Evaluation of the National Bereavement Care Pathway (NBCP)

Wave one final report

October 2018

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Contents

1. The National Bereavement Care Pathway

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

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

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

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

The desired outcomes from the NBCP project are:

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

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[1] 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.

[2] 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

The evaluation is being generously supported by a donation from the charity Teddy's Wish (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.
Fiveways (www.fivewaysnp.com) specialise in strengthening charity governance, assessing and managing risk, and evaluating services to drive future improvement.

The Evaluation subgroup

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

3. Executive Summary

The National Bereavement Care Pathway was piloted by eleven NHS Trusts in England, most of which had started implementation between October 2017 and January 2018.

This evaluation aimed to understand the impact and effectiveness of the pathway after 8-10 months of implementation, and to develop key learning that can be used to improve its future development and wider national rollout.

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

3.1. The parents' perspective

The online survey provides a snap shot of 56 parents' experiences of bereavement care in the period the pathway was used. It reveals high levels of satisfaction with the care received.[3]

- 95% agree the hospital was a caring and supportive environment.
- 98% agree they were treated with respect.
- 92% feel the decisions they made in hospital were the right ones at the time.
- 96% feel they were communicated with sensitively.
- 94% feel that all staff could provide a consistently high level of care.
- 84% were offered access to ongoing emotional support after they left hospital.

The qualitative feedback illustrates 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. There is almost universal praise and gratitude from parents for the skill, compassion and commitment of staff (especially bereavement midwives), and for the information, time and options parents are given to make their decisions.

Parents' responses also reveal examples of the inconsistent care the pathway is trying to resolve. In the main, though not exclusively, this concerns a lack of sensitivity by some staff outside of maternity teams.

Parents also highlight a lack of emotional support in the community once they have left hospital. 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. Some parents report difficulties in accessing such provision and prefer to remain in touch with those healthcare professionals who have cared for them in the hospital setting.

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[3] 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.

As a result, the lines between bereavement care and ongoing emotional support are blurred with bereavement midwives increasingly continuing to support parents for some time after their hospital stay.

3.2. The health professional perspective

The baseline and follow up surveys (taken by 530 and 337 health professionals respectively), and interviews with the 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.

- 77% of professionals who were aware of the pathway (166)[4] agree that, overall, bereavement care has improved in their trust during the period of the pilot (none disagreed).
- 48% of professionals who were aware of the pathway agree that the consistency of bereavement care has improved in the period of the pilot (4% disagree).
- 41% of professionals who were aware of the pathway, agree that there have been fewer mistakes in bereavement care since its introduction (7% disagree)
- The proportion of professionals feeling prepared to communicate with bereaved parents has increased from 55% to 71%.[5]
- The proportion of professionals feeling capable to discuss bad news with bereaved parents has increased from 64% to 70%.
- The proportion of professionals feeling supported to deliver good quality bereavement care has increased from 68% to 77%.
- 56% of professionals who were aware of the pathway agree that it is easy to use (6% disagree). 57% agreed the content was simple to follow (7% disagree).

Analysis of the survey data, and qualitative feedback shed more light on the use and impact of the pathway.

Midwives are more likely than professionals in other roles to feel that the consistency of bereavement care has improved during the pilot. This may reflect the fact that 8 of the 11 pilot projects were led from within maternity teams[6], but it is also attributed to the recruitment of specialist bereavement midwives who have a positive impact both on parents (by providing excellent care in many areas such as attending scans and helping with funeral arrangements) and within the hospital (by engaging other departments outside of maternity, providing training, and ensuring a trust's bereavement processes support staff to deliver effective care).

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[4] Nb. The number of respondents answering each question can differ.

[5] This is amongst 73 matched responses (i.e. responses from the same people at baseline and follow up).

[6] For wave two of the pilot, sites were specifically chosen so that more were led by teams other than maternity – this will help develop and share learning on how to achieve a hospital wide approach.

Improvements in preparedness and capability to communicate with bereaved parents are also mainly seen amongst midwives. There is less evidence of improvements amongst non-midwives, reflecting the challenge of embedding the pathway in teams outside of maternity.

Securing buy in for the pathway and its use by other professionals has been a recurring challenge for the site leads, who are required to influence staff in other teams without the carrot of increased resources or the stick of management authority. In addition, internal management support to address this challenge has often been in short supply. Though good examples exist of other teams (e.g. neonatal, gynaecology, paediatric A&E) reviewing their procedures in light of the pathway – these changes are often hard won and time consuming for site leads already working in a pressured environment.

Qualitative feedback indicates that whilst most professionals are confident of its content, there is a desire for the pathway to be more concise, practical and directive – clearly articulating what parents should expect from trusts. This feedback is already being acted on by the project team.

3.3. Next steps

The evaluation has revealed that implementation of the pathway has prompted improvements in bereavement care and staff capability. It is also evident that the pathway's effectiveness is dependent on the extent to which the pilot site leads have been able to engage and influence departments other than their own (usually maternity).

For the National Bereavement Care Pathway to deliver the maximum improvement in bereavement care for parents, trusts using the pathway need to be supported to:

- Encourage a "hospital wide" approach. It is important that all relevant teams are engaged at all levels (rather than relying on an individual in one team to influence others) and that senior management provide staff with support to embed the pathway.
- Ensure those leading the project within trusts are provided with the necessary time and resources to affect change within a challenging working environment.

The National Bereavement Care Pathway project should:

- Continue to develop the pathway in line with feedback from professionals and bereaved families – as has already been the case - to ensure it is as easy to use as possible and addresses the elements of care that bereaved families identify as having the greatest impact.
- Learn from the second wave of 21 NBCP pilot sites (who started implementation in April 2018), especially those that are being led by professionals in teams other than maternity.

4. Evaluating the National Bereavement Care Pathway

4.1. Background

The initial pilot of the National Bereavement Care Pathway was launched on 9th October 2017. It involved eleven NHS Trusts who started to implement the pathway at different times, but most were up and running by January 2018[7]. A list of the pilot sites is included in appendix one.

4.2. Evaluation aims and measurable indicators

The evaluation aimed to measure the impact and effectiveness of the pathway and to develop 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 subgroup, parents' advisory group and Teddy's Wish (see appendices two and three). The findings in this report are structured by these outcomes.

4.3. Evaluation method

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

Month	Evaluation activity
Oct-Dec 2017	• An online baseline survey amongst health professionals – distributed by pilot leads to relevant colleagues within their trust (530 responses)
Mar 2018	• Focus group discussions with pilot site leads
Apr-Sept 2018	• An online survey amongst bereaved parents – distributed by each trust in a manner decided locally (56 responses) • 11 telephone interviews with parents recruited from the survey
Jul – Sept 2018	• An online follow up survey amongst health professionals – distributed by pilot leads to relevant colleagues within their trust (337 responses) • Ten telephone interviews with pilot site leads and one with a professional recruited from the follow up survey

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[7] The second wave of the NBCP pilot was launched in April 2018 and involves 21 trusts.

5. Feedback from parents

5.1. Interpreting the findings

The parents' survey and telephone interviews provide a snap shot of care within trusts during the implementation of the pathway. It is difficult to ascertain what specific contribution the pathway would have made to this care. As we will see below (7.2) influencing process changes - especially within teams outside of maternity – can require more time than that covered by this evaluation. It is also the case that most sites involved in the pilot were already conscious of, and motivated by, the need to provide high-quality bereavement care before the pathway was implemented.

5.1.1. Profile of participants

56 parents who had experienced bereavement care since the implementation of the pathway completed the online survey and 13 of those participated in telephone interviews. The responses by pilot site is shown below.

Trust	Survey responses	Telephone interviews
Heart of England	24	4
Liverpool	16	4
Ipswich	9	3
York	4	1
Medway	1	-
Northern Devon	1	-
Chelsea and Westminster	1	-
Total	**56**	**13**

It is important to acknowledge the likelihood of response bias. Most responses are from Heart of England and Liverpool, trusts that have comparatively large, established, specialist and well-resourced bereavement team services.

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

Trust	Survey responses	Telephone interviews
Miscarriage	16	2
TOPFA[8]	13	6
Stillbirth	17	-
Neonatal death	9	5
SUDI	1	-
Total	**56**	**13**

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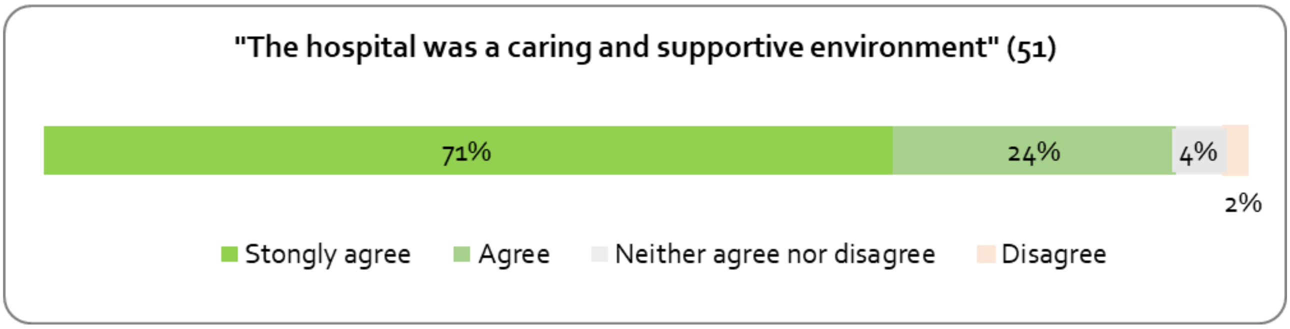
[8] As noted above, the "termination for fetal anomaly" (TOPFA) was used in the healthcare professionals' surveys. Following input from parents this was changed to "Ended the pregnancy after a prenatal diagnosis" for the parents' survey.

5.2. Parents' overall experience of bereavement care

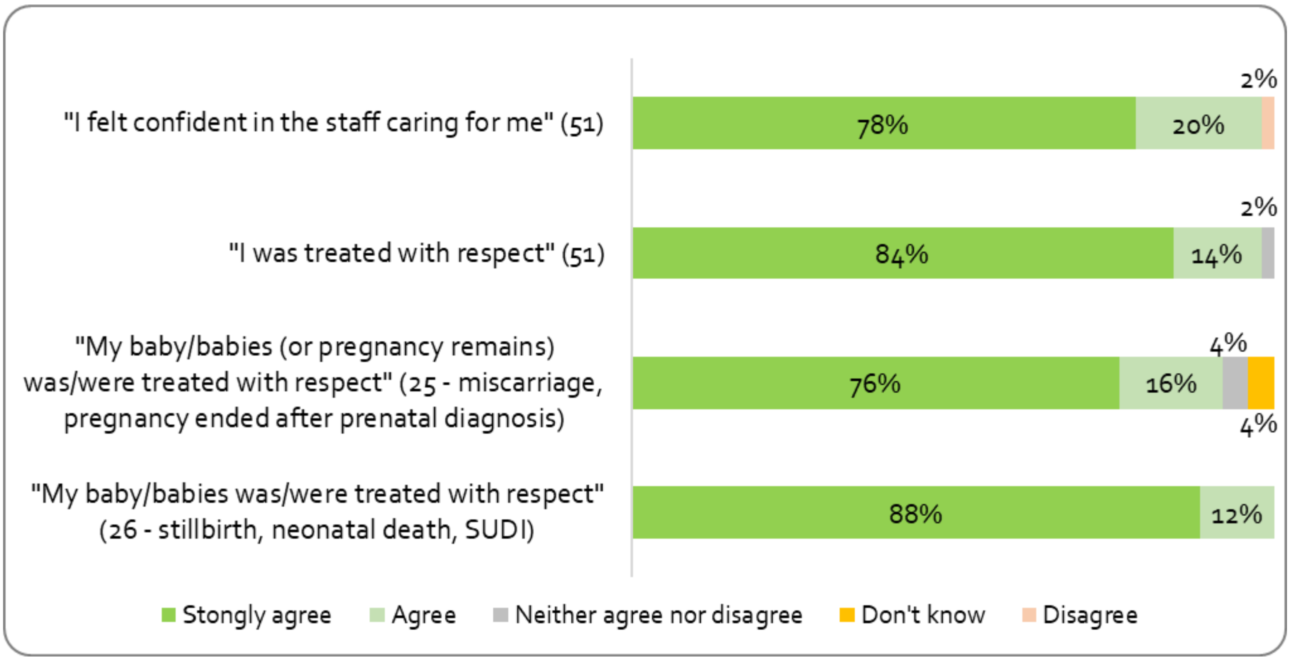
The evaluation aimed to measure whether:

- 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).

95% of parents surveyed (51) agreed the hospital was a caring and supportive environment, with 71% strongly agreeing.



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



Parents' positive overall experiences of bereavement care were highlighted in the qualitative feedback. Praise was given to midwives (often bereavement midwives) who had supported parents in many ways including attending scans, helping people get GP appointments quicker, finding burial grounds, calling to see how things were the day after a funeral, and making personalised Christmas decorations.

> "I cannot fault the [bereavement service], they were beyond excellent and helped us through the worst time of our lives." (Parent 4, neonatal death – survey)
>
> "The bereavement midwife came into theatre with me and literally held my hand. That is the best care ever and I am truly grateful." (Parent 23, pregnancy ended after a prenatal diagnosis – survey)
>
> "I have three other children and although this was the worst possible outcome from a delivery this was my nicest birth and the midwives were so wonderful. You made our awful situation the best it could possibly be. For this I will forever be grateful. Thank you." (Parent 13, stillbirth – survey)
>
> "I went [in] with the fear of the unknown. I didn't know what to expect, how to feel, or what to do. Then as soon as I got there till the minute I left, I felt more content because they made me feel at ease. The emotional support for me and my family, the physical care of myself, the care of my precious baby boy was well and truly fantastic. The staff… go above and beyond and gave me strength and courage when I thought I had none. They made me feel safe. If it wasn't for them I don't think I could have got through the whole experience. I cannot express enough how much all the amazing staff mean to us." (Parent 40, miscarriage – survey)
>
> "I was shocked at the level of care, I thought 'this is the NHS, why are they making such an effort for me?" "I didn't know care like this existed and I was blown away by it – my expectations were exceeded in every way." (Parent 33, pregnancy ended after a prenatal diagnosis – interview)
>
> "[They were] very compassionate and would give me hugs if I looked like I needed one. It was completely tailored care to what I needed. I was really lucky to go into that bereavement ward." (Parent 45, neonatal – interview)
>
> "When I have my next baby I definitely want to be in that hospital, so they must have done something right." (Parent 1, neonatal death – interview)

Some pointed out the respect shown towards their babies.

