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Fetal alcohol spectrum disorders

Strategies to address information gaps

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Authoritative information and statistics to promote better health and wellbeing

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Contents

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Abbreviations

AIHW	Australian Institute of Health and Welfare
ARBD	alcohol-related birth defects
ARND	alcohol-related neuro-developmental defects
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorders
ICD	International Classification of Diseases
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification
pFAS	partial Fetal Alcohol Syndrome

Summary

- Limited information is currently available about the incidence and prevalence of Fetal Alcohol Spectrum Disorders (FASD) in Australia and internationally. This lack of data reflects the low level of awareness by clinicians of FASD conditions, the complexity of diagnosis and the absence of nationally agreed and consistent diagnostic criteria and definitions.
- The quality of information available in existing data collections is variable and incomplete for ascertaining Fetal Alcohol Syndrome cases. There is no information available on other disorders in the spectrum.
- Regular surveillance and monitoring have been identified as priorities for determining incidence and prevalence. It is considered that the most feasible medium-term model for FASD data collection is to enhance the scope of national and jurisdictional congenital anomalies collections to include FASD.
- In the short term, a program of data development regarding FASD and the use of record linkage to monitor 'statistical FASD' will provide more complete data than are available now. A national data repository on FASD would enable appropriate resources and services to be delivered to those affected (and their families), as well as providing support to researchers and clinicians.

1 Introduction

Fetal Alcohol Spectrum Disorders (FASD) is emerging as a public health issue in Australia. This group of disorders has been cited as the most common preventable cause of intellectual impairment among children (O'Leary 2004).

An early and accurate FASD diagnosis can help to improve the outcomes and quality of life for those affected and their families; however, this is difficult without an agreed FASD diagnostic instrument. Support and services for FASD-affected children could be provided by including FASD in the List of Recognised Disabilities, and in the Better Start for Children with a Disability initiative (FaHCSIA 2013). However, services are available according to the level of functional impairment and do not depend on a formal diagnosis of FASD.

Purpose of this project

Health-care providers and policy makers need accurate and timely data in a useable format to monitor and prevent FASD. There is widespread concern about the lack of information on FASD and the impact this has on health-care planners and providers in managing the problem in a timely and effective way (Bower et al. 2000; Elliott et al. 2006; May et al. 2009; Mutch et al. 2009; O'Leary 2004; Payne et al. 2005; Premji & Semenic 2009).

The main purpose of this project was to identify ways to facilitate the collection and reporting of FASD-related information in Australia. The use of existing data collections and data sets to develop an ongoing reporting system was examined. Opportunities for data development and options for storage of the data collection were also identified.

Project scope and methodology

This project looked at four interrelated issues for collecting FASD information in Australia:

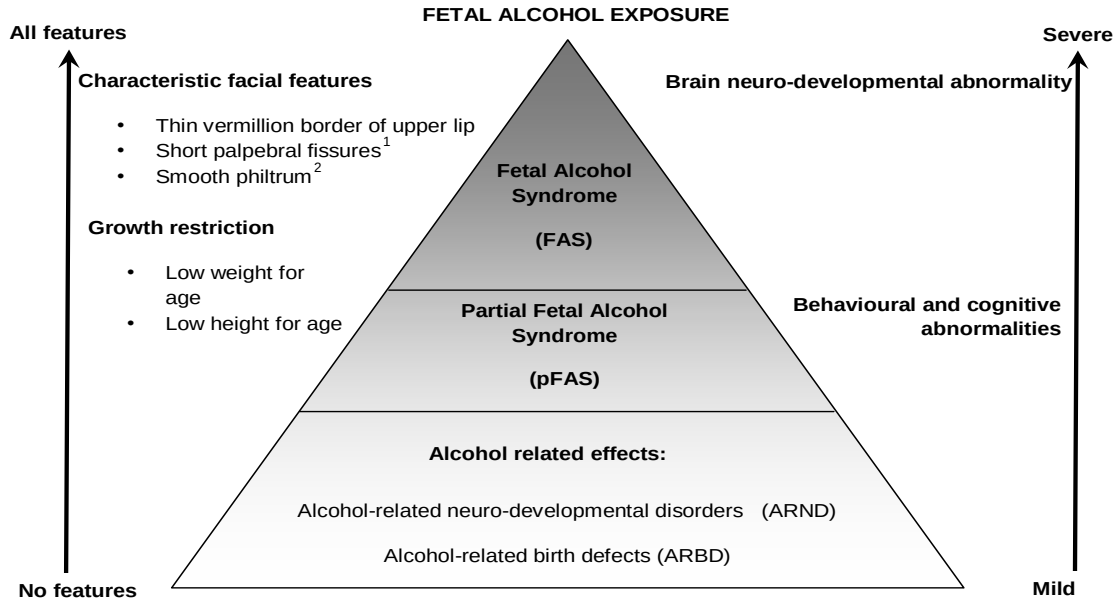
- current status and reliability of the epidemiological information
- FASD-related contents of various administrative and non-administrative collections
- methods to enhance, link and better use existing data collections
- structure and format of the new potential data set or collection.

