

**National Perinatal Statistics Unit and
National Perinatal Data Development Committee
Business rules for data development**

The National Perinatal Statistics Unit (NPSU)

The NPSU is Australia's national agency for perinatal health, statistics and information. It was established in 1979. It is a collaborating unit of the Australian Institute of Health and Welfare and is currently based at the University of New South Wales and located at the Sydney Children's Hospital.

The main objectives of the NPSU are to:

- coordinate, monitor and interpret national data in reproductive and perinatal morbidity and mortality;
- provide a reproductive and perinatal epidemiology service;
- conduct epidemiological research;
- enhance national reproductive and perinatal health data systems; and
- publish national reports on reproductive and perinatal health which cover pregnancy outcomes, maternal morbidity and mortality, assisted reproduction and birth defects.

The NPSU is the source organisation for the Perinatal National Minimum Data Set (NMDS), a core set of data elements agreed to be collected by States and Territories for mandatory collection and reporting at a national level. The Perinatal NMDS is core to the business of the NPSU.

The National Perinatal Data Development Committee (NPDDC)

The NPDDC is a committee of the NPSU. The principal role of the NPDDC is to provide an expert forum to review existing perinatal data elements and ensure new and proposed data elements are clinically meaningful and congruent with national and international data standards.

The role of the Committee is to:

- provide expert technical advice on perinatal data and statistics;
- review and recommend perinatal data elements for inclusion, modification or deletion in the National Health Data Dictionary (NHDD) or Perinatal National Minimum Data Set through the National Health Information and Technology governance process;
- advise the NPSU on State and Territory data collection processes and instructions relating to perinatal health;
- facilitate and report on the testing or trial of draft perinatal data elements in the respective jurisdictions of committee members;
- provide advice on the costs and timing of implementing proposed perinatal data elements for national reporting, including the capacity and preparedness of the States, Territories and other relevant bodies/agencies to collect and provide these data to the NPSU;

- advise on the content and structure of the annual report - *Australia's mothers and babies*;
- work with the National Birth Anomalies Steering Committee on an integrated program of data development for the national congenital anomalies and perinatal data collections;
- exchange information and consult with other stakeholders in perinatal health in Australia on the appropriateness, relevance, quality, comprehensiveness and clarity of national perinatal data; and
- promote the use of perinatal data elements contained in the NHDD in relevant local and national data collections.

Membership

Membership shall consist of permanent stakeholder representatives from the following bodies/agencies that are signatories to the National Health Information Agreement. The

- National Perinatal Statistics Unit;
- Australian Institute of Health and Welfare;
- Australian Bureau of Statistics;
- Department of Health and Ageing; and
- each State and Territory government health authority.

Additional temporary members may be invited on a transitory basis, as their experience is required for certain issues. This may include representatives from the following bodies/agencies who have been identified as significant stakeholders. The

- Australian, New Zealand Neonatal Network;
- Women's Hospitals Australasia;
- National Centre for Classification in Health;
- Royal Australasian College of Physicians, Paediatrics and Child Health Division;
- Royal Australian College of Obstetricians and Gynaecologists;
- Australian College of Midwives;
- Perinatal Society of Australia and New Zealand;
- National Maternity Data Collaboration Project;
- Ministry of Health, New Zealand; and
- Rural Doctor's Network.

Meeting frequency

Quarterly

The majority of meetings will be held via teleconference, with at least one face to face meeting per calendar year.

Business Rules for Data Development

On 21 July 2003 the Australian Health Minister's Advisory Council endorsed new governance arrangements for health information management and information technology to provide a more balanced and integrated approach to policy development and decision-making nationally. The NPSU is committed to following the processes outlined by the new governance arrangements to manage, maintain and develop national perinatal health data.

The following business rules are based on the business rules for the Health Data Standards Committee, published in 2004. These rules have been developed to ensure that there is a coordinated national approach to perinatal health data development and to ensure that those participating in the process are aware of their responsibilities.

Responsibilities of the NPSU:

- Develop and manage a work program on behalf of the NPDDC, based initially on the outcomes of the "Report on the evaluation of the Perinatal National Minimum Data Set, 2004" and other agreed priorities.
- Provide Secretariat support to the NPDDC.
- Seek expert clinical and/or technical advice from relevant medical colleges and other relevant bodies/agencies as necessary on behalf of the NPDDC.
- Coordinate all necessary information for members of the Committee to be able to make informed decisions.
- Undertake the completion of submissions to the Health Data Standards Committee (HDSC) and the Statistical Information Management Committee (SIMC) as required.
- Provide advice on known developments in other related national committees or projects.
- Promote the NPDDC as the national expert body on perinatal health data.
- Ensure consensus amongst members of the Committee prior to proceeding with any changes to the perinatal data set (where consensus cannot be reached, papers will be sent to HDSC and/or SIMC identifying the issues).
- Ensure data elements are presented in the required format e.g. update the AIHW's MeTEOR database as required.

Responsibilities of members of the NPDDC:

- In addition to the responsibilities tabled in the terms of reference, individual Committee members are required to consult with relevant stakeholders within their jurisdictions in a timely manner (e.g. clinicians, data providers) and keep their HDSC and SIMC representative abreast of any issues.
- Consider the development of new items or changes to existing items from a national perspective, taking into consideration that any state/territory idiosyncrasies can be catered for at the local level.
- Provide advice on the costs and timing of implementing proposed perinatal data elements for national reporting.
- Promote the NPDDC as the national expert body on perinatal health data.
- Where there is more than one representative from an agency at a meeting, the agency must provide a single agency position on issues.
- Provide comments on papers/issues in the timeframe agreed to (if a jurisdiction has no comment, this should be conveyed to the Secretariat. Where a member fails to provide comment on a submission, the view of that jurisdiction may not be able to be taken into consideration).
- Where a member is on leave, membership responsibilities should be delegated to another individual within their jurisdiction.