



# **Evaluation of the National Bereavement Care Pathway (NBCP)**

**Interim report (Wave two)**

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## The National Bereavement Care Pathway

The National Bereavement Care Pathway (NBCP) aims to improve the bereavement care parents receive after pregnancy or baby loss. It helps professionals to support families in their bereavement after any pregnancy or baby loss. The pathway covers five bereavement experiences: miscarriage<sup>1</sup>, termination of pregnancy for fetal anomaly (TOPFA)<sup>2</sup>, stillbirth, neonatal death, and sudden unexpected death in infancy (SUDI).

The project is backed by the government and has received funding from the Department of Health and Social Care. The NBCP is supported by the All-Party Parliamentary Group on Baby Loss and championed by health ministers. Sands is leading the project, and the core group of organisations involved includes:

- Sands
- ARC (Antenatal Results and Choices)
- Bliss
- Lullaby Trust
- Miscarriage Association
- Neonatal Nurses Association
- Royal College of Midwives
- Royal College of Nurses
- Royal College of Obstetricians and Gynaecologists
- Institute of Health Visiting
- NHS England
- A representative of the health research community

The overall aim of the NBCP is to overcome inequalities and increase the quality in the provision and experience of bereavement care. To achieve this, the project has produced a series of five pathways (relating to the five bereavement experiences above) for professionals to follow.

The desired outcomes from the NBCP project are:

- **For bereaved parents:** increased choices, improved care, improved experience.
- **For frontline health professionals:** increased confidence, streamlined processes.
- **For decision makers:** improved service delivery, increased satisfaction, streamlined processes, improved data quality.

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<sup>1</sup> The healthcare professionals' survey used the term "miscarriage." Since then the NBCP project has adopted the term "miscarriage, ectopic pregnancy and molar pregnancy" to describe this bereavement experience.

<sup>2</sup> The term "termination for fetal anomaly" (TOPFA) was used in the healthcare professionals' surveys. Following input from parents this was changed to "Ended the pregnancy after a prenatal diagnosis" for the parents' survey.

## **Organisations involved in the NBCP evaluation**

### **Teddy's Wish**

The evaluation is being generously supported by a donation from the charity Teddy's Wish ([www.teddyswish.org](http://www.teddyswish.org)), founded by Jennifer and Chris Reid, who themselves are bereaved parents. The charity aims to support grieving families and continue research into the causes behind sudden infant death syndrome (SIDS), neonatal death and stillbirth.

### **Fiveways**

In late August 2017, following a competitive tender process, Fiveways were commissioned to undertake an evaluation of the NBCP during its first wave of implementation, this was subsequently extended to cover wave two. Fiveways ([www.fivewaysnp.com](http://www.fivewaysnp.com)) specialise in strengthening charity governance, assessing and managing risk, and evaluating services to drive future improvement.

### **The Evaluation subgroup**

The evaluation subgroup was established at the outset to provide support and guidance for the evaluation. Its remit is to agree the approach to evaluation and agree measures against which to assess the impact of the project. The group consists of representatives from the charities in the core group (see above) and Teddy's Wish, and from researchers with experience in this area. The subgroup has provided valuable input into the deciding which outcomes to measure and ensuring survey questions are worded sensitively.

## 1. Executive Summary

The second wave of pilot sites for The National Bereavement Care Pathway was launched in spring 2018, with 21 trusts implementing the pathway (following the 11 in wave one).

The evaluation of the second wave of implementation aims to understand the impact and effectiveness of the pathway and to develop key learning that can be used to improve its future development and wider national rollout.

The first stage in the evaluation is a baseline survey amongst health professionals in the participating sites. This report covers the findings from that research.

1,268 health professionals from all the sites participated in an online survey which ran from 2<sup>nd</sup> May to 9<sup>th</sup> July 2018. The main aim of the survey was to set baseline measures so that changes prompted the NBCP can be measured in a follow up survey in early 2019. Qualitative questions were included to further understand professionals' perspective on bereavement care issues in their trust.

### 1.1. Key Findings

Key findings from the baseline survey were as follows:

- Many professionals are very positive about the bereavement care their trust provides – 67%<sup>3</sup> of participants in the survey feel reassured there is an effective approach to bereavement care in their trust.
- Overall 8 out of 10 professionals surveyed know what they need to do to provide effective bereavement care, 5 out of 10 feel prepared to communicate with bereaved parents and a similar number feel capable to deliver bad news. Although there is no significant difference in these levels between those in midwife roles and those not in midwife roles, in every case those with less experience of working with bereaved parents show significantly lower levels of knowledge, preparedness and capability than those with more experience.
- Specialist bereavement midwives are having a positive influence on bereavement care where they are in post – however there is a risk that bereavement care is left to more experienced staff. This means that more junior staff are not having the opportunity to build their skills, and that bereavement care can be inconsistent when the bereavement midwife is not present. Only 4 out of 10 agreed that bereaved parents received a consistent approach to their care across the hospital<sup>4</sup>.
- The survey revealed significant areas of inconsistent care that the NBCP aims to address. Care for parents experiencing early miscarriage, those experiencing termination for fetal abnormality, those attending A&E, and those in gynaecology wards was most often

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<sup>3</sup> Only 11% are not reassured, the remainder being "somewhat" reassured (see p13)

<sup>4</sup> Questions also included options to respond "neither agree nor disagree" or "I don't know" to certain statements. Therefore if, say 40% of respondents agreed it does not follow that the remainder (60%) disagreed as some would have chosen a neutral option, or indicated that they didn't know.

highlighted as in need of improvement. In short, the earlier the loss, the less consistent the bereavement care both in hospital and in the community.

- Handovers within the hospital and between the hospital and community were identified as a problematic area – particularly improving communications to ensure postnatal visits are conducted appropriately.
- The scope of the pathway includes the signposting and referring of parents to ongoing support, and to mental health services where these are needed, but not the provision of these services. However, respondents revealed a strong demand for increased provision of ongoing counselling and mental health support for bereaved parents.
- In terms of barriers to more effective bereavement care, increased training, better facilities, more dedicated staff time, and simplified paperwork were cited most often as issues to address.

## 2. Evaluating the NBCP

### 2.1. Evaluation aims

The evaluation aims to measure the impact and effectiveness of the pathway and develop key points of learning that can be used to improve subsequent development of the pathway. It aims to answer the following overarching questions:

For parents:

- What are parents' experiences of bereavement care in trusts that implement the pathway?
- What aspects of bereavement care could be improved?

For health professionals:

- What are health professionals' experience of implementing and working with the pathway?
- How has the pathway made a difference to bereavement care in their trust?
- What aspects of bereavement care could be improved?

To answer these questions, measurable outcomes for health professionals and parents were agreed by the evaluation subgroup, parents' advisory group and Teddy's Wish (see Appendices 3 and 4).

### 2.2. Evaluation method

The method agreed to generate the insight to measure the agreed outcomes is outlined in the table below, along with the status of each activity.

Month	Evaluation activity	Status at 31/8/18
May-July 2018	<ul style="list-style-type: none"><li>• Online baseline survey amongst health professionals – distributed by pilot leads to relevant colleagues within their trust</li></ul>	<ul style="list-style-type: none"><li>• Completed</li></ul>
Sept 18-Feb 19	<ul style="list-style-type: none"><li>• Online survey amongst bereaved parents – link distributed by each trust</li><li>• 16 telephone interviews with parents recruited from the survey</li></ul>	<ul style="list-style-type: none"><li>• Wave one survey and discussion guide approved.</li><li>• Sites briefed</li></ul>
Jan– Mar 2019	<ul style="list-style-type: none"><li>• Online follow up survey amongst health professionals – distributed by pilot leads to relevant colleagues within their trust</li><li>• 16 telephone interviews with professionals recruited from the follow up survey.</li></ul>	<ul style="list-style-type: none"><li>• Wave one survey and discussion guide approved</li></ul>
Mar 2019	<ul style="list-style-type: none"><li>• Telephone interviews with 12 site leads</li></ul>	<ul style="list-style-type: none"><li>• To be arranged</li></ul>

### 2.3. About this report

This interim report falls part way through the implementation of the evaluation. It covers analysis of the baseline survey amongst healthcare professionals (conducted May-July 2018).

### 3. Findings from the health professionals' baseline survey

The key insight from the survey is described below. The number of people who responded to the relevant question is shown in round brackets.

The analysis of the survey that follows is focussed on the following comparable groups. Total numbers in each group are shown in brackets.

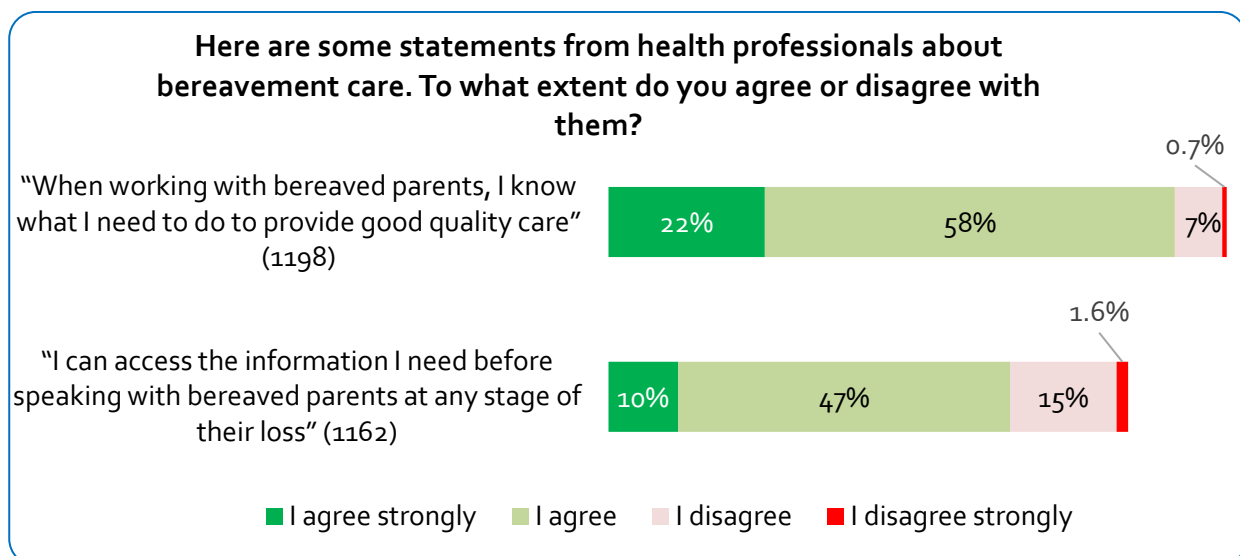
- Those in a midwife role (599) and those not (696)
- Those who had worked with parents who have experienced pregnancy or baby loss for different periods of time.
  - Less than 2 years (117)
  - 2-5 years (209)
  - 5-10 years (257)
  - More than 10 years (712)

The findings presented below are those where there is a significant difference (plus or minus 30%) between comparable groups.

