

# AIMS



## Ensuring good births for all

Why are too many women dying or being  
injured during childbearing?

Time to listen to women and their birth  
companions

More to be done to prevent poor care

[www.aims.org.uk](http://www.aims.org.uk)

# Diary

## AIMS meetings

Friday 5 June 2015, Lincoln  
Friday 24 July 2015, London

All AIMS members are warmly invited to join us. For further details, to let us know you are attending or to send apologies please email [secretary@aims.org.uk](mailto:secretary@aims.org.uk)

## AIMS AGM

### and talk with Nicky Leap

Saturday 12 September 2015  
Bristol

**AGM 10.30 for 11.00 start**  
AIMS members only

### Lunch 1.30 - 2.30

For AIMS members and those attending the talk  
Please bring food to share

### General Discussion 2.30 - 3.30

### AGM talk and workshop

Open to all

### Working with Pain in Labour with Nicky Leap

3.30 – 6.00pm

Close 7.00pm

(Tickets for talk must be purchased in advance)

For further information and tickets please email [talks@aims.org.uk](mailto:talks@aims.org.uk)  
Please contact [secretary@aims.org.uk](mailto:secretary@aims.org.uk) if you wish to attend the AGM or send your apologies.

Please always check our website or contact us to confirm details as sometimes these change.

### Human Rights in Childbirth (HRiC)

#### *Africa Summit*

30 - 31 July 2015

Johannesburg, South Africa

A first Pan-African assembly on the role of human rights in women's healthcare during the childbearing period

and

#### *India Conference*

28 - 31 January 2016

Bangalore, India

Addresses how maternity care can optimise maternal and infant health outcomes within a respectful, culturally sensitive, human rights framework.  
[humanrightsinchildbirth.com](http://humanrightsinchildbirth.com)

#### *Midwifery Today*

#### *Pillars of Midwifery: Insight, Information and Intuition*

21-25 October 2015

Bad Wildbad, Germany

[www.midwiferytoday.com/  
conferences/Germany2015/](http://www.midwiferytoday.com/conferences/Germany2015/)

#### *Association of Radical Midwives*

#### *Oxytocin*

31 October 2015

Nottingham, England

[www.midwifery.org.uk](http://www.midwifery.org.uk)

# AIMS

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in the Maternity Services  
Registered Charity Number 1157845

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AIMS Research Group

A group has been established to review research for the Journal. If you are interested in joining the team, please email [research@aims.org.uk](mailto:research@aims.org.uk)

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founded in 1960  
by

Sally Willington 1931 – 2008

# AIMS

campaigning for better maternity services for over 50 years

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**Cover Picture:**

The Tree of Life Aran pattern was knitted by Ann Maxwell for the blanket commemorating those mothers who have died in Ireland.

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# AIMS for the Future

*A vision without a plan is just a dream*

*A plan without a vision is just drudgery*

*But a vision with a plan can change the world*

*Old proverb*

AIMS has always been a volunteer run organisation. It began 55 years ago and has survived with pretty much the same structure – a lay chairperson, a committee of lay members and many other volunteers. Last year, AIMS became a Charity because we decided that there were some advantages to doing so which will help to ensure our existence.

With the Charity status comes additional responsibilities for the Trustees; we felt it was time to reflect on the future of our organisation, so the committee held a long working weekend. We withdrew to a secluded house, cooked and fed ourselves and generally talked a lot about AIMS and childbirth.

As a result we have come away with renewed energy and enthusiasm and very exciting plans for our future. We discussed the ethos of AIMS and our vision for its future and are very much in agreement with what we would like to achieve. We want to remain an organisation with volunteers at its heart, but recognise that we do have to pay for some work to be done on occasions, as our Committee and volunteers are already contributing a great deal. We are about to start a project to create a virtual office that better suits our volunteer ethos, then we'll see whether we need to pay a co-ordinator to help us.

We discussed finances (which are reasonably healthy now in comparison to previous years), and the need for fundraising for a new website and new publications. We

## **The AIMS committee, talking childbirth and reminding ourselves of the wonders of nature**



**A selection of the squares knitted in memory of our Irish sisters – see page 14**

have exciting ideas about how a specially designed website could be far more accessible to many more people, meaning that many more could benefit from AIMS' information – but this will cost us – watch out for a new fundraising effort over the coming months!

The session on the Journal and our books highlighted many areas we still need to cover and we explored ways of finding more people to write for us.

Campaigning always gets the juices flowing and case loading midwifery came top of our (long) list as it encompasses so much of what women and their families need for a 'better birth' – and works for midwives too.

Social Media is still a mystery to some of us, but we recognise the value of Facebook and Twitter in particular and we are working to increase our presence on them. Equally we are not all experienced enough to cope with the management of the technology needed to run our organisation, so we shared information and made plans for more training.

AIMS' telephone and email helplines are staffed by a small number of volunteers and it was a good time to share experiences and issues which arise from providing such a service.

We decided at the end of our weekend that we had achieved many things – got to know each other better, agreed what AIMS' future looks like and made some decisions. Intensive yes, exciting yes, tiring yes, inspiring yes, but no conflict or falling out – who needs outward-bound courses! Our weekend was very productive for knitting too – we all knitted squares to remember the avoidable maternal deaths in Ireland that Jo Murphy Lawless and others have campaigned about over the recent years.

*Shane Ridley*

# Like Oliver Twist, we want more

Jean Robinson looks at studies of death and injury during and after pregnancy and birth

**I** have always thought that Oliver Twist should not have been asking for more gruel, he should have been demanding meat and vegetables too, with gravy on top. That's how it is with research data; the more you get, the more you realise how much more you need.

To be fair, our requests for 'more' data on maternal deaths have met with some success. When we asked for information on deaths from suicide, Dr. Gwyneth Lewis (then in charge of the Confidential Enquiries into Maternal Deaths) listened and for the first time this information was collected.<sup>1</sup> This appeared in the next report, again showing that suicide was at that time the largest single cause of maternal death<sup>2</sup> and it is still a major cause. The leading cause is now sepsis.

Both these reports and later ones, showed that women who killed themselves feared their babies might be removed, or had already had them taken, for fear of their being harmed by mentally ill mothers. But it was the women who died. 'Safeguarding' was killing women.

But there was something else we asked for that we have not yet achieved:

- a voice for bereaved relatives and birth companions in the enquiry process,
- or a voice for mothers themselves in cases of *near miss* maternal deaths.

Often when bereaved relatives have obtained records, they realise that there are differences between what has been written and what they know happened. We have seen similar discrepancies in many cases where women complained about care and had obtained their case notes. Observers may include birth companions who are health professionals themselves, or doulas who have seen many births. Yet Enquiries are based solely on case notes and reports from the professionals involved. This means that much valuable data which could be used for prevention is lost, and that the Enquiries are not as balanced as they could be.

On survivable damage and injury, there has been great improvement. Cases where women might have died, but did not – 'Near Miss' cases – are now studied, and this information is particularly useful because there are more of these, and important lessons are learned on prevention. As the women survived, their voices could be valuable. It is important that when a serious complication arises, the woman or her relatives should ask questions and obtain records.

- Ask if there has been a Serious Incident Review (if not, ask why not?)
- Get a copy of the report.

Last year, a study showed that there is considerable variation between maternity units as to which incidents triggered a review. For example, 99% of hospitals reviewed cases where there had been maternal severe blood loss, but only 62% looked at cases where the baby

had been cut during a caesarean section, or the mother had suffered trauma to her bladder or other organs.<sup>3</sup>

## Mothers' health after birth

### *The forgotten study*

But it's not just serious cases which interest us. From our busy helpline, we learn about ill health after pregnancy or birth which is not life-threatening, but which makes it hard to cope, means constant discomfort or misery, and can threaten marriages and relationships. The last big study in this country was done in Birmingham based on data collected 30 and more years ago<sup>4</sup> Mothers were asked about problems they had after the six week postnatal check. Most symptoms had lasted more than a year, and some up to nine years. The authors wrote:

*The extent and persistence of the reported morbidity surprised us:*

*47% of the women reported at least one new health problem.*

## worrying level of hidden severe and persistent ill health

Backache was a common problem (14%) and had often become chronic. However it was more common after epidurals (18.9%). But backache risks were not increased after elective caesareans, suggesting the cause might be related to posture and immobility during labour. Asian women were particularly prone to post-epidural problems. Other risks which increased with epidurals were headaches, neck-aches and tingling in hands and fingers. Problems unconnected with epidurals included stress incontinence, haemorrhoids, depression and fatigue. Yet many of these long term problems had not been reported to GPs or treated. Of course if the study were repeated now, the pattern of postnatal problems is likely to be different, but unless we look, we shall not know how common or serious they are.

That large study on over 11,000 women, published by Her Majesty's Stationery Office, described a worrying level of hidden severe and persistent ill health in women who were caring for babies and children. The authors' important recommendations in a summary article<sup>5</sup> seem to have been forgotten:

*'Consideration should be given to a re-defined mode of postnatal follow-up, providing a progressive schedule of discharge rather than routine discharge at 6 weeks.'*



Campaigning through knitting at the AIMS planning weekend – see page 14

And even the quality of the existing six week postnatal check has been criticised – and not only by our callers. In 2014 a joint survey by NCT and Netmums found that almost half (45%) of mothers thought their six week postnatal check was not thorough enough.<sup>6</sup>

We suggest that women about to have a postnatal check, or those who think theirs was unsatisfactory, should look at NICE Guideline CG37 on Postnatal Care, to see what the recommended standard is. If the standard was not met, complain. And if problems persist, keep going back.

One of the problems which often comes up on the helpline, is the difficulty of recovering from postnatal depression when you have a physical problem from the birth, and the fact that it's harder to get over the damage if you are feeling mentally low. It's a vicious circle. But many of our callers report GPs were too quick to see their problems only in terms of depression, and respond with a prescription for anti-depressants rather than support, without enquiring about the physical problems which they knew were important. Both need to be treated.<sup>7</sup>

Fatigue and exhaustion are too often dismissed as 'normal' or 'expected', yet are often severe and prolonged. This is an under-researched and under-investigated problem, which hinders recovery from both physical and mental problems. Women simply cope in different ways, soldier on, and nowadays are keen to show the health visitor there are no problems, since HVs nowadays are seen as part of the health police.

The major hindrance to investigating and understanding postnatal illness is the current child safeguarding policy, as we have already reported in the Journal.<sup>8,9</sup> Researchers have confirmed our impression that women were concealing mental illness for fear of being referred to social workers at a time when, at government behest, they were harvesting babies for adoption. As we know

from our cases, fears that babies could be taken away from you if you were ill, were sadly justified. The news has spread like wildfire – as correspondence on Mumsnet shows.<sup>10</sup>

### Unanswered questions

This means that many crucial questions about outcomes in maternity care remain unanswered. Are there fewer cases of depression and post traumatic stress disorder after continuous care by one midwife, or after home birth, or midwifery units versus obstetric units? This can only be researched by asking women, and as too many are now afraid to tell the truth, we shall never know. Yet mental health outcomes are a crucial measurement, since they affect the development of the newborn, health of all the family, and the woman herself – including risk of suicide.

*Jean Robinson*

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# Sally Rowlette's inquest

Jo Murphy Lawless asks what it tells us about the context of maternal deaths in Ireland

**This is the eighth verdict of medical misadventure in a maternal death since 2007. The MBRRACE Report follows another inquest verdict**

On 9 December 2014, the MBRRACE *Saving Lives, Improving Mothers' Care* UK report was published with the principal finding that maternal death rates have declined from 11 per 100,000, in the period 2006-8, to 10 per 100,000 for the current reporting period of 2009-2012.<sup>1</sup> Ireland, through the Maternal Death Enquiry (MDE), has been part of this confidential enquiry process since 2009 when, we are told, 'formal prospective collection of data concerning Irish maternal deaths'<sup>2</sup> commenced.

