the national census. Legal access to alcohol began around that time. The first social club, serving alcohol, was opened in the largest Tiwi community in 1967.

Some early insights into remote-living Aboriginal people in the NT are provided by Ellen Kettle, the first Rural Survey Sister in the NT, who pioneered mobile health work in isolated areas and established health records for individuals, and by Dr John Hargrave, the first Aboriginal Health Officer, who personally examined members of many communities in 1957/1958. Both advanced understanding of Aboriginal health and development of services and policy. They described endemic conditions (yaws, malaria, infestations, trachoma), imported conditions like leprosy, syphilis (arguably), tuberculosis, measles, small pox and influenza. They documented florid malnutrition and frank starvation, high infant and maternal mortality and conspicuously low birthweight. They then described, over time, dramatic reductions in infant mortality, the appearance of alcohol related disorders, and of occasional overweight and obesity, as well as the emergence of non-communicable chronic diseases.^{6,7}

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3 These phenomena occurred against a background of continuous improvements in remote
4 Aboriginal health services, including management of infections and infestations,
5 immunisations, better obstetric services, better maternal and child care, and cancer
6 surveillance. Chronic non-communicable diseases, predominantly type 2 diabetes,
7 cardiovascular disease, chronic lung disease and chronic kidney disease now dominate the
8 adult health profile and are the focus of most of health service provision for remote-living
9 Australian Aboriginal adults.⁸

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13 Clinical services were established by the mission, starting as first aid facilities on the beach
14 at Nguuiu (now Wurrumiyanga) on Bathurst Island. These eventually evolved into a clinic and
15 local hospital, run by the Sisters of the Order of Our Lady of Sacred Heart (OLSH), with
16 additional clinics in the Melville Island communities of Milikapiti and Pirlangimpi. Medical
17 records were established for individuals, along with clinic-based registers for births and
18 deaths. Doctors from Darwin eventually provided backup support. More recently, there
19 have been resident doctors for intermittent periods. Local hospital beds were closed in the
20 early 1990s, and all persons needing hospital admission were thenceforth streamed to the
21 Royal Darwin Hospital, transported by small plane. Responsibility for clinical services was
22 transferred from the mission to the NT government in the early/mid-1990s.

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28 Anthropologist Charles Hart enumerated a Tiwi population of 1,062 in 1928.³ Dr John
29 Hargrave estimated the Tiwi population at about 800 to 900 in 1957, compatible with a
30 1954 Commonwealth Government estimate of 920.^{9,10} Regular government census
31 estimates have been published every five years since 1986.

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34 Traditionally, Tiwi people have only occasionally transmigrated, usually for purposes of
35 intermarriage according to tribal edicts. The destinations of people who travel, and the
36 movements and locations of community members, are known by all. Deaths of people who
37 die out of community (usually in Darwin or while visiting other communities) are
38 documented in their medical records on in their “home” community clinic and added to the
39 death register.

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43 Death rates in the Tiwi community, along with those in Aboriginal people in Arnhem Land,
44 have among been the highest in Australia: in the 1990s, with age-standardisation, they were
45 six times those of the Australian mainstream.¹¹ This generally reflects the much younger age
46 of Tiwi people at death. Cases of kidney failure began to attract attention in the 1980s;¹² for
47 several decades Tiwi people had the highest rates of renal failure yet described, and the first
48 hemodialysis unit in a remote Aboriginal location was established in Wurrumiyanga on
49 Bathurst Island in the late 1990s. High renal failure rates have followed in other remote
50 communities. The characteristics and speculative causes of the renal disease have been
51 described extensively.^{12,13,14} We have previously described the high rates of low
52 birthweight in this community and the risk exacerbations for natural deaths in infants,
53 children and young adults associated with low birthweight.^{15,16}

Methods

Data sources were the written logs of deaths maintained by the clinics, dialysis unit records of NT Renal Services, and in this staunchly Catholic community, records maintained by the parish priests of all funerals and burials. We report recorded deaths over the 51 year period from 1960 to 2010, beginning when clinic recording of details of death (age, date and explanation) was becoming more systematic.

Starting in the 1980s, maintenance dialysis has been available to Tiwi persons with end-stage renal disease; numbers of patients starting treatment increased steadily until apparently stabilising at about 6 persons a year in the early 2000s. In this study, initiation of dialysis is considered a natural (renal) death, occurring when dialysis began, because without that treatment all participants would have died shortly thereafter. There was no additional assignment of date or cause of death when they finally expired.

Description of cause of death became more detailed over time. In the early years the only discrimination for some deaths was of natural versus unnatural causes, while, in later years, there was more detailed narrative on cause(s) and associations of death. In the early years, deaths in people over 60 years of age often received a causal assignment of “old age” or “debility”, but with time “disease or organ-specific” assignments increased for them as well. In some recorded natural deaths the assignments were approximate and the contribution of multiple causes was underestimated. Cause of death was assigned by clinic directors and always took into account the previous health profile of each deceased person. In the context of sometimes sparse clinical detail, and conforming to the methodology for the Global Burden of Disease study, we derived and assigned a principal cause of death only.

Unnatural deaths, or deaths of misadventure, included those due to vehicular accidents, drownings, fire (burns and smoke inhalation), homicide, suicide, poisonings, jelly fish stings, crocodile and shark attacks etc. We defined the main categories of natural deaths as cardiovascular (heart attack, congestive heart failure, ischemic heart disease, coronary artery disease and stroke), respiratory (chronic lung disease, chronic obstructive airways disease, chronic bronchitis, bronchiectasis, pneumonia), renal (death with terminal renal failure, and also, after 1985, institution of dialysis in people with terminal renal failure), various other causes (eg sepsis, liver failure, lupus, cancer etc.), and debility or old age. When there was uncertainty about deaths or persons, data were checked with several senior community members, who had lived through much of the study interval and had known most community members.

Analyses were conducted using Stata 14 (StataCorp. 2015. *Stata Statistical Software: Release 14*. College Station, TX: StataCorp LP). Numbers and rates of deaths were calculated by age-group and cause of death. Five-year moving averages were created using the `tssmooth` package. Mortality rates, per 100,000 population, could be calculated only since 1986, the first year of the subsequent quinquennial national census that specifically

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3 enumerated Aboriginal Tiwi people. Total population estimates were also taken from census
4 figures.¹⁷
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7 Results

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9 1,190 deaths were recorded, and age was documented or age group could be inferred in
10 1,156 (97.1%) of these (for 452 or 95.0% of deaths in the first two decades, and 704 or
11 98.6% of deaths in the last three decades).
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14 Of these 1,156 deaths, 222 (19.2 %) were in infants and children (<1 years and 1 to <15
15 years respectively), and 934 (78.5%) were deaths of adults (at ages ≥ 15 years). Twenty-five
16 (11.3%) deaths of infants and children were deaths of misadventure and 197 (88.7%) were
17 of natural causes. Among adults, 114 (12.2%) of deaths were due to misadventure and 820
18 (87.8%) were natural deaths.
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21 Figure 2 shows deaths by age-group and interval (frequencies are tabulated in
22 Supplementary Table 1). Early on, most deaths were in infants and children. These fell
23 rapidly at first, then more slowly. The main categories of death in infants and children were
24 diarrhoea, respiratory disease and failure to thrive, with some cases of sudden infant death,
25 and a few congenital abnormalities.¹⁵ In 1973, a house fire killed six siblings, making a major
26 contribution to deaths due misadventure in this group.
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30 As infant and childhood deaths fell, numbers of deaths of adults increased. Many of these
31 have been among young adults (ages 15 to <45 years) with high numbers of both natural
32 death and deaths of misadventure. The latter include motor vehicle accidents, drownings,
33 homicide, and suicide; there were 50 suicides (50% of deaths of misadventure) between
34 1985 and 2010, of which 47 (94%) were among males.
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38 Since 1975 most deaths are in people of ≥ 45 years, and most of these are of natural causes.
39 The numbers have not perceptibly increased since the early 1990s. Only 13 (2.5%) of these
40 older adult deaths were due to misadventure.
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43 Figure 3 shows the trends in natural deaths in adults over time, by primary causal
44 assignment. Numbers peaked in the later 1980s but have since had an indeterminate or
45 falling trend. Through the mid-1980s there were substantial numbers of natural deaths with
46 no further details and deaths with assignments of "old age" or debility", but there have
47 been more "organ-system" assignments since the early 1990s. Among specific assignments,
48 cardiovascular deaths, and cancer/liver/other deaths were represented over the continuum,
49 while pulmonary (respiratory) deaths became prominent but more recently have been
50 decreasing. Renal deaths become prominent in the 1980s; there were 25 renal deaths in the
51 1980s, 42 in the 1990s and 52 from 2000 to 2009, constituting 14.7, 24.1 and 31.7% of all
52 natural deaths in those intervals.
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3 Figures 4 A-C show the smoothed estimated rates of natural deaths by age-group since
4 1986.¹⁷ Rates of death in infants and children have fallen remarkably (4A). There was an
5 early increase in death rates among young adults (4A), followed by a progressive decline
6 since the mid-1990s. Death rates of people age ≥ 45 years have markedly declined, at least
7 until the last few years of the observation interval (4B). The net effect of all these changes
8 is a decrease overall death rates of the entire population.
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11 These trends are further summarised in Table 1, which shows the rates of natural deaths by
12 age-group in the first and last 5-year blocks of the observation interval. Death rates of
13 infants and children fell by 88.9 %, those of young adults fell by 23.5%, while of people age
14 ≥ 45 years fell by 65.1%. For the population as a whole, rates of natural death fell by 51.6 %.
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18 Figures 5 A-D show that the population age structure has changed over <40 years to include
19 higher numbers and proportions of young and middle age adults.^{17,18} In addition, the size of
20 the total population has increased by 85%.
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23 Discussion

