

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

## **Final report (Wave two)**

**May 2019**

*"Overall, the care we received cannot be faulted, and we are so grateful to have had this level of care. I truly hope this becomes a national standard that all bereaved parents will benefit from, as I cannot express how much it has helped us navigate through this most difficult time."*

Parent of a stillborn baby

**Richard Donaldson**

FivewaysNP Ltd

[www.fivewaysnp.com](http://www.fivewaysnp.com)

@FivewaysNP

## Contents

1.	The National Bereavement Care Pathway (NBCP).....	1
2.	Organisations involved in the NBCP evaluation .....	2
3.	Executive Summary .....	3
3.1.	The parent perspective .....	3
3.2.	The health professional's perspective .....	4
3.3.	Conclusion .....	5
3.4.	Next steps.....	6
4.	Evaluating the NBCP .....	8
4.1.	Background.....	8
4.2.	Evaluation aims and measurable indicators .....	8
4.3.	Evaluation method.....	8
5.	Feedback from parents .....	9
5.1.	Interpreting the findings .....	9
5.2.	Parents' overall experience of bereavement care.....	10
5.3.	Informed choice .....	11
5.4.	Communication .....	13
5.5.	Consistency of care .....	15
5.6.	Other aspects of high-quality care .....	18
5.7.	Results for both waves .....	21
6.	Feedback from health professionals .....	23
6.1.	Interpreting the findings .....	23
6.2.	The overall impact of the pathway.....	24
6.3.	A more consistent approach for all parents.....	26
6.4.	Capability and preparedness.....	30
6.5.	Support to deliver good quality care .....	33
6.6.	Handovers.....	35
6.7.	Room for improvement.....	37
6.8.	Evaluation results for both waves of pilot sites .....	38
7.	Using the NBCP .....	38
7.1.	Practical use.....	38
8.	Managing the project: Feedback from the pathway site leads.....	42
9.	Appendices .....	43

## 1. The National Bereavement Care Pathway (NBCP)

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
- Royal College of General Practitioners
- 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.

---

<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.

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

### **Teddy's Wish**

Elements of the evaluation work programme have been 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 commission was then extended to include the second wave.

Fiveways ([www.fivewaysnp.com](http://www.fivewaysnp.com)) is dedicated to finding practical solutions to the issues that prevent charities from achieving more, specialising in strengthening charity governance, assessing and managing risk, and evaluating services to drive future improvement.

### **The Evaluation Sub Group**

The NBCP Evaluation Sub Group was established at the outset of the project 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 and Teddy's Wish, and from researchers with experience in this area. The sub group has provided valuable input into the deciding which outcomes to measure and ensuring survey questions are worded sensitively.

### **NBCP Parent Advisory Group**

An advisory group of bereaved parents have generously supported many elements of the NBCP's development, including the evaluation workstream. This support included ensuring sensitive wording of survey questions for parents, disseminating findings, and speaking at public events.

### 3. Executive Summary

Insight was gathered through survey and interview responses from parents and professionals in the pilot sites.

The second wave of pilot sites for The National Bereavement Care Pathway (NBCP) was launched in April 2018, with 21 trusts implementing the pathway (following the 11 sites in wave one<sup>3</sup>).

This 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.

#### 3.1. The parent perspective

The online survey provides a snap shot of 63 parents' experiences of bereavement care in 11 of the wave two sites in the period the pathway was used. It reveals high levels of satisfaction with the care received.<sup>4</sup>

- 84% agree the hospital was a caring and supportive environment (6% disagreeing)
- 92% agree they were treated with respect (4% disagreeing)
- 89% feel the decisions they made in hospital were the right ones at the time (2% disagreeing)
- 89% feel they were communicated with sensitively (5% disagreeing)
- 75% feel that all staff could provide a consistently high level of care (11% disagreeing)
- 87% were offered access to ongoing emotional support after they left hospital (11% disagreeing)
- 89% were given information about relevant support organisations they could access in the community.

The qualitative feedback supports these findings, giving a compelling picture of the impact that receiving good bereavement care can make, as well as providing a more nuanced understanding of the parents' perspective.

In some cases, parents can experience specific episodes of inconsistent or insensitive bereavement care (which the pathway aims to resolve), but this does not necessarily influence their overall impression of the care they received in hospital which, for most, is positive about the compassion and respect shown by staff, the time and information they received to make informed decisions, and the opportunities they had to create memories of their babies.

Parents also highlight that follow up care after hospital can be patchy. Some parents report difficulties regarding timely access to post mortem results and accessing ongoing psychological therapies and emotional support. The scope of the pathway includes the signposting and

---

<sup>3</sup> Wave one launched in October 2017 and was evaluated in October 2018.

<sup>4</sup> Survey questions included options to respond "neither agree nor disagree" or "I don't know" to certain statements. Therefore if, say 95% of respondents agreed it does not follow that the remainder (5%) disagreed. Across all statements levels of disagreement were very low or non-existent.

referring of parents to support, and to mental health services where these are needed, but not the provision of these services. However, increasingly bereavement leads continue to support parents for some time after their hospital stay.

### **3.2. The health professional's perspective**

The baseline and follow up surveys (taken by 1,268 and 494 health professionals respectively), and qualitative interviews with professionals and site leads, allow us to report on how the pathway has been used and the changes associated with its introduction.

Overall there is evidence that the pathway is associated with improvements in staff capability and bereavement care practice. This is both amongst those professionals who were aware of the pathway and, to a lesser extent, those who were not.

- 76% of professionals who were aware of the pathway agree that, overall, bereavement care has improved in their trust during the period of the pilot (2% disagreed). This high level of agreement was also found amongst midwives, a group who may have been the most aware of where quality of bereavement care needed to improve with their hospital.
- 54% of professionals who were aware of the pathway agree that the consistency of bereavement care has improved in the period of the pilot (7% disagreed).
- 36% of professionals who were aware of the pathway, agree that there have been fewer mistakes in bereavement care since its introduction (7% disagreed)
- The proportion of professionals feeling prepared to communicate with bereaved parents has increased from 88% to 92%.<sup>5</sup>
- The proportion of professionals feeling capable to discuss bad news with bereaved parents has increased from 66% to 72%.
- The proportion of professionals feeling supported to deliver good quality bereavement care has increased from 66% to 79%. As part of this, the proportion of professionals who feel they have the opportunity to debrief after difficult conversations with bereaved parents has increased by 7%.
- 64% of professionals who were aware of the pathway agree that it is easy to use and that it was easy to follow (3% disagreed).

Analysis of the survey data, and qualitative feedback shed more light on the use and impact of the pathway, which has prompted several changes in working practice amongst wave two sites (for example around follow up care) that have improved bereavement care.

Many professionals report having more streamlined, consistent bereavement care guidelines (sometimes amalgamated with clinical care guidelines) which better support them to provide effective care. Reflecting this there has been a 17% increase in the proportion of professionals feeling they can access the information they need before speaking with bereaved parents at any

---

<sup>5</sup> This is amongst 113 matched responses (i.e. responses from the same people at baseline and follow up).

stage of their loss and a 14% increase in the proportion feeling supported to deliver good quality bereavement care that meets the specific needs of parents.

Securing buy in for the pathway and its use by departments less connected to maternity has been a recurring challenge for the site leads, although many have had considerable success in doing so. Feedback indicates the NBCP has been valuable in lending credibility and providing supporting evidence for the need to change working practices in bereavement care. It is also clear that the pathway has prompted increased collaboration between departments, and with professionals in the community which has ensured care is delivered more consistently across different settings. There has been an 11% increase in the proportion of professionals agreeing that there is a smooth handover of bereavement care when parents move between departments in the hospital and a 16% increase in those agreeing that handover is smooth between the hospital and the community.

As a result, the proportion of professionals agreeing that "There is a lot we need to do to improve the delivery of bereavement care in our Trust" has fallen by 17%.

In comparison with wave one, more wave two professionals agree with statements that the pathway was user friendly, and fewer disagree. Therefore, steps taken to improve the usability and accessibility of the NBCP by the project team and the pathway editors following the feedback from the wave one pilot sites, have had a positive effect.

### **3.3. Conclusion**

In conclusion, this evaluation reflects the positive impact of the National Bereavement Care Pathway (NBCP). The majority of professionals surveyed agree that bereavement care has improved and become more consistent in their hospitals over the period of the NBCP pilot.

Those parents surveyed who received bereavement care during the pilot overwhelmingly agree that they were treated with respect, communicated with sensitively, and that the hospital was a caring and supportive environment. It is evident from parents' responses that many aspects of the NBCP are being effectively implemented within the pilot hospitals - for example being able to create memories and being signposted to support they can receive in the community.

This report concerns the second wave of sites piloting the NBCP, the first wave being completed in October 2018. The positive results for parents and professionals in the second wave are consistent with those achieved by the first wave.

The National Bereavement Care Pathways are not static processes, they are designed to be continually refined over time. It is evident that improvements to the pathways between the two pilot waves have increased their utility and allowed them to be more easily embedded into working practices, for example their amalgamation with clinical guidelines.

The evaluation of the second wave has, in turn, provided insight that can be considered to further improve the pathways, their implementation, and bereavement care more widely. This insight primarily relates to ensuring a combination of written and verbal communication of information to parents and addressing issues outside of the scope of the NBCP particularly ongoing psychological and emotional support services in the community and the sensitive handling of subsequent appointments and meetings at the hospital.

The second wave of pilot sites, like the first, has demonstrated that the NBCP is a useful and needed catalyst for establishing and improving a collaborative, multi-disciplinary approach to bereavement care that has benefited parents and professionals alike.

### **3.4. Next steps**

As a result of this evaluation, the NBCP project makes the following recommendations;

#### **3.4.1. National policy makers**

- The NBCP has had two independent evaluations demonstrating its positive impact. It now must be rolled out to all NHS trusts
- To facilitate this the Department of Health and Social Care and NHS England must continue to actively support and promote the NBCP
- The NBCP must be embedded across inspection and other frameworks including the Care Quality Commission and national guidance.
- Access to appropriate psychological therapies are not covered within the NBCP. The evaluation findings show this is a significant gap for bereaved parents that the government should take steps to address.
- In addition, steps should be taken to reduce waiting times for bereaved parents to receive post mortem results.

#### **3.4.2. NHS Trust leaders**

- Successful implementation of the NBCP requires buy in from senior NHS Trust staff, especially to protect the staff time needed to deliver this work (particularly bereavement leads)
- Trust leaders should increase support for staff through access to emotional and peer support and opportunities to debrief. In addition, they must ensure staff are supported to access bereavement care training
- High quality bereavement care for parents who have ended their pregnancy after a prenatal diagnosis or had an early pregnancy loss is still often a challenge as care is provided away from a maternity setting. Trust leaders need to pay attention to the quality of all bereavement care, and how the NBCP can support the delivery of effective care in these settings.
- Trusts need to be aware of what psychological and emotional support is available in the community and voluntary sectors and establish effective referral systems.

#### **3.4.3. NBCP Core Group**

- Work to support national rollout of the NBCP by creating a process for trusts to access tools and resources to support uptake (i.e. self-assessment, action planning and impact monitoring)
- Continue the process of improving the resources to ensure that the NBCP materials remain up-to-date and are as useable and useful as possible.



- Produce resources to help NHS Trust leaders support the implementation of the NBCP as well as further developing a range of training resources for professionals.
- Evaluate the effectiveness and impact of national rollout by building on the methodology used in the pilot evaluations, seeking views of parents as well as professionals, and explicitly measuring progress against the nine bereavement care standards embedded in the NBCP.

## 4. Evaluating the NBCP

### 4.1. Background

The second wave of the NBCP pilot sites was launched on 16<sup>th</sup> April 2018. It involved 21 NHS Trusts, listed in appendix one. The second wave overlapped with the first wave of the pilot, involving 11 sites which launched in October 2017 and was evaluated in October 2018<sup>6</sup>.

### 4.2. Evaluation aims and measurable indicators

The evaluation of both waves of NBCP pilot sites aimed to measure the impact and effectiveness of the pathway and to identify key learning to inform its subsequent development. Specifically, the evaluation focussed on answering 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 indicators were agreed by the Evaluation Sub Group, Parents' Advisory Group and Teddy's Wish (see appendices two and three). The findings in this report are structured around these outcomes.

### 4.3. Evaluation method

The method agreed to generate the insight to measure the agreed indicators for the wave two sites is summarised in the table below. More details are provided in section nine.

Month	Evaluation activity
May-July 2018	<ul style="list-style-type: none"><li>• An online baseline survey amongst health professionals – distributed by pilot leads to relevant colleagues within their trust (1,268 responses)</li></ul>
Sept 2018 – March 2019	<ul style="list-style-type: none"><li>• An online survey amongst bereaved parents – distributed by each trust in a manner decided locally (63 responses)</li><li>• 13 telephone interviews with parents recruited from the survey</li></ul>
Jan-March 2019	<ul style="list-style-type: none"><li>• An online follow up survey amongst health professionals – distributed by pilot leads to relevant colleagues within their trust (494 responses)</li><li>• 7 telephone interviews with health professionals (not site leads) who had used the pathway, recruited from the survey</li><li>• 10 telephone interviews with pilot site leads</li></ul>

<sup>6</sup> The final report of wave one can be found here

[http://www.nbcpathway.org.uk/file/evaluation/nbcp\\_wave\\_one\\_evaluation\\_report\\_oct\\_2018.pdf](http://www.nbcpathway.org.uk/file/evaluation/nbcp_wave_one_evaluation_report_oct_2018.pdf)

## 5. Feedback from parents

### 5.1. Interpreting the findings

The parents' survey and telephone interviews provide a snap shot of care within wave two sites during their implementation of the pathway. It is challenging to determine the specific contribution the pathway has made to the parents' care as, in most cases, they have nothing to compare it to. Furthermore, pilot sites were at different stages of development – some had well established bereavement care practices in place before the pathway, others were developing a service from scratch. Finally, introducing new ways of working and broadening expertise - especially within teams outside of maternity (where, historically, most bereavement leads are based) – can require more time to bed in than the twelve months covered by this evaluation.

#### 5.1.1. Profile of participants

63 parents who had experienced bereavement care since the implementation of the pathway completed the online survey and 10 of those participated in telephone interviews, with three additional interviews with their partners. The responses by pilot site is shown below.

Trust	Survey responses	Telephone interviews
Coventry & Warwickshire	19	2+1 partner
Derby	10	3
Pennine (Oldham)	8	1
Kettering	6	1
Bath	5	0
Morecambe Bay	3	1+1 partner
Norfolk & Norwich	3	1
Cornwall	3	0
Leicester	3	0
Nottingham	2	1+1 partner
Leeds	1	0
<b>Total</b>	<b>63</b>	<b>10+3 partners (13)</b>

It is important to acknowledge the likelihood of response bias, with 57% of survey responses coming from three trusts. The specific situations at those trusts will have an influence over the overall findings.

The profile of parent participants by bereavement experience was as follows:

Experience	Survey responses	Telephone interviews
Miscarriage	24	3
TOPFA <sup>7</sup>	16	4
Stillbirth	13	5
Neonatal death	10	1
SUDI <sup>8</sup>	0	-
<b>Total</b>	<b>63</b>	<b>13</b>

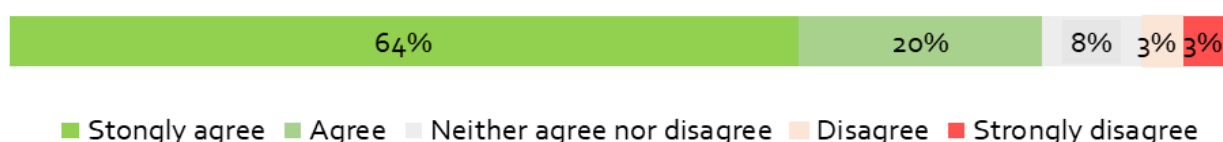
## 5.2. Parents' overall experience of bereavement care

The evaluation aimed to measure whether:

- Parents feel the hospital was a caring and supportive environment.
- Parents feel confident in the staff caring for them.
- Parents feel they were treated with respect.
- Parents feel their baby/babies were treated with respect (not miscarriage, ectopic pregnancy, molar pregnancy, or miscarriage or pregnancy ended after a prenatal diagnosis).
- Parents feel their baby, fetus or pregnancy remains were treated with respect (miscarriage, ectopic pregnancy, molar pregnancy, or miscarriage or pregnancy ended after a prenatal diagnosis only).

84% of parents surveyed (61) agreed the hospital was a caring and supportive environment, with 64% strongly agreeing and only 6% disagreeing.

