

Maternal, Newborn and Infant Clinical Outcome Review Programme



MBRRACE-UK Perinatal Confidential Enquiry

Stillbirths and neonatal deaths in twin pregnancies



January 2021

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on behalf of the MBRRACE-UK collaboration

January 2021

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Executive Summary

Background

This report represents the findings of the fourth perinatal confidential enquiry carried out as part of the MBRRACE-UK programme of work and focuses on stillbirths and neonatal deaths in twin pregnancies. This topic was selected as part of the standard process for the selection of topics for the Clinical Outcome Review Programme.

Over the past two decades there has been population-based evidence of reductions in perinatal mortality in multiple pregnancy [1]. The MBRRACE-UK perinatal surveillance report for UK perinatal deaths for births from January to December 2017 [2] showed that over the period 2013 to 2017 rates of both stillbirth and neonatal mortality for twins had reduced: from 9.03 to 6.99 per 1,000 total births for stillbirths and from 8.01 to 5.45 per 1,000 live births for neonatal deaths. Three important factors are likely to have had a significant influence in reducing perinatal loss: (i) invasive interventions for pre-morbid monochorionic complications; (ii) advancements in neonatal care; and (iii) improved antenatal care pathways. Several professional bodies and guidelines have made important contributions to the latter, including the first National Institute for Health and Care Excellence (NICE) recommendations for antenatal care for twin and triplet pregnancies [3] and in 2013 the publication of eight quality standards for the clinical care for multiple pregnancies [4]. Nevertheless, and despite these reductions, the increased risk of mortality associated with twins compared to singletons is almost double for stillbirths (relative risk (RR) 1.93 in 2017) and over threefold for neonatal deaths (RR 3.53 in 2017).

The stillbirths and neonatal deaths in twin pregnancies enquiry

The development of the enquiry followed the standard methodology used by MBRRACE-UK for perinatal confidential enquiries. Firstly, a multidisciplinary topic expert group (TEG) was established and one face-to-face meeting was held where a series of questions and potential checklists were developed (using the relevant guidance from the Royal College of Obstetricians and Gynaecologists, the Royal College of Anaesthetists, the Royal College of Pathologists, NICE, the Resuscitation Council (UK), and Sands) to facilitate the evaluation of the quality of care provision for each step of the care pathway:

- Antenatal care
- Care during labour
- Care at birth
- Resuscitation
- Neonatal care
- Postnatal and bereavement care
- Follow-up visit and review of care
- Post-mortem and placental histology

Pregnancies eligible for inclusion in this enquiry were defined as twin pregnancies (two fetuses identified at the dating scan) involving at least late fetal loss, stillbirth or neonatal death, where the gestational age at birth was 22⁺⁰ weeks or more, and the babies were born in 2017. Pregnancies which involved terminations of pregnancy (including fetal reductions) were excluded.

As in previous enquiries, the MBRRACE-UK perinatal mortality surveillance system provided the sampling frame for the selection of a random sample of twin pregnancies involving at least one late fetal loss, stillbirth or neonatal death, stratified by UK country. A sample of 118 out of a potential 285 pregnancies fulfilling the inclusion criteria was selected in October 2018 and submitted for review by confidential enquiry until saturation of themes was

achieved and no new lessons for future care were emerging: 50 pregnancies and 80 baby deaths were reviewed at 11 separate multidisciplinary review panels.

Representativeness of the sample

Given the availability of the total sample of potential cases for any enquiry being available from the MBRRACE-UK perinatal mortality surveillance data, a random sample of eligible cases can be selected for the enquiry. Therefore, as in previous MBRRACE-UK enquiries, we have been able to generate results from the enquiry which are not only rich in depth following the review of the individual case notes, but are also generalisable despite the relatively small sample. This enabled us to produce both quantitative and qualitative results, thus maximising our understanding of how care was provided at all points on the care pathway for all twin pregnancies 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 the quality of care provision affecting the outcome for both the babies 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(s). From the woman's perspective outcome was interpreted as the care the woman received after birth including her physical and psychological wellbeing and full consideration of her future fertility.

Overall, in terms of the outcome for the babies, the panel consensus was that in just over half of the pregnancies improvements in care were identified which may have made a difference to the outcome for the babies. This may represent a single issue at one point in the care pathway with all remaining care being considered appropriate or multiple issues at one or more points on the care pathway.

Confidential enquiry summary of grading of quality of care by pregnancy

Overall quality of care	Babies		Mother	
	n	%	n	%
Good care; no improvements identified	8	16	6	12
Improvements in care identified which would have made no difference to outcome	15	30	12	24
Improvements in care identified which may have made a difference to outcome	27	54	32	64
TOTAL	50	100	50	100

In terms of the care after birth, physical and psychological outcome and/or future fertility for the woman, in two-thirds of cases the consensus of the panels was that improvements in care may have made a difference to the outcome for the woman.

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Key findings

Key findings from the Confidential Enquiry Review Panels

- In just over half of pregnancies improvements in care were identified which may have made a difference to the outcome for the baby.
- In two-thirds of pregnancies improvements in care were identified which may have made a difference to the outcome for the woman.
- There was major sub-optimal antenatal care in half of pregnancies.
- There was major sub-optimal follow-up care for three-quarters of women.

Key findings for antenatal care

- For two fifths of women (20 of 50) care was not provided by a specialised multidisciplinary team as recommended by national guidance. For only 5 of the 50 women was care documented as including a specialist midwife and specialist sonographer involvement.
- Discussions concerning the risks of twin pregnancy before 24 weeks were documented for only half the women.
- Extreme preterm labour was the most frequent cause of perinatal loss in dichorionic twin pregnancies. In a significant proportion of these pregnancies preterm birth occurred before any specialist obstetrician input into the care. Furthermore following admission with suspected or established preterm labour there was lack of prompt consultant obstetrician input into the care plan.
- Prophylactic aspirin is recommended for women with multiple pregnancy identified on risk assessment to be at increased risk of preeclampsia, but this was only documented as being prescribed for nearly half (18/40) of those women eligible.
- Emergency assessment in maternity triage was particularly problematic in twin-to-twin transfusion syndrome (TTTS) which went unrecognised in women presenting with maternal concerns of classical 'red-flag' signs and symptoms.
- There were examples of good antenatal care in several complex pregnancies, including extensive multidisciplinary counselling of parents and preparation for birth in pregnancies complicated by discordant twin prognosis.

Key findings for scanning

- Chorionicity was determined in 98% of women whose twin pregnancy was diagnosed before 13⁺⁶ weeks gestational age.
- Frequency of ultrasound (US) scanning failed to follow guidance for monochorionic pregnancies with 1 in 5 eligible women not having 2 weekly scans from 16 weeks gestational age onwards.
- There was inconsistent labelling of twins on the scan reports of 1 in 6 (n=8) of the women reviewed, resulting in inaccurate monitoring of each twin.
- Ultrasound monitoring of fetal growth failed to comply with NICE guidance, with almost half of the women lacking a completed ultrasound growth chart.
- There was no evidence of the percentage difference in the estimated fetal weight of the two babies being calculated for almost two thirds of women with a twin pregnancy (n=31).

- In a quarter of the women (5 of 19) where a discordance in estimated fetal weight of greater than 25% was identified, there was a failure to follow guidance and provide either increased surveillance or additional assessment with fetal Dopplers.
- There was a failure to act on abnormal growth/liquor volume in 7 of 18 affected cases.
- Of the 13 women with complex monochorionic twins in one quarter there was a failure to refer or a delayed referral to a tertiary fetal medicine centre for specialist involvement in the care.
- In a small number of women there were significant failures to recognise signs and symptoms or a delay in diagnosis of twin-to-twin transfusion syndrome which led to delays in referral to regional centres for fetal interventional procedures.

Key findings for care during labour and birth

- There was no sub-optimal care during the intrapartum period for over half of the women (31/50) and there was evidence of compassionate care. Of the 19 pregnancies where the panels agreed intrapartum care was sub-optimal, 14 were at extreme preterm gestations (22-26 weeks).
- There was a lack of senior review on admission of women with multiple pregnancies and lack of preparedness for birth in 11 of the 19 cases where sub-optimal care was found.
- For 13 of these 19 sets of parents there was limited MDT/joint review by obstetric and neonatal teams and for seven of the 19 a lack of evidence of discussions with parents regarding the chances of survival, decisions about resuscitation, and signs of life at birth.
- In four of 19 pregnancies following preterm vaginal birth of the first twin, the second twin was augmented and birth expedited without clinical indication.
- Despite national guidance directing that antenatal steroids and magnesium sulphate should be considered and/or offered prior to preterm birth to improve neonatal outcomes, such interventions were not documented to have been considered or initiated in nearly a third of applicable pregnancies (8/27) and a partogram to record progress in labour was only started for half the women for whom it was possible, and completed for only three.

Key findings for resuscitation and neonatal care

- Mortality varied with gestational age and chorionicity. Almost two-thirds of deaths occurred before 28 weeks gestational age compared to just over 1 in 20 at term. Both twins died in just under half of dichorionic pregnancies compared with almost three-quarters of monochorionic pregnancies.
- Overall the neonatal care provided was considered to be good but there were notable instances of a lack of specific skills related to airway management at birth, variation in resuscitation in babies born <26 weeks and poor communication with families both before and after birth.
- Recently-published guidance may improve performance in these key areas of care.

Key findings for post-natal and follow-up care

- Overall, postnatal and follow-up care accounted for far more significant or major issues around care than any other aspect of the care pathway. 37 women had at least one issue graded as major sub-optimal care. Another five had at least one issue graded as significant sub-optimal care.
- Involvement of a bereavement midwife was documented for only 29 women and a bereavement checklist was missing or incomplete in half of the notes (n=26).
- Bereavement counselling was offered to around a third of parents.
- All but three women were offered a post-mortem (n=47); however there was lack of detailed documentation noted around post-mortem counselling (n=19).

- Ongoing community midwifery support following discharge was only noted in a third of women and the number of postnatal contacts were variable (with majority of women receiving only up to two visits). The overall level of bereavement and follow-up care was poorer in pregnancies with single twin demise, compared to those with demise of both twins.
- Where one or both twins died following an intervention in a tertiary centre (monochorionic twin pregnancy), disjointed communication regarding follow-up care between tertiary and referring unit, and lack of ownership for local review was noted.
- Only half of the women (n=24) had a follow-up bereavement appointment and of these only 11 women received a summary letter following this appointment. The majority of the letters were of poor quality and addressed to the GP. Where no follow-up was arranged, the reasons were not clearly documented in the notes.
- The timing of the follow-up visit was highly variable, ranging from 6 weeks to up to 35 weeks after the demise of one or both twins.
- Local review into perinatal death was documented for 1 in 5 women. Only one review was judged to be of good standard, with 2 being adequate, and 8 of poor standard. Most (n=8) local reviews lacked broad multidisciplinary healthcare professional input. When reviews were undertaken, pertinent issues around care were not identified; this was more evident at the extremes of viability, or where there was single twin demise.
- There was no evidence of involvement of parents in any reviews.

Key findings for post-mortem examination and placental histology reporting

- Consent for full post-mortem examination including placental histology was obtained in only around one quarter of the baby deaths.
- Where performed, all post-mortem examinations were carried out by specialist perinatal pathologists and in all these instances the quality of the post-mortem report was either good or excellent. The placenta was submitted for pathological examination in all autopsy cases and in all these cases, the placental histology report was of good quality with appropriate comments on the clinico-pathological correlation.
- For babies where there was no consent for autopsy (n=60), the placenta was submitted for histological examination in around two-thirds of the cases.
- When assessed against Royal College of Pathologists guidelines, around two-thirds of placental histology reports were regarded as excellent, good or satisfactory. However, around a third of reports were found to be of poor quality.
- A limiting factor in the clinico-pathological correlation was related to the paucity of clinical information supplied to pathologist by the obstetric / neonatal teams.
- There is an acute shortage of perinatal pathologists nationally which may be a critical factor impacting upon the quality of placental histology reports. Consequently, around a third of the placental histology was reported by general pathologists.
- In a minority of cases, there were avoidable human errors resulting in the placenta not being sent for formal pathological examination.

Key findings for communication, supervision and leadership

- Communication failures were identified in almost three-quarters of the pregnancies although in two-fifths of pregnancies there were also examples of clear communication.

- In just over half of the pregnancies there was:
 - a failure in supervision or leadership. Additionally these same issues were noted in half of twin pregnancies where significant or major suboptimal care was identified that was probably or almost certainly relevant to the outcome of the babies or the mother;
 - missing or poorly completed documentation at different points of the care pathway;
 - a failure in or a lack of communication between health professionals at one or more points of the care pathway.
- There was a failure in communication between health professionals and women/parents in nearly a third of pregnancies.
- Electronic notes provided limited information, were repetitive and difficult to follow. In particular, there was a lack of recording of the details of conversations both between clinicians and with parents.

Recommendations

This section presents a summary of the key recommendations identified by the enquiry together with those responsible for implementing them. Individual recommendation numbers are in brackets.

The full recommendations can be found in the corresponding chapters and as a standalone Chapter 9:

Recommendation	Chapter
A.	2. Antenatal: general
S.	3. Antenatal: scanning
L.	4. Labour and birth
N.	5. Resuscitation and neonatal care
F.	6. Post-natal, bereavement and follow-up care
P.	7. Post-mortem examination and placental histology reporting
C.	8. Communication, supervision and leadership

Recommendations identified from existing guidance required to reduce stillbirth and neonatal death in twin pregnancy

- Fully implement national guidance and resources. This includes:
 - National guidance for care of women with multiple pregnancy, particularly:
 - Core, multidisciplinary team of specialists within a dedicated multiple pregnancy clinic, including specialist midwife and sonographer. (A.1)
 - Discussion with parents of risks associated with twin pregnancy before 24 weeks. (A.3)
 - High quality ultrasound service with dedicated expertise in multiple pregnancy. (S.1)
 - BAPM Clinical Framework for the Perinatal Management of Extreme Preterm Birth, in particular:
 - Involvement of parents in the joint decision making around resuscitation, stabilisation and on-going care. (L.9-11, N.2-6)
 - National Bereavement Care Pathway for parents of twins experiencing pregnancy and one or more baby loss. (F.1)
 - High quality pathological examination of the placenta and the baby, including ensuring the pathologist is provided with a complete clinical history. (P.1-2)
 - Review of the perinatal death using the National Perinatal Mortality Review Tool and early engagement with parents in the process with the offer of a follow up appointment once the review is completed. (F.2-3)
- Improve communication (both verbal, written and electronic) throughout the care pathway. (C.1-2)

ACTION: Commissioners, Academic Health Science Networks, Clinical Directors, Heads of Midwifery, Maternity Safety Champions

New recommendations to reduce stillbirth and neonatal death in twin pregnancy

- The lead specialist obstetrician of the core team should provide each woman with a 16 week antenatal check to assess and explain the general and specific risks of her pregnancy. (A.2)

ACTION: Professional organisations, NICE, Clinical directors, heads of midwifery, health professionals

- Ensure prompt review by an obstetrician (experienced in the management of multiple pregnancies), for all women upon attendance at maternity triage units and upon admission in labour, and throughout labour. In particular:
 - Ensure that all clinical staff working within a maternity triage or emergency assessment area are able to recognise the warning signs of preterm labour and TTTS. (A.5-7)
 - Produce a clear plan for monitoring in labour, mode of birth and when referral is required, particularly in extremely preterm labour: senior review at least daily. (L.1, L.3)
 - Where necessary ensure prompt review by senior neonatologist. (L.1)

ACTION: Professional organisations, NICE, Clinical Directors, Heads of Midwifery, Maternity Safety Champions, health professionals

- Following spontaneous birth of Twin 1 at less than 24 weeks consider delaying the birth of the surviving second twin, if there are no contraindications such as infection, fetal compromise, bleeding or coagulopathy. (L.4, L.6)
- Counsel parents prior to the birth of Twin 1, regarding the possible option of delayed birth of Twin 2 including the maternal risks as well as the risk of Twin 2 being born at the extremes of prematurity. (L.5)

ACTION: Professional organisations, NICE, Clinical Directors, Heads of Midwifery, research funders



Contents

1. Enquiry development and overall findings.....	1
1.1 Key findings	1
1.2 Background.....	1
1.3 Topic choice.....	1
1.4 Context for the enquiry	2
1.5 Aims	2
1.6 The confidential enquiry process.....	3
1.7 Topic Expert Group – development of panel guidance documents	3
1.8 Development of enquiry-specific checklists.....	4
1.9 Panel members.....	5
1.10 Case review panel meetings	5
1.11 Eligible pregnancies.....	6
1.12 Representativeness of the sample	7
1.13 Overall findings	10
2. Antenatal care: general	14
2.1 Key findings	14
2.2 Background.....	14
2.3 Lack of provision of specialist antenatal care	15
2.4 Failure to recognise symptoms of TTTS in triage.....	17
2.5 Twin-to-twin transfusion syndrome commonest cause of pregnancy loss in MCDA pregnancies. 18	
2.6 Examples of good quality antenatal care.....	18
2.7 Conclusions	19
3. Antenatal care: scanning	21
3.1 Key findings	21
3.2 Background.....	21
3.3 Summary of findings	22
3.4 Determining chorionicity	22
3.5 Frequency and timing of scans in uncomplicated MCDA and DCDA twins	23
3.6 Inconsistent labelling of twins	23
3.7 Assessment and reporting of fetal growth	23
3.8 Identification and management of complex twin pregnancies.....	24
3.9 Conclusions	26
4. Labour and birth	28
4.1 Key findings	28
4.2 Background.....	28
4.3 Summary of findings	28

4.4	Lack of senior review on admission and preparation for birth	29
4.5	Limited MDT/joint review by obstetric and neonatal teams	30
4.6	Immediate augmentation/birth of second twin after vaginal birth of first twin at extremes of prematurity	31
4.7	Suboptimal use of antenatal steroids and MgSO ₄ prior to birth	32
4.8	Sub-optimal use of partograms	32
4.9	Discussions with parents regarding birth at extreme prematurity.....	33
4.10	Examples of good quality intrapartum care	34
4.11	Conclusions	34
5.	Resuscitation and neonatal care	37
5.1	Key findings	37
5.2	Background.....	37
5.3	Summary of findings	38
5.4	Place of birth.....	38
5.5	Resuscitation	39
5.6	Neonatal care following admission	40
5.7	Examples of good resuscitation and neonatal care.....	41
5.8	Conclusions	41
6.	Postnatal and bereavement care, follow-up and review	43
6.1	Key findings	43
6.2	Background.....	44
6.3	Summary of findings	44
6.4	The quality of postnatal and bereavement care	44
6.5	The quality of follow-up care.....	48
6.6	Clinical governance: evidence and quality of local reviews.....	49
6.7	Examples of good quality care	50
6.8	Conclusions	50
7.	Post-mortem examination and placental histology reporting	53
7.1	Key findings	53
7.2	Background.....	53
7.3	Quality of post-mortem reports	54
7.4	Quality of placental reports.....	54
7.5	Conclusions	57
8.	Communication, supervision and leadership issues	59
8.1	Key findings	59
8.2	Background.....	59
8.3	Summary of findings	60
8.4	Missing or poor quality documentation	61
8.5	Communication between health professionals.....	61

8.6	Communication with parents	62
8.7	Supervision and leadership	63
8.8	Conclusions	64
9.	Recommendations.....	67
	Appendices	70
	Acknowledgements.....	87

Figures

Figure 1:	Flow chart for cases selected for confidential enquiry	6
Figure 2:	Deaths per pregnancy by gestational age	38

Tables

Table 1:	Characteristics of eligible twin pregnancies for 2017 compared with those selected for enquiry....	7
Table 2:	Baby characteristics of all late fetal losses, stillbirths and neonatal deaths in eligible twin pregnancies for 2017 compared with those selected for enquiry	9
Table 3:	Characteristics of the mothers and pregnancies reviewed by the enquiry	10
Table 4:	Characteristics of the babies reviewed by the enquiry	10
Table 5:	Summary of grading of quality of care for each pregnancy	11
Table 6:	Poorest grading of quality of care by point on the care pathway affecting the outcome for the babies.....	12
Table 7:	Poorest grading of quality of care by point on the care pathway affecting the outcome for the mother	12
Table 8:	Submission of the placenta according to whether or not there was a livebirth, by gestation at birth	55
Table 9:	Issues identified with placenta examination: information not provided to the pathologist by the requesting clinician.....	55
Table 10:	Issues identified with placenta examination: information not provided to the requesting clinician by the pathologist.....	56

Vignettes

Vignette 1: The impact of lack of ownership or awareness of increasing risk.....	16
Vignette 2: Inappropriate emergency triage	18
Vignette 3: The benefits of co-ordinated multidisciplinary expert care.....	19
Vignette 4: Incorrect frequency of scans in a monochorionic pregnancy.....	23
Vignette 5: Inconsistent labelling of twins.....	23
Vignette 6: Delayed review by a fetal medicine specialist.....	25
Vignette 7: Delay in referral for intervention	25
Vignette 8: Lack of senior review on admission	29
Vignette 9: Lack of foresight and preparation for birth	30
Vignette 10: Immediate augmentation and birth of Twin 2 after the birth of Twin 1 at extreme prematurity	31
Vignette 11: Good quality intrapartum care.....	34
Vignette 12: Failure to facilitate face-to-face parental counselling for babies born at extreme prematurity	39
Vignette 13: Lack of discussion and joint decision-making around extremely preterm birth	40
Vignette 14: Inappropriate and prolonged neonatal care	40
Vignette 15: Neonatal counselling and review during the antenatal period	41
Vignette 16: Inadequate postnatal and bereavement care and substandard follow-up	45
Vignette 17: Failure to provide joined-up multidisciplinary postnatal and bereavement care in a high-risk pregnancy.....	45
Vignette 18: Ineffective and unsafe MDT communication in the postnatal period	46
Vignette 19: Missed opportunity for bereavement care planning in the antenatal period	47
Vignette 20: Lack of involvement of a tertiary unit in the local review.....	47
Vignette 21: Lack of follow-up appointment and joint obstetric/neonatal review.....	48
Vignette 22: Failure of local review to identify contributory factors to serious adverse incidents or to acknowledge and identify urgent need for improvement	49
Vignette 23: Failure to identify, acknowledge and act upon lack of specialist expertise and system failure	49
Vignette 24: Excellent MDT communication by a specialist twin clinic	50
Vignette 25: Continuity of care by a specialist twin team	50
Vignette 26: Excellent MDT communication.....	61
Vignette 27: Inadequate intrapartum documentation	61
Vignette 28: Poor communication between health professionals and social services	62
Vignette 29: Insensitive letter to parents	63
Vignette 30: Communication failures across the pathway	64

Definitions used in this report

Late fetal loss	A baby born between 22 ⁺⁰ and 23 ⁺⁶ weeks gestational age showing no signs of life, irrespective of when the death occurred.
Stillbirth	A baby born at or after 24 ⁺⁰ weeks gestational age showing no signs of life, irrespective of when the death occurred.
<i>Antepartum stillbirth</i>	A baby born at or after 24 ⁺⁰ weeks gestational age showing no signs of life and known to have died before the onset of care in labour.
<i>Intrapartum stillbirth</i>	A baby born at or after 24 ⁺⁰ weeks gestational age showing no signs of life and known to have been alive at the onset of care in labour.
Neonatal death	A liveborn baby (born at 20 ⁺⁰ weeks gestational age or later, or with a birthweight of 400g or more where an accurate estimate of gestation is not available) who died before 28 completed days after birth.
<i>Early neonatal death</i>	A liveborn baby (born at 20 ⁺⁰ weeks gestational age or later, or with a birthweight of 400g or more where an accurate estimate of gestation is not available) who died before 7 completed days after birth..
<i>Late neonatal death</i>	A liveborn baby (born at 20 ⁺⁰ weeks gestational age or later, or with a birthweight of 400g or more where an accurate estimate of gestation is not available) who died after 7 completed days but before 28 completed days after birth.
Perinatal death	A stillbirth or early neonatal death.
Extended perinatal death	A stillbirth or neonatal death.
Termination of pregnancy	The deliberate ending of a pregnancy, normally carried out before the embryo or fetus is capable of independent life.



1. Enquiry development and overall findings

Elizabeth S Draper, Ian D Gallimore

1.1 Key findings

- In just over half of pregnancies improvements in care were identified which may have made a difference to the outcome for the baby.
- In two-thirds of pregnancies improvements in care were identified which may have made a difference to the outcome for the woman.
- There was major sub-optimal antenatal care in half of pregnancies.
- There was major sub-optimal follow-up care for three-quarters of women.

1.2 Background

National confidential enquiries into perinatal deaths have been carried out in the UK for over twenty years to monitor quality of care provision and to address the consistently high rates of perinatal mortality compared to many of our European partners. The present programme of maternal and perinatal enquiries is run by the MBRRACE-UK collaboration as part of one of the four Clinical Outcome Review Programmes overseen by the Healthcare Quality Improvement Partnership (HQIP) on behalf of the NHS organisations and governments of the UK. The confidential enquiry methodology is used to investigate the quality of care provided to a selected group of women and babies where the baby died (or cases of perinatal morbidity), and in particular to:

- assess quality and safety of maternity and infant services
- support improvements in service quality through national learning
- produce evidence-based recommendations and good practice points
- influence clinical practice, service provision, health policy and clinical education

This report presents the findings of the fourth perinatal confidential enquiry carried out as part of the MBRRACE-UK programme of work and focuses on stillbirths and neonatal deaths in twin pregnancies. The enquiry aimed to assess the quality of care provision along the whole care pathway. The findings from the enquiry identify areas of care for improvement in the future.

1.3 Topic choice

There is a standard process in place for the selection of topics for the Clinical Outcome Review Programme. A call for topic proposals was circulated via email and the MBRRACE-UK website from September to December 2013 inviting any potential stakeholders including individuals, charities and professional organisations to suggest topics for our rolling programme of confidential enquiries. There was an excellent response to this call with twelve topic proposals submitted for consideration. Following their three-stage selection process the Maternal Newborn and Infant Clinical Outcome Review Programme Independent Advisory Group selected topics for both the previous enquiry into term intrapartum stillbirths and intrapartum-related neonatal deaths (2016/17) and for the current enquiry into stillbirths and neonatal deaths in twin pregnancies (2018/19).

