



2023

# Bereaved parents' experiences of care survey report

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Supporting bereaved families.





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# Sands 2023 Bereaved parents' experiences of care survey

In June 2023, Sands launched an online survey asking bereaved parents about their experiences of all aspects of their care. We were keen to identify gaps and inequalities in maternity care to drive improvements across the UK.

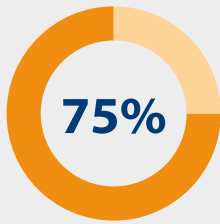
We promoted the survey through social media and other communications channels and received almost 2,000 responses. We were able to analyse 1,699 of these. In this report, we summarise the responses of the 707 families who had experienced pregnancy loss or the death of a baby in the past three years and compare them to the 990 families whose experience was four or more years ago.

We aimed to capture the current state of maternity care, neonatal care, parents' experiences of hospital reviews, bereavement support in the hospital and workplace, and post-mortem services. By comparing parents' experiences in two time periods - that is, in the last three years and those who experienced pregnancy loss or the death of their baby four or more years ago - we also aimed to capture changes over time.

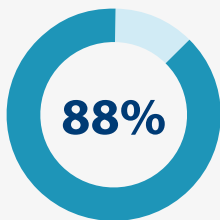
Parents' experiences of loss, reflected in this report, include stillbirth (53%), miscarriage and late fetal loss (25%); the death of their baby within the first 28 days of being born (20%), and the death of an infant (4%), and TMFR (1%). We would like to thank them all for their courage in sharing their experiences.

**Our report breaks down their responses to each stage of their care pathway.**

## Headline findings:



- The most positive responses along the clinical pathway were from those families whose baby received care in a special baby care unit or neonatal intensive care unit; 75% felt they were treated with respect.



- Parents' experiences of bereavement care have improved over time, with 88% saying they were able to make memories of their baby in the last three years compared to 74% before this.



- The proportion of parents who were told about reviews and investigations into their care has more than doubled, and more parents were offered the opportunity to share their questions and concerns with the team reviewing the quality of their care.



- Parents were taking more time off work after their loss regardless of their baby's gestation.



- Among people who lost their baby more recently, 34% did not have confidence in the staff caring for them; almost half felt more could have been done for them and their baby.



- There was little difference in parents' confidence in their care if their baby died during labour or shortly after birth. Many parents still go home feeling more could have been done to save their baby.



- The average time it takes for parents to receive their post-mortem results has significantly worsened. Not only has it doubled over the two time periods, but the proportion of parents waiting six months or more has trebled.

# Safe and personalised care during pregnancy

Individual and personalised care is a marker of safety. We asked families about the information they received from healthcare professionals during pregnancy and how well they understood it. Sixty-one per cent of parents bereaved in the last three years felt they could easily understand the information they were given. Despite the improvements made in this area over the two time periods, some more recently bereaved parents said they received information that was not shared sensitively or took into account their communication needs.

*"I didn't have any worries and no health issues with me or the baby, but stillbirth was never mentioned, not even once, as a risk in going overdue. Looking back, had that been discussed, I might have considered induction more seriously and/or gone to the hospital sooner."*

**Mother of a baby stillborn at 40 weeks**

Evidence and previous Sands surveys have identified that parents often have concerns about their baby before they died.<sup>1,2</sup> In this survey, among more recently bereaved respondents:

63%

□ 63% said they had concerns

48%

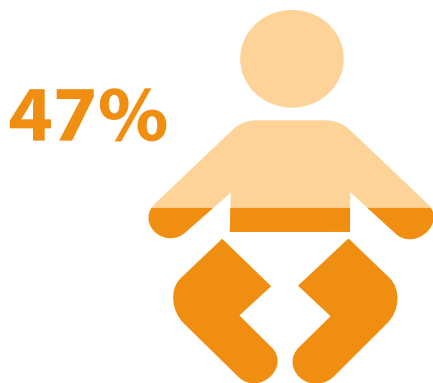
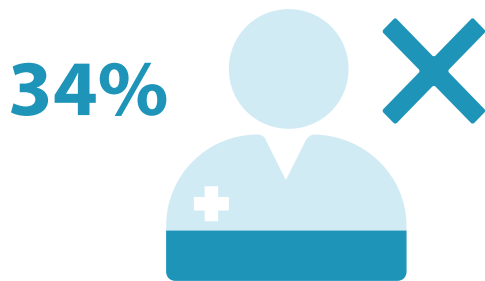
□ 48% did not feel their concerns were taken seriously

50%

□ 50% felt healthcare professionals did not act on their concerns.