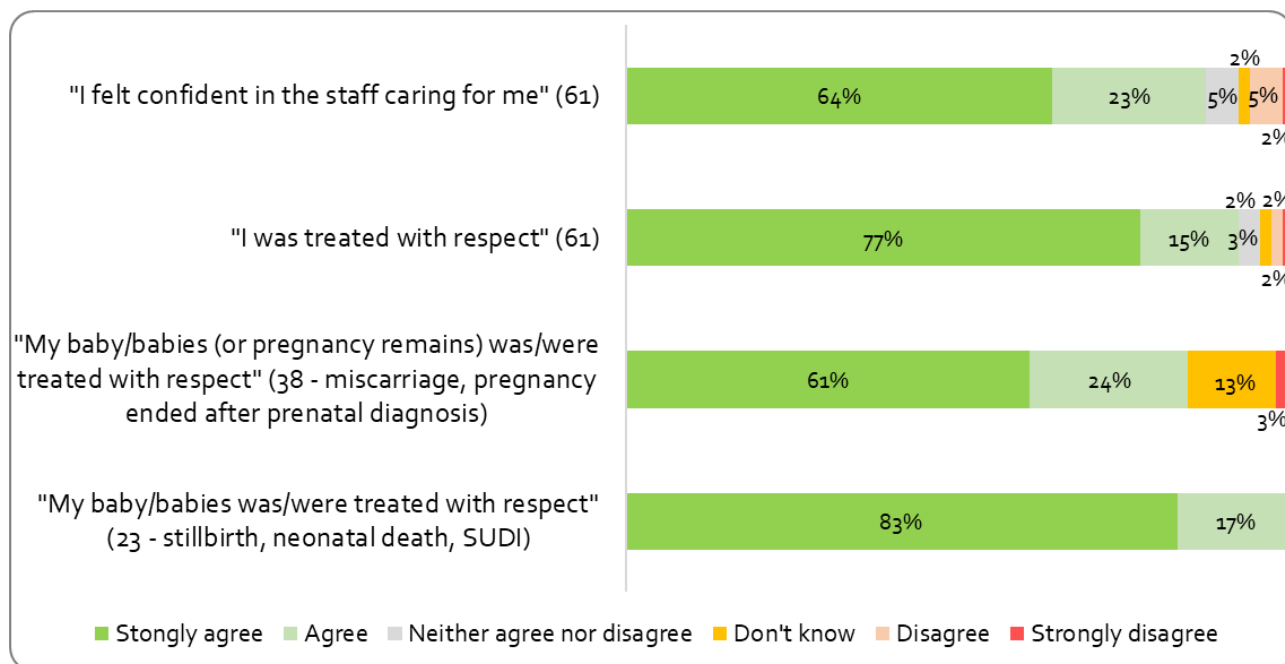
### "The hospital was a caring and supportive environment" (61)



Parents also strongly agreed with other statements relating to confidence in the staff caring for them and being treated with respect.

<sup>7</sup> As noted above, the terminology "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.

<sup>8</sup> SUDI cases are rare. In 2012 there were 221 unexplained infant deaths across England and Wales. Because of these low numbers it was unlikely for this experience to appear in the parent sample. See [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/431396/London\\_sudden\\_deaths\\_in\\_infancy\\_update\\_factsheet.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/431396/London_sudden_deaths_in_infancy_update_factsheet.pdf)



Parents' positive overall experiences of bereavement care were also highlighted in the qualitative feedback.

"So many people have negative things to say about the NHS in general; I just think it's amazing. I don't know what there is to whinge about." (Parent 40, stillbirth – interview)

Some parents mentioned, and were grateful for, the respect shown towards their babies.

"The hospital was amazing at comforting me and my partner during the birth of our son... they were also very gentle with him once he was born which was a main concern of mine, we both felt our son was well taken care of and so was I. We cannot thank all the staff that dealt with us enough." (Parent 60, TOPFA – survey)

"[Midwife] also bathed our daughter, which meant so much to us. They treated us and our daughter with dignity and respect." (Parent 15, TOPFA – survey)

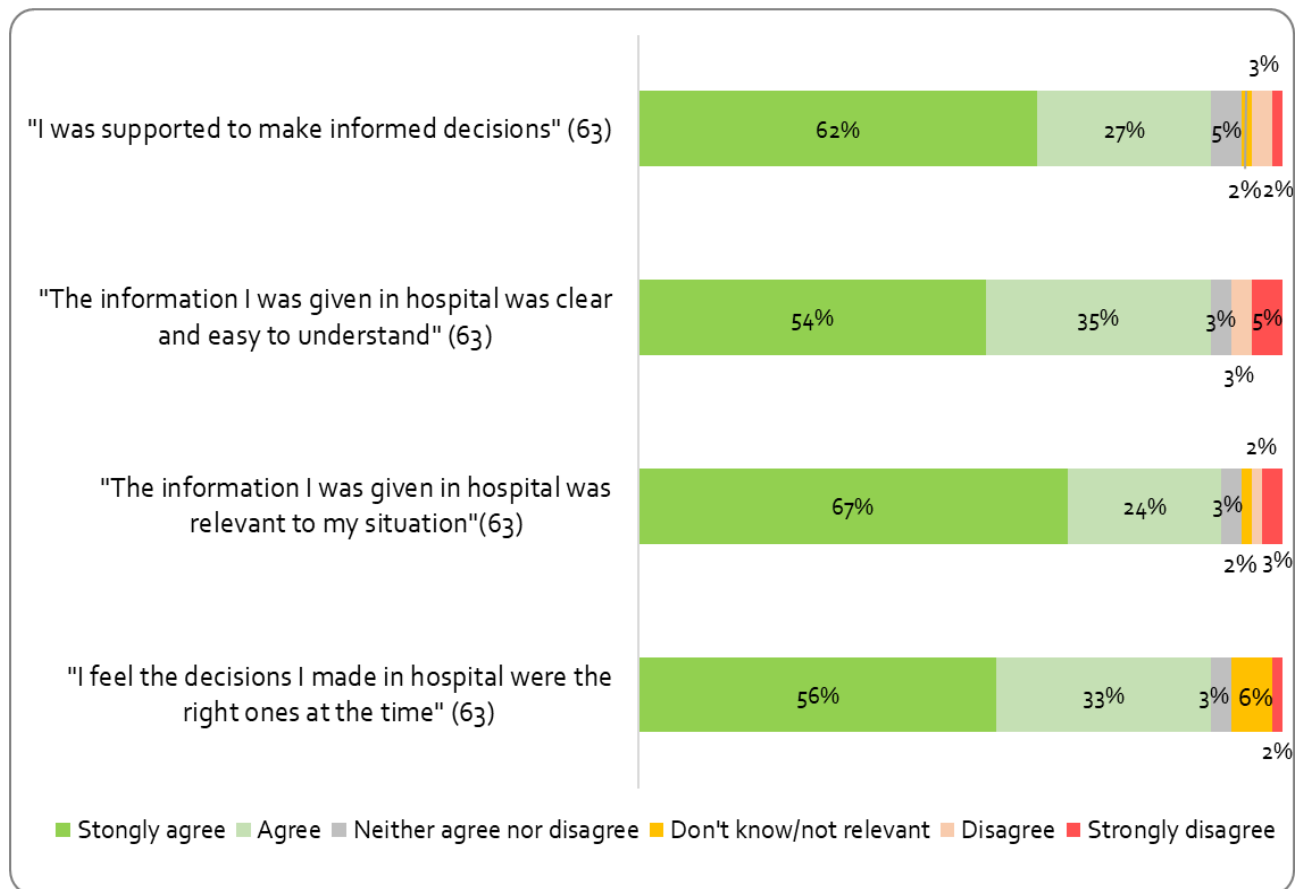
"[Bereavement midwife] so carefully and respectfully dressed our daughter in fresh clothing after her post mortem and before she was taken to the funeral directors. I will be forever grateful for this." (Parent 22, stillbirth – survey)

### 5.3. Informed choice

The evaluation aimed to measure whether:

- Parents were supported to make informed decisions
- Parents were provided with information that was clear and easy to understand
- Parents were provided with information that was relevant to their situation
- Parents feel the decisions they made were the right ones at the time

A clear majority of parents surveyed felt they were provided with the right information and support to make informed decisions. 89% of parents agreed that the decisions they made in hospital were the right ones at the time (with only 2% disagreement).



The qualitative responses reveal a more varied experience than the quantitative results. Some parents reflected the more positive aspects experiences by the majority of survey respondents.

"All the health professionals we came in contact with always allowed us to make a decision following their suggestions, for example, when we were ready to say goodbye and leave the hospital." (Parent 45, TOPFA – survey)

"We were given the opportunity to reflect on the situation calmly and offered the right support to make the decisions that we were most comfortable with. We felt that someone would always be available to listen and discuss any of our concerns." (Parent 44, miscarriage – survey)

"[Re: funeral arrangements]. I was left to think about it, I wasn't rushed or pressured. I was given the information to help me. They did that consistently all day. They told me that they were going to bring her in and gave me time to wait until I was ready – no pushing or rushing – she [the midwife] held my hand the whole way. When something that shocking happens you need to be spoon fed because your mind isn't functioning as it usually would." (Parent 21, neonatal death – interview)

When dissatisfaction around information and decision making occurs it tends to concern not having enough time to process information, not being given information to prepare for what will happen or make choices, and an over reliance on conversations alone when many would value

those conversations to be supported by written information including who to contact for further discussion. . Several parents mentioned that they were in state of shock and despair, emphasising the importance of ensuring information is effectively imparted at these times.

"There was the lack of options I was given about the way to deliver the baby. I've been told only that I had to take pills to deliver the baby and that's how it had to happen. At that moment I had no information that I could choose surgery. I believe this been done with utmost care for my physical wellbeing but still I feel it was not right to be left with no choice... it would be helpful to know that the bereavement midwife [was] not in the hospital during the weekends. It might be me not asking '*what will my baby look like at the moment of delivery?*' or '*can I hold him?*', and '*can the baby stay with us for few hours?*' Maybe it was [because] we were so shocked... we never thought of taking our personal pictures with him, [and we were not] confident enough to hold and give him a kiss. Now this is haunting me and my partner every single day. A gentle conversation initiated by the member of the staff would open my eyes about these possibilities and would give this inner peace I need now when he is not anymore with me." (Parent 42, miscarriage – survey)

"Looking back, it would have been helpful to have someone explain each stage to me in advance, rather than as it was happening. I had no idea what to expect when I had given birth, I wasn't aware that our daughter would be bathed, that they had a cold cot, or even that if I needed stitches, I'd have to wait in the bed, and how long I'd have to wait for a midwife to do the stitches. These may be things I could have asked at the time, but I'm not sure I had the capacity to realise all of this in those moments." (Parent 34, miscarriage – survey)

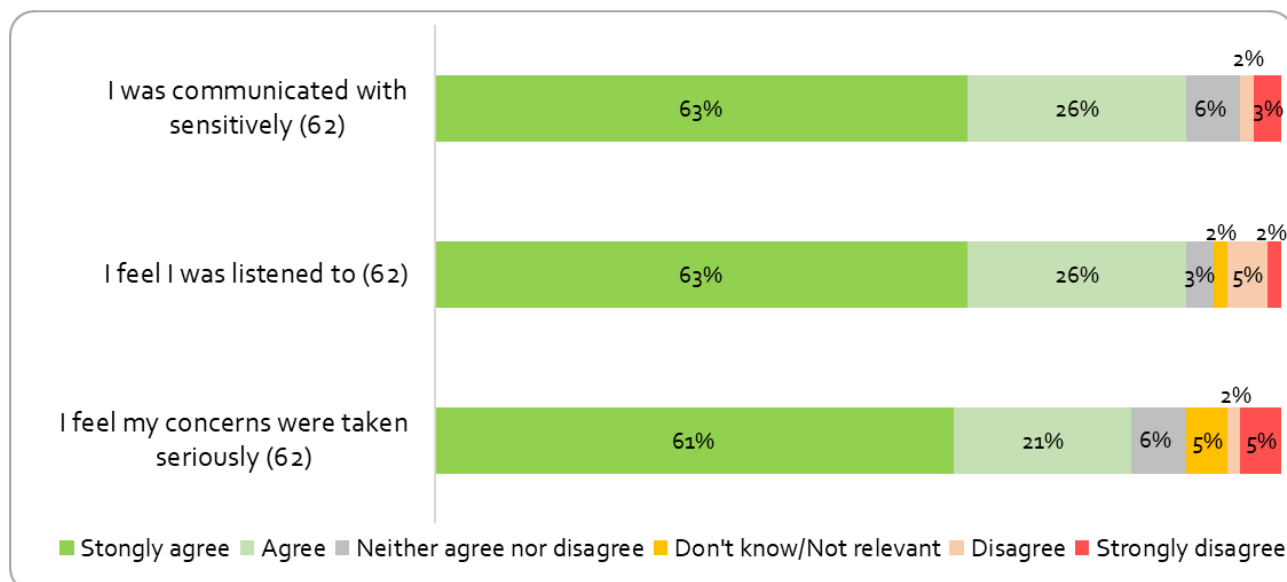
"There was no time to absorb what was happening. It was very overwhelming, but the staff team didn't give us time – we were told instantly to think about what we wanted to do. It was a lot to process in just one conversation. I sometimes think it would have been nice to be given the information, have time to absorb it, go back and discuss. I appreciate you do have to make a decision, and there are time pressures. But sometimes you just need time to process." (Parent 8, TOPFA – interview)

#### 5.4. Communication

The evaluation aimed to measure whether:

- Parents feel they were communicated with sensitively
- Parents feel they were listened to
- Parents feel their concerns were taken seriously

Parents report high levels of effective communication – over 80% felt listened to, that they were communicated with sensitively and that their concerns were taken seriously.



The qualitative feedback highlights that parents value the time staff take to communicate with them and most feel staff communicate with kindness and with prior knowledge of their situation (i.e. having read notes).

"For me personally most helpful was the kind approach to us as parents. Our heart was broken the minute we heard he is dead. Almost everyone we met spoke with utmost respect and expressed their condolences to us." (Parent 42, miscarriage – survey)

"The midwives in the hospital were so friendly didn't feel uncomfortable around them at all, they felt like friends... caring, nice, could speak to them and not feel judged. It was the worst time of my life, but they all helped so much to get me through it." (Parent 15, TOPFA – survey)

"The midwives were absolutely amazing. I was supported immensely by the team. They took the time to speak to me and ensure my wellbeing was okay. Everyone treated me like a person, they were going through it with me rather than me being another patient" (Parent 31, miscarriage – survey)

"[There was] constant communication every step of the way with every detail [we] needed." (Parent 57, stillbirth, survey)

Areas of improvement highlighted concern insensitivity, avoiding communication or not acknowledging the situation, and a lack of opportunities for one to one communication.

"The lady scanning me didn't talk to me at all during the scan I spent the whole-time petrified waiting to find out if my baby was ok. At the first scan they told me what the problem was but made no indication that it was something bad. The final scan I spent 15 minutes anxiously waiting to know if my baby no longer had a heartbeat. Or if it was even still there at all. I would have liked to have known sooner and would have liked them to talk through all of what they were doing." (Parent 35 – miscarriage – survey)

"We had been made to think that nothing was wrong, even before we went in the room we were told not to worry. It would have been better for people to have acknowledged there might have been a problem than not really tell us anything. It was like they knew it was



happening, but they didn't want to tell us – we didn't need molly coddling, we're adults not children, we can understand what's going on." (Parent 56, stillbirth – survey)

"Some [members of staff] came across that they were walking on egg shells. You lose your sense of control; you need someone to take charge. If you have got someone who is worried about doing the wrong thing and they feel if they are going to offend you and upset you, then you have to take that role and it is not a situation you can be in control, you've lost control, you've lost a big part of your life, you have no control over what has happened – and if, by means of people's attitudes, if you have to step into that role its tough." (Parent 2, stillbirth, interview)

"It would be less intimidating and more caring if medical staff could see you on a one to one basis while on the ward and not have a team of people stood at the end of the bed. I know in reality no one was judging me for our decision but less people would mean less anxiety about being judged." (Parent 29, TOPFA – survey)

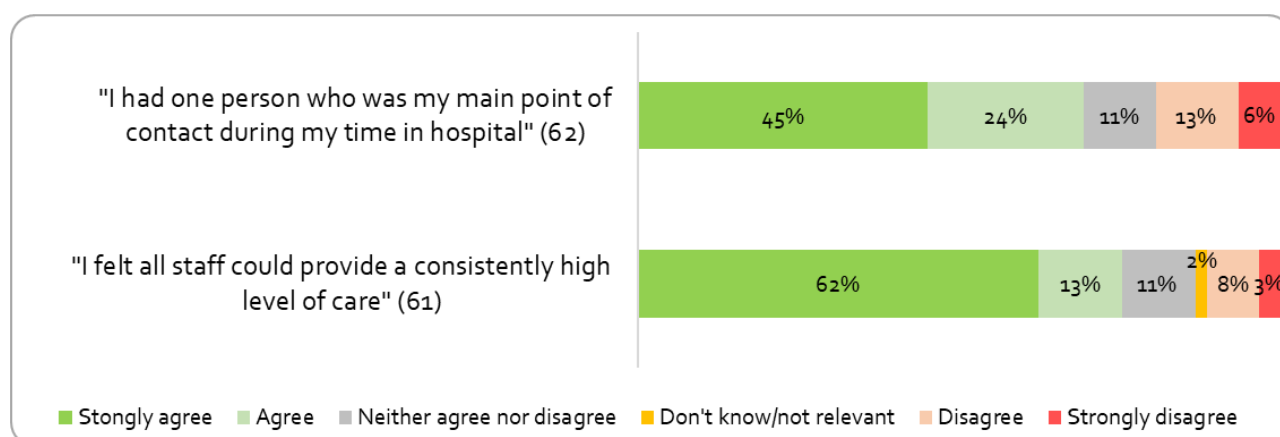
## 5.5. Consistency of care

The evaluation aimed to measure whether:

- Parents had a single person/point of contact throughout the process.
- Parents feel the quality of care they received was consistent across all hospital staff.
- Parents were offered ongoing emotional support (in the community).
- Parents were offered information about relevant support organisations (for example: Lullaby Trust, ARC, Miscarriage Association, Sands or Bliss).

