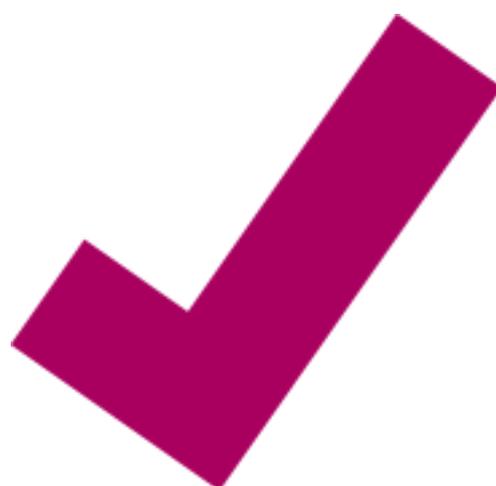


Recommendations for the Improvement of Stillbirth and Bereavement Care in Yorkshire and the Humber



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1 Introduction

1.1 Background

A wide variation in stillbirth rates continues to exist between regions in England (CMACE 2011). In January 2014 the House of Commons report stated that stillbirths and early neonatal deaths remain higher in England than the other UK nations (House of Commons 2014). The average rate for England is reported to be 4.7/1000 births with the lowest regional rate being South East Coast (3.8 / 1000 births) and Yorkshire and the Humber (Y&H) amongst the highest rates at 5.3 / 1000 births (ONS).

Data from ONS shows:

2011: National rate for England & Wales	=	5.3 / 1000 births
Yorks & the Humber	=	5.7 / 1000 births
2012: National rate for England & Wales	=	4.9 / 1000 births
Yorks & the Humber	=	5.1 / 1000 births
2013: National rate for England & Wales	=	4.7 / 1000 births
Yorks & the Humber	=	5.3 / 1000 births

Reducing stillbirth rates and improving women and their families experiences has been highlighted as a national priority as identified in the NHS England Mandate and the NHS Outcomes Framework Domain 1: Preventing people from dying prematurely and Domain 4: Ensuring that people have a positive experience of care (DH 2014). The National Clinical Director for Maternity & Women's Health also highlights stillbirths as a continued, significant risk during pregnancy and a priority for improvement work.

Stillbirths were identified as a local priority at the Yorkshire and the Humber Strategic Clinical Network (SCN) Stakeholder Engagement Event in September 2013. Subsequently, a Y&H Stillbirth Task & Finish Group was established in May 2014 and identified four priority areas for change. The aim of the Task & Finish Group was to develop a set of recommendations which if implemented could result in:

- A reduction in stillbirth rates
- A reduction in regional variation
- An improved user experience

1.2 Scope

The scope of these recommendations includes reducing the risk of stillbirth (24 weeks gestation or more) and the provision of bereavement care for women and families experiencing a stillbirth across Y&H and does not include care for women with late miscarriages.

1.3 National Recommendations

National recommendations for reducing stillbirths in the form of a Stillbirth Care Bundle are under development and consist of the following elements:

- Smoking cessation
- Small for gestational age
- Reduced fetal movement
- Fetal monitoring

The proposed national recommendations have been taken into consideration in developing the Y&H recommendations to prevent duplication.

1.4 Development of the Yorkshire and the Humber Recommendations

The Y&H Stillbirth Task & Finish Group reviewed current practice, best available evidence and key documents to consider areas for development in reducing stillbirth rates and improving care for bereaved women and their families. Four areas were identified:

- Risk Reduction
- Bereavement Care
- Stillbirth Investigations
- Subsequent Pregnancies

The Y&H recommendations were developed based on these four areas following a Yorkshire and the Humber Stillbirth Workshop held in November 2014. Delegates included stakeholders from all Y&H Trusts (both midwifery and obstetric colleagues), commissioner representation, public health, service users, Stillbirth and Neonatal Death Charity (SANDS), Maternity Service Liaison Committee and bereavement midwives.

2 Recommendations

Each of the four areas were considered to identify:

- Recommendations for commissioners and provider trusts
- Recommendations for Maternity Services
- An area where further work or consideration is required

Summary pages for each of these can be found in appendix 1 - 3.