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25 This is the most complete description of deaths in any indigenous Australian community. It
26 shows a profound change in patterns, rates and causes of death over a 51 year interval.
27 Infant and childhood deaths have fallen dramatically; now most people die as adults (≥ 15
28 years), and of natural causes. Furthermore, in the last 25 years, rates of natural deaths of
29 adults have been falling. The population is increasing and is progressively ageing.
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33 With continued improvements in prevention and treatment of infectious diseases, adult
34 deaths are increasingly due to non-communicable diseases, with chronic lung disease,
35 cardiovascular disease and renal disease making the greatest contribution. These chronic
36 diseases have usually overlapped and been co-contributors to death, although this is
37 obscured by our use of mutually exclusive categories of primary cause of adult death.
38 Among specific assignments, cardiovascular deaths, and cancer/liver/other deaths etc. have
39 been represented over several decades, while pulmonary deaths became prominent in the
40 1970s, but have decreased since the early 1990s. Kidney failure has become prominent
41 since the 1980s, and is now the single leading assignment.
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46 The still excessive (although improving) rates of natural deaths are compatible with the
47 "Barker hypothesis", which proposes that survivors of lower birthweights have accentuated
48 susceptibility to chronic diseases and premature natural death in adult life.^{15,16,19} We have
49 shown that the dramatic reductions in early life mortality have been experienced across the
50 birthweight spectrum, so that, against a background of seriously low birthweights, large
51 cohorts of underweight infants, who were previously at greatest risk for early death, have
52 now survived to adult life. As adults, they have enhanced susceptibility to chronic disease, as
53 the hypothesis proposes and as we have demonstrated.^{15,20,21} Through 2010, rates of
54 natural adult deaths before the age of 41, in Tiwi people of low birthweight, were twice that
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3 of those with higher birthweights, with the greatest accentuation of risk being for
4 pulmonary deaths, a 6-fold increase.¹⁶
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7 The continued evolution of the chronic disease rates and patterns and rates over time is
8 probably influenced by improving birthweights, changing age structure among adults,
9 improved prevention, screening and management of chronic disease and changes in
10 competing causes of deaths. With reductions in deaths from pulmonary disease and
11 postponement of cardiovascular deaths, flowing from a secular increase in birthweights,¹³
12 and from better medical management, coexisting nephropathy has more opportunity to
13 pursue its more leisurely course to renal failure.²² We have published extensively on the
14 expression, course and biopsy representation of the underlying renal disease.¹² It is clearly
15 multideterminant with risk enhanced by low birthweights, inflammation and infection,
16 episodes of post-streptococcal glomerulo nephritis and higher BMIs and diabetes in adult
17 life.^{23,24}
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22 Availability and use of the clinic-based death records and the supporting parish burial
23 records sets this study apart. The NT-wide government register of deaths dates only back to
24 the mid-1980s, and in that register, community assignment has sometimes been
25 incomplete. Moreover, government records do not capture the full burden of renal failure,
26 due to deficient documentation of a renal cause of death, both in people receiving renal
27 replacement therapy (RRT), and in those dying of renal failure without receiving RRT.^{14,25}
28 Our composite definition of “renal deaths” as the start of RRT and a renal death without RRT
29 more fully reveals the burden of renal failure disease. That approach is necessary for
30 monitoring, prevention and intervention strategies, especially in the context of the burden
31 and costs of RRT.^{13,26} Furthermore, it is the only way that kidney failure rates can be
32 compared with populations in other countries for whom RRT is not widely available.
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38 Our data also reveal an excess of deaths by misadventure in young adults in more recent
39 years. Such deaths, often alcohol or drug-fuelled, are prominent among young Aboriginal
40 adults nationwide, and are of grave concern.^{27,28}
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43 Limitations include the fact that some Tiwi deaths were probably not captured in our data
44 sources. This is more likely in the earlier years, so that that the earlier numbers and rates of
45 deaths, as well as the subsequent fall in deaths, have probably been understated.
46 Moreover, from 1985 to 2009, the government agencies recorded 18% fewer deaths for the
47 Tiwi community than we have recorded, with under-identification varying from 10 to 30%
48 over five consecutive 5 years intervals (In an email from Y Zhao, (yuejen.zhao@nt.gov.au)
49 2016 Oct 24). An additional limitation is assignment of a single category of cause of death,
50 whereas natural deaths in adults have multiple causes and associated conditions; the
51 coexistence of cardiovascular risk and lung disease, and of renal disease with cardiovascular
52 disease are well recognised. However, the use of a single underlying cause of death is
53 dictated by the detail of the source data. It is also the approach employed until recently for
54 the mortality component of the study of Global Burden of Disease.
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4 Is it credible that about half the deaths in Tiwi people in the 1960s were in subjects less than
5 15 years of age? The World Health Organization estimated that, in 1955, fully 40% of global
6 deaths were in children age <5 years, so presumably an even greater proportion were
7 deaths of people <15 year old).²⁹ Furthermore, analyses of skeletal remains of some
8 premodern cultures have suggested that up to 68% of deaths occurred people <15 years old
9 (Chamberlain cited in Roser, 2006).^{1,30} Hart's comment that, around 1928, five of 15
10 bestowed wives (females promised in marriage to specific Tiwi community members), died
11 before puberty, supports a high childhood mortality.³

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16 Other Aboriginal groups in remote areas of Australia over the same intervals have
17 undoubtedly experienced similar transitions. NT government agencies have described
18 similar trends in early life mortality since 1967, and improvements in natural death rates
19 overall since the late 1980s (Figures 6 and 7).³¹ In the Shire of Broome, Western Australia,
20 Gracey et al. described excessive levels of Aboriginal infant and childhood infection and
21 under-nutrition in the 1970s and 1980s and increasing deaths by misadventure in young
22 Aboriginal adults between 1971 and 1994.³² Our findings are also consistent with events in
23 many other countries and regions. Figure 8 shows the fall in early life mortality since 1960,
24 which is most dramatic in disadvantaged populations like Yemen, Afghanistan, Bangladesh
25 and Nepal,³³ while Figure 9 shows the simultaneous increase in life expectancy at birth,
26 again most marked in disadvantaged settings.³⁴ Our Tiwi data show that the improvement in
27 life expectancy is a function of reduced early life mortality as well as increasing adult
28 longevity.

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35 These changes represent triumphs of inter-sectoral improvements, public health policy and
36 health care more broadly, which are to be celebrated. This is especially welcome news for
37 the Tiwi Aboriginal people, whose mortality rates have been the worst in Australia,¹¹ and for
38 remote-living Aboriginal people more broadly. It is also comforting for health care providers
39 and policy makers to see such large scale progress demonstrated through an historical
40 perspective, and should support resolve to stay the course in ongoing improvements.⁸ More
41 broadly, this information should moderate the negative discourse which has pervaded the
42 Aboriginal health literature.

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47 Encouraging as these trends are, further improvement in adult death rates can still be
48 anticipated. Birthweights continue to improve, so that accentuated chronic disease risk from
49 that source should decline; adult health services continue to improve, especially in
50 prevention, screening and management of chronic disease,⁸ and rates of smoking are
51 falling.³⁵ Continuing challenges, however, include high rates of obesity,³⁶ poor diet,
52 especially sugar excess,³⁷ drug use, alcohol abuse, and foetal alcohol syndrome.⁷
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60 Interpersonal violence, especially high rates of suicide and accidents, remain serious
challenges. Efforts to improve education, skills training, employment opportunities,
empowerment and socioeconomic status must be unflagging and be robustly supported.

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4 continuing support of this research. We specifically acknowledge the expertise and
5 dedication of the sisters of the order of Our Lady of the Sacred Heart (OLSH) who
6 maintained fastidious clinical records which now underlie much of this report. We are
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8 on Bathurst Island, and of Milikapiti and Pirlangimpi on Melville Island. We thank the
9 Catholic Diocese of Darwin for allowing access to the medical records, and supplying records
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11 records of Tiwi people who started dialysis. We thank Centre of Chronic Disease staff for
12 their contribution to data management and analyses throughout the course of this and
13 related projects.
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3 Contributors: WH conceived and designed this work, collected data, directed data analyses,
4 interpreted the findings and wrote the manuscript. BMcL conducted field work, and
5 performed data collection and data preparation. SM prepared data, performed analyses and
6 contributed to interpretation, produced figures and tables, and coordinated preparation
7 and editing of the manuscript. All authors had full access to all of the data in the study and
8 can take responsibility for the integrity of the data and the accuracy of the data analysis. All
9 authors reviewed, revised and approved the manuscript.
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31 interest in the submitted work in the previous three years; no other relationships or
32 activities that could appear to have influenced the submitted work.
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37 Transparency: The lead author affirms that the manuscript is an honest, accurate, and
38 transparent account of the study being reported; that no important aspects of the study
39 have been omitted; and that any discrepancies from the study as planned have been
40 explained.
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49 Data sharing statement: Data are potentially accessible for all legitimate parties under
50 standard and usual conditions.
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Table 1. Mean (95%CI) natural death rate per 100,000 population by five-year intervals and age-group

Time interval	<15 years	15-44 years	45+ years	All ages
1986-1990	547.4 (406, 689)	426.3 (240, 613)	8065.4 (6778, 9353)	1480.7 (1240,1721)
2006-2010	60.5 (0, 202)	326.3 (140, 513)	2815.2 (1528, 4103)	716.8 (476,957)

Note: The mean of aggregate natural deaths over years 2001-2010 is used for deaths of those <15 years of age.

Sources: 1986-2011 census data, Australian Bureau of Statistics (Catalogues: 1987, #2460.0; 2012,#2002.0).¹⁷

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Figure 1. The Tiwi Islands, Northern Territory, Australia

Note: Wurrumiyanga was formerly named Nguui.

Source: Adapted from Google Map data. The Tiwi Islands. Google; ©2017 [cited 2017 Jan 10]. Available from: <https://www.google.com.au/maps/@-12.2087082,130.7314414,8.75z>

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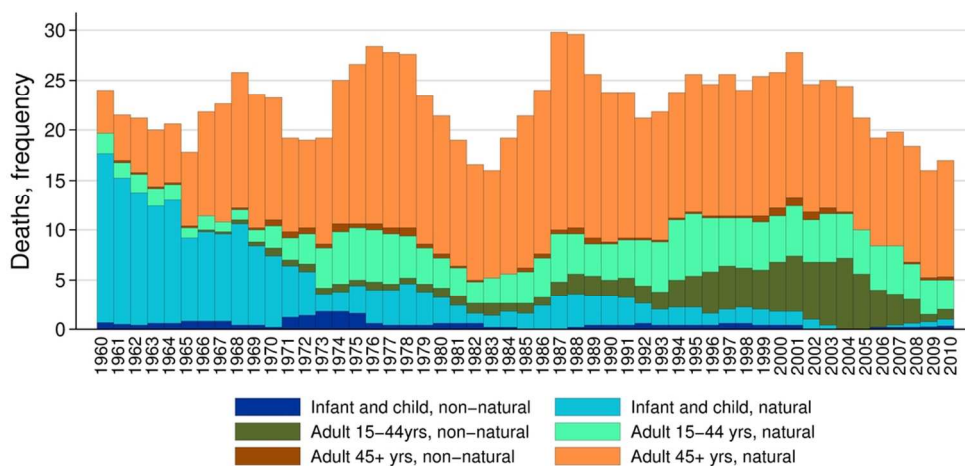


Figure 2. Numbers of Tiwi deaths by age-group and broad cause of death, 1960-2010
 Note: A five-year rolling average of frequencies is presented; people who have started dialysis are included among natural deaths.

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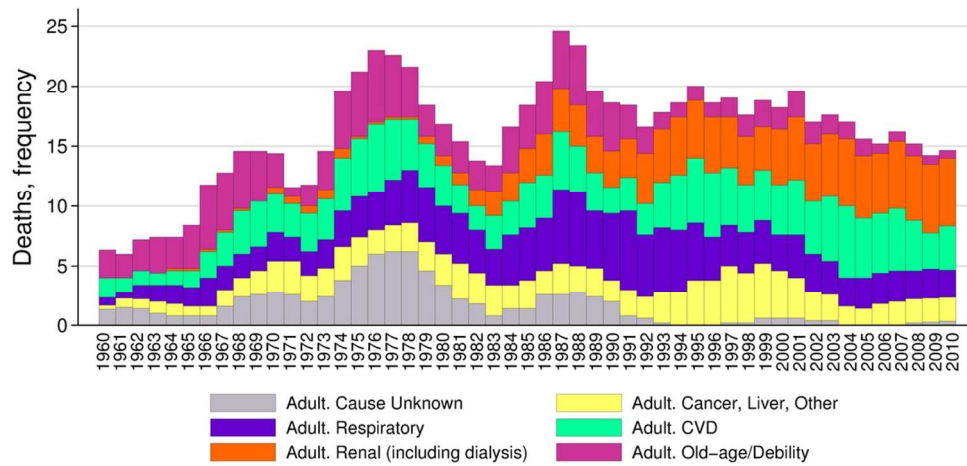
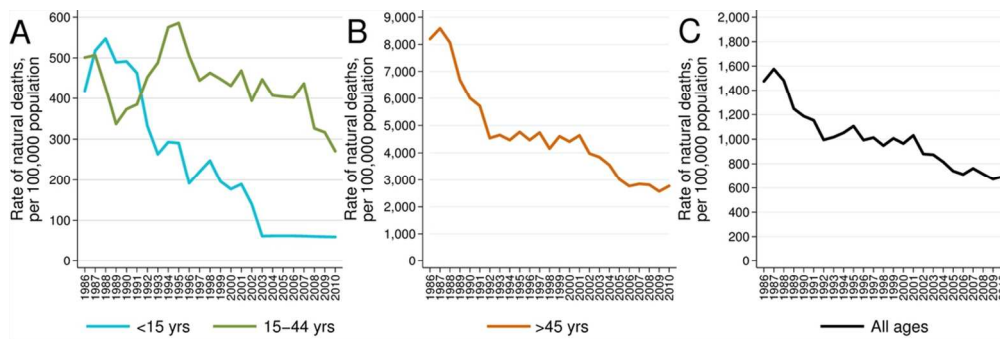


Figure 3. Numbers of Tiwi natural adult deaths by age-group and cause of death, 1960-2010
Note: A five-year rolling average of frequencies is presented; people who have started dialysis are included among renal deaths.