The project methodology involved:

- reviewing recent information on the epidemiology of FASD (including incidence/prevalence, sociodemographics, maternal alcohol consumption and specific clinical criteria)
- reviewing current collections; identifying data gaps and opportunities and strategies to enhance, expand or modify these collections to generate suitable information related to FASD with input from experts and various stakeholders
- developing models to effectively use various data collections, including through record linkage and risk factor–disease association studies, and exploring mechanisms for new data development.

FASD epidemiology

'FASD' is an umbrella term that encompasses four conditions that are considered to be the result of exposure of an unborn baby to alcohol during pregnancy. These disorders are separated into Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), alcohol-related neuro-developmental disorders (ARND) and alcohol-related birth defects (ARBD). These conditions represent a continuum of alcohol effect during fetal life on the structural and functional development of the brain, structural development of the face, and effects on growth and development generally (Figure 1.1).



Notes

1. Palpebral fissures are the opening between the eyelids.
2. The philtrum is the vertical groove in the middle area of the upper lip.

Figure 1.1: Continuum of FASD features and neuro-developmental abnormalities

The available data related to FASD are incomplete because of the general lack of recognition of FASD by clinicians and by poor or delayed diagnosis. The poor quality of these data limits their use in monitoring, preventing and planning treatment for these disorders. There is limited information about the prevalence of FASD in Australia, and the available statistics relate almost exclusively to FAS. There are currently no national population estimates of the prevalence of FAS. In Western Australia, FAS prevalence has been estimated as 0.18 per 1,000 children (Bower et al. 2000); in the Northern Territory, 0.68 per 1,000 children (Harris & Bucens 2003); and in Victoria, 0.01 to 0.03 per 1,000 children (Allen et al. 2007). For Indigenous children, the reported prevalence of FAS was 2 to 3 times as high as that for non-Indigenous children (Bower et al. 2000; Harris & Bucens 2003). The published rates in Australia are lower than those reported in the United States of America where between 1 and 1.5 per 1,000 children have been estimated to be FAS affected, with rates reported as being 5 times as high as those in Australia for African American children and 16 times as high for American Indian children (Sokol et al. 2003).

In Australia, there is no dedicated national data collection for FASD that provides information about this group of disorders.

Diagnosis of FASD

The classification and description of FASD was first formalised by the Institute of Medicine in 1996, citing 4 conditions (Stratton et al. 1996). A simplified description of each of these conditions follows:

- Children with FAS have distinct facial characteristics (Figure 1.1), together with evidence of growth retardation and neuro-developmental abnormality of the brain.
- Those with pFAS have one or more of the FAS facial features, along with growth retardation and/or developmental abnormality of the brain.
- ARND children show characteristic behavioural and cognitive impairments but without any obvious FAS facial features.
- ARBD is a specific group of congenital anomalies but without any obvious FAS facial features.

Aetiology of FASD

Maternal alcohol consumption in pregnancy is considered to be the primary risk factor for the development of FASD. There may, however, be other risk factors that are contributing causes to the development of individual FASD conditions that are not yet fully understood. Individuals with FASD show marked variation in facial features and in neurological development. Some of this variation may be related to alcohol intake patterns or other lifestyle choices of the mother. Other agents that may disturb the development of an embryo or fetus (referred to as teratogens) may also play a role (Anthony et al. 2010). Existing research shows that while alcohol exposure during fetal development is a prerequisite for the development of FASD, the effects of alcohol exposure can be modified by maternal metabolism of alcohol, nutrition, maternal and fetal genetics, and maternal age (Chasnoff 1985; Streissguth & Dehaene 1993; Warren & Li 2005).