The tables below take each area in turn identifying recommendations, good practice and further work.

2.1 Risk Reduction

Element 1: Risk Reduction

Background

This element considered the following risk reduction issues (in addition to those already identified in the National Stillbirth Care Bundle):

- Obesity
- BME (Black and Minority Ethnic) & vulnerable women
- Advance Maternal Age
- Preventable Congenital Abnormalities
- IVF (In Vitro Fertilisation)
- Teenage Pregnancies
- Postmaturity & Induction of Labour
- Management of Latent Phase
- Smoking (other than the National Stillbirth Care Bundle interventions)

Recommendations for Commissioners and Trusts

Data Collection

1. Commissioners should require Trusts to consistently collect and review data on all stillbirths on an annual basis as a minimum. Commissioners should require Trusts to communicate the data review outcomes to them through a local forum with evidence of responding to local trends or themes. [links to 'Further Work' section – development of a stillbirth minimum dataset]

Smoking in Pregnancy

2. Commissioners should as a minimum, require Trusts to undertake a repeat Carbon Monoxide (CO) test for all women between 28-36 week appointment (ASH 2013, NICE 2010).

Recommendations for Maternity Services

National Guidance

1. Trusts should benchmark their Reduced Fetal Movements and Small for Gestational Age policies against the RCOG green-top guideline recommendations.

Public Health

2. Trusts should provide all pregnant women (including low risk) with consistent messages regarding healthy lifestyle advice including nutrition and smoking cessation (NICE 2008).
3. Trusts should ensure they work in partnership with Smoking Cessation Services to develop services to meet the needs of pregnant teenagers (NCSCCT 2014).

Vulnerable Women

4. Trusts should have a systematic approach to identify vulnerable isolated women at booking. There should be clear processes for engaging non-attendance at clinics with consideration to personalised care pathway.

Early Detection of Congenital Abnormalities

5. Trusts may consider an extra ultrasound scan at 16 weeks for women with recognised recurrent risk e.g. a recessive genetic condition, neural tube effect.

Management of Latent Phase

6. Trusts should ensure guidelines include definition, management and fetal risk assessment in the latent phase of labour.
7. Trusts should ensure women getting consistent advice for latent phase from Labour Ward, Triage or Community. Rotation of staff & appropriate skill mix may facilitate this.

Further Work / Considerations

Data Collection

1. The SCN will facilitate development of a stillbirth minimum dataset. This will support comparative data collection across Y&H to provide regional evidence and support inter-organisational peer review.

Networking

2. The SCN will set up a bereavement midwife network email group across the region to share good practice and discuss challenges.

Obesity

3. Trusts should consider how to maximise the contact time with women attending for glucose tolerance tests (GTT's) to include healthy lifestyles / dietary advice and to consider the use of service users / videos.
4. Local Authority and Primary Care should consider ways to reduce Body Mass Index (BMI) in women of child-bearing age.

Early Detection of Congenital Abnormalities

5. The SCN will map the fetal / maternal medicine and genetic services available to women to identify opportunities for access to pre-conceptual care and maternity services. This information will be shared with the provider trusts.
6. Trusts should audit integrated pre-conceptual/early pregnancy advice in care planning packages for women with medical conditions e.g. Diabetes, Epilepsy.
7. The SCN should consider GP primary care education events and ways of training to include pre-conceptual care, risk reduction and advice in pregnancy.

Research Questions

8. If health professionals spend more time with women is there a reduction in stillbirth rates?
9. When, if at all, should a stillbirth conversation take place during the antenatal period?
10. Do specialist clinics for women with raised BMI's make a difference to outcome?
11. Is there any regional or national IVF evidence to determine the need for recommendations?
12. Is there a requirement for a regional care package for women of advanced maternal age?
13. Is there a requirement for a regional Induction of Labour (IOL) guideline and information to provide consistent advice?
14. Is there a need for a 'Yorkshire Pregnancy App' to help with healthy living messages, weight tracking, advice on fetal activity, advice on safe exercise during pregnancy etc?
15. Is there an opportunity to hold a national stillbirth campaign similar to cot deaths?
16. Is there an opportunity to work with Local Authorities to explore ways to improve health in those likely to become pregnant?