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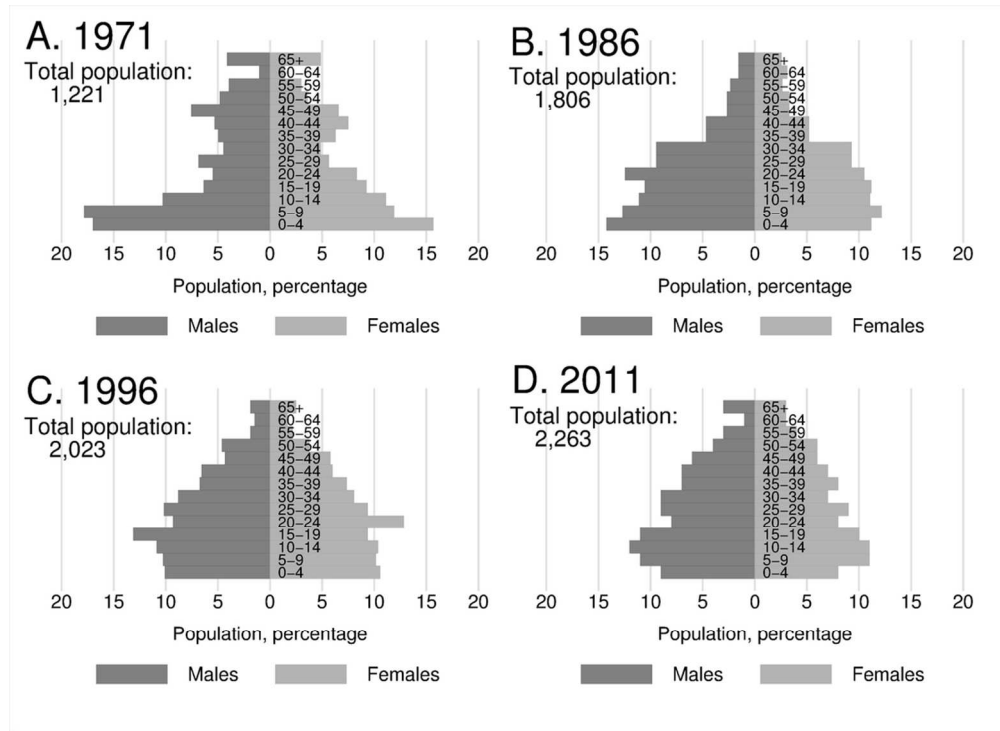


Figures 4 A-C. Tiwi rates of natural death per 100,000 population by age-group, 1986-2010
 Note: The figure presents a five-year rolling average of natural death rates by age-group: <15 and 15-45 years (A); ≥45 years (B); all ages (C). People who started dialysis are included among natural deaths. The low rates of death depicted for those <15 years from 2003 to 2010 are each based upon the average of the very small number of events (four) that occurred between 2001 and 2010.

Sources of 1986-2010 population data: quinquennial Census estimates (Australian Bureau of Statistics Catalogues: 1987, #2460.0; 1993, #2730.7; 2000, #70609; 2007, #2001.0; 2002, #2002.0; 2012, #2002.0);17

101x33mm (300 x 300 DPI)

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Figures 5 A-D. Age distribution of the Tiwi population at four time-points, by sex, 1971-2011
 Note: The figure presents population pyramids and total population for 1971 (A); 1986 (B); 1996 (C); 2011 (D).
 Sources: A, cited in Peterson, 1988;18 B-D, census data, Australian Bureau of Statistics (Catalogues: 1987, #2460.0; 2000, #70609; 2012,#2002.0).17

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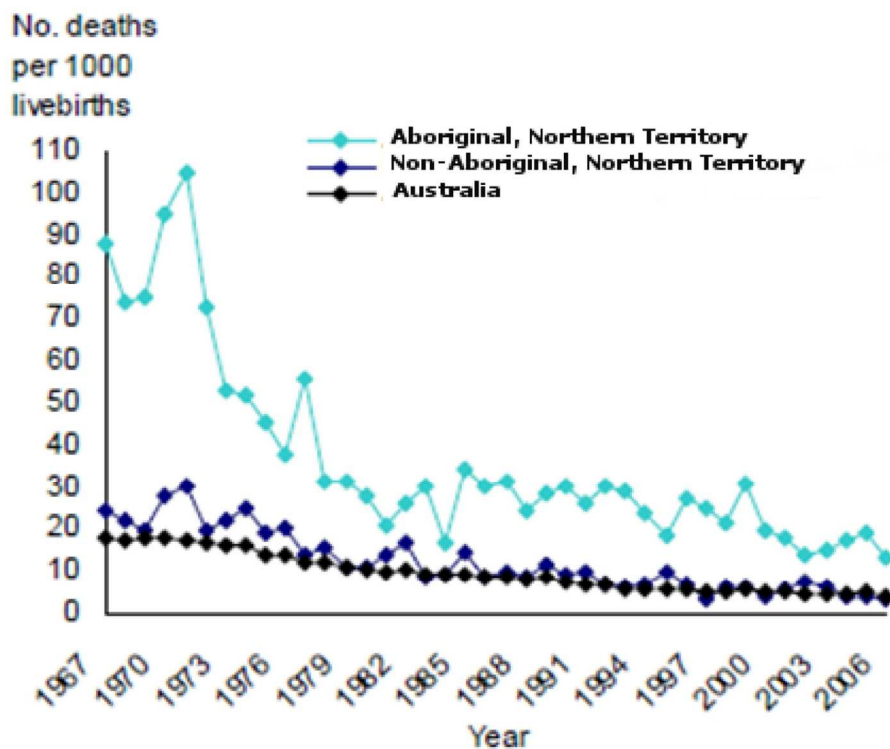


Figure 6. Infant mortality, Northern Territory and Australia, 1967-2007
 Source: Northern Territory Department of Health, 2011.31

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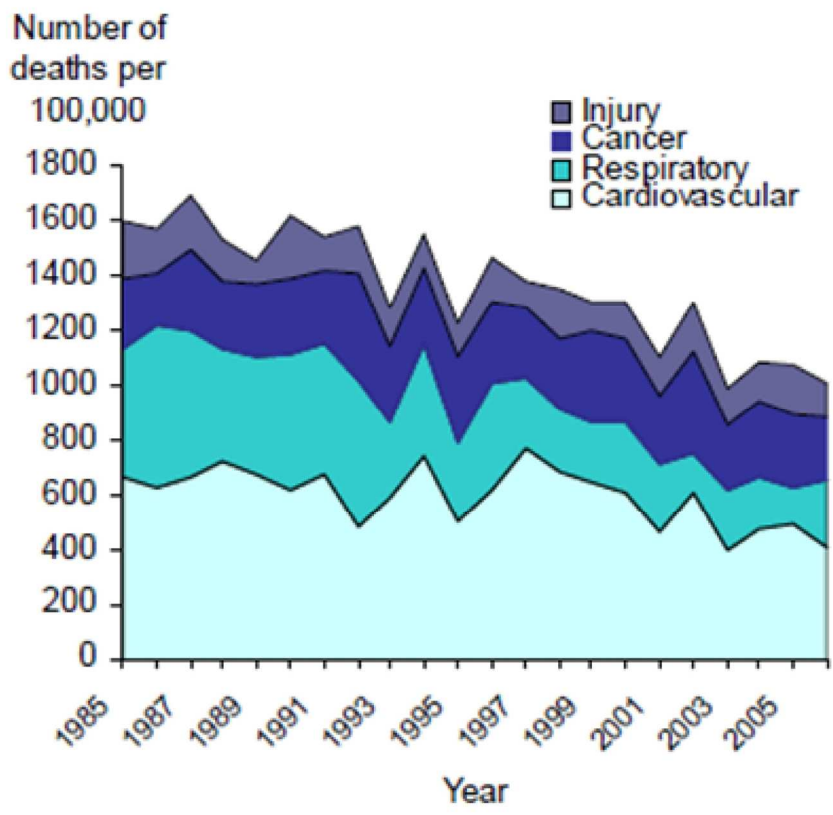


Figure 7. Leading causes of death in the Aboriginal population of the Northern Territory: 1985-2006
Source: Northern Territory Department of Health, 2011.31

