

Gathering feedback from families following the death of their baby

A resource to support professionals in maternity care

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Gathering feedback from families when a baby dies

Dedication

We would like to thank the parents who helped us with this work, generously donating their time in memory of their babies, knowing that they will make a difference to other bereaved parents.

In memory of Hugo, Jada, Vera, Freddie, Chloe, Grace, Gina, Theo, and all other babies who are missed.

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Introduction

Many parents who have experienced bereavement want to offer feedback to ensure lessons are learned and good practice is shared. This can be instrumental to inform improvements in care.

However, seeking out these experiences in bereavement care can feel difficult, and there has been no nationally validated measure to capture women's experiences of childbearing loss.

Better Births, the report of the National Maternity Review, stated that if teams, organisations and systems are to improve, they must know where they are, how they compare to others and to the best, and how they are improving over time. Better Births found that the appropriate, regular and accurate capturing of outcomes and experience of care reported by women and families is currently proving to be a challenge. It recommended the development of user reported experience measures and that local services should supplement this with in-depth qualitative discussions with individual women to get into the detail of how they feel about services.

During the autumn of 2016 Sands (the Stillbirth and neonatal death charity) undertook a survey to identify if and how parents wanted to share their experiences after the loss of a baby (*Appendix 1, page 12*). Responses were obtained from 437 parents, and an overwhelming majority felt that it is appropriate for bereaved parents to feed into bereavement care service improvements and gave their views about the most appropriate way of doing so. This feedback has directly informed the development of this Maternity Bereavement Experience Measure (MBEM) questionnaire and supporting resource, which was created collaboratively by Sands, NHS England and the London Maternity Clinical Network.

The questionnaire is designed to seek feedback from bereaved parents where a baby or babies have died during pregnancy or shortly after birth. It is grounded on clear research methodology and was tested with bereaved families, in order to ensure it will effectively and sensitively capture the experiences of bereaved parents.

The wider resource offers practical suggestions on how to apply the questionnaire locally in order to improve local bereavement care. It should enable Local Maternity Systems (LMSs) -- groups of commissioners and providers -- to collect and understand women's insight from all communities, cultures and ethnic groups to help explore where local improvements may be needed.

We are grateful to all the women, families and health care professionals who have contributed to this work and hope that everyone in maternity care: clinical teams, patient experience teams, patient advice and liaison services, third sector organisations, and LMSs find this resource useful in driving forward local improvement in maternity bereavement care.



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The importance of feedback and co-production

The impact of care received by women and families around the time of the loss of their baby (or babies) can have profound short and long term effects on their wellbeing¹. The importance of gaining insight and co-producing services is well recognised by commissioners and providers as vital to enhancing services and securing direct improvements in care.

A 2014 study by the National Perinatal Epidemiology Unit (NPEU), *Listening to parents after stillbirth or the death of their baby after birth*² highlighted areas that were particularly important for the care of bereaved parents. It noted that:

- » Some aspects of care can only be assessed by asking bereaved women and families.
- » Listening to parents and monitoring their needs and experiences of care is vital, and acting upon that feedback is essential.
- » Using toolkits and principles developed by user groups, such as Sands and Bliss, to provide frameworks for checks on progress and implementation can help support and embed clinical change in maternity bereavement care.

“Bereaved parents want to be involved in talking about the care they and their baby received. We want to give praise where it is due, and to help make improvements where needed for the benefit of other families. We also want to be involved so that we can talk about our babies, to say their name, to show that they matter.”

-- Leigh Kendall, mother of baby Hugo

Women and families are experts by experience and often provide ideas and suggestions for improvements which healthcare professionals may not have considered.

The Maternity Bereavement Experience Measure (MBEM) questionnaire (Appendix 3, page 15) and accompanying resource offers some practical suggestions as to how to gain this feedback and drive forward recommendations.

“We need to know that our current service provision supports bereaved parents and families in the best way possible. We have to listen to them and then act on that feedback to make service improvements that we know matter to parents. The challenge remains to embed what we are told into everyday clinical practice and going forward to sustain that change.”

