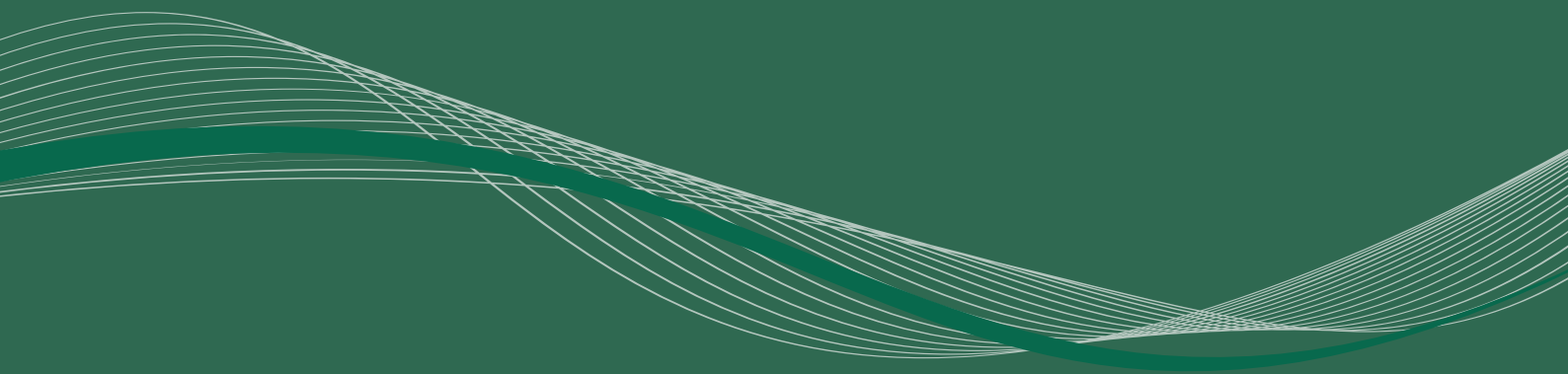


A review of support available for loss in early and late pregnancy

February 2014





The word cloud on the front cover was created using words taken from experiences of miscarriage and stillbirth on Patient Opinion www.patientopinion.org

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1. Introduction

It has been well documented that the loss of a pregnancy at any stage is an emotional and stressful time and affects every family member in some way. Some still feel that miscarriage and stillbirth, along with neonatal death, are taboo subjects as pregnancy and childbirth are seen as happy life events. This is compounded by a western culture which still struggles to talk about death openly. There are particular challenges for women who miscarry early in pregnancy as they may not have shared their news with family, friends and work colleagues but may have known of the pregnancy very early due to the sophistication of home pregnancy testing.

To put into context, in the UK, 17 babies are stillborn or die shortly after birth every day (1) and 20% of all pregnancies end in miscarriage, leaving thousands of families in need of bereavement support and care (2). Many people are unaware that stillbirths happen in the 21st century, yet stillbirth is ten times more common in the UK than cot death (3).

One of the biggest challenges is gathering data on experiences of care following bereavement. National surveys such as those carried out in Accident and Emergency in 2012 (4) and the Maternity Services Survey 2013 (5) have excluded bereaved mothers, for understandable reasons, but this results in there being no voice or feedback mechanism for these patients at a national level. There are many examples of the failures of the NHS but there are also some fantastic examples of where staff and services have really made a positive difference for patients. Our aim is not to apportion blame but to begin open and honest discussions in order to ensure that all women receive excellent care.

In September 2013, Kath Evans, Head of Patient Experience Maternity, Newborn, Children and Young People in the Nursing Directorate at NHS England, commissioned NHS Improving Quality to scope out how women and their families are supported through the loss of a baby in pregnancy. The work has concentrated on unplanned loss and for this report neonatal death and planned termination is excluded.

Specifically this report:

- I. Scopes what support currently exists for women and families across England who experience loss at less than 24 weeks gestation
- II. Scopes what support exists for women and families across England who experience loss at greater than 24 weeks gestation
- III. Scopes what support exists for stillbirth, pre and post-delivery, identifies the key charities involved in this and determines what they offer
- IV. Identifies areas of good practice, soft intelligence and stories from women with experience of loss.

For the purpose of this report the following definitions have been used:

Early loss (first trimester) – loss of pregnancy up to 13 weeks gestation

Late loss (second trimester) – loss of pregnancy between 13 and 24 weeks gestation

Stillbirth (third trimester) – loss at 24 weeks gestation and above

The purpose of this work is threefold:

1. To highlight with stakeholders the need to consider this patient group when commissioning services and quality monitoring processes
2. To identify gaps and opportunities to work in partnership across all sectors to improve the experience, quality and consistency of care provided
3. To acknowledge practitioners and practice, and in doing so, encourage others to reflect on their own service and practice and if needs be take action to move forwards.

“If there’s ever a time to get right care it's during this time.”

Bereavement midwife

2. Summary

The authors of this report found that support comes in many forms both from within the NHS and from national and local charities (see appendices 1 and 2). When, why and what support is accessed is a very individual choice and encompasses many aspects of daily living.

More than 100 experiences of loss in pregnancy were reviewed and very clearly demonstrated that:

1. Support required was individual to the people who suffer the loss
2. Some parents want to remember their baby whatever the gestation and should have the opportunity to do so
3. Compassion and attitude of the staff have a lasting impact on the experience
4. The environment of care during and after loss needs to be somewhere away from the main business of the maternity ward or gynaecology ward
5. Staff want to provide emotional support but struggle with the workload and competing priorities.

“ You can make the worst experience of someone’s life as good as is possible, by your caring compassion, empathy and listening...”

Mel Scott, After Finley (6)

3. Approach

Over a three month period all 12 Strategic Clinical Networks (SCNs) were approached for contacts and/or information on the support offered to women and their families who have suffered loss during pregnancy. As the networks' structures are still maturing, it is recognised that the level of information provided is not comprehensive, and has not lead to a widespread interaction. However, as the networks develop this is likely to change.

In December 2013 the Maternity, Newborn, Children and Young People clinical networks began to set out their key priorities for both maternity and children's services. For maternity the main focus emerging is on mental health, stillbirth and reduction in preterm births. Whilst no network signalled that support for loss during pregnancy was a high priority, there are certainly opportunities for further discussions which should be utilised, for example with:

1. Greater Manchester, Lancashire and South Cumbria, which plans to review its current provision for late foetal loss and stillbirth guidelines
2. West Midlands, which is consolidating local service reviews with a view to commissioning quality maternity and neonatal care
3. East Midlands, which is developing a commissioning service specification for non-specialised maternity services
4. London, which amongst other priorities is improving patient experience and implementation of best practice guidelines
5. Northern, which has well-established networks and plans to look at variation, and which has been very supportive of including loss in pregnancy in its work.

While the detail of the work plans is not known, it is encouraging that mental health features in the key three priorities for maternity as there is research to suggest that loss in pregnancy has a long term impact on women, even after the birth of a healthy baby (7).

In a study published by the Royal College of Psychiatrists, researchers looked at 13,133 pregnant women who were taking part in a long-term study known as the Avon Longitudinal Study of Parents and Children (ALSPAC). The women were asked to report the number of previous miscarriages and stillbirths they had experienced. They were assessed for symptoms of depression and anxiety twice during their pregnancy (at 18 and 32 weeks gestation), and four times after giving birth (at eight weeks, eight months, 21 months and 33 months).

The majority of women (10,310) reported no miscarriages. 2823 women (21%) reported having one or more previous miscarriages. 108 (0.5%) reported having one previous stillbirth and just three women had two previous stillbirths.

