Contents

Message from the Principal Investigator .............................................................. 3
Background on AMOSS ...................................................................................... 4
AMOSS’s key achievements 2010–2011 ............................................................. 6
Participation ....................................................................................................... 7
Studies .............................................................................................................. 10
“My world tilted on its axis”: Experiencing AFE ................................................... 16
Publications ....................................................................................................... 21
Conferences and meetings ................................................................................. 22
International collaboration .................................................................................. 23
Acknowledgements ............................................................................................ 24
Funding ............................................................................................................. 24
Investigators ....................................................................................................... 25
References ........................................................................................................ 28
AMOSS participating sites 2010–2011 ............................................................. 30
Contact AMOSS ................................................................................................. 32

Printed August 2012
Message from the Principal Investigator

It has been an exciting and challenging four years since the National Health and Medical Research Council (NHMRC) funded the establishment of AMOSS (Australasian Maternity Outcomes Surveillance System), a bi-national surveillance and research system for severe and rare maternal morbidity. Surveillance of severe maternal morbidity is now internationally accepted as a core component of maternal health programs. Previously, Australia and New Zealand lagged behind peer countries that monitor severe maternal morbidity.

Significantly, it has been the overwhelming ongoing support from our stakeholders across many disciplines that has given AMOSS such a strong base. Data collectors from nearly 300 maternity units throughout Australia and New Zealand actively participate in AMOSS’s monitoring in order to gain a better understanding of severe and rare maternal morbidity. The success is also built on the collaboration with and support by professional colleges, particularly the Royal Australia and New Zealand College of Obstetricians (RANZCOG), Australian College of Midwives (ACM), New Zealand College of Midwives, Society of Obstetric Medicine of Australia & New Zealand (SOMANZ), Perinatal Society of Australia and New Zealand (PSANZ) and Australian and New Zealand Intensive Care Society (ANZICS) and jurisdictional and national bodies including the Perinatal and Maternal Mortality Review Committee (PMMRC) in New Zealand.

By the end of 2011, over 1000 women with rare and serious conditions in pregnancy had been reported using the AMOSS surveillance system; and five of the seven studies have completed data collection with data validation and analyses underway. The preliminary results demonstrate the significant burden that maternal morbidity places on the healthcare systems of Australia and New Zealand, and underpin the value and imperative of such a system as AMOSS. AMOSS now contributes to the evidence base of risk factors, management and outcomes of these conditions both at a national and international level – including collaborative studies with the UK Obstetric Surveillance System (UKOSS) and active participation in the evolving International Network of Obstetric Survey Systems (INOSS).

This report includes an interview with a woman about her experience surviving amniotic fluid embolism (AFE). Her story, along with clinical comments by her surgeon, provide a poignant reminder of the trauma and emotions experienced by women who suffer such conditions, their families and care providers.

There are a number of new studies commencing in the second half of 2012 – including rheumatic heart disease in pregnancy, gestational breast cancer, vasa praevia and admission to intensive care – that will utilise AMOSS to provide an evidence base of the incidence, management and outcomes for women who experience these conditions. Additionally, a research program that explores women’s experiences of receiving care for these conditions will commence.

Our primary goal remains the same: to improve the safety and quality of maternity care in Australia and New Zealand.

Professor Elizabeth Sullivan, on behalf of the AMOSS Investigators and Project Team
Background on AMOSS

AMOSS is a national surveillance and research system for rare and severe conditions experienced by women during pregnancy, childbirth and the postpartum period. Surveillance is conducted in Australia and New Zealand of maternity units (including antenatal, delivery and postnatal) which have more than 50 births per year. A five-year NHMRC project grant funded the establishment of AMOSS in 2008 and the initial studies. The aims of AMOSS are to: improve the knowledge of rare obstetric disorders and their management in Australia and New Zealand; undertake national research of rare disorders evident during pregnancy and the puerperium; and translate research findings into policy, clinical guidelines and educational resources for clinicians. AMOSS has been modelled on the successful UK Obstetric Surveillance System (UKOSS).

AMOSS is an essential surveillance and research mechanism because:

- individually, rare serious obstetric conditions are uncommon, but as a group they cause considerable burden for women, families and the health sector
- there is a paucity of data available on the incidence, risk factors and outcomes of these sometimes fatal conditions
- the rarity of these conditions makes them logistically difficult to study
- clinical practice is rarely based upon a robust evidence base
- maternal mortality is rare in Australasia, and studies into ‘near-miss’ events may give greater insight into risk factors and possible preventative measures.

How AMOSS Works

- An AMOSS site coordinator(s) including midwife, obstetrician, obstetric physician, anaesthetist or risk manager, as nominated within each maternity unit, leads the local data collection.
- Conditions investigated have an estimated incidence of less than 1 in 1,000 births per year.
- A typical study period is between one and two years.
- Monthly reporting is conducted via a web-based data capture system, employing a negative reporting system.
- Non-identifiable patient data are collected from case notes.
- A formal process is used for disseminating results, including peer review publications, annual reports, e-newsletters and the AMOSS website.

AMOSS is a multidisciplinary research system with stakeholders from all clinical groups involved in maternity care. It is designed to complement existing maternal health information systems, and the findings can be used to audit existing clinical guidelines. The system encourages capacity building in population-based research on maternal morbidity.
Aim and Objectives

Our long-term aim is to improve the safety and quality of maternity care in Australia and New Zealand by:

- establishing AMOSS as an institutionalised surveillance and research system for rare and severe obstetric morbidity
- providing evidence-based information for use in clinical care and service planning
- raising public awareness of severe maternal morbidity during pregnancy and birth
- increasing the level of research and research funding in Australia and New Zealand allocated to AMOSS for investigating rare and severe conditions of pregnancy
- working in collaboration with stakeholders in maternal and Indigenous health as well as clinical specialisations, government departments and peak bodies in order to better inform the AMOSS and leverage findings.

