

A decorative graphic on the left side of the slide featuring several overlapping circles in various colors: a large purple circle, a yellow circle, a small orange circle, a green circle, and a pink circle. Each of these larger circles contains a smaller white circle with a thick colored border matching the outer circle's color.

National Maternity Review Online Survey Analysis – Survey on Loss and Complications

NECS Consultancy Unit

Accessibility



This document supports the report of the National Maternity Review and provides an analysis of the online consultation held as part of the public engagement phase. In support of this a number of charts and diagrams are shown to illustrate findings. If you struggle to view; read, or understand, any of this information please contact england.maternityreview@nhs.net

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Introduction (1)



This is a survey about the care provided through pregnancy, birth and after birth. It forms part of the NHS Maternity Review online consultation. The review team have been working in collaboration with the charities Sands and Bliss to ensure that important views are heard from people who have experienced complications in pregnancy, neonatal admission after their baby's birth, or whose baby died at any point during pregnancy or shortly after birth.

This survey is specifically for two groups of people: Firstly, those whose baby died during pregnancy (including miscarriage), labour or soon after birth; and secondly, for families who experienced pregnancy complications affecting the health of the mother or baby and/or neonatal admission after birth.

In response to feedback from Sands and Bliss, we worked in partnership to develop this survey. Whilst we understand that it may have been difficult and upsetting to respond, we value your views and suggestions as they help to ensure that we improve services in the future. All your comments and answers were treated anonymously.

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Introduction (2)



At the close of the consultation, the number of responses received totalled 1355. To ensure an independent review, NHS England contracted the North of England Commissioning Support Unit (NECS) to analyse the responses and focus on the analysis of the qualitative data from the consultation.

The analysis has broadly followed a content analysis methodology, which centres on the quantification of text; it places significance on the frequency of a phrase or comment to an individual question. This approach enables presentation of results in a format more readily associated to quantitative analysis e.g. graphs and tables based on percentage results.

The table below outlines the process for undertaking content analysis. All analysis was iterative and involved reassessment of both the categories and groups continually through the compiling of this report.

Stage	Description
1. Categories	Review all qualitative responses and categorise the different comments within each statement
2. Groups	Combine the initial categories into groups around a similar topic
3. Evaluate sub groups	Additional analysis undertaken on a subset of questions to identify any variation in responses due to age or ethnicity of the respondent
4. Compile report	Provide a transparent report outlining the results of the analysis. This will include both qualitative and quantitative results. Selected comments from the responses will be included to encapsulate the main points raised. The report however will not draw any conclusions or recommendations

Methodology – Advantages and Limitations of Approach



The results of the analysis present how frequently a statement or group is present by quantifying the text from the online responses. This analytical approach rests upon the assumption that the frequency of commentary infers the level of importance or priority in relation to each other.

As with all methodologies for analysis, there are limitations with this approach. As individual responses are broken down and categorised; the original context of the response can be lost or undermined. In particular, the analysis does not take into consideration any implied meaning or tone. Similarly, this approach does not make any adjustment or consideration for preference or priority stated by an individual. For example, if an individual suggests five improvements to their experience during labour, the analysis will weight each the same regardless of whether one was stated as the top priority.

To mitigate the potential for bias based on professional experience all coding and analysis of the results has been undertaken by individuals not involved in maternity services. Due to the interpretative nature of qualitative analysis, a level of interpretation from those undertaking the analysis may influence the analysis' overall objectivity. To mitigate this as much as possible, the people involved in the data analysis ensured they performed their duties without prejudice or bias based on personal experiences or beliefs.

Restrictions



Due to time restrictions, there are a number of limitations to the analysis undertaken:

- The majority of questions have been analysed in batches based on the type of question. This has resulted in similar groupings between questions but no overarching review of the identified groups.
- Where respondents refer to an answer to a previous question, unless the information is repeated, it has not been captured in the analysis
- No analysis has been undertaken on comments made which do not relate to the question
- Due to grouping of comments presented within overarching groups, there is an element of generalisation of the findings. A breakdown of the sub groups which make up the top two or three main groupings is provided for each question
- There is no judgement on the transferability of results from the analysis.

Overview of Respondents



The survey received approximately 1355 responses.

The 1355 respondents were able to choose multiple statements which described their experience. From the 1355 responses 2434 statements were ticked. Based on the statements ticked by each individual respondents, they were directed to complete one or both of the following sections of the survey:

Section 2: Questions for people whose baby died during pregnancy (including miscarriage), during labour, or after birth

Section 3: Questions for families who experienced pregnancy complications (affecting the health of mother or baby), and/or neonatal admission after birth

An individual was able to respond to both sections of the questionnaire.

What did you experience? (1355 respondents)	No. of ticks	%	Relevant section of survey
Complications during pregnancy with mother's health	353	15%	Section 3
Complications during pregnancy with baby's health	407	17%	Section 3
Miscarriage	353	15%	Section 2
Stillbirth before baby born	243	10%	Section 2
Stillbirth during labour	59	2%	Section 2
Death of your baby very soon after birth	105	4%	Section 2
Premature labour	314	13%	Section 3
The admission of your baby to a neonatal unit	516	21%	Section 3
The death of your baby in neonatal care	84	3%	Sections 2 & 3
Total	2434	100%	

Presentation of Analysis



This report focuses on the presentation of the output from the online consultation analysis. The results are categorised by one of four cohorts that the respondent identified themselves with at the beginning of their submission. These are:

Section 2: Questions for people whose baby died during pregnancy (including miscarriage), during labour, or after birth

- Antenatal care - thinking about your pregnancy before your baby died
- During pregnancy - if your baby died in pregnancy, thinking about your care in hospital after the death was diagnosed
- During labour or soon after birth -if your baby died during labour or in the maternity unit shortly after birth, please think about the care you received during and after labour.
- Neonatal care - if your baby was transferred to a neonatal unit
- Postnatal care - thinking about your care after you went home after your baby's death

Section 3: Questions for families who experienced pregnancy complications (affecting the health of mother or baby), and/or neonatal admission after birth

- Antenatal care -if complications arose during pregnancy related to the mother's health or the health of the baby
- During labour - if your baby suffered harm during labour, thinking about the care you received during and after labour
- Neonatal care - If your baby was transferred to a neonatal unit
- Postnatal care - thinking about your care after you went home

Presentation of Analysis



For each question, relating to the specific cohort, the following information (where applicable) is presented:

- The number of responses to each question –no question was mandatory, the number of respondents varies by question
- The number of relevant responses - in all the questions a small number of responses contained the classification of not relevant or containing only comments not directly related to the question
- The total number of comments – the total number of individual comments coded.
- The total number of comments by groupings: the total number of comments broken down into the different groups identified within that question
- Representative quotes: extracts from responses which have been coded against the most commented sub group are included as part of each sub group breakdown

Section 2: Questions for people whose baby died during pregnancy (including miscarriage), during labour, or after birth



Twenty three questions were asked in this section. The questions are grouped under five headings. These are:

- Antenatal care - thinking about your pregnancy before your baby died
- During pregnancy - if your baby died in pregnancy, thinking about your care in hospital after the death was diagnosed
- During labour or soon after birth - if your baby died during labour or in the maternity unit shortly after birth, please think about the care you received during and after labour.
- Neonatal care - if your baby was transferred to a neonatal unit
- Postnatal care - thinking about your care after you went home after your baby's death

Antenatal Care



Within this section of the survey, respondents were asked to think about their pregnancy before their baby died. This section is made up of eight questions which are outlined below:

No	Question
2.1	At what stage did your baby die?
2.2	How many weeks gestation/ how old (in days and weeks) was your baby when he or she died?
2.3	Do you feel that you received good quality care in your pregnancy?
2.4	What could have been done differently to improve your care during pregnancy?
2.5	Did you feel involved in decisions about your care during pregnancy?
2.6	Did you have enough time with your midwife or doctor to talk through decisions and concerns during your pregnancy?
2.7	Did you feel after talking through your decisions and concerns they were acted on?
2.8	What did you think about the information you were given during pregnancy (i.e. did it give you the information you needed in a way you could understand?)
2.9	We would like your thoughts on continuity of care. How important would it be for you to be supported by the same midwife before, during and after birth?