-- Donna Ockenden, Midwife and
Co-Clinical Director
London Maternity Clinical Network

“There is an opportunity to raise the standards in maternity bereavement care so that by listening to parents, all families receive high quality care at this difficult time.”

--- Jane Scott, Bereavement Midwife
Imperial College Healthcare NHS Trust

1. Heazell, A.E., Siassakos, D., Blencowe, H., Burden, C., Bhutta, Z.A., Cacciatore, J., Dang, N., Das, J., Flenady, V., Gold, K.J. and Mensah, O.K., 2016. Stillbirths: economic and psychosocial consequences. *The Lancet*, 387(10018), pp.604-616.

2. National Perinatal Epidemiology Unit (NPEU), *Listening to parents after stillbirth or the death of their baby after birth* (2014) www.npeu.ox.ac.uk/downloads/files/listeningtoparents/Listening%20to%20Parents%20Report%20-%20March%202014%20-%20FINAL%20-%20PROTECTED.pdf

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How to gather feedback with the MBEM questionnaire

The MBEM questionnaire (*Appendix 3, page 12*) is designed to gather insight and feedback from the personal experience of women and their families when a baby or babies die. The themes that emerged from feedback gathered through Sands (*Appendix 1, page 12*) served as a baseline to develop the questions within the questionnaire. These questions were then tested with women and their partners to ensure that they were appropriate, understandable and addressed the issues which mattered most to them. The questions were further reviewed by a wider cohort of families for increased validation and to minimise any risk of harm or distress. Therefore, it is recommended that the questions should be amended only where absolutely necessary.

Feedback from the questionnaire will enable local healthcare systems to collect both quantitative and qualitative data, which will allow comparison across areas (eg across Local Maternity Systems) and identify areas for service development.

“It’s important we know how services are performing in this area as reported by bereaved women and their families themselves. This insight, when obtained sensitively, will assist providers and commissioners in enhancing services and lead to ongoing direct improvements in care.”

— Kath Evans, Experience of Care Lead
NHS England

“I want to be part of the survey, but I don’t want it to take too long or be too complicated. It’s hard when it was your baby.”

— Bereaved parent
(Sands survey, 2016)

As a result of parent feedback, Imperial College Healthcare NHS Trust commissioned a Petals counselling service to help parents psychologically process the trauma following pregnancy loss or the death of a baby.

“Counselling helped us get through the worst thing that could happen. It has helped us talk to each other, it has helped us cope with questions from other people, it has allowed us to look forward and helped us let Vera find a place in our lives and that the really bad days do come to an end.”

— Alice and David Bailey, parents of Vera
(reflecting on the care they received from Petals)

All bereaved parents should be given a choice of how and when to feed back. The appropriate time to seek feedback depends on individual circumstances and the method used. The Sands survey indicated differing views from families, though approximately half (51 per cent) of parents felt that this could occur between two and six months after bereavement. Therefore, this needs to be locally determined based on relationships between families and the professionals caring for them. The survey also revealed that many women and families would prefer to be approached by someone with whom they have a pre-existing relationship.

The flow chart (*page 7*) provides some key areas for consideration when using the questionnaire locally and gives prompts for consideration around:

- » Preparing internal channels
- » Developing the process
- » Collecting feedback

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Collecting feedback | What to consider

Prepare internal channels

- » Be clear about how the information will be used. Information should only be collected with a clear plan of how to use it.
- » Identify and agree with local Information Governance teams the arrangements for appropriate storage and management of the questionnaire (eg locked or password protected area).
- » Consider engaging chaplains, Healthwatch, liaison services, local community groups and third sector to support parents with completing the questionnaire to ensure that the voices of all bereaved parents are heard, regardless of demographic or socio-economic group.
- » Check local trust policy for participants who are 18 years old or under.
- » Talk to maternity staff about gathering feedback from women and families when loss occurs. Proactively identify and address any staff concerns.
- » Caring for a bereaved family can have a long lasting, psychological impact on staff. Receiving positive feedback can boost morale and create positive staff experiences, whereas professionals may require support for negative feedback. Ensure debriefs for all staff are provided. The Sands helpline is available for professionals as well as parents (0808 164 3332).

