Original Article

The Australasian Maternity Outcomes Surveillance System: An evaluation of stakeholder engagement, usefulness, simplicity, acceptability, data quality and stability

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Background: The Australasian Maternity Outcomes Surveillance System (AMOSS) conducts active, prospective surveillance of severe maternal conditions in Australia and New Zealand (ANZ). AMOSS captures greater than 96% of all births, and utilises an online, active case-based negative reporting system.

Aim: To evaluate AMOSS using the United States Centres for Disease Control (*MMWR* 2001; 50 (RR13): 1–35.) surveillance system evaluation framework.

Methods: Data were gathered using multiple methods, including an anonymous online survey administered to 353 AMOSS data collectors, in addition to review of case data received during 2009–2011, documented records of project board and advisory group meeting minutes, publications, annual reports and the AMOSS database.

Results: AMOSS is a research system characterised by its simplicity and efficiency. The socio-demographic, risk factor and severe morbidity clinical data collected on rare conditions are not duplicated in other routine data systems. AMOSS is functioning well and has sustained buy-in from clinicians, stakeholders and consumers and a high level of acceptability to data collectors in ANZ maternity units.

Conclusions: AMOSS is the only existing national system of surveillance for rare and severe maternal conditions in ANZ and therefore serves an important function, utilising data collected from reliable sources, in an effective, efficient and timely way.

Key words: epidemiology, evaluation, maternal complications, pregnancy, surveillance.

Introduction

Although individually rare, severe obstetric and maternal conditions affecting Australian and New Zealand women are burdensome, and historically, have been difficult to study because they are uncommon, often poorly ascertained in routine data collections and not captured by

standard classification systems. This has resulted in a lack of epidemiological and clinical data to guide clinical practice. Researchers in Australia recognised this issue in 2008 and established the Australasian Maternity Outcomes Surveillance System (AMOSS).

AMOSS is a national research system designed to study severe (and often rare, <1:1000 births) maternal conditions in pregnancy, childbirth and the six weeks after birth through a combined clinical and population approach. The objectives of AMOSS are to improve the safety and quality of maternity care in Australia and New Zealand (ANZ) through development of evidence-based information on severe maternal morbidity for use in clinical care, service planning and for patient information. AMOSS works in collaboration with stakeholders across maternal and indigenous health (eg Royal Australian and

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New Zealand College of Obstetrics and Gynaecology (RANZCOG), Australian and New Zealand Colleges of Midwives (ACM; NZCM), Society of Obstetric Medicine of Australia and New Zealand (SOMANZ), Perinatal and Maternal Mortality Review Committee (PMMRC), Australian and New Zealand College of Anesthetists (ANZCA), Women's Hospitals Australasia (WHA) and the Perinatal Society of Australia and New Zealand (PSANZ) as well as clinical specialisations, government departments and peak bodies.¹ The AMOSS system is designed to complement existing maternal health information systems. This study reports an evaluation of AMOSS undertaken to determine whether it is meeting its objectives and to establish whether this method of case ascertainment is appropriate for maternity units in ANZ.

The AMOSS surveillance process

Public health surveillance systems have been defined as those that involve the ongoing systematic collection, analysis, interpretation and dissemination of data regarding a health-related event² and facilitate the timely dissemination of results to appropriate decision makers³. AMOSS fulfils this definition and is designed to minimise burden on reporting clinicians and facilitate participation, while at the same time maximising true case ascertainment (see Fig. 1). The system is modelled on the successful United Kingdom Obstetric Surveillance System⁴ (UKOSS) and applies similar methodologies. The designated AMOSS data coordinators in each of the participating hospitals are sent a monthly email requesting either a 'case' or a 'nil case' (negative reporting) response to distinguish between 'no cases' and missing data. When a case is ascertained, the data collector (using their unique AMOSS username and password) completes a condition-specific case survey form via the secure web-based data capture and validation system⁵. Only nonidentifiable data are collected with summary aggregate reporting.

Identification of study conditions

The study conditions are identified through consultation with the AMOSS project board, advisory group and relevant collaborators, stakeholders and consumers to determine their suitability for the system. The AMOSS advisory group includes representation from RANZCOG,

ACM, NZCM, SOMANZ, PMMRC, PSANZ, ANZCA, WHA, consumers, Aboriginal Health, maternal-fetal medicine and major medical subspecialties. Since 2009, AMOSS has collected data on the following conditions: antenatal pulmonary embolism (APE), amniotic fluid embolism (AFE), Eclampsia, Placenta Accreta, Peripartum hysterectomy, H1N1 Influenza A, R and Morbid Obesity. Conditions are surveyed for between 12 and 24 months. The AMOSS can initiate surveillance at short notice to facilitate effective healthcare responses, such as for H1N1 Influenza A with ICU admission during pregnancy.