2.2 Bereavement Care

Element 2: Bereavement Care

Background

Variations in the bereavement care provided to mothers and their families exist. The stakeholder group at the Y&H Stillbirth Workshop discussed a minimum standard for bereavement care across the region.

Discussion points included;

- Variation in bereavement care across the region
- Pathways of care
- The use of the Stillbirth and Neonatal Death Charity (SANDS) Audit Tool
- Funeral arrangements and funding variation between Trusts
- Registering the birth/death
- Bereavement midwives and midwifery care during and post-delivery
- Bereavement room facilities
- Options offered to parents following delivery and mementoes available
- Bereavement care literature and its provision
- Pain relief
- Training
- Support groups
- User feedback and development of a regional questionnaire

Many recommendations for the environment are included in the SANDS Audit Tool and have therefore been excluded from the recommendations below to prevent repetition.

Recommendations for Commissioners and Trusts

Audit

1. Commissioners should require Trusts to audit the provision of bereavement care using the SANDS Audit Tool for Maternity Services (SANDS 2011), develop an action plan and share with commissioners. This should be completed every 3 years as a minimum.

Bereavement Care and Training

2. Commissioners should require Trusts to demonstrate a designated bereavement midwife at the unit with allocated hours to provide expertise and dedicated support (SANDS 2011).
3. Commissioners and Trusts should require all maternity staff involved in bereavement care to complete bereavement care training (in-house or external) and attend updates 3 yearly as a minimum.

Follow up Care

4. Commissioners should require Trusts to ensure there is a process for support for all bereaved women and their partners.
5. Commissioners should ensure the availability of counselling for bereaved women and their partners (RCOG 2010).

Learning

6. Commissioners should require Trusts to review all stillbirth cases at a multidisciplinary case review meeting (SANDS 2011).

Recommendations for Maternity Services

National Guidance

1. Trusts should benchmark their Bereavement Care policies against the RCOG green-top guideline recommendations.

Bereavement Care and Training

2. Trusts should provide training which aims to be multidisciplinary and include:
 - update on unit policies and procedures
 - causes of stillbirths
 - care of a woman with an intrauterine fetal death
 - postnatal care following a stillbirth
 - effective and sensitive communication with bereaved parents including self-awareness
 - cultural or religious aspects
 - postmortem
 - funeral arrangements (RCOG 2010, SANDS 2011)
3. Trusts should ensure clinical and psychological support, along with mentoring, is provided for staff providing bereavement care, with an opportunity to debrief following the event (SANDS 2010, SANDS 2011).
4. Trusts should ensure that students are exposed to bereavement care if the opportunity arises.
5. Trusts should, where possible, inform bereaved mothers what to bring into the hospital with them in preparation for labour/induction and what to bring in for the baby.
6. Trusts should aim to allocate bereaved mothers the same midwife for all or the majority of their care and the midwife should not be allocated another woman to care for.
7. Trusts should ensure that pain relief is offered in the same way as for any mother.
8. Trusts should ensure that there are no restrictions on visiting times throughout delivery and aftercare – meeting the wishes of the mother.
9. Trusts should ensure that parents who may not wish to see their baby straight away should be offered the opportunity to see their baby at any time during their stay and following discharge prior to the funeral.
10. Trusts should ensure that consent for clinical photographs (including those taken for the health records) is provided by the parents (RCOG 2010). Where consent is verbal, this must be documented as obtained.
11. All Trusts should have a cold cot or cuddle cot available.

Follow up Care

12. Trusts should ensure that follow up arrangements with a senior member of staff should include the bereavement midwife and should be held in a venue away from pregnant women, other mothers and babies.
13. Trusts should ensure that bereaved mothers and families are offered postnatal visits on an individual basis.