The researchers found that women who had lost a baby in the past experienced significantly higher levels of anxiety and depression during pregnancy and this continued nearly three years after they gave birth to a healthy baby.

“ This study is important to the families of women who have lost a baby, since it is so often assumed that they get over the event quickly, yet as shown here, many do not. This has implications for the medical profession as well as the woman and her family.”

Professor Jean Golding

Information was also gathered on local and national charities, drawing from websites, telephone calls or face-to-face meetings. There are many local charities across the country which offer support and practical help to families during their time of need. The report authors met with two national charities - the Miscarriage Association (MA) and the Stillbirth and Neonatal Death Charity (Sands). Both these organisations have strong working relationships with the Royal Colleges and a history of collaborative working. There have also been conversations with the Royal Colleges including the Royal College of Nursing, Royal College of Midwives and the Royal College of Obstetrics and Gynaecology and, perhaps most importantly, with bereaved parents and front line staff who have shared their stories, some of which are interspersed throughout this document.

4. Key findings

1. Opening hours of Early Pregnancy Units are limited in some areas despite NICE guidance.
2. Out of hours care and support in small units for women who miscarry may be on a surgical ward as specialist gynaecological wards are not always available.
3. The use of social media is a popular mechanism for support. The Miscarriage Association reported a significant shift in the way people access their services. For example, they reported that many are posting on the Miscarriage Association Facebook page whilst they are on an Early Pregnancy Unit, gathering immediate feedback in a closed forum.
4. Miscarriage can be seen not to be as impactful for parents as late loss or stillbirth, and even family members can be dismissive.
5. The availability of local support, particularly for miscarriage, varies between and within regions, and can be difficult to find using internet search engines.
6. Support is available for Black and Minority Ethnic (BME) communities from the main charities, but there are also a handful of charities specifically set up by communities.
7. A quiet environment separate from, but close to, the maternity unit or gynaecology ward, as many women find it distressing to be around new borns or to be with other pregnant women.
8. The numbers of stillbirths in a maternity led unit/District General Hospital (DGH) are small compared to those in a tertiary centre. Therefore, many midwives do not have the opportunity to regularly practice their skills in using sensitive communication and support.
9. The cut-off point after which mothers who are miscarrying are cared for on the labour ward varies in different units between 14 and 24 weeks.
10. There needs to be better recognition of the bereavement midwife role. Generally, these roles are not part of the original establishment. Trusts are beginning to recognise the value in having these specialised posts and they are becoming more commonplace.
11. Health care professionals report the value of supportive colleagues when working in an emotionally challenging area. However, appropriate provision of this support is more difficult to gauge for temporary and transient staff, such as agency staff and students.
12. Student midwives are generally protected from those women who suffer loss. Therefore they may have limited experience of communicating with these women in training, which may impact on their skills, knowledge and confidence to know what to do once they are qualified.
13. Accurate numbers of early miscarriages are unknown as many will be treated in a primary care setting.
14. Access to comprehensive data can be difficult to find, which impacts on service planning.
15. Sensitivity around miscarriage and stillbirth makes it hard to capture data in the national surveys, leaving the parents' voices unheard by the service.
16. Collaborative working between the Royal Colleges and charities, and charities, chaplaincy and healthcare professionals, is evident and offers an opportunity to move forwards.



5. Support for women and families who experience loss at less than 24 weeks gestation

Ectopic pregnancy and miscarriage have an adverse effect on the quality of life of many women. Tommys Charity www.tommys.org (which funds research into perinatal death and stillbirth) states that accurate statistics on the number of miscarriages in England is difficult for a multitude of reasons but recognises that one in four pregnancies will end in miscarriage.

For women who experience miscarriage the Miscarriage Association (MA) reports on its website that, of nearly 300 women questioned:

1. Nearly half (45%) of them did not feel well informed about what was happening to them
2. Only 29% felt well cared for emotionally
3. Nearly four out of five (79%) received no aftercare.

For the service this presents significant challenges as unsupported loss can lead to emotional stress for the woman and her family.

6. Loss in the first trimester - up to 13 weeks

Early pregnancy loss accounts for more than 50,000 admissions in the UK annually. The rate of ectopic pregnancy is 11 per 1,000 pregnancies, with a maternal mortality of 0.2 per 1000 estimated ectopic pregnancies (8). There are particular challenges for women who miscarry early in pregnancy as they may not have shared their news with family, friends and work but may have known of the pregnancy very early due to the sophistication of home pregnancy testing. Women often access information from the internet and on some sites they are advised not to tell anyone they are pregnant until they reach 12 weeks – but this can make it very hard to talk about miscarriage if it happens (9).

The authors of this report found support comes in many forms both from within the NHS and from local and national charities. It was found that support in the workplace varies.

Jane reported that she received good support from her colleagues who allowed her to take time off for treatment and investigations.

However,

Laura felt that, because her managers are male, she was not able to access the support she would have liked in the workplace.

The National Institute for Health and Care Excellence (NICE) clearly sets out in CG 154 *Diagnosis and initial management in early pregnancy of ectopic pregnancy and miscarriage* (8) what the standard of care should be for women in the first trimester of pregnancy - that is up to 13 completed weeks of pregnancy.

It recommends that support and information and access to local seven day Early Pregnancy Units are two key priorities for implementation. The guideline comes with a range of tools to support implementation. NICE has an implementation programme (10) and publishes reports, but currently there is nothing available to assess how widespread uptake is or the impact that this guideline has made.

Early Pregnancy Units

Currently there are more than 200 Early Pregnancy Units (EPU) across England (this figure is likely to be higher but there is no definitive list). These units are staffed by healthcare professionals competent to diagnose and care for women with pain and/or bleeding in early pregnancy. They also offer ultrasound and assessment of serum hcg levels (a hormone which indicates pregnancy). These staff should also have been trained in sensitive communication and breaking bad news.

Many Early Pregnancy Units are aligned to the Association of Early Pregnancy Units (AEPU) which aims to provide collaborative working by maximising opportunities to share resources. It also aims to maintain and improve standards of care to patients by offering educational and networking opportunities.

The AEPU also provides training for professionals with an annual conference. Additionally, it is currently developing e-learning training resources for its members in collaboration with the Miscarriage Association. On its website www.earlypregnancy.org.uk women can find details of their local unit along with a range of patient information leaflets and useful links.

Despite the NICE guidelines calling for seven day services, fewer than 20 units appear to have this level of access, and six of these are in the North West. Extended opening hours are common but some units are only open for a few hours each day. A very small number were available only once or twice a week. All units offer direct referral to a range of healthcare professionals and approximately 50 allow self-referral, especially if in the case of previous miscarriage or ectopic pregnancy.

In some units, sonographers are contracted to work Monday to Friday. Weekend cover is often provided by overtime on a voluntary basis. This has implications for the skill mix of the workforce to meet the needs of the patients. In response to this need, some organisations are training other appropriate healthcare professionals to be competent in scanning uncomplicated pregnancies.

“The most important question to women is will the pregnancy continue? Although we are not as extensively trained as sonographers, we can provide that answer for some.”

Ward sister

“Not everyone can scan like a sonographer.”

Sonographer

If the EPU is unavailable, women are directed towards emergency gynaecology units. In the absence of provision of the specialist areas women often find themselves in Accident and Emergency units, gynaecology wards and sometimes even general surgical beds where the staff may not have the time or the skills to offer the level of compassionate support and advice needed.