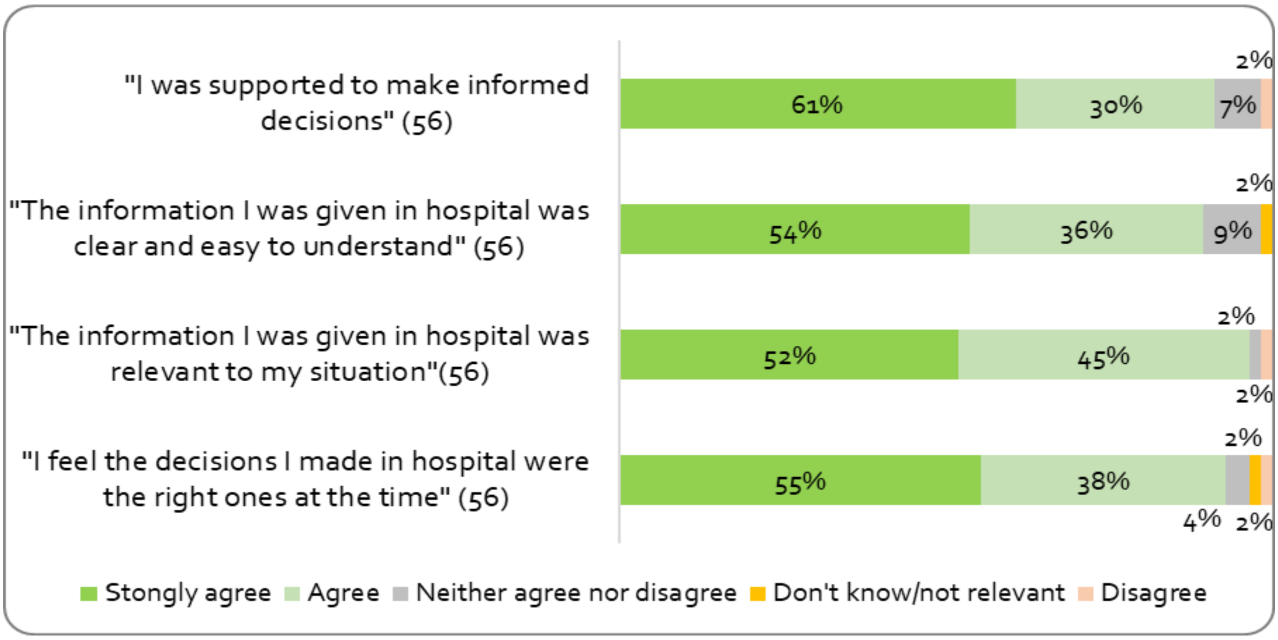
> "[She] spoke with so much care and thought – and treated baby with so much respect, so loving and caring. The midwife was talking to baby while doing prints although he had died – treating him like a person. (Parent 20, miscarriage – interview)
>
> "Most people that we came across were sensitive and spoke about the baby just as she were a healthy baby… speaking about the baby as if it were a full term really helps." (Parent 3, pregnancy ended after a prenatal diagnosis – interview)

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. 92% of parents agreed that the decisions they made in hospital were the right ones at the time.



The qualitative responses expand on this positive feedback concerning the information and support provided to parents. As they can be in a state of shock and despair, parents appreciate being given options, time to consider them, and having their decisions respected. In addition, not being pressured, having written information to refer to, and the opportunity to change one's mind are also valued.

> "We were given plenty of time. Time enough to be left alone to digest the information and make decisions. We never felt rushed or worried that the rooms we were using were intended for someone else after a certain time. This time enabled us to really process. The relevant people were never far away whenever we had any questions." (Parent 15, stillbirth - survey)

> "I never once felt that I was rushed [in the fetal medicine unit]; they gave us all the information about the process of the labour, and what was going to happen, and the medication that I was going to have to take; we never felt rushed." (Parent 3, pregnancy ended after a prenatal diagnosis – interview)

> "I know that it was an informed decision. They gave me all of the options. It was very balanced, but then it was up to me to decide." (Parent 54, pregnancy ended after a prenatal diagnosis – interview)

> "Every decision we made at the time I would make again" (Parent 20, miscarriage – interview)

> "When someone is saying something to you, it's so overwhelming you don't take it in. But if somebody actually gives you something in writing to take away, you can look back at that, you can read that as many times as you want." (Parent 6, neonatal death – interview)

> "At first I struggled to process what had happened but [midwife] gave us lots of information and we were given time to process the information and think about what had happened and what we wanted to do going forward with tests etc. On reflection I found it very helpful being given lots of information as I could think about this as and when I wanted to." (Parent 46, stillbirth – survey)

Some parents mentioned how skilled staff were in anticipating what information, or decisions were required.

> "They pointed us towards things that we weren't aware of, for example having photographs and stuff taken. That would never have occurred to me. At the time when it was first mentioned, I remember thinking, 'Is she joking? Of course, I don't want them.' But a couple of days later I changed my mind, and I'm so glad now. We made the decisions ultimately, but they pointed us in the right direction because we literally didn't have a clue what we were doing." (Parent 6, neonatal death – interview)

> "They were good at reading my emotions, which did change throughout the procedure. They adapted at every stage to what I wanted at the time… They are highly trained to know what you want individually. They just did it – they didn't ask 'do you want a memory box?' We weren't in any position to know what we wanted. They were ten steps ahead of us – in their heads they knew what was going to happen, they gave me options (but they had it sorted)." (Parent 35, neonatal death – interview)

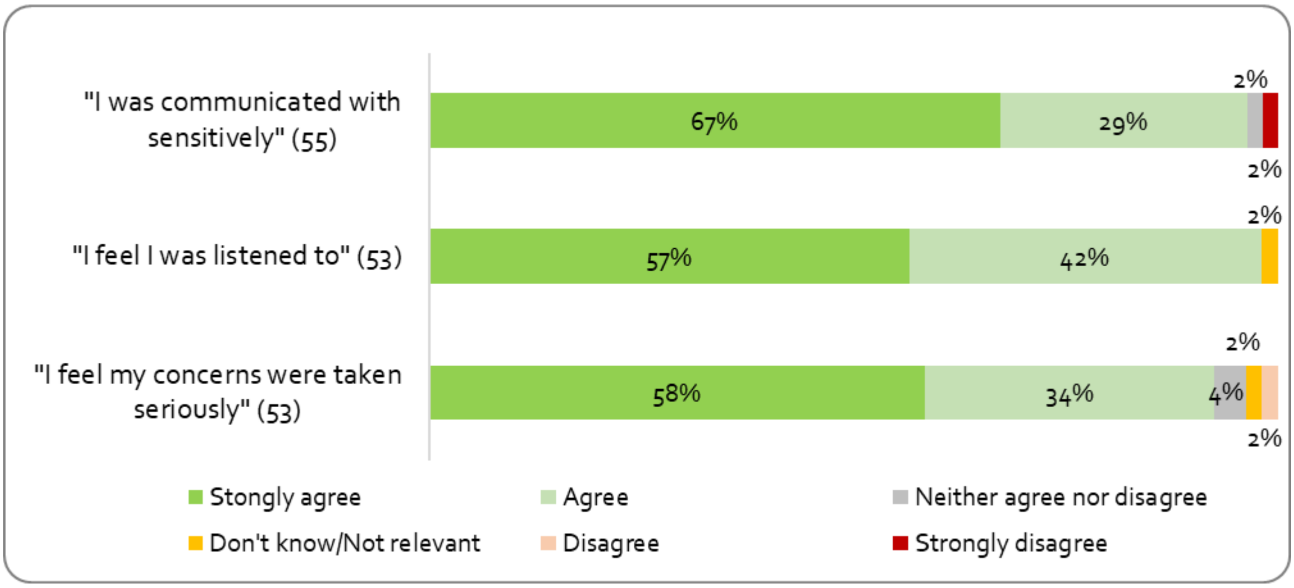
> "I have things I wouldn't have otherwise - while I was in critical care they did prints of his hands and feet and took photos. That is a massive thing, they just did it we didn't have to think about it" (Parent 20, miscarriage)

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 90% felt listened to, that they were communicated with sensitively and that their concerns were taken seriously.



The qualitative feedback contained a great deal of positive comments about how parents were communicated with. In general, the characteristics of effective communication highlighted by parents were taking time, compassion, patience (for example repeating information), being available to answer questions, and making things simple. In addition, parents often mentioned the fact that staff had read notes and updated each other was helpful as they did not have to repeat their situation every time they met someone new.

> “The nurse we had caring for us was amazing and constantly communicated what was going to happen or what could happen, and we were kept informed the whole time and [they were] always on call if we needed [them] to come back into the room.” (Parent 19, miscarriage – survey)

> “The team made us feel normal (as in a normal pregnancy/birth), calm, relaxed. They did this by the way they presented themselves to us, in the way they spoke, what they said, the information they offered, and the care they showed to both of us.” (Parent 52, pregnancy ended after a prenatal diagnosis – survey)

> “[They were] Good at repeating answers to questions I had already asked. Didn’t sound patronising.” (Parent 45, neonatal death – interview)

> “They weren’t doing it because it was their job, they were doing it because they wanted to – made a big difference.” (Parent 48, pregnancy ended after a prenatal diagnosis – interview)

> “The sonographer was amazing. He [the sonographer] was really sweet, really sensitive. I was really shocked at how good [it was] the way he talked, he was very gentle, soft. He was just really lovely.” (Parent 23, pregnancy ended after a prenatal diagnosis – interview)

> “Communication for us was exceptional. We were met by a bereavement midwife. We explained our wishes to her and they were passed on incredibly well as we didn’t need to explain ourselves again to new the midwives who then looked after us during the waiting time and then actual delivery. This is very impressive to us.” (Parent 7, pregnancy ended after a prenatal diagnosis – survey)

> “There was a doctor who was really, really helpful with me. It was such a shock and took such a long time for me to process why and how this happened; I must have gone in about five times, where she had to sit me down and tell me the same thing again and again. It was never too much trouble for her, and I needed that. Having patience with someone is really, really important – because you might have said it five or six times, but I need you to say it again. She’s a doctor, she’s a very busy woman, but she always made time to speak to me.” (Parent 6, neonatal death – interview)

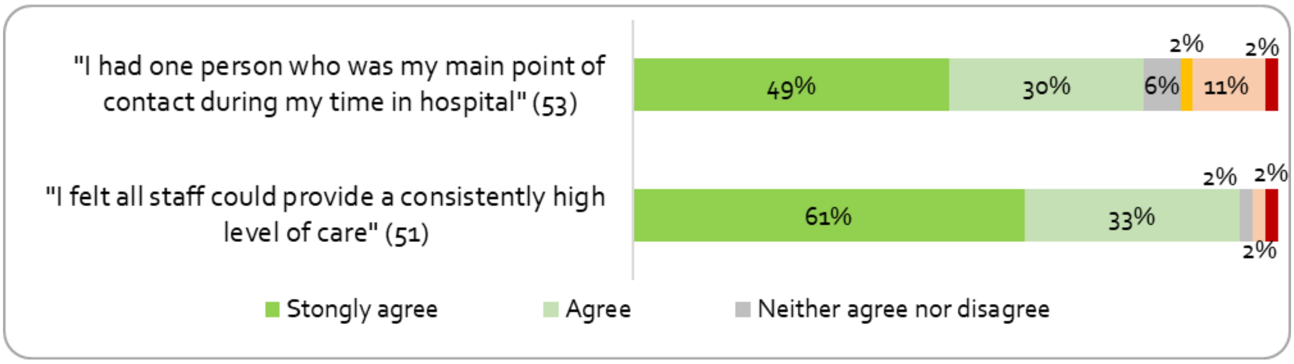
5.5. Continuity of care

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 groups (for example: Lullaby Trust, ARC, Miscarriage Association, Sands or Bliss).

5.5.1. Within the hospital

79% of parents agreed they had a single point of contact during their time in hospital, however not having one was not always considered an issue if the levels of care were consistently high throughout the team.



> "Having a dedicated point of contact who we could liaise with about anything at any time was a huge comfort and allowed us to work through our emotions and decisions carefully, in our own time and feeling as fully informed as possible." (Parent 34, pregnancy ended after a prenatal diagnosis – survey)

The quote above, and those in the previous section (5.4), reveal that many parents had experience of effective bereavement care by a wide range of professionals. However, although 94% of parents agree that all staff could provide a consistently high level of care, qualitative responses paint a more nuanced picture with plenty of examples of the type of inconsistent care the pathway is trying to resolve – both within and without of maternity.

> "Some staff who were taking my observations etc before my C section were smiling saying 'oh it's twins' which also upset us when we said one had died. I understand this was probably due to lack of communication." (Parent 41, stillbirth – survey)

> "The receptionist... was so rude and didn't have an ounce of compassion. Everyone else was amazing though." (Parent 11, miscarriage - survey)

> "One of the doctors was very insensitive and had no concern for my worries or the anxiety I developed after childbirth, however one of the midwives was with me from the day I lost baby until I left hospital after delivery and she went above and beyond." (Parent 37, miscarriage – survey)

> "Although we hand on heart found everyone to be great, there was one person who from the moment we found out there was a problem was very negative and to be honest needs to go on a course on how to handle emotional parents. She had no emotion. She told me, my husband and mother that [child] would die. Everything she said was negative. When I then told her to stop being so negative and have some hope she said she could not give false hope. We appreciate that she's not allowed to sit there and say that everything would be okay, but her way was inappropriate, hurtful and she was also very rude." (Parent 56, neonatal death - survey)

> "The obstetrician in attendance sadly compared our lives not going to plan that day with the death of our daughter with his broken ankle. 'Life doesn't go to plan' he said. 'I didn't plan this leg.'" (Parent 22, stillbirth – survey)

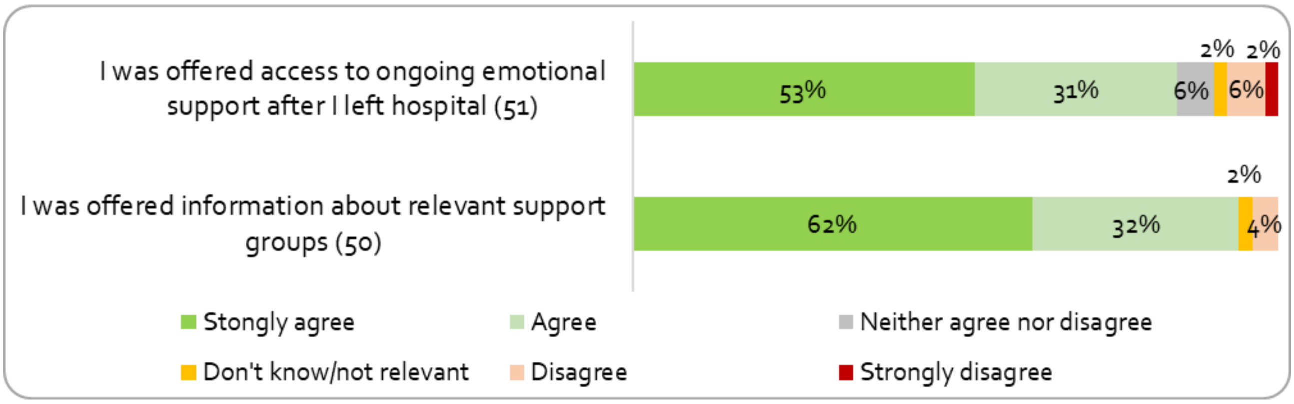
> "Overall the care we had was fantastic by the designated team who initially dealt with us but there were certain members of staff who could have done with some help on how to deal with ladies who have just lost their baby. My second night was the worse as I was in a room and left alone with the nurse just coming in every couple of hours, I was told to go out into the ward if I wanted to talk to midwives about what had happened but I didn't feel confident enough to do so especially as I could hear the other pregnant ladies on the ward. It wouldn't have been fair on them or me going into the ward with what had just happened. The evening midwife came into me, told me her husband had died suddenly 12 months previously and to go on social media groups as that would help. Don't get me wrong 90% of the staff I dealt with where fantastic." (Parent 46, stillbirth – survey)

> "Catering staff/auxiliary didn't know why we were crying. It didn't register we had a dead baby next to us." (Parent 45, neonatal – interview)

5.5.2. In the community

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 (84%) and information about relevant support groups (94%). These results indicate that the pathway's guidance to refer and signpost parents to support in the community is being followed.