In addition to surveillance of AMOSS case conditions, a series of incidence and case-control studies are undertaken to describe the epidemiology of conditions and identify risk and clinical factors that predispose women to severe, maternal complications, diseases and interventions as well as determine disease progression and treatment factors that lead to specific interventions. Case-controlled studies (currently placenta accreta and peripartum hysterectomy) include data on two control cases per case. 'Control cases' refer to the two women who gave birth in the same unit immediately before the woman with the AMOSS condition, regardless of their mode of birth or any complicating pre-existing medical or obstetric conditions.

The system utilises a multitiered approach to inform stakeholders and disseminate results that includes both targeted and open access dissemination through formal and informal modalities. The targeted dissemination includes the quarterly newsletters to all data providers and all stakeholders, the annual report and annual advisory group meeting. The latter is a formal consultation and dissemination meeting with national-level stakeholders. Formal peer review dissemination is through national conferences and peer review publications^{1,6-13} with informal dissemination through the AMOSS website. AMOSS investigators have presented at over 20 national and international conferences and site visited and presented at over 60 hospitals.

Methods

Evaluation methodology

The framework for evaluation disseminated by the United States (US) Centres for Disease Control and Prevention (CDC)¹⁴ is well established and has commonly been used

Figure 1 Flow chart of the Australasian Maternity Outcomes Surveillance System (AMOSS) data collection process.

to assess public health surveillance systems.^{15–21} CDC suggests the evaluation should involve an assessment of stakeholder engagement, system usefulness, as well as a description of specific system attributes, including simplicity, acceptability, data quality and stability as part of a balanced evaluation process.¹⁴

Ethical consent to undertake this evaluation was covered by generic approval from the institutional HREC. To engage stakeholders and determine their perspectives on the system, an anonymous, eleven-question survey developed by AMOSS investigators using online software²² was distributed. The survey was accessed through an online link emailed to a total of 353 registered (with existing AMOSS unique, personalised username and password), 'active' data collectors (having responded to the monthly reporting email within the previous three months. Data collectors who were logged as 'inactive' in the AMOSS database (having left their previous role/moved hospitals/were no longer actively collecting data) were not contacted. The data collectors surveyed consisted of midwives/research nurse/general nurse ($n = 292$), obstetrician/obstetric physician/maternal-fetal medicine specialist ($n = 47$), data manager/health information manager/quality assurance ($n = 12$) and anaesthetist ($n = 2$). Reminder emails were distributed two and four weeks after the initial request. The survey was scored using either a two response (yes/no) format or a five-point Likert Scale,²³ with the final question designed using an open response to allow further comments or suggestions to be added. Descriptive statistics were computed for survey responses, and comments entered into the open response section were analysed thematically (coded and placed into emerging categories, which were then consolidated allowing significant themes to be identified).²³

To determine system usefulness and describe specific system attributes (simplicity, acceptability, data quality and stability), documentation from project and advisory group meetings, publications, official correspondence and data collections were also reviewed.

Results

Simplicity

The simplicity of a public health surveillance system refers to both its structure and ease of operation.¹⁴ The AMOSS system allows a streamlined data entry process, automated data quality checks, rapid search, retrieval and visualisation capabilities. It is intended to provide minimal burden on data collectors. 188 data collectors responded to the survey (53%), which has been suggested to be acceptably large enough to ensure an adequate response range,²⁴ although may reflect a biased response. The responses demonstrated the monthly email reminders were considered to be a straightforward reporting system, and collectors could notify cases through direct input into a dedicated web capture system. Monthly reporting using the online dedicated reporting site was seen as effective

with 89% ($n = 163$) of surveyed data collectors, indicating they always respond to the monthly reporting email with the view it is an effective means of registering new cases. Sixty-nine per cent of respondents ($n = 125$) found the online forms very easy to complete and agreed or strongly agreed that the AMOSS reference folder was very useful and informative, easy to understand, user friendly and contained relevant information to aid with electronic form completion. Similarly, 88% ($n = 163$) found the website very easy to use, 69% ($n = 124$) thought the forms and instructions were very clear and 59% ($n = 106$) stated help was easy to access whether they had problems with reporting. A significant majority (86%, $n = 161$) claimed that AMOSS posed a negligible burden and was easy to integrate into their usual workload.

Acceptability

Acceptability reflects the willingness of persons and organisations to participate in the surveillance system.¹⁴ Out of Australia's 279 hospitals with over 50 births per year, 268 (96%) are currently participating in AMOSS. All 24 New Zealand sites are participating. Since 2009, a total of 525 collectors, located in almost 300 units throughout ANZ (96% of eligible units with >50 births per year in Australia, and all units in New Zealand), have reported 1189 individual cases. A significant majority 81% ($n = 149$) enjoy being involved with the project, and 78% ($n = 143$) felt their contribution is valuable. Ninety-two per cent ($n = 166$) agreed the AMOSS project was very important, with 72% ($n = 130$) stating they were more aware of rare and serious obstetric conditions because of the project. Open response comments indicated that participation in AMOSS was seen as valuable and enjoyable, and contributed to education by their increased knowledge and awareness of severe obstetric conditions in pregnancy.

