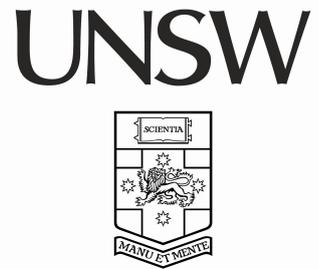




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The Australian and New Zealand Stillbirth Alliance (**ANZSA**), the Perinatal Society of Australia and New Zealand Perinatal Mortality Group (**PSANZ PMG**) and the Australian Institute of Health and Welfare (**AIHW**) National Perinatal Statistics Unit (**NPSU**) presents a half-day meeting into:

Perinatal Mortality Audit Data Collection in Australia and New Zealand

Thursday 11th December 2008

MEETING NOTES

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Robyn Kennare Prof Yee Khong	Government of South Australia Women's and Children's Hospital ANZSA Research Committee Chair/Regional Coordinator - SA
TAS	
Dr Amanda Dennis (via teleconference)	Perinatal Mortality and Morbidity Subcommittee of the Council of Obstetric and Paediatric Mortality and Morbidity ANZSA Regional Coordinator - TAS
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1.0 EXECUTIVE SUMMARY

The purpose of the Meeting was:

To reach consensus on perinatal mortality data collection for clinical audit in Australia and New Zealand by reviewing the data collection form as recommended in the Perinatal Society of Australia and New Zealand (PSANZ) guidelines, with an emphasis at this stage on what data are to be collected and not how they are collected.

Summaries of presentations showed that :

A survey of midwives and doctors in Australia and New Zealand showed

- Poor awareness of the PSANZ Guidelines (55 % midwives; 28% doctors)
- Moderate use of the PSANZ classification system was used when conducting hospital perinatal mortality review (60%)
- Less than optimal uptake of guidelines

Uptake of the PSANZ Perinatal Mortality Audit Guidelines:

- Of the nine regions in the survey, four had produced reports on perinatal deaths according to the PSANZ Perinatal Death and Neonatal Death Classification
- Perinatal autopsy rates in eight regions ranged from 61.2% to 30.1%; the majority reported rates of 40% or less.

New Zealand experience

- A multidisciplinary committee, established under an Act at Cabinet level, reviews and classifies all perinatal deaths using PSANZ Perinatal Death and Neonatal Death Classification and, for international comparison, CEMACH mortality definition. The committee reports to the Health Minister.
- The support of key stakeholders and government was essential for establishing the committee and securing funding for a sustainable committee.

Classification systems

- There is no perfect classification system. Problems are inherent and specific to perinatal mortality.

Current processes for national reporting of perinatal deaths

- The purpose of NPSU is to undertake national perinatal data collection and reporting. This requires State and Territory, professional and clinical stakeholder support.

Conclusions:

- A systematic approach to implementation of the guidelines and providing support and advice to users is required
- A high autopsy rate together with a high quality autopsy performed by specialists in perinatal pathology underpins accurate classification of stillbirths. The PSANZ Perinatal Death and Neonatal Death Classification should be uniformly applied in all states and territories, even if other classifications are additionally used.
- Continual refinement to the classification system is accepted as necessary.
- There was agreement on the data fields to be collected and the need for a nationally-agreed form.
- The NPSU is a good repository for the data and close relationship between ANZSA and NPSU is essential for its success.

2.0 MEETING SUMMARY

Session One: Current status of perinatal mortality review

(David Ellwood, Vicki Flenady and Yee Khong)

2.1 Introduction and welcome

David Ellwood (ANZSA Chair)

Purpose of Meeting:

To reach consensus on perinatal mortality data collection for clinical audit in Australia and New Zealand by reviewing the data collection form as recommended in the Perinatal Society of Australia and New Zealand (PSANZ) guidelines.

The emphasis here lies in what is collected and not how it is collected. This will be explored at a later date, after a consensus has been achieved.

David reminded the participants that ANZSA has announced a call for Research Committee and Board Nominations.

2.2 PSANZ Guideline recommendations and experience

Yee Khong (ANZSA Research Committee Chair)

2.2.1 Purpose of the PSANZ Guidelines:

The PSANZ Guidelines came out through the PSANZ Perinatal Mortality Group in 2006. They were developed to create a systematic approach to the investigation and audit of perinatal deaths across Australia and New Zealand

In order for the guidelines serve their purpose, five factors that must be considered:

- Implementation of the guidelines
- Perinatal mortality review committees
- Review of perinatal committees
- Data collection, documentation and reporting
- Communication and feedback – in order to implement and review there needs to be feedback

2.2.2 Uptake of the PSANZ Perinatal Mortality Audit Guidelines: A survey of midwives and doctors in Australia and New Zealand

A telephone survey of hospitals providing maternity care in Australia and New Zealand with <1000 births/year. There were 79 eligible hospitals.

