

**Minutes of the meeting of the Australasian Mortality Data Interest Group (AMDIG)  
Queensland University of Technology, Victoria Park Rd, Kelvin Grove  
Thursday 20 November 2003, A105 Conference Room, 9am to 12pm**

Meeting Chairperson: Richard Madden, Director AIHW, Canberra. (RM)

Facilitators: Sue Walker (SW), Associate Director NCCH (Brisbane), Garry Waller (GW), Senior Classification Officer, NCCH (Brisbane)

**Participants:**

Ching Choi	Head, Health Division, AIHW (CC)
Chris Gordon	Health Section, ABS (CG)
Ron Casey	Director, Population and Social Branch, ABS (RC)
Brian Oldenburg	Head, School of Public Health, QUT (BO)
Josie Di Donato	Lecturer, School of Public Health, QUT (JDD)
Christine Fowler	Team Leader, Mortality Clinical Coding Systems-NZHS (CF)
Paul Jelfs	Head, Population Health Unit, AIHW (PJ)
James Harrison	Director, RCIS (JH) – via telephone
Michael Coghlan	Manager Registration Services, NSW BD&M (MC)
Alan Lopez	Head, School of Population Health, UQ (AL)
Chalapati Rao	Lecturer, School of Population Health, UQ (CR)
Heather Booth	Coordinator, Population Modelling and Forecasting Network, ANU (HB)
Stephen Begg	Lecturer, School of Population Health, UQ (SB)
Ian Ring	Health Information Centre, QLD Health (IR)
Len Smith	Australian Centre for Population Research, ANU (LS)
Ken Tallis	Head, Resources Division, AIHW (KT)
Gavin Turrell	Centre for Health Research, School of Public Health, QUT (GT)
Andrew Klisanin	Senior Research Assistant, NCCH (Minute Taker)

**Apologies:**

Charles Naylor	Chief Forensic Pathologist, QLD Health Scientific Services
Tony Barnes	CEO, CRC Aboriginal Health
Trevor Stacey	Registrar, NSW BD&M, Chair BDMOz
Ian Burnley	Professor of Geography, UNSW

**1. Welcome and introduction**

RM warmly welcomed everyone to this meeting of the Australasian Mortality Data Interest Group (AMDIG). RM explained that he was chairing this meeting due to the AIHW's interest in mortality data, and to assist the facilitators (SW and GW). Participants were asked to briefly introduce themselves and to indicate their interest in mortality data.

RM inquired about the absence of a representative from the Monash University National Centre for Coronial Information (MUNCCI). GW commented that he had contacted MUNCCI for a representative to attend the Summer School this year and to be part of this meeting but due to limited resources and staffing issues they were unable to send anyone. JH said that he would be willing to relay any messages to MUNCCI from the committee.

RM especially welcomed New Zealand's representation on AMDIG with the presence of Christine Fowler from the New Zealand Health Information Service.

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RM was confident that AMDIG would be an important vehicle in addressing understanding and use of mortality data within the Australasian region. An overall comment was made that generally the quality of mortality data in Australia and New Zealand is good and that there is an organised approach to the creation of data and statistics, but that mortality data is generally underutilised and under-resourced. RM also commented on the gradual focus of mortality expertise in Queensland over the last 10 years with the location of NCCH Brisbane, ABS Causes of Death Unit, research into mortality at QUT and UQ, arrival of Alan Lopez and colleagues from WHO etc. It is appropriate then to hold discussions in Queensland, following the workshop examining mortality issues conducted as part of the 2003 International Health Summer School at QUT.

RM also commented on the representation of people from the ACT, QLD, NSW, SA and NZ but not from VIC, TAS, WA, NT or from other areas in the region eg PNG, Indonesia and Malaysia. Should we look at encouraging people from these areas to contribute?

## **2. Background to AMDIG**

GW explained the concept of the mortality data workshops held in 2002 and 2003 and described the initial call to establish a mortality data interest group after last year's workshop. GW went on to explain progress to date including an initial teleconference meeting earlier in 2003 and discussions and feedback about the Terms of Reference during this year's workshop. GW noted the general feeling of participants at the Summer School as enthusiastic about the creation of a forum to discuss mortality data issues. Delegates provided a number of key issues regarding mortality data which are summarised in the notes of the discussion session (see attachment 1).

## **3. General discussion**

JH mentioned that the group assembled today are 'a heavy bunch' and would be beneficial in establishing a workable group and implementing a relevant work program.