1.4 Context for the enquiry

Multiple pregnancy is associated with an increased risk of maternal and perinatal morbidity and mortality [1]. Within the United Kingdom the challenge to deliver effective care to women with a multiple pregnancy led to the publication of recommendations by two Scientific Study Groups of the Royal College of Obstetricians and Gynaecologists (RCOG) [2, 3] and in 2011 the publication of national antenatal guidance from the National Institute for Health and Care Excellence (NICE) [4]. Subsequently, to emphasise the specific risks of monochorionicity the RCOG published a 'Green-top' guideline for the management of monochorionic twins in 2016 [5], updating guidelines published in 2008. Internationally, drawing upon available evidence and expert consensus, similar guidelines have been produced, including those from the International Society of Ultrasound in Obstetrics and Gynaecology (ISUOG) [6].

Monochorionicity increases gestational age specific mortality due to complications arising from the conjoined fetal circulations within the shared placenta [7]. In monochorionic twins this shared placenta can result in the complications of twin-to-twin transfusion syndrome (TTTS), severe selective fetal growth restriction (sFGR), twin anaemia polycythaemia sequence (TAPS), and acute cardiovascular compromise in monoamniotic fetuses. All these complications are associated with an increased risk of fetal demise [7, 8]. Single fetal demise in a monochorionic complement of fetuses can be associated with acute hypoperfusion and subsequent demise of the co-monochorionic fetus(es) or significant risk (at least 25%) of pathologic neurologic sequelae in co-monochorionic survivors [8].

RCOG, ISUOG and NICE guidelines [9] have all emphasised the need for regular fetal ultrasound surveillance in dichorionic (monthly from 20 weeks gestation) and monochorionic twins (every 2 weeks from 16 weeks) until birth (as well as holistic antenatal care provided by multidisciplinary teams). In addition, to minimise perinatal deaths, in uncomplicated dichorionic twin pregnancies birth should be considered at 37 weeks gestation and in monochorionic pregnancies birth should be considered at 36 weeks [10].

Over the last two decades there has been population-based evidence of reductions in perinatal mortality in multiple pregnancy [11]. The MBRRACE-UK perinatal surveillance report for UK perinatal deaths for births from January to December 2017 [12] showed that over the period 2013 to 2017, rates of both stillbirth and neonatal mortality for twins had reduced: from 9.03 to 6.99 per 1,000 total births for stillbirths and from 8.01 to 5.45 per 1,000 live births for neonatal deaths. Three important factors are likely to have had a significant influence on reducing perinatal loss: (i) invasive interventions for pre-morbid monochorionic complications; (ii) advancements in neonatal care; and (iii) improved antenatal care pathways. Several professional bodies and guidelines have made important contributions to the latter including the first NICE recommendations for antenatal care for twin and triplet pregnancies [4] and in 2013 the publication of eight quality standards for the clinical care for multiple pregnancies [13]. Nevertheless, and despite these reductions, the increased risk of mortality associated with twins compared to singletons is almost double for stillbirths (relative risk (RR) 1.93 in 2017) and over threefold for neonatal deaths (RR 3.53 in 2017).

1.5 Aims

The aims of this enquiry were to assess:

- adherence to clinical guidelines (Royal College of Obstetricians and Gynaecologists Green-top, Royal College of Anaesthetists, Royal College of Pathologists, National Institute for Health and Care Excellence and Sands) (see Appendix A4);
- the standard of care provision throughout the care pathway encompassing all relevant specialties (obstetrics, midwifery, neonatology, anaesthetics and pathology);
- the role, availability and multidisciplinary working of bereavement teams;
- the role of placental pathology review and post-mortem.

1.6 The confidential enquiry process

As detailed in previous MBRRACE-UK reports [14, 15], a confidential enquiry is a process of systematic, multidisciplinary, anonymous case review where a consensus opinion is reached about the quality of care provision for all cases undergoing review. In common with the previous enquiry anonymisation of the case notes was limited to identifiers for the family and babies only. Experience from previous enquiries highlighted the limitations of more extensive anonymisation, particularly of the place of care and health professionals, making it difficult for reviewers to obtain an accurate view of the contextual setting, resources and clinical expertise involved in each case.

The focus of the enquiry was on both good and poor quality care in order to both identify examples of good practice with examples of excellent working by all members of the multidisciplinary team across the care pathway and of care where improvements are required. The standard Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP) criteria adopted by all enquiries for the programme were used to summarise the assessment of the overall quality of care for each mother and babies reviewed:

Box 1: Overall grading of care

- 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.

A summary assessment was provided separately for the babies and the mother regarding the quality of care provision for each case, identifying whether factors could have affected the outcome for the babies and also those factors that could potentially affect the future health and wellbeing of the mother (see Appendix A4). In addition to the overall assessments, each aspect of care along each point of the care pathway was evaluated with respect to the quality of care provision as follows:

Box 2: Grading of care at each point of the care pathway

- 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.

In all enquiries reviewers are also asked specifically to flag immediately any cases which meet the HQIP "Cause for Concern" criteria (see Appendix A1).

1.7 Topic Expert Group – development of panel guidance documents

Each new confidential enquiry developed for the MBRRACE-UK perinatal programme convenes a Topic Expert Group (TEG) to inform the development of the enquiry and guide the process. Professional bodies were approached to ask for nominations of members with appropriate expertise and interest in multiple pregnancies

and the care provision for women and their babies. Interested health professionals and lay stakeholders were asked to submit a curriculum vitae and to outline any relevant experience as well as evidence of their interest in multiple pregnancies. Review of these documents was carried out to check their background and standing with their relevant professional organisation and a multidisciplinary group was then selected. All accepted members of the TEG were asked to sign a confidentiality agreement prior to attendance at the TEG confidential enquiry development meeting (see Appendix A2).

The membership of the TEG for this enquiry included: fetal medicine specialists and obstetricians; hospital, bereavement and multiple pregnancy specialist midwives; neonatologists; neonatal nurses; obstetric anaesthetists; perinatal pathologists; and lay representatives from Sands, the Twins Trust and The Multiple Births Foundation. The group identified the appropriate standards of care and guidance against which care should be assessed and modified the standard MBRRACE-UK assessment tool for the topic. A panel guidance document providing electronic links to the relevant guidance and standards was developed for panel members to consult during their preparation for panel meetings. This encompassed Royal College of Obstetricians and Gynaecologists (RCOG) Standards and Green-top guidelines, National Institute for Health and Care Excellence (NICE) Quality Standards and Guidelines as well as guidelines from the Royal College of Pathologists, the Human Tissue Authority, Resuscitation Council UK, Sands and the British Association of Perinatal Medicine service standards for neonatal care (see Appendix A4).

The points on the care pathway for evaluation at panel meetings were identified as follows:

- antenatal care;
- care during labour;
- care at birth;
- resuscitation;
- neonatal care;
- postnatal and bereavement care;
- follow-up visit and review of care;
- post-mortem / placental histology.

1.8 Development of enquiry-specific checklists

Following experience from previous MBRRACE-UK confidential enquiries [14, 15], checklists were developed with the support of 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. This additional information facilitated the writing of the report, providing contextual data. For this enquiry two versions of the main confidential enquiry checklist were produced: for monochorionic and dichorionic pregnancies (Appendix A6). Checklists for post-mortem (Appendix A7) and placental histology (Appendix A8) were also developed. These checklists were used to support discussion at panel meetings and to facilitate discussions around emerging themes.

Whilst there have been recent initiatives and updates to national guidance around care for multiple pregnancies, care was reviewed against the standards in place during the time period covered by the enquiry. The structure and content of each checklist was therefore based on the aspects of care for which guidance and standards were available at the time of care in 2017. They were developed to collect information about the aspects of care which should routinely be recorded in the medical case notes. All notes were requested for each case and, following detailed checks, any missing notes were chased to ensure all available information was included in the enquiry. Where there was no written information about an aspect of care, it was reported as *not recorded in the case notes*. As in legal cases, we followed the principle that if there was nothing written in the notes then, in effect, it did not occur.

1.9 Panel members

In order to ensure comprehensive review of all cases, panel members were selected from the multidisciplinary team providing the care for the women and their babies across all points of the care pathway. Panel members therefore included: tertiary and district general hospital obstetricians, including fetal medicine specialists; hospital, community and bereavement midwives; neonatal nurses, neonatologists; and perinatal pathologists. The selection of this group was carried out alongside the selection of TEG members.

All selected panel members were provided with the documentation for the enquiry panels including a summary outcome form, a reference checklist, a list of and electronic links to the standards and guidance being used to assess the quality of care, and a document providing the background to the enquiry (see Appendix A1). Selected members who had not previously participated in an MBRRACE-UK perinatal confidential enquiry had one-to-one telephone training with an MBRRACE-UK team member to provide information about confidentiality issues, how to register and use the web-based notes review system and an overview of the confidential enquiry process.

1.10 Case review panel meetings

Between December 2018 and November 2019, 11 panel meetings were held in a central location to allow for attendance by panel members from all four countries of the UK. Due to the excessive length of some case notes, four or five cases were discussed at each panel meeting; therefore, a total of 50 pregnancies and 80 baby deaths were discussed, at which point saturation of the themes emerging from the enquiry had been achieved.

Three weeks prior to each panel meeting the anonymised notes for each case were uploaded and made available for review via the secure MBRRACE-UK web-based notes viewing system. Panel members were sent an email to alert them that the cases were ready for review, allowing them to access the specific case notes they had been allocated for their panel meeting. Although a lead presenter was identified for each case at each panel, panel members were asked to review all cases ahead of the meeting so that they were prepared for an informed consensus discussion.

Panel meetings were chaired by one of three neutral chairs: Professor Elizabeth Draper, Professor Sara Kenyon or Professor Jenny Kurinczuk. To ensure standardisation of the process all three chairs attended the first meeting and shared the chairing of the case reviews. The remaining panel meetings were split between the chairs. Each panel comprised three obstetricians (including at least one fetal medicine specialist), two neonatologists, two midwives and a perinatal pathologist, along with the Chair and a panel facilitator. Each case was discussed in turn, commencing with an overview by a panel member who had been appointed as lead for the case in advance. This was followed by a general discussion of all stages of care leading to a consensus opinion on the quality of care provision for the case, with any aspects of poor care or particularly good care identified being recorded and any particular themes noted. A summary form (Appendix A5) was then completed by the Chair, recording the consensus opinion reached by the panel. All documentation prepared for panel meetings by all members was collected to ensure that all relevant issues had been recorded and to maintain confidentiality. In addition, contextual data for each case was collected via a checklist which was completed by the MBRRACE-UK clinical advisor prior to the meeting and checked for accuracy with panel members at each panel meeting.

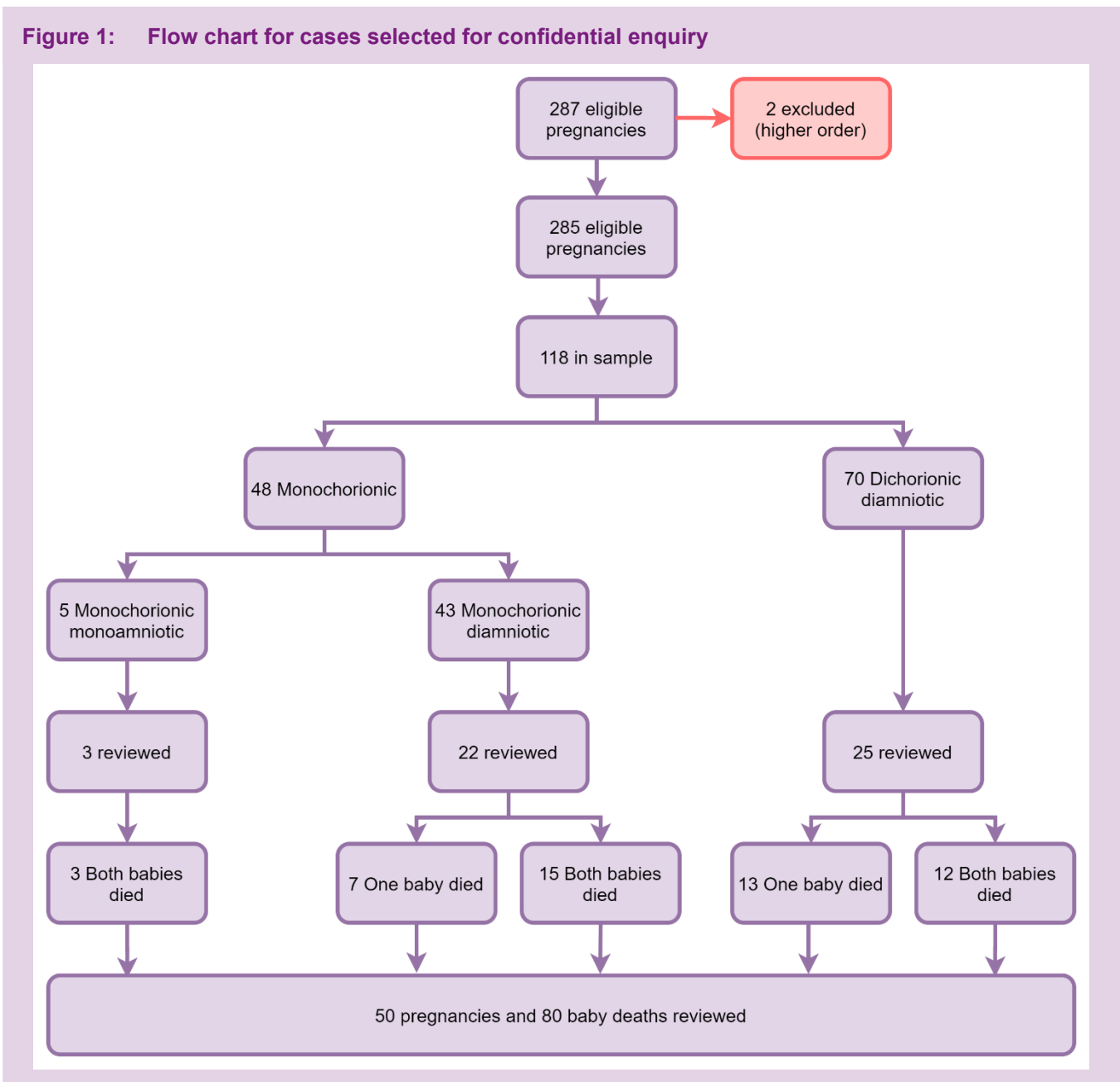
In order to ensure there were no conflicts of interest, panel members were selected to review cases where they had no personal involvement. However, in situations where there had been a change in circumstances (e.g. staff changes) panel members were asked to notify the Chair so they could be excluded from the discussions. Panel members were instructed to follow strict confidentiality guidelines for all cases and each signed an appropriate confidentiality agreement.

1.11 Eligible pregnancies

Pregnancies eligible for inclusion in this enquiry were defined as twin pregnancies (two fetuses identified at the dating scan) involving one or more late fetal losses, stillbirths or neonatal deaths, where the gestational age at birth was 22⁺⁰ weeks or more, and the babies were born in 2017. Pregnancies which involved terminations of pregnancy (including fetal reduction) were excluded.

As in previous enquiries, the MBRRACE-UK perinatal mortality surveillance data provided the sampling frame for the selection of a random sample of twin pregnancies involving at least one late fetal loss, stillbirth or neonatal death, stratified by UK country. The sample was also stratified by chorionicity to ensure that a sufficient number of each type of twin pregnancy was reviewed to enable the saturation of emerging themes to be achieved. Following validity checks, during which two higher order pregnancies were excluded, a final sample of 118 out of a potential 285 pregnancies fulfilling the inclusion criteria was selected in October 2018. Cases were then submitted for review by confidential enquiry until saturation of themes was achieved and no new lessons for future care were emerging: in total 50 pregnancies and 80 baby deaths were reviewed. A flow chart describing the selection process is provided in Figure 1.

Figure 1: Flow chart for cases selected for confidential enquiry



A request for copies of all relevant notes for each case was sent to the local Trust or Health Board teams with a detailed list of all the sections of notes required for the enquiry. Trusts and Health Boards were asked to provide details concerning any sections of the notes that were unavailable and any helpful information about who might be able to locate them. Copies of the notes were supplied to the MBRRACE-UK office in Leicester. Northern Ireland has different data protection arrangements from the rest of the UK and there is no mechanism to export identifiable data out of Northern Ireland without consent. As a consequence, the Northern Ireland Maternal and Child Health office within the Health and Social Care Public Health Agency were responsible for redacting the records of identified cases and seeking individual parental consent.

After checking that cases fulfilled the relevant criteria for the confidential enquiry and that the office had received all available notes the MBRRACE-UK clinical advisor prepared the notes for the enquiry panels, organising the notes into a logical order, carrying out further checks for completeness, removing any irrelevant documentation, writing a detailed synopsis of each case as a starting point for the lead presenter at the panel meetings, and completing the main checklist for each case in order to provide additional contextual data.

1.12 Representativeness of the sample

The representativeness of the random sample of twin pregnancies (50 mothers and 80 babies) selected from the MBRRACE-UK perinatal mortality surveillance for 2017 was compared to the remaining eligible twin pregnancies (235 mothers and 312 babies) affected by one or more late fetal loss, stillbirth or neonatal death with respect to their socio-demographic, behavioural and care characteristics (Tables 1 and 2). Using a random sample allows for the generation of results that are representative of all relevant twin pregnancies thus allowing for both the quantitative analysis of the data and a qualitative investigation of how care was provided to women and their families.

The only statistically significant difference between the selected and non-selected pregnancies in any of the characteristics presented in Tables 1 and 2 was for mode of birth. We therefore concluded that the results from this enquiry are representative of all late fetal losses, stillbirths and neonatal deaths in twin pregnancies in the UK in 2017.

Table 1: Characteristics of eligible twin pregnancies for 2017 compared with those selected for enquiry

Characteristic	Not selected (n=235)		Selected (n=50)		p-value*
	n	%	n	%	
Maternal age (years)					
<20	4	1.7	3	6.0	0.08
20-24	30	12.8	5	10.0	
25-29	64	27.2	11	22.0	
30-34	69	29.4	20	40.0	
35-39	50	21.3	11	22.0	
40+	18	7.7	0	0.0	
Missing	0	0.0	0	0.0	
Babies' ethnicity					
White	173	73.6	43	86.0	0.57
Mixed	12	5.1	1	2.0	
Asian	26	11.1	4	8.0	
Black	18	7.7	2	4.0	
Other	6	2.6	0	0.0	
Not known	0	0.0	0	0.0	

Characteristic	Not selected (n=235)		Selected (n=50)		p-value*
	n	%	n	%	
Deprivation quintile					
Least deprived	46	19.7	13	26.0	0.35
2	41	17.5	12	24.0	
3	41	17.5	4	8.0	
4	56	23.9	12	24.0	
Most deprived	50	21.4	9	18.0	
Missing	1	0.0	0	0.0	
Country of residence					
England	212	90.2	40	80.0	0.17
Northern Ireland	4	1.7	2	4.0	
Scotland	8	3.4	4	8.0	
Wales	10	4.3	4	8.0	
Other	1	0.0	0	0.0	
Maternal body mass index (BMI)					
<18.5	7	3.4	0	0.0	0.35
18.5-29.9	136	65.1	33	75.0	
30+	66	31.6	11	25.0	
Missing	26	0.1	6	0.1	
Smoking status					
Never smoked/Gave up before pregnancy	188	82.1	44	89.8	0.21
Gave up during pregnancy/smoker	41	17.9	5	10.2	
Not known	6	0.0	1	0.0	
Employment status					
Employed or self-employed	146	66.7	33	76.7	0.18
Unemployed (looking for work)	22	10.4	6	14.0	
Student	2	0.9	0	0.0	
Looking after home/family/other	49	22.4	4	9.3	
Not known	16	0.0	7	0.0	
Support during pregnancy					
Partner, cohabiting	173	78.3	38	79.2	0.28
Partner, not cohabiting	4	1.8	1	2.1	
Family/friend	44	19.9	8	16.7	
None	0	0.0	1	2.1	
Not known	14	0.0	2	0.0	
Gestation at booking					
Before 10 ⁺⁰ weeks	94	44.1	18	40.0	0.74
At or after 10 ⁺⁰ weeks	119	55.9	27	60.0	
Not known	22	0.1	5	0.1	

* p-value for Fisher's Exact test: selected versus non-selected with known characteristic
Date source: MBRRACE-UK

Table 2: Baby characteristics of all late fetal losses, stillbirths and neonatal deaths in eligible twin pregnancies for 2017 compared with those selected for enquiry

Characteristic	Not selected (n=312) [†]		Selected (n=79) [†]		p-value*
	n	%	n	%	
Gestation at birth (completed weeks)					
22-23	116	37.2	32	40.5	0.39
24-27	84	26.9	27	34.2	
28-31	46	14.7	6	7.6	
32-36	53	17.0	11	13.9	
37-41	13	4.2	3	3.8	
42+	0	0.0	0.0	0.0	
Sex					
Male	162	51.9	37	46.8	0.45
Female	150	48.1	42	53.2	
Not known	0	0.0	0	0.0	
Mode of birth					
Spontaneous vaginal	179	57.4	53	67.9	0.01
Assisted	19	6.1	8	10.3	
Pre-labour caesarean section	80	25.6	16	20.5	
Caesarean section after onset of labour	34	10.9	1	1.3	
Not known	0	0.0	1	0.0	
Type of care at birth					
Obstetric unit	308	98.7	79	100	1.00
Midwifery-led unit	1	0.3	0	0.0	
Home/born before arrival/unknown	3	1.0	0	0.0	
Outcome					
Late fetal loss	60	19.2	17	21.5	0.65
Stillbirth	112	35.9	31	39.2	
Neonatal death	140	44.9	31	39.2	
Post-mortem					
Full	68	22.6	21	26.9	0.23
Limited	17	5.6	1	1.3	
None	216	71.8	56	71.8	
Not known	11	0.0	1	0.0	
Placental histology					
Yes	250	92.3	63	86.3	0.16
No	21	7.7	10	13.7	
Not known	41	0.1	6	0.0	

[†] Babies who survived the neonatal period are excluded as data on these deaths is not collected by MBRRACE-UK. One baby in the selected group died after more than 28 days.
* p-value for Fisher's Exact test: selected versus non-selected with known characteristic
Date source: MBRRACE-UK

1.13 Overall findings

The characteristics of the mothers and their pregnancies and babies reviewed by the enquiry are shown in Tables 3 and 4.

Table 3: Characteristics of the mothers and pregnancies reviewed by the enquiry

Pregnancy/maternal characteristic	Chorionicity			
	Monochorionic (n=25)		Dichorionic (n=25)	
	n	%	n	%
Chorionicity diagnosed by 13⁺⁶	24	96	22	88
Amnionicity diagnosed by 13⁺⁶	21	84	22	88
Amnionicity				
Monoamniotic	3	12	0	0
Diamniotic	22	88	25	100
One or both babies died				
One	7	28	13	52
Both	18	72	12	48
Pregnancy affected by congenital anomaly	2	8	5	20
Mode of conception				
Spontaneous	25	100	17	68
Any Infertility treatment	0	0	8	32
Mother's ethnicity				
White	21	84	23	92
Asian/Asian British	3	12	1	4
Black/Black British	1	4	1	4

Table 4: Characteristics of the babies reviewed by the enquiry

Baby characteristic	Chorionicity			
	Monochorionic (n=50)		Dichorionic (n=50)	
	n	%	n	%
Sex				
Female	27	54	27	54
Male	20	40	20	40
Indeterminate	3	6	3	6
Gestation at birth				
22 ⁺⁰ to 23 ⁺⁶	14	28	20	40
24 ⁺⁰ to 27 ⁺⁶	16	32	16	32
28 ⁺⁰ to 31 ⁺⁶	8	16	0	0
32 ⁺⁰ to 36 ⁺⁶	10	20	10	20
37 ⁺⁰ to 41 ⁺⁶	2	4	4	8
Outcome				
Late fetal loss	9	18	8	16
Stillbirth	21	42	10	20
Neonatal death	13	26	18	36

Baby characteristic	Chorionicity			
	Monochorionic (n=50)		Dichorionic (n=50)	
	n	%	n	%
Post-neonatal death	0	0	1	2
Surviving twin	7	14	13	26
Post-mortem (excluding surviving twins)	13	30	8	20
Placental histology	35	70	28	56

A summary of the consensus findings of the panel reviews is provided in Table 5, indicating the quality of care provision for the outcome of both the babies and the mother across all aspects of the care pathway.

Table 5: Summary of grading of quality of care for each pregnancy

Overall quality of care	Babies		Mother	
	n	%	n	%
Good care; no improvements identified	8	16	6	12
Improvements in care identified which would have made no difference to outcome*	15	30	12	24
Improvements in care identified which may have made a difference to outcome*	27	54	32	64
TOTAL	50	100	50	100

* From the point of view of the babies the panels broadly interpreted 'outcome' to represent whether the care provision may have contributed to the death(s). From the mother's perspective 'outcome' was interpreted as her physical and psychological wellbeing and full consideration of her future fertility.

Overall, in terms of the outcome for the baby, the panel consensus was that in just over half (54%) of cases improvements in care were identified which may have made a difference to the outcome for the baby. In terms of the mother's physical and psychological outcome and/or future fertility, the consensus of the panels was that improvements in care may have made a difference in almost two thirds (64%) of cases. Our previous confidential enquiries have shown that reducing such complex cases to a single number (or two in this case) is limited and does not provide a complete picture of the entire pathway of care provision. The basis of the allocation of the grade of quality of care may be based on one aspect alone so an improvement in care might be identified for a case which had excellent care throughout the whole of the care pathway except for one element. Alternatively, a case may have had poor care throughout the care pathway affecting both the ultimate outcome for the baby and the future health and wellbeing of the mother. In contrast, a case may have had several aspects of care quality that did not affect the ultimate outcome for the baby but which may well have resulted in care that may have made a difference in terms of the mother's experience and future health and fertility.

Tables 6 and 7 provide information about the poorest grading of quality of care affecting the outcome for the baby and mother at each relevant point along the care pathway. Where significant or major issues were identified, these were relevant to the outcome in almost three quarters (71%) of instances.