### 5.5.1. In hospital

79% of parents agreed they had a single point of contact during their time in hospital (with 19% disagreement). However, this was not considered a negative if care was delivered consistently by all, and likewise it was not necessarily positive if all the knowledge was with one person who can't be there all the time. 75% agreed that all staff could provide a consistently high level of care (with 11% disagreement).



These results and those above, confirm that most parents have a positive experience of their bereavement care in hospital, with staff consistently providing high levels of care.

"I had one midwife throughout – it didn't feel like she was my midwife, I felt like she was my best friend...When we went back to hospital after the checks on the placenta the same consultant was there which was brilliant, they had been through my journey from diagnosing the child had passed away to the end, so that continuity was nice, you don't have to explain things over and over again because they understand." (Parent 31, miscarriage – interview)

"My bereavement midwife was perfect - anything and everything I could ever asked for." (Parent 17, miscarriage – survey)

"Overall, the care we received cannot be faulted, and we are so grateful to have had this level of care. I truly hope this becomes a national standard that all bereaved parents will benefit from, as I cannot express how much it has helped us navigate through this most difficult time." (Parent 22, stillbirth – survey)

However, qualitative responses reveal instances where care was not consistently delivered at that high level and, whilst these experiences may not have been enough to alter parents' overall impression of their care, they do reveal the type of inconsistencies the pathway aims to reduce.

"I saw a huge number of different staff members who spoke to me, around 20 different people. I found this exceptionally draining and felt I received no personal care at such a key time of my life. I felt like I was an inconvenience when doctors and some nurses spoke to me. Each time a new doctor came to see me I had to re-explain how I was losing my baby which was exceptionally hard." (Parent 19, miscarriage – survey)

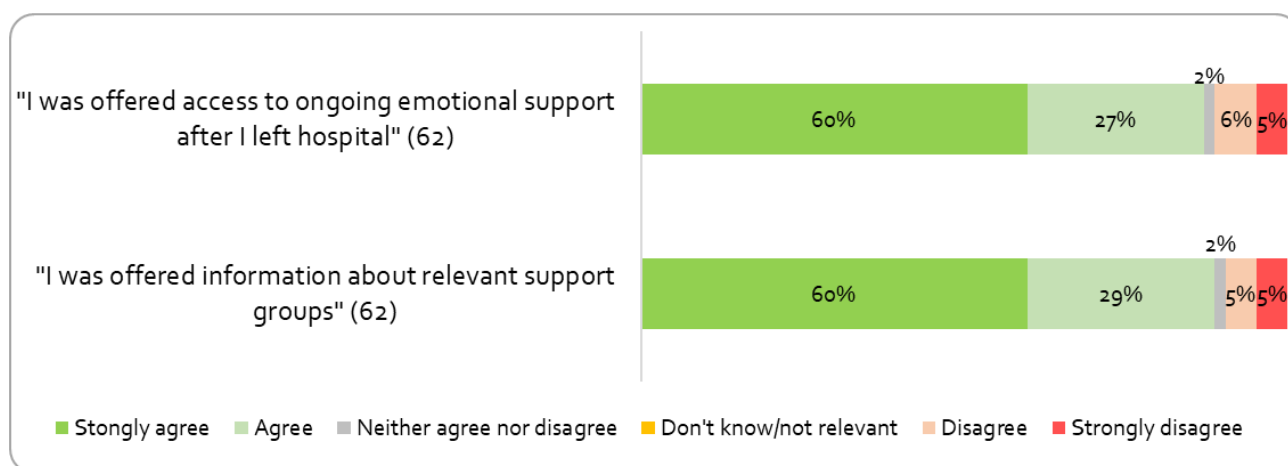
"The doctor seemed a bit out of his depth. He was appropriate, but he felt uncomfortable. You would be hard pressed to find a parent who doesn't want the staff to speak their child's name – obviously midwives are very aware of that, whether there needs to be any training for doctors about things like that – I'm not sure." (Parent 20, stillbirth – interview)

Because I was on a gynae ward they were treating it as a medical issue rather than a pregnancy issue. I went in on a Sunday. When I was in A&E the nurse was ringing to say they were sending me up for a scan, the consultant was shouting at her down the phone saying, 'I'm not scanning her today if that is what she thinks she is going to get'. The consultant didn't care, she was like "you've had a miscarriage, an ectopic pregnancy" and that was it. She may have been busy. I have a busy job too but there is no excuse for talking to people like crap. I never saw her again, I don't remember her name. My friend has had three miscarriages on that ward and has had amazing care – it isn't the team; it is individuals that let the system down." (Parent 52, miscarriage – interview)

### **5.5.2. Aftercare**

The scope of the pathway includes the signposting and referring of parents to support, and to mental health services where these are needed, but not the provision of these services.

A clear majority of parents agree that they were offered access to ongoing emotional support (87%) and information about relevant support organisations (89%). These results indicate that the pathway's guidance to refer and signpost parents to support in the community is largely being followed.



"We have had brilliant support from our bereavement midwife, she has taken care of organising things in memory of our baby and given us the opportunity to talk freely about our feelings, lead us to support networks should we wish to tap into them and has gone above and beyond, thank-you." (Parent 56, stillbirth – survey)

As noted above with information given in hospital (5.3), qualitative feedback reveals many parents prefer being given written information about available support and being able to talk it through.

"We would have found it helpful if the bereavement midwife could have talked us through some of the support charities when we came home from the hospital and needed them most. Although we had the charities' leaflets, we needed someone to explain what they could do for us. We were in too much grief to work it out for ourselves." (Parent 45, TOPFA – survey)

In terms of emotional and psychological support in the community, parents revealed a large unmet need. This is not within the scope of the NBCP but clearly has an impact on the recovery of bereaved parents, several of whom felt they did not receive any aftercare. Some put this down to lack of services in the community or not being considered ill enough to access psychological support.

"I think the care we received [in hospital] was amazing. I think maybe the aftercare could be better. I was never checked over or anything so felt a bit alone after we came home" (Parent 50, miscarriage – survey)

"The support in hospital was brilliant, the bereavement team are amazing. The only let down was the lack of support in my local community, there are no bereavement support groups relevant to me locally. I also tried to seek some help from [local council wellbeing service], I had one appointment whereby they decided that as I didn't want to kill myself, I wasn't important enough. I wasn't able to get one-one counselling unless I paid for private treatment which we obviously couldn't afford as I was off work recovering from our devastating loss." (Parent 40, stillbirth – survey)

"I'm medicated for anxiety and depression – but was deemed by the perinatal mental health team as not requiring the counselling available – you have to be borderline suicidal to speak to someone." (Parent 2, miscarriage – interview)

Organising and waiting for subsequent meetings and results was a cause of distress for several parents. As above, these issues sit outside the scope of the pathway – but are clearly an area of concern when considering bereavement care when parents have returned home.

“I was told it was six weeks to get the result [of the post mortem]. I put it in my diary – but it takes longer, double that. They should have more of a realistic timeframe. You fixate on that date that that’s when you are going to hear and when you don’t then it is hard to be pushed back.” (Parent 21, neonatal death – interview)

“When I needed the 6 week GP check – the community midwife said they would get the GP practice to contact me - presumably to avoid awkward conversations with a receptionist - but I had to chase it up and that fell through the gaps because the conversation went ‘Oh, haven’t you had that date because we usually book that in when you come to register the baby’ – it was very difficult to have that awkward conversation with the receptionist five weeks after having had my daughter.” (Parent 20, stillbirth – interview)

“It’s not helpful that the meeting for the results of the post mortem with the consultant, was back in the ante-natal area of the hospital. In particular we were shown down to the same room that we had been in 3 months previously when I called my husband to come in from work only to have to be the one to tell him that our daughter had died. It was highly emotive to be back there. We felt we coped and so didn’t raise this as an issue, but many other couples would not have been able to cope with this.” (Parent 20, stillbirth – interview)

Several value the ongoing support of their bereavement midwife or lead, others would like more communication.

“You are going through such an emotional time and don’t always take all the information in so a follow up email/call/letter would have been good.” (Parent 18, TOPFA – survey)

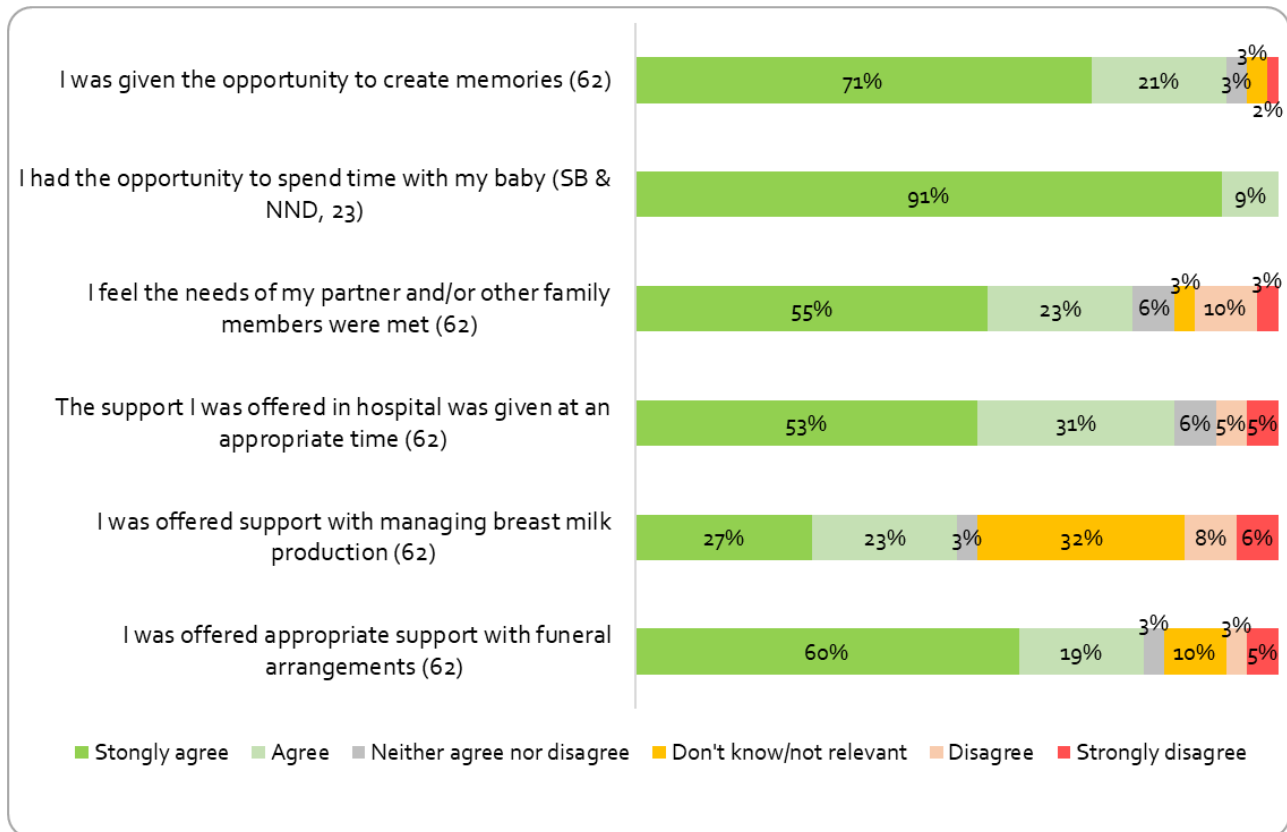
“She [bereavement midwife] checks how we are I suppose and has been able to link us in and signpost us to other things – charities that have support groups, bereavement counselling. That’s been really helpful. I don’t think that we would’ve had the head space to find those things out for ourselves. In that state of shock, she was able to point us in the direction – and give us as much or as little support as we wanted. It wasn’t too overbearing; it was just right. She was able to gauge it quite well.” (Parent 22, stillbirth – interview)

## 5.6. Other aspects of high-quality care

The evaluation aimed to measure whether:

- Parents were given the opportunity to make memories.
- Parents were given the opportunity to spend time with their baby (SUDI, stillbirth and neonatal death only).
- Parents feel the needs of their partners and/or family members were met.
- Parents feel the timing of the support offered was appropriate.
- Parents feel they were offered appropriate support with managing breast milk production.
- Parents feel they were offered appropriate support with funeral arrangements.

Feedback on specific aspects of bereavement care was very positive – parents are regularly being given the opportunity to spend time with their baby (91% agree<sup>9</sup>) and make memories (83% agree). Support for other family members, for funeral arrangements and breast milk production (where necessary) is also being provided to a clear majority of parents, and the timing of the support provided is considered appropriate by 84% of parents.



### 5.6.1. Memory making

Several parents in the qualitative feedback stated their appreciation for the time and support they had received to make memories with their child.

“The midwife looking after us was extremely helpful. We thought we wouldn't be able to keep any footprints/handprints of our baby due to his size, but she insisted to try and do it for us, and we are so glad she did, as we treasure this wonderful memory now.” (Parent 44, miscarriage – survey)

“They left our son with us for about an hour and a half which really helped with the process of saying goodbye they were brilliant staff and so understanding we also had a memory box which we still look through two months later - everything they did helped us grieve for our baby” (Parent 60, TOPFA – survey)

“The memory box helped me a lot to help me remember my baby in a positive light and not negative” (Parent 34, miscarriage – survey)

<sup>9</sup> Only asked of 23 parents experiencing stillbirth or neonatal death.

"When we came back to hospital after the post mortem, the midwife gave us another chance to see her again. We had already thought we had seen her for the last time. I'm glad we went and saw her again; this was quite important to us." (Parent 22, stillbirth – interview)

A couple of parents made suggestion as to how memory making can be made more effective

"I'm genuinely grateful for the pictures and footprint taken by the staff and the memory box I've been given. These are my precious memory. We did no other pictures for the short time with our boy. I believe the shock was too big at that time for us to think clearly. However, the painkillers left me really dizzy and I would have liked more information about the effect of them before they were administered – and maybe been given a lower dose. I am tremendously grateful I've been saved all the pain, but it also left me so drugged so I barely could keep my eyes open after the birth. I wish to turn time back and spend more time with him in that moment with as clear mind as it was possible considering the great loss I've experienced." (Parent 42, miscarriage – survey)

"A 'cuddle cot' would have been good on the ward. We felt we had to say goodbye earlier than we were ready for because baby was deteriorating." (Parent 54, TOPFA – survey)

#### **5.6.2. Support for partners**

78% of respondents to the survey felt the needs of their partner and other family members were met. Qualitative comments reflect both good and less good practice.

"There was particularly good communication with my husband – I was in intensive care, but bereavement midwife kept in touch with him regardless. He was found a room to sleep in, and staff found him food." (Parent 40, stillbirth – interview)

"It felt like us, rather than just me, which I really appreciated. It was so important that he wasn't just on the side – he was involved, in the appointments prior to the procedure he was involved, but even on the day – even down to small things, even on the labour ward, he was included. Small things – he got food. I noticed it at the time – it was so lovely." (Parent 58, TOPFA – interview)

"During our time in the bereavement suite, there was nowhere for my husband to comfortably sleep. I feel that if there had been somewhere suitable for my husband to rest, we would have stayed longer, and been able to spend more time with our daughter." (Parent 22, stillbirth – survey)

"They could have been more flexible with rules for partners – some nurses were treating [mother] as the patient and me as a visitor. It got on my partner's nerves." (Parent 56, stillbirth – interview)

#### **5.6.3. Funeral advice**

79% of respondents to the survey agreed they were offered appropriate support with funeral arrangements. On the whole, qualitative feedback supports this with several clearly valuing the support.