Q 2.1 At what stage did your baby die? (Antenatal Care)



Out of the 774 respondents who answered this question, 542 (70%) stated their loss of baby occurred before birth and 83 (11%) said their baby died during labour/birth.

Stage	Number	%
After birth	149	19%
Before birth	542	70%
During labour/birth	83	11%
Total	774	100%

Q 2.2 How many weeks gestation was your baby when he or she died? (Antenatal care)



Information on 596 losses of baby before birth were recorded, this included multiple cases for individual respondents.

Weeks	Number	%	Weeks	Number	%
4	7	1%	24	8	1%
5	12	2%	25	15	3%
6	32	5%	26	13	2%
7	18	3%	27	13	2%
8	44	7%	28	8	1%
9	23	4%	29	5	1%
10	34	6%	30	4	1%
11	33	6%	31	7	1%
12	33	6%	32	12	2%
13	12	2%	33	9	2%
14	9	2%	34	11	2%
15	9	2%	35	6	1%
16	15	3%	36	20	3%
17	20	3%	37	20	3%
18	9	2%	38	14	2%
19	12	2%	39	20	3%
20	19	3%	40	15	3%
21	16	3%	41	9	2%
22	7	1%	42	3	1%
23	18	3%	unknown	2	0%

Q 2.2 How many weeks gestation was your baby when he or she died? (Antenatal care)



Information on 86 losses of baby during labour and birth were recorded, this included multiple cases for individual respondents.

Weeks	Number	%	Weeks	Number	%
15	1	1%	26	2	2%
16	1	1%	29	2	2%
17	2	2%	34	4	5%
18	3	3%	35	1	1%
19	2	2%	37	4	5%
20	6	7%	38	1	1%
21	8	9%	39	6	7%
22	13	15%	40	9	10%
23	4	5%	41	10	12%
24	3	3%	42	3	3%
25	1	1%			

Q 2.2 How many weeks gestation was your baby when he or she died? (Antenatal care)



Information on 78 losses of baby after birth were recorded, where the individual shared the gestation period at birth but not the age of baby when they died.

Weeks	Number	%	Weeks	Number	%
15	1	1%	30	4	5%
19	2	3%	31	2	3%
20	2	3%	33	2	3%
21	5	6%	34	1	1%
22	7	9%	36	2	3%
23	5	6%	37	2	3%
24	8	10%	38	2	3%
25	7	9%	39	3	4%
26	3	4%	40	6	8%
27	3	4%	41	4	5%
28	3	4%	42	1	1%
29	3	4%			

Q 2.2 How old was your baby when he or she died? (Antenatal Care)



Information on 73 losses of baby after birth were recorded, where the individual shared the age of the baby when they died.

Days	Number	%	Days	Number	%
1	21	29%	15	1	1%
2	4	5%	17	2	3%
3	9	12%	19	2	3%
4	2	3%	21	3	4%
5	3	4%	28	3	4%
6	1	1%	33	3	4%
7	3	4%	35	3	4%
8	2	3%	40	1	1%
9	1	1%	49	2	3%
11	1	1%	51	1	1%
13	2	3%	56	1	1%
14	1	1%	63	1	1%

Q 2.3 Do you feel that you received good quality care in your pregnancy? (Antenatal care)



761 individuals answered the yes/no part of this question, 444 (58%) answered yes and 317 (42%) answered no. 185 who said yes and 296 who said no left further comments. In addition, 11 respondents who did not answer yes or no left further comments.

Answer	No. of respondents	%	No. of text responses	%
Yes	444	58%	185	63%
No	317	42%	296	101%
Not answered			11	4%
Total	761	100%	492	100%

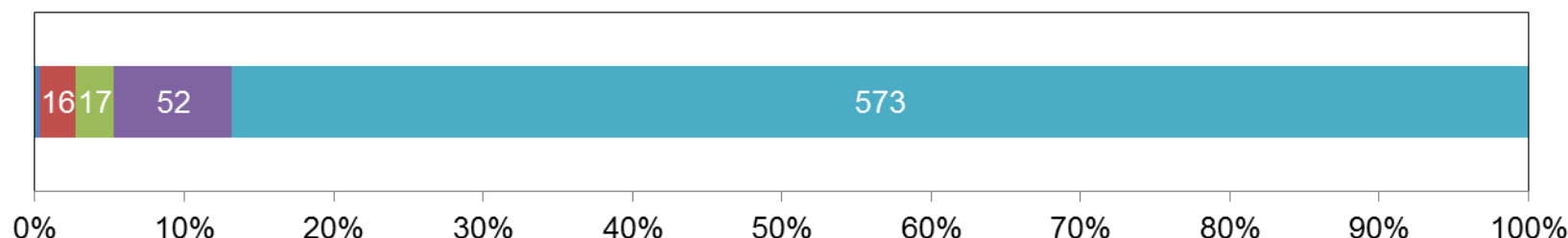
492 individuals chose to leave a comment, including 11 who had not responded either yes or no. From the 492 individuals who left a response, 674 comments were identified and broken down into two groups:

Group	No. of comments	%	Sub Group	Description	No. of comments	%
Negative	481	71%	Patient care and support	Comments included; complications not dealt with or explained clearly, poor communication.	336	50%
			Staff Attitude	Comments around poor care received from staff due to a perceived lack of compassion	148	21%
Positive	190	29%	Patient care and support	Comments included; they felt supported throughout, communication was good, things were explained well and regular monitoring was received	145	22%
			Staff Attitude	Comments around positive experience due to the attitude of staff. Comments included fantastic, kind, sympathetic and supportive staff	45	7%

Q 2.4 What could have been done differently to improve your care during pregnancy? (Antenatal care)



From the 660 responses 573 (87%) contained comments on what could have been done differently to improve care during pregnancy. 52 (8%) stated there was nothing to improve, 16 (2%) made only a general negative statement, 2 (<1%) made only an general positive statement. 17 (3%) responses stated that the question was not applicable to them.



Group	Description
Improvements	Comments received identified improvements = 573
Nothing	Comments received identified no improvements required = 52
Not applicable	N/A entered into field, or response not applicable = 17
General Positive	General positive comment made but no specified improvement = 16
General Negative	General negative comment made but no specified improvement = 2

Q 2.4 What could have been done differently during pregnancy (Antenatal Care) - Key areas for improvement



From the 573 relevant responses, 1152 comments on areas for improvement were identified. 221 (19%) stated that improvements were needed around quality of care, 219 (19%) related to improvements in communication between service users and healthcare professionals.

Top Groups	No. of comments	%	Description
Quality of care	221	19%	Improving the standards of the treatment and care provided, problems with inaccurate medical notes
Communication	219	19%	Improving communication by increasing transparency, sharing information more frequently and in more detail with patients
Scans	146	13%	Regular scanning provisions and improvements in the quality of those already undertaken
Emotional support	117	10%	More emotional support being provided to parents
More Staff	115	10%	More staff, including access to those with breadth of experience
Staff attitude	109	10%	Improving the attitude and language staff use with service users
More check ups and on time	104	9%	More regular check ups
Closer monitoring	33	3%	More monitoring and support for those who have suffered loss of a baby in the past
Other	88	8%	Other individual suggestions for improvements to antenatal care

Q 2.4 What could have been done differently during pregnancy (Antenatal Care) – Quality of care



The quality of care group accounted for 19% of all comments made. These comments were broken down further into seven groups. The two most common sub groups were general statements on quality of care with 85 (38%) comments, and consistency in the quality of care with 45 (20%) comments.

Quality of Care

- “Should have been admitted on my first visit to triage. I'd lost my mucus plug and was in pain but was sent home! Went back to triage haemorrhaging then things became critical.”
- “Swabs taken by GP when I went with an unusual discharge. They weren't really interested & said it was normal, but it was an infection which caused the death of my babies.”

Group	No. of comments	%	Description
General	85	38%	General comments on the quality of care provided
Consistency	45	20%	More consistency in the care delivered
Early in pregnancy	32	14%	Improvements specifically in the care early on in pregnancy
Medical notes not accurate	24	11%	Improve the accuracy and management of medical notes
Continuity	17	8%	Provide a continuity in staff
Group B streptococcus testing	16	7%	More Group B streptococcus testing
Dilatation and Curettage	2	1%	Improve the dilatation and curettage procedures

Q 2.5 Did you feel involved in decisions about your care during pregnancy? (Antenatal care) – Yes/ No



Question 2.5 gave respondents the opportunity to answer yes or no to whether they felt involved in decisions about their care during pregnancy. 759 respondents answered yes or no, with 498 (37%) selecting yes and 261 (195) selecting no. A total of 319 respondents provided a comment, including 11 individual who did not answer the yes/no part of the question.

