

**Maternal, Newborn and  
Infant Clinical Outcome  
Review Programme**



**MBRRACE-UK 2015  
Perinatal Confidential Enquiry**

**Term, singleton, normally-formed,  
antepartum stillbirth**



**November 2015**





# Maternal, Newborn and Infant Clinical Outcome Review Programme



## **MBRRACE-UK Perinatal Confidential Enquiry: Term, singleton, normally formed, antepartum stillbirth**

Editors: Elizabeth S Draper, Jennifer J Kurinczuk, Sara Kenyon.

on behalf of the MBRRACE-UK collaboration

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# FOREWORD – Term, singleton, normally formed, antepartum stillbirth

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We welcome this report as a continuation of the re-establishment of the national perinatal confidential enquiries. We are pleased to see that despite the continuing pressures on front line clinical staff they remain fully committed to the national programme of perinatal and maternal mortality surveillance and confidential enquiries run by MBRRACE-UK. Without the active support of staff who are willing to find and supply case notes for the enquiries and the enthusiastic and active involvement of clinical staff in the enquiry panels it would simply not be possible for the confidential enquiry process to run.

Term, singleton, normally formed antepartum stillbirths were last reviewed in a national confidential enquiry over 15 years ago and, as this report shows, the main areas of concern remain remarkably similar. Although at first sight this may seem disheartening, in many ways it is not surprising that the identification of risk factors and screening for gestational diabetes, the identification of fetal growth restriction and the response to reduced fetal movements all remain of concern. The first two of these represent two of the main known clinical factors on the pathway to stillbirth and the third represents a fetus showing signs of severe compromise. However, it is particularly disappointing, that yet again another confidential enquiry has to report a lack of local reviews and that although some local reviews, when carried out, were excellent, improved local review processes are still needed.

The findings and recommendations of this report clearly identify some of the actions needed to reduce the number and rate of stillbirths and these must be implemented since, as was evident from the recent MBRRACE-UK perinatal mortality surveillance report, the UK is still a long way behind some of our European neighbours in terms of our stillbirth rate. Whilst actions in the three key areas may not prevent all term antepartum stillbirths, if we get this right a substantial proportion may be prevented in the future.

We have clear guidance from NICE on the screening, diagnosis and management of gestational diabetes, the first step of which is the identification of women with risk factors. Comprehensive history taking at booking is the starting point in this process. Whilst not all women with risk factors for diabetes will actually develop gestational diabetes nor will this necessarily have been the cause of their stillbirth, a failure to follow the guideline represents a clear potential missed opportunity where this was the case.

The measurement of fetal growth is far from an exact science. However it is disappointing that this enquiry found missed opportunities when growth was measured but not plotted on a growth chart and the identification of failing growth was missed. Perhaps more depressing still was where growth failure was evident from the growth chart and appropriate action was not taken.

Fetal movements represent the most constantly available measure of fetal wellbeing. The failure to monitor appropriately when movements changed or reduced, to misinterpret the fetal heart trace and the failure to investigate when reduced fetal movements were reported again represent missed opportunities to intervene. Evidence of whether increasing women's awareness of the need for prompt reporting of a decrease in fetal movements followed by a clear management plan will come from the AFFIRM trial, the results from which are eagerly awaited.

The report provides clear recommendations of key actions required at all levels of the health service and the Royal Colleges will have a particular role to play in the development of guidelines for the management of the induction of labour for antepartum stillbirth, particularly for women who have had a previous caesarean section, and the management of lactation suppression; both areas with a wide variation in practice at present.

We were heartened to see evidence of good bereavement care and also evidence of good quality post mortems where these were performed. Whilst it is not clear whether we should be aiming at a particular target for the proportion of post mortems performed all placentas should nevertheless be submitted for histological examination and this was not always the case.

The findings from this enquiry and the preliminary findings from the RCOG Each Baby Counts programme emphasise that local reviews following stillbirth remain an area in need of clear improvement and we eagerly await the implementation of the standardised audit tool recommended by the Sands/ Department of Health Perinatal Mortality Review Task and Finish Group.

The year 2015 has been a year of particular scrutiny for maternity care with the publication of the Kirkup report of the findings of the Morecambe Bay investigation as well as the Maternity Services Review in England which is due to report in December. This report provides us with a clear set of actions in relation to term antepartum stillbirth and we commend it to every health professional working in the area of maternity care, to read it carefully and identify where the services they delivery can improve and where as individuals they need to act.



David Richmond

President

Royal College of Obstetricians and Gynaecologist



Lesley Page

President

Royal College of Midwives

# Executive Summary

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## Background

This report presents the findings of the second perinatal confidential enquiry carried out as part of the MBRRACE-UK programme of work and focuses on term, singleton, normally formed, antepartum stillbirths. This topic was selected as part of the standard process for the selection of topics for the Clinical Outcome Review Programme.

Although there has been a small reduction in the stillbirth rate for the UK over the past ten years, the UK stillbirth rate still remains relatively high compared to the rest of Europe and other high income countries. Most stillbirths occur prior to the onset of labour and just over half of all stillbirths are unexplained. This enquiry focuses on this group, specifically those normally formed and born at term, in order to exclude issues of preterm birth and major mortality and morbidity associated with congenital anomalies. The premise of the enquiry was that if a baby had been delivered in the days prior to intrauterine death there would be every chance of the survival of a healthy infant and negligible risk associated with induction of labour for the woman.

The group selected for enquiry constituted around one third of all stillbirths (1039 (32%) out of 3286 in the UK in 2013). The enquiry aimed to identify potentially preventable failures of care which might have contributed to the death and to help improve care in the future.

## The term, singleton, normally formed, antepartum stillbirth enquiry

A multidisciplinary topic expert group (TEG) was established and one face-to-face meeting was held where a series of questions and checklists were developed (using the relevant RCOG Green-top and NICE guidance) to facilitate the evaluation of the quality of care provision in relation to each of the following aspects of the care pathway:

- Antenatal Care
- Intrapartum Care
- Postnatal Care
- Bereavement and Psychosocial Care
- Follow-up Care
- Post Mortem Examination and Placental Histology

The TEG identified a number of specific areas, for which guidance has been developed, to inform the confidential enquiry process, which included the identification and appropriate management of gestational diabetes, intrauterine growth restriction, reduced fetal movements as well as other known risk factors for antepartum stillbirth. The guidance documentation (Appendix 1) formed the framework against which cases were assessed.

The MBRRACE-UK perinatal mortality surveillance system provided a sampling frame for the selection of a random sample of term, singleton, normally formed, antepartum stillbirths stratified by UK country for review by multidisciplinary enquiry panels. An initial sample of 146 potential cases was selected in April 2014 and submitted for review by confidential enquiry until saturation of themes was achieved and no new lessons for future care were emerging. Following exclusions (n=10) and a number of cases for which notes were not available (n=3), 133 sets of cases notes were received by the MBRRACE-UK office for review. In total nine multidisciplinary confidential enquiry panels were held where a total of 85 cases were reviewed, at which point thematic saturation had been reached. Although the final 48 cases were not reviewed by the panel members, they were reviewed by the in-house clinical team and data were collected for the checklists developed for the enquiry which were included in the findings for all 133 cases.

## Representativeness of the sample

One of the benefits of reviewing this particular topic was our capacity to make use of the MBRRACE-UK perinatal mortality surveillance data to randomly select a sample of eligible cases for the enquiry. This enabled us to generate results from the enquiry which are not only rich in depth following the review of the individual case notes, but also statistically generalisable despite the relatively small sample. This capacity is often not available in other confidential enquiry processes. Thus, we have been able to explore this topic from both a quantitative as well as a qualitative perspective to maximise our understanding of how care was provided overall as well as to individual women and their families.

## Consensus findings from the enquiry panels

The overall findings from the enquiry panels are provided in the table below which indicates both the quality of care provision for the outcome of the baby and the woman across all aspects of the care pathway. In terms of the baby the panels broadly interpreted 'outcome' to represent whether the care provision may have contributed to the death. From the woman's perspective outcome was interpreted as her physical and psychological well-being and full consideration of her future fertility.

### Confidential enquiry summary grading of quality of care

Overall quality of care	Baby n %	Woman n %
Good care; no improvements identified	18 (21)	11 (13)
Improvements in care identified which would have made no difference to outcome	16 (19)	19 (22)
Improvements in care identified which may have made a difference to outcome	51 (60)	55 (65)
<b>TOTAL</b>	<b>85 (100)</b>	<b>85 (100)</b>



Overall in terms of the outcome for the baby the panel consensus was that in 60% of these cases improvements in care were identified which may have made a difference to the outcome of stillbirth. In terms of the physical and psychological outcome and/or future fertility for the woman, in almost two thirds of cases the consensus of the panels was that improvements in care may have made a difference.

Key areas for action have been developed from the key findings at each point in the care pathway for both the baby and the woman.

## Key areas for action

### For Policy-makers, Service Planners, Commissioners and Professional Organisations

- There is a need for the development of national evidence-based guidelines for the induction of labour following diagnosis of intrauterine death. This should include the care of women with a previous history of caesarean section.
- Evidence-based guidance regarding lactation suppression should be developed.
- The standardised approach to perinatal death review developed by the Sands/Department of Health Perinatal Mortality Review Task and Finish Group should be implemented.

### For Medical Directors, Clinical Directors, Heads of Midwifery and Clinical Service Managers

- All units should implement national guidance regarding:
- Screening and identification of women who should be offered a glucose tolerance test to detect gestational diabetes.
  - Routine measurement of growth by symphysis fundal height measurement and recording at each antenatal appointment from 24 weeks gestational age.
  - The management of reduced fetal movements and identification of additional risk factors.
  - Standardised multidisciplinary review of ALL term stillbirths.
- Effective interpreting services should be available to all women unable to communicate in English.
- A checklist should be developed to ensure that the recommended maternal tests are undertaken following a stillbirth prior to discharge from hospital.
- Units should implement a policy to ensure that all parents of a stillborn baby are offered a post mortem. Placental histology should be undertaken in all cases.
- Consideration should be given to the recommendation of at least one member of staff having specialist knowledge and training in bereavement care to ensure that bereaved parents are supported in an appropriate and sensitive manner.
- All members of staff who could potentially interact with bereaved parents should have access to basic bereavement skills training.

- In a climate where resources are limited, maternity units should protect the funding directed towards bereavement care to ensure the quality of the support provided is not compromised for this vulnerable group of women and their families.

## **For Doctors, Midwives and Allied Health Professionals:**

### ***Regarding routine care for all women***

- All women with risk factors for gestational diabetes should be identified and offered glucose tolerance testing in line with current national guidance. Testing should be performed at the appropriate time, with documentation of results and correct clinical management of abnormal results.
- Growth should be monitored from 24 weeks by measurement of the symphysis fundal height and plotting the measure on a growth chart. Abnormal findings should be acted upon.
- Midwives and obstetricians should emphasise the importance of fetal movements to women at each antenatal contact as a method of fetal surveillance, and document the detail of this conversation.
- The presence of reduced fetal movements with additional risk factors, or recurrence of reduced fetal movements in an otherwise low risk woman, should prompt referral for an ultrasound scan and senior obstetric review.

### ***Regarding care following stillbirth***

#### ***Immediate care***

- Following a stillbirth all relevant health professionals should be telephoned as soon as possible to prevent any insensitive or inappropriate communications with parents.

#### ***Care in labour***

- The obstetric and midwifery management of the labour of women with an intrauterine death should be no different in quality and content to that of women having a live birth, including the use of a partogram to monitor the progress of labour.

#### ***Post mortem examination***

- All parents of a stillborn baby should be offered a post mortem. Documentation of this offer and the provision of the written information for parents should be clearly recorded in the maternal notes.
- Regardless of whether the parents give consent for full post mortem examination, the placenta should always be submitted for histological examination by a specialist pathologist.
- A clear, concise and evidence-based clinico-pathological correlation should be included in every post mortem and placental histology report.
- Clear communication of findings is important and attempts must be made in each hospital to ensure that the clinical and pathological findings can be discussed with parents in an open, honest and constructive way to enable them to gain the best understanding of events leading to stillbirth and any impact on future pregnancy plans.

### *Following discharge from hospital*

- Continuing midwifery support, following discharge from hospital, should be offered to and documented for all women after the birth of a stillborn baby.
- All parents should be offered a follow-up appointment, in an appropriate setting, with a consultant obstetrician to discuss events leading to their baby's stillbirth, the actual or potential cause, chances of recurrence and plans for any future pregnancy.
- A summary of their follow-up appointment written in plain English should be sent to the parents and also to their GP.

### *Review of care*

- Standardised multidisciplinary review of all stillbirths should be undertaken to include classification of death, grading of care, adequacy and accuracy of documentation and the generation of a local action plan for any improvements required.
- Parents' perspectives of their care should be included in the review of their stillborn baby and the results of the review shared with them.

# Key Findings

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## Key findings for the provision of antenatal care

- At least one element of the antenatal care for half of all term, singleton, normally formed, antepartum stillbirths included in the enquiry was identified as requiring improvement.
- There was evidence of a failure to identify risk factors for gestational diabetes and to refer women for testing as per the NICE Guideline on Diabetes in Pregnancy.
- There was evidence of a failure to monitor fetal growth in line with NICE guidance, either by not taking symphysis fundal height measurements, not plotting the measurements on a chart or not responding when growth was abnormal
- There was evidence of a failure to respond appropriately to attendance and repeat attendance by women with reduced fetal movements; either a lack of investigation, misinterpretation of the fetal heart trace or a failure to respond appropriately to additional risk factors.
- Key findings for diagnosis of the stillbirth and intrapartum care
- The majority of case notes reviewed in the enquiry documented good and compassionate care of the woman and her family during labour and birth.
- The notes reviewed suggest that care was sometimes compromised by a lack of resources, leading to delays in analgesia provision, absence of the midwife for periods of time and women labouring on the antenatal ward to deliver a stillborn baby.
- The methods of induction of labour used following diagnosis of intrauterine death varied significantly, especially in women with a history of previous caesarean section, reflecting the lack of clear evidence and guidance.
- Guidance for care is particularly required for women with a previous history of caesarean section who have an intrauterine death for whom uterine rupture is a very real risk.
- Several cases were identified where a partogram was not completed and the normal prompts regarding maternal care were therefore missed. In a number of cases the duration of labour exceeded normal good practice by a significant degree. Women delivering a stillborn baby should receive the same quality of obstetric and midwifery care as those delivering a healthy baby.

## Key findings for care after birth

The enquiry panels found a good standard of bereavement care documented as being given to parents immediately following birth. Nearly all parents were offered the opportunity to create memories. Bereavement checklists were present and completed in the majority of notes.

- A number of areas for improvement were identified for which information was specifically requested from maternity units if available:
  - There was wide variation in the availability of a specialist bereavement midwife with only one third of case notes showing evidence of their involvement.
  - There was wide variation in the documentation as to whether recommended maternal investigations were undertaken prior to discharge from hospital.

- Nearly one third of cases had no documented offer of post mortem examination or written confirmation of the provision of associated literature.
- Only half of the cases reviewed included documentation that lactation suppression was discussed and prescribed if requested.
- Just under half of the reviewed cases had no documentation to indicate continuing midwifery involvement in the postnatal period.
- There was a lack of documented evidence of contact with other healthcare professionals and organisations to inform them of the stillbirth.
- There was scarce evidence in the notes that information was provided for parents with regard to the possible need for longer term counselling and support.

## Key findings for follow-up care and local review

- Although documentation relating to internal review of the case was requested from all units that were included in the confidential enquiry, only a quarter of cases included documentation indicating that an internal local review had taken place. One in ten of the cases had documented evidence that they were compliant with RCOG guidance, in that a multidisciplinary review took place. The quality of reviews was highly variable.
- Parental involvement in the review process has been highlighted as important by the Stillbirth and neonatal death society (Sands) but was only evident in the notes of a small number of the cases. Only six out of 133 (5%) cases had documented evidence that parents' concerns were included in the review, The results of the internal review were only fed back to 12 sets of parents.
- A follow-up appointment was documented as taking place in only two thirds of the 133 cases selected for enquiry. The majority of the appointments (two thirds of the cases) took place between six and twelve weeks after the stillbirth, with the vast majority of the appointments being with a consultant obstetrician.
- Despite the recommendation that parents receive a letter summarising the findings of the review of their care, this was only evident in just over two thirds of the cases undergoing review, with a letter documented as having been sent to the GP in about four fifths of cases.

## Key findings for pathological and histological investigations

- Only half of the cases selected for the confidential enquiry underwent full post mortem examination; one third of cases had placental histology only and the remaining fifth of cases had neither post mortem nor placental histology carried out.
- Post mortem and placental reports were evaluated according to a predefined checklist based upon guidelines from the Royal College of Pathologists. In the majority of cases, post mortem reports were of satisfactory or good quality, with adequate levels of detail provided.
- Four fifths of reports contained an interpretation of pathological findings in terms of clinical significance (clinico-pathological correlation) as recommended by the Royal College of Pathologists.

## Key findings for communication issues

- The enquiry panels found issues of poor communication and/or documentation in two thirds of the cases reviewed. This ranged from simple mistakes in the notes to a total lack of documentation of key aspects of care.
- Out of 12 women identified who did not speak English only six had access to adequate interpretation services during critical parts of the care pathway.
- Sharing of information between health professionals appeared inconsistent and sometimes incomplete which prevented effective interagency working, which on occasion created mixed messages for parents.
- One in ten cases reviewed contained examples of insensitive interaction with bereaved parents.

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# Glossary of terms

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<b>ARM</b>	Artificial rupture of the membranes
<b>BMI</b>	Body Mass Index
<b>BP</b>	Blood pressure
<b>BRIPPA</b>	British and Irish Paediatric Pathology Association
<b>CB</b>	Commissioning Board
<b>CESDI</b>	Confidential Enquiry into Stillbirth and Deaths in Infancy
<b>CORP</b>	Clinical Outcome Review Programme
<b>CRP</b>	C-reactive Protein
<b>CTG</b>	Cardiotocography
<b>DGH</b>	District General Hospital
<b>DNA</b>	Did not attend
<b>DH</b>	Department of Health
<b>EFW</b>	Estimated fetal weight
<b>GDM</b>	Gestational Diabetes Mellitus
<b>GTT</b>	Glucose tolerance test
<b>HQIP</b>	Healthcare Quality Improvement Partnership
<b>IUFD</b>	Intrauterine fetal death
<b>IUGR</b>	Intrauterine growth restriction
<b>LSCB</b>	Local Safeguarding Children Board
<b>MBRRACE-UK</b>	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
<b>MNI-CORP</b>	Maternal, Newborn and Infant Clinical Outcome Review Programme
<b>NHS</b>	National Health Service
<b>NICE</b>	National Institute for Health and Care Excellence
<b>NIMACH</b>	Northern Ireland Maternal and Child Health
<b>NPSA</b>	National Patient Safety Agency
<b>PCA</b>	Patient Controlled Analgesia
<b>PM</b>	Post mortem
<b>RCM</b>	Royal College of Midwives
<b>RCOG</b>	Royal College of Obstetricians and Gynaecologists
<b>RCPATH</b>	Royal College of Pathologists
<b>RCT</b>	Randomised controlled trial
<b>SFH</b>	Symphysial fundal height
<b>SGA</b>	Small for gestational age
<b>TEG</b>	Topic Expert Group

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Malcolm Buchanan, Administrator

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Catherine Calderwood (Chair until March 2015), National Clinical Director for Maternity and Women's Health for NHS England and Medical Advisor for Women and Children's Health for the Scottish Government

Alan Fenton, Consultant in Neonatal Medicine, Newcastle upon Tyne (member from March 2014; Chair from September 2015)

Janice Allister, General Practitioner, Peterborough

David Bogod, Consultant Anaesthetist, Nottingham University Hospitals NHS Trust (member until March 2014)

Zoe Boreland, Midwifery and Children's advisor, Department of Health, Social Services and Public Safety Northern Ireland (member March 2014 to September 2014)

Cath Broderick, Lay Representative (member from October 2013)

Roch Cantwell, Consultant Psychiatrist, Southern General Hospital, Glasgow (member until March 2013)

Richard Cooke, Professor of Neonatal Medicine, Liverpool Women's Hospital NHS Foundation Trust (member until October 2012)

Andy Cole, Chief Executive, Bliss (member until March 2014)



Jacqueline Cornish, National Clinical Director Children, Young People and Transition to Adulthood, NHS England (member from March 2014)

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Polly Ferguson, Lay member (member until March 2013)

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Melissa Green, Interim Chief Executive, Bliss (member from September 2014 to March 2015)

David James, Clinical Co-director at the National Collaborating Centre for Women's and Children's Health (member until September 2014)

Mervi Jokinen, Practice and Standards Development Adviser, Royal College of Midwives

Jim Livingstone, Northern Ireland Department of Health, Social Services and Public Safety (member until March 2013)

Heather Livingston, Department of Health, Social Services and Public Safety, Northern Ireland (member until March 2014)

Heather Mellows, Professional Advisor in Obstetrics, Department of Health (England) (member until March 2013)

Kate McKay, Senior Medical Officer, Scottish Government

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Heather Payne, Senior Medical Officer for Maternal and Child Health, Welsh Government

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Jane Abbott, BLISS (for babies born too soon, too small, too sick)  
Francine Bates, Lullaby Trust  
Beverley Beech, Association for Improvement in the Maternity Services (AIMS)  
Charlotte Bevan, Stillbirth and Neonatal Death Charity (Sands)  
Jane Brewin, Tommy's  
Ann Chalmers, Child Bereavement UK  
Jenny Chambers, Intrahepatic Cholestasis of Pregnancy (ICP) Support  
Debbie Chippington Derrick, Association for Improvement in the Maternity Services (AIMS)  
Jane Denton, Multiple Birth Foundation (MBF)  
Caroline Davey, Bliss (for babies born too soon, too small, too sick)  
Jane Fisher, Antenatal Results and Choices (ARC)  
Pauline Hull, electivecesarean.com  
Penny Kerry, Miscarriage Association  
Helen Kiranne, Bliss (for babies born too soon, too small, too sick)  
Beckie Lang, Tommy's  
Neil Long, Stillbirth and Neonatal Death Charity (Sands)  
Sarah McMullen, National Childbirth Trust (NCT)  
Jane Plumb, Group B Strep Support (GBSS)  
Andrea Priest, Best Beginnings  
Gwynne Rayns, National Society for the Prevention of Cruelty to Children (NSPCC)  
Keith Reed, Twins and Multiple Births Association (TAMBA)  
Jean Simons, Lullaby Trust (formerly FSID)  
Liz Thomas, Action Against Medical Accidents (AvMA)  
Cheryl Titherly, Antenatal Results and Choices (ARC)  
Maureen Treadwell, Birth Trauma Association (BTA)

## **MBRRACE-UK Royal College and Professional Association Stakeholder Group and Representatives who Attended Meetings:**

Carmel Bagness, Royal College of Nursing  
Pamela Boyd, Neonatal Nurses Association  
Patrick Cadigan, Royal College of Physicians  
Hilary Cass, Royal College of Paediatrics and Child Health  
Paul Clyburn, Obstetric Anaesthetists Association & Royal College of Anaesthetists  
Sanjeev Deshpande, British Association of Perinatal Medicine  
Denise Evans, Neonatal Nurses Association

Roshan Fernando, Obstetric Anaesthetists Association & Royal College of Anaesthetists  
Jacque Gerrard, Royal College of Midwives  
Steve Gould, British and Irish Paediatric Pathology Association  
Diane Hulbert, College of Emergency Medicine  
Flora Jessop, British and Irish Paediatric Pathology Association  
Sara Johnson, Royal College of Obstetricians and Gynaecologists  
Hannah Knight, Royal College of Obstetricians and Gynaecologists  
Lucy Mackillop, Royal College of Physicians  
Liz McDonald, Royal College of Psychiatrists  
Lisa Nandi, British Association of Perinatal Medicine  
Catherine Nelson-Piercy, Royal College of Physicians  
Tim Overton, British Maternal and Fetal Medicine Society  
Lesley Page, Royal College of Midwives  
Marcia Philbin, Royal College of Paediatrics and Child Health  
David Richmond, Royal College of Obstetricians and Gynaecologists  
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# 1. Background, Methods and Key Findings

Elizabeth S Draper and Pauline Hyman-Taylor

## 1.1. Background

The programme of national confidential enquiries into perinatal deaths commenced in 1993 with the establishment of the Confidential Enquiry into Stillbirth and Deaths in Infancy (CESDI) to address the relatively high stillbirth and infant mortality rates in the UK through mortality surveillance and confidential enquiries. This programme of work has been through a number of organisational changes over the past twenty years or so and is now carried out as part of the Clinical Outcome Review Programme (CORPs). The contract for the Maternal Newborn and Infant Clinical Outcome Review Programme (MNI-CORP) was awarded to the MBRRACE-UK collaboration by the Healthcare Quality Improvement Partnership (HQIP) on behalf of the funders starting on 31<sup>st</sup> May 2012.

This report presents the findings of the second perinatal confidential enquiry carried out as part of the MBRRACE-UK programme of work and focuses on term, singleton, normally formed, antepartum stillbirths.