Table 6: Poorest grading of quality of care by point on the care pathway affecting the outcome for the babies

Quality of care issues	Point on the care pathway							
	Antenatal		Labour & birth		Resuscitation		Neonatal care	
	n	%	n	%	n	%	n	%
None	12	24	14	28	12	48	7	29
Minor	3	6	2	4	2	8	1	4
Significant	11	22	15	30	6	24	8	33
Major	24	48	19	38	5	20	8	33
TOTAL	50	100	50	100	25*	100	24*	100

*Denominator reflects applicable pregnancies at this point in the care pathway

Table 7: Poorest grading of quality of care by point on the care pathway affecting the outcome for the mother

Quality of care issues	Point on the care pathway					
	Postnatal & bereavement		Pathology		Follow-up & review	
	n	%	n	%	n	%
None	26	52	17	47	6	12
Minor	1	2	2	6	3	6
Significant	10	20	7	19	4	8
Major	13	26	10	28	37	74
TOTAL	50	100	36*	100	50	100

*Denominator reflects those pregnancies where an element of pathological examination was carried out.

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2. Antenatal care: general

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2.1 Key findings

- For two fifths of women (20 of 50) care was not provided by a specialised multidisciplinary team as recommended by national guidance. For only 5 of the 50 women was care documented as including a specialist midwife and specialist sonographer involvement.
- Discussions concerning the risks of twin pregnancy before 24 weeks were documented for only half the women.
- Extreme preterm labour was the most frequent cause of perinatal loss in dichorionic twin pregnancies. In a significant proportion of these pregnancies preterm birth occurred before any specialist obstetrician input into the care. Furthermore, following admission with suspected or established preterm labour there was lack of prompt consultant obstetrician input into the care plan.
- Prophylactic aspirin is recommended for women with multiple pregnancy identified on risk assessment to be at increased risk of preeclampsia, but this was only documented as being prescribed for just under half (18/40) of those eligible.
- Emergency assessment in maternity triage was particularly problematic in twin-to-twin transfusion syndrome which went unrecognised in women presenting with maternal concerns of classical 'red-flag' signs and symptoms.
- There were examples of good antenatal care in several complex pregnancies, including extensive multidisciplinary counselling of parents and preparation for birth in pregnancies complicated by discordant twin prognosis.

2.2 Background

This chapter presents the findings of the reviews of the quality of overall antenatal care provided to women with a twin pregnancy experiencing late fetal loss (LFL), stillbirth (SB) or neonatal death (NND). The quality of ultrasound assessments which is pivotal for prenatal care in twins is reviewed separately in detail and commented upon in Chapter 3.

The enquiry panels compared the antenatal care provided to these women with relevant published national and international guidelines and standards available in 2017 [1-4]. This professional, clinical guidance recommends that multiple pregnancy should be managed by a specialist antenatal core team comprising a named lead consultant obstetrician, specialist midwives and sonographers (each with specialised knowledge and expertise in managing multiple pregnancy). The clinical care pathways offered to women should be influenced and determined by ultrasound-identified chorionicity before 13⁺⁶ weeks gestational age. Inclusion of women (and their partners) in the management of their holistic pregnancy care should be facilitated by explanation of the differences between singleton and multiple pregnancies and the potential risks associated with multiple pregnancy, especially preterm birth (complicating around 55% of twin pregnancies) and the signs and symptoms or preterm labour [2]. Women with monochorionic twin pregnancies should have an evidence-based discussion about the increased risks that can arise from the shared placenta, specifically twin-to-twin transfusion syndrome (TTTS), and should be advised to seek immediate review if they develop the symptoms of acute abdominal distension or dyspnoea which may be associated with the development of acute TTTS [1]. In addition, twin pregnancy is a predisposing factor for the development of pre-eclampsia, and this should be actively considered within a discussion and risk assessment at the twin pregnancy booking visit to determine if pharmaco-

prophylaxis with low dose aspirin is appropriate [4]. All women (and their partners) with a twin pregnancy should be actively involved in the planning of birth of their babies in timing and mode [2].

The confidential enquiry involved review by MBRRACE-UK assessment panels of written and electronic medical notes. The use of prospectively-recorded electronic medical records was still emerging in obstetric and midwifery practice in 2017. The use of this type of record was (and indeed remains) in its infancy and data extraction from these records can be complex and difficult. It was recognised by the panel of expert reviewers that incomplete recording of discussions, interventions and prescriptions was likely in these electronic records, with a tendency to use shorthand. However, as the aim of the panel review was to assess the documented care against applicable standards, if no documentation could be found relevant to an aspect of care, it was deemed not to have been successfully provided.

Antenatal care was provided for 10 women within district general hospitals, for 21 women within tertiary care centres and for 19 women was shared or transferred between both types of clinical settings. Expert review of antenatal care provided to women experiencing loss focused on 25 dichorionic twin pregnancies, 22 monochorionic diamniotic (MCDA) twin pregnancies and 3 monochorionic monoamniotic (MCMA) twin pregnancies.

2.3 Lack of provision of specialist antenatal care

Lack of involvement of specialised multidisciplinary team

There was evidence that the care provided to a significant proportion of the twin pregnancies was not provided by a core team of specialists within a dedicated antenatal clinic. In the vast majority of pregnancy records there was evidence of care by a consultant obstetrician, but not as a lead specialist within a dedicated clinical team. In the majority of pregnancies (90%) there was no recorded evidence of a named specialist midwife being involved in the care nor that ultrasound assessments were performed by a named specialist sonographer.

For over half of the women there was no documented evidence that the risks of preterm birth or symptoms of preterm labour were discussed with them. There was no evidence in three quarters of the monochorionic pregnancies that the risks of monochorionicity, including the complication of twin-to-twin transfusion syndrome, were discussed before 16 weeks gestational age. The lack of a specialist core team appeared to contribute to a lack of active recognition and the management of risks specific to individual pregnancies. This almost certainly contributed to pregnancy loss in several cases.

Lack of timely specialist counselling as to the risk of preterm birth

Perinatal loss in this cohort of pregnancies highlighted the risk of extreme preterm labour in twin pregnancies. Of the 25 dichorionic diamniotic twin pregnancies reviewed, 14 resulted in perinatal loss as a consequence of spontaneous preterm labour and all of these births occurred between 22⁺¹ and 24⁺² weeks gestational age, resulting in the loss of 23 babies. One death was classified as a late fetal loss and the remainder as neonatal deaths.

The 2011 NICE guideline 'Multiple pregnancy: twin and triplet pregnancies' [2] recommends that women with dichorionic diamniotic twin pregnancies should be offered at least eight antenatal visits with their specialist multiple pregnancy antenatal core team and recommends that the lead specialist obstetrician should review the women on at least two occasions. It would seem logical that the 16 week visit is the optimal time for the lead clinician to first meet, explain and plan antenatal care with a woman so that risks of spontaneous preterm labour and possible care pathways and interventions can be comprehensively and prospectively explained. However, the timing of the first lead clinician review of the pregnancy was not specified in 2011 NICE guidance [2] nor indeed in the updated 2019 guidance [5]. Lack of lead obstetric specialist input into pregnancies and discussions of preterm birth in those giving birth between 22-24 weeks cannot therefore be designated substandard care, but it is, as highlighted by several of the pregnancy losses due to prematurity included in this enquiry, deficient care.

Although there are at present no proven interventions to attenuate the risk of preterm birth, equipping women with knowledge of its risk, signs and symptoms can enable her to present promptly for care if she suspects this complication of her pregnancy. This may optimise time for multidisciplinary obstetric and neonatal assessment, counselling and for interventions such as the administration of antenatal steroids and magnesium sulphate, thereby reducing the risk of perinatal mortality and morbidity. Four women gave birth between 24⁺⁰ and 24⁺² weeks gestational age, of which only two women received antenatal steroids and magnesium sulphate to optimise fetal condition at birth. The other two women gave birth shortly after presentation.

Lack of risk assessment for pre-eclampsia and initiation of prophylactic therapy.

Secondary to spontaneous preterm birth, iatrogenic preterm birth is recognised as a major cause of neonatal loss and morbidity in twin pregnancy. Effective screening for risk factors of pre-eclampsia and targeted prophylactic therapy in the form of low dose aspirin (LDA) is the most effective intervention to avoid such iatrogenic harm. The enquiry panel assessed that 40 of the 50 twin pregnancies should have been prescribed LDA based on contemporary risk assessment advice [4]. There was evidence that only 18 of these 40 pregnancies received LDA. One pregnancy not receiving LDA was complicated by severe pre-eclampsia, preterm emergency birth and neonatal death.

Lack of a core specialist team: negative impact on the wider maternity service

In several twin pregnancies it was evident that there was an unrecognised accumulation of risk factors for adverse pregnancy outcome, with several of these risk factors occurring out-with scheduled antenatal care. The lack of a core specialist team, to whom new complications arising in twin pregnancy can be easily, quickly and expectantly escalated, appeared to result in delayed or deficient overall risk assessment by the attending clinical team and therefore failure to recognise the need for urgent intervention.

Vignette 1: The impact of lack of ownership or awareness of increasing risk.

A woman was diagnosed with MCDA twins at 10 weeks gestational age. She had optimally documented and timed antenatal care and ultrasound scans, but this was performed through a non-specialist antenatal clinic. Growth discrepancy of the babies was diagnosed at 30 weeks gestational age and monitoring was escalated to provide CTG assessments rather than enhanced ultrasound assessments. Increased growth discordance of the babies, with selective growth restriction, was evident by 32 weeks gestational age. There was evidence of discussion and the possible transfer of the woman to a tertiary centre to expedite birth, but no review of timing of birth was considered. Two days later the woman was admitted due to suspected infection and received care with a sepsis pathway. Birth by caesarean section was delayed by 5 days to await local neonatal cot availability with no evidence of consideration of transfer to a tertiary centre. No antenatal steroids were prescribed or administered. On auscultation both fetal heart rates appeared present before caesarean section. At birth, one baby was born without a heart rate (signs of life) and the other was, after attempted resuscitation, a confirmed neonatal death in theatre.

Recommendations

- A1. Ensure antenatal care for all women pregnant with twins is provided by a core, multidisciplinary team of specialists within a dedicated multiple pregnancy clinic.
- A2. The lead specialist obstetrician of the core team should provide each woman with a 16 week antenatal check to assess and explain the general and specific risks of her pregnancy.
- A3. The a priori risks and potential symptoms and signs of preterm labour, and the 'red flag' warning signs of TTTS if her pregnancy is monochorionic, should be explained to the woman at the 16 week antenatal visit, with advice to immediately self-refer for assessment if she experiences any of these symptoms.

Recommendations (continued)

- A4. Twin pregnancy is a risk factor for pre-eclampsia. The presence of other risk factors should therefore be carefully identified and documented to ensure prophylactic treatment is offered where indicated.

2.4 Failure to recognise symptoms of TTTS in triage

The most concerning finding in the assessment of care provided to women with monochorionic twins experiencing pregnancy loss was a lack of recognition within emergency triage areas as to 'red flag' warning symptoms of TTTS (Box 3). Four women self-referred to their hospital for emergency advice as they were experiencing "abdominal distension and pain". This was associated with reduced fetal movements in one case and acute maternal dyspnoea in another. The women were all between 21⁺⁰ and 24⁺⁶ weeks pregnant. None of these women with monochorionic twin pregnancies had an ultrasound scan arranged either within triage or within 24 hours of presentation. Loss of all fetuses was diagnosed at the next scheduled ultrasound assessment or following readmission with acute amniorrhexis or active labour.

In addition, two further women presented with reduced fetal movements; one at 21 weeks gestational age and one at 27 weeks gestational age in whom routine fortnightly surveillance scans for TTTS had not been performed as recommended by national guidelines. These women were also not investigated for TTTS or fetal wellbeing by during their acute presentations at obstetric triage/delivery suite. Ultrasound assessments were not performed until at least six days after presentation, by which time three of the four fetuses had died.

For these six women, undiagnosed TTTS was assessed by the enquiry panel members to have been the most likely premorbid pathology. The outcome of these pregnancies may have been altered by timely recognition of TTTS and the offer of fetoscopic laser ablation therapy.

Box 3: 'Red flags' for twin-to-twin transfusion syndrome include one or more of the following:

Symptoms reported by the mother:

- Sudden abdominal distension
- Abdominal pain
- Sudden breathlessness
- Inability to lie on her back
- Reduced fetal movements

Clinical signs

- Rapidly increased abdominal girth
- Inability to feel fetal parts on abdominal palpation
- Ultrasound changes based on Quintero criteria.

Vignette 2: Inappropriate emergency triage

A woman was diagnosed with a MCDA twin pregnancy at 12 weeks gestational age. She was appropriately counselled as to the risks of complications of monochorionicity (including TTTS) and had appropriately-timed ultrasound assessments to screen for this potential complication. All scans were carried out by a midwife sonographer. At 22⁺² weeks gestational age she self-referred to her maternity assessment unit with a three day history of reduced fetal movements and increasing abdominal distention. She was reassured there was no complication following an antenatal clinical examination (but no ultrasound scan) and discharged home. Three days later she re-presented following two interim telephone calls reporting reduced fetal movements and that she felt her abdomen was rapidly increasing in size. Again, she was assessed clinically by a specialist obstetrician in training and a senior midwife, reassured, then discharged home. No ultrasound assessment of liquor volumes was performed nor arranged for the next working day. At 23⁺⁰ weeks gestational age she presented with ruptured membranes and both babies had died in utero.

Recommendations

- A5. Prompt review by an obstetrician (experienced in the management of multiple pregnancies) for all women with a multiple pregnancy attending maternity triage units with unscheduled pregnancy-related concerns is essential.
- A6. Ensure that all clinical staff working within a maternity triage or emergency assessment area are equipped with knowledge of the pathophysiology and warning signs of extreme preterm birth and of twin-to-twin transfusion syndrome.
- A7. Consider reduced fetal movements in a twin pregnancy as a 'red-flag warning sign' of TTTS, in addition to rapid maternal abdominal distension, abdominal pain, and acute dyspnoea.

2.5 Twin-to-twin transfusion syndrome commonest cause of pregnancy loss in MCDA pregnancies

In 22 MCDA pregnancy losses reviewed, 12 were secondary to TTTS, including the 6 cases with associated undiagnosed pathology. Three of the 12 pregnancies received good antenatal care, timely diagnosis, and referral to a tertiary centre for the performance of fetoscopic laser therapy. Despite optimal care these pregnancies resulted in one late fetal death, 2 stillbirths and 2 neonatal deaths. One other mother also had a timely diagnosis, but the parents declined intervention and the pregnancy resulted in stillbirths at 24 weeks gestational age. Despite this poor outcome there was evidence of excellent supportive care for these parents throughout the antenatal course. Two women had sub-optimal ultrasound surveillance and lack of timely referral on diagnosis to a tertiary centre; one of these was complicated by TTTS diagnosis immediately preceding a public holiday.

2.6 Examples of good quality antenatal care

Several women with complex twin pregnancies had evidence of intensive and supportive antenatal care. Although these pregnancies resulted in the loss of one or both babies the optimal care given to the woman (and her family) was judged highly valuable in providing emotional and physical support through these difficult pregnancies. Two MCMA pregnancies resulted in fetal death between 21⁺⁶ and 24⁺⁵ weeks gestational age, despite optimal antenatal care.

The fetal and neonatal deaths that occurred with the following pregnancies were inevitable and anticipated. Two pregnancies with complications of monochorionicity resulted in fetal death as the offer of intervention (with or without resultant loss) was declined by the parents. The care they received sensitively respected their concerns, with ongoing intensive monitoring and parental support. Four DCDA and one MCDA pregnancies were complicated by discordant lethal fetal malformations. The parents were provided with ongoing intensive and comprehensive antenatal care, and received bereavement support prior to and following the stillbirth of the affected baby, delivery of which was timed in the interests of the surviving twin.

Vignette 3: The benefits of co-ordinated multidisciplinary expert care

A woman was diagnosed with MCDA twins at 13 weeks gestation. A preliminary diagnosis of a lethal anomaly in one of the twins was later confirmed by 20 weeks. She was sensitively counselled by a consultant obstetrician who provided excellent continuity throughout the rest of the pregnancy. There were additional supportive sessions that involved the wider MDT, including consultant neonatologist and bereavement midwife, who ensured that the parents' wishes were clearly documented in anticipation of the birth of their babies. She self-referred to the maternity unit at nearly 34 weeks with a SROM and vaginal bleeding. Her babies arrived by emergency caesarean section in the hour following admission and as expected one of the twins died shortly after birth. The surviving twin progressed well and the parents were able to view their baby's improvement via a camera in the neonatal unit whilst the mother remained on the delivery suite. In line with parental wishes, which had been identified during the antenatal counselling sessions, both babies spent time together following birth. Both mother and the surviving twin were discharged home.

2.7 Conclusions

The antenatal care provided to women pregnant with twins complicated by one or both of the babies dying was reviewed against contemporary national guidelines and standards. Sub-optimal prenatal care was provided to approximately half of the pregnancies reviewed. In just over two-fifths of pregnancies (44%) the overall quality of antenatal care was graded as 2 or 3 (significantly or majorly sub-optimal). In all the cases this was assessed to be probably or almost certainly relevant to the physical and/or emotional adverse outcome of the pregnancy. The primary contributory factor was a lack of evidence that the care of many women with a twin pregnancy was delivered by a dedicated named core team of specialists. The updated NICE guidance for twin and triplet pregnancy [5] continues to advocate the importance of this dedicated team of specialists. A number of initiatives suggest beneficial outcomes with this model [6].

In the cohort of women with twin pregnancies experiencing loss in 2017 there was evidence that the lack of a dedicated core team of specialists in a significant number of maternity hospitals was associated with sub-optimal screening for the specific risks associated with twin pregnancy, untimely management of complications, and may have contributed to the wider hospital clinical team lacking sufficient knowledge as to the risks of twin pregnancies.

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3. Antenatal care: scanning

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In this chapter the focus is on the antenatal ultrasound (US) scan pathways for twin pregnancies, from initial diagnosis and determination of chorionicity to ongoing growth and fetal assessment, including referral to fetal medicine specialists.

3.1 Key findings

- Chorionicity was determined in 98% of women whose twin pregnancy was diagnosed before 13⁺⁶ weeks gestational age.
- Frequency of ultrasound (US) scanning failed to follow guidance for monochorionic pregnancies, with 1 in 5 women not having two-weekly scans from 16 weeks gestational age onwards.
- There was inconsistent labelling of twins on the scan reports of 1 in 6 of the women reviewed, resulting in inaccurate monitoring of each twin.
- Ultrasound monitoring of fetal growth failed to comply with NICE guidance, with almost half of the women lacking a completed ultrasound growth chart.
- There was no evidence of the percentage difference in the estimated fetal weights being calculated for almost two-thirds of women with a twin pregnancy.
- In a quarter of women where a discordance in estimated fetal weights of greater than 25% was identified, there was a failure to follow guidance and provide either increased surveillance or additional assessment with fetal Dopplers.
- There was a failure to act on abnormal growth/liquor volume in 40% of affected women.
- Of the 13 women with complex monochorionic twins there was a failure to refer or a delayed referral to a tertiary fetal medicine centre for specialist involvement in the care in one quarter of cases.
- In a small number of women there were significant failures to recognise signs and symptoms or a delay in diagnosis of twin-to-twin transfusion syndrome (TTTS) which led to delays in referral to regional centres for fetal interventional procedures.

3.2 Background

Ultrasound assessment is a key component for the diagnosis, risk assessment, anomaly screening and recognition of growth related complications in twin pregnancies. It plays a significant role in the identification, monitoring and intervention of specific complications for monochorionic pregnancies, including twin-to-twin transfusion syndrome (TTTS), selective fetal growth restriction and fetal demise. There are different levels of skills and expertise required for scanning twin and higher order multiple pregnancies. The obstetric scan service for twin pregnancies is provided by sonographers, midwife sonographers, obstetricians and fetal medicine specialists depending upon the risk assessment and complications identified by the local unit and service models. The diagnosis of twins and chorionicity is crucial in establishing the pathway required for the care of the woman and her pregnancy. The lack of availability of trained personnel to conduct these scans was highlighted as part of the recent report published by the Twins and Multiple Births Association (now known as the Twins Trust) [1].

The routine use of clinical palpation and symphysis-fundal height (SFH) measurements as a tool for screening to assess for fetal growth concerns is not useful in twin pregnancies. Hence, scanning plays a vital role in the antenatal management of these pregnancies. There is currently a lack of consensus for use of specific twin growth charts. However, routine growth charts can be used for assessing growth trends and any discordance in estimated fetal weights should be calculated at each growth scan. Early diagnosis of TTTS is important to allow for timely referral to tertiary units for fetal interventional procedures that will improve the chances of survival for one or both twins. This process should incorporate a full discussion of the risks and potential pregnancy outcomes with women (and their partners).

Appropriately-skilled senior clinicians need to be available to review high risk twin pregnancies, as complications such as preterm labour, TTTS, reduced fetal movements or the loss of one or both twins may be diagnosed out of hours. Although this level of review may not necessarily change the outcome for some of these pregnancies, it is likely to improve the overall care and experience for these women (and their partners). Ongoing management of complex twin pregnancies and those following interventional procedures should be continued under the care of specialist fetal medicine teams.

3.3 Summary of findings

Issues were identified with non-adherence to national guidance for scanning in just over one-third of reviewed pregnancies (n=18), encompassing the frequency of scans, labelling of twins, assessment by appropriately trained professionals, documentation of scan findings, a lack of or inadequate counselling, assessment for fetal growth, Doppler assessments and failure to recognise the complications of twin pregnancies. Substandard care was identified for 5 of 12 MCDA pregnancies complicated by TTTS, where a failure to recognise TTTS resulted in a lack of timely referral to regional fetal medicine services and supra-regional fetal medicine centres for intervention.

Overall, both babies died for 30 of the 50 women whose twin pregnancies were reviewed: 15 of the 22 MCDA twin pregnancies, 12 of the 25 DCDA twin pregnancies and all three of the MCMA pregnancies. The vast majority of these twin pregnancies were diagnosed in the first trimester (47 of 50). The death and diagnosis of a single twin tended to be later in pregnancy than for those women where both babies died (median gestation of 34 and 23 weeks, respectively). Specific issues identified for these women included the lack of an offer of an out of hours scan by a senior clinician and failure to recognise a high risk pregnancy despite presenting with symptoms suggestive of evolving TTTS or a compromised fetus with reduced fetal movements (n=11).

One-fifth of all the scans were carried out by district general hospital (DGH) teams, just over two-fifths had fetal medicine scans in tertiary units, and just under two-fifths had input from clinicians both at DGH and tertiary fetal medicine units.

3.4 Determining chorionicity

RCOG (2016) and NICE guidelines (2011) recommend that all women with a twin pregnancy should have chorionicity and amnionicity confirmed by 13⁺⁶ weeks [2, 3]. This is crucial to determine the scan care pathway these women will need to follow through the pregnancy. Ultrasound assessment in the first trimester, to determine chorionicity and amnionicity, includes assessment for the number of separate placentae, presence of Lambda or T sign insertion of the intertwin membrane onto the placenta, and membrane thickness to determine chorionicity and the presence or absence of the intertwin membrane to determine the number of amniotic sacs. The sensitivity and specificity of these signs for determining chorionicity is greater than 95% when the scan is performed before 14 weeks [4].

The chorionicity was confirmed in all but one of the women (46/47) where twin pregnancy had been identified on ultrasound scan before 13⁺⁶ weeks. Of the remaining four women, two booked late, one was referred too late from the community and in one woman pregnancy dating issues were identified.

3.5 Frequency and timing of scans in uncomplicated MCDA and DCDA twins

Early confirmation of a twin pregnancy is required to ensure timely confirmation of chorionicity. Fetal ultrasound assessment should take place every 2 weeks in uncomplicated monochorionic pregnancies from 16⁺⁰ weeks gestational age. For uncomplicated dichorionic twins scans should be carried out every 4 weeks from 20⁺⁰ weeks gestational age until birth [2].

Despite determining chorionicity in a timely manner for almost all women reviewed (47/50), there was substandard care identified with respect to the timing and frequency of scans. The timing of scanning followed guidance for all DCDA and MCMA twin pregnancies reviewed. However, the appropriate scan care pathway of 2 weekly scans carried out from 16 weeks until birth was not followed for 1 in 5 MCDA twins. It was not always possible to identify from the notes whether the scanning was performed by an appropriately experienced sonographer/clinician.

Vignette 4: Incorrect frequency of scans in a monochorionic pregnancy

A woman had an MCDA twin pregnancy confirmed at 12⁺⁶ weeks of gestation. None of her scans were performed by an obstetrician or twin specialist and they were completed at three-weekly intervals from 16 weeks gestational age instead of two-weekly as per national guidance. Liquor volume was only recorded as normal until 28⁺⁵ weeks when a deepest vertical pool was measured, and discordant liquor volume noted. There was also poor consistency of umbilical artery Dopplers at each scan. Twin 1 was identified as an IUFD at 29⁺⁰ weeks. Scans following the loss of Twin 1 were also not performed in line with guidance and no fetal MRI was arranged.

3.6 Inconsistent labelling of twins

It is important to have a systematic approach to the labelling of twins for all aspects of care. Nomenclature used to identify each twin should be recorded in the notes following diagnosis and all documentation should then be appropriately labelled as indicated in guidelines for assessing twin pregnancies [2, 5]. Consistent documentation of fetal growth assessment scans is imperative to ensure that any growth concerns in either twin can be identified as early as possible to facilitate any required intrauterine or neonatal intervention. At panel review inconsistent labelling of babies leading to inaccurate documentation of findings contributed to a failure to identify growth concerns in 1 in 6 twin pregnancies.

Vignette 5: Inconsistent labelling of twins

A woman was diagnosed with MCDA twins at 12 weeks gestation. An appropriate referral was made to a fetal medicine specialist who performed all the subsequent scans according to the timings in NICE guidance. At 22 weeks the possibility of selective IUGR or early TTTS was suggested. The subsequent scan swapped the labelling of the babies and normal growth and liquor volume was incorrectly documented for each baby. There was an inconsistent reporting of fetal Dopplers and an overall poor quality of scan reports. Both babies were confirmed as a double IUFD at an ultrasound scan at almost 26 weeks of pregnancy.

3.7 Assessment and reporting of fetal growth

Accurate assessment and reporting of fetal growth is an important aspect of antenatal care in twin pregnancies in order to identify any growth discordance in both monochorionic and dichorionic twin pregnancies. However scan growth charts were only present in the clinical notes of just over half of the twin pregnancies reviewed

(n=27). Although in two-thirds (n=19) the measurements were plotted on the chart, in only 17 of the 19 were they plotted accurately.