For staff in these areas miscarriage is a routine part of their daily work, but for the women it is an individual journey that should be proactively supported by sensitive care, good information, effective communication and choice.

The Patient Opinion Portal www.patientopinion.org.uk has many examples of patient experiences, both good and bad. Below are two experiences of care which highlight the difference that effective communication and support can make.

"Shortly after arrival my name was called out by a rather unenthusiastic voice followed by a matching face. Undeterred we happily assumed to follow the lady, even though there was no greeting or instructions or given eye contact. In the room, I was eventually told to lie down and advised that the gel might be cold. Within minutes she said in a blasé tone 'there is only a sac'. It was said so casually and in such a passing manner that I didn't register it at first. I asked for her to repeat it and subsequently asked what she meant. Her simple answer (and I mean that literally) was 'there is no baby'. I broke down and cried my eyes out. The midwife called a colleague to verify and her next words were 'ok, you can clean yourself up now and I will call EPG'. After her call she gave me my file back and said 'ok, bye'. I was shocked not only about the news but the absolute lack of counselling, compassion and psychological care given my circumstances and history. Thank God my husband was present as I am not sure I would have physically made it out of there with my three year old in tow. I have subsequently had to 'google' everything to understand what happened and potentially why. I have gone from being under shock to grieving to being disgusted at my treatment, in particular after reading the sonographer's note of 'counselling provided and referred to epg'. From one woman to another, from one mom to another, from a human to another, please let's not forget to be human."

Anon - www.patientopinion.org.uk

"I was admitted to A&E recently by ambulance after suffering an agonising miscarriage. I could not fault the service and fantastic teamwork; from the paramedics, to nurses and the doctors/gynaecologists, I was well looked after. Staff were thorough, efficient and very much put me at ease. Given the usual nature of an A&E department, I felt I was given sufficient attention and care, staff were sympathetic to my needs and very attentive."

Anon - www.patientopinion.org.uk

Emergency Gynaecological Units

These are ideally open 24/7 and run alongside Early Pregnancy Units (EPUs). As such, they provide an out-of-hours early pregnancy assessment for when and if the EPU is closed. They are commonly located in larger hospital trusts and teaching hospitals. They offer services to women with a range of gynaecological problems but are not always specialist in supporting women who are miscarrying as they cover a range of conditions all requiring assessment and treatment support.

Some charities and women reported that investigation into why a woman may miscarry happens after the third miscarriage. The Miscarriage Association reports that:-

1. Fewer women have three miscarriages than have two
2. Investigations provide less than 50% with an obvious cause
3. Only a few have something that is treatable.

" For most tests in healthcare, you don't want to know that you have something, but with potential miscarriage you do."

Miscarriage Association

Jane's story

Jane had four miscarriages within a two year period. All lost between 11 -13 weeks. In the same time frame she also lost her father and grandmother, to whom she was very close.

"Getting pregnant was not the issue. Going full term was.

"The GP practice is well linked in with my local hospital where the miscarriages were also managed. Major bleeding was the main symptom prior to the loss of the first three pregnancies.

"With the first pregnancy we were very excited and getting used to being pregnant. When I lost the first pregnancy we didn't know what to expect. I was quite a lot older at 37 to have my first pregnancy. I had not had my first scan.

"With the first miscarriage you can be quite 'accepting'but with each subsequent one it felt very different, and not so easy to accept. No-one handed out leaflets/contacts to support groups. It felt that there was little for early miscarriages. I had masses of support from family and friends.

"After the second miscarriage, because of my age, I was told, investigations started. My scans were undertaken very early. It wasn't until after my third loss, that I was referred to a haematologist who was doing some research. He was the only person that offered something else. At no time was I offered an explanation by the gynaecology team who were looking after me. So I was left thinking that there was nothing that could be done."

Jane has not gone on to have a successful pregnancy.

Laura's Story

There was a long wait for the 10am appointment – mostly they were people having routine scans – Laura feels that this was the hardest bit of the whole experience for them. Paul (Laura's husband) found it was a big thing as Laura was sitting in her pyjamas with a cannula in her hand and was obviously different to everyone else. There were lots of ladies there with bumps and one girl had pictures of her 12 week scan which she was showing to her friends. Laura felt that the hardest thing was watching the others. She couldn't stop crying and felt that it wasn't good for the other people there either. They eventually went into the scan at 11am – they felt they had to wait a long time and wished it could have been done differently so there weren't all put together. The couple who came out before them were very upset and so was the lady performing the scan - "it wasn't a good start". The scanning lady didn't really tell them anything – just said that she was very sorry she couldn't see anything. Laura thought "is that it?" The lady said she had taken some pictures and these were sent to the ward.

7. Loss in the second trimester - 13-24 weeks

Late miscarriages, after 13 weeks of pregnancy but before 24 weeks, are less common: 1–2 in 100 (1–2%) pregnancies end in a miscarriage in the second trimester (9). Loss at this gestation is rare and usually due to a medical cause. Women are usually referred to the maternity wards and deliver their baby in a special suite. However there is variability of when women would be routinely admitted to a maternity unit, with The Stillbirth and Neonatal Death Charity (Sands) reporting that it can be anywhere from 14-24 weeks but with the average at 20 weeks. It should be noted that babies delivered pre 24 weeks with signs of life raises ethical dilemmas for parents and staff and is a very emotive and complex area of practice.

At present, survival at 22 weeks of gestation is very rare and, below this stage, almost unrecorded; these babies are sometimes termed 'pre-viable' for this reason (11). During the period of borderline viability (before 26 weeks), relatively few babies are born and most do not survive. In England and Wales in 2011, 7.2 percent of births were pre-term (under 37 weeks gestation). Of these, 1.3 percent were born before 24 weeks (12).

Currently there are no NICE guidelines but publication is expected in 2016.

Some hospitals have written their own guidelines to support staff through the process and ensure women and their families have the best of care. The Royal Cornwall Hospital uses a series of checklists to try to ensure that women get the information and support needed.

The British Association of Perinatal Medicine (BAPM) offers guidance to staff in *"The Management of Babies born Extremely Preterm at less than 26 weeks of gestation. A Framework for Clinical Practice at the time of Birth"* (13) which sets out the need to involve the parents, and discuss with them the practicalities of commencing, withholding and withdrawing intensive care, and the positive role of palliative care where appropriate.

"Poor or insensitive care at this traumatic time adds significantly to parents 'distress. Good care should be universal and should not depend on where a mother happens to live or to be cared for."

Sands, 2010

In 2010 Sands, in its Bereavement Care Report 2010 (18), highlighted that there was variation in the cut-off point of when a mother who is miscarrying is always cared for on the labour ward. This varies in different units between 14 and 24 weeks, but commonly appears to be at 20 weeks. In most units mothers who are miscarrying and who are not cared for on the labour ward are accommodated on a gynaecology ward and they felt that:

“...giving birth in these areas, with staff who do not have the necessary training, support or experience, adds to the trauma of the loss and to parents’ distress. For the staff too, the knowledge that they are unable to give good care to these mothers is frightening and stressful. It is unfair to put them in this position”

Sands, Bereavement Care Report 2010



8. Sensitive disposal of foetal materials

For many parents, what happens to their baby after miscarriage is very important. Sensitive disposal of any foetal remains pre 24 weeks gestation is supported by a range of guidelines, in particular the Royal College of Nursing's *Sensitive Disposal of Fetal Remains. Guidance for Nurses and Midwives* (14). In conjunction with guidance from Sands and the Institute of Cemetery and Crematorium Management, this guidance offers advice and support to practitioners on a range of sensitive issues. In addition, the Human Tissue Authority introduced a code of practice *Disposal of human tissue* (15), which offers advice and information on the development of policy on disposal of foetal material pre 24 weeks.