Answer	No. of respondents	%	No. of text responses	%
Yes	498	66%	122	38%
No	261	34%	186	58%
Not answered			11	4%
Total	759		319	

Q 2.5 Did you feel involved in decisions about your care during pregnancy? (Antenatal care)



From the 319 comments, 301 (94%) were related to whether they felt involved in decisions about their care during pregnancy. 18 (6%) responses did not specifically identify whether they did or did not feel involved.



0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Group	No. of respondents	%	Description
Relevant responses	301	94%	Specific response on how involved they felt in their or their baby's care
N/A or stated elsewhere	18	6%	Not applicable or stated elsewhere in the survey

From the 301 relevant responses, 407 comments were identified and broken down into negative and positive groups. 279 (69%) were specifically negative responses and 128 (31%) were positive.

Q 2.5 Did you feel involved in decisions about your care during pregnancy? (Antenatal care) – Negative comments



From the 301 relevant responses, 407 comments related to how involved they felt in decisions about their care, with 279 (69%) comments being negative about their involvement.

From the 279 negative comments, 49 (18%) comments were made around how they didn't receive options or choices, and staff failed to involve them in their care. 54 (19%) comments stated that they were not appropriately involved however did not comment on any specific aspects.

Negative Group	No. of comments	% of negative	Description
General negative experience	54	19%	General comments which state that they were not involved, too involved or not involved at certain points
Lack of choice	49	18%	The approach was too rigid or they were told what to do rather than given choice
Not listened to	39	14%	Individuals felt that either they or their partner was not listened to
Concerns	35	13%	Concerns raised were not addressed or taken seriously
Uninformed	38	14%	Individuals were not kept informed by healthcare professionals
Staffing	29	10%	More staff/ better access to staff
Decisions	21	8%	Problems with decision making such as not enough support given when making choices
Care/ non-Specific	14	5%	Negative comments on the overall experiences of care rather than specifically on their level of involvement

Q 2.5 Did you feel involved in decisions about your care during pregnancy? (Antenatal care) - General negative comments



There were 54 general negative comments with 29 (54%) not feeling involved. 11 (20%) comments were about inconsistencies in their level of involvement and 10 (19%) comments were in relation to having to fight to be involved.

Not involved

- “We were told what would happen and when. No consultation.”
- “No I felt disempowered.”

Sub Group	No. of comments	% of comments
Not involved	29	54%
Inconsistently involved	11	20%
Had to fight to be involved	10	19%
Not involved during labour	2	4%
Too involved	1	2%
Not involved pre 13 weeks	1	2%

Q 2.5 Did you feel involved in decisions about your care during pregnancy? (Antenatal care) - Lack of choice



There were 49 comments from respondents who said they experienced a lack of choice. The most commented on sub group related to being told what to do 36 (78%) respondents. 13 (28%) respondents stated that they felt that the process was too rigid for them to be able to be involved.

Uninvolved

- “I didn't feel that I would have been supported if I'd challenged decisions or wanted to know more about alternative birthing etc.”
- “I felt pushed to have a medical miscarriage reuse - I wasn't given any rationale about why so I felt uninformed about the choices .”

Sub Group	No. of comments	% of comments	Description
Uninvolved	36	73%	Not given the chance to be involved and told what should or should not be done
Poor process	13	27%	Process is too rigid and does not allow room to be involved in decisions

Q 2.5 Did you feel involved in decisions about your care during pregnancy? (Antenatal care) - Positive comments



There were 407 comments relating to how involved individuals felt in decisions about their care. The largest sub group with 128 (31%) comments was general positive comments about their involvement.

Group	No. of comments	Comments (% of positive)	Description
General positive experience	32	25%	General comments which state that they were involved in decisions
Decisions respected	32	25%	Decisions they made were respected and delivered
Positive experience from staff	19	15%	Feeling fully informed by members of staff
Given options/choice	18	14%	Appropriate options and choices given
Informed	17	13%	Individuals felt informed on progress during pregnancy
Personalised experience	4	3%	Positive and personalised experience of care, feeling compassion from staff
Concerns dealt with	3	2%	Concerns were appropriately dealt with
Specific positive experience	3	2%	Their positive experience of specific services such as during IVF

Q 2.5 Did you feel involved in decisions about your care during pregnancy? (Antenatal care) - General positive comments



There were 32 general positive comments in relation to feeling involved in decisions about care during pregnancy. The most commented on sub group was being involved with 23 (72%) respondents. 5 (20%) respondents stated that they received appropriate advice and support to make decisions about their care.

Involved

- “Yes I was involved at all stages.”
- “We were always consulted well on this aspect.”

Sub Group	No. of comments	% of comments	Description
Involved	23	72%	Felt involved in antenatal pregnancy decisions
Felt supported	5	16%	Received appropriate advice and support throughout pregnancy
Felt involved in hospital	2	6%	Felt fully involved during the time spent in hospital
Felt involved following loss	2	6%	Felt fully involved in decisions about care following the loss of a baby

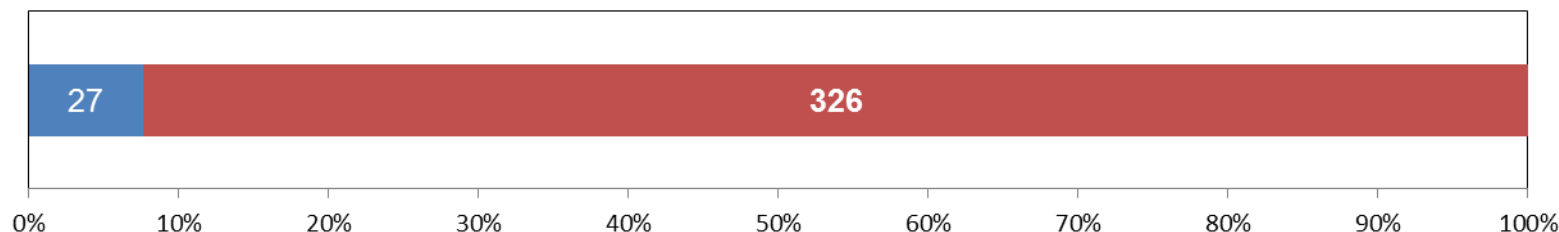
Q 2.6 Did you have enough time with your midwife or doctor to talk through decisions and concerns during your pregnancy? (Antenatal care)



342 Individuals answered yes or no to this question. 234 (68%) answered no and 108 (32%) answered yes. 107 who said yes and 234 who said no went on to leave further comments. In addition, another 12 left comments however did not respond to the yes/no part.

Answer	No. of respondents	%	No. of text responses	%
Yes	234	68	107	30%
No	108	32	234	66%
Not answered			12	3%
Total	342	100%	353	100%

353 individuals provided a comment, 27 were not applicable or had already responded in a different question and therefore 326 relevant responses were analysed.