Data quality

Data quality reflects the completeness and validity of the data recorded in the public health surveillance system.¹⁴ In disease surveillance, it is important to maximise true case ascertainment and remove duplicate or incorrect reports to avoid selection bias.²⁵ The AMOSS reporting base includes general, specialist and community clinicians and has excellent binational coverage. Rates of responding to monthly reporting emails remain stable at 86% overall (ANZ), although this has risen to an average of more than 90% with active follow-up from AMOSS administrative staff, such as email reminders to complete outstanding case details, or telephone conversations concerning specific data inputting enquiries. To ensure that data complies with case definitions, and reporting system requirements are met. AMOSS employs a rigorous procedure: (i) a first tier of checking for completeness and accuracy is undertaken by the system, which utilises negative reporting; (ii) the web-based reporting system confirms which hospitals have reported each month, and

nonparticipating sites are followed up using a semi-automatic system with additional notifications and contact; (iii) continuous assessment of data quality is conducted with randomised audit of data entry, which is undertaken four times a year; and (iv) data are checked for completion and accuracy using a range of tools in specified database (Filemaker 12 Pro, Filemaker Inc., Santa Clara, CA, USA) and statistical (SPSS version 17, Chatswood, NSW, Australia) applications when a study is completed. Few false cases are reported (3.74%, not including duplicate reporting from collectors, nor those cases outside the study period), reflecting the systems high level of specificity and sensitivity.²⁶ Where possible case ascertainment of data collected in AMOSS are compared with routine data collections through a comparison of rates. Processes to ascertain cases through routine data collections vary considerably both within and between jurisdictions. Custom reporting to support AMOSS case identification has been developed in a few obstetric clinical database systems. Other sites use queries of the National Hospital Morbidity Database (NHMD) as well as referencing perinatal data collections and are supported by their own internal unit processes of AMOSS case identification. These data are not linked. For morbid obesity, data were available from the Queensland Health Statistics Centre, which reported a rate of 2.6/1000 per 1000 births compared with AMOSS rate of 2.4/1000. Hospital policies on weighing women during pregnancy impacted on case ascertainment: some sites did not weigh women during pregnancy after the booking visit (policies on weighing women have been reviewed in many sites since the AMOSS study was conducted). Other case validations are in progress.

Stability

Stability refers to the ability of the system to collect, manage and provide data in a timely manner.¹⁴ The median number of days from the date that the monthly email was distributed and the date of responding was two days (mode = 0 or same day, mean 12.28 days, range 0–545). Lag in reporting necessitated active follow-up by AMOSS project staff to ensure accurate reporting and completion of all cases.

87 comments related to case reporting were entered into the open response section of the survey and indicated several barriers data collectors encountered that impeded their ability to input data in a timely manner. These included not having access to a work computer, or not being able to access an available workspace due to shared computers in the units. Not all data collectors received the reporting email to their own accounts, but instead to a shared 'unit' email address. This posed a number of problems, particularly being able to access the computer due to multiple users, or working in many different locations and secondly, accessing the reporting email when not on shift, on leave or annual holiday. Difficulty accessing the required specific information or case notes

postevent was also noted, or when medical records had left the unit, which added extra burden to data collectors because they often had to make numerous calls and visits to the medical records department to track the notes.

The AMOSS web-based reporting system appears stable and has performed well with no noted system outages or technical problems. Nonetheless, an upgrade of the existing system is pending and dependent on securing further competitive funding. The upgrade will further improve efficiency and speed of reporting, web page access and usage. It will also involve the development of the AMOSS website to include a dedicated consumer forum and resource portal.