Funeral arrangements and post mortem

14. Trusts should ensure that all parents who have agreed to a post mortem are able to discuss the results within 2 weeks (or at most 3) of the results being received by the referrer (60% results should be received within 6 weeks, 90% received within 8 weeks unless complex and a specialist opinion is required) (SANDS 2011).
15. Trusts should ensure that all staff seeking post mortem consent should be appropriately trained to do so e.g. Human Tissue Authority training (RCOG 2010, SANDS 2011). This training must be recorded and kept up to date as required.
16. Trusts should ensure that where a coroner's post mortem is required, the bereavement midwife or if unavailable, a trained clinician explains why it is necessary and why it may take a while to get the results.
17. Trusts should ensure that a discussion about dressing the baby for the cremation/burial takes place with the mother and family.
18. Each Trust should review their funeral contract to support the families' choice of cremation or burial.

Discharge Information

19. Trusts should provide discharge information including the following information as a minimum;
 - Follow up arrangements
 - Bereavement services/midwife contact details
 - Counselling contact details
 - Loss of baby information
 - Charities with contact details
 - Chaplaincy contact details
 - Consider information for the father/partner and extended family(SANDS 2011)

Family and user feedback and support networks

20. Trusts should consider requesting feedback on bereavement care at the follow-up appointment.

Learning

21. Trusts should ensure that learning points are shared at local risk and governance meetings and consider other methods of sharing: newsletters, handovers, supervisor of midwives meetings, regional meetings, meetings with commissioners.

Further Work / Considerations

Development of a Yorkshire & the Humber Questionnaire

(once developed to be considered as a recommendation)

1. The SCN should facilitate the development of a short regional questionnaire to be sent to women possibly 1 month following the stillbirth with a more detailed questionnaire sent approximately 1 year following the stillbirth.
2. Permission and consent should be sought and documented from the parents to receive the questionnaire.
3. Information provided with the questionnaire should include what will be done with the information obtained and whether they will receive any feedback.
4. Questions should not be asked where the answer could be obtained in the hospital notes.
5. Services users should be asked their view regarding what questions should be asked, how many and the times at which questionnaires should be sent out.

Counselling

6. Currently when specialist counselling is required, women are referred to their GP and can wait up to 10 weeks for an appointment. Commissioners should consider supporting the development of a care pathway with a focus on personalised care.

Leaflets

7. Trusts should consider their local need for information leaflets in pictorial form to aid understanding in non-English speaking communities and mothers/families with known learning difficulties.

2.3 Stillbirth Investigations

Element 3: Stillbirth Investigations

Background

All maternity units in Y&H provide investigations and follow up after a baby is stillborn. However there are variations in current practice. The aim of this element is to review evidence and share best practice across the region in managing stillbirth investigations and follow up care.

Recommendations for Commissioners and Trusts

Bereavement Midwife

1. Commissioners should require Trusts to demonstrate a designated bereavement midwife at the unit with allocated hours to provide expertise and dedicated support (SANDS 2011).

Follow up Consultation

2. Commissioners should require Trusts to audit the provision of bereavement care using the SANDS Audit Tool for Maternity Services (SANDS 2011), develop an action plan and share with commissioners. This should be completed every 3 years as a minimum.

Recommendations for Maternity Services

Audit

1. Trusts must consider the auditable standards in the RCOG green-top guideline No.55 Late Intrauterine Fetal Death and Stillbirth (RCOG 2010) when auditing follow up care.

Training for Post Mortem Consent Taking

2. Trusts should ensure that all staff seeking post mortem consent are appropriately trained to do so e.g. Human Tissue Authority training (RCOG 2010, SANDS 2011). This training must be recorded and kept up to date as required.

Receiving Post Mortem Results

3. Trusts must explore the possibility of setting up secure nhs.net accounts to receive results in a timely fashion.

Investigations Offered

4. Trusts should ensure that, all women are offered appropriate full stillbirth investigations, including post mortem.
5. Trusts must ensure a checklist of investigations is used, based on RCOG guidance and allows for recording which tests are undertaken and supports individualised care.

Communication

6. Trusts should ensure that all staff involved in bereavement care receive training and support to enable them to care sensitively and confidently for parents whose baby is dying or has died (SANDS 2011).

Follow up Consultation

7. Trusts should ensure that all women are offered a written summary of the discussions at their follow up consultation, including investigation results and plans for subsequent pregnancies.

