

Australasian Mortality Data Interest Group (AMDIG) Face to Face Meeting QUT Kelvin Grove Campus

The following is a summary of the discussion of the AMDIG Face to Face Meeting conducted on Thursday 23 and Friday 24 November 2006.

AMDIG Terms of reference are available at:

<http://www3.fhs.usyd.edu.au/ncchwww/site/7.8.htm>

The following acronyms and abbreviations are used within the document.

ABS	Australian Bureau of Statistics
AG(s)	Attorney(s) General
AHMAC	Australian Health Ministers Advisory Council
AIHW	Australian Institute of Health and Welfare
AISRAP	Australian Institute of Suicide Research and Prevention
AMDIG	Australasian Mortality Data Interest Group
ANU	Australian National University
ATSB	Australian Transport Safety Bureau
BDM	Births, Deaths and Marriages
COAG	Council of Australian Governments
COAR	Council of Australasian Registrars
COD	Cause of Death
CCYPCG	Commission for Children Young People and the Child Guardian
CDCR	Child Deaths and Critical Reports (Unit)
CURF	Confidentialised Unit Record File
DoHA	Department of Health and Ageing
ERN	Entity Reference Number
FBI	Federal Bureau of Investigation (US)
ICD	International Classification of Diseases and Health Related Problems
MCCD	Medical Certificate of Cause of Death
MCOD	Multiple Cause of Death

MJA	Medical Journal of Australia
MMDS	Medical Mortality Data System
MOH	Ministry of Health
MOU	Memorandum of Understanding
MRG	Mortality Reference Group
NCCH	National Centre for Classification in Health
NCHS	National Centre for Health Statistics (US)
NCIS	National Coronial Information System
NDI	National Death Index
NDN	National Data Network
NHDC	National Health Data Committee
NHMRC	National Health and Medical research Council
NHIMG	National Health Information Management Group
NISU	National Injury Surveillance Unit
NPHIWG	National Health Information Working Group
NZHIS	New Zealand Health Information Service
OH&S	Occupational Health and Safety
PAS	Patient Administration System
PHAA	Public Health Association of Australia
QA	Quality Assurance
RCIS	Research Centre for Injury Studies
RG(s)	Registrar(s) General
UCOD	Underlying Cause of Death
UQ	University of Queensland
UR	Unit Record
URF	Unit Record File

**Summary of AMDIG Discussion
Thursday 23 November 2006**

Australian Bureau of Statistics (ABS)

External Cause of Death Data Quality – Including Progress on suicide data issues.

- 2005 COD due 30/11/06. Delayed until 14/03/2007 - delay in processing Coronial Cases. Will be released with concurrent paper on “External Causes of Death Data Quality”.
- Increase funding to NCIS to provide individual servers for WA and NSW to reduce backlog of coronial cases. Other states are OK with improved completion times.
- Implemented ‘coding review work groups’ to improve coding quality and consistency. Training modules from the NCHS on “Multiple Cause Coding” completed for all coders.
- Negotiating with RGs for different data supply format to streamline processing.
 - New format with split lines instead of one continuous text string. The intention is to standardise data supply across all RGs.
 - Additional fields to be added and some deleted because they are not utilised. First files have been obtained and all worked well.
- Other changes to COD processing include:
 - New processing system from 2006 data year.
 - Demographic processing improved by identifying duplicates.
 - MMDS – new version implemented.
 - Quality control samples:
 - Particular COD e.g. 10 % recode
 - Horizontal and vertical cuts through data for coder to coder consistency.
 - Update to 2006 version of MMDS in 2006-2007.
 - Study statistical effects of changes of MRG decisions.
 - QA study into morbidity and mortality validation.

Feedback from AMDIG: Discussion on external causes of death and use of MMDS in the United States. The NCHS pays each state for a particular level of quality depending on degree of quasi validation and coding that they do, or do not do, including provision of coronial information; therefore there is incentive for states to provide quality data.

ABS has a much higher level of quality assessment of external cause coding.

- Quality control exercises using comparisons of manual to auto coding and reporting back to NCHS regarding potential quality issues.
- NCHS has developed a “Big Book of Death” - terms used on death certificates; separate column of Australian terms is maintained within the MMDS. ABS has found 140 terms so far that are not used elsewhere other than Australia. Commonly see new “turns of phrase” on coronial records and old terminology is often evident on death certificates.