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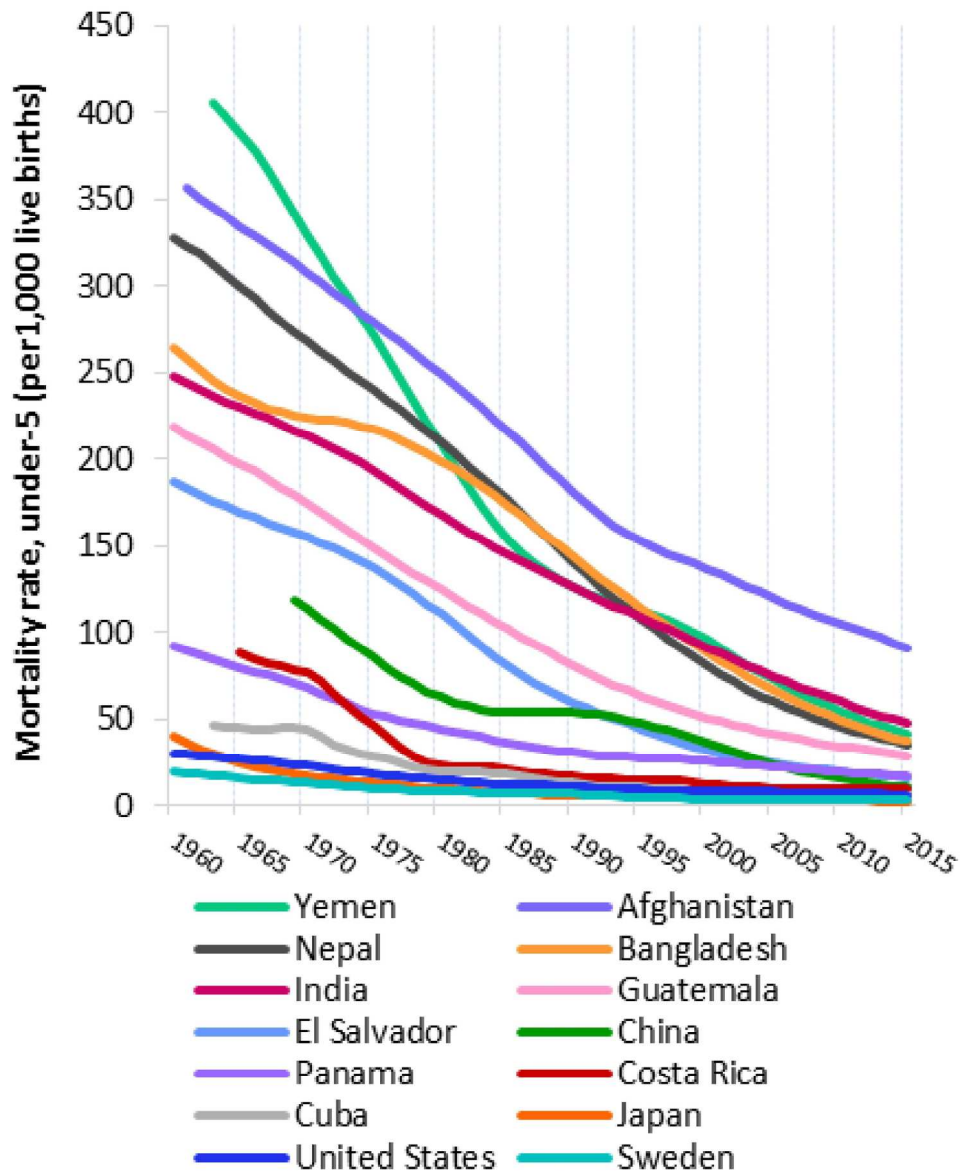


Figure 8. Under-five mortality rates for selected countries, 1960-2015
 Source: adapted from UNICEF Global Database, 2015.33

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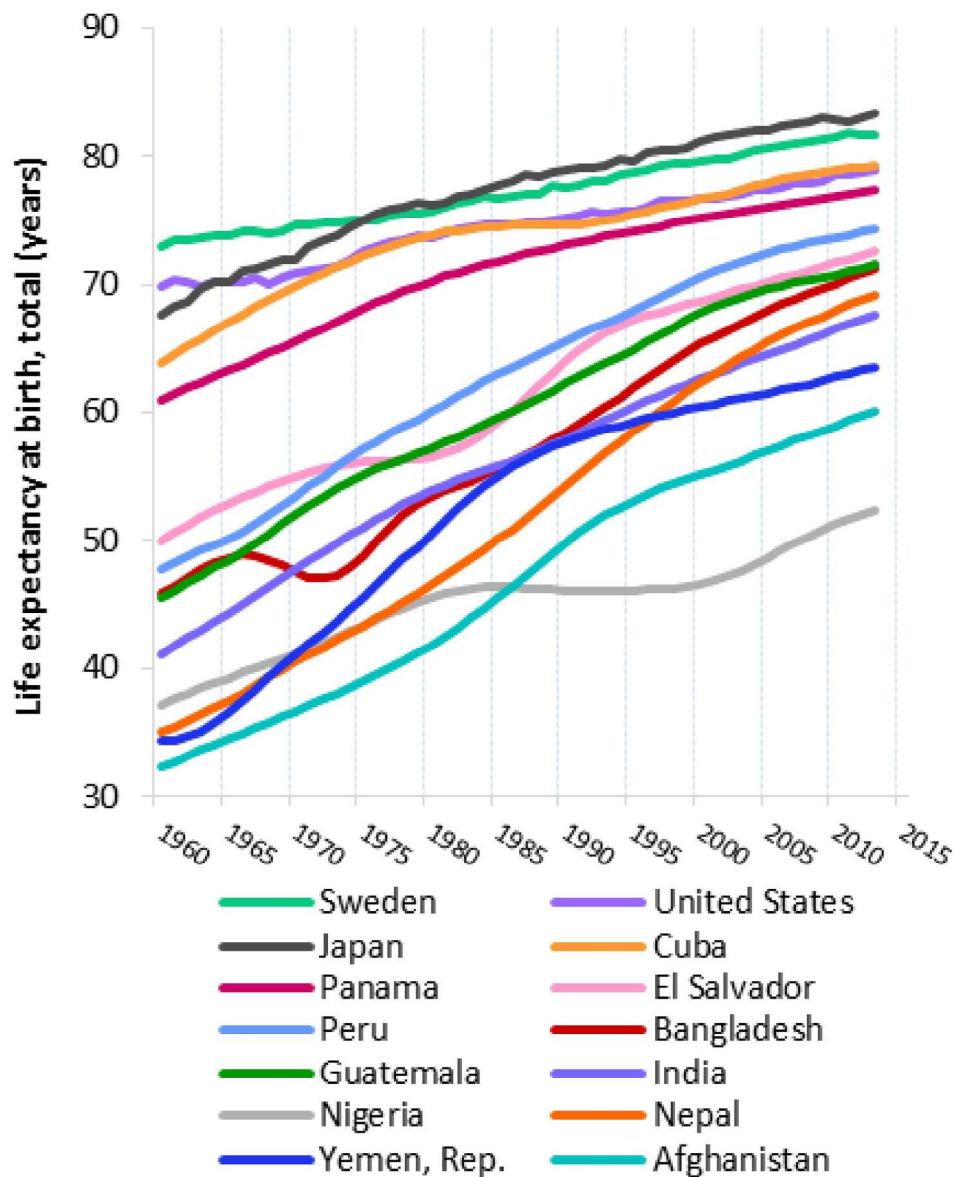


Figure 9. Life expectancy at birth for selected countries, 1960-2013

Source: adapted from The World Bank, 2016.³⁴

Source notes: Derived from male and female life expectancy at birth from sources such as: United Nations Population Division; World Population Prospects; United Nations Statistical Division. Population and Vital Statistics Report (various years); Census reports and other statistical publications from national statistical offices; Eurostat: Demographic Statistics; Secretariat of the Pacific Community: Statistics and Demography Programme; and U.S. Census Bureau: International Database.

189x223mm (300 x 300 DPI)

Supplementary Table 1. Frequencies of Tiwi deaths by age-group and time interval, 1960-2010

Age-group	Deaths N (%), by time interval											
	1960-1964	1965-1969	1970-1974	1975-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009	2010	Total
Under 15 years	69 (65.1)	48 (42.9)	29 (30.5)	20 (14.4)	8 (9.6)	17 (11.4)	13 (12.3)	10 (7.8)	5 (4.1)	2 (2.0)	1 (6.3)	222 (19.2)
15 - <45 years	9 (8.5)	6 (5.4)	19 (20.0)	28 (20.1)	16 (19.3)	31 (20.8)	32 (30.2)	46 (35.9)	50 (40.7)	40 (40.4)	2 (12.5)	279 (24.1)
45 years and over	28 (26.4)	58 (51.8)	47 (49.5)	91 (65.5)	59 (71.1)	101 (67.8)	61 (57.6)	72 (56.3)	68 (55.3)	57 (57.6)	13 (81.3)	655 (56.7)
Total	106 (100)	112 (100)	95 (100)	139 (100)	83 (100)	149 (100)	106 (100)	128 (100)	123 (100)	99 (100)	16 (100)	1,156 (100)

Note: 5-yearly time intervals are presented except for the single year of 2010; people who started dialysis are included among deaths

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page No.(s) [Paragraph No.(s)]
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3[1-9]
Objectives	3	State specific objectives, including any prespecified hypotheses	3[1]
Methods			
Study design	4	Present key elements of study design early in the paper	4[6]-5[5]
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4[6]-5[5]
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	4[4] 5[5]
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	-
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	4[5]-5[4]
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4[5]-5[4]
Bias	9	Describe any efforts to address potential sources of bias	5[1-3] 7[3-4] 8[1,3]
Study size	10	Explain how the study size was arrived at	4[5]-5[3]
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4[5]-5[4]
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	5[3]
		(b) Describe any methods used to examine subgroups and interactions	5[4]
		(c) Explain how missing data were addressed We believe that the ascertainment of deaths overall is as good as it can be. We have accessed the original sources for this information (4[5]). There are no published government estimates prior to 1985. From 1985, our ascertainment compares favourably with that of government agencies (8[3]). Subjects included are those with available death data, plus age at death or age-group and natural or unnatural cause of death classification.	

As a more detailed description of the cause of death was not consistently documented until after 1985 we restricted analyses by cause of death to 1985-2010. Additionally, as census data also became available from that time, death rates were calculated in the same time period.

(d) *Cohort study*—If applicable, explain how loss to follow-up was addressed

Case-control study—If applicable, explain how matching of cases and controls was addressed

Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy

(e) Describe any sensitivity analyses

Continued on next page

Results		Page No.(s) [Paragraph No.(s)]
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence

1
2 Generalisability 21 Discuss the generalisability (external validity) of the study results 9[1]

3 **Other information**

4 Funding 22 Give the source of funding and the role of the funders for the present study and, 11[3]
5 if applicable, for the original study on which the present article is based
6
7

8 *Give information separately for cases and controls in case-control studies and, if applicable, for exposed and
9 unexposed groups in cohort and cross-sectional studies.
10

11 **Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and
12 published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely
13 available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at
14 <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is
15 available at www.strobe-statement.org.
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BMJ Open

Transformation of mortality in a remote Australian Aboriginal community: a retrospective observational study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-016094.R2
Article Type:	Research
Date Submitted by the Author:	28-Jun-2017
Complete List of Authors:	Hoy, Wendy; The University of Queensland, Centre for Chronic Disease, UQCCR, Faculty of Medicine Mott, Susan; The University of Queensland, Centre for Chronic Disease, UQCCR, Faculty of Medicine McLeod, Beverly ; The University of Queensland, Centre for Chronic Disease, UQCCR, Faculty of Medicine; Menzies School of Health Research
Primary Subject Heading:	Epidemiology
Secondary Subject Heading:	Public health
Keywords:	Australian Aboriginal, Mortality transition, Demographic profile, Remote-living, Chronic disease

SCHOLARONE™
Manuscripts

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3 **Transformation of mortality in a remote Australian Aboriginal community: a retrospective**
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5 **observational study**
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Abstract

Objectives To describe trends in ages and causes of deaths in a remote-living Australian Aboriginal group over a recent 50 year period.

Design A retrospective observational study, from 1960 to 2010, of deaths and people starting dialysis, using data from local clinic, parish, dialysis and birthweight registers.

Setting A remote island community in the Top End of Australia's Northern Territory, where a Catholic Mission was established in 1911. The estimated Aboriginal population was about 800 in 1960 and 2,260 in 2011.

Participants All Aboriginal residents of this community whose deaths had been recorded.

Outcome measures Annual frequencies and rates of terminal events (deaths and dialysis starts) by age-group and cause of death.

Results In all, and against a background of high rates of low birthweight, 223 deaths in infants and children and 934 deaths in adults (age ≥ 15 years) were recorded; 88% were of natural causes. Most deaths in the 1960s were in infants and children. However, these fell dramatically, across the birthweight spectrum, while adult deaths progressively increased. The leading causes of adult natural deaths were chronic lung disease, cardiovascular disease and, more recently, renal failure, and rates were increased two-fold in those of low birthweight. However, rates of natural adult deaths have been falling briskly since 1986, most markedly among people of age 45+ years. The population is increasing and its age structure is maturing.