"Doctors and all the other staff were very kind to us at this difficult time and we are especially thankful for funeral arrangements, because at that time we didn't really understand what do we have to do, and how to arrange all this" (Parent 4, neonatal death – survey)

"The hospital was amazing at arranging the funeral and all aftercare can't thank them enough for everything they did to make sure everything went as good as possible." (Parent 15, TOPFA – survey)

"[Bereavement midwife] went above and beyond and phoned the funeral parlour ahead and explained what happened ahead of me calling. This was such a hard, hard step for me, and that support was a huge help. It would have been a horrible situation if she hadn't been there – she has been vital in my recovery"" (Parent 21, neonatal death – survey)

Others refer to receiving incomplete information and process issues that caused difficulties with the arrangements that affected parents' impression of the care they received.

"It's amazing that the funeral was organised and paid for. In the information given before leaving hospital, it may have been helpful to include a list of things people may want to do to make the funeral more personal, e.g. flowers, music, items to go in with baby, as it wasn't aware I was allowed to do these things and no one asked me if I wanted to organise/choose them. I rang the funeral director to ask but had I not done that, I think our baby would have gone without flowers and generic music would have been chosen. That all probably seems obvious to someone who has lost someone close before, but for us, we this was all new and we knew nothing about funerals. Also [we would have liked] more information on what will happen to baby, e.g. will they travel on their own to the funeral or with other babies? Will they be cremated with other babies? Will the service be individual? Will the ashes be individual?" (Parent 29, TOPFA – survey)

"I wasn't contacted with a date my baby was being buried. I ended up missing the burial and service." (Parent 18, TOPFA – survey)

"Doctor ticking the wrong box on post mortem form and us having to return to the ward very soon after losing our baby was not helpful at all. Baby arrived at funeral directors without the blessing cross we left with him and wearing clothes we hadn't left for him. This caused us to doubt that the baby was ours when we went to visit. We wouldn't have gone at all, but we were (incorrectly it turns out) told that no photos had been taken despite us requesting this, so we went to take some more. It took a long time to resolve - we weren't told until almost 5 weeks later that the clothes had been put on and provided by the mortuary." (Parent 54, TOPFA – survey)

## **5.7. Results for both waves**

Both waves contained sites with well-established services delivering high quality bereavement care and those with very little service in place before the pathway project. In addition, both waves contained sites that implemented the pathway extensively and those who were unable to make much progress, and sites who were more successful at obtaining parent feedback than others.

Therefore, belonging to wave one or two is not an indicator of a certain “type” of site and, therefore, the following table is not comparing the results from both waves - rather it shows the same measurement being made amongst a similar audience group, but at a slightly different time.

Indicator	% agree Wave one	% agree Wave two
"The hospital was a caring and supportive environment"	95	84
"I felt confident in the staff caring for me"	98	87
"I was treated with respect"	98	92
"My baby/babies (or pregnancy remains) was/were treated with respect" (miscarriage, pregnancy ended after prenatal diagnosis)	92	85
"My baby/babies was/were treated with respect" (stillbirth, neonatal death, SUDI)	100	100
"I was supported to make informed decisions"	91	89
"The information I was given in hospital was clear and easy to understand"	90	89
"The information I was given in hospital was relevant to my situation"	97	91
"I feel the decisions I made in hospital were the right ones at the time"	93	89
"I was communicated with sensitively"	96	89
"I feel I was listened to"	99	89
"I feel my concerns were taken seriously"	92	82
"I had one person who was my main point of contact during my time in hospital"	79	79
"I felt all staff could provide a consistently high level of care"	94	75
"I was offered access to ongoing emotional support after I left hospital"	84	87
"I was offered information about relevant support groups"	94	89
"I was given the opportunity to create memories"	88	92
"I had the opportunity to spend time with my baby (stillbirth and neonatal death)"	96	100
"I feel the needs of my partner and/or other family members were met"	84	78
"The support I was offered in hospital was given at an appropriate time"	88	84
"I was offered support with managing breast milk production"	63	50
"I was offered appropriate support with funeral arrangements"	81	79



## 6. Feedback from health professionals

### 6.1. Interpreting the findings

The key insight from health professionals is described below. The analysis focusses on the following groups.

- “All respondents” – 1,268 professionals participated in the baseline survey and 494 participated in the follow up survey approximately eight months later. In terms of role, experience and the range of bereavement experience supported the sample of respondents to the baseline and follow up surveys is comparable. However, some individual sites were either over or under represented when comparing the two surveys. (See 9.1.1. below)
- “Matched respondents” – by means of a tracking code using information provided by respondents we were able to match 113 respondents from the baseline survey to the follow up survey. This is therefore an identical sample and is the most robust comparison. This matched group has a greater proportion of midwives (58%) compared with the “all respondents” groups (baseline 46%, follow up 54%).
- Midwives and non-midwives – analysis is split by those in midwife roles (hospital or community based) and those not. This is to give an indication of perspectives within and outside a maternity setting.
- Years of experience working with parents who have experienced pregnancy or baby loss. The proportion of those with ten or more years’ experience is greater in the matched group (72%) than the “all respondents” groups (baseline 55%, follow up 53%).
- Awareness of the pathway – the follow up survey respondents can be split into those who were aware of the pathway (54%) and those who had not come across it (46%).

When looking at the findings below, the number of people who responded to the relevant question is shown next to the axis label in round brackets or after a dash. More detail on the respondents to the surveys is given below (Section 9).

## **6.2. The overall impact of the pathway**

### **6.2.1. Confirming best practice and identifying gaps**

For some sites, the pathway provided assurance that the care they were currently providing was in line with best practice.

"I feel in our trust the suggestions made in the NBCP are already implemented. We provide exemplary care to our bereaved parents and their families and are already using the suggestions made." (Hospital midwife, site 18 - survey)

"It has confirmed best practice. We did a gap analysis and felt we were compliant. It's good to have that minimum standard." (Lead, site 13 - interview)

"At our Trust we were already delivering bereavement care to the standard of the pathways" (Hospital midwife, site 3 - survey)

For others, the pathway as a tool to identify areas of practice that required improvement or design a service from scratch.

"It raised some inequitable practice between maternity and gynae. It gave us the ammunition we needed to make changes. It legitimised a review of practice and confirmed the standard and we had to find a way of doing it." (Lead, site 4 - interview)

"As we already had a very well-established bereavement service the improvements will not be as provable as other trusts who are piloting the pathways. It has however helped us to identify gaps in practice and we are now working more closely with paediatrics and gynae." (Bereavement midwife, site 19 – survey)

"The pathway has been our framework to desire our bereavement service. It feels like we're on the right foot from the start (Lead, site 11 – interview)

It has also been valuable to lend credibility and evidence for the need to change

"With TOPFA, stillbirth and miscarriage we now know what we're missing. It's been brilliant, it is not like I'm stamping my feet and saying, 'this needs to change' – these are national guidelines!" (Lead, site 16 – interview)

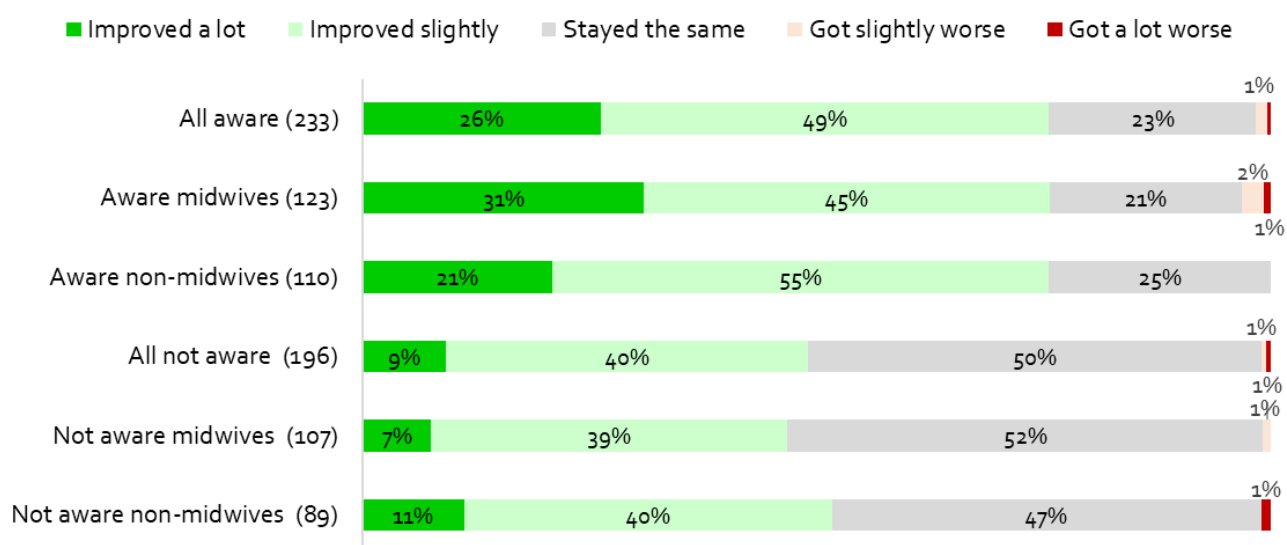
"It gives you more authority – we can say, 'this is what other units are doing'" (Matron, site 20 – interview)

"It has provided a valuable tool with a national benchmark which has been helpful to precipitate and initiate change, giving evidence and standards to management in making case for change." (Neonatal consultant, site 14 – survey)

### **6.2.2. Improvements in bereavement care**

For many the pathway has prompted improvements in bereavement care. At follow up, 76% of professionals who were aware of the pathway (233) felt that bereavement care had improved over the previous 7 to 8 months. 26% felt it had improved a lot – only 2% felt it had got worse. Roughly half (49%) of professionals who were not aware of the pathway (196) felt that care had improved (50% felt it had stayed the same).

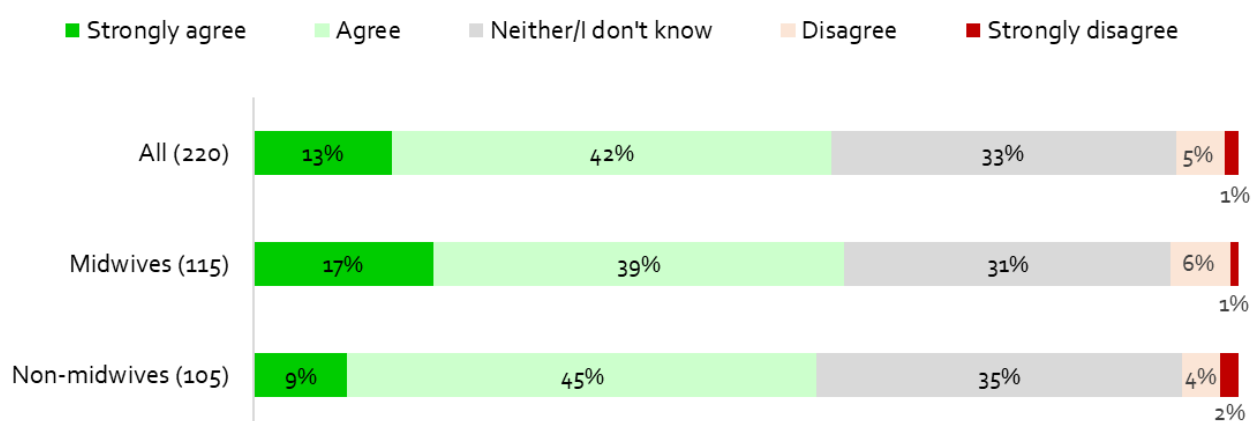
### Would you say that overall, over the last 7 to 8 months bereavement care at your trust has...?



### 6.2.3. Raising the profile of bereavement care

The profile of effective bereavement care is also higher. 55% of those aware of the pathway (220) agreed it has helped to raise the profile of effective bereavement care in their trust - 6% disagreed. This is supported by the qualitative feedback; several professionals mention the pathway providing a new “focus” or “spotlight” on bereavement care.

#### *“The National Bereavement Care Pathway has helped to raise the profile of effective bereavement care in our trust” (those aware of the pathway)*



### 6.3. A more consistent approach for all parents

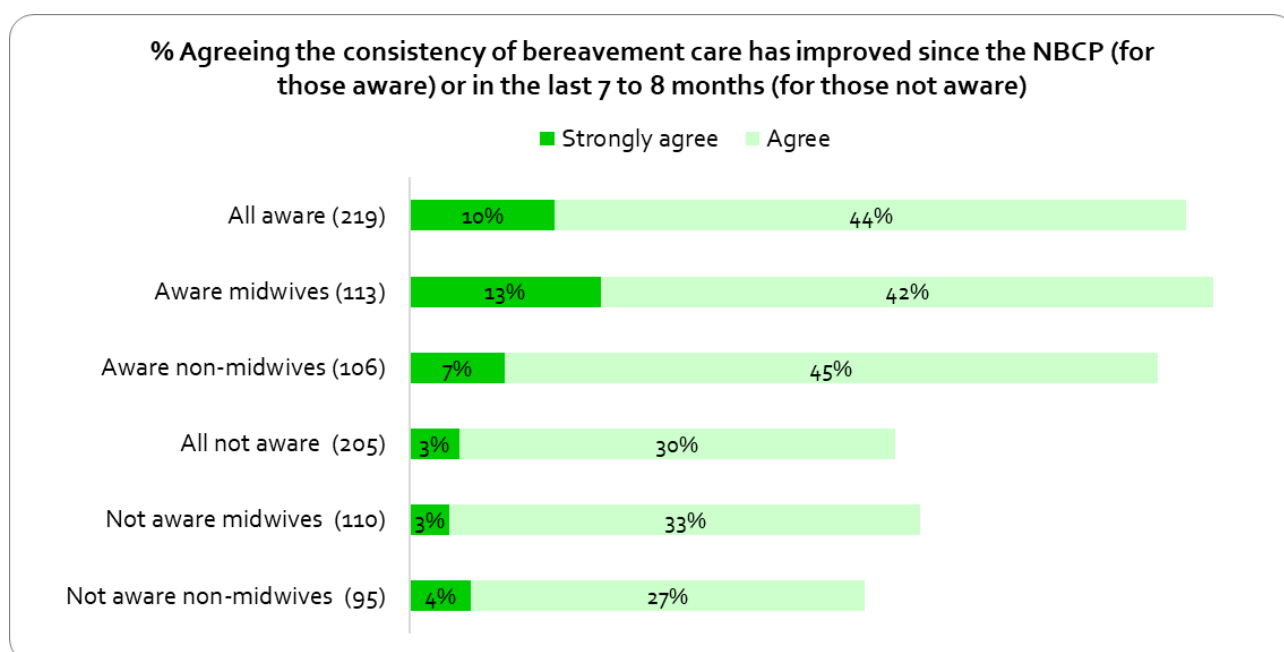
The evaluation aimed to measure whether:

- Staff feel there is a consistent approach to care in the hospital
- Staff feel everyone is aware of what is happening, what has been agreed and what needs to be done, and that responsibilities are clear
- Staff feel fewer mistakes are made

#### 6.3.1. The overall consistency of bereavement care

The baseline survey highlighted the issue of inconsistent care that the NBCP aims to address. Care for those parents experiencing early miscarriage, being treated in A&E or gynaecology wards, or requiring care when the specialist bereavement midwife was not available, were most often highlighted as in need of improvement.

The pathway has driven an improvement in the consistency of care. In the follow up survey 54% of respondents who were aware of the pathway (219) agreed that consistency of bereavement care had improved since its introduction (with 7% disagreeing). An improvement in the consistency of care was also reported by those who weren't aware of the pathway - 33% felt that it had improved over the previous 7-8 months (with 8% disagreeing).



Qualitative feedback reveals the pathway project has been successful at stimulating new levels of collaborative working across teams which has contributed to a more consistent approach to care.