Guidance recommends estimated fetal weight discordance should be calculated at each growth scan and where there is more than a 20% discordance increased surveillance and/or referral is warranted, although this guideline specifically addresses management of monochorionic twins only [2]. Updated NICE guidance recommends referral to fetal medicine specialists if there is a greater than 25% difference in estimated fetal weights or weight less than 10th centile [2, 3, 6]. For the purpose of this review, discordance in weights of more than 25% on antenatal scans was used for assessment. At review, evidence of the percentage difference in fetal weights was only reported for two-fifths of the twin pregnancies (n=19), all of which had growth discordance documented with more than 25% difference in the estimated fetal weights. Despite concerns with growth, just over a quarter of these women (n=5) did not have increased weekly US surveillance for follow up scans, and for four of these women there was no evidence of fetal Doppler assessments [2].

3.8 Identification and management of complex twin pregnancies

Screening for TTTS includes assessment for biometry, deepest vertical pool, umbilical artery Doppler pulsatility index and visualisation of the bladder in MCDA twins, every two weeks from 16 weeks. Screening for growth restriction should include calculating percentage discordance in estimated fetal weights between the twins using the formula for calculation in the guidance [2]. Discordance of greater than 20% should prompt increased surveillance and/or referral to fetal medicine specialists. Discordance in estimated fetal weights of greater than 25% and/or estimated fetal weight of any of the twins less than 10th centile should be referred urgently to the fetal medicine teams in regional or supra regional centres as appropriate as both are associated with increased risk of perinatal mortality [2, 6]. Monochorionic monoamniotic twins have a higher risk of perinatal mortality and morbidity. NICE quality standards [5] state that 'Women with a higher-risk or complicated multiple pregnancy [should] have a consultant from a tertiary level fetal medicine centre involved in their care.'

Complicated multiple pregnancies are defined by NICE [6] as those with:

- fetal weight discordance (of 25% or more) and an estimated fetal weight of any of the babies below the 10th centile for gestational age;
- fetal anomaly (structural or chromosomal);
- discordant fetal death;
- feto-fetal transfusion syndrome;
- twin reverse arterial perfusion sequence (TRAP);
- conjoined twins or triplets;
- suspected twin anaemia polycythaemia sequence (TAPS).

Thirteen of the 22 MCDA twin pregnancies reviewed were complicated by a fetal anomaly or TTTS, fulfilling the NICE criteria above. All of the MCDA pregnancies affected by a congenital anomaly were referred to a fetal medicine specialist. However, in five of the MCDA pregnancies affected by TTTS (n=12) it was not recognised by the clinical team, resulting in a failure to refer to a tertiary fetal medicine centre for specialist involvement in the care.

Following the death of one of the twins in utero, increased surveillance is required to assess for signs of complications such as hypoxic brain injury and fetal anaemia in the surviving twin, including referral for specialist fetal medicine opinion [7]. Monochorionic pregnancies are at a greater risk of subsequent complications following a single twin loss than dichorionic pregnancies [7]. In the MCDA pregnancies complicated by the loss of one twin in utero (n=7) six women were referred to a fetal medicine specialist. Two of these woman should have been subsequently referred for a fetal MRI within 4-6 weeks, but this occurred for only one. In the remaining

four pregnancies there was no referral for a fetal MRI as the second twin either died or was born shortly after the death of the first twin. In one pregnancy no referral to a fetal medicine specialist took place despite there being adequate time to do so.

Vignette 6: Delayed review by a fetal medicine specialist

A woman was confirmed with DCDA twins at 11 weeks of pregnancy. Despite have risk factor for pre-eclampsia in addition to her twin pregnancy, she was not commenced on aspirin as per NICE and RCOG guidance. At 13 weeks her NT scan identified a growth discrepancy as Twin 2 was noted to be below the 10th centile and a fetal medicine review was requested. This review took place at 24 weeks gestational age with likely causes discussed as placental insufficiency, chromosomal factors and genetic abnormalities. An amniocentesis was offered but declined, and the possibility of demise of Twin 2 in utero was discussed. The following week she was admitted via the community midwife with severe hypertension (as defined by NICE), proteinuria and symptomatic for pre-eclampsia. She remained an inpatient till the birth of her babies at 27 weeks. Twin 1 was born and quickly transferred to the neonatal unit. Twin 2 was provided with comfort care and died later the same day. There was a missed opportunity early in the pregnancy for a timely referral to a fetal medicine specialist to discuss pregnancy options which may have affected the outcome for these babies.

All three MCMA twin pregnancies discussed at review panels were diagnosed by 13 weeks and had appropriate and timely scanning by the fetal medicine teams. In two of these, complications related to selective fetal growth restriction or TTTS were identified and appropriate options were offered.

Despite referral to fetal medicine specialists, there were a number of instances where there was a failure to follow guidance, leading to sub-standard care provision that may have contributed to the deaths of one or both twins, including a lack of Doppler assessment despite concerns for selective fetal growth reduction and/or TTTS.

Vignette 7: Delay in referral for intervention

A woman was confirmed as having an MCDA twin pregnancy at 12⁺⁴ weeks. At 18⁺⁴ weeks of pregnancy there was a suspicion of TTTS and a referral to a fetal medicine unit (FMU) was made. Appropriate recognition of the development of TTTS with Type 2 selective fetal growth restriction was confirmed eight days later. Laser ablation was discussed at this appointment with a plan to review and perform the following week. Due to a long bank holiday weekend the woman was not further reviewed at the FMU for a further five days, at 20⁺³ weeks of pregnancy. At this appointment the death of one of her babies was identified. A fetal MRI and subsequent growth scans at appropriate intervals followed at the same fetal medicine unit. Her pregnancy was monitored closely and the surviving twin was born at 38 weeks of pregnancy.

Recommendations

S1. Audit adherence to the national guidance for scan frequency, the quality of scans, and training, in order to improve the quality of scanning and documentation of scans provided by the multidisciplinary team at all levels (sonographers, obstetricians and fetal medicine specialists).

Particular attention should be paid to:

- Consistent labelling of the twins;
- Plotting measurements on a growth chart;
- Calculating weight discordance (where appropriate);
- Recognition of the complications of twin pregnancy and referral to fetal medicine specialist in line with national guidance;
- Ensuring the availability of adequately trained sonographers to monitor twin pregnancies.

S2. Develop a local process for regularly reviewing the training and expertise of sonographers and the quality of scanning of twin pregnancies.

3.9 Conclusions

The provision of local ultrasound services and availability of the expertise and skills for managing twin pregnancies may vary depending upon the local models of care. Findings from the confidential enquiry panels concerning the quality of care provision measured against the standards and guidance in place in 2017 [2, 3, 5] indicated that sub-optimal quality of care relating to antenatal scanning was present in up to two-thirds of the cases reviewed. Improvements in care for these women and their babies were identified that may have made a difference to the outcomes for some of these pregnancies. It is essential that local services review their care for women with twin pregnancies provision in the light of these findings.

Areas of sub-optimal care included non-adherence to clinical guidance for the frequency of scan care pathways, inconsistency in labelling of twins, problem with the estimation and reporting of fetal growth and growth discordance, and lack of referral to fetal medicine specialists for women with complex twin pregnancies. There was sometimes involvement of staff without appropriate training and skills, or staff whose training was not evident from the notes. The increased perinatal morbidity and mortality associated with complex twins warrants urgent and timely review of these pregnancies by expert teams, including fetal medicine scan assessments using fetal biometry, liquor assessment for deepest vertical pools in both twins, and fetal Doppler assessments with umbilical artery, middle cerebral artery and ductus venosus. Collaborative working and clear documentation of scan findings using the national recommended standards for scanning are required to ensure a seamless service for women and their babies cared for by more than one centre due to the complex nature of the twins.

Whilst there were areas that needed improvement, it was noted that the determination of chorionicity was achieved almost for all women who had a scan before 14 weeks. There were also examples of exemplary clinical practices related to counselling, early detection of complications with twins, excellent management for discordant anomalies and single IUFD, appropriate referrals to fetal medicine services and intervention offered and implemented.

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4. Labour and birth

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4.1 Key findings

- There was no sub-optimal care during the intrapartum period for over half of the women (31/50) and there was evidence of compassionate care. Of the 19 pregnancies where the panels agreed intrapartum care was sub-optimal, 14 were at extreme preterm gestations (22-26 weeks).
- There was a lack of senior review on admission of women with multiple pregnancies and lack of preparedness for birth in 11 of the 19 cases where sub-optimal care was found.
- For 13 of these 19 sets of parents there was limited MDT/joint review by obstetric and neonatal teams and for seven of the 19 a lack of evidence of discussions with parents regarding the chances of survival, decisions about resuscitation, and signs of life at birth.
- In four of 19 pregnancies following preterm vaginal birth of the first twin, the second twin was augmented and birth expedited without clinical indication.
- Despite national guidance of the need to give steroids and magnesium sulphate prior to birth, this was not given to nearly a third of applicable women (8/27) and a partogram to record progress in labour was only started for half the women for whom it was possible, and completed for only three.

4.2 Background

There has been a steady increase in multiple pregnancies with the increasing use of assisted reproductive technology and increase in maternal age. Multiple pregnancies are associated with higher risks for the woman and babies. Specifically the stillbirth rate and preterm birth rates are significantly higher in multiple pregnancies, with mono chorionic twins having a thirteen fold increase in rates of stillbirth and a fivefold increase in dichorionic twins compared with singleton pregnancies [1]. These factors mean that there are unique complexities in the management of labour and birth in multiple pregnancies, with a greater burden on neonatal services. Particularly in the extremes of prematurity, the parents may be in a situation where there are conflicting survival chances for the twins, with different neonatal management options, or even in a situation where they are grieving the loss of one twin whilst celebrating the birth of the other. Therefore, intrapartum care and birth in these highly complex multiple pregnancies needs senior leadership with close multidisciplinary collaboration between midwives, obstetricians and neonatologists working in partnership with the parents.

4.3 Summary of findings

In total there were 50 twin pregnancies reviewed. Thirty were in primiparous women and 20 in multiparous women. In 25 pregnancies the onset of labour was spontaneous, 22 of which had a gestational age between 22⁺¹ and 26⁺⁵ weeks at birth. Thirteen pregnancies had labour induced (including 11 following an antenatal diagnosis of demise of both twins). Six pregnancies were delivered by planned caesarean section (including 4 following an antenatal diagnosis of a single in-utero fetal demise). Thirteen pregnancies were delivered by emergency caesarean section: 7 following induced or spontaneous labour and six for acute antenatal concerns (antepartum haemorrhage or non-reassuring fetal monitoring).

There were 13 single intrauterine deaths (8 occurring between 20 and 26 weeks gestation). Two of these 13 pregnancies also involved the subsequent neonatal loss of the co-twin. There were 12 double intrauterine deaths, of which 10 occurred between 21 and 26 weeks gestation. There were 11 single neonatal deaths (2

following co-twin intrauterine demise as above). The gestational age at delivery of these neonatal losses ranged from 23 and 36 weeks gestation, 3 followed birth between 23 and 26 weeks gestation. There were 16 pregnancies which suffered loss of both neonates. All 16 of these pregnancies had a gestational age of between 22 and 26 weeks.

In 19 of the 50 cases there were issues of significant or major sub-optimal intrapartum care where it was deemed that the sub-optimal care probably or certainly led to the poor outcome. Importantly, in 14 out of these 19 cases the intrapartum care and birth were at the very extremes or prematurity (22-26 weeks), where the complexities of care are at their greatest.

4.4 Lack of senior review on admission and preparation for birth

In 6 of the 19 cases where there was sub-optimal intrapartum care, there was either no senior review by a consultant obstetrician or the counselling parents received was inconsistent, with poor or no preparation for the birth of the babies. In 11 of the 19 cases with sub-optimal care there was a lack of preparedness for the birth. The main issue was again at the extremes of prematurity, where there was a lack of appreciation for the possibility of a precipitate labour, resulting in babies delivering unexpectedly in inappropriate clinical surroundings without the relevant clinical staff being present.

The decision making in multiple pregnancies is significantly more complicated than that in singletons. Complicating factors include increased risk of precipitate labour, fetal presentation of each twin, discordant growth restriction, discordant fetal anomaly or prolonged premature ruptured membranes of one twin. These factors can result in conflicting survival chances for each twin. Alternatively, the pregnancy may have been affected by a single in-utero demise indicative or potentially predisposing to a hostile in-utero environment for the surviving fetus. Therefore, senior consultant review to deliver considered experienced decision-making is essential in these complicated cases. However, there was no clear recommendation in any of the contemporary national guidance on senior decision-making on intrapartum care and birth at the extremes of prematurity in a multiple pregnancy [2-4].

The recently updated NICE guidance on the management of twin and triplet pregnancies [5] makes the recommendation that women presenting with suspected, diagnosed or in established preterm labour before 26 weeks should be offered “individualized assessment of mode of birth ... taking into account the risks of caesarean section and the chance of survival of the babies”. Although not stated, the individualised assessment should be performed by, or discussed with, a senior obstetrician. Obstetric consultant involvement should be a required standard of care in emergency obstetric triage of multiple pregnancies.

Vignette 8: Lack of senior review on admission

A woman was diagnosed with a DCDA twin pregnancy at 21 weeks gestational age following late booking and referred for a Consultant review and ultrasound scan. The woman did not receive an obstetric review before she was admitted to a delivery suite with a spontaneous rupture of membranes at 24 weeks gestational age. On admittance she was reviewed by a Senior Obstetric and Neonatal Registrar and an appropriate plan was made surrounding the immediate intrapartum care and support for her babies following birth. Twin 1 died a short time later following birth. A decision to augment the labour for Twin 2 was initiated then promptly discontinued following discussion with the on-call Obstetric Consultant. During the birth of Twin 2 the following day midwifery staff made two requests for obstetric support for the pre-term birth. These requests were declined by the Registrar with a direction that this should be a midwifery-led birth. Twin 2 was a breech birth without obstetric support. The neonatal team were present for the birth and the Obstetric Registrar attended shortly after. Resuscitation of Twin 2 was attempted and then discontinued by the Neonatal Consultant in attendance.

Vignette 9: Lack of foresight and preparation for birth

A woman with a confirmed DCDA pregnancy was admitted to the antenatal ward via maternity triage with a confirmed SROM at 22⁺⁵. Abdominal tightenings were reported the following day and oral analgesia was commenced. An overnight obstetric review at 23 weeks gestational age due to continuing maternal discomfort identified a closed cervix with a rising infection markers. Oral antibiotics continued as did the need for stronger oral analgesia. The woman continued to report constipation-like tenderness, difficulty sitting and abdominal discomfort and was moved into a side room on the antenatal ward. Despite the clear signs that were being reported to the midwifery team, no further assessment was made to ensure that labour was not progressing. Twelve hours after the last cervical examination the woman rang the emergency bell to alert staff that Twin one had been born unexpectedly in the bathroom. The baby arrived without midwifery, obstetric and neonatal support and without the necessary resuscitation equipment.

4.5 Limited MDT/joint review by obstetric and neonatal teams

In 13 of the 19 cases of sub-optimal care in labour there was evidence of a lack of obstetric and neonatal multidisciplinary review and therefore evidence of a lack of a comprehensive management plan to aid the care of the parents, the care of babies (including interventions to improve outcomes where appropriate) and the performance of clinical team during birth. A failure to invite or limited late involvement of the neonatal team was the most frequent barrier to optimal multidisciplinary care at the time of birth. This particularly applied to extremes of prematurity, where there was evidence that decision-making was performed by the obstetric team. The expert panel considered that in a number of pregnancies isolated obstetric review resulted in inappropriate decision making regarding the value of neonatal assessment and or resuscitation. There was also evidence of the neonatal team declining to review the pregnancy and input into delivery planning and care because an inappropriate decision had already been made not to resuscitate the baby/babies.

The publication of the British Association of Perinatal Medicine (BAPM) Framework for Clinical Practice for the management of babies born extremely preterm at less than 27 weeks of gestation [6] aims to address some of the large variances in practice of management of extreme prematurity and equally apply to multiple pregnancies as it does to singletons. The basis of this guidance results from advances in perinatal care, which have led to steadily improving outcomes for babies admitted to neonatal intensive care units, especially for the most extremely preterm babies. The framework advocates a risk-based approach to decision making regarding life sustaining treatment for extreme prematurity using several factors affecting fetal and maternal health, rather than just relying on gestational age alone. This guidance recognises the complexities of multiple pregnancy and its association with an increased risk of adverse neonatal survival rates.

The BAPM framework emphasises the importance of a multidisciplinary discussion between senior midwives, obstetricians and neonatologists, and the importance of involving parents in perinatal decision-making and ensuring their hopes and expectations are explored in a compassionate and realistic way.

Recommendations

- L1. Ensure prompt senior obstetric review for all women with a multiple pregnancy (particularly those with threatened preterm labour at the extremes of prematurity) upon attendance at maternity services. Produce a clear plan made regarding monitoring in labour, mode of delivery and when referral is required. When necessary, there should be prompt senior neonatal involvement.
- L2. Where birth is anticipated between 22⁺⁰ and 26⁺⁶ weeks gestational age ensure prompt discussions between the parents, obstetric and neonatal teams to guide whether active resuscitation or palliative care should be undertaken. Care of the woman and her baby/babies should reflect the wishes and values of the woman and those of her partner, informed and supported by consultation and in partnership with obstetric and neonatal professionals.

Recommendations (continued)

L3. Ensure a review of individual plans of care is conducted by senior staff at least daily.

4.6 Immediate augmentation/birth of second twin after vaginal birth of first twin at extremes of prematurity

In 4 of the 19 cases of sub-optimal care, when Twin 1 was born vaginally at 23-24 weeks gestational age there was an immediate decision to induce delivery of the second twin without evidence of in-utero distress, maternal infection or other compromise. The benefits and harms of offering delayed birth of the second twin to parents cannot be assessed within the MBRRACE-UK perinatal mortality reviews. However, several publications regarding pregnancies managed conservatively after vaginal birth of the first twin report delayed birth intervals of up to several weeks [7-10]. This is associated with a significantly increased chance of survival of the second twin compared to the first twin, but at the expense of a high (>30%) risk of severe maternal morbidity [9, 10].

Although there are no national guidelines on delayed birth of the second twin, it was considered sub-optimal care that consideration was not given to the potential benefits of conservative management for a time period to optimally prepare Twin 2 for preterm birth by, at least, initiating antenatal steroid therapy and administering magnesium sulphate (MgSO₄) for neuroprotection. In most cases the option of delayed birth will not be possible because labour will continue naturally, but in a few cases where contractions stop and membranes of the second twin are intact, expectant management can be considered, especially at extremely preterm gestations (<24 weeks), where even one day can make a difference in survival. However, because of the increased maternal risks and the possibility of survival with neurodevelopmental problems, where appropriate, the decision for immediate birth of the second twin or consideration of delayed birth needs to be made by a consultant obstetrician as part of a multidisciplinary team following careful counselling of the parents. If a decision for delayed birth of Twin 2 is made, careful monitoring for signs of maternal and/or fetal compromise, especially infection, is essential.

Vignette 10: Immediate augmentation and birth of Twin 2 after the birth of Twin 1 at extreme prematurity

A woman had a DCDA twin pregnancy diagnosed at 12 weeks gestation. A limited number of antenatal contacts were acknowledged for a young woman with significant complex needs. A two day history of abdominal tightening were reported and this resulted in a presentation to Accident and Emergency followed by a transfer to the labour ward at 24 weeks of pregnancy. Despite several attempts to expedite a Senior Obstetric review, a spontaneous rupture of membranes 2 ½ hours later led to a quick birth of Twin 1 and a decision to augment the labour. Twin 2 was born within the hour. Antenatal steroids and the administration of MgSO₄ was not considered. Twin 1 died on day 8 whilst Twin 2 was discharged home after a prolonged neonatal stay.

Recommendations

- L4. Consider delaying the birth of Twin 2 following the spontaneous preterm birth of Twin 1 at less than 24 weeks, if there are no contraindications such as infection, fetal compromise or bleeding.
- L5. Counsel parents prior to the birth of Twin 1, regarding the possible option of delayed birth of Twin 2 including the maternal risks as well as the risk of Twin 2 still being born at the extremes of prematurity.
- L6. In cases where delayed birth of Twin 2 is an option, manage the pregnancy as high risk in a tertiary centre, with close monitoring for signs of infection, clotting abnormalities and fetal growth.

4.7 Suboptimal use of antenatal steroids and MgSO₄ prior to birth

Despite national guidance directing that antenatal steroids and magnesium sulphate (MgSO₄) should be considered and/or offered prior to preterm birth to improve neonatal outcomes, such interventions were not documented to have been considered or initiated in nearly a third of applicable pregnancies.

In 8 of the 27 cases where birth occurred before 34 weeks antenatal steroids were not given or documented to be offered when expert review considered this would have been appropriate and there was enough time before delivery for this therapy to be initiated. Likewise, in 8 of 20 cases where birth was before 30 weeks, antenatal MgSO₄ for neonatal neuroprotection was not given or documented to be offered prior to delivery, when it was considered appropriate and there was time to be initiated.

The revised 2019 NICE guidance on the management of twin and triplet pregnancies [5] clearly recommends the use of targeted antenatal steroids with twin deliveries, although this guidance was not available during the period covered by the enquiry. However, the 2015 NICE guidance on preterm birth and labour [4], which was in place during the period reviewed, recommends that antenatal steroids should be offered to all women at risk of preterm birth from 23⁺⁰ to 33⁺⁶. The same guidance also recommends that this option should be considered for women at risk of preterm birth between 34⁺⁰ and 35⁺⁶ weeks gestation. The risks and benefits of antenatal steroids should be discussed with the woman and her family in the context of her individual circumstances. Likewise, this guidance also recommends offering antenatal MgSO₄ for neonatal neuroprotection to all women from 23⁺⁰ to 29⁺⁶ weeks who are in established preterm labour or having a planned preterm birth within 24 hours, and that this therapy should be considered for pregnancies between 30⁺⁰ and 33⁺⁶ weeks gestation.

The benefits of antenatal steroids and MgSO₄ have been further advocated since the 2017 period covered by this enquiry, and at the very earliest potentially-viable gestational age. A multicenter observational study by Ehret et al [11] showed that, even at the extremes of prematurity of 22⁺⁰ to 25⁺⁶ weeks, use of antenatal steroids was associated with significantly higher survival and survival without major morbidities compared with neonatal life support alone. The BAPM Framework for Clinical Practice for the management of babies born extremely preterm at less than 27 weeks of gestation [6] encourages a considered approach for maternal interventions for pregnancies between 22⁺⁰ and 26⁺⁶ weeks gestation on the basis of risk assessment for potential benefits.

In the cases where antenatal steroids and/or MgSO₄ were missed when appropriate, there were various issues, but the common trend was a lack of senior obstetric leadership and MDT involvement in care.

Recommendation

L7. In multiple pregnancies where a woman is in established labour or having a planned preterm birth, where appropriate, offer antenatal steroids between 22⁺⁰ and 35⁺⁶ weeks and antenatal MgSO₄ between 23⁺⁰ and 33⁺⁶ weeks.

4.8 Sub-optimal use of partograms

In 28 women there was sufficient time before birth for a partogram to be started. However in only half of these women was a partogram started and in only 3 women was it fully completed.

There is no national guidance on the use of partograms in twin pregnancies but the NICE guidance on intrapartum care for healthy woman and babies [12] recommends use of a pictorial record of labour (partogram) once labour is established. The partogram allows monitoring of the progress of labour such that an abnormal labour can be identified and appropriate interventions actioned.

Recommendation

- L8. In a twin pregnancy when established labour has been diagnosed, initiate and complete a partogram throughout all stages of labour.

4.9 Discussions with parents regarding birth at extreme prematurity

In 4 out of the 19 cases of sub-optimal intrapartum care, there appeared to be little evidence of detailed counselling of the parents regarding the neonatal management of the baby/babies after birth. This applied not just in the cases where active resuscitation was undertaken, where the survival chances for the baby/babies or the plans for resuscitation were not communicated with the parents, but also in the cases where palliative care was planned. In cases where the fetuses were alive at onset of labour at the extremes of prematurity, parents were not warned of what to expect in terms of whether the babies may die intrapartum or be born showing signs of life and what palliative care would involve.

The revised BAPM Framework on extreme prematurity [6] is clear that the “management of labour, birth and the immediate neonatal period should reflect the wishes and values of the woman and her partner, informed and supported by consultation and in partnership with obstetric and neonatal professionals”. Where the risk stratification identifies the babies at high risk of poor outcome, the “decision to provide either active (survival focused) management or palliative care should be based primarily on the wishes of the parents”.

Even in cases where a discussion with the parents had taken place, there was little or no documented evidence of the contents of the discussion, which made regular review of the decisions difficult and more stressful for parents. The BAPM framework again clearly states that “conversations with parents should be clearly documented and care taken to ensure that the agreed management plan is communicated between professionals and staff shifts. Decisions and management should be regularly reviewed before and after birth in conjunction with the parents; plans may be reconsidered if the risk for the fetus/baby changes or if parental wishes change”.

Such examples of sub-optimal preparation of the parents for neonatal care of their babies was judged by the panel of experts to have been unacceptable in the context of what would have been good practice in 2017

Recommendations

- L9. Adopt the BAPM Clinical Framework for the Perinatal Management of Extreme Preterm Birth before 27 weeks of gestation; in particular:
- Management of labour, birth and the decision on active resuscitation or palliative care should be made with the parents at the centre of the decision-making and informed and supported in partnership with a multidisciplinary team including obstetric and neonatal professionals.
 - Conversations with parents must be clearly documented and agreed management plans carefully and clearly communicated between professionals and staff shifts.
 - The decisions on management should be regularly reviewed before and after birth in conjunction with the parents and the plans reconsidered if the risk for the baby/babies changes or if parental wishes change.

4.10 Examples of good quality intrapartum care

Despite the issues of poor intrapartum care highlighted in this chapter, there were several examples of exceptionally good care, with 31 out of the 50 cases investigated not having any significant issues during the intrapartum period. There were several examples of detailed discussions with parents, with the decisions on care being based on the parental wishes and clearly documented.

In two pregnancies involving extreme preterm labour the clinical team critically assessed the gestational age of the pregnancy during the intrapartum care and concluded that this had not been calculated accurately. In one of these pregnancies correction of the estimated date of delivery and the gestational age advanced the gestation by several days and contributed to an active decision to resuscitate the babies at delivery. One of these babies survived. In the second pregnancy the gestational age of the babies at delivery was less advanced than initially documented. This corrected information and neonatal assessment at delivery influenced the decision to provide comfort care at delivery.