RM explained his vision of the two possible purposes of AMDIG, the first of these being to provide leadership and advocacy and the second to provide technical expertise. RC asked what the status of the group will be – formal or informal? He sees a need for influencing people who are responsible for the collection and processing of data. For example, discussions at the Summer School highlighted the lack of knowledge of participants about the existence of the Mortality Reference Group. Ron sees the AMDIG as providing expertise to comment on recommendations for change to international classifications.

LS noted the importance of improving accessibility to mortality data for users, especially for students doing research. He stressed specifically the cost (sometimes up to \$50K) of accessing unit record mortality data, compounded with the issues of confidentiality / privacy which can cause major heartache for individuals and institutions without adequate funding or without contacts with agencies such as ABS etc. He envisioned AMDIG would have some influence in addressing such issues.

AL agreed noting the need for a critical mass to support use of mortality data. He described WHO work on comparative risk assessment using a standard framework for risk factors – he felt that there is scope for similar work to be conducted in Australia. He sees the AMDIG group having a role in increasing the analytical agenda for Australia's mortality data, with an intellectual role as well as a role in relation to data issues.

JH commented that maybe AMDIG should be split into two levels a) formal academic consultative committee b) informal referencing and information dissemination group.

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CC agreed with the general analytical framework, but also linking traditional mortality and trend analyses to risk factors with the aim of linking to Australian government policies.

RM commented on WHO framework for identification of avoidable deaths, which has policy relevance but has not been pursued in the Australian context. IR indicated that this is an area of interest to the National Health Performance Committee and definitely something this group could contribute to.

Indigenous mortality data quality issues were raised by IR and a number of other participants as being relevant to the AMDIG. These are issues with considerable policy relevance and central public health importance. The subject is complex and will be more complex as time goes by, but essential for AMDIG to get involved and foster linkage with Indigenous groups.

JH suggested that the CRC for Aboriginal Health may be an important collaborator. GW commented he contacted Joan Cunningham from the Menzies School of Health Research initially, and subsequently Professor Tony Barnes, CEO of CRCATH, but neither was able to attend. JH is going to CRCATH convocation next week and indicated that he would be happy to pass on information from this meeting.

GT noted that one of the issues regarding use of mortality data is the lack of analytical capacity and a skill base in Australia. He sees that the group could advocate for improvements in this area. CR extended this thought to give it a regional focus and suggested that the group could promote capacity building for analysis as well as data collection and processing. SW agreed that, in her experiences overseas, these latter are necessary as many countries do not have effective vital registration systems. She also sees the group as providing expertise to assist her in her role as Australia's representative on the WHO Mortality Reference Group.

PJ believes that AMDIG needs to be a clearinghouse for information regarding mortality and promoted as such. There is a need for clear communication and direction for information flow.

AL noted that this group has a true opportunity to influence the way mortality data is collected and used in Australasia. There is the potential for the group, or members of it, to be contracted to undertake policy or analytical research. As an example, he suggested that the analysis published as part of a recent intergenerational report was a bit 'light-on' but agreed that this was a budget report and should be read in that context. He indicated that a challenge for the AMDIG is to ensure that when the next report is produced in 2007, the required data is available and is of high quality. RC agreed with AL. He sees the value of AMDIG in providing one consolidated voice on important issues, rather than people working as individuals. The ABS would see the value in using the group for feedback and comments.

HB believes that the value of the AMDIG is unquestionable but is somewhat sceptical of the degree of influence that AMDIG may have in government departments to work together.

JH stressed the importance of running a meeting back to back with a relevant event as a good way to disseminate information. He suggested that there would be benefits to attaching any AMDIG meeting to another meeting or conference that drew people with an interest in mortality data and research eg registrars' conference, summer school

LS asked about the National Death Index as a resource for the research community. RM noted that the NDI is low cost and available, although access to it is governed by the AIHW ethics committee. CC noted that the majority of costs involved in accessing the data are related to the ethics approval process. He believes that use of the NDI should be promoted more widely. RM then spoke about issues relating to access to data and highlighted the development of the GRIM books by the AIHW.

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PJ outlined this development which includes 150 workbooks for various diseases and disease groups containing mortality information as far back as 1907 for age and sex groups.

LS commented also on the importance of improved access to unit record data by researchers to facilitate better usage for research activities. Access issues such as increases in cost and confidentiality restraints need to be considered. He outlined development of a demographic databank at the ANU, which will complement the GRIM books. It will contain detailed data at state level for individual ages back to 1901, although there are plans to include data back to the 1800s in the future. LS sees this as a significant historical resource.