*"I fully believe (although it cannot be proven) that my daughter would be here living with me if I had been listened to. I raised concerns on three separate occasions and on the last instance, it was too late. When a young, inexperienced mother says she knows her body, medical staff need to LISTEN and act accordingly."*

**Mother of a baby, born at 24 weeks, who died neonatally**



We asked families about the tests and monitoring they received during pregnancy, whether they had confidence in staff caring for them, and whether they felt everything possible had been done for them. Respondents who lost a baby in the past three years were equally divided between those who felt they did and those who felt they didn't have all the tests or monitoring they needed.

**Of people who lost their baby more recently, 34% did not have confidence in the staff caring for them. Almost half (47%) felt more could have been done for them and their baby.**



# Care during labour and delivery when the baby is born alive

National enquiries have identified that 8 out of 10 babies who die due to something going wrong in labour at term might have been prevented with better care.<sup>3</sup> Of those families whose baby died in the last three years, over half (62%) felt they had confidence in the staff caring for them, while 36% did not. While most (60%) felt they had all the tests and monitoring they and their baby required, a significant proportion (34%) felt they did not. There was little difference in the responses from parents over the two time periods, suggesting parents' confidence in care remains largely unchanged, with many parents still leaving hospital feeling more could have been done to save their baby.

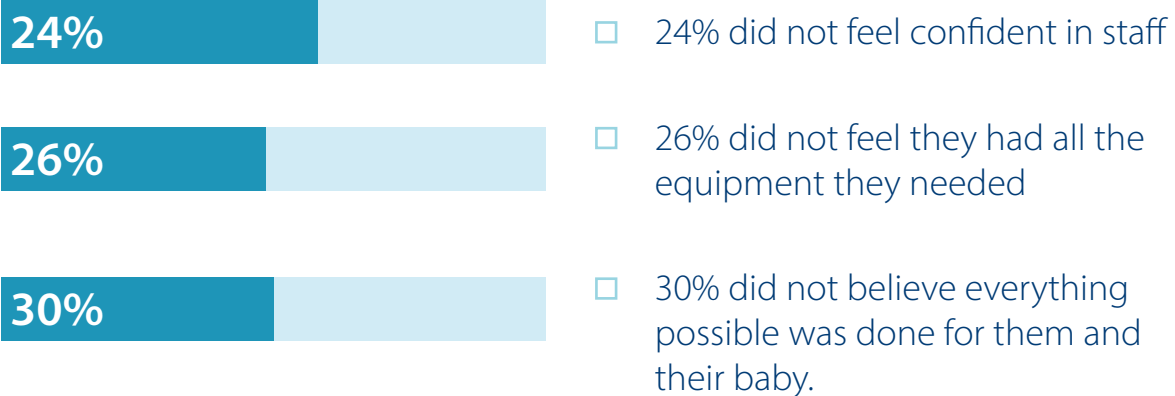
This mother highlighted the lack of equipment needed:

*The maternity unit did not have fetal scalp electrodes available - how can this ever be acceptable? All efforts should be directed to ensure that this is mandatory for maternity units.*

**Mother of a baby, born at 40 weeks, who died neonatally**

## Care for mothers and babies very shortly after birth

We know from research that the minutes and hours after birth are key for parents whose baby is born in poor condition and may die.<sup>4</sup> When we asked parents whose baby had died in the past three years about their experiences on the labour ward after their baby was born:

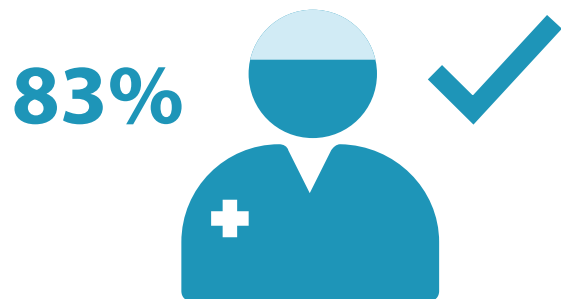


There was only a very slight increase in the number of parents who felt confident in their care in the minutes and hours after their baby was born, over the two time periods.