On 3 December 2014, the inquest into the death of Sally Rowlette in the maternity unit in Sligo Regional Hospital on 5 February 2013, returned a verdict of medical misadventure. This is the eighth such inquest and verdict since the death of Tania McCabe and her son Zach in Our Lady of Lourdes Hospital Drogheda in 2007. Five of these maternal deaths which went to inquest occurred since 2009, four of them between 2010 and 2012, while the fifth, Ms Rowlette's death in 2013, is outside the reporting period for the current MBRRACE/MDE summary.

Fundamental problems with the official internal hospital Health Service Executive (HSE) sanctioned review and investigation into Ms Rowlette's death were raised in the course of her inquest, with that hospital review scant on detail and seriously at odds with the clinical detail which emerged in the course of the inquest.<sup>3,4,5</sup>

These discrepancies raise very serious questions, sitting uncomfortably as they do alongside similar revelations from the seven other inquests since 2007. A number of these inquests were hard-fought for by the women's widowers, most notably, the inquest for Bimbo Onanuga who died in March 2010 in the Rotunda Hospital and Dhara Kivlehan, who died in September 2010, in the Royal Victoria Hospital, Belfast having been airlifted there from Sligo Regional Hospital. All these inquests and the surrounding efforts by families and legal teams to get at the core detail for the reasons eight young women died have featured delaying and obstructionist tactics on the part of the individual hospitals and the HSE itself.

The HSE, in full operation as the overall management body for the Irish health services since 2005 under the Department of Health, is not directly accountable to Irish citizens through parliamentary process, but is a so-called 'arms-length body'. The HSE promotes itself and its hospitals with the accepted language of good governance, accountability, best clinical standards, putting the person at the centre of its endeavours and so on, yet this proves meaningless when serious lapses of care occur. Individuals and families can register complaints with the HSE but in reality, individuals have no immediate chance of redress save through initiating a legal process.

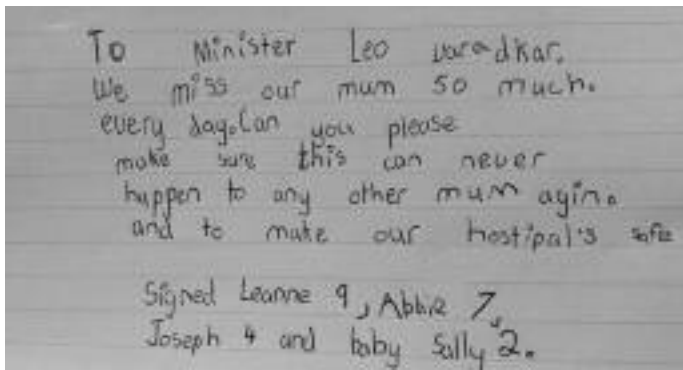
Ireland's formal health and social care institutions have a vicious history in the 20th century of secrecy, suppression and denial of the truth of women's needs and circumstances as mothers: the older scandal of the Magdalene homes and the current scandal of the treatment of women who experienced symphysiotomy are testament to this culture of which the HSE has also become a willing participant.<sup>6,7</sup> Under the circumstances, we need to ask two questions: how secure and reliable is the current process of data collection and collation on maternal deaths in Ireland as part of the MBRRACE confidential review, and how is better, safer care to be secured for women coming out of these tragedies.

## Securing accurate accounts of why women die

Nine months after Sally Rowlette's death, upon its becoming a focus of discussion in the press, the HSE issued a statement, saying that patient safety in Sligo Regional Hospital was paramount. It stated that 'we take all action necessary to ensure the safety and welfare of all pregnant women and all other patients attending the hospital'. It also said that 'risk management' and 'clinical governance' procedures ensure 'safe practice within the Obstetrical Service', with every 'adverse incident' reviewed and 'appropriate action taken'.<sup>8</sup>

That might sound reassuring had it not emerged during the recent inquest that the HSE's internal review of Sally's death from HELLP syndrome (a life threatening condition described as a variant, complication or severe form of pre-eclampsia which affects 1-2 women in every 1000 during pregnancy or after birth) failed completely to identify, let alone examine in detail, the disastrous failures in her clinical care. Astonishingly, this slim report contained a single recommendation, that women who developed HELLP syndrome be informed of same so they could reach decisions about family planning in respect of future pregnancies. There were no recommendations whatsoever about changing or improving the clinical management of HELLP syndrome.<sup>9</sup> The expert witness, a prominent Dublin consultant obstetrician, Dr Peter Boylan, brought in by the Sligo Coroner to review the HSE document, stated in his testimony that the lapses in care for Sally Rowlette began as early as 35 weeks but that her care on admission in labour was non-existent for what was by then a 'medical emergency'.<sup>9</sup>

More astonishingly and worse still, Ms. Rowlette's inquest followed that for Dhara Kivlehan which concluded in September 2014. That inquest, long-sought by Ms Kivlehan's widower and ultimately requiring an order from the Attorney General to hold the inquest,<sup>10</sup> took place a full four years after Ms Kivlehan's death in 2010, also from HELLP syndrome which was left untreated and undealt with in Sligo Regional Hospital after her baby was born by caesarean.



### A letter from Sally Rowlette's children to the Minister for Health

If the widowers of Dhara Kivlehan and Sally Rowlette and their dedicated legal teams had not pressed so hard for an inquest, none of the critical details in lapses of clinical care would be available to be provided to the Maternal Death Enquiry at any point.<sup>9</sup> The same is true for Bimbo Onanuga who died following treatment for an intrauterine fetal death in the Rotunda Hospital in March 2010. This was yet another prolonged struggle to gain an inquest, with her widower being left with no answers at all as to the reason Ms Onanuga died, until November 2013. Again the so-called internal HSE hospital review completely failed to disclose the circumstances surrounding Ms Onanuga's death, although the public was reassured of an HSE 'review' of her death in 2011, following questions being raised in the Dáil (Irish Parliament) about why no inquest had been held. At that point the HSE issued a very belated press release, extending their 'sympathies' to the family of Ms Onanuga for whom they claimed to have no contact details (although the inquest revealed that they did) and claiming as well to have submitted a report to the MDE.<sup>12</sup> Yet that report would have been woefully incomplete. Another slim review document comprising the HSE 'investigation' into Ms Onanuga's death was finally produced to her widower under challenge from his legal team during the prolonged inquest in 2013. The 'findings' in this review in no way matched the circumstances revealed in the course of the inquest, at the end of which Ms Onanuga's death certificate, originally reading 'natural causes', was changed by order of the Coroner at the inquest's conclusion to 'death by medical misadventure'.

We can hope that this revised account of events about Ms Onanuga's death found its way into the analysis of the just published 2009-2012 MBRRACE/MDE (which does accept coroners' reports). However, the full details of Dhara Kivlehan's case did not. The reporting period had closed and the MBRRACE report itself was being finalised before her inquest was held at the end of September 2014. We will need to hope that the next MBRRACE/MDE report will fully reflect the details from Sally Rowlette's inquest.

What we also need to understand is that if these courageous, bereaved men had not succeeded in securing inquests, the Irish data for the MBRRACE/MDE report would be even more incomplete. The very instrument lauded as a way of improving maternal safety has been shown by the inquests themselves to be critically

undermined as a result of the culture of secrecy and failure to disclose which has been shown to lie at the heart of the HSE.

### Securing better practice in the wake of maternal deaths

There has been a consistent and long-running disregard by the obstetric community in Ireland and by the HSE throughout its managerial layers as to the necessary work to incorporate lessons from experience and best practice evidence.

Tania McCabe's death and that of her son Zach in 2007 gave rise to a 2008 HSE report with the issuing of recommendations and directions to the country's 19 maternity units.<sup>13</sup> This report drew attention to:

- Delays in care
- Failure to diagnose signs of impending collapse
- Gaps in communication
- Failure to respond clinically at the highest levels of skill

These are the same issues pertinent to all eight maternal deaths which have gone to inquest since 2007. The HIQA (Health Information and Quality Authority) 2013 report on the death of Savita Halappanavar noted many of the same outstanding failures as the HSE 2008 report. It also noted that following on from that 2008 report, only five of the 19 units could even issue a 'status update' on HSE recommendations about critical care and directions from the HSE on developing a safer evidence-based system of monitoring and care for women with the potential to develop sepsis and, by extension, other serious conditions.<sup>14</sup>

In the UK, both NICE (National Institute for Health and Care Excellence) and the RCOG (Royal College of Obstetrics and Gynaecology) have published and updated specific evidence and protocols for identifying, dealing with and responding to HELLP, and other serious syndromes since 2000,<sup>15,16</sup> long before Sally Rowlette and Dhara Kivlehan's deaths.

National clinical guidelines for obstetric care in Ireland did not even begin to be produced until 2010 by the Institute of Obstetricians and Gynaecologists (IOG). The IOG was set up in the 1990s, but had not worked on developing guidelines in the way that its UK counterparts the RCOG had.

However the IOG guideline dealing with preeclampsia, eclampsia and HELLP syndrome was produced in 2011 and revised and updated in 2014.<sup>17</sup> Dhara Kivlehan died in 2011. If this IOG guideline had been adhered to, or indeed any lessons learned from Dhara Kivlehan's death, Sally Rowlette might not have died.

The indications from the inquests to date are that there are multiple failures by clinicians, local hospital environments and our national overseeing institutions in relation to their deaths and the deaths of the other women who have died since the 2008 HSE report on Tania McCabe: Bimbo Onanuga, Nora Hyland, and Savita Halappanavar.

Not only were the broad general lessons from the 2008 HSE report not applied to maternity units at local



hospital level, the HSE itself failed to apply proper and continuing scrutiny to ensure that standards were exacting and that units were complying with the evidence in the wake of these maternal deaths. Even if this country's senior clinicians and administrators did not want to rely on the long-running standards set in the UK by NICE and the RCOG, they did have, albeit belatedly, several years after Tania McCabe's death, the beginnings of IOG guidelines.

Why did the HSE deliver merely status updates after issuing the 2008 Report on Tania McCabe, apparently requesting these only after Savita Halappanavar's death in 2012?

Why did the HSE not insist on each unit validating that it was up to date in fulfilling the 2011 IOG guideline for preeclampsia, eclampsia and HELLP?

Why, after Dhara Kivlehan's death, was there not a similarly rigorous inspection of the facts and actions taken at Sligo Regional Hospital, as happened in Galway University Hospital after the death of Savita Halappanavar?

In the wake of Ms Kivlehan's death, where were the senior clinicians and administrators in HSE West who should have ensured that better procedures were put in place?

Did it take the international outrage over Savita Halappanavar's death, because of the complicating factor of abortion, to provoke any action in Ireland?

HSE managers, hospital administrators and senior clinicians are receiving and have received significant remuneration (their salaries plus allowances and top-ups), despite six years of austerity which have wreaked havoc on the pay levels for ordinary workers in the health services.<sup>18</sup> Indeed the number of senior hospital administrators has risen by 11 percent since 2011.<sup>19</sup>

The just released figures from the Rotunda's 2013 clinical report revealed three maternal deaths for that year: pulmonary embolism was cited as an issue for two of those three.<sup>20</sup> All we have from the Rotunda Hospital (which has yet to complete its 'business plan' for the HSE in order to justify the extent of top-up payments enjoyed by the Master and senior administrators)<sup>21</sup> is the assurance from the current Master, Dr Sam Coulter-Smith, that the hospital '*is looking at improving systems to tackle the difficult-to-predict but often fatal risk of embolism in some pregnant women*'.<sup>22</sup> Are consultant obstetricians and senior managers unable to access the RCOG Greentop 37A, on reducing the risk of thrombosis and embolism, first published in 2004?<sup>23</sup> The issue of 'insufficient staff', which the current Master asserts as an excuse, cannot cover the fact that senior staff have not done their jobs at hospital or at HSE levels in introducing guidelines about women in need of urgent attention.