RM explained while he didn't want to go into pricing policies here today, he acknowledged these were important points of discussion for the future. He also noted the climate of healthy competition between the ABS and the AIHW.

There was general discussion about the 'function and form' of AMDIG. GW stressed that the group should be multi-faceted and address policy, analytical and general issues impacting on mortality data. GW encouraged suggestions for the structure of AMDIG, emphasising that the need to carefully look at the way we disseminate information (eg newsletters, list server, bulletin board). RC offered the ABS Bulletin Board as an option for the dissemination and communication for general membership of the AMDIG.

JDD suggested that profiling AMDIG is important, but promoting the benefits of mortality data generally and how it can inform other disease-based initiatives within Australia are also necessary. CR briefly spoke of the importance of the descriptive power of multiple cause mortality data. CC agreed that, although multiple cause data has been available since 1997, it has not been utilised as much as anticipated to date, especially for prevention purposes. It may be necessary to develop a 'pool' of experts to assist researchers utilising mortality data. SW mentioned that the Summer School workshop participants had identified a general lack of understanding and access to analytical tools for multiple cause data. The use of AUSTATS and Supertable were mentioned, however RC noted that only underlying cause data is available in these tools.

GW explained the importance of workshops / seminars to assist in getting people together to discuss issues and identify future activities. SW noted that there is a sometimes-mooted perception that mortality data is of poor quality and this needs to be dispelled by AMDIG activities. Of particular importance is educating clinicians about the significance of the information that they provide on death certificates.

The form that AMDIG should take and the importance of the ToR were discussed. IR said that in his view there are 4-5 central issues for AMDIG:

- direct international links regarding applications/use/methods
- access issues are fundamental
- need to foster use and application of mortality data, although not in a vacuum
- methodological and data issues
- development of a series of topics of particular interest eg indigenous mortality.

After discussion, further points were added:

- dissemination of activities of the group
  - user and provider issues and their relationship to quality
  - capacity building
  - more routine linkage with other statistical collections, as already happens in New Zealand. LS asked about improvements in the linkage of mortality data with hospital data. CF commented that New Zealand currently do this and also noted their linkage of birth data to
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mortality data. RC commented that the ABS is currently exploring the possibility of linking different data series between ABS collections, with the expectation it will later expand to include linkages from non-ABS sources. It was stated that this is a window of opportunity which should be grabbed and exploited.

The group discussed a framework of areas of interest to guide the work of the AMDIG – see attachment 3.

PJ reported on issues raised by participants during the mortality workshop and discussed the revised Terms of Reference (see attachment 2). The participants assigned each point to areas of common interest identified in the proposed AMDIG framework. RM explained the need to include ‘communication’ in the framework rather than ‘dissemination’ or a ‘clearinghouse’ function for mortality information. RM encouraged feedback from other countries in the region (eg New Zealand) for other potential issues to be included in the framework. Membership should be open to these other countries as well.

There was general consensus by the group that for AMDIG to survive and prosper there is a need to be seen to be doing things. CF commented that everyone gathered here today wanted to see the organisation survive and would support it. RM mentioned that he was keen to see the AIHW involved with AMDIG and to see it grow.

CF enquired whether the Funeral Directors’ Association has been approached to become a member of AMDIG. MC believed that the Australian Funeral Directors’ Association would be interested due to their close working relationship with the state Registrars. SW also mentioned the possibility of including the Australian Coroners’ Society.

The group discussed organisational issues for AMDIG. What form should the group take? Should there be an executive committee and a discussion group committee? GW commented that a part of the group may act at a ‘high level’ regarding policy issues. The key is to ensure that the ‘discussion group’ members are able to also comment on these issues.

SW saw this as a two way street with advocacy and policy work on one side together with the identification of issues by the users on the other. Communication forms the bridge between the two. RM said that he believed that a partition of AMDIG into executive and discussion group components would be unfruitful and concluded that advocacy would be more beneficial if we remained one group, perhaps with a smaller ‘leadership’ group. RM agreed that our framework should be broad enough to encourage all users of mortality data to participate. If there are particular policy issues to be considered, this might be facilitated through smaller groups with individuals with specific interests leading each group. CC noted the need for a mechanism to advocate issues both formally and informally, possibly also the need for a formal structure for the group. RC thought that the group needs to have some ‘status’ whatever the communication mechanisms. The leadership group could be used to provide authoritative advice and to advocate on issues raised by other members. There is a need to have contact lists for group members available so that existing expertise can be accessed.