"Different departments are working together more closely – they are more aware of what each other is doing, before we may not have come together. We are communicating better. We have a lady who had a pregnancy loss at term last year and she has found out she is pregnant again, she's just nine weeks, I've been able to contact the early pregnancy unit for a reassurance scan, they are now a lot more open to doing that as they realise it's importance." (Lead, site 8 – interview)

"Care is more joined up. We've reached out to other areas – e.g. GPs – now they can contact us, and they have more information. I've also met with children's ED. We had twin babies brought in four months old, one sadly died. The matron came to see me for a hard copy of the pathway, I was able to give her a memory box. Before she would have probably tried to deal with things in her own way, which is fine, but something must have gone off in her head to think "I'll contact [the bereavement midwife]" and it was really helpful for her to have that pathway to be sure all the processes were being followed" (Lead, site 15 – interview)

"Now if someone has a loss who has other children, I have a link with the health visitors, not just to support the parents and baby but the other children too (Lead, site 7 – interview)

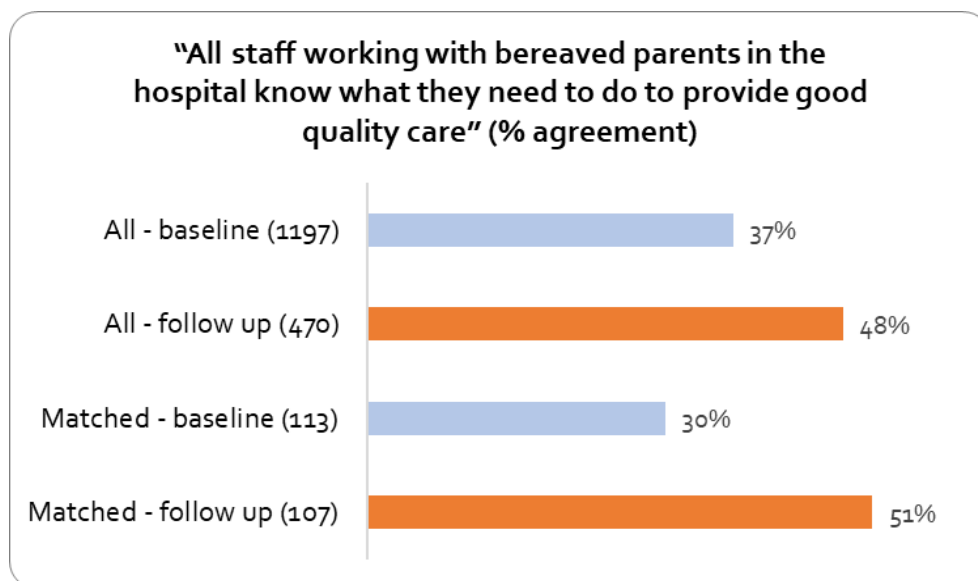
"The pathway has helped to reach out to other teams – following a neonatal death, we reached out to the maxillofacial reconstruction team and they did hand and footprint casts to make sure the family got good care. They were really helpful, and we are going to make it a permanent link. (Hospital midwife, site 4 – interview)

"The pathway has improved links between departments and a general willingness to improve bereavement care for all parents who experience the loss of a baby or infant." (Hospital midwife, site 10 – survey)

"It's been helpful to drive forward better care. It has ironed out some of the inequalities for example between having a loss at 18 weeks and going to the gynae ward and having a loss at 22 weeks and having midwifery care in the birth centre." (Lead, site 16 – interview)

### 6.3.2. Consistent delivery of care across all staff

The proportion of professionals agreeing that all staff working with bereaved parents know what they need to do to provide good quality care has also increased for both all and matched respondents between baseline and follow up. The increase amongst the matched group, where the sample group is effectively the same was 69%.

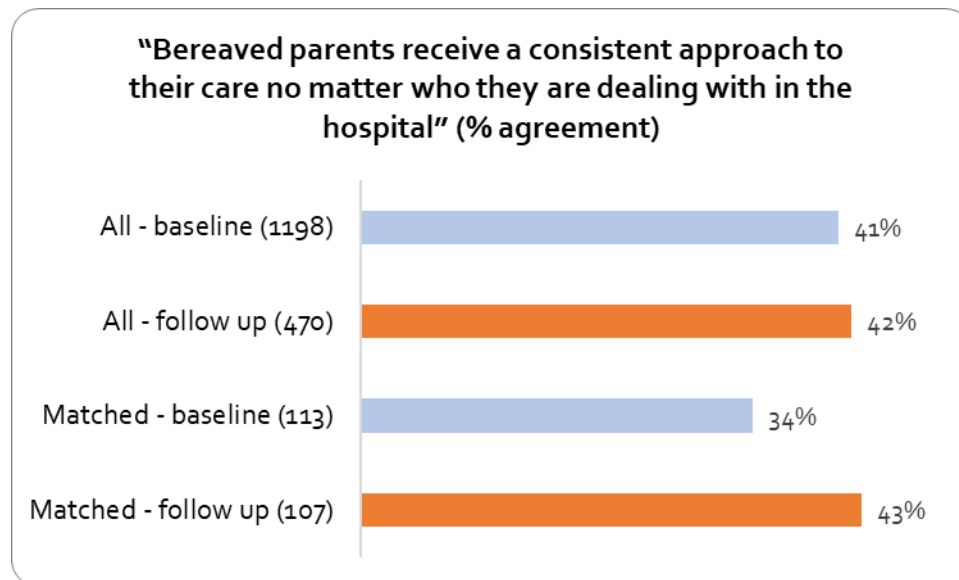


Qualitative feedback reveals the pathway prompted increased information and support for staff, including its incorporation in mandatory training and study days.

“More staff have had training on the elements of care we can offer to bereaved parents.”  
(Neonatal Practice Educator, site 19 – survey)

“We now have communication and difficult conversations as part of the unit mandatory study days.” (Nurse, site 13 – survey)

The proportion of professionals agreeing that parents receive a consistent approach no matter who they are dealing with in the hospital has broadly stayed the same when considering all respondents, but there was a 27% increase amongst matched respondents.

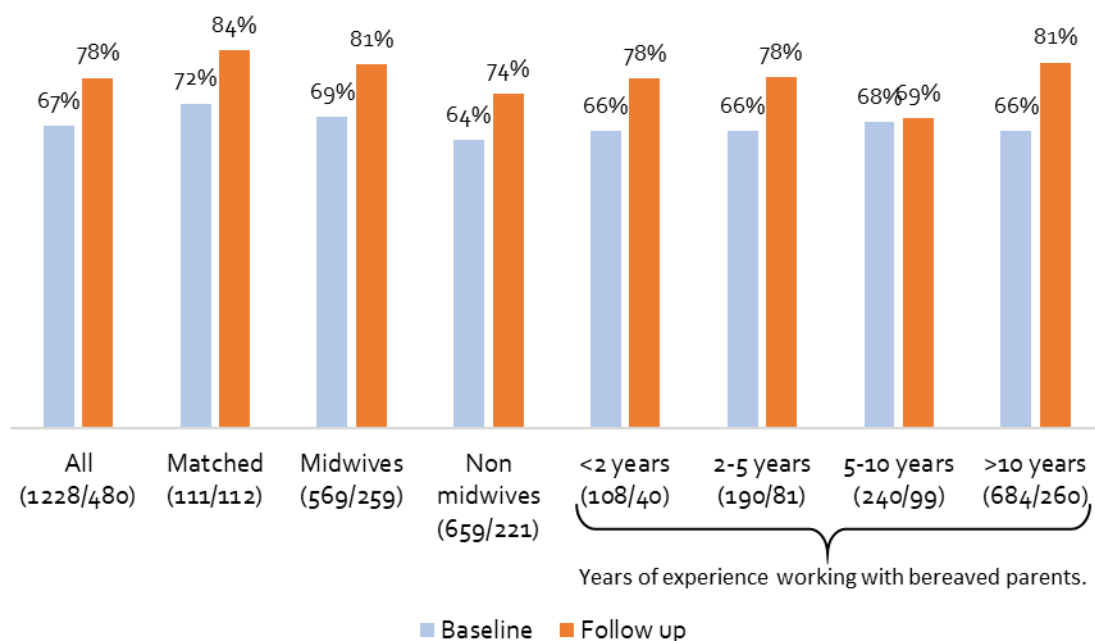


### 6.3.3. Reassurance that the trust has an effective approach in place

The proportion of professionals feeling reassured<sup>10</sup> that their trust has an effective approach to delivering good quality bereavement care to all parents has increased by around 16% between baseline and follow up. The biggest increase (23%) was amongst those professionals with over ten years' experience of caring for bereaved parents.

<sup>10</sup> i.e. answering “reassured”, “very reassured” and “completely reassured”.

**How reassured are you that your Trust has an effective approach to delivering good quality bereavement care to all bereaved parents whatever their experience? (% reassured, very reassured, or completely reassured)**



The qualitative responses include several examples of the changes made to improve the effectiveness of a trust's approach to bereavement care.

In trusts where a bereavement midwife had been appointed, this was considered a big step change in care for families.

"THE most excellent appointment, she is knowledgeable and supportive to midwives and families." (Hospital midwife, site 10 – survey)

Others pointed to a more consistent approach to following up parents.

"Ladies who came through gynae were not getting any follow up – now they let the community midwives know and they see the women. It wouldn't have happened without the pathway. (Lead, site 16 – interview)

"The midwives in fetal medicine are following up local women following termination for fetal abnormality and getting really good feedback." (Hospital midwife, site 8 – interview)

There were also several examples in the qualitative feedback of improved bereavement practices being adopted for parents in the areas highlighted as concerns in the baseline survey (e.g. early losses, TOPFA and A&E, see 6.3.1 above)

"Women with a surgical termination were left out in the cold before the pathway – that's the biggest change we've done – they are now in the maternity pathways. A midwife now attends a surgical termination, all are now offered memory boxes, details of the bereavement midwife and details of organisations. (Lead, site 19 - interview)

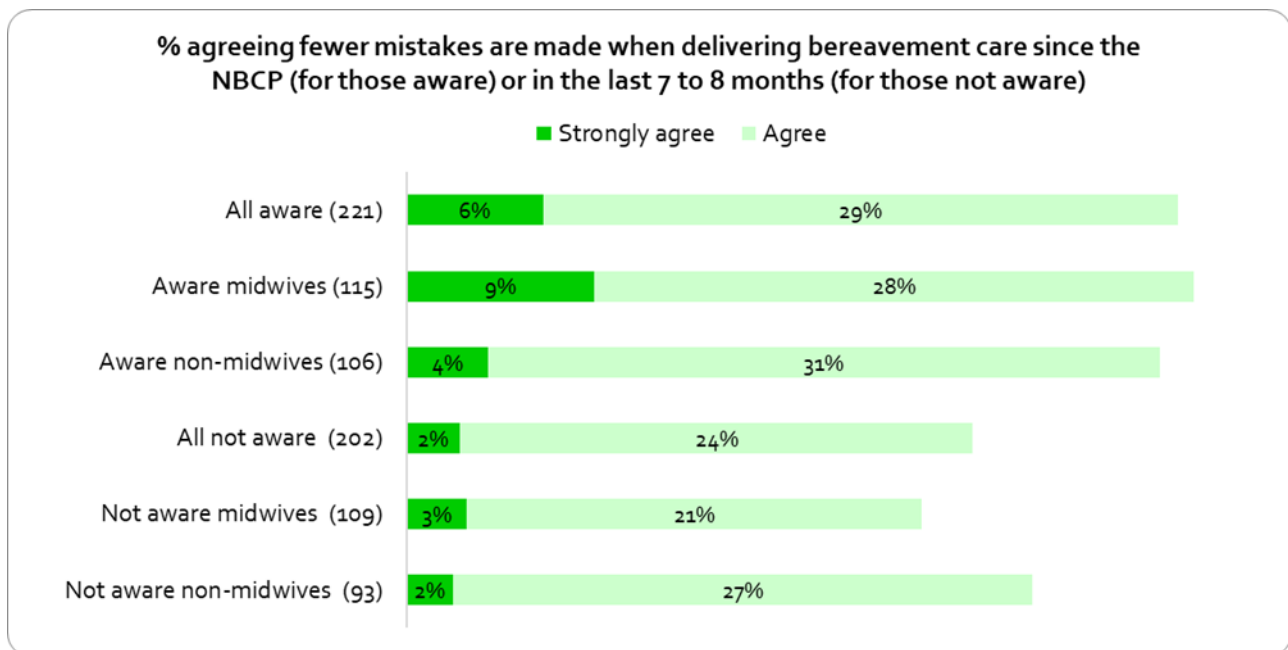
"The SUDI team of nurses are now doing memory making side of things that they hadn't done previously." (Lead, site 11 - interview)

"We've developed care bags with bereavement information, toiletries etc. for gynae and A&E early losses. They must be using them as the contact me when they need more."  
(Lead, site 7 – interview)

"Gynae are doing more memory making and have more focus on compassionate support. Staff feel better, before it was 'I know I've got to do footprints', now it is 'I want to do footprints because I know it is good for the family.'" (Lead, site 13 - interview)

#### 6.3.4. Reduction in mistakes

The desired outcome from this improved consistency is that fewer mistakes are made. 25% of professionals aware of the pathway feel that fewer mistakes have been made when delivering bereavement care since its introduction (only 7% disagree). 26% of those not aware of the pathway also feel fewer mistakes are made (6% disagree).



#### 6.4. Capability and preparedness

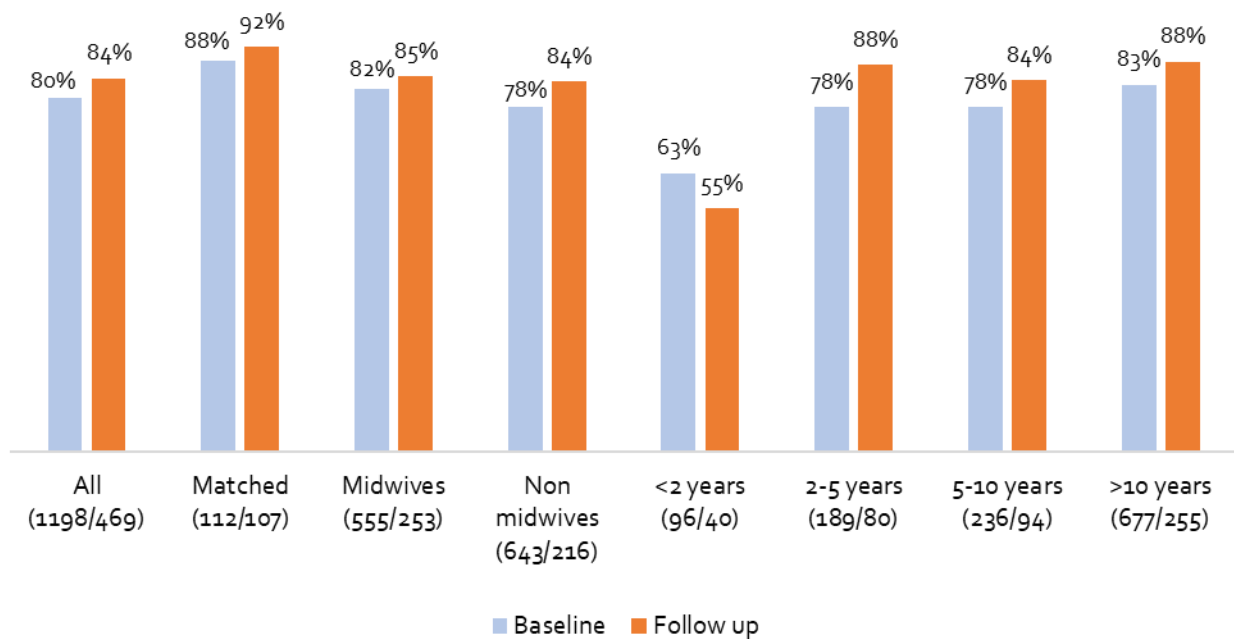
The evaluation aimed to measure whether:

- Staff feel more capable to break bad news appropriately.
- Staff improve their skills in communication.
- Staff can access all information they need about parents' situations before speaking to them.
- Staff feel well prepared for communicating with parents.

The baseline and follow up survey asked people whether they knew what they needed to do to provide good quality care. There has been a small increase in agreement for all respondents and matched respondents. The only group to show a decrease was those with less than two years' experience of working with bereaved parents. The proportion of agreement was also lower in this group compared with those with more experience, perhaps revealing a training need for staff newer to bereavement care.