Results

- 12 hospitals declined leaving 67 hospitals to survey (119 staff completed survey: 64 midwives & 55 doctors)

- 35% of respondents said they were aware of the PSANZ Guidelines (55 % midwives; 28% doctors)
- 80% of doctors and 60% of midwives surveyed attended meetings which reviewed cases of stillbirth and neonatal death
- 50% of doctors and 30% of midwives surveyed said they did not receive feedback from perinatal mortality meetings
- 60% of respondents indicated that the PSANZ classification system was used when conducting hospital perinatal mortality review.

2.2.3 Discussion Points

- Less than optimal uptake of guidelines
- Hospitals might not be aware of the guidelines
- There is potential for version confusion.
- The large nature of the document may mean it is more desirable to have the main document for reference and an additional supplementary working policy document which is more user-friendly/accessible.
- There is an assumption that people who are given the guidelines will encourage their use, resulting in a trickle down affect. Some suggested this is not always the case.

2.2.4 Conclusions

A systematic approach to implementation of the guidelines and providing support and advice to users is required

2.3 Perinatal Mortality review practices in Australia and New Zealand *Vicki Flenady (Secretary)*

2.3.1 Survey Summary

In preparation for this meeting, each state and territory perinatal committee chair in Australia and New Zealand completed a questionnaire on their region's perinatal mortality practices.

Of the nine regions in the survey, four had produced reports on perinatal deaths according to the PSANZ Perinatal Death and Neonatal Death Classification up to the year 2006 (by date of birth); two up to 2005, one to 2004 and one to 2003. One State applies Whitfield in addition to the PSANZ Classifications.

One state has not yet commenced reporting deaths according to PSANZ PDC and one State has stopped doing so (last State report published in 2005).

Perinatal autopsy rates were reported by eight regions with rates ranging from 61.2% to 30.1%. The majority reported rates of 40% or less.

Five regions provided autopsy rates for stillbirths or neonatal deaths separately. The highest reported stillbirth autopsy rate was 69.7% and the lowest 30.7% with three of the five reporting rates of 41.6% or lower.

Of the five regions reporting autopsy rates for neonatal deaths, rates were generally lower than for stillbirths; four regions reported rates of less than 34% with the lowest 24.7%.

The majority reported that all perinatal deaths are reviewed and classified by a multidisciplinary team (6 of 9). One region was unsure and a further two reported that this was not undertaken. (NB one of these regions did so for the majority of deaths).

Hospital committees undertook classification in some centres across six regions. In five of these regions, the health departments accepted these classifications and two undertook routine quality assurance activities to check the quality of these data. One committee reported a routine feedback mechanism on the results of this QA activity.

In three regions, the PSANZ Perinatal Mortality Guidelines had been circulated to maternity hospitals and four regions had undertaken some form of educational activity about the use of the guidelines.

New Zealand had a systematic approach which is unequalled in Australia.

2.3.2 Discussion points

A. Classification

SA experience: Still uses Whitfield classification (along with PSANZ PDC and PSANZ PNC) due to requests for historical data.

- Will continue with a dual classification system as is good to map data.

Should classification be done centrally, at a state level, or at a regional level?

- Preference is at the local hospital committee review with those smaller hospitals feeding into a regional committee where there is more expertise.

WA experience: Adrian Charles said paediatrician and obstetrics go through notes with a multidisciplinary team of 12 for every death. This means every case is reviewed by the same committee.

B. Autopsy

NSW: Bill Walters highlighted the importance of autopsy and the importance of expertise by those performing autopsy due to likelihood of difficult cases.

NSW Committee is concerned about the difficulty in performing autopsy as there are only a few pathologists across ANZ who have the experience to do this. It was suggested that there is coordination of these pathologists, with central centres around ANZ which are a place to conduct autopsy.

There are problems with logistics, cost and pathologist time.

David Ellwood: We need to consider the optimal rate of autopsy. Would it be better to look at an autopsy rate by presenting scenarios? Are autopsies being undertaken for important cases?

Vicki Flenady: Communication between clinician and patient is often suboptimal. We need to ensure parents are getting adequate information about autopsy to make an informed choice.

C. Funding for Autopsy

SA (Yee Khong): Centralised services require funding. The DOHA have not looked kindly at a centralised system. In terms of a data record, there is no agreement across the nation. We need a national approach to autopsy before we can collectively go to the government.

Jeremy Oates: Victoria has centralised funding for autopsy. It is important that if autopsy takes place it is done to the best standards. If standard is sub optimal it is not worth it.