Between 2009 and 2013 there have been 13 maternal deaths in the Rotunda.<sup>20</sup> For the sake of comparison, when there were 10 maternal deaths in Northwick Park Hospital in London between 2002 and 2005, the hospital was put under special measures, an external team was

## The eight women who have lost their lives in Ireland's maternity services through medical misadventure, 2007-2013

### Tania McCabe

died 9 March 2007, Our Lady of Lourdes Hospital

### Evelyn Flanagan

died 19 October 2007, Mayo General Hospital

### Jennifer Crean

died 10 February 2009, St. Vincent's Hospital after being transferred in a coma from National Maternity Hospital, July, 2008

### Bimbo Onanuga

died 4 March 2010, after being transferred from the Rotunda Hospital to the Mater Hospital Dublin where she died later that evening

### Dhara Kivlehan

died 28 September 2010, Belfast Royal Victoria Hospital, after being transferred from Sligo Regional Hospital on 24 September 2010

### Nora Hyland

died 13 February 2012, National Maternity Hospital

### Savita Halappanavar

died 28 October 2012, Galway University Hospital

### Sally Rowlette

died 5 February 2013, Sligo Regional Hospital

*The inquest for a ninth woman who died in Ballinasloe, having been discharged from Portiuncula Hospital, is due to begin shortly.*

sent in to safeguard women while far-reaching independent investigations were carried out and changes demanded before the special measures were lifted.<sup>24,25</sup>

Why do the HSE and the senior obstetric establishment in this country consistently choose to ignore the application and follow-through on good guidance to prevent and reduce the numbers of maternal deaths?

### An inquest for every maternal death

The extent of the lack of secure clinical governance at local hospital, regional and national levels is laid bare by the series of inquests families have endured since Tania McCabe's death. Given the consistent patterns of poor to non-existent care which have been revealed, along with the institutional obfuscation, dissembling, and denial which have characterised all eight inquests, we can also conclude that these same patterns are likely to be found in many of the additional deaths which escaped the scrutiny of an inquest process because, under current law, maternal deaths are not automatically subject to inquests.<sup>26</sup>

We can now see how the assumed comprehensive nature of the Maternal Death Enquiry report has been jeopardised; unless the MDE team was enabled to draw on inquest findings, its understandings of why individual deaths have occurred is woefully incomplete. By extension, this also means that any

maternal death which did not get to inquest is unlikely to have the full facts recorded for the MDE team in Cork, as hospitals and the HSE scrabble to withhold and deny. As part of MBRRACE, the MDE report seeks to lay claim to be part of a trusted instrument, the UK national confidential death enquiry which has been rightly accorded massive prestige internationally for over six decades. Instead, we can see that in the Irish context, it is massively misleading.

On its website, the Institute of Obstetricians and Gynaecologists states that it 'aims to pursue excellence in the delivery of healthcare to women and maintain high standards of practice.'<sup>27</sup>

We would like to see that happen in reality throughout the HSE maternity units whose clinical directors are members of the IOG. And yet it appears that Ireland's vicious institutional history of suppression of the needs and lives of pregnant women and women giving birth is set to continue.

**Jo Murphy Lawless**

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# When a mother dies...

*Manisha Nair, Charlotte McClymont, Anjali Shah and Marian Knight explain the work of MBRRACE-UK*

**A**lthough fortunately very rare in the UK, every maternal death is a tragedy. Each woman leaves behind a family without a wife, a mother, a daughter. The importance of learning from the death of every woman during or after pregnancy has been recognised in the UK for more than 60 years, and has been highlighted once again by the review of events that occurred at Furness General Hospital. By learning lessons for future care, we can make changes which will hopefully save more lives in the future.

The UK Confidential Enquiry into Maternal Deaths is the programme through which each mother's death is investigated. It is accepted as a gold standard worldwide. Considerable progress has been made following the introduction of these Enquiries. The chances of a woman dying during pregnancy, childbirth and within 42 days of giving birth has decreased over the 60 years the Enquiry has been in progress from 90 to 10 per 100,000 maternities.<sup>1</sup> Most recently, the Enquiry has been conducted by a collaboration of doctors, midwives and researchers called MBRRACE-UK (Mothers and Babies: Reducing Risks through Audits and Confidential Enquiries across the UK). The work now not only includes reviews of the care of every woman who dies, but also the care of women who have specific severe complications in pregnancy, but survive.

## What happens when a mother dies?

In order to ensure that the care of all women who die during or immediately after pregnancy is investigated, all hospitals in the UK report every woman's death to the MBRRACE-UK administration team, based at the National Perinatal Epidemiology Unit in Oxford.<sup>1</sup> Sometimes women's deaths are also reported by Coroners (Procurators Fiscal in Scotland), pathologists, supervising Midwifery Officers, the woman's friends or family, or we find out about them through reports in the media. The reported women's details are further cross-checked with records from the Office for National Statistics and National Records of Scotland to confirm that no women have been missed.<sup>1</sup>

Following the notification of a death, the doctor or midwife who reports the woman's death fills in a form that collects basic information about the woman who died (such as her age, occupation and any health problems she had before she became pregnant), details of the care she received during pregnancy and childbirth, and what she is thought to have died from. The hospital is also asked to send a full copy of all the mother's medical records. The doctors and midwives responsible for caring for the women who died are also asked to describe the women's care and to identify any lessons learned for changing care in the future. All the records received by the MBRRACE-UK team are made completely

anonymous, so any names of women, their families, staff and hospitals are removed from all the documents.

Once complete, the records are scanned and uploaded onto a secure computer system for review by independent experts. The first review that takes place is to try to find out what the woman died from. For some women, the cause of her death may be very clear, but for other women who collapse suddenly and unexpectedly, for example, this may be more difficult to determine. We need to find this out first, so that we can then assess whether the care for her condition was appropriate. After the reason a woman died has been identified, her records are examined in detail by two midwives, two obstetricians, two pathologists, one or two anaesthetists and other specialists as required to assess the care she received. MBRRACE-UK has more than 100 assessors who voluntarily review all mother's medical records to assess the quality of care delivered and to identify lessons that can be learned to improve care of future mothers.<sup>1</sup> The assessors are from a wide variety of health specialities, and as well as obstetricians, midwives, pathologists and anaesthetists also include obstetric physicians, psychiatrists, general practitioners, neurologists, cardiologists, specialists from intensive care and infectious diseases, and any others who we feel are needed. This comprehensive and detailed review is to ensure that we identify as many possible changes that need to be made to future care to prevent mothers from dying.

The entire process is strictly anonymous, so that none of the assessors know who individual women are, or the hospitals where they were cared for. The recommended changes to future care are drawn together and published in an annual report. However, under certain circumstances, concerns about a woman's care are fed directly back to hospitals and notified to the Healthcare Quality Improvement Partnership (HQIP).<sup>1</sup> The criteria which HQIP specify for raising concern include: deaths attributable to abuse or neglect; staff members displaying abusive behaviour; serious professional misconduct or a dangerous lack of competency when it is not clear if this has been reported to senior staff; and standards in care that indicate a dysfunctional or dangerous department or organisation, or grossly inadequate service provision.<sup>1</sup>

## Report publication

After completion of reviews of the care of all women who died, a group of writers are convened from all specialities from the pool of assessors. They identify important themes about the quality of care received by the mother who died and the lessons learned. The main themes related to care, lessons identified for improving the care of future mothers, information about the numbers of women who die and their causes of death, and the women's characteristics are all included in an

annual report.<sup>1</sup> In addition, a group of writers from some of the voluntary organisations involved in maternity care work together to produce a lay summary of this clinical report, which includes key messages particularly for women who are planning to have a child, pregnant women and women who have recently given birth.<sup>2</sup>

### Key messages for women from the 2014 report

The latest enquiry, *Saving Lives, Improving Mothers' Care*, published in December 2014 reported that 321 women died in the three years, 2009-12, during pregnancy, childbirth or within 42 days of giving birth.<sup>1</sup> One third of these women died from direct pregnancy-related complications such as bleeding and the other two-thirds from medical and mental health problems which developed or became worse during pregnancy.<sup>1</sup> Three-quarters of women who died had medical or mental health problems before they became pregnant.<sup>1</sup> Almost a quarter of women died from severe infections during pregnancy (sepsis) and one in eleven of the women who died had flu.<sup>1</sup>

## important messages for women who are planning to have a child

The report highlighted the need for joint medical and pregnancy care, and prompt recognition and management of danger signs as key to preventing deaths.<sup>1</sup> The report makes recommendations for policy makers, professional organisations, hospitals and healthcare staff. There are also important messages for women who are planning to have a child, for pregnant women, and for those who have recently giving birth.<sup>2</sup>

Women who have known medical conditions or mental health problems should seek advice from their doctor before they become pregnant or as soon as possible after they find out they are pregnant. It is important that women do not stop any medicines they are already taking unless they have discussed this with their doctor or midwife.

Women who have known medical or mental health problems should make their condition known to their doctor or midwife and not simply assume that it will be picked up from their existing medical notes.

More than half of the deaths due to flu could have been prevented if the women had a flu jab during pregnancy. Flu jabs during pregnancy can prevent complications of flu and save the lives of both mothers and babies.

Sepsis, which is a severe reaction of the body to infection, can develop rapidly. It is important that pregnant women and women who have recently given birth are aware of the signs and symptoms of sepsis (which can include high temperature, chills and shivering, fast heartbeat, fast breathing, breathlessness, headache,

severe abdominal pain, extreme sleepiness) and seek prompt care from senior doctors and midwives. Rapid diagnosis and treatment with appropriate antibiotics can save the lives of both mother and her baby.

Women should be persistent in asking their doctor or midwife to refer them to a senior doctor or midwife for consultation if they feel that they are not receiving the care that they need.

Women have the right to know about all aspects of their care. If anything goes wrong, women and their family should ask for a report of the review of their care, which the maternity unit should have undertaken.

### Moving forward

It is important to remember that the chance of a woman dying in pregnancy and childbirth in the UK is very small. However, although maternal deaths in the UK are rare, for every woman who dies there are about another hundred women who suffer severe life-threatening complications during pregnancy and may be left with life-long disability. To continue to save mothers' lives and improve the quality of maternity care, we must examine the care of women who have these major complications as well as every woman who dies, in order to drive change for the future and give every woman and her baby the high quality care they deserve.

*Manisha Nair, Charlotte McClymont, Anjali Shah and Marian Knight*

*Manisha Nair is a senior epidemiologist  
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### Editor's Note:

AIMS is aware, from members' discussion and calls to our helpline, that women are concerned about the potential effects of having or not having vaccinations for them and their babies and about possible long term effects on children of any medication in pregnancy. The evidence and guidance available to them can be lacking and is sometimes contradictory.

More research is needed on the efficacy, benefits and harms of vaccinations overall and how that applies to specific situations, so that women have good quality, wide-ranging evidence on which to base their decisions.

# Work in progress

Exploring midwives' deepest concerns in practice

**I**t may or may not have something to do with the forthcoming general election, but the problems of the National Health Service currently appear to be attracting more than their fair share of media attention.