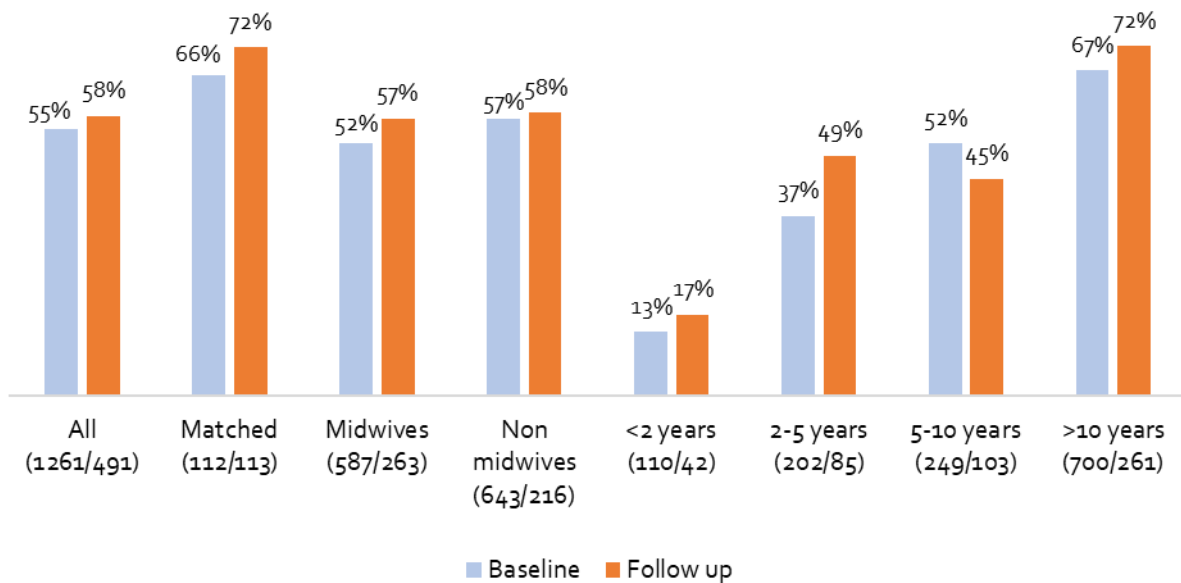


**"When working with bereaved parents, I know what I need to do to provide good quality care" (% agreement)**

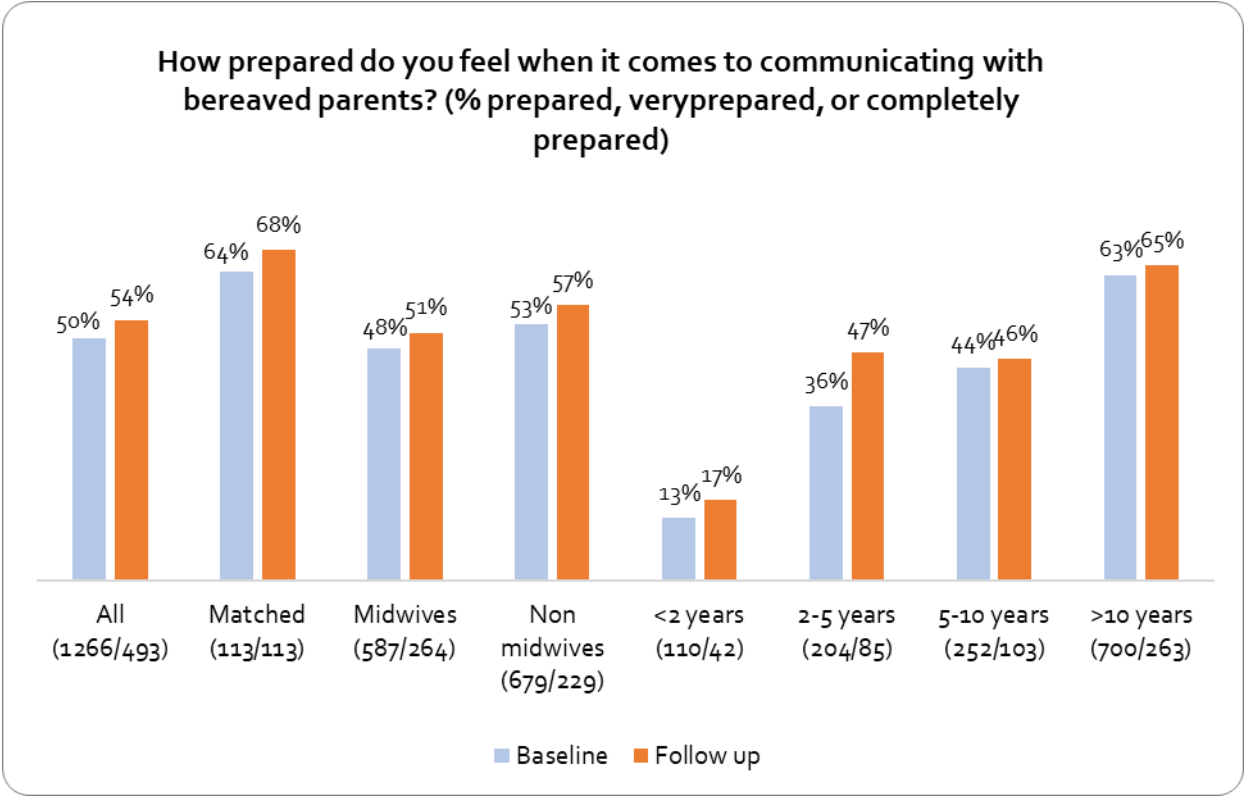


In terms of feeling capable of discussing bad news with bereaved parents appropriately, there has been a small increase amongst all and matched respondents. Although those with less experience have shown an increase, this is from a low base – broadly, the more experience someone has, the more capable they feel.

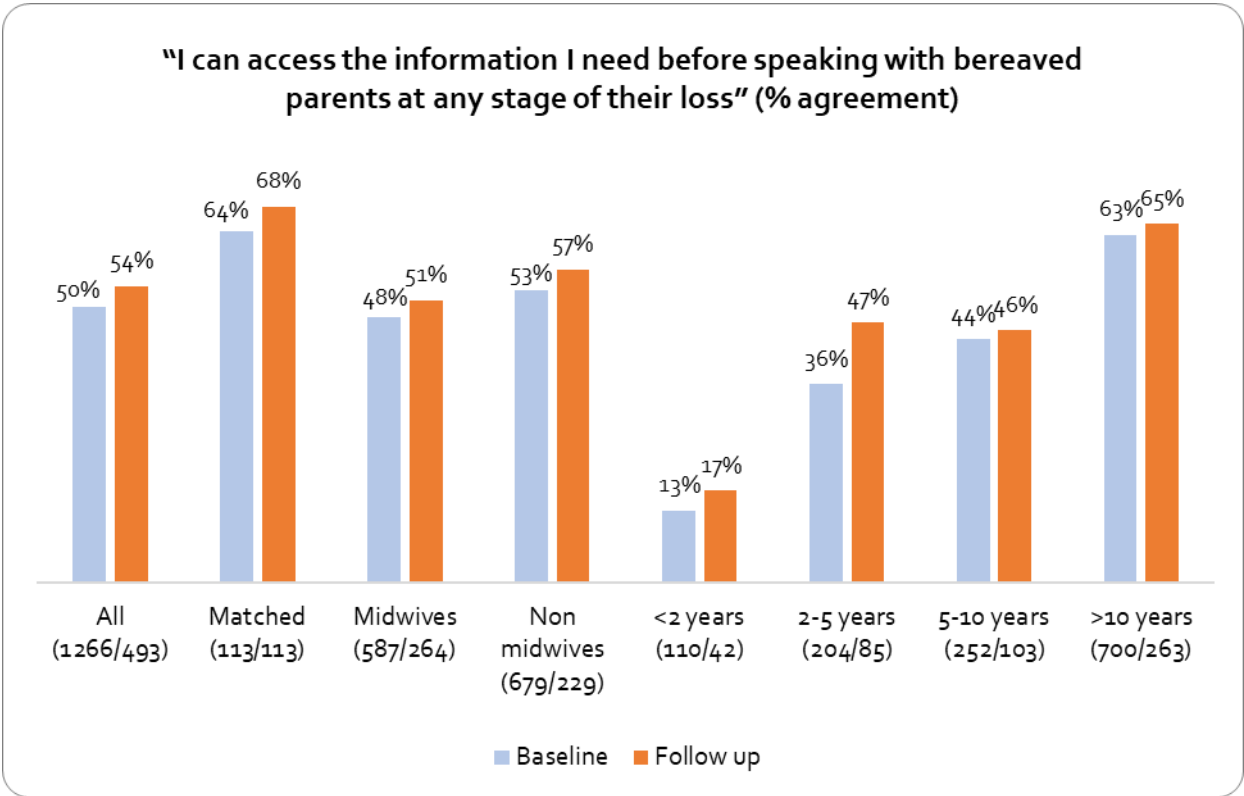
**How capable do you feel when it comes to discussing bad news to bereaved parents appropriately? (% capable, very capable, or completely capable)**



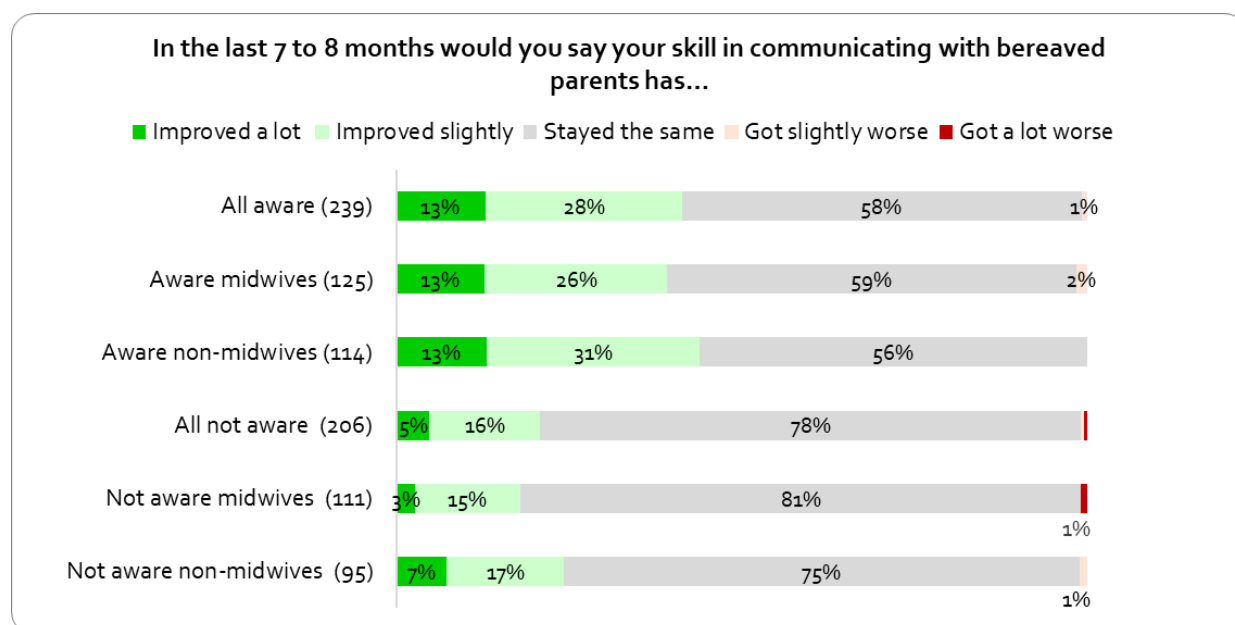
When it comes to feeling prepared to communicate with bereaved parents. There has been a small increase amongst all and matched respondents – and within every group.



There have also been improvements in each group when it comes to accessing information required before speaking to bereaved parents.



41% of all respondents who were aware of the pathway feel their skills in communicating with bereaved parents has improved. This compares with 21% of those who were not aware of the pathway. Only 2% of respondents in total said their skills had worsened.

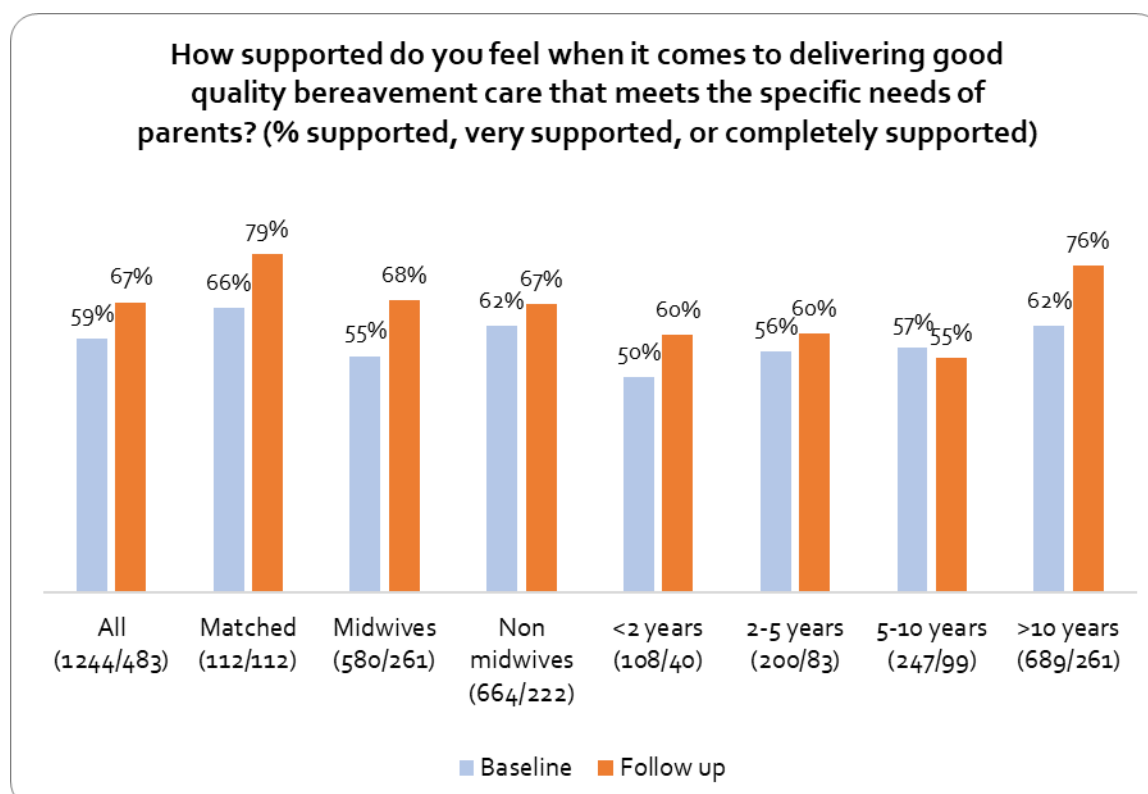


## 6.5. Support to deliver good quality care

The evaluation aimed to measure whether:

- Staff feel better supported to deliver effective bereavement care.
- Staff can debrief after difficult situations.

The proportion of all respondents who feel supported to deliver good quality bereavement care has increased by 14% (19% amongst matched respondents). The largest increases were seen within the midwives' group (23%), those with over ten years' experience of working with bereaved parents (22%) and those with less than two years' experience (20%).



It is clear from the qualitative feedback that these improvements have been stimulated by the changes in practice and increase in training prompted by the pathway covered above. Responses also reveal that staff increasingly feel that their trusts guidelines and processes are more streamlined and better support them to deliver effective care.

In some cases, this has been achieved by amalgamating the bereavement care pathway with clinical guidelines. Others saw the need to combine the two as an important step in embedding effective bereavement care.

"The families don't care about the clinical care because the worst thing has happened – the trust cares that they have had excellent clinical care – the families only care that we are kind, know how to support them and can pass them on to other services Our guidelines now have the family and the clinical care as equally important. Our SOP (Standard Operating Procedure) is our clinical care in with the NBCP – you are doing the clinical things the family need but also the bereavement care. They [staff] can't escape it. Even if you have never cared for a bereaved family everything is there staff pick up that booklet and they work through it beginning to end and that booklet becomes their care documentation." (Lead site 11 - interview)

"We've created a document that leads someone through from diagnosis to follow up visits and references to the guidelines. People don't have to start hunting around for the guidelines, both clinical and bereavement care are in one place – it has some very practical things like dosing schedules, but also reminders on photos and softer issues. There is space for notes and checklists for investigations and follow up" (Lead site 20 – interview).

"The pathway helps to ensure parity of esteem with the clinical guidelines, people would just jump ahead and deal with the physical condition those – but pathway ensures that, by doing the psychosocial aspects of care that can get missed, you can make such a difference. I think it is brilliant – and something we can't do without". (Hospital midwife, site 4 – interview)

Several professionals indicated that they appreciated the new standardised and streamlined guidance and tools.