AMOSS Governance

The success of AMOSS in carrying out its objectives is dependent on close working relationships with its partners across the public and private healthcare systems throughout Australasia. The Project Board is responsible for setting the strategic direction of AMOSS and ensuring that project deliverables align with the project plan and original grant proposal. The Board works closely with the Project Team who is responsible for the implementation and administration of the project on a daily basis.

The Advisory Group’s role is to represent stakeholders and more broadly advise the Project Board on the clinical, policy and service delivery context of severe maternal morbidity. This includes annual consultation about future conditions to be monitored by AMOSS.

Individual Study Groups are responsible for the content and direction of each study and are responsible for the protocol development, scientific and ethical approval, funding, and coordination of primary and secondary data collection, analysis of data and publication of results. These groups work closely with the Project Board, Project Team and Advisory Group.

Vanessa Watkins, Clinical Midwife Consultant and AMOSS data coordinator, Box Hill Hospital, Victoria.
AMOSS’s Key Achievements 2010–2011

- Ongoing support by nearly 300 maternity units across Australia and New Zealand who participate in the negative AMOSS surveillance and studies investigating rare and serious conditions in pregnancy.

- Developing and maintaining a robust data collection system.

- Development of a national maternity network of collaborators with a reliable and efficient system for communication and dissemination of information.

- Presentation (both oral and poster) at nearly 20 national and international conferences and meetings related to perinatal and Indigenous health.

- A successful NHMRC project grant to study Rheumatic Heart Disease (RHD) in pregnancy (2012–2015).


- Funding by the International Vasa Previa Foundation to study this condition (2012–2013).

- Submission of several other funding applications to provide ongoing project funding and study specific conditions, including maternal admission to Intensive Care, massive obstetric haemorrhage requiring transfusion, and a proposal to expand the AMOSS data infrastructure and develop eResearch tools.


- Visits and presentations carried out at over 70 hospitals.

Deanna Stuart-Butler, Senior Aboriginal Maternal Infant Care Practitioner at Anangu Bibi Birthing Program, Port Augusta, South Australia
As at December 2011, participation in AMOSS covered over 95% of births in Australia, and all New Zealand births. Of Australia’s 278 hospitals with more than 50 births per year, 266 are currently participating in AMOSS. All 24 New Zealand sites are participating. The number of sites that reported a condition was 111 in both 2010 and 2011 calendar years; the total number of sites reporting conditions during 2010–2011 was 155. Figure 1 shows AMOSS participation by births, by state and territory for Australia and New Zealand.

Thank you to all our AMOSS participating maternity units.

**Figure 1:** AMOSS participation by births, 2010–2011, Australia and New Zealand

* Total births from AIHW Australia’s Mothers and Babies 2009* and PMMRC Sixth Annual Report of the Perinatal and Maternal Mortality Review Committee 2010*

**AMOSS Data Collection**

Data are collected through a secure web-based system. The AMOSS database is a user-friendly reporting system that has been designed to minimise the burden placed upon the reporting maternity unit. The nominated AMOSS site coordinator(s) reports monthly, regardless of whether or not an AMOSS condition (or intervention) has occurred in their maternity unit. Figure 2 details the case reporting workflow in the maternity units.
Figure 2: AMOSS reporting flow chart

Figure 3 shows the consistently high levels of monthly reporting to AMOSS by maternity units.

Figure 3: Monthly responses, Australia and New Zealand, 2010–2011
Figure 4 shows the number of cases reported by AMOSS participants, by month, compared to the number of surveys entered. The chart highlights the disproportionate number of cases during the surveillance period and study of extreme morbid obesity. (New Zealand completed surveillance only of extreme obesity during 2010. An NZ retrospective study is currently in progress).

Figure 4: Cases reported vs entered, Australia and New Zealand, 2010–2011
Studies

The initial conditions monitored by AMOSS in 2010–2011 are either leading causes of maternal mortality or emerging public health problems in maternity care in Australia and New Zealand. Unless otherwise specified, the results included in this report represent the analysis of cases reported and data available up to and including 31 December 2011. The data are preliminary and are not peer reviewed, and definitive conclusions should not be drawn from them. Table 1 below lists AMOSS studies for the period 2009–2015, including planned conditions.

See the Funding section for acknowledgements and funding sources.

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Other conditions added according to study priority and funding availability
* To be confirmed
^ Study continues in NZ

Table 1: AMOSS study timetable, 2009–2015
COMPLETED AND CURRENT STUDIES

Extreme morbid obesity

Background

Extreme morbid obesity is a major public health problem in Australasia. Obesity in pregnancy is an independent risk factor for obstetric complications, such as preeclampsia, and is also associated with adverse fetal outcomes. Furthermore, caring for women who have obesity in pregnancy and childbirth can have resource and planning implications for maternity service providers including provision of appropriately designed equipment and trained clinical staff.

Research questions

1. What is the prevalence of morbid obesity (BMI > 50 or weight over 140kg) during pregnancy in Australia and New Zealand?

2. What management issues and other difficulties arise in the care of pregnant women who are morbidly obese in Australia and New Zealand?

3. What are the outcomes for both the mother and the infant of women who are morbidly obese during pregnancy in Australia and New Zealand?