Conclusions The changes in death profiles, the expression of the Barker hypothesis and the ongoing increases in adult life expectancy, reflect epidemiologic and health transitions of astonishing rapidity. These probably flow from advances in public health policy and health care delivery, as well as improved inter-sectoral services, which are all to be celebrated. Other remote communities in Australia are experiencing the same phenomena, and similar events are well advanced in many developing countries.

Strengths and limitations of this study

- The broad sweep and historical depth of this study, the unique data sources and the integration of clinical and demographic information have allowed delineation of the profound and recent transformation of mortality not previously appreciated in the Australian Aboriginal setting.
- It is inevitable that we have failed to capture some deaths in the past, which probably resulted in understatement of the magnitude of this transition. In some recorded natural deaths the assignments were approximate and the contribution of multiple causes was underestimated.

Background

Recent literature describes a rapid shift in patterns and causes of death in most countries and regions. Infant and childhood deaths have decreased, life expectancy has increased,¹ and more deaths in adults are associated with non-communicable chronic diseases.² Here we describe such a transition in a remote-living Aboriginal Australian group over the last 51 years.

The Tiwi people live in three major communities (and several smaller ones) on Bathurst and Melville Islands off the coast of the Northern Territory, about 90 km by sea from Darwin (Figure 1). They lived in relative isolation for perhaps 7,000 to 15,000 years, and consider themselves distinct from mainland Aboriginal people, with their own unique origins, language, and customs.³

In 1911, a Catholic mission was established by the Missionaries of the Sacred Heart (MSC), led by Father Francis Xavier Gsell.⁴ Changes followed in lifestyle (from nomadic hunter gatherers to living in fixed dwellings), in diet (from food from the bush and sea to depot supplies of less perishable, high caloric density food, of flour, fat, meat and sugar), in family and community structures (from polygamy and networks of carers within extended families to monogamy), and in the establishment of dormitories, schools and clinics. Transition has been especially accelerated since World War 2. Cigarettes were widely introduced around this time (anecdotal evidence). The 1967 referendum formally recognised Aboriginal people in Australia⁵ and they were thenceforth included as residents in the national census. Legal access to alcohol began around that time. The first social club, serving alcohol, was opened in the largest Tiwi community in 1967.

Some early insights into remote-living Aboriginal people in the NT are provided by Ellen Kettle, the first Rural Survey Sister in the NT, who pioneered mobile health work in isolated areas and established health records for individuals, and by Dr John Hargrave, the first Aboriginal Health Officer, who personally examined members of many communities in 1957/1958. Both advanced understanding of Aboriginal health and development of services and policy. They described endemic conditions (yaws, malaria, infestations, trachoma), imported conditions like leprosy, syphilis (arguably), tuberculosis, measles, small pox and influenza. They documented florid malnutrition and frank starvation, high infant and maternal mortality and conspicuously low birthweight. They then described, over time, dramatic reductions in infant mortality, the appearance of alcohol related disorders, and of occasional overweight and obesity, as well as the emergence of non-communicable chronic diseases.^{6,7}

These phenomena occurred against a background of continuous improvements in remote Aboriginal health services, including management of infections and infestations, immunisations, better obstetric services, better maternal and child care, and cancer surveillance. Chronic non-communicable diseases, predominantly type 2 diabetes,

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3 cardiovascular disease, chronic lung disease and chronic kidney disease now dominate the
4 adult health profile and are the focus of most of health service provision for remote-living
5 Australian Aboriginal adults.⁸
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8 Clinical services were established by the mission, starting as first aid facilities on the beach
9 at Nguuu (now Wurrumiyanga) on Bathurst Island. These eventually evolved into a clinic and
10 local hospital, run by the Sisters of the Order of Our Lady of Sacred Heart (OLSH), with
11 additional clinics in the Melville Island communities of Milikapiti and Pirlangimpi. Medical
12 records were established for individuals, along with clinic-based registers for births and
13 deaths. Doctors from Darwin eventually provided backup support. More recently, there
14 have been resident doctors for intermittent periods. Local hospital beds were closed in the
15 early 1990s, and all persons needing hospital admission were thenceforth streamed to the
16 Royal Darwin Hospital, transported by small plane. Responsibility for clinical services was
17 transferred from the mission to the NT government in the early/mid-1990s.
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22 Anthropologist Charles Hart enumerated a Tiwi population of 1,062 in 1928.³ Dr John
23 Hargrave estimated the Tiwi population at about 800 to 900 in 1957, compatible with a
24 1954 Commonwealth Government estimate of 920.^{9,10} Regular government census
25 estimates have been published every five years since 1986.
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29 Traditionally, Tiwi people have only occasionally transmigrated, usually for purposes of
30 intermarriage according to tribal edicts. The destinations of people who travel, and the
31 movements and locations of community members, are known by all. Deaths of people who
32 die out of community (usually in Darwin or while visiting other communities) are
33 documented in their medical records on in their “home” community clinic and added to the
34 death register.
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38 Death rates in the Tiwi community, along with those in Aboriginal people in Arnhem Land,
39 have among been the highest in Australia: in the 1990s, with age-standardisation, they were
40 six times those of the Australian mainstream.¹¹ This generally reflects the much younger age
41 of Tiwi people at death. Cases of kidney failure began to attract attention in the 1980s;¹² for
42 several decades Tiwi people had the highest rates of renal failure yet described, and the first
43 hemodialysis unit in a remote Aboriginal location was established in Wurrumiyanga on
44 Bathurst Island in the late 1990s. High renal failure rates have followed in other remote
45 communities. The characteristics and speculative causes of the renal disease have been
46 described extensively.^{12,13,14} We have previously described the high rates of low
47 birthweight in this community and the risk exacerbations for natural deaths in infants,
48 children and young adults associated with low birthweight.^{15,16}
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53 **Aims and objectives**

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55 To describe trends in mortality over more than fifty years in a remote Aboriginal community
56 in the Northern Territory (NT) of Australia.
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Methods

Data sources were the written logs of deaths maintained by the clinics, dialysis unit records of NT Renal Services, and in this staunchly Catholic community, records maintained by the parish priests of all funerals and burials. We report recorded deaths over the 51 year period from 1960 to 2010, beginning when clinic recording of details of death (age, date and explanation) was becoming more systematic.

One thousand, one hundred and ninety deaths were ascertained, and with exclusion of 34 who lacked a recorded cause of death, date of birth or date of death, 1,156 were included in analyses. Amongst them, some details were sometimes still lacking. Eighty five of 1,017 people (8.4%) who died as adults (at ≥ 15 years of age) of natural causes, did not have a precise cause of death recorded: they were described as natural deaths of unknown cause. Deaths of misadventure had been clearly documented. Deaths in those age < 15 years had clear natural or non-natural death assignments.

Age was documented or age group was inferred for the 1,156 deaths. Analyses were conducted using broad age-groups, rather than a single year of age. Sixteen death records lacked a date of birth but did have date of death and cause of death – based on cause of death, clinical judgement and local knowledge they were assigned an age of 50 years, which put them into the category of the oldest adults (≥ 45 years). Five did not have date of birth but did have date of death and cause of death had been recorded as old age. They were assigned an age of death of 60 years, which also put them into the category of the oldest adults (≥ 45 years).

Starting in the 1980s, maintenance dialysis has been available to Tiwi persons with end-stage renal disease; numbers of patients starting treatment increased steadily until apparently stabilising at about 6 persons a year in the early 2000s. In this study, initiation of dialysis is considered a natural (renal) death, occurring when dialysis began, because without that treatment all participants would have died shortly thereafter. There was no additional assignment of date or cause of death when they finally expired.

Description of cause of death became more detailed over time. In the early years the only discrimination for some deaths was of natural versus unnatural causes, while, in later years, there was more detailed narrative on cause(s) and associations of death. In the early years, deaths in people over 60 years of age often received a causal assignment of “old age” or “debility”, but with time “disease or organ-specific” assignments increased for them as well. In some recorded natural deaths the assignments were approximate and the contribution of multiple causes was underestimated. Cause of death was assigned by clinic directors and always took into account the previous health profile of each deceased person. In the context of sometimes sparse clinical detail, and conforming to the methodology for the Global Burden of Disease study, we derived and assigned a principal cause of death only.

Unnatural deaths, or deaths of misadventure, included those due to vehicular accidents, drownings, fire (burns and smoke inhalation), homicide, suicide, poisonings, jelly fish stings,

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3 crocodile and shark attacks etc. We defined the main categories of natural deaths as
4 cardiovascular (heart attack, congestive heart failure, ischemic heart disease, coronary
5 artery disease and stroke), respiratory (chronic lung disease, chronic obstructive airways
6 disease, chronic bronchitis, bronchiectasis, pneumonia), renal (death with terminal renal
7 failure, and also, after 1985, institution of dialysis in people with terminal renal failure),
8 various other causes (eg sepsis, liver failure, lupus, cancer etc.), and debility or old age.
9 When there was uncertainty about deaths or persons, data were checked with several
10 senior community members, who had lived through much of the study interval and had
11 known most community members.
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16 Analyses were conducted using Stata 14 (StataCorp. 2015. *Stata Statistical Software:
17 Release 14*. College Station, TX: StataCorp LP). Numbers and rates of deaths were calculated
18 by age-group and cause of death. Five-year moving averages were created using the
19 tssmooth package. Mortality rates, per 100,000 population, could be calculated only since
20 1986, the first year of the subsequent quinquennial national census that specifically
21 enumerated Aboriginal Tiwi people. Total population estimates were also taken from census
22 figures.¹⁷
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26 Results

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28 Among the 1,156 deaths, 222 (19.2 %) were in infants and children (<1 years and 1 to <15
29 years respectively), and 934 (78.5%) were deaths of adults (at ages ≥ 15 years). Twenty-five
30 (11.3%) deaths of infants and children were deaths of misadventure and 197 (88.7%) were
31 of natural causes. Among adults, 114 (12.2%) of deaths were due to misadventure and 820
32 (87.8%) were natural deaths.
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36 Figure 2 shows numbers of all deaths by major cause group (natural and misadventure),
37 age-group and interval (frequencies are tabulated in Supplementary Table 1). Early on, most
38 deaths were in infants and children. These fell rapidly at first, then more slowly. The main
39 categories of death in infants and children were diarrhoea, respiratory disease and failure to
40 thrive, with some cases of sudden infant death, and a few congenital abnormalities.¹⁵ In
41 1973, a house fire killed six siblings, making a major contribution to deaths of misadventure
42 in this group.
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46 As infant and childhood deaths fell, numbers of deaths of adults increased. Many of these
47 have been among young adults (ages 15 to <45 years) with high numbers of both natural
48 death and deaths of misadventure. The latter include motor vehicle accidents, drownings,
49 homicide, and suicide; there were 50 suicides (50% of deaths of misadventure) between
50 1985 and 2010, of which 47 (94%) were among males.
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54 Since 1975 most deaths are in people of ≥ 45 years, and most of these are of natural causes.
55 The numbers have not perceptibly increased since the early 1990s. Only 13 (2.5%) of these
56 older adult deaths were due to misadventure.
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3 Figure 3 shows the trends in natural deaths in adults over time, by primary causal
4 assignment. Numbers peaked in the later 1980s but have since had an indeterminate or
5 falling trend. Through the mid-1980s there were substantial numbers of natural deaths with
6 no further details and deaths with assignments of “old age” or debility”, but there have
7 been more “organ-system” assignments since the early 1990s. Among specific assignments,
8 cardiovascular deaths, and cancer/liver/other deaths were represented over the continuum,
9 while pulmonary (respiratory) deaths became prominent but more recently have been
10 decreasing. Renal deaths become prominent in the 1980s; there were 25 renal deaths in the
11 1980s, 42 in the 1990s and 52 from 2000 to 2009, constituting 14·7, 24·1 and 31·7% of all
12 natural deaths in those intervals.
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18 Figures 4 A-C show the smoothed estimated rates of natural deaths by age-group since
19 1986.¹⁷ Rates of death in infants and children have fallen remarkably (4A). There was an
20 early increase in death rates among young adults (4A), followed by a progressive decline
21 since the mid-1990s. Death rates of people age ≥ 45 years have markedly declined, at least
22 until the last few years of the observation interval (4B). The net effect of all these changes
23 is a decrease overall death rates of the entire population.
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27 These trends are further summarised in Table 1, which shows the rates of natural deaths by
28 age-group in the first and last 5-year blocks of the observation interval. Death rates of
29 infants and children fell by 88·9 %, those of young adults fell by 23·5%, while of people age
30 ≥ 45 years fell by 65·1%. For the population as a whole, rates of natural death fell by 51·6 %.
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34 Figures 5 A-D show that the population age structure has changed over <40 years to include
35 higher numbers and proportions of young and middle age adults.^{17,18} In addition, the size of
36 the total population has increased by 85%.
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38 Discussion