Importantly for parents, these guidelines stress that there are a range of options for sensitive disposal of foetal tissues, and these should be discussed with the parents regardless of the gestation of the foetus. Again in its work in 2010, Sands reviewed practice and found that the vast majority of units offered good care and support at this time to parents, but that information could be improved around shared graves.

The sensitive disposal of foetal tissue is complicated. Some healthcare professionals reported that the trust protocols made it mandatory for remains to not be disposed of by the trust without the written consent from the parent(s). The challenges are that:-

1. The best timing of getting the consent will be different for each individual.
2. The paperwork may be incomplete and so a 'do nothing' approach is taken until it is correct.

As a result, foetal remains are commonly kept in the sluice until consent or the parent's preference for the disposal of the remains is confirmed.

" There is nothing sensitive about keeping foetal remains in the sluice in the meantime."

Emergency Gynaecology Ward Sister

" While being examined by the doctor, he said I had just passed tissue, which I didn't completely understand until I asked him if it was my foetus/baby. He said yes. I asked to see it, which he did show me in a tissue. I wasn't offered options of whether I wanted to take the foetus with me or how the foetus would be disposed of and I was too upset to think rationally and ask these questions myself, which I now greatly regret and feel guilty about. It haunts me to think that my baby may just be discarded with general hospital waste and I regret not asking to have my baby go home with me to be respectfully buried in the garden"

Anon Patient Opinions

9. Loss in the third trimester - Stillbirth

The Perinatal Mortality Surveillance Report (CEMACH) identifies stillbirths as 'babies delivered with no signs of life known to have died after 24 completed weeks of pregnancy' (16). In terms of numbers, in the UK annually over 6,500 babies die just before, during, or soon after birth.

The Royal College of Obstetricians and Gynaecologists (RCOG), in its Green-top Guideline No. 55 *Late Intrauterine Fetal Death and Stillbirth* (17), stresses the importance of sensitivity at this time and in section 8, the importance of psychological and social aspects of care. The guideline also offers advice on supporting parents with the loss and stresses the importance of parental choice at every point in the pathway.

In 2007 Sands published "*Guidelines for professionals caring for parents whose baby has died*" (18), which covers loss at every stage of the pregnancy and focuses on a range of topics including communication, with practical advice to staff caring for bereaved parents.

Sands followed this in 2010 with its "*Bereavement Care Report* (19). This document reported on its survey of UK maternity units and the care they provide to parents whose baby dies before, during, or shortly after birth. The aim of the survey was to find out the extent to which units were following the recommendations contained in the Sands 2007 publication.

The document reports that 77 units had responded to the survey and felt that although things were improving there was still more to be done.

Issues raised were:

The need for

1. More bereavement midwives
2. Improved access and provision of training for all staff
3. Improved quiet and accessible areas away from the main gynaecology or maternity areas
4. Improved communication across the NHS
5. Parental choice

The four stories next illustrate why these things are important in the service for patients.

Bereavement Midwives

Princess Alexandra Hospital:

The bereavement midwife goes to the ward and supports staff on matters such as consent for post mortems. Junior doctors go in with her to learn about communication – giving bad news, difficult conversations, etc. She offers teaching to consultants and has held 'Death of a Baby' study days twice a year for eight years, and there is always a waiting list. Every new member of staff in maternity has to attend. Doctors, Consultants, GPs, health visitors, students and funeral directors are able to access the training to ensure service provision is appropriate.

Environment

"...due to shortage of beds I was moved to the maternity department where I was put in a side room and forgotten about. All through the night I lay awake and crying to myself as the new born, very new born baby next door cried all through the night as if it was in my own room. When I finally saw a nurse and my concerns were raised they just said get some rest and try and sleep. Then I found out I was near the food prep area so there were constant loud voices and the clattering of plates and cutlery along with the door banging and the babies crying."

Carla, Patient Opinion.

Communication

"We were asked to visit a lady to dress a caesarean wound. My colleague was excited to go as we don't often get to see young patients – especially one with a baby. When the door was opened, my colleague said "let's have a cuddle with the baby then!" Sadly, the baby had died. We had not been told. This was distressing for the family – and for the District Nurse!"

District Nurse

Parental Choice

"My own experience was life-saving precisely because we were given all the options and allowed to make our own informed decision based on comprehensive information. For instance, while we were told we could keep Finley in the room with us if we wished, the recommendation was that he be kept in the morgue overnight because otherwise his skin would deteriorate. We chose to keep Finley with us."

"The thought of Finley being with strangers was more upsetting to us than the thought of his skin worsening. I was even able to hold him throughout the night on our last night together. His skin did change – his lips got darker. But overall the skin colour became much more even. He actually looked better after three days than he had on the day he was born. If a hospital has a cold cot of course, things become far easier on parents who have to make such choices. A cold cot ensures that the baby deteriorates less quickly and so can remain with the parents as long they wish. In an ideal world, I would like to see hospitals able to loan parents a cold cot so that they can take their baby home for the desired period of time."

"All this said, the most important factor in our survival was time. The length of time we spent in hospital. The time people took with us to make sure we understood all the information and had considered our decision. As much time as we needed, not as much time as the pressures of the job would allow. Jill's care was above and beyond the call of duty – she stayed with us well after the end of her shift. The experience of grief is an individual one. But the right information delivered with time and compassion is indispensable in every single case."

After Finley – Mel Scott: (6)

The Audit Tool for maternity services: *Caring for parents whose baby has died*, published by Sands and accredited by the Royal College of Midwives, was published in 2011. This tool aims to help those responsible for commissioning and providing maternity services to assess the quality of care they provide to bereaved parents. In addition it also recommends five key changes that would impact on the experience of care:

1. Bereavement care training for all staff caring for parents whose baby has died
2. All maternity unit staff should have access to a specially trained bereavement midwife
3. Dedicated bereavement room away from the main ward
4. Access to bereavement care literature
5. Post mortem consent package and training.

In 2013 Professor Soo Downe published *"Bereaved parents' experience of stillbirth in UK hospitals"* (19): a qualitative interview study which looked at what bereaved parents wanted during this time. She interviewed 29 families who had experienced stillbirth and the key messages of the report are:

1. Everyone involved (parents, clinicians, and support staff) has 'only one chance to get it right' at the time a baby is stillborn.
2. Parental recovery from the experience of stillbirth can be influenced as much by staff attitude and caring behaviours as by high-quality clinical procedures.

" My care all the way through at Leighton Hospital Cheshire was fantastic when I found out I had lost my son at 33 weeks and we then had to be induced. The care and compassion me and hubby received from the midwives and doctors was brilliant and today we have been given the post mortem results and again the consultant was wonderful. Throughout the tragedy of losing our son the hospital and midwives could not have been more supportive and I feel so lucky."

Loucotty, Patient Opinions

10. Charities

The authors looked at what was available in the third sector both nationally and locally for loss at any stage in the pregnancy, including the support that might be available for Black and Minority Ethnic (BME) communities. Charities are complementary to statutory services and a resource for:-

1. Raising awareness of patients, their families, the public and healthcare professionals.
2. Promoting good practice.
3. Individual support face-to-face, on the telephone, via email, accessing a 'closed' forum online, using social media, such as the charity's Facebook pages, or via their website.
4. Group support for women and/or parents and families, enabling a 'safe space' to share experiences and feelings with others who also have an individual, personal experience of pregnancy loss.
5. Written advice and information about what to expect in changes to the body, and services available.
6. Signposting other practical resources available, for example access to memorial services, and how to inform baby product companies to stop any targeted marketing when the pregnancy is unable to continue.
7. Responding to a need for support in a different way than the statutory services can provide.
8. Research.
9. Collaboration between charities and also with the Royal Colleges and local healthcare providers.