Heather Jeffery: An Australia wide approach to autopsy is necessary.

D. Role of the Coroner

How long does it take for the Coroner to make a decision? Although autopsy is mandatory, results may not be returned for a year.

What expertise does the Coroner have?

Are the communication channels open enough?

All perinatal deaths can not be expected to be reported to the Coroner.

9:54 am: Amanda Dennis joined meeting via teleconference

ACT: the Coroner is not interested in all perinatal cases

NZ: In NZ baby's body is transported to one of four separate cities. Parents do not seem to mind the baby being transported.

NSW: Susan Arbuckle is taking the majority of autopsies in NSW which are sent back within a day or two.

VIC: unexpected deaths

Sympathetic response to all parties

Abide changed laws

A national approach should adhere to the modifiable review of the Coroners Review

TAS: There was a case in TAS where the ANE had no contact and the baby's body was taken to the police before an autopsy could be made.

2.3.3 Conclusions

A high autopsy rate together with a high quality autopsy performed by specialists in perinatal pathology underpins accurate classification of stillbirths.

The PSANZ Perinatal Death and Neonatal Death Classification should be uniformly applied in all states and territories, even if other classifications are additionally used.

2.4 New Zealand experience

Cindy Farquhar

2.4.1 Summary of Presentation

In 2004 there were 55 000 births in NZ with 441 stillbirths. There were 144 in-hospital neonatal deaths. These numbers do not account for out-of-hospital births or deaths.

The New Zealand approach to perinatal mortality is drawn closely from PSANZ Guidelines. The Perinatal Maternal and Mortality Review Council (PMMRC) was established in 2005 following the publication of 4 reports during the 2000 – 2004 period (Maternity and Newborn Information System, National Minimum Discharge, Maternity claims and Birth and death certificates). These helped develop the administrative data set.

This review committee was set up in 2005 under the New Zealand Public Health and Disability Act 2000. The 10 members of the PMMRC were appointed by the Minister of Health. Committee members are from midwifery, nursing, obstetrics, paediatrics, pathology, anaesthetics, consumers, as well as Māori and Pacific communities. As a multidisciplinary committee, it was established under an Act at Cabinet level, which was/is obliged to report to the Health Minister. The PMMRC developed strategic plans with quality assurance apart of the funding agreement.

The development of the NZ PMMRC required much consultation. In 2003 the Ministry of Health sought the views of stakeholders on the need for a national maternal and perinatal mortality review committee.

Stakeholders consulted included consumers, health professionals and providers, coroners, government and non governmental organisation. The election of a NZ Green/Labor coalition in 1999 saw a government which supported maternity and child care.

New Zealand is split into 21 District Health Boards - each appointing a local coordinator in 2006. While eight were initially holding a perinatal review, all 21 are now.

A national database has been created with a data entry website and a storage database. Information feeds into this database from BDM, Ministry of Health, Coroner, Ministry of Transport, and Ministry of Justice.

At a local level individuals must complete the PSANZ data collection form, which allows for the strengthening of local and national processes at the same time. Data collected includes Mother and Baby forms and the National and local coordinators ensure complete coverage of all deaths. After local Perinatal Mortality Meeting, the PMMRC Local Coordinators and a multidisciplinary team review the deaths.

Information collected includes the mother's age, ethnicity, height, weight, previous medical history, previous obstetric history and details of this pregnancy and delivery; the baby's ethnicity, gestation, weight, stillbirth or neonatal death, neonatal procedures; comments; post mortem and histology reports; and from 2009 the avoidable factors

PMMRC Classification is completed using the PSANZ Classification system for perinatal death and avoidable factors. Classification is submitted to the PMMRC along with post mortem and histology reports. An audit of notes for accuracy of classifications showed between 6 and 10 per cent incorrect classifications

The guidelines were piloted for six months. Information provided in the data collection forms is strictly confidential. If people do not abide by this the legislation allows for a \$10 000 fine.

NZ uses the PSANZ perinatal mortality definition. International comparisons are made using this and the CEMACH definition of perinatal mortality.

Information leaflets on information for parents about post mortem are disseminated by the PMMRC.

Recommendations:

- Ministry of Health Secretariat
- National coordinator– this *key* person provides support to local coordinators and lead maternity carers
- Communication is important – publish a regular newsletter

- Hold national workshops for local coordinators and teleconferences

2.4.2 Discussion points

NZ: This is new ground with a lot of feedback. There is general lack of consensus in approach for perinatal mortality review and reporting. Getting legal advice is necessary.

- There are legal ramifications of sharing information which are largely overcome by agents of committee
- Sudden deaths are reviewed by the Coroner

What funding is required to sustain a national committee in New Zealand?