"It's been priceless – it gives a structure for the midwives to work from, something to aspire to if we are not doing it, or if we are, we know we're doing a good job. It gives us a checklist when emotions are running high. (Matron, site 20 – interview)

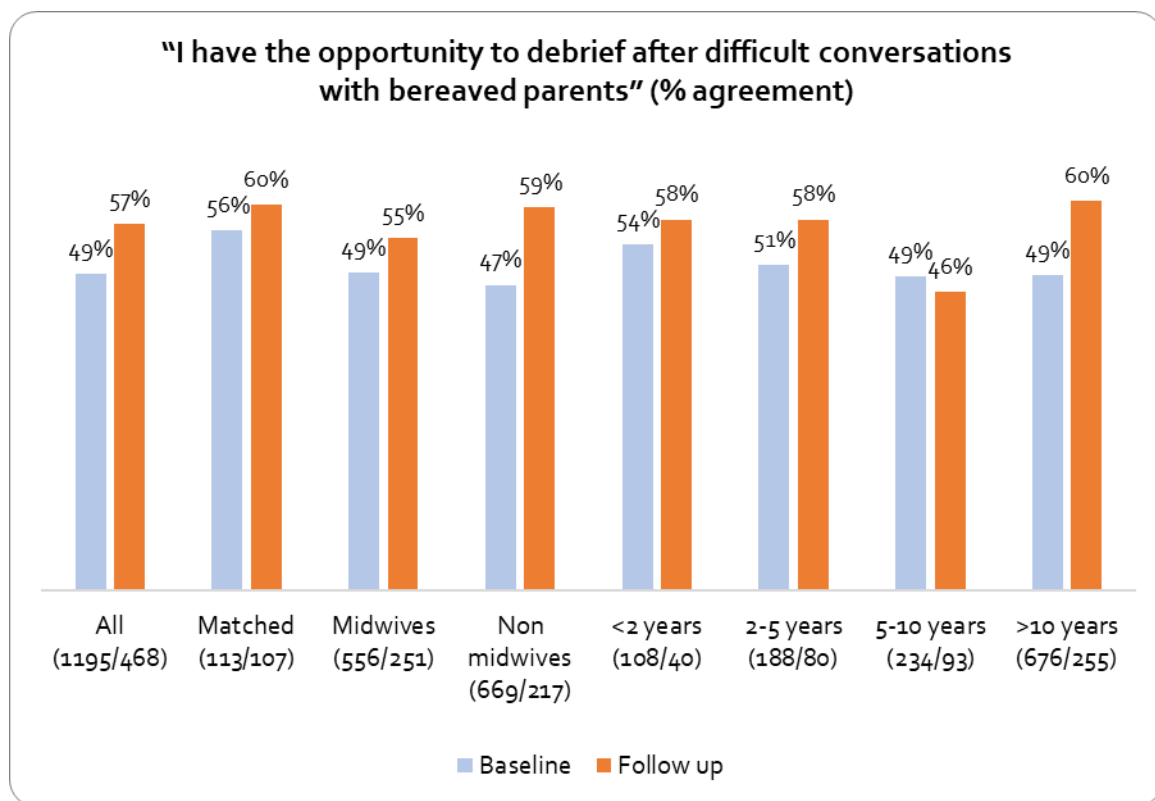
"It is clearer which investigations are required following still birth and pregnancy loss. The debriefing of parents' proforma is a good aide memoire." (Consultant Obs/Gynae, site 20 – survey)

"There have been changes to paperwork from Gynae ward to ensure community midwives are informed of loss." (Hospital midwife, site 10 – survey)

"We've updated nursing guidelines and checklists relating to patient care - therefore there is less room for error, and improved patient care. We have tighter, clearer guidelines around which investigations are offered and from what gestation. (Nurse, site 19 - survey)

"We have easier pathways to transfer people between A&E and appropriate services.  
(Consultant, Obs/Gynae, site 7 – survey)

The proportion of all respondents who can debrief after difficult conversations with bereaved parents has increased by 16% (7% amongst matched respondents). The largest increases were seen within the group of non-midwives (25%) and those with over ten years' experience of working with bereaved parents (24%). One of the pilot sites had developed an emotional wellbeing leaflet for staff, other qualitative feedback pointed to the role played by bereavement leads in supporting colleagues as well as parents.

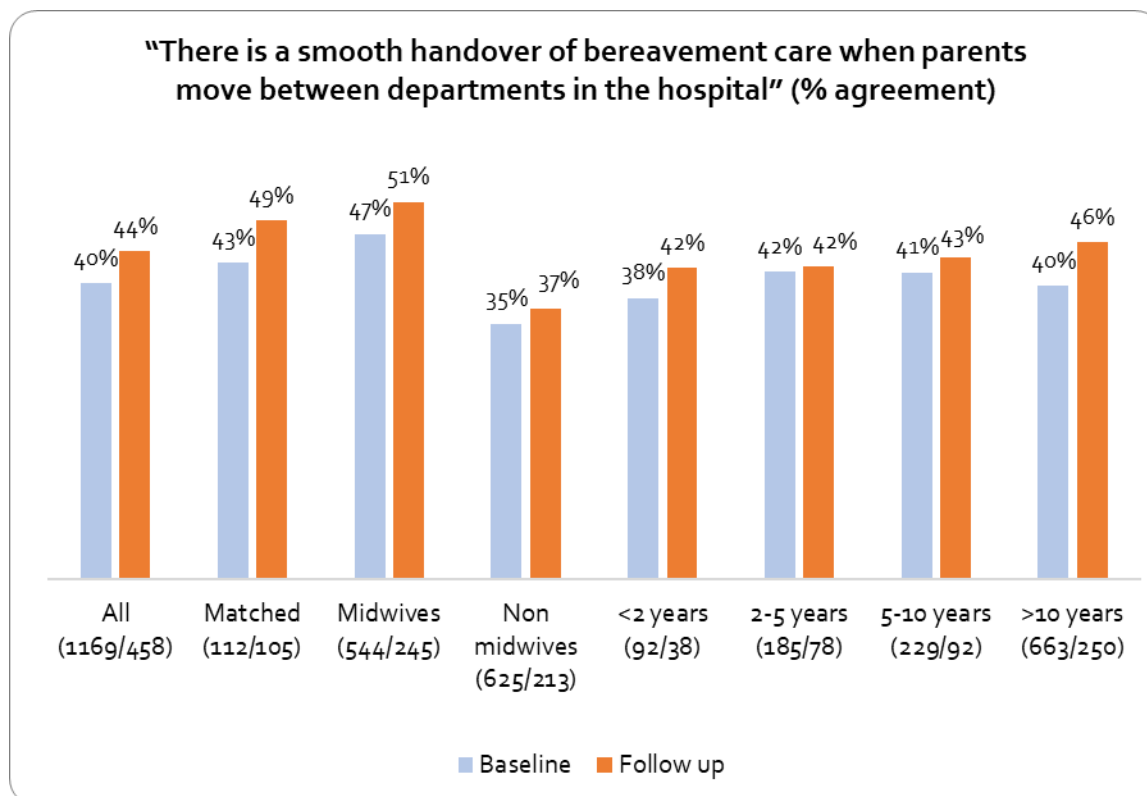


## 6.6. Handovers

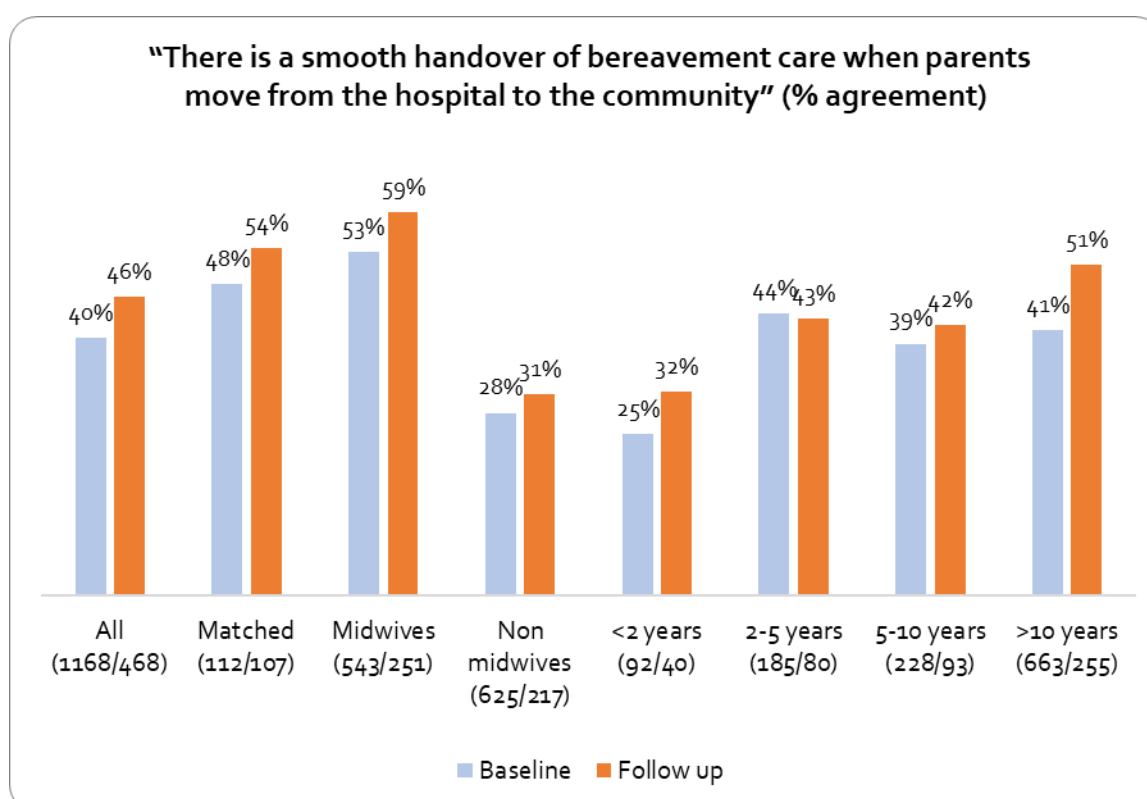
The evaluation aimed to measure whether:

- Staff feel handovers are smooth - within hospital (across departments) & between hospital and community.

When considering all respondents there is an 11% improvement in agreement that there is a smooth handover of bereavement care within the hospital, this increases to 13% amongst matched respondents.



There was also an increase in the proportion of professionals agreeing that handover from hospital to the community was smoother at follow-up compared with baseline (16% for all respondents and 12% for matched respondents).



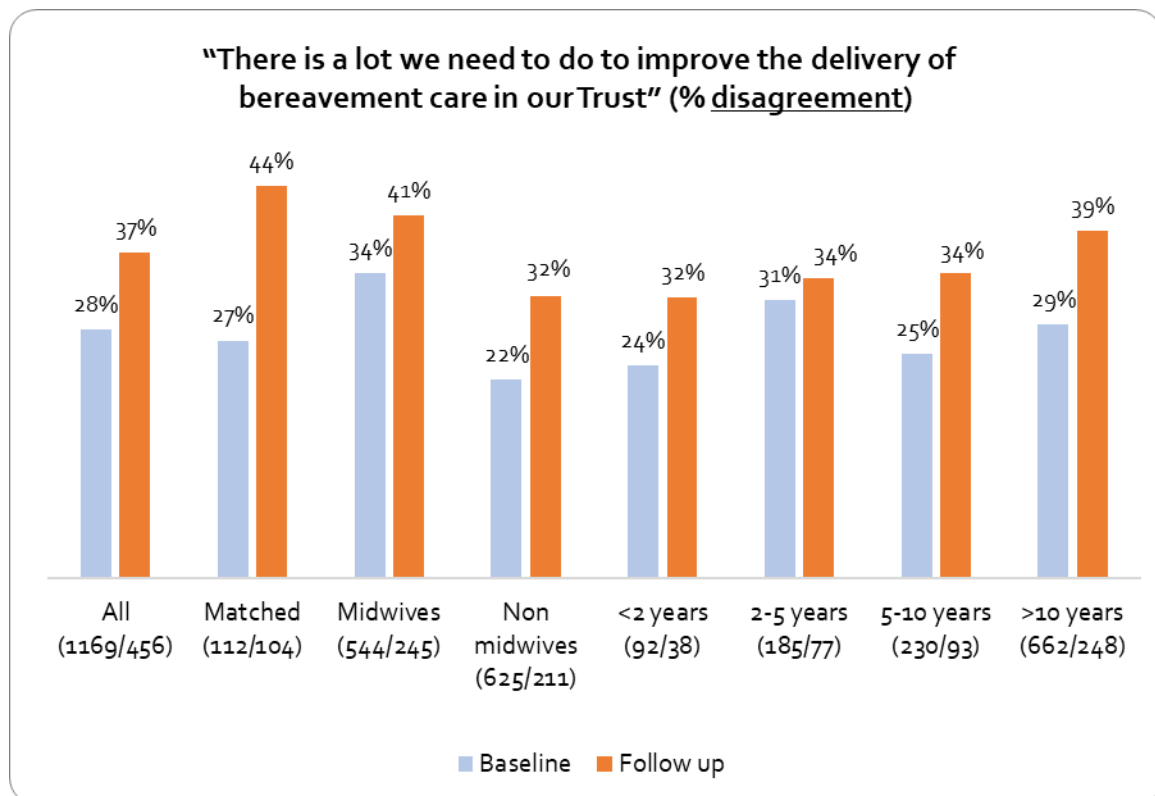
Several professionals mentioned that, although handover has improved, follow up services in the community for bereaved parents are not always available, and that bereavement midwives often

“fill a gap” when it comes to emotional support. Some called for more investment in community services to extend the service being offered through the pathway.

“The pathway has galvanised some very important improvements in bereavement care. However, significant funding increases and community-based services absolutely need to happen for real changes to take place.” (Neonatal nurse, site 10, survey)

## 6.7. Room for improvement

The baseline and follow up surveys asked whether professionals felt there was “a lot we need to do to improve the delivery of bereavement care in our trust”. At follow up, 31% of all respondents and 65% of matched respondents disagree with this statement (i.e. do not think there is much to improve) than at baseline – a possible indicator that, whilst there is always room for improvement, changes made in the interim have had a positive impact on care. Increases in disagreement (i.e. feeling that there is not room for much improvement) are largest in the non-midwife group (47%) and those with more than ten years’ bereavement care experience (37%).



## 6.8. Evaluation results for both waves of pilot sites

As mentioned above (see 4.1) this report concerns the second wave of sites piloting the NBCP, a previous wave had been completed in October 2018. The proportion of professionals agreeing that there had been positive outcomes in bereavement care following the introduction of the NBCP was broadly similar across both waves. When considering results by wave it should be remembered that the composition of the trusts in each wave was different and therefore not directly comparable.

% of all professionals in agreement that	Wave 1	Wave 2
Bereavement care has improved	77%	76%
NBCP raised profile of effective bereavement care	66%	55%
Consistency of bereavement care improved	48%	54%
Fewer mistakes are made	41%	36%

## 7. Using the NBCP

The evaluation aimed to measure whether:

- Staff feel the pathway...
  - Is easy to use
  - Has straightforward/simple content
  - Has clear guidance for using it
  - Has links with other pathways
  - Is locally adaptable
  - Has “buy in” from a range of professionals
  - Is used by a range of professionals

### 7.1. Practical use

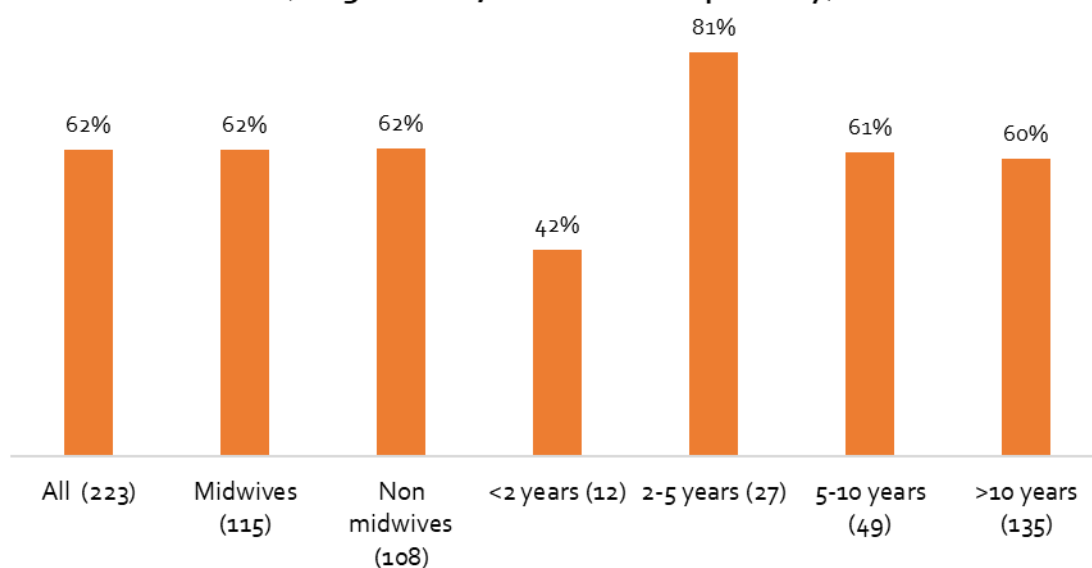
Overall, professionals’ experience of using the pathway is positive – especially for midwives.