In this cohort of pregnancies there were no cases identified where the management of labour itself or the management of fetal monitoring in labour contributed to perinatal loss. However, the number of pregnancies undertaking delivery by labour at gestations more advanced than 26⁺⁶ weeks is too small in this cohort to assess if care provided during labour was to optimal standards.

Vignette 11: Good quality intrapartum care

A woman was diagnosed with DCDA twins at 12 weeks. One of the twins died in-utero at 24 weeks gestational age. She continued with regular scans by the same fetal medicine specialist, who delivered the surviving twin at 38 weeks gestational age. She had excellent continuity and bereavement care. A plan for the birth, which was discussed in detail during the antenatal period, identified all parental wishes and was placed at the front of the woman's notes. This included the names of both babies and how both parents wished to meet their babies at the time of birth and in the immediate postnatal period. Ongoing details of bereavement support were also acknowledged and all appropriate future referrals were already in place.

Recommendation

L10. Confirm the accurate gestational age of a pregnancy when a woman presents with threatened or established extreme preterm labour to enable the correct risk assessment for potential neonatal survival and therefore direct the optimal multidisciplinary care bundle.

4.11 Conclusions

In two-fifths of the cases reviewed the care during the intrapartum and birth period was considered to be significantly sub-optimal. These care issues were primarily centered around the lack of clinical leadership and multidisciplinary counselling and decision-making, particularly at the extremes of prematurity. The intrapartum period and birth in a twin pregnancy is an extremely complex situation with multiple combinations of factors that need to be considered. Often parents are faced with having to process information and counselling which may be conflicting, with differing survival chances for each baby. Indeed they may have to face situations where they are grieving for one baby, whilst having to consider active resuscitation for the other. The emotional and management complexity of these cases means that clear and compassionate leadership from a multidisciplinary team of professionals, with regular reviews of the decisions, is absolutely essential.

To some extent the inconsistency of care and decision-making highlighted in this chapter is a reflection of the paucity of good quality evidence and contemporary national guidelines regarding the intrapartum care of multiple pregnancies, particularly at the extremes of prematurity. This has partly been addressed by the recently updated NICE guidance on the management of twin and triplets pregnancies [5] published in 2019, which makes

recommendations on intrapartum care and monitoring for pregnancies from 23⁺⁰ weeks gestation. The 2019 BAPM Framework, which covers the management of extremely preterm birth [6], will play an important function to optimize care of the extremely premature neonate during delivery and enable this to be delivered to a consistent standard nationally.

This MBRRACE-UK report and recommendations aim to highlight the unique complexities identified in the intrapartum care and birth of multiple pregnancies. However, there needs to be a recognition that future updates of national guidance on the management of multiple pregnancies should expand in more detail the complexities of intrapartum care and birth, especially at the extremes of prematurity.

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5. Resuscitation and neonatal care

Alan C Fenton, Ngozi Edi-Osagie, Kathryn Johnson, Tina Evans

5.1 Key findings

- Mortality varied with gestational age and chorionicity. Almost two-thirds of deaths occurred before 28 weeks gestational age compared to just over 1 in 20 at term. Both twins died in just under half of dichorionic pregnancies compared with almost three-quarters of monochorionic pregnancies.
- Overall the neonatal care provided was considered to be good but there were notable instances of a lack of specific skills related to airway management at birth, variation in resuscitation in babies born <26 weeks and poor communication with families both before and after birth.
- Recently-published guidance may improve performance in these key areas of care.

5.2 Background

This chapter examines the care given to the babies who required resuscitation or neonatal care. It focuses firstly on events around the initial resuscitation and stabilisation following birth and secondly on the care delivered if the babies were admitted to a neonatal unit following successful resuscitation.

The transition from placental respiration to air breathing is a key part of the change from intra- to extra-uterine life and normal function may be interrupted by a number of pathological events before or during the birth process. Compromised infants or those born preterm are more likely to need resuscitation to achieve a successful transition [1].

Initial resuscitation involves numerous steps, including placental transfusion via delayed cord clamping to promote a healthy cardiopulmonary transition, maintaining normal body temperature and supporting the baby's airway, breathing and circulation. Of these, endotracheal intubation is the most technically challenging, particularly in the smallest neonates.

There is increasing evidence that extreme preterm infants should be born in an appropriate centre to improve outcomes [2]. The additional challenges of multiple pregnancy on this decision must be recognized, as additional resources are required which includes two or more full teams of appropriately trained staff to enable initiation of prompt resuscitation for each baby of the pregnancy. Resuscitation should be led by the most senior available neonatal paediatrician and be individualised for each baby.

The increased incidence of preterm birth in multiple pregnancies significantly impacts on neonatal unit occupancy: keeping babies from multiple births together may be difficult in all cases. This places additional emotional and financial burdens on families at what is an already stressful time. This situation may also occur if one baby subsequently requires transfer for specialist care, for example neonatal surgery, and accommodating both babies at the referral centre is not possible.

Where the baby is likely to be extremely preterm, involvement of parents in perinatal decision-making is essential [3-6]. Differences in practice and outcome exist at various levels both nationally and internationally, but advances in perinatal care have resulted in improved outcomes for babies born at extremely low gestations. Discussion with parents should include likely outcomes in terms of mortality and neurodevelopmental issues in survivors: this may influence what interventions are considered during resuscitation and subsequent stabilisation. Resuscitation should be in line with national guidance and conversations with families should be

led by a senior neonatal paediatrician. Such conversations should always include parental views and be accurately and contemporaneously documented.

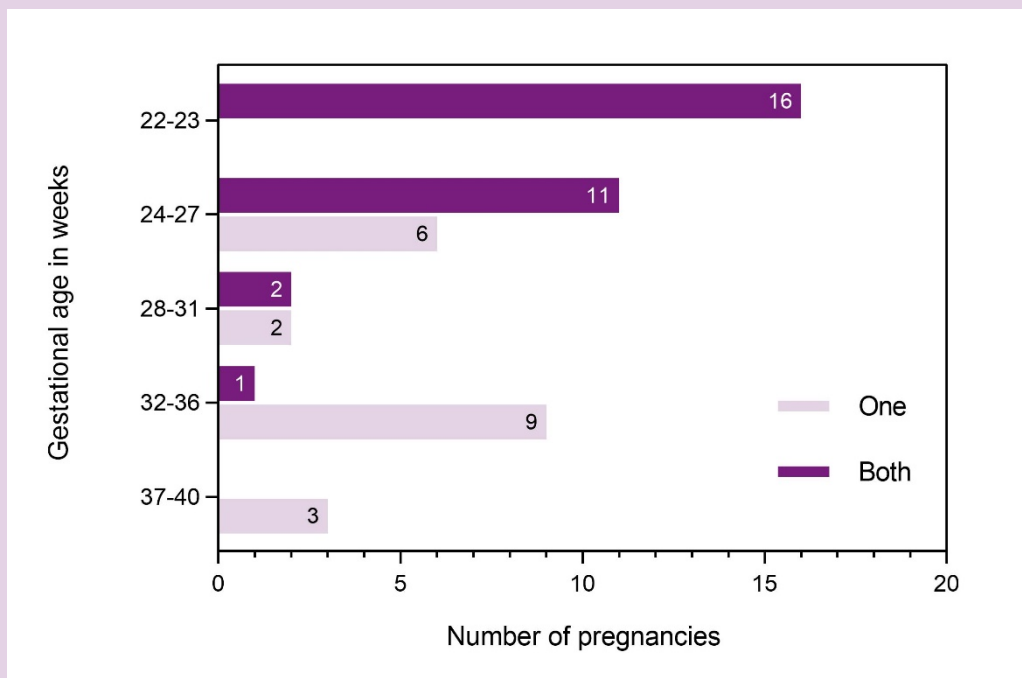
Continued regular, fully documented communication with families over the course of a neonatal unit admission should be a routine part of neonatal care.

5.3 Summary of findings

Mortality in the cohort had a strong correlation with chorionicity: both twins died in all 3 monoamniotic pregnancies, in 15 of 22 monoamniotic, diamniotic pregnancies and 12 of 25 dichorionic, diamniotic pregnancies. In 25 pregnancies at least one baby required resuscitation, and in 24 pregnancies at least one baby was admitted for neonatal care.

The other important influence on mortality was gestation: 66% of deaths occurred <28 weeks gestational age with only 6% occurring at term. Death of both twins was also more likely to occur at lower gestational ages as illustrated in the Figure 5.

Figure 2: Deaths per pregnancy by gestational age



Note: Where babies were born on different dates the highest gestational age is used

The neonatal management was considered to be of a good standard. However, for 16 of the women a range of issues affecting either one or both babies were identified that were graded as being significant or major sub-optimal care and at review were felt to be either a) probably or b) almost certainly relevant to the outcome. These issues occurred either during resuscitation, during the neonatal unit admission, or during both.

5.4 Place of birth

Twelve sets of twins <27 weeks gestational age were born outwith a tertiary centre, which included six sets at 22 weeks gestational age. Only three of these 24 babies were liveborn, of whom one survived. It was unclear as to whether there had been consideration of in-utero transfer.

Recommendation

- N1. Where birth is at <27 weeks gestational age, every attempt should be made to deliver the babies in a centre with a tertiary level neonatal unit.

5.5 Resuscitation

At least one instance of sub-optimal care around resuscitation was identified in 9 of the 25 cases involving resuscitation. All but one instance related to either:

- a failure to act appropriately; or
- communication failure.

In some cases parents were not collaboratively counselled regarding the management of extreme prematurity by senior members of the neonatal team despite there being adequate time for this to have occurred. Gestational age was used inappropriately in decision-making in one case. Communication failures influenced decision-making around starting resuscitation and senior neonatal staff were not universally present. There were several instances where the reviewers judged that resuscitation did not follow national guidelines, leading in some cases to inappropriate re-orientation of care. Tracheal intubation was unsuccessful in a small number of the cases despite multiple attempts by several practitioners: this delayed escalation of treatment.

Vignette 12: Failure to facilitate face-to-face parental counselling for babies born at extreme prematurity

A primiparous woman with an ICSI DCDA pregnancy was admitted to a delivery suite at 23 weeks of pregnancy with worsening abdominal discomfort and a brown PV loss. She was reviewed by the Obstetric Registrar and on examination was confirmed to be in labour. The parents were informed that their babies were likely to be born too early in the pregnancy and so resuscitation would not be recommended. This was reinforced as an appropriate plan following a telephone call for advice to a Neonatal Registrar. Condolences were offered and the parents were advised that babies may still be born with signs of life but that comfort care would be the most appropriate in this situation. At no point did the parents have a balanced, objective, face-to-face conversation or review with a Senior Neonatologist. The decision-making was led by the obstetric/neonatal registrars despite there being sufficient time to facilitate this essential conversation. Both babies were born within hours, in good condition and at an appropriate weight for their gestation. They remained with their parents and died a few hours later.

Recommendations

Extreme preterm birth is not rare in twin pregnancies. Neonatal clinicians should:

- N2. Involve parents in joint decision-making around resuscitation and stabilisation using both local and national outcome data to assist families to make an informed decision.
- N3. Ensure appropriately-trained senior staff lead parental counselling and subsequent interventions.
- N4. Undertake regular training and simulation sessions to maintain team skills in acute resuscitation.

5.6 Neonatal care following admission

At least one instance of sub-optimal care following neonatal unit admission was identified in 12 of 24 cases. All but one instance related to either:

- a failure to act appropriately; or
- communication failure; or
- a failure to recognise a problem.

Several of the issues noted during resuscitation were also seen during the babies' subsequent care. Difficulties related to tracheal intubation, often undertaken by relatively junior members of the team were noted. Parental autonomy was not respected in several cases, particularly around decisions to re-orientate intensive care in extreme preterm babies. This was compounded by poor documentation of changes in management, MDT discussions and conversations with families.

Vignette 13: Lack of discussion and joint decision-making around extremely preterm birth

A woman with a DCDA twin pregnancy was admitted to the hospital at 22⁺⁵ weeks with a history of bleeding. She remained an antenatal inpatient for three days before the unexpected arrival of Twin 1 on the antenatal ward. Despite there being sufficient time to counsel the parents during the antenatal period of the risks of the babies being born extremely preterm this was not facilitated. Following the birth of Twin 2 an initial discussion with the neonatal team acknowledged that the babies were both critically unwell. A blessing was facilitated and following this both parents said they did not want unnecessary intervention. Twin 1 died on day 3 and Twin 2 died in the post-neonatal period after a continuing escalation and invasive plan of treatment and intervention.

There were delays in recognising babies who were clearly deteriorating, both in the neonatal unit and postnatal ward. Cues that indicated extreme preterm babies were clearly not responding to intensive care were overlooked or ignored, and opportunities to re-orientate care were missed. This resulted in prolonged and inappropriate intensive care.

Vignette 14: Inappropriate and prolonged neonatal care

A woman with a DCDA pregnancy was admitted with a two day history of abdominal pain at 24⁺¹ weeks gestation and was confirmed to be in established labour. There was no neonatal counselling facilitated prior to the birth. Both babies were born within two hours with the neonatal team present for the birth. Neonatal care for Twin 1 went on too long with multiple invasive procedures required in order to support a critically unwell baby. Despite several timely senior neonatal reviews with parents the decision to reorient care should have been made sooner. An overemphasis on conceding to parental decision-making was evident despite it not being in the best interests of their baby.

Recommendations

Extreme preterm admissions form an increasing part of neonatal unit populations. Neonatal clinicians should:

- N5. Involve parents in joint decision-making around the care of their baby and respect their autonomy.
- N6. Consider re-orientation of care for babies deteriorating despite maximum intensive care and discuss the best interests of the baby with the parents.

5.7 Examples of good resuscitation and neonatal care

The reviewers noted some particularly good care around resuscitation and subsequent care, including:

- Well-documented discussions with parents around resuscitation and of those wishes being respected.
- Appropriate numbers of staff were present at most deliveries in view of the need to accommodate a twin birth.
- Parents were able to spend time with their babies before transfer to a neonatal unit.
- Instigation of high quality palliative care in the delivery suite, even in cases where one twin survived. This was undertaken sensitively.
- High-quality multidisciplinary care in the neonatal unit.
- Extensive discussions with parents around the care of their babies following admission.
- Identification of the surviving twin on the neonatal unit i.e. referred to as a twin which is valued by families.

Vignette 15: Neonatal counselling and review during the antenatal period

A woman was diagnosed with MCDA twins at 13 weeks gestation. A preliminary diagnosis of a lethal anomaly in one of the twins was later confirmed by 20 weeks. She was sensitively counselled by a consultant obstetrician who provided excellent continuity throughout the rest of the pregnancy. There were additional supportive sessions that involved the wider MDT, including consultant neonatologist and bereavement midwife, who ensured that the parents' wishes were clearly documented in anticipation of the birth of their babies. She self-referred to the maternity unit at nearly 34 weeks with a SROM and vaginal bleeding. Her babies arrived by emergency caesarean section in the hour following admission and as expected one of the twins died shortly after birth. The surviving twin progressed well and the parents were able to view their baby's improvement via a camera in the neonatal unit whilst the mother remained on the delivery suite. In line with parental wishes, which had been identified during the antenatal counselling sessions, both babies spent time together following birth. Both mother and the surviving twin were discharged home.

5.8 Conclusions

It is encouraging to see that many of the case reviews concluded that neonatal resuscitation and subsequent care were felt to be good. In particular, engagement with families and delivering high quality active and palliative care at an extremely challenging time is to be commended.

However this standard of care was not universal and in a few instances the clinical management was sub-optimal to the point of affecting the outcome. For those involved in clinical care the arenas where most sub-optimal care occurred (communication, documentation, failing to recognise problems and failing to act) will come as no surprise. They are the major issues that feature in the majority of clinical incident or mortality reviews and, indeed, complaints. Those working in perinatal care must regularly reflect on all aspects of their practice to minimise the likelihood of these issues arising.

One area where practice was notably inconsistent was in the approach to families whose babies were considered to be at the margins of viability, including whether they were counselled prior to birth. This inconsistency extended to the subsequent resuscitation and continuing care that these babies and their families received. It is clear that developments in the overall 'package' of intensive care that is now offered have resulted in a gradual improvement in outcomes. This has impacted on both the public perception of and the clinical approach to extreme preterm babies. We hope that recently-published national guidance [7-9] regarding the approach to babies at the margins of viability (particularly given the considerable number of babies at 22-23

weeks gestational age in this cohort) and shared decision-making may improve the consistency of practice in this area.

A new development for many clinicians involved in this Confidential Enquiry was the use of electronic clinical records for some of the cases. For many organisations the direction of travel is clearly towards using this form of clinical case notes. Reviewers commented that in some electronic notes it was extremely difficult to follow the clinical narrative. Whilst this may in part have been due to unfamiliarity with particular electronic systems it is possible that this problem will impact on an individual organisation's abilities to review care delivered: an important Clinical Governance issue. It is essential that going forward electronic case note systems have an ability for narrative notes to be read and followed easily.

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6. Postnatal and bereavement care, follow-up and review

Surabhi Nanda, Lisa Barker, Tina Evans, Manjiri Khare, Ngozi Edi-Osagie, Sara Kenyon

Twin pregnancies, compared to singletons, are at higher risk of complications, and perinatal mortality and morbidity. Some of this may be inevitable (especially when related to complications of shared placentation, or extreme prematurity). Nevertheless, considerate, compassionate, and joined-up multidisciplinary care for bereaved parents, with continuity of carer during follow-up, and a robust local review process goes a long way in providing support during their grieving process.

The focus of this chapter is the quality of care around postnatal care, bereavement support, and follow-up. It also addresses the content, quality and membership of the local review into perinatal death (where performed).

6.1 Key findings

- Overall, postnatal and follow-up care accounted for far more significant or major issues around care than any other aspect of the care pathway. 37 women had at least one issue graded as major sub-optimal care. Another five had at least one issue graded as significant sub-optimal care.
- Involvement of a bereavement midwife was documented for only 29 women and a bereavement checklist was missing or incomplete in half of the notes (n=26).
- Bereavement counselling was offered to around a third of parents.
- All but three women were offered a post-mortem (n=47); however there was lack of detailed documentation noted around post-mortem counselling (n=19).
- Ongoing community midwifery support following discharge was only noted in a third of women and the number of postnatal contacts were variable (with majority of women receiving only up to two visits). The overall level of bereavement and follow-up care was poorer in pregnancies with single twin demise, compared to those with demise of both twins.
- Where one or both twins died following an intervention in a tertiary centre (monochorionic twin pregnancy), disjointed communication regarding follow-up care between tertiary and referring unit, and lack of ownership for local review was noted.
- Only half of the women (n=24) had a follow-up bereavement appointment and of these only 11 women received a summary letter following this appointment. The majority of the letters were of poor quality and addressed to the GP. Where no follow-up was arranged, the reasons were not clearly documented in the notes.
- The timing of the follow-up visit was highly variable, ranging from 6 weeks to up to 35 weeks after the death of one or both twins.
- Local review into perinatal death was documented for 1 in 5 women. Only one review was judged to be of good standard, with 2 being adequate, and 8 of poor standard. Most (n=8) local reviews were limited to consultant and midwifery input. When reviews were undertaken, pertinent issues around care were not identified; this was more evident at the extremes of viability, or where there was single twin demise.
- There was no evidence of involvement of parents in any reviews.

6.2 Background

Twin pregnancies are at a higher risk of perinatal morbidity and mortality [1-3]. Such complications, including stillbirth of one or both twins, should be discussed during antenatal counselling with specialist multiple pregnancy teams, as recommended in the NICE and RCOG guidelines [2, 3]. This is especially important in a complicated multiple pregnancy, e.g. those with growth discordance, or complications of shared placentation like twin-to-twin transfusion syndrome (TTTS) or selective fetal growth restriction (sFGR), or for preterm births.

Care during and after the death of a baby or babies that die in pregnancy, labour or after being born, has a profound immediate effect on women, their partners and the wider family. The death of a baby affects physical health and psychological wellbeing of both parents, the extended family and also other relationships, including the parental interactions with the healthcare system [4]. Appropriate, kind and respectful care at this time makes a difference to how parents feel and their experiences [5].

Parents who lose all the babies in a multiple pregnancy may grieve more intensely and for longer than parents who lose a single baby [6]. Parents may grieve for each baby individually rather than as a “collective baby” and it is important that staff acknowledge each baby [7]. Parents may also experience grief more intensely if the grief for their multiple babies is not acknowledged. Additionally, parents may also experience grief over the decreased likelihood that they will have another multiple pregnancy.

There is extensive guidance for management of complications in multiple pregnancy that have a higher risk of stillbirth, as well as clinical management of multiple pregnancies with single twin demise [1-3]. However, there is limited information for healthcare professionals around care of families with multiple pregnancy bereavement, and specialist bereavement counselling and follow-up. The impact on parents, the emotions, and the grieving process becomes even more difficult in parents where one baby has demised, and the other has survived. The National Bereavement Care Pathway [8] acknowledges this and provides limited guidance to staff caring for families under such circumstances, although this was not available to Trusts and Health Boards during the period reviewed.

6.3 Summary of findings

Postnatal and follow-up care accounted for far more significant or major issues than any other aspect of the care pathway. Sub-optimal care relating to postnatal, bereavement and follow-up were identified for 42 of the 50 women included in this Confidential Enquiry. In two-fifths of women one of the twins died and in three-fifths both twins died. Significant concerns around care (major sub-optimal care) was identified in two-thirds (13 of 20) of pregnancies with single twin demise, and in four-fifths (24 of 30) of pregnancies where both twins had died. The themes and areas of sub-optimal care did not differ by chorionicity.

6.4 The quality of postnatal and bereavement care

Substandard care was identified in the provision of bereavement care and support, lack of communication among healthcare professionals, lack of use of bereavement checklists, and inadequate community midwifery follow-up. Using a standardized rating, the confidential enquiry panels rated the quality of postnatal and bereavement care as majorly or significantly sub-optimal for half of all women.

Access to a bereavement midwife and continuity of bereavement care

Sands, in their guidance for professionals, recommends that maternity units have access to a bereavement midwife with specialist knowledge and an overview of all the essential components of perinatal bereavement care [9]. There was evidence of a bereavement midwife providing care for 29 of 50 women. Where the woman is still in the hospital, it is recommended that the healthcare professionals looking after her antenatally are informed of the events around birth, so they are able to arrange follow-up appointments, or if possible see the woman whilst she is an inpatient. The value of continuity of care in a high risk group like women with a multiple pregnancy has been acknowledged in the Better Births and Best Start initiatives [10, 11]. A specialist multiple pregnancy team (particularly specialist twin midwives) can offer continuity of care not only antenatally, but ideally

should offer intra- and post-partum support. This also mitigates automated reminders, or accidental “congratulations” letters. The latter was found in one set of case notes, although it was unclear if this letter was actually sent to the family. There was another instance where a standard letter was sent to the family to register birth, when both twins had died in utero at 22⁺³ weeks gestational age.

Most Trusts and Health Boards have developed bereavement checklists which are designed to improve the quality of bereavement care and facilitate good communication between different healthcare professionals, as well as meeting parents’ specific individualised care requirements. Their use is recommended by the Sands guideline for professionals [9]. Whilst there was a bereavement checklist in 46 of the 50 sets of notes, this was completed in only 20.

Vignette 16: Inadequate postnatal and bereavement care and substandard follow-up

A woman booked at 20 weeks gestational age with a confirmed DCDA twin pregnancy. She presented with preterm pre-labour rupture of membranes at 24⁺¹ weeks gestational age, and had a spontaneous vaginal birth of Twin 1. The baby was born in poor condition, and resuscitation was discontinued. Labour was augmented the following day due to maternal sepsis. Twin 2 was born in poor condition, and resuscitation was discontinued. Despite consultant involvement around labour, there was no medical input for the 4 days that she stayed in the postnatal period. Lactation suppression was not offered, and she did not receive postnatal thromboprophylaxis (due to her BMI). There was confusion around registration of the twins, death certificate, and criteria for coroner involvement. A follow-up appointment was carried out 5 weeks later, but did not cover pertinent areas, and there was no evidence of a follow-up letter. The local review was superficial and inadequate.

Lack of individualized and compassionate care when offering memories and keepsakes to the parents

Some Trusts & Health Boards also include the “memories” and “keepsakes” in their bereavement checklist. There were at least four sets of parents who did not receive any memories or photographs, either due to lack of availability of a camera or missed opportunities to take photographs.

Lack of documented discussions about post-mortem examination

The Sands Audit Tool [12] and the RCOG Maternity Standards [13] recommend that all parents whose baby dies should be offered a post-mortem and given written information. There was documented evidence of discussion regarding post-mortem examination for only 19 of the 50 sets of parents, although all but three sets of parents were offered a post-mortem. In two of these instances post-mortem was not offered because the baby had died in utero several weeks before birth with the co-twin.

Vignette 17: Failure to provide joined-up multidisciplinary postnatal and bereavement care in a high-risk pregnancy

A woman missed fetal medicine and community midwifery appointments during the antenatal care for her DCDA twins. IUFD of Twin 2 was identified at 23⁺⁶ weeks gestational age, and an in-utero transfer was arranged for birth of Twin 1 due to her gestation. Safeguarding concerns were identified but were inadequately communicated to the unit where she was transferred. She gave birth at 24⁺⁰ weeks gestational age, and although a bereavement midwife was present at the time of birth, there was no ongoing bereavement care, or follow-up arrangement. In addition, there were issues with the death certificate and registration of the death, with no acknowledgment of the death of Twin 2 on the certificate. Despite significant safeguarding issues there was a lack of communication between her care providers. There was no evidence of follow-up care, community midwifery support or local review.

Ineffective communication and lack of consistent community midwifery care

Bereavement midwives provided care for almost three-fifths (n=29) of women and documentation of the offer of formal bereavement counselling was noted in around a third of cases (n=18) Following discharge just over half of the women were seen by community midwives, with the majority having at least two visits.

Twins Trust (formerly TAMBA) and NPEU produced a joint report following a survey of women's experiences of birth in 2007 [14]. The report found that fewer mothers of multiples were visited at home by a midwife after leaving the hospital. This was noted particularly when an extended neonatal stay for the surviving twin was required, lack of joined up bereavement and midwifery care. Mothers of singletons and twins who saw a midwife at home had a similar number of contacts (average 4 visits) and one in 5 similarly would have liked more home visits. This confidential enquiry reports far fewer community midwifery contact for mothers with the loss of one or both twins, compared to the experience survey in 2007.

