



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

**Interim report**

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## The National Bereavement Care Pathway

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

The project is backed by the government and received initial funding from the Department of Health. 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 (the stillbirth and neonatal death charity)
- ARC (Antenatal Results and Choices - charity helping parents and healthcare professionals through antenatal screening and its consequences)
- Bliss (charity for babies born premature or sick)
- Lullaby Trust (charity raising awareness of Sudden Infant Death Syndrome (SIDS) and offering emotional support for bereaved families)
- Miscarriage Association (charity offering support and information to anyone affected by the loss of a baby in pregnancy)
- Neonatal Nurses Association
- Royal College of Midwives
- Royal College of Nurses
- Royal College of Obstetricians and Gynaecologists
- Institute of Health Visiting
- NHS England
- Representative of the Health Research community, based at University of Bristol

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 commissioners:** improved service delivery, increased satisfaction, streamlined processes, improved data quality

In the first phase of the project ("wave one") the pathway is being piloted by eleven NHS Trusts (see appendix 1). The pathway launched on 9th October 2017<sup>3</sup>.

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

<sup>2</sup> This term was used in the healthcare professionals' survey. Following the input of parents this has been changed to "Ended the pregnancy after a prenatal diagnosis" in the parents' survey.

<sup>3</sup> The pilot sites started to implement the pathway at slightly different times and most were up and running by January 2018.

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

### **Teddy's Wish**

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

### **Fiveways**

In late August 2017, following a competitive tender process, Fiveways were commissioned to undertake an evaluation of the NBCP during its first wave of implementation.

Fiveways ([www.fivewaysnp.com](http://www.fivewaysnp.com)) specialise in strengthening charity governance, assessing and managing risk, and evaluating services to drive future improvement.

### **The Evaluation subgroup**

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

## **1. Summary of key learning so far**

### **1.1. Findings from the healthcare professionals baseline survey**

530 health professionals participated in an on-line survey which ran from 26th October to 29th December 2017. The main aim of the survey was to set baseline measures so that changes can be measured in a follow up survey in summer 2018. Qualitative questions were included to further understand professionals' perspective on bereavement care issues in their trust. Key findings from the baseline survey were as follows:

- Many professionals are very positive about the bereavement care their trust provides – 69% of participants in the survey feel reassured there is an effective approach to bereavement care in their trust.
- It is clear from the survey that, where in post, bereavement midwives are making a significant and positive difference to bereavement care in their trusts.
- The survey highlighted the issue of inconsistent care that the NBCP 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 was most often highlighted as in need of improvement.
- Staff on lower grades (3-5) feel less prepared to communicate, less capable to discuss bad news, and less supported to deliver good quality bereavement care than those at higher grades (6-8). This may reveal a training need amongst more junior staff.
- In terms of barriers to more effective bereavement care, increased training, better bereavement suite facilities, more staff resources, and simplified paperwork were cited most often as issues to address.

### **1.2. Implementing the pathway**

A discussion took place with leads from the pilot sites during the wave one pilot site workshop in Walsall on 20<sup>th</sup> March 2018. This discussion focussed on the issues leads had faced when implementing the pathway in their trusts, and how they had overcome them.

- The experience of implementing the pathway had been beneficial in raising the profile of bereavement care, improving internal relationships, and bringing the working practices of some departments closer together.
- Although colleagues in other departments were supportive of the pathway in principle, the practicalities of engaging with some departments outside maternity teams, and especially A&E, has been a challenge. Making the pathway content shorter and more practical, increasing the visibility of the pathway within the trust, and forming a steering group with representatives from each department were suggestions to overcome this challenge.

- Engaging senior management to back the implementation of the pathway had also been difficult. It was thought that the reputational benefits of providing high quality bereavement care and being involved in a high profile, national pilot were important messages to influence senior management.

### **1.3. Delivering the evaluation**

- Pilot trusts successfully implemented the health professionals' baseline survey. Almost two thirds of responses were from midwives. In future waves of the NBCP more needs to be done to ensure increased participation from professionals working outside the maternity team.
- In most cases, the health professionals' baseline survey was conducted after or during the implementation of the NBCP. Therefore, the data presented in this interim report were collected before, during or very early in the implementation process. We expect to see improvements from this position as the pathway becomes embedded, and these data will be presented in the final Wave 1 report (October 2018). In future waves the baseline survey would ideally be completed before implementation to ensure the full impact of the pathway can be evidenced.
- The input of bereaved parents and the NBCP's participating charities has been invaluable in deciding which outcomes should be measured and how to word the parents' survey.

## 2. Evaluating the NBCP

### 2.1. Evaluation aims

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

For parents:

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

For health professionals:

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

To answer these questions, measurable outcomes for health professionals and parents were agreed by the evaluation subgroup, parents' advisory group and Teddy's Wish (see Appendices 2 and 3).

### 2.2. Evaluation method

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

Month	Evaluation activity	Status at 4/4/18
Oct-Dec 2017	<ul style="list-style-type: none"> <li>• Online baseline survey amongst health professionals – distributed by pilot leads to relevant colleagues within their trust</li> </ul>	<ul style="list-style-type: none"> <li>• Completed</li> </ul>
Mar 2018	<ul style="list-style-type: none"> <li>• Focus group discussions with pilot site leads</li> </ul>	<ul style="list-style-type: none"> <li>• Completed</li> </ul>
Apr-Aug 2018	<ul style="list-style-type: none"> <li>• Online survey amongst bereaved parents – link distributed by each trust (in a way decided by them – see below)</li> <li>• 22 telephone interviews with parents recruited from the survey</li> </ul>	<ul style="list-style-type: none"> <li>• Survey approved – to be distributed to sites</li> <li>• Discussion guide to be drafted</li> </ul>
Jul – Aug 2018	<ul style="list-style-type: none"> <li>• Online follow up survey amongst health professionals – distributed by pilot leads to relevant colleagues within their trust</li> <li>• 12 telephone interviews with professionals recruited from the follow up survey.</li> </ul>	<ul style="list-style-type: none"> <li>• Survey and discussion guide to be drafted and approved</li> </ul>

### **2.3. About this report**

This interim report falls part way through the implementation of the evaluation. It covers the following areas:

- The analysis of the baseline survey amongst healthcare professionals (conducted November-December 2017)
- Qualitative feedback from the pilot site leads relating to their experience of implementing and using the pathway so far
- The development of the survey to be used with parents (this survey will start in April 2018, so no results have been generated yet).