# Parents' experiences of neonatal care

The experiences of parents whose baby spent time in Neonatal Intensive Care Unit (NICU) or a Specialist Care Baby Unit (SCBU) were significantly better compared to other parts of the care pathway and had improved over time. For two-thirds (66%) of families whose baby had died in the last three years, most (79%) agreed that they had all the necessary tests and monitoring done, and 85% agreed that all the equipment and facilities were available.

**The majority (83%) had confidence in staff and felt that everything possible was done for them and their baby (78%).**



*"The midwives held my hand and supported me until I was well enough to travel to the hospital my little boy was transferred to. Once I arrived at the NICU, very late at night, the midwives and nurses let me see him immediately. They answered all my questions and never made me feel rushed or that I had to leave despite the time of day! They cared for my baby boy like he was their own, and I will be forever grateful that the three days he was alive, he was surrounded by such loving, caring people!"*

**Mother of a baby, born at 34 weeks, who died neonatally**

This wasn't the case for everyone, however. A mother whose baby was on the neonatal ward for over a month told us:

*"We went through the NICU experience in two separate hospitals. The first hospital was a level 3 (highest) unit where we felt we weren't very included in things that went on. During the rounds, the doctors would just talk amongst themselves while they were stood in front of us and our baby."*

**Mother of a baby, born at 26 weeks, who died neonatally**

While most (71%) families felt involved in decisions about their child's care,



71%

18% of respondents felt this wasn't the case,



18%

and 26% felt that their choices and opinions were not taken seriously.



26%

## Parents' experiences of bereavement care

The vast majority of respondents felt positive about their bereavement care experiences, which had improved over time. Most (80%) recently bereaved parents of stillborn babies felt staff caring for them had the right skills and knowledge to look after them as well as possible during the delivery of their baby. This compares to 73% of respondents from the earlier time period.

Almost all (88%) families bereaved in the last three years had the opportunity to make memories with their baby; felt confident in the staff caring for them (82%); felt they and their baby were treated with respect (85%); and felt that they were communicated with sensitively (82%).

*"The care we received was outstanding. The staff were so kind and respectful. They made what was an awful time feel peaceful. One of the main things the midwives did was refer to our baby by his name; they talked to him and showed him love and respect."*

**Mother of a baby stillborn at 40 weeks**

# Parents' experiences of post-mortem services

Delays in parents receiving post-mortem results have significantly worsened over time. Almost 1 in 5 (21%) parents reported waiting up to six months or more for the results of their baby's post-mortem.

Almost all parents who consented to a post-mortem spoke about long waiting times and significant impact that has had on them. For some parents, the delay meant they could not plan for another child:

*The wait was particularly difficult. I wanted to try for another baby, but I was told to wait. The wait delayed our grieving process.*

**Mother of a baby, born at 36 weeks, who died during labour**

*We are still waiting for the post-mortem results, 3 1/2 months later, with no indication of when they'll be ready. This is incredibly distressing as we still do not know why our baby died. It is adding to our difficulty in accepting she's no longer with us.*