Vignette 18: Ineffective and unsafe MDT communication in the postnatal period

A woman with a DCDA twin pregnancy self-referred to the maternity assessment unit at 34⁺¹ weeks gestation, when Twin 1 was confirmed as an IUFD. Twin 2 was born the following day. Despite a history of social service involvement, they had not been advised of this pregnancy during the antenatal period. Mother and baby were discharged home three days later after a short stay on the postnatal ward. There was poor communication between the MDT surrounding the safeguarding issues and a recognition of the potential risks. Following discharge home there was a failure by the community midwifery team to recognise and appropriately refer a premature and hypothermic baby with significant weight loss. There was no follow up appointment and the local review failed to identify any of these issues.

Involvement of bereavement team following the death of a single twin

In two-fifths of women one twin died; these occurred across the full range of gestational ages. It is important that staff acknowledge the importance of the baby who has died, and avoid focusing only on the baby that is alive [9]. The lack of timely involvement of the bereavement team following the death of a single twin, and avoidance of discussion, may prolong and complicate the grieving process for the parents. It is vital to have a specialist multidisciplinary team approach involving twin and bereavement midwives, and clear documentation of the parents' wishes around how they want the staff caring for them to acknowledge their loss. In almost half of the pregnancies where one baby died in utero (8 of 18) there was no evidence of any bereavement care planning during the antenatal or pre-birth period.

The grief that parents may experience with the loss of one baby in a multiple pregnancy may be as profound as if the loss was of a single child although their experience of grief may be more complex. In some cases, grieving is delayed or suppressed while parents focus on the surviving baby who may be vulnerable or unwell (eg: premature gestation, or the surviving twin still being in the neonatal unit) only to emerge or re-emerge later, often unexpectedly. Some parents may also feel guilty about their grief and may worry about possible long-term effects on the relationship with the surviving baby [9].

Vignette 19: Missed opportunity for bereavement care planning in the antenatal period

A woman was diagnosed with DCDA twins at 8 weeks. A lethal fetal anomaly was suspected in one of the twins at the 20 week anomaly scan which was later confirmed by a fetal MRI. The woman attended a further three fetal medicine growth scans and three community midwife appointments. None of these contacts facilitated an appropriate MDT review or counselling session to prepare the mother for the birth. There was no bereavement planning for a woman who had been informed that one of her twins would die shortly after birth. She was not provided with an opportunity to meet the neonatal team in the antenatal period and to have a joint discussion about the compassionate care that the team could offer. The babies were born by emergency caesarean section at 34⁺⁶ weeks following a preterm pre-labour rupture of membranes. One twin died shortly after birth, after being provided with comfort care, and the surviving twin was discharged home at 16 days.

Care across secondary and tertiary units

With clear guidance for referral to a tertiary unit for a second opinion on management of complicated multiple pregnancy, and for interventions, as recommended by RCOG [2], ISUOG [1], and NICE [3], comes shared ownership and ongoing care for this high-risk subset of women in an already high-risk pregnancy. However, sub-optimal care was noted in a lack of documentation for ongoing care from a tertiary unit, and a lack of involvement of a tertiary unit in the review and follow-up, especially when preterm birth or IUFD occurred shortly after an intervention.

Vignette 20: Lack of involvement of a tertiary unit in the local review

A woman with an MCDA twin pregnancy complicated by TTTS and sFGR was referred to a tertiary unit for fetoscopic laser ablation of placental vessels (and selective fetocide). The procedure was complicated and was abandoned after multiple attempts. Both babies died shortly after the procedure. This information was not shared with the referring hospital. There was no evidence of local review at the tertiary unit (procedure related complication), or involvement of the tertiary unit by the referring hospital to participate in the local review. A follow-up was arranged by the referring unit, and the letter lacked detail and compassion, with no explanation around events that led to both babies dying. The family did not engage with care at the referring unit, thereafter.

Recommendation

F1. Adopt the standards of National Bereavement Care Pathway for pregnancy and baby loss regarding care of these parents. Particular attention should be given to:

- Involvement of the bereavement team, where one exists;
- Sensitive and caring consideration being given to the parents' wishes regarding seeing and holding the baby/babies and making memories, particularly if one twin survives;
- Development and use of a bereavement checklist bespoke to multiple pregnancy;
- Discussion of consenting to post-mortem examination as appropriate;
- Joint working between the maternity and neonatal teams;
- Continuity of care from the specialist multiples team (obstetrician and midwives) for postnatal and follow-up support.

6.5 The quality of follow-up care

The vast majority of parents wish to understand why their baby or babies died and to be able to ask questions of the health professionals involved. It is recommended that all available test data and findings should be ready so that parents are able to discuss these within twelve weeks of birth at a follow-up appointment [9, 15]. There is no specific guidance for this regarding multiple pregnancy, but these recommendations should be extrapolated for this high-risk group. It is good clinical practice to follow up this meeting with a letter summarizing the pregnancy care, labour, events around the death of the baby or babies, results of investigations, and a plan for subsequent pregnancy. It is imperative that the parents' GP is informed of the outcome of this meeting, but ideally the letter should be written directly to the parents in a compassionate manner.

Missed opportunities for follow-up appointments following discharge

Opportunities were missed in offering follow-up appointments after discharge from the hospital, and in particular, poor coordination was noted between obstetric and neonatal teams for follow-up visits. The panel identified that follow-up reviews were either missed when one or both twins died at the threshold of viability (e.g. 22 weeks gestational age), or lacked multidisciplinary or joint input from obstetrics and neonatal teams when one or both babies died in the neonatal period. A formal bereavement appointment after discharge took place for only half of the women. The actual timing of this appointment was extremely variable ranging from 6 to 35 weeks after demise of one or both twins.

Poor quality or absent letters to parents

A letter summarising the results of the review of care, investigations relating to the mother, post-mortem examination, and a plan for managing future pregnancies was sent **and addressed** to the parents in only 11 instances. In one case, the letter was defensive, lacked empathy and the mother was spoken about in the third person. In another case, a standard bereavement letter was sent referring to the recent multiple pregnancy demise as the death of "baby" rather than "babies".

Ideally, the woman's GP, community midwife and health visitor, as well as the link healthcare professional/obstetrician involved in her care should be notified of the death(s). In this confidential enquiry, a letter to the GP was documented to be sent either at discharge or after follow-up appointment in only 21/50 (42%) women.

Lack of joint follow-up for neonatal deaths

More recent statutory guidance on child death reviews [16] and the Perinatal Mortality Review Tool [17] state that for neonatal deaths the follow-up meeting (following investigations and ideally after local review) should involve both the obstetrician and neonatologist. Only five of the 32 women whose babies had died after birth had a follow-up appointment with a neonatologist, and there was evidence of only one joint obstetric and neonatal appointment for any of the neonatal deaths in the enquiry.

Vignette 21: Lack of follow-up appointment and joint obstetric/neonatal review

A woman with an MCDA pregnancy had appropriate antenatal care as per the MCDA twin pathway. She received extensive fetal medicine input with prompt recognition of TTTS, and fetoscopic laser treatment followed by extensive counselling following preterm pre-labour rupture of membranes at 19⁺² weeks gestational age. She had spontaneous birth of both twins at 23⁺⁰ weeks gestational age. Both twins died within 2 days. Despite extensive antenatal involvement of fetal medicine specialists and neonatal involvement at resuscitation, there was lack of multidisciplinary input and joint review. There was also a lack of obstetric and fetal medicine follow-up despite an adverse outcome in a high risk pregnancy following an intervention.

Recommendation

F2. Follow national guidance regarding offering a follow-up appointment to all women. Particular attention should be paid to:

- Joint obstetric and neonatal review where it is appropriate;
- Ensuring that the letter sent to parents is personalised and caring, and includes advice regarding any future pregnancies.

6.6 Clinical governance: evidence and quality of local reviews

RCOG recommends that all stillbirths should be reviewed in a multi-professional meeting using a standardised approach to analyse for substandard care and means of future prevention [13]. Results of the discussion should be recorded in the mother's notes and discussed with the parents. In addition, there are also clearly defined pathways for investigating intrapartum deaths (Serious Incident Framework) and neonatal deaths (CDOP; Child Death Overview Panels). The operational framework and logistics of conducting the reviews are usually adapted to suit the local team of investigators.

In this enquiry, the panel noted that local reviews were carried out for 11 of the 50 twin pregnancies. The quality of the review was judged to be poor in 8 cases, adequate in 2 and good in 1 case. Despite the reviews being "multi-professional" the membership was limited to obstetricians (or neonatologist, depending on the nature of the review), midwife or nurse, risk manager or governance lead and senior manager. There was evidently a lack of presence of perinatal pathologists and any parental input, and two reviews failed to identify anyone involved in the review. Actions (either individual or institutional) to improve care and share learning were identified in only 5 of these 11 local reviews.

Vignette 22: Failure of local review to identify contributory factors to serious adverse incidents or to acknowledge and identify urgent need for improvement

A woman with MCDA twins was identified as having increasing inter twin growth discordance. There was a discussion around appropriate place of birth (i.e. referral to a larger maternity unit), but she was admitted at 33⁺⁰ weeks gestational age with sepsis. Following a delay of five days (due to a lack of cot availability) both babies were born by elective caesarean section at 33⁺⁵ weeks gestational age. Twin 1 was born with no fetal heart rate and care was withdrawn for Twin 2 at 28 minutes. No issues were identified in the local review or highlighted in the Root Cause Analysis. Furthermore, the review was followed by a very defensive letter from the obstetrician to the GP (with the parents copied in). The letter lacked empathy, and included a very poorly formulated and inadequate plan for a subsequent pregnancy.

Vignette 23: Failure to identify, acknowledge and act upon lack of specialist expertise and system failure

A woman was confirmed to have an MCDA twin pregnancy at 14⁺⁶ weeks gestational age. IUFD of both twins was diagnosed at 28⁺² weeks gestational age, followed by an induction and vaginal birth of both twins the following day. There was inadequate and delayed antenatal obstetric care, with lack of documented advice around risks in MCDA twin pregnancy, sub-optimal scanning for complications of shared placentation, no follow-up appointment after birth, and a discharge letter dated a year after the event, when the patient booked in her next pregnancy. The local review failed to identify any learning.

The period of study of cases for this confidential enquiry just predates the Perinatal Mortality Review Tool (PMRT), which was developed in 2017 and launched in 2018. This tool encourages multidisciplinary discussions, parental involvement and extends to gestations that are around threshold of viability [17].

Recommendation

F3. Where either one or both babies have died, as part of the PMRT process pay particular attention to:

- Sensitive inclusion of parents' views;
- Ensuring the tertiary centre is also included in the review process.

6.7 Examples of good quality care

Multiples are high risk pregnancies. Adverse outcomes may be inevitable in some cases, despite exemplary care. However, with a core team of specialists including those with a special interest in multiple pregnancy, the overarching responsibility for shared care is usually extended into the postnatal period, especially when there is an adverse or unexpected outcome. Where there was adherence to NICE guidance or continuity of care, with defined pathways for management of twin pregnancy based on chorionicity, the panel did not identify any areas of substandard care.

Vignette 24: Excellent MDT communication by a specialist twin clinic

A woman with an MCDA pregnancy was offered fetoscopic laser ablation for complications of shared placentation at 17 weeks gestational age. Despite early identification and the offer of intervention the parents were uncertain and their wishes were respected following good discussion in the MDT clinic. A double twin IUFD was noted at 25⁺⁰ weeks gestational age shortly after the consent for fetoscopic intervention was given and completed successfully. Despite the adverse outcome, there was excellent communication between the team, especially the midwives and the specialists in the dedicated twin clinic. The bereavement midwife was involved prior to discharge from hospital and provided excellent continuity in the immediate postnatal period. She also facilitated a timely bereavement review which was followed by a concise and compassionate letter.

Vignette 25: Continuity of care by a specialist twin team

A woman with MCDA twins was confirmed to have a double IUFD at 32⁺⁴ weeks gestational age when she presented with a 48 hour history of reduced fetal movements and backache. She had been counselled about the complications of monochorionic twins, and had her care in the specialist twins clinic. The same team of clinicians looked after her both antenatally and postnatally, including providing bereavement and follow-up care.

6.8 Conclusions

Postnatal and follow-up care accounted for far more significant or major issues around care than any other aspect of the care pathway. The quality of care after birth was extremely variable, and assessed as either poor or with insufficient information in the notes in majority of cases. 37 women had at least one issue graded as majorly sub-optimal. Another five had at least one issue graded as significantly sub-optimal. The remaining eight had no major or significant issues.

Issues and major concerns around sub-standard care did not differ by chorionicity. It can be argued that the postnatal, bereavement and follow-up care, as well as the local reviews in multiple pregnancy should be at least on a par with the those offered in singleton pregnancies, if not more robust, as this is a high-risk cohort. Overall,

all aspects of the care pathway after birth (bereavement, postnatal follow-up, debrief, review) were felt to be sub-standard. The need for a follow-up appointment to discuss what happened with the parents is particularly important for these women, and discussion about any future pregnancy is particularly crucial. Robust local review including parental involvement and external review will ensure institutional learning from any failures in care. It is vital that the specialist twins team (where they were involved in providing antenatal care) are a part of the local review, to identify where improvements in the care pathway are needed and learn from events.

There was evidence of a bereavement midwife being involved in only 29 pregnancies, with clear documented evidence of discussion of post-mortem in only 19 pregnancies. A letter to the GP was documented as sent either at discharge or after the follow-up appointment for only 21 women. Lack of use of bereavement checklists resulted in omissions and errors in care at a very sensitive time for bereaved families. Bereavement counselling was offered to only a third of families, and ongoing community midwifery support following discharge was also evidenced only in a third of the pregnancies.

Some of the concerns the panel identified about the quality of the local reviews have been addressed by the introduction of the Perinatal Mortality Review Tool (PMRT) and in particular its mandatory use in England, which has been used by maternity units since 2018, after these women gave birth. This gives a clear structure to the review and materials to support parental involvement.

Where there was a demise of one or both twins following an intervention in a tertiary centre (monochorionic twin pregnancy), disjointed communication regarding follow-up care between tertiary and referring unit, and lack of ownership for local review was noted. Most local reviews lacked multidisciplinary healthcare professional input. When reviews were undertaken, pertinent issues around care were not identified, and there was no evidence noted of communication with or involvement of parents during these reviews. A third of all the issues of substandard care in bereavement, postnatal and follow-up pathway were noted in pregnancies that resulted in a single twin demise.

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7. Post-mortem examination and placental histology reporting

Srinivas R Annavarapu, Marta C Cohen and Samantha Holden

7.1 Key findings

- Consent for full post-mortem examination including placental histology was obtained in only around one quarter of the baby deaths.
- Where performed, all post-mortem examinations were carried out by specialist perinatal pathologists and in all these instances the quality of the post-mortem report was either good or excellent. The placenta was submitted for pathological examination in all autopsy cases and in all these cases, the placental histology report was of good quality with appropriate comments on the clinico-pathological correlation.
- For babies where there was no consent for autopsy (n=60), the placenta was submitted for histological examination in around two-thirds of the cases.
- When assessed against Royal College of Pathologists guidelines, around two-thirds of placental histology reports were regarded as excellent, good or satisfactory. However, around a third of reports were found to be of poor quality.
- A limiting factor in the clinico-pathological correlation was related to the paucity of clinical information supplied to pathologist by the obstetric / neonatal teams.
- There is an acute shortage of perinatal pathologists nationally which may be a critical factor impacting upon the quality of placental histology reports. Consequently, around a third of the placental histology was reported by general pathologists.
- In a minority of cases, there were avoidable human errors resulting in the placenta not being sent for formal pathological examination.

7.2 Background

Post-mortem examination of the baby and placenta in stillbirths and neonatal deaths associated with twin pregnancy may yield very important diagnostic clues as to why the twin(s) died and may help the clinician and the parents to understand the cause and timing of intrauterine death [1]. The yield is higher when the examination is conducted by a trained perinatal pathologist. This chapter examines the role and current status of the autopsy and placental histological examination in the investigation of stillbirth and neonatal death associated with twin pregnancy to identify areas where the quality could be improved.

A total of 50 twin pregnancies and 80 baby deaths (48 stillbirths and late fetal losses; 31 neonatal deaths and 1 post-neonatal death) were reviewed. The twin pregnancies comprised 25 dichorionic diamniotic (DCDA), 22 monochorionic diamniotic (MCDA) and 3 monochorionic monoamniotic (MCMA) twin pregnancies. Post-mortem reports and placental histology reports were evaluated according to a pre-defined checklist based upon guidelines from the Royal College of Pathologists (RCPATH) [2].

There has been an increase in the number of twin pregnancies over the past decades, mainly related to the use of assisted reproductive techniques such as in-vitro fertilisation (IVF) [3]. IVF more commonly results in dizygotic twins, but there is also a 2-12 times increased incidence of monozygotic twins [3-5]. Twin pregnancies

can be complicated by the same medical issues relating to the singleton placenta, such as infection, advancing maternal age, maternal disease, obstetric complications and intrauterine growth restriction. However, twin pregnancies are at higher risk of stillbirth compared to singleton pregnancies [6]. There is a 13-fold higher risk if the twins share the placenta (monochorionic) and a 5-fold higher risk when they have their own placental disks (dichorionic) [7]. In addition, monochorionic twins may present clinically with acute twin-to-twin transfusion syndrome (TTTS) due to a varying degree of vascular sharing [3, 5]. Hence, all women who have a stillbirth should be offered a post-mortem examination with placental examination in accordance with RCOG guidance [8].

Even if consent for a full post-mortem examination is declined, it is important to encourage the parents to submit the placenta for pathological examination, as in a significant number of cases it may provide vital clues as to the cause of an adverse perinatal outcome and may be critical in the management of subsequent pregnancies by obstetricians and neonatologists [7, 8]. In twin pregnancy, placental pathology may help confirm chorionicity of the placenta by examination of the dividing membranes. Examination of the chorionic surface of the monochorionic twin placenta in cases of suspected TTTS may help in evaluation of vascular anastomoses in the vascular equatorial plane, especially if there has been attempted laser ablation of anastomosing vessels. All cases with an adverse perinatal outcome in twin pregnancy should be discussed at local multidisciplinary team meetings so that local practices can be evaluated for quality. There should be active communication at multidisciplinary team meetings between obstetricians, neonatologists and the perinatal pathologist to discuss any learning points that could improve parental counselling or direct future management [7-9].

In this chapter we will evaluate the quality of the post-mortem examination when consented to and the availability and quality of the placental pathology report. The adequacy of the placental histology report will be assessed for the presence of key data in accordance with the RCPATH placenta pathway [2] and for the presence within the reports of a relevant clinico-pathological comment. We will also explore various other factors that inform the quality of placental pathology examination.

7.3 Quality of post-mortem reports

Of the 80 babies included in this review, a total of 20 post-mortem examinations were recorded from eight sets of twins who died in-utero, in only one of the deceased twins in one case, and in the deceased twin in three cases where there was a surviving co-twin. Post-mortem examination was offered to almost all parents (47/50 parents). Of the three cases where post-mortem examination was not offered, two involved babies who were severely macerated and autolysed due to an extended period between the diagnosis of IUID and birth with the sibling. Post-mortem examinations were carried out in regional tertiary hospitals by a specialist perinatal pathologist. In all these cases the placenta was submitted for pathological examination, which is good practice; placental examination was conducted at the same institution as the post-mortem in all but one case where the places of birth and death were different. Moreover, the quality of all combined post-mortem examinations and placental histology was either of excellent or good quality with good clinico-pathological correlation. There were clinical summaries in all cases which included good clinical information. Appropriate ancillary investigations and radiology was performed in most cases. Overall, the quality of the post-mortem reports including the placental histology was good. However, the panel found that the overall post-mortem consent rate for autopsy was low (20/80 babies). It is recommended by the RCOG that women who have had a stillbirth should be offered a post-mortem and placental examination [8]. In accordance, the placenta should always be submitted for pathological examination in stillbirths associated with twin pregnancies as it may reveal important information about the death of the baby/babies and the timing of death in relation to their birth [9].

7.4 Quality of placental reports

In cases where there was no consent for autopsy, the placenta was submitted in around two-thirds of pregnancies (34/50). Although the quality of two-thirds of the placental reports was of excellent, good or satisfactory standard (23/34 cases), in a third (11/34 cases), the quality of the placental examination was of poor quality.

Table 8: Submission of the placenta according to whether or not there was a livebirth, by gestation at birth

Pregnancy	Number of placental reports according to gestation at birth N (%)									
	22 ⁺⁰ to 23 ⁺⁶		24 ⁺⁰ to 27 ⁺⁶		28 ⁺⁰ to 31 ⁺⁶		32 ⁺⁰ to 36 ⁺⁶		37 ⁺⁰ to 41 ⁺⁶	
Involved livebirth										
Yes	10	(20)	9	(18)	2	(4)	10	(20)	3	(6)
No	7	(14)	7	(14)	2	(4)	0	(0)	0	(0)

Closer evaluation of the poor quality placental histology reports revealed that certain key parameters were missing in the report. In a significant number of placental reports, the following key data were absent from the clinical history: relevant maternal history; birthweights of the twins; clinical indication for twin placenta examination; maternal BMI; information regarding previous pregnancies; information regarding the surviving twin and the gestational age of the twin pregnancy (Table 9). In a number of cases, the reporting pathologist failed to include certain key features in their reports such as: clinico-pathological correlation; comment on chorionicity; territories shared by the twins; umbilical cord length; umbilical cord coiling index; number of vessels in the umbilical cord; appearances of the placental membranes; fetal surface and maternal surface; assessment of cut-section of the placenta, and placental weight (Table 10). Of the 11 cases with TTTS, the pathologist failed to confirm laser ablation of the vessels in 8 cases. Of the 11 cases with a poor placental histology report, multiple issues were identified: ranging from those relating to the reporting pathologist (6 cases); the midwives/obstetricians (6 cases); and/or pointed towards team/system failure (5 cases).

Table 9: Issues identified with placenta examination: information not provided to the pathologist by the requesting clinician

Key information missing	Cases with placental reports (n=34)	
	n	%
Gestational age of twins	3	9
Relevant maternal history	19	56
Birthweights of the twins	16	47
Maternal BMI	26	77
Information regarding previous pregnancies	20	59
Information regarding the surviving twin (n=18)	10	56
Indication of placental examination	11	32
Comment on chorionicity	8	24
History of laser ablation in acute TTTS cases (monochorionic twins: n=11)	8	73

Table 10: Issues identified with placenta examination: information not provided to the requesting clinician by the pathologist

Key information missing	Cases with placental reports (n=34)	
	n	%
Twin territories clearly indicated	24	71
Weight of the placenta	2	6
Umbilical cord length	7	21
Umbilical cord coiling index	19	56
Site of umbilical cord insertion	7	21
Number of vessels in the umbilical cord	7	21
Appearance of placental membranes	9	27
Appearance of fetal surface	10	30
Appearance of maternal surface	7	21
Assessment of cut sections	5	15
Optimal sampling (at least 2 full thickness placenta blocks)	8	24
Villous development	6	18
Maternal decidua	12	35
Relevant clinico-pathological correlation	18	53
Weight of the placenta	2	6

Although 'gross examination of the twin placenta' alone may be justified in an uncomplicated twin pregnancy where the only clinical indication may be confirmation of chorionicity, placental histology blocks (in accordance with RCPATH guidelines) should always be taken in all cases of stillbirths associated with twin pregnancy. Valuable information may be extrapolated from placental examination that could be relevant to the surviving twin or which may be useful in the management of a subsequent pregnancy. Preterm birth is frequent in twins and chorioamnionitis of the lower presenting twin may show a more prominent inflammatory response. IUGR in pregnancy-induced hypertension and macrosomia as a result of gestational diabetes are more common in twin pregnancies, especially in those with assisted reproduction. Assessment of the twin placenta after laser photocoagulation/twin anaemia-polycythaemia sequence may also provide important clinical information.

Human errors were identified in 5/50 cases where the placental examination was not available. In 4 cases, there was an intention for the placenta to be examined by a pathologist, but it was not sent due to a communication or team/system failure. In one case, an incorrect placenta was sent for pathological examination; this discrepancy was missed by the reporting pathologist too, who reported it as a singleton placenta. The reasons for the issues highlighted here are beyond the scope of this review, but there is a clear need for reviewing local placental examination pathways [10].

Recommendations

- P1. Ensure the pathologist is provided with a complete clinical history when requesting post-mortem or placental examination. In cases of twin pregnancy, this should be clearly indicated on the request, including chorionicity and details of the other twin should the examination be requested separately or if there is a surviving sibling.

Recommendations (continued)

- P2. Non-specialist pathologists who routinely report placental histology should engage in relevant training and CPD activities to improve the quality of their interpretation and reporting.
- P3. Document discussions with parents regarding placental examination.

7.5 Conclusions

Pathological examination of the placenta is an integral part of the investigation of stillbirth and the placenta should be submitted for examination all cases. Placental examination directly contributes to the understanding of the cause of death and should be encouraged in all cases, even if post-mortem examination is declined by the family. It is therefore a matter of some concern that a third of placental reports were regarded as poor or unsatisfactory. This is in sharp contrast to the placental histology reported by specialist perinatal pathologists alongside a post-mortem examination, where all placental histology reports were of good or excellent quality. This is clearly a significant, though not unexpected finding. A good placental report requires good clinical information in the request form and a nuanced understanding of the clinico-pathological aspects of the case.

Ideally, in cases of stillbirth in a singleton or twin pregnancy, the placenta should be examined by a specialised perinatal pathologist. However, it is well recognised that there is a national shortage of such experts in most of the perinatal centres across the country. Consequently, as was evident in the review, around a third of the placentas were examined and reported by non-specialist pathologists. It is strongly recommended that non-specialist pathologists who undertake placental histology reporting engage in relevant training and CPD activities to enhance and maintain their knowledge in the field. A significant number of placental reports lacked any meaningful clinico-pathological correlation or interpretation of histological findings. This is contrary to RCPPath guidance [2].

Placental pathology may provide relevant and useful clinical information even when the parents have declined a full post-mortem examination. The findings of this enquiry highlight the need for improved communication between obstetricians, neonatologists and perinatal pathologists. The value of a good clinical history on the request form cannot be overemphasised here, as the quality of the pathology report is directly related to the quality of the clinical information provided. Limited clinical information supplied to the pathologist will invariably lead to limited meaningful clinico-pathological correlation. In addition, the review finds that quality of the pathological examination of the placenta carried out by specialist pathologists was superior to those of non-specialist pathologists. All perinatal deaths should be discussed at local multidisciplinary meetings, ensuring that all clinical facts are addressed and correlated with the autopsy and placental findings. Overall, a good quality post-mortem and placental examination remains the gold standard in the clinical care of babies who are stillborn and those who die in the neonatal period.