However, parents do report difficulties once they are discharged from hospital. The most common concern is a feeling of being on your own once back home and finding it hard to ask for help. Parents would appreciate more proactivity, such as calls to see how they were – especially from those who had cared from them in hospital. In addition, returning to the hospital for subsequent meetings can be difficult for some.

> "I was asked if I wanted the bereavement team to be involved which I agreed to, however this just consisted of a letter weeks later which basically placed all the responsibility on us to reach out for help. Even though it wasn't intentional this very much made me feel as though they clearly didn't have the resources to help everyone and that I would be taking the help from people who they thought needed it more or who had had 'proper' babies die." (Parent 10, miscarriage – survey)

> "The care I had when I was going through the birth was amazing and then once it was over I felt like the care then stopped." (Parent 24, pregnancy ended after a prenatal diagnosis – survey)

> "Although we have been informed about the different organisations out there who can help bereaved parents I feel once you leave you are just left with no contact with anyone who knows what has happened. Writing that first email or phone call 'Hello, I've lost a baby' doesn't come naturally, you need a referral – it would be better if someone contacted me. I don't know what to say, a midwife would know how to approach the charities I think it would help parents to maybe receive a follow up with their bereavement team." (Parent 48, pregnancy ended after a prenatal diagnosis – survey)

> "I felt that because I was out of hospital they just didn't care." (Parent 56, neonatal death – survey)"

> "Whilst I feel we were offered the right support it was extremely difficult for us to return to the hospital for meetings and quite distressing…In the very early days after we came

> home it would have been nice to have been contacted or even visited by someone just to see how we were coping… it's kind of down to you to make contact with the bereavement team." (Parent 6, neonatal death – survey)

> "The Community midwife – you could tell she wasn't trained. She didn't have the same compassion, she asked me to tell her what happened which I didn't think was appropriate. She didn't check me over to see if I was okay physically." (Parent 35, neonatal death – interview)

> "It would be good to see the bereavement midwives we saw in hospital, but you don't see them again. The Community Midwife didn't know the details – we had to explain. You can open up more to people who know you and what happened – you trust them because you've dealt with them. They can't do enough for you in hospital, lots of things I was amazed that happened – it's the aftercare that is lacking if you want help you have to come and get it yourself. You're left out on your own, to deal with it yourself." (Parent 48, pregnancy ended after a prenatal diagnosis – interview)

There is also a clear demand from some for counselling support. Those who receive it are very positive about it, though one barrier to access is having to explain your story to someone new.

> "I felt really privileged to be able to do that [bereavement counselling]; I can't believe how amazing it was, how it's helped me. Before it, I'd always cry, even during the counselling sessions I'd really struggle with talking about it. But now I'm talking to you, and I feel very calm." (Parent 23, pregnancy ended after a prenatal diagnosis – interview)

> "I received counselling but because I was proactive and pushed for it. If you receive a loss of this magnitude I believe you should be put automatically on the list to see someone. You are dealing with enough and having to fight to receive support and help when all you want to do is hide from the world is unfair." (Parent 13, stillbirth – survey)

> "I always got replies to any emails sent and phone calls, I got some information about Sands and their memorial garden, just unfortunate the hospital doesn't offer a counselling service or more regular drop in sessions." (Parent 4, neonatal death – survey)

> "Perhaps part of the reason why I didn't access counselling elsewhere myself is you are having to meet someone else and go through the whole thing again." (Parent 3, pregnancy ended after a prenatal diagnosis – interview)

One mother we spoke to had had a difficult time trying to access mental health services:

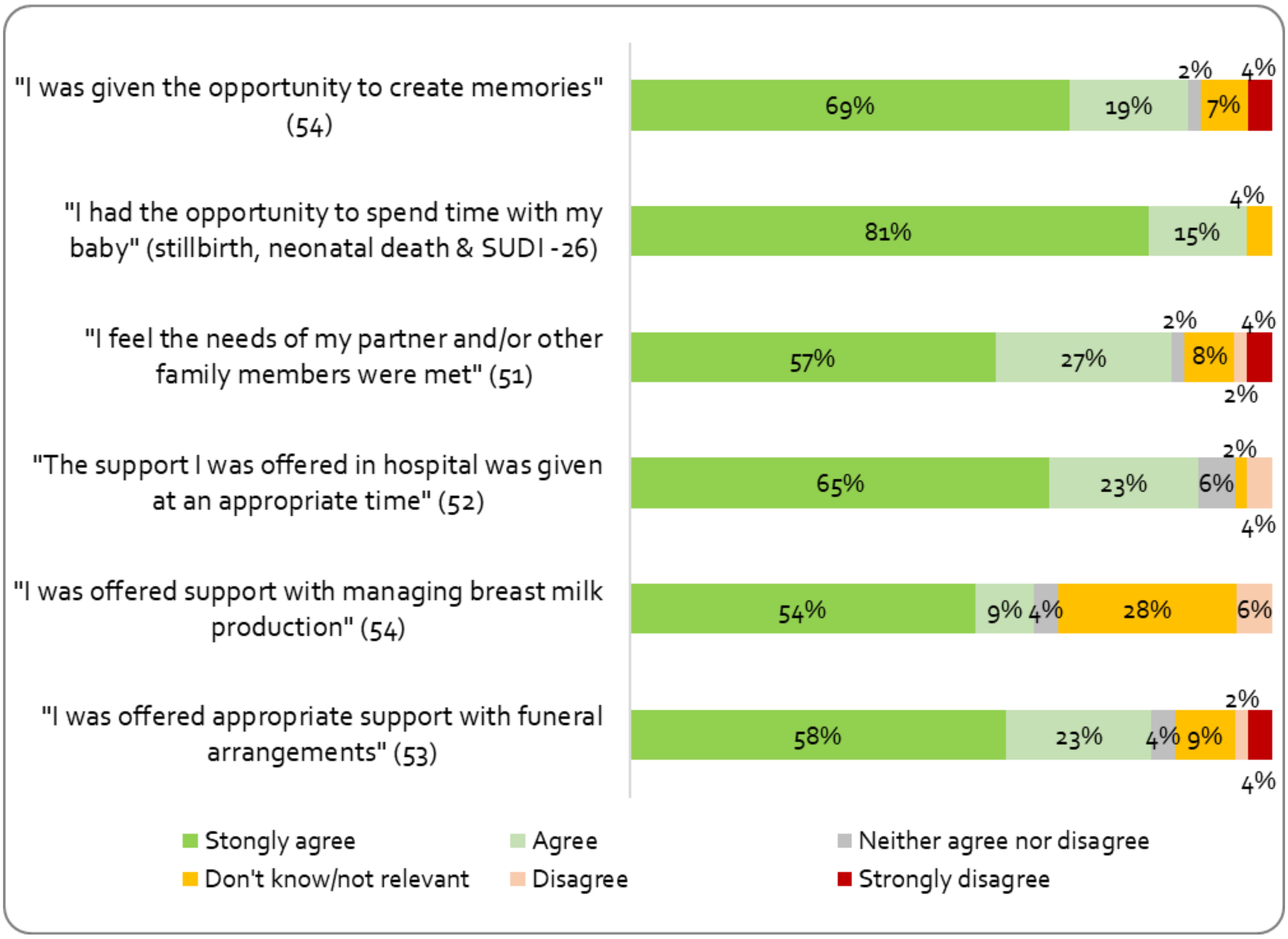
> "I was discharged from perinatal mental health team - they don't want to know because you haven't got a baby, the Community mental health team won't help me because I am not an at-risk patient. They told me to go to the local healthy minds service – but they said my situation was too complex, so they sent me to Cruise, who have a six-month waiting list. I have to explain my story every time. If I had a child that lived I would have support for up to a year after. I was at high risk… now my baby died and I'm more at risk, I'm in a post-natal depression period and have been through a trauma and I have no-one but my GP to go to. I can't get my head around it – my baby died, and I've been discharged from mental health services." (Parent 45, neonatal death – 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 also very positive – parents are regularly being given the opportunity to spend time with their baby (96% agree[9]) and make memories (88% 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 88% of parents.



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[9] Only asked of 26 parents experiencing stillbirth, neonatal death and SUDI

5.6.1. Memory making

Several parents in the qualitative feedback stated their appreciation for the time they had to make memories with their child, and the dedicated spaces to visit them.

> "We were amazed with the options for after care for our baby, even though they were only 13 weeks. It really helped us grieve and process our loss by having somewhere to visit and feel close to baby and not forgotten." (Parent 19, miscarriage – survey)

> "I'll forever be grateful for the opportunity of spending time with my princess, it greatly helped with my grieving process, very caring staff always asked if I wanted her or not." (Parent 49, stillbirth – survey)

> "My family were very well supported and given lots of opportunities to memory build with our baby, this made our experience even more precious… and have helped me to deal with the situation in the best possible way." (Parent 55, stillbirth – survey)

> "I could spend as much time with my baby as I wanted, and the bereavement midwife brought us lunch, so we could spend longer with our baby and have them special memories." (Parent 1, neonatal death – survey)

> "I found the love and respect the midwives has for myself and my baby made my stay a lot easier. The midwives helped me bond with my baby even once I was home from hospital, all of the midwives were still more than happy to support me and help me when going to spend time with my baby." (Parent 43, stillbirth – survey)

> "I liked that we could go and visit (baby) whenever we liked while she was still at the hospital and the room where we went was so nice and made it a little easier." (Parent 5, neonatal death – survey)

However, a couple of parents who had experienced early miscarriage were less positive about their opportunity to make memories.

> "I work in the hospital so am aware of how wonderful the bereavement team alongside all the other departments staff are at helping parents create positive memories, so it was particularly hard to have none of this offered after miscarriage. It would have been nice to have had anything to acknowledge the fact your pregnancy and baby existed even if this was just a certificate." (Parent 10, miscarriage – survey)

> "Having a miscarriage before 12 weeks there was not much provided. I had my first miscarriage at a different hospital, they arranged a communal cremation and baby funeral service. This wasn't an option." (Parent 11, miscarriage – survey)

5.6.2. Support for partners

Parents refer to bereavement midwives asking partners how they are and units allowing partners to stay in the hospital, however there was also a feeling that more support could be provided.

> "My husband found it very hard to deal with - I think a lot of the support appears to be aimed at just the mother." (Parent 19, miscarriage – survey)
>
> "He went through it just as much as I did, but his information was all second-hand through me, rather than having any point of contact himself. I don't know how that's affected him… Perhaps some kind of line of communication for the father as well would be good." (Parent 54, pregnancy ended after a prenatal diagnosis – interview)

5.6.3. Funeral advice

Many parents clearly valued the support they were given to arrange funerals including speaking with funeral directors, attending the funeral and the provision of memorial gardens.

> "We would like to say a massive thank you to everyone for caring so much and for all your help and kindness. It was an extremely difficult time, but you made the funeral arrangements easier to deal with and the aftercare was great. Thank you xx." (Parent 56, neonatal death – survey)
>
> "I would have struggled with it [the funeral] if there hadn't been any after care and follow up [from the chaplain] and follow up." (Parent 54, pregnancy ended after a prenatal diagnosis – interview)
>
> "Cannot thank the staff…enough for the beautiful memories that were made whilst I was there. I will treasure these memories forever. I was also advised on funeral arrangements as I had no clue on what to do or to expect. This helped me prepare massively for what was to come and again feel grateful I had the advice." (Parent 40, miscarriage – survey)

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" - 530 professionals participated in the baseline survey and 337 participated in the follow up survey approximately nine months later. In terms of role, grade 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 73 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 (80%) compared with the "all respondents" groups (baseline 63%, follow up 67%).
- 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.
- Lower and higher grades – those respondents on Agenda for Change[10] pay grades have been split by those in grades 2-5 and those in 6-8. This is a proxy for experience[11]. There is a large overlap between the grade 6-8 group and the midwife group above as most midwives in the NHS workforce are at band 6 or 7.
- Awareness of the pathway – the follow up survey respondents can be split into those who were aware of changes in bereavement care following the introduction of the pathway (37%), those who were not aware of changes but who had come across the pathway in their work (14%), and those who had not come across it (49%).

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).

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[10] Agenda for Change is the national pay system for all NHS staff, except for doctors, dentists and most senior managers.

[11] In the wave two research we have asked an explicit question about years' experience working with bereaved parents.

6.2. The overall impact of the pathway

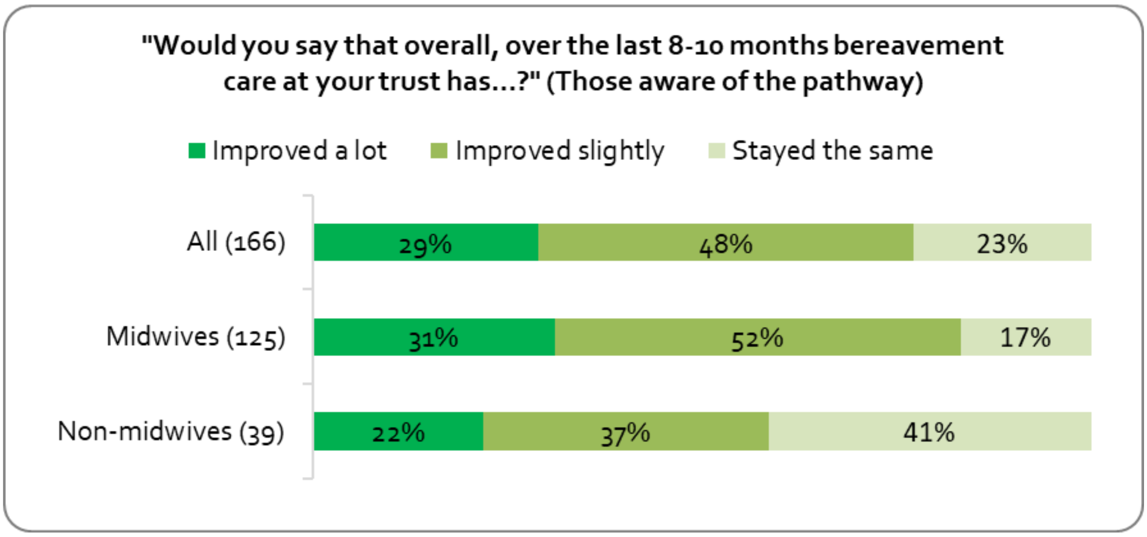
6.2.1. Confirming best practice

The pilot sites were committed to improving bereavement care and saw the need for increased standardisation within their trust (and nationally). Therefore, as a sample, they may already have been closer to providing best practice (at least within maternity) than other trusts. For those sites the pathway provided reassurance that they were doing the right things as well as ideas for improvement.