Develop process

- » Review individual circumstances to decide how and when individuals will be invited to feedback. Consider a phone call or postnatal appointments, where sufficient time is allocated.
- » Consider that some families may prefer to be approached by someone with whom they have a pre-existing relationship. Agree who will do this; the required competencies of staff to undertake this; and how discussions will be recorded.
- » Ensure that both positive and negative feedback can be offered and received.
- » Localise the template letter (*Appendix 2, page 14*) to ensure parents understand how their feedback and experiences will be used by staff to improve services.
- » Have a clear self referral pathway available for women who wish to discuss their feedback further. Ensure there are clear policies in place to manage any complaints that may arise. Have procedures in place for continued contact with parents and an agreed escalation policy.

Collect feedback

- » Obtain informed consent and ensure that parents know their information will be kept confidential and that they can withdraw from providing feedback at any time.
- » Ensure that the anonymity of those providing feedback is maintained unless expressly disclosed otherwise.
- » Determine if and how women who decide not to give feedback will be followed up.
- » Managers should be informed promptly of issues or concerns raised by parents in the questionnaire.

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Using feedback to drive improvements

Improvement should occur as part of an ongoing culture of learning from feedback. Preparing the framework or wider infrastructure for receiving feedback is essential to ensure that improvements are made in a sustainable way. Feedback may uncover common themes that need to be addressed, or issues may arise from a smaller number of respondents which provides valuable insight. As well as ensuring an effective feedback mechanism for improvement it is also important to celebrate positive feedback when things are done well.

Below are some practical points for consideration for what to do once feedback is gathered, and how this insight can be used to implement changes in your service.

Share findings

- » Agree how the feedback will be collated and presented for discussion at wider meetings (eg the frequency of reporting).
- » Consider the MBEM questionnaire feedback alongside other feedback sources such as compliments, complaints, local focus groups, third sector, chaplaincy services.
- » Identify all key stakeholders with whom the information should be shared:
 - » Trust – Services / staff within the trust (eg executive team, non executive directors, women's and children's divisional forums, experience of care forums, chaplaincy, Patient Advice and Liaison Service [PALS], gynaecology and neonatal staff.
 - » Commissioners, clinical commissioning groups.
 - » Partner organisations, such as Maternity Voices Partnership.
 - » Wider system - Local Maternity Systems geographies, third sector, etc.

Take action

Develop an action plan for improvement. Consider:

- » **Always Events service improvement methodology** (*See right.*)
- » **Immediate improvements** - A robust escalation policy to ensure prompt notification and response of concerns, in line with the trust's risk management, complaints and concerns policies.
- » **Local improvements** within the immediate environment.
- » **System improvements** requiring trust executive or commissioner support (eg development of a bereavement suite, improved environments of care, staff training, better primary care support, or access to counselling).

Evaluate and communicate

- » Collect data to analyse whether improvements are being realised.
- » Identify how improvements made as a result of feedback can be shared with families (eg trust websites or memorial events).
- » Demonstrate the value of feedback for improving the experience of other women and families.
- » Ensure that there is a robust system by which decisions are made for future action that sensitively addresses potential differences of opinion within the feedback received.

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Using feedback to drive improvements

Always Events | A service improvement methodology

Improvements in maternity bereavement services can be influenced through information gathered from this questionnaire in an evidence based manner by adopting an Always Events approach to service improvement.

The Always Events approach brings rigor to experience of care improvement work, helping to achieve sustainable improvement that is embedded in practice.

The feedback from women and families gathered from the questionnaire will identify aspects of care that should always happen, for example the provision of accessible information, a point of contact on discharge. You will identify the issues specific to your local service. The Always Events methodology validates the importance of seeking out what matters to people most, and then exploring how to address this using a *Plan, Do, Study, Act* improvement approach. It offers a way for healthcare providers, in partnership with women and families, to identify, develop, and achieve reliability in person- and family-centered care in bereavement care.

NHS England, working with the Picker Institute Europe and Institute of Healthcare Improvement has developed a toolkit to support organisations wanting to codesign and implement an Always Event framework, freely available on the NHS England website:

www.england.nhs.uk/ourwork/pe/always-events.