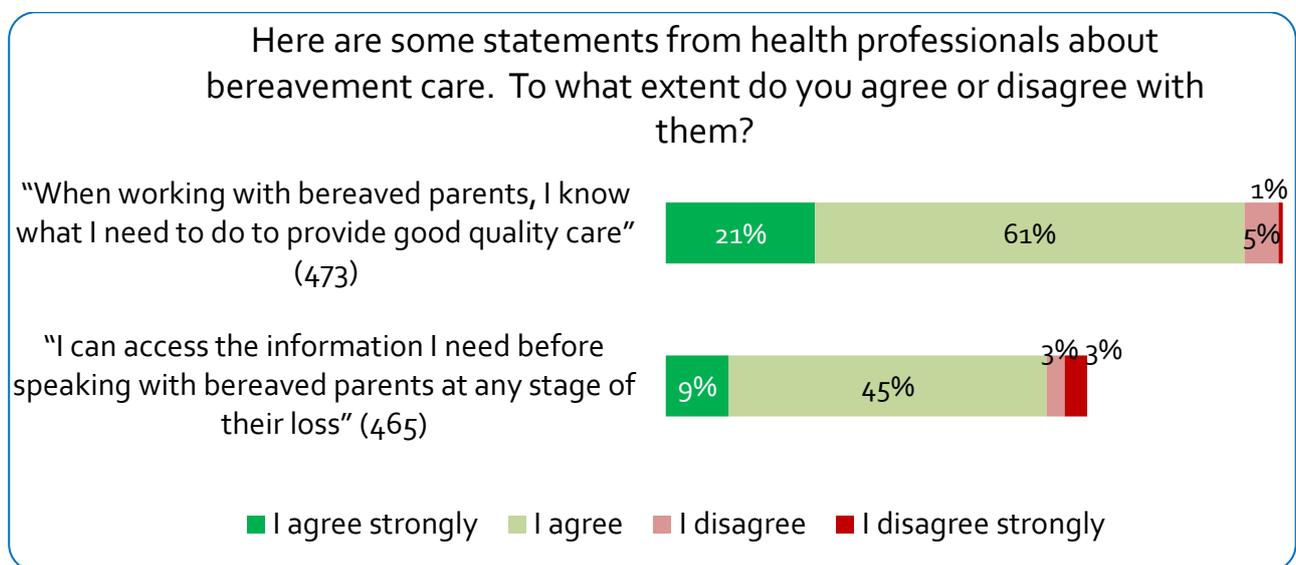
### 3. Key findings from the health professionals' baseline survey

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

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

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

- 82% of respondents agreed that they know what they need to do to provide good quality bereavement care (only 6% disagreed<sup>4</sup>).
- 54% of respondents agreed they could access the information they needed before speaking with bereaved parents (with only 6% disagreeing).



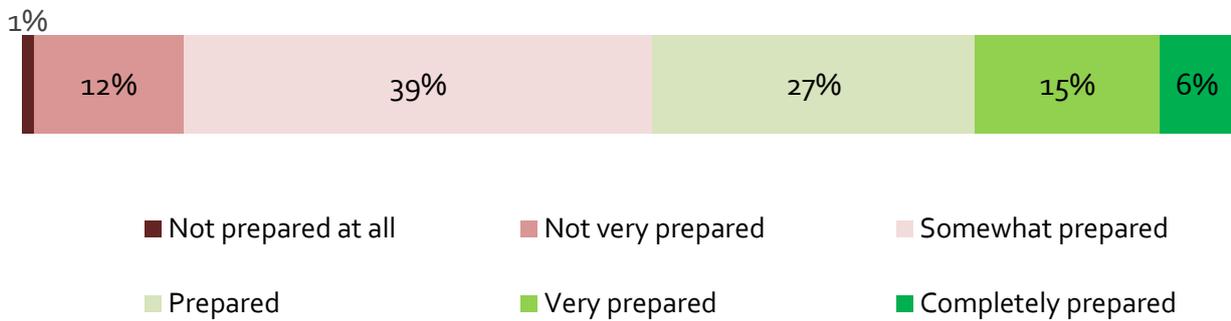
Some health professionals mentioned that difficulties accessing the relevant notes and paperwork can impact on the quality of care provided.

"I find it difficult to offer good bereavement care following on from a death because there is often a long delay in getting post mortem results back. This feels very unsatisfactory and is definitely something which could be improved to ensure that families have answers to questions in a timely manner."

- When communicating with bereaved parents, 52% of all respondents feel somewhat prepared, not very prepared or not prepared at all. Those in non-midwife roles are slightly more likely to feel prepared than midwives. Those on lower Agenda for Change grades are much less likely to feel prepared than those on higher grades.

<sup>4</sup> The figures for these "statement" questions do not add up to 100% as respondents could also answer "neither agree nor disagree" or "I don't know".

How prepared do you feel when it comes to communicating with bereaved parents?  
(500)

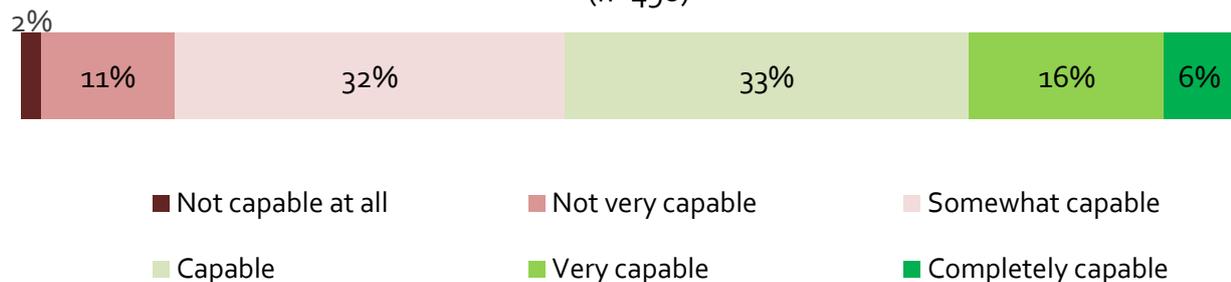


How prepared do you feel when it comes to communicating with bereaved parents?  
(% feeling less than prepared)

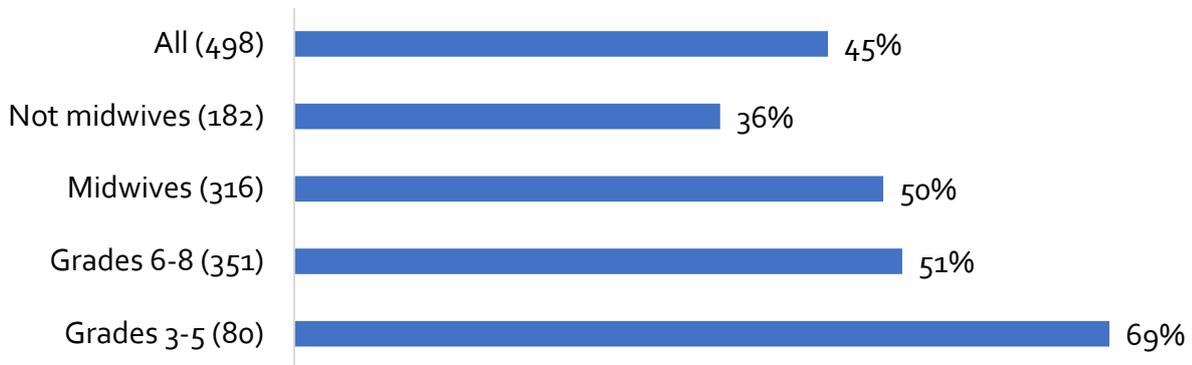


- In terms of discussing bad news with bereaved parents, 45% of all respondents feel somewhat capable, not very capable or not capable at all to do this appropriately. As with preparedness above, those in higher grades and non-midwife roles show more positive results.