## 1.2. Topic choice

As part of the standard process for the selection of topics for the Clinical Outcome Review Programme, a call for topic proposals was sent out via email and the MBRRACE-UK website in September 2012, inviting proposals from individuals, charities and professional organisations for the perinatal confidential enquiry to be carried out in 2014/15 and to report at the end of 2015. Ten suggested topics were submitted for consideration and following a three stage selection process the MBRRACE-UK Independent Advisory Group selected the topic of term, singleton, normally formed, antepartum stillbirth.

## 1.3. Term, singleton, normally formed, antepartum stillbirth

Over the past ten years there has been a small reduction in the stillbirth rate for the UK <sup>1</sup>. However the UK stillbirth rate still remains relatively high compared to the rest of Europe and other high income countries <sup>2</sup>, despite major efforts to raise the profile of stillbirths and initiatives for the reduction of stillbirth rates by the Stillbirth and neonatal death charity (Sands) and other organisations. Just over half of all stillbirths are unexplained, the vast majority of which occur prior to the onset of labour. It is this particular group that was the focus of this confidential enquiry, specifically those normally formed and born at term in order to exclude issues of preterm birth and major mortality and morbidity associated with congenital anomalies. The assumption is that if a baby had been delivered in the days prior to intrauterine death there would be every chance of the survival of a healthy infant and negligible risk associated with induction of labour for the woman. It therefore follows, that an examination of all aspects

of antenatal care provision in such cases should be carried out to investigate whether opportunities for intervention were missed and to evaluate the quality of care provided, against current guidelines and standards.

This specific group of stillbirths has only been the subject of a UK national confidential enquiry once since the start of the perinatal confidential enquiry programme in 1993. The conclusions from that enquiry conducted in 1996/97 were: (i) that women should be appropriately screened for gestational diabetes; (ii) that the care for women presenting with reduced fetal movements must be improved; (iii) that screening for fetal growth restriction is frequently poorly performed; and (iv) lessons for future practice must be learned where failures of care lead to, or contribute to, stillbirth<sup>3,4</sup>. This group constitutes around one third of all stillbirths (1039 (32%) out of 3286 in the UK in 2013) and justified the focus of this enquiry on these cases. The enquiry aimed to identify potentially preventable failures of care which might have contributed to the stillbirth and to help improve care in the future.

## 1.4. Aims

The aims of the term, singleton, normally formed, antepartum stillbirth confidential enquiry, were to assess:

- Adherence to clinical guidelines (RCOG Green-top / NICE)
- The standard of obstetric and midwifery care throughout the care pathway
- The role of the bereavement midwife and the community midwife
- The role of post mortem and placental histology review, including the role of the *perinatal* pathologist
- Access to and impact of psychosocial counselling/care

## 1.5. The confidential enquiry process

A confidential enquiry is a process of systematic, multidisciplinary, anonymous case review<sup>5,6</sup>. The MBRRACE-UK perinatal mortality surveillance provided a sampling frame for the selection of a random sample of term, singleton, normally formed, antepartum stillbirths stratified by UK country for review by multidisciplinary enquiry panels. An initial sample of 146 potential cases was selected in April 2014 and submitted for review by confidential enquiry until saturation of themes was achieved and no new lessons for future care were emerging.

Confidential enquiries focus on both good and poor care quality, in order to inform practice and improvements in the care of women and families in the future. For the Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP) as a whole, we have adopted the following criteria to summarise the assessment of the overall quality of care for individual cases:

- Good care; no improvements identified
- Improvements in care\* identified which would have made no difference to outcome
- Improvements in care\* identified which may have made a difference to outcome

(\*Improvements in care should be interpreted to include adherence to guidelines and standards, where these exist and have not been followed, as well as other improvements which would normally be considered part of good care, where no formal guidelines exist.)

In this enquiry a summary assessment of the care provision was provided separately for the baby and the woman based on previous experience<sup>7</sup>. In addition, in order to provide more detail about the care provision across all aspects of the care pathway, each aspect was also assessed separately. Each care factor identified along the care pathway was evaluated with respect to the quality of care provision and coded to four levels of care:

- None - good quality care identified.
- Minor - minor issues with the quality of care identified.
- Significant - significant issues with the quality of care identified.
- Major - major issues with the quality of care identified.

Confidential enquiries are sometimes criticised for being overly judgmental and therefore every effort was made to also identify examples of good practice where evident. Care throughout was compared with national guidance and standards where such guidance and/or standards existed.

In all enquiries reviewers are also asked specifically to flag immediately any cases which meet the HQIP cause for concern criteria. The HQIP protocol defines “Identified Causes for Concern” as follows:

- Death (child or adult) attributable to abuse or neglect, in any setting, **but** no indication of cross agency involvement (i.e. no mention of safeguarding, social services, police or the Local Safeguarding Children Board LSCB).
- Staff member displaying:
  - Abusive behaviour (including allegations of sexual assault)
  - Serious professional misconduct
  - Dangerous lack of competency
  - but not clear if incident has been reported to senior staff
  - Standards in care that indicate a dysfunctional or dangerous department or organisation, or grossly inadequate service provision.

## 1.6. Topic Expert Group – development of panel guidance documents

MBRRACE-UK convenes a multidisciplinary Topic Expert Group (TEG) to steer each confidential enquiry. For the term antepartum stillbirth enquiry this comprised members from the relevant clinical specialties and a patient representative from the charity Sands. Selection of members for the TEG was carried out concurrently with the selection of panel members and was made through an approach to the relevant professional bodies. Applications were sought from members with the appropriate expertise, experience and interest. Those who expressed interest were asked to provide a brief summary of their experience to ensure that they had a relevant background and were in good standing with their professional organisation. Once accepted for the TEG, members were asked to sign a confidentiality statement prior to their participation.

One face-to-face meeting of the TEG was held where a series of questions and checklists were developed (using the relevant RCOG Green-top and NICE guidance). This facilitated the evaluation of the quality of care provision in relation to each of the following aspects of the care pathway:

- Antenatal Care
- Intrapartum Care
- Postnatal Care
- Bereavement and Psychosocial Care
- Follow-up Care
- Post Mortem Examination and Placental Histology

The TEG identified a number of specific areas, for which guidance has been developed, to inform the confidential enquiry process. This included the identification and appropriate management of gestational diabetes, intrauterine growth restriction, reduced fetal movements as well as other known risk factors for antepartum stillbirth. The guidance documentation (Appendix 1) formed the framework against which cases were assessed.

## 1.7. Development of enquiry-specific checklists

As indicated, a series of checklists (Appendix 2) were developed by the TEG to facilitate a description of the risk factors present in the enquiry cases and to identify measurable aspects of the quality of care provided. The structure and content of the checklists was based on the aspects of care for which guidance and standards were available at the time of care delivery in 2013. They were developed to collect information about the aspects of care which should routinely be recorded in the medical case notes. Where there was no written information about an aspect of care, it was reported as *not recorded in the case notes*. Although this does not necessarily equate to the absence of care, from a legal perspective if something is not written down then it did not occur and we followed this principle.

## 1.8. Cases

Once cases had been identified our initial request to the local teams was for relevant sections of the notes to be copied, and supplied to the MBRRACE-UK office in Leicester. As per our standard protocol <sup>5,8</sup> – see also Appendix 3 – all notes were anonymised by redaction of the case and family identifiers, hospital and clinician names. The information relating to the type and grade of staff recording information in the notes was retained for the purposes of the enquiry. Northern Ireland has different data protection arrangements from the rest of the UK and as such there is no mechanism for the export out of Northern Ireland of identifiable data without consent. As a consequence the Northern Ireland Maternal and Child Health (*NIMACH*) office within the Health and Social Care Public Health Agency were responsible for redacting the records of identified cases and facilitated individual parental consent.

After checking that cases fulfilled the relevant criteria for the confidential enquiry all records were reviewed in Leicester prior to assessment by panel members. This allowed notes to be prepared in a logical order, completeness to be checked and any documentation not needed as part of the review process to be removed.



## 1.9. Reviewers

The care pathway for a woman and her stillborn baby involves a multidisciplinary team of health professionals, including midwives, obstetricians, fetal medicine specialists and perinatal pathologists. The selection of this group is described in section 1.6.

All those who were accepted as potential assessors were asked to join an online training session which covered confidentiality issues, use of the web-based note review system and an explanation of the enquiry process. All participants were given an opportunity to ask questions and raise any issues prior to participating in the confidential enquiry process (Appendix 3:).

## 1.10. Case review panel meetings

The enquiry process commenced once the notes for an individual case had been checked, anonymised and confirmed as complete. The relevant records were then uploaded and made available for review via the MBRRACE-UK web-based notes viewing system. Panel members logged onto the system using a secure username and password to access the specific case notes they had been allocated for their panel meeting and were asked to review each case ahead of the meeting.

Panel meetings were planned as face-to-face discussions lasting up to six hours; up to nine cases were reviewed per panel. Both in the preparation for the panel meetings and during the consensus discussion, members were asked to consider the extent to which, there were any lessons to be learned to improve care and thus prevent stillbirths in similar cases in the future. In order to provide a balanced overview of the care provision, panels were also asked to identify any markers of good quality care.

To ensure standardisation of the process each panel was chaired by either Professor Elizabeth Draper or Dr Sara Kenyon from the MBRRACE-UK Collaborator's Group. The composition of the panel comprised unit, community and bereavement midwives, tertiary centre and District General Hospital obstetricians, and a perinatal pathologist for panels where cases had undergone a post mortem examination. Each case was discussed in turn, commencing with an overview by a panel member who had been allocated as lead for the case in advance and was designated to complete the relevant checklists for the case. This was followed by a general discussion leading to a consensus opinion of any aspects of poor care or particularly good care identified. In addition recurring themes were also noted. At the end of this discussion the Chair and a member of the MBRRACE-UK team both completed an assessment form based on the consensus reached by the panel. The individual assessment forms completed by each panel member were also collected to ensure that all relevant issues had been recorded.

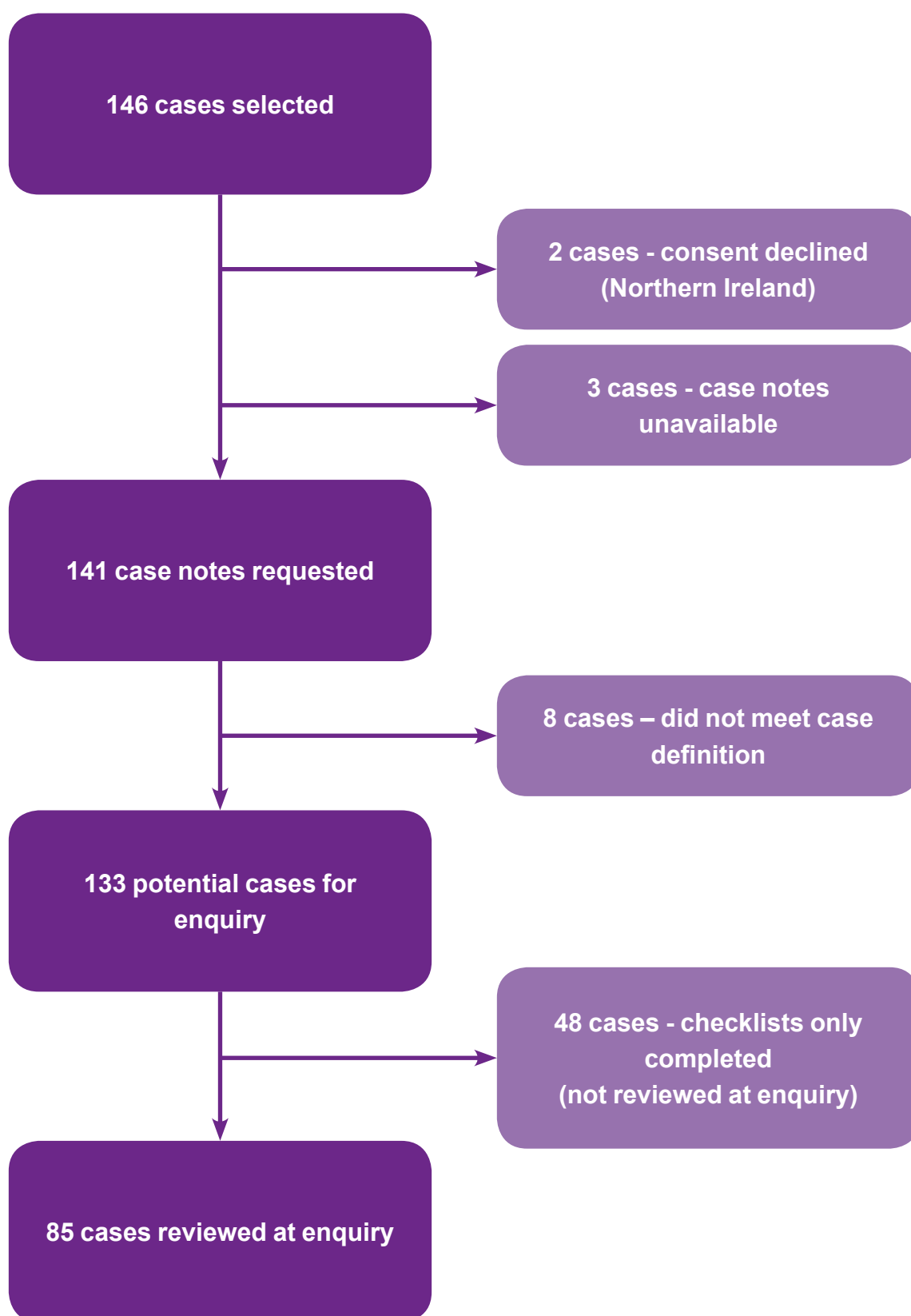
Every attempt was made to ensure that cases were always reviewed by panel members who had no personal involvement with either the case, or as a member of staff in the unit of care. Unfortunately due to the time delay between the cases and the panel reviews, a number of staff had changed posts and therefore this was not achieved in a small number of cases. Panel members were asked to notify the chair when this occurred so they could be excluded from the discussions. Panel members were instructed to follow strict confidentiality guidelines for all cases, especially where they were able to recognise the provenance of a case, or the identity of an individual involved in the care despite the anonymisation process.



## 1.11. Details of cases reviewed

A random sample of 146 potential term, singleton, normally formed, antepartum stillbirths were selected from the MBRRACE-UK surveillance for cases born in 2013. Requests for notes began in July 2014, with the aim to carry out confidential enquiry panels until thematic saturation was reached and no new lessons for the future were emerging. Of the cases selected as part of the sample, consent was not obtained for two cases from Northern Ireland (where consent is required for participation). The records for the case notes of two cases from England and one from Wales were not provided as they could not be found. Notes were identified and retrieved for 141 of the cases, eight of these cases were subsequently excluded as on review it was clear that they failed to meet the inclusion criteria. Nine multidisciplinary confidential enquiry panels were held where a total of 85 cases were reviewed. The remaining 48 cases were not reviewed at confidential enquiry panels as the point of thematic saturation had been reached, with no new issues or themes emerging that had not already been highlighted. Although the final 48 cases were not reviewed by the panel members, they were reviewed by the in-house clinical team and data were collected for the checklists developed for the enquiry which were included in the findings for a total of 133 cases (Figure 1).

**Figure 1: Flow chart for cases selected for confidential enquiry**



## 1.12. Representativeness of the sample

One of the benefits of reviewing this particular topic was our capacity to make use of the MBRRACE-UK perinatal mortality surveillance data to randomly select a sample of eligible cases for the enquiry. This enabled us to generate results from the enquiry which are not only rich in depth following the review of the individual case notes, but also statistically generalisable despite the relatively small sample. This capacity is often not available in other confidential enquiry processes. Thus, we have been able to explore this topic from both a quantitative as well as a qualitative perspective to maximise our understanding of how care was provided overall as well as to individual women and their families. Available socio-demographic, behavioural and care characteristics of UK resident women of all singleton, term, normally formed, antepartum stillbirths for 2013 are presented in Table 1 and compared to the sample for which checklist data were collected from the notes (n=133) and from those which were reviewed at enquiry panel (n=85).

There were no significant differences, in any of the characteristics presented in Table 1, between all cases of term, singleton, normally formed, antepartum stillbirths not selected for enquiry and those selected for enquiry for which the checklist data were collected (n=133). Comparison of those who underwent full enquiry (n=85) with those not undergoing full enquiry (i.e. non-sampled and those sampled but not discussed at panel) indicated that there were no statistically significant differences although there were slightly fewer women of white ethnicity who were included in the full enquiry (p=0.05). However overall the samples selected for checklist data alone and for full enquiry appear representative of term, singleton, normally formed, antepartum stillbirths in 2013 for the UK and thus we concluded that within the constraints of the relatively small sample size the findings of this enquiry are generalisable.

**Table 1: Characteristics of all term, singleton, normally formed, antepartum stillbirths for 2013 compared with those selected for full enquiry and those undergoing full enquiry**

Characteristic	Not Selected N=905		Selected for enquiry n=133			Full enquiry n=85		
	n	%	n	%	p-value*	n	%	p-value*
Maternal age (years)								
<20	42	5	11	8	0.425	7	8	0.612
20-24	138	15	25	19		17	20	
25-29	255	28	29	22		19	22	
30-34	255	28	38	29		21	25	
35-39	148	16	22	17		15	18	
>=40	40	4	5	4		3	4	
missing	27	3	3	2		3	4	
Ethnicity								
White	626	69	77	58	0.105	49	58	0.050
Mixed	31	3	9	7		8	9	
Asian	145	16	27	20		14	17	
Black	56	6	9	7		7	8	
Other	16	2	3	2		3	4	
Not known	31	3	8	6		4	5	
Deprivation quintile								
Least deprived	137	15	18	14	0.956	10	12	0.816
2	166	18	21	16		15	18	
3	189	21	31	23		16	19	
4	197	22	31	23		19	22	
Most deprived	210	23	31	23		24	28	
missing	6	1	1	1		1	1	
Region / country of residence								
London	176	20	21	16	0.855	11	13	0.435
Midlands & Eastern	194	21	31	23		22	26	
North	246	27	33	25		20	24	
South	170	19	28	21		16	19	
Northern Ireland	27	3	3	2		3	4	
Scotland	59	7	10	8		10	12	
Wales	31	3	7	5		3	4	
Islands	2	0	0	0		0		
Post mortem								

Characteristic	Not Selected N=905		Selected for enquiry n=133			Full enquiry n=85		
	n	%	n	%	p-value*	n	%	p-value*
Full	393	43	61	46	0.648	45	53	0.107
Limited	34	4	4	3		3	4	
None	438	48	65	49		37	44	
Not known	40	4	3	2		0	0.0	

#### Maternal BMI

<18.5	19	2	6	5	0.260	4	5	0.375
18.5 to 29.9	627	69	95	71		61	72	
30+	235	26	30	23		19	23	
Missing	24	2.7	2	2		1	1	
	n	%	n	%	p-value	n	%	p-value

#### Previous pregnancy<sup>1</sup>

Never Pregnant	379	42	55	41	0.909	35	41	0.901
Stillbirth or Neonatal death	28	3	5	4	0.683	3	4	0.848
Pre 24 week loss	203	22	32	24	0.675	21	25	0.635
Surviving Child	425	47	54	41	0.170	36	42	0.464
Not known	6	1	0	0	0.346	0	0	0.463

#### Smoking Status

Never smoked/Gave up before pregnancy	673	74	101	76	0.775	67	79	0.63
Gave up during pregnancy/Smoker	217	24	29	22		17	20	
Not known	15	2	3	2		1	1	

#### Employment status

Employed or self employed	516	57	74	56	0.733	46	54	0.606
Unemployed	128	14	22	17		18	21	
Student	23	3	4	3		2	2	
Looking after home/family	170	19	24	18		15	18	
Permanently sick/disabled	1	0	0	0		0	0	
Other	8	1	3	2		0	0	
Not Known	59	7	6	5		4	5	

#### Support during pregnancy

Characteristic	Not Selected N=905		Selected for enquiry n=133			Full enquiry n=85		
	n	%	n	%	p-value*	n	%	p-value*
Partner, cohabiting	760	84	118	89	0.453	75	88	0.789
Partner, not cohabiting	52	6	5	4		3	4	
Family/friend	54	6	8	6		5	6	
None	8	1	0	0		0	0	
Not Known	31	3	2	2		2	2	

#### Gestation at first booking

Before 10 <sup>+</sup> weeks	418	46	64	48	0.667	39	46	0.980
On or after 10 weeks	462	51	67	50		44	52	
Missing	25	3	2	2		2	2	
ALL	905		133			85		

<sup>1</sup> can be in multiple groups

\*p-value for Chi-squared test: selected vs non-selected and full enquiry vs non full enquiry.

## 1.13. Key findings from the enquiry panels

A summary of the consensus findings of the panel reviews is provided in Table 2 indicating both the quality of care provision for the outcome of the baby and the woman across all aspects of the care pathway. In terms of the baby the panels broadly interpreted 'outcome' to represent whether the care provision may have contributed to the death. From the woman's perspective outcome was interpreted as her physical and psychological well-being and full consideration of her future fertility.

**Table 2: Confidential enquiry summary grading of quality of care**

Overall quality of care	Baby n %	Mother n %
Good care; no improvements identified	18 (21)	11 (13)
Improvements in care identified which would have made no difference to outcome	16 (19)	19 (22)
Improvements in care identified which may have made a difference to outcome	51 (60)	55 (65)
<b>TOTAL</b>	<b>85 (100)</b>	<b>85 (100)</b>

Overall in terms of the outcome for the baby, the panel consensus was that in 60% (n=51) of these cases, improvements in care were identified which may have made a difference to the outcome of stillbirth. In terms of the physical and psychological outcome and/or future fertility for the woman in almost two thirds of cases (n=55) the consensus of the panels was that improvements in care may have made a difference. However as discussed in our previous confidential enquiry <sup>7</sup>, reducing such complex cases to a single number (or two in this case) is limited and does not provide an complete picture of the entire pathway of care provision. The basis of the allocation of the grade of quality of care is often based on

one aspect alone so an improvement in care might be identified for a case which had excellent care throughout except for one element. In contrast a case may have had several aspects of care quality that did not affect the ultimate outcome but which may well have resulted in care that might have made a difference in terms of the woman's experience.

## Lessons to improve care to prevent stillbirth

Table 3 provides additional information about the quality of care provision at the six points of the care pathway reviewed by the enquiry panels and is based on the documentation used by the panels. For each case the poorest grading of quality of the care recorded for each point of the care pathway is provided. In half of the cases there was at least one aspect of care during the antenatal period where there was a major issue with the quality of care provided. A further fifth of the cases reviewed were identified as having a significant issue with their antenatal care. The main issues raised as areas for improvement in antenatal care provision included the identification and recognition of known risk factors for high risk pregnancies, monitoring of fetal growth and monitoring of fetal movements.

**Table 3: Confidential enquiry poorest grading of quality of care by point on the care pathway for each case**

Quality of care issues	Point on the care pathway					
	Antenatal n %	Intrapartum n %	Postnatal n %	Bereavement n %	Follow-up n %	Pathology n %
None	12 (14)	36 (42)	46 (54)	51 (60)	32 (38)	47 (55)
Minor	13 (15)	15 (18)	6 (7)	5 (6)	5 (6)	18 (21)
Significant	18 (21)	13 (15)	14 (17)	14 (17)	17 (20)	11 (13)
Major	42 (50)	21 (25)	19 (18)	15 (18)	31 (37)	9 (11)
<b>TOTAL</b>	<b>85 (100)</b>	<b>85 (100)</b>	<b>85 (100)</b>	<b>85 (100)</b>	<b>85 (100)</b>	<b>85 (100)</b>

## Lessons to improve care at diagnosis of a stillbirth and during the subsequent labour and delivery

One quarter of cases had an aspect of intrapartum care identified as having major issues with the care quality with a further 15% having significant issues in the quality of care provided. Areas for improvement in the intrapartum period included the diagnosis of an intrauterine fetal death, delays in care provision, staffing resources and the management of induction and labour for such cases.

Lessons to improve the immediate postnatal care provided to mothers following the birth of a stillborn baby

Over half of the cases reviewed were assessed as having good care in the postnatal period. In the third (34%) of cases with major or significant issues identified in the quality of care provided, areas of concern were around consent for post mortem and other investigations and preparing the woman for discharge from hospital.

## **Lessons to improve bereavement care for parents following the birth of a stillborn baby**

On a positive note 60% of women/parents were provided with a high standard of bereavement care encompassing many aspects of the Sands guidance <sup>9</sup>. Nevertheless the bereavement care for one third (34%) of cases was considered to have elements that had significant or major problems with care quality which were mainly focused around the lack of a plan for discharge and care at home or inadequate documentation.

## **Lessons for the follow-up of women following the birth of a stillborn baby**

The main issues concerning follow-up care were a lack of written documentation available to the panels despite units having been asked to provide the documentation for the whole care pathway and the follow-up appointment and letter. In addition the quantity and quality of hospital review for many cases was of concern. Whilst one third (37%) of cases were considered to have had major issues with the quality of follow-up care. For a further third (38%) follow-up care was noted to be of good quality.