4. What are the outcomes for both the mother and infant in Australia and New Zealand?

Methods

The aim of the prospective Australian study was to estimate the incidence, and examine the management and outcomes of extreme morbid obesity among women who gave birth in Australia in 2010. The study was a cohort study using a comparison group (controls drawn from two other AMOSS studies). Obstetric interventions and birth outcomes were measured for both groups. Health professional involvement in antenatal care, pregnancy complications, specified medical and obstetric complications and special bariatric equipment availability were recorded for the case women only.

A subsequent survey was distributed to maternity unit managers in Australia to explore policies and resource burdens associated with women with extreme obesity during pregnancy.

A retrospective study of eligible New Zealand women with extreme obesity is in progress.

Case definition

Australian and New Zealand maternity units returned monthly reports on the numbers of women with a BMI over 50 (or weight over 140kg) at any point in pregnancy who gave birth during this period. Australian participating maternity units also completed case surveys for eligible women.

Study period

Surveillance: (Australia and New Zealand) January to December 2010  Cohort study: (Australia) January to October 2010

The original Australian study period was January to December 2010. However, it became evident that the relatively high numbers of women with extreme BMIs, along with strong regional differences gave an incidence estimate that placed the study outside of the AMOSS criteria of a rare disorder (< 1:1000 births). The study period was subsequently reduced from 12 months to 10 months.
The relatively high volume of cases underpins one of the rationales for the study: to quantify the burden on maternity units in addition to providing valuable information about management and outcomes of extreme morbid obesity in pregnancy.

**Preliminary results**

There were 370 Australian women with extreme obesity with an estimated prevalence of 2.14 cases per 1000 deliveries (95% CI 1.93–2.37; n= 171,289 women giving birth in 2010 in participating AMOSS sites).

In New Zealand, 297 women with extreme obesity gave birth, with an estimated prevalence of 4.56 cases per 1000 deliveries (95% CI 4.07–5.11; n= 65,124 women giving birth in 2010). The Australian study showed the demographic profile of women with extreme obesity differed markedly from the comparison group. Although the age profile of the two groups was similar, the extremely obese women had a significantly higher parity. Women residing in lower socio-economic areas were disproportionately represented.

In addition to significantly higher rates of obstetric/medical problems, the models of care of the two groups differed significantly, with extremely obese women much more likely to access a hospital-based medical model. These women and their infants had increased risks of poor perinatal outcomes.

**Preliminary conclusions**

The increased incidence of morbid obesity has important implications for maternity service provision. The Australian findings reinforce the urgent need to address the issue of pre-pregnancy care and create weight management programs to reduce prevalence, and ensure that appropriate services are in place to reduce associated inequalities in outcomes. Further analysis of findings are in progress.

**Influenza A in pregnancy (ICU admission)**

**Background**

Influenza A (leading to intensive care admission) in pregnant women was an extension of a collaborative study between AMOSS and the Australian and New Zealand Intensive Care Society (ANZICS) Influenza Investigators during 2009. This population-based cohort study demonstrated that pregnant women, particularly in the second half of pregnancy, were more likely than non-pregnant women to develop critical illness associated with the 2009 H1N1 influenza. For women who developed critical illness, there were poorer outcomes including death of mother or baby. AMOSS and ANZICS continued their collaborative work looking at pregnant women admitted to intensive care as a result of influenza A (all subtypes) in 2010.

The research was extended to also examine medical and obstetric management and maternal and infant outcomes when pregnancy was complicated by influenza A-related critical illness. It studied the impact of immunisation on the incidence and severity of influenza A in Australia and New Zealand in 2010.

**Research questions**

1. What is the current incidence of intensive care admissions for women who have influenza in Australia and New Zealand and who are pregnant or within 42 days post-partum?

2. What are the risk factors for severe influenza-related critical illness in pregnancy?

3. How is influenza in pregnancy managed by medical and obstetric clinicians in the intensive care setting?
4. What are the outcomes for both the mother and infant where a woman has been admitted to an intensive care unit in Australia or New Zealand as a result of an influenza A-related critical illness?

**Methods**

A prospective incidence study using a monthly negative surveillance system including all participating AMOSS sites. Cross-notification by both AMOSS and the ANZICS influenza coordinator occurred. Separate AMOSS and ANZICS Influenza Investigators registry surveys were completed.

**Case definition**

All women in Australia and New Zealand who were: admitted to an intensive care unit and subsequently diagnosed with influenza A (all subtypes), and who were a) pregnant, or b) gave birth within six weeks of admission to intensive care.

**Study period**

June 2010 to December 2010 (Australia and New Zealand)

**Preliminary results**

Of the 46 notified cases, one woman was excluded as she did not fit the case criteria and 18 surveys were duplicates due to transfer of the woman between hospitals. Data analysis is in progress for the 36 women who had Influenza A.

Preliminary findings show there were no fatalities in the notified cases. There was only one case where the woman was immunised.

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**Peripartum hysterectomy**

**Background**

**Peripartum hysterectomy** is a surgical intervention to control obstetric bleeding with the aim of saving the woman’s life. Severe obstetric haemorrhage is a leading cause of severe maternal morbidity in Australia and remains a major cause of maternal death. Consequently, women who undergo a peripartum hysterectomy represent the most serious cases of obstetric haemorrhage. The incidence in Australia is increasing, with the number of identified cases tripling over a three-year period in a one-off Victorian study. This study seeks to identify risk factors and preventative measures.