How capable do you feel when it comes to discussing bad news with bereaved parents appropriately?  
(n=498)



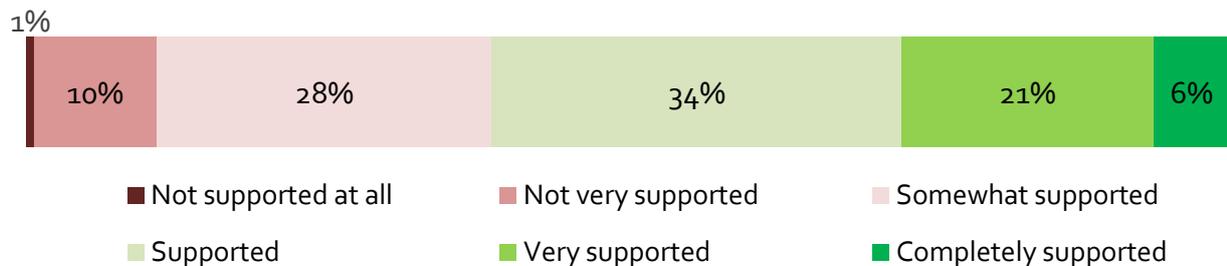
How capable do you feel when it comes to discussing bad news with bereaved parents appropriately?  
(% feeling less than capable)



3.2. Feeling supported to deliver good quality care

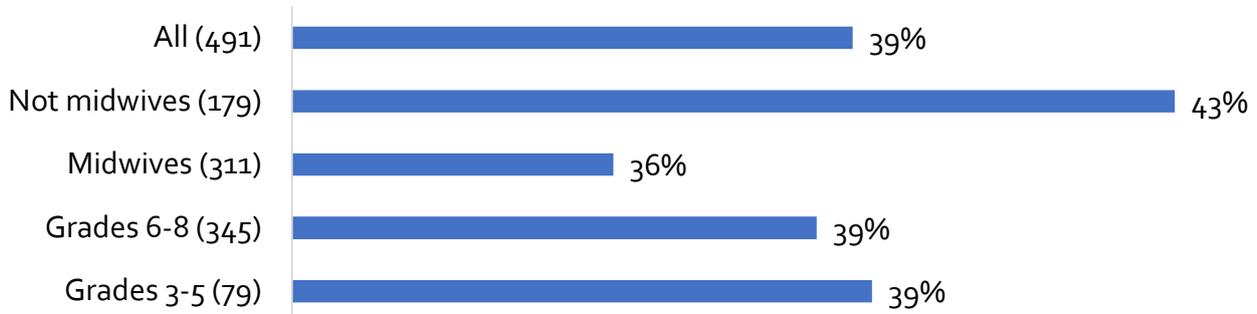
- 39% of all respondents feel somewhat supported, not very supported or not supported at all to deliver good quality bereavement care. The proportion of those feeling supported is the same across grades – but those in midwife roles feel more supported to deliver good quality bereavement care than others.

How supported do you feel when it comes to delivering good quality bereavement care that meets the specific needs of parents?  
(n=491)



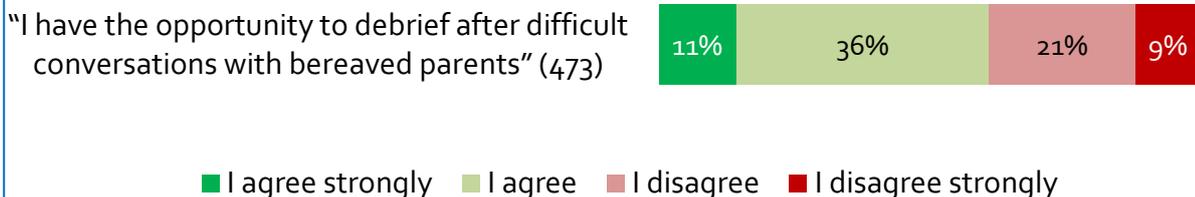
How supported do you feel when it comes to delivering good quality bereavement care that meets the specific needs of parents?

(% feeling less than supported)



- 47% of respondents agreed they had the opportunity to debrief after difficult conversations with bereaved parents – however 30% disagreed.

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



The need for, and importance of, training and support for staff was a recurrent theme in the qualitative responses:

"I feel that staff try their best but due to lack of training and communication reflection, or being unaware of serious incidents, there is no format to improve - staff repeat their behaviours which isn't always effective, compassionate or patient centred."

"[I] regularly look after families undergoing medical termination for anomaly and feel confident in my delivery of bereavement care but [I] need to extend my knowledge more in regard to a number of the conditions seen as often lots of questions [are] asked about this during the course of providing care."

"Junior staff should be provided more support in dealing with bereavement care. As a band 5 I was allocated to work with a Band 7 supervising me as I provided care for a family following a stillbirth, but the Band 7 was pulled away to care for someone else. I felt like I didn't know what

I needed to say or do and that I was going to give the wrong information at a vital time. I know how to be kind and caring and compassionate when it comes to a bereavement, but better training of the 'pathway' for all staff would make it so much easier."

"I feel the core staff who are delivering care to bereaved families all want to do the best they can at such a sad and emotional time. A big thing for me within our trust is the lack of understanding from all staff. Everyone needs to be trained and working in the same way and communicating effectively with other staff/departments. I do not feel we get the support from the senior management teams to do this."

"I have recently completed a bereavement study day funded partly by the trust and partly by a local charity and run by SANDS. This has greatly increased my confidence and understanding in dealing with bereaved families and I would like to see this training extended to many more staff members."

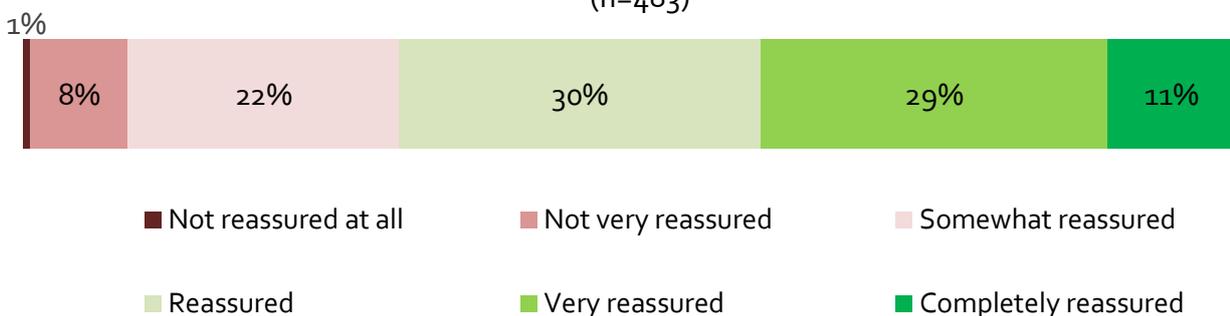
"My concern is not with different groups [of parents] but with different staff members. Certain staff whether this be on gynaecology, maternity or neonatal directorate are very good at delivering care to bereaved families, however other staff are not good at doing this. If feel we need training for all staff across all directorates."