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40 This is the most complete description of deaths in any indigenous Australian community. It
41 shows a profound change in patterns, rates and causes of death over a 51 year interval.
42 Infant and childhood deaths have fallen dramatically; now most people die as adults (≥ 15
43 years), and of natural causes. Furthermore, in the last 25 years, rates of natural deaths of
44 adults have been falling. The population is increasing and is progressively ageing.
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48 With continued improvements in prevention and treatment of infectious diseases, adult
49 deaths are increasingly due to non-communicable diseases, with chronic lung disease,
50 cardiovascular disease and renal disease making the greatest contribution. These chronic
51 diseases have usually overlapped and been co-contributors to death, although this is
52 obscured by our use of mutually exclusive categories of primary cause of adult death.
53 Among specific assignments, cardiovascular deaths, and cancer/liver/other deaths etc. have
54 been represented over several decades, while pulmonary deaths became prominent in the
55 1970s, but have decreased since the early 1990s. Kidney failure has become prominent
56 since the 1980s, and is now the single leading assignment.
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4 The still excessive (although improving) rates of natural deaths are compatible with the
5 “Barker hypothesis”, which proposes that survivors of lower birthweights have accentuated
6 susceptibility to chronic diseases and premature natural death in adult life.^{15,16,19} We have
7 shown that the dramatic reductions in early life mortality have been experienced across the
8 birthweight spectrum, so that, against a background of seriously low birthweights, large
9 cohorts of underweight infants, who were previously at greatest risk for early death, have
10 now survived to adult life. As adults, they have enhanced susceptibility to chronic disease, as
11 the hypothesis proposes and as we have demonstrated.^{15,20,21} Through 2010, rates of
12 natural adult deaths before the age of 41, in Tiwi people of low birthweight, were twice that
13 of those with higher birthweights, with the greatest accentuation of risk being for
14 pulmonary deaths, a 6-fold increase.¹⁶

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19 The continued evolution of the chronic disease rates and patterns and rates over time is
20 probably influenced by improving birthweights, changing age structure among adults,
21 improved prevention, screening and management of chronic disease and changes in
22 competing causes of deaths. With reductions in deaths from pulmonary disease and
23 postponement of cardiovascular deaths, flowing from a secular increase in birthweights,¹³
24 and from better medical management, coexisting nephropathy has more opportunity to
25 pursue its more leisurely course to renal failure.²² We have published extensively on the
26 expression, course and biopsy representation of the underlying renal disease.¹² It is clearly
27 multideterminant with risk enhanced by low birthweights, inflammation and infection,
28 episodes of post-streptococcal glomerulo nephritis and higher BMIs and diabetes in adult
29 life.^{23,24}

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35 Availability and use of the clinic-based death records and the supporting parish burial
36 records sets this study apart. The NT-wide government register of deaths dates only back to
37 the mid-1980s, and in that register, community assignment has sometimes been
38 incomplete. Moreover, government records do not capture the full burden of renal failure,
39 due to deficient documentation of a renal cause of death, both in people receiving renal
40 replacement therapy (RRT), and in those dying of renal failure without receiving RRT.^{14,25}
41 Our composite definition of “renal deaths” as the start of RRT and a renal death without RRT
42 more fully reveals the burden of renal failure disease. That approach is necessary for
43 monitoring, prevention and intervention strategies, especially in the context of the burden
44 and costs of RRT.^{13,26} Furthermore, it is the only way that kidney failure rates can be
45 compared with populations in other countries for whom RRT is not widely available.

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50 Our data also reveal an excess of deaths by misadventure in young adults in more recent
51 years. Such deaths, often alcohol or drug-fuelled, are prominent among young Aboriginal
52 adults nationwide, and are of grave concern.^{27,28}

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3 deaths, as well as the subsequent fall in deaths, have probably been understated.
4 Moreover, from 1985 to 2009, the government agencies recorded 18% fewer deaths for the
5 Tiwi community than we have recorded, with under-identification varying from 10 to 30%
6 over five consecutive 5 years intervals (In an email from Y Zhao, (yuejen.zhao@nt.gov.au)
7 2016 Oct 24). An additional limitation is assignment of a single category of cause of death,
8 whereas natural deaths in adults have multiple causes and associated conditions; the
9 coexistence of cardiovascular risk and lung disease, and of renal disease with cardiovascular
10 disease are well recognised. However, the use of a single underlying cause of death is
11 dictated by the detail of the source data. It is also the approach employed until recently for
12 the mortality component of the study of Global Burden of Disease.
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18 Is it credible that about half the deaths in Tiwi people in the 1960s were in subjects less than
19 15 years of age? The World Health Organization estimated that, in 1955, fully 40% of global
20 deaths were in children age <5 years, so presumably an even greater proportion were
21 deaths of people <15 year old).²⁹ Furthermore, analyses of skeletal remains of some
22 premodern cultures have suggested that up to 68% of deaths occurred people <15 years old
23 (Chamberlain cited in Roser, 2006).^{1,30} Hart's comment that, around 1928, five of 15
24 bestowed wives (females promised in marriage to specific Tiwi community members), died
25 before puberty, supports a high childhood mortality.³
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30 Other Aboriginal groups in remote areas of Australia over the same intervals have
31 undoubtedly experienced similar transitions. NT government agencies have described
32 similar trends in early life mortality since 1967, and improvements in natural death rates
33 overall since the late 1980s (Figures 6 and 7).³¹ In the Shire of Broome, Western Australia,
34 Gracey et al. described excessive levels of Aboriginal infant and childhood infection and
35 under-nutrition in the 1970s and 1980s and increasing deaths by misadventure in young
36 Aboriginal adults between 1971 and 1994.³² Our findings are also consistent with events in
37 many other countries and regions. Figure 8 shows the fall in early life mortality since 1960,
38 which is most dramatic in disadvantaged populations like Yemen, Afghanistan, Bangladesh
39 and Nepal,³³ while Figure 9 shows the simultaneous increase in life expectancy at birth,
40 again most marked in disadvantaged settings.³⁴ Our Tiwi data show that the improvement in
41 life expectancy is a function of reduced early life mortality as well as increasing adult
42 longevity.
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48 Gratifying as these reductions in adult death rates are, further improvements can still be
49 anticipated. Birthweights continue to increase, so that accentuated chronic disease risk
50 from that source should decline. In addition adult health services continue to improve,
51 especially in prevention, screening and management of chronic disease,⁸ and rates of
52 smoking are falling.³⁵ Current challenges in all of remote Aboriginal Australia, however,
53 include high rates of obesity,³⁶ poor diet, especially sugar excess,³⁷ drug use, alcohol abuse,
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3 and foetal alcohol syndrome,⁷ and rates of interpersonal violence, as well as of suicide and
4 accidents, remain high.
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7 These changes described in the manuscript are especially welcome news for the Tiwi
8 Aboriginal people, whose mortality rates have been the worst in Australia,¹¹ and for remote-
9 living Aboriginal people more broadly. They represent triumphs of inter-sectoral
10 improvements, public health policy and health care more broadly, which are to be
11 celebrated. Health care providers and policy makers should be comforted to see such large
12 scale progress demonstrated through an historical perspective, and encouraged in their
13 resolve for ongoing improvements in preventative health care.⁸ Better education, skills
14 training, employment opportunities, empowerment and socioeconomic status must also be
15 unflaggingly supported. More broadly, this information should moderate the negative
16 discourse which has pervaded the Aboriginal health literature.
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3 Contributors: WH conceived and designed this work, collected data, directed data analyses,
4 interpreted the findings and wrote the manuscript. BMcL conducted field work, and
5 performed data collection and data preparation. SM prepared data, performed analyses and
6 contributed to interpretation, produced figures and tables, and coordinated preparation
7 and editing of the manuscript. All authors had full access to all of the data in the study and
8 can take responsibility for the integrity of the data and the accuracy of the data analysis. All
9 authors reviewed, revised and approved the manuscript.
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37 Transparency: The lead author affirms that the manuscript is an honest, accurate, and
38 transparent account of the study being reported; that no important aspects of the study
39 have been omitted; and that any discrepancies from the study as planned have been
40 explained.
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46

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50 Data sharing statement: Grouped, de-identified data can be requested from the Corresponding
51 Author, Wendy E Hoy (w.hoy@uq.edu.au).
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Table 1. Mean (95%CI) natural death rate per 100,000 population by five-year intervals and age-group

Time interval	<15 years	15-44 years	45+ years	All ages
1986-1990	547.4 (406, 689)	426.3 (240, 613)	8065.4 (6778, 9353)	1480.7 (1240,1721)
2006-2010	60.5 (0, 202)	326.3 (140, 513)	2815.2 (1528, 4103)	716.8 (476,957)

Note: The mean of aggregate natural deaths over years 2001-2010 is used for deaths of those <15 years of age.

Sources: 1986-2011 census data, Australian Bureau of Statistics (Catalogues: 1987, #2460.0; 2012,#2002.0).¹⁷



Figure 1. The Tiwi Islands, Northern Territory, Australia

Note: Wurrumiyanga was formerly named Nguui.