**Research questions**

1. What is the current incidence of peripartum hysterectomy in Australia and New Zealand?

2. What are the risk factors for peripartum hysterectomy in Australia and New Zealand?

3. How is severe obstetric haemorrhage resulting in peripartum hysterectomy managed in Australia and New Zealand?

4. What are the outcomes for both the woman and the infant when a woman’s pregnancy results in peripartum hysterectomy in Australia and New Zealand?

**Methods**

A prospective, case-control study using a monthly negative surveillance system, including all participating AMOSS maternity units.

**Case definition**

Any hysterectomy that occurs immediately following or within six weeks of the end of a pregnancy was classified as a case.
Study period
2010–2011 (Australia); 2010–2012 (New Zealand).

Status
Data validation and analysis are in progress in Australia.
Data collection continues in New Zealand.

Placenta accreta

Background
Placenta accreta occurs when the placenta attaches abnormally to the uterine lining. Placenta increta refers to when the placenta invades the uterine muscle (myometrium), whilst placenta percreta refers to when the placenta grows through the myometrium and into adjacent structures, such as the bladder and ureters. The term placenta accreta is often used as a general term to describe all of these conditions. There is a strong association between previous caesarean section and placenta accreta. The published incidence rate ranges from 1 in 2510 to 1 in 553 women who give birth. There has been a notable increase in the incidence of placenta accreta over the past three decades and placenta accreta is a common cause of peripartum hysterectomy. The incidence, management and maternal and perinatal outcomes for women who have placenta accreta are not well characterised in Australia and New Zealand.

Research questions
1. What is the current incidence of placenta accreta in Australia and New Zealand?
2. What are the risk factors for placenta accreta in Australia and New Zealand?
3. How are women with placenta accreta managed in Australia and New Zealand?
4. What are the outcomes for both the mother and the infant in Australia and New Zealand?

Methods
A prospective, case-control study using a monthly negative surveillance system, including all participating AMOSS maternity units.

Case definition
Placenta accreta or increta or percreta: diagnosed by antenatal imaging; and/or at operation and/or by pathology specimen.

Study period
2010–2011 (Australia); 2010–2012 (New Zealand).

Status
Data validation and analysis are in progress in Australia.
Data collection continues in New Zealand.

Eclampsia

Background
Eclampsia is a rare condition associated with severe morbidity for both the mother and baby. Eclampsia is defined as the occurrence of convulsions, not caused by any concurrent neurological disease such as epilepsy, in a woman whose condition also meets the diagnostic criteria for preeclampsia (a hypertensive disorder of pregnancy). The UKOSS eclampsia study identified an incidence of 2.7 cases per 10,000 births in the United Kingdom, with a reduction demonstrated from earlier studies due to improved treatment of preeclampsia. The incidence of eclampsia and the associated severe morbidity is unknown in Australia and New Zealand. The extent to which Australasian clinicians have adopted the treatment recommendations for eclampsia since...
publication of the major international trials is unknown. Inclusion of eclampsia as an AMOSS initial condition seeks to address the urgent need to understand the epidemiology of eclampsia in Australasia and its treatment.

Research questions

1. What is the current incidence of eclampsia in Australia and New Zealand?
2. What are the risk factors for eclampsia in Australia and New Zealand?
3. How is an eclamptic episode treated in Australia and New Zealand?
4. What are the outcomes for mother and infant in Australia and New Zealand?

Methods

A prospective incidence study using a monthly negative surveillance system, including all participating AMOSS sites.

Case definition

A case is defined as any woman having convulsions during pregnancy or in the first 14 days’ postpartum, together with at least two of the following features (or only one if that feature is hypertension): hypertension (BP ≥ 140 systolic or ≥ 90 diastolic), renal involvement, haematological involvement, liver involvement, pulmonary oedema, fetal growth restriction, placental abruption.

Study period


Status

Data validation and analysis are in progress.

STUDIES IN PROGRESS

Amniotic fluid embolism

Background

Amniotic fluid embolism (AFE) occurs when some of the amniotic fluid surrounding the fetus enters the maternal circulation and results in profuse uncontrolled bleeding from a coagulopathy in nearly all cases, accompanied by cardio-vascular collapse in many women. There is currently little understanding of the incidence of this condition with estimates ranging from 1 in 8,000 to 1 in 80,000 women giving birth\textsuperscript{13}. AFE was a leading cause of maternal death in Australia in the last Maternal Deaths published report\textsuperscript{14}. There has been no comprehensive study on this major cause of maternal mortality in Australia, with the epidemiology and management of this condition unknown.

Research questions

1. What is the current incidence of AFE in Australia and New Zealand?
2. How are women who experience AFE managed in Australia?
3. What are the outcomes for both mother and infant in Australia and New Zealand following an AFE?
4. Are there any risk factors that may alter the outcomes for mothers and infants?

Methods

A prospective incidence study using a monthly negative surveillance system, including all participating AMOSS sites is underway.
“My world tilted on its axis”: Experiencing AFE

Cara Johnson# experienced an AFE in 2006 at Lyell McEwin Hospital in Adelaide, South Australia. This profile on Cara and comments by her surgeon highlight the impact (long term as well as immediate) that such an event has on family and clinical/maternity staff. Lyell McEwin is a participating site in AMOSS.

I had a natural birth. I remember James being placed on my chest: my husband and I were so in awe of our precious boy! I don’t remember what happened next. Apparently I was taken up to theatre to repair a perineal tear, and went into shock on the way. When I woke up in ICU I thought ’What sort of hospital puts you in ICU for having a baby? I’ve had a baby not a hysterectomy’.