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

- 31% of all respondents feel somewhat reassured, not very reassured or not reassured at all that their trust has an effective approach to delivering good quality bereavement care to all bereaved parents. The proportion of those feeling reassured is similar between the midwife and non-midwife groups, but those on lower grades are less reassured than those on higher grades.

How reassured are you that your trust has an effective approach to delivering good quality bereavement care to all bereaved parents whatever their experience?

(n=483)



How reassured are you that your trust has an effective approach to delivering good quality bereavement care to all bereaved parents whatever their experience?  
(% less than reassured)



The recruitment and work of specialist bereavement midwives was seen by several respondents as a positive development that was improving their trust's approach to bereavement care:

"We quite recently have had a bereavement midwife appointed and this is already making a difference, I have liaised with her with regards to bereaved women and it has certainly improved and enhanced the support women and families receive."

"Bereavement Care quality has increased greatly with the introduction of our bereavement midwife, who does a fantastic job, and although some areas of staff still require improvement, it has improved greatly over the last year."

"Our bereavement midwife is fabulous, [I] am so pleased she has the resource and support now to take things further... she is held in great esteem by staff and families alike."

"Since the appointment of a bereavement midwife I feel more confident in delivering bereavement care as I not only have a point of contact - our bereaved parents also do. Historically the same midwives would provide care to bereaved families however this is now changing, all midwives are given the opportunity to deliver care."

"The appointment of a bereavement midwife with an interest in pregnancy loss at any gestation has hugely improved the care and support offered to women."

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

Respondents were asked how bereavement care differed depending on the bereavement experience of the parent they were working with.

A common theme in the qualitative responses was that respondents were less confident in the care those parents experiencing miscarriage (and in particular early miscarriage) received:

"I feel we have great support for women in our trust who have miscarriage post 12 weeks or fetal anomalies or still births. However, I feel the care is lacking in the miscarriages prior to 12 weeks. Yes, they are very common, and as a health care professional I understand that - however as a patient it is still an unborn that you have lost and never got to meet. Below 12 weeks I feel that medical personnel treat it very much matter of fact and very distant to the fact that was an unborn to that patient."

"For people with no history of miscarriage who come in for routine scans and we find they have miscarried, the care pathway is very different depending on what time of day it is and what nursing staff/medical staff they see. We sometimes struggle to find a quiet room where they can go to. For women who have had a couple of (hospital known) miscarriages in the past they only get routine scans and so are booked into clinics of women of all gestation. If you then do have to break bad news they are in a busy pregnancy clinic with posters and TV about baby and prams and what to buy, how to feed etc."

"I think the early miscarriages are pushed between departments which is wrong, and they have to arrange their own management of their miscarriage."

"I have experienced feedback from patients that follow-up miscarriage care is lacking. Both a lack of information/support for practical information advice about the physical process and the follow up care emotionally afterwards."

"There is a defined pathway for bereaved parents who have a loss after 20 weeks which works well most of the time. Parents who experience a loss between 12 and 20 weeks gestation do not receive best care when they leave our department. The care is very fragmented and follow up is poor. There is not a designated place for these parents to deliver their baby only a side room on a massively busy Gynae ward. They feel isolated and sometimes unsupported. All women who are going through this traumatic event need privacy and support from staff throughout the complete event and a follow up process to ensure they are coping following the loss of their baby."

The care for parents following a termination for fetal abnormality was another area that people commented on:

"I believe miscarriages and termination for abnormalities are not always given the same degree of importance, empathy and support as the loss of 'a baby'."

"I feel that a diagnosis of fatal anomaly is met with the assumption that the couple will choose to terminate. It would be helpful if clinicians - particularly the senior clinician dealing with the couple in the first instance following diagnosis - were able to offer careful objective information without making an assumption that this is the way the couple will wish to proceed."

"Sometimes [to] arrange [a]surgical termination of pregnancy in my trust can be difficult and time consuming with no clear guidelines about who to contact for a quick appointment often when time is of the essence."

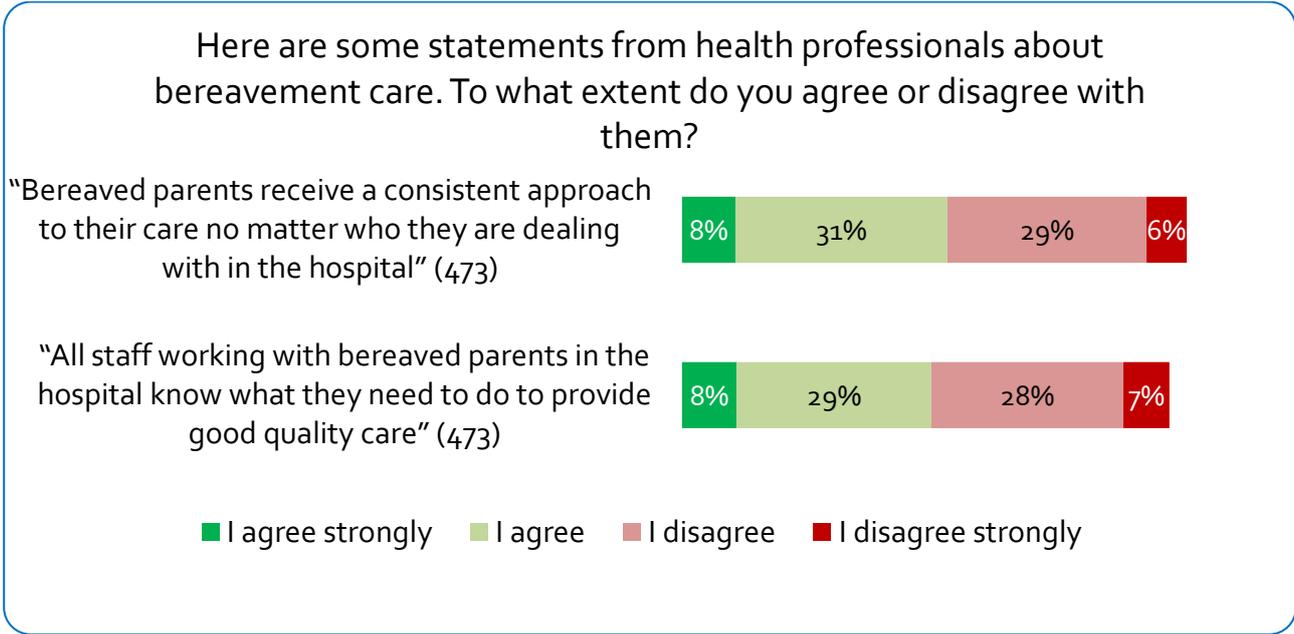
“Our patients deserve speedy management once the decision has been made to terminate a pregnancy due to fetal anomaly.”