**Mother of a baby, born at 40 weeks, who died neonatally**

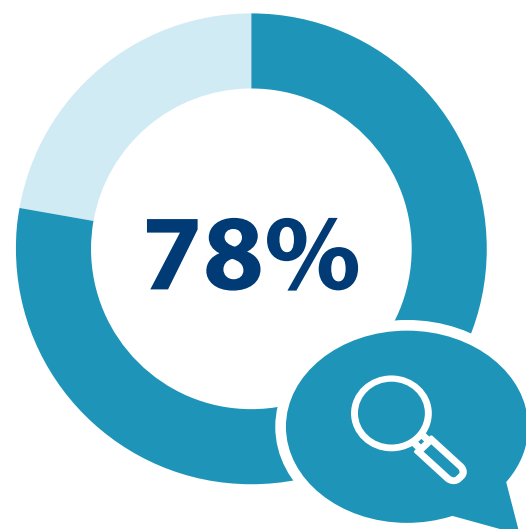
Encouragingly, the majority (89%) of more recently bereaved parents felt able to make a decision about post-mortem that was right for them compared to 82% of people whose baby died four or more years ago.

*I am very glad that I had a post-mortem done. The staff explaining and consenting to the procedure were very knowledgeable, both about the medical side but also about how they treat the baby with respect. I was able to know where my baby was at all times, which was very important to us.*

**Mother of a baby, born at 40 weeks, who died neonatally**

## Parents' experiences of hospital review and other investigations

A review supports parents in understanding why their baby died and hospitals in identifying where improvements are needed to make care safer for future parents. **Our survey found significantly more people were told about the review within the past 3 years compared to those whose baby died four or more years ago, with an increase from 44% to 78% of parents being told.**



While the latest national report around reviews undertaken in the UK found that 18% of baby deaths might be avoided with better care, research also indicates that including parents' perspectives needs to be part of any review process in order to drive improvements in patient safety.<sup>5,6</sup> It was positive to see, therefore, that our survey found the number of parents being given the opportunity to share their concerns and questions about their care has more than doubled over time, from 25% to 64%.

Nevertheless, while just over half (54%) of recently bereaved parents said the review answered some or all of their questions about why their baby died, a significant proportion (34%) said they did not receive answers, either because they were unaware of the review (11%) or because they took part in the review, but it did not provide any answers (23%).

Parents' experiences of being invited to contribute to the review were not always positive:

*I contacted multiple staff members at the hospital to ask questions about the review, my placenta, blood test results, and many other things. No one ever got back to me until I put a complaint in, then they responded to that months late with a completely poor response that didn't in any way deal with the issues I had raised.*

**Mother of a baby, born at 40 weeks, who died during labour**

While parents' overall satisfaction with the review process has improved from 31% to 56% over time, a third of recently bereaved parents are still unsatisfied.

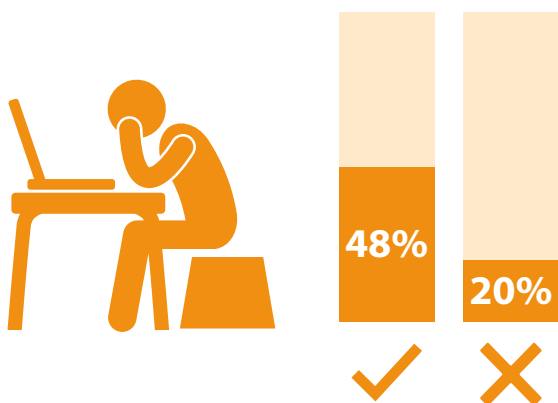


# Parents' experiences of bereavement in the workplace



Families who experience pregnancy loss or the death of a baby after 24 weeks are now taking more time off work than parents who experienced loss four or more years ago, with an average of 20 weeks off work compared to 12 weeks.

Our survey shows that parents who have experienced earlier pregnancy losses are also taking longer off work after their loss than in the past, with an average increase of 1.5 weeks more off work.



**While 48% of respondents who experienced pregnancy loss or the death of a baby in the past three years felt supported in the workplace upon returning, 20% said they did not.** Forty per cent of parents said their employer did not have a baby loss policy, and 42% did not know if their employer had a policy or not.