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8. Communication, supervision and leadership issues

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8.1 Key findings

- Communication failures were identified in almost three-quarters of the pregnancies, although in two-fifths of pregnancies there were also examples of clear communication.
- In just over half of the pregnancies there was:
 - a failure in supervision or leadership. Additionally these same issues were noted in half of twin pregnancies where significant or major suboptimal care was identified that was probably or almost certainly relevant to the outcome of the babies or the mother;
 - missing or poorly completed documentation at different points of the care pathway;
 - a failure in or a lack of communication between health professionals at one or more points of the care pathway.
- There was a significant failure in communication between health professionals and women/parents in nearly a third of pregnancies.
- Electronic notes provided limited information, were repetitive and difficult to follow. In particular, there was a lack of recording of the details of conversations both between clinicians and with parents.

8.2 Background

In this final chapter we pull together the cross-cutting issues from the panel reviews: communication, supervision and leadership. Communication plays a role in every interaction between health professionals and with service users, at all points of the care pathway. As part of the confidential enquiry process, where a care issue is identified the panel considers not only *who* is ultimately responsible, but also *what* caused the issue; communications failure and failure to supervise are two key categories used (see Appendix A5). Panels can assign an issue to a number of categories. Unsurprisingly, communication issues are frequently identified as playing a role in the sub-optimal care described, although supervision and leadership issues are less common.

The provision of high quality health care is dependent upon effective communication between health care providers and the population they serve. Confidential enquiries have consistently identified communication issues that may have contributed to poor quality care provision [1-4], encompassing both written and verbal communication between specific health professional groups and multidisciplinary team members, as well as between health professionals and service users. Detailed, accurate and empathetic communication is important at all points on the care pathway and previous chapters have already highlighted concerns in this area. In twin pregnancies, high levels of expertise are required, so it is of particular importance that all aspects of communication are clear, accurate, unambiguous and timely, in order to facilitate joint planning and decision-making. This applies equally to antenatal, peripartum and postnatal settings. Similarly effective communication at all levels is of paramount importance to the physical and psychosocial well-being of bereaved parents [5].

8.3 Summary of findings

Where the consensus view of the panel was that an issue was either significant or major sub-optimal care which was either probably or almost certainly relevant to the pregnancy outcome, communications failures were identified in 36 of 50 pregnancies and supervision/leadership failures in 26 of the 50.

Confidential enquiry panels rely on an assessment of the case notes and are therefore limited by the availability of the complete notes for each case being provided to the MBRRACE-UK team. Requests for all notes relating to each twin pregnancy in the enquiry were sent to hospitals with a checklist to ensure all relevant documentation was provided. Any potential missing notes were followed up with the appropriate healthcare professionals and hospitals were asked to confirm that all notes had been despatched. At the consensus panel evaluation it was therefore considered that where there was no written information about a particular aspect of care then, following the principle of legal cases, it was reported as not recorded in the case notes and the assumption made that it did not occur.

The use of electronic notes is increasing within hospitals and a recurring theme throughout all the panels was the limited information that they contain compared to written notes, in particular a lack of recording of the detail of conversations both between clinicians and with parents. Panels found that many electronic notes tended to be repetitive, making the timeline and narrative difficult to follow. Relevant clinical information was not readily accessible and often required trawling through multiple repeated entries in order to find the most recent clinical findings. Some hospitals used a number of different and unconnected electronic systems at different parts of the care pathway, making a holistic view of the pregnancy difficult not only for the reviewers, but for the professionals caring for the woman and her babies. On several occasions apparently missing notes were subsequently discovered to have been recorded on a different electronic system.

The Better Births report [6] states that “Unbiased information should be made available to all women to help them make their decisions and develop their care plan. This should be through their own digital maternity tool, which enables them to access their own health records and information that is appropriate to them, including the latest evidence and what services are available locally”. Similarly, the Scottish Government’s Best Start plan [7] involves a move towards a national electronic maternity records system. However at enquiry panels there was no evidence of what information was available to women in their hand held notes when information was stored digitally. Problems with electronic notes have been identified in a number of the previous chapters and to address this more fully in our next enquiry we will include a standardised approach to measuring the impact of electronic notes on the care of mothers and babies to identify potential improvements for the future. The issues we have identified may also impact on medico-legal scrutiny of cases and Trusts and Health Boards must consider these potential problems when switching from written to electronic health records.

The provision of comprehensive information for women to be able to make informed choices about their care is of utmost importance and previous confidential enquiries have identified problems for women who have difficulty speaking or understanding English. In this enquiry all women had indicated that they were able to communicate in English so in all but one instance, where a partner was translating medical terms, the need for an interpreter was not raised as an issue.

An overview of the three aspects of communication covered by the enquiry are considered here, namely: missing or poor quality documentation, communication between health professionals, and communication with the parents. For over half of the pregnancies where such failures were identified (22 of 36) there were multiple communication issues highlighted from different points of the care pathway. However, there were also many instances where communication was highlighted as being exemplary: in 20 of the 50 pregnancies there were excellent examples of clear documentation and communication between members of the multidisciplinary team within the notes, in particular between midwives. There was also recording of detailed discussions and counselling with the parents, of which six had repeated examples along the care pathway.

Vignette 26: Excellent MDT communication

A woman with MCDA twins was being prepared for elective birth at 36 weeks of pregnancy. Prior to admission to theatre only one fetal heart was audible and a decision was made for a Category 1 emergency caesarean section. Following the birth there was an appropriate and sensitive debrief to the parents by both the obstetric and neonatal teams. They were kept fully updated on the surviving twin's progress during the baby's admission to the neonatal unit. There was also good continuity of care from the midwifery team in the postnatal period who ensured that the wider community team, including health visitor, were aware of the events surrounding birth.

8.4 Missing or poor quality documentation

Accurate and detailed record keeping is required to ensure adequate monitoring and treatment of women throughout their pregnancy, to provide insight into decision-making and to facilitate communication between members of the multidisciplinary team. This is of particular importance in twin pregnancies, where women are often transferred between hospitals and teams for specialist treatment. Some of the emerging themes around missing or poorly completed documentation have been highlighted in previous chapters. In total, in just over half (n=26) of the notes there were missing or poorly completed checklists or charts, many of which were bereavement checklists as discussed in the Chapter 6. For 12 women there were issues with the completeness, accuracy or consistency of the written notes during the antenatal, labour and birth or postnatal periods. Issues such as the inconsistent labelling and reporting of scan results have been mentioned in Chapter 3. Others include a lack of clarity regarding planning, decision-making and case management, a lack of notes following transfer from A&E, provision of limited or inaccurate information for maternal follow-up and poor documentation concerning the need for resuscitation. A specific area for concern was the lack or poor quality of follow-up letters for over a fifth (n=11) of the women.

Vignette 27: Inadequate intrapartum documentation

A woman with a DCDA twin pregnancy was admitted to delivery suite with a SROM and abdominal tightening at 22⁺³ weeks. There were signs of sepsis which were treated appropriately and conservative management was discussed due to the extremely preterm gestation of the babies. The neonatal team were not requested to be part of the discussion with the parents. Both babies were born within 6 hours. The last documented intrapartum entry was an urge to push reported by the mother followed immediately by details of a transfer to the postnatal ward. The only information available about the babies was sex and weight which was identifiable from the infant examination record. There was no follow-up appointment documented.

8.5 Communication between health professionals

Failures in or a lack of communication between health professionals at one or more point on the care pathway were identified in half (n=25) of the reviewed pregnancies. Specific issues during antenatal care related to delays or non-referral/escalation of women with identified risks to specialist teams or a lack of documented risk information for a fifth of pregnancies (n=9). During labour, birth and resuscitation there was a lack of appropriate obstetric/neonatal input or documented multidisciplinary discussion around the timing and mode of birth or monitoring of labour for just over a fifth of pregnancies (n=11). In a small number of cases a failure of communication between health professionals was identified at the postnatal stage, including a delay in consultant postnatal review and a failure to identify ongoing health issues for the surviving twin. Panels identified four instances where there was a failure of communication between health professionals during resuscitation and/or neonatal care provision. Issues concerning a lack of MDT discussions or any follow-up and review were identified for around a sixth of women (n=8). There were also examples of poor quality clinical summaries being sent to the perinatal pathologist with requests for placental histology and/or post-mortem leading to limited meaningful clinico-pathological correlation in reports.

Informing the health and relevant social care professionals who work in the community is recognised as a priority in caring for mothers and families immediately following stillbirth and neonatal death. Where a follow-up letter was available in the notes there were frequent instances where the letter had been written to the GP alone and just copied to the mother. Panels also identified a small number of cases where there was a failure to identify a need or to contact social services for vulnerable women.

Vignette 28: Poor communication between health professionals and social services

A woman was diagnosed with DCDA twins at her first booking appointment at 13 weeks gestation. Following the late booking the woman missed a consultant appointment and self-referred with several admissions to the maternity assessment unit with a brown PV loss. Handheld notes were not always available. There were clear signs that the woman had a complex history which was not identified in the early stages of her pregnancy. At 23⁺⁶ Twin 2 was confirmed as an IUFD. An in utero transfer was facilitated following a SROM the next day and Twin 1 was born shortly after. Information received post-delivery confirmed a complex psycho-social history which may have placed the woman at risk. This information was passed to the neonatal unit and managed appropriately.

8.6 Communication with parents

Following the diagnosis of a twin pregnancy it is important to provide information for women so that they are aware of any problems that may arise and how and when to access support. However, we identified examples at each stage of the care pathway where there was a failure in communication between health professionals and women/parents. Chapter 2 has already identified that there was no documented evidence that the risks of preterm birth was discussed with over half of the women during the antenatal period, nor was there any documented evidence of a timely discussion of the complication of twin-to-twin transfusion syndrome for three quarters of the monochorionic pregnancies. During the intrapartum period there were issues raised for around a fifth of pregnancies (n=9) where there was no record of any discussion with the mother about decisions concerning mode of birth or a failure to discuss or clarify parents' views concerning the potential for resuscitation and the prognosis for the babies. Failures to involve parents in discussions around decision-making continued into neonatal care where, for a small number of cases, there was no clear recording of parental views concerning the prognosis or reorientation of care for their baby. In others the parents' views were known but were ignored or overruled.

Communicating with bereaved parents is complex and requires expertise, sensitivity and empathy and can be especially difficult in multiple pregnancies. Parents need to be supported through this difficult time and provided with the information they require in order to make decisions following the death of their baby or babies. Whilst the panels commented on the good or excellent bereavement care provided for almost a third (n=14) of parents in this enquiry, unfortunately this was not the case for all. For almost a fifth (n=9) of the parents there was a lack of evidence of any bereavement care provision, whilst the offer of more formal bereavement counselling was only offered to just over a third (n=18). The main issues around provision of bereavement care and the specific issues relating to twin pregnancies are discussed more fully in Chapter 6 [8].

It is important that parents are offered an opportunity to ask questions of the health professional involved in their care to try and understand why their babies died. As such, parents should be offered a follow-up appointment to be held within twelve weeks of birth, allowing time for all relevant test data to be collated [9, 10]. However, there was evidence of the offer of a follow-up appointment with parents for only half of the twin pregnancies, including two cases where the mother was only offered a follow-up visit after having contacted the unit personally. Further details of the issues surrounding follow-up appointments are provided in Chapter 6. Evidence of a letter summarising the results of any investigations and/or post-mortem findings and any plans for managing any future pregnancy was noted for less than half (n=23) of the pregnancies. Only half of these letters were addressed directly to the parents (n=12), with a further nine letters addressed to the GP with a copy sent to the parents and the remaining two letters addressed to the GP alone. A fifth (n=5) of these letters were considered poor quality by the enquiry panels.

Vignette 29: Insensitive letter to parents

A woman with a complicated MCMA twin pregnancy was appropriately referred to a tertiary unit for fetal medicine review and intervention following a diagnosis of TTTS. There were technical complications during laser ablation and the procedure was abandoned. Both babies died shortly after. A follow up letter was sent to the mother by the referring hospital who offered condolences for the death of her baby despite this being a known twin pregnancy. The plan for future pregnancy was poor and there was no acknowledgment of the complexities of twin pregnancy loss.

In the 11 pregnancies that underwent a local review there was no evidence of communication with or involvement of the parents in the process. The cases selected for this enquiry were from 2017 and thus before the launch of the Perinatal Mortality Review Tool (PMRT) in 2018 [11]. Use of the tool is now part of the Maternity Incentive Scheme and the associated Clinical Negligence Scheme for Trusts (CNST) in England, which requires reviews of all stillbirths and neonatal deaths. Parental involvement in reviews is a key assessment criteria so the lack of communication with parents seen in this enquiry should no longer occur. Early results from the first 1,500 reviews completed with the PMRT indicate that 84% of parents were told that a review was taking place, and parental perspectives were sought in 75% of cases [12]. This is a clear and considerable improvement on the level of parent involvement seen in this and other MBRRACE-UK confidential enquiries and the Each Baby Counts programme [1, 2, 13].

8.7 Supervision and leadership

Leadership and supervision skills are critical for the management of twin pregnancy especially when problems arise. Timely and appropriate decision-making requires confidence and skill, with adequate and responsive supervision of more junior staff, multidisciplinary working and a recognition of the need for referral to specialist services when necessary. It is important that all staff are able to escalate the care and interventions required in complex pregnancies, gaining support and involving more senior staff in complex decision-making.

Supervision and leadership issues were noted in half (n=26) of the reviewed twin pregnancies where significant or major sub-optimal care was identified that was probably or almost certainly relevant to the outcome for the babies or the mother. During the antenatal period around a fifth (n=9) of pregnancies had issues with poor leadership or a lack of supervision identified. These included a number of cases where there was minimal or a total lack of medical input until after 20 weeks gestation, women cared for by teams with inadequate experience of twin pregnancy, delays in referral to fetal medicine units, no recognition of the signs and symptoms of TTTS by unsupervised midwife sonographers or obstetric trainees, and a failure of triage by midwifery staff. In a quarter (n=13) of pregnancies there was evidence of poor leadership and planning during labour and birth, including a lack of review of fetal monitoring, failure to prepare for preterm birth, confusion over the management of the birth of individual twins, a lack of consultant/MDT input, and poor management of the third stage of labour. Panel consensus highlighted sub-optimal care around leadership and supervision, with a lack of situational awareness, for a third (8 of 24) of cases admitted for neonatal care, with instances where there was poor leadership and a lack of consultant review and planning, an example where the care was described as 'chaotic', a lack of supervision of junior staff at intubation/extubation of the baby in two instances, and a failure to escalate care where required.

Vignette 30: Communication failures across the pathway

A woman with DCDA twins was appropriately referred to a fetal medicine unit following a size discrepancy noted on scan. However, selective fetal growth restriction was not recognised and therefore was not acted upon. Following a SROM at 26⁺⁵ the mother was admitted to the labour ward. A lack of leadership and supervision during the intrapartum period led to confusion around the mode of birth, with two visits to theatre, culminating in an emergency caesarean section for Twin 2 following the unexpected precipitate birth of Twin 1. There was a lack of senior neonatal supervision at the time of birth resulting in four attempts at intubation and a significant drop in temperature in Twin 2 prior to admission to the neonatal unit. There was no neonatal or obstetric follow-up and no plans made for a future pregnancy.

Recommendations

- C1. Practice and assess communication skills. Consider this as important as any other clinical skill.
- C2. Consider all aspects of communication throughout the care pathway as part of any perinatal death review.
- C3. Ensure that the adoption of electronic health care records does not impair clear communication between healthcare professionals and between healthcare professionals and service users.

8.8 Conclusions

A wide range of communication issues have been identified in this enquiry where improvements could be made at all points of the care pathway. As highlighted in previous enquiries, problems with record keeping remain an area of concern. Every effort should be made to improve documentation, recording all interactions and decision-making with mothers and their partners and clearly recording 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. Trusts and Health Boards must ensure that the adoption of electronic case notes does not add a layer of difficulty to following clinical planning and following case narrative.

Once again this enquiry has highlighted the need to improve communication between all members of the MDT within the main hospital of care, between non-specialist and specialist teams, between hospitals, and to ensure that the wider MDT members (e.g. perinatal pathologists and community teams) are provided with clear and accurate information. The establishment of multiple birth clinics, as suggested by the Twins Trust report [14] should enhance communication and leadership leading to improvements in the quality of care provision for women with twin or higher order pregnancies.

The added risks associated with twins or higher order pregnancies make it more likely that management plans will change over time. This makes the need for clear communication from all health care professionals with women and their partners absolutely vital at every stage of pregnancy. This should be undertaken by staff with the appropriate knowledge, and in situations where urgent or difficult decisions have to be made senior staff should be closely involved. All communications should be clearly and contemporaneously recorded in the case notes. Whilst it was not a major issue in the cases reviewed for this Confidential Enquiry, appropriate information and interpreting services must be readily available for women and their partners whose first language is not English.

Since communication issues lie at the heart of many health care-related problems that subsequently end in complaints it is essential that all staff regularly reflect on, practise and update their communication skills as they would other more technical aspects of the care they deliver.

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9. Recommendations

The following recommendations should be actioned by professional organisations, NICE, Clinical Directors, Heads of Midwifery, Maternity Safety Champions and health professionals.

Antenatal care: general

- A1. Ensure antenatal care for all women pregnant with twins is provided by a core, multidisciplinary team of specialists within a dedicated multiple pregnancy clinic.
- A2. The lead specialist obstetrician of the core team should provide each woman with a 16 week antenatal check to assess and explain the general and specific risks of her pregnancy.
- A3. The *a priori* risks and potential symptoms and signs of preterm labour, and the 'red flag' warning signs of TTTS if her pregnancy is monochorionic, should be explained to the woman at the 16 week antenatal visit, with advice to immediately self-refer for assessment if she experiences any of these symptoms.
- A4. Twin pregnancy is a risk factor for pre-eclampsia. The presence of other risk factors should therefore be carefully identified and documented to ensure prophylactic treatment is offered where indicated.
- A5. Prompt review by an obstetrician (experienced in the management of multiple pregnancies) for all women with a multiple pregnancy attending maternity triage units with unscheduled pregnancy-related concerns is essential.
- A6. Ensure that all clinical staff working within a maternity triage or emergency assessment area are equipped with knowledge of the pathophysiology and warning signs of extreme preterm birth and of twin-to-twin transfusion syndrome.
- A7. Consider reduced fetal movements in a twin pregnancy as a 'red-flag warning sign' of TTTS, in addition to rapid maternal abdominal distension, abdominal pain, and acute dyspnoea.

Antenatal care: scanning

- S1. Audit adherence to the national guidance for scan frequency, the quality of scans, and training, in order to improve the quality of scanning and documentation of scans provided by the multidisciplinary team at all levels (sonographers, obstetricians and fetal medicine specialists). Particular attention should be paid to:
 - Consistent labelling of the twins;
 - Plotting measurements on a growth chart;
 - Calculating weight discordance (where appropriate);
 - Recognition of the complications of twin pregnancy and referral to fetal medicine specialist in line with national guidance;
 - Ensuring the availability of adequately trained sonographers to monitor twin pregnancies
- S2. Develop a local process for regularly reviewing the training and expertise of sonographers and the quality of scanning of twin pregnancies.

Labour and birth

- L1. Ensure prompt senior obstetric review for all women with a multiple pregnancy (particularly those with threatened preterm labour at the extremes of prematurity) upon attendance at maternity services. Produce a clear plan made regarding monitoring in labour, mode of delivery and when referral is required. When necessary, there should be prompt senior neonatal involvement.
- L2. Where birth is anticipated between 22⁺⁰ and 26⁺⁶ weeks gestational age ensure prompt discussions between the parents, obstetric and neonatal teams to guide whether active resuscitation or palliative care should be undertaken. Care of the woman and her baby/babies should reflect the wishes and values of the woman and those of her partner, informed and supported by consultation and in partnership with obstetric and neonatal professionals
- L3. Ensure a review of individual plans of care is conducted by senior staff at least daily.
- L4. Consider delaying the birth of Twin 2 following the spontaneous preterm birth of Twin 1 at less than 24 weeks, if there are no contraindications such as infection, fetal compromise or bleeding.
- L5. Counsel parents prior to the birth of Twin 1, regarding the possible option of delayed birth of Twin 2 including the maternal risks as well as the risk of Twin 2 still being born at the extremes of prematurity.
- L6. In cases where delayed birth of Twin 2 is an option, manage the pregnancy as high risk in a tertiary centre, with close monitoring for signs of infection, clotting abnormalities and fetal growth.
- L7. In multiple pregnancies where a woman is in established labour or having a planned preterm birth, where appropriate, offer antenatal steroids between 22⁺⁰ and 35⁺⁶ weeks and antenatal MgSO₄ between 23⁺⁰ and 33⁺⁶ weeks.
- L8. In a twin pregnancy when established labour has been diagnosed, initiate and complete a partogram throughout all stages of labour.
- L9. Adopt the BAPM Clinical Framework for the Perinatal Management of Extreme Preterm Birth before 27 weeks of gestation; in particular:
 - Management of labour, birth and the decision on active resuscitation or palliative care should be made with the parents at the centre of the decision-making and informed and supported in partnership with a multidisciplinary team including obstetric and neonatal professionals.
 - Conversations with parents must be clearly documented and agreed management plans carefully and clearly communicated between professionals and staff shifts.
 - The decisions on management should be regularly reviewed before and after birth in conjunction with the parents and the plans reconsidered if the risk for the baby/babies changes or if parental wishes change.
- L10. Confirm the accurate gestational age of a pregnancy when a woman presents with threatened or established extreme preterm labour to enable the correct risk assessment for potential neonatal survival and therefore direct the optimal multidisciplinary care bundle.

Resuscitation and neonatal care

- N1. Where birth is at <27 weeks gestational age, every attempt should be made to deliver the babies in a centre with a tertiary level neonatal unit.
- N2. Involve parents in joint decision-making around resuscitation and stabilisation using both local and national outcome data to assist families to make an informed decision.
- N3. Ensure appropriately-trained senior staff lead parental counselling and subsequent interventions.

- N4. Undertake regular training and simulation sessions to maintain team skills in acute resuscitation.
- N5. Involve parents in joint decision-making around the care of their baby and respect their autonomy.
- N6. Consider re-orientation of care for babies deteriorating despite maximum intensive care and discuss the best interests of the baby with the parents.

Postnatal and bereavement care, follow-up and review

- F1. Adopt the standards of National Bereavement Care Pathway for pregnancy and baby loss regarding care of these parents. Particular attention should be given to:
 - Involvement of the bereavement team, where one exists;
 - Sensitive and caring consideration being given to the parents' wishes regarding seeing and holding the baby/babies and making memories, particularly if one twin survives;
 - Development and use of a bereavement checklist bespoke to multiple pregnancy;
 - Discussion of consenting to post-mortem examination as appropriate;
 - Joint working between the maternity and neonatal teams;
 - Continuity of care from the specialist multiples team (obstetrician and midwives) for postnatal and follow-up support.
- F2. Follow national guidance regarding offering a follow-up appointment to all women. Particular attention should be paid to:
 - Joint obstetric and neonatal review where it is appropriate;
 - Ensuring that the letter sent to parents is personalised and caring, and includes advice regarding any future pregnancies.
- F3. Where either one or both babies have died, as part of the PMRT process pay particular attention to:
 - Sensitive inclusion of parents' views;
 - Ensuring the tertiary centre is also included in the review process.

Post-mortem examination and placental histology reporting

- P1. Ensure the pathologist is provided with a complete clinical history when requesting post-mortem or placental examination. In cases of twin pregnancy, this should be clearly indicated on the request, including chorionicity and details of the other twin should the examination be requested separately or if there is a surviving sibling.
- P2. Non-specialist pathologists who routinely report placental histology should engage in relevant training and CPD activities to improve the quality of their interpretation and reporting.
- P3. Document discussions with parents regarding placental examination.

Communication, supervision and leadership

- C1. Practice and assess communication skills. Consider this as important as any other clinical skill.
- C2. Consider all aspects of communication throughout the care pathway as part of any perinatal death review.
- C3. Ensure that the adoption of electronic health care records does not impair clear communication between healthcare professionals and between healthcare professionals and service users.

Appendices

A1. Case review panel member guidance and training

Thank you for agreeing to take part in the confidential enquiry into multiple births, specifically twin pregnancies ending in at least one late fetal loss (22-23 weeks gestation), stillbirth or neonatal death. 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 perinatal deaths reported to MBRRACE-UK for babies born during 2017. Approximately 100 pregnancies have been selected to form the basis of the confidential enquiry and have been chosen to represent a geographical spread across the UK. The case notes of the selected women and babies have been anonymised to safeguard the identity of the babies and families involved. A Topic Expert Group was convened to steer the enquiry (a multidisciplinary group comprising of clinical experts and parent representatives). The aim of this group is to develop a framework against which cases can be assessed.

The assessment process

You will be asked whether you are able to 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 possible) 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 last the whole day and it is essential that all the members of the panel are present for the entire meeting. Each meeting will comprise a maximum of 12 panel members of mixed speciality and will be chaired by one of the MBRRACE-UK team.

Approximately 3-4 weeks 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 case notes and “score” the care. In addition one or perhaps two cases will be identified for which you will be asked to lead the discussion 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 consensus evaluation form, based on the panel review, 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 and 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 via telephone for all new panel members. 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 1 and 2).

Panel members will access the case notes they have been allocated online 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 available for viewing in an anonymised format and no attempt should be made by reviewers to try to identify the identity of cases.

We have developed a form to support the review process. 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, but also includes free text boxes for reviewer's opinions or other points they wish to raise, including examples of good care.

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 panel meeting, 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 the organisation which commissions MBRRACE-UK) 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.

A2. Confidentiality statement

Confidential Enquiry Panel Assessors

MBRRACE-UK is a collaboration led from the NPEU, University of Oxford who was appointed by the Healthcare Quality Improvement Partnership “HQIP”) to deliver the national Maternal, Newborn and Infant Clinical Outcome Review Programme, including the Confidential Enquiry into Perinatal Mortality and Morbidity. The MBRRACE-UK collaborators are delighted that you have agreed to act as an MBRRACE-UK Confidential Enquiry Panel Assessor.

