

Minutes of Discussion on Australasia Mortality Data Interest Group (AMDIG)

Introduction to concept, draft Terms of Reference (ToR) and membership opportunities

Tuesday, 18th November 2003, N518, QUT Kelvin Grove Campus, Brisbane

Facilitator:

Garry Waller- National Centre for Classification in Health (GW)

Discussion panel:

Mrs Sue Walker- National Centre for Classification in Health (SW)

Christine Fowler- New Zealand Health Information Service (CF)

Ron Casey- Australian Bureau of Statistics (RC)

Charles Naylor- Queensland Health Scientific Services (CN)

Paul Jelfs- Australian Institute of Health and Welfare (PJ)

Michael Coghlan- New South Wales Registry of Births, Deaths and Marriages (MC)

Discussion Group:

As per attendance register for Summer School Mortality Data workshop

Introduction:

GW warmly welcomed interested parties present to this inaugural discussion group on the Terms of Reference for the Australasian Mortality Interest Data Group (AMDIG). GW explained the reasons behind the need to establish ToR, membership categories including executive committee membership for AMDIG. ToR were distributed amongst interested parties before the meeting for comment and discussion.

The ToR was subsequently discussed in open forum with comments shown below:

There was some discussion on point 1 of the ToR surrounding establishing methods of communication and information dissemination for the group. Suggestions such as websites, electronic list server, email, bi-annual meetings, workshops, newsletters, bulletin boards and journals were put forward as ways to communicate information. SW commented on the need to make this process as painless as possible for the organisation that takes on the role of coordination. For this reason, she preferred either an internet bulletin board or list serv email group. RC suggested that we should firstly gauge the level of interest in the activities of the AMDIG before making a firm decision. RC stressed that the group will need to discuss different strategies for communication and their effectiveness.

GW asked the assembled group their opinion regarding the holding of an annual meeting for AMDIG. The audience agreed that this would be useful.

CN mentioned that we could also incorporate teleconferencing and videoconferencing technologies into our meetings for participants who are unable to attend in person.

Rosemary Korda wanted to know if we could set-up an answer response service to queries on mortality data. SW explained the current use of the NCCH's Code-L list serv for morbidity coding discussion and how it facilitates the exchange of information between morbidity coders within Australia. Possible similar use but for mortality??

RC mentioned the use of the ABS bulletin board for mortality. Possible expansion??

ToR 2 was explained by SW and GW. There are two aspects to possible international efforts by the AMDIG. One is a support role, to assist countries of the Asia-Pacific region in the development and operation of vital registration systems, data collection and coding methods. GW reiterated that we should consider further international membership and invite people from the region to become members of AMDIG to allow them to get exposure to Australian expertise. For example, GW commented on the need to standardise education with regard to mortality coding and that AMDIG would be perfect forum for a discussion about this.

The second aspect of international work is to provide a mechanism to feed opinions and advice to organisations such as WHO, through its Mortality Reference Group. Sue Walker is Australia's representative on this group, which makes recommendations for changes to the ICD-10 from the point of view of those who use the classification for mortality coding, research and analysis.

There was discussion about the degree of overlap of some of the existing draft TORs and the need to rationalise these into more succinct points. It was agreed that a drafting committee should be established to undertake the redrafting but it was thought that this could wait until after the Executive committee meeting on Thursday in case there are additional points to be added.

Karen asked if the group should be looking towards the development of a journal to publish members' work in the mortality data field. SW mentioned that she believed that these issues should be included in Public Health journals and if not currently to the extent that they could be, maybe AMDIG should advocate this as an important area of public health.

CN discussed the need to include coroners and forensic pathologists in the work on an AMDIG. He mentioned the possibility of contacting the Australian Coroners' Society for membership representation / training advice. CN said we need to beat a path to the door of some key stakeholders regarding contemporary issues such as electronic death certificates etc. Also other 'missing' stakeholders that he believed should be consulted include the Royal Colleges (particularly GPs, surgeons (spec. trauma), Australian Funeral Directors Association (AFDA). MC agreed that the AFDA is an important group to engage.

PJ commented that GPs would be interested in this process especially regarding electronic death certification issues.

Virginia asked if there are any international mortality groups that are similar to AMDIG that we could source. MC asked if NCHS in the US had a mortality group similar to AMDIG. SW said she did not know of any groups like the AMDIG, but would investigate.

RC asked 'who are we to be providing advice?' 'How will / should such advice be provided or used?'

AMDIG should become the voice of the group with expertise in mortality data issues and, as such, should carry weight because of its members' knowledge.

CN mentioned we should be clearing house for information collection and dissemination rather than a closed academic group.

Issues identified from the workshop to date from PJ

- a) Indigenous identifier – need for improvements
- b) Electronic Cause of Death notification – NSW is moving ahead, what about other states and territories?
- c) Supply of multiple cause data in alphabetical order or as supplied on the death certificate? ABS currently supplies the codes in alphabetical order.

- d) Speed of release of mortality data – is it possible to obtain provisional data quicker? Eg monthly?
- e) Death Certification quality, Metadata on death information – need for information about coding systems used, how changes over time are handled and other issues that people become aware of when analysing mortality data
- f) Chronicle development- linked to NHDD processes
- g) Minimum dataset for deaths - SW reported that NCCH has the development of a Minimum Data Set for deaths on its work program
- h) Linking mortality data with other data collections eg hospital morbidity data, cancer data, census data – RC reported that ABS has altered its position on data linkage and is likely to begin linkage work with mortality and census data.
- i) Data exchange between NDI and ABS data??
- j) Publication of deaths by registration year versus year of death
- k) Discussion about event driven versus person driven models of data collection – SW talked about the other health information initiatives such as *HealthConnect* which may impact on the development of birth to death records

The group discussed issues regarding the lack of current data specifications from ABS in particular information regarding what coding systems are available and used in different years of data.

The need for an indigenous representative on AMDIG was also noted. GW mentioned this had been investigated but unfortunately no representative was able to attend this meeting.

John mentioned need to look at how indigenous statistics are compiled in other countries. Can we learn something from overseas?

Further discussion about the need for coronial representation was held. SW explained the precarious position of the National Coroners' Information System and the consequent unavailability of MUNCCI representation at this year's workshop due to budget restraints. Next year?

ABS discontinuing their use of mortality flags was raised as an issue of some concern. It was stressed that issues like this should be brought to AMDIG for discussion of the impact of the decision. RC mentioned reasons why the flags are to be discontinued - additional information is now available in ICD-10 codes, the imposition of extra clerical workload to set the flags, NCIS provides this information. RC stated that a letter had been sent to organisations and individuals known to have used the flags regarding their abolition, but few comments received.

The group discussed future meetings, including the possibility of back-to-back mortality workshop with an Australian Coroners Society conference? Or Registrars-General group to possibly partition their annual meeting to deal specifically with our issues?

MC mentioned work the NSW Registrar is doing re linkage of his state's birth and death databases.

Rosemary asked about membership status for the AMDIG? Levels of membership? Individuals or institution-based?

SW said don't really know yet and may be clearer after Thursday's meeting. She would prefer a relatively informal network but if we are to vote on issues, for example, maybe we need to consider a more formal group with a constitution. Most participants agreed with the less formal group.