But I had had a hysterectomy. And an amniotic fluid embolism and DIC [disseminated intravascular coagulation]. I was in and out of surgery/ICU and had 125 bags of blood products along the way. Fourteen hours after giving birth the doctors ’ceased active management’ and my husband was told to say goodbye. Thank goodness I proved them wrong.

Afterwards, I got tired of hearing about the saga and just wanted to be left to be a mum. They said I’d be in hospital for three months, but I managed to get home three weeks later. And then... James got a twisted and gangrenous bowel with a 20% chance of survival*. That’s when the reality hit, that’s when I went downhill.

There was an enormous network of support. It seemed that every which way I fell there was someone there to help me. And it wasn’t just me: they walked along the path with us all. People just don’t understand because they haven’t experienced it. The whole thing is surreal. The physical impact was incredible. I was so weak – I couldn’t lift a phone. But it was the emotional stuff: knowing I couldn’t care for my baby properly, that I couldn’t enjoy the new baby moon with my husband and family.

There’s the practical aspect too: all the parts that people don’t see. Our kids stuck at the hospital for hours on end, them not really understanding what was happening and not coping, the financial strain, all the stress on extended family and friends. Lachlan [Cara’s autistic son who was 12 when she had the AFE] still thinks I’ll die every time I go back into hospital. It all adds to the anguish. You understand why people go into a shell. The impact on partners and family is profound. You can see why there are relationship breakdowns. For my husband, there was the initial trauma of being told I wouldn’t make it – contemplating raising our family alone – and then there’s the aftermath.

It’s six years on now, and I’m the lucky one. I’m so blessed to spend every day with my beautiful family, especially my husband.

Knowing other women and families who’ve had an AFE and survived is so important. Talking with others through online media [there is an AFE foundation run through the USA and a Facebook page in Australia] is great but we need to build better networks of support. That’s why this [AMOSS AFE research] is so important. It’s collating the numbers and getting better information about what works and what can be done... so fewer women experience what I have.

(Note: AMOSS has submitted an NHMRC project grant application for Phase II which will continue AMOSS studies, as well as explore the experiences of women with rare and severe conditions.)

# Not her real name
*James has now recovered from his bowel condition.
Clinical comments from Cara’s surgeon

Amniotic fluid embolism is often an acute event. In Cara’s case, what started as a brisk bleed following a perineal tear, quickly developed into a massive haemorrhage. From the relative calm of the labour ward, Cara found herself being transported to an operating theatre filled with doctors and nurses. After several hours of treatment, including conservative medical and surgical options, Cara required a hysterectomy to control the bleeding. Although stable in theatre, Cara started to bleed again several hours later. The bleeding continued in spite of what at the time seemed to be a successful attempt at uterine artery embolisation. Cara required over 100 bags of blood products including packed cells, cryoprecipitate, fresh frozen plasma, platelets, factor VII and prothrombinex. Eventually we exhausted the State’s reserves and in the middle of the night we had to inform Paul that it was unlikely that Cara would survive.

Thankfully Cara had other ideas. The bleeding stopped and her condition stabilised. Like many serious conditions, Cara’s recovery was far from straightforward, made even more complicated by the sudden illness of her newborn baby James. The stress that such an event places on patients, family and medical staff cannot be emphasised enough. The more we can learn about these serious conditions in pregnancy the better.

Case definition

All women in Australia and New Zealand identified as having AFE through: a) a clinical diagnosis of AFE (acute hypotension or cardiac arrest, acute hypoxia and coagulopathy in the absence of any other potential explanation for the symptoms and signs observed); or b) a pathological/post mortem diagnosis (presence of fetal squames/debris in the pulmonary circulation).

Study period

2010-ongoing

Status

In progress

Antenatal pulmonary embolism

Background

Antenatal pulmonary embolism (APE) remains a leading cause of maternal death in Australia.14 Pulmonary embolism occurs when a woman develops a clot in a distal blood vessel, such as a pelvic vein, and part or the entire clot travels to and lodges in the lungs. This can cause cardio-vascular collapse. A UKOSS study found that antenatal pulmonary embolism was rare at 1.3 cases per 10,000 births and that there were many cases where thromboprophylaxis was not provided according to United Kingdom national guidelines15. These findings emphasise that APE is preventable and best practice must be implemented for all pregnant women. There is currently no reliable data on the incidence and management of women who experience non-fatal pulmonary embolism during pregnancy in Australia and New Zealand.
Research questions

1. What is the current incidence of antenatal pulmonary embolism in Australia and New Zealand?

2. How are women with antenatal pulmonary embolism managed in Australia?

3. What are the outcomes for both mother and infant following antenatal pulmonary embolism in Australia and New Zealand?

4. Are there any risk factors that may alter the outcomes for mothers and infants?

Methods

A prospective incidence study using monthly negative surveillance system of all participating AMOSS sites is underway.

Case definition

All women in Australia and New Zealand confirmed as having APE through: a) using suitable imaging (angiography, computed tomography, echocardiography, magnetic resonance imaging or ventilation-perfusion scan that shows a high probability of pulmonary embolism); or b) surgery or post-mortem; or c) clinically diagnosed based on signs and symptoms consistent with APE, where the woman has received a course of anticoagulation therapy (>1 week duration).

Study period

2010–2012

Status

In progress

NEW STUDIES

The following studies have been funded and approved by the AMOSS Project Board to commence in 2012.