#### 3.1. Feeling knowledgeable, prepared and capable

The survey asked how individuals felt about their preparedness to provide good quality bereavement care.

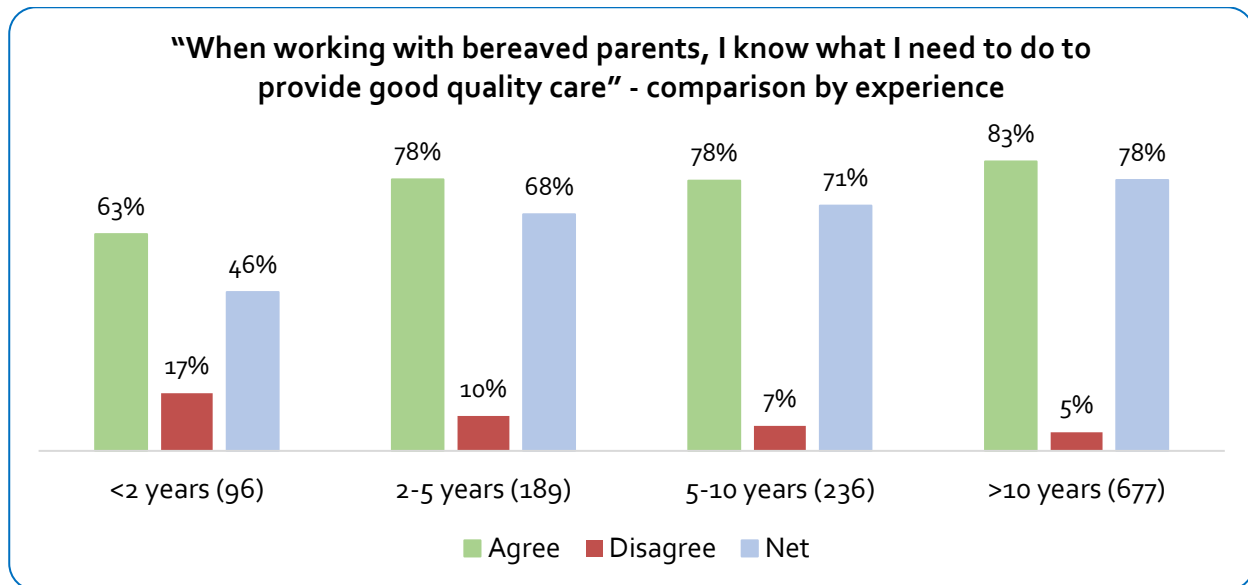
- 80% of respondents agreed that they know what they need to do to provide good quality bereavement care (only 8% disagreed<sup>5</sup>).
- 57% of respondents agreed they could access the information they needed before speaking with bereaved parents (with 17% disagreeing).



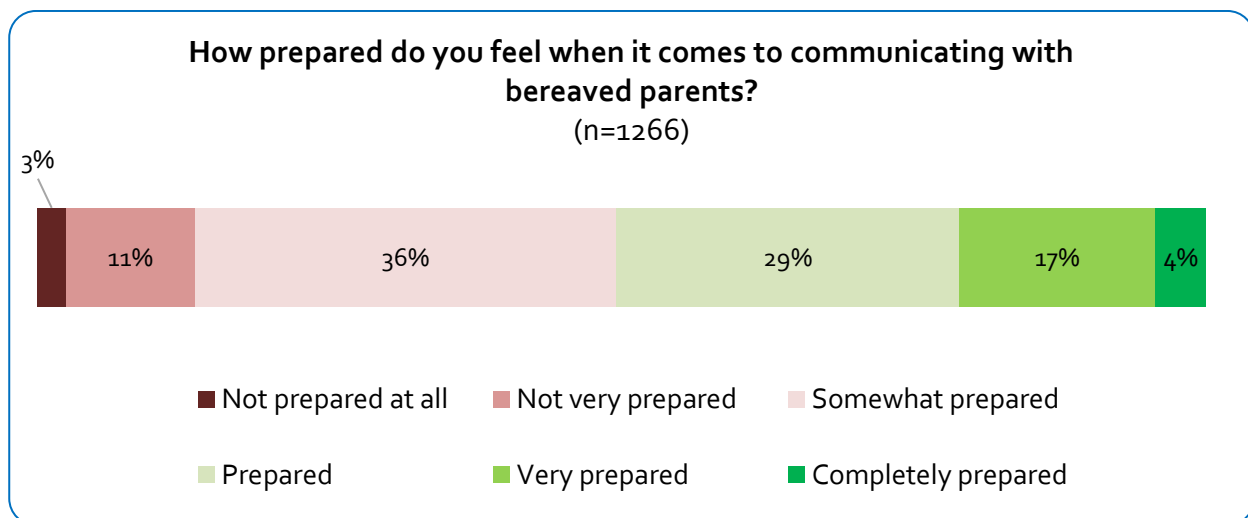
<sup>5</sup> The percentages in these charts may not add up to 100% as respondents could also answer "neither agree nor disagree" or "I don't know".



Levels of agreement with these statements are similar between midwives and those not in midwife roles. However, understandably, agreement with the statement *"When working with bereaved parents, I know what I need to do to provide good quality care"* increases with experience, with net agreement<sup>6</sup> 70% higher amongst those with ten or more years' experience compared with those with two or fewer years' experience.



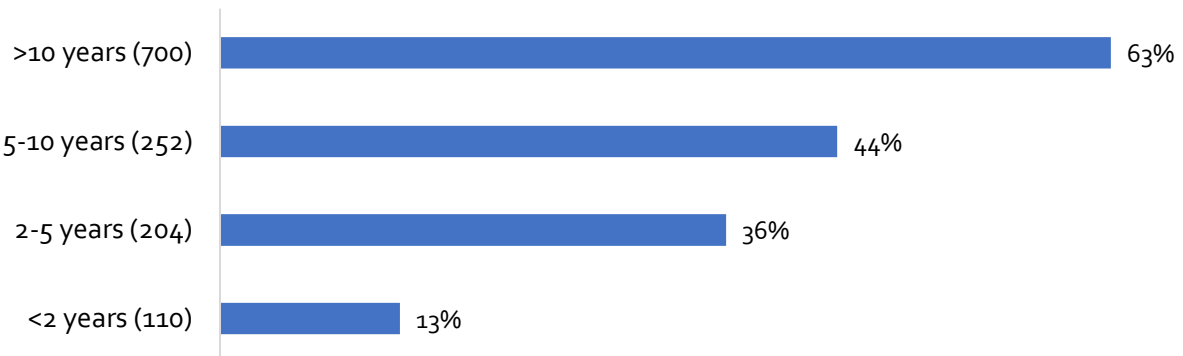
When communicating with bereaved parents, 50% of all respondents feel somewhat prepared, not very prepared or not prepared at all. Only 4% describe themselves as "completely prepared".



Those in non-midwife roles are slightly more likely to feel prepared than midwives (53% vs 48%). However, feeling prepared increases significantly with experience only 13% of those with less than two years' experience feeling prepared, very prepared or completely prepared.

<sup>6</sup> Net agreement is the product of those who agree less those who disagree.

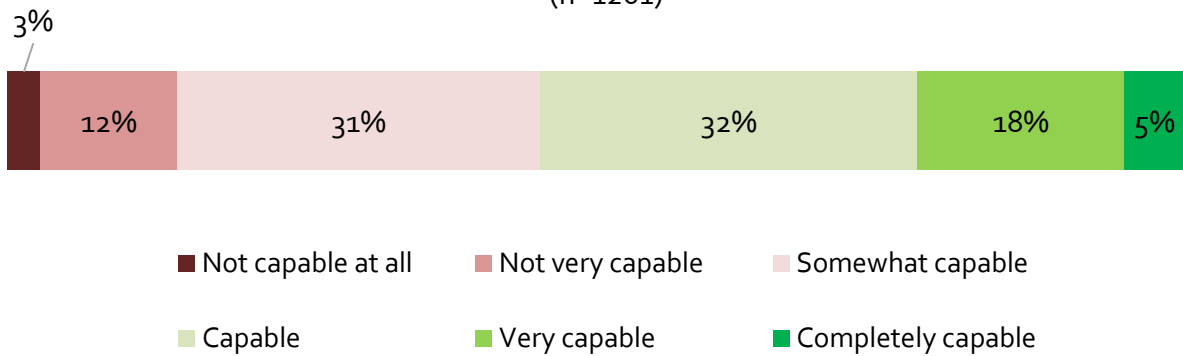
**How prepared do you feel when it comes to communicating with bereaved parents? (% feeling prepared, very prepared, or completely prepared)**



In terms of discussing bad news with bereaved parents, 45% of all respondents feel somewhat capable, not very capable or not capable at all to do this appropriately. Only 5% describe themselves as “completely capable”.

**How capable do you feel when it comes to discussing bad news to bereaved parents appropriately?**

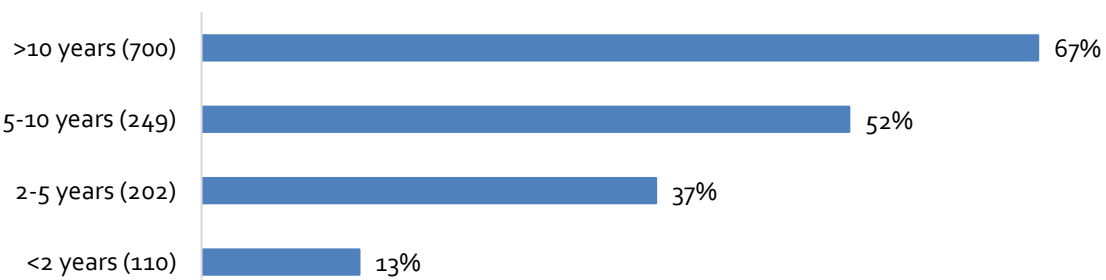
(n=1261)



As above, those with less experience are less likely to feel capable. Those in non-midwife roles are slightly more likely to feel capable than midwives (56% vs 52%).

**How capable do you feel when it comes to discussing bad news to bereaved parents appropriately?**

(% feeling capable, very capable, or completely capable)



In the qualitative feedback, many respondents highlighted the need for more training across the board to ensure consistent and effective bereavement care.