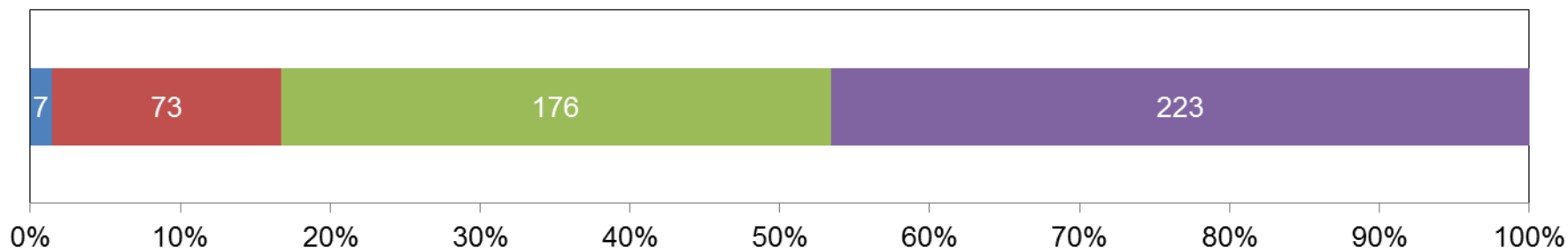


Group	No. of respondents	%	Description
Relevant responses	326	92%	Specific response on how the amount of time with their midwife or doctor
N/A or stated elsewhere	27	8%	Not applicable or stated elsewhere in the survey

Q 2.6 Time with midwife/doctor (Antenatal care)



326 relevant responses were analysed and 479 comments were identified and broken down in to four groups:



Group	Description
Negative Comments	Negative comments made by respondents on the availability of healthcare professionals, the use of the time when available, and the attitude of staff during their interactions = 223
Role specific breakdown	Comments where respondents specifically identified a professional groups were not available for sufficient time to discuss their concerns during pregnancy = 176
Positive	Comments made by respondents which were positive about the time with healthcare professionals = 73
Mitigation due to experience	Comments made by respondents who state loss of baby was too early in pregnancy to require more time with healthcare professionals = 7

Q 2.6 Time with midwife/doctor (Antenatal care) Relevant responses breakdown – Negative



223 (47%) negative comments were made about the amount of time with healthcare professionals. These comments were broken down further into two sub groups. 127 (57%) comments related to the lack of availability or the use of the time made available. 96 (43%) comments related to problems with the healthcare professionals attitude during those meetings.

Negative comments

- “The pregnancy never got as far as booking in with a midwife. The one doctor’s appointment I had was a waste of time. He did nothing to make me worry less about the symptoms I was having, he didn’t know how to date my pregnancy and just couldn’t get me out of the door fast enough.”
- “Absolutely not! The midwife appointments were like a conveyer belt. She was clearly late which was fine but as a result she couldn’t get me out the door quick enough in both occasions. She also dismissed my concerns that i felt something wasn’t right.”

Main Grouping	No.	%	Sub Group	Description	No.	%
Negative	223	47%	Availability and use of time	Issues with the availability, repetition due to changing staff, professionals appearing conscious of time and feeling rushed	127	57%
			Issues with staff attitude	Respondents used negative descriptors of their professional’s conduct during appointments such as blunt or dismissive of concerns and insensitive.	96	43%

Q 2.6 Time with midwife/doctor (Antenatal care) - Relevant responses breakdown



There were 251 comments which referenced, either positively or negatively, a specific healthcare professional group whom they spent time with.

85 contained generally negative comments relating to the time they were given. 166 contained generally positive comments.

The most commented on group was midwives 36 (42%) positive and 94 (57%) negative comments.

Role	Positive		Negative	
	No. of comments	%	No. of comments	%
Midwife	36	42%	94	57%
Consultant	30	35%	46	28%
GP	5	6%	6	4%
Hospital	14	16%	20	12%

Q 2.7 Did you feel after talking through your decisions and concerns they were acted on? (Antenatal care) – Yes/No



735 individuals answered the yes/no part of this question, 421 (57%) answered yes and 314 (43%) answered no.

Answer	No. of respondents	%	No. of text responses	%
Yes	421	57%	87	30%
No	314	43%	189	64%
Not answered			18	6%
Total	753	100%	294	100%

294 individuals chose to leave a comment, including 18 who had not responded to the yes / no part. Of these respondents, 25 (9%) individuals stated that the question was not applicable to them. 39 (13%) provided comments which were not relevant to the specific question. From the 230 relevant responses, 275 comments were identified and broken down into two groups:

Group	No. of comments	%	Sub Group	No. of comments	%	Description
Negative	228	84%	Patient care and support	212	78%	Respondents felt staff dismissed their concerns, better care and support to be offered to service users
			Time with Staff	16	6%	Staff appeared too busy to talk through in detail
Positive	47	16%	Happy with care	47	16%	Concerns were acted upon quickly, support provided from a bereavement midwife, care plan and wishes fully followed and staff were helpful

Q 2.7 Decisions acted on (Antenatal care) – Negative experience of patient care/support



There were 212 comments in relation to patient care and support, 86 (41%) said that their concerns and wishes were dismissed and 33 (16%) said they felt unsupported, with a number of people stating they felt neglected during subsequent pregnancies. 31 (15%) said they were not given chance to talk or discuss their concerns.

Concerns and wishes dismissed

- “I didn't want to terminate but was put under a lot of pressure to do it before I was 22 weeks as "it would get complicated after that!" And if I waited the baby would start to suffer”

Unsupported

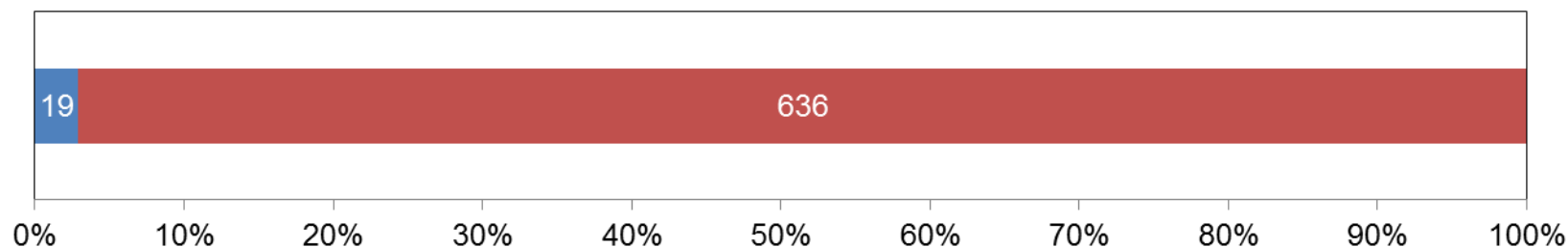
- “After knowing that the baby had died was still told that due to protocol I had to wait a further week for yet another scan. Emotionally it was very hard”

Group	No. of comments	%	Description
Concerns and wishes dismissed	86	41%	Staff appeared to dismiss concerns and believe this resulted in complications, service user felt decisions were made without them
Unsupported	33	16%	Service users were left feeling unsupported after talking through decisions and waiting for them to be acted upon.
Didn't have chance to talk or discuss	31	15%	Little opportunity to discuss concerns, appointment times not long enough to discuss concerns and feeling rushed
Delay in getting appointments	24	13%	Opportunity to act upon concerns was felt to be too late by the time healthcare professional was able to be seen.
Had to push for decisions	16	7%	Service users felt action was only taken if they were persistent in their requests
Poor information	11	4%	Lack of information received even when concerns raised, particularly around why complications arose
Other	11	4%	Other negative comments in relation to concerns being acted on

Q 2.8 What did you think about the information you were given during pregnancy? (Antenatal care)



There were 655 responses in relation to this question, 19 of which were not applicable or stated that they had answered this question already previously in the survey.



Group	No. of respondents	%	Description
Relevant responses	636	97%	Specific response on the amount of information given
N/A or stated elsewhere	19	3%	Not applicable or stated elsewhere in the survey

Q 2.8 Information during pregnancy (Antenatal care) - Positive/negative breakdown



Of the remaining 536 responses, 887 individual comments were identified and grouped into negative or positive comments. 521 (59%) detailed negative comments and 366 (41%) made positive comments.

Group	Description
Negative	Negative comments include issues around the volume of information, the way the information was delivered and the actual content of the information = 521
Positive	Positive comments include those that stated they received the information that they needed and in a way that they could understand = 366

Q 2.8 Information during pregnancy (Antenatal care) – Negative comments



521 comments were made which were negative about the information received. These have been broken down further into three sub groups. The most prevalent group with 226 (43%) comments related to information being too general and not tailored or specific to the individual's situation.

Negative Comments

- When asking questions about Down's Syndrome tests, junior Dr was going back and forth to office with consultant to get the answers, the consultant should have come in"
- "I did with my consultant, but that wasn't that often so would of liked more time with community midwife"

Main Grouping	No.	%	Sub- Group	Description	No.	%
Negative	521	59%	Not tailored to individual situation	Content of information shared was largely aimed at 'normal' pregnancies. Comments were made relating to the lack of a tailored approach to individuals.	226	43%
			Not satisfied with level of information	Respondents were not satisfied with the volume of information received.	206	40%
			Information not easily understood	Respondents were dissatisfied with the way that information was delivered impacting on understanding, i.e. including medical terminology, language barriers,	89	17%

Q 2.8 Information during pregnancy (Antenatal care) – Positive comments



366 comments were positive about the information received. These have been broken down into three sub groups. The most prevalent group with 163 (44%) comments related to how easily the information was understood.