Case study: Central Manchester University Hospitals

“As a result of our parent survey at St Mary’s Hospital, we developed a card with contact details and information about passive movements following the confirmation of a fetal death.”

-- Dr Alexander Heazell, Obstetrician
Central Manchester University Hospitals
NHS Foundation Trust

Case study: Heart of England, Birmingham

Using a locally developed questionnaire, staff at the Heart of England NHS Foundation Trust in Birmingham offer families the opportunity to provide feedback to bereaved families.

“We are allocated time to sit with bereaved parents and go through the questionnaire with them which translates to changes in our practice. Some feedback received may require immediate action. In those cases, face to face discussions are offered to the families in order to clarify their concerns and the changes they would like to see. These concerns are also raised at the trust’s monthly multidisciplinary perinatal mortality meetings from where action can be taken to improve the service. All feedback where a specific staff member is named is forwarded to that person and their manager.”

-- Clare Beesley, Bereavement Midwife
Heart of England NHS Foundation Trust

“There were positives of care, such as how supportive our midwives were. However, as the hospital kept my maternity notes, I had no contact details to reach my community midwife once we left the hospital. This was a small, practical detail that would have made a big difference. I felt very alone once we were home.”

-- Parent

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Further reading

National Perinatal Epidemiology Unit (NPEU), *Listening to parents after stillbirth or the death of their baby after birth* (2014)

www.npeu.ox.ac.uk/downloads/files/listeningtoparents/Listening%20to%20Parents%20Report%20-%20March%202014%20-%20FINAL%20-%20PROTECTED.pdf

Sands, *Pregnancy loss and the death of a baby: Guidelines for professionals* (2016)

www.sands.org.uk/professionals/professional-resources/sands-guidelines-new-edition

Sands, *Audit of bereavement care provision in UK maternity units* (2016)

www.sands.org.uk/sites/default/files/Bereavement%20Care%20Audit%20Report%202016%20DIGITAL%20-%2010.01.17.pdf

Sands, *Sands supporters impact NHS England customer service survey* press release (2013)

www.uk-sands.org/news/professionals/2013-12-05/sands-supporters-impact-nhs-england-customer-service-survey

NHS Choices, *The NHS Friends and Family Test*

www.nhs.uk/NHSEngland/AboutNHSservices/Pages/nhs-friends-and-family-test.aspx

NHS England, *Guidance on handling the Friends and Family Test in sensitive situations*

<https://www.england.nhs.uk/ourwork/pe/fft/fft-miscarriage-stillbirth/>

NHS Improving Quality, *A review of support available loss in early and late pregnancy* (2014)

http://webarchive.nationalarchives.gov.uk/20160805124122/http://www.nhs.uk/media/2441777/pregnancy_loss_final_1.pdf

Care Quality Commission, *Maternity services survey* (2015)

www.cqc.org.uk/publications/surveys/maternity-services-survey-2015

All bereaved parents are entitled to good care: A mixed-methods multicentre study (INSIGHT) Dimitrios Siassakos^{1,5}, Sue Jackson², Kate Gleeson³, Caroline Chebsey⁴, Alison Ellis⁴, and Claire Storey^{1,5} for the INSIGHT Study Group (to be published imminently)

Downe, S., Schmidt, E., Kingdon, C. and Heazell, A.E. *Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study*. *BMJ open*, 3(2), p.e002237 (2013).

Heazell AEP, Siassakos D, Blencowe H, Burden C, Bhutta ZA, Cacciatore J, Dang N, Das J, Flenady V, Gold KJ, Mensah OK, Millum J, Nuzum D, O'Donoghue K, Redshaw M, Rizvi A, Roberts T, Toyin Saraki HE, Storey C, Wojcieszek AM, Downe S. *Stillbirths: economic and psychosocial consequences*. *The Lancet*. 2016;387(10018):604-16.