"I think more education needs to be given in how professionals approach parents or families who have had a bereavement, such as how to set up the discussion, the method of structuring the conversation and how to speak to the family in terms of being sensitive but also giving the family enough information but yet being sensitive to their emotional wellbeing and needs at the time" (Site 20, Paediatrician, 5-10 years' experience)<sup>7</sup>

"Sadly, I feel that not all staff (but only a minority), across all departments 'get' pregnancy loss, most especially if it is early pregnancy or when there is a termination for fetal abnormality. There is a clear need for education across all disciplines and departments to improve the overall experience for families." (Site 19, Midwife (bereavement), More than 10 years' experience)

"Regular updating and education for staff is important to help them deal with families in an effective, knowledgeable and caring manner." (Site 13, Midwife (Hospital based), More than 10 years' experience)

This need for training was particularly recognised by those with less experience, and by those whose roles may not regularly bring them into contact with parents experiencing certain types of bereavement.

"As a Maternity Care Assistant who works on delivery suite at times I would be very grateful of bereavement training being made available for my job role as I feel unprepared and unsure what to say when caring for them." (Site 22, Maternity Care Assistant, less than 2 years' experience)

"The bereavement midwives provide excellent care to women and their families however I feel as though midwives not specialised in bereavement could have further training and support to be able to understand the process (paperwork, drugs administration, psychological support)." (Site 17, Midwife (student), less than 2 years' experience)

"I feel more confident giving care to parents whose baby has a diagnosed fetal anomaly than I do giving care to a woman who has experienced a missed miscarriage. This is because I don't do this often and have never really had training in that area." (Site 17, Antenatal Screening Co-ordinator, 5-10 years' experience)

Several respondents mentioned that as some bereavement experiences, such as SUDI and losses within has become multiple pregnancies, can be rare events in a busy hospital, the need for support, training and updating more important.

"As a Paeds A&E nurse, I do feel like there is very little training surrounding infant death and bereavement care. As the situation happens so infrequently (fortunately), we are lacking in experience and learning." (Site 19, A&E nurse, 5-10 years' experience)

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<sup>7</sup> Quotes are attributed by site (numbered randomly), role, and years' experience of working with parents who have experienced pregnancy or baby loss.

“(There is a need for) more support for healthcare professionals when a family has lost one of more in a multiple pregnancy - how to support them with the living baby and what support to provide” (Site 8, Maternity Support Worker, 5-10 years’ experience)

“I have happened to have had much experience with SUDIs whereas some of my colleagues have rarely had to deal with such situations and therefore are unaware and unexperienced in handling such situations, communicating with such families, and knowing the procedures and what options are available to make the experience more streamlined and high quality. I fear there is huge inconsistency with the information families get and opportunities such as the viewing suite, spiritual services, mementos/memory making.” (Site 6, A&E nurse, 2-5 years’ experience)

“There has been a reduction in the resources and commitment to supporting bereaved parents as thankfully within paediatrics and neonates this is a relatively uncommon event - however I think this means we need to be particularly well prepared for the occasions when it does occur. (Site 4, A&E nurse, 2-5 years’ experience)

The need for training amongst less experienced staff, and fact that bereavement care skills may not be required frequently, can result in an over reliance on more experienced staff to deliver bereavement care and a lack of opportunities for others to develop their skills.

“Care I have witnessed (on the delivery suite) appears to go above and beyond. Only more senior midwives given the task though and there is a missed opportunity for others to help and learn.” (Site 8, Midwife (Hospital based), 2-5 years’ experience).

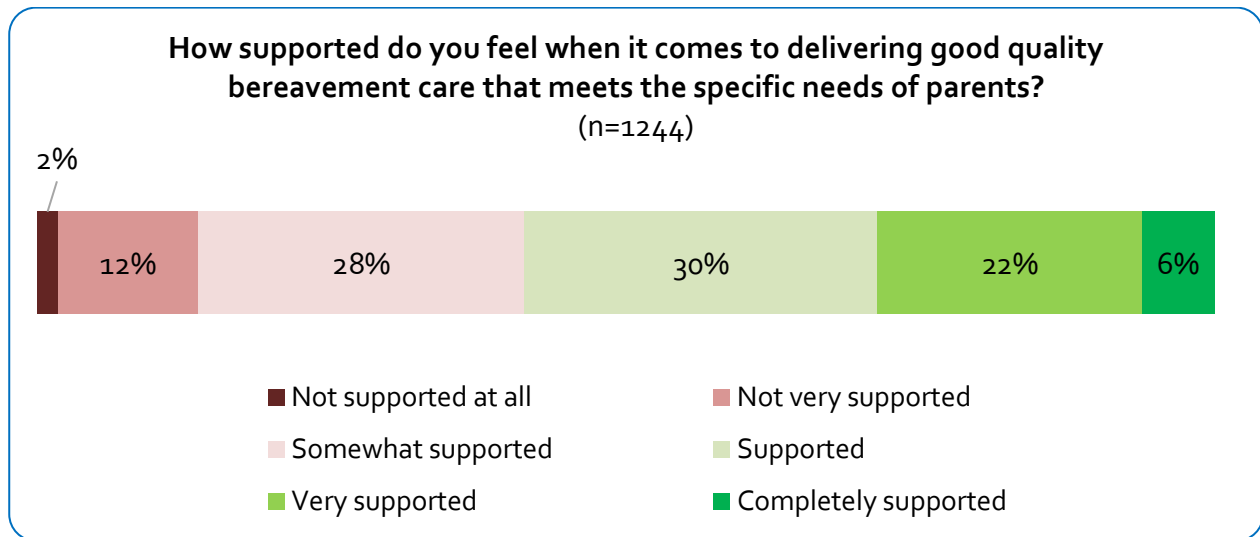
“The knowledge of how to care for bereaved parents is mainly known by a few experienced staff and is done very well, but training others up to have that same level of knowledge is not acknowledged at a higher level to support and encourage that.” (Site 2, Health visitor, More than 10 years’ experience)

“I believe we have a reasonably good service. I think further training for less experienced staff could be beneficial for example working with a more experienced member of staff to gain confidence in having difficult conversations with parents and providing the care required.” (Site 22, Midwife (Community based), More than 10 years’ experience)

“Generally, we provide good support and the midwifery team are sound with their care and advice. I feel there is room for improvement, in that some midwives just lack experience dealing with bereaved parents. Our Delivery Suite is generally very busy; therefore, bereavement cases are allocated to the more experienced midwives - it would be ideal to allow the more inexperienced midwives to take the lead with support from seniors” (Site 18, Midwife (Hospital based), more than 10 years’ experience)

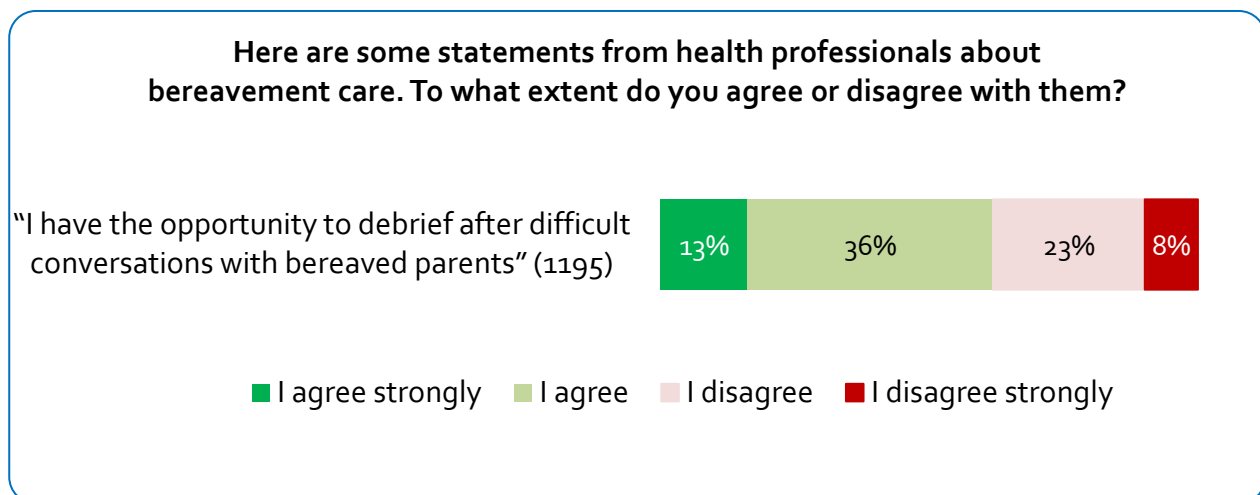
### 3.2. Feeling supported to deliver good quality care

41% of all respondents feel somewhat supported, not very supported or not supported at all to deliver good quality bereavement care.



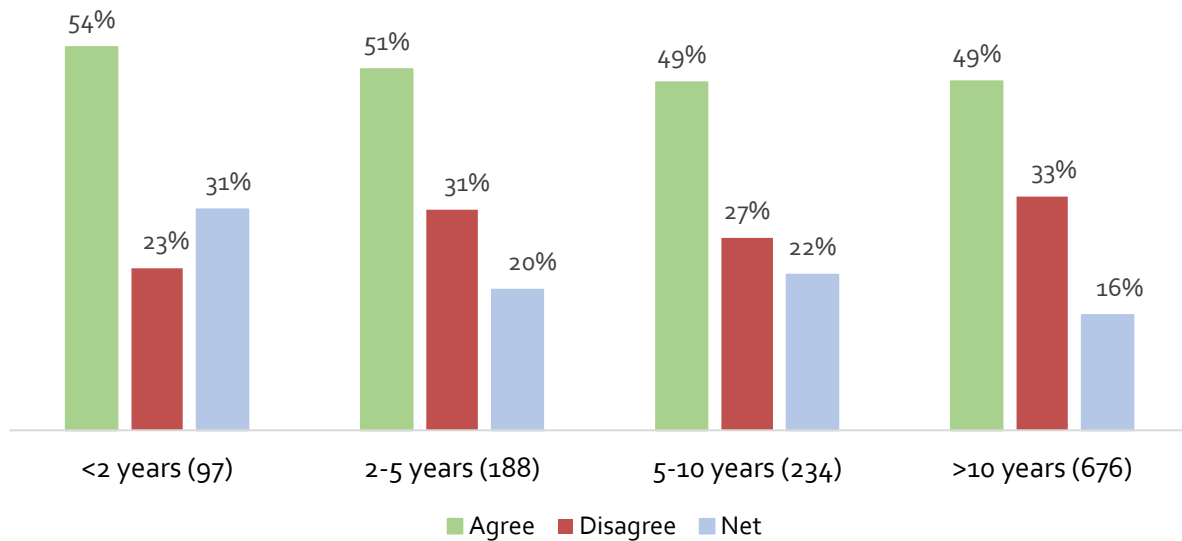
The proportion of those feeling supported is broadly similar between groups by role and experience.