Further Work / Considerations

Networking opportunities

1. Trusts to consider sharing details of the role of the bereavement midwife and how they were secured with trusts that do not currently have one in a substantive role.
2. The SCN to facilitate a regional resource for sharing best practice.

2.4 Subsequent Pregnancies

Element 4: Subsequent Pregnancies

Background

Women who have had a previous stillborn baby may be more anxious and vulnerable in their subsequent pregnancies. The following aspects of care were considered as part of this element;

- Documentation
- Early access to midwifery/obstetric care
- Role of bereavement midwife
- Early scans
- Providing care closer to home

Recommendations for Commissioners and Trusts

Subsequent Pregnancy Care Pathway

1. Commissioners should require Trusts to develop and implement a referral pathway in all subsequent pregnancies, from potential first point of contacts e.g. genetic department, bereavement midwife, fetal medicine department, to ensure an early booking appointment.
2. Commissioners should require Trusts to offer women with a previous unexplained, normally formed stillbirth or with evidence of fetal growth restriction, serial scans for growth, liquor & umbilical artery doppler assessment every 4 weeks as a minimum, from 24-26 weeks until birth.

Bereavement Midwife

3. Commissioners should require Trusts to have a designated bereavement midwife at the unit with allocated hours to provide expertise and dedicated support (SANDS 2011).

Recommendations for Maternity Services

Subsequent Pregnancy Care Pathway

1. Trusts should have a process in place that provides the woman with easy access to the maternity service. Woman could be provided with the contact details of a bereavement midwife to ensure they have the option of contacting a health professional early in their subsequent pregnancy.
2. Trusts should offer an early referral for a reassurance scan.
3. Trusts should provide a subsequent pregnancy service for bereaved families for all subsequent pregnancies.
4. Trusts should have a process to ensure all maternity staff who see a bereaved mother for an appointment are aware that she has experienced a previous perinatal loss.
5. Trusts should involve the woman to develop a pathway of communication that she is comfortable with including agreeing the lead clinician who will co-ordinate her care.
6. Trusts should ensure continuity of care with the offer of regular assessment and extra support.

7. Trusts should provide an early referral for an obstetric consultant appointment. Full set of women's hospital notes should be available for this appointment.
8. Trusts should ensure a management plan for the current pregnancy is developed including a review of previous pregnancies e.g. cause of stillbirth, documented management plan regarding next pregnancy.
9. Trusts should ensure that timing and mode of birth is discussed with women and documented.
10. Trusts should ensure that women with a previous unexplained stillbirth should have an antenatal glucose tolerance test (GTT) at 26-28 weeks gestation to screen for gestation diabetes (RCOG 2010).

Further Work / Considerations

Information

1. Trusts to consider developing a booklet containing key contacts and information relevant to women and their families.

Further Research

2. How are women supported when they are fearful and need to regain their confidence? i.e. how the woman's anxiety is managed throughout pregnancy and especially near the gestation of the stillborn baby.

3 Immediate Action

During the development of these recommendations, a network for Bereavement Midwives (or a midwifery contact where a Bereavement Midwife is not in post), across all Y&H Provider Trusts was requested by stakeholders attending the workshop. This would enable Trusts to communicate to provide support to the Bereavement Midwives and to share good practice and discuss challenges. This network was established in February 2015 and has shared information including best practice information, documentation for recording care and the availability of mementoes for bereaved families.

4 Summary

The implementation of these recommendations, along with the further considerations for future work, aims to reduce both stillbirth rates and the variation in care within Y&H. The aspects of bereavement care considered as part of this project has the ambition to improve women and families experiences along with supporting the staff involved in providing bereavement care.

These recommendations have been approved and agreed by the Maternity Clinical Expert Group, Commissioners Forum and the Maternity Strategy Group. The published document will be circulated to commissioners and provider trusts across Y&H for consideration of implementation.

The Stillbirth Task & Finish Group will review the further work/considerations sections following publication of this document.

APPENDIX 1

Y&H Stillbirth Recommendations Summary for Commissioners & Provider Trusts

This summary contains the recommendations for commissioners and provider trusts to improve bereavement care and reduce variation across Yorkshire and the Humber. Please refer to the main document for further information.