- ABS has initiated a Suicide Coding Review Group and plans for other external causes to be examined by similar groups.
- Open coronial cases – ABS are currently investigating whether to leave cases as open or uncoded until such time as data is available rather than defaulting to accidental codes. Possibility of separate code for suspected suicides, separate code for open cases.

Feedback from AMDIG: Issue of user's view of data. Concern about how data is perceived and lack of confidence in the data. Consideration should be given to recoding processes to get more realistic figures – need for revised data.

Review of ABS Cause of Death Product suite.

ABS reviews suggest that COD data be released in 2 different ways:

- Ministerial requests and submissions require speedy data release and generally there are no concerns about external causes – primarily natural death groups.
- Other users prefer delay until the data is complete and don't care how late it is released.
- Possible publication of natural causes first and later release of external causes. NZ are considering the same thing.
- 2 separate files or preliminary file versus final UR files; or continue to release year of registration data but update year of occurrence files for 5 years - birth defect register files might be a useful model for this.
- Formal review with significant consultation required. ABS is inviting contact regarding possibilities for review as they are currently shaping ideas.

Discussion: An AMDIG Position Statement is needed to provide co-ordinated feedback. AMDIG strengths are a range of views and ability for considered feedback on system issues affecting data quality and resource considerations. Coronial involvement in AMDIG is also required.

- AMDIG support for three data releases:
 - Non-coronial natural -> least susceptible to change - big public health demand.
 - Coronial natural deaths
 - Coronial cases where the deaths are due to external causes.
- One organisation should be responsible for the update/recode/revision, but this shouldn't occur in isolation.
- ABS and AIHW roles and responsibilities regarding mortality data collection need to be teased out.
- Suicide deaths have system issues and diametrically opposed interests.
 - Coroners and Registrars are reluctant to record word "suicide".
 - Representations have been made to use the word as a statistical marker.
 - Recommendations should be made in light of Statistical Vs Family use and medical practitioners need to agree. Intent recorded as suicide is the only issue.
 - ABS uses flags for specific issues.
 - Suicide Coding Review Group is exploring all options.

Question: Which organisation makes decisions now about suggested coding changes discussed by AMDIG? NIHMG makes decisions about Australian family of classifications.

Discussion: AMDIG attracted by 2 releases per year – Year of registration and causes of death updatable over 5 years.

- Mechanism could be coded early but not intent – use flag or U Code for these to “box” them.
- Acknowledge limitations of intent reporting and the ways it is collected and coded. It may be a phenomenon that can't be analysed at an individual level but only at a population level looking at risk factors etc.
- Users need to be made aware of limitations of intent reporting.
- Coding self inflicted could be collected but remove suicide.
- Possible use of tick box labelled “on the basis of” or “as currently understood”. Some US death certificates include such a tick box to facilitate coding of intent.
- Need standard coronial reporting processes and forms.
- New Zealand does not have the same problems because death reporting and investigation processes are centralised.
- Analysis of differences are required to:
 - Show magnitude of the problem.
 - Attract resources.
 - AMDIG Position Statement for group feedback and then distributed to all key stakeholders and jurisdictions.
 - If changes are proposed to death registration and reporting processes, we need to go through AHMAC, COAR Standards Committee, AGs etc. to get them effected.
 - A consolidated proposal is required.

Progress on ABS and Registrars of Births, Deaths and Marriages discussions – Including proposals by Registrars for a revised Medical Certificate of Cause of Death.

- ABS and RGs have had discussions regarding an MOU to improve data timeliness and address quality issues. 6 Jurisdictions are actively participating, 2 jurisdictions are not actively involved at the moment but will increase efforts in 2007.
- There is no statistical role in legislation for RGs. No funding beyond legislative requirements.
- ABS and RGs have discussed:
 - Revision of MCCD - moves to nationalise the form.
 - Eventual flow on to electronic certification.
 - Electronic data transfer - ABS in initial planning stages. Consultation with key stakeholders and conduct a workshop in 2007.
 - Strengthening the partnership between ABS and RGs.
 - Formalising ABS advice back to RGs.
- New Zealand RG is devolving ownership and administration of the MCCD to present to the New Zealand MOH.