Positive comments

- “I had gestational diabetes but the information I was given was easy to understand, due to this I found my condition was easily managed.”
- “They couldn't have explained it any better. He told us straight how it was which we appreciated.”
- “Very good. Much improved information on babies movements compared to first pregnancy.”
- “Yes all information was given appropriately and carefully.”

Main Grouping	No.	%	Sub Group	Description	No.	%
Positive	366	41%	Easy to understand	Respondents said they did receive sufficient or plenty of information in a way in which they could understand it	163	44%
			Tailored to individual	Respondents rated the information very good or excellent also referred to the way in which it was delivered, i.e. the information was provided with consideration for them and their circumstances and they felt it was accurate and honest	110	31%
			Opportunity to discuss	Respondents described the information as easy to understand, helpful, informative and that they had the opportunity to ask further questions if needed	93	25%

Q 2.9 Same midwife before, during and after birth(Antenatal care) - Scores



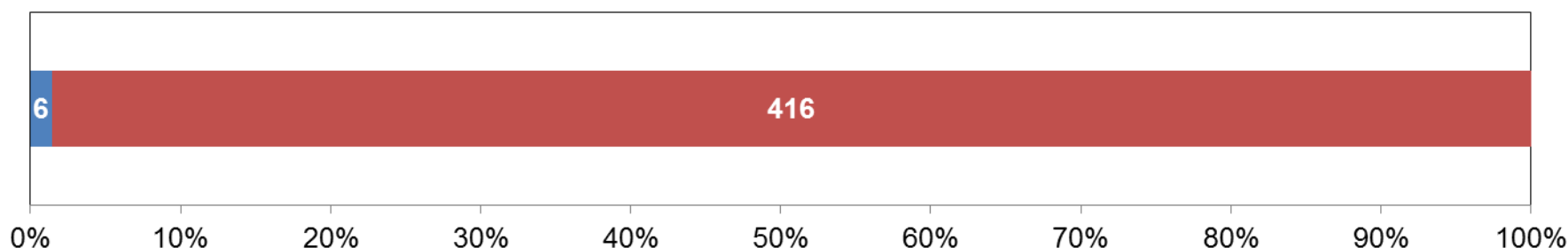
Question 2.9 gave respondents the opportunity to score how important they thought it was to be supported by the same midwife before, during and after birth with 5 being very important and 1 being not important at all. Of the 760 respondents who scored this question, 506 (37%) said this was very important with a score of 5

Score	No. of respondents	%
1 = not important	33	2%
2	14	1%
3	83	6%
4	124	9%
5 = very important	506	37%
Total	760	100%

Q 2.9 How important would it be for you to be supported by the same midwife before, during and after birth? (Antenatal care)



There were 422 responses in relation to this question, of which, 416 (99%) made a relevant responses around how important it was for them to be supported by the same midwife. 6 (1%) respondents stated the question did not relate to them or had stated their answer elsewhere.



Group	No. of responses	%	Description
Relevant responses	416	99%	Relevant responses on how important they considered being supported by the same midwife
N/A or stated elsewhere	6	1%	Not applicable or stated elsewhere in the survey

Q 2.9 Same midwife before, during and after birth (Antenatal care) – Specific comments



From the 416 relevant responses, 530 comments were identified and grouped under seven headings. The most prevalent group with 206 (39%) comments related to the perceived benefits continuity of care would bring to the overall of level care they received..

Benefits

- “Continuity in such a sensitive matter is so important, you need people you can trust.”
- “Continuity of care extremely important when experiencing difficulties and frightening situations.”

Experiences

- “My midwife has been amazing. Even with all the follow up after loosing my baby she has been invaluable help...”
- “My midwifed changed half way through, she never answered her phone when I rang a couple of times. I still had my first midwives num and she answered and helped even though she had moved.”

Group	No. of comments	%	Description
Benefits	206	39%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Experiences	95	18%	Personal experience on the benefits of having the same midwife or the negative experience of dealing with multiple midwives
Positive	84	16%	Seen to be important or a good thing to have if possible
Problems	66	12%	Identifies some of the problems with attempting to do this, such as it would depend on the midwife and questions over the practicality of it
Specific times	33	6%	Comments on how at specific times or scenarios it would be most important to have the same midwife i.e. high risk pregnancy
Unimportant	24	5%	Unimportant or not as important as other areas
Advice	22	4%	Advice on how to improve the service such as the importance of good handovers, allowing women to change their midwives and the need for good communication

Q 2.9 Same midwife before, during and after birth (Antenatal care) - Benefits



There were 206 comments relating to benefits, these have been broken down further into five sub groups. 83 (40%) comments were around the ability to build trust. 63 (31%) comments stated it would be helpful in knowing history and identifying problems and 50 (24%) comments said that this would prevent them from needing to repeat themselves.

Build up trust

- “Pregnancy is such a vulnerable time and being able to create a trusted bond with your midwife is essential.”
- “Consistency ensures that the midwives build a relationship with the mother and this then prevents loss of information on both parties”

Sub Group	No. of comments	%	Description
Build up trust	82	40%	You would be able to build up trust more easily
Quality of care	63	31%	Would improve the standard of the treatment and care provided and prevent problems with inaccurate medical notes
Reduces repeating information	50	24%	Would reduce the need to tell multiple healthcare professionals same information
Support choice	8	4%	Would help choices to be supported as the midwife would have built a relationship and know history
Reduces risk of information being lost	3	1%	Information is less likely to be lost in transition between different midwives

Q 2.9 Same midwife before, during and after birth (Antenatal care) - Experiences



There were 95 comments relating to the impact on the service user's experience, these have been broken down further into nine sub groups. The majority of comments related to poor continuity, with 25 (26%) stating that they seen different staff. 17 (18%) said they had a positive experience of their midwife and 17 (18%) stated that the seen the same midwife throughout and this was a benefit.

Sub Group	No. of comments	%	Description
Poor continuity	25	26%	Seeing different staff can have a negative impact upon patient experience
Positive experience of midwife	17	18%	Previous experience with a midwife leads individuals to believe the same midwife throughout would be of benefit.
Same midwife	17	18%	Same midwife attended throughout and was seen as a benefit
No follow up	8	8%	No follow up care received from midwife
Negative experience of midwife	8	8%	Negative experience with a midwife which could be avoided if individual had same midwife throughout
Did not receive midwife care	5	5%	Did not receive any care from a midwife or did not see a midwife at all throughout their antenatal care
Good experience of labour midwives	5	5%	Good experience reported of the midwives involved in labour
Does not happen	3	3%	Did not see the same midwife before, during and after birth
More checks	3	3%	More checks and appointments with the midwife
Other	4	4%	Other experiences around having the same midwife before, during and after birth

Q 2.9 Same midwife before, during and after birth (Antenatal care) - Positive



There were 84 general positive comments in relation to seeing the same midwife. These were broken down into three sub groups, 48 (55%) said that it would be nice to have the same midwife, 34 (40%) said it was important and 4 (5%) said it would be nice however not always necessary.

Would be nice

- “I would think it would be good if the same midwife was there all the way through your pregnancy and birth “
- “Would have been great if I saw the same person through my pregnancy rather than a different person on each appointment“

Sub Group	No. of comments	%	Description
Would be nice	46	55%	Would be nice/ helpful to have the same midwife
Important	34	40%	Important to have the same midwife to prevent repeating same information to different professionals
Nice but not necessary	4	5%	Would be nice however not always necessary

Q 2.9 Same midwife before, during and after birth (Antenatal care) - Scores



The following slides provide additional breakdown of comments based on the score provided by each respondent. This information is provided as additional analysis.

Q 2.9 Same midwife before, during and after birth (Antenatal care) - Specific comments, scores 1 and 2



There were 38 comments made by people who scored this question 1 or 2.