The maternity services are not exempt from this scrutiny, as demonstrated by the Kirkup Report<sup>1</sup> on the Morecambe Bay debacle. Amid such devastation, the midwife has not fared well. Accusations and counter-accusations about staff shortages feature prominently in a health care system of which more is being expected while, simultaneously, being pared down to the bone. In the midst of this media feeding frenzy, there have been probably well-meant attempts to present the midwife as both squeaky clean and content with her lot.<sup>2,3</sup> Meanwhile, the NMC guidance on whistleblowing<sup>4</sup> demonstrated more tunnel vision than insight. In such a confused and confusing environment, resilience has been presented as an essential qualification and personality characteristic for the midwife.<sup>5</sup>

Against this conflicted background, the Birth Project Group ([www.pregnancyandparents.org.uk/birth-project-group/](http://www.pregnancyandparents.org.uk/birth-project-group/)) has undertaken a research project to listen to the voices of midwives and midwifery students in Britain and Ireland to present an accurate portrayal of the midwife's experiences and concerns. The survey comprised a confidential online questionnaire which was publicised through midwifery journals and social media. The data are being analysed qualitatively and quantitatively to provide a complete representation of how midwives and students are facing the current challenges. This short report seeks to alert readers to this work in progress and some of the data which are beginning to emerge.

Concerns about staff shortages pervaded and underpinned many of the responses. Inevitably, these concerns related to standards not being maintained:

*'Staffing always impacts quality of care ... Occasionally I believe that safety is compromised by staffing shortages.'*

Because of these staffing difficulties, many midwives found themselves 'doing extra' in the form of staying on duty late or taking work home with them:

*'It is not unusual to miss meal breaks and be off duty late. More often than not I am off duty late due to completing management documentation which I have had to delay in order to put the care of women first ... The women may get unsafe care but woe betide if we miss filling in the Infection Control Audit!'*

In this difficult environment midwives wrote of their need for interpersonal support and the benefits to them and their practice when such support was forthcoming:

*'If staffing and capacity are ok, I feel well supported and communication is good.'*

Those midwives, however, who could not locate such support, reported a very different and much bleaker experience:

*'At this stage nothing enables me to feel supported. I feel required to survive.'*

The questionnaire sought information about the midwives' and students' perceptions and experiences of 'raising concerns', which focused attention on whistle blowing. Many midwives reported that they were comfortable with the process:

*'Easy reporting process and open and honest culture encouraged.'*

Others, though, were less sanguine:

*'I'm not sure what would happen and may never get any feedback unless I ask for it.'*

*'The risk midwife is always encouraging us to report incidents, then she does a monthly report and its nearly always the midwife who gets the rap.'*

As has been mentioned in the literature, horizontal violence or bullying is familiar to many midwives:

*'Toxic culture, "if you can't stand the heat, stay out of the kitchen" attitude, machismo midwifery, bullying, jadedness, professional ambition ... lack of love and compassion for women and midwives ... etc etc etc.'*

Many midwives considered that protocols and guidelines only added to the challenges facing them:

*'We are encouraged to "bend" guidelines rather than challenge those that are clearly outdated and inappropriate.'*

In many of the responses to questions about what hinders good practice fear featured prominently:

*'I feel walking on egg shells when I go to the unit, you never know what you walk into, there is always a frisson of fear somewhere.'*

Particularly in the context of staff shortages, concerns about the welfare of women and babies were widespread:

*'I am worried that I miss something important which could have a detrimental effect on the mother or baby.'*

Or even:

*'[Concern] that someone will die.'*

Midwives frequently expressed disquiet about, not only their own future in midwifery, but also the future of the midwifery profession.

This brief account shows that the midwife and midwifery student respondents expressed anxiety about a wide range of aspects of their practice and the maternity services. These anxieties related to both clinical as well as organisational aspects and while some were immediate or relatively short term, others were far-reaching.

## Article

To remedy this sorry scenario midwifery needs a complete change of attitude. Midwives need to move away from the all too familiar power-based top-down arrangement. There needs to be more community-oriented partnerships which are both collaborative and involve both users and providers.

### *Birth Project Group.*

*The group is a collaboration between the Pregnancy and Parents Centre, Trinity College Dublin, the University of Edinburgh and Edinburgh Napier University.*

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# Knitting as commemoration, knitting for legal change

In the autumn of 2014, following yet another inquest into a maternal death ending with a verdict of medical misadventure, I felt strongly that something needed to be done.



Mary Smyth, knitting for the blanket for Irish women

We needed to draw public attention to the number of these inquests since 2007, what they have revealed about dysfunctional maternity services, to the devastating consequences for the families who have lost wives, partners and mothers, and the consequences for midwifery students and newly qualified midwives who have trained under the shadow of these catastrophic events. We needed to work with some concrete way to honour the women. Sara Wickham's thoughtful and timely suggestion of a concrete way to raise spirits and get the wider public thinking was a quilt along the lines of Ina May Gaskin's work (also see page 23); while quilting is not an Irish tradition, knitting is, and thus a project began to take shape: a large square to commemorate each individual woman, designed by skilled knitters, set

amongst many small squares by knitters of all ages and all levels of skill, the whole to be surrounded by a knitted border of those natural guardians of their own when birthing, elephants. We currently have nearly 100 knitters. Our youngest is 11 year old Grace Wood, whose mother, Catherine, is a second year midwifery student, while our oldest is Bridie Nolan, 87, whose granddaughter, Hayley is a third year midwifery student. The hanging should be ready to launch in the autumn of 2015, along with a short documentary. We will seek to use the launch as a way to gain support for a change in coronial law so that every maternal death is subject to an inquest.



Squares knitted at the AIMS planning weekend

Jo Murphy Lawless



Square knitted by Suzy Sabo

# Keeping women and babies safe

Becky Reed reflects on outcomes from the Albany Practice

**F**ollowing the recently published Kirkup investigation into poor outcomes at Morecambe Bay NHS Foundation Trust,<sup>1</sup> and the widely reported findings that in many cases it was the midwifery care that was to blame, it feels like the right time to re-examine the safety record of the Albany Midwifery Practice (AMP), which was set up in April 1997 and closed down by King's Healthcare Trust in December 2009.

The AMP had held a sub-contract with King's for over 12 years, enabling the midwives to offer a gold standard model of care to local women within the NHS. Following concerns expressed by the Trust about perinatal morbidity statistics (based on a highly questionable 'case series' produced at the end of 2008), and a subsequent report by CMACE (which did not recommend closure of the Practice, as AIMS<sup>2</sup> and others highlight), the contract with the AMP was abruptly terminated, and King's published a statement on its website, declaring: 'We have become concerned about the safety record of the Practice in comparison with the Trust's overall maternity safety record.' As Albany midwives we had admittedly pursued the goal of normal birth where possible, and had been proud of our lower than expected caesarean section (CS) rate. So to see that a group of midwives at Morecambe Bay has been charged with pursuing 'natural childbirth at any cost' prompts a desire to examine what this might mean, and its possible repercussions in the wider midwifery world.

The history of the AMP has been written about in previous issues of this journal, and there is a website where information about the Practice is available ([thealbanymodel.com](http://thealbanymodel.com)). The Practice (originally The South East London Midwifery Group Practice) was started by a group of dedicated midwives following the publication of *Changing Childbirth* in 1993.<sup>3</sup> The aim was to deliver excellent NHS midwifery care to an all-risk group of women; to be based in the community, and to provide choice and continuity of midwifery carer. We were acutely aware that this was an innovative model, and wanted to show that as well as being woman and midwife-friendly, it was a safe and effective way to provide care. Clinical outcomes were kept from the start in order to monitor this. An early evaluation of the AMP in 2001 reported that 'there is a clear pattern of woman centred care being offered and of partnership with women, which may contribute to the positive evaluations... and good clinical outcomes.'<sup>4</sup>

An analysis of the total outcomes of the AMP (1997-2009) is under way and is expected to be published later this year. However, an interim study was done examining the outcomes of 2000 women cared for by the Practice between 1999 and 2007, and was presented at the ICM in Glasgow in June 2008. One of the stated aims of the study was to 'investigate the quality and safety of caseload midwifery in this setting'.

The 2000 women study showed that women cared for by the AMP had a homebirth rate of 44%, a spontaneous vaginal birth rate of 80%, a CS rate of 16%, and an instrumental delivery rate of 3%. In comparison, the CS rate for England in 2007 was 23.5%, the instrumental delivery rate was 11.1%, and the national homebirth rate for England during the period of the study never rose above 3%.<sup>5</sup>

So here lies the fundamental question: were these impressive birth outcomes somehow compromising the safety of women and babies being cared for by the AMP? Looking at the outcomes in the study quoted above, it is clear that this was not the case. During this period the perinatal mortality rate (PNMR) for the AMP was 4.9/1000, compared with a PNMR for England and Wales in 2006 of 7.9/1000 (CEMACH 2008) and 11.4/1000 for Southwark, the London borough where the AMP was based. Based on these statistics, the AMP – at least for the period of the 2000 women study, and based on mortality rates – could clearly not be described as a dangerous model of care. Obviously it is important to review the outcomes for the total period (adding in data from 1997/98 and 2008/9), but there is no reason to believe that either the caseload or the midwifery care was substantially different during those years. This begs the question of why and how King's came to the shocking conclusion that the safety record of the AMP was concerning, and indeed why the Trust took the dramatic and devastating action that it did.

## Safety in midwifery care is clearly paramount

Safety in midwifery care is clearly paramount. An expectation of care that is as safe as possible should be a given for all women, and their families. As Cathy Warwick, General Secretary of the Royal College of Midwives (RCM) says in her comment for the RCM on the Kirkup report: '...safety is the priority both for women and babies... The basis of competent midwifery practice is high quality decision making based on assessment throughout the care pathway and with appropriate consultation...'. The lack of consultation with obstetricians is a strong criticism in the report. Embedded in the AMP's philosophy of care was the need to work alongside other like-minded professionals, and for many years this was achieved. A mutually-agreed named obstetrician was available for consultation at all times, with the obvious consideration that the AMP was caring for an all-risk caseload. Relationships were good, and we met socially as well as



### Becky with Alex, Justin and baby Freya

professionally. At the AMP's 10 year celebration party 'our' obstetrician gave a speech saying how much she had learned from the midwives about 'cooperation between midwives and doctors, and particularly being the advocate for the woman...', also stating: 'I think they're remarkable... because they never stop thinking about at any point in a woman's pregnancy or labour, what is the best thing for her. So it's never about what's easy for them, it's always about what's best for the woman.' These comments appear particularly extraordinary now, given that less than two years later, this same obstetrician was joining in with calls for the closure of the Practice. We can only speculate on the reasons for this. One theory is that it was the loss of a strong and supportive head of midwifery, combined with the involvement of other professionals with an entirely different agenda, which led to the undermining of relationships and the subsequent vulnerability of the AMP contract.

Safety is defined as '*not likely to lead to harm or injury*', which implies that morbidity as well as mortality should be included in the concept of keeping women and their babies safe. Deaths are a stark and obvious measure; in the AMP there were no maternal deaths and the PNMR (at least for the period of the study outlined above) was less than half that of the local borough. Morbidity is much harder to define, and yet it was morbidity rates (most specifically admissions to the neonatal unit of babies with alleged Hypoxic Ischaemic Encephalopathy) that were the catalyst for the allegations against the AMP in the lead-up to its demise. The poor quality 'case series' that was put together in an attempt to show that the AMP was practising dangerously was carefully examined by Professor Alison Macfarlane, perinatal epidemiologist and statistician, who concluded that '*it is impossible to draw any inferences*' from the evidence put forward. Even if the AMP did for a short period have a slightly higher than expected rate of babies admitted to SCBU, it has been pointed out by Professor of Midwifery Mavis Kirkham that with a decrease in mortality rates this could be an expected outcome, since babies 'saved' from death may well suffer from a certain morbidity.

Keeping women and babies safe also covers many aspects of disease prevention. Breastfed babies are less likely to become ill in their first year; the AMP midwives actively promoted an expectation of breastfeeding, and worked hard to maintain high rates of exclusive breastfeeding. 92% of AMP babies were exclusively breastfed at birth, 81% at ten days and 74% at 28 days. In comparison, at the time of the study, only 35% of UK babies were being exclusively breastfed at one week and 21% at six weeks.