## **Lessons for post mortem and placental histology following stillbirth**

Just over half (55%) of all cases received good quality care in terms of pathology input and a further fifth (21%) had only minor issues identified. Only a small proportion of cases (11%) had major issues with the quality of post mortem and/or placental histology highlighted by the panels. The main issues of concern identified included no placental histology being carried out, the quality and interpretation of the post mortem and/or placental histology examination and report and the timeliness of feedback of the results to the relevant obstetric team. A full discussion of the themes identified by the confidential enquiry panels is provided in the remaining chapters of the report.

## **1.14. Summary Data from the checklists**

Panel members were asked to complete checklists for the relevant points on the care pathway. These checklists were developed to facilitate the panel members review of case notes and to provide an overview of the risk factors and care provision for the cases selected for confidential enquiry. For those cases not reviewed at confidential enquiry the data for the checklists was collated by the MBRRACE-UK enquiry midwives. Data relating to booking and antenatal care from the checklists are presented in Table 1 to Table 3 and provide a description of all cases selected for enquiry and those that actually underwent the full enquiry process. Tables 4-6 provide information about the known medical, obstetric and social risk factors developed from standards and guidelines <sup>10, 11</sup>, which should be used to determine the level of care requirement for women at booking for antenatal care. The chapter describing the issues identified for the antenatal period includes information from these three tables to describe the characteristics of the population of women whose case notes were reviewed at the enquiry panels.



**Table 4: Significant medical and/or obstetric risk factors present at booking for all cases of term, singleton, normally formed, antepartum stillbirth**

Risk factor identified	All selected cases n=133	Reviewed cases n=85
Diabetes or other endocrine disorders e.g. thyroid function	12 (9%)	6 (7%)
Hypertensive disease (e.g. PIH, Pre-eclampsia, HELLP)	4 (3%)	1 (1%)
Cardiac disease	2 (2%)	1 (1%)
Uterine or other significant surgery	22 (17%)	11 (13%)
Psychological/mental health issues e.g. depression, puerperal psychosis	28 (21%)	12 (14%)
Psychological or mental disability e.g. learning disability	2 (2%)	0 (0%)
Hepatitis B or C	2 (2%)	0 (0%)
Inherited disorder e.g. cystic fibrosis, haemoglobinopathies	4 (3%)	2 (2%)
Epilepsy requiring anti-convulsants	2 (2%)	1 (1%)
Significant respiratory disease	4 (3%)	2 (2%)
Thromboembolic or haematological conditions	2 (2%)	1 (1%)
Three or more consecutive miscarriages, fetal loss	2 (2%)	1 (1%)

**Table 5: Obstetric risk factors from a previous pregnancy identified in the term, singleton, normally formed, antepartum stillbirths**

Risk Factor Identified	All selected cases n=78	Reviewed cases n=50
Intrauterine growth restriction	8 (10%)	7 (14%)
Birth weight >90th centile	2 (3%)	1 (2%)
Antepartum haemorrhage	3 (4%)	3 (6%)
Postpartum haemorrhage	1 (1%)	1 (2%)
Stillbirth or neonatal death	6 (8%)	5 (10%)
Reduced fetal movements	16 (21%)	13 (26%)
Other*	9 (12%)	9 (18%)

\* includes previous caesarean section, uterine problems, glycosuria, group B streptococcus, pre-eclampsia, ectopic pregnancy

**Table 6: Social and behavioural risk factors identified in the term, singleton, normally formed, antepartum stillbirths**

Risk Factor Identified	All selected cases n=133	Reviewed cases n=85
Smoking	25 (19%)	16 (19%)
Alcohol abuse	2 (2%)	0
Substance misuse	3 (2%)	2 (2%)
New migrant (<1 year in UK) or asylum seeker	7 (5%)	4 (5%)
Social services or child protection involved	3 (2%)	2 (2%)
Domestic abuse	3 (2%)	2 (2%)
Teenage pregnancy	12 (9%)	8 (9%)
Lack of social support	0	0
Housing or benefit issues	2 (1%)	2 (2%)
Mother has difficulty reading	8 (6%)	6 (7%)
Late booking or did not attend two or more appointments	15 (11%)	10 (12%)
<b>Multiple (between two and five) social risk factors present</b>	<b>21 (16%)</b>	<b>12 (14%)</b>

Key factors used to screen for the risk of developing maternal gestational diabetes were collected for all cases identified for the enquiry to determine whether current guidelines were being followed. These data are presented in Table 7 and discussed further in the antenatal care chapter.

**Table 7: Risk factors for developing maternal gestational diabetes**

Risk factor identified	All selected cases n=133	Reviewed cases n=85
Body mass index above 30 kg/m <sup>20</sup> (obese)	28 (21%)	19 (22%)
Previous gestational diabetes	5 (4%)	3 (4%)
Family history of diabetes (first-degree relative with diabetes)	24 (18%)	16 (19%)
Family origin with a high prevalence of diabetes	20 (15%)	13 (15%)
South Asian origin	27 (20%)	15 (18%)
Black Caribbean	4 (3%)	4 (5%)
Middle Eastern origin	1 (1%)	1 (1%)
Total women with any risk factor for gestational diabetes identified	69 (52%)	40 (47%)
<b>Proportion with identified risk factor(s) offered testing for gestational diabetes</b>	<b>32 (47%)</b>	<b>15 (38%)</b>

**Table 8: Women attending with reduced fetal movements**

Risk Factor Identified	All selected cases n=64	Reviewed cases n=39
Previous stillbirth	1 (2%)	0
Raised Body Mass Index	18 (28%)	11 (28%)
Smoking	13 (20%)	7 (18%)
Poor obstetric history	1 (2%)	1 (3%)
Recurrent episodes of reduced fetal movements	2 (3%)	1 (3%)
Pre-existing or gestational diabetes	2 (3%)	2 (5%)
Small for gestational age - known or suspected	4 (6%)	4 (10%)
Extremes of maternal age (<18yrs, >40yrs)	3 (5%)	3 (8%)
Substance misuse	1 (2%)	0
Hypertensive disease (e.g. PIH, Pre-eclampsia, HELLP)	1 (2%)	1 (3%)
Multiple non-attendance	1 (2%)	0

Almost half of the women selected for the enquiry attended with reduced fetal movements (Table 8) and of these just over one quarter were overweight or obese and around one fifth smoked during their pregnancy.

## 2. Antenatal care

Gordon Smith and Moira Maclean

### 2.1. Key findings

- At least one element of the antenatal care for half of all term, singleton, normally formed antepartum stillbirths included in the enquiry was identified as requiring improvement.
- There was evidence of a failure to identify risk factors for gestational diabetes and to refer women for testing as per the NICE Guideline on Diabetes in Pregnancy.
- There was evidence of a failure to monitor fetal growth in line with NICE Guidance, either by not taking symphysis fundal height measurements, not plotting the measurements on a chart or not responding when growth was abnormal .
- There was evidence of a failure to respond appropriately to attendance and repeat attendance by women with reduced fetal movements; either a lack of investigation, misinterpretation of the fetal heart trace or a failure to respond appropriately to additional risk factors.

### 2.2. Introduction

Approximately one third of all antepartum stillbirths occur at term.<sup>12</sup> Unlike high risk pregnancies at extreme preterm gestational ages, there is a known intervention which is highly effective in preventing stillbirth without causing a concomitant increase in the risk of neonatal death, or severe morbidity, namely, induction of labour <sup>13</sup>. A meta-analysis of RCTs demonstrates that routine induction of labour at term and post term reduces the risk of perinatal death by about 50%. Hence, the failure to identify or respond to antenatal risk factors at term which are associated with the risk of stillbirth represents a potential lost opportunity to prevent deaths. A series of maternal characteristics have been shown to be associated with an increased risk of any stillbirth, and the size of the associated risk for identified factors is shown in Table 9. Some of these risk factors are seen as justifying routine delivery at early term, even in the absence of other concerns: the NICE Guideline on Diabetes in Pregnancy (2008)<sup>14</sup> recommended induction of labour at 38 weeks gestational age in women with type 1 diabetes mellitus. Other factors should be taken into account when making a general risk assessment. For example, there is an argument for routine induction of labour of women aged over 40 when they reach 39-40 weeks gestational age, and the case is stronger in the presence of other risk factors.<sup>15</sup>

**Table 9: Maternal characteristics identifiable at booking associated with the risk of stillbirth\***

Characteristic	Adjusted Odds ratio
Black race/ethnicity	2.1
Previous stillbirth	5.9
First pregnancy &/or previous losses at <20 weeks	3.1

Characteristic	Adjusted Odds ratio
First pregnancy	2.0
Diabetes mellitus	2.5
Maternal age $\geq 40$ yrs	2.4
Maternal AB blood group	2.0
History of drug addiction	2.1
Smoking	1.6
Overweight/obese	1.7
Not living with a partner	1.6

\*Data from The Stillbirth Collaborative Research Network Writing Group, 2011.<sup>16</sup>. See publication for adjustment and referent categories. The definition of stillbirth in this analysis uses the gestational age threshold 20 weeks.

Women who do not have pre-existing risk factors may experience complications of pregnancy which subsequently place them at increased risk of stillbirth. These include development of acquired disorders of pregnancy (e.g. gestational diabetes, obstetric cholestasis and pre-eclampsia) or experiencing symptoms/signs associated with an increased risk of stillbirth (reduced fetal movements, antepartum haemorrhage). A range of UK guidelines exist which make specific recommendations regarding antenatal care in pregnancy which may mitigate the risk of stillbirth in some high risk women (Table 10) and adherence to this guidance was reviewed in the enquiry panels.

**Table 10: UK guidelines relevant to mitigating the risk of term stillbirth**

Organisation	Guideline	Year
NICE*	Clinical Guideline 62, Antenatal Care	2008
	Quality Standard QS22, Antenatal Care	2012
	Clinical Guideline 70, Induction of labour	2008
	Clinical Guideline 110, Pregnancy & complex social factors	2010
	Clinical Guideline 45, Antenatal & postnatal mental health	2007
	Clinical Guideline 62, Antenatal Care	2008
	Clinical Guideline, Diabetes in pregnancy	2008
RCOG	Standards for Maternity Care	2008
	Green-top Guideline No. 43, Obstetric Cholestasis	2011
	Green-top Guideline No. 63 Antepartum Haemorrhage	2011
	Green-top Guideline No. 57, Reduced fetal movements	2011
	Green-top Guideline No. 31, Investigations and management of SGA fetus	2013

\* NICE guidelines were relevant at the time of the death

## 2.3. Findings

### Summary of antenatal risk factors present in the cases

Three quarters of women who experienced a term stillbirth had at least one significant demographic, medical, or social risk factor for stillbirth which was identifiable at booking (Table 4 to Table 6). A quarter of women had a weight issue (either underweight, overweight or obese) and the next most common risk factor was mental health problems, which occurred in 12 out of 85 (14%) women. Epidemiological studies have demonstrated that women experiencing complicated previous live births are at increased risk of stillbirth in future pregnancies<sup>17</sup>. Just over half of the cases who had a previous pregnancy had a past history of complications with the two main categories being previous pregnancies affected by intrauterine growth restriction and reduced fetal movements. Five of the women reviewed at panel had experienced a previous stillbirth or neonatal death. Just over two fifths of the women had a social or behavioural risk factor for stillbirth. The most common, accounting for almost half of this group, was maternal smoking. The next most prevalent, which was present for almost one in four of the women with these risk factors was teenage pregnancy. As expected, social factors tended to cluster: of all women with a social or behavioural factor identified (n=35), one third had multiple (between two and five) social risk factors present.

### Findings from the panels

Half of the cases discussed at panels were assessed as having an aspect of antenatal care identified as exhibiting major sub-optimal care (Table 3). Only 12 cases (14%) had no sub-optimal features in the care preceding the baby's death. Key areas for improvements in care provision were identified at the enquiry panels and these fall into four main themes: diagnosis of gestational diabetes, reduced fetal movements, screening for fetal growth restriction and failure to learn lessons from adverse events.

### Gestational diabetes

Approximately half of the women reviewed (47%) had at least one risk factor for gestational diabetes which should have led to biochemical testing according to the NICE Guideline on Diabetes in Pregnancy<sup>14</sup>. None of the cases reviewed at enquiry indicated that testing had been refused. However, testing was only performed in just over one third of cases with an identified risk factor (38%). The two most common groups of women who were not tested were those who were obese (BMI > 30kg/m<sup>2</sup>) and women who were from high risk ethnic groups. Among the obese women, testing was not performed in around one quarter. Among women who came from an ethnic background with a high prevalence of type 2 diabetes mellitus (South Asian, Black Caribbean or Middle Eastern), testing was omitted in almost half. It is known that diabetes is a risk factor for stillbirth, and randomised controlled trials have shown that diagnosing and treating gestational diabetes prevents complications in the offspring<sup>18</sup>. It follows, therefore, that failure to screen these women for gestational diabetes represents a potential lost opportunity to intervene to improve outcomes. A clear example of this is illustrated in Vignette 1 where it was not clear that a glucose tolerance test had actually been performed despite being requested twice.

## Vignette 1: gestational diabetes

*A non-English speaking woman with two children (birth weights 4 kg and 3.6 kg) had ethnicity as a risk factor for gestational diabetes. No interpreter was present at the booking visit. Glucose tolerance tests were apparently requested at 17 and 28 weeks gestation, but no results were recorded in the woman's medical notes. The woman attended the antenatal clinic at term having telephoned to report she had not felt her baby move for 2 days. The fetal heart could not be heard on auscultation and fetal death was confirmed by ultrasound scan. She delivered a stillborn baby weighing over 5 kg. The letter to the parents and GP stated that there was "no evidence of diabetes mellitus" and there was no mention of the possibility of gestational diabetes as the cause of death or suggestions for appropriate care in future pregnancies.*

## Reduced fetal movements

Just under half of the cases reviewed had experienced reduced fetal movements. In almost two thirds of these cases there were one or more additional risk factors such as, extremes of maternal age, obesity, smoking, or suspected fetal growth restriction. In one third of the cases with reduced fetal movements panels agreed that there were major issues with the quality of care and the provision of good care may have potentially prevented the death of the baby. In over half of cases with a major failure of care, there was no investigation following the maternal report of reduced fetal movements. In other cases, (i) traces of the fetal heart rate were obtained but were misinterpreted, (ii) the reduced fetal movements occurred in situations where there were multiple other risk factors which should have led to immediate induction of labour, and (iii) there were several cases where women attended with recurrent episodes of reduced fetal movements but this did not trigger appropriate investigations or intervention as illustrated in Vignette 2.

The RCOG guidelines<sup>19</sup> recommend that women should be informed that the type of movements may change as their pregnancy progresses and that the frequency of those movements should not reduce. However, a recurrent theme from the panel enquiries was a delay in women reporting a reduction in fetal movements. Lack of evidence over what comprises reduced fetal movements makes compliance with advice difficult and panel findings highlight the wide variation in the interpretation of what is best practice from clinicians regarding assessment and any resulting action related to changes in fetal activity. This finding is in line with the finding of Heazell et al<sup>20</sup>. A more recent evaluation<sup>21</sup> found that despite the introduction of RCOG guidelines in 2011<sup>19</sup> local unit guidelines failed to incorporate evidence to standardise the management of reduced fetal movements.



## Vignette 2: reduced fetal movements

*A low risk primigravid woman reported an absence of fetal movements at 39<sup>+1</sup> weeks gestation when she attended the community midwifery unit. CTG monitoring, appeared to be within normal limits and she was reassured that all was well. She attended at 40<sup>+1</sup> weeks gestation for a membrane sweep and reported a reduction in her baby's movements and spontaneous rupture of membrane. She was discharged home without a CTG or further investigation. She attended again at 41<sup>+0</sup> weeks gestation with irregular contractions. She was prescribed analgesia and discharged home. At 41<sup>+5</sup> weeks she attended with irregular contractions and on admission, intrauterine death was confirmed by ultrasound scan.*

## Screening for fetal growth restriction

Epidemiological studies have shown that about one in three term, normally formed, antepartum stillbirths are related to abnormalities of fetal growth<sup>22</sup>. Hence, appropriate screening for growth abnormalities is a key aspect of antenatal care. Nearly two thirds of cases had some form of failure of care in relation to screening for growth disorders. In half of these cases the consensus of the panel was that there were major issues with the quality of care and that the correct course of action might have prevented the baby's death. The most common problem was either failure to perform symphysial-fundal height (SFH) measurement, or failure to plot the SFH measurements. However, in a further third of cases, SFH measurements were performed and indicated a problem, but no action was taken as illustrated in Vignette 3. In one in five cases there was failure to respond to risk factors either present at booking or emerging during the pregnancy which should have resulted in serial ultrasound assessment of fetal growth.

## Vignette 3: intrauterine growth restriction

*A woman with a history of multiple miscarriages and one live child delivered by Caesarean section was initially referred for obstetrician-led care but then was seen by the midwifery team throughout her pregnancy. A glucose tolerance test was performed at 16 weeks gestation because of glycosuria and found to be within normal limits. Despite persistent glycosuria and a plan to repeat the glucose tolerance test there was no record that this took place. A customised fetal growth chart was completed, but a reduction in the growth rate was not acted upon. At 38 weeks gestation she reported a reduction in her baby's movements since the previous evening. The fetal heart beat was undetectable and intrauterine death was confirmed by ultrasound scan. Although the blood pressure was within normal limits earlier in the day, the mother was noted to be hypertensive at this point and labetalol was prescribed. There was a delay of 6 hours before her labour was induced due to high workload on the delivery suite. She delivered a stillborn baby weighing <1.5 kg. The cause of death was attributed to severe intrauterine growth restriction and placental insufficiency related to hypertensive disease, which were not identified during pregnancy.*



## Failure to learn lessons from adverse events

Adverse events in general and stillbirth in particular, will always occur. Some of these may never have been preventable. A key strategy for reducing the number of future cases is to recognise where previous failures in care occurred, and to learn lessons from each loss. A recurring theme in the case reviews was the missed opportunity to learn from adverse events, due to no local review having been carried out, or a superficial or inadequate review was conducted; an example is illustrated in Vignette 4

### Vignette 4: missed opportunities to learn lessons from local review

*This case involves a woman with a previous history of an elective caesarean section and preterm delivery of growth restricted twins. Induction of labour was planned for 41<sup>+6</sup> weeks but at 35<sup>+0</sup> weeks she had fresh vaginal bleeding. She was prescribed dexamethasone and admitted for observation and a scan the next day. The estimated fetal weight was <5<sup>th</sup> percentile. Later that day there was a further vaginal blood loss. A CTG monitoring demonstrated an active baby with a normal fetal heart rate. At 41<sup>+1</sup> weeks gestation, she attended the maternal assessment unit reporting a reduction in her baby's movements; a CTG was requested but revealed nothing abnormal. Despite the presence of multiple risk factors: previous caesarean section, reduced fetal movements, a known small-for-gestational age fetus, previous antepartum haemorrhage, and a history of intrauterine growth restriction in a previous pregnancy, induction of labour was not offered. Two days later, the mother attended in labour reporting a reduction in her baby's movements. Intrauterine death was diagnosed by ultrasound scan. The mother gave birth to a small for gestational age stillborn baby. Local review by hospital staff failed to identify any issues with the care the mother received.*

## 2.4. Conclusions

All stillbirths are tragic events. Stillbirth of normally formed babies at term seems particularly tragic as, in most cases, it could reasonably be assumed that, had the baby been delivered in the days prior to intrauterine death, bereavement might have been prevented and a whole life might have been saved. This latter characteristic distinguishes these particular stillbirths from the similarly traumatic but less potentially preventable stillbirths that occur at extreme preterm gestational ages, or are associated with major congenital anomalies. A major obstacle in reducing stillbirth rates has been a fatalistic view, that these deaths are inevitable and that preventing stillbirth is extremely difficult. However, when the context of the stillbirth is a woman at term who either had risk factors in her history, or presents with complications known to be associated with an increased risk of stillbirth, such deaths should be viewed as potentially preventable. This view is reinforced by the results of the present confidential enquiry. The key conclusion in relation to antenatal care is that half of the cases of term stillbirth reviewed had a major issue with the quality of care provided and improvements to the care may have made a difference to the outcome. Indeed, it was a small minority of cases where the care was assessed as being good quality. Disappointingly the key lessons for practitioners from this enquiry are very similar to those identified in the last confidential enquiry for antepartum stillbirths carried out in 1996/97<sup>3,4</sup>:

- (i) that women should be appropriately screened for gestational diabetes;

- (ii) that the care for women presenting with reduced fetal movements must be improved;
- (iii) that screening for fetal growth restriction is frequently poorly performed and when identified not always acted upon; and
- (iv) lessons for future practice must be learned where failures of care lead to, or contribute to, stillbirth.

Twenty years on it is imperative that action is taken to ensure that these problems are appropriately managed which, in turn has the potential to lead to a reduction in the antepartum stillbirth rate.

## 3. Diagnosis of the stillbirth and intrapartum care

Penny McParland, Carol Liptrot and Jan Latham

### 3.1. Key findings

- The majority of case notes reviewed in the enquiry documented good and compassionate care of the woman and her family during the labour and birth.
- The notes reviewed suggest that care was sometimes compromised by a lack of resources, leading to delays in analgesia provision, absence of the midwife for periods of time, and women labouring on the antenatal ward.
- The methods of induction of labour used following diagnosis of intrauterine death varied significantly, especially in women with a history of previous caesarean section, reflecting the lack of clear evidence and guidance.
- Guidance for care is particularly required for women with a previous history of caesarean section who have an intrauterine death and for whom uterine rupture is a very real risk.
- Several cases were identified where a partogram was not completed, and the normal prompts regarding maternal care were therefore missed. In a number of cases the duration of labour exceeded normal good practice by a significant degree. Women delivering a stillborn baby should receive the same quality of obstetric and midwifery care as those delivering a healthy baby.

### 3.2. Introduction

The diagnosis of a late intrauterine fetal death (IUFD), and subsequent delivery of a stillborn baby, may occur in a pregnancy which until then was normal and with no forewarning even in those pregnancies where antenatal complications were identified. Diagnosis is always a time of distress to the woman and her family, and care in labour needs to be provided with sensitivity to the grieving family, but also needs to pay due regard to the potential underlying pathology and health consequences for the woman. During this time health care professionals are undertaking many tasks, providing medical and midwifery care to the woman, and gathering investigation results which may inform the cause of the death and affect decisions about future pregnancies and fertility.

The care aspects of the diagnosis of intrauterine death and the subsequent intrapartum care were reviewed for each set of case notes and judged against the standards and guidance (Table 11) in existence at the time of the stillbirths reviewed in this enquiry (2013).

**Table 11: Guidelines and standards relating to diagnosis and delivery of antepartum stillbirths**

Organisation	Guideline	Year
RCOG	Standards for Maternity Care	2008
	Green-top Guideline No. 55, Late Intrauterine Fetal Death and Stillbirth	2010
Sands	The Sands Audit Tool for Maternity Services: Caring for parents whose baby has died	2011
	Pregnancy Loss and the Death of a Baby: Guidelines for Professionals	2007
NICE	Quality Standard 70 : Induction of labour	2008

The panels were specifically asked to consider good practice for the diagnosis of the intrauterine fetal death (IUFD) including timing and the occurrence of a second opinion, planning of intrapartum care, availability of necessary resources, quality of care in labour and the presence of a one-to-one midwife, location of delivery, provision of analgesia, and care of other family members.

### 3.3. Findings

The quality of intrapartum care provided for the antepartum stillbirth cases discussed at enquiry panels was judged to be good for nearly half of the cases during the diagnosis of the fetal death and the subsequent labour and delivery and a further fifth of the cases only had minor care issues identified. In one quarter of the cases major issues with the quality of care were identified.

#### Diagnosis of fetal death

Real time ultrasonography is essential for accurate diagnosis of intrauterine death. This should ideally be available at all times, and a second opinion should be sought wherever practical<sup>23</sup>. In the majority of case notes reviewed by the enquiry panels it was apparent that the diagnosis was made and communicated in a timely and sensitive manner. Isolated examples of poor practice were identified and included one woman who was sent home and asked to return the next day for a repeat scan to confirm the fetal death, and another who waited 2 hours for the second opinion.

Once the diagnosis of fetal death was made, an appropriate plan of care was made in nearly all cases, although practice varied widely regarding the timing of induction of labour, and whether the woman had the opportunity to go home and return at a later date.

#### Delays and resource issues

After diagnosis of the death, and during the intrapartum period, support and guidance for bereaved women and their families is paramount. It is recommended that maternity units aim to develop a special labour ward room for well women with an otherwise uncomplicated IUFD that pays special heed to emotional and practical needs without compromising safety<sup>23</sup>. These facilities should ideally be away from women whose pregnancies and labours are progressing normally and parents with healthy

babies<sup>24</sup>. Review of anonymised notes does not always allow this type of service delivery to be identified. However in a small number of notes it was clear that women either laboured on the antenatal ward, or were transferred back and forth between the antenatal ward and delivery suite.

Ensuring adequate staffing in maternity units and the presence of an appropriate skill mix is vital. If under-resourcing occurs this then has an impact on the level of care offered. In the majority of cases reviewed, the enquiry panels noted that midwives provided one-to-one care, and paid attention to both the medical and emotional needs of the woman and her family. However some cases were identified where the level of activity on the delivery suite led to women being left on their own for several hours. For instance a case was identified where a woman was left alone while her midwife attended another woman to undertake perineal suturing and another where the woman had no midwife present for 3 hours during labour. One woman had her induction of labour delayed by 6 hours due to pressure of workload of the delivery suite. Pain relief in the form of epidural was delayed in a small number of women due to the anaesthetist being unavailable, although the reason for the lack of availability was often not documented.