*When I told my manager I'd had a silent miscarriage, all she said was 'okay.' It's heartbreaking when somebody shows such a lack of emotion about something that's torn your whole world apart. There are people out there who understand your pain and want to help you but when your workplace shows such lack of support, it's very lonely.*

**Mother who experienced an early pregnancy loss**

Even if workplace policies are in place, inequalities still exist for those who can and can't afford to take time off work:

*My wife took around four weeks off work. Her employer is absolutely amazing, but I wasn't able to stop working as in the financial support for our family and self-employed. It would be lovely just to have a rest from the world, but they still want the rent money.*

**Father where the pregnancy was terminated for medical reasons**

## Thank you and next steps

We would like to thank all the families who shared their experiences with us. Sands is committed to listening to parents' voices, and ensuring the experiences they share are used to influence policy and practice change wherever we can.

This is the largest survey of bereaved parents that Sands has undertaken to date, and whilst we recognise it is not representative of the UK adult population, we are confident that these important findings complement and support other research and data to help create a better understanding of pregnancy loss and baby death.

This summary report contains our headline findings. Further in-depth analysis of specific areas of care and care in specific nations will be undertaken as appropriate.



## References

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3. Draper, E., Kurinczuk, J., & Kenyon, S. (2017). MBRRACE-UK Perinatal Confidential Enquiry: term, singleton, intrapartum stillbirth and intrapartum-related neonatal death.
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6. <https://www.bristol.ac.uk/policybristol/policy-briefings/engaging-parents-baby-loss/>