- The Victorian RGs are reviewing their position on what data they will give the ABS due to strict requirements of privacy legislation. Awaiting advice from the Attorney-General. Concerns are mainly regarding births, not deaths.

Discussion: The issue of RGs reporting requirements needs to be raised with the Department of Human Services as this is vital information for the public good.

Meeting closed at 4:48pm EST, to reconvene 9.15am 24 November 2006.

Summary of AMDIG Discussion Friday 24 November 2006

AMDIG Position Statement

Brief discussion about Draft AMDIG Position Statement.

Group agreed the need for a strategy for moving AMDIG activities forward.

- The major issues are systemic.
- We should assume suicide data in the short term will be a difficult issue but ABS primacy acknowledged.
- External resources for ABS should be considered.
 - Consider a business plan with more government appropriation.
 - ABS never goes to Government for additional resources transfers from one department to another.

Reports on ACTION Items from previous minutes

a) Classification of Acts of Terrorism – Feedback from NCIS.

- Acts of terrorism – to be considered for ICD-11 by international colleagues. Might be dealt with by flagging data – ABS have included this in the design of a new system but no plans for how to use it yet. All such cases will go to coroner, who will determine the intent.
- Remove from agenda.

Action: Add information about use of flag as a mechanism for capturing such details to AMDIG Position Statement. Remove as agenda item.

b) New Members of AMDIG

- Tim Driscoll, Private Consultant affiliated with University of Sydney - Uses NCIS extensively, OH&S perspective to his work and interested in biohazards.
- Generally group is happy to accept any members who have an interest. All members need to be self funded for travel etc.

Seek representation from:

- Statistical Information Management Committee (SIMC).
- New Zealand researcher.
- Indigenous representation.

**Action: Draft letter of invitation to: Tim Driscoll
New Zealand researcher
Indigenous representative**

c) Proposal for access and availability of Unit Record Files

- Some RGs have expressed interest in handing over their rights for release to the ABS. Currently 5 jurisdictions have agreed and this will speed up access. Western Australian RG is leading the way.

d) Text based interrogational database

- Remove from agenda.

e) Data issues relevant to rapid reporting and detection

- Overtaken and subsumed by other discussions.
- Remove as agenda item.

f) Purposes and functions of a statistical database for mortality statistics

- The ABS has discussed with RGs a suggestion to create a statistical database and to place it on NDN as a resource. NDN is now being piloted and if successful this idea will be further considered.
- Will need due consideration of privacy and security issues but it is not on agenda until late 2007.
- This may overtake issue re distribution of URFs – See issue c) above.
- Update on NDN
 - Board meeting soon following demonstration phase. Report recommended a need for pilot phase before going live – need more work on access by users and researchers. Nodes will be stored and maintained by custodians but access will be through the NDN. NDN will manage protocols for access.
 - ABS will give presentation about this for next AMDIG meeting. AIHW website has reasonable amount of data available on it – presentation next meeting from AIHW as well.

Action: ABS presentation on NDN at next meeting.

Action: AIHW presentation on NDN at next meeting.

h) Mortality Quality Framework

- ABS suggested using its generic quality framework for assessing quality of mortality data – this has grown into a research project which is becoming bigger to cover all quality issues. ABS to keep AMDIG informed on the continuing development of the framework.
- Submission for last NHMRC research round untimely - but intention to revitalise proposal for next round.

i) Suicide Coding Procedures

- Proposed AMDIG response to MJA article on decline in suicide rates and relevant data issues. Highlight that a lot of work being done in the area now whilst acknowledging data issues. The topical nature of the issue provides an opportunity to explain the process which is not currently well understood.

- Letter will contain:
 1. Cautionary advice
 2. This is how the situation came about.
 3. What is being done about it?

General business

2007 meetings

Mid year meeting June/July 2007

- Mid year meeting to continue in 2007 to feed into ABS strategic planning processes.
- Tie in with another workshop or conference e.g. in Melbourne with NCIS / RGs / Coroners' conference in 2007.
- ABS could provide facilities for a meeting in Melbourne.
- Victorian RG to discuss RG issues.
- Future meeting in New Zealand might be useful.