Good communication between healthcare professionals and the woman is always essential,<sup>25</sup> therefore access to an interpreter should be available where required. Delay occurred in one case as no interpreter was available and the woman was left alone as the unit was busy. In their guidelines Sands describe how stress, grief and shock affect the ability of women and their partners to communicate in their own language, and these effects are further heightened when trying to communicate in another language<sup>24</sup>. They therefore recommend that all staff should have appropriate training in how to communicate across a language barrier when there is no interpreter. Interpreters in this situation need to be experienced in health care interpreting, and have additional skills in interpreting for people who are bereaved. It is important that they are able to understand the stages of grief, the principles of giving support to families, are confident when dealing with strong emotions and are able to translate these between cultures<sup>24</sup>.

## Induction of labour and management of labour

Induction of labour and subsequent care in labour should be undertaken with primary regard to the wellbeing and safety of the woman. The management plan should take into account the woman's preferences as well as her medical and obstetric history<sup>23</sup>. Whilst there is agreement that the induction of labour should be carried out using mifepristone and a prostaglandin, there is no agreement regarding the best regimen to use. The RCOG Green-top Guideline<sup>23</sup> suggests that 200mg mifepristone is appropriate for women with an unscarred uterus. The most commonly used prostaglandin is misoprostol, although its use in this context is off-label. NICE recommend that the choice and dose of vaginal prostaglandins should 'take into account the clinical circumstances, availability of preparations and local protocols'<sup>26</sup>. The RCOG do not explicitly recommend a dose/regime of misoprostol. However they do reference a study which used a regime of 100µg misoprostol 4 hourly for up to 24 hours for women with an unscarred uterus from 27 weeks gestation onwards. There is even less agreement regarding the best induction regime in women with a prior Caesarean section in whom uterine rupture is a risk, with up to 600mg mifepristone suggested (to minimise the dose of misoprostol required) and subsequent

doses of 25-50µg misoprostol (referenced in the relevant RCOG Green-top Guideline <sup>26</sup>). It should be noted that misoprostol in the UK is supplied as 200µg tablets and administration of doses lower than this would involve splitting tablets.

The regimes used for induction of labour in women included in the enquiry varied widely. The majority received 200mg mifepristone, with a small number receiving 600mg (including one woman with an unscarred uterus). Prostaglandin regimes varied widely. Some women received prostaglandin E2 (Prostin™) at varying doses. The majority of women received misoprostol with a lack of consistency of dosage used between different cases. One woman received a 3<sup>rd</sup> dose of misoprostol when already apparently labouring actively and subsequently ruptured an unscarred uterus (Vignette 5).

#### **Vignette 5: uterine rupture**

*A woman with a previous vaginal birth of a 34 week stillborn baby attended for planned Caesarean at 39 weeks gestation for breech presentation. On admission the fetal heartbeat was absent and an IUD diagnosed. Induction of labour was carried out with administration of 200mg mifepristone and 100µg misoprostol (simultaneously). A second dose of misoprostol was given 3 hours later. Two hours after this, the woman was noted to be contracting and was 3-4cm dilated. A third dose of misoprostol was given 3 hours after the second dose. An epidural was used for analgesia. After a further 5 hours the cervix was 9cm dilated. Vaginal bleeding was noted, and at the examination the presenting part could not be felt. Contractions were noted to have diminished. A possible uterine rupture was diagnosed and decision made for delivery by Caesarean. This was carried out after an unexplained 90 minute delay. At the time of the Caesarean section, the consultant noted that the 'anterolateral and right side' of the uterus had 'exploded at lower end'. This was repaired, however he advised the woman against further pregnancy at her postnatal review appointment.*

Women in spontaneous labour and also those being induced with an IUFD need the same level of information about pain relief as women with a healthy baby. The different options, advantages, disadvantages and side effects should be discussed to permit the woman to make an informed choice<sup>24</sup>. The RCOG recommend that regional anaesthesia should be available for women with an IUFD, and that assessment for disseminated intravascular coagulopathy and sepsis should take place before it is administered<sup>23</sup>. Most women included in the enquiry were reviewed by an anaesthetist, and appropriate pain management discussed, often comprising either an epidural or morphine Patient Controlled Analgesia (PCA). However, the enquiry panels identified a number of cases where pain management was inadequate. Two women were identified where no discussion about pain management was recorded in the notes at all. A number had a significant delay to their epidural either due to the level of activity on the delivery suite, or due to concerns about the potential risk of disseminated intravascular coagulopathy. One woman received ten doses of 20mg oral morphine solution and four doses of 50-100mg tramadol over 26 hours before being provided with morphine PCA.



Management of labour in women with an IUFD should follow the same principles as labour in women with a healthy baby. In addition to good emotional support women should receive excellent physical care<sup>24</sup>. This should include completion of a partogram, which serves to assess maternal wellbeing and progress in labour. Prolonged labour can lead to increased risk of complications of delivery including postpartum haemorrhage, as well as causing long term damage to the maternal pelvic floor and bladder. Several cases were identified where a partogram was not completed, and the normal prompts regarding maternal care were therefore missed. In a number of cases the duration of labour exceeded normal good practice by a significant degree. A second stage labour with a duration in excess of 6 hours was identified in three women (Vignette 6). A total labour duration of 35 hours occurred in another woman. Lack of attention to bladder care was also noted in a number of women; one woman did not have her bladder emptied for 17 hours during labour.

### **Vignette 6: extended period of labour**

*A woman in her 30's in her 3<sup>rd</sup> pregnancy had one previous vaginal delivery and one previous Caesarean section. She developed hypertension in the third trimester and was managed with oral labetalol. She had an intrauterine fetal death diagnosed at 39 weeks gestation. Induction of labour was by artificial rupture of the membranes (ARM) followed by oxytocin infusion 9 hours after ARM. Full dilatation was reached 5 hours later. Active pushing was delayed for 3 hours whilst a dose of nifedipine was given to lower her blood pressure and a second cannula was sited. Lack of descent of the head was noted after 1½ hours of pushing, but a medical review did not occur for over 2 further hours. A 2.5kg baby was finally delivered by forceps after a second stage of total duration of 7 hours 35 minutes.*

The reasons for delays in care in labour were often not clear. In some cases the reasons for delays can be inferred from the notes, in other cases only hypothesised. The notes suggested that most of these women received one-to-one midwifery care during labour. From the documentation available one-to-one care was provided in four fifths of cases. Delays in obtaining review by medical staff were occasionally noted, despite multiple requests by the midwife. Some notes suggest that the doctors were unsure or anxious about undertaking forceps delivery of a stillborn baby, and delayed making a decision to do so. It is also possible that in an attempt to provide the compassion and support required during such a difficult time, the normal medical and midwifery needs of the woman were overlooked or considered less important. This may be a misguided attempt not to interfere with the labour, or disturb the woman, knowing that the needs of the baby did not require consideration. It is also possible that women with healthy babies were prioritised on the delivery suite when resources were limited. However the potential short-term and long-term consequences of long labours in difficult and traumatic circumstances should not be forgotten or underestimated (Vignette 7).

## Vignette 7: urological issues following extended period of labour

*A primigravid woman had an intrauterine death diagnosed at 38 weeks gestation. Labour was induced with prostaglandin E2 and oxytocin. A morphine PCA was used for analgesia. Once full dilatation was diagnosed a passive second stage of 2½ hours occurred. A medical review was undertaken after 2½ hours of active pushing, and the notes suggest that a forceps delivery was contemplated. However it was a further 2 hours before the woman was transferred to theatre for this to be performed. The anaesthetist then asked for blood tests to check a clotting profile prior to a spinal block, which lead to a further 1½ hour delay. The total duration of the second stage of labour was 8½ hours. The woman was incontinent postpartum and required an indwelling urinary catheter for 2 weeks. She was still carrying out intermittent self-catheterisation when seen by the consultant for postnatal review at 6 weeks postpartum*

Three women whose notes were reviewed in the enquiry suffered a ruptured uterus; one as the cause of the IUFD, and two during the labour following induction (Vignette 8). The first of these had an apparently painless uterine rupture during the time she waited on delivery suite for a planned Caesarean. The fetal heartbeat was present in the morning, and following a change in shape of the uterus, the fetal heartbeat was absent and the baby was found to be in the peritoneal cavity at Caesarean section. The other uterine ruptures followed induction of labour: one in a scarred uterus and one in an unscarred uterus. None of the women required hysterectomy, although all required a high level of postnatal care due to massive obstetric haemorrhage.

## Vignette 8: failure to progress in labour - uterine rupture

*A woman with a history of previous Caesarean section had an intrauterine death diagnosed at 37 weeks gestation. She had originally been booked for a planned Caesarean at 39 weeks gestation. In view of the intrauterine death she was advised that vaginal delivery was preferable. She was given 600mg mifepristone, followed by artificial rupture of the membranes and an oxytocin infusion was commenced 2 hours later. Although some notes are missing, it appears that Caesarean section was performed 18 hours after ARM for lack of progress in labour. Unexpectedly uterine rupture was found at Caesarean, with the arms and hands of the baby protruding through the ruptured uterine scar. The uterus was repaired and despite a 3.5 litre blood loss the woman was able to go home 2 days later.*

## 3.4. Conclusions

Diagnosis of an intrauterine fetal death was carried out promptly for the majority of women, with appropriate plans made, and appropriate care in labour. It is clear that the care of a few women was adversely affected by limited resources within the maternity unit, leading to delays in care, or absence of care at times. In a number of cases the medical needs of the woman appear to have been overlooked, with excessively long labours occurring. This has potential consequences for current and future maternal health and wellbeing. Care of women labouring with an IUFD is demanding and complex for staff. However completion of a partogram is essential and the attention to the midwifery and medical needs



of the woman should be balanced with supporting her emotional needs. Provision of analgesia was timely and appropriate in most cases, but in a few delays occurred both due to resource issues, as well as concern about medical complications.

There is a wide variation in practice of induction of labour in women with an IUFD, in part due to lack of clear evidence and guidelines. Care of women with a prior Caesarean section is particularly difficult where the wish for a vaginal birth should be considered alongside the risk and sequelae of uterine rupture. This is a need that will only increase with time as the Caesarean section rate continues to rise steadily.

It should be reiterated that despite the examples of poor care that are highlighted, the enquiry panels noted that in the majority of cases supportive compassionate one-to-one midwifery care was provided to the bereaved women and their families. Sands guidelines<sup>27</sup> highlight:

- a need for sensitivity and empathy when caring for the needs of women and their families, with personal preferences, cultural or religious needs taken into account.
- health professionals should endeavour to provide good emotional support, alongside excellent physical care during and after the loss of a baby
- health professionals should provide information and support, encouraging families to make their own decisions about what happens to them and their baby.
- In the majority of cases reviewed at panel there was evidence that these principles were adhered to.

## 4. Care after birth

Sara Kenyon, Ruth Paul, Tracey Glanville, and Maggie Redshaw

### 4.1. Key findings

- The enquiry panels found a good standard of bereavement care documented as being given to parents immediately following birth, nearly all were offered the opportunity to create memories. Bereavement checklists were present and completed in the majority of notes.
- A number of areas for improvement were identified for which information was specifically requested from maternity units if available:
  - There was wide variation in the availability of a specialist bereavement midwife with only one third of case notes showing evidence of their involvement.
  - There was wide variation in the documentation as to whether recommended maternal tests were undertaken prior to discharge home from hospital.
  - Nearly one third of cases had no documented offer of post mortem examination or written confirmation of the provision of associated literature.
  - Only half of the cases reviewed included documentation that lactation suppression was discussed and prescribed if requested.
  - Just under half of the review cases had no documentation to indicate continuing midwifery involvement in the postnatal period.
  - There was a lack of documented evidence of contact with other healthcare professionals and organisations to inform them of the stillbirth.
  - There was scarce evidence in the notes that information was provided for parents with regard to the possible need for longer term counselling and support.

### 4.2. Introduction

Care during and after the birth of a stillborn baby has a profound effect on the short and long term wellbeing of the parents, their ability to care for others and their contact with health services in the future<sup>28-30</sup>. Sensitive and thoughtful care will not take away the pain and shock of what has happened but it may provide some comfort and play a part in the parents' understanding and to help them to come to terms with what has happened. This chapter will look at the immediate care following birth (both in hospital and the community), maternal tests undertaken and discussion of the offer and information provided in relation to post mortem examination.

The panels were asked to consider the care compared to a series of checklists developed by the Topic Expert Group. These included issues which could reasonably be extracted from the case notes and were based on the standards and guidance available in 2013 (Table 12).

**Table 12: Guidelines and standards relating to care after birth for antepartum stillbirth**

Organisation	Guideline	Year
RCOG	Green-top Guideline No. 55, Late Intrauterine Fetal Death and Stillbirth	2008
NICE	Antenatal and Postnatal Mental Health: clinical management and service guidance	2014
Sands	The Sands Audit Tool for Maternity Services: Caring for parents whose baby has died	2011

The quality of care given was reviewed from the case notes and encompassed whether there was documentation regarding:

- Immediate physical (including lactation suppression) and emotional care including: whether information was given regarding funeral arrangements and local and national support groups and whether specialist bereavement services were provided i.e. midwifery bereavement services or checklists were available.
- Whether the recommended maternal investigations were undertaken and if parents were offered post mortem examination.
- Communication with external healthcare professionals and/or organisations and continuing midwifery support following discharge from hospital.
- Whether interpreting services were required and what was available.

## 4.3. Findings

### The immediate physical and emotional care

It was apparent for the cases reviewed that the quality of care the parents received was generally good, with the majority of parents given opportunities to see and hold their babies and to create memories (Vignette 9). Full details from the checklists completed for all 133 cases, who fulfilled the criteria for the confidential enquiry and for whom notes were received are provided in Table 13.

**Table 13: Bereavement care around the time of labour and birth**

Aspect of care documented	All selected cases n=133	Reviewed cases n=85
One-to-one midwifery care	115 (87%)	73 (86%)
Bereavement checklists were present in case notes	110 (83%)	70 (82%)
Specific documentation for bereavement care present in the case notes	26 (20%)	18 (21%)
Involvement of a specialist bereavement midwife	48 (36%)	31 (37%)
Parents were given the opportunity to see and hold their baby	130 (98%)	84 (99%)

Aspect of care documented	All selected cases n=133	Reviewed cases n=85
Parents were given opportunities to make memories of their baby e.g. take the baby's hand and footprints, a lock of hair	124 (93%)	80 (94%)
Parents were given opportunities to have photos taken	120 (90%)	77 (91%)
Access to a suitable chaplain, priest or other religious person was discussed with the mother	103 (77%)	65 (77%)
There was an offer for the parents to take the baby home	18 (14%)	7 (8%)
Written details of national and local sources of support were provided to parents prior to discharge	105 (79%)	68 (80%)
Written details regarding funeral arrangements were provided to parents prior to discharge	99 (74%)	65 (77%)
Written details of the registration process for a stillborn baby were provided to parents prior to discharge	100 (75%)	62 (73%)
An offer was made for lactation suppression	67 (50%)	33 (39%)
A post mortem examination was offered and associated written information made available	93 (70%)	62 (78%)

### Vignette 9: an example of excellent postnatal care

*This case involved a 28 year old woman in her second pregnancy who presented with an intrauterine death at 38 weeks gestation. Hospital documentation upon discharge included details about informing the GP, Health Visitor, Community and Bereavement midwives about the death and discharge. Written information was given, including contact numbers and details of the process of birth and death registration.*

*In the community, she had five visits by two community midwives known to her, and a visit at home by the bereavement midwife. Documentation showed evidence of both physical and psychological care, including concern about the partner's emotional wellbeing.*

*The last visit was at 15 days postpartum when the couple felt ready for discharge.*

## Taking the baby home

From the evidence documented within the notes the opportunity for parents to take their baby home was rarely offered. Parents may decline this option, preferring to say goodbye in the hospital, but for others it can be an important and memorable experience. One parent who asked to take her baby home was advised this would not be a good idea, as the baby would 'deteriorate' quickly.

Sands recommend that parents should always be offered the option of taking their baby out of the unit (Audit Tool 8.1 and 8.2)<sup>9</sup> along with instructions of how to care for the body. Some maternity units have adopted the use of cold cots, thus enabling parents to spend more time with their baby<sup>31</sup>.

## Suppression of lactation

There was there documented evidence of lactation suppression being given in only half of the cases selected for enquiry. There was a lack of consistency in the written documentation and not all women appeared to be offered lactation suppression. Milk production may be very upsetting for some women whose babies have died and can be associated with additional physical pain. For others it may be an opportunity to donate breast milk to a milk bank and feel that this is positive outcome from their bereavement.

While the offer of lactation suppression is not currently a Sands auditable standard<sup>9</sup>, there is evidence that this is an issue for parents, with a third of women who took part in the 'Listening to Parents' survey<sup>31</sup>, identifying they were not given enough information about managing breast milk production. Amongst the panels there was discussion about whether drug therapy should be offered, and the safety profile of cabergoline and potential drug interactions. Bromocriptine was historically used but has been withdrawn over concerns of safety. This appears to be an area where there is a lack of a consensus and lack of a consistent approach and needs to be addressed.

## Specialist bereavement services

Sands, in their position statement<sup>32</sup>, state that it is essential for maternity units to have access to at least one member of staff who has specialist knowledge and training in bereavement care. S/he should have an overview of all the departments that may be involved - from the time a baby's death is suspected to the time the parents leave the hospital, the baby's body is buried or cremated or released to the family for the funeral, the post mortem results have been discussed with the parents and the follow-up consultation appointment has taken place.

Currently, there is no nationally recognised job specification for bereavement midwives. The hours allocated to this work vary and the role is interpreted in different ways in different places. Many staff are also expected to fulfil this role in very few hours per week or month, without a title to recognise the role or the appropriate pay grade.

There was an apparent wide variation in the availability of a specialist bereavement midwife; with just over a third of the case notes having evidence of their involvement. Such a member of staff may have been involved in other cases but it was not possible to identify this from the documentation made available for review by the confidential enquiry.

## Use of bereavement checklists

The majority of the cases reviewed contained a checklist for bereavement care but there was variation in what was contained within them. Specific documentation for bereavement care was only noted in one fifth of cases within the documentation provided. It is possible that this information was held elsewhere and not provided when requested for the confidential enquiry.

## Recommended maternal tests,

Understanding why their baby died is of vital importance to parents, both in terms of starting to come to terms with what has happened but also for planning for any future pregnancies. In this group of women and babies where the cause of the stillbirth is often unclear, maternal investigations and examination of the baby may provide significant information. The RCOG Green-top Guideline <sup>23</sup> Late Intrauterine Fetal Death and Stillbirth, contains an extensive list of recommended tests following late intra uterine fetal death (Appendix 5:)

Good practice suggests that there should have been a clear comprehensive checklist within the clinical notes but this was often lacking, making data extraction difficult.

In the majority of cases, the appropriate investigations were carried out with clear documentation in the clinical notes. However this finding was not consistent with, at times, omission of significant investigations, for example Kleihauer-Betke test not being performed when there was a strong suspicion of a fetal-maternal haemorrhage. There was also evidence of tests not being repeated or further investigated when abnormal, for example a raised HbA<sub>1c</sub>. There were examples of poor practice with women advised that no maternal investigations were required when the cause of death was unknown.

## Offer of post mortem examination to parents

The Sands Audit Tool for maternity services suggests that all parents whose baby dies should be offered a post-mortem<sup>9</sup> and this is endorsed by NHS England <sup>33</sup>. Of the 133 cases, a full post mortem was performed in nearly half of the cases (n=63) of which 45 were reviewed by the panels. A limited post mortem was performed in three cases, all of which were reviewed by the panel. Placental histology alone was performed in 37 cases of which 25 were reviewed by the panel. In 30 cases no post mortem was performed.

The Human Tissue Authority together with Sands have produced a model consent form and information and guidance for health professionals seeking consent for post mortems on babies who have died before, during or shortly after birth<sup>34</sup>. How parents are approached and how the issue of post mortem is discussed is pivotal to whether they agree. There was evidence within the cases reviewed by the panels that post mortem was not considered necessary in some cases as the stillbirth had been unavoidable; that may well have been the case but careful consideration regarding post mortem examination should be given by both healthcare professionals and parents. More recent evidence suggests that parents' predominant reasons for not giving consent are not wanting their baby examined or that the reason for the stillbirth was already known <sup>31</sup>. This study also found that whilst most parents felt they were well informed and had sufficient time to make a choice regarding post mortem, not all felt this way, with some feeling pressured to decide quickly under what were very difficult circumstances <sup>31</sup>.

The grade of staff discussing options around post mortem was not always clear from the clinical notes. Parents should be made aware of the options regarding a full post mortem but also other options including an external examination, limited post mortem or X-rays. The Human Tissue Authority guidance recommends that all staff who approach parents for consent for a post mortem should have received adequate training <sup>34</sup>. While it was not possible to ascertain the level of training, there were some cases which suggest that the grade of staff was not appropriate, for example, a GP trainee. In another case

a woman was offered a post mortem by letter. The timing of consent was in some cases inappropriate, with consent being taken during the night when it was clearly documented that the woman was distressed.

Sands recommend<sup>9</sup> that all parents should be offered written information (relevant to perinatal deaths) regarding post mortem examinations, to read prior to giving consent. There was often no written information to confirm that this had occurred. Although the panels acknowledge that the absence of written evidence in the notes does not mean this was not done, units should consider the need for this information to be clearly documented in their checklists. This should also be evident in cases when post mortem was subsequently declined.

#### Requirement for and availability of interpreting services

Of the cases reviewed by the panels, 12 cases documented that English was not the mother's first language and there was a need for an interpreter. There was a wide variation in how communication was addressed, and care provided. For some, the same midwife provided continuity and arranged an interpreter or LanguageLine (<http://www.language.co.uk/>) whenever needed. In other cases, different midwives visited at each appointment, or provided telephone contact alone. There was some evidence of the partner interpreting in inappropriate circumstances (e.g. regarding the baby's death, request for post mortem or at the follow-up appointment) and Sands recommend that parents should always be offered an interpreter when a problem is diagnosed antenatally or in labour, or a baby dies. An example of good practice is provided in Vignette 10.

#### **Vignette 10: example of excellent follow-up care**

*In this case, a 27 year old Asian woman delivered a stillborn baby at term. Although she spoke no English, her partner did; when the couple had questions about post mortem, their midwife arranged an appointment at the hospital with an interpreter to discuss this, rather than simply using the father to translate. An interpreter was also booked for the consultant follow-up appointment. The community midwife provided good continuity of care by arranging to see the couple herself on all visits.*

In cases where written information was provided for parents it was often not documented whether this was in the mother's or father's own language. Frequently only physical not psychological care was recorded in the notes of women who did not speak English as a first language. There was also evidence that using an interpreting service was 'saved' for the consultant postnatal follow-up appointment at a later date.

Arranging an interpreter, and using one in a three-way conversation, takes two or three times longer, requiring resources that are frequently limited. Sands recommend that more time and flexibility should be allowed for appointments in which an interpreter is required (Audit tool 15.8)<sup>9</sup> and evidence of this was lacking within the cases reviewed.



## Preparation for discharge home from hospital and continuing support

The need for other healthcare professionals to be informed about the stillbirth in a timely manner is clearly important for parents and should reduce unnecessary distress. Within the cases selected for the confidential enquiry there was some evidence that this was not always done. Sands recommend a designated person should always ensure the woman's GP and community midwife are informed when a stillbirth occurs<sup>9</sup>. Documentation in cases reviewed suggests that community midwives and GPs were not always contacted (Table 14). The 'Listening To Parents' <sup>31</sup> survey underlines how much parents value the support of their GP following the death of a baby. Even where a mother declines a visit, the GP and midwife should be made aware. Also of note was that less than half of health visitors were documented as having been informed, and Bounty were informed even less frequently. Contact by professionals who are unaware of the stillbirth is distressing for parents and suggests poor communication between the services, likewise the receipt of promotional literature and products through Bounty.

**Table 14: Documentation of contact with other healthcare professionals after stillbirth**

Contact with other healthcare professionals after the stillbirth	All selected cases n=133	Reviewed by panel n=85
Antenatal Clinic	72 (54%)	41 (48%)
Community Midwife	103 (77%)	65 (77%)
Health Visitor	64 (48%)	38 (45%)
General Practitioner	96 (72%)	60 (71%)
Others	29 (22%)	17 (20%)
Bounty Pack	39 (29%)	15 (17%)
<b>Documentation that the mother received continuing midwifery support</b>	74 (56%)	47 (55%)
Average number of documented visits	3.3	3.4

Perhaps the most concerning finding was that there was documentation of continuing midwifery follow-up for only just over half of the women. Information about postnatal follow-up was requested from units by MBRRACE-UK. There were some cases where there was documentation and that community midwifery visits had been declined. For the majority of the remaining cases there was no evidence as to whether community midwifery visits had been offered or undertaken. As with care in labour, the care for these women should be the same as if they delivered a healthy baby and assessment of their physical and emotional health is as important following stillbirth as it is following a live birth. Some parents will not want to see the same midwife and others will, so asking the parents which they would prefer is important.