> "I believe we gave very good bereavement care here already at this trust, the care pathway has enabled us to focus on areas that needed some improvement." (Midwife, site 10)
>
> "Very little changes were needed as the Trust already had a robust bereavement pathway in Maternity." (Midwife, site 1)

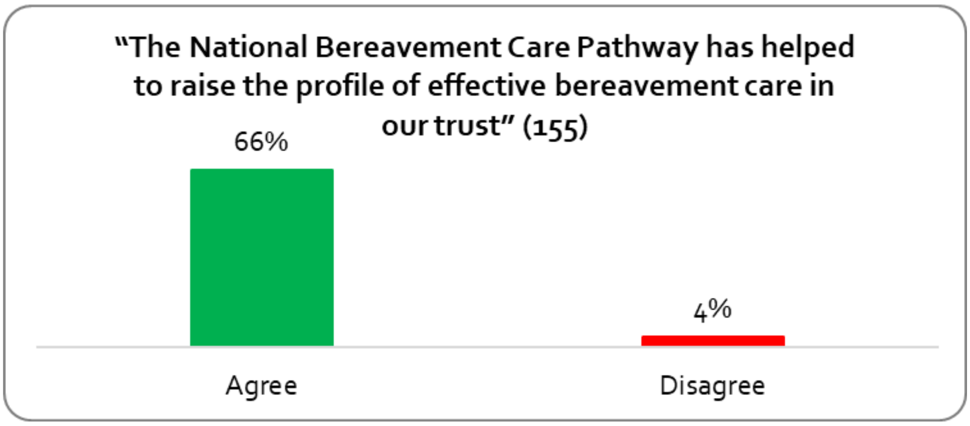
6.2.2. Improvements in bereavement care

At follow up, 77% of professionals who were aware of the pathway (166) felt that bereavement care had improved over the previous 8-10 months. 29% felt it had improved a lot – none felt it had got worse. 83% of midwives felt care had improved compared with 59% of non-midwives.



6.2.3. Raising the profile of bereavement care

66% of those aware of the pathway (155) agreed it has helped to raise the profile of effective bereavement care in their trust - 4% disagreed.[12]



Agreement that the pathway had helped to raise the profile of effective bereavement care was higher amongst midwives (116) at 72% compared with 49% amongst non-midwives (39).

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 National Bereavement Care Pathway aims to address. Care for those parents experiencing early miscarriage, those experiencing termination for fetal abnormality, those attending A&E, and those in gynaecology wards were most often highlighted as in need of improvement.

In the follow up survey 48% of respondents who were aware of the pathway (155) agreed that consistency had improved because of it, with only 4% disagreeing. Agreement was higher amongst midwives (53%) compared with non-midwives (36%).

An improvement in the consistency of care was also reported by those who weren't aware of the pathway. 26% felt that it had improved over the previous 8-10 months (with 6% disagreeing). As with those who were aware of the pathway, agreement was higher amongst midwives (34%) than non-midwives (12%).

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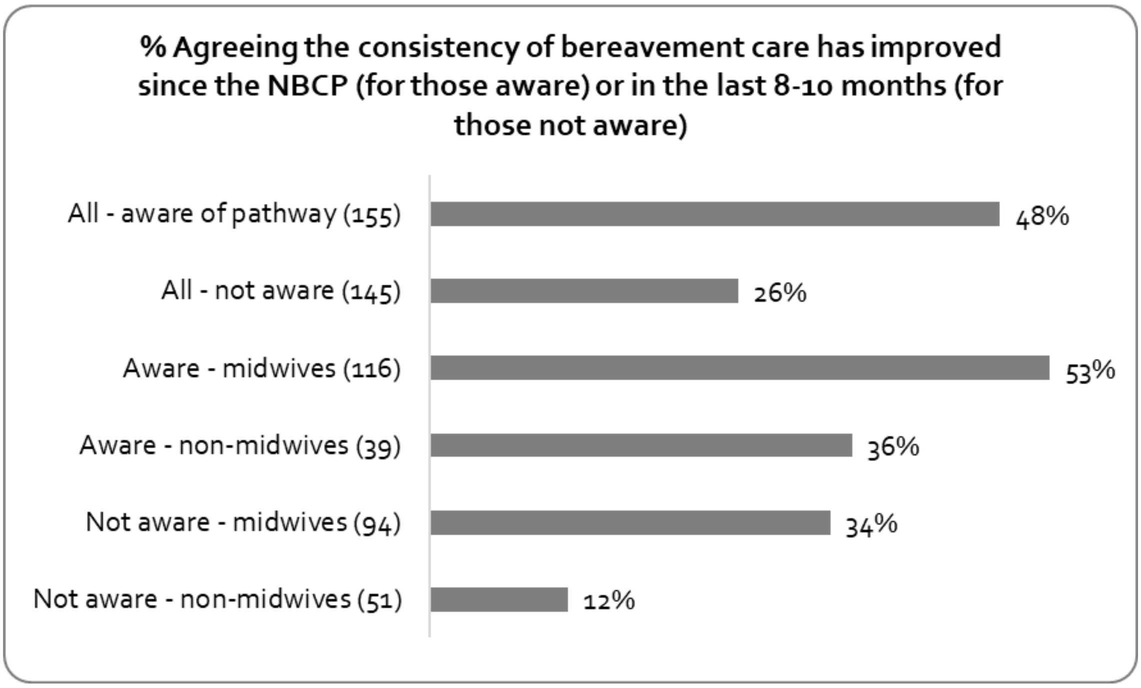
[12] Questions that ask about agreement also include answer options "neither agree not disagree" and "I don't know" so the figures do not add up to 100%



The role of bereavement midwives in driving a consistent approach was mentioned often in the qualitative response from health professionals. In some cases, the pathway project coincided with the appointment of a new bereavement midwife.

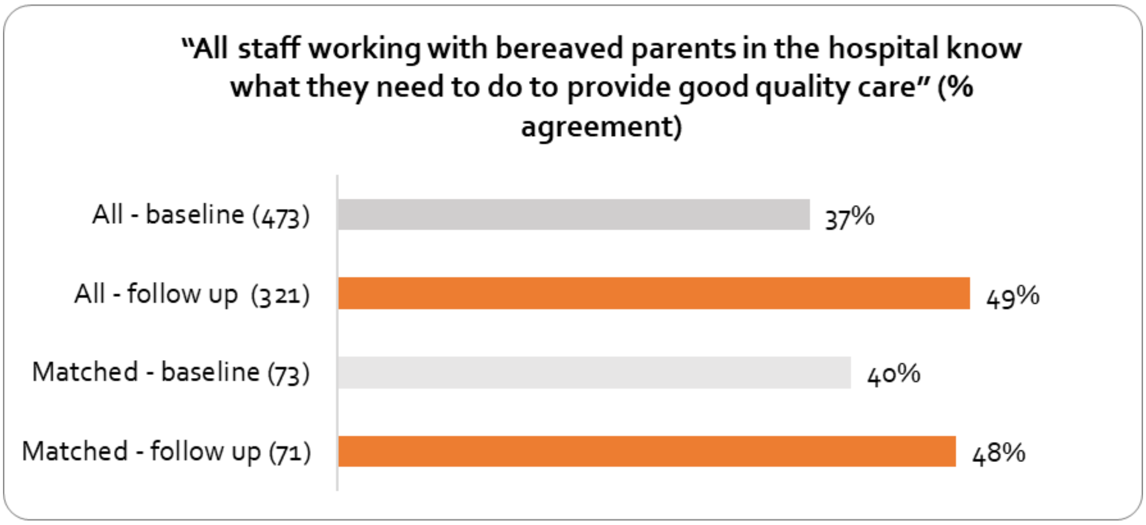
> "There is a new bereavement midwife appointed who has enabled changes to the paperwork allowing the process to be smoother and easier to follow." (Midwife, site 7)

The qualitative feedback also reveals that, as the pathway helped to raise the profile of bereavement care, it enabled an increase in cross departmental working including the identification of bereavement leads or champions in teams other than maternity.

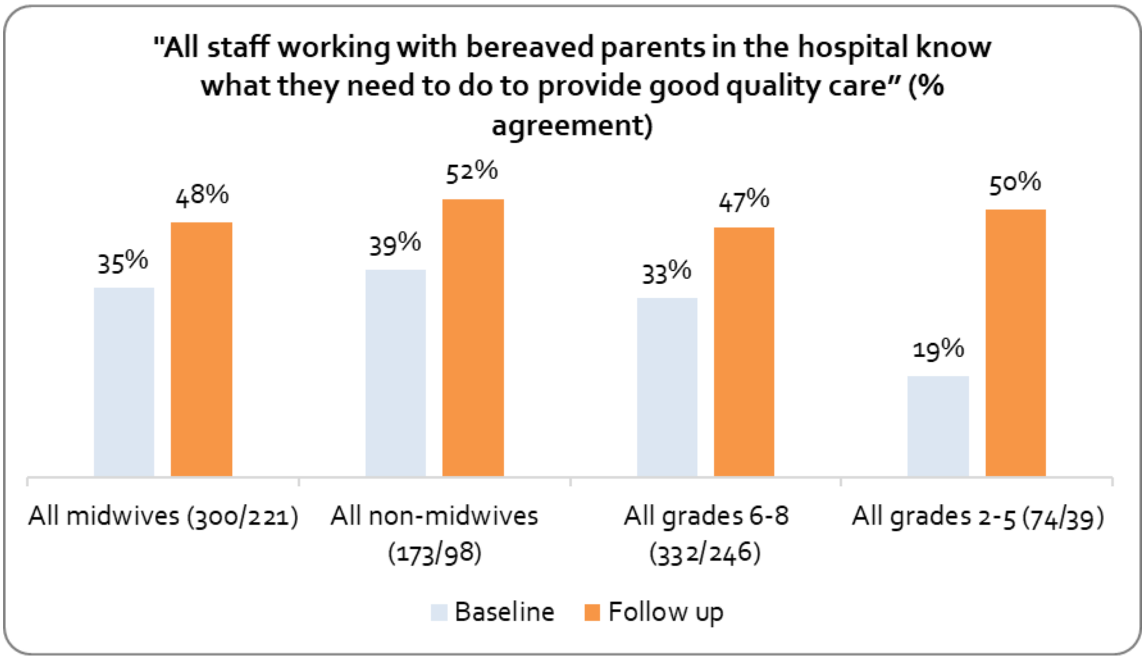
> "There are now key staff in A&E, SCBU and Gynae services who all meet together to standardise care across the hospital." (Midwife, site 2)
>
> "Improved collaboration between bereavement team, gynae and neonatal unit which has led to an improvement in standardising care whatever the pregnancy loss." (Midwife, site 3)
>
> "The pathway highlighted the need to be consistent throughout the hospital and helped me get more people involved – it has made bereavement care a much wider team – it has really helped." (Project lead, site 5)
>
> "It has improved the standardisation of care and plugged the gap for early pregnancy loss. Now I know all women get the same kind of care – everybody follows the pathway." (Project lead, site 6)

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.



Agreement has also increased across groups by role and grade.



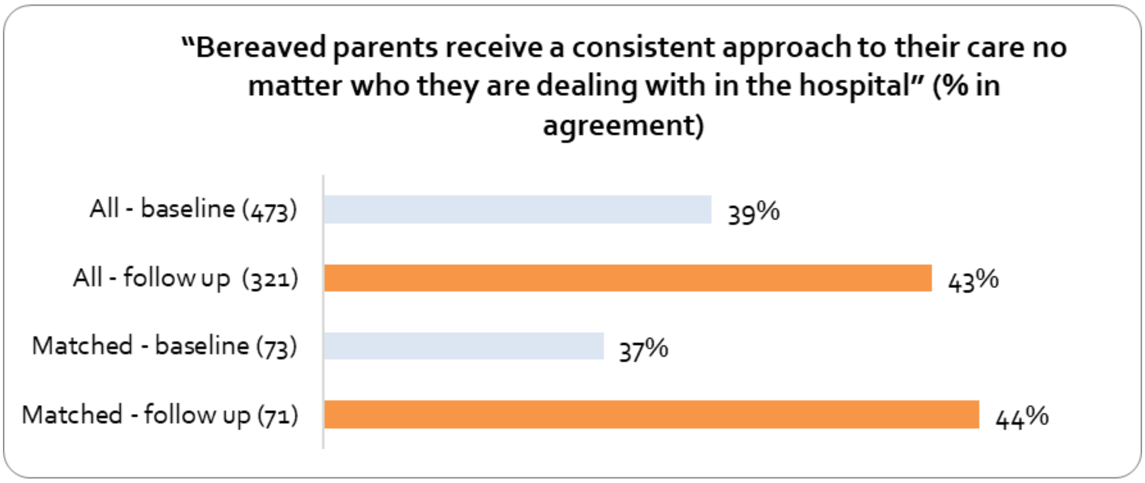
Qualitative feedback reveals the pathway prompted increased information and support for staff, including training and study days.