**3.5. Consistency of care**

We saw above that 8 out of 10 respondents feel they know what to do to provide good quality bereavement care, however only 4 out of 10 (37%) agreed that all staff working with bereaved parents knew what they had to do to provide good quality bereavement care (with a similar proportion disagreeing). This disparity between respondents’ perception of their knowledge compared with their perception of others’ knowledge is best illustrated using “net agreement” – i.e. taking those who disagree away from those who agree.

Providing good quality bereavement care...	Agree	Disagree	Net agreement
I know what I need to do	82%	6%	76%
All staff know what they need to do	37%	35%	2%

When considering whether bereaved parents received a consistent approach to their care across the hospital respondents were also split – with 39% agreeing and 35% disagreeing.



In the qualitative feedback, professionals described how the bereavement care provided can vary between departments (affecting parents with different bereavement experiences):

“I feel the care provided from the maternity side and from our bereavement officer is excellent, however sometimes when you need the input from the obstetric team the rapport you build with the woman can be ruined by their bluntness and lack of compassion particularly when dealing with termination for fetal anomaly.”

"Neonatal bereavement services are very good, but A&E services seem inadequate for an infant brought in dead and [there is] a general lack of in-depth nurse training and support."

"We have a lot of early miscarriage present to the Emergency Department. The information we currently provide is very limited - we have no leaflets, and the patients are often sent home with an appointment. Having had 2 miscarriages myself, I feel well equipped to answer questions and offer support. However general knowledge and support of parents is poor in [the] Emergency Department."

"When patients are first seen in A&E, they do not always get the same level of care/attention they would receive on the gynae/obstetric wards. I once had a report of a patient passing a fetus on the floor in A&E and she said, 'the nurse just swiped it up in tissue and threw it in the bin'".

"Neonatal deaths are well supported by a specific bereavement midwifery team. In paediatrics that is left to the consultants only and we do not get the chance to be as close with the families."

"I don't believe that patients delivering on the gynae ward receive the same level of bereavement care as those of a greater gestation - and in some cases the difference is only a couple of days resulting in a different experience altogether."

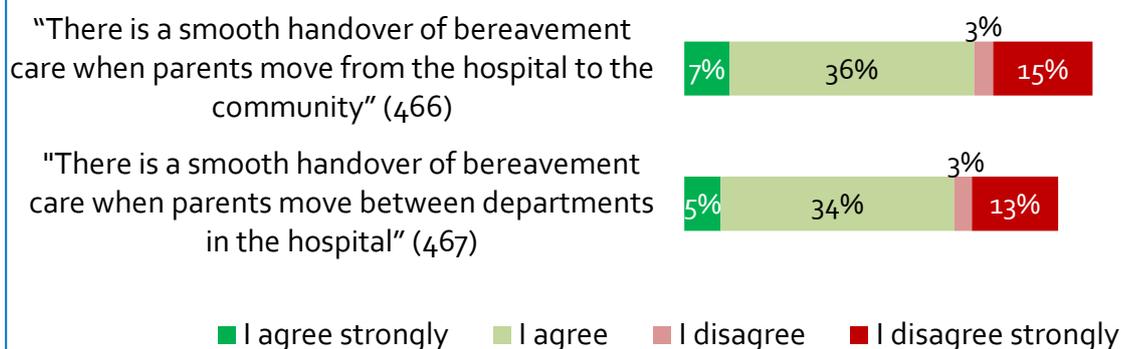
"I feel very reassured in the maternity setting, however there is scope for improvement in the gynaecology service with regard to women who suffer an early miscarriage and the sudden infant death group of parents."

### 3.6. Handovers

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

- More respondents (43%) agreed that handovers were smoother between the hospital and the community settings than within the hospital (39%). Although slightly more people disagreed that there was a smooth handover between hospital and community making the net agreement for both questions similar.

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



Qualitative comments expand on some of the challenges of effective handover. As above, those parents who have suffered miscarriage or termination for fetal anomaly seem more likely to have bad experiences:

"We need a more structured plan for the delivery of bereavement care as when we handover to the next shift some things are repeated, and this can be upsetting for the parents."

"There is a repetitive mistake in communication for the ladies who have miscarriage in the process of informing other departments. It is better for stillbirth/TOP for abnormality couples but even worse for families who have a neonatal death or sudden infant death."

"Handover between departments is not as smooth as it could be as occasionally other departments do not appreciate the situation and its effects on the parents. Handover to community midwives has improved greatly. Overall, communication needs to improve. It could be made more simple and concise, then it may eventually be ingrained in our practice."

"I believe the care given to parents in the hospital setting is excellent. However, when they are discharged to the community there can be several barriers to good care. Sometimes the discharge information is not complete, and, on several occasions, there has been very little information...That can be quite difficult when you meet the bereaved parents for the first time and they think you have prior knowledge and information regarding their loss."

"Not much support or communication between hospital and community for those who have had TOPs or early miscarriage."

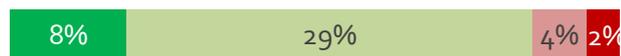
"Communication needs to be improved between hospital and GP surgery i.e. if an appointment has been made for a first booking with community midwife - there needs to be a better system when that lady miscarries before her appointment. I have come across two recently [when] appointments weren't cancelled. Both women received reminders of their appointment by text message. [I] find that wrong and it must be very upsetting for the lady."

### 3.7. Room for improvement

A third of respondents (37%) agreed that there was a lot their trust needed to do to improve bereavement care. Only 6% disagreed. This question drew the most non-committal answers with 33% neither agreeing nor disagreeing and 24% answering "I do not know".

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

"There is a lot we need to do to improve the delivery of bereavement care in our Trust" (466)



■ I agree strongly ■ I agree ■ I disagree ■ I disagree strongly

The qualitative comments shed light on the aspects of care that could be improved. The most common issues were around facilities, resources and (to a lesser extent) over-complicated paperwork.

#### Facilities:

"[It is] very difficult to sometimes facilitate good care as we do not have a bereavement room/facility for women and their families. Often, they are at the end of a labour ward, which can be difficult for them and us."

"The main issue we have in our department is having to deliver patients on the labour ward, which is often busy and often not very supportive to the care of a woman having TOPFA or delivery after a stillbirth."

"The biggest problem is the lack of facilities, whilst the staff are well taught, supported etc we do not have a quiet room, women have to deliver on the labour ward. There is no relatives room. Improving the facilities would be a major step towards being able to offer parents the appropriate support and environment to deliver/ grieve etc in."

"A bereavement suite would be beneficial or somewhere other than the sluice to use once the baby is born."

"The bereavement rooms are not nice, having had this experience myself at another hospital I had a large room with a bed for my husband, tv, radio, tea and coffee making facilities, fridge for milk etc. The room was also not on the delivery suite so no crying babies, mothers screaming in labour or chance of seeing other parents with their newborns."