Discussion

This evaluation, based on the first two full calendar years of data collection, has confirmed AMOSS is achieving its research objectives as a national surveillance system by raising awareness of and by providing a focus for research into rare and severe conditions in pregnancy in ANZ. AMOSS was seen as being useful, as it addressed an unmet need in ANZ. Population-based binational research has been conducted for the first time in ANZ on eight under-researched conditions in pregnancy developing an evidence base for counselling, practice and service delivery.^{6,7} Additionally, AMOSS contributes to, and benefits from international studies (three to date) and the development of international best practice and is a founding member of the International Network of Obstetric Survey Systems (INOSS). The development of INOSS will strengthen the utility of AMOSS through international collaborations of an affiliation of researchers in serious morbidity in pregnancy and childbirth from Australia, New Zealand, UKOSS and countries across Western Europe and the development of international evidence base on rare severe maternal morbidity. There is currently no other way to effectively study these rare conditions prospectively at a national level in ANZ. The evaluation has demonstrated by the 89% response rate to the monthly reporting email, a high level of acceptability of AMOSS by ANZ maternity units. Previous research has noted conflicting findings when comparisons are made between postal and electronic reporting systems, with enhanced,^{17,27} poorer¹⁶ or no differences²⁸ observed in response rates and case ascertainment. AMOSS participation rates have increased significantly over time, and case completion accuracy has improved during 2011, in part due to increased emphasis on active follow-up by AMOSS staff. AMOSS utilises a web-based negative case reporting process and has achieved consistently high case ascertainment, demonstrating the efficacy of this method, which minimises missing data and ensure completeness and accuracy of reported cases. However, it is noted that access to unit computers to comply with reporting requirements, is not always easy or convenient for coordinators when working within a busy maternity unit. It is suggested that alternative methods for reporting/

reminder emails, such as text messages, may be offered as a complimentary medium for individuals affected by computer access issues.

Previous evaluations of surveillance systems in Australia,^{16–18,21} the UK²⁰ and Canada²⁷ have also demonstrated reasonably high levels of participation from clinicians and data collectors and have together made significant contributions to clinical practice. These evaluations, many based on postal card reporting, emphasised the need to minimise the burden of reporting by ensuring that case forms developed by investigators are easy to complete. Additional noted aims were to improve dissemination of study findings and to develop methods for auditing the wider impact of surveillance²⁰. The CDC¹⁴ framework is the most frequently utilised for health surveillance systems¹⁵. Notably, however, studies have focussed on specific aspects of the framework, which often results in an unbalanced evaluation¹⁵.

The AMOSS, a multinational research collaboration, provides an invaluable collaboration of researchers, clinicians and a research infrastructure supported by almost 300 ANZ maternity units, which contribute robust monthly surveillance and research data. It has fostered strong relationships with and is endorsed by a number of professional colleges and organisations, including RANZCOG, ACM, SOMANZ, PMMRC, ANZCA, WHA and ANZICS Clinical Trials Group, and benefits from a multidisciplinary, highly experienced research team. It has secured engagement of maternity care providers, states and territories and consumers who have firsthand experience of receiving critical, emergency obstetric and midwifery care for complex pregnancies and birth events that require a specialised response in maternity units in Australia.

The results of this evaluation, consistent with previous evaluations of health systems^{19,29–32} demonstrates the system is well received by stakeholders and voluntary data collectors. However, the bias inherent in the survey response rate of 53%, although suggested to be adequate²⁴ may reflect only those data collectors who are happy with the system. Nonresponders may have alternative views that have not been determined by these findings. Attempts to maximise completion rates through reminder emails (at two- and four-week postinitial contact) were undertaken, although the anonymous nature of the survey made more focussed attempts impossible. Additionally, it was difficult to determine which hospitals were included in the survey responses, and whether data collectors in hospitals that have had a higher number of cases to report are as happy with the system as those who have reported fewer cases. Nonetheless, the fact that over half of the active collectors responded to the survey reflects the benefit of using electronic reporting processes and a dedicated web-based server with user support, as a relatively effective, efficient and inexpensive method of case reporting that is valued by participating data collectors³. The person time burden is manageable, and the system user friendly. AMOSS has provided important audit data for international

comparison about the AMOSS, a successful and established surveillance system. Surveillance of rare obstetric conditions by the AMOSS is valued by clinicians and has significantly increased awareness of severe (and rare) obstetric complications. Formal evaluation has identified the key strengths of the AMOSS as the system's simplicity, the quality of the data collected and the high level of acceptance by participating clinicians.

This study reports on the evaluation of the AMOSS's first two complete years of data collection, as such, the evidence is limited and would benefit from further periodic evaluation to ensure that the AMOSS continues to be an effective method for ascertainment of data and information about severe, rare maternal complications and interventions in ANZ. In addition, although de-identified patient data are important in determining incidence, treatment, management and clinical outcomes, the ability to collect identifiable data would strengthen AMOSS's value further, by allowing longitudinal study of patients and qualitative research to determine the socio-emotional, psychological and economic impact of maternal complications and interventions during pregnancy. AMOSS has recognised this area as significant in providing a holistic picture of maternal complications and interventions, and plans to develop into Phase II, once ongoing funding is secured.

Conclusion

This systematic assessment¹⁵ has confirmed the significant role played by the AMOSS in providing binational surveillance data for severe and rare maternal conditions and interventions. As development, the AMOSS has been a valuable resource for clinicians and policy makers providing high-quality surveillance data concerning a wide range of severe maternal conditions and complications. Participation rates are consistently high and responses from surveyed clinicians indicate that they value the research outcomes, considering these to have been instrumental in raising awareness of severe rare maternal conditions and informing clinical practice.

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