Recommendations

1. Commissioners should require Trusts to consistently collect and review data on all stillbirths on an annual basis as a minimum. Commissioners should require Trusts to communicate the data review outcomes to them through a local forum with evidence of responding to local trends or themes.
2. Commissioners should require Trusts to audit the provision of bereavement care using the SANDS Audit Tool for Maternity Services (SANDS 2011), develop an action plan and share with commissioners. This should be completed every 3 years as a minimum.
3. Commissioners should require Trusts to demonstrate a designated bereavement midwife at the unit with allocated hours to provide expertise and dedicated support (SANDS 2011).
4. Commissioners and Trusts should require all maternity staff involved in bereavement care to complete bereavement care training (in-house or external) and attend updates 3 yearly as a minimum.
5. Commissioners should as a minimum, require Trusts to undertake a repeat CO test for all women between 28-36 week appointment (ASH 2013, NICE 2010).
6. Commissioners should require Trusts to ensure there is a process for support for all bereaved women and their partners.
7. Commissioners should ensure the availability of counselling for bereaved women and their partners (RCOG 2010).
8. Commissioners should require Trusts to review all stillbirth cases at a multidisciplinary case review meeting (SANDS 2011).
9. Commissioners should require Trusts to develop and implement a referral pathway in all subsequent pregnancies from a potential first point of contact e.g. genetic department, bereavement midwife, fetal medicine department, to ensure an early booking appointment.
10. Commissioners should require Trusts to offer women with a previous unexplained, normally formed stillbirth or with evidence of fetal growth restriction, serial scans for growth, liquor & umbilical artery doppler assessment every 4 weeks as a minimum, from 24-26 weeks until birth.

APPENDIX 2

Y&H Stillbirth Recommendations Summary for Maternity Services

This summary contains the good practice points for maternity services to improve bereavement care and reduce variation across Yorkshire and the Humber. Please refer to the main document for further information.

Recommendations

Element 1: Risk Reduction

National Guidance

1. Trusts should benchmark their Reduced Fetal Movements and Small for Gestational Age policies against the RCOG green-top guideline recommendations.

Public Health

2. Trusts should provide all pregnant women (including low risk) with consistent messages regarding healthy lifestyle advice including nutrition and smoking cessation (NICE 2008).
3. Trusts should ensure they work in partnership with Smoking Cessation Services to develop services to meet the needs of pregnant teenagers (NCSCT 2014).

Vulnerable Women

4. Trusts should have a systematic approach to identify vulnerable isolated women at booking. There should be clear processes for engaging non-attendance at clinics with consideration to personalised care pathway.

Preventable Congenital Abnormalities

5. Trusts may consider an extra ultrasound scan at 16 weeks for women with recognised recurrent risk e.g. a recessive genetic condition, neural tube effect.

Management of Latent Phase

6. Trusts should ensure guidelines include definition, management and fetal risk assessment in the latent phase of labour.
7. Trusts should ensure women getting consistent advice for latent phase from Labour Ward, Triage or Community. Rotation of staff & appropriate skill mix may facilitate this.

Element 2: Bereavement Care

National Guidance

8. Trusts should benchmark their Bereavement Care policies against the RCOG green-top guideline recommendations.

Bereavement Care and Training

9. Trusts should provide training which aims to be multidisciplinary and include:
 - update on unit policies and procedures
 - causes of stillbirths

- care of a woman with an intrauterine fetal death
 - postnatal care following a stillbirth
 - effective and sensitive communication with bereaved parents including self-awareness
 - cultural or religious aspects
 - postmortem
 - funeral arrangements (RCOG 2010, SANDS 2011)
10. Trusts should ensure clinical and psychological support, along with mentoring, is provided for staff providing bereavement care, with an opportunity to debrief following the event (SANDS 2010, SANDS 2011).
 11. Trusts should ensure that students are exposed to bereavement care if the opportunity arises.
 12. Trusts should, where possible, inform bereaved mothers what to bring into the hospital with them in preparation for labour/induction and what to bring in for the baby.
 13. Trusts should aim to allocate bereaved mothers the same midwife for all or the majority of their care and the midwife should not be allocated another woman to care for.
 14. Trusts should ensure that pain relief is offered in the same way as for any mother.
 15. Trusts should ensure that there are no restrictions on visiting times throughout delivery and aftercare – meeting the wishes of the mother.
 16. Trusts should ensure that parents who may not wish to see their baby straight away should be offered the opportunity to see their baby at any time during their stay and following discharge prior to the funeral.
 17. Trusts should ensure that consent for clinical photographs (including those taken for the health records) is provided by the parents (RCOG 2010). Where consent is verbal, this must be documented as obtained.
 18. All Trusts should have a cold cot or cuddle cot available.