Group	No. of comments	%	Description
Negative	11	29%	Unimportant or not as important as other areas
Experiences	9	24%	Experiences of care such as having had different / the same midwives or receiving good / bad care
Problems	8	21%	Identifies some of the problems with attempting to do this such as the fact it would depend on the midwife and questions over the practicality of it
Benefits	6	16%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Positive	3	8%	Important or would be a good thing to have
Advice	1	3%	Advice on how to improve the service such as the importance of good handovers, allowing women to change their midwives and the need for good communication
Times when it is most important	0	0%	Times when this would be most important for example during labour, after birth or in high risk pregnancies

Q 2.9 Same midwife before, during and after birth (Antenatal care) - Specific comments, score 3



There were 63 comments made by people who scored this question 3.

Group	No. of comments	%	Description
Problems	20	32%	Identified some of the problems with attempting to do this such as the fact it would depend on the midwife and questions over the practicality of it
Advice	11	17%	Advice on how to improve the service such as the importance of good handovers, allowing women to change their midwives and the need for good communication
Negative	8	13%	Unimportant or not as important as other areas
Experiences	7	11%	Experiences of care such as having had different / the same midwives or receiving good / bad care
Times when it is most important	7	11%	Times when this would be most important for example during labour, after birth or in high risk pregnancies
Positive	6	10%	Important or would be a good thing to have
Benefits	4	6%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust

Q 2.9 Same midwife before, during and after birth (Antenatal care) - Specific comments, scores 4 & 5



There were 425 comments made by people who scored this question 4 or 5.

Group	No. of comments	%	Description
Benefits	196	46%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Experiences	77	18%	Experiences of care such as having had different / the same midwives or receiving good / bad care
Positive	75	18%	Important or would be a good thing to have
Problems	37	9%	Identifies some of the problems with attempting to do this such as the fact it would depend on the midwife and questions over the practicality of it
Times when it is most important	26	6%	Times when this would be most important for example during labour, after birth or in high risk pregnancies
Advice	10	2%	Advice on how to improve the service such as the importance of good handovers, allowing women to change their midwives and the need for good communication
Negative	4	1%	Unimportant or not as important as other areas

During Pregnancy - if your baby died in pregnancy, thinking about your care in hospital after the death was diagnosed



In this section of the survey, respondents who had lost their baby during pregnancy were asked to think about their care in hospital after the death was diagnosed. The questions in this section of the survey are broken down below:

No	Question
2.10	Did you feel involved in decisions about your care regarding the delivery of your baby after he/she had died?
2.11	What could have been done differently to improve your care during and after the delivery of your baby?
2.12	What was good about the care during this time?

Q 2.10 Did you feel involved in decisions about your care regarding the delivery of your baby after he/she had died? (During pregnancy) – Yes/No



This question gave respondents the opportunity to answer yes or no to whether they felt involved in decisions about their care regarding the delivery of their baby after he/she had died. There were 627 respondents who answered yes or no, 391 (62%) said yes, 236 (38%) said no.

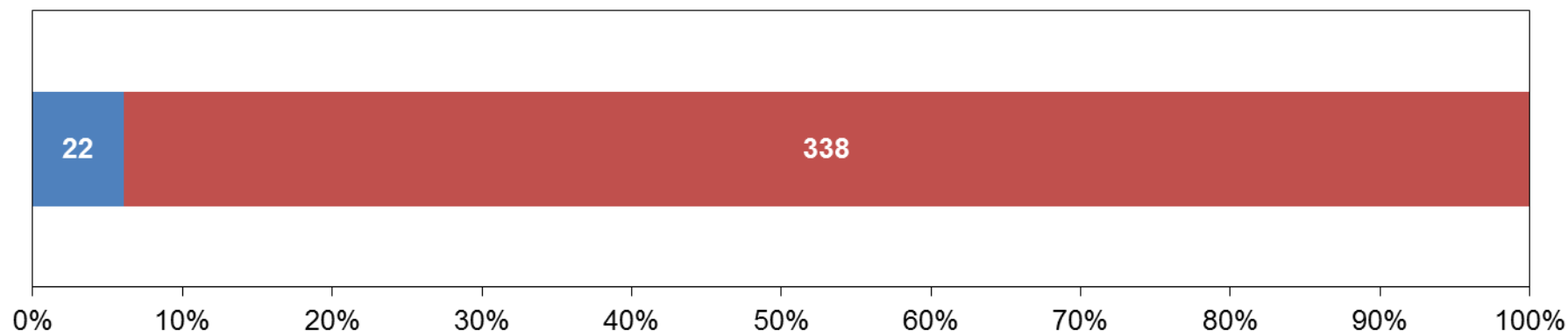
360 respondents left a comment, including 20 (6%) who did not leave a yes or no answer.

Answer	No. of respondents	% of respondents who answered yes/no	No including text response	% of all text response
Yes	391	62%	165	46%
No	236	38%	175	49%
Not answered			20	6%
Total	627		360	

Q 2.10 Involved in decisions about your care (During pregnancy)



In total there were 360 responses, of which, 338 (94%) made a specific comment in relation to how involved they felt in decisions about their care. 22 (6%) respondents did not specifically respond to whether they felt involved or their answer had been text elsewhere in the survey.



Group	No. of respondents	%	Description
Relevant responses	338	94%	Relevant responses on how involved they felt in decisions about their care regarding the delivery of their baby after he/she had died
N/A or stated elsewhere	22	6%	Not applicable or stated elsewhere in the survey

Q 2.10 Involved in decisions about your care (During pregnancy) - Specific Comments



There were 388 relevant responses, 440 comments were identified and broken down into six groups. 179 (41%) did not feel involved in decisions about their care. 113 (26%) described how they had been involved and 49 (11%) made general comments on their overall experience of care. These three groups are broken down further in the following three slides.

Group	No. of comments	%	Description
Felt uninvolved	179	41%	Service users had not been involved in decisions, such as consent not being requested, decisions being made without their involvement, or decisions not being respected
Felt involved	113	26%	Service users had been involved, for example being well informed or through good communication
Comments on Care	49	11%	Not specifically relating to how involved they were but rather to their overall experience of care
Personal experience	42	10%	Personal experiences of being involved, such as being happy to rely on healthcare professionals or having to fight to be involved in decisions
Specific	36	8%	Specific times they were involved or not involved in decisions
General	21	5%	General comments on how involved the respondent had felt in decisions

Q 2.10 Involved in decisions about your care (During pregnancy) - Felt uninvolved



There were 179 comments relating to being uninvolved, 38 (21%) were around service users not being given options or choice. 34 (21%) comments stated that they were poorly informed and 26 (15%) comments said that decisions were made without their involvement.

Sub Group	No. of comments	%	Description
Not given options or choice	38	21%	Not given any options or choices in the care they received
Poorly informed	34	19%	Received little advice or information about options, choices or circumstances
Decisions made without respondents involvement	26	15%	Not included in the decision making process
Pressurised into making certain decisions	11	6%	Coerced into decisions without all the facts
Poor decisions or medical advice by healthcare professionals	11	6%	Staff made poor decisions and provided poor advice
Felt not supported or left alone	10	6%	Received little assistance, bedside support or interaction
Felt not listened to	9	5%	Staff did not listen to mother's wishes or concerns
Too hurried or happened too quickly	8	4%	Process was rushed and felt like a conveyor belt
Choices not respected	7	4%	Staff did not listen or ignored mother
Not given more time with the baby	7	4%	Given limited time to spend with baby
Negative experiences of staff	6	3%	Staff displayed negative attitude, behaviour or standards of care
Choices could not be delivered	6	3%	Choices were not delivered
Other	6	4%	Other comments in relation to feeling uninvolved in decision making

Q 2.10 Involved in decisions about your care (During pregnancy) - Felt involved



There were 113 comments relating to feeling involved, 41 (36%) comments said that they were given options and choices. 36 (32%) stated that they were well informed and 17 (15%) stated that good staff had kept them involved.

Sub Group	No. of comments	%	Description
Given options	41	36%	All options explained so mother could make a decision
Well informed	36	32%	Received advice to make informed decision
Good staff	17	15%	Friendly and helpful staff
Given time	11	10%	Given time to make choices
Choices respected	4	4%	Staff respected mother's wishes
Given information on support groups	2	2%	Received advice and information on support services
Good communication	2	2%	Received good communication from staff

Q 2.10 Involved in decisions about your care (During pregnancy) – Comments on care



There were 49 comments about care received during pregnancy, 21 (43%) comments reflected a negative experience of care. 12 (24%) comments were from respondents who said they received good care and 9 (18%) made positive comments in relation to the hospital in which they received their care.