There was documentation that only about three quarters of GPs were informed about the stillbirth and this represents a missed opportunity for continuing ongoing support after discharge. In the 'Listening to Parents' study <sup>31</sup> women were asked if they had been given a postnatal check by their GP approximately four to eight weeks after the birth of their baby. Of those women whose baby was stillborn, just



over half reported such a check. Of those not receiving a check, most (85%) reported not being offered a follow-up appointment of this kind, although a small number had not wanted a postnatal check. This contrasts with data from a national survey of women whose babies were not stillborn, indicating that 90% had a postnatal check of this kind <sup>35</sup>.

There was evidence of variation in the continuity and support given to parents as illustrated in the following vignettes (11 and 12).

#### **Vignette 11: an example of excellent bereavement care**

*A woman in her early 30's, with two previous children, presented at 40 weeks gestation with an intrauterine death. The community midwife provided good continuity of care, by seeing her for all four postnatal visits and documented both physical and psychological care.*

*Discussions about the birth, the funeral and family support were documented, as well as the partner's wellbeing. Of particular note, was the wish expressed by the woman to have the photographs and memory box which she had previously declined. The midwife went to the hospital the same day and brought them for the parents, offering to stay or leave while they viewed them. Discharge was by the same midwife at 18 days postpartum.*

#### **Vignette 12: inappropriate risk assessment and follow-up**

*A woman in her mid 30's presented with a history of multiple miscarriages and one live child delivered by Caesarean section. After initial referral for obstetrician-led care she was subsequently seen by the midwifery team throughout her pregnancy. She was referred to the maternity unit at 38 weeks by the community midwife, with a reduction in her baby's movements since the previous evening. She delivered a stillborn baby weighing <1.5 kg. There was no documented bereavement care either in hospital, or by the community midwifery team and limited postnatal screening was undertaken. There was no evidence of an offer to provide mementos, information leaflets or conduct a post mortem examination.*

## **4.4. Conclusions**

Documentation reviewed for the confidential enquiry provides reassuring evidence that most parents are being cared for according to national guidance. However areas for improvement have been identified which require future action. There is clear evidence that sensitive and thoughtful postnatal care really does make a difference <sup>28, 31, 36-38</sup> and while it will not take away the pain and shock of what has happened, it can provide some comfort and can play an important part in helping parents to come to terms with what has happened.

## 5. Follow-up care and local review

Sara Kenyon, Coralie Rogers and Tracey Johnston

### 5.1. Key findings

- Although documentation relating to internal review of the case was requested from all units that were included in the confidential enquiry, only a quarter of cases included documentation indicating that an internal local review had taken place. One in ten of the cases had documented evidence that they were compliant with RCOG guidance in that a multidisciplinary review took place. The quality of reviews was highly variable.
- Parental involvement in the review process has been highlighted as important by the Stillbirth and neonatal death society (Sands)<sup>39</sup> but was only evident in the notes of a small number of the cases. Only six out of 133 (5%) notes had documented evidence that parents' concerns were included in the review. The results of the internal review were only fed back to 12 sets of parents.
- A follow-up appointment was documented as taking place in only two thirds of the 133 cases selected for enquiry. The majority of the appointments (two thirds of the cases), took place between six and twelve weeks after the stillbirth with the vast majority of the appointments with a consultant obstetrician.
- Despite the recommendation that parents receive a letter summarising the findings of the review of their care this was only evident in just over two thirds of the cases undergoing review, with a letter documented as having been sent to the GP in about four fifths of cases.

### 5.2. Introduction

Review of a stillbirth is vitally important for the parents to ensure they are given an honest and considered assessment of what led to the death of their baby. It should include an open and transparent review of care, not only to help parents make sense of and start to come to terms with what has happened, but also to facilitate unit-based learning and ensure, where needed, improvements in care are implemented.

The need for the NHS to review and learn from incidents was highlighted in 2000<sup>40]</sup> in the report by Liam Donaldson 'An Organisation With a Memory.' The report explained how adverse events occur in healthcare organisations, why these events can never be entirely eliminated, but how organisations and healthcare systems as a whole can understand and learn from incidents, and act to reduce risks and improve safety. Clinical governance within healthcare provides a framework through which health services are accountable for continually improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish. Implicit within this is the need to review and learn from incidents, and yet repeatedly we find evidence that this has not been the case, most recently from the Francis<sup>[41]</sup>, Berwick<sup>[42]</sup> and Keogh<sup>[43]</sup> reports. Particularly relating to maternity care, the Kirkup investigation<sup>[44]</sup> into Morecambe Bay has highlighted the continuing need for clear standards for incident reporting and investigation in maternity services.

Guidance as to which incidents should trigger incident reporting has been suggested by the RCOG,<sup>[23]</sup> and included within these is stillbirth. However, there is evidence within maternity services of variation in the incidents which trigger local incident review within units<sup>[45]</sup>. A systematic appraisal of the quality

of local review guidelines in UK maternity units[[46] ] also showed variation and, while the study found the guidance was mostly of good or high quality, the authors suggested that stakeholder participation could be wider and editorial independence more clearly stated.

The RCOG Green-top Guideline ‘Late Intrauterine Fetal Death and Stillbirth’ published in 2010 <sup>23</sup> recommended: “All stillbirths should be reviewed in a multi-professional meeting using a standardised approach to analyse for substandard care and means of future prevention. Results of the discussion should be recorded in the mother’s case record and discussed with the parents”.

More recently, the NHS has made it a priority to reduce stillbirth rates:

- Reducing stillbirth is a mandated objective from the government to NHS England and is therefore in the NHS England Business Plan 2014-15[[47] ].
- The Scottish Government, via the Scottish Stillbirth Working Group, has a target to reduce stillbirth by 15% by 2015.
- The National Stillbirth Working Group for Wales is targeting stillbirth reduction <sup>48</sup>.
- In Northern Ireland the NI Maternal and Infant Loss steering group has identified preventable stillbirth as an area of special interest.
- Reducing deaths in babies and young children; specifically, neonatal mortality and stillbirths is also a key NHS indicator in the NHS Outcomes Framework for England [[49] ].
- Within the Royal College of Obstetricians and Gynaecologists (RCOG) the ‘Each Baby Counts’ national quality improvement programme[ 50]] has highlighted the need for robust local review to learn lessons and improve care to women and their babies, although this focuses on intrapartum events.

The National Patient Safety Agency (NPSA) provided information and education about the different tools and methodologies that can be used to try to identify the root cause of incidents <sup>51</sup>.

This chapter will look at the number of local reviews undertaken following antepartum stillbirth, the composition of the group that undertook the review, the quality of the review, whether root cause analysis was undertaken and provide details of the follow-up visit.

## 5.3. Findings

### Number of reviews undertaken

Documentation relating to internal review of all the cases selected for confidential enquiry was requested from all units, but only 30 (23%) included documentation indicating that an internal local review had taken place, of which 20 were reviewed as part of the confidential enquiry. While there was mention of a review in the maternity notes in a further five cases, no documentation was provided for these cases. In total, there was no recorded evidence in the notes that a local review had taken place in 102 (77%) of the 133 cases initially selected for the enquiry.

## Composition of the group that undertook the review

Composition of the group that undertook the review in the units was extracted for all 30 cases (table 15). There were details of the multidisciplinary composition of the panel for only 13 of the cases. These panels included obstetricians, midwives, medical directors, risk or clinical governance leads, neonatologists and specialist midwives. A further two out of the 30 cases underwent review by a single person (one midwife and one risk manager) and the remaining fifteen cases underwent review but detail of the composition of the panel was missing. Of these fifteen, five were reviewed by a single undefined health professional, and two by a group that was not detailed. Of the remaining eight cases, in four there was a PowerPoint slide from the local perinatal mortality meeting, in three a copy of the Datix report was included and for the remaining case, a summary page from the risk management meeting. There was no evidence in the documentation provided of external representation on the review panel in any of the 30 cases.

**Table 15: Summary of composition of review groups in units**

Composition	Number
Multidisciplinary review undertaken	13
Single reviewer (Midwife and risk manager)	2
Single professional (unknown)	5
Group not detailed	2
Slide from Perinatal Meeting - multidisciplinary attendance	4
Copy of Datix report	3
Summary from Risk management meeting – multidisciplinary attendance	1
External representation on review group	0
Total reviews undertaken	30

In summary, of all cases selected for confidential enquiry only thirteen of the 133 cases (10%) had documented evidence that they were compliant with RCOG guidance<sup>23</sup> in that a multidisciplinary review took place. Root cause analysis enables analysis of the contributing factors and root causes to be undertaken and yet there was only evidence within the documentation obtained that this had been undertaken in 21 of the 133 (16%) cases selected for confidential enquiry.

## Quality of the review

There is currently no standardised national tool used for the review of perinatal death, although one has been developed as part of the Sands/Department of Health Perinatal Mortality Review Task and Finish Group<sup>39</sup>. Of the local reviews undertaken and assessed at confidential enquiry panels, some were of good quality in that there was an appropriate review of care and development of an appropriate action plan which clearly defined responsibilities and timelines (Vignette 13). However this was frequently not the case as detailed in Vignette 14 and Vignette 15.

### Vignette 13: an example of an appropriate case review

*A woman in her early thirties, with one previous child delivered by Caesarian section, was admitted as planned for an elective repeat caesarean section at 38 weeks gestation following an uneventful antenatal course with documented antenatal care of a good standard. On admission to hospital, her baby was noted by the midwife to be moving as usual and the fetal heart rate was normal. One hour 44 minutes later, no fetal heart beat could be heard and this was confirmed by ultrasound scan. Uterine rupture was confirmed at the time of delivery. The serious incident review highlighted that there were a number of obstetric emergencies at this time which meant that surgery for elective caesarean section was deferred for this case and one other as per hospital policy. Dehiscence of the previous caesarean section scar resulted in placental abruption and uterine rupture. A comprehensive internal review was undertaken which identified the salient issues and the results were fed back to the parents.*

### Vignette 14: an example of a poor quality case review

*A woman attended the maternity unit at term with an intrauterine death. She had attended the previous day with reduced fetal movements and had a CTG performed. This was interpreted as being normal despite absence of accelerations in the fetal heart rate, and the woman was discharged from hospital. She re-attended a few hours later still concerned about the lack of fetal movements, and was kept waiting for two hours before being seen, following which the baby was found to have died. The review, while being undertaken by a multidisciplinary group, identified that interpretation of the CTG was incorrect, but not that the delay in being seen was problematic. In the action plan some actions were vague, and many lacked timescales.*

### Vignette 15: an example of IUGR and poor quality case review

*An 18 year old woman having her second baby booked for antenatal care at about 20 weeks. During the antenatal period the symphysial fundal height was only measured and plotted at 30 and 34 weeks. In the third trimester she attended the maternity unit with an intrauterine death. The baby's birth weight was 2.5kg and was identified as being growth restricted. Subsequent review undertaken by a single health care professional failed to identify the lack of monitoring of growth and concluded 'no suboptimal care'.*

Where root cause analysis was undertaken there was evidence that this had not been undertaken thoroughly, and often stopped short of identifying a possible root cause (Vignette 16).

*A woman had a previous baby that had been small for gestational age. Routine growth scans were undertaken in the third trimester and growth were said to be normal, despite plotted data indicating static growth. The last scan was at 38[+2] and estimated fetal weight was 3053g. The baby was stillborn at 41 weeks and the baby's birth weight was below the fifth centile at 2630g. While a detailed review was undertaken which identified that appropriate growth surveillance had been undertaken, there was no evidence that review of the scan images had been undertaken to assess whether the biometry had been performed appropriately.*

## Parents' involvement in the review process

Parental involvement in the review process has been highlighted as important by Sands <sup>39</sup> but was only evident in a small number of the cases reviewed as part of the confidential enquiry. One in twenty reported that parents' concerns were included in the review, and only 12 sets of parents were provided with the results of the internal review.

## Follow-up appointment

RCOG Green-top Guidelines <sup>23</sup> make the following recommendations for the content of the follow-up appointment.

**Figure 2: Recommendations regarding the follow-up appointment - RCOG Green-top guideline 55**

- *Parents should be advised about the cause of late IUD, chance of recurrence and any specific means of preventing further loss.*
- *Women should be offered general pre-pregnancy advice, including support for smoking cessation.*
- *Women should be advised to avoid weight gain if they are already overweight (body mass index over 25 kg/m<sup>2</sup>) and to consider weight loss.*
- *An offer should be made to discuss the potential benefit of delaying conception until severe psychological issues have been resolved.*
- *Carers should be aware that while mothers tend to experience greater anxiety when conception occurs soon after a fetal loss, partners are more likely to suffer anxiety if conception is delayed.*
- *Parents can be advised that the absolute chance of adverse events with a pregnancy interval less than 6 months remains low and is unlikely to be significantly increased compared with conceiving later.*
- *The meeting should be documented for the parents in a letter that includes an agreed outline plan for future pregnancy.*



Of the 133 cases selected for enquiry, a follow-up appointment was documented as taking place in two thirds of cases (Table 16). It did not take place in 14 cases, with follow up being declined in two of these, and in 27 cases there was no documentation that follow up had taken place. Three quarters of cases appointments took place between six and twelve weeks after the stillbirth and the vast majority of the appointments involved the consultant obstetrician. Despite the recommendation above that parents receive a letter summarising the meeting, this was only evident in 63 of 90 cases (70%), with such a letter documented as having been sent to 73 GP's (81%).

No detail is given within the guidance as to the format of the letter to parents but many were unsympathetic in tone and used complex medical terminology. Some gave inaccurate advice (Vignette 1 and Vignette 17).

**Table 16: Summary of follow-up appointment**

Activities	All selected cases n=133
Documentation that a follow-up appointment took place	90 (68%)
Consultant obstetrician involved	82 (62%)
Summary letter sent to parents	63 (47%)
Summary letter sent to GP	73 (55%)
<b>Follow-up appointment did not take place</b>	<b>14 (11%)</b>
Follow-up appointment declined	2 (14%)
<b>No documentation as to whether follow-up appointment took place</b>	<b>27 (20%)</b>

#### **Vignette 17: incorrect attribution of the cause of death and a sub-optimal case review**

*Following the stillbirth of a baby associated with intrauterine growth restriction, the letter from the consultant obstetrician to the parents disregarded the fact that the symphysial fundal height was not systematically measured or plotted (there was no chart in the notes), and or the maternal hypertension that developed at the end of pregnancy. The letter focused on the incidental finding of Group B streptococcus. Consequently, advice regarding future pregnancies was inappropriate and the serious incident review documented minor consequences and concluded that there were no lessons to be learned.*

## **5.4. Conclusions**

Results from this evaluation of local reviews make disappointing reading, with the majority of cases of term, singleton, normally formed, antepartum stillbirth not undergoing local review thereby missing opportunities to identify the root causes. Improvements must be made moving forward, firstly to give parents a full and accurate explanation of what happened, and secondly to ensure organisational learning and thus improve care for the future.

Results highlight the need for a standardised approach to perinatal death review. Work has been completed on a core data set which sets out principles to underpin perinatal review Figure 3 <sup>39</sup>. The RCOG recommend that the review tool should include classification of the cause of the stillbirth, grading of care and the generation of an action plan for improvements to care. In consultation with parents and health professionals Sands has made recommendations for the best way to ensure parental input into the process of review in an appropriate and empathetic manner. The next stage is to turn the perinatal review data set into a usable, electronic, web-based review tool. A web-based approach was successfully piloted by the West Midland Perinatal Institute's SCOR system in 2012, against which this collaboratively-developed tool was benchmarked.

**Figure 3: Sands/ DoH Perinatal Mortality Review Task and Finish Group, Principles of Perinatal Mortality Review**

- 1. There should be comprehensive and robust review of all perinatal losses from 22<sup>+0</sup> weeks gestation until 28 days after birth, excluding termination of pregnancy and those with a birth weight <500g (but organisations should aspire to include these also).*
- 2. Such review should be conducted using a standardised nationally accepted tool, ideally web-based, that includes a system for grading quality of care linked to outcomes.*
- 3. A multidisciplinary group should review each case at a meeting where time is set aside for doing the work.*
- 4. There should be scope for parental input into the process from the beginning.*
- 5. The outcome of individual reviews should be shared with the parents/families in a timely and sensitive manner.*
- 6. There should be a quality control/review process with both internal and external peer review of cases.*
- 7. Action plans generated by such reviews must be implemented and monitored.*
- 8. There should be biannual reporting to the relevant Trust/Health Board committee, with evidence of organisational learning.*
- 9. These reports should feed up regionally, potentially to the NHS Commissioning Board Senates, and nationally, potentially to the National Stillbirth Oversight Group, to allow benchmarking and publication of results, to ensure national learning\*.*

*\*relates to England only.*

More recent guidance regarding incident reviews has also been published in March 2015 in the Serious Incident Framework by NHS England <sup>52</sup>. This revised framework explains the responsibilities and actions for dealing with serious incidents and the tools available. It outlines the process and procedures to ensure that serious incidents are identified correctly, investigated thoroughly and, most importantly, learned from, to prevent the likelihood of similar incidents happening again.



Since October 2014, all NHS providers have been required to comply with the *Statutory Duty of Candour*. The obligations associated with the statutory duty are contained in regulation 20 of The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014<sup>53</sup>. Health care providers are legally obliged to be clear, open and honest about the care that has been provided, including apolo- gising to patients when significant harm or death has been caused due to mistakes or failures in care. The stages for fulfilling this obligation include both recognising and subsequently investigating when an incident occurs where a patient has come to harm, so that the correct information can be shared with the family and lessons can be learned.

Recommendation 23 from the Kirkup report<sup>44</sup> states that:

*“Clear standards should be drawn up for incident reporting and investigation in maternity services. These should include the mandatory reporting and investigation as serious incidents of maternal deaths, late and intrapartum stillbirths and unexpected neonatal deaths. We believe there is a strong case to include a requirement that investigation of these incidents be subject to a standardised process, which includes input from and feedback to families, and independent, multidisciplinary peer review, and should certainly be framed to exclude conflicts of interest between staff. We recommend that this build on national work already begun on how such a process would work.”*

## 6. Pathological and histological investigations

Kerry Turner, Neil Sebire and Margaret Evans

### 6.1. Key findings

- Only half of the cases selected for the confidential enquiry underwent full post mortem examination; one third of cases had placental examination only and the remaining fifth of cases had neither post mortem nor placental histology carried out.
- Post mortem and placental reports were evaluated according to a predefined checklist based upon guidelines from the Royal College of Pathologists. In the majority of cases, post mortem reports were of satisfactory or good quality, with adequate levels of detail provided.
- Four fifths of reports contained an interpretation of pathological findings in terms of clinical significance (clinico-pathological correlation) as recommended by the Royal College of Pathologists<sup>54, 55</sup>.

### 6.2. Introduction

Several studies have reported that good post mortem examination combined with detailed placental histopathology can lead to improved understanding of stillbirth and identify areas that should be addressed in future pregnancies<sup>56-59</sup>. It is undoubtedly true that in a significant proportion of cases, placental disease is causally associated with stillbirth, and such pathology may be identified by specialist placental examination and/or perinatal post mortem<sup>34, 54, 55</sup>. Whilst fetal post mortems performed by an experienced pathologist can identify the likely cause of death in between 50% and 90% of cases, with placental disease accounting for the majority<sup>56, 58</sup>, data derived from numerous studies indicates that there is marked variation in both the identification and suggested clinical significance of many such placental findings making interpretation of their importance in any individual case problematic. Ptacek et al<sup>59</sup> conducted a systematic review of data from 13 studies, including more than 3,000 stillbirths and demonstrated that the proportion due to placental causes varied from as few as 10% to 70% across the studies. This was due to differences in classification systems, criteria for 'lesions' and subjective, qualitative, unblinded, descriptions of placental findings. For these reasons it should be recognised that the final 'cause' of stillbirth is often based on subjective opinion. It is therefore important that the overall circumstances of the case are evaluated in a multidisciplinary setting, including a perinatal pathologist, for appropriate interpretation of contributory factors, highlighting areas of concern and leading to improvements in care<sup>57</sup>.

This part of the report examines the role and current status of the post mortem and placental histological examination in the investigation of antepartum stillbirth and identifies areas that might be improved upon. The standards and guidance in place for pathology following stillbirth at the time care took place are provided in Table 17.

**Table 17: Guidelines and standards relating to pathology and histology following stillbirth**

Organisation	Guideline	Year
RCPATH	Guidelines for autopsy investigation of fetal and perinatal death	2002
RCOG	Green-top Guideline No. 55, Late Intrauterine Fetal Death and Stillbirth	2010
RCPATH	Tissue pathway for histopathological examination of the placenta	2011

## 6.3. Findings

### Overall pathology input

Despite recommendations from the Royal College of Obstetricians and Gynaecologists (RCOG)<sup>23</sup> that all parents be offered post mortem following stillbirth to help determine the cause of death and aid future pregnancy management, less than half of the 133 stillbirths reviewed in the confidential enquiry underwent formal post mortem examination. The data provided does not allow the reasons for this to be investigated further, but clearly highlights the need for further research in this area since the current system is not meeting the needs of the majority of parents. Issues may include access to the service, education of clinicians and consent takers, and acceptability of the procedure itself.

In addition to those undergoing post mortem, a further third had placental examination only. Since this is the single most useful component of the investigation of stillbirth, it should be strongly encouraged in all cases regardless of whether a post mortem is performed. Most concerning, one in five of the stillbirths had no form of pathological examination documented, therefore undergoing neither autopsy nor placental investigation.

#### Vignette 18: necessity for post mortem examination

***A true knot in the umbilical cord was noted at the time of delivery. The consultant obstetrician was satisfied this was the cause of the stillbirth, so instructed that placental examination and postnatal blood tests were not to be performed. In the absence of further examination, it is not possible to determine whether the true knot was an incidental finding or indeed the cause of death.***

***It is not known whether the remaining cases with no pathology input were deemed to have an 'adequate' clinical explanation, whether such services were unavailable or whether the parents refused such investigation, however in the absence of pathological investigations, significant underlying mechanisms, which may affect counselling and management of future pregnancies, may be missed*** (Vignette 18).

Quality of post mortem, placental reports and communication of findings

Post mortem and placental reports were evaluated according to predefined checklist based upon guidelines from the Royal College of Pathologists (RCPATH)<sup>54, 55</sup>. In the majority of cases, post mortem reports were of satisfactory or good quality, with adequate levels of detail provided. The main issues

identified were those surrounding the clinico-pathological correlation (Vignette 19), or interpretation of pathological findings in terms of clinical significance. With regards to placental examination reports reviewed, more than 80% were satisfactory..

### Vignette 19: clinico-pathological correlation and cause of death

*A post mortem examination of a baby of 38 weeks gestational age, revealed a small placenta, significant fetal thrombotic vasculopathy and mild acute chorioamnionitis (but with no fetal inflammatory response). The relative insignificance of the infection was not made clear in the clinico-pathological correlation of the post mortem report; subsequently, during discussion with the parents, the infection was suggested as the likely cause of death when the more likely explanation was an underlying placental problem.*

**Table 18: Placental histology rating**

Placental Histology Rating	All selected cases n=133	Reviewed cases n=85
Excellent	28 (21%)	22 (26%)
Good	36 (27%)	22 (26%)
Satisfactory	20 (15%)	15 (18%)
Poor	18 (14%)	13 (15%)
Rating missing	1 (1%)	1 (1%)
Total	103 (77%)	73 (86%)
<b>Reports containing clinico-pathological comment</b>	<b>80 (60%)</b>	<b>53 (62%)</b>

### Vignette 20: post mortem examination declined and the value of placental histology

*A primiparous woman was diagnosed with an intrauterine death after a low risk pregnancy. She delivered a stillborn baby at 38 weeks gestation. A post mortem examination was declined but the placenta was sent for histological examination. The placenta was small with 'lesions' (possibly infarctions) occupying 50% of the parenchyma. Blocks were taken but no sections for microscopy were cut (this was to be performed only if requested by the clinical team).*

The lack of microscopy indicated in Vignette 20: post mortem examination declined and the value of placental histology is contrary to the guidance of the RCPATH Placenta Tissue Pathway<sup>55</sup>. Other poorly-rated placenta reports lacked detail and for more than one in five cases there was no specific clinico-pathological correlation statement or interpretation of histological features. In addition, it was noted during the case reviews that in many cases non-specific findings were variably interpreted, regarding their significance. Whilst post mortem and placental examination are important components of the investigation of stillbirth, areas of uncertainty in which published evidence is lacking or inconclusive, should be clearly stated in the report.

## Issues raised

The main issues raised by the pathology review are first, why is the autopsy rate below 50%? Further work is required to determine which aspects of current practice lead to either lack of availability of pathology services or make the option unacceptable to parents. In this regard, it may be that the role of more limited post mortem and/or placental examination and other investigations should be explored, and placental examination as a minimum should be recommended in all cases. Second, post mortem and placental reports should provide clear clinico-pathological correlation statements including the likely clinical significance of any abnormal histological findings. In this regard, it is important that areas of controversy or uncertainty are also highlighted in the report, with statements based on published evidence and subjective interpretations clearly distinguished from factual observations.

## Overall summary of quality of care

Overall, the findings suggest that, when performed, post mortem and placental examinations are of good quality and can contribute significantly to understanding why the stillbirth occurred and to the future clinical care and pregnancy plans for parents. Pathology input remains important even if parents refuse standard post mortem since, in such cases, placental examination alone may be useful. Pathologists must ensure that placental histology and post mortem reports provide maximum value by including accurate clinico-pathological interpretation and issuing reports within an acceptable time frame

## 6.4. Conclusions

These findings highlight the need for improved communication between obstetric staff and pathologists. Further, there is a need for stillbirth post mortems and placentas to be examined by specialists within this field who contribute to multidisciplinary discussions, ensuring that all the clinical facts are addressed and correlated with the post mortem and placental findings.

# 7. Communication issues

Elizabeth S Draper and Pauline Hyman-Taylor

## 7.1. Key Findings

- The enquiry panels found issues of poor communication and/or documentation in two thirds of the cases reviewed. This ranged from simple mistakes in the notes to a total lack of documentation of key aspects of care.
- Out of 12 mothers identified who did not speak English only six had access to adequate interpretation services during relevant parts of the care pathway.
- Sharing of information between health professionals appeared inconsistent and sometimes incomplete which prevented effective interagency working which on occasion created mixed messages for parents.
- One in ten cases reviewed contained examples of insensitive interaction with the bereaved parents.

## 7.2. Introduction

Issues of poor communication and documentation, whether verbal or written, between health professionals or between health professionals and parents<sup>7, 60, 61</sup>, are issues frequently raised in confidential enquiries. For bereaved parents effective communication at all levels is of paramount importance to their physical and psychosocial well-being. Detailed, accurate and empathetic communication is important at all points on the care pathway and some concerns in this regard have already been highlighted in the report. This chapter summarises the main themes relating to communication issues emerging from this enquiry.

Care for pregnant women involves detailed history taking as well as many investigations, procedures and regular monitoring, often carried out by a number of different health professionals, all of whom need to be fully appraised of the proposed care plan. Accurate and timely record keeping is not only good practice (Standard 24, RCOG standards for maternity care)<sup>10</sup> but has a direct influence on care and treatment. As such the maternal notes should include accurate documentation and recording of the reasons for booking for obstetrician or midwifery-led care as well as results from routine monitoring and screening tests. All proposed changes to the care plan should be detailed so that all members of the multi-disciplinary team are informed. The recording of discussions between health professionals, including telephone conversations, should be clearly recorded in the hospital and hand held notes in order to facilitate continuity of care and to provide information about the rationale for decisions and requests. This will ensure effective communication between healthcare professionals which is of particular importance when dealing with bereaved parents.

The 'Listening to Parents' report<sup>31</sup> highlights the importance parents attach to all aspects of the behaviour of healthcare professionals, but particularly communication, during times of anxiety and grief. Such circumstances may be related to their expressions of concerns about their pregnancy, the

circumstances and approach to the breaking of the bad news that their baby has died, or during discussions intended to provide information about the cause or circumstances of their baby's death. Parents value the care of professionals who generate confidence in their clinical expertise whilst maintaining a kind, sensitive and empathetic attitude <sup>62</sup>.

Parents with complex social needs present a particular challenge. This situation can arise from a variety of circumstances such as difficulties with language and understanding, substance misuse or mental health problems. Achieving effective communication and engagement in such cases generally requires both additional skills and resources in order to fulfil these needs. This is not an easy task and the NICE guidance (CG110)<sup>11</sup> and the RCOG's Standards for Maternity Care <sup>10</sup> outline the need for the provision of staff training to enable those caring for such women to conduct a multi-agency needs assessment, develop a co-ordinated care plan, consider cultural sensitivities and be aware of national guidelines regarding information sharing between health and social care agencies.

For those women who do not speak English, the provision of both an interpreter who is not related to the woman and also verbal confirmation of understanding of the information imparted is recommended <sup>11</sup>. The RCOG standards for maternity care<sup>10</sup>, stress the need for sufficient funding to be made available to ensure adequate interpreter availability can be provided.

Communication and documentation issues were reviewed across the whole care pathway for all cases of term, singleton, normally formed, antepartum stillbirth reviewed at enquiry, and judged against standards and guidance (Table 19) in existence at the time of the delivery (2013).

**Table 19: Guidelines and standards relating to communication and documentation issues for antepartum stillbirth**

Organisation	Guideline	Year
RCOG	Standards for Maternity Care	2008
NICE	Clinical Guideline 110: Pregnancy and complex social factors	2010
Sands	The Sands Audit Tool for Maternity Services: Caring for parents whose baby has died	2011
NICE	Quality Standard 37: Postnatal care	2013
NICE	Clinical Guideline 192: Antenatal and Postnatal Mental Health	2014

## 7.3. Summary of the findings from the panels

Communication and documentation issues were found at all points of the care pathway. Overall nearly two thirds of the cases had at least one issue identified where improvements in communication were required, ranging from mistakes in the notes and a lack of recording of test results, to communication problems between health professionals and poor communication with parents. In terms of the latter this included both problems with the manner and content of various interactions and language difficulties / inadequate availability of an interpreter. At the other end of the spectrum 12 (14%) cases were identified as having excellent documentation throughout the care pathway and/or communication both between health professional and with parents.



## Language difficulties and interpreting services

The provision of adequate interpreting services for all pregnant women who require them in the UK poses a major challenge to planners of obstetric and midwifery services for an ever changing population affected by regular waves of migration from the EU, countries outside the EU and most particularly areas of political unrest across the world. Ensuring that timely access to interpreters for the wide range of languages required is not always possible despite being part of current guidance and standards. Twelve of the mothers in the review were identified as requiring interpretation services. Problems with language and a lack of the presence of an interpreter, or access to interpretation services such as 'LanguageLine' was identified in the antenatal care provision for six of these cases where the recording of an accurate obstetric and medical history and the subsequent identification of potential risk factors was limited by communication difficulties. However there were a number of cases where the use of interpretation services was exemplary (see Vignette 10: example of excellent follow-up care

Themes emerging from the enquiry panels included situations where the lack of interpretation services meant that some mothers were unable to convey their concerns about their pregnancy to the antenatal care team. This included: repeated attendances by mothers to the antenatal clinic with problems such as abdominal pain which failed to trigger further review or change in care due to poor communication; and non-attendance for follow-up appointments following the delivery of a still born baby where there was no recorded use of an interpreter throughout the care pathway. Inappropriate use of friends and other patients to act as an interpreter was identified at enquiry as well as the use of close family members which may inhibit the accurate collection of confidential information including social risk factors.

Following the confirmation of a stillbirth, an inability to communicate clearly with the midwives and doctors can lead to feelings of isolation and distress, a situation exacerbated by the grief associated with this diagnosis. This situation was made worse for one mother discussed by the panel as she was not only left alone in labour for several hours but also arrangements were not made for her to have access to an interpreter because of a particularly high workload on the unit.

## Issues with record keeping

Accurate and detailed record-keeping throughout the care pathway is imperative to provide information concerning monitoring and treatment. This provides insight into decision-making to facilitate communication between members of the multidisciplinary team and ensure appropriate care provision for pregnant women. Themes emerging from panel discussions encompassed contradictory information recorded in the notes by different health professionals, a lack of recording of test results and other procedures, inaccurate recording of risk factors and absent or sparse detail of care provision and appointments.

In nearly one quarter of cases, poor history taking relating to risk factor status such as the delivery of a previous small for gestational age baby, body mass index and a family history of stillbirth were overlooked, resulting in the mother being wrongly identified as low risk. As a consequence of this, some mothers were not referred for consultant-led care, whilst in other cases there were issues around missed static growth, leading to inaccurate prediction of fetal size, a topic discussed in detail in the antenatal care chapter.



Details of all notes for cases selected for enquiry were requested from all units with a checklist included to facilitate the process. If part of the notes appeared to be missing when received in the MBRRACE-UK office, then units were chased to provide any missing information. However in one fifth of the cases, little or no documentation of the postnatal or follow-up care was provided for the enquiry and as such panel members assumed that this was either missing or had potentially been filed elsewhere. Nevertheless, even if there was additional information available it was clearly not filed with the case notes and therefore not readily available for the care of the mothers in any subsequent clinical interactions.

In around one tenth of cases details of which postnatal investigations were carried out and/or the results were missing. This is important information for the postnatal review, future counselling of parents and the professional communication concerning each case.

In a small number of cases there was inappropriate or contradictory information recorded about cases in different sections of the maternal notes including completion of the wrong type of stillbirth certificate, a forceps delivery recorded where it had been a normal spontaneous vaginal delivery, incorrect information provided to the mother's GP regarding Group B streptococcal infection and speculation as to a possible cause of death on a death certificate without any supporting evidence from the notes.

## **Communication between health care professionals and parents**

Interactions with bereaved parents require a high level of expertise, empathy, patience and sensitivity. Health professionals need to support the family and ensure that they are given time and appropriate information to make the required decisions following the death of their baby. Bad news is often met with anger and frustration that more could not have been done to prevent the death. It was clear that in some cases discussed by the panels that mothers felt their concerns about reduced fetal movements or potential growth issues had been ignored or they felt that they had been falsely reassured.

Following the diagnosis of a stillbirth parents will have many questions. It is important to provide information that will explain what will happen next, their possible choices for care and how to access support for themselves and their family. In around one fifth of cases discussed at panel there was no documented evidence that any supplementary information had been provided for the parents following diagnosis, the full details of which are presented in Table 13.

Establishing the cause of death in term, singleton, normally formed, antepartum stillbirths is often difficult. However the provision of written information summarising the discussions with the consultant about the circumstances of the death and the results of any post-mortem and other investigations may help bereaved parents to understand why their baby died and to try to come to terms with the death. Findings from the panel reviews indicated that in around one tenth of the cases there was no evidence that the parents had received any correspondence from their consultant follow-up appointment regarding the death of their baby. A further handful of cases received only limited feedback from the clinical team who cared for them. In a small number of the cases, parents received a letter from their consultant summarising the findings of investigations and/or post mortem results where the information provided was either confusing or contradictory in nature.

Communication between health professionals and pregnant women is, nevertheless a two way interaction and despite every effort on the part of the health professionals communication can be compromised.

## Interactions with parents

An insensitive approach to bereaved parents by healthcare professionals may have a long lasting effect and is not easily forgotten. In one tenth of the cases reviewed, issues were identified where it was felt by the panel members that the care could be described as insensitive or inappropriate. A number of the issues related to the letters received by parents in relation to a follow-up visit following a stillbirth and/or post-mortem. These included an insensitively worded letter to parents written by a junior obstetrician and an abrupt letter to parent who had not attended for their follow-up appointment with no further offer of an appointment. Other issues included a failure to use a respectful term for the baby or their name in the notes, for example the use of the term 'fetal remains' to describe the baby and use of an inappropriate setting for follow-up appointments i.e. within the antenatal clinic. Whilst it is acknowledged that maternity services are often overstretched, the example of a consultant obstetrician who left bereaved parents part way through the discussion following the stillbirth diagnosis to carry out an elective caesarean section was felt by the panel to be highly insensitive.

Although there were problems noted at enquiry with some of the interactions between health professionals and parents, there were also examples of excellent interactions with parents and between members of the multidisciplinary team (Vignette 21).

### Vignette 21: example of excellent interactions with parents

*A woman with two previous children was identified early on in her pregnancy as having problems with the abuse of her pain relief medications. Despite her initial lack of engagement, her antenatal care was well managed throughout her pregnancy, due to the effective collaborative efforts of all members of the multidisciplinary team. Her GP and social worker received regular reports on her progress during her pregnancy. She was referred to the addiction clinic and attended for weekly visits to the antenatal clinic. The woman contacted the antenatal triage service, reported a "show" and reduced fetal movements for 2 days. She was advised to attend the local maternity unit and an ultrasound scan confirmed that her baby had died. The labour and delivery were timely and uneventful with excellent bereavement care provided by midwifery staff. A cold cot was provided and a blessing conferred by the hospital chaplain. She consented to a post mortem examination, this was of good quality and the results were fed back to the parents in a timely fashion although there was no evidence of a letter to the parents outlining an appropriate care plan for future pregnancies. The community midwife visited her 3 times at home and recorded that she had been given the opportunity to explore her feelings and express her grief. The local team reviewed the case to identify any possible improvements in care. The midwife most involved in her care was noted to be distressed by the baby's death and the team also provided her with clinical supervision and support.*

## Lack of evidence

Evidence provided to confidential enquiry panels is limited to the notes provided by the units. Every effort was made to obtain all available documentation with units being chased if the notes received by the MBRRACE-UK office were felt to be incomplete. Historically problems with poor record keeping have been highlighted at almost every confidential enquiry. The trend for electronic health care records with the accompanying drop down menus and tick boxes which help to make them quicker and easier to complete may seem to be a step forward, though the quality of the information may be affected. This view is supported by the experiences of the panel members who reviewed case notes in this format, finding that in fact, in many cases this made the notes very difficult to review. Hand written or dictated and typed notes allow a richer and more detailed description of care to be documented and consequently reviewed and are not limited by a standardised proforma which may not allow adequate space for recording all aspects of care provision and support, in what are often complicated situations.

The panel identified a lack of evidence and documentation at all points along the care pathway, affecting the care of one fifth of the cases reviewed. The most sparsely documented area was bereavement care. Discussions amongst panel members (including those currently with the specialist role of bereavement midwife) suggest this may be due to the common practice of creating discrete documentation for this aspect of care. This may then be filed separately from the mother's maternity case notes and therefore unlikely to be available for review. However in order to ensure that this information is available to the members of the multidisciplinary team when caring for a bereaved mother, the records of her psychosocial care should either be integrated in the main record or at least readily available to review by all who might need the information, and as such sent to the enquiry for review.

## 7.4. Conclusion

This enquiry has identified a range of communication issues where improvements could be made at all points of the care pathway. There is an increasing requirement for interpreters with an ever expanding range of language needs of pregnant women which is a growing area of concern and increasing resource requirement. Interaction with bereaved parents can be stressful for staff and adequate training should be provided to ensure that they have the required skills. Problems with record keeping has once again been identified as an area of concern. Every effort should be made to improve documentation, recording all interactions with mothers, their partners and other family members and the results of all investigations so that members of the multidisciplinary team are fully aware of all aspects of care provision and can act accordingly.

## 8. Appendices

### 8.1. Appendix 1: Panel guidance & evaluation form

## **MBRRACE-UK 2014 Perinatal Confidential Enquiry into:**

### **term, normally-formed, antepartum stillbirth**

#### **Case review panel member guidance and training**

Thank you for agreeing to take part in the confidential enquiry into normally formed antepartum term singleton stillbirth at  $\geq 37$  weeks. The purpose of the enquiry is to look at quality of care identifying aspects of both good practice and aspects where there is a need for improvement. By way of preparation for the process this document sets out the key steps in the process and the general principles that will be applied.

#### **Preparation for the enquiry process**

The cases to be reviewed have been randomly selected from cases reported to MBRRACE-UK during 2013. 131 cases have been selected to form the basis of the confidential enquiry and have been chosen to represent a geographical spread across UK. The notes of the selected cases have been anonymised both in terms of the hospitals and clinicians involved although entries in the notes should record the type and grade of staff who made the entry. A Topic Expert Group was convened to steer the enquiry (a multidisciplinary group comprising of clinical experts and a patient representative (see Appendix 1). The aim of this document is to provide a framework against which cases can be assessed and a copy of the document is attached (see Appendix 2).

#### **The assessment process**

You will be asked whether you can attend an assessment panel on a particular date and once it is clear that a full multidisciplinary team can be convened (joining by telephone will not be acceptable) all the members of the assessment team will receive a confirmed date and venue (we will do our best to make travel arrangements as easy as possible). The meeting will generally last the whole day. Each meeting will comprise a maximum of 12 panel members of mixed specialty and will be chaired by one of the MBRRACE-UK team.

Approximately one month ahead of the meeting you will be given access to the notes of the cases to be discussed on that day. You will be asked to read all of the cases and “score” the care. In addition one or perhaps two cases will be identified for which you will be asked to lead the presentation at the face to face consensus meeting.

When you attend case review panel consensus meetings the Chair (neutral) will re-iterate the principles of the process and answer any questions prior to the start of the meeting. During the course of the case review panel meetings each case will be discussed with the aim of resolving any differences of opinion about the standard of care provided. At the end of each discussion a confidential enquiry case summary form based on the panel view will be completed. The final consensual assessment of each case will be collated by the MBRRACE-UK team.

### Access to case notes

All details of allocated cases (surveillance data, case notes, post-mortem report, local review) will be available for viewing **only** via a secure online high compliance system. Full details for accessing the anonymised notes via the case viewer will be provided to each case reviewer in an email, as well as an invitation to access an online demonstration of the system before the review process begins. Please note: all users of the MBRRACE-UK system are required to complete and return our confidentiality statement and declaration of interest form before access is granted to view the selected cases (see Appendix 3 and 4).

Panel members will access the case notes they have been allocated on-line and assess each case using the standard form. As a case review panel member you will be sent copies of the assessment forms by the MBRRACE-UK office and instructed to complete the forms for each case allocated for review. A summary score will be determined for inclusion in the final report.

***For the purposes of this enquiry, we will consider the outcome for the baby and for the mother separately.***

### Anonymisation of cases

All cases will be supplied in an anonymised format and no attempt should be made to try to identify the identity of cases, individuals or hospitals.

We have developed a form to support the review process (Appendix 2). The assessment form asks the reviewer to consider a series of steps on the care pathway which map to the various headings on the document produced by the topic expert group. It comprises questions about the quality of care at each stage using a grading system (see below) but also includes free text boxes for reviewer's opinions or other points they wish to raise.

### **Categorisation of cases**

For each aspect of care along the pathway reviewers will be asked to grade the care into one of the following three categories separately for the outcome for the mother and the baby:

#### **Good care; no improvements identified**

#### **Improvements in care\* identified which would have made no difference to outcome**

#### **Improvements in care\* identified which may have made a difference to outcome**

(\*Improvements in care should be interpreted to include adherence to guidelines, where these exist and have not been followed, as well as other improvements which would normally be considered part of good care, where no formal guidelines exist.)

At the end of the discussion of each case at the, a consensus score will be agreed by the panel for the mother and for the baby for inclusion in the final report.



**Please note** that whilst the aim of the enquiry is to focus on quality of care HQIP has specific guidance that applies in any case where any deficiencies in care are of a more serious nature:

### **HQIP Cause for Concern Guidance**

**Death (child or adult) attributable to abuse or neglect, in any setting, but no indication of cross agency involvement (i.e. no mention of safeguarding, social services, police or LSCB).**

**Staff member displaying:**

- **Abusive behaviour (including allegations of sexual assault)**
- **Serious professional misconduct**
- **Dangerous lack of competency**

**But not clear if incident has been reported to senior staff**

**Standards in care that indicate a dysfunctional or dangerous department or organisation, or grossly inadequate service provision.**

***Cases felt to fulfil these criteria must be notified separately and urgently.***

## **MBRRACE-UK 2014 Perinatal confidential enquiry into term normally formed antepartum stillbirth.**

### **Guidelines for judging/grading of cases for review.**

The following document represents the views of a Topic Expert Group representing a range of specialisms (see appendix 1) who met to reach a consensus on an appropriate method of evaluating care for this group of women and their babies based on the relevant available guidelines and standards of good practice. The document is meant to guide those who review the selected cases in judging / grading the various aspects of care provided using the system described earlier:

It is not possible to grade the presence or absence of good clinical practice markers in isolation. The markers of good clinical care set out below need to be graded within the clinical context of each individual case. What might not have influenced outcome in one case might well do so in another. How each is graded will depend on the assessor's clinical interpretation of how the various aspects of care were delivered in relation to the circumstances of the particular case being reviewed.

Listed below are the standards to be looked at when reviewing the notes for your allocated cases. These have been devised by the topic expert group as a regulated way of evaluating the care received by this particular group of women. Please click on the web link for direct access to the full guidance (right click, then choose the "open hyperlink" option).

## Evaluable standards

### Antenatal care

Was the woman correctly identified as low or high risk? See **Checklist A**

If low risk – were the tests for routine scheduled antenatal care followed? See **Checklist B**

Relevant Guidance: [NICE clinical 62 \(2008\)](#), [RCOG Standards for Maternity care \(2008\)](#), [NICE Antenatal Pathway 2014](#), [NICE quality standard QS22 \(Sep 2012\)](#), [NICE clinical guideline 55 \(Sep 2007\)](#), [NICE Clinical Guideline 70 \(2008\)](#)

High risk pregnancies could include the following categories (**click highlighted links for direct access to full guidance**):

[Diabetes](#) - see **Checklist C**

[Small for Gestational Age \(IUGR\)](#) - see **Checklist D**

[Reduced Fetal Movements](#) – see **Checklist E**

[Timing of Induction of Labour](#)

### [Obesity](#)

Pregnant women with a body mass index of 30 kg/m<sup>2</sup> or more at the booking appointment are offered personalised advice from an appropriately trained person on healthy eating and physical activity. *An appropriately trained person can demonstrate expertise and competencies in weight management in pregnancy, including providing advice about nutrition and/or physical activity. This may include obstetricians, GPs, midwives, health visitors, nurses, dieticians, midwifery assistants, support workers and those working in weight management programmes (commercial or voluntary).*

[Maternal age >40](#)

[Complex Social Factors](#)

Were any **other** significant medical risk factors present? Were they identified and managed in line with national guidance?

Relevant Guidance: [NICE clinical 62 \(2008\)](#), [RCOG Standards for Maternity care \(2008\)](#), [NICE Antenatal Pathway 2014](#), [NICE quality standard QS22 \(Sep 2012\)](#)

Were any **other** significant obstetric risk factors present? Were they identified and managed in line with national guidance? See **Checklist F**

Relevant Guidance: [NICE clinical Guideline 62 \(2008\)](#), [RCOG Standards for Maternity care \(2008\)](#), [NICE Antenatal Pathway 2014](#), [NICE quality standard QS22 \(Sep 2012\)](#)

Were any **other** social factors present? Were they identified and referrals made in line with best practice? See **Checklist G**

Relevant Guidance: [NICE clinical guideline 110 \(2010\)](#), [RCOG Standards for Maternity care \(2008\)](#), [NICE quality standard QS22 \(Sep 2012\)](#), [Antenatal and Postnatal Mental health NICE Clinical Guideline 45 \(2007\)](#),

Was antenatal screening as per national guidelines (non-invasive)? See **Checklist H**

Relevant Guidance: [NICE quality standard QS22 \(Sep 2012\)](#), [RCOG Standards for Maternity care \(2008\)](#)

Was the number and timing of low risk pregnancy antenatal appointments in line with national guidance or in line with best practice if a high risk pregnancy? Were missed appointments followed up in line with best practice?

Relevant Guidance: [NICE clinical 62 \(2008\)](#) , [RCOG Standards for Maternity care \(2008\)](#), [NICE Antenatal Pathway 2014](#), [NICE quality standard QS22 \(Sep 2012\)](#)

Were there any issues with record keeping? Did this affect care?

Relevant Guidance: [NICE quality standard QS22 \(Sep 2012\)](#), [RCOG Standards for Maternity care \(2008\)](#), [NICE Antenatal Pathway 2014](#), [NICE clinical 62 \(2008\)](#)

Were any parental concerns raised and, if so, appropriately acted upon during care?

Relevant Guidance: [NICE Antenatal Pathway 2014](#), [NICE quality standard QS22 \(Sep 2012\)](#)  
[RCOG Standards for Maternity care \(2008\)](#)[RCOG Green-top Guideline 57 reduced fetal movements \(2011\)](#)

Psychosocial care is an ongoing part of care. Please evaluate this aspect of care at each time-point of the pathway (ante-natal, labour and delivery, post-natal, follow-up care). Please refer to the “Listening to Parents” report commissioned by the Dept. of Health and the SANDS Audit Tool for Maternity Services for standards.

[Listening to parents report; The SANDS Audit Tool for Maternity Services](#)

## Intrapartum

Was management and care surrounding the diagnosis of intrauterine death and subsequent delivery, in line with national guidelines?

Relevant Guidance: [RCOG Green Top Guideline 55 \(Oct 2010\)](#) , [RCOG Standards for Maternity care \(2008\)](#), [SANDS The Sands Audit Tool for Maternity Services \(2011\)](#)

Was there any delay between diagnosis and confirmation of the death to the parents?

Did the mother go home following diagnosis and before delivery? Was a 24 hour contact number provided?

Relevant Guidance: [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#) , [RCOG Standards for Maternity care \(2008\)](#), [SANDS The Sands Audit Tool for Maternity Services \(2011\)](#)

Were there any issues with availability of critical care, equipment, bed / or other resources?

Relevant Guidance: [RCOG Standards for Maternity care \(2008\)](#)

Did the mother have one to one care in labour? What was the grade of the staff member providing care?

Was there a discussion about analgesia and what were the options offered?

Was the baby delivered in a bereavement suite away from other mothers and babies?

Relevant Guidance: [NICE clinical guideline 55 \(Sep 2007\)](#), [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#), [RCOG Standards for Maternity care \(2008\)](#), [SANDS The Sands Audit Tool for Maternity Services \(2011\)](#), [RCOG Green Top Guideline 55 \(Oct 2010\)](#)

Was the mother's partner present at the birth and offered the opportunity to stay overnight if necessary? If unaccompanied did staff offer to phone her partner/relative/friend?