Follow up Care

19. Trusts should ensure that follow up arrangements with a senior member of staff should include the bereavement midwife and should be held in a venue away from pregnant women, other mothers and babies.
20. Trusts should ensure that bereaved mothers and families are offered postnatal visits on an individual basis.

Funeral Arrangements and Post Mortem

21. Trusts should ensure that all parents who have agreed to a post mortem are able to discuss the results within 2 weeks (or at most 3) of the results being received by the referrer (60% results should be received within 6 weeks, 90% received within 8 weeks unless complex and a specialist opinion is required) (SANDS 2011).
22. Trusts should ensure that all staff seeking post mortem consent should be appropriately trained to do so e.g. Human Tissue Authority training (RCOG 2010, SANDS 2011). This training must be recorded and kept up to date as required.
23. Trusts should ensure that where a coroner's post mortem is required, the bereavement midwife or if unavailable, a trained clinician explains why it is necessary and why it may take a while to get the results.

24. Trusts should ensure that a discussion about dressing the baby for the cremation/ burial takes place with the mother and family.
25. Each Trust should review their funeral contract to support the families' choice of cremation or burial.

Discharge Information

26. Trusts should provide discharge information including the following information as a minimum;
 - Follow up arrangements
 - Bereavement services/midwife contact details
 - Counselling contact details
 - Loss of baby information
 - Charities with contact details
 - Chaplaincy contact details
 - Consider information for the father/partner and extended family (SANDS 2011)

Family and User Feedback and Support Networks

27. Trusts should consider requesting feedback on bereavement care at the follow-up appointment.

Learning

28. Trusts should ensure that learning points are shared at local risk and governance meetings and consider other methods of sharing: newsletters, handovers, supervisor of midwives meetings, regional meetings, meetings with commissioners.

Element 3: Stillbirth Investigations

Audit

29. Trusts must consider the auditable standards in the RCOG green-top guideline No.55 Late Intrauterine Fetal Death and Stillbirth (RCOG 2010) when auditing follow up care.

Receiving Post Mortem Results

30. Trusts must explore the possibility of setting up secure nhs.net accounts to receive results in a timely fashion.

Investigations Offered

31. Trusts should ensure that, all women are offered appropriate full stillbirth investigations, including post mortem.
32. Trusts must ensure a checklist of investigations is used, based on RCOG guidance and allows for recording which tests are undertaken and supports individualised care.

Communication

33. Trusts should ensure that all staff involved in bereavement care receive training and support to enable them to care sensitively and confidently for parents whose baby is dying or has died (SANDS 2011).

Follow up Consultation

34. Trusts should ensure that all women are offered a written summary of the discussions at their follow up consultation, including investigation results and plans for subsequent pregnancies.

Element 4: Subsequent Pregnancies

Subsequent Pregnancies Care Pathway

35. Trusts should have a process in place that provides the woman with easy access to the maternity service. Woman could be provided with the contact details of a bereavement midwife to ensure they have the option of contacting a health professional early in their subsequent pregnancy.
36. Trusts should offer an early referral for a reassurance scan.
37. Trusts should provide a subsequent pregnancy service for bereaved families for all subsequent pregnancies.
38. Trusts should have a process to ensure all maternity staff who see a bereaved mother for an appointment are aware that she has experienced a previous perinatal loss.
39. Trusts should involve the woman to develop a pathway of communication that she is comfortable with including agreeing the lead clinician who will co-ordinate her care.
40. Trusts should ensure continuity of care with the offer of regular assessment and extra support.
41. Trusts should provide an early referral for an obstetric consultant appointment. Full set of women's hospital notes should be available for this appointment.
42. Trusts should ensure a management plan for the current pregnancy is developed including a review of previous pregnancies e.g. cause of stillbirth, documented management plan regarding next pregnancy.
43. Trusts should ensure that timing and mode of birth is discussed with women and documented.
44. Trusts should ensure that women with a previous unexplained stillbirth should have an antenatal glucose tolerance test (GTT) at 26-28 weeks gestation to screen for gestation diabetes (RCOG 2010).