2 Review of current data collections

A review of Australian data collections and sources holding FASD-relevant information was undertaken. Suitable data collections were identified from the literature and published reports.

Methodology

A two-step approach was taken to obtain information about data collections. Firstly, information about collections was obtained from the published and grey literature; then further information was sought from data custodians and project managers. A data collection statement was used to assess the features of each of the collections in a standardised format. Data items relevant to FASD in these collections were then identified using an electronic FASD checklist instrument. In the absence of diagnosis data on one or more FASD conditions, an overall assessment of relevant collections was made against the following five features common to one or more FASD conditions:

- fetal alcohol exposure
- facial anomalies
- growth retardation
- neuro-developmental problems
- birth defects.

Data collections reviewed

A total of 20 collections were reviewed and assessed for content relevant to FASD. The following collections contained some relevant information:

- The Australian Paediatric Surveillance Unit collection, based on information provided by paediatricians, was the most relevant collection. It contained information on all domains of alcohol exposure: facial features, growth retardation, neuro-developmental disorders and birth defects. However, this collection was time limited to the period from January 2001 to December 2004 and restricted to a diagnosis of FAS, the most severe form of FASD. This resulted in under-ascertainment of FASD.
- The Bettering the Evaluation and Care of Health survey collects a rolling set of health-related information from a sample of general practitioners, including information about alcohol use in pregnancy. The survey, however, does not collect information about the woman's children so as to relate this to a potential or definitive FASD diagnosis.
- The perinatal collections (national, state and territory) contain some FASD-related information, in particular about maternal use of alcohol and fetal growth retardation. In addition, all perinatal collections include data on birthweight for gestational age (a widely used proxy measure of fetal growth), and further anthropometric information is obtained by some of the jurisdictional collections.
- The congenital anomalies data (national, state and territory) includes reports of problems evident at birth, including facial features. The collections use the International Statistical Classification of Diseases, 9th Revision, British Paediatric Association (ICD-9-BPA)/ International Statistical Classification of Diseases and Related Health Problems,

10th Revision, Australian Modification (ICD-10-AM) codes to flag various anomalies. However, there is no information available about maternal consumption of alcohol during pregnancy in these collections. Any FASD-type symptoms and anomalies therefore cannot be flagged as FASD.

- The National Aboriginal and Torres Strait Islander Social Survey monitors changes in social circumstances, including health, of Indigenous Australians. Some limited information about alcohol use in pregnancy by Indigenous women is available through this survey; however, it provides no information on FASD.
- Footprints in Time: longitudinal study of Indigenous children provides high-quality quantitative and qualitative data that will help to monitor the gap in life circumstances of Indigenous and non-Indigenous children. Information is collected about antenatal care and health risk behaviours such as smoking and alcohol consumption during pregnancy.
- The Healthy for Life program is aimed at improving the health of Aboriginal and Torres Strait Islander mothers, babies and children. It is focused on improving the capacity of Indigenous primary health-care services, in particular maternal and child health services and chronic diseases care. The collection contains information about alcohol use by Indigenous mothers during pregnancy.
- The National Drug Strategy Household Survey, a cross-sectional survey of people aged 12 years or older living in private dwellings in Australia, includes specific questions on alcohol use in pregnancy. This information can provide population-based information that can be used to validate other data to determine alcohol use in pregnancy nationally.
- The National Hospital Morbidity Database, an ongoing collection, contains information about growth retardation, neuro-developmental disorders and birth defects as well as information related to the mother who may be admitted due to alcohol-related illnesses or conditions. The information, however, relates to the extreme end of the spectrum of various conditions, and therefore may lack the sensitivity to detect many cases of FASD in the community.

In summary, no single collection or combination of data sets was fit for purpose. No data collection contained definitive FASD diagnoses other than FAS and pFAS. The range and quality of available information relevant to FASD varied. While some collections could provide relevant FASD data following data enhancements, others have the potential to provide certain supplementary and contextual information.