Were parents given information to supplement discussions about diagnosis and what happens next? eg. SANDS leaflet 'When a baby dies.'

Was counselling documented as regards content, provided in a way to meet the mother's / family's needs and with the appropriate multidisciplinary team?

Relevant Guidance: [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#), [RCOG Standards for Maternity care \(2008\)](#), [SANDS The Sands Audit Tool for Maternity Services \(2011\)](#), [NICE clinical guideline 55 \(Sep 2007\)](#).

Were the parents offered the opportunity to create memories/mementos?

Were the parents offered the opportunity to see and hold the baby?

Were parents offered a PM? Was this at an appropriate time? Carried out by perinatal pathologist? Who obtained informed consent? Full examination / partial / limited?

Was there a referral to the Coroner? Who completed the death certificate?

Relevant Guidance: [RCOG Green Top Guideline 55 \(Oct 2010\)](#), [RCOG Standards for Maternity care \(2008\)](#), [Human Tissue Authority \(2009\) code of Practise 3 Post-Mortem Examination](#), [SANDS The Sands Audit Tool for Maternity Services \(2011\)](#)

## Postnatal

Were maternal post-death screening tests conducted in line with best practice? See **Checklist I**

Relevant Guidance: [NICE clinical guideline 37 \(2006\)](#), [RCOG Standards for Maternity care \(2008\)](#), [RCOG Green Top Guideline 55 \(Oct 2010\)](#)

Was placental histology carried out? Conducted by perinatal pathologist? Was the placental pathology and histology of sufficient quality?

Relevant Guidance: [RCOG Green Top Guideline 55 \(Oct 2010\)](#), [RCOG Standards for Maternity care \(2008\)](#), [SANDS The Sands Audit Tool for Maternity Services \(2011\)](#)

Was the PM of sufficient quality and detail? A checklist and written guidance to assist panel members to make this assessment is provided in **Appendix 5**.

Was information provided regarding registering the death and funeral arrangements?

Was information provided regarding suppression of lactation?

Was the mother referred to a community midwife?

Was the GP informed? Were other relevant healthcare professionals informed? Was support offered from the healthcare team in the primary care setting?

Was there a care plan for planning the next pregnancy?

Relevant Guidance: [NICE clinical guideline 45 \(2007\)](#), [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#), [RCOG Standards for Maternity care \(2008\)](#), [RCOG Green Top Guideline 55 \(Oct 2010\)](#), [SANDS The Sands Audit Tool for Maternity Services \(2011\)](#)

Was care and support offered from the hospital chaplaincy team or an appropriate spiritual advisor?

Was there evidence of a bereavement checklist in the notes? Was it completed?

Were parents given appropriate bereavement support literature? Were they offered further support and information?

What did the bereavement services offered comprise of? What information was provided? What options were offered?

Was a 24 hour contact number provided after discharge?

Were the parents / mother offered counselling services?

Relevant Guidance: [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#), [RCOG Standards for Maternity care \(2008\)](#), [SANDS The Sands Audit Tool for Maternity Services \(2011\)](#)

## Follow -up

Was follow-up care provided? By whom? Was it individualised to the care needs of the mother/parents? Where was it documented?

Was the care internally reviewed by a multi-disciplinary group? Did senior staff and staff involved in care of that woman and baby attend that meeting?

Relevant Guidance: [RCOG Green Top Guideline 55 \(Oct 2010\)](#), [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#)

Were results of the review fed back to parents? Were details of parental discussions recorded – did this include the scope and content of the reports and how “parent- friendly” they were, the timings etc?

Relevant Guidance: [RCOG Green Top Guideline 55 \(Oct 2010\)](#), [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#), [RCOG Standards for Maternity care \(2008\)](#), [SANDS The Sands Audit Tool for Maternity Services \(2011\)](#)

Were parents given appropriate information and an appointment to see an obstetric consultant within 6-12 weeks?

Relevant Guidance: [RCOG Standards for Maternity care \(2008\)](#), [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#), [SANDS The Sands Audit Tool for Maternity Services \(2011\)](#)

Was all appropriate paperwork ready at this time: PM results, any other relevant test results?

Relevant Guidance: [RCOG Green Top Guideline 55 \(Oct 2010\)](#), [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#), [RCOG Standards for Maternity care \(2008\)](#)

Was the PM report available within 8 weeks (if it was a standard full PM or less)?

Relevant Guidance: [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#)

Was the PM report available within 12 weeks (if there were more complex PM tests under-taken)?

Relevant Guidance: [The Sands Guidelines, Pregnancy Loss and the Death of a Baby: Guidelines for professionals \(2007\)](#)



## Checklist and guidance for evaluation of placental histology and post mortem examination reports

RCPATH Guidelines for Autopsy Investigation of Fetal and Perinatal Death 2002

All hospital post-mortem procedures are subject to parental consent that must not be exceeded. The following guidelines apply to an unrestricted post-mortem examination.

### A6.1 External examination

- Body weight (to nearest gram if less than 5kg)
- Head circumference
- Crown-heel and crown-rump lengths
- Foot length
- Apparent gestation
- Maceration (if baby is born dead)
- Meconium staining
- Full description to include, e.g. fontanelles, eyes, ears, nose, mouth and palate, digits, palmar creases, umbilicus and state of cord, genitalia, anus, etc.
- Dysmorphic features, congenital malformation and deformities
- Other abnormalities (e.g. oedema, abnormal pallor).

### A6.2 Internal examination

- Comment on cranial, thoracic and abdominal cavities
- Retention and fixation of the brain where practicable, subject to informed consent
- Systematic description of major organs and tissues
- Specific reference to ductus arteriosus and umbilical vessels
- Weights of all major organs in a digital balance (to 0.1g)
- Comment on muscle and skeleton.

### A6.3 Placenta

Placenta to be examined in all cases. A convenient method of ensuring that the placenta is available in each case may be to send all placentas from babies admitted to the special care baby unit/neonatal intensive care unit to the pathology department. Whilst these need not be examined unless the baby dies, many departments would, in any case, consider it good practice to examine them.

- Dimensions
- Trimmed weight
- Umbilical cord (length, vessels, abnormalities)
- Membranes (complete, incomplete, colour, abnormalities)
- Fetal, maternal and cut surfaces.

### A6.4 Histology

- At least one block of all major thoracic and abdominal organs (right and left lungs, heart, liver, kidney, thymus, adrenals and pancreas)

- Costochondral junction (over 24 weeks' gestation)
- Adequate sampling of brain (varies with case: minimum of one block from hind brain and one from cerebral hemispheres)
- Adequate sampling of placenta (cord, membranes, focal lesions, grossly normal parenchyma to include amnion and decidua).

#### A6.5 Special procedures and investigations

- X-ray mandatory for suspected skeletal dysplasia and multiple malformations
- Photography mandatory for dysmorphic fetuses and babies without ante-mortem diagnosis; advised for other gross abnormalities
- Bacteriology (blood/spleen/lung/CSF), IF CLINICALLY INDICATED
- Virology, if clinically indicated
- Karyotype, if clinically indicated
- Storage of fibroblasts/frozen tissue/DNA, if clinically indicated
- Biochemistry, if clinically indicated
- Haematology, if clinically indicated
- Neuropathology, if clinically or radiological evidence of CNS pathology or the brain appears abnormal on external examination

#### A6.6 Autopsy reports

- Demographic details
- Date of autopsy
- Details of consent and any restrictions
- Availability of clinical records at time of post-mortem, including anomaly scans if relevant
- Attendance of clinician
- Clinical history
- Systematic description of external, internal and placental examination and results of X-rays and other ancillary investigations
- Summary of major findings including sex and apparent gestation, estimated timing of death in babies born dead, adequacy of growth and nutrition, presence/absence of congenital abnormalities, major pathological lesions, evidence of chronic stress or disease prior to death, placental examination
- Commentary addressing the clinical questions and significance of pathological findings
- Mode/cause of death
- Record of photographs and any samples retained
- Record of disposal of any tissues or samples
- A provisional report on the macroscopic findings should be issued within 24-48 hours of the autopsy, with the histology and further investigations incorporated into a final report when available
- Timely dispatch to clinicians with particular reference to the timing of postnatal appointments.

## Case Evaluation Form

Case number:

MBRRACE-UK 2014 Perinatal Confidential Enquiry

**Sub-optimal care**  
0: No sub-optimal care  
1: Minor sub-optimal care  
2: Significant sub-optimal care  
3: Major sub-optimal care

**Relevance of grade of care to outcome**  
0: Not relevant  
1: Possibly relevant  
2: Probably relevant  
3: Almost certainly relevant

**What:**  
R: Failure to recognise problem  
A: Failure to act appropriately  
C: Communications failure  
S: Failure to supervise  
H: Any lack of human resource  
E: Any lack or failure of equipment  
O: Other (please specify)

**Who:**  
Type of Health Professional or carer involved (e.g. GP, Hospital Midwife, Obstetrician, parents). If more than one person for this factor, write on separate lines.

No:	Ante-natal Care Please refer to "Guidelines for judging/grading of cases for review" document	Sub-optimal care	Relevance of grade of care to outcome	What	Who	Grade of Staff	Locum Yes/No
1.							
2.							
3.							
4.							

*\*Improvements in care should be interpreted to include adherence to guidelines, where these exist and have not been followed, as well as other improvements which would normally be considered part of good care (see consensus document), where no formal guidelines exist.)*

*MBRRACE-UK 2014 Perinatal Confidential Enquiry*

Case number:

**Sub-optimal care**  
O: No sub-optimal care  
1: Minor suboptimal care  
2: Significant suboptimal care  
3: Major suboptimal care

**Relevance of grade of care to outcome**  
O: Not relevant  
1: Possibly relevant  
2: Probably relevant  
3: Almost certainly relevant

**What:**  
R: Failure to recognise problem  
A: Failure to act appropriately  
C: Communications failure  
S: Failure to supervise  
H: Any lack of human resource  
E: Any lack or failure of equipment  
O: Other (please specify)

**Who:**  
Type of Health Professional or carer involved (e.g. GP, Hospital Midwife, Obstetrician, parents). If more than one person for this factor, write on separate lines.

No:	Intra-partum Care Please refer to "Guidelines for judging/grading of cases for review" document	Sub-optimal care	Relevance of grade of care to outcome	What	Who	Grade of Staff	Locum Yes/No
1.							
2.							
3.							
4.							

**Case number:** *MBRRACE-UK 2014 Perinatal Confidential Enquiry*

**Sub-optimal care**  
O: No sub-optimal care  
1: Minor sub-optimal care  
2: Significant sub-optimal care  
3: Major sub-optimal care

**Relevance of grade of care to outcome**  
O: Not relevant  
1: Possibly relevant  
2: Probably relevant  
3: Almost certainly relevant

**What:**  
R: Failure to recognise problem  
A: Failure to act appropriately  
C: Communications failure  
S: Failure to supervise  
H: Any lack of human resource  
E: Any lack or failure of equipment  
O: Other (please specify)

**Who:**  
Type of Health Professional or carer involved (e.g. GP, Hospital Midwife, Obstetrician, parents). If more than one person for this factor, write on separate lines.

No:	Post-natal Care Please refer to "Guidelines for judging/grading of cases for review" document	Sub-optimal care	Relevance of grade of care to outcome	What	Who	Grade of Staff	Locum Yes/No
1.							
2.							
3.							
4.							

(\*Improvements in care should be interpreted to include adherence to guidelines, where these exist and have not been followed, as well as other improvements which would normally be considered part of good care (see consensus document), where no formal guidelines exist.)

*MBRRACE-UK 2014 Perinatal Confidential Enquiry*

**Case number:**

**Sub-optimal care**  
O: No sub-optimal care  
1: Minor suboptimal care  
2: Significant suboptimal care  
3: Major suboptimal care

**Relevance of grade of care to outcome**  
O: Not relevant  
1: Possibly relevant  
2: Probably relevant  
3: Almost certainly relevant

**What:**  
R: Failure to recognise problem  
A: Failure to act appropriately  
C: Communications failure  
S: Failure to supervise  
H: Any lack of human resource  
E: Any lack or failure of equipment  
O: Other (please specify)

**Who:**  
Type of Health Professional or carer involved (e.g. GP, Hospital Midwife, Obstetrician, parents). If more than one person for this factor, write on separate lines.

No:	<b>Bereavement/Psychosocial Care</b> Please refer to "Guidelines for judging/grading of cases for review" document					Relevance of grade of care to outcome	What	Who	What	Who	Grade of Staff	Locum Yes/No
1.												
2.												
3.												
4.												

*MBRRACE-UK 2014 Perinatal Confidential Enquiry*

**Case number:**

**Sub-optimal care**  
O: No sub-optimal care  
1: Minor suboptimal care  
2: Significant suboptimal care  
3: Major suboptimal care

**Relevance of grade of care to outcome**  
O: Not relevant  
1: Possibly relevant  
2: Probably relevant  
3: Almost certainly relevant

**What:**  
**R:** Failure to recognise problem  
**A:** Failure to act appropriately  
**C:** Communications failure  
**S:** Failure to supervise  
**H:** Any lack of human resource  
**E:** Any lack or failure of equipment  
**O:** Other (please specify)

**Who:**  
Type of Health Professional or carer involved (e.g. GP, Hospital Midwife, Obstetrician, parents). If more than one person for this factor, write on separate lines.

No:	Post-mortem Examination/Placental Histology Please refer to "Guidelines for judging/grading of cases for review" document	Sub-optimal care	Relevance of grade of care to outcome	What	Who	Grade of Staff	Locum Yes/No
1.							
2.							
3.							
4.							



**Sub-optimal care**  
O: No sub-optimal care  
1: Minor sub-optimal care  
2: Significant sub-optimal care  
3: Major sub-optimal care

**Relevance of grade of care to outcome**  
O: Not relevant  
1: Possibly relevant  
2: Probably relevant  
3: Almost certainly relevant

**What:**  
R: Failure to recognise problem  
A: Failure to act appropriately  
C: Communications failure  
S: Failure to supervise  
H: Any lack of human resource  
E: Any lack or failure of equipment  
O: Other (please specify)

**Who:**  
Type of Health Professional or carer involved (e.g. GP, Hospital Midwife, Obstetrician, parents). If more than one person for this factor, write on separate lines.

No:	Follow-up Care Please refer to "Guidelines for judging/grading of cases for review" document	Sub-optimal care	Relevance of grade of care to outcome	What	Who	Grade of Staff	Locum Yes/No
1.							
2.							
3.							
4.							

Case number: *MBRRACE-UK 2014 Perinatal Confidential Enquiry*

(\*Improvements in care should be interpreted to include adherence to guidelines, where these exist and have not been followed, as well as other improvements which would normally be considered part of good care (see consensus document), where no formal guidelines exist.)

Continuation sheet. Case number:

*MBRRACE-UK 2014 Perinatal Confidential Enquiry*

**Sub-optimal care**  
O: No sub-optimal care  
1: Minor suboptimal care  
2: Significant suboptimal care  
3: Major suboptimal care

**Relevance of grade of care to outcome**  
O: Not relevant  
1: Possibly relevant  
2: Probably relevant  
3: Almost certainly relevant

**What:**  
R: Failure to recognise problem  
A: Failure to act appropriately  
C: Communications failure  
S: Failure to supervise  
H: Any lack of human resource  
E: Any lack or failure of equipment  
O: Other (please specify)

**Who:**  
Type of Health Professional or carer involved (e.g. GP, Hospital Midwife, Obstetrician, parents). If more than one person for this factor, write on separate lines.

No:	<i><b>Insert area of care pathway</b></i> Please refer to "Guidelines for judging/grading of cases for review" document	Sub-optimal care	Relevance of grade of care to outcome	What	Who	Grade of Staff	Locum Yes/No

**Case Evaluation Form** (Baby) MBRRACE-UK 2014 Perinatal Confidential Enquiry

Case number:

<p><i>Summary comments:</i></p>	<p><b>Overall Grade</b></p>
<p><b>Grade of care</b></p> <p><b>1:</b> Good care; no improvements identified</p> <p><b>2:</b> Improvements in care* identified which would have made <b>no difference</b> to outcome</p> <p><b>3:</b> Improvements in care* identified which <b>may have made a difference</b> to outcome</p>	

## Case Evaluation Form (Mother) MBRRACE-UK 2014 Perinatal Confidential Enquiry

Case number:

Summary comments:

Overall Grade

**Grade of care**

- 1:** Good care; no improvements identified
- 2:** Improvements in care\* identified which would have made **no difference** to outcome
- 3:** Improvements in care\* identified which **may have made a difference** to outcome

☐

# 8.2. Appendix 2: Checklists

### Significant Risk Factors present at booking

Were any of the following **present (P)**, **identified (I)** and **managed(M)** in line with national guidance?

	<b>P</b>	<b>I</b>	<b>M</b>
1. Weight issues e.g. obesity, underweight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Diabetes or other endocrine disorders e.g. thyroid function	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Hypertensive disease (e.g. PIH, Pre-eclampsia, HELLP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Cardiac Disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Uterine or other significant surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Psychological/mental health issues e.g. depression, anxiety, puerperal psychosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Psychological or mental disability e.g. learning disability, deafness, spina bifida	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Hepatitis B or C	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Inherited disorder e.g. cystic fibrosis, haemoglobinopathies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Epilepsy requiring anti-convulsants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Significant respiratory disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Renal Disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Rhesus isoimmunisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Thromboembolic or haematological conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Autoimmune disease e.g. lupus, coeliac disease, rheumatoid arthritis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Thrombophilia / clotting disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. 3 or more consecutive miscarriages, fetal loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Tests for routine scheduled antenatal care

The minimum set of tests for routine scheduled antenatal care has been developed from the appointment schedule in appendix D of [NICE clinical guideline 62](#).

Investigation	Timing
Blood pressure	All routine appointments
Urine test for proteinuria	All routine appointments
Blood group and rhesus D status	At booking
Haemoglobinopathies screen	At booking
Hepatitis B virus screen	At booking
HIV screen	At booking
Rubella susceptibility	At booking
Syphilis screen	At booking
MSU for asymptomatic bacteriuria	At booking
Height, weight and body mass index	At booking
Haemoglobin	At booking and 28 weeks
Red-cell alloantibodies	At booking and 28 weeks
Ultrasound scan to determine gestational age	Between 10 weeks 0 days and 13 weeks 6 days
Down's syndrome screen	Combined test: between 10 weeks 0 days and 14 weeks 1 day. Serum quadruple test: 14 weeks 2 days to 20 weeks 0 days.
Ultrasound screen for structural anomalies	Between 18 weeks 0 days and 20 weeks 6 days
Measure of symphysis–fundal height Fetal presentation	All routine appointments from 25 weeks 36 weeks
<b>Women should be able to make an informed choice about whether to accept or decline each test, and notes should include a record of any tests offered and declined as well as the results of tests accepted.</b>	



### Screening tool for risk of developing Maternal Gestational Diabetes:

Were any of the following risk factors **present (P)** and **identified (I)** at the booking appointment?

	<b>P</b>	<b>I</b>
1. Body mass index above 30 kg/m <sup>2</sup>	<input type="checkbox"/>	<input type="checkbox"/>
2. Previous macrosomic baby weighing 4.5 kg or above	<input type="checkbox"/>	<input type="checkbox"/>
3. Previous gestational diabetes	<input type="checkbox"/>	<input type="checkbox"/>
4. Family history of diabetes (first-degree relative with diabetes)	<input type="checkbox"/>	<input type="checkbox"/>
5. Family origin with a high prevalence of diabetes:	<input type="checkbox"/>	<input type="checkbox"/>
6. South Asian (specifically women whose country of family origin is India, Pakistan or Bangladesh)	<input type="checkbox"/>	<input type="checkbox"/>
7. Black Caribbean	<input type="checkbox"/>	<input type="checkbox"/>
8. Middle Eastern (specifically women whose country of family origin is Saudi Arabia, United Arab Emirates, Iraq, Jordan, Syria, Oman, Qatar, Kuwait, Lebanon or Egypt).	<input type="checkbox"/>	<input type="checkbox"/>
9. If so was the woman offered testing for gestational diabetes?	<input type="checkbox"/>	<input type="checkbox"/>

Testing for gestational diabetes should be carried out in accordance with [NICE clinical guideline 63](#):

'The 2-hour 75 g oral glucose tolerance test (OGTT) should be used to test for gestational diabetes and diagnosis made using the criteria defined by the World Health Organization<sup>1</sup>. Women who have had gestational diabetes in a previous pregnancy should be offered early self-monitoring of blood glucose or an OGTT at 16–18 weeks, and a further OGTT at 28 weeks if the results are normal. Women with any of the other risk factors for gestational diabetes should be offered an OGTT at 24–28 weeks.'

<sup>1</sup> Fasting plasma venous glucose concentration greater than or equal to 7.0 mmol/litre or 2-hour plasma venous glucose concentration greater than or equal to 7.8 mmol/litre. World Health Organization Department of Noncommunicable Disease Surveillance (1999) Definition, diagnosis and classification of diabetes mellitus and its complications. Report of a WHO consultation. Part 1: diagnosis and classification of diabetes mellitus. Geneva: World Health Organization.

Case ID:



**Small for Gestational Age (Please complete for all cases)**

**Please tick Yes or No in answer to the following questions:**

	Yes	No
1. Were customised growth centile* charts present in the notes?	<input type="checkbox"/>	<input type="checkbox"/>
2. Were fundal height measurements performed at correct times and intervals?	<input type="checkbox"/>	<input type="checkbox"/>
3. Were referrals for scans / further investigations undertaken where required?	<input type="checkbox"/>	<input type="checkbox"/>
4. Were estimated fetal weights correctly plotted and followed up?	<input type="checkbox"/>	<input type="checkbox"/>
5. Was the pregnancy identified as being small for gestational age?	<input type="checkbox"/>	<input type="checkbox"/>
6. Were parents informed and explanations given regarding investigations and management?	<input type="checkbox"/>	<input type="checkbox"/>

Case ID:



### Reduced Fetal Movements

Did the mother attend for reduced fetal movements? Yes ☐ No ☐

**If yes please complete the following:**

Please tick Yes or No in answer to the following questions:

	Yes	No
1. Fetal anomaly	<input type="checkbox"/>	<input type="checkbox"/>
2. Previous stillbirth	<input type="checkbox"/>	<input type="checkbox"/>
3. Raised BMI	<input type="checkbox"/>	<input type="checkbox"/>
4. Smoking	<input type="checkbox"/>	<input type="checkbox"/>
5. Poor obstetric history	<input type="checkbox"/>	<input type="checkbox"/>
6. Recurrent episodes of reduced fetal movements	<input type="checkbox"/>	<input type="checkbox"/>
7. Diabetes	<input type="checkbox"/>	<input type="checkbox"/>
8. SGA (small for gestational age - known or suspected)	<input type="checkbox"/>	<input type="checkbox"/>
9. Extremes of maternal age (<18yrs, >40yrs)	<input type="checkbox"/>	<input type="checkbox"/>
10. Substance misuse	<input type="checkbox"/>	<input type="checkbox"/>
11. Hypertension/pre-eclampsia	<input type="checkbox"/>	<input type="checkbox"/>
12. Systemic lupus erythematosus (SLE)	<input type="checkbox"/>	<input type="checkbox"/>
13. Genetic factors	<input type="checkbox"/>	<input type="checkbox"/>
14. Multiple non-attendance	<input type="checkbox"/>	<input type="checkbox"/>
15. Placental insufficiency (uterine notching)	<input type="checkbox"/>	<input type="checkbox"/>

Case ID:



### Obstetric Risk Factors from previous pregnancy

Were any of the following **present (P)**, **identified (I)** and **managed(M)** in line with national guidance?

	P	I	M
1. Intrauterine growth restriction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. High birth weight baby >90th centile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. APH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. PPH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Placenta accreta	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Pre-term labour <34/40	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Still birth or Neonatal death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Fetal congenital anomaly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Reduced fetal movements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Case ID:



**Social Risk Factors (Please complete for all women)**

Were any of the following **present (P)**, **identified (I)** and **managed(M)** in line with national guidance?

	P	I	M
1. Smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Alcohol abuse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Substance abuse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. New Migrant (<1year in UK) or Asylum Seeker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Social Services or Child Protection involved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Domestic abuse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. This is a teenage pregnancy (<20years old)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. There is a lack of social support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. There are housing or benefit issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Mother has difficulty reading,	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Late booking or not arriving for 2 or more appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Case ID:



**Antenatal Screening (Please complete for all women)**

Were any of the following: **Offered, Undertaken, Declined?**

	Offered	Undertaken	Declined
1. Dating USS (between 10+0weeks and 13+6weeks using crown-rump measurement)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Booking bloods (including full blood count, blood group, red-cell alloantibodies, haemoglobinopathies if needed, rubella, hepatitis B, syphilis, HIV)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Down's syndrome: 'Combined test' between 11+0 weeks and 13+6 weeks or serum screening test (triple or quadruple test) between 15+0 weeks and 20+0 weeks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Mid trimester USS for fetal anomalies: between 18+0 weeks and 20+6 weeks by USS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Post Perinatal Death Screening Tests (Please complete for all stillbirths)**

 Were any of the following **present (P)**, **identified (I)** and **managed(M)** in line with national guidance?