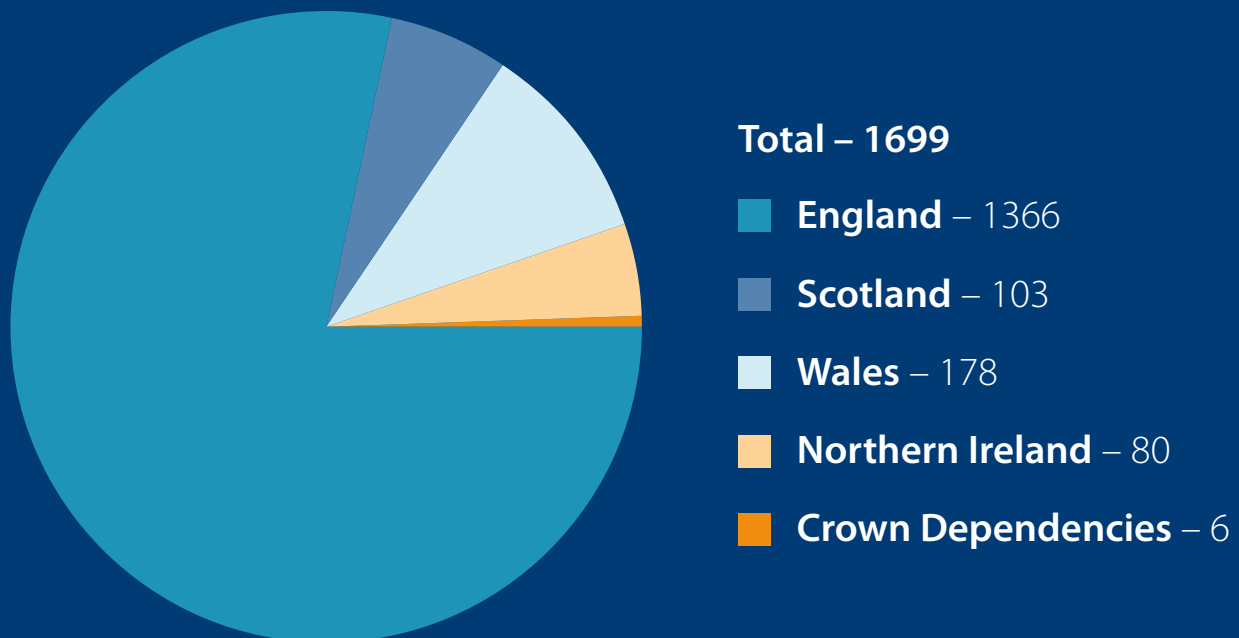
## Appendix 1

# What we did and who responded

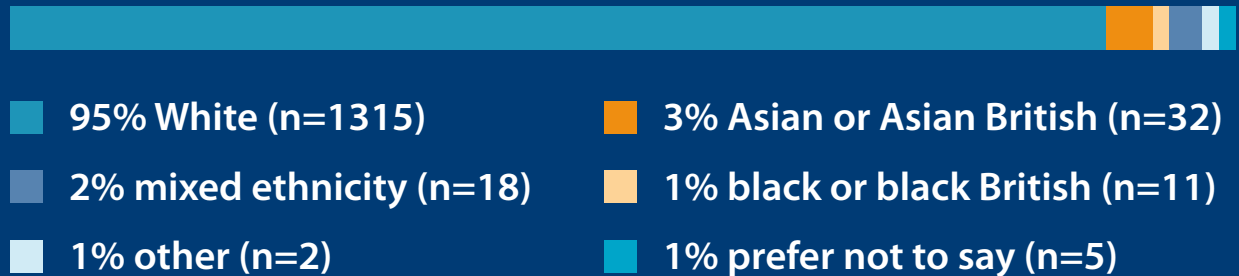
The survey was promoted through communication channels, including Twitter, Facebook and Instagram. The survey was open for one month in June 2023. Due to this recruitment method, we acknowledge that the respondents are self-selecting.

The respondents to this survey were broken down into those who were bereaved in the last 0-3 years, and those bereaved 4 or more years ago, allowing us to measure change over time. The data below is the demographics for all respondents.

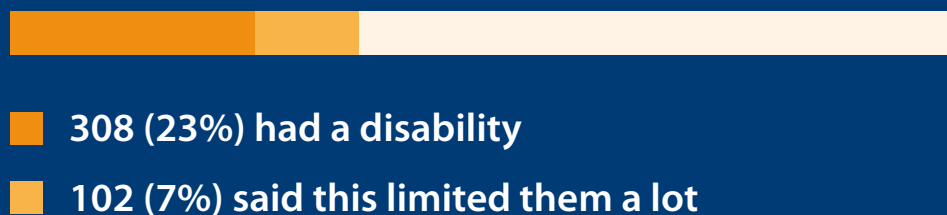
### Country and region where care took place



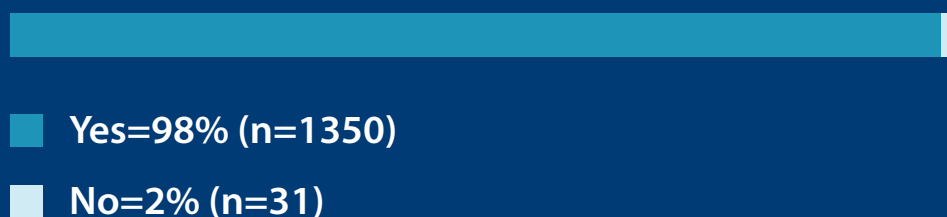
## Ethnicity



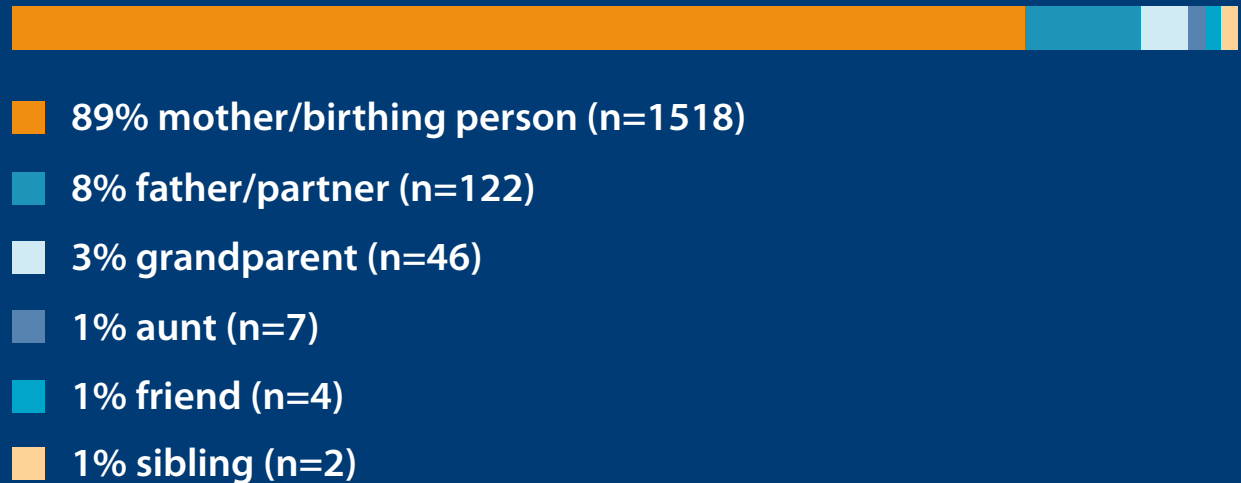
## What proportion had a disability, and said their disability impacted their daily life?