In the main, charities are supporting anyone who asks for their help regardless of when and how the baby died.

“Importantly, we provide listening support and information without pretending to be medical.”

Miscarriage Association

Many charities, national and local, include a range of volunteers, in the capacity of befrienders, trainers, and advisers, providing resource information and /or financial advice. Many local charities and healthcare providers use the written information provided by national charities such as the Miscarriage Association and Sands.

It appears that very few areas are not covered in some way by local charities. The size, number and what support is provided, however, varies across the country. This is not surprising as many charities were set up by grieving parents who offer a level of enthusiasm, depth of understanding and support that is commendable. Being volunteers, often with extensive other commitments, and depending on the size of the charity, has implications for their capacity. That said, the authors have been impressed with the speed of response and what is available with limited funding.

Numerous internet searches were undertaken, using different key words, which demonstrated that it could be difficult to find the local charities. Top results often featured pages on weight loss and miscarriage of justice.

A search on NHS Choices brought up both miscarriage and stillbirth. The site points women to the main national charities but a postcode search for local charities is often blank. It would be a great opportunity going forward to address this.

Miscarriage Association

For loss in early pregnancy nationally, the most well-known charity is the Miscarriage Association (MA) www.miscarriageassociation.org.uk which was founded in 1982 by people who had experienced miscarriage. The charity provides support and information to anyone affected by the loss of a baby in pregnancy, raising awareness of miscarriage and promoting good practice in medical care.

The charity provides a number of local support groups, which offer a safe space where people can meet and share their experiences and feelings.

The website has approximately 50,000 hits each month and the staff deal with around 6,000 phone, calls and emails per year from those who have suffered the loss of a baby in pregnancy.

Research is currently underway on the needs of partners of women who miscarry, as their needs are often ignored. The Miscarriage Association also has an active social media presence providing online support, and 70 volunteer telephone contacts across the UK who offer support and understanding from the perspective of people who have been through miscarriage themselves.

The charity also provides information on the most commonly asked questions about pregnancy loss. This information is commonly used by NHS services and women are often provided with the contact details and web address for the charity.

A comprehensive training package which includes communication and breaking bad news is also offered by the MA, and it is currently working with the Association of Early Pregnancy Units (AEPU) to develop e-learning modules to be available from 2014. The partnership aims to attract staff from gynaecology units, Early Pregnancy Units, district general hospital wards and both clinical and non-clinical staff.

The MA is also keen to develop:

- An understanding of the needs and ways to support and provide resources for young people (i.e. 13 -19 years)
- Provision of increasingly inclusive information, for example when English is the woman's second language, or if she has communication difficulties. There is now one leaflet available in pictorial form.

The Miscarriage Association also encourages healthcare providers to make positive use of patient and public experiences, thoughts and feedback, and offers advice and support to staff as well as parents and families.

A range of validated information booklets that have been developed with colleagues from the RCOG is also available from the charity.

Pre 24 weeks, there is no requirement to register a birth but many parents want to recognise the presence of their baby in some way and this is left to local services to provide support in this area. There are many examples across the country of charities that provide memory boxes, quiet spaces and memorial services for families to remember their child, regardless of gestation.

Stillbirth and Neonatal Death Charity

The Stillbirth and Neonatal Death Charity (Sands) is a well-known national charity that offers support to both the bereaved family and the staff who care for them. As well as the work mentioned previously, the charity also offers a range of support options for families including online discussions, phone contact, social media and local support groups.

The charity reports that last year:

1. Its helpline responded to over 4,000 requests for support, via phone or email
2. 104 Sands local groups throughout the UK were in place
3. 25,000 support leaflets and books were distributed
4. 700 people visited the website

Sands offers training to both staff and volunteers and has just recently revised its training programme for staff.

In April 2014 it will publish "*The Listening to Parents survey*", which has been undertaken with Bliss and the National Perinatal Epidemiology Unit. This survey will report back on the experiences of parents who lost a baby in the perinatal period between January and August 2012. It also will pick up on the provision of training for staff in the service.

Sands also works closely with the Royal Colleges and local hospitals and charities.

11. Social media

The use of social media is a popular mechanism for support with the vast majority of charities having a social media presence often on multiple channels. The Miscarriage Association reported a significant shift in the way that people access their services. For example, they told us that many are posting on the Miscarriage Association Facebook page whilst they are on an Early Pregnancy Unit, requesting quick immediate support from forum members.

Social media forums are also used to seek and access opinion on issues that matter to people with experience of loss in pregnancy. In 2011 Mumsnet www.mumsnet.com conducted a survey asking subscribers to share their experiences of miscarriage. Nearly 1,400 respondents shared their stories (21).

The results showed:

- Nearly two thirds (63%) of women who miscarried at home following a hospital scan said they weren't offered adequate pain relief
- Over a fifth of women referred for a scan (21%) had to wait three or more days
- Of those treated in hospital, nearly half (48%) were treated alongside pregnant women
- Over a third (35%) of those who required a surgical procedure following miscarriage had to wait four or more days
- 15% who were treated in hospital rated their consultant's sympathy and compassion as 'awful'
- A fifth (19%) of respondents dealt with their miscarriage at home, only alerting medical staff after the event
- Over a quarter of those who had information from healthcare staff (29%) rated the information they received as 'poor' or 'inadequate'
- More than one in 10 (11%) women didn't tell family and friends about their miscarriage.

These social networks offer us a great opportunity to engage with service users to try to break the silence around loss in pregnancy.



12. Education, training and support for staff

There is no doubt that to provide support in this complex area staff need access to regular good quality training. Both the Miscarriage Association and Sands provide training to staff and some local charities will also support their local hospitals. Training is aimed at the multidisciplinary teams across accident and emergency services, gynaecology services and maternity. We heard in our discussions with Sands that the numbers accessing training could be improved but we also heard that accessing training is difficult in some organisations due to the many competing priorities on their time.

There is a national shortage of midwives and the priority for the Royal College of Midwives (RCM) is to push for the number of midwives available to be increased.

“Workforce planning is affected by how many we can afford, rather than how many we need”.

They reported that there are generally 30 - 50 applications for every midwifery student place.

The RCM supports the continuous professional development of midwives including:-

1. An annual conference in collaboration with some charities, which has over 250 participants on a regular basis
2. I-learn, which is an online learning programme with approximately, 7,000 registered members, and I- folio, which is an online community, where groups can be set up.

There is also a bereavement network within the RCM for nurses, midwives and students who provide, or who are interested in, the care offered to parents whose baby has died. This was developed in partnership with Sands and Bliss (the special care baby charity). This bereavement care network helps practitioners to share good practice and procedures, exchange ideas and provide informal support. It is also a way for RCM, Sands and Bliss to keep professionals informed of relevant information, developments and resources.

The Royal College of Obstetricians and Gynaecologists (RCOG) has developed competencies in early loss in pregnancy around sensitive communication and breaking bad news, which are incorporated into training programmes (22). For non-medical staff, Skills for Health has set out some very broad competencies around communication and supporting the bereaved, but not specifically in this area (23).

Whilst many Trusts will offer general bereavement training as part of their training programmes it is very likely that they will be targeted at the professional groups, but consideration should also be given to the ancillary and support staff who are often on the side lines but still can be impacted. In terms of support, staff need to have the choice of when and how to be supported. Many staff will have been impacted in their own lives by miscarriage. At University Hospital Leicester a support and counselling service is offered for staff, but many staff value and will use peer support, mentorship and debriefs first. The hospital is also sensitive to the needs of transient staff, such as students, who may have experienced loss in their own lives.

13. Good practice

The following are examples of good practice. This is not intended as a comprehensive list, but instead provides a snapshot of some of the innovative services that have been established around the country.

The Princess Alexandra Hospital NHS Trust, Harlow

Bereavement Service

This has been in place for four years. The service is for any woman experiencing a pregnancy loss at any gestation, providing support on the ward following a miscarriage or a termination for foetal abnormality, through to stillbirth. Telephone support is also given when women get home, and physical and emotional wellbeing is assessed the day after they go home. Support can include practical matters such as registration of the birth and the funeral. There is a funeral for every baby, regardless of gestation, at no cost to the parents – a funeral director is instructed on their behalf. Parents can be as involved as they wish. Some parents choose to have private reflections, while others want to attend and are supported to do so. Ongoing support is tailored for each individual as some need more than others. Parents are invited back to a sensitive appointment clinic where they see a consultant and the bereavement midwife for half an hour, typically 5/6/7 weeks after delivery. The bereavement midwife will have already been speaking to them on the phone before this appointment, and will help signpost ongoing support. At the appointment the doctor usually talks about any test or post mortem results and implications for future pregnancies.

Training is provided by the bereavement service for all Trust staff including A&E, theatres, and wards. All areas notify the bereavement service of any pregnancy loss (this includes the pathology and mortuary departments). All departments are provided with the appropriate paperwork in packs, so high quality materials from a single source can be given to families. The packs are sealed so pages don't go missing. The bereavement midwife has a good relationship with mortuary staff who inform the bereavement service of any pregnancy loss. If the miscarriage occurs in A&E the foetus is sent to pathology and any identifiable baby parts are sent to the mortuary. The service also has links to GPs and midwives in Hertfordshire and Essex.

Women identified with potential loss are given a card with details of the bereavement service for self-referral.

The Trust has an Early Pregnancy Unit (EPU), where scanning is carried out, and which has a dedicated room for recovery time. The bereavement midwife has her own office in the department which is decorated in a non-clinical fashion, to provide women with comfort and space if needed. The ward has invested in a recliner chair which turns into a bed for partners and friends to stay with the women during this time.

If a woman has to have a termination at 12 weeks due to foetal abnormalities, the remains can be buried or cremated, and parents may attend if they wish. All products of conception are cremated and a record kept for parents in the future.

The bereavement midwife also goes to hospital wards to support staff on matters such as consent for post mortem. Junior doctors see the patient with the bereavement midwife to learn about communication – giving bad news, and having difficult conversations. Teaching is offered to consultants and the Trust has held ‘Death of a Baby’ study days twice a year for eight years. Every new member of staff in maternity has to attend and there is always a waiting list.

Further to the bereavement work came the realisation that some women who deliver a live baby don’t have the birth experience they had expected – for example if their baby went to Neonatal Intensive Care Unit (NICU) or if there was a major obstetric event causing trauma. The Trust now offers a Birth Reflection service where the mother can debrief, fill in gaps, find out why things happened the way they did, and make plans for the next time. The idea is to turn negatives to positive implications for further pregnancies.

Royal Derby Hospitals NHS Foundation Trust

Bereavement Service

Following the success of a business case submission, a Lead Specialist Midwife in Bereavement was established in 2004. The bereavement midwife works alongside the primary midwife, as a:

“ Different level of support in needed in bereavement midwifery.”

Bereavement midwife

The bereavement midwife provides face to face support and care. Additionally, there is liaison with Bereavement Support services, the mortuary, funeral directors, chaplaincy, pathology and post mortem services.

As well as the community midwife, who is available up to 28 days post discharge, parents can be proactively supported with a longer term support of the bereavement midwife. On discharge, permission is asked to ring the parents in 4 -5 days’ time. Many require telephone support only, while others prefer to be seen face-to-face. This generally takes place in a different location to where the loss was experienced, and typically lasts up to six sessions. The bereavement midwife is also present in clinic if the woman returns to see the consultant.

If required, there can be referral on to other services, such as counselling, (for example with The Laura Centre in Leicester www.the.lauracentre.org.uk) or return to the GP to access Improving Access to Psychological Therapies (IAPT). This underlines the need for a case by case approach to be taken.

The bereavement midwife is often contacted again by the parents should they go on to have a successful pregnancy. The bereavement midwife is also a resource for training other staff groups.

For some of the services we spoke with they have a single person as opposed to a team of bereavement midwives. This level of provision makes the service difficult to sustain as it is not clear what provision is in place to cover absence.

Ask the Experts. Improving NHS service quality through frontline staff and patient engagement.

The Newcastle Upon Tyne NHS Trust in partnership with Newcastle University

Allison Farnworth, Professor Stephen Robson, Dr Ruth Graham, Mr Robert January, Ms Diane Palmer.

This project aimed to examine a way of supporting the engagement of frontline NHS staff and NHS service users in improving health care services, specifically in relation to the services offered to women experiencing an early pregnancy loss (miscarriage, <14 weeks of pregnancy). The project began with a qualitative interview study involving four health care Trusts in the North East of England. 24 women who had recently received health care for an early pregnancy loss at one of the participating hospitals were interviewed (11 interviews also included the woman's partner). 38 health care staff members involved in the delivery or management of early pregnancy loss services were also interviewed. A thematic analysis was conducted and this established a model describing the features of 'ideal' early pregnancy loss care as described by interviewees and described below:

Place: The right environment in which to deliver early pregnancy loss services was difficult to define. There were positives and negatives to delivering this care within maternity services, gynaecology services and general surgical services. A stand-alone service was seen as the ideal facility.

People: The staff delivering care would ideally be sensitive, able to deal with grief, knowledgeable, and able to be proactive in offering appropriate care (e.g. offering pain relief rather than waiting to be asked). Appropriate training to deliver this type of health care was described as an experiential rather than academic exercise.

Process: The ideal processes for the delivery of early pregnancy loss services included continuity of care and carer, smooth transitions between departments and services, timely access to diagnosis and treatment, provision of choices regarding treatment, provision of realistic practical information, and attention to emotional as well as physical needs.

The results of the first phase of the study, and a subsequent patient survey, were shared in a series of three workshops in the Women's Services Directorate at Newcastle. They were attended by a variety of people involved in early pregnancy loss services (including health care practitioners, health care managers, a social scientist, a patient representative, and the Directorate Financial Manager). The workshops then used the knowledge and enthusiasm of the workshop participants to develop service development ideas which would move the service further towards the features of 'ideal' care. Twelve ideas were generated, and three priority ideas, along with an implementation plan, were agreed by the frontline staff and managers within the Directorate.

This project collected valuable, in-depth information from women experiencing early pregnancy loss. Interviewing health care staff also improved the understanding of the barriers and facilitators to their involvement in improving services. Feeding back locally relevant information from service users was met with interest and enthusiasm by those involved in delivering and managing these services; focusing the workshops on what was already good about care, and how it could be even better

(rather than only considering negative experiences of care) was motivating and reassuring to NHS staff. The processes used in this project were developed into a toolkit now held by the Quality and Effectiveness department at the Newcastle upon Tyne Hospitals NHS Foundation Trust.