**Resources:**

"Prior to the recent cost cutting strategies the service was excellent. However, in view of the loss of the second Bereavement midwife I have fears that this could result in the decline in the quality of the service and the risk of our Bereavement midwife 'burning out'."

"I see staff trying to care for women who are suffering or have suffered a miscarriage on the ward where I work as a midwife at weekends. I feel that this is where the care can fall below an acceptable standard. This is not down to the nurses not caring or not doing the job properly but the logistics of one nurse caring for patients across several different sites."

"Recently our bereavement care midwifery hours have been cut as a cost cutting exercise, which means our service which, I feel was good and improving all the time is now going backwards despite the midwives' best efforts."

"Because of staffing levels, staff are often allocated more than one patient to care for on a shift. This means that they are potentially simultaneously caring for a woman in labour as well as giving care to bereaved parents which I feel is unfair on both staff and bereaved parents and needs to be addressed."

"I think the main problem is time to spend with families due to labour ward work load. I rarely have enough time to do everything I want to."

"Budget constraints means [we are] unable to reach gold standard of bereavement care. Unable to plan and refurbish more bereavement suites/rooms, despite workload increasing no budget to give more hours to Bereavement Team. Not enough hours in the day, difficult to arrange workshops as staff can't get away from clinical areas."

**Paperwork:**

"We spend more time trying to complete documentation and trying to work out what we are supposed to complete, than we do caring and supporting our women."

"The paperwork that needs completing following the various bereavements is very complicated and [we] definitely need guidance to ensure the correct information is recorded."

However, there were also many positive comments about the care provided in the pilot sites:

"I am proud of the support, care and compassion our trust provides to all bereaved parents and their families."

"I feel that the care we give is wonderful. We have a good team that support not only the parents but the staff also. The support for staff and parents is ongoing. For staff there are many training opportunities and the option to rotate or shadow members of the team working

on the bereavement suite. Band 7 staff allocate appropriately for delivery suite staff and support them also when dealing with bereavements.”

“I believe that as a trust we deal with bereavement extremely well. That's not to say that we don't need to improve, but on the whole, we provide excellent support.”

“We have an excellent bereavement team. They are at hand for support, assistance, debriefing, any practical help that staff may require in giving care to these parents. They provide excellent ongoing care for parents and support the work midwives do in delivering clinical care. I am very grateful for the many times they have given me advice and practical help in caring for bereaved parents. They are completely invaluable.”

### 3.8. Baseline outcome measurements

The following table confirms the indicators that will be revisited in the follow up survey to measure the impact of the pathway on professionals<sup>5</sup>.

Indicator	Baseline measure
% who agree they know what to do to provide good quality bereavement care	82
% who agree they can access the information they need before speaking to parents	54
% who feel prepared for communicating with parents	48
% who feel capable to break bad news appropriately	55
% who feel supported to deliver effective bereavement care	61
% who agree they can debrief after difficult conversations	47
% who feel reassured there is an effective approach to bereavement care in the hospital	69
% who agree parents receive a consistent approach to their care from all staff	39
% who agree all staff know what to do to provide good quality bereavement care	37
% who agree handovers within hospital departments are smooth	39
% who agree handovers between the hospital and community are smooth	43
% who disagree that there is a lot needed to improve bereavement care in their trust	63

<sup>5</sup> As noted above these baseline figures will be adjusted to include “matched” responses only – i.e. those who complete both the baseline and the follow-up survey (identified by their unique code)

## 4. Survey timing and response

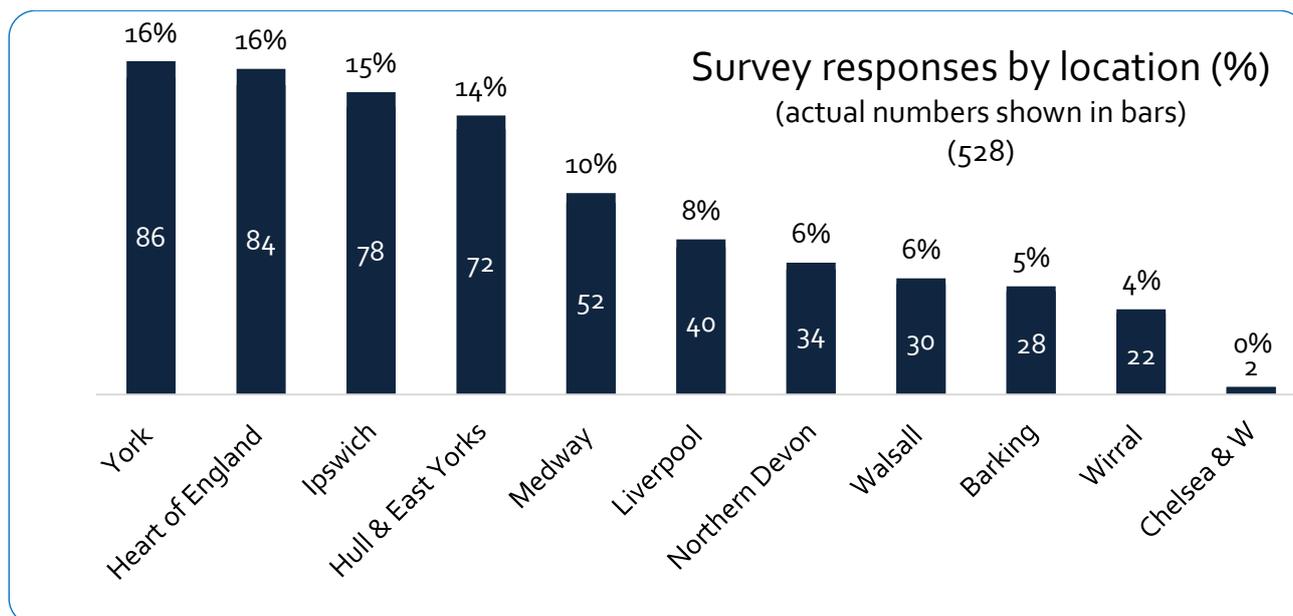
At least three trusts had started to implement aspects of the pathway before it was possible to send the baseline survey. An important point of learning for subsequent waves of NBCP implementation is that, to be able to demonstrate the full impact of the pathway on health professionals, the baseline survey should be conducted prior to the wave's launch.

The survey link was distributed by the NBCP pilot lead to colleagues in relevant departments. In some cases, the leads also relied on contacts in other departments to distribute the link for them. It is difficult to know exactly how many people were given the opportunity to do the survey and, therefore, calculate a response rate. Seven sites gave an indication of how many people the link was circulated to in their trust. Approximate response rates in those sites ranged from 8% to 29% (an average of 17%).

Respondents were asked to provide a unique ID to enable the comparison of the same people in the follow up survey in summer 2018<sup>6</sup>.

### 4.1. Location

York and The Heart of England provided the most responses to the baseline survey. Chelsea and Westminster were unable to circulate the survey widely within their trust.