> "Staff are better trained to deliver a good standard of care and have more knowledge to give them the confidence to deal with sensitive situations." (Nurse, site 3)

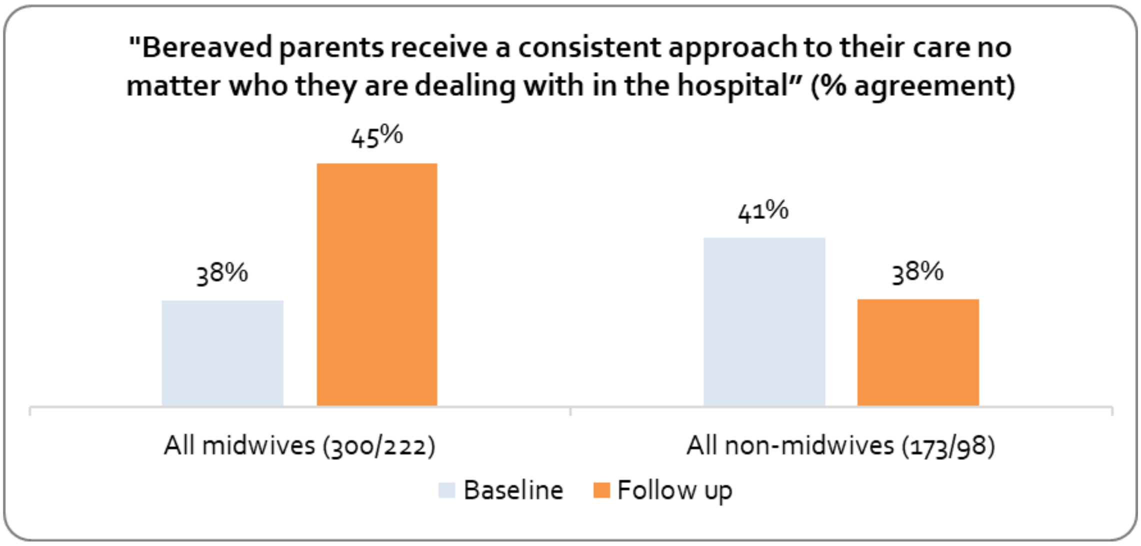
> "[Changes have included] training & induction days for all staff, bereavement midwives sharing information in every working area, flow charts on pin boards, postings on social media, adjusting our pregnancy loss booklet which staff use as a prompt when caring for bereaved families." (Midwife, site 4)

> "There are study sessions with an allocated midwife to disseminate the new information and what is expected of staff, and how to make the experience for all smoother. This gives staff a firm guideline to follow." (Midwife, site 8)

The proportion of professionals agreeing that parents receive a consistent approach no matter who they are dealing with has also increased between baseline and follow up - a 10% increase (from 39% to 43%) for all respondents, and an 18% increase (from 37% to 44%) for matched respondents.



This overall increase in agreement appears to have been driven by midwives. Levels of agreement have increased amongst midwives (from 38% to 45%) but it has decreased amongst non-midwives (from 41% to 38%).



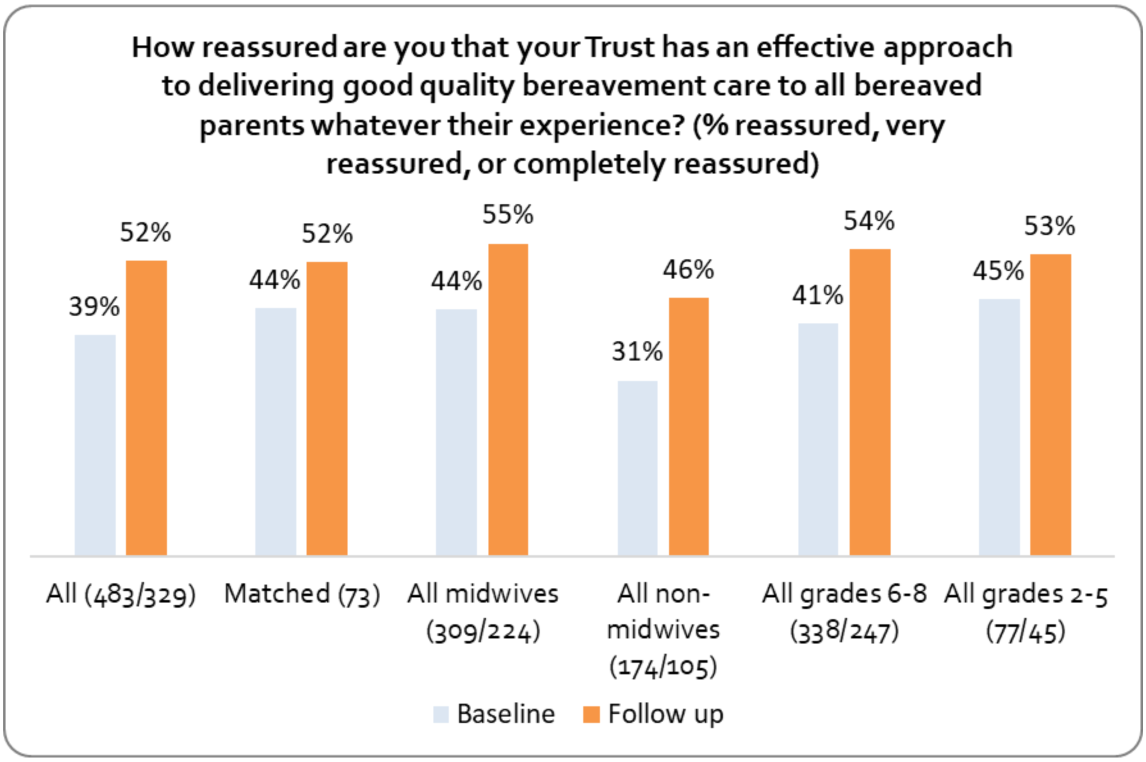
This difference between midwives and non-midwives may be explained by increased awareness of the inconsistencies within departments other than maternity. Whereas midwives are seeing the standard of bereavement care they offer being spread more widely to other teams, those in other roles are discovering that what they have been doing previously may not have been best practice.

> "Midwives are in touch with care – maybe the pathway has brought the required standards into the foreground. Maybe people in other departments assumed bereavement care was 'just dealt with' but the pathway highlighted that it isn't just dealt with - we have to deal with it." (Site lead, site 2)
>
> "People were surprised when I spoke with them about the pathway – people were in their own little bubbles. There wasn't much sharing, nothing was passed around as a standard, now they know they need to improve." (Site lead, site 5)

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

The proportion of professionals feeling reassured[13] that their trust has an effective approach to delivering good quality bereavement care to all parents has increased between baseline and follow up, particularly for non-midwives.

For all respondents there has been an increase of 34% (from 39% to 52%) and for matched respondents an increase of 19% (from 44% to 52%). The biggest increase (47%) was amongst non-midwives (from 31% to 46%).



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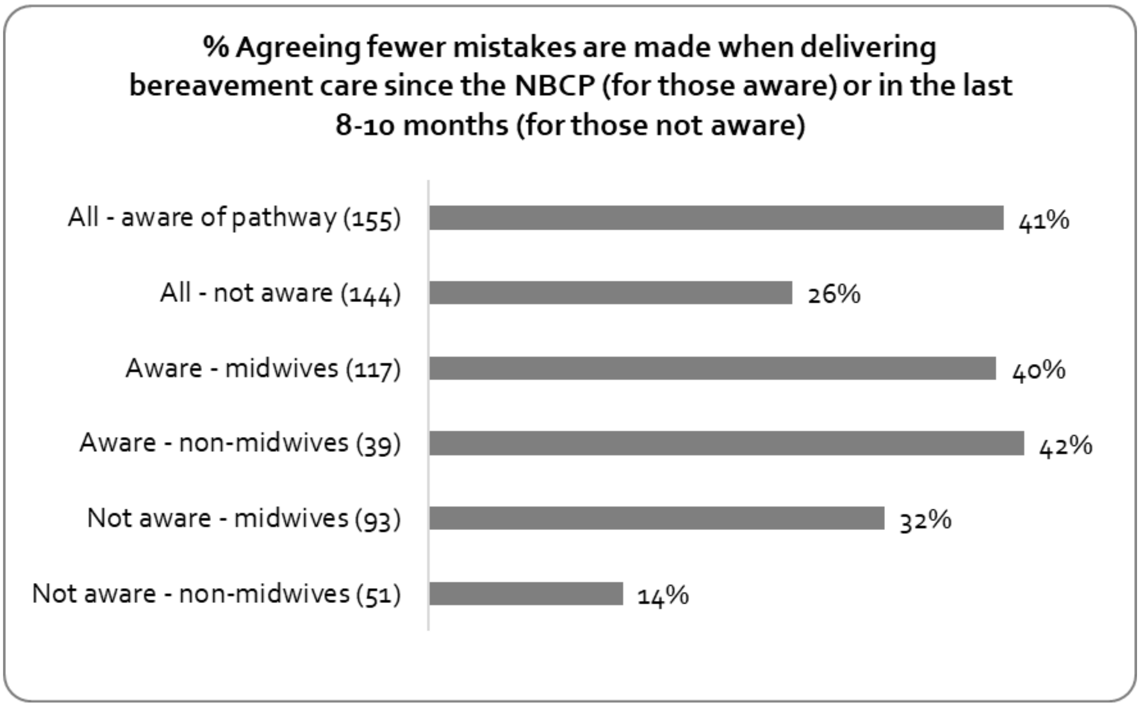
[13] i.e. answering "reassured", "very reassured" and "completely reassured".

The qualitative responses include several examples of the changes made to improve the effectiveness of a trust's approach to bereavement care including streamlined processes, follow up meetings by bereavement midwives to increase continuity of care, and increased resources.

> "The project helped, it became a became a spotlight for bereavement care which we hadn't had before. We were a bit lost, the midwives were good individually, but we had four guidelines – now they are amalgamated which has helped a lot." (Site lead, site 2)
>
> "Thanks to the NBCP we were able to put in our hospital guidelines that bereaved women require one to one care." (Site lead, site 8)

6.3.4. Reduction in mistakes

The desired outcome from this improved consistency is that fewer mistakes are made. 41% 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 (again, 7% disagree).



6.3.5. Challenges to consistency

One theme that came up in the evaluation is the potential over-reliance on referring to bereavement specialists at the expense of other staff developing or using their bereavement care skills – so rather than expertise being spread, it is becoming concentrated on a few people. It was also recognised achieving competency across all staff would take a time to achieve.

> "The midwives think it is my job – I've been banging the drum that it is everybody's job. If the bereavement role has done anything it has de-skilled everyone a little bit. I pick up messages in the diary on a Monday that people could have dealt with themselves. That's frustrating. If I'm off it feels like the wheel's not turning." (Site lead, site 4)

> "When I'm not here it reverts back to normal and its upsetting - it goes back to the default. Change is slow. They do their best, they are kind and friendly, but it is not where it needs to be yet." (Site lead, site 8)

> "I wasn't aware of the introduction of the care pathway only the change with the requirement to refer all women with pregnancy loss to the bereavement service" (Obs/Gynae – mixed role, site 6)

This finding should also be seen in conjunction with the feedback from parents above that care can be variable depending on who they are dealing with (See 5.5.1).

Another challenge is the complexity of engaging with departments beyond those that work most closely with maternity. Several site leads reported that engaging neonatal and gynaecology teams had been relatively straightforward compared with A&E and sonography. Reaching GPs and health visitors was also very difficult.

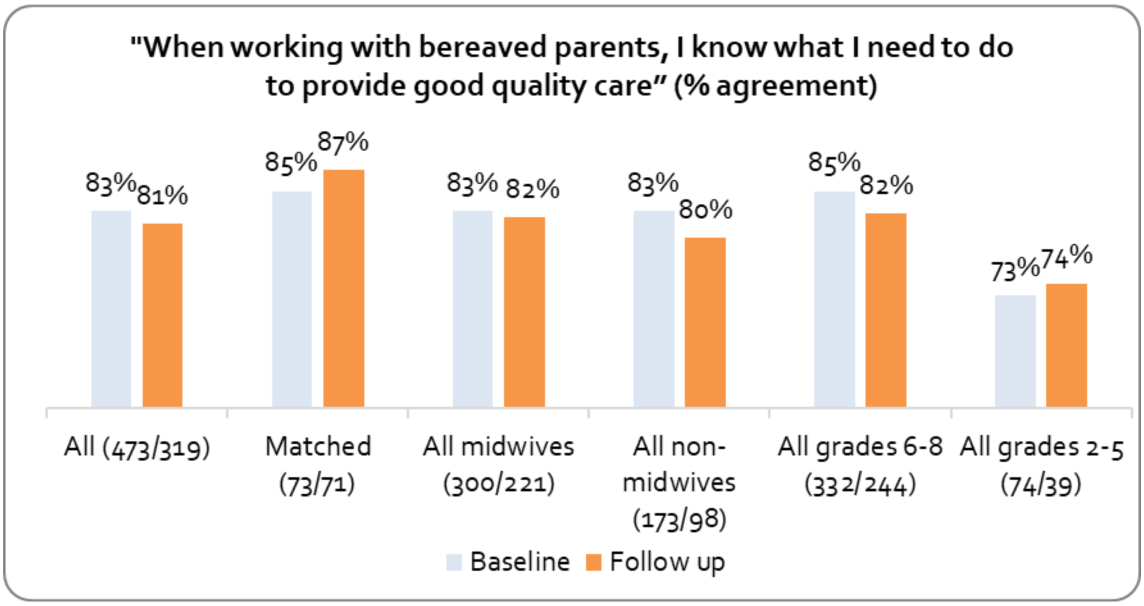
Most leads mentioned that the project was the start of a process that would need more time, resources, and senior commitment to impact on these more peripheral teams. This point is developed further below (See 7.2).

6.4. Capability and preparedness

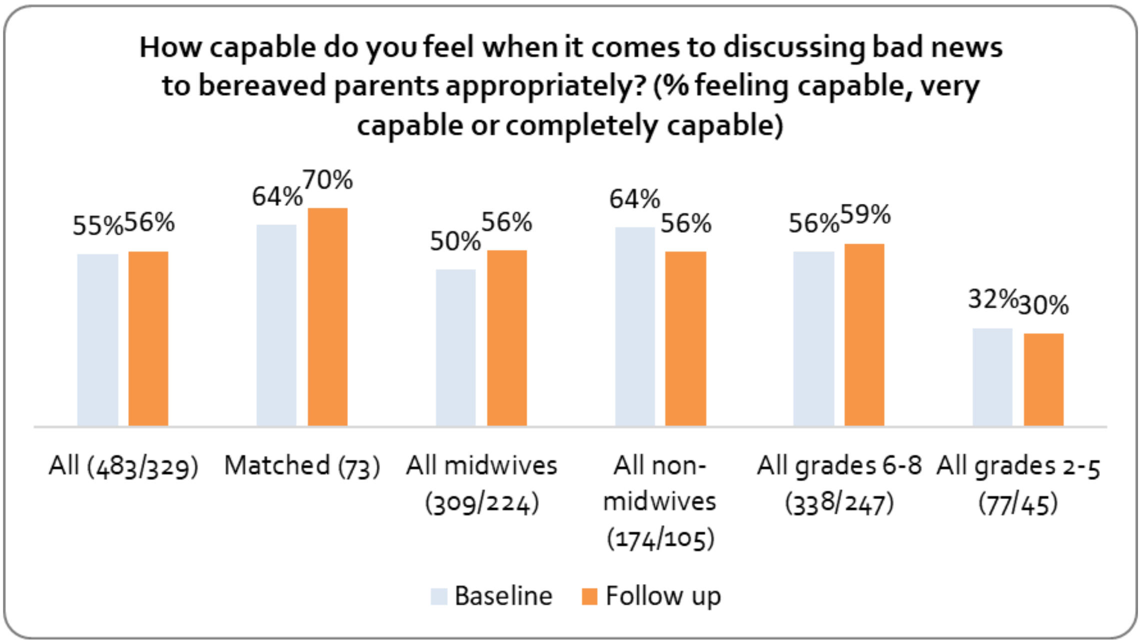
The evaluation aimed to measure whether:

- 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.