Morbidity for mothers includes scarring (from a caesarean wound) or perineal damage, and possible associated postnatal infections. When CS rates are kept low, and when midwives work hard to minimise perineal trauma, women are healthier as they start out as mothers. These things are of enormous importance to women, and yet are often overlooked in the morbidity statistics.

Mental health is harder to quantify, but overwhelmingly important. Suicide is the second leading cause of maternal death in the UK, therefore anything that can be done to help prevent postnatal depression should be examined and embedded into models of care. The AMP midwives believed passionately that continuity of carer, building a relationship with women and their families, and providing individualised midwifery care all contributed to a safer, healthier and happier outcome for mothers and babies. Postnatal support was given a high priority, with AMP women not discharged from midwifery care until 28 days after the birth, and then encouraged to attend the postnatal group for as long as they wished.

With all of the above evidence about safety in mind, a campaign is ongoing to vindicate the Albany model of care, which has been so besmirched since the closure of the Practice just over five years ago. After continued requests to remove the damaging (and libellous) statement about the safety of the Practice from King's website, this has finally been done. And when the complete statistics are available we are planning a publicity campaign to ensure that all those charged with organising maternity services in the future are aware of the enormous benefits to mothers, babies, families and midwives of an Albany-style model of midwifery care.

**Becky Reed**

*Becky Reed is an ex-Albany midwife, grandmother, doula, writer and birth activist*

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# Stories behind the numbers

Christine Morton looks at the social invisibility of maternal morbidities in the United States

**M**aternal mortality and morbidity are on the rise in the United States.<sup>1</sup> Reasons for the rise are being investigated at the national and state levels, with a number of states conducting in-depth, medical record reviews of maternal deaths.

In the wake of the Amnesty International report,<sup>2</sup> and determined advocacy by organisations, there is growing public awareness in the US about the rise and to a lesser extent, about the much greater numbers of women who experience life-threatening or severe physical complications as a result of pregnancy or childbirth.

Numbers don't provide explanations as to why more women are experiencing severe complications in the US. I am often asked whether women who died had access to prenatal care or whether outcomes are worse because women are older, weigh more, or enter pregnancy with chronic health conditions. While some of those factors contribute, the reality is more complex. Findings from the California maternal mortality review provide associations between women's demographic characteristics and causes of death, but are not able to compare women who die with women who have the same condition, but do not die.<sup>3</sup> In addition, data sources for maternal death reviews come from official institutions: vital records (death certificates); medical examiners (autopsy and coroner reports) and health care (medical records and discharge data). This data can provide some insight into the process of care during the acute event, but very little on the nature of the health care interaction or the meanings women give to their experience.

My research colleagues (Adina Nack and Jamie Banker) and I have been conducting interviews with women, sometimes their partners, and a sample of health care practitioners who see women throughout pregnancy, birth and postpartum, and sometimes years after. We are interested to learn how women understood their experiences of severe morbidity as they occurred but also how they recovered and healed. We want to assess the impact of these severe events on their social relationships and long-term health. There have been few studies looking at these issues in the United States. We have learned much from the research done in other countries.<sup>4,5,6,7,8,9</sup> We are in the early stages of our research; about to begin analysis of the first 25 interviews with women who experienced a range of maternal morbidities – including haemorrhage (severe bleeding), preeclampsia/eclampsia, cardiomyopathy (heart muscle problems), amniotic fluid embolism (life threatening condition where fluid surrounding the baby or other fetal material enters the mothers blood stream) and severe perineal tears. To find women to interview, we seek referrals from friends and colleagues; from healthcare practitioners and from many organisations that advocate for and support those with particular conditions.

## Organisational advocacy and resources around maternal mortality and morbidity

Organisations don't exist for every complication nor do all organisations offer the same type of support or resources for women and their families. After a significant morbidity, women seek information to understand what happened to them and why. Sometimes women turn to organisations in lieu of therapy to connect with others and normalise their own experience:

*'I never actually did get therapy or any kind of one on one, which I probably should have done. But overall, I think that's one of the reasons why I sought out the March of Dimes and the Preeclampsia Foundation, because I think that was my form of therapy, to find other women who had been through circumstances with the prematurity and the preeclampsia. It normalised it in a lot of ways so I could talk about it and I could figure out, Oh hey! I wasn't alone in this.'* (Jane)

Many individuals and groups are working to put a face to the growing numbers of women who die, or nearly die, as a result of pregnancy or childbirth. These efforts are nearly always either single-issue or uncoordinated and focused on a particular condition. Some grow out of personal loss and take the form of a foundation named after a loved one. Other efforts are broader in scope such as the Unexpected Project. Designed at first as a documentary film project, the project has evolved into a national movement to raise awareness and foster discussion, with a blog, a Facebook page and a regular column on the Huffington Post. Even broader is the Every Mother Counts organisation, based in New York City and focused on the global context of maternal mortality, including the United States.

Organisations such as the Preeclampsia Foundation and the Amniotic Fluid Embolism Foundation are also single issue, but have a mission to support women and families affected by the condition as well as develop patient-data registries, raise funds to support research, and engage clinical research experts as Advisory Boards. Single-issue groups attract women who got a specific diagnosis, especially when the condition is often fatal:

*'I started doing research online. I started looking. I was, like, how did I not know about this before I had him? Why did I not know anything? Why was this never even mentioned to me? I found where there were links to Pitocin, you know. And I said, God. If I had known that, I would have never had Pitocin. ... Why did I not know these things? I realise it would scare the crap out of me, yeah, if I had been pregnant and then found out about it. But at the same time, maybe I might have made different decisions. I don't know.'* (Julie)

[Editor's note. Pitocin is called Syntocinon in the UK. It is a drug used to induce labour. For more information see the AIMS book *Inducing Labour*.]

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Finally, it is important to note that women who experience one of the most common complications of pregnancy – severe postpartum haemorrhage – have no particular organisation or advocacy group to turn to for support and information. In addition, we are not aware of US-based organisations for women who experience significant perineal damage requiring surgical repair. Indeed, those women often describe feeling erased from public awareness of, and support for, their complication, as injuries like fistulas are not assumed to occur in high income countries. Even their physicians downplay the possibility, as Athena experienced when she returned to her obstetrician at nine months postpartum:

*'I told her, "I'm still having multiple cases of fecal incontinence..." ...because she had warned me a bit that I could have..., I think it was even the next day after the birth, she said I'm at 50% risk of incontinence. Now to me, incontinence, I always thought meant urine. I never thought that fecal incontinence really was [possible].'* (Athena)

Our research on women's experiences with severe maternal morbidity will include analysis of organisational missions and their strategies and engagements with clinical and research experts.

### Childbirth is a unique health condition

Childbirth is a unique health condition, with not one but two 'patients,' and the meanings attached to the birth of a baby are qualitatively different from other medical treatments where a mishap or diagnosis error may occur. Patient advocacy groups addressing medical errors, or 'medically induced trauma' bring unique contributions from patient perspectives to hospital level process improvements. Yet while these advocacy groups are gaining recognition within healthcare quality improvement circles, they tend not to address (or include) the unique set of concerns facing women who experience severe complications in pregnancy and childbirth.

One of the common concerns raised by women after a severe maternal event is how health care providers communicate with them, especially when there has been an unexpected or unwanted outcome:

*'I can remember waking up and feeling...I was just mad. I was angry that it [a hysterectomy] had happened. I don't remember how I knew that everything had happened. I was told that a nurse had told me. She didn't know that I didn't know, that I wasn't going to be able to have any more kids. I had no clue what she was talking about and no one wanted to tell me at that point because I still wasn't stable and I guess this nurse kind of messed up and told me.'* (Annabel)

After a severe morbidity, some women fear being back at home and alone with their baby, post-hospital discharge. Many women may be physically weak and require additional help at home. The US has no national maternity leave policy; family members may not live nearby, and partners may have to return to work. Terri describes how she felt after her third trip to the hospital postpartum after passing out and experiencing severe bleeding at home:

*'I got released the next day and I wasn't feeling too bad. I went back to my mom's house and baby and I stayed there*

*for a couple days because my husband had used any time he had off during the birth and afterwards. So he still had to be at work all day and ...even though I really didn't think it was going to happen again, I was nervous about being alone. With the passing out.'* (Terri)

Women who have experienced a life-threatening event experience an existential crisis as well as a medical one.<sup>6,8,9,10</sup> They need to process the event yet often find that family members and friends wish to put the ordeal behind them.

*'There are times...when people say, "Oh, you should just be thankful you're alive." Well, I totally agree with that, but ...you know, it's hard. I guess every once and awhile you need a pity party and just to feel bad.'* (Julie)

Our research is ongoing; we have much still to learn about how women recover and heal from a severe morbidity; some women carry the burden for years, with the child's birthday an annual reminder of what they have but also what they have lost. Our research is informing national initiatives around supporting women and their families after a severe maternal event and we hope our findings will also help the women who share their stories with us as well as those who are yet to experience this most unexpected outcome of pregnancy.

**Christine Morton**

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# Maternal Death Reporting

*Ina May Gaskin* looks at financial pressures versus accurate maternal death reporting within the US private healthcare 'system'

**I**certainly can't predict what is going to happen in the UK, where since the early 1950s, those in the know take accurate maternal death reporting for granted. I can, however, explain to some extent (it would require a book to list all of the weaknesses in the US system) how large a role financial considerations have played in my country in the prevention of designing a system of even accurately identifying and reporting maternal deaths, let alone extending that system to reviewing, analysing and then making public their findings.

I was shocked when I first became aware that in my beloved country, it was possible in some hospitals for a mother to die as a result of a mistake and then to have the actual cause of her death falsified on her death certificate in order to lessen the chance that the real cause of her death might be discovered.

I had already read a brief report in a bulletin published in 1998 by the Centers for Disease Control (CDC) to the effect that maternal deaths in the US were seriously underreported – to such a degree that possibly more than half of the actual pregnancy-related deaths were not identified. That impressed me as a pretty serious flaw in the system, one that prompted me to start asking questions. I listened to countless stories from doctors, bereaved family members, nurse-midwives and nurses about how lies and cover-ups happen when death certificates are filled out.

Realise that it was only in 2003 that a standard US Death Certificate intended for use in all fifty states came into being. It took at least two decades of strenuous effort by state epidemiologists to reach consensus on the questions that should be included on a death certificate to catch those deaths that could possibly have been pregnancy-related. The brilliant new idea was that the standard certificate would replace the fifty individual state death certificates that were in use prior to 2003.

Our epidemiologists are not idiots. They have to be aware of the statistical garbage that results from data gathered in such an inconsistent, haphazard way. How embarrassing it must be for them to attend international conferences and have to admit to international colleagues how primitive our maternal death reporting 'system' has always been.

However, having created a standard death certificate form in a country in which private medicine and private hospitals are the norm and states' rights are held sacred, particularly as related to matters of health care, does not mean that the product will come into use in every state. That next step may take as long or longer than it took to create the standard form.

It might be different if the CDC had the clout to make it mandatory for the states to replace the form they are currently using with the standard. It doesn't. The states have the right of refusal. Who will pay for the change?

Only Congress could settle that question once and for all, but it is not a US habit to think about national solutions in such matters. Old habits die hard, to say the least. The states were left to bear the financial burden, and quite a few decided not to switch to the new standard form. The CDC can coax, but it cannot compel.

Now more than a decade has passed since the Standard Death Certificate became available and the CDC began encouraging its use. I tried calling every state several years ago to find out how many states had refused and found more than fifteen 'hold-outs' then. Living in one of them let me know they still exist. The CDC hasn't told us how many still refuse to open the state purse strings to make this one-time change to help the CDC be able to make an announcement that the Standard Death Certificate actually deserves its name.