The project was conducted during a Knowledge Transfer Partnership between Newcastle upon Tyne Hospitals NHS Foundation Trust and the Department of Geography, Politics and Sociology at Newcastle University. It was jointly funded by the Technology Strategy Board, the Economic and Social Research Council, the Department of Health, and the Newcastle upon Tyne Hospitals NHS Foundation Trust. For more information contact Alison Farnworth, Research Midwife/ NIHR Knowledge Mobilisation Fellow a.farnworth@newcastle.ac.uk

Supporting women from Black and Minority Ethnic (BME) groups

Leicestershire Sands

There is often an assumption that the 'close knit' BME communities are a source of support for the woman who has experienced loss. If this assumption is made by healthcare professionals, then they may not make the woman aware of ongoing support available. *"She's alright. She's got a close family and community"*. However, it is this 'closeness' that means there may be an expectation to not acknowledge the loss. *"The woman is expected to get on with it....although all she wants to do is cry. She has no- one to talk to."*

At Leicestershire Sands, befrienders include people with a BME background, who have an awareness of the constraints sometimes placed by religious and cultural dimensions of a wider range of cultures. The support groups are open to all, encouraging a cross section of the community to attend.

" They all have a need to be supported in their grief, regardless of their cultural diversity. Simply being Asian helps some to identify that this support is also for them."

Roopal Shah

Perinatal Institute

The Perinatal Institute has carried out work around Bereavement Postnatal Notes for Mothers, which have been developed and tested with users and providers. They aim to promote sensitive individualised care, ensuring appropriate support for the mother and to address the communication breakdown between healthcare professionals.

Please contact notes@perinatal.org.uk

Butterfly awards

Mel Scott, the founder of Finleys Footprints, www.finleysfootprints.com has set up awards to recognise the fantastic work that staff and parents do to support grieving parents.

Winners this year include:

Heart of England Foundation Trust. Category: Best Hospital Care

At Heart of England, a holistic approach to care is provided, from when the family is bereaved through the birth, funeral, follow up appointment, ongoing support, as well as care in future pregnancies.

Eden and Snowdrop Bereavement Suites have been designed to create a home from home environment. This is intended to provide families and the people that are important to them the space and time they need with their baby. Experienced and highly trained midwives are based within the bereavement suites. They are there to support families and provide advocacy and information that may be needed to enable families to make their own decisions. Care is always individualised, non-judgemental and led by the parents.

The families and their babies are treated with respect and dignity with religious and personal preferences always taken into account. Wherever possible, families can stay on the unit for as long as needed. Whatever the individual wishes are, appropriate ongoing support is put in place for families. The suites also have mortuary facilities, so that the babies are kept on the bereavement suite until the funeral has been arranged. This enables those families who wish to return and spend more time with their baby, unlimited access whenever they wish. Most importantly it means families know exactly where their babies are and that they are safe in the care of the bereavement team.

All cases are reviewed by the Perinatal Team to see if any improvements in care could have been made. Statistics and recommendations for future practice are provided and acted upon wherever necessary. This important work has led to changes in clinical practice and is vital in working together with Sands 'Why 17?' (24) campaign to improve perinatal rates.

Spiritual Support

Veronica Lee Hospital Chaplain Bristol

"I work as a Hospital Chaplain in Bristol where I have a lead role in the Maternity Hospital. During the years I have worked there, I am always amazed at being given the privilege of being asked to visit the parents of little dots who have died. This is the most awful time for parents - as well as their families - and to be invited in to be with them at such an emotional and vulnerable time is something which I still find very humbling. I visit parents of all faiths and none - what matters most to me is that I can offer them help and support at such a difficult time. To be able to talk with the parents, to be able to see their little one and to chat to their little dot is a very moving experience. I feel that pastoral care and help is paramount in such a situation as well as being honest when faced with such questions as "Why should this happen to me?" - If I don't know the answer then I always say so. Being able to arrange a service for their little one is also important as it has to be exactly right for the parents - this is always about the family, not about me or what I believe - as a Chaplain I am here for them. Sometimes the service is religious, (by that I mean a service for parents of all faiths); sometimes it isn't - but as I have said, this is about the parents' wishes and what feels right for them.

I always ask if they would like a phone call later on, or whether they would like to meet up - sometimes parents prefer not to have any contact as it can be so very painful for them; others do want to talk, to ask questions and to be with someone who saw their little one - often the extended family don't have this privilege."

Reproduced with the kind permission of Mel Scott

Details of all the winners can be found at: <http://www.thebutterflyawards.com/index.php/2013-award-winners>

Royal College of Midwife (RCM) awards

The RCM Annual Midwifery Awards reward, celebrate and share outstanding achievement in midwifery across the UK. They recognise the best new evidence-based practice projects and the best in team working. They discover outstanding individuals making a difference for women, families and the new-born. There is a bereavement care category – described as follows:

This award recognises the difficult challenges that result from this area of maternity care. The award will provide funding for Jake's Scholarship to enable a midwife with at least five years' experience to undertake education and training into bereavement care, with the aim of improving care to women and families.

Details of the nominees and winner can be found here: <http://www.rcmawards.com/shortlist/>

14. Next steps

In partnership with the charitable sector and the Royal Colleges, the NHS may want to consider the following next steps:

1. Set up or utilise existing mechanisms to actively encourage the sharing and/or spread of best practice.
2. Bring together a national stakeholder event promoting best practice. Delegates and presenters should be from all areas – primary care, A&E, and acute care and charities.
3. Work in partnership with the Royal Colleges and charities to follow up on the uptake of NICE guidelines and toolkits such as the Sands audit tool.
4. Work in partnership with the Miscarriage Association to take forward their work on the needs of young people and fathers.
5. Consider working with NHS Choices to improve the access to local charities through the search facility on their website.
6. Undertake an in-depth audit of training in terms of provision access and uptake across all staff who may come into contact with women who undergo loss in pregnancy and their families, to ensure that patient experience is everyone's business.
7. Review ways of engaging with bereaved parents to seek feedback on experience of care across the pathways.
8. Widen the scope of work to include support for termination of pregnancy and neonatal death.

Appendix 1 National charities

Organisation name	Website	Purpose
A Child of Mine	www.achildofmine.co.uk	Providing accurate, up to date practical information and guidance after the death of a child. Ensuring professional bereavement services are improved through the experience of other bereaved families. Designing and delivering more direct services to families after the death of a child, including financial assistance, support and practical advice.
Aching Arms	www.achingarms.co.uk	Aching Arms is a baby loss charity run by a group of bereaved mothers who have experienced the pain and emptiness of leaving hospital without their much wanted baby.
ARC Antenatal Resource and choices	www.arc.org.uk	Provides non-directive support and information to expectant and bereaved parents throughout and after the antenatal screening and testing process.
Babyloss	www.babyloss.com	Babyloss is a UK-based resource of information and support for bereaved parents and their families who have lost a baby at any stage of pregnancy, at birth, or due to neonatal death. They work with other major national charities to raise awareness.
Care for the family	www.careforthefamily.org.uk	They offer support and information to anyone affected by the loss of a baby in pregnancy.
Child Bereavement UK	www.childbereavementuk.org	Offer a service for bereaved families and professionals when a child has died and when a child is bereaved. Organisation provides information and guidance, signposting to other agencies, support and resources. The CBC website has discussion forum for families and for professionals.