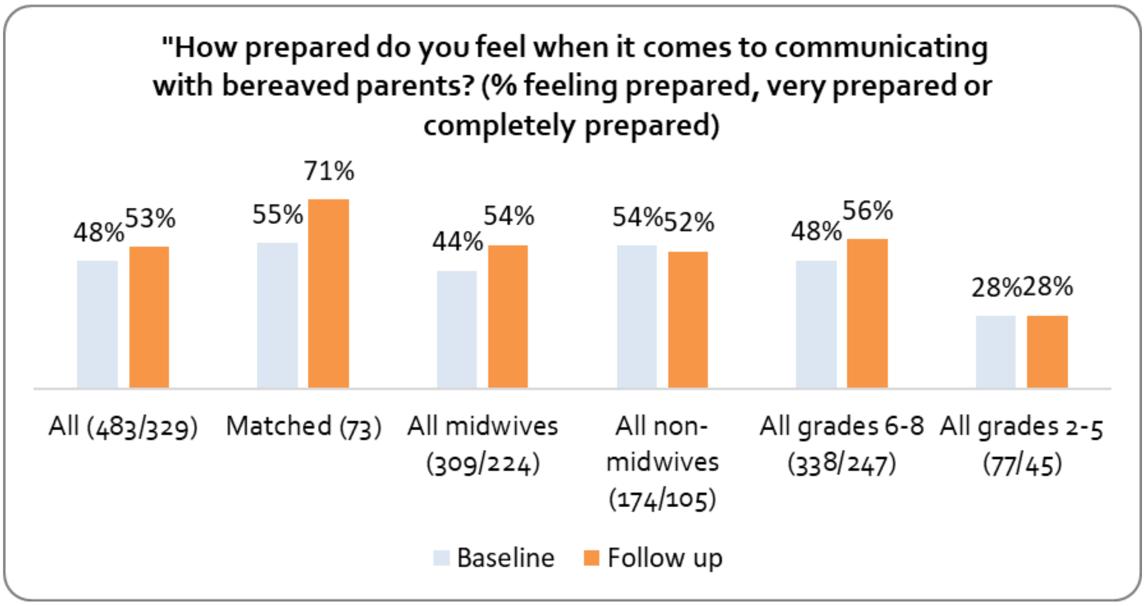
The baseline and follow up survey asked people whether they knew what they needed to do to provide good quality care. There has been a small increase in agreement for matched respondents and a larger increase for all those on grades 2-5. Other groups show a small decrease in agreement.



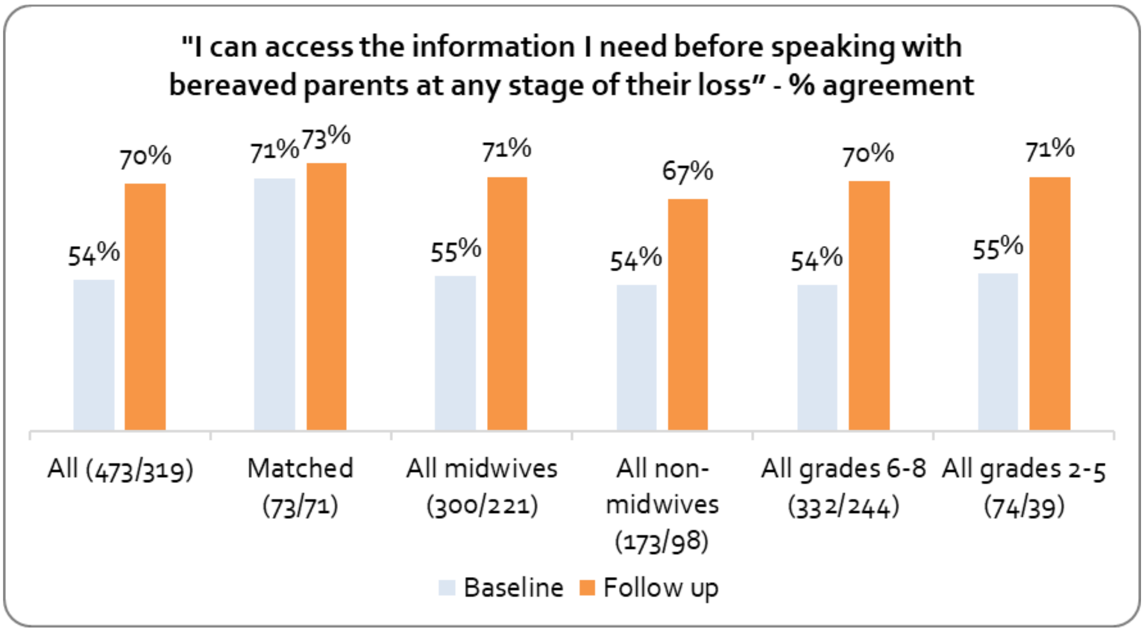
In terms of feeling capable of discussing bad news with bereaved parents appropriately, there has been a small increase amongst matched responses (whereas all responses are similar). There has been a 12% decrease (from 64% to 56%) in the number of (all) non-midwives feeling capable – this may reflect the point above (6.3.2) that those working in teams may have questioned their capability having been made aware of what is required for effective bereavement care, and that more time is needed to demonstrate positive change in teams beyond maternity.



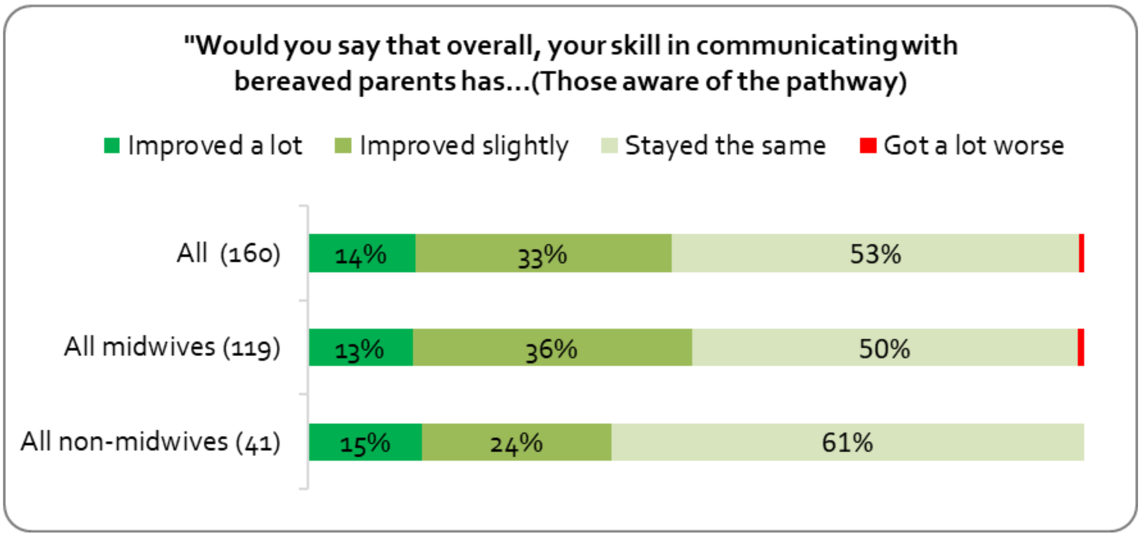
When it comes to feeling prepared to communicate with bereaved parents. There has been a 30% increase (from 55% to 71%) in the number of matched respondents feeling prepared, and small increases in all other groups except (all) non-midwives.



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



47% of all respondents who were aware of the pathway feel their skills in communicating with bereaved parents has improved. Only one respondent said their skills had worsened[14]. Midwives are more likely to say there has been improvement than non-midwives.



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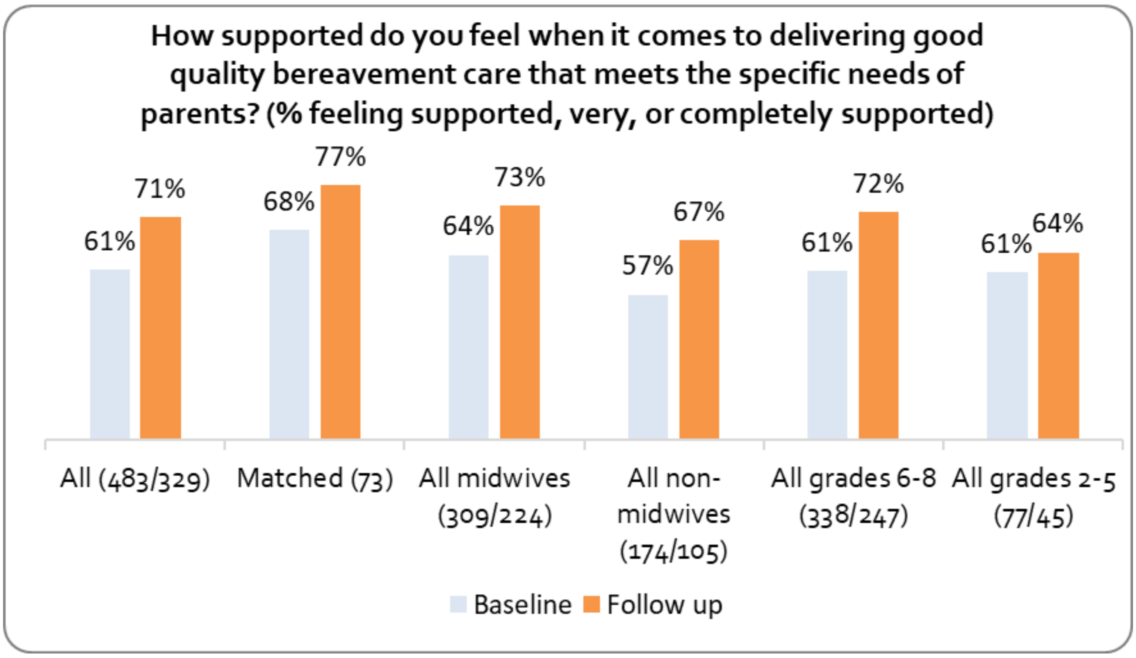
[14] The question also included a "got slightly worse" option but no-one answered that.

6.5. Support to deliver good quality care

The evaluation aimed to measure whether:

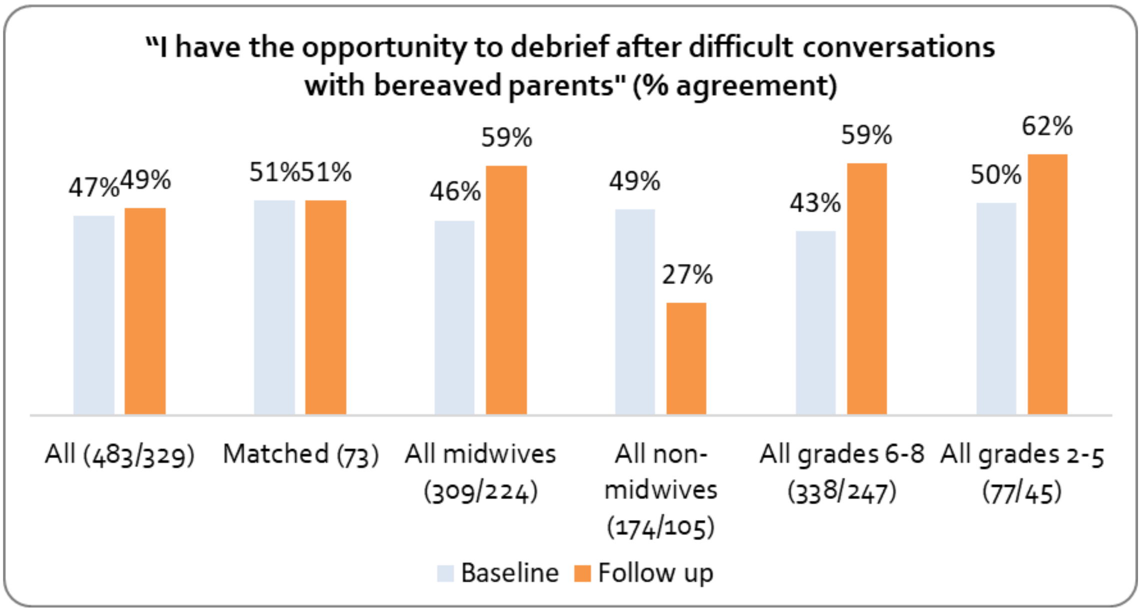
- Staff feel better supported to deliver effective bereavement care.
- Staff can debrief after difficult situations.

In every group agreement that professionals feel supported to deliver effective bereavement care has increased.



In addition to the impact of the bereavement midwife role in terms of training and support to colleagues, qualitative responses from professionals highlight clearer guidelines, streamlined systems and reduced paperwork - all of which may translate into a feeling that their trust's bereavement processes increasingly support them to deliver effective care.

When it comes to the opportunity to debrief after difficult conversations, there has been a considerable decrease in the agreement amongst non-midwives. As with the findings above, there is a picture developing of teams outside maternity being made aware of what is required to deliver effective care – but more time and increased engagement from those teams is required to convert that awareness into tangible improvements to existing working practices.