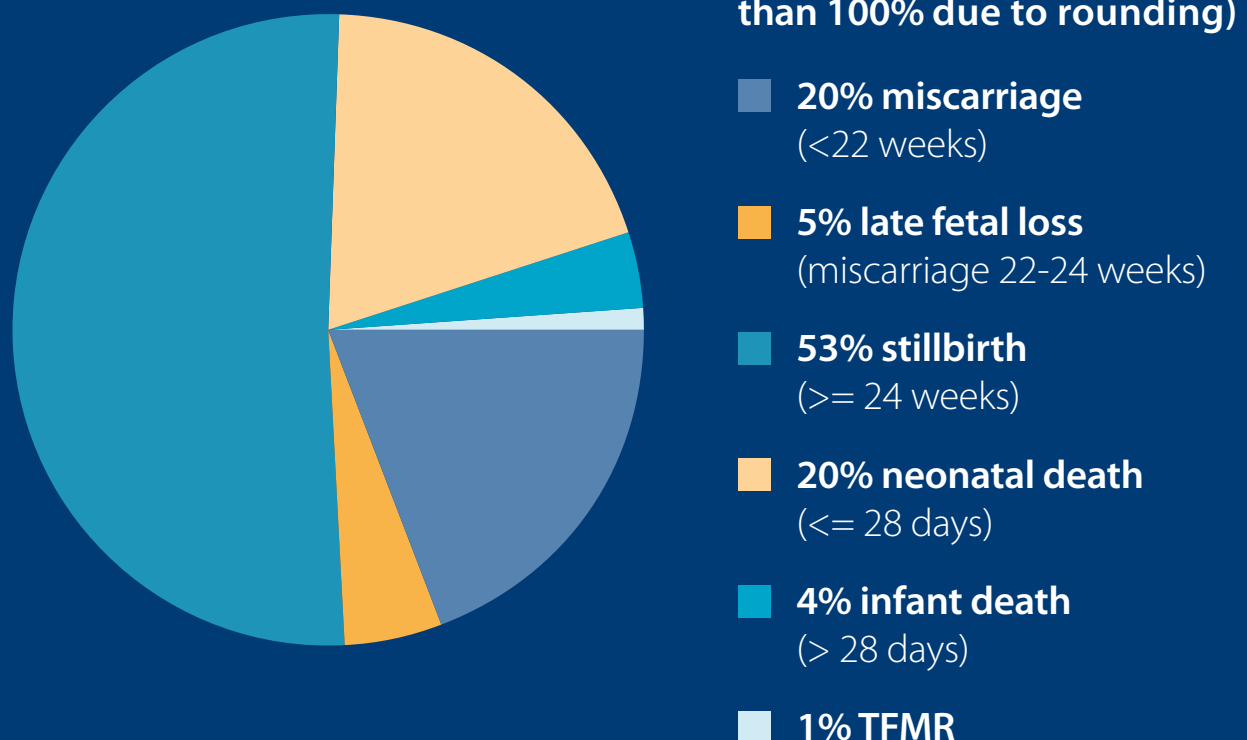
## Is English your first language?



## Who responded?



## Experience of loss



## Single pregnancy or multiple (twins etc.)



■ 94% single

■ 6% multiple



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