Rheumatic Heart Disease (RHD)

Background

RHD is a serious (yet preventable) complication of acute rheumatic fever (ARF), where damage to heart valves can lead to severe morbidity and even death. It is a disease associated with poverty and deprivation. ARF and RHD have virtually disappeared from most parts of Australia and New Zealand\(^\text{16}\). However, Aboriginal and Torres Strait Islanders and Māori and Pacific Islander peoples have among the highest documented rates of RHD in the world\(^\text{17}\) with a reported incidence approaching that described in sub-Saharan Africa\(^\text{18}\).

Increased cardiac demands in pregnancy often lead to the worsening of clinical symptoms, particularly in those women with mechanical heart valve replacements who require ongoing anticoagulation. However, there is a lack of international and national research on the epidemiology, management and clinical outcomes of women with RHD in pregnancy. Most recommendations are based on generic studies of severe RHD in non-pregnant adults apart from isolated references to specific features of RHD in pregnancy\(^\text{19-22}\).

This study will provide an evidence base with a view to improving clinical care within a culturally safe model, and associated improvements in maternal and perinatal outcomes for women with RHD in pregnancy.
Research questions

1. What is the prevalence and distribution of RHD in pregnancy in Australia and New Zealand?

2. How do the models of care for women with RHD in pregnancy vary by severity of disease, place of residence and place of health service delivery in Australia and New Zealand?

3. What is the association between the severity of RHD and maternal and fetal outcomes?

4. Are maternal and fetal complications increased in women who have a new diagnosis of RHD during pregnancy?

5. What are the specific cultural, community and social needs of Aboriginal and Torres Strait Islander women in Australia and Māori and Pacific Islander women in New Zealand that are not currently addressed in health service access, counselling and clinical management for women with RHD in pregnancy?

Methods

A mixed methods study of women with RHD in pregnancy across Australia and New Zealand is planned. This includes a prospective incidence study using monthly negative surveillance of all participating AMOSS sites; and a qualitative study in the Northern Territory (NT), New South Wales (NSW) and New Zealand to explore women's experiences with RHD.

Case definition

All pregnant women with rheumatic heart disease diagnosed before or during the index pregnancy will be included in the study.

Study period

2012–2015

Gestational breast cancer

Background

Breast cancer is the most common cancer in pregnant women. Due to pregnancy-related physiological changes, delays in diagnosis are common. Currently little is documented about how women from Australia and New Zealand, diagnosed with breast cancer during pregnancy, are cared for or how they experience maternity care.

This study of the incidence, management and outcomes of breast cancer in pregnancy will be conducted using data primarily collected through AMOSS. A second qualitative study will explore the experience of pregnancy and birth for women diagnosed with breast cancer during pregnancy.

Information and knowledge generated from this project will provide an evidence base for consumers, as well as important guidance for obstetricians, oncologists, midwives and other allied health professionals about the diagnosis, management and outcomes of breast cancer experienced during pregnancy and about providing optimal maternal and fetal care.

Research questions

1. What is the current incidence of newly diagnosed (de novo) gestational breast cancer in Australia and New Zealand?

2. How are women with gestational breast cancer managed in Australia and New Zealand?

3. What is the experience of women who are diagnosed with gestational breast cancer in relation to diagnosis and the maternity care they receive during pregnancy?

4. What are the outcomes for both mother and infant?
5. Are there any factors that may improve maternal and perinatal outcomes and the women’s care experiences?

**Methods**

The project is a mixed methods study of women with gestational breast cancer across Australia and New Zealand, including a prospective incidence study using monthly negative surveillance of all participating AMOSS sites; and a qualitative study to explore the care experiences of women diagnosed with breast cancer during pregnancy.

**Study period**

2012–2013

**Vasa praevia**

**Background**

Vasa praevia (VP) is a serious complication that occurs in an estimated 1 in 2,500 pregnancies, where the blood vessels involved in the baby’s circulation grow along the membranes in the lower part of the uterus at the cervical opening. When the condition is not detected in advance, the blood vessels can rupture during labour and is associated with high rates of stillbirth. There is limited experience among individual practitioners in detecting and treating VP and little information about the best way to manage it.

This study will research the incidence, management and outcomes of VP and examine the pregnancy and birth experiences for women with the condition.

Findings will provide an evidence base for women affected by VP, as well as contributing to important guidance about the diagnosis, management and outcomes of VP in order to provide optimal maternal and fetal care.

**Research questions**

1. What is the current incidence of vasa praevia in Australia and New Zealand?
2. How is vasa praevia diagnosed and managed in Australia and New Zealand?
3. What is the experience of women who are diagnosed with vasa praevia in relation to diagnosis and the maternity care they receive during pregnancy?
4. What are the maternal and fetal outcomes?
5. Are there any factors that may improve perinatal outcomes and the women’s care experiences?

**Methods**

A mixed methods study of women with vasa praevia across Australia and New Zealand, including a prospective incidence study using monthly negative surveillance of all participating AMOSS sites; and a qualitative study to explore the care experiences of women diagnosed with vasa praevia during pregnancy and childbirth.

**Study period**

2012–2013

**ETHICAL REVIEW PROCESS AND AMOSS**


This paper described the ethics/governance review pathway undertaken by AMOSS, a multi-centre population health study considered low-risk with minimal ethical impact.

**PLANNED VAGINAL OR CAESARIAN DELIVERY IN WOMEN WITH EXTREME OBESITY**

Homer CSE, Kurinczuk JJ, Spark P, Brocklehurst P, Knight M. Planned vaginal delivery or planned caesarean delivery in women with extreme obesity. BJOG, 2011;118:480-487.