3 Models for developing FASD data

Based on the assessment of the content and quality of various collections, the need for regular surveillance and monitoring, and consideration at a national workshop of various stakeholders, a number of options were developed by the Expert Advisory Group. These were:

- record linkage
- time-limited new collection
- enhancement of congenital anomalies collections.

Record linkage

FASD conditions arise during pregnancy; however, they are more often diagnosed in childhood. FASD can impact on many interrelated services including health, education, justice and social services. Developing effective surveillance and monitoring will require information at different life stages and services. Record linkage has a central place in developing FASD-related information but it could never serve as the primary source of FASD data. Rather, data from notifications of FASD diagnosis by health professionals need to be able to be linked with other collections, such as those for health, education and justice. This approach could facilitate the production of a longitudinal profile of the health and intellectual development of persons with FASD.

Strategies for facilitating data linkage are critical to the successful use of FASD data. These include incorporating statistical linkage keys into data collections across health, education, justice and social services and developing strong governance arrangements for the use of data and the protection of privacy.

Time-limited new collection

One option to increase knowledge about FASD and to help monitor the incidence and prevalence of FASD is to develop a time-limited clinical register of FASD cases and use this in conjunction with data linkage. This approach would support research in this field, including the development of the diagnostic and screening instrument. Once available, the instrument would need to be promoted to health professionals nationally.

A register could provide a short-term repository for clinical notifications of FAS, pFAS, ARND and ARBD conditions. It could enable analysis of demographic distribution and other information with the potential for assessing the magnitude of the syndrome and the development of intervention and management programs.

However, registers are expensive and resource intensive to establish. A more sustainable approach may be to embed registers within the congenital anomalies register in each jurisdiction.

Enhancement of congenital anomalies registers

Using jurisdictional congenital conditions/anomalies registries to accommodate notifications would make use of existing resources and infrastructure. However, some development of

jurisdictional congenital anomalies register to accommodate FASD would be required. The scope of these collections would need to be extended to cover notifications for children from birth up to the age of 7. This would require enhancing some of the current jurisdictional registers where there is no, or only limited, facility for notifications after the newborn period.

4 Strategies to address gaps in FASD information

Data development to address critical data gaps is a priority before a national FASD data collection could be established. These data gaps include the absence of a national definition of FASD and nationally agreed guidelines for screening and diagnoses, the lack of specific coding for FASD conditions, and limited collection of information on alcohol use during pregnancy.

Development of diagnostic criteria for FASD

Currently in Australia, there are no screening, diagnostic or treatment services for FASD and no national guidelines for screening and diagnosing FASD. Doctors may miss or lack knowledge of key clinical criteria to make a FASD diagnosis. Theoretically, all children should have an equal chance of being diagnosed with FASD through population screening at birth or in early childhood to ensure that all those at risk are clinically assessed.

The Australian Government announced on 25 June 2014 that it will provide $9.2 million to the National FASD Action Plan (Department of Health, 2014). The funding includes $3.1 million for grants to drug and alcohol services to support alcohol dependent women; up to $1.5 million in targeted grants to undertake further research to develop best practice guidelines; an additional $4 million to the New Directions: Mother and Babies program; and $100,000 to establish the FASD Technical Network. An investment of $500,000 will support the finalisation of the National FASD Diagnostic Tool. It is essential that the standards for the diagnosis of various FASD conditions are accepted by paediatricians and incorporated into clinical practice. Endorsement by the Royal Australasian College of Physicians: Paediatrics and Child Health Division would facilitate this process.

The Australian FASD Collaboration, through the Telethon Institute for Child Health Research, conducted the Alcohol, Pregnancy & FASD project during 2010-2012. The aim of this project was to develop a diagnostic instrument that consists of a set of tests and measurements that could be used to diagnose FASD in Australia. The development of diagnostic guidelines for Australia was informed by an evaluation of health professionals' assessment of diagnostic instruments used in other countries (Watkins et al. 2012). A key message from this work was that national guidelines in Australia should incorporate elements of the University of Washington diagnostic criteria, but that further work would be needed to develop guidelines suitable for Australian populations.