- Approximately \$1 million in the set up year.
- Then there are coordinators, main coordination, child and youth worker costs and secretariat support costs
- There is no payment for the local coordinators.
- Each District Health Board has a local coordinator which requires 1/10th of time (where there are 150 deaths per year)
- Administrative person is ½ of the their time
- Clerical support = 2-3/10th

2.5 Classification

Adrian Charles

2.5.1 Discussion points

There is no perfect classification system. Problems are inherent and specific to perinatal mortality. Once we understand that these problems will always exist, it will help us understand and think of solutions

Other problems include:

- Time
- Audience
- Multidimensional (comparisons of different causes)
- The more available categories the better but the more difficult it becomes if there is not enough expertise
- There is a degree of interpretation
- Often not a single cause of death
- Legal and medical constraints

Improvements lie with:

- Multidisciplinary nature of committees
- Train classifiers better
- Minimum data set
- Capture relevant information
- Flag important potential risk factors (IVF, maternal obesity etc)

2.5.2 Recommendations

- 1) Send out training cases to teams
- 2) Algorithms for problematic cases may be helpful
- 3) Selective review
- 4) Data on positive/negative return of consent is still needed as well as unexplained pregnancies

2.6 Current processes for national reporting of perinatal deaths

Elizabeth Sullivan

2.6.1 Discussion Points

A core purpose of NPSU is to maintain the national perinatal data collection and to undertake national reporting of pregnancy and birth outcomes. This requires State and Territory support and provision of data; and professional and clinical stakeholder consultation and engagement.

NPSU has requested that induced abortions are flagged (identifying whether a death is a stillbirth or an induced abortion most relevant for gestations 20 – 24 weeks) in the data set. The provision of this data varies by jurisdiction.

When reviewing the reporting of perinatal deaths at the national level. We need to ask the following questions:

1. What information is currently being collected and supplied?
2. How is the information being collected?
3. What new information needs to be collected and supplied?
4. On what data sets and where is the information stored?

Current reporting of Perinatal Mortality Data

1. Variability in scope of data classified by jurisdiction impacts on utility of data
 - Congenital anomaly (issue for 22 weeks): NSW did not report
 - Maternal conditions (issue in comprehensiveness of data): 19.4% (VIC) vs. 4.8% (WA)
 - Unexplained antenatal death: consistent
 - 32-36 weeks
 - Congenital abnormality
 - Spontaneous preterm
 - Less than 20 weeks
 - Maternal conditions

Jeremy Oats: We need to get agreement on specific areas on which to focus eg late gestation deaths - funding bodies may be supportive of this approach.

Engagement mechanism

- Meeting of mandatory conditions all result from a bottom up approach.
- Consultation of stakeholders is very important when trying to get a consensus on classification and reporting
NPSU has included reporting of PSANZ classification.
However unit record data not available nationally for reporting.
PSANZ classification is a public health classification.

Bill Walters: We provide information and never hear any feedback
Need educational arm feeding back to improve quality care
Response: we are not here to fund that

2.6.2 Recommendations

Inform leaders in terms of implementation

The New Zealand model is highly effective. The problem in Australia is the sustainability issue (100 deaths vs. 500 deaths).

There is an annual meeting to explore reporting methods. In light of this annual meeting NPSU will now:

- Review perinatal reporting within Australia's Mothers and Babies
- Ad-hoc okay but we need a central group to oversee maternal and perinatal morbidity and mortality

Session Two: consensus on data collection for perinatal audit

(Lesley McCowan, Vicki Flenady, Yee Khong)

2.7 Consensus on data collection for perinatal audit

Facilitated by Lesley McCowan, Vicki Flenady and Yee Khong, the basis of this discussion was to compare the NZ form and the PSANZ form against each other aiming to reach consensus.

2.7.1 Purpose:

To come as far as we can in gaining a consensus on data collection for perinatal audit

Current Situation:

- There are 9 perinatal mortality data collection forms. Two of these are similar and comprehensive (PSANZ and NZ)
- NZ has been tested
- PSANZ has not

2.7.2 Wrap Up and recommendations

Yee Khong

- To establish a common data form which is user friendly (aim for a web based form).
- Time frame: aim for this group to re-convene before the PSANZ Annual Congress scheduled for April 2009 in Darwin – with further discussions at the Congress
- To create an email forum
- Identify funding opportunities
- Legal considerations
- National Committees

A document outlining the data Items that were agreed on will be circulated in early 2009.

- There was agreement on one form
- There was agreement on the data fields
- It was suggested that NPSU is a good place to have as a repository and that we must make sure we continue to have a favourable relationship with NPSU.