This study compared the outcomes of planned vaginal versus planned caesarean delivery in a cohort of extremely obese women (BMI ≥50kg/m2).

**CRITICAL ILLNESS WITH AH1N1V INFLUENZA IN PREGNANCY: A COMPARISON OF TWO POPULATION-BASED COHORTS**


* A collaboration of the ANZIC Society Clinical Trials Group (CTG), the ANZIC Research Centre, the Australasian Society for Infectious Diseases CTG, the Paediatric Study Group of the ANZIC Society and the ANZIC Society Centre for Outcome and Resource Evaluation.

This paper described the epidemiology of 2009 A/H1N1 influenza in critically ill pregnant women.
Conferences and Meetings


Vaughan G, Sullivan EA on behalf of the AMOSS Investigators. *AMOSS: a collaborative surveillance and research system looking at rare and serious conditions in pregnancy*, Women’s Hospitals Australasia (WHA) and Children’s Hospitals Australasia (CHA) 2010 Annual Conference, Melbourne, 2010 (poster).


International Collaboration

AMOSS is a founding partner in the International Network of Obstetric Survey Systems (INOSS), a body of clinicians and researchers from countries in Europe, United Kingdom, Australia and New Zealand. Professor Marian Knight, AMOSS Investigator and UKOSS Principal Investigator is Chair of INOSS. The aim of INOSS is to provide international leadership and foster international collaborative research of rare severe maternal morbidity and maternal mortality. In 2010, Professor Elizabeth Sullivan and Dr Claire McLintock represented AMOSS at an invited international meeting on AFE convened by the UK Obstetric Surveillance System (UKOSS) in Oxford UK. The 2011 INOSS meeting in Germany focused on maternal mortality and was attended by Chief Investigator Dr Claire McLintock. Current studies underway include peripartum hysterectomy.
Acknowledgements

The AMOSS project would not be possible without the generous contribution of the many clinicians, researchers and others who have brought their expertise and drive to help establish AMOSS. We are grateful for the enthusiastic and committed input of reporting clinicians and participating hospitals that provide the data and valuable feedback for our research. Thank you.

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- Gestational breast cancer is funded by the National Breast Cancer Foundation Novel Concept Breast Cancer in Pregnancy Award.

- Vasa praevia is funded by the International Vasa Preria Foundation.
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Dr Lesley Halliday, Project Assistant (2011)

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Dr Stephen Raymond, The Royal Hobart Hospital, Tasmania
AMOSS is fortunate to have invaluable input and generous strategic advice from representatives across a range of disciplines and groups. Annual advisory group workshops held in 2010 and 2011 drew on the expertise of over 40 participants from clinical sectors, risk management, public health, state perinatal committees, Departments of Health, and Indigenous and consumer groups.

AMOSS continues to extend its collaborative and strategic partnerships in order to strengthen and inform its studies and to enhance sustainability.

Ms Rachael Lockey, ACM representative AMOSS, Integrated Maternity Services, Health Services Division, Department of Health, Northern Territory

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**Rheumatic Heart Disease (RHD) in Pregnancy**

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Research Officer (Darwin): to be appointed

Research Coordinator NZ: to be appointed

Vicki Masson, New Zealand Perinatal and Maternal Mortality Review Committee (PMMRC) National Coordinator

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Intensive Care Admission

AMOSS is collaborating with Nepean Hospital Sydney researchers Dr Nhi Nguyen, Dr Ian Seppelt and Professor Michael Peek (AMOSS Chief Investigator), who have been given funding by the Australian Women and Children’s Research Foundation (OZWAC) to conduct a pilot study on ICU admission in pregnancy (2012). This prospective cohort study of obstetric admissions to selected intensive care units in Australia and New Zealand will inform a broader study of admission to intensive care in pregnancy.

References


AMOSS participating sites
2010–2011

AUSTRALIA

Australian Capital Territory
Calvary Health Care
Calvary John James Hospital
The Canberra Hospital

New South Wales
Armidale Hospital
Auburn Hospital
Bankstown-Lidcombe Hospital
Bega Hospital
Blacktown Hospital
Blue Mountains District Arzac Memorial Hospital
Bowral Hospital
Broken Hill Health Service
Calvary Health Care Riverina
Campbelltown Hospital
Canterbury Hospital
Casino Hospital
Coffs Harbour Base Hospital
Cooma Hospital
Cootamundra Hospital
Cowra Health Service
Deniliquin Hospital
Dubbo Base Hospital
Fairfield Hospital
Figtree Private Hospital
Forbes Hospital
Glen Innes Hospital
Gosford Hospital
Goulburn Base Hospital
Grafton Base Hospital
Griffith Base Hospital
Gunnedah Hospital
Hawkesbury District Health Service
Hornsby Ku-ring-gai Hospital
Hurstville Private Hospital
Inverell Health Service
John Hunter Hospital
Kareena Private Hospital
Kempsey District Hospital
Leeton Hospital
Lismore Base Hospital
Liverpool Hospital
Macksville Hospital
Maitland Hospital
Manning Base Hospital
Milton-Ulladulla Hospital
Moree Hospital
Moruya District Hospital
Mudgee District Hospital
Mullumbimby Hospital
Murwillumbah District Hospital
Muswellbrook District Hospital
Narrabri Hospital
Narran德拉 Hospital
Nepean Hospital
Nepean Private Hospital
Newcastle Private Hospital
North Gosford Private Hospital
North Shore Private Hospital
Northern Beaches Maternity Services
Norwest Private Hospital
Orange Base Hospital
Parkes Hospital
Port Macquarie Base Hospital
Queanbeyan District Hospital & Health Service
Royal Hospital for Women
Royal North Shore Hospital (RNSH)
Royal Prince Alfred Hospital (RPAH)
Ryde Hospital
Scott Memorial Hospital
Shoalhaven District Memorial Hospital
Singleton District Hospital
St George Hospital
St George Private Hospital
Sutherland Hospital
Sydney Adventist Hospital
Sydney Southwest Private Hospital
Tamara Private Hospital
Tamworth Rural Referral Hospital
Temora District Hospital
The Mater Hospital Sydney
The Tweed Hospital
Turner Hospital
Wagga Wagga Base Hospital
Westmead Hospital
Wollongong Hospital
Wyong Hospital
Young Hospital