Improving clinical diagnosis of FASD

Once FASD conditions are diagnosed, this information needs to be captured in data collections. An issue affecting the effective surveillance of FASD is the lack of specific coding for FASD conditions, apart from FAS (Q86.0) in the current version of ICD-10-AM. Consequently, none of the other conditions can be captured in routine data collections that rely on ICD-10-AM for diagnostic coding, such as the jurisdictional admitted patient collections or the National Hospital Morbidity Database.

Monitoring maternal alcohol use

Despite the recommendation of the National Health and Medical Research Council not to consume alcohol while pregnant, over 47% of women in Australia continue to do so (AIHW 2014). Monitoring patterns of alcohol consumption in pregnancy using validated screening tools provides an indirect view of the extent of FASD and is a requirement for diagnosis of FASD conditions in the Canadian guidelines (Chudley 2008). Screening tools for alcohol consumption in pregnancy have been reviewed in Australia and there are strong arguments for introducing them into routine antenatal care (Muggli et al. 2010).

The national collection of information on alcohol use during pregnancy is a priority area for the Council of Australian Governments (COAG 2008). A project for the National Perinatal Data Collection drafted standardised data elements that could be used in conjunction with validated screening tools to produce consistent national data about alcohol use in pregnancy. A pilot study is needed to progress the development of these data elements and to validate the instrument before use with other collections. It is also necessary that stakeholders agree on the instrument's use, interpretation and acceptability.

In 2012, an inquiry into the prevention, diagnosis and management of FASD recommended that the Australian Government establish mechanisms for clinicians to record women's alcohol consumption during pregnancy so as to ensure that this information is recorded in perinatal data collections or notifications throughout Australia (House of Representatives Standing Committee on Social Policy and Legal Affairs 2012).

Box 1 summarises the recommended strategies to address the data gaps.

Box 1: Strategies to address data gaps

- Development of a diagnostic tool to nationally standardise diagnosis of FASD.
- Endorsement of the standard by the Paediatrics and Child Health Division of the Royal Australasian College of Physicians.
- National implementation of standard practice by paediatricians, and by community and child health development clinics and other sectors, as appropriate.
- Incorporation of all FASD conditions in ICD-10-AM and in other classification systems, as appropriate.
- Incorporation of reporting of FASD in routinely collected information systems including those for health, education, families and community services, corrections and disability services.
- Monitoring and recording of maternal alcohol use.

5 The way forward

Developing a repository of FASD related data would provide prevalence and demographic data to enable further research and directed prevention strategies to be initiated and delivered. A national data repository on FASD would also allow appropriate resources and services to be delivered to those affected, and their families.

Data development

Strategies for developing a national FASD data collection are predicated on the recognised critical diagnostic and health information gaps being addressed. These include having a national definition of FASD, a nationally standardised FASD diagnostic instrument and nationally mandated collection of information on alcohol use during pregnancy. Once nationally agreed FASD diagnostic and notification practices are established, ongoing surveillance could start.

National data collection

Establishing a condition-specific register is resource intensive. A more sustainable approach is to build on the existing infrastructure and embed FASD registers within each jurisdiction's congenital anomalies/conditions register.

A register could provide a repository for clinical notifications of FAS, pFAS and ARND conditions. It could also enable demographic distribution and other valuable information to be analysed, with the potential for assessing the magnitude of the disease and developing intervention and management programs.

Further research

A FASD register embedded into jurisdictional congenital anomalies/conditions register would support the research still required in this field. It could also provide a platform for assessment during the testing and implementation phases of introducing the diagnostic and screening instrument. Further research, facilitated by data linkage to other data collections such as disability services, could provide information on outcomes for FASD-affected children and provide information on long-term management.

The aetiology of FASD is complex and still not completely understood. Data collections made available to researchers can further our knowledge of the aetiology and assist in developing effective programs for prevention. Screening studies with longitudinal follow-up in a representative population could add to the evidence base. Periodic studies of this nature can also provide validation data.

The incidence and prevalence of FASD in Australia are currently unknown. Australia is lacking in its national approach to recognition, diagnosis and response to FASD. There is no cure for FASD, only treatment and prevention. A national data collection would provide essential information to researchers, clinicians and policy makers to develop and implement an appropriate response to this preventable condition.

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