It boggles the mind to understand how hard it is in a country where private health care and hospital ownership have long been the norm, for the concept of the necessity for accurate maternal death reporting to be introduced, let alone accepted. How would one 'sell' such a revolutionary concept to national or state legislators? Who has the attention span to follow the argument? There is so much inertia, indifference, deception, denial and disbelief to overcome that people can't find the words to make something different happen. I tried but in the end, I've had to leave that work to others.

I nearly wept the first time I was handed a copy of the book that was published triennially in the UK by the Confidential Enquiries into Maternal Deaths before its privatisation and saw the care, the detail, the thorough planning and the level of social agreement that had produced such a continuing effort. To be told that this book (*Why Mothers Die* and later *Saving Mothers' Lives*) could actually be purchased by any member of the public at a bookseller was a revelation to me. I realised that people in my country are far from imagining that such an effort could be possible, let alone why it might be necessary.

The more questions I asked, the more I found out that maternal mortality review committees in several states which had previously been organised by certain obstetricians with active consciences had been undone and disbanded during the 1980s and 1990s. This backward step taken by several states was prompted by pressure from lobbying groups representing the interests of private hospitals. These groups claimed that the continued existence of the statewide mortality and morbidity review committees would increase the chance of reports resulting from such investigations being obtained as evidence in malpractice lawsuits. Never mind that laws could be passed to provide confidentiality for such reviews. Fears of bad publicity or financial loss to private hospitals trumped any

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positive action to reduce maternal death rates by first reaching a high degree of ascertainment.

Need I mention that if lies are legal and may protect the financial interest of a hospital, they will be told?

It boggles the mind to realise how little provision for preventing maternal death exists in the current US system, even after so many media reports have appeared about the rising maternal death rate in our country. These reports rarely mention the serious underreporting factor or the fact that failure to gather data in a way that meets international epidemiological standards is only one of the many reasons behind the underreporting.

Journalists continue to assume that the CDC's reported maternal death rates are reasonably accurate when that is still far from the case. Few people understand that women of childbearing age die for all kinds of reasons that can be easily covered up when there are no rules governing the process of data collection that provide for punishment when they are not followed. How many legislators at the state or national level even know that accurate data gathering is vital to accurate answers as to the leading causes of death?

When these answers aren't available, it becomes habitual to guess, and such guesswork often leads to answers that would suggest that the woman herself might have been the author of her own demise. She was too old or too overweight for her own good.

A maternal-fetal specialist told me that 'amniotic fluid embolism' recorded as a cause of death is often suspect, because it's the 'waste-basket diagnosis' – the cause of death least likely to invite suspicion or investigation. When I first started asking questions that might shed some light on why there could be so much underreporting on such a grave matter I remember a case in which the family had first been told that the mother's uterine artery had been nicked and repaired during an emergency caesarean but that she had survived. When the repaired artery burst and she haemorrhaged a few hours later, her life couldn't be saved. I decided to see if an ordinary citizen such as myself could have a look at the death certificate. Since I had lived in the university town where she died, I knew the name of the county and was told that I could get a copy if I sent \$10. (This would no longer be possible, by the way). Cause of death: amniotic fluid embolism.

The fact that autopsies after a pregnancy-related death in the US are not required by law or custom creates another reason to doubt the answers to the 'cause of death' questions on death certificates. A nurse-midwife from California told me about a death from the haemorrhage that followed a sliced uterine artery in which the cause of death was filled out with 'anaemia'. Tears came to her eyes when she told me the story.

The fact that most of our fifty states allow hospitals to have internal, closed-door, highly confidential reviews following a maternal death because there is no morbidity-mortality review committee at the state level with the authority to demand access to the records of the deceased woman's care adds another incentive to record a lie on a death certificate. There is no audit. I can't count how many times I have listened to stories of frustration from obstetric

nurses and nurse-midwives who were not allowed to be part of the 'review' that was carried out after a maternal death in their maternity unit and were left suspecting that a cover-up was being made.

Another important issue within a private system is that an autopsy following maternal death is not covered by public insurance or by most private maternity care insurance. This puts the burden of payment on the family in grief and is a big factor in why autopsies are more rarely done than they were decades ago. Autopsies tend to be reserved for cases of criminal death, not for death in the maternity ward. I have talked to several bereaved family members who wished, months or years after a mother's death, that they had insisted on an autopsy to identify the real cause of her death, who were influenced not to by a person in the hospital who was represented as a 'grief counsellor'. One woman told me that such a hospital employee had made comments to her daughter's husband about how an autopsy wouldn't bring her back to life and linked this to his decision to forgo one in her case, a decision he later regretted.

What I have written here is far from complete, I have only touched on some of the fundamental reasons for the gross inaccuracy of US maternal death reporting and the failure to organise a system of enquiry worthy of the name.

Another time when I felt like crying was when I read about the removal of the Confidential Enquiries process in the UK from directly under the Department of Health to a commissioned consortium that reports to a number of different bodies and realised that the four copies of that comprehensive triennial report that I made sure to get while they were still being published stand now as evidence of a bygone era in the UK. Fortunately the enquiries are currently being carried out by the National Perinatal Epidemiology Unit (NPEU), but there is the possibility of these being placed elsewhere and of them not being in such good hands, as the state increasingly gives up responsibilities for services.

*Ina May Gaskin*

*Ina May is a midwife and the founder of The Farm Midwifery Centre, Tennessee, USA*

### Unnecessary intervention increases risk

A new scientific report published in January 2015 shows that unnecessary medical interventions in labour and during birth is putting mothers and babies at risk.

Dr Sarah Buckley, in her report *Hormonal Physiology of Childbearing: Evidence and Implications for Women, Babies and Maternity Care*, details the evidence showing that promoting and protecting innate biological processes results in healthier outcomes for women and newborns as well as optimising breastfeeding and maternal infant attachment.

The report, consumer booklet, infographics and other materials are all available online, free of charge, at [ChildbirthConnection.org/HormonalPhysiology](http://ChildbirthConnection.org/HormonalPhysiology).

# Future Mothers 2014

MBRRACE UK conference on the Confidential Enquiry into Maternal Deaths and Morbidity

**T**he day<sup>1</sup> was opened by Maureen Watt, Scottish Minister for Public Health. Other speakers included the many people who have worked directly on the report.

The 120 page report, *Saving Lives, Improving Mothers' Care: Lessons learned to inform future maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2009-2012*<sup>2</sup> is produced by the National Perinatal Epidemiology Unit in Oxford and available to the public.

This was a sombre day – 321 women died, 581 children were left motherless and for each mother who died, 100 women had severe complications. Avoidable or not, the human cost is profound.

Marian Knight told delegates about the Confidential Enquiry process: the report will now be annual, include Ireland and will focus on specific morbidities (any one of us can propose a topic for this). Collecting information for this enquiry was particularly challenging, due to a 14 month gap in data collection. The team had to go to coroners (not all maternal deaths are reviewed by a coroner), Local Supervising Authorities and others. It also covers four years rather than the usual three. The maternal mortality rate in the UK of 10 women in every 100,000 is apparently comparable to many other European countries, despite media criticisms. Marion suggested that in half of the maternal deaths, better care might have made a difference.

Numbers of speakers expressed concerns about how reviews of maternal deaths are conducted: not all staff are involved and not all are rigorous. For example, Sara Kenyon told us that 47% of maternal deaths due to sepsis were not critically reviewed and only 5% were externally reviewed.

Numbers of speakers stated that having a flu vaccine, greater awareness of sepsis and better care for women with epilepsy (currently there is a lack of consensus about good care) would have saved some mothers' lives, and that many women who died were older, poorer, from ethnic minority groups, born in other countries, overweight, had pre-existing medical problems, and/or mental health problems.

Speakers urged practitioners to improve basic clinical skills such as: history taking and observations (as was highlighted in the last Confidential Enquiry), engaging women (especially those with social and/or medical complications), developing better ways of team working, creating individual and flexible care plans, and contacting senior clinicians with any concerns.

Many speakers emphasised the need to observe and listen to women; carrying out full assessments and approaching a developing crisis in a structured and systematic way, with the right senior staff, based on best available evidence, making sure that a plan is in place and that decisions are carried out.

Sepsis was one of the topics focused on by this Confidential Enquiry and numbers of talks covered it in detail: it is apparently the most common cause of death worldwide, the incidence is higher following forceps and caesarean births and it is more common among women postnatally than the general population.

Alison Rodger pointed out that repeated self-referral should

be a 'red flag' to practitioners and should trigger investigation (as should reports of abdominal pain). Kevin Rooney described how he contributed to a collaborative approach to reduce sepsis mortality rates in Scotland.<sup>3</sup> Craig Stobo gave a personal account of the tragic death of his wife and unborn child through sepsis and provided information about the Trust that has been set up to increase awareness and knowledge about sepsis in her memory ([www.featurk.org.uk](http://www.featurk.org.uk)).

## Other topics included:

**The rise and treatment of severe haemorrhage** The key messages were to anticipate, recognise, observe, record, communicate, act quickly with the correct treatments and make sure someone continues to take responsibility.

**Amniotic fluid embolism** The main message here was that we have good guidelines – implement them.

**Neurology** Adrian Wills suggested that while not many women could have survived, there is insufficient access to neurologists who can diagnose serious from non urgent cases and that this is a complicated area requiring much discussion.

**Anaesthesia** Deaths from anaesthesia have been reduced, but prompt, correct responses and follow up are vital.

Whatever was discussed, the same themes were repeated:

- good team working and communication
- fast recognition and treatment of serious problems
- getting senior staff involved
- regular observations and recording these
- good resuscitation skills

These are not dissimilar to the recommendations of the previous Confidential Enquiry. But, where resources are stretched to their limits, it is not difficult to see why some women may not receive the prompt and correct treatment they need in an emergency.

The new NICE Guideline on Intrapartum Care which recommends that practitioners should inform healthy women that out of hospital settings are safe for them and their babies and that they reduce intervention rates are a welcome addition to the creation of safety for women and babies. Implementing these recommendations would leave more time and resources for obstetricians to look after the women who need their care.

One final issue that has not to my knowledge arisen in previous Confidential Enquiries is that of changing financial arrangements for health care which can lead to delays in treatment. This played a part in the care of at least one of the woman who died. If the relentless privatisation of the NHS in England is to continue, this will surely feature more prominently in maternal and other deaths.

*Nadine Edwards*

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# Maths and miscommunications

Colm OBoyle and Joan Lalor explore maternal death reporting in Ireland

**F**ebruary 2015 marked the joint launch in Ireland of the MBRRACE-UK report (which now includes Irish cases in its confidential enquiry) and the Irish Maternal Death Enquiry (MDE).

National maternal death statistics allow us to recognise patterns and make comparisons about the ongoing quality of maternity services over time. Statistics, however, can only tell you so much. In-depth enquiry into individual deaths reveals much more and allows focused recommendations for the improvement of services. Recent cases in Ireland<sup>1,2</sup> demonstrate that internal enquiries into maternal deaths and serious incidents in Irish maternity settings have been entirely inadequate.