Mortality Data Workshop 2007 and November meeting

- ISS may not run in 2007 and may be better opportunities for linking with other conferences.
- ABS request to consider time of year because peak processing time. Middle part of year is better or February.
- Midyear meeting in Melbourne in June.
- Next workshop to be held in conjunction with Australia's Health 2008.

Action: ABS, NCIS and NCCH to liaise and make plans.

AMDIG Committee Discussion List

- Increased AMDIG activity highlights need for separate discussion list for AMDIG committee to facilitate activity without getting everyone else involved and to progress work on confidential issues.
- General email discussion group for feedback to general AMDIG Discussion List subscribers.

Update on NCIS Strategic Planning Process

- NCIS has conducted 3 workshops with stakeholders and a major planning day to discuss strategic plan and use of coroners' database.
 - Increased access to data proposed for people who already use it.
 - Key goals are to re-assess quality accuracy, timeliness and international users.
- NCIS has secured an additional 3 years' of funding but no increase in funding level.
 - Require an increase in staff numbers - currently 6.
 - May require relocating out of Victorian Institute of Forensic Medicine.
 - Need for funding of dedicated NCIS coders in coronial jurisdictions.

- NCIS is interested in formal training/ education for coders and possibility of certification to recognise skills.
- National Police Form is coming and is a searchable codeable form. Proposed drug module, based on a Victorian module, due for national roll out.
- Increased access to aggregate mortality statistics
- Increase NCIS research functions.
- Considering placing commonly requested statistics on NCIS web site.
- Other issues being considered include:
 - Use of Geocoding to determine fatality patterns.
 - Automated notification of deaths of interest to researchers.
 - Harmonisation of coronial practices and procedures and recommend best practice to standardise findings.
 - Linkage with other groups e.g. ATSB to continue their fatal crash database.
- Improving backlog and access.
- Mechanism of injury coding delayed because it may change when coronial findings are released.
- Noted need to explain caveats in the data and the population being analysed to avoid misinterpretation.
- Access to New Zealand coronial system.

Other business

Indigenous Statistics Collection: Collaboration with other initiatives

- Jane Freemantle is building collaborations, dealing with the importance of getting good indigenous data. Recent meeting with the ABS resulted in agreement to take this to a higher level such as COAG – increasing and matching data to make it available to researchers.
- Initiatives to improve indigenous statistics are likely to draw funding.
- New Zealand has good statistics on indigenous status with people keen to self identify. Mortality Statistics have benefited by linking data sources.
- New Zealand collections can identify multiple ethnic groups but in death statistics usually only one group is reported.
- In Canada a change in the registration form and a different format is being used to enhance collection of indigenous status.
- Should revisit this issue, especially the ABS work on census enhancement project and Len Smith's "Methodologist Approach". Add to next meeting agendas – important and difficult issue.

Action: Add to agenda for next meeting.

- Suggestion that workshop on the issue would be useful, the ABS are working towards this at the moment.
- Need to put information out into the public domain. Suggested that a non-government forum is needed to act as clearing house to get information out.
- ABS is to engage in a QA activity on indigenous identification next year.
- Registrars report indigenous status of the deceased. WA can also link birth and death data to determine indigenous status.
- There is potential for incorrect indigenous status to be reported on hospital PAS systems.
- In Australia there is a different propensity to report depending on circumstances.

- New Zealand records the source of indigenous identification.
- In Australia we don't know urban/rural differential in indigenous status. Official statistics do not support routine analysis of this.
- ABS are to geocode all births and deaths by usual residence from 2007.

HIMAA Journal Issue – “Mortality Data: The silent witness”

- Back ground provided on upcoming HIMAA Journal editorial “Mortality Data: The silent witness”. Could be a good vehicle on indigenous identification issue.