Negative experience

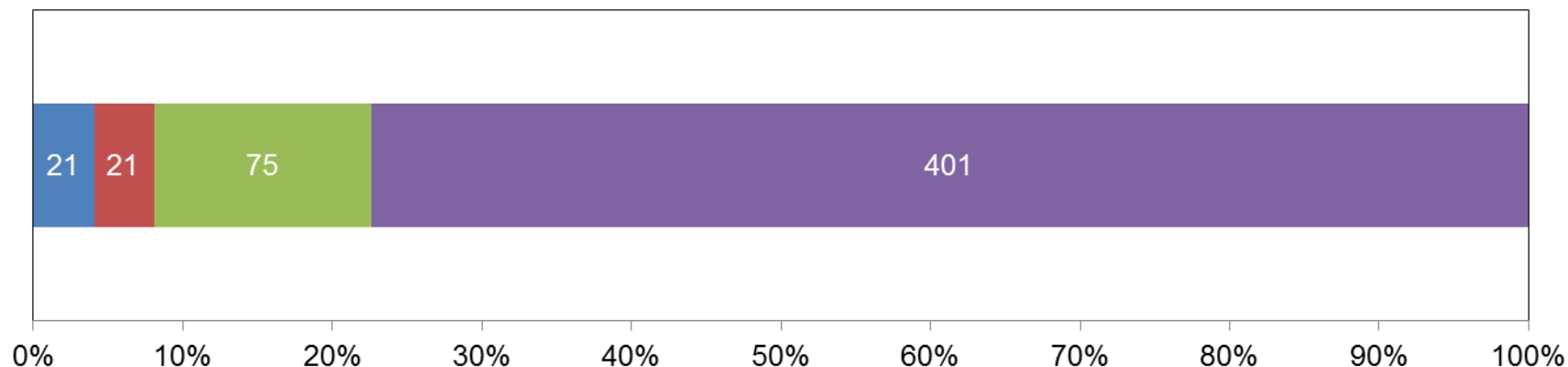
- “They treated me terribly and pretty much left me alone with no pain relief to deliver the baby.”
- “There was no care I was treated in A&E with complete disregard as to what was happening.”
- “We were just left on the labour ward for 3 days “

Sub Group	No. of comments	%	Description
Negative experience of care	21	43%	Not happy with the quality or standard of care
Good care	12	24%	Happy with quality or standards of the care
Good hospital	9	18%	Happy with the services and facilities of the hospital
Had time with baby	3	6%	Able to spend adequate time with baby
Took too long	1	2%	Certain processes and procedures took too long
Delays in confirming miscarriage	1	2%	Delays in the processes, procedures or results of confirming miscarriage
Early pregnancy Unit was good	1	2%	Positive experience of the standards or quality of care provided by EPU
Did not receive counselling	1	2%	Lack of emotional or mental health support during or after birth

Q 2.11 What could have been done differently to improve your care during and after the delivery of your baby? (During pregnancy)



There were 518 responses received in relation to this question, 401 (77%) were applicable to the question, 75 (15%) stated that “nothing” could have been done differently. 21 (4%) left a general positive comment which could not be categorised into anything specific. There were 21 (4%) responses that were deemed not applicable.



Group	No. of responses	%
Relevant responses	401	77%
Positive general	21	4%
Nothing	75	15%
Not applicable	21	4%

Q 2.11 What could have been done differently (During pregnancy) - Relevant responses



There were 401 relevant responses around what could have been done differently. 765 comments were made around specific aspects of care that could have been improved. The majority of which were around staff, with 1166 (22%) in relation to continuity of care, more highly skilled and experienced staff and better communication. 135 (18%) wished to feel more supported and 103 (14%) made comments around privacy.

Group	No. of comments	%	Description
Improvements from staff	166	22%	Including continuity of care, more highly skilled and experienced staff and improved communication
More support	135	18%	To feel involved and be listened to, improved communication and more focus on emotional support especially following the loss of a baby
Improved environment	103	14%	More privacy for discussions, not being put on a ward with other mothers and their healthy babies and a dedicated room to spend time with baby following their death
Preparation/information for loss of baby	99	13%	Including more improved information received in a more timely manor around things such as funerals and dealing with the loss of a baby
Postnatal support/care	65	8%	Care and support following the loss of a baby with opportunities to hold them and spend time with them before going home
Hospital facilities	51	7%	Improved facilities in hospitals, including food and better parking and partner and visitors able to stay for longer
Increased Monitoring	51	7%	Information given earlier and more checks support for those who have suffered miscarriage in the past
Organisation	36	5%	Improved organisation around appointments, with more consistent care and information and improved communication
Waiting times	30	4%	Less delays when checking or confirming loss of baby and reduce waiting times
Pain management	29	4%	Improvements in pain relief and care throughout birth and following

Q 2.11 What could have been done differently (During pregnancy) - Improvements from staff



There were 166 comments made in relation to staff, 84 (51%) said that more caring / sensitive staff would have improved their care, 20 (14%) said that better communication and more transparency / sharing of information would have helped, another 18 (12%) said that there staff should be better trained in dealing with death.

More caring/sensitive/compassionate/empathetic staff

- “Staff should be warmer and caring towards the parents and baby, especially as their appearances start to deteriorate. I should not have had to ask for a Joshua's box and cleanliness”

Improved Communication

- “Communication when it was found my son's heart had stopped beating. Although difficult to convey I felt the staff present weren't trained to deal with such a difficult situation and they went and fetched someone else to advise me...”

Group	No. of comments	%	Description
Staff attitude	84	51%	Make sure staff are more compassionate, empathetic and sensitive
Improved communication	20	14%	Share information with service user and other staff & improve use of medical records
Staff better trained (bereavement)	18	12%	Staff should be able to deal with death and the impact upon parents
Staff improvements	13	8%	Staff should have the skill and experience to deal with all eventualities
Midwife	11	7%	Midwives to be assertive & able to deal with situations promptly and compassionately
GP	6	4%	Doctors to be fully appraised, accurate and sensitive to service user
Staff consistency	6	4%	Medical history, recognising irregularities and medical history
Consultants	5	3%	Consultants should see service users more frequently, listen and respect wishes
Same / consistent midwife	3	2%	Knows medical history, recognises irregularities builds service user's confidence

Q 2.11 What could have been done differently (During pregnancy) - Improved environment



There were 103 comments made around this sub group. 45 (44%) stated that care and services should be available away from pregnant women and new born babies. 33 (32%) said that their own room would have improved their care, and 13 (13%) said there should be more privacy when confirming miscarriage.

Care and services away from pregnant women and new born babies

- “Having a separate space for mums who have lost their children before birth, in my case a stillborn child during pregnancy, has to happen...”

Better information following loss

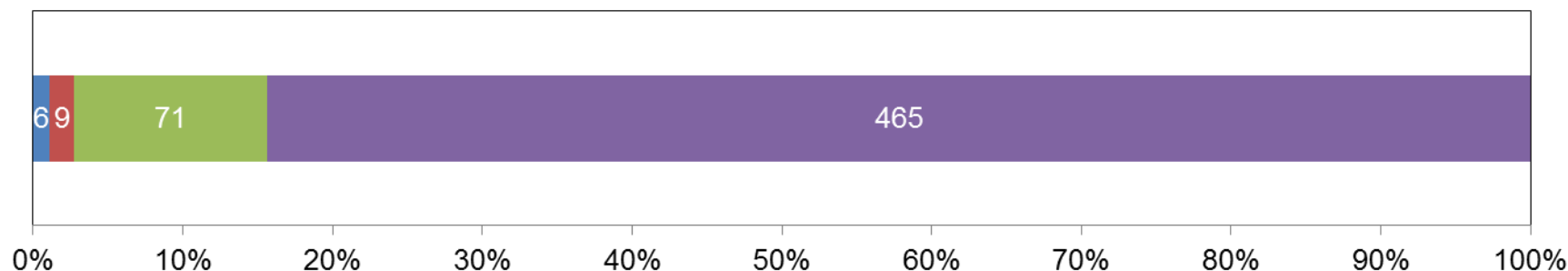
- “I was admitted to a ward after miscarrying in A&E, where I was placed in a bed next to a pregnant lady, and when I had to return 2 days later for a scan I was sent to sit in the early pregnancy assessment unit waiting room...”