49% of respondents agreed they had the opportunity to debrief after difficult conversations with bereaved parents – however 31% disagreed.



Levels of agreement with this statement are similar between midwives and those not in midwife roles. However, those with less experience are more likely to agree that they have the opportunity to debrief after difficult conversations (and are less likely to disagree) than those with more experience.

**"I have the opportunity to debrief after difficult conversations with bereaved parents"**



The importance, and sometimes lack of, support for staff providing bereavement care - particularly outside of the hospital environment - was identified as an issue in the qualitative comments. For one, implementing the NBCP pathway was seen as supportive in itself.

"I think the bereavement team are amazing at my trust, I as a staff nurse could not fault them. They always make sure to ask if the staff are ok after the loss of a child which seems like a small gesture but if you have lost a patient on your shift it can affect you too." (Site 14, Nurse, less than 2 years' experience)

"I feel there is a lot of support for ward-based staff to access debriefing but often those of us not ward-based are forgotten even if we have had a previous or ongoing relationship with the family" (Site 19, CNS – paediatric, more than 10 years' experience)

"I feel the inpatient bereavement care is excellent in our hospital but out in the community I do not feel very confident in dealing with bereaved parents. The training we receive is very much aimed towards inpatient care and ensuring the hospital staff give consistent advice/care, but I feel the bereavement team is not familiar with working within the community and what happens when women are discharged. It would be good to have some training specific to community midwives and maternity support workers . (Site 6, Midwife (Community based), more than 10 years' experience)

"Whilst I think the care we provide to bereaved families is excellent now, the care we provide to staff who undertake this care is sorely lacking. It can be very emotionally and psychologically draining caring for bereaved families, but on busy shifts the midwife is expected to care for other women either at the same time or directly after caring for these families. There is often no opportunity for midwives to debrief or to regain their resilience within the shift before moving on. There is support on offer, but staff have to go and find it and access it during their time off. It would be beneficial if the Trust sought out the staff and offered it directly, as often (I feel) staff see it as a show of weakness and that they 'can't cope' with something they see others 'coping' with and are unaware that everybody

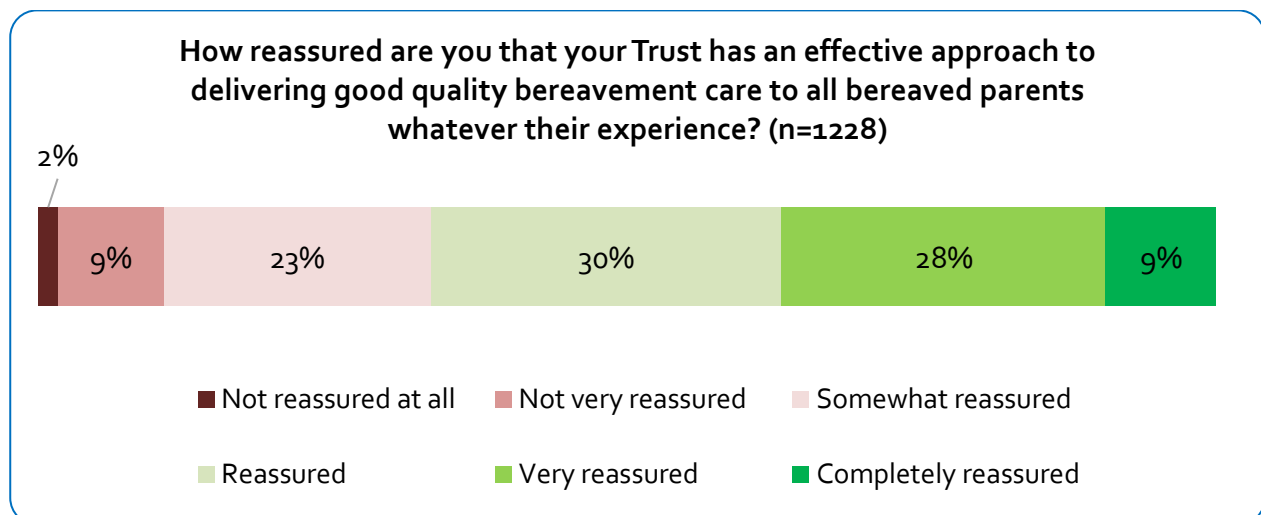
struggles with the mental and emotional strains of providing excellent care to bereaved families. Caring for bereaved families is an honour and a privilege which is valued by staff, but we seem to forget how tough it is on them.” (Site 22, Midwife (Hospital based), more than 10 years’ experience)

“To have a pathway where you know that parents will be supported or potential parents who suffer a loss can access support allows you better closure when dealing with traumatic circumstances as a nurse.” (Site 2, A&E nurse, more than 10 years’ experience)

### 3.3. Having an effective approach for all bereaved parents

33% of all respondents feel somewhat reassured, not very reassured or not reassured at all that their trust has an effective approach to delivering good quality bereavement care to all bereaved parents.

The proportion of those feeling reassured is similar between the midwife and non-midwife groups, and by levels of experience.



In the qualitative feedback, several respondents reported that elements of good practice were already in place at their trust.

“We deal with a variety of patients that have had a miscarriage through spontaneous delivery and with fetal abnormalities we have an excellent support system in place. We have chaplaincy, bereavement midwives and ourselves. Regardless of the situation patients need to be supported as...these babies are very much wanted and loved. All patients are supported individually, and we are guided by what they would like. They are followed up by bereavement midwives and chaplaincy. They are also given information to support groups such as Sands and counselling. All of these patients are offered pictures and mementos, hand and footprints where ever possible and the option to have babies blessed. The chaplaincy and nurses discuss funeral options and post mortem over 16 weeks pregnant.” (Site 11, Nurse, 5-10 years’ experience)

“When caring for a family who had suffered a loss shortly after birth I find that it is important to keep anything that will help create memories, for example footprints, the hat they wore,

the blanket they were swaddled in, even the saturation probe will be kept for families and placed into a memory box. We have a memory card that families can keep in order to take photos of their baby. Parents may wish to have counselling via the midwifery advocacy service. When caring for families who have had a loss of an older infant the process is very similar. If the infant was receiving palliative care, then multidisciplinary meetings will take place with families. These meetings will ensure that families are aware of all options of support and the plan of care made is placing them at the heart whilst always ensuring that they can make informed decision for their baby. Regardless of which group all parents will be provided with information for support groups, national and local. They will have the opportunity to talk to the bereavement councillor and our bereavement midwife." (Site 18, Neonatal nurse, more than 10 years' experience).

"I experience bereavement care within the neonatal unit and feel that it is done very well. We are fortunate to have charity support which enables us to provide a wide range of memory making opportunities to enable families to create loving memories with their baby before death. We also experience a lot of senior nursing support in providing bereavement care and opportunities to attend study days, some also charity supported, to enable us as nurses to become more comfortable and confident in providing support and speaking with parents in bereavement and withdrawal of care situations." (Site 12, Nurse, 2-5 years' experience)

"Not only do we give emotional and practical support to parents and families from the point of death in our bespoke bereavement suites, the door to bereavement care support is never closed to our families. This is because we are able to provide long term support encompassing a range of therapies, e.g. counselling, holistic, creative etc. as well as support groups e.g. a Dad's group." (Site 14, Bereavement officer, more than 10 years' experience).

Many respondents also mentioned the positive impact of bereavement midwives on the bereavement care in their trust.

"We have a new bereavement midwife in post, so although our care has a long way to go she has made a huge amount of positive changes and I feel she will continue to do so. (Site 1, Midwife, 5-10 years' experience)

"We are lucky that we have great support from a specialist bereavement midwife who is not only accessible to patients but also staff too." (Site 15, Midwife (Hospital based), 5-10 years' experience)

"I feel the bereavement midwife we have in place works hard to ensure good practice and has improved the service in the last few years. (Site 18, Midwife (Hospital based), more than 10 years' experience)

"There are some issues, but I think that care has improved since we have had bereavement midwives in place." (Site 20, Consultant (Obs/Gynae), more than 10 years' experience)

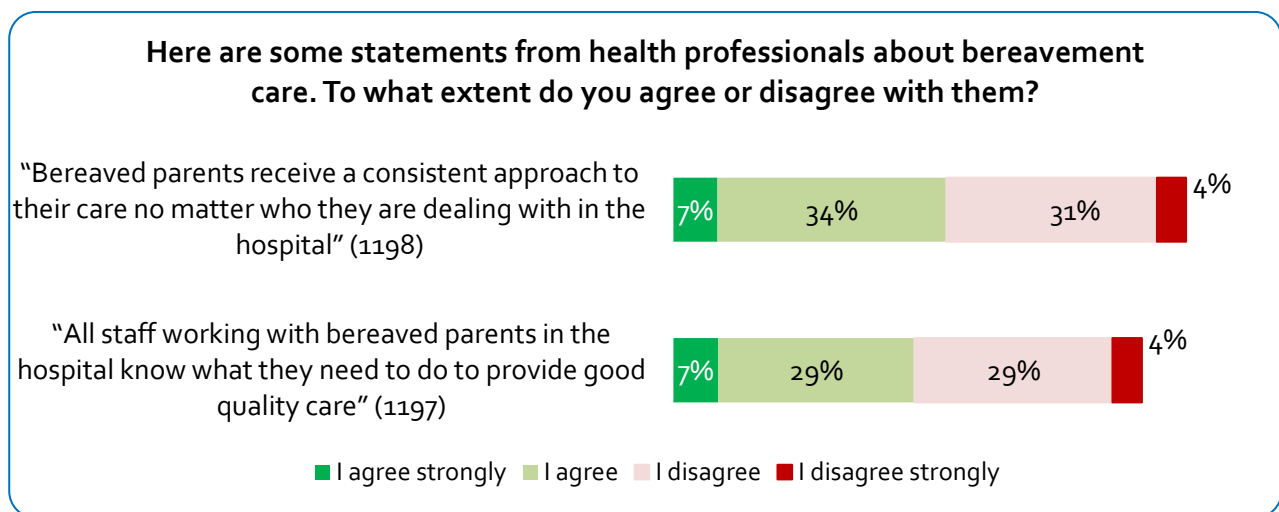


### 3.4. Consistency of care

We saw above (3.1) that 8 out of 10 respondents feel they know what to do to provide good quality bereavement care, however only just over a third (36%) agreed that all staff working with bereaved parents knew what they had to do to provide good quality bereavement care (with a similar proportion disagreeing). This disparity between respondents' perception of their knowledge compared with their perception of others' knowledge is best illustrated using "net agreement" – i.e. taking those who disagree away from those who agree.

Providing good quality bereavement care...	Agree	Disagree	Net agreement
I know what I need to do	80%	8%	72%
All staff know what they need to do	37%	33%	4%

When considering whether bereaved parents received a consistent approach to their care across the hospital respondents were also fairly equally divided – with 41% agreeing and 35% disagreeing.



Some respondents reported that bereavement midwives often worked limited hours and could be over stretched. As noted above, as there may be an over-reliance on experienced staff to deliver effective care, when the bereavement midwives or other specialist staff aren't present the quality of care delivered by others may not be as of high a standard.

"The specialist bereavement midwife is well received and offers good support, but there are not enough hours in the day for her to see everyone. We all need to be encouraged to offer more support – appropriately." (Site 3, Midwife (Community based), more than 10 years' experience)

"We have a very good bereavement sister, but she obviously doesn't work 24/7. It's when she is not available that I feel the parents don't have that expert care at that immediate time, although she would follow up when she is next on duty. This is when I also feel less supported and the care I give is basic as that is the extent of my experience." (Site 18, Midwife (Hospital based), 2-5 years' experience)

"There are still enormous variations on how bereaved people are treated and handled by all grades of staff. I have no doubt that no offence is intended by the Trust or by individual care

givers but the core elements of what can often be very rigid policies and procedures, intermingled with some of the consultant staff's personal feelings and their interest in specific research can often not "fit" with the very individual and bespoke needs of the bereaved." (Site 13, Anatomical Pathology/Mortuary, more than 10 years' experience)

"I feel as a whole the bereavement care within our trust is good. However, it is dependent upon the person/persons delivering the care. Some staff members offer better bereavement care than others, although all bereavement care given is good we need to further develop staff in order for all staff to offer all families consistency in the very best care that can be given, this is the difference between delivering good to outstanding bereavement care." (Site 22, Nursery nurse - bereavement support, less than 2 years' experience)

"I'm not always confident that the care is consistent and delivered to a high standard, it depends on the staff member caring for the bereaved family and how confident they feel in delivering the care. (Site 7, Midwife (Hospital based), more than 10 years' experience)

This inconsistency particularly affects woman who have lost babies earlier in their pregnancy (the care provide to these families is explored further below).

"Stillbirths receive very good care/continuity mainly due to our bereavement midwife. What lacks is the continuity when she is not around so relying on one person is difficult as a trust." (Site 16, Obs/Gynae (mixed role), 5-10 years' experience)

"In early pregnancy major problem is the junior senior house officer who is often thrown into the deep end and I feel patients do not receive best care or communication when they have been told they have miscarried. Often muddled & disjointed due to unfamiliar protocols." (Site 2, Sonographer, less than 2 years' experience)

### 3.5. Different levels of care for different bereavement experiences

Respondents were asked how bereavement care differed depending on the bereavement experience of the parent they were working with. Comments frequently mentioned that the quality of bereavement care was not as high for those parents who experienced miscarriage (particularly early miscarriage) or termination for fetal abnormality compared with those who lost babies later in their pregnancy.

"I think we do well for stillbirth and neonatal. But our care for miscarriage and termination is poor" (Site 8, Obs/Gynae (mixed role), 2-5 years' experience)

"Sometimes the care of women after miscarriage is poor. There can be a lack of communication between areas. Care of women following still birth seems to be far superior" (Site 12, Midwife (Community based), More than 10 years' experience)

"I feel that women and their families who suffer an early and/or multiple pregnancy loss(es) aren't always offered as much support as those experiencing later losses." (Site3, Nurse, 2-5 years' experience)

"For those women under 24 weeks I feel the care is more variable and relies more on the doctors to follow pathways/fill in forms and provide consistent and correct information which not everyone is doing." (Site 16, Obs/Gynae (mixed role), 5 -10 years' experience)

One contributing factor to this situation is the fact that often, women experiencing miscarriages present in A&E and are treated in general or gynaecology wards – where bereavement care practice and experience may be less embedded than in maternity and neonatal settings.

#### **A&E**

"I believe families who experience early pregnancy loss often experience poor care. Sitting in A&E is not appropriate when experiencing a miscarriage." (Site 4, Midwife (Community based), more than 10 years' experience)

"I work in A&E. If there is a sudden infant death, then there is very good support for parents. But women who attend the department with a threatened or actual miscarriage, I feel the support can be very poor. They have to wait days for an Early Pregnancy Unit (EPU) appointment and I feel that staff don't have the training or time to support them." (Site 13, A&E nurse, 2-5 years' experience)

"I have had to attend bereaved parents in the emergency department where the care was sub optimal. The baby had been brought in as a sudden infant death and the nurse was inexperienced with dealing with bereaved parents. There were no facilities or equipment for dressing the baby and the parents were left in a bare decontaminating room with their baby who was naked apart from a hospital towel." (Site 6, Neonatal nurse, more than 10 years' experience)

#### **General or gynaecology wards**

"I feel that the absence of a gynaecology ward, any dedicated gynae beds or any gynae nurses trained in Bereavement Care in my Unit is appalling. There is complete lack of provision for women experiencing early pregnancy loss and they are often cared for on general wards or in A&E." (Site 2, Midwife (Hospital based), more than 10 years' experience)

"Women experiencing miscarriage report poor levels of empathy from nursing staff on the wards. I get the impression that women feel their miscarriage is being treated like a medical procedure rather than the loss of a child. There is minimal privacy and dignity when women miscarry on the wards. It would be better to have this managed by midwives in a specialist area of the hospital not alongside other gynae cases." (Site 10, Midwife (Hospital based), 2-5 years' experience)

"Gynae have particular difficulties as there is no bereavement input there." (Site 5, Midwife (bereavement), more than 10 years' experience)

"Good care in obstetrics from accommodation, policies and particularly specialist bereavement midwife. Gynaecology less well equipped as no side rooms to care for these women, less staff to provide one-to-one care and no counsellor for follow up." (Site 18, Consultant, Obs/Gynae (mixed role), more than 10 years' experience)

"I believe women suffering bereavement loss of a baby over 16/40 gestation who go to Delivery suite get excellent 1-1 care. Those women suffering earlier pregnancy loss do not get the standard of care in our Trust that I believe they should. The needs of this cohort of women and families cared for on the gynaecology wards are not held in high regard by the Trust as a whole and their requirements and need for protected 1-1 service are overwhelmed by the need to support the capacity and demands of the hospital. The space, nursing time and bed space used for early pregnancy patients is used for outlying patients on the gynaecology wards. The space and nursing support are not protected." (Site 20, Matron, more than 10 years' experience).

In addition, several respondents highlighted that those bereaved parents experiencing early pregnancy loss should not be cared for on a labour and/or a postnatal ward.

"Inappropriate to have mothers with early pregnancy loss to be cared for in a busy delivery suite. Also, not pleasant for other mothers with pregnancy loss to hear other women in labour or hear babies crying." (Site 19, Midwife (Community based, more than 10 years' experience)

"It is essential that women are protected as much as possible from hearing women birthing and babies crying. I really believe that bereaved parents should not be made to have their care on a Delivery Suite and then a Postnatal Ward." (Site 6, Midwife, more than 10 years' experience)

"I really would to see a better area for parents dealing with a stillbirth, (so they are) not having to be on a ward with crying babies and screaming mothers. Then when exiting the ward having to go past the full waiting room and a busy ward, when your heart is breaking you don't want to be around others celebrating" (Site 13, Receptionist, 5-10 years' experience)

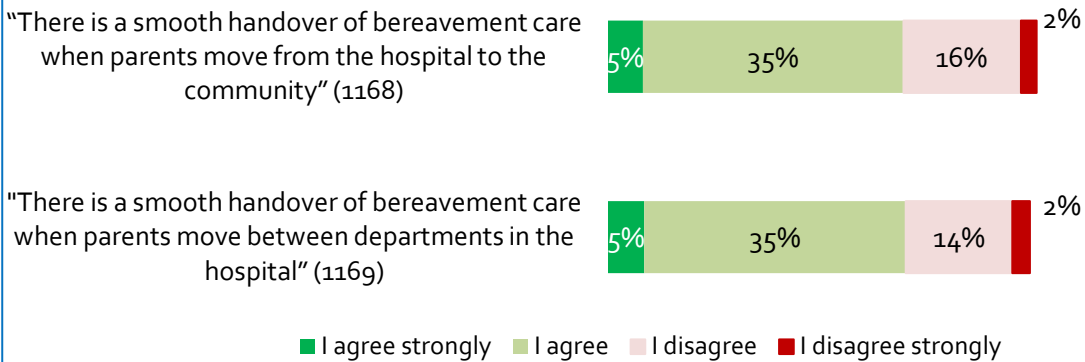
"I feel that women undergoing termination for fetal abnormality do not receive good bereavement care. Currently women are sent to a busy gynae ward where the nurses do not have the time to care for these families due to competing priorities. I feel that families should be given the choice of delivering with the support of midwifery care - often these pregnancies are much wanted babies and to be cared for on a gynae ward is sometimes inappropriate." (Site 20, Midwife (Antenatal & New-born Screening), more than 10 years' experience)

### 3.6. Handovers

Ensuring parents are effectively moved from the care of one team (or shift) to another in the hospital and eventually to support in the community is an important element of bereavement care.

The same proportion of respondents (40%) agreed that handovers were smooth within the hospital and between the hospital and community. Slightly more respondents (18%) disagreed that there was a smooth handover between hospital and community, than those who disagreed there was a smooth handover within the hospital (16%).

**Here are some statements from health professionals about bereavement care. To what extent do you agree or disagree with them?**



Qualitative comments expand on some of the challenges of effective handover, some highlighted opportunities to improve communication between hospital departments.