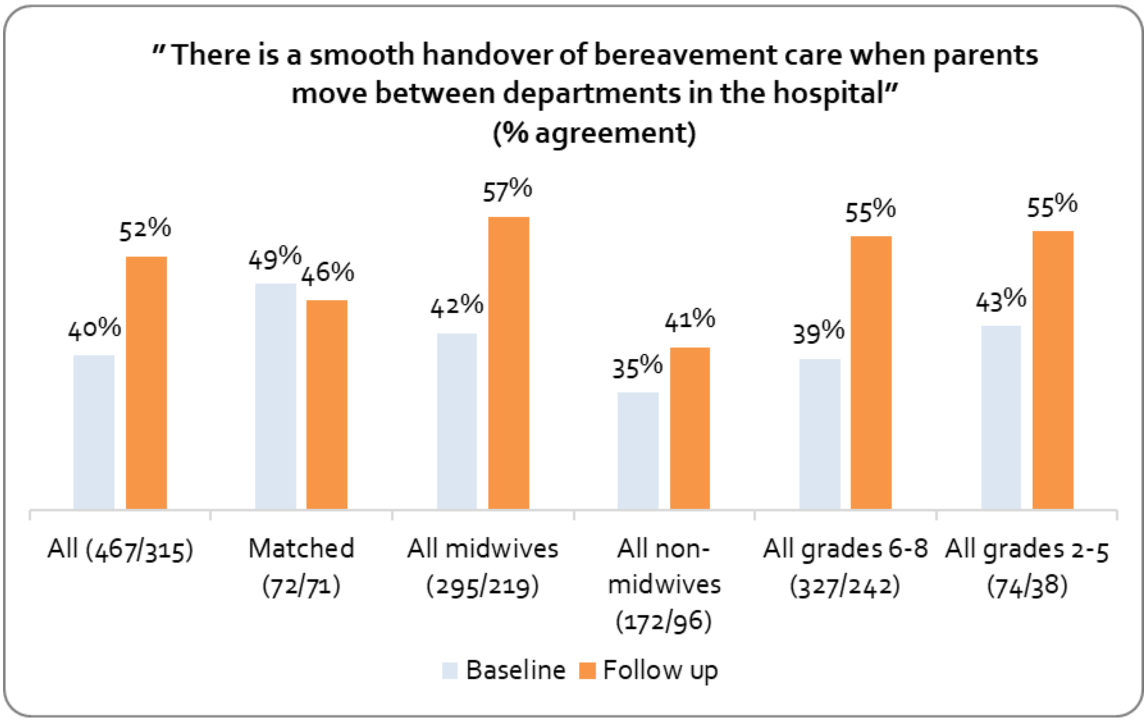


6.6. Handovers

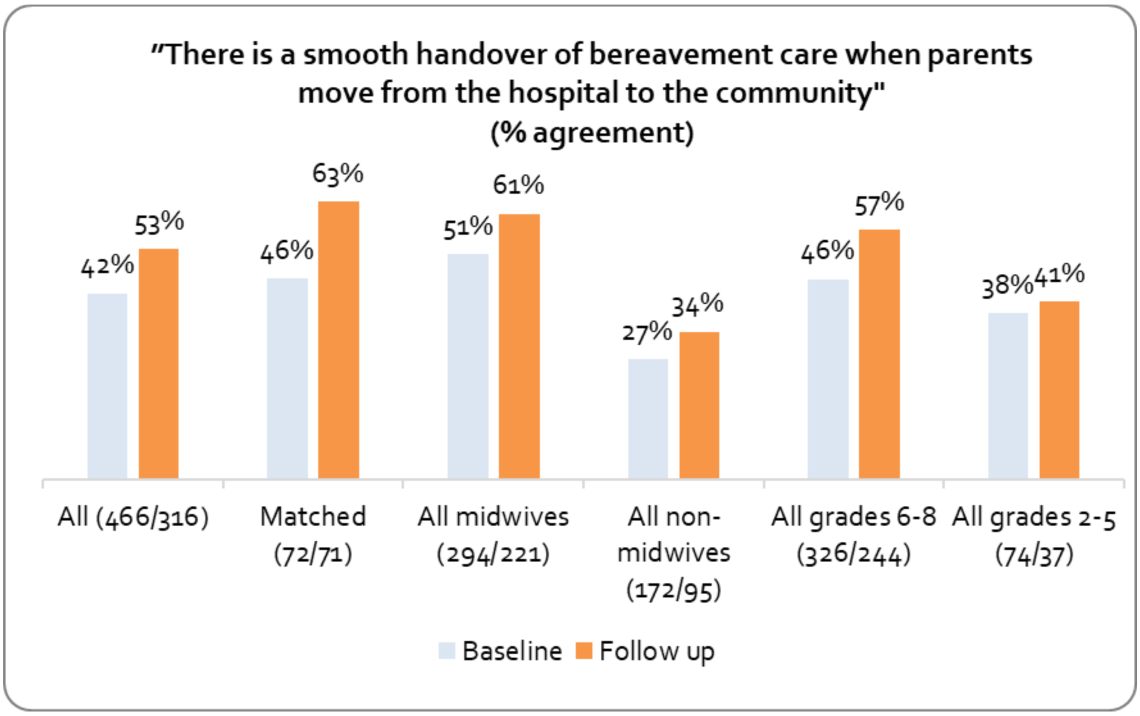
The evaluation aimed to measure whether:

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

When considering all respondents there is a 30% improvement in agreement (from 40% to 52%) that there is a smooth handover of bereavement care within the hospital, however that is not supported by matched respondents (a 6% decrease, from 49% to 46%).

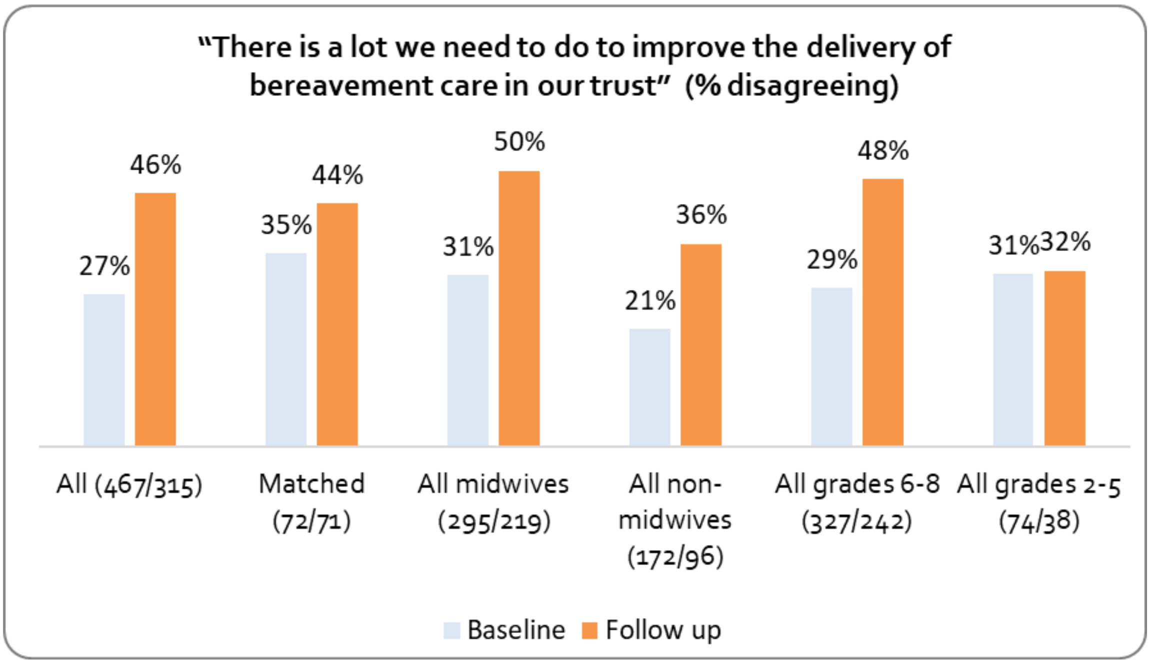


All groups, including matched respondents, were more positive about improvements in handing over from the hospital to the community.



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, more people 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.



7. Using the pathway

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.

- 56% of those aware of the pathway (158) agreed that it was easy to use (only 6% disagreed) – levels of agreement were similar between comparable groups (by role and grade)
- 57% (158) agreed the content was simple to follow (with 7% disagreeing). Agreement was 58% amongst midwives (118) and 53% amongst non-midwives (40).
- 62% (156) agreed that the pathway contained clear guidance for using it (only 6% disagreed). Agreement was 66% amongst midwives (116) but 50% amongst non-midwives (40).
- 53% (156) agreed that the pathway "linked well with other pathways used within our trust" (with 4% disagreeing), with agreement rising to 55% amongst midwives (117) and falling to 49% amongst non-midwives (39).

Qualitative feedback from health professionals and site leads indicates that whilst most are confident of its content, there is a desire for the pathway to be more concise and practical. Professionals see it more as a guidance document about how to run a service ("the bible of bereavement care" – Site lead, site 1) to be used sporadically for reference, rather than a "checklist" for day to day use. Although some recognised the challenge of creating something more succinct without omitting something important, and the fact that the "soft skills" approach of the pathway does not always lend itself to a clinical style checklist.

> "I think the document is wordy, when you are dealing with a loss you do not have the time to sit and trawl through even more paperwork, whilst I think the content is what everyone should be following, I think it needs to be a far more straightforward list of expectations." (Midwife, site 2)
>
> "The documents were too large and repeated the same themes over and over. Would have been better if more summarised version." (Consultant, Obs/Gynae mixed role, site 10)
>
> "It is not easily digestible – you are giving someone in the NHS a big document to read. I found that difficult to do. It is not a document that you can just give to people and say, 'just do this'." (Site lead, site 6)

> "Midwives like checklists – they like to tick off they've done things. It is not a document you can work with – midwives won't pick it up use it – if more practical more people would use it, you'll involve more people that way and reduce the reliance on the specialist." (Site lead, site 4)

7.2. Buy in and use by other professionals

The site leads, and others, have used the pathway to encourage teams to review their practice and identify improvements, and to form the basis of training sessions for other teams.

> "The pathway has given me the tools to make the care how we would like it to be." (Site lead, site 4)

> "We now have a full-time midwife in the gynae ward. The pathway it is the evidence/back up she needs – some of the girls think that memories don't need to be offered, but the pathway is the evidence it does, the midwife is making a checklist that they have never had before." (Site lead, site 1)

> "Paediatric A&E are using it to adapt their practices – they actually want to extend it to all child deaths beyond the one-year mark." (Site lead, site 7)

7.2.1. Engaging other departments

It was generally the case that 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.

All site leads mentioned the challenge of securing active engagement in the project from other teams - especially when they were coming from another team and needing to influence without management authority.

> "We are working hard – but there is no funding attached to the pathway – we are expecting people to do it out of their own good will when they are already under pressure. There is no incentive for them. The biggest challenge is gynae – we've done well so far – they now know there is scope for improvement and they have done what they can do." (Site lead, site 3)

> "It has taken a long time to get the early pregnancy loss people on board. I don't have anything to do with early pregnancy loss in my job, so it is hard to influence – what does it matter to them what I'm saying?" (Site lead, site 6)

> "We can't tell people how to run their ward." (Site lead, site 2)

> "Here (maternity) we are preaching to the converted – I don't have any power whatsoever [with others]. I'm not a high enough grade. I can just say 'this is a good idea, this is what we're doing'. They don't have to listen to me – it needs to be from someone in power, especially if involves finance or funding for training." (Site lead, site 1)

> "It took me 3 or 4 months to get someone to read the miscarriage one, there's no point me reading it, it doesn't mean anything in my world. I finally got an obstetrician involved. I organised a meeting and its purpose was for them to read the pathway." (Site lead, site 6)

This challenge was compounded at the outset as several site leads were not aware that the project encompassed bereavement experiences that would necessitate change from teams other than maternity until the day of the launch. If they had known more could have been done in advance to prepare others for change and secure adequate resources. This emphasises the importance of clear, consistent and sustained communication from the project team to reduce any risk of misconception about the scope of the pathway.

> "I didn't get the paperwork until we were going to the launch – I thought it was only maternity. If I had known I would have been thinking about it beforehand. I would have had a better plan for rolling it out quicker." (Site lead, site 7)
>
> "If we had known at the beginning what it involved we could have been clearer on what time was needed. We had not seen anything beforehand, we didn't know the time commitment. Providing dedicated time should have been part of the hospital signing up." (Site lead, site 5)

Other leads raised the need for the pathway to be more directive, with clearer expectations and of auditable standard to be achieved, as that would engage people at a senior level.

> "I would have liked 'these are the minimum standards – decided by the royal colleges, pilot sites are expected to do this' so we could have gone to the commissioners for funding. But we were told 'In an ideal world, this is what you want' – but we are not in an ideal world, we don't have the money. The commissioners are not going to buy in to something so woolly." (Site lead, site 10)
>
> "It's a double-edged sword – people may have not wanted to be in the pilot if expectations were too high. But if they did want to get the benefits of being in the pilot – then that should come with a commitment to resource it." (Site lead, site 3).
>
> "I was surprised they weren't more directive. I tried to get our audit team to turn them into standards, but they couldn't. They should look at what NICE does, they break guidelines down into 'do you do this? do you do that?' Then you could have a baseline and follow up measurement to see how far you have come." (Site lead, site 6)

The following other suggestions were made to resolve the challenge of engaging other teams in subsequent pathway projects.

- Allow more time for change in other teams to happen - site leads generally don't have the time to tackle all the areas requiring improvement at once. Most found it hard to do the amount of chasing required to get others on board and then prevent the project slipping off their radar.
- Maximise the message it is a national project with backing from professional bodies.
- Printing out the pathways and giving the relevant ones to the relevant teams.
- Using video clips and animations to make the pathway more easily accessible.

- Ensure it is a project aimed at establishing and maintaining a hospital wide benchmark for continuity of bereavement care. One way of doing this would be for several disciplines (e.g. maternity, nursing and sonography) to sign up to the project in the first place (rather than just one team), another (attempted by several site leads), was to form a cross departmental project team or network of champions).
- Use the central project team to communicate directly with the management of other teams – so it is not solely the voice of the site lead being heard.
- Developing draft business cases to make the case as to why other teams should be involved.
- Using the feedback from and engagement with the evaluation baseline survey as evidence to show management which teams aren't engaging with the project
- Incorporate the standards into the CQC inspection so senior management are aware of the level of care the CQC, and patients, expect.

We understand that several of these points are already under consideration by the project team to support site leads in wave two of the project.

8. Managing the project: Feedback from 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 not all were able to secure the cost of travel). However, support from senior management to secure additional resources or instigate change in other teams was less evident.

> "I was supported in theory - but got no practical help. They left me by myself to do everything – I'm now doing this strategic project and day to day care." (Site lead, site 7)
>
> "I felt on my own. I got no support from management. I took it [the project] on, so I had to pull it through." (Site lead, site 10)
>
> "I wish I had more time for it, if I had I would be a lot further on. It takes longer to make difference, I can only do one thing at a time." (Site lead, site 5)

All leads were positive about the support they had received from the central project based at Sands, *"it's been run extremely well"* (Site lead, site 7). Several welcomed the resources provided by the project (e.g. flyers, and PowerPoint slides to introduce the pathway to others), the collaborative approach, and the opportunity to share experiences with other leads. Some would have liked for more collaboration to be facilitated online (to lessen the reliance on face to face meetings).

Several leads called for more understanding of the challenging context in which they are working, their competing priorities, and that change within the NHS can be a slow process. Some felt the pressure to report on changes that they, or others, had not had the time or opportunity to progress.