Group	No.	%	Description
Away from pregnant women and new born babies	45	44%	Provide care for service users who have lost their babies away from pregnant women and babies
Own room / not on labour ward	33	32%	Provide a private room where service users can stay when they have poorly babies or when they have experienced the loss of a baby
More privacy when dealing with miscarriage	13	13%	Privacy when suspected miscarriage and advise of loss in a private setting
EPU (Early Pregnancy Unit) away from other pregnancy / birth services	5	5%	EPU to be located in a separate setting e.g. not on a delivery unit
Separate from termination services	3	3%	Provide care not in the same location as termination services
Appropriate space for providing care	4	4%	Provide parents with an appropriate setting, services for parents who have lost their babies to be kept separate to those who have not

Q 2.12 What was good about the care during this time? (During pregnancy)



There were 551 responses received on this question, 465 (84%) applicable responses, with 71 (13%) of people stating that nothing was good about their care, 6 (1%) of the respondents said “Everything” about their care was good. 9 (2%) of the responses were deemed not applicable.



Group	No. of responses	%	Description
Specific responses	465	84%	Responses specific to certain aspects of care received
Nothing	71	13%	Nothing was good about the care received during this time
Not applicable	9	2%	Question not answered or not applicable
Everything	6	1%	Everything was good about the care received

Q 2.12 What was good about the care during this time? (During pregnancy)



There were 465 specific responses in relation to this question, 710 comments were made on different aspects of care, these include 439 (62%) of people saying their care was received by caring, compassionate and understanding staff, 171 (24%) of comments in relation to being well supported and 73 (10%) around privacy.

Well Supported

- “Whilst I was in hospital after having my daughter every medical professional I saw knew what was happening and the lines of communication seemed to be open.”
- “The doctor and team who delivered my baby kept me informed as things happened (it all happened over the course of an hour). Looking back they did the best they could with the resources they had at the time.”

Group	No. of comments	%	Description
Positive experience of staff	439	62%	Caring, compassionate and understanding staff
Well supported	171	24%	Good communication, kept informed and supported throughout
Privacy	73	10%	Suitable accommodation away from new mums and their babies or private rooms to spend time with babies
Partner allowed to stay overnight	15	2%	Partner allowed to stay overnight
Regular checks	12	2%	Seen and monitored regularly

During labour or soon after birth



Within this section of the survey, respondents who has lost babies during labour, in the maternity unit or shortly after birth were asked to think about the care they received during and after labour. The questions within this section are broken down below:

No	Question
2.13	Did you feel you received good quality care during your labour?
2.14	If you had concerns did you feel they were listened to and acted on?
2.15	What could have been done differently to improve the care you received during and after labour?
2.16	What could have been done differently to improve your care after the birth of your baby while you were in hospital?
2.17	What was good about your care at this time?

Q 2.13 Did you feel you received good quality care during your labour? (During labour or soon after birth) – Yes/No



Q 2.13 gave respondents the opportunity to answer yes/no. 444 individuals responded, 308 (69%) answered yes and 136 (31%) answered no. 116 of those who said yes and 107 of those who said no left further comments. In addition, 39 (13%) did not answer yes or no however left further comments.

Answer	No. of respondents	%	No. of text responses	%
Yes	308	69%	116	39%
No	136	36%	107	36%
Not answered			39	13%
Total	444	100%	264	100%

The 264 comments have been broken down further into four groups:

Group	No. of comments	%	Description
Lack of care and support	146	56%	Unsatisfactory care and support during labour, not being listened to or ignored and poor response times when concerns arise
Happy with care	85	32%	Able to trust staff and positive experiences of care during labour
Negative experience of staff	30	11%	Staff perceived to be too busy, units too short staffed and negative attitude from staff
Unsuitable facilities	3	1%	Lack of available beds, resources and appropriate space

Q 2.13 Good quality care during labour (During labour or soon after birth) - Lack of care and support



There were 146 comments in relation to the lack of care and support service users received, of which, 69 (45%) said that they received inadequate care and 33 (22%) said that the response time to complications was slow and they were being sent home during labour.

Group	No. of responses	%	Description
Inadequate care	69	45%	Staff failing to pick up displayed risk factors, failing to take medical observations and a lack of compassion from staff
Poor response time	33	22%	Experiences of being sent home during early labour, delays in being admitted onto ward from A&E and the need for quicker access to caesarean when needed
Not being listened to	18	12%	Staff ignoring concerns or wishes of service user
Inadequate pain relief	12	8%	Not receiving pain relief to deliver a baby who would not survive and inadequate offers of pain relief during labour
Lack of information / inaccurate information	11	7%	Service users want to know why their baby died, what happened during induction and what happened to the babies body.
Other	3	2%	Other comments in relation to lack of care and support including poor communication between staff and with service user

Q 2.14 If you had concerns did you feel they were listened to and acted on? (During labour or soon after birth) - Yes/No



425 individuals answered the yes / no part of this question, 283 (66%) answered yes and 142 (34%) answered no. 62 of those who said yes and 90 of those who said no left further comments. In addition, 24 (8%) left further comments however did not answer yes or no.

Answer	No. of respondents	%	No. of text responses	%
Yes	283	66%	62	21%
No	142	34%	90	31%
Not answered			24	8%
Total	425	100%	176	100%

176 individuals chose to leave a comment, including 24 who had not responded to the yes / no part. 24 (14%) individuals stated that the question was not applicable to them. 9 (5%) provided comments which were not relevant to the question. From the 119 relevant responses, 173 comments were identified and broken down into four groups:

Group	No. of comments	%	Description
Better patient care and support	106	61%	Service users not to be left alone for long periods of time and to feel more cared for during labour
Happy with care	39	23%	Service users trusting staff during labour, being listened to, and staff being reassuring and resolving worries / concerns as best they could
Negative experience of staff	25	14%	Comments included there not being enough staff available, staff being overworked and staff too busy to deal with concerns
Lack of facilities	3	2%	Lack of available resources, beds and space

Q 2.14 Concerns listened to and acted on (During labour or soon after birth) - Better patient care and support



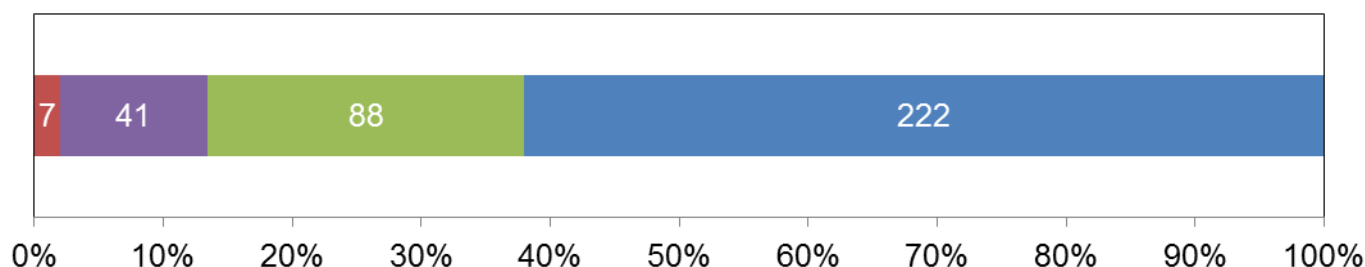
There were 106 comments in relation to better care and support, of which, 46 (43%) included reports of service users not feeling listened to or ignored, 32 (30%) felt they received a lack of care and support.

Group	No. of comments	%	Description
Not listened to / ignored	46	43%	Service users feeling ignored when they voiced concerns and not feeling listened too until it was too late
Lack of care and support	32	30%	Service users left alone for long periods of time and being told to 'wait and see' in response to concerns
Limited opportunities to discuss concerns	14	13%	Not having the opportunity, or being asked to raise concerns with staff
Insufficient time	10	10%	Insufficient time to raise concerns and where concerns were raised the length of time it took for them to be dealt with was unacceptable
Lack of communication	4	4%	Suggested improvements include staff being more experienced to deal with concerns and the need to improