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# **Access to data for Enhanced Mortality Database project: Issues and problems**

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**Fadwa Al-Yaman, AIHW**

**Len Smith, ANU**

**Tetteh Dugbaza, AIHW**

# Background to the Enhanced Mortality Database (EMD)

- Current estimates of Indigenous mortality suffer from imperfect identification of Indigenous deaths in the death notification collection and also from changes in coverage in the estimates of the Indigenous population.
- While estimates of the size of the Indigenous population have improved through better population census counts, improvements in death data have been slow.

# Purpose of Enhanced Mortality Database

## Objectives

- To improve information on Indigenous status on the registered deaths data set by linking it to several additional data sources that contain information on Indigenous deaths and Indigenous identification.
  - The enhanced death data are expected to enable more accurate estimates of Indigenous mortality, including life expectancy, to be made
- To provide evidence-based confidence that enhanced death data developed through the joint use of several death data sources can result in better estimates of Indigenous mortality, including life expectancy estimates.
- To maintain an ongoing researchable linked database to support research in Indigenous mortality and life expectancy

## Phases of EMD Project

- Phases 1-2: 2001-2006
  - Feasibility study
  - State and territory estimates
  - Yearly estimates
- Phase 3
  - Feasibility of using NTSCORP Research Database to validate results of Phases 1-2
- Phase 4
  - 2007-2011
  - Use of additional algorithms
  - Feasibility of using additional data sets
  - Validation of results for NSW using NTSCORP Research Database

## Data sets

- National Death Index
- Extracts of National Mortality Database
- National Hospital Morbidity Database
- National Perinatal Data Collection
- Residential Aged Care Data set

## Data custodians

Data custodian	National Death Index	National Mortality Database	National Hospital Morbidity Database	National Perinatal Data Collection	Residential Aged Care Database
NSW	Registrar of B, D & M	Registrar of B, D & M	Relevant Health Dept.	Relevant Health Dept.	
Vic	✓	✓	✓	✓	
Qld	✓	✓	✓	✓	
SA	✓	✓	✓	✓	
WA	✓	✓	✓	✓	
Tas	✓	✓	✓	✓	
ACT	✓	✓	✓	✓	
NT	✓	✓	✓	✓	
Commonwealth					✓ 6

# Ethics review

- AIHW Ethics Committee, established and operating according to NHMRC guidelines
  - Each phase of the project was ethically reviewed
- SA Health Research Ethics Committee
- WA Health Research Ethics Committee
- WA Aboriginal Health Ethics Committee
- ACT Health Research Ethics Committee

# Access to data: Phases 1 & 2

- Permission for access to all data sets except the Medical Certificate of Cause of Death (MCCD) data set was granted by all data custodians within 7 months of initial request
- A few data custodians required follow-ups and additional processes, such as additional ethics applications to their respective ethics committees
- Some approvals were for a relatively short period of time (e.g. 3 months) leading to the need to apply for extensions even before the data linkage was completed.

## Delays in access to data: Phase 4

- Permission by most data custodians to access data was relatively quick (about 6 months)
- Most data custodians granted data access for only 3 years
- Other data custodians granted data access up to 2010 only
- Victoria declined access to the perinatal data set
- Some states granted access to the MCCD data, but the data are actually not available
- Other states declined access to the MCCD data on privacy grounds, data unavailability or the fact that the MCCD data are already incorporated in the NDI. Follow-up requests yielded no change of heart.

## Delays in access to data: Phase 4 (continued 1)

- Some data custodians only granted conditional approval to their respective data sets, requiring extended negotiations to seek final approval. E.g.
  - Victoria granted access to their hospital data set “provided names are stripped off other sources such as death registrations before data linkage”
  - WA Maternal and Child Health Unit requested separate ethics approvals from the WA Health Ethics Committee as well as from the WA Aboriginal Health Ethics Committee before we could access their perinatal data
  - WA Health also challenged the project’s data linkage methodology, and suggested they would not give us grant access data unless we changed our linkage methodology to be consistent with theirs
  - ACT Health requested ethics approval from their Health Research Ethics Committee in addition to ethics approval from the AIHW Ethics Committee
  - Qld had also changed their data access protocols, requiring long periods of negotiation.

## Delays in access to data: Phase 4 (continued 2)

- Three factors contributed to the delays in access to data:
  - We did not have timely access to the NMD to enable the linkage to proceed. The NMD is usually late by 2 years, meaning that final data for 2010 will not be available till 2012 or even 2013.
    - In fact, the 2010 data used in the linkage is the revised and not the final 2010 data. Death data for 2011 are still preliminary
  - The ABS had implemented a “return to source” policy, which further delayed access to the mortality data for 2009 and 2010.
  - Most data custodians gave us a 2-3 years approval to access their data. Waiting 2-3 years for the mortality data meant that these approvals had expired by the time we were ready to undertake the data linkage. This required further requests to data custodians to extend approval to access their data sets. <sup>11</sup>

## Delays in access to data: Phase 4 (continued 3)

- There were some legislative and administrative changes between 2009 when data access for Phase 4 was initially given, and 2012, when the next round of requests for data access was being made.
  - These changes introduced new processes and further delays to the data access protocols (e.g. Vic, Qld, WA and the ACT):
    - request for additional ethics applications
    - request to change data linking methodology
    - Rules for data access were tightened
- Phase 4 involved a change in our data linkage methodology from linking only Indigenous perinatal deaths to the remaining data sets, to linking all perinatal deaths to the remaining data sets.
  - These changes required us to make new ethics applications as well as fresh applications to data custodians for access to the perinatal data. This caused considerable delays because most of the legislative and personnel changes affected mostly the perinatal.

## Delays in Publishing results and report

- The report on Phases 1 & 2 took about 18 months to publish
- Initial results were sent to all data custodians in the Commonwealth and jurisdictions for their comments
- Some data custodians responded very quickly
- A few data custodians took over 4 months to respond, and only responded after several follow-ups
- One particular stakeholder took over 12 months to respond
- Personnel changes in some jurisdictions caused delays because the officials who received the draft reports did not pass them on to their successors. This meant having to start all over again with the new incumbents of those positions. This caused undue delays.
- Some data custodians delayed approving the report unless parts of the report that were critical of the quality of their data were modified for fear the press might exaggerate the problems with their data<sup>13</sup>

## Results

- The death registration data set used for this project contained 10,547 deaths listed as Indigenous. The linkage of the additional data sets to the death registration data set identified 1,081, or 10.2%, more deaths than the 10,547 originally recorded on the death registration data set as 'Indigenous'.
- Using these linked data sets produces national estimates of Indigenous expectation of life at birth, of 66.6 years for males and 72.7 for females.
  - These estimates are close to estimates of 67.2 years for Indigenous males and 72.9 for Indigenous females, prepared by the ABS from the Mortality Quality Study, which was conducted as part of the 2006 Census Data Enhancement Study.
- NTSCORP validation problematic due to divergent data models. To be addressed using graph-based linkage.

# Report

The report to Phases 1-2 of the Enhanced Mortality Database project has been published as:

**AIHW 2012: An enhanced mortality database for estimating Indigenous life expectancy: a feasibility study, Cat. No IHW 75,. Canberra: AIHW**

Below is the link to the publication

<http://www.aihw.gov.au/publication-detail/?id=10737422286>