"In the area of my work I meet with the parent(s) who wish to view their child in the chapel of rest, so to that end I'm working with all ages of fetal/child loss. The problem that I find is that I'm not always aware of the background history of the parent and this can make it difficult to answer their questions or facilitate the viewing according to their needs. I'm aware that this is not intentional as the medical staff are very busy, but it would be helpful to me to know a little of the patient's history so that I can feel more prepared." (Site 15, Anatomical Pathology/Mortuary, more than 10 years' experience)

"There is the potential for a breakdown in communication and therefore a negative impact on bereavement care where parents move from one area to another or where their care crosses different areas e.g. baby dies on the neonatal unit and mum is on the postnatal ward. There is a lot of good care in most of the clinical areas, but it sometimes lacks a joined-up approach." (Site 22, Midwife (Hospital based), more than 10 years' experience)

However, more concern was evident in the comments about discharge and handover to the community. This can lead to postnatal home visits being conducted without the medical professional knowing the situation.

"Parents are often sent home from hospital not knowing information or how to arrange funerals. Liaison is not good between hospital staff and community staff." (Site 3, Midwife (Community based), more than 10 years' experience)

"I think that within the hospital setting, there is usually good handover of care between departments. But from hospital to community it is very limited. I have more than once gone on a postnatal visit, completely unaware that there had been a bereavement, until I entered the house and discovered the truth for myself. There was no message left to inform me. It is very embarrassing for me and upsetting for the family." (Site 22, Midwife (Community based), more than 10 years' experience)

"The worst aspect in my own opinion is the quality of communication. I was given a postnatal visit to attend with just the information that the lady was 4 days postnatal following a normal

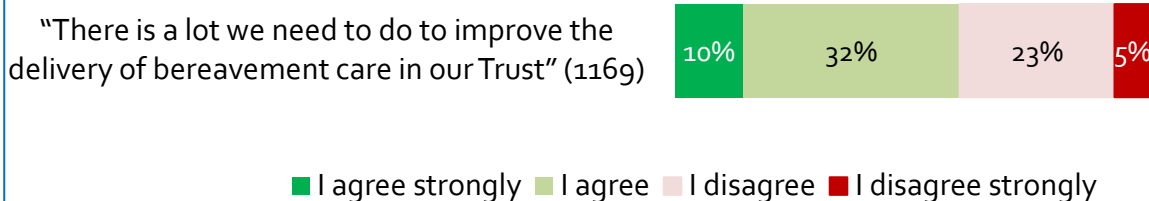
delivery. I wasn't told that the baby had died. I still feel traumatised now.” (Site 19, Midwife (Community based), more than 10 years’ experience)

“Our main communication breakdown is misinformation on discharge regarding returning to the unit to meet with their consultant for results. Parents will ring to the outpatient area who don't know who they are, requesting an appointment with their consultant. They can phone numerous times and speak to a different member of staff each time and have explain who they are each time.” (Site 17, Midwife (Hospital based), more than 10 years’ experience)

### 3.7. Room for improvement

42% of respondents agreed that there was a lot their trust needed to do to improve bereavement care. 28% disagreed.

**Here are some statements from health professionals about bereavement care. To what extent do you agree or disagree with them?**



The qualitative comments shed light on the aspects of care that could be improved. The most common issues were around follow up and counselling, facilities, resources and over-complicated paperwork.

#### 3.7.1. Follow up

Linked to the issues on discharge, many respondents also pointed to the lack of follow up and aftercare, particularly for those with early pregnancy losses.

“We offer no support to families when they leave the hospital, we signpost them to access support provided by others, but we offer nothing from our trust.” (Site 9, A&E nurse, 5-10 years’ experience)

There is no support in community for miscarriages, termination for fetal abnormalities ectopic pregnancies and molar pregnancies. Support for still births and neonatal deaths is provided by the Trust only until the mother is discharged by the community midwives. The care afterwards is provided by health visitors and GP, (Site 9, Consultant Obs/Gynae (mixed role), more than 10 years’ experience)

“We offer postnatal visits to women who have an intrauterine fetal death or a neonatal death, but often we don't offer to women who miscarry early or who have a termination, but I think it is equally important and hope that we can begin to offer a smoother community care.” (Site 7, Midwife (Hospital based), 5-10 years’ experience)

The scope of the pathway includes the signposting and referring of parents to ongoing support, and to mental health services where these are needed, but not the provision of these services. However, respondents stressed the need for more counselling and mental health support for bereaved parents.

“There is a lack of perinatal mental health input when a mother loses her baby. The perinatal mental health teams currently do not provide any support for bereaved mothers even if they have existing mental health problems and will be even more vulnerable at this time.” (Site 17, Consultant Obstetrician, more than 10 years’ experience)

“Counselling was previously offered, and this service is no longer available either; women and families are now having to self-refer to their GP for an extremely long wait for a service which should be provided at this traumatic time for them” (Site 4, Midwife (Hospital based, more than 10 years’ experience)

“I need better direct immediate access to psychological / counselling support for all women who suffer loss. There needs to be funding to provide for this very important service, within secondary care, which currently there is not. This is a particular problem in women with recurrent miscarriage and late miscarriage.” (Site 7, Consultant, Obs/Gynae (mixed role, more than 10 years’ experience)

### 3.7.2. Facilities

Inadequate and inappropriate facilities were often mentioned as a major impediment to delivering effective care. Many respondents called for more dedicated space to care for parents and babies.

“The early pregnancy unit is well equipped with a counselling room, however in the obstetric ultrasound department we are very short of space. The patients would benefit from a quiet space/room in which to be counselled and supported.” (Site 19, Sonographer, more than 10 years’ experience)

We desperately need a dedicated bereavement area for admission, delivery and postnatal. there are currently no rooms which can be used solely by these women and their families. we need to make better provision (Site 11, Midwife (Hospital based), more than 10 years’ experience)

“I feel that we need to be more open about how poor our facilities are here. In clinic we break devastatingly bad news in a truly horrible room with filthy plastic sofa and a stained carpet.” (Site 13, Midwife (Hospital based), more than 10 years’ experience)

“I completely disagree with stillborn babies being cared for in the sluice, I think it is disrespectful and there needs to be a separate and appropriate room preferably with a fridge available to care for these babies (Site 9, Midwife (Hospital based), 5-10 years’ experience)

### 3.7.3. Resources

Respondents called for more resources, especially staff time, to provide one to one care. Several referred to key bereavement staff leaving and not being replaced, putting further pressure on the time available.

"I feel all areas lack the resources to offer good quality bereavement care at all times." (Site 22, Midwife (Hospital based), more than 10 years' experience)

"The bereavement care team offer a fabulous service to the women and their families. The trust fails women by not ensuring staffing levels are protected to provide one to one care in the bereavement suite. Women and their families can be left to feel uncared for at a devastating time in their life." (Site 6, Midwife (Hospital based), 2-5 years' experience)

"We have had the services of a trust bereavement midwife but I'm aware this post is under review as she is retiring. The bereavement officer for maternity has also left the trust and has not been replaced and I feel her role was valuable in supporting the neonatal service." (Site 4, Neonatal nurse, more than 10 years' experience)

### 3.7.4. Paperwork

Several respondents indicated that the requirement to complete paperwork following a bereavement, the complexity of that paperwork and the time it takes to complete, were barriers to providing effective bereavement care.

"I think that all staff are compassionate and kind to the women we care for. I think we are worried about getting the process wrong and it always feels like there is a lot of paperwork to complete and there is a worry about getting this bit wrong too. Generally, the feedback is what has been done wrong and little feedback is related to what we have done well, which in turn supports the worry of incorrect process." (Site 17, Midwife (Hospital based), More than 10 years' experience)

"I feel there needs to be a streamlining of the reporting required following stillbirth, TOP and neonatal death. The current process of reporting is convoluted with many different forms. Mistakes and omissions are frequent, and it means less time to focus on the grieving family." - (Site 7, Midwife (Hospital based), 2-5 years' experience)

"There needs to be a less complex discharge process to ensure women are not staying on labour ward longer than they want because we have delayed them due to systems issues and paperwork. I feel a simpler discharge process which applies to all would ensure consistent care is achieved for all bereaved parents." - (Site 18, Midwife (Hospital based), More than 10 years' experience)

"It would help if we had another study day on bereavement care explaining how the paperwork works so that this part isn't so time consuming. The focus is the parents, but the daunting part is making sure all the correct forms are completed." - (Site 13, Midwife (Hospital based), More than 10 years' experience)



### 3.8. Baseline outcome measurements

The following table confirms the indicators that will be revisited in the follow up survey to measure the impact of the pathway on professionals<sup>8</sup>. The equivalent measures from wave one are included for comparison

Indicator	Baseline (Wave 2)	Baseline (Wave 1)
% who agree they know what to do to provide good quality bereavement care	80	82
% who agree they can access the information they need before speaking to parents	57	54
% who feel prepared for communicating with parents	50	48
% who feel capable to break bad news appropriately	55	55
% who feel supported to deliver effective bereavement care	58	61
% who agree they can debrief after difficult conversations	49	47
% who feel reassured there is an effective approach to bereavement care in the hospital	67	69
% who agree parents receive a consistent approach to their care from all staff	41	39
% who agree all staff know what to do to provide good quality bereavement care	37	37
% who agree handovers within hospital departments are smooth	40	39
% who agree handovers between the hospital and community are smooth	40	43
% who <i>disagree</i> that there is a lot needed to improve bereavement care in their trust	28	27

## 4. Survey timing and response

Wave 2 of the NBCP project was launched on 16<sup>th</sup> April 2018. The baseline survey was distributed to sites on 1<sup>st</sup> May.

The survey link was distributed by the NBCP pilot lead to colleagues in relevant departments. In some cases, the leads also relied on contacts in other departments to distribute the link for them. We do not know exactly how many people were given the opportunity to do the survey and, therefore, we cannot calculate a response rate.