Organisation name	Website	Purpose
Children of Jannah	www.childrenofjannah.com	Their mission is to meet the needs of grieving Muslim parents in the UK and beyond, providing practical, emotional and spiritual support, whilst educating friends, families, professionals and others to be better able to support them.
Compassionate Friends	www.tcf.org.uk	A charitable organisation of bereaved parents, siblings and grandparents dedicated to the support and care of other bereaved parents, siblings, and grandparents who have suffered the death of a child/children. They offer support both directly to bereaved families and indirectly by fostering understanding and good practice amongst professionals concerned with child death and by increasing public awareness.
Count the Kicks	www.countthekicks.org.uk	Count the Kicks is a UK registered charity that aims to empower mums to be with knowledge and confidence throughout their pregnancy. A baby's movement indicate its wellbeing and by understanding their baby, mums can be empowered to trust their instincts and ensure the healthy delivery of their baby.
Cruse Bereavement Care	www.cruse.org.uk	Cruse has a special website for young people, www.rdf4u.org.uk A special feature of this site is a message board where young people can share their experiences and receive replies from trained young supporters. Cruse also has a dedicated freephone helpline for young people, open 9.30am-5pm on weekdays. Cruse offers a range of helpful publications about bereavement.

Organisation name	Website	Purpose
Ectopic pregnancy Trust	www.ectopic.org.uk	The Ectopic Pregnancy Trust: Providing information, education and support to those affected by early pregnancy complications and to the health professionals who care for them.
Joshuas Boxes	www.joshuasboxes.co.uk	Provides memory boxes to gynaecology and maternity units across the country. Supports parents to provide similar services to their local hospitals.
Miscarriage Association	www.miscarriageassociation.org.uk	The Miscarriage Association has various channels to offer support and information to anyone affected by the loss of a baby in pregnancy. They also raise awareness of miscarriage and promote good practice in medical care.
National Maternity Support Foundation	www.jakescharity.org	Works in partnership with the Royal College of Midwives to raise awareness of consequences of changes to maternity services.
SANDS	www.uk-sands.org	Sands supports anyone who has been affected by the death of a baby before, during or shortly after birth. Offers emotional support and information for parents, grandparents, siblings, children, families and friends, health professionals and others.

Organisation name	Website	Purpose
Saying Goodbye	www.sayinggoodbye.org	Part of the Mariposa Trust. Saying Goodbye, which was started last year to provide Cathedral remembrance services for anyone who has lost babies at any stage of pregnancy, at birth or in infancy, has seen such support and demand for its work, that it is increasing from 7 services in 2012 to over 20 in 2013.
Tommys	www.tommys.org	In the UK 1 in 4 mums and dads will lose a baby during pregnancy or birth. Tommy's exists to change this and their goal is to help more mums and dads have a healthy baby and to halve the number of babies who die during pregnancy or birth by 2030.

Appendix 2 Local charities

Please note Sands has around 100 local branches which are not listed here, but can be found at www.uk-sands.org/support/sands-groups

Region	Organisation name	Area covered	Website	Purpose
Midlands and East	Nottingham Miscarriage Support Group	Nottingham	www.facebook.com/pages/Nottingham-Miscarriage-Support-Group	Charity that creates and maintains strong local peer support system for people who have lost a baby through miscarriage, through volunteers and helpers.
Midlands and East	The Laura Centre	Based in Leicester with new centres due to open in Derby and Coventry.	www.thelauracentre.org.uk	The Laura Centre offers specialist bereavement counselling to parents whose child has died and to children or young people who have been bereaved of a parent or significant person.
Midlands and East	The Lilly Mae Foundation	West Midlands: Links with Heartlands, Coventry and Warwickshire and Warwick hospitals	www.lilymaefoundation.org	The Lily Mae Foundation is working to promote research and improvements in practice which could save babies' lives. Also raised funds to provide cold cots and memory boxes to hospitals.
Midlands and East	Walsall Acorns	Walsall	www.acorns.org.uk	Offers counselling and support for those in a pregnancy related crisis. The counselling is a service that is charged to the participant.
North	Bluebell Foundation	Cumbria	www.bluebell.org.uk	Provides information and support to anyone who has been affected by the loss of a baby before and after birth and through childhood.

Region	Organisation name	Area covered	Website	Purpose
North	Bluebell Foundation	Cumbria	www.bluebell.org.uk	Provides information and support to anyone who has been affected by the loss of a baby before and after birth and through childhood.
North	4Louis	Based in the north east, supply upon request any hospital in UK with free memory boxes	www.4louis.co.uk	4Louis aim to offer support and help to these families, to capture those lasting precious memories of their baby. 4Louis provides memory boxes to hospitals in the north of England and some cold cots.
North	Sweet dreams our angels	South Tyneside, Darlington and national	www.sweetdreamsourangels.org	Raise money to supply hospitals with memory boxes for the parents of babies born sleeping and neonatal death.
North	Teardrops	North Tyneside and Northumberland	www.teardropsupportgroup.co.uk	Provide support for parents and families who have experienced the loss of a baby through miscarriage, stillbirth, neonatal death and termination of pregnancy for foetal abnormality.
South	Ask Wiltshire	Wiltshire – Frome	www.askwiltshire.org	Supporting parents and carers in Wiltshire through the provision of information, advice and services. There is a Facebook group and a support group is planned.

Region	Organisation name	Area covered	Website	Purpose
South	Child Bereavement UK	Buckinghamshire & Milton Keynes + National	www.childbereavement.org.uk	Groups for children who have been bereaved; Awareness raising in schools, victim support, social care, police, coroners etc. Young people's group
West Midlands	Cherished Forever	not known	www.cherishedforever.org	Provides memory boxes and keepsakes for West Midlands all maternity and neonatal units.

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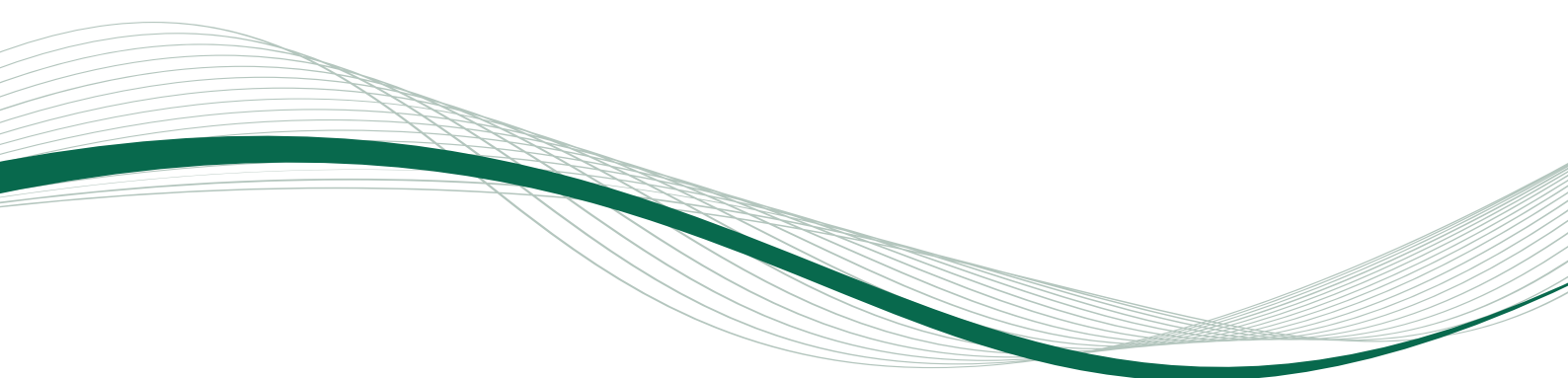
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