	<b>P</b>	<b>I</b>	<b>M</b>
1. Chromosomal analysis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. FBC	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Biochemistry e.g. CRP, LFT, Bile salts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Maternal coagulation times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Plasma fibrinogen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Kleihauer-Betke Test	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Maternal bacteriology e.g. blood cultures, MSU, vaginal/cervical swabs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Serology e.g. viral screen, syphilis, tropical infections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Random Blood sugar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. HbA1c	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Thyroid function	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Thrombophilia e.g. factor v leiden mutation, prothrombin gene variant, anti-cardiolipin antibodies, lupus anticoagulant, protein C, protein S and anti-thrombin III	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Antibody serology e.g. anti-red cell, anti-Ro, anti-La maternal alloimmune, antiplatelet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Parental blood for karyotyping if needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Fetal and placental micro-biology e.g. blood sample, swabs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Fetal and placental tissue for karyotyping e.g. skin, cartilage, placenta	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Maternal urine for cocaine metabolites if needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## Bereavement Care

Please tick Yes or No in answer to the following questions:

Specific staff available and templates for standard of care	Yes	No
1. Was there evidence of a bereavement midwife being involved?	<input type="checkbox"/>	<input type="checkbox"/>
2. Was there a bereavement check list in the notes?	<input type="checkbox"/>	<input type="checkbox"/>
3. Was there specific documentation for bereavement care? (Perinatal Institute notes)	<input type="checkbox"/>	<input type="checkbox"/>
4. Was any need for an interpreter documented?	<input type="checkbox"/>	<input type="checkbox"/>
5. If yes, was attendance/use of a service documented?	<input type="checkbox"/>	<input type="checkbox"/>

Labour and birth	Yes	No
6. Is it possible to determine whether the woman was cared for in a dedicated room?	<input type="checkbox"/>	<input type="checkbox"/>
7. Is it possible to determine whether one to one care was given in labour?	<input type="checkbox"/>	<input type="checkbox"/>
8. Was it documented that the parents were given opportunities to see and hold their baby?	<input type="checkbox"/>	<input type="checkbox"/>
9. Was it documented that the parents were given opportunities to make mementoes of their baby: take the baby's hand and footprints, a lock of hair?	<input type="checkbox"/>	<input type="checkbox"/>
10. Was it documented that the parents were given opportunities to have photos taken?	<input type="checkbox"/>	<input type="checkbox"/>
11. Was it documented that a suitable chaplain, priest or other religious person was discussed with the mother?	<input type="checkbox"/>	<input type="checkbox"/>
12. Was it documented whether she was offered to take the baby home?	<input type="checkbox"/>	<input type="checkbox"/>
13. Prior to discharge was there documentation that written details of national and local sources of support were given?	<input type="checkbox"/>	<input type="checkbox"/>

**Labour and birth**

	Yes	No
14. Prior to discharge was there documentation that written details of funeral arrangements were given to the parents?	<input type="checkbox"/>	<input type="checkbox"/>
15. Prior to discharge was there documentation that written details of the registration process for a stillborn baby were given to parents?	<input type="checkbox"/>	<input type="checkbox"/>
16. Was it documented whether lactation was suppressed?	<input type="checkbox"/>	<input type="checkbox"/>

**Communication with staff outside the hospital**

	Yes	No
17. Was there a record of informing:		
Antenatal clinic?	<input type="checkbox"/>	<input type="checkbox"/>
Community midwives?	<input type="checkbox"/>	<input type="checkbox"/>
Health visitor?	<input type="checkbox"/>	<input type="checkbox"/>
GP?	<input type="checkbox"/>	<input type="checkbox"/>
Others?	<input type="checkbox"/>	<input type="checkbox"/>
Bounty Pack?	<input type="checkbox"/>	<input type="checkbox"/>

**Community midwifery care**

	Yes	No
18. Was she seen by a community midwife?	<input type="checkbox"/>	<input type="checkbox"/>
If yes, how many visits are documented?		Number

**Post mortem**

	Yes	No
19. Was it documented whether the parents were given written information about the PM?	<input type="checkbox"/>	<input type="checkbox"/>

**Perinatal death review**

	Yes	No
20. Was there evidence that a review of the death was undertaken?	<input type="checkbox"/>	<input type="checkbox"/>
21. If so, was root cause analysis included?	<input type="checkbox"/>	<input type="checkbox"/>
22. Was their documented evidence of lesson learning and an action plan outlined for improvements to care?	<input type="checkbox"/>	<input type="checkbox"/>
23. Did the review include parents' concerns about their care?	<input type="checkbox"/>	<input type="checkbox"/>
24. Were the results fed back to parents?	<input type="checkbox"/>	<input type="checkbox"/>
25. If yes, how were results fed back to parents?		
Letter?	<input type="checkbox"/>	<input type="checkbox"/>
Meeting?	<input type="checkbox"/>	<input type="checkbox"/>

**6 week postnatal check-up appointments**

	Yes	No
26. Was there a checklist to make sure all results were collected before the appointment?	<input type="checkbox"/>	<input type="checkbox"/>
27. Did the follow up appointment take place?	<input type="checkbox"/>	<input type="checkbox"/>
28. If so how long after the baby's death? _____		
29. If the follow up appointment did not take place, was it documented why?	<input type="checkbox"/>	<input type="checkbox"/>

Case ID:



30. Was it documented whether she was seen by her consultant?	<input type="checkbox"/>	<input type="checkbox"/>
31. Was it documented whether a plan was discussed for any future pregnancy?	<input type="checkbox"/>	<input type="checkbox"/>
32. Was a letter summarising results of the review/any investigations on the mother/post mortem and a plan for future pregnancy if relevant sent to parents?	<input type="checkbox"/>	<input type="checkbox"/>
33. Was a letter summarising results of review/any investigations on the mother/post mortem and plan for future pregnancy if relevant sent to the GP?	<input type="checkbox"/>	<input type="checkbox"/>

Case ID:

## Placental Histology Reporting

Clear Form

<i>Was the following information available to the pathologist?</i>	Yes	No	Unknown
Gestational age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Birth-weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Indication for referral	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<i>Were the following noted in the macroscopic description?</i>	Yes	No	Unknown
Length of umbilical cord and approximate diameter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Site of cord insertion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Number of umbilical cord vessels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Degree of coiling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appearance of the placental membranes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appearance of the fetal surface	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appearance of the maternal surface (complete or incomplete, attached clot, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weight of trimmed placental disc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Measurement of placental disc (in 3 dimensions)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appearance of the cut surface (if no lesions - is this stated)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rough assessment of percentage of infarction, if present	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weight of clot if received			

<i>Was there adequate sampling for histology?</i>	Yes	No	Unknown
One transverse section of umbilical cord	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
One roll of membranes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At least two full thickness blocks of the placental parenchyma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At least one block of any lesion described macroscopically	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Case ID:



<i>Does the report contain a microscopic description of the following?</i>	Yes	No	Unknown
Umbilical cord	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Membranes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Villous development (in relation to gestational age)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any focal lesions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Maternal decidua (i.e. maternal vessels)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Yes	No	Unknown
<i>Does the report contain a clinicopathological comment (where appropriate)?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<i>Specific considerations for twin placentas</i>	Yes	No	Unknown
Was chorionicity established?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<i>In monochorionic placentas:</i>	Yes	No	Unknown
Was the site and distance between the two umbilical cords recorded?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Was the relative shares of the placental disc commented upon?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Was the vasculature of the chorionic plate assessed for anastomoses?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<i>Overall, how would you grade the quality of this placental pathology report?</i>			
Poor	<input type="checkbox"/>	Satisfactory	<input type="checkbox"/>
		Good	<input type="checkbox"/>
		Excellent	<input type="checkbox"/>

**Submit to MBRRACE**

## 8.3. Appendix 3: Guidance for anonymisation of case notes



## MBRRACE-UK guidance document for the anonymisation of case notes

### Processing on arrival:

#### Storage and Identification:

Identify the MBRRACE ID (normally on the front page or at the bottom of each page).

If the MBRRACE ID has not been supplied, contact the lead reporter and ask for confirmation by email. Print out this page and attach to the front of the case notes.

Attach a paper copy checklist, record the date of receipt and file in the locked filing cabinet labelled 'received'. Cases should be stored in numerical order.

**Ensure that the cabinet is locked and this key is locked in the key cabinet.**

#### Logging arrival:

Log the arrival of the case notes on the Access database

#### Acknowledgment

Send an email of acknowledgement (and a thank you) to the lead reporter or person nominated to retrieve and forward the case notes.

#### Checking for completeness:

Please use the document checklist supplied to the Trust with the initial request. Identify any missing sections and request them from the Trust as soon as possible

### Case Notes requiring removal of all identifiers

#### Structure and ordering:

Please use the following section breaks: 'Antenatal care' 'Delivery care' 'Bereavement care' 'Post-natal follow-up' to divide up the case notes and insert into the appropriate place in the case notes.

Order the sections chronologically in the above order. All charts (except ultrasounds and antenatal diagnostic tests which should be filed under 'antenatal' at the back in chronological order) may be filed separately from the main body of the notes. The exception would be for example if a test is repeated e.g. blood tests - these may be filed together for comparison to help the reviewer understand the progress of the case.

#### Summary Sheet

Create a summary sheet at the front of each set of case notes to help to differentiate the case during the course of the enquiry.

### Synopsis sheet

Create a synopsis sheet for the panel reviewer at the beginning of each set of case notes. This is similar to the summary sheet but is **anonymised** and assists the reviewer by providing an overview of the case

### Check list:

Write dates of when you have received, acknowledged, anonymised, ordered, indexed, summary sheet, synopsis and made a paper copy checklist.

### Do not review more than one set of notes at one time.

Scan and upload the notes using the MBRRACE case ID as the file name.

**Do not** obscure the following:

- Race or religion
- Occupation of mother & partner/father
- Age of mother
- Birth year of mother
- Birth weight of baby (or previous pregnancies)
- Birth year of previous pregnancies, type of delivery and outcome
- Time/date of birth
- Time/date of death
- Time/date of discharge
- Dr/ Mrs or other title which gives an indication of the role/responsibility of the health care professional providing care.

### The redaction process:

Import the case note file into Adobe X Pro and save under the MBRRACE ID as the filename. Obscure the following information using the redaction facility.

- Mother's name
- Baby's name
- Mother's or baby's NHS number
- Partner/ other relative's name
- Mother's exact DOB (redact day and month but not the year)
- Information relating to other siblings e.g. names/exact DOB (redact day and month but not the year) the type of birth should remain.
- Addresses of family members
- Telephone numbers

Annotate, where applicable, i.e. replace **all** the identifying hospital or base names with "tertiary centre", "base hospital", "PICU" "NICU", "level3 unit", "GP address" etc. (this

information can be gleaned from the synopsis sheet and asking advice from the clinical advisor).

Remove personal mother and baby names and annotate "mother" and "baby" "patient" within text when electronically redacting. If a consultant name is removed, replace with **consultant and their specialism**, where applicable.

Redact any tag lines that are associated with a specific trust - Please remember to remove hospital or Trust logos, hospital telephone numbers, extensions, fax numbers, abbreviations and any codes which contain the initials of the hospital must also be removed

Please redact:

- Hospital code
- Any hospitals mentioned e.g. for transfers even if only discussed or mentioned as a hospital with an ECMO team
- Hospitals the baby/mother has been referred from or is to be transferred to
- Hospital staff mentioned by name
- Names of wards, initials or code of wards
- Names or code of laboratories
- Codes unique to the individual e.g. event code
- Telephone numbers of hospital or help lines
- Email addresses
- Postal addresses

It is helpful to assign designations or descriptions of persons identified in the case notes before you start your redaction. Please make a list of these before you start and then shred them once you have finished the redaction process. Details of consultant grade staff can be found in the discharge summary and in the discharge letters.

Once anonymisation is complete, log the case in the access database with the date and then your details. Save the anonymised case file in the MBRRACE section of the X drive which is accessible only by MBRRACE-UK staff using their unique username and password.

# 8.4. Appendix 4: Training for panel members

## **MBRRACE-UK panel training session – confidential enquiry process**

Welcome to the panel training session for the MBRRACE-UK 2014 perinatal confidential enquiry which will evaluate the care of those women who experience a normally formed antepartum term singleton stillbirth at a gestation of  $\geq 37$  weeks or more

The aim of the session is to familiarise panel members with the case review process explain the guidance and training document and the evaluation form.

This enquiry is part of a rolling programme of maternal and perinatal mortality and morbidity confidential enquiries commissioned by the Department of Health which occur annually. Topics are chosen from those proposed by UK clinicians via an open call on the MBRRACE-UK website. The cases for this enquiry, were randomly selected and chosen from cases reported to MBRRACE-UK during July-September 2013.

- Cases for the 2014 enquiry will be reviewed by multidisciplinary panels with approximately 10-12 cases per panel
- Cases allocated to that panel will receive individual panel member review using the guidance document and evaluation form provided, prior to the panel meeting. Panel members are requested to bring the completed forms with them to the panel meeting.
- Panel meetings are face-to-face. A lead panel member will be identified to present a summary of each case. The case will be discussed and once the panel has reached a consensus a final grading of the care will be agreed and recorded

The multidisciplinary panels will consist of

- Maternal fetal medicine specialists,
- Midwives (hospital-based, community-based, bereavement care specialists)
- Obstetricians (level I/II/III units in the UK),
- Perinatal pathologists

You will have received a copy of the guidance document and evaluation form by email. The guidance was produced with the help of a topic expert group convened for the enquiry. The members of the group are listed in appendix 1 of the document. The guidance is divided into 6 sections to encapsulate the care pathway for this group of women and their babies. The evaluation form also follows this format. Each of the sections contains questions you may wish to ask and aspects of the care pathway covered by current guidelines and standards. There are links to the guidelines wherever possible to help you evaluate the care and sign-post you to relevant information. The guidance and evaluation form are there to help you but are not an exhaustive list. Please feel free to comment and evaluate on any aspect of care within the case notes. You may wish to limit your

review to the sections of the case notes which relate to your area of expertise. This is acceptable, but if you wish, you are free to comment on any aspect of care or treatment.

The grading of care for the purposes of the enquiry conforms to the process used by all of the Department of Health Clinical Outcome Review Programmes. There are 3 grades of care used:

- Good care; no improvements identified
- Improvements in care\* identified which would have made no difference to outcome
- Improvements in care\* identified which may have made a difference to outcome

Our funders: HQIP request that we draw your attention to their Cause for Concern Guidance. We ask that panel members report any instances of abuse or neglect, misconduct, lack of competency, dysfunctional dangerous department or grossly inadequate service provision are reported immediately to the MBRRACE UK team. We will then refer this on to HQIP who will investigate the case further.

The panel review meetings are an all-day event usually between 10am and 4pm at a venue convenient to panel members wherever possible. All cases are reviewed on the day. Each case is presented to the panel by a panel member. The case is discussed, a consensus is reached and receives a final evaluation at the meeting

- Analysis

The enquiry process collates qualitative data as well as the numerical scores. The analysis is thematic and iterative and is performed by the MBRRACE-UK team in Leicester

- Reporting

The findings of the enquiry will be provided in a report available on-line via the MBRRACE-UK website with paper copies available on request

- Dissemination

This will be made available to all UK healthcare professionals. There will also be a lay-report available.

## **Panel training session – on-line viewing system for case note review**

Welcome to the panel training session for the MBRRACE-UK 2014 perinatal confidential enquiry which will evaluate the care of those women who experience a normally formed antepartum term singleton stillbirth at a gestation of 37 weeks or more

The aim of this session is to demonstrate the on-line viewing system for the case note review for the enquiry. This will cover the preparation needed, how to log-on and access the cases, how to view the cases, how to annotate the case notes and how to evaluate the care using the grading system

This is the web address for the MBRRACE-UK on-line database. The secure web portal incorporates the maternal and perinatal death surveillance systems and the case notes for both the ongoing maternal and perinatal death confidential enquiries

Before we can provide access to the case notes we request that panel members provide us with a signed copy of the Confidentiality statement and Declaration of interest form we sent by email and complete the on-line training session.

We suggest you use Mozilla Firefox as your web browser. This is a list of all of the available compatible web browsers. You may need to ask your IT dept. to help you with this, or prefer to access the cases on your personal PC/laptop.

You will need to provide us with an NHS or University email address for correspondence and registration. Your username will then be this email address. We will then email your username and details of the cases available for review.

If you are already registered, log-in as usual. If you are new to the system, you will need to request an activation code (password). This will be emailed to you and you can then choose your own password.

Now we are going to look at how we access the viewing system through the MBRRACE-UK web portal and view the cases. This will be very similar to your own experience the only difference is that I have additional privileges which allow me to access reports from the surveillance system. So you may not see all of the options or tabs when you log in yourself.

- Using the MBRRACE-UK web address for the portal will bring up this home page
- Type in your username (this will usually be your university or nhs email address)
- If you are already a registered user of the system type in your password
- If you are logging in for the first time click on “request a new activation code”
- Enter your username again
- Click on “make request”
- Your activation code will now be sent to the email address (username)
- Cut and paste it from the email into the password box.
- You will now have the opportunity to create your own password
- Click on the log on button

This page has a series of tabs across the page. These will vary from user to user, be tailored to your level of access and relate your username

Although this is counter-intuitive you are looking for the maternal deaths tab. We are in the process of creating a separate section of the portal for perinatal confidential enquiries but until then we share the same tab.

Click on the maternal deaths tab, now click on case assessment

Clicking on the select a case option in the dropdown menu will reveal all of the cases allocated to you for review.

Click on the case you would like to review, this will appear in the box

Click on view case notes and the case will open.

Underneath the case number in a line across the screen are a series of buttons

The first changes the view option to full screen, click allow to change the view and click the same button again to return the screen to the default position

You can skip to a particular page by typing the page number into this box

You can go back to the previous page, forward to the next page, go to the beginning or the end of the document using the arrow buttons

The plus and minus buttons allow you to zoom in and out. The last 3 allow you to set the size to 100% or change the height or the width of the page. There are also scroll bars for the page and for the screen

You will notice that the first two pages of each case are similar. On page one we provide a table of contents with the relevant page numbers to help you navigate around the case notes easily by typing in the page number of the section you are interested in.

Page two is a synopsis to help you quickly gain a sense of the story of the case

You will also notice that each page has a yellow box on the right hand side.

This can be used for annotations but has its limitations.

It is only accessible by you no-one else can see it.

It may be a useful aide de memoire, a scribble pad, to help you record your thoughts as you review the case notes and it will auto save each time you leave the page.

It does not allow you to cut and paste and you will not be able to print off your notes. Some panel members find it useful, others do not.

Using the case notes: please complete all sections of the evaluation form which apply and bring the forms with you to the panel meeting.

**Thank you for listening. We look forward to working with you.**



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## 8.5. Appendix 5: Postnatal investigations recommended by RCOG

## Tests recommended for women with a late IUFD

(taken from RCOG Green-top Guideline 55, Table 1, Section 5.3, 10 Nov 2010)

Test	Reason(s) for test	Additional comments
<b>Maternal standard haematology and biochemistry including CRPs and bile salt</b>	Pre-eclampsia and its complications Multi-organ failure in sepsis or haemorrhage Obstetric cholestasis	Platelet count to test for occult DIC (repeat twice weekly)
<b>Maternal coagulation times and plasma fibrinogen</b>	DIC	Not a test for cause of late IUFD Maternal sepsis, placental abruption and pre-eclampsia increase the probability of DIC Especially important if woman desires regional anaesthesia
<b>Kleihauer</b>	Lethal feto-maternal haemorrhage  To decide level of requirement for anti-RhD gammaglobulin	Feto-maternal haemorrhage is a cause of IUFD  Kleihauer should be recommended for all women, not simply those who are RhD-negative (ensure laboratory aware if woman is RhD-positive)  Tests should be undertaken before birth as red cells might clear quickly from maternal circulation  In RhD-negative women, a second Kleihauer test also determines whether sufficient anti-RhD has been given
<b>Maternal bacteriology:</b> • blood cultures • midstream urine • vaginal swabs • cervical swabs	Suspected maternal bacterial infection including <i>Listeria monocytogenes</i> and <i>Chlamydia</i> spp.	<b>Indicated in the presence of:</b> • maternal fever • flu-like symptoms • abnormal liquor (purulent appearance/offensive odour) • prolonged ruptured membranes before late IUFD  Abnormal bacteriology is of doubtful significance in the absence of clinical or histological evidence of chorioamnionitis  Also used to direct maternal antibiotic therapy

Test	Reason(s) for test	Additional comments
<b>Maternal serology:</b> <ul style="list-style-type: none"> <li>viral screen</li> <li>syphilis</li> <li>tropical infections</li> </ul>	Occult maternal-fetal infection	<p>Stored serum from booking tests can provide baseline serology</p> <p>Parvovirus B19, rubella (if nonimmune at booking), CMV, herpes simplex and <i>Toxoplasma gondii</i> (routinely)</p> <p>Hydrops not necessarily a feature of parvovirus-related late IUFD</p> <p>Treponemal serology – usually known already</p> <p>Others if presentation suggestive, e.g. travel to endemic areas</p>
<b>Maternal random blood glucose</b>	Occult maternal diabetes mellitus	<p>Rarely a woman will have incidental type 1 diabetes mellitus, usually with severe ketosis</p> <p>Women with gestational diabetes mellitus return to normal glucose tolerance within a few hours after late IUFD has occurred</p>
<b>Maternal HbA<sub>1c</sub></b>	Gestational diabetes mellitus	<p>Most women with gestational diabetes mellitus have a normal HbA<sub>1c</sub></p> <p>Need to test for gestational diabetes mellitus in future pregnancy</p> <p>Might also indicate occult type 1 and type 2 diabetes</p>
<b>Maternal thyroid function</b>	Occult maternal thyroid disease	TSH, FT4 and FT3
<b>Maternal thrombophilia screen</b>	Maternal thrombophilia	<p><b>Indicated if</b> evidence of fetal growth restriction or placental disease</p> <p>The association between inherited thrombophilias and IUFD is weak, and management in future pregnancy is uncertain</p> <p>Most tests are not affected by pregnancy – if abnormal, repeat at 6 weeks</p> <p>Antiphospholipid screen repeated if abnormal</p>
<b>Anti-red cell antibody serology</b>	Immune haemolytic disease	<b>Indicated if</b> fetal hydrops evident clinically or on post mortem
<b>Maternal anti-Ro and anti-La antibodies</b>	Occult maternal autoimmune disease	<b>Indicated if</b> evidence of hydrops, endomyocardial fibro-elastosis or AV node calcification at post mortem

Test	Reason(s) for test	Additional comments
<b>Maternal alloimmune antiplatelet antibodies</b>	Alloimmune thrombocytopenia	<b>Indicated if</b> fetal intracranial haemorrhage found on post mortem
<b>Parental bloods for karyotype</b>	Parental balanced translocation Parental mosaicism	<b>Indicated if:</b> <ul style="list-style-type: none"> <li>fetal unbalanced translocation</li> <li>other fetal aneuploidy, e.g. 45X (Turner's syndrome)</li> <li>fetal genetic testing fails and history suggestive of aneuploidy (fetal abnormality on post mortem, previous unexplained IUFD, recurrent miscarriage)</li> </ul>
<b>Maternal urine for cocaine metabolites</b>	Occult drug use	With consent, if history and/or presentation are suggestive
<b>Fetal and placental microbiology:</b> <ul style="list-style-type: none"> <li>fetal blood</li> <li>fetal swabs</li> <li>placental swabs</li> </ul>	Fetal infections	More informative than maternal serology for detecting viral infections  Cord or cardiac blood (if possible) in lithium heparin  Written consent advisable for cardiac bloods  Need to be obtained using clean technique
<b>Fetal and placental tissues for karyotype (and possible single-gene testing):</b> <ul style="list-style-type: none"> <li>deep fetal skin</li> <li>fetal cartilage</li> <li>placenta</li> </ul>	Aneuploidy Single gene disorders	<b>Absolutely contraindicated if</b> parents do not wish (written consent essential)  Send several specimens – cell cultures might fail  Culture bottles must be kept on labour ward in a refrigerator – stored separately from formalin preservation bottles  Genetic material should be stored if a single-gene syndrome is suspected
<b>Post mortem examination:</b> <ul style="list-style-type: none"> <li>external</li> <li>autopsy</li> <li>microscopy</li> <li>X-ray</li> <li>placenta and cord</li> </ul>	See RCOG Green Top Guideline 55, section 5.6	<b>Absolutely contraindicated if</b> parents do not wish (written consent essential)  External examination should include weight and length measurement  IUGR is a significant association for late IUFD

Some tests should be taken before birth. Tests below the bold line are fetal. Shaded tests are selective.

AV = atrioventricular; CMV = cytomegalovirus; CRP = C-reactive protein; DIC = disseminated intravascular coagulation; FT3 = free triiodothyronine; FT4 = free thyroxine index; HbA<sub>1c</sub> = glycated haemoglobin; IUFD = intrauterine fetal death; IUGR = intrauterine growth restriction; RhD = rhesus D; TSH = thyroid-stimulating hormone

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