APPENDIX 3

Y&H Stillbirth Further Work / Considerations Summary

This summary contains the further work / considerations to continue to improve bereavement care and reduce variation across Yorkshire and the Humber. Please refer to the main document for further information.

Further Work / Considerations

1. The SCN will facilitate development of a stillbirth minimum dataset. This will support comparative data collection across Y&H to provide regional evidence and support inter-organisational peer review.
2. The SCN will set up a bereavement midwife network email group across the region to share good practice and discuss challenges.
3. Trusts should consider how to maximise the contact time with women attending for GTT's to include healthy lifestyles / dietary advice and to consider the use of service users / videos.
4. Local Authority and Primary Care should consider ways to reduce BMI in women of child-bearing age.
5. The SCN will map the fetal / maternal medicine and genetic services available to women to identify opportunities for access to pre-conceptual care and maternity services. This information will be shared with the provider trusts.
6. Trusts should audit integrated pre-conceptual/early pregnancy advice in care planning packages for women with medical conditions e.g. Diabetes, Epilepsy.
7. The SCN should consider GP primary care education events and ways of training to include pre-conceptual care, risk reduction and advice in pregnancy.
8. Currently when specialist counselling is required, women are referred to their GP and can wait up to 10 weeks for an appointment. Commissioners should consider supporting the development of a care pathway with a focus on personalised care.
9. Trusts should consider their local need for information leaflets in pictorial form to aid understanding in non-English speaking communities and mothers/families with known learning difficulties.
10. Trusts to consider sharing details of the role of the bereavement midwife and how they were secured with trusts that do not currently have one in a substantive role.
11. The SCN to facilitate a regional resource for sharing best practice.
12. Trusts to consider developing a booklet containing key contacts and information relevant to women and their families

Development of a Yorkshire & the Humber Questionnaire

(once developed to be considered as a recommendation)

13. The SCN should facilitate the development of a short regional questionnaire to be sent to women possibly 1 month following the stillbirth with a more detailed questionnaire sent approximately 1 year following the stillbirth.
14. Permission and consent should be sought and documented from the parents to receive the questionnaire.

15. Information provided with the questionnaire should include what will be done with the information obtained and whether they will receive any feedback.
16. Questions should not be asked where the answer could be obtained in the hospital notes.
17. Services users should be asked their view regarding what questions should be asked, how many and the times at which questionnaires should be sent out.

Research Questions

18. If health professionals spend more time with women is there a reduction in stillbirth rates?
19. When, if at all, should a stillbirth conversation take place during the antenatal period?
20. Do specialist clinics for women with raised BMI's make a difference to outcome?
21. Is there any regional or national IVF evidence to determine the need for recommendations?
22. Is there a requirement for a regional care package for women of advanced maternal age?
23. Is there a requirement for a regional Induction of Labour guideline and information to provide consistent advice?
24. Is there a need for a 'Yorkshire Pregnancy App' to help with healthy living messages, weight tracking, advice on fetal activity, advice on safe exercise during pregnancy etc?
25. Is there an opportunity to hold a national stillbirth campaign similar to cot deaths?
26. Is there an opportunity to work with Local Authorities to explore ways to improve health in those likely to become pregnant?
27. How are women supported when they are fearful and need to regain their confidence? i.e. how the woman's anxiety is managed throughout pregnancy and especially near the gestation of the stillborn baby.

Appendix 4

References

These documents are available in the 'Stillbirth Key Documents' folder on the Y&H Strategic Clinical Network website. <http://www.yhscn.nhs.uk/children-maternity/maternity-network/maternity-documents-and-links.php>

Please see the SANDS website for availability of resources or publications.

www.uk-sands.org

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