Future Vision for Mortality Data

- Feedback and follow up from James Harrison's presentation at Understanding Mortality Data Workshop 2006.
<http://www3.fhs.usyd.edu.au/ncchwww/site/downloads/AMDIG/2006MortalityWorkshop/Harrison.pdf>
- Role of AGs Departments in supporting AMDIG initiatives.
 - Problems with public good element of RGs work including funding difficulties hampering ability to support high quality data. Laurie Glanfield, NSW Deputy Attorney General, invited Richard Madden to talk about RG's quality issues.
 - COAR Annual Meeting to discuss issues which the ABS and AIHW attend. There are litanies of people who speak with them. ABS may consider providing resources to support an additional workshop day specifically for ABS issues to ensure sufficient time for issues to be aired. Richard to discuss this with Val Edyvean or Catherine McCahon and arrange meeting with Laurie Glanfield.

AMDIG Position Statement

A proposed “AMDIG Statement” was tabled for discussion and AMDIG considered the following points vital in development of the statement:

- Highlight specific system issues.
 - These are the things that are working well so there is no need to change then.
 - These have current activity that should be encouraged.
 - These areas don't get attention that they require. And this is what we need to do to give them attention.
- Include wider use of resultant statistics for analysis of health status, public health programs, contemporary issues such as indigenous health statistics, suicides etc. that they depend on good statistics and responsibility for this.
- Alternate sources of indigenous identification.
- Statement could be used for more than one purpose:
 - State and federal departments
 - Publications in MJA, for example
 - For granting agencies or for monetary support.
- Utilise the statement as a PR and publication strategy:
 - Website
 - Publications and newsletters
- Important thing is to have AMDIG positions that we stand behind.
- Support for revision of data over time - seems inevitable for quality framework.

- Include thanks to ABS for year of occurrence implementation – this is how revisions are to be done.
- Need topic on indigenous status as we have discussed today. The ABS has an internal paper on their Indigenous data strategy that could be summarised and distributed to AMDIG for information about how ABS is trying to address relevant issues.
- Dispatch to:
 - Government Statistician
 - AIHW Director.
 - Chair of RGs
 - Coroner's people
 - Laurie Glanfield
 - NZ Statistician
 - DoHA – Patricia Faulkner – courtesy briefing
 - NZHIS

Len Smith presentation on Access to mortality data.

There are substantial system issues affecting the quality of mortality data and the roles of key stakeholders, national and state jurisdictions and data users that affect access for legitimate research purposes.

- In the future ABS may take over responsibility for release of RGs data, previously referred back to RGs for approval.
- NT has decided not to allow access to birth URFs due to privacy concerns. Might spread to other registrars in future.
- MOUs with RGs will enshrine decisions in document because the “return to source” is a contravention inconsistent with the census and statistics acts.
- Concerns about future of NDI – will be handled the same way as release of data to other organisations and groups such as cancer registries.
- Health Services Research Organisation has also discussed these issues and desire to develop a process position statement about this. Might be worthwhile to collaborate.
- AIHW and ABS to consolidate their access views but AIHW do not provide UR mortality data to external parties.
- Promote a strategic basis for AMDIG operations.
- Include strengths of current system.
- Include same process for New Zealand – different issues e.g. 2 jurisdictions responsible for mortality data
- Take account of various data collections that can and do feed into mortality system – potential affiliations – quality of these collections.
- Need to describe fundamental principles e.g. Public good aspects, similarities and differences to other data systems, fundamental nature of official statistics. E.g. UN principles of official statistics and national treasure.
- Identify and declare impediments to high quality systems.
- Need to understand inconsistencies in legislation between the states and differences in what can be done where states differ and breaches in privacy legislation.
- Health Industry is significantly lacking in the document.
- NZ has medical referee process for bodies to be cremated – usually a retired doctor.
- All bodies that are referred to Victorian Institute for Forensic Medicine (VIFM) are CT scanned.

Discussion about producing a polished document that can be used for PR.

- ABS paper for State Statistical Forum on vital statistics in Australia – For meeting next February. This paper will be perfect. We should separate out into things that won't change and things that are in a state of flux due to vagaries of different governments, elections etc.
- Need document soon for NHMRC proposal.
- Distribute twice – once for initial run through identify areas where people are working and can write about.
- Need to be fairly forceful so we can have more polished document for finalisation in June.
- Prime motivation to get NHMRC proposal in by late February.

Next meeting.

- June meeting – Lunch time start with presentations and full day for strategic document finalisation.

Meeting ended at 2:31pm.