In the UK, maternal death statistics have been presented alongside in-depth, confidential enquiries into individual deaths as part of the national confidential triennial enquiry process. The issue of confidentiality might be seen by the bereaved family as a failure of transparency and a denial of responsibility and accountability. It is argued, however, that confidential enquiries encourage openness on the part of staff and enable an objective examination of the circumstances surrounding each mother's death. This year, for the first time, confidential enquiries into maternal deaths in Ireland, as distinct from the Irish maternal death statistics, have been included in the MBRRACE-UK confidential enquiry into maternal deaths and morbidity report,<sup>2</sup> while the Irish statistics themselves appear only in the Maternal Death Enquiry Ireland (MDE).<sup>1</sup>

It is perhaps unfortunate that these Irish statistics are reported under the title Confidential Maternal Death Enquiry Ireland (MDE). The inclusion of 'confidential' and 'enquiry' in the title has led to much confusion, because it could be inferred that all Irish maternal deaths are subject to this same process of enquiry that has been established for a very long time in the UK. An overriding problem is capturing data on all maternal deaths. Although the MDE reports Irish maternal death statistics, albeit more accurately than those available from the Irish civil death registration system, it may very well be that as few as one in four of these tragic deaths are included in the review.

This commentary focuses on two aspects of the system for finding, investigating and reporting of maternal deaths in Ireland: mathematics and miscommunication.

## The mathematics of calculating maternal death statistics

In order to make meaningful comparisons and to allow for very different population sizes, health indicators need to be collected and reported in the same way.

Simple fractions will be used to illustrate this point. In fractions, the numerator is the number above the line and the denominator is the number below. To determine how safe a maternity service is, we need to know how many women died (the numerator) out of the total number of

women cared for by that service (the denominator). Differences in how the numerator and the denominator are determined will undermine fair international comparison.

## Identifying the numerator

The authors of the MDE Report in Ireland have stated that as many as four times the number of maternal deaths reported by the Central Statistics Office (CSO) have been discovered through their 'active case ascertainment'. This entirely undermines any claims to the 'safety' of Ireland's maternity services.<sup>4</sup>

Ascertainment here, basically means the ability to search for and find cases of maternal death. It is worrying however, that despite being more effective at identifying maternal deaths than the statutory mechanism of death certification, the accuracy of the MDE's data still depends on the individual drive and enthusiasm of the MDE group as well as goodwill from service providers toward the initiative.

## Determining the denominator

The number of deaths needs to be presented with a common denominator, often per one hundred (that is percent) or per thousand people. Maternal deaths, are quite rare and so the international standard for reporting maternal death rates is per 100,000 live births.

The UK and Ireland have adopted 100,000 'maternities' as the most appropriate denominator. One should remember that there are always more pregnancies (or 'maternities') than live births. Using a larger denominator (maternities) than is usual internationally (live births), gives an unfair impression in that UK and Irish maternal death rates may 'look' better. (For example,  $\frac{1}{4}$  is bigger than  $\frac{1}{5}$ , the only difference is the denominator; but 1 in 4 deaths is certainly worse than 1 in 5). Consequently, comparisons using different denominators is inappropriate.

The UK and Ireland's use of maternities might falsely give the impression of improvement from prior years (where live births had been used as the denominator) and a false impression of better outcomes compared to countries still using live births as the denominator. Furthermore, live births may be relatively easily determined in most countries, but 'maternities' are somewhat more difficult. Think, for example, that most pregnancy miscarriages happen before health personnel, epidemiologists or even women, know about it.

As data are available to calculate maternal death rates based on either denominator (maternities or live births) we suggest that both should be presented in future MDE reports, so that Irish maternal death rates can be fairly compared not only with the UK, but also internationally.

## Communication and miscommunication - a central theme in maternal deaths

The MDE group recommends therefore that all

maternal deaths 'should' be reported to the group. However, we suggest that this measure alone will not result in the detection of all maternal deaths. Post-mortem reports alone are also inadequate because while they identify the cause of death (such as haemorrhage), they do not investigate the circumstances surrounding the death. It seems from the MDE report, that too often they even fail to identify the death as a maternal death at all.

In Ireland, when a death due to unnatural causes occurs, an inquest is required by law (Coroner's Act 1962). We suggest that this requirement should be broadened to include all cases of maternal death, so that the circumstances of all maternal deaths can be investigated fully. Although the inclusion of Irish data in the MBRRACE-UK enquiry is to be welcomed, it will not, nor is it intended to, assist Ireland with the identification of suboptimal care within its maternity service. If all maternal deaths were subject to a Coroner's inquiry, each case could be reported to the Minister of Health for surveillance purposes, without breaching the confidentiality of those involved. A precedent exists for such ministerial oversight in Irish maternity services, as under the Protection of Life During Pregnancy Act (2013), data on all cases of termination of pregnancy under the Act must be forwarded to the minister.

The authors of the MDE report state that women born outside of Ireland were over-represented in reported deaths. They indicate that this reflects UK reports of increased risk of maternal death among migrant ethnic minorities. Their recommendation that interpretation services should be used to avoid miscommunication would, at first sight, appear to be aimed at the over representation of non-Irish women in Irish statistics. Language difficulties however were not implicated in the deaths of many of the recent and prominent cases of maternal deaths of non Irish born women. As ethnicity would seem to be a recurrent theme in Ireland and in the UK, a more focused and penetrating enquiry into the possible causes of this association is urgently required.

## Conclusion

Improved ascertainment, that is, the ability to search for and find all maternal deaths, is critical to an accurate calculation of the maternal death rate in Ireland. The public requires reassurance that a mechanism to ensure accurate and systematic recording is in place. The MDE authors need to identify in future reports HOW missed cases have been missed, and propose HOW those loopholes can be closed. The absence of statutory and infrastructural support for national reporting undoubtedly means that the identification of cases will continue to be challenging. Without the continued commitment of the MDE team, the determination of cases would be significantly worse and our national statistics would continue to be appallingly unreliable. We wish therefore, despite this critical commentary, to declare our full support for the MDE in the difficult and essential work that it undertakes on our behalf.

**Colm OBoyle and Joan Lalor**

*Colm is a midwifery lecturer in Trinity College Dublin with a specific interest in homebirth and was until recently, a home birth midwife.*

*Joan is an Associate Professor and Director of Teaching and Learning (Postgraduate) in the School of Nursing and Midwifery, Trinity College Dublin.*

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# The Safe Motherhood Quilt Project

The Safe Motherhood Quilt Project is a national effort developed to draw public attention to the current maternal death rates, as well as to the gross underreporting of maternal deaths in the United States, and to honour those women who have died of pregnancy-related causes since 1982, the year that the United States Center for Disease Control reported the lowest maternal death rate.

The Project is the vision of Ina May Gaskin, midwifery pioneer and author of *Ina May's Guide to Childbirth*, the classic *Spiritual Midwifery* and *Birth Matters: A Midwife's Manifesta*.



# Working together

Hannah Robertson shares her experiences of meetings between midwives and doulas

In the last four years the community of doulas in York has grown considerably from a small number of four to around 11 doulas. The doula community is thriving with a fairly cohesive support network. Naturally, with the growth of doulas in our small city the volume of doula attended births started to grow.

In 2012 there was a huge increase in the number of women being visited by supervisors of midwives (SoM) during pregnancy if they planned to have a doula supporting them during labour. I think there are several reasons for this, one being that women who have experienced an inappropriately risk-based and/or unsupportive approach during their pregnancies have been more likely to hire doulas. When the SoMs started to realise that the women they were being asked (by the community midwives) to visit had booked doulas, the doulas started to get invited to midwifery meetings set up by the SoMs to discuss care of women who were making decisions outside existing guidelines. Part of the aim of having doulas at these meetings was to put faces to our names and I think to assess how we work as doulas.

One of our community of doulas had a complaint made against her after a homebirth in 2012. The complaint (made by a midwife) was dismissed after the SoM met with the mother and the doula post birth. The complaint was made because the doula, following the mother's wishes, had presented the midwife with a birth plan when she (the midwife) entered the mother's home. The midwife felt this stopped her doing her job and obstructed her from speaking to the mother directly. At the post birth meeting the complaint was raised and the SoM listened to the mother who told her that it was her idea that the doula greet the midwife. The midwife had also raised another concern with the SoM – that she had been called too late to the birth (the baby was born 40 minutes after the midwife's arrival) and the mother told the SoM that this had also been her decision as she felt she did not need the support of the midwife until they called her. After this meeting the SoM thought it would be helpful to meet with the local doulas so that we could discuss our role and boundaries.

In 2013, the first meetings were planned and in 2014 we met four times. We started off by discussing what was felt by the midwives to be a contentious issue: whose decision it is to decide when to call a midwife during labour at home. The SoM initially asked us to share with women that the midwives were all very lovely and to urge them to call the midwives out earlier rather than later in labour. The doulas explained this was not their role or responsibility and that doulas can only facilitate the wishes of the mother, and provide information rather than advise. This was understood and accepted by the midwives.



© Hannah Robertson

Doulas and midwives, meeting and working together in York

We moved on to discuss advocacy, birth preferences and not speaking for women but encouraging them to find their own voices and speak up when their words have not been listened to.

After the first couple of meetings we started getting into the nitty gritty of feeding back our thoughts and experiences after births. For example, basic birth etiquette can sometimes be lost in the NHS system. Women need quiet and privacy, as we all know, but not all of the midwives attending births have recognised this. We have fed all this back to the SoMs, requesting that midwives' mobile phones be on silent, suggesting that most women need darkness, silence and a minimum of language to be used. Since we started our discussions, I have definitely seen an improvement in the birth etiquette of midwives. Our discussions have now moved to; the need for midwifery training to support women having vaginal breech births; the use and impact of language; and women's mental health in the perinatal period. The SoMs are feeding back the main points of our discussions to the doctors this month, and will also talk to them about the effect of using the 'dead baby card' on women and will discuss how to present risk in a way which excludes manipulation. All we can hope for is to chip, chip, chip away at this system.

Changes are afoot, slowly. Midwives meeting us at births are becoming warmer, which is huge progress from earlier hostile encounters. I feel very lucky that we have this regular forum with midwives to discuss what women want, as ultimately this increases safe, good care for women and their babies and families.

**Hannah Robertson**

*Hannah is a mother, doula and antenatal advocacy worker*



# Controlled cord traction

Gill Gyte asks, is it needed to deliver the placenta?

**C**ontrolled cord traction (CCT) is traction applied to the umbilical cord once the woman's uterus has contracted after the birth of her baby, and her placenta is felt to have separated from the uterine wall, whilst counter-pressure is applied to her uterus beneath her pubic bone until her placenta delivers. This is part of the active management of third stage of labour (AMTSL) which is currently recommended by NICE.<sup>1</sup> Some women can find CCT unpleasant and some wish to avoid it.

Active management of third stage of labour was originally described as a combination of three interventions: 1) a routine drug to contract the uterus (uterotonic drug, previously syntometrine, now usually syntocinon, in the UK) given just before, with or just after the birth of the baby, 2) early cord clamping and cutting, and 3) controlled cord traction (CCT)<sup>2</sup> but this can cover many variations in practice.<sup>3</sup> Active management has been shown to reduce the risk of severe blood loss (postpartum haemorrhage or PPH) following the birth of a baby in a population of women at mixed risk of PPH compared with expectant management of third stage of labour (EMTSL).<sup>3</sup> Expectant management is where the placenta births naturally, so there is no routine uterotonic drug, the cord is clamped and cut after the placenta is born or when cord pulsation ceases, and the placenta birthed spontaneously or with maternal effort.<sup>3</sup> A number of recent guidelines use differing definitions of active management, and recommend deferred cord clamping although they differ in how long to wait.<sup>1,4,5</sup> So it is important for women to check exactly what care is given in their localities when active or expectant management are used.