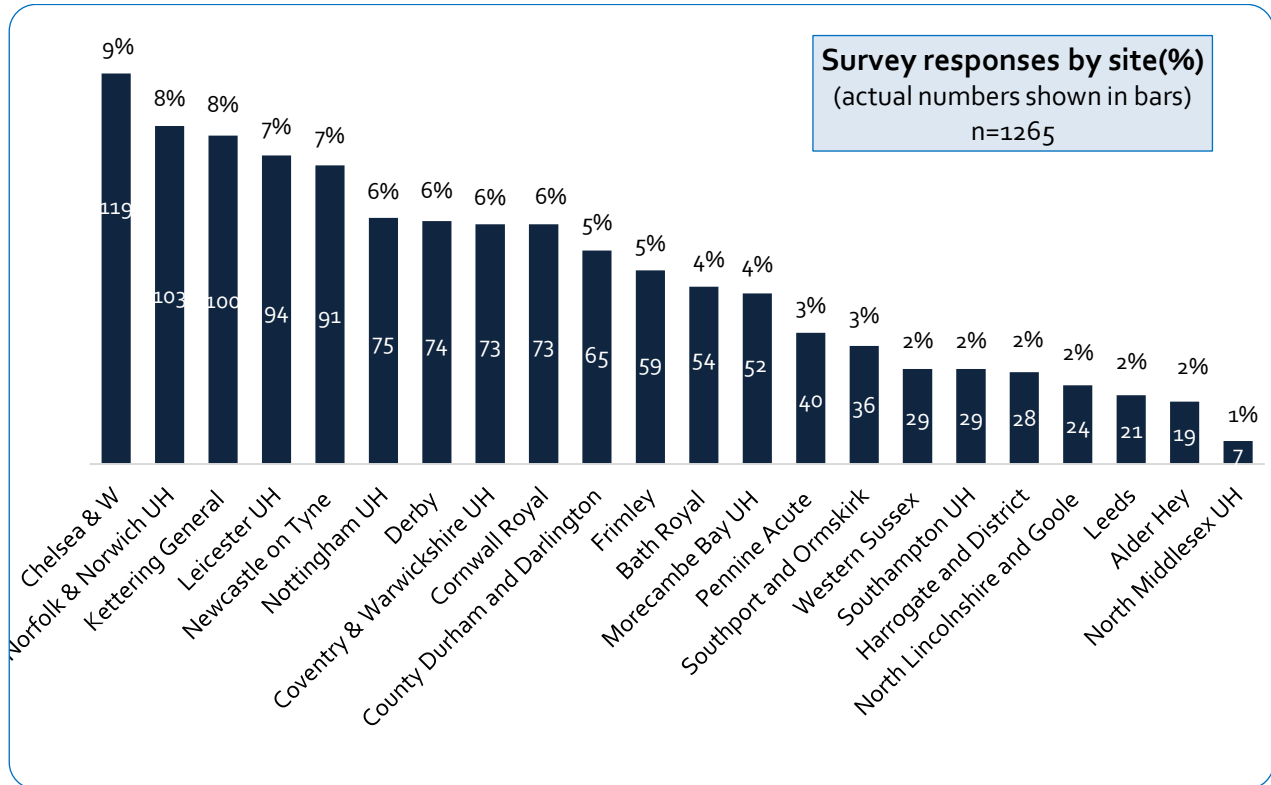
Sites started their survey at different times. Responses were received between 2nd May and 9th of July. The last site to receive their first response did so on 19th June.

<sup>8</sup> As noted below (5.2) these baseline figures will be adjusted to include “matched” responses only – i.e. those who complete both the baseline and the follow-up survey (identified by their unique code)

Respondents were asked to provide a unique ID to enable the comparison of the same people in the follow up survey in early 2019<sup>9</sup>.

#### 4.1. Location

Every site provided responses to the survey. Chelsea and Westminster provided the most (119)<sup>10</sup>.

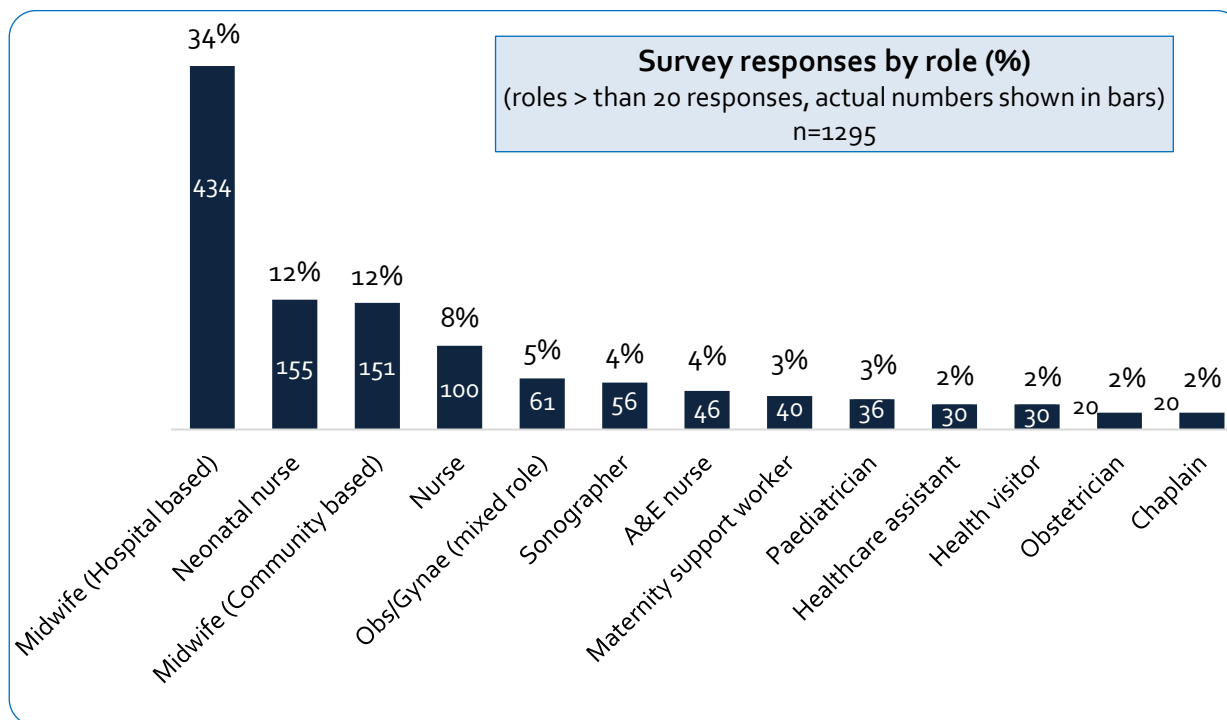


<sup>9</sup> Where responses to the baseline and follow up survey can be matched the baseline will be adjusted to reflect the perspectives and opinions of those matched.

<sup>10</sup> Chelsea and Westminster were originally a wave one site but were unable to conduct their baseline survey. As the pathway had yet to be implemented fully at the time wave 2 was launched, it was decided to include them in the wave two baseline and follow up surveys.

## 4.2. Role

The survey did generate responses from a wide range of roles. Roughly a third of the responses to the survey were from hospital-based midwives – and 46% from all midwives, including those based in the community. The roles which provided 20 or more responses are shown in the graph below.



## 4.3. Grade

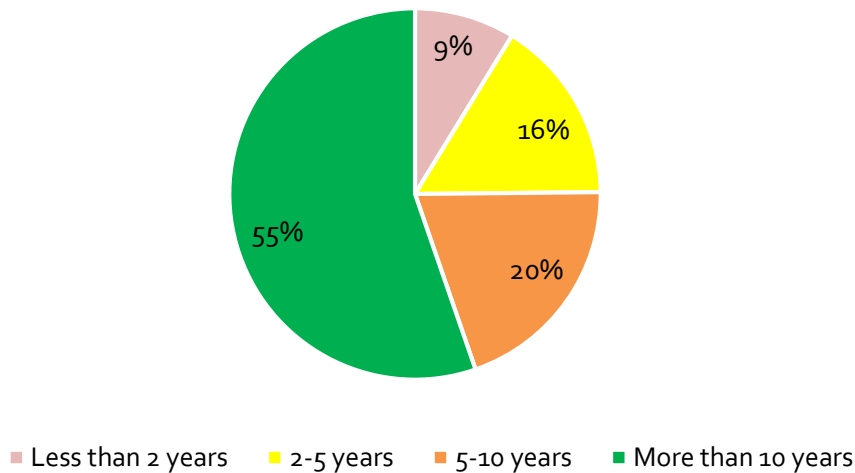
41% of survey respondents (n=1,286) were on Agenda for Change salary band 6. The majority of midwives in the NHS workforce are at band 6, so this profile reflects the respondents by role above).

Band	Responses	%
1	2	0.2%
2	46	4%
3	39	3%
4	18	1%
5	150	12%
6	526	41%
7	275	22%
8A-D	65	5%
FY1-2	2	0.2%
CT1-3	2	0.2%
ST1-8	20	2%
Consultant	108	9%
Other	15	1%
<b>Total</b>	<b>1286</b>	

#### 4.4. Experience

Over half (55%) respondents had over 10 years' experience working with parents who had experienced pregnancy or baby loss. Only 9% had less than two years' experience.

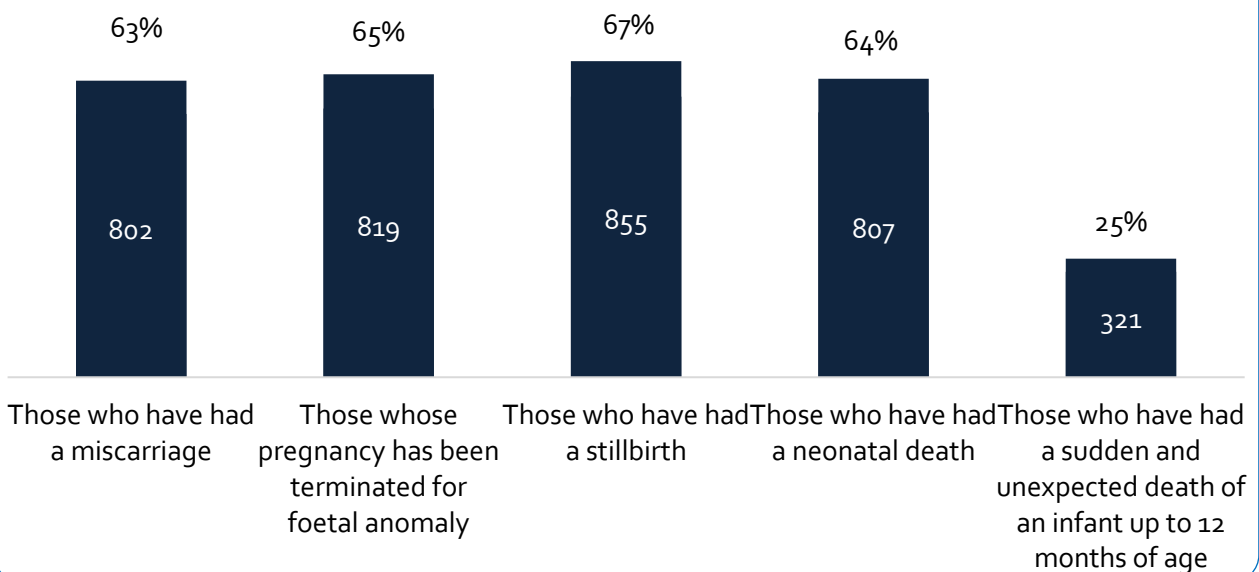
**Approximately how many years have you worked with parents who have experienced pregnancy or baby loss? (n=1268)**