### 4.2. Role

Roughly half the responses to the survey (n=522) were from hospital-based midwives – and 63% from all midwives, including those based in the community. This is to be expected as 8 of the 11 pilots are being led by midwifery teams (two are being led by obstetrics teams and one by a neonatal team).

<sup>6</sup> Where responses to the baseline and follow up survey can be matched the baseline will be adjusted to reflect the perspectives and opinions of those matched.

Although the survey did generate responses from a wide range of roles, the volume of response from departments such as gynaecology, A&E and paediatrics was low. In future waves of the NBCP, more time to plan the survey in advance of implementation and increased discussion and sharing of experiences amongst the pilot trusts would help to increase participation from professionals working outside maternity teams.

Role	Responses	%
Midwife (Hospital based)	253	48.5
Midwife (Community based)	78	14.9
Nurse	34	6.5
Maternity support worker	27	5.2
Obs/Gynae (mixed role)	26	5.0
Neonatal nurse	23	4.4
Sonographer/Radiographer	23	4.4
Obstetrician	8	1.5
Paediatrician	8	1.5
A&E nurse	7	1.3
Other	7	1.3
A&E doctor	5	1.0
Healthcare Assistant	5	1.0
Bereavement Officer	4	0.8
Maternal Fetal Medicine Specialist	4	0.8
Neonatologist	4	0.8
Anatomical Pathology/Mortuary	3	0.6
Gynaecologist	2	0.4
Anaesthetist	1	0.2
<b>Total</b>	<b>522</b>	

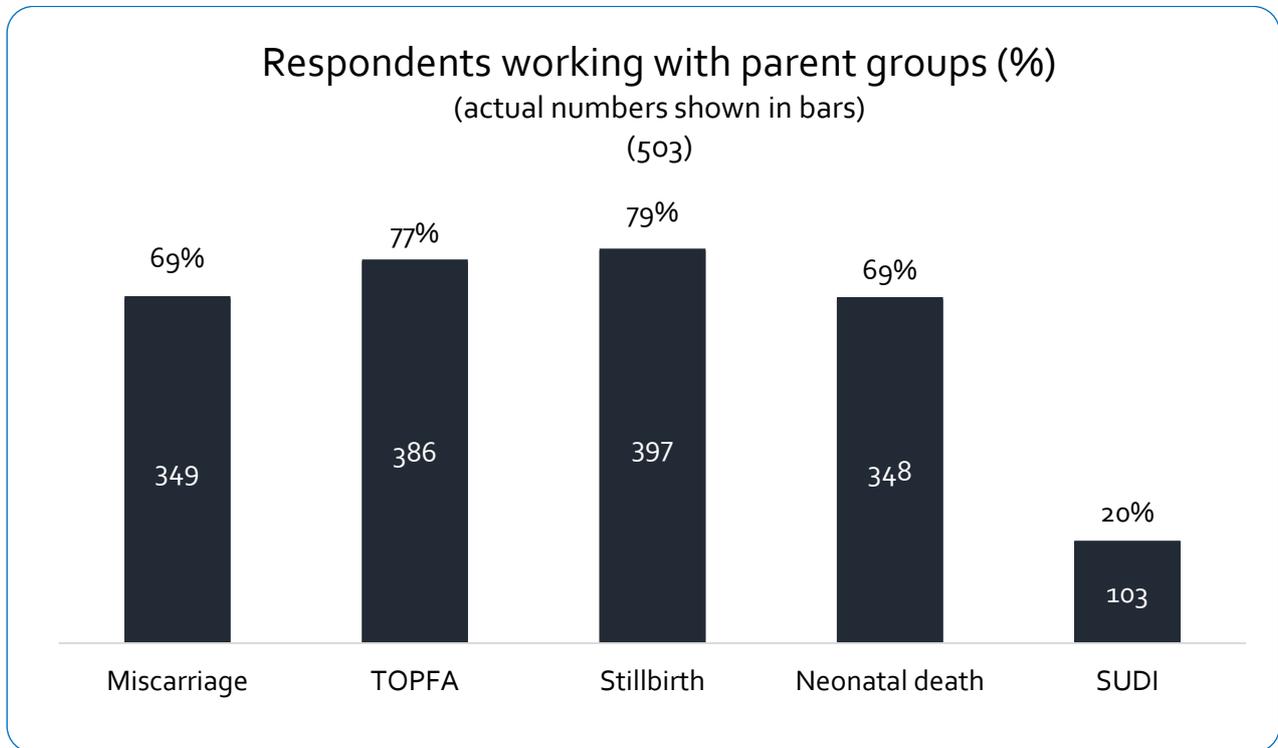
#### 4.3. Grade

Almost half of survey respondents (n=504), and 69% of midwives who responded (n=324) were on Agenda for Change salary band 6. The majority of midwives in the NHS workforce are at band 6, so this profile is as expected.

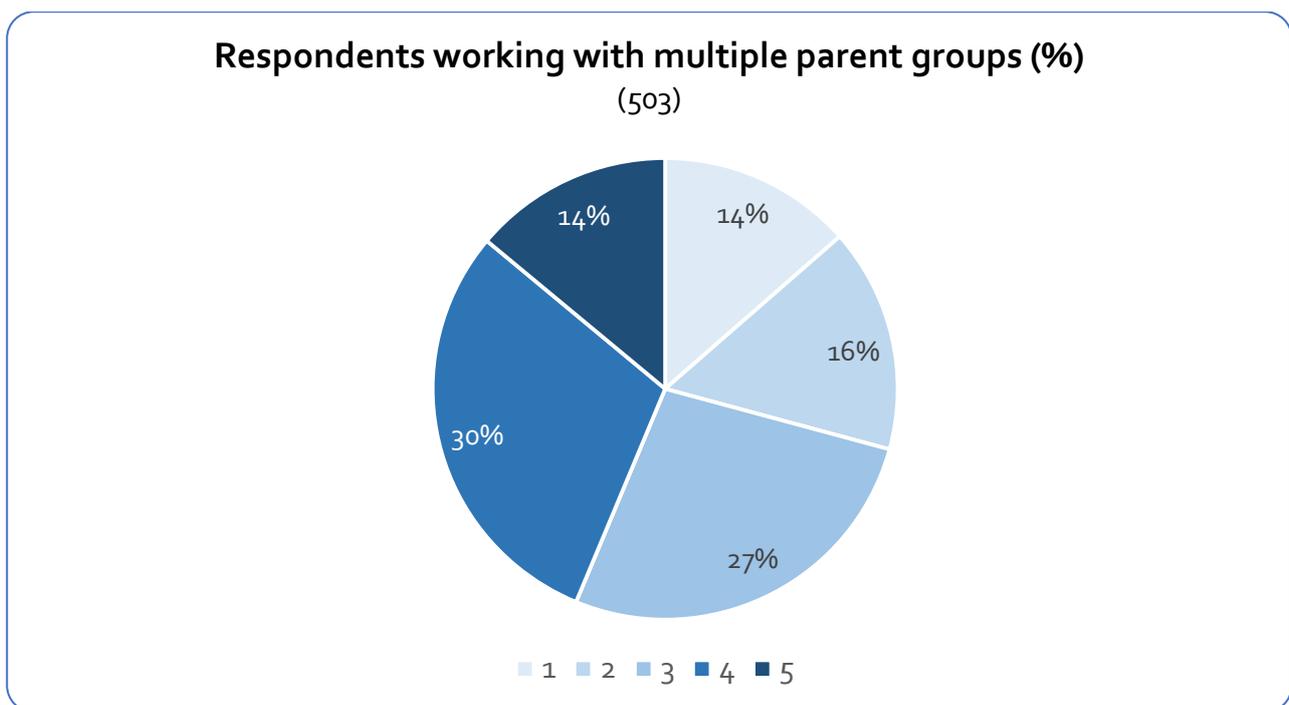
Band	Responses	%
2	28	6
3	7	1
4	4	1
5	46	9
6	243	48
7	101	20
8	19	4
Trainee doctor	15	3
Consultant	41	8
<b>Total</b>	<b>504</b>	