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Donna Ockenden, Co-Clinical Director, London Maternity Clinical Network

Jane Scott, Senior Bereavement Midwife, Imperial College Healthcare NHS Trust

Cheryl Titherly, Improving Bereavement Care Manager, Sands

Emily Webster, Maternity Lead, London Clinical Networks

We encourage you to visit the websites of the following organisations which offer support resources for staff and families:

Antenatal Results and Choices (ARC).....	arc-uk.org
Bliss.....	bliss.org.uk
Child Bereavement UK.....	childbereavementuk.org
Miscarriage Association.....	miscarriageassociation.org.uk
Petals.....	petalscharity.org
Sands.....	sands.org.uk

Maternity Bereavement Experience Measure: Sands Survey 2016

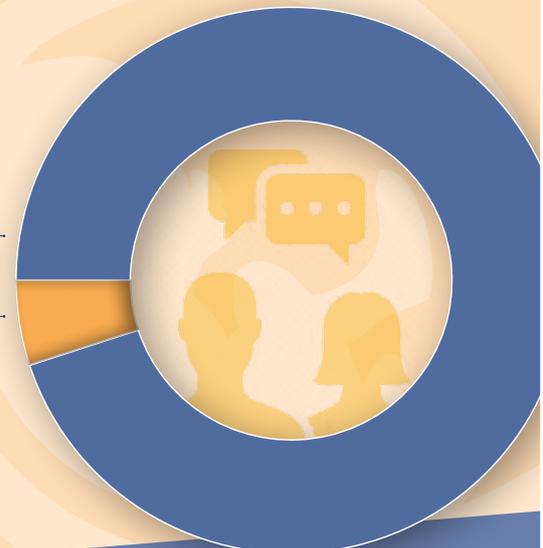
Sands, NHS England and the London Maternity Network are working together to create an appropriate feedback mechanism to enable bereaved parents to inform service improvements. In 2016 Sands carried out a survey to ensure that the parents' voice informed this work.

99%

feel bereaved parents should be asked to feed into bereavement care service improvements.

Do you feel it is appropriate to ask bereaved parents for feedback about their experience of bereavement care after their baby died?

Yes **95%**
No **5%**

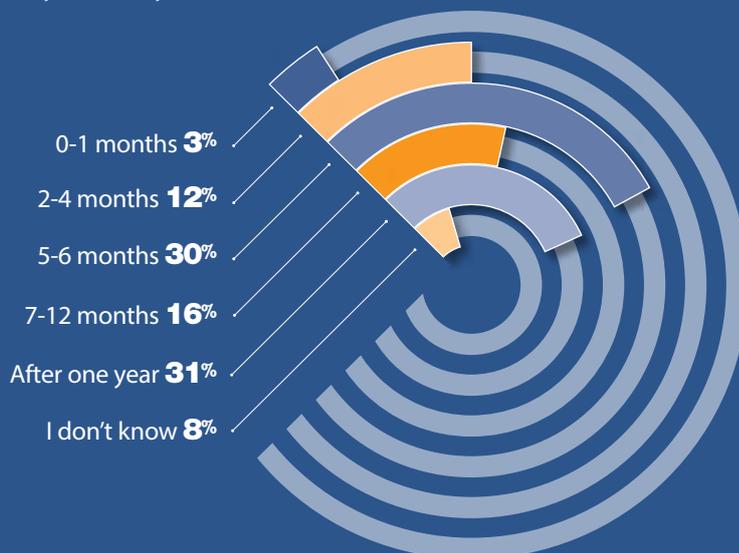


I was happy with our care at the time, the midwife that looked after us during that time was amazing. I would have liked for her to know how pleased we were to have her that day.

Many felt that healthcare services should engage with bereaved parents via **a mix of contact and interaction methods**, to access feedback from the greatest number of people.