BO noted that he felt the work of the group will evolve over time, and that the important thing is to identify particular work to take forward now and see what eventuates. BO questioned whether AMDIG is an organisation of interested (independent) individuals who use mortality data or an organisation that has members who represent their respective jurisdictions? RM commented that he was happy to write to each organisation represented at this meeting to seek formal representation on AMDIG. JH enquired whether we should incorporate a secretariat position into the framework. RM said that the NCCH (Brisbane) is currently doing an excellent job fulfilling this role and that he

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would like to see this continue with the assistance of the AIHW and ABS. He agreed to continue as Chair of the group although expected that an independent Chair may eventually 'fall out' of the AMDIG's work program. LS asked if there are actuaries who might also be interested in the AMDIG's work.

The group discussed the name of the AMDIG and agreed that it is appropriate.

#### **4. Other issues**

BO mentioned that the Asia-Pacific Academic Consortium for Public Health (APACPH) will be holding its 2004 conference in Brisbane from 29 November – 3 December and that this will take the place of the Summer School. The theme of the conference is 'Public Health Networks and Alliances - Building Capacity in the Asia-Pacific Region.' BO invited participants to the conference and said that it would possibly be a good opportunity for AMDIG to 'piggy back' an event onto this conference.

PJ and RC discussed the imminent release of ABS' 2002 mortality data. RC said that this was a little overdue, but was confident that a PDF file would appear on the web soon. Once this has occurred, unit record data will also be available.

JH noted that he had a discussion paper regarding the sharing of data between the National Coroners' Information System and ABS which he will circulate to interested members for comments. He also noted that he will discuss the AMDIG at the CRCATH meeting in the next week.

#### **5. Closure of the meeting**

RM thanked all for their interest in the establishment of the AMDIG and their attendance at this meeting. He suggested that if any participants have ideas about other individual or groups who should be invited to participate, that they should send a message to Sue Walker or Garry Waller. The meeting was closed at 11:45am.

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## **Attachment 1**

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

**Introduction to concept, draft Terms of Reference (ToR) and membership opportunities  
Tuesday, 18<sup>th</sup> November 2003, N518, QUT Kelvin Grove Campus, Brisbane**

#### **Facilitator:**

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

#### **Discussion Panel:**

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 were 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, e-mail, 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 e-mail 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??

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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
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- 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 vs 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.

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## Attachment 2

### **Australasian Mortality Data Interest Group (AMDIG) SECOND DRAFT Terms of Reference (TOR) 19 November 2003**

This committee meets annually on a face to face basis and at other times by teleconference as required. Its overall function is to facilitate information sharing relating to the collection, collation, coding, dissemination and analysis of causes of death data in Australia, New Zealand and potentially within the Asia-Pacific region.

#### **SECOND DRAFT Terms of reference:**

##### **Communication**

- Provide a forum for exchanging mortality information issues for users and information managers.
- Provide a link between local mortality information issues and international developments.

##### **Technical discussion**

- Provide advice to managers *and users* of mortality information on technical standards related to data collection, analysis and reporting.

##### **Policy discussion**

- Provide advice to managers of mortality information on policy and procedures.
- Promote the scope, coverage and quality of mortality information.

##### **Communication Mechanisms**

Meetings

Newsletters

Bulletin Boards

List Servers

Web sites

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## **Attachment 3**

### **Draft Framework for AMDIG activities**

#### *1. Capacity building*

#### *2. Access*

- speed of release of mortality data
- publication of deaths by registration year versus year of death

#### *3. Uses of mortality data*

- linkage
  - event driven vs. person driven models of data collection
  - linking mortality data with other data collections eg hospital morbidity data, cancer data, census data
- avoidable deaths and risk factors
- indigenous issues
  - indigenous identifier
- projections
- multiple causes of death
  - supply of multiple cause data in alphabetical order or as supplied on the death certificate
- policy applications

#### *4. Quality*

- electronic Cause of Death notification
- death certification quality
- metadata on death information
- minimum dataset for deaths
- data exchange between NDI and ABS data
- publication of deaths by registration year versus year of death
- discussion about event driven vs. person driven models of data collection
- classification issues
- main players – identification and engagement

#### *5. Methodology*

- Chronicle development- linked to NHDD processes
- multiple causes of death

#### *6. Communication*

- dissemination
- clearing house

#### *7. International collaboration*

- education
- capacity building
- linkage and comparisons
- expert advice
- classification issues

#### *8. Advocacy*

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