#### 4.4. Parents supported

Over two thirds of respondents worked with parents who had suffered miscarriage, termination for fetal anomaly, stillbirth or neonatal death. However, only 1 in 5 worked with parents who had suffered the sudden unexpected death of an infant (less than 12 months old).



14% of respondents worked with parents from all five groups and 44% with four or more of the five groups.



## 5. Feedback from pilot sites

A discussion took place with leads from the pilot sites during the wave one pilot site workshop in Walsall on 20<sup>th</sup> March 2018. This discussion focussed on the issues leads had faced when implementing the pathway in their trusts and how they had overcome them. The findings from this discussion are captured below.

- The experience of implementing the pathway had been beneficial in raising the profile of bereavement care (*"it has prompted others to take the patient's perspective"*) and bringing the working practices of some departments closer together for example standardising overlapping checklists. Relationships with some other teams have also improved (*"we talk to gynae a lot more now"*).
- Although colleagues in other departments were supportive of the pathway in principle, the practicalities of engaging with some departments outside maternity teams has been a challenge. A&E teams were particularly challenging when they were facing high demand due to winter pressures and when treating parents experiencing baby loss represents a very small aspect of a very large workload. In addition, leads fed back that the pathway documents were too long and wordy which did not help to engage busy, time poor colleagues.
- Suggestions for increasing engagement amongst other departments included:
  - Ensuring the pathway has a high visual prominence within the trust (e.g. posters and leaflets attached to patient notes)
  - Forming a steering group with representatives from each department *"you need staff enthusiasm within a ward. If no one is interested it is hard to establish the pathway. We have asked for each area to appoint a bereavement link."*
  - Ensuring the pathway documents were short and practical – for example using a flowchart format or developing a "quick reference guide."
- Engaging senior management to support the implementation of the pathway had also proved difficult. As providing high quality bereavement care *"doesn't make money"* it was too often *"put to the bottom of the pile"* and the pathway seen as *"pie in the sky"*. However, site leads reported that the reputational benefits of implementing the pathway did resonate with management as they need to be *"seen to do the right thing"*. The fact that this is a high profile, national pilot, and the inclusion of bereavement care in CQC inspections, were considered positive factors to influence senior management. Leads felt that their voice was not as influential as it could be as they were already known to be passionate about bereavement care. Having an external voice (for example a letter about the pathway sent to senior management from the MPs involved) would help leads engage senior staff.
- Site leads had found it challenging to incorporate the work involved to implement the pathway into their existing roles (*"I was already at capacity"*). The expectations on them were *"bigger than expected"* and some mentioned that they were not aware at the outset that there would be five pathways (*"I thought it would just be a maternity tool"*). Leads felt that implementing the pathway *"single handed"* was difficult and, as noted above, it requires a

team of people from different departments to sign up to the project to ensure effective implementation.

- To support their work, trusts requested more opportunity to communicate with their peers in other trusts to celebrate success and share best practice. Simpler, clearer communications and instructions from the NBCP project are also preferred.

## **6. Next steps for the evaluation**

### **6.1. Gathering insight from parents**

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

The survey will invite parents to participate in telephone interviews to discuss their experience in more depth. 22 of these interviews will be conducted between April and August 2018.

The pilot sites are responsible for ensuring parents have the opportunity to complete the on-line survey. They have been given the freedom to promote the survey in the way they feel is best for their patients.

- Seven trusts are promoting the on-line survey through information provided to parents before, during and after their postnatal appointment
- Two are sending letters to parents (c4-6 weeks) after delivery with details about the survey
- One is sending an email to parents six months after delivery.

Fiveways have produced written materials to support these methods. All trusts are being encouraged to ensure their recruitment method covers all the relevant bereavement experiences in the NBCP.

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

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

- Trusts should administer the survey themselves; as no identifying patient details will be transferred outside the trust, this circumvents confidentiality issues.
- Trusts should ensure they contact their local Research & Development office, or Caldicott Guardian, to check local requirements in advance of making the survey available and the trust should sign off the survey and arrangements.

- The survey has a section that gives an option for parents to be contacted for an in-depth follow-up phone call - this should have standard advice regarding use of data and be clear about how the information will be used.

Some pilot trusts were already using The Maternity Bereavement Experience Measure (MBEM) to gather feedback from parents<sup>7</sup>. However, the tool does not cover all the bereavement experiences included in the NBCP. Rather than ask bereaved parents to complete two surveys about their bereavement care experience, it was decided that the NBCP survey would take precedence over MBEM for the duration of this evaluation.

## **6.2. Healthcare professionals**

A follow up survey will be distributed amongst health professionals in late summer/early autumn. This will essentially be a repeat of the baseline survey and will also include questions about professionals' experience of using the pathway. The survey will invite professionals to participate in telephone interviews to discuss their experience in more depth. 12 of these interviews will be conducted from July 2018.

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

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<sup>7</sup> MBEM is a questionnaire and supporting resource, developed by Sands, NHS England and the London Maternity Clinical Network. It is designed to seek feedback from bereaved parents where a baby or babies have died during pregnancy or shortly after birth.

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

### Appendix three: measurable outcomes (parents)

Overall NBCP project outcome	Area	Measurable outcomes/indicators	Does this outcome apply to all parents?
Increased choice	Informed choice/decisions	1. Parents were supported to make informed decisions	Yes
		2. Parents were provided with information that was clear and easy to understand	Yes
		3. Parents were provided with information that was relevant to their situation	Yes
		4. Parents feel the decisions they made were the right ones at the time	Yes
High quality care	Good communication	5. Parents feel they were communicated with sensitively	Yes
		6. Parents feel they were listened to	Yes
		7. Parents feel their concerns were taken seriously	Yes
	Memory making	8. Parents were given the opportunity to make memories	Yes
		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 (into the community)	12. Parents were offered ongoing emotional support	Yes	
Partner and family	13. Parents feel the needs of their partners and/or family members were met	Yes	
Aspects of support provided	14. Parents feel the timing of the support offered was appropriate	Yes	

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