Research has looked at the individual components of active management to see what part each might play in reducing PPH. A Cochrane review shows that the routine uterotonics play an important part in reducing PPH.<sup>6</sup> However, for mothers of babies born at term, early cord clamping did not reduce severe haemorrhage, blood loss, the need for blood transfusion or postnatal haemoglobin,<sup>7</sup> (studies on preterm births did not assess maternal outcomes).<sup>8</sup>

## Does CCT reduce PPH?

A Cochrane review was undertaken to evaluate the effects of CCT during the third stage of labour, either with or without conventional active management.<sup>9</sup> The review includes only randomised controlled trials (RCTs) and the authors assessed each trial for quality using the Cochrane risk of bias tool.<sup>10</sup> Authors identified three RCTs, one very large trial conducted by WHO across eight countries (Argentina, Egypt, India, Kenya, the Philippines, South Africa, Thailand, and Uganda) involving over 23,000 women.<sup>11</sup> Another trial was conducted in several sites in France involving over 4000 women<sup>12</sup> and the third trial was a single centre trial in Uruguay involving nearly 200 women.<sup>13</sup> Data from the very large WHO trial dominates the pooled data in the Cochrane review but smaller studies did show similar findings and trial quality is good.

All three trials administered a routine uterotonic, generally oxytocin given intramuscularly (IM) or intravenously (IV), although some centres in the WHO trial used oxytocin plus

ergometrine. All three trials used some form of deferred cord clamping: in the WHO trial, cord clamping was between 1-3 minutes,<sup>11</sup> in the French trial it was within 2 minutes<sup>12</sup> and in the Uruguay trial once pulsation stopped or after 3 minutes.<sup>13</sup> The WHO trial, and thus the Cochrane review, include both term and preterm births.

## What the review found

The review found no difference in severe PPH (blood loss over 1000 ml) when CCT was used compared with no CCT, nor were there any differences identified in the use of additional uterotonics, blood transfusion, maternal death/severe morbidity, operative procedures or maternal satisfaction. Manual removal of the placenta (MRP) was reduced with CCT, although this outcome was only assessed in the WHO and French trials.<sup>11,12</sup> In the WHO trial, the reduction in MRP with CCT disappeared (0.7% in both groups) when the centres routinely using oxytocin plus ergometrine were excluded from the analysis.<sup>11</sup> In the French trial,<sup>12</sup> which also showed a reduction in MRP with CCT (4% with CCT versus 6% with no CCT), the clinicians waited 30 minutes before performing MRP so it is not known whether there would have been a difference if clinicians had waited an hour. The review also found a small reduction in blood loss over 500 ml and length of third stage was shorter with CCT.

## What does this mean for women in the UK?

The authors of the review concluded that the skills of providing CCT need to be maintained as there are circumstances where CCT would be required, but authors also said:

*Women who prefer a less interventional approach to management of the third stage of labour can be reassured that when a uterotonic agent is used, routine use of CCT can be omitted from the "active management" package without increased risk of severe PPH, but that the risk of manual removal of the placenta may be increased.<sup>9</sup>*

However, the recent UK NICE updated guidelines for intrapartum care<sup>1</sup> recommend CCT, so women wishing to avoid CCT should discuss this with their caregivers ahead of labour. Since NICE no longer recommends syntometrine (oxytocin plus ergometrine) but now recommends 10iu oxytocin (syntocinon) by intramuscular injection routinely for third stage, MRP is unlikely to be affected if there is no CCT and time for birthing the placenta is not restricted to 30 minutes, (as the subgroup analysis in the Cochrane review indicates<sup>9</sup> with data from the large WHO trial<sup>11</sup>).

## Finally

So for women wishing to have minimal intervention in the third stage of labour, this recent evidence is helpful. The evidence shows that the routine uterotonic component of active management is the key component in reducing PPH, and with the current NICE guidance to defer cord clamping<sup>1</sup> and the evidence of little benefit from CCT in the Cochrane review,<sup>11</sup> women have good grounds on which to discuss their requests. In addition, observational data from New Zealand showed an association between normal blood loss and expectant management of third stage in women following a physiological labour and in the care of skilled midwives,<sup>14</sup> but further research is needed on this.

## Reviews

If women have particular wishes for care during the third stage of labour, then it is important to discuss these carefully with their midwife ahead of labour as misunderstandings around care during third stage can have severe consequences. It is helpful if the birth companion also understands the woman's wishes and the available evidence.

**Gill Gyte**

*Gill is the Consumer Editor,  
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### Editor's Note:

The AIMS publications *Am I Allowed?* and *Birthing Your Placenta* could be very useful to anyone planning this aspect of their care.

# Reviews

## *Am I Allowed?*

By Beverley Lawrence Beech

AIMS 2014

Publisher's recommended price £8.00

ISBN 13: 9781874413356

Available from [www.aims.org.uk](http://www.aims.org.uk)

This updated and fully revised edition has been eagerly awaited and does not disappoint.

The 2014 *Am I Allowed* has almost doubled the size of the 2003 edition, but the focus remains the same – in order to make informed decisions about what happens to them and their baby, women need good quality, up to date information, and, above all, they need to know their rights.

As well as revisiting all the evidence for topics previously covered, the new version also includes loads of information on new developments in maternity care and pregnancy screening tests.

The section on antenatal screening is extended to cover all the screening tests currently offered, with discussion and links for further research should you seek information beyond the scope of this book. It also covers new topics such as the assessment of maternal BMI and maternal blood serum screening.

The section on your rights to birth care and the responsibility of the maternity system is also brought right up

to date, with discussion of the *Birthplace Study* and reference to the research included in other new AIMS publications. A very helpful section on your rights to decide who is present at the birth of your baby includes a section on planned freebirth and a clear

acknowledgement of the difference between actively and positively choosing to birth without professional attendance and the situation for those women who have been unable to get the care they wanted and have ended up with less support than they would have chosen.

This version also, very helpfully, puts at the beginning a list of the acronyms in common use in maternity care. This not only helps when using the book, it is also invaluable when deciphering maternity notes, care plans and keeping up to speed in discussions about your care. Decoding the jargon enables you to remain on an equal footing in discussions with those professionals who might otherwise not offer full explanations.

AIMS truly listens to what women are saying, and, as a result, of all the pregnancy books I have read to date, this is far and away the most comprehensive, helpful and accurate summary I have found. It is a must-have for women, doulas, midwives and anyone else involved in women's rights.

**Vicki Williams**



# A tribute to Sheila Kitzinger

Sheila devoted much of her life to raising awareness about medicalised birth practices, women's rights and the emotional and spiritual transition from woman to mother. She was enormously well-respected and influential, as can be seen from the many personal tributes in the press and on social media, since her death in April 2015.

In 2010, on the eve of the 100th International Women's Day, The Independent on Sunday published its guide to *the 100 British women who, arguably, have done most to shape the world we live in today* ([www.independent.co.uk/news/people/news/a-century-of-distinction-100-women-who-changed-the-world-1917427.htm](http://www.independent.co.uk/news/people/news/a-century-of-distinction-100-women-who-changed-the-world-1917427.htm)), with Sheila included. As a childbirth activist, focused on women's rights, it was particularly apt, as it coincided with 100 years since the campaign to improve women's rights was founded.

Sheila Helena Elizabeth Kitzinger MBE was born at home in Taunton, Somerset on 29 March 1929 and died on 11 April 2015. She became a social anthropologist, specialising in pregnancy, birth and parenting. She was an honorary professor at the University of West London and Thames Valley University and frequently lectured to midwives and birth activists here and abroad, appearing on radio and television and for many years writing *Sheila Kitzinger's Letter from Europe* for the influential magazine, *Birth*. Perhaps most importantly she touched the lives of many women and families, supporting them personally, or through her writing to feel empowered, give 'Birth Your Way', and to heal after the devastating consequences of birth trauma.

It is impossible to cover all Sheila's achievements – her books, articles and website ([www.sheilakitinger.com](http://www.sheilakitinger.com)) demonstrate the breadth and depth of these. Topics include the politics of birth, homebirth, water birth, women's experiences of sex, birth and becoming a mother and grandmother, life after birth, caring for a new baby, birth trauma, breastfeeding, midwifery, birth in other cultures and more. She was an outspoken and effective critic of the use of routine obstetric procedures and spent her career advocating for women's right to information and decision-making – advocating for all women regardless of circumstances. We look forward to reviewing her new book, due to be published in May 2015, *A Passion for Birth: My Life – Anthropology, Family and Feminism*.

Sheila's colourful, passionate, knowledgeable and wise presence will be missed by us and by very many others.

*Sheila Kitzinger's book Birth Crisis was the turning point for me in the understanding that my postnatal PTSD wasn't all my fault. Before I read her words I thought I was too sensitive, not prepared enough for the birth, couldn't cope as a new mum. Her book described what conditions need to be present to create PTSD and at the moment I read that I could let go of the shame, guilt and fear of the future, and for that I am eternally grateful.*

**Marie – AIMS Member**



Sheila Kitzinger with AIMS Trustee Chloe Bayfield

*Sheila was a national treasure. Her involvement in maternity issues were so wide ranging. Just one example, those of us who decided to organise the First International Home Birth Conference invited Sheila to join the organising committee and a few years later to join the first International Waterbirth Conference committee. Her skills at media involvement were invaluable and she enthusiastically offered to approach her wide range of international contacts as we developed the programmes. These are but two examples of Sheila's activities. She was generous with her time and was always willing to be involved. She will be sorely missed.*

**Beverley**

*Years ago, young, and passionate about women's rights and the harms of unnecessary obstetric interventions, I wrote in response to an article by Sheila, suggesting that she had not gone far enough in her criticism of the routine use of electronic fetal monitoring. The letter was published and Sheila immediately phoned to congratulate and agree. That was her style: generosity and encouragement for those becoming involved in the politics of childbirth. Her work has been invaluable to me. I have recommended her books to countless women, knowing that they would find not only sound information, but affirmation of their feelings and experiences. Every page, no matter which book, acknowledges that childbirth and mothering are rites of passage that engage us physically, emotionally, spiritually, socially and culturally – and can be magical and deeply transformative when we have socially sensitive care that listens and empowers.*

**Nadine**

*Over the years I have been involved in the politics of childbirth and women's rights, I have had the pleasure of meeting Sheila on numerous occasions. She was always inspiring, always enormously generous with her time, wisdom and supporting ear, and practically helpful to the last. Recently I met her at a Birth Crisis workshop, run by her and her equally enthusiastic daughter, Celia. Not only was the workshop packed with tools for helping women in crisis and campaigning, Sheila was keen to teach women to support others by giving space to their own journeys and by personally validating each and every experience. That personal touch, leading by example, is typical of her very much 'hands-on' approach to support. Her energy and skill will be missed far and wide, and her loss will be deeply felt by many.*

**Vicki**

# How you can help AIMS

AIMS has just become a Charity. It still has no paid staff – our committee and volunteers give their time freely. All monies raised go towards providing women with support and information.

All AIMS members are invited to the

## AIMS AGM

Saturday 12 September 2015

Bristol

10.30 for 11.00 start

please contact [secretary@aims.org.uk](mailto:secretary@aims.org.uk) if you wish to attend or send your apologies.

Followed by

Lunch

for AIMS members attending the AGM and those attending talk

Please bring food to share

1.30 - 2.30

and

**Interactive talk with Nicky Leap**

**Working with Pain in Labour**

3.30 - 6.00pm

Presentation followed by workshop

Tickets for talk must be purchased in advance

For more information or to buy tickets please email [talks@aims.org.uk](mailto:talks@aims.org.uk)

**If you are not already a Member, you could join**

As a Member, your benefits include four AIMS Journals a year and access to the AIMS Members Yahoo Group. You will be able to stay in touch and have more of a say in what AIMS is doing. You will receive updates from committee meetings and early notice of events such as AIMS talks, as well as being able to contribute to discussions of current issues.

Visit [www.aims.org.uk](http://www.aims.org.uk)

If all our Members just encouraged one other person to join, we would double our membership and income!

A really easy way for everyone to help AIMS is to order cards and notelets from our website [www.aims.org.uk](http://www.aims.org.uk) and consider giving the new canvas bag or mugs for presents.

**A big thank you,  
whatever you can do!**