Northern Territory
Alice Springs Hospital
Darwin Private Hospital
Gove District Hospital East Arnhem
Katherine Hospital
Royal Darwin Hospital

Queensland
Atherton Tableland Hospital
Ayr Hospital
Biloela Hospital
Bundaberg Hospital
Caboolture Hospital
Cairns Base Hospital
Cairns Private Hospital
Charleville Hospital
Chinchilla Hospital
Daly Bay Hospital
Emerald Hospital
Gladstone Hospital
Gladstone Mater Hospital
Gold Coast Hospital
Goondiwindi Hospital
Gympie Hospital
Hervey Bay Hospital
Innisfail Hospital
Ipswich Hospital
John Flynn Gold Coast Private Hospital
Kingaroy Hospital
Logan Hospital
Longreach Hospital
Mackay Base Hospital
Mareeba Hospital
Mater Misericordiae Hospital Mackay
Mater Misericordiae Hospital Rockhampton
Mater Mothers Hospital Brisbane
Mater Private Hospital Redland
Mater Women’s and Children’s Hospital
Hyde Park
Mount Isa Hospital
Nambour General Hospital
Pindara Private Hospital
Proserpine Hospital
Redcliffe Hospital
Redland Hospital
Rockhampton Hospital
Roma Hospital
Royal Brisbane and Women’s Hospital
Selangor Private Hospital
St Andrew’s Ipswich Private Hospital
St George Hospital Queensland
St Vincents Private Hospital
Stanthorpe Hospital
Sunnybank Private Hospital
The Sunshine Coast Private Hospital
The Wesley Hospital
Thursday Island Hospital
Toowoomba Base Hospital
Townsville Hospital
Warwick Hospital
Ashford Hospital

South Australia
Burnside War Memorial Hospital
Calvary Health Care
Flinders Medical Centre
Flinders Private Hospital
Gawler Health Service
Kapunda Hospital
Loxton Hospital Complex
Lyell McEwin Hospital
Millicent & District Hospital
Mount Barker District Soldiers' Memorial Hospital
Mount Gambier & District Health Services
North Eastern Community Hospital
Port Augusta Hospital & Regional Health Services
Port Lincoln Health Services Inc
Burnside War Memorial Hospital
Calvary Health Care
Flinders Medical Centre
Flinders Private Hospital
Gawler Health Service
Kapunda Hospital
Lynott Hospital Complex
Lyell McEwin Hospital
Millicent & District Hospital
Mount Barker District Soldiers' Memorial Hospital
Mount Gambier & District Health Services
North Eastern Community Hospital
Port Augusta Hospital & Regional Health Services
Port Lincoln Health Services Inc
North Eastern Community Hospital

Tasmania
Calvary Health Private Hospital
Hobart Private Hospital
Launceston General Hospital
Mersey Community Hospital
North West Private Hospital Burnie Campus
Royal Hobart Hospital
Women's and Children's Hospital

Victoria
Albury Wodonga Health
Angliss Hospital
Ararat Campus
Bairnsdale Regional Health Service
Ballarat Health Services
Benalla & District Memorial Hospital
Bendigo Health Care Group
Box Hill Hospital
Casey Hospital
Central Gippsland Health Service

Western Australia
Albany Regional Hospital
Armadale Health Service
Attadale Private Hospital
Bentley Health Service
Bridgetown District Hospital
Broome District Hospital
Bunbury Regional Hospital
Busselton District Hospital
Carnarvon Regional Hospital
Collie District Hospital
Derby Regional Health
Esperance District Hospital
Galliers Private Hospital & Specialist Centre
Geraldton Regional Hospital
Glengarry Private Hospital
Joondalup Health Campus
Kalgoorlie Hospital
Kalgoorlie Regional Hospital
Katanning District Hospital
King Edward Memorial Hospital For Women
Kununurra District Hospital
Margaret River District Hospital
Mercy Hospital Mount Lawley
Narrogin Regional Hospital
Northam Regional Hospital
Osborne Park Hospital
Peel Health Campus
Port Hedland Regional Hospital
Rockingham General Hospital
St John of God Geraldton
St John of God Health Care Bunbury
St John of God Health Care Subiaco
St John of God Hospital Murdoch
Swan Kalamunda Health Service

NEW ZEALAND
Auckland City Hospital
Bay of Plenty DHB
Christchurch Women's Hospital
Dunedin Hospital
Gisborne Hospital
Grey Base Hospital
Hawke's Bay Hospital
Hutt Valley Hospital
Middlemore Hospital
Nelson Hospital
Palmerston North Hospital
Rotorua Hospital
Southland Hospital
Taranaki Base Hospital
Tauranga Hospital
Timaru Hospital
Waikato Hospital
Wairarapa Hospital
Waitakere Hospital
Waitemata DHB
Wellington Hospital
Whanganui Hospital
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