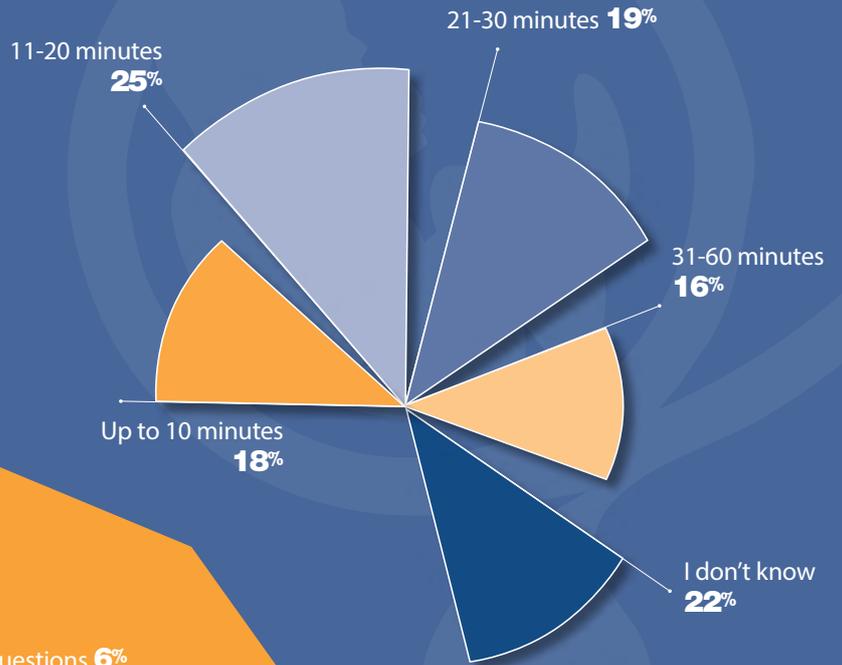
What do you feel is an appropriate time frame for giving feedback about your experience of bereavement care after your baby died?



When seeking feedback, it's important for healthcare providers to bear in mind that each person's experience and reaction is different.

Each person's experience and reaction is different and different people will choose different ways to feed back and what they're willing to discuss.

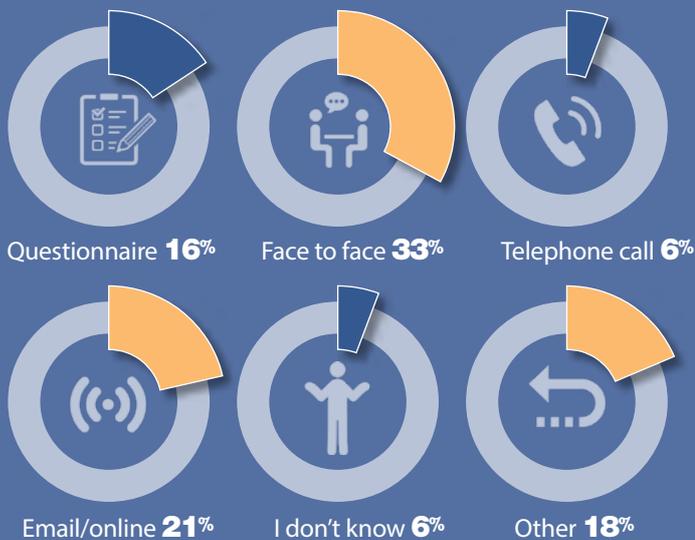
How long should it take to provide feedback about your experience?



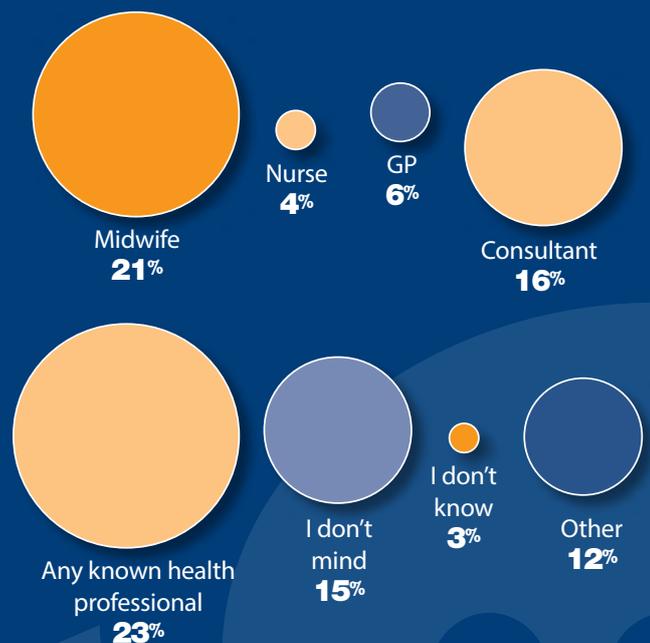
How many questions do you feel is an appropriate number to be asked?