- 62% of those aware of the pathway (223) agreed that it was easy to use (only 4% disagreed).
- 64% (226) agreed the content was simple to follow (with 3% disagreeing).
- 65% (223) agreed that the pathway contained clear guidance for using it (only 1% disagreed).
- 55% (226) agreed that the pathway “linked well with other pathways used within our trust” (with 4% disagreeing).

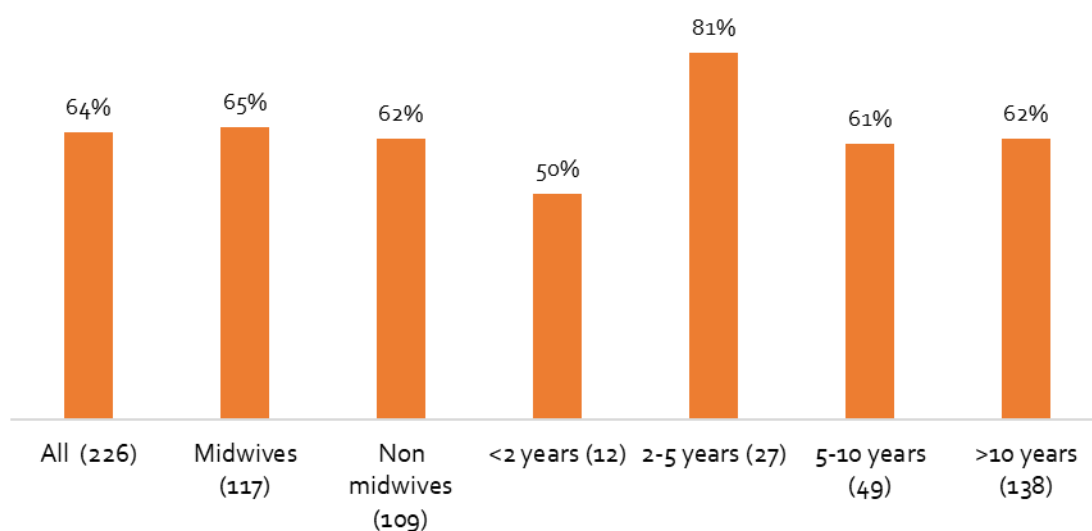
In all cases, those with between two- and five-years’ experience of working with bereaved parents were the most positive about the usability of the pathway.

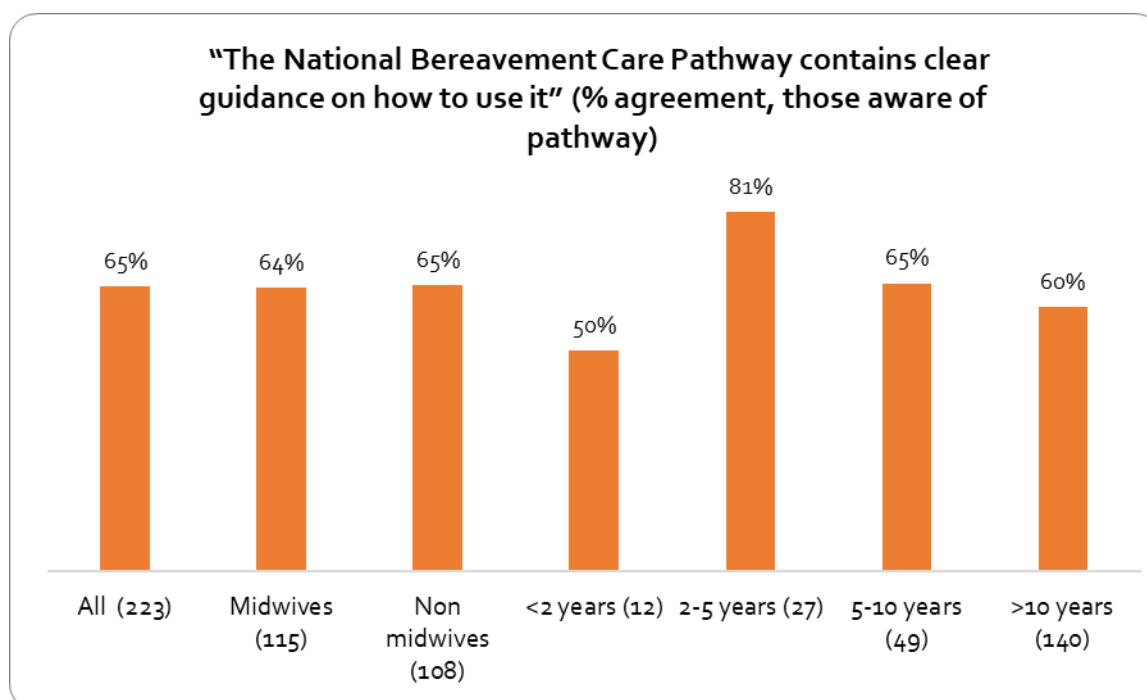


**"The National Bereavement Care Pathway is easy to use"**  
 (% agreement, those aware of pathway)



**"The content of the National Bereavement Care Pathway is simple to follow"**  
 (% agreement, those aware of pathway)





Compared with wave one, there were very few comments from wave two professionals about the pathway documents being too long. There were a few requests to include diagrams and flow charts.

"I imagined there would be something a little more simplistic to refer to like a flowchart and staff have fed that back to us – having that as an additional document would be great."  
(Lead, site 19 – interview)

"They [the pathways] are great – wording nice and concise, broken down into stages. Add a flow chart with the key points - e.g. when a woman arrives at ED miscarrying, an ED person may not have time to look through the whole thing." (Lead, site 7 – interview)

Comparing the waves, we can see that more wave two professionals agree with statements that the pathway was user friendly, and fewer disagree. Therefore, steps taken to improve the usability and accessibility of the pathway, following the feedback from the wave one pilot sites, had a positive effect.

	Agree		Disagree		Net agreement	
"The National Bereavement Care Pathway..."	Wave 1	Wave 2	Wave 1	Wave 2	Wave 1	Wave 2
...is easy to use"	56%	62%	6%	4%	50%	58%
...is simple to follow"	57%	64%	7%	3%	50%	61%
...contains clear guidance on how to use it"	62%	65%	6%	1%	56%	64%
...linked well with other pathways used within our trust"	53%	55%	4%	4%	49%	51%

Some suggestions were made more increasing the usability of the pathway.

"I would have liked it to be less woolly and less open to interpretation – it is like how a friend would guide you, but clinicians want 'this is what you must do – A to Z' so they know they can't mess it up which is their worry." (Lead site 11, interview)

"It would be good to have a minimum standard as trusts do things differently. It just says to offer some funeral arrangement choices – but doesn't specify a minimum standard – some do incineration, some offer batch cremations, some individual after 12 weeks – would be helpful to have a recommended standard e.g. batch up to this many weeks and then offer individual from this many weeks" (Lead, site 4, interview)

"It would have been useful to have a bereavement midwife job description that describes the role as co-ordinating and facilitating care rather than doing it all." (Lead, site 15 – interview)

#### **7.1.1. Engaging other departments**

Most of the site leads came from departments (mainly maternity teams) that were already relatively confident in the bereavement care they were providing. But the baseline survey confirmed it was teams outside of maternity (e.g. A&E, sonography or gynaecology), as well as those working in the community, that had the furthest distance to travel to ensure consistent, high-quality patient care.

Although there is evidence (see above) of great strides being made in these areas - most sites managed to recruit "champions" to take responsibility for different pathways – site leads reported on how challenging it can be to involve others – especially A&E where there were few existing relationships, where staff lack time, and do not encounter a large number of cases in proportion to their total workload.

"A&E was a nightmare – no one will take the lead, they [are] short staffed and just try and get women to Gynae as soon as possible. We have raised awareness and made it more likely they will offload the families to the most appropriate place to receive their care." (Lead, site 11 - interview)

"Maternity sites sign up to the project, but they have a different viewpoint to ED, they don't regularly go there, they don't have the links. You need those relationships to get things done." (Lead, site 13 - interview)

"I finally got ED to engage when I offered to help them with training – they are more interested now they are getting something back." (Lead, site 16 – interview)

Often leads were reliant on motivated individuals in other departments to progress the work.

"When the other teams realised that we weren't going to do all the work their interest dwindled. We did a presentation and some people self-declared their interest and were motivated to take it forward." (Lead, site 20 – interview)

Having, or at least alluding to, the backing of senior staff was helpful to encourage others on board.

"The winning card is that our Head of Midwifery signed up for it and our Director for Women and Children is very on board – they have not come to any meetings or knocked on any doors for me, but they are keen for me to say I have their support. That has been a massive driving factor to say that these two people who are very high up in the hospital are backing this project - it does make sisters and matrons think 'this isn't some midwife with a fancy idea this is something we need to pay attention to and get right.'" (Lead, site 16 – interview)

However, it was clear that often this backing was not in place.

"I suspect the people higher up in the trust didn't have much idea of what was involved" (Lead, site 20 – interview)

"I think there needed to be more buy in from Heads of Midwifery (HOM) to add more credibility to the pathway. Getting support took time. I think the safer births care bundle was easier to implement because HOMs were recruited to cascade." (Hospital Midwife, site 5 - interview)

Several felt that including the pathway in CQC inspections would mobilise more senior support for its implementation.

"Once it becomes 'you must do it' then things will change." (Lead, site 11 – interview)

"If it was a CQC inspection I would get support from matrons and other departments, it would be 'we all need to do this'". (Lead, site 16 - interview)

## **8. Managing the project: Feedback from the pathway site leads**

Many site leads felt that they had a basic level of support from their trust to implement the project – for example, most got time to attend project meetings (although many had to fund the cost of travel themselves). As noted above, support from senior management to secure additional resources or instigate change in other teams was less evident.

Many felt they might have achieved even more with more time, and some mentioned the personal toll delivering the project had taken on them - especially when asked to manage the project in addition to their already significant workload. Most called for protected time to be given to all those involved in implementing the pathway.

Several leads would have welcomed more opportunity for more collaboration and sharing (for example of local guideline documents) and all leads interviewed praised the co-ordination of the project and the support they had received from the project lead.

## 9. Appendices

### Appendix one: health professional survey response and profiles

#### Health professionals

Both the baseline and follow up survey link were distributed by the sites lead to colleagues in relevant departments. In some cases, the leads also relied on contacts in other departments to distribute the link for them. It is difficult to know exactly how many people were given the opportunity to do the survey and, therefore, calculate a response rate. Most site leads indicated that this is the most appropriate methodology for gathering insight from colleagues (accepting that they are asked to complete surveys quite often).

As we saw above (6.1), the baseline survey attracted many more responses than the follow up – possibly because it was conducted at the same time as the project’s launch, so interest was probably higher.

#### Responses by site

- Chelsea and Westminster, Kettering, Norfolk and Norwich, Leicester and Newcastle provided the largest proportion of responses to the baseline survey (combined 41%)
- Chelsea and Westminster, Kettering, Nottingham, Coventry and Warwickshire and Bath provided the largest proportion of responses (combined 56%) to the follow up survey.
- Chelsea and Westminster, Kettering, Norfolk and Norwich, Nottingham, Derby and Bath provided the largest proportion of matched responses (combined 70%).

	Baseline		Follow up		Matched	
Chelsea & Westminster	132	10%	51	10%	13	12%
Kettering	109	8%	65	13%	20	18%
Norfolk & Norwich	107	8%	45	9%	15	13%
Leicester	99	7%	21	4%	6	5%
Newcastle	95	7%	0	0%	0	0%
Nottingham	79	6%	56	11%	10	9%
Coventry & Warwickshire	79	6%	56	11%	7	6%
Derby	76	6%	44	9%	10	9%
Cornwall	74	6%	17	3%	3	3%
Co. Durham & Darlington	68	5%	6	1%	2	2%
Frimley	64	5%	2	0.4%	1	1%
Bath	55	4%	48	10%	11	10%
Morecambe Bay	52	4%	12	2%	0	0%
Pennine	42	3%	20	4%	6	5%
Southport & Ormskirk	36	3%	0	0%	0	0%

Western Sussex	32	2%	2	0.4%	0	0%
Southampton	31	2%	2	0.4%	1	1%
Harrogate	28	2%	0	0%	0	0%
North Lincs & Goole	26	2%	20	4%	5	4%
Leeds	23	2%	24	5%	3	3%
Alder Hey	20	1%	0	0%	0	0%
North Middlesex	8	1%	0	0%	0	0%
<b>Total</b>	<b>1335</b>		<b>491</b>		<b>113</b>	

## Responses by role

The proportion of hospital-based midwives in the sample increases from the baseline (34%), follow-up (42%) and matched (46%) samples. The proportion of neonatal nurses also increases.

	Baseline		Follow up		Matched	
Midwife (Hospital based)	450	34%	207	42%	52	46%
Neonatal nurse	157	12%	67	14%	18	16%
Midwife (Community based)	155	12%	59	12%	14	12%
Nurse	106	8%	37	7%	8	7%
Obs/Gynae (mixed role)	61	5%	18	4%	7	6%
Sonographer/Screening	60	5%	11	2%	3	3%
A&E nurse	48	4%	2	0%	0	0%
Maternity support worker	44	3%	13	3%	1	1%
Other	42	3%	17	3%	0	0%
Paediatrician	37	3%	8	2%	2	2%
Healthcare assistant	31	2%	18	4%	2	2%
Health visitor	30	2%	3	1%	0	0%
Obstetrician	24	2%	12	2%	1	1%
Chaplain	20	2%	5	1%	1	1%
Anatomical Pathology/Mortuary	12	1%	3	1%	0	0%
Administration	11	1%	3	1%	1	1%
GP/registrar	9	1%	5	1%	1	1%
Neonatologist	7	1%	5	1%	1	1%
Ward clerk	7	1%	1	0%	0	0%
A&E doctor	6	0%	0	0%	1	1%
<b>Total</b>	<b>1317</b>		<b>494</b>		<b>113</b>	

## Responses by experience of working with bereaved parents

The representation of experience is consistent between the baseline and follow up survey, however those with more than ten years' experience are more represented in the matched sample.

	Baseline		Follow up		Matched	
Less than 2 years	117	9%	42	9%	1	1%
2-5 years	209	16%	85	17%	15	13%
5-10 years	257	20%	103	21%	16	14%
More than 10 years	713	55%	264	53%	81	72%
<b>Total</b>	<b>1296</b>		<b>494</b>		<b>113</b>	

## Responses by parents supported

The proportion of professionals working with each bereavement experience, is broadly consistent across all surveys.

	Baseline		Follow up		Matched	
Those who have had a miscarriage	810	64%	296	60%	66	58%
Those whose pregnancy has been terminated for fetal anomaly	826	65%	338	69%	84	74%
Those who have had a stillbirth	864	68%	355	72%	85	75%
Those who have had a neonatal death	812	64%	355	72%	85	75%
Those who have had a sudden and unexpected death of an infant up to 12 months of age	323	25%	103	21%	24	21%
<b>Total</b>	<b>1271</b>		<b>490</b>		<b>113</b>	

## Recruitment for the parents' survey

Sites chose how and when to promote the survey link to parents. Many different approaches were used including leaving laminated information sheets in the hospital for parents to photograph, using follow up meetings, including information in discharge materials, and sending letters, emails and text messages to those who had given their permission to be contacted in that way. Most responses to the parents' survey were from trusts who were able to text or email parents.

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

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



### Appendix three: 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 four: 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 2. Parents were provided with information that was clear and easy to understand 3. Parents were provided with information that was relevant to their situation 4. Parents feel the decisions they made were the right ones at the time	Yes Yes Yes Yes
High quality care	Good communication	5. Parents feel they were communicated with sensitively 6. Parents feel they were listened to 7. Parents feel their concerns were taken seriously	Yes Yes Yes
	Memory making	8. Parents were given the opportunity to make memories 9. Parents were given the opportunity to spend time with their baby	Yes SUDI, stillbirth and neonatal death only
	Continuity of bereavement care (in hospital)	10. Parents had a single person/point of contact throughout the process 11. Parents feel the quality of care they received was consistent across all hospital staff	Yes Yes
	Continuity of bereavement care (to the community)	12. Parents were offered ongoing emotional support	Yes
	Partner and family	13. Parents feel the needs of their partners/family members were met	Yes
	Aspects of support provided	14. Parents feel the timing of the support offered was appropriate 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 Yes

Overall NBCP project outcome	Area	Measurable outcomes/indicators	Does this outcome apply to all parents?
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 pregnancy ended after a prenatal diagnosis Miscarriage and pregnancy ended after a prenatal diagnosis only