Source: Adapted from Google Map data. The Tiwi Islands. Google; ©2017 [cited 2017 Jan 10]. Available from: <https://www.google.com.au/maps/@-12.2087082,130.7314414,8.75z>

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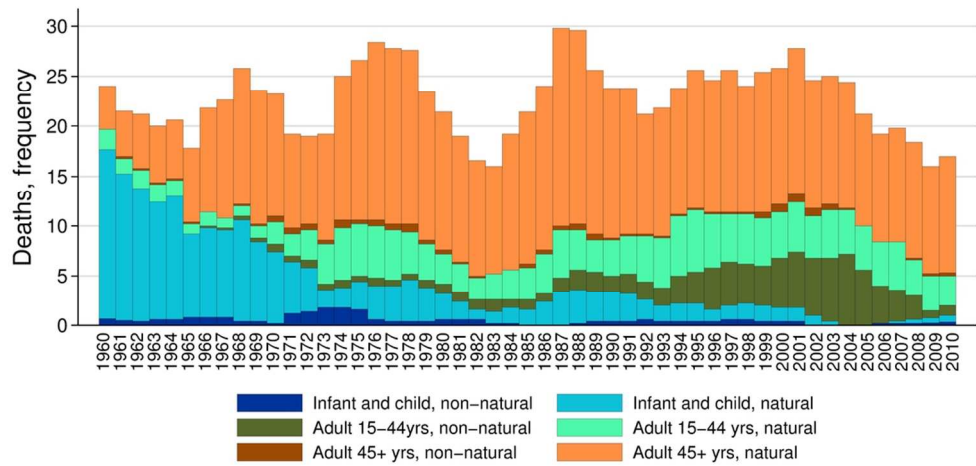


Figure 2. Numbers of Tiwi deaths by age-group and broad cause of death, 1960-2010
 Note: A five-year rolling average of frequencies is presented; people who have started dialysis are included among natural deaths.

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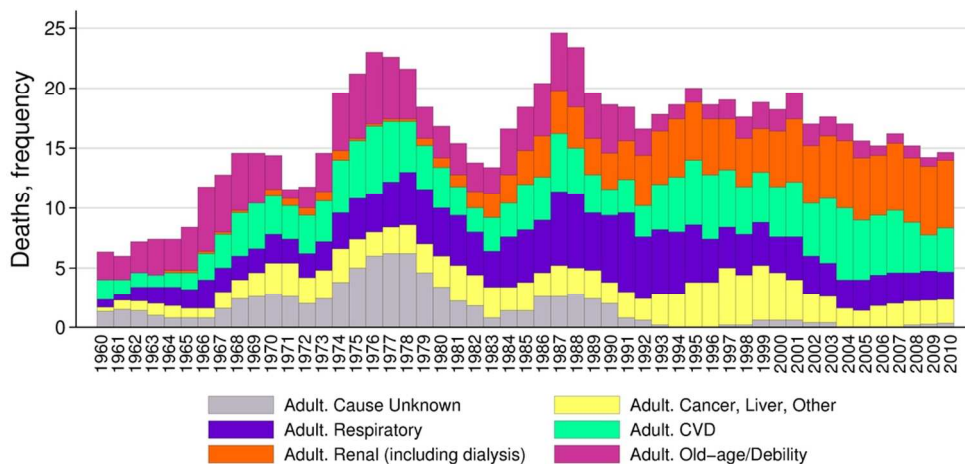
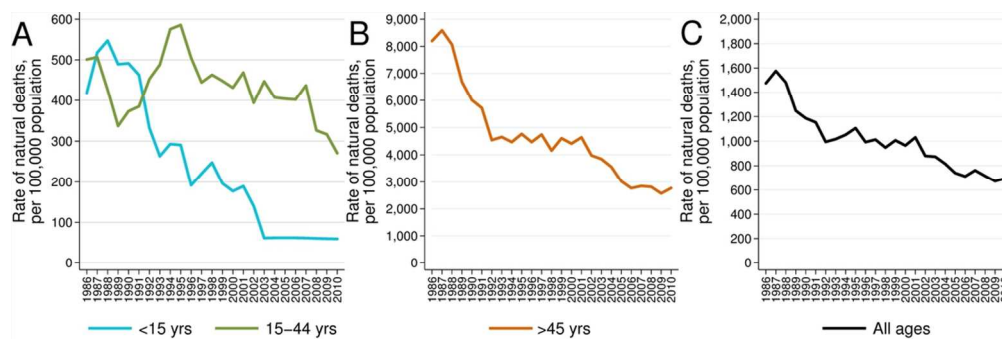


Figure 3. Numbers of Tiwi natural adult deaths by age-group and cause of death, 1960-2010
 Note: A five-year rolling average of frequencies is presented; people who have started dialysis are included among renal deaths.

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Review only

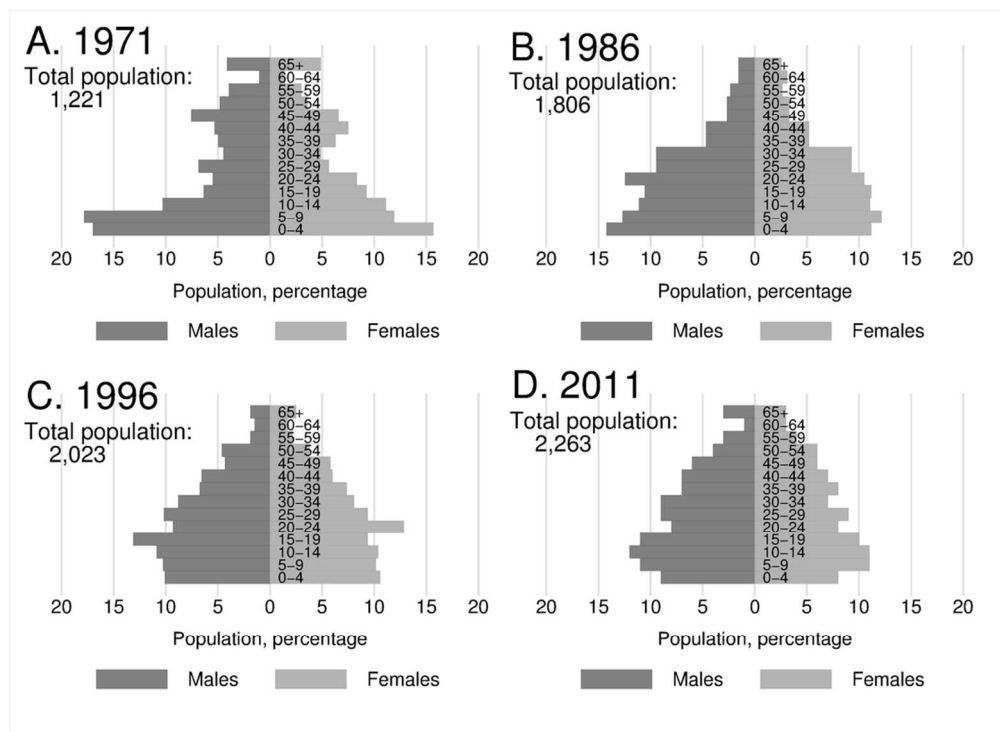


Figures 4 A-C. Tiwi rates of natural death per 100,000 population by age-group, 1986-2010

Note: The figure presents a five-year rolling average of natural death rates by age-group: <15 and 15-45 years (A); ≥ 45 years (B); all ages (C). People who started dialysis are included among natural deaths. The low rates of death depicted for those <15 years from 2003 to 2010 are each based upon the average of the very small number of events (four) that occurred between 2001 and 2010.

Sources of 1986-2010 population data: quinquennial Census estimates (Australian Bureau of Statistics Catalogues: 1987, #2460.0; 1993, #2730.7; 2000, #70609; 2007, #2001.0; 2002, #2002.0; 2012, #2002.0);17

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Figures 5 A-D. Age distribution of the Tiwi population at four time-points, by sex, 1971-2011
 Note: The figure presents population pyramids and total population for 1971 (A); 1986 (B); 1996 (C); 2011 (D).

Sources: A, cited in Peterson, 1988;18 B-D, census data, Australian Bureau of Statistics (Catalogues: 1987, #2460.0; 2000, #70609; 2012,#2002.0).17

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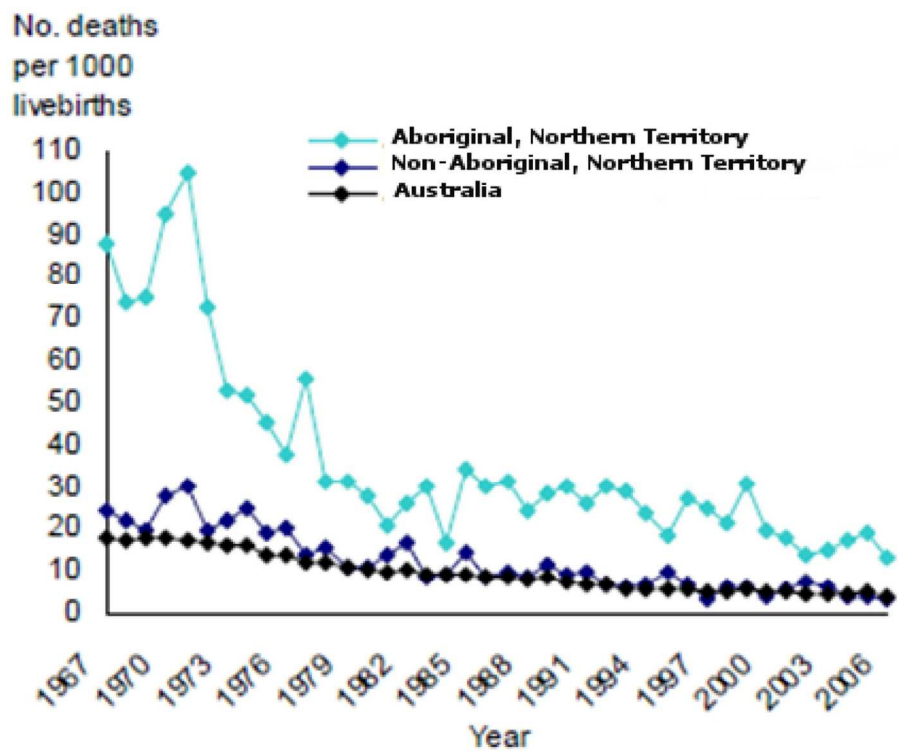


Figure 6. Infant mortality, Northern Territory and Australia, 1967-2007
Source: Northern Territory Department of Health, 2011.31

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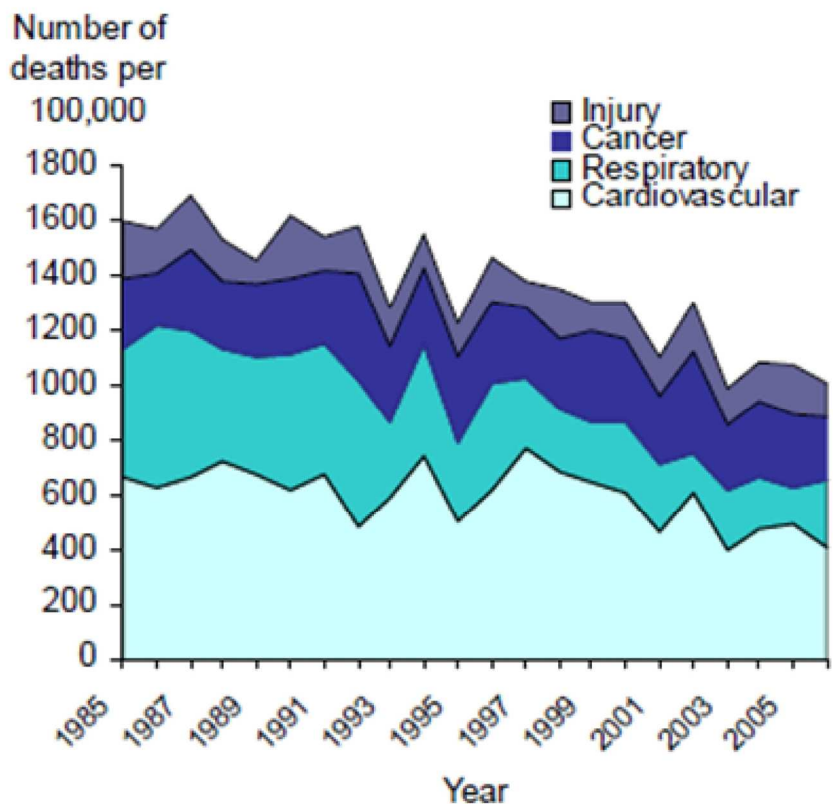