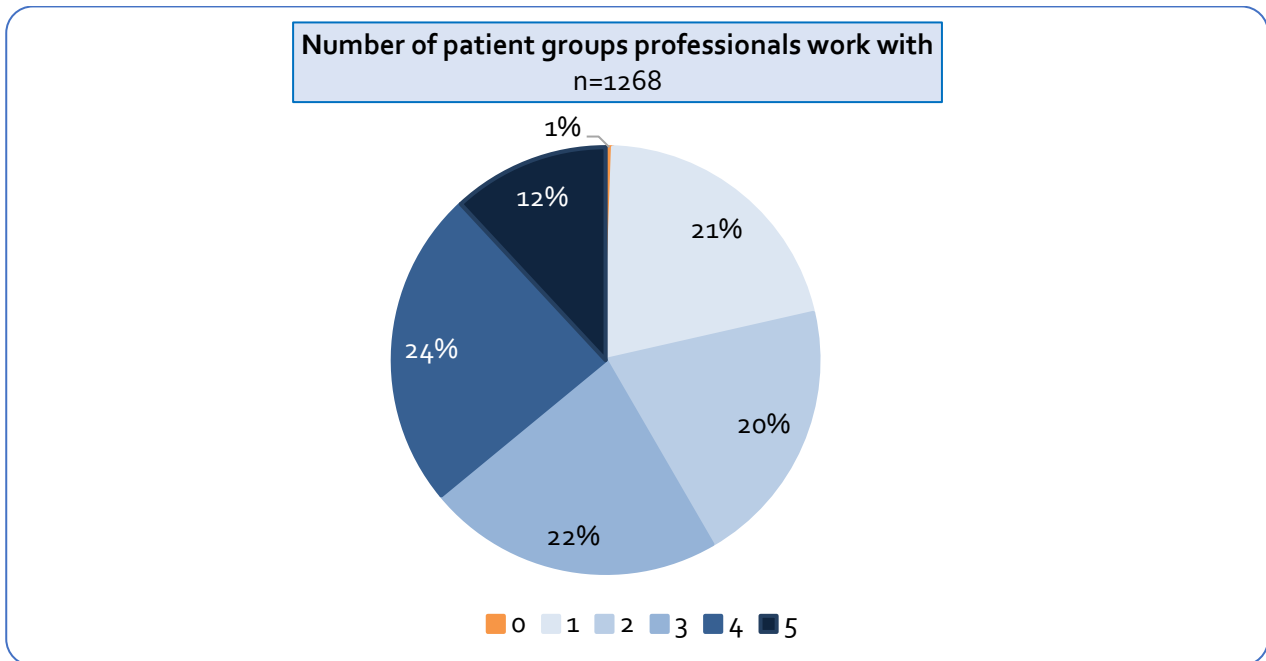
#### 4.5. Parents supported

Approximately two thirds of respondents worked with parents who had suffered miscarriage, termination for fetal anomaly, stillbirth or neonatal death. However, only 1 in 4 worked with parents who had suffered the sudden unexpected death of an infant (less than 12 months old).

**Respondents working with each parent group (%)**  
(actual numbers shown in bars)  
n=1268



12% of respondents worked with parents from all five groups and 36% with four or more of the five groups.



## 5. Next steps for the evaluation

### 5.1. Gathering insight from parents

The parents' survey will be conducted between September 2018 and February 2019 and August 2018. The desired outcomes to measure have been approved by the Parents Advisory Group and the Evaluation Sub Group (see Appendix 3 below). These groups also commented on the introductory copy of the survey itself. The survey has been approved by the NBCP project group.

The survey will invite parents to participate in telephone interviews to discuss their experience in more depth. 16 of these interviews will be conducted from September 2018.

The pilot sites are responsible for ensuring parents from all the relevant bereavement experiences in the NBCP have the opportunity to complete the on-line survey. They have been given the freedom to promote the survey in the way they feel is best for their patients. The experience from wave one is that promoting the survey link by email is five times more effective than using information leaflets.

Before the wave one research, a query was raised with the Health Research Authority (HRA) as to whether this insight gathering amongst parents should be classified as "research" which requires an ethical review by a NHS Research Ethics Committee (REC). The HRA confirmed that they considered the project "service evaluation" rather than "research" so it did not require a review.

The approach was also discussed with a member of the Patient Insight team at NHS England who advised that:

- Trusts should administer the survey themselves; as no identifying patient details will be transferred outside the trust, this circumvents confidentiality issues.

- Trusts should ensure they contact their local Research & Development office, or Caldicott Guardian, to check local requirements in advance of making the survey available and the trust should sign off the survey and arrangements.
- The survey has a section that gives an option for parents to be contacted for an in-depth follow-up phone call - this should have standard advice regarding use of data and be clear about how the information will be used.

Some pilot trusts may be using The Maternity Bereavement Experience Measure (MBEM) to gather feedback from parents<sup>11</sup>. However, this tool does not cover all the bereavement experiences included in the NBCP. Rather than ask bereaved parents to complete two surveys about their bereavement care experience, it was decided that the NBCP survey would take precedence over MBEM for the duration of this evaluation.

## **5.2. Healthcare professionals**

A follow up survey will be distributed amongst health professionals in early 2019. This will essentially be a repeat of the baseline survey and will also include questions about professionals' experience of using the pathway. The survey will invite professionals to participate in telephone interviews to discuss their experience in more depth. 16 of these interviews will be conducted from January 2019.

The follow up survey will allow us to measure the change in the baseline measures above. As we will ask for unique identifiers in both surveys we will be able to report on "matched responses" – i.e. those who completed both the baseline and the follow up surveys.

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<sup>11</sup> MBEM is a questionnaire and supporting resource, developed by Sands, NHS England and the London Maternity Clinical Network. It is designed to seek feedback from bereaved parents where a baby or babies have died during pregnancy or shortly after birth.

## **Appendix one: wave two pilot sites**

- Alder Hey Children's NHS Foundation Hospital,
- County Durham and Darlington NHS Foundation Trust
- Derby Teaching Hospitals NHS Foundation Trust
- Frimley Health NHS Foundation Trust
- Harrogate and District NHS Foundation Trust (Health Visiting Team)
- Kettering General Hospital NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust
- Newcastle on Tyne Hospitals NHS Foundation Trust
- Norfolk & Norwich University Hospitals NHS Foundation Trust
- North Lincolnshire and Goole NHS Foundation Trust (based at Scunthorpe General)
- North Middlesex University Hospital NHS Trust
- Nottingham University Hospitals NHS Trust
- Pennine Acute Hospitals NHS Trust (Oldham Hospital)
- Royal Cornwall Hospitals NHS Trust
- Royal United Hospitals Bath NHS Foundation Trust
- Southport and Ormskirk Hospital NHS Trust
- University Hospital Southampton NHS Foundation Trust
- University Hospitals Coventry & Warwickshire NHS Trust
- University Hospitals of Leicester NHS Trust
- University Hospitals of Morecambe Bay NHS Foundation Trust
- Western Sussex Hospitals NHS Foundation Trust

## Appendix two: measurable outcomes (health professionals)

Overall NBCP project outcome	Measurable outcome indicators
Increased confidence	<ol style="list-style-type: none"> <li>1. Staff feel more capable to break bad news appropriately</li> <li>2. Staff can debrief after difficult situations</li> <li>3. Staff feel better supported to deliver effective bereavement care</li> <li>4. Staff improve their skills in communication</li> </ol>
Streamlined processes	<ol style="list-style-type: none"> <li>5. Staff feel everyone is aware of what is happening, what has been agreed and what needs to be done - within hospital (across departments) &amp; between hospital and community</li> <li>6. Staff feel that responsibilities are clear</li> <li>7. Staff feel there is a consistent approach to care in the hospital</li> <li>8. Staff feel handovers are smooth - within hospital (across departments) &amp; between hospital and community</li> <li>9. Staff feel fewer mistakes are made</li> <li>10. Staff can access all information they need about parents' situations before speaking to them</li> <li>11. Staff feel well prepared for communicating with parents</li> </ol>
Process objective	Measurable process indicators
Using the pathway	<p>The pathway has:</p> <ol style="list-style-type: none"> <li>12. straightforward/simple content</li> <li>13. clear guidance for using it</li> <li>14. links with other pathways</li> <li>15. "buy in" from a range of professionals</li> </ol> <p>The pathway is:</p> <ol style="list-style-type: none"> <li>16. locally adaptable</li> <li>17. easy to use/navigate</li> <li>18. used frequently</li> <li>19. used by a range of professionals</li> <li>20. to be recommended to others</li> </ol>



### Appendix three: measurable outcomes (parents)

Overall NBCP project outcome	Area	Measurable outcomes/indicators	Does this outcome apply to all parents?
Increased choice	Informed choice/decisions	1. Parents were supported to make informed decisions	Yes
		2. Parents were provided with information that was clear and easy to understand	Yes
		3. Parents were provided with information that was relevant to their situation	Yes
		4. Parents feel the decisions they made were the right ones at the time	Yes
High quality care	Good communication	5. Parents feel they were communicated with sensitively	Yes
		6. Parents feel they were listened to	Yes
		7. Parents feel their concerns were taken seriously	Yes
	Memory making	8. Parents were given the opportunity to make memories	Yes SUDI, stillbirth and neonatal death only
		9. Parents were given the opportunity to spend time with their baby	
	Continuity of bereavement care (in hospital)	10. Parents had a single person/point of contact throughout the process	Yes
		11. Parents feel the quality of care they received was consistent across all hospital staff	Yes
Continuity of bereavement care (into the community)	12. Parents were offered ongoing emotional support	Yes	
Partner and family	13. Parents feel the needs of their partners and/or family members were met	Yes	
Aspects of support provided	14. Parents feel the timing of the support offered was appropriate	Yes	

Overall NBCP project outcome	Area	Measurable outcomes/indicators	Does this outcome apply to all parents?
		15. Parents feel they were offered appropriate support with managing breast milk production 16. Parents feel they were offered appropriate support with funeral arrangements 17. Parents were offered information about relevant support groups (for example: Lullaby Trust, ARC, Miscarriage Association, Sands or Bliss)	Yes  Yes  Yes
Increased satisfaction	Overall experience	18. Parents feel the hospital was a caring and supportive environment 19. Parents felt confident in the staff caring for them 20. Parents feel they were treated with respect 21. Parents feel their baby/babies were treated with respect  22. Parents feel their baby, fetus or pregnancy remains were treated with respect	Yes Yes Yes Not miscarriage or TOPFA Miscarriage and TOPFA only