The appointment requires you to review case studies and to provide your written findings, conclusions and recommendations in relation to your assessment of the case. Accordingly, your appointment will involve the disclosure to you, both directly and indirectly, of confidential case materials in a variety of forms and media. In consideration of the opportunity to be involved in this project as an MBRRACE-UK Confidential Enquiry Panel Assessor, please read the terms set out below, and confirm your agreement to these terms by signing the enclosed duplicate where indicated.

In my role as an MBRRACE-UK assessor I declare that:

- I undertake not to make or keep an electronic or paper copy of the case materials with which I am provided for the purposes of MBRRACE-UK confidential enquiries.
- I will only discuss the details of any individual case findings, conclusions and recommendations) which I assess in my role as an MBRRACE-UK assessor with other MBRRACE-UK assessors and members of the MBRRACE-UK team unless otherwise specifically authorised to do so by the MBRRACE-UK Perinatal Lead Prof Elizabeth Draper.
- I will at all times keep completely confidential any information relating to the review of individual cases, discussions with other MBRRACE-UK panel assessors and MBRRACE-UK team members, and any other aspects of my role as an MBRRACE-UK panel assessor.
- Should I recognise a case from my clinical work, medico-legal work or some other set of circumstances I will immediately stop reviewing the case and declare this prior knowledge to the MBRRACE-UK Perinatal Lead Prof Elizabeth Draper, or to the MBRRACE-UK Lead Prof Jenny Kurinczuk. I understand that depending upon the circumstances it may be necessary to reallocate the case.
- Having reviewed an individual case for the purposes of the MBRRACE-UK confidential enquiries should I encounter this case at any point in the future in relation to medico-legal work or any other similar work, that I will declare a conflict of interest and withdraw from that work thereby ensuring that I do not make use of any privileged information arising from my involvement in MBRRACE-UK for any other purposes and that all such activities are kept completely separate and confidential.
- In the course of my work for MBRRACE-UK that I understand that I am bound by my usual professional code of conduct.
- I understand that this agreement will extend in perpetuity beyond my tenure as an MBRRACE-UK panel assessor.

Signature: Date:

Name:

A3. Declaration of Relevant Interests form

Name:	
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Relevant paid interests it is not necessary to disclose the amount):

Other relevant interests e.g. membership of organisations or unpaid work):

Relevant interests of the panel assessor personal partner and other close family members:

Is there any other information which would be deemed reasonable for the MBRRACE-UK team to be informed of that could give rise to a conflict or perceived conflict of interest with the MBRRACE-UK Confidential Enquiry work?

I have declared above all current, relevant interests and I will identify any future interests to the MBRRACE-UK team if and when they arise.

Signed **Date**

Name

A4. Standards and guidelines

The table below lists the standards and guidelines for good practice which were in effect during the period when the reviewed deaths occurred. These are available to you for reference when evaluating the care provision from the case notes allocated to you for review. Please click on the web link for direct access to the full guidance.

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.

Organisation	Code	Name	Date	Applicable stage of the care pathway
RCOG	GTG55	Late intrauterine fetal death and stillbirth	Oct 2010	Antenatal, intrapartum, postnatal, bereavement care, post-mortem examination
RCOG	GTG57	Reduced fetal movements	Feb 2011	Antenatal care
RCOG	GTG51	Management of monochorionic twin pregnancy	Nov 2016	Antenatal care
RCOG	-	Providing quality care for women: a framework for maternity service standards	Nov 2016	Antenatal, intrapartum, resuscitation, postnatal, bereavement care, post-mortem examination
NICE	CG37	Postnatal care up to 8 weeks after birth	Jul 2006	Postnatal care
NICE	CG62	Antenatal care for uncomplicated pregnancies	Mar 2008	Antenatal care
NICE	CG70	Inducing labour	Jul 2008	Antenatal, intrapartum care
NICE	CG110	Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors	Sep 2010	Antenatal, intrapartum, resuscitation, postnatal, bereavement care, post-mortem examination
NICE	CG132	Caesarean section	Nov 2011	Intrapartum care
NICE	CG129	Multiple pregnancy: antenatal care for twin and triplet pregnancies*	Sep 2011	Antenatal care
NICE	CG149	Neonatal infection early onset): antibiotics for prevention and treatment	Aug 2012	Neonatal care
NICE	CG190	Intrapartum care for healthy women and babies	Dec 2014	Intrapartum care
NICE	CG192	Antenatal and postnatal mental health: clinical management and service guidance	Dec 2014	Antenatal, postnatal care
NICE	NG3	Diabetes in pregnancy: management from preconception to the postnatal period	Feb 2015	Antenatal, intrapartum, postnatal care
NICE	PH27	Weight management before, during and after pregnancy	Jul 2010	Antenatal, postnatal care
NICE	QS22	Antenatal care	Sep 2012	Antenatal care
NICE	QS35	Hypertension in pregnancy	Jul 2013	Antenatal, intrapartum, postnatal care

Organisation	Code	Name	Date	Applicable stage of the care pathway
NICE	QS46	Multiple pregnancy: twin and triplet pregnancies	Sep 2013	Antenatal care
OAA/AAGBI	-	Guidelines for Obstetric Anaesthetic Services	Jun 2013	Anaesthetic care
RCUK	-	Resuscitation and support of transition of babies at birth	2015	Resuscitation care
BAPM	-	Service Standards for Hospitals Providing Neonatal Care*	Aug 2010	Neonatal care
Sands	-	Pregnancy Loss and the Death of a Baby: Guidelines for professionals, 4th edition	2016	Resuscitation, bereavement care, post-mortem examination
Sands	-	The Sands Audit Tool for Maternity Services*	2014	Intrapartum, resuscitation, postnatal, bereavement care, post-mortem examination
RCPATH	-	Guidelines on autopsy practice	Sep 2002	Post-mortem examination
RCPATH	-	Tissue pathway for histopathological examination of the placenta	Sep 2011	Placental histology
HTA	-	Standards and Guidance: B - Post-mortem Examination	Jan 2016	Post-mortem examination

* Link removed as document is no longer available.

A5. Evaluation form



**MBRRACE-UK Confidential Enquiry 2018
CONSENSUS EVALUATION**

Case number: PCE _____

Panel: _____

Sub-optimal care

- 0: No sub-optimal care
- 1: Minor suboptimal care
- 2: Significant suboptimal care
- 3: Major suboptimal care
- C: Comment only

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.

	STAGE OF CARE PATHWAY:	Sub-optimal care	Relevance	What	Who
1		0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> C <input type="checkbox"/>	0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/>	R <input type="checkbox"/> A <input type="checkbox"/> C <input type="checkbox"/> S <input type="checkbox"/> H <input type="checkbox"/> E <input type="checkbox"/> O <input type="checkbox"/>	
2		0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> C <input type="checkbox"/>	0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/>	R <input type="checkbox"/> A <input type="checkbox"/> C <input type="checkbox"/> S <input type="checkbox"/> H <input type="checkbox"/> E <input type="checkbox"/> O <input type="checkbox"/>	
3		0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> C <input type="checkbox"/>	0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/>	R <input type="checkbox"/> A <input type="checkbox"/> C <input type="checkbox"/> S <input type="checkbox"/> H <input type="checkbox"/> E <input type="checkbox"/> O <input type="checkbox"/>	
4		0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> C <input type="checkbox"/>	0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/>	R <input type="checkbox"/> A <input type="checkbox"/> C <input type="checkbox"/> S <input type="checkbox"/> H <input type="checkbox"/> E <input type="checkbox"/> O <input type="checkbox"/>	
5		0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> C <input type="checkbox"/>	0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/>	R <input type="checkbox"/> A <input type="checkbox"/> C <input type="checkbox"/> S <input type="checkbox"/> H <input type="checkbox"/> E <input type="checkbox"/> O <input type="checkbox"/>	
6		0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> C <input type="checkbox"/>	0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/>	R <input type="checkbox"/> A <input type="checkbox"/> C <input type="checkbox"/> S <input type="checkbox"/> H <input type="checkbox"/> E <input type="checkbox"/> O <input type="checkbox"/>	
7		0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> C <input type="checkbox"/>	0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/>	R <input type="checkbox"/> A <input type="checkbox"/> C <input type="checkbox"/> S <input type="checkbox"/> H <input type="checkbox"/> E <input type="checkbox"/> O <input type="checkbox"/>	
8		0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> C <input type="checkbox"/>	0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/>	R <input type="checkbox"/> A <input type="checkbox"/> C <input type="checkbox"/> S <input type="checkbox"/> H <input type="checkbox"/> E <input type="checkbox"/> O <input type="checkbox"/>	

MBRRACE-UK Confidential Enquiry: Case Evaluation Form v2 Consensus version

Summary comments:

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

Care relating to the death of the baby/babies: 1
2
3

Care after the death of the baby/babies: 1
2
3

A6. Checklist variables

ANTENATAL CARE		Coding
ANC1	Location of antenatal care tick all that apply):	1=DGH 2=Tertiary 3=Both
ANC2	Was the diagnosis of twin pregnancy made before 13 ⁺⁶ ?	0=No 1=Yes
ANC3	If no, was it documented why?	0=No 1=Yes 99=N/A
ANC4	Was chorionicity defined before 13 ⁺⁶ ?	0=No 1=Yes
ANC5	If no, was it documented why?	0=No 1=Yes 99=N/A
ANC6	If chorionicity was not defined did the pregnancy follow the monochorionic pathway?	0=No 1=Yes 99=N/A
ANC7	Was amnionity defined before 13 ⁺⁶ ?	0=No 1=Yes
ANC8	If no, was it documented why?	0=No 1=Yes 99=N/A
ANC9	Was the woman referred to a specialised team?	0=No 1=Yes
	If yes, please indicate which of the following are documented:	
ANC10	Core team of named obstetricians	0=No 1=Yes
ANC11	Specialist midwives	0=No 1=Yes
ANC12	Ultrasonographers	0=No 1=Yes
ANC13	Was it documented that there was a discussion with the woman about chorionicity-based risk before 16 weeks?	0=No 1=Yes
ANC14	Was it documented that there was a discussion with the woman about the risk of preterm birth?	0=No 1=Yes
ANC15	Was it documented that there was a discussion with the woman about the timing and mode of birth by 32 weeks?	0=No 1=Yes
Scanning		
SCAN1	Were the twins scanned every 2 weeks from 16 weeks MC) / every 4 weeks from 20 weeks DC)?	0=No 1=Yes
SCAN2	Was the scanning carried out by a fetal medicine consultant or consultant obstetrician with special interest?	0=No 1=Yes 2=Partially
SCAN3	Was there a scan growth chart in the notes?	0=No 1=Yes
SCAN4	If yes, were the growth scans plotted?	0=No 1=Yes 99=N/A
SCAN5	If yes, were they plotted correctly?	0=No 1=Yes 99=N/A
SCAN6	Were abnormalities responded to?	0=No 1=Yes 99=N/A
SCAN7	Was the percentage difference in the estimated fetal weight identified?	0=No 1=Yes
	If yes and this was greater than 25%:	
SCAN8	Was there evidence of increased weekly) ultrasound surveillance?	0=No 1=Yes 99=N/A
SCAN9	Was there evidence of fetal doppler assessments?	0=No 1=Yes 99=N/A
SCAN10	Was there evidence of referral to local fetal medicine expert?	0=No 1=Yes 99=N/A
Screening		
	Were any of the following risk factors present/identified?	
SCREEN1	Pre-eclampsia/ hypertension present	0=No 1=Yes
SCREEN2	Pre-eclampsia/ hypertension identified	0=No 1=Yes 99=N/A
SCREEN3	If identified, was 75mg aspirin started by 16 weeks	0=No 1=Yes 99=N/A
SCREEN4	Was TTTS identified?	0=No 1=Yes
	If yes:	
SCREEN5	Was this referred to local fetal medicine expert or consultant obstetrician within 24 hours of diagnosis	0=No 1=Yes 99=N/A

SCREEN6	Was a management plan discussed with tertiary fetal medicine centre within 3 working days	0=No 1=Yes 99=N/A
	During the antenatal period were any of the following fetal complications present/identified? Please tick all that apply	
SCREEN7	Spontaneous single IUD present	0=No 1=Yes
SCREEN8	Spontaneous single IUD identified	0=No 1=Yes
SCREEN9	Spontaneous single IUD managed appropriately	0=No 1=Yes 99=N/A
SCREEN10	Spontaneous double IUD present	0=No 1=Yes
SCREEN11	Spontaneous double IUD identified	0=No 1=Yes
SCREEN12	Spontaneous double IUD managed appropriately	0=No 1=Yes 99=N/A
	If there were antenatal complications was the planned timing of delivery:	
SCREEN13	Reviewed?	0=No 1=Yes 99=N/A
SCREEN14	Appropriate?	0=No 1=Yes 99=N/A
SCREEN15	Discussed with the mother?	0=No 1=Yes 99=N/A
INTRAPARTUM CARE		
Onset of labour		
INTRA1	Mode of onset of labour:	1=Spontaneous 2=Induction 3=Planned C/S
INTRA2	Gestation at onset of labour:	Weeks + days
Birth		
	What was the final mode of birth?	
INTRA3	Twin 1	1=Vaginal vertex 2=Vaginal breech 3=C/S
INTRA4	Twin 2	1=Vaginal vertex 2=Vaginal breech 3=C/S
INTRA5	If birth occurred before 34 weeks were antenatal steroids initiated?	0=No 1=Yes 99=N/A
INTRA6	If no, why not?	Text
INTRA7	If birth occurred before 30 weeks gestation was magnesium sulphate initiated for fetal neuroprotection?	0=No 1=Yes 99=N/A
INTRA8	If no, why not?	Text
Monitoring		
INTRA10	Was there sufficient time before the birth to consider the use of a partogram?	0=No 1=Yes
INTRA11	Was a partogram filed in the mother's medical case notes?	0=No 1=Yes
INTRA12	If yes, was the partogram completed? Please choose one option	0=Not at all 1=Full 2=Partially 99=N/A
NEONATAL CARE		
Twin 1		
NEO1	Did the baby require neonatal care, including resuscitation or stabilisation?	0=No 1=Yes
	If no, please skip to Twin 2	
NEO2	Did the baby require resuscitation/stabilisation?	0=No 1=Yes 99=N/A
NEO3	Was the offer of resuscitation in line with the parents' wishes?	0=No 1=Yes 99=N/A
NEO4	Were there problems with the resuscitation?	0=No 1=Yes 99=N/A
	If yes, were these related to: Please tick all that apply	
NEO5	Trained resuscitator not requested to attend prior to birth	0=No 1=Yes 99=N/A
NEO6	Inadequate leadership	0=No 1=Yes 99=N/A

NEO7	Insufficient numbers of personnel present	0=No 1=Yes 99=N/A
NEO8	Problems in achieving intubation	0=No 1=Yes 99=N/A
NEO9	Problems in achieving lung aeration	0=No 1=Yes 99=N/A
NEO10	Problems with equipment	0=No 1=Yes 99=N/A
NEO11	Insufficient equipment	0=No 1=Yes 99=N/A
NEO12	Overall approach to resuscitation inadequate	0=No 1=Yes 99=N/A
NEO13	Other please specify):	Text
NEO14	Were the parents counselled by senior members of the neonatal team regarding likely outcomes?	0=No 1=Yes 99=N/A
NEO15	Before birth	0=No 1=Yes 99=N/A
NEO16	After birth	0=No 1=Yes 99=N/A
NEO17	Was the decision-making in relation to any decision to re-orientate care appropriate?	0=No 1=Yes 99=N/A
Twin 2		
NEO18	Did the baby require neonatal care, including resuscitation or stabilisation?	0=No 1=Yes
	If no, please skip to Both Babies	0=No 1=Yes
NEO19	Did the baby require resuscitation/stabilisation?	0=No 1=Yes 99=N/A
NEO20	Was the offer of resuscitation in line with the parents' wishes?	0=No 1=Yes 99=N/A
NEO21	Were there problems with the resuscitation?	0=No 1=Yes 99=N/A
	If yes, were these related to: Please tick all that apply	
NEO22	Trained resuscitator not requested to attend prior to birth	0=No 1=Yes 99=N/A
NEO23	Inadequate leadership	0=No 1=Yes 99=N/A
NEO24	Insufficient numbers of personnel present	0=No 1=Yes 99=N/A
NEO25	Problems in achieving intubation	0=No 1=Yes 99=N/A
NEO26	Problems in achieving lung aeration	0=No 1=Yes 99=N/A
NEO27	Problems with equipment	0=No 1=Yes 99=N/A
NEO28	Insufficient equipment	0=No 1=Yes 99=N/A
NEO29	Overall approach to resuscitation inadequate	0=No 1=Yes 99=N/A
NEO30	Other please specify):	Text
NEO31	Were the parents counselled by senior members of the neonatal team regarding likely outcomes?	0=No 1=Yes 99=N/A
NEO32	Before birth	0=No 1=Yes 99=N/A
NEO33	After birth	0=No 1=Yes 99=N/A
NEO34	Was the decision-making in relation to any decision to re-orientate care appropriate?	0=No 1=Yes 99=N/A
Both babies		
NEO35	Was there confusion over which twin was which? Please tick all that apply	
NEO36	Antenatally	0=No 1=Yes
NEO37	Postnatally	0=No 1=Yes
BEREAVEMENT CARE		
BEREAVE1	Was there evidence of a bereavement midwife being involved?	0=No 1=Yes
BEREAVE2	If one twin died in utero was there evidence of bereavement planning pre-delivery?	0=No 1=Yes 99=N/A

	Who provided the bereavement care? Please tick all that apply	
BEREAVE3	Community midwifery team	0=No 1=Yes
BEREAVE4	Obstetric/hospital midwifery team	0=No 1=Yes
BEREAVE5	Neonatal team	0=No 1=Yes
BEREAVE6	Was the bereavement care coordinated between the maternity and neonatal teams?	0=No 1=Yes
BEREAVE7	Were the parents offered follow-up counselling?	0=No 1=Yes
Community midwifery care		
BEREAVE8	Was the mother seen by a community midwife?	0=No 1=Yes 99=Not known
BEREAVE9	If yes, how many visits were documented?	Number
Post-mortem examination		
PM1	Was it documented whether the parents were given written information about post-mortem examination?	0=No 1=Yes
PM2	If one twin died and the other survived, were the parents counselled about the significance of the post-mortem findings for the surviving twin?	0=No 1=Yes 99=N/A
PM3	Were the parents given the opportunity to delay consent for a post-mortem if one twin died and one survived, where survival of the second twin was not certain?	0=No 1=Yes 99=N/A
PM4	If a post-mortem or placental histology examination took place was it conducted by a specialist perinatal pathologist?	0=No 1=Yes 99=N/A
Bereavement follow-up visit		
FOLLOW1	Did the bereavement follow-up appointment take place?	0=No 1=Yes
	If yes:	
FOLLOW2	How long after the baby's death in weeks):	Weeks
	Who was the appointment with? Please tick all that apply	
FOLLOW3	Obstetrician	0=No 1=Yes
FOLLOW4	Neonatologist	0=No 1=Yes
FOLLOW5	Senior midwife	0=No 1=Yes
FOLLOW6	Other please specify):	Text
FOLLOW7	Was it documented whether a plan was discussed for any future pregnancy?	0=No 1=Yes 99=N/A
	Was a letter summarising results of the review of care/investigations relating to the mother/post-mortem examination and a plan for managing future pregnancies if relevant) sent to:	
FOLLOW8	Bereaved parents	0=No 1=Yes
FOLLOW9	GP	0=No 1=Yes
LOCAL REVIEW OF PERINATAL DEATH		
REVIEW1	Was a local review of care undertaken?	0=No 1=Yes
	If yes:	
	Who was involved? Please tick all that apply	
REVIEW2	Midwife	0=No 1=Yes 99=N/A
REVIEW3	Obstetrician	0=No 1=Yes 99=N/A
REVIEW4	Neonatologist	0=No 1=Yes 99=N/A
REVIEW5	Pathologist	0=No 1=Yes 99=N/A
REVIEW6	Anaesthetist	0=No 1=Yes 99=N/A
REVIEW7	Senior manager	0=No 1=Yes 99=N/A
REVIEW8	Risk manager/governance lead	0=No 1=Yes 99=N/A
REVIEW9	Parents/family members	0=No 1=Yes 99=N/A
REVIEW10	External person	0=No 1=Yes 99=N/A
REVIEW11	Other please specify):	0=No 1=Yes 99=N/A

REVIEW12		Not recorded	0=No 1=Yes 99=N/A
REVIEW13	Were any actions identified?		0=No 1=Yes 99=N/A
	If yes, were these:		
REVIEW14		Individual	0=No 1=Yes 99=N/A
REVIEW15		Institutional	0=No 1=Yes 99=N/A
REVIEW16	What was the quality of the review?		1=Good 2=Adequate 3=Poor 99=N/A

A7. Post-mortem examination checklist



Case ID: PCE_____

Twin 1 Twin 2 Both

Perinatal Confidential Enquiry 2018/19: Multiple Births Post-mortem checklist v1.1

Last updated 12/12/18

INFORMATION ABOUT CURRENT PREGNANCY			
1. Was the following information available to the pathologist?			
Maternal History			
Maternal Age	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Maternal BMI	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Relevant family history e.g. anomalies or consanguinity	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Information relating to previous pregnancies	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Information relating to previous pregnancy losses	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Current Pregnancy			
Estimated date of delivery	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Antenatal infection screen	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Abnormal findings on scan eg TTTS	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Any history of discrepancy in growth of twins	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Any history of discrepancy in liquor volume between twins	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Any history of antenatal therapy eg ablation or reduction	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Any history of maternal hypertension or PET	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Any history of pyrexia	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Any history of membrane rupture	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Gestational age Twin 1 and Twin 2	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Birth weight of Twin 1 and Twin 2	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Indication for referral including possible history of TTTS	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Chorionicity	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
History of laser ablation if monochorionic	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A
Information relating to any surviving twin	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A
REPORT			
2. Was there a statement regarding consent or authorisation?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
3. Was there a clinical summary?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
4. Does the report contain a clinicopathological comment?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
If yes:			
Was the clinicopathological comment appropriate?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Did it relate to the clinical history?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Did it include appropriateness of growth in relation to other twin and for gestation?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Did it include any discrepancies between the placentas of each twin?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A
5. Does the report make reference to the other twin?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
EXTERNAL EXAMINATION			
6. Did the report contain the following:			
Detailed description of the infant?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Birthweight and centile	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
OFC	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Length	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Foot length	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
7. Was there a comment on appropriate size of infant for gestation?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
8. Was there a comment relating to any described dysmorphic features?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	

INTERNAL EXAMINATION

9. Was there a detailed description of each system?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
10. Were any abnormalities described in detail?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
11. Were organ weights recorded with appropriate reference ranges?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	

INVESTIGATIONS

12. Does the report include a list of investigations and findings (positive or negative)?			
Bacteriology	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Virology	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Genetics	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Clinical photographs	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Radiology	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
MRI or other	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
13. Was there adequate sampling for histology of each organ?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
14. Was there a list of all histology taken?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
15. Does the report contain a microscopic description of the following?			
Lungs	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Heart	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Liver	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Kidneys	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Neuropathology	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
16. Does the report include a description of the placenta?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
17. Does the report include the histology of the placenta?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	

18. Additional comments :

Overall, how would you grade the quality of this post-mortem report?

Poor

Satisfactory

Good

Excellent

A8. Placental histology checklist



Case ID: PCE _____

Twin 1 Twin 2 Both

Perinatal Confidential Enquiry 2018/19: Multiple Births Placental histology checklist v1.1

Last updated 10/12/18

1. Was the following information available to the pathologist?			
Gestational age Twin 1 and Twin 2	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Birthweight of Twin 1 and Twin 2	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Indication for referral including possible history of TTTS	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Chorionicity	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
History of laser ablation if monochorionic	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A
Twin territories clearly indicated	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Maternal history	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Maternal BMI	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Information relating to previous pregnancies	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Information relating to surviving twin	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A
2. Were the following noted in the macroscopic description for each twin?			
Comment on chorionicity	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Length of umbilical cords and approximate diameter	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Site of cord insertion for each twin	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Number of umbilical cord vessels, each twin	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Degree of coiling, each twin	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Appearance of the placental membranes, both territories	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Appearance of the fetal surface, both territories	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Appearance of the maternal surface (complete or incomplete: attached clot)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Weight of trimmed placental disc (state fixed or unfixed)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Measurement of placental disc (in 3 dimensions)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Appearance of the cut surface (if no lesions - is this stated?)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Rough assessment of percentage of infarction if present	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A
Weight of clot if received	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A
3. Was there adequate sampling for histology of each placental territory?			
One transverse section of umbilical cord (preferable two) taken 1 cm above insertion	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
One roll of membranes to include parenchyma	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
At least two full thickness blocks of the placental parenchyma	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
At least one block of any lesion described macroscopically	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
4. Does the report contain a microscopic description of the following?			
Umbilical cord	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Membranes	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Villous development (in relation to gestational age)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Any focal lesions	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Maternal decidua (i.e. maternal vessels)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
5. Does the report contain a clinicopathological comment including any discrepancies between the placentas of each twin?			
	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
6. Specific considerations for monochorionic placentas:			
Was the site and distance between the two umbilical cords recorded?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Was the relative shares of the placental disc commented upon?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Was the vasculature of the chorionic plate assessed for anastomoses?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Were dye studies carried out?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	

7. Additional comments:

Overall, how would you grade the quality of this placental pathology report?

Poor Satisfactory Good Excellent

A9. Abbreviations

BAPM	British Association of Perinatal Medicine
BMI	Body Mass Index
CTG	Cardiotocography
HQIP	Healthcare Quality Improvement Partnership
ICSI	Intra-Cytoplasmic Sperm Injection
ISUOG	International Society of Ultrasound in Obstetrics and Gynaecology
IUFD	Intrauterine Fetal Death
IUGR	Intrauterine Growth Restriction
IVF	In-Vitro Fertilisation
LDA	Low Dose Aspirin
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MNI-CORP	Maternal, Newborn and Infant Clinical Outcome Review Programme
NICE	National Institute for Health and Care Excellence
RCOG	Royal College of Obstetricians and Gynaecologists
RCPATH	Royal College of Pathologists
sFGR	Selective Fetal Growth Restriction
SFH	Symphysis-Fundal Height
SROM	Spontaneous Rupture of Membranes
TAPS	Twin (or Triplet) Anaemia Polycythaemia Sequence
TEG	Topic Expert Group
TTTS	Twin-to-Twin Transfusion Syndrome

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