> "Sometimes I feel under pressure to say I'm improving things all the time, but it is an ongoing thing –month to month I'm not really doing anything that amazing." (Site lead, site 1)

9. Survey response and profiles

9.1. Health professionals

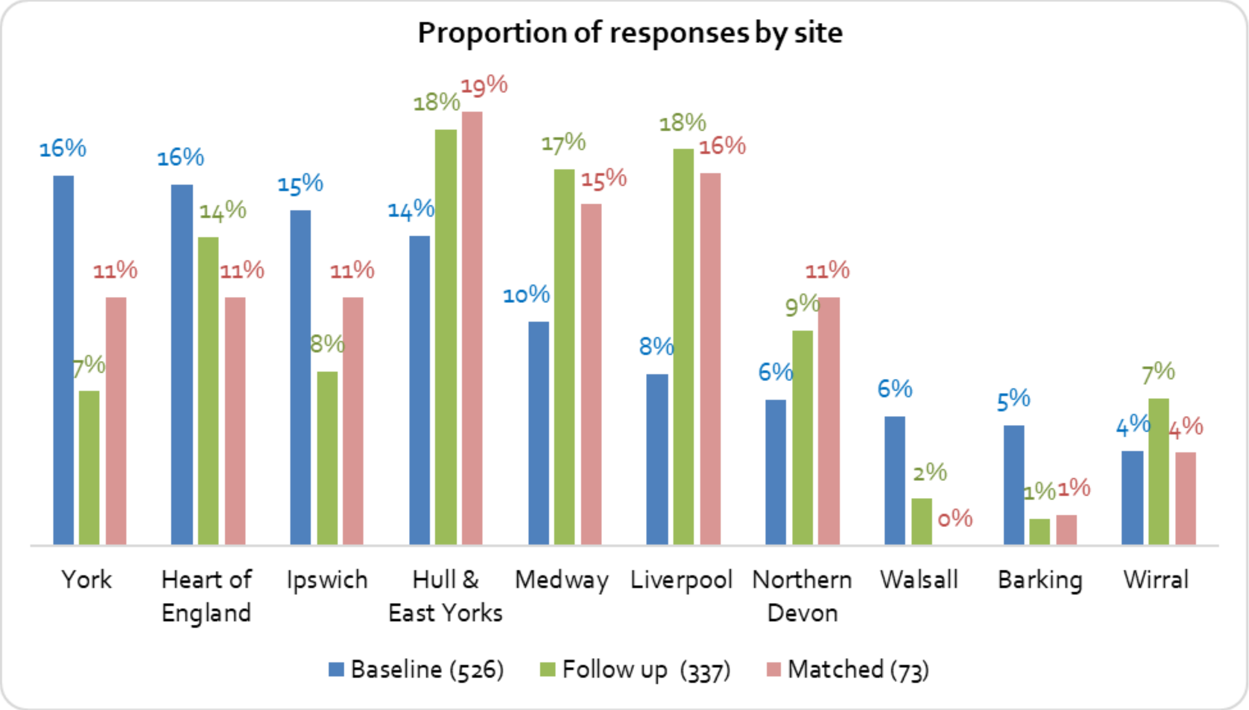
Both the baseline and follow up survey link were distributed by the sites lead to colleagues in relevant departments. In some cases, the leads also relied on contacts in other departments to distribute the link for them. It is difficult to know exactly how many people were given the opportunity to do 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 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. The lower response to the follow up impacted on the volume of professionals who opted in to a telephone interview – we were only able to secure on interview with someone who was not a site lead.

9.1.1. Location

The respondents across both surveys were from ten of the pilot sites. Chelsea and Westminster were unable to conduct the baseline survey, so they are being included in the baseline and follow-up for the wave two project.

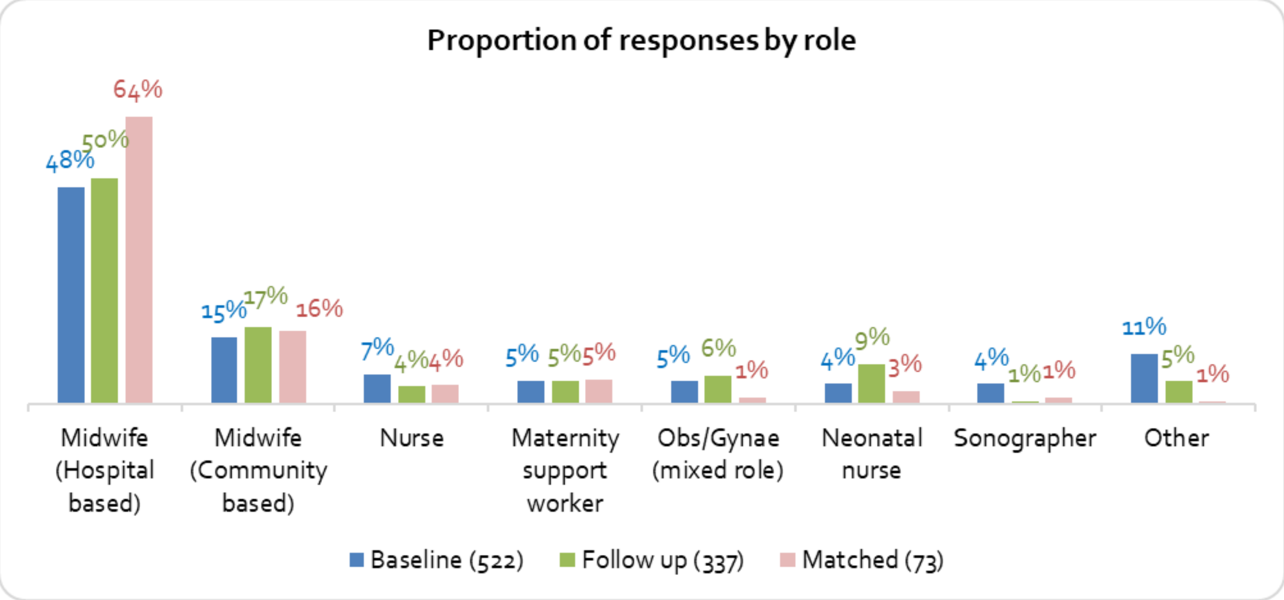
York, Heart of England, Ipswich and Hull provided the largest proportion of responses to the baseline survey (combined 61%), whereas Heart of England, Hull, Liverpool and Medway provided the largest proportion of responses (combined 66%) to the follow up survey.



9.1.2. Role

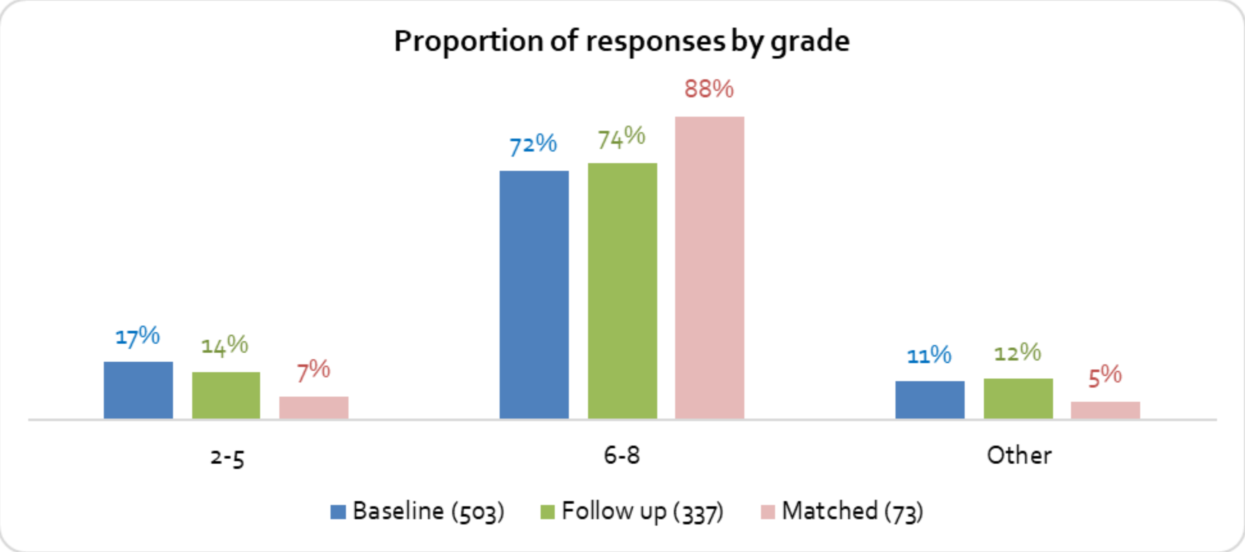
Hospital based midwives account for approximately 50% of the responses to the baseline and follow up surveys. They also make up 64% of the matched responses.

All those in midwifery roles (in the hospital or community) make up 8 out of 10 of the matched responses. This is to be expected as 8 of the 11 pilots included in the evaluation are being led by midwifery teams.



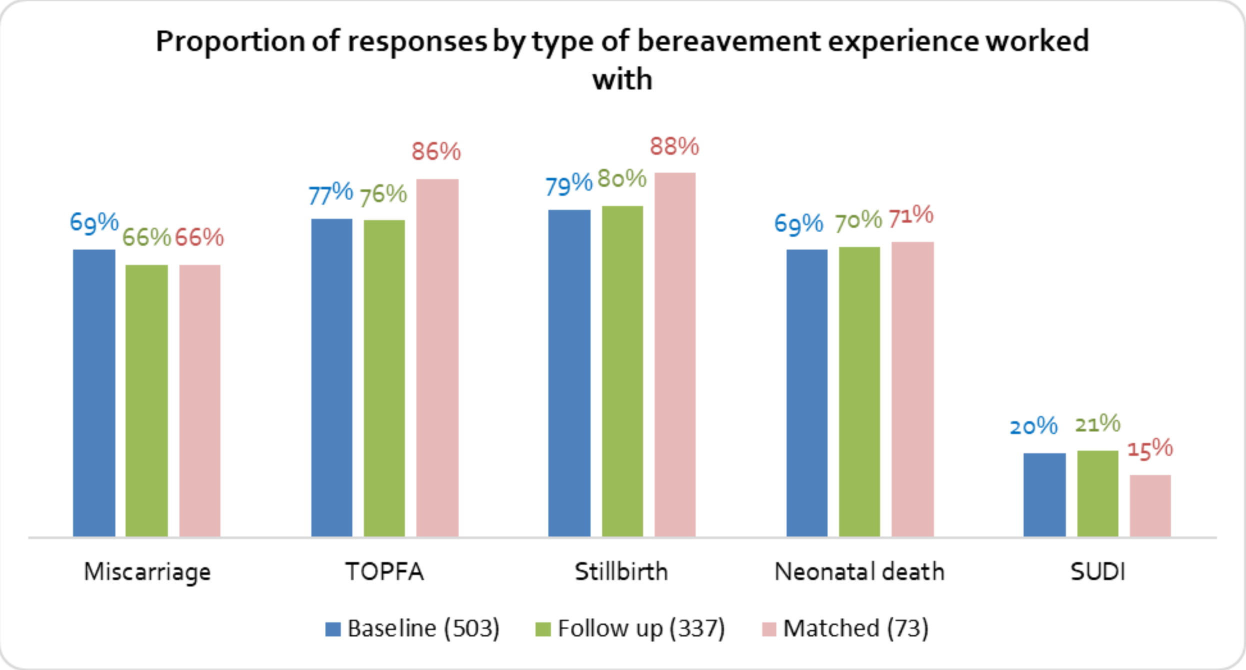
9.1.3. Grade

The representation of grades is consistent between the baseline and follow up survey, however those in grades 6-8 represent roughly 9 out of 10 of matched responses.



9.1.4. Parents supported

The proportion of professionals working with each bereavement experience, is broadly consistent across the surveys - those working with pregnancy ended after a prenatal diagnosis and Stillbirth are slightly over-represented in the matched group.



9.2. Parents

Sites chose their own method for distributing the survey link to parents. Many chose the follow up meeting to do so (or the discharge information if people didn't receive a follow up). Sites that were able to email or text the survey link generated a 26% response rate compared with 4% from sites that relied on letters or distributing the link on paper.

10. Appendices

Wave one pilot sites

- Barking, Havering and Redbridge University Hospitals NHS Trust
- Chelsea and Westminster Hospital NHS Foundation Trust
- Heart of England NHS Foundation Trust
- Hull & East Yorkshire Hospitals NHS Trust
- Ipswich Hospital NHS Trust
- Liverpool Women's NHS Foundation Trust
- Medway NHS Foundation Trust
- Northern Devon Healthcare NHS Trust
- Walsall Healthcare NHS Trust
- Wirral University Teaching Hospital NHS Foundation Trust
- York Teaching Hospital NHS Foundation Trust

Appendix two: measurable outcomes (health professionals)

Overall NBCP project outcome	Measurable outcome indicators
Increased confidence	1. Staff feel more capable to break bad news appropriately 2. Staff can debrief after difficult situations 3. Staff feel better supported to deliver effective bereavement care 4. Staff improve their skills in communication
Streamlined processes	5. Staff feel everyone is aware of what is happening, what has been agreed and what needs to be done - within hospital (across departments) & between hospital and community 6. Staff feel that responsibilities are clear 7. Staff feel there is a consistent approach to care in the hospital 8. Staff feel handovers are smooth - within hospital (across departments) & between hospital and community 9. Staff feel fewer mistakes are made 10. Staff can access all information they need about parents' situations before speaking to them 11. Staff feel well prepared for communicating with parents
Process objective	**Measurable process indicators**
Using the pathway	The pathway has: 12. straightforward/simple content 13. clear guidance for using it 14. links with other pathways 15. "buy in" from a range of professionals The pathway is: 16. locally adaptable 17. easy to use/navigate 18. used frequently 19. used by a range of professionals 20. to be recommended to others

Appendix three: measurable outcomes (parents)

Overall NBCP project outcome	Area	Measurable outcomes/indicators	Does this outcome apply to all parents?
Increased choice	Informed choice/decisions	1. Parents were supported to make informed decisions	Yes
		2. Parents were provided with information that was clear and easy to understand	Yes
		3. Parents were provided with information that was relevant to their situation	Yes
		4. Parents feel the decisions they made were the right ones at the time	Yes
High quality care	Good communication	5. Parents feel they were communicated with sensitively	Yes
		6. Parents feel they were listened to	Yes
		7. Parents feel their concerns were taken seriously	Yes
	Memory making	8. Parents were given the opportunity to make memories	Yes
		9. Parents were given the opportunity to spend time with their baby	SUDI, stillbirth and neonatal death only
	Continuity of bereavement care (in hospital)	10. Parents had a single person/point of contact throughout the process	Yes
		11. Parents feel the quality of care they received was consistent across all hospital staff	Yes
	Continuity of bereavement care (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	Yes
		15. Parents feel they were offered appropriate support with managing breast milk production	Yes
		16. Parents feel they were offered appropriate support with funeral arrangements	Yes
		17. Parents were offered information about relevant support groups (for example: Lullaby Trust, ARC, Miscarriage Association, Sands or Bliss)	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	Yes
		19. Parents felt confident in the staff caring for them	Yes
		20. Parents feel they were treated with respect	Yes
		21. Parents feel their baby/babies were treated with respect	Not miscarriage or pregnancy ended after a prenatal diagnosis
		22. Parents feel their baby, fetus or pregnancy remains were treated with respect	Miscarriage and pregnancy ended after a prenatal diagnosis only