What do you feel is the most sensitive way to ask bereaved parents for their feedback about the care they received after their baby died?



Who would you want to contact you for your feedback?



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Appendix 2 | Covering letter to accompany MBEM

Parent feedback questionnaire

Dear *(name)*,

We are very sorry for the loss of your baby, and appreciate that this is a difficult time for you.

The following questionnaire is a way for our hospital to capture your feedback after the loss of your baby/ babies.

We have worked with bereaved parents to develop this questionnaire to help to ensure that we are asking about what matters most to parents, and that we do this as sensitively as possible. We have included some open ended questions where you can freely express your thoughts and feelings. A member of staff can be with you when you fill out the questions, if you wish, or you can post it back to us.

We will use your answers and comments to continually improve care for bereaved parents.

If you would like future updates on the progress of the maternity bereavement services, please contact the bereavement midwife at your hospital.

(Insert contact details)

If you feel it would be helpful to speak to someone, you may wish to contact the Sands national helpline on 0808 164 3332.

(or local contact)

We appreciate how painful it may be considering the answers to these questions. We are very grateful for your thoughts which will help us improve care for families in the future and are very sorry for any distress that may be caused by responding to our letter.

Kindest regards,

(Organisation)

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Appendix 3 | Maternity Bereavement Experience Measure (MBEM)

Parent feedback questionnaire

We are very sorry for your loss, and we appreciate that this is an extremely difficult time for you.

This questionnaire is for women and their partners that have experienced the loss of their baby/babies during pregnancy or shortly after birth. Please complete as much or as little of the form that you are able to. Some questions may not be relevant to your experience.

Please tick the relevant box for each question and write any comments you might have. All information given will remain anonymous unless you wish to provide your contact details at the end of this questionnaire. If you would like to discuss any aspects of your care, please contact the bereavement team at the hospital.

What is your relationship to the baby / babies who have died?

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree	This was not relevant to my situation
1) I was cared for in an appropriate environment during the delivery of my baby/babies.						
Comments						
2) NHS staff communicated with me/us in a sensitive way.						
Comments						
3) I felt confident in the NHS staff caring for us.						
Comments						

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Appendix 3 | Maternity Bereavement Experience Measure (MBEM)

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree	This was not relevant to my situation
4) I was able to be involved in any decisions about my baby/babies.						
Comments						
5) I was fully informed about what had happened to my baby/babies.						
Comments						
6) I was given the opportunity to spend the time I wanted with my baby/babies.						
Comments						
7) I was given the opportunity to create memories with my baby/babies in the time I needed without feeling rushed (eg photography, foot and handprints, washing and dressing my baby/babies).						
Comments						
8) I felt that my baby/babies were always treated with respect and sensitivity.						
Comments						
9) My family members and my other children were included appropriately in my care.						
Comments						

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Appendix 3 | Maternity Bereavement Experience Measure (MBEM)

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree	This was not relevant to my situation
10) I was given guidance and support when asked about next steps for my baby/babies (such as whether to have a post mortem).						
Comments						
11) I was given time and an opportunity to express my wishes clearly regarding arrangements for my baby/babies (eg a funeral or memorial service).						
Comments						
12) I felt assured that my GP and community midwife had been informed of my loss before I left the hospital.						
Comments						
13) I was provided with all the contact support numbers that I needed at discharge from the hospital.						
Comments						
14) I was able to access bereavement counselling at an appropriate time for me.						
Comments						

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Appendix 3 | Maternity Bereavement Experience Measure (MBEM)

Tell us about any part of the care you received that was most helpful?

Is there any part of your care that could have been improved?

Is there anything you would like to see introduced into the service or anything else you would like to feedback on?

We value the time that you have taken to share your thoughts and experiences with us.
Thank you.

About the London Clinical Networks

The London Clinical Networks bring stakeholders together – providers, commissioners and patients – to create alignment around programmes of transformational work that will improve care for the 8+ million residents of the capital.

The networks provide the clinical expertise and leadership to drive commissioning decision making. In this way, the networks:

- » Improve quality outcomes
- » Advance the delivery of services
- » Reduce unacceptable variations of care