Figure 7. Leading causes of death in the Aboriginal population of the Northern Territory: 1985-2006
 Source: Northern Territory Department of Health, 2011.31

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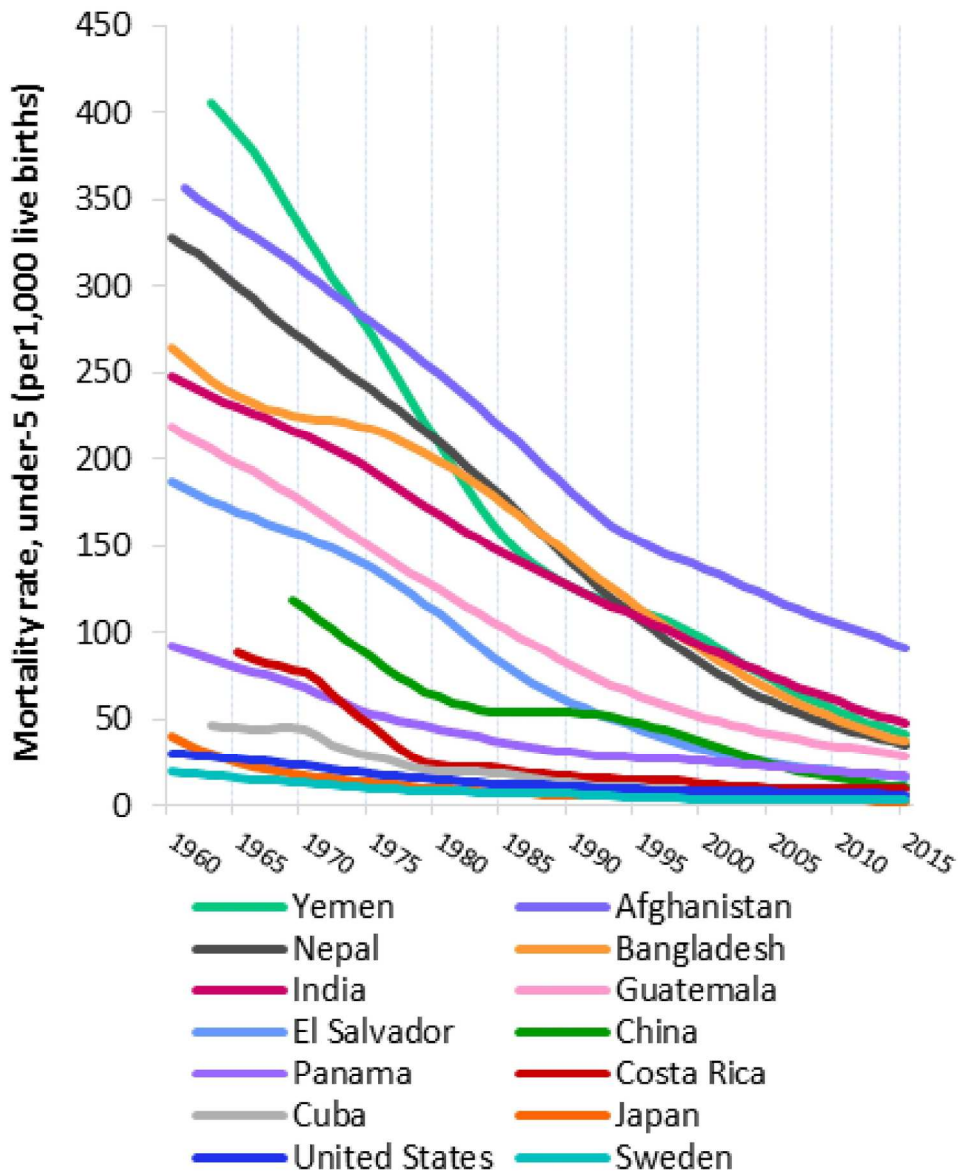


Figure 8. Under-five mortality rates for selected countries, 1960-2015
Source: adapted from UNICEF Global Database, 2015.33

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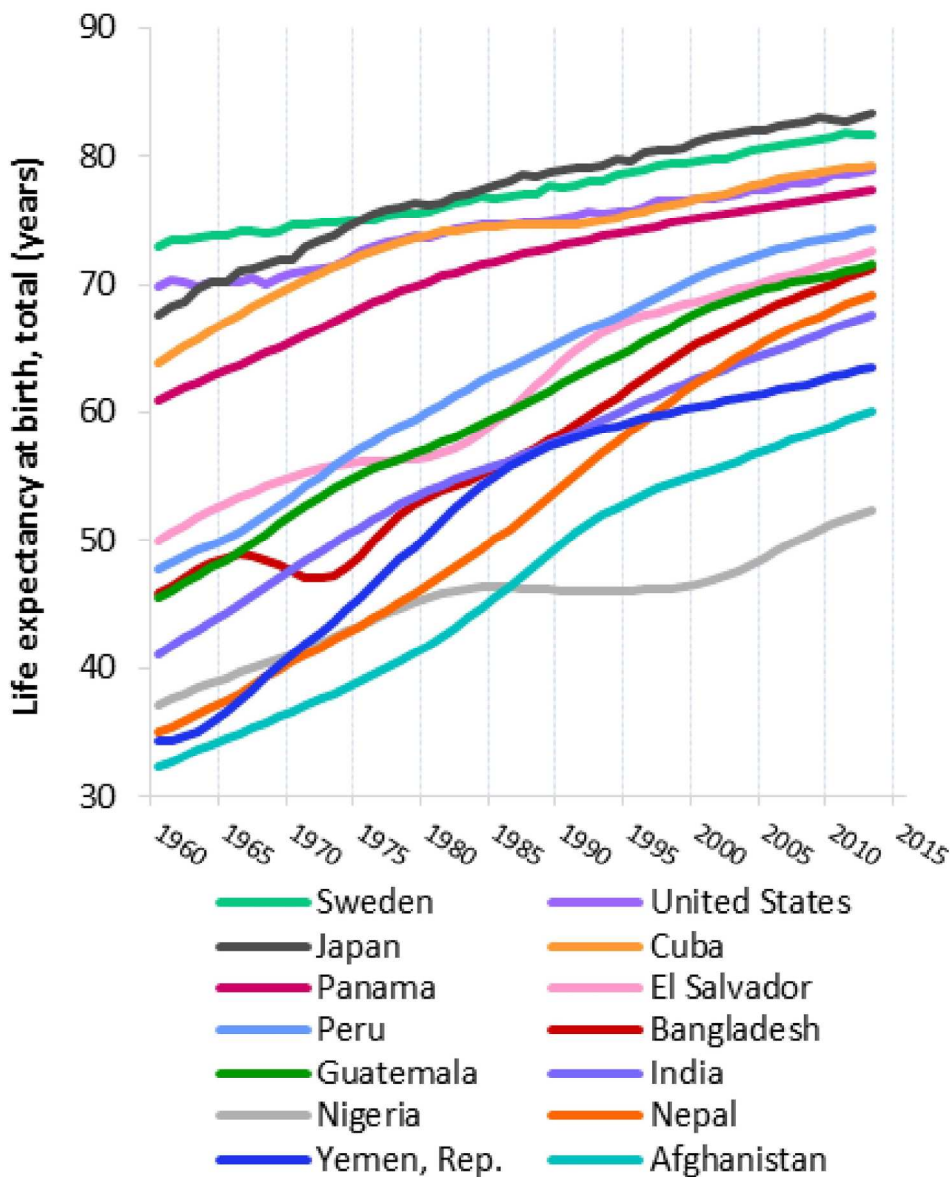


Figure 9. Life expectancy at birth for selected countries, 1960-2013

Source: adapted from The World Bank, 2016.³⁴

Source notes: Derived from male and female life expectancy at birth from sources such as: United Nations Population Division; World Population Prospects; United Nations Statistical Division. Population and Vital Statistics Report (various years); Census reports and other statistical publications from national statistical offices; Eurostat: Demographic Statistics; Secretariat of the Pacific Community: Statistics and Demography Programme; and U.S. Census Bureau: International Database.

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Supplementary Table 1. Frequencies of Tiwi deaths by age-group and time interval, 1960-2010

Age-group	Deaths N (%), by time interval											
	1960-1964	1965-1969	1970-1974	1975-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009	2010	Total
Under 15 years	69 (65.1)	48 (42.9)	29 (30.5)	20 (14.4)	8 (9.6)	17 (11.4)	13 (12.3)	10 (7.8)	5 (4.1)	2 (2.0)	1 (6.3)	222 (19.2)
15 - <45 years	9 (8.5)	6 (5.4)	19 (20.0)	28 (20.1)	16 (19.3)	31 (20.8)	32 (30.2)	46 (35.9)	50 (40.7)	40 (40.4)	2 (12.5)	279 (24.1)
45 years and over	28 (26.4)	58 (51.8)	47 (49.5)	91 (65.5)	59 (71.1)	101 (67.8)	61 (57.6)	72 (56.3)	68 (55.3)	57 (57.6)	13 (81.3)	655 (56.7)
Total	106 (100)	112 (100)	95 (100)	139 (100)	83 (100)	149 (100)	106 (100)	128 (100)	123 (100)	99 (100)	16 (100)	1,156 (100)

Note: 5-yearly time intervals are presented except for the single year of 2010; people who started dialysis are included among deaths

Peer review only

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page No.(s) [Paragraph No.(s)]
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3[1-9]
Objectives	3	State specific objectives, including any prespecified hypotheses	3[1]
Methods			
Study design	4	Present key elements of study design early in the paper	4[6]-5[5]
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4[6]-5[5]
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	4[4] 5[5]
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	-
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	4[5]-5[4]
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4[5]-5[4]
Bias	9	Describe any efforts to address potential sources of bias	5[1-3] 7[3-4] 8[1,3]
Study size	10	Explain how the study size was arrived at	4[5]-5[3]
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4[5]-5[4]
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	5[3]
		(b) Describe any methods used to examine subgroups and interactions	5[4]
		(c) Explain how missing data were addressed We believe that the ascertainment of deaths overall is as good as it can be. We have accessed the original sources for this information (4[5]). There are no published government estimates prior to 1985. From 1985, our ascertainment compares favourably with that of government agencies (8[3]). Subjects included are those with available death data, plus age at death or age-group and natural or unnatural cause of death classification.	

As a more detailed description of the cause of death was not consistently documented until after 1985 we restricted analyses by cause of death to 1985-2010. Additionally, as census data also became available from that time, death rates were calculated in the same time period.

(d) *Cohort study*—If applicable, explain how loss to follow-up was addressed

Case-control study—If applicable, explain how matching of cases and controls was addressed

Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy

(e) Describe any sensitivity analyses

Continued on next page

Results		Page No.(s) [Paragraph No.(s)]
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence

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Generalisability	21	Discuss the generalisability (external validity) of the study results	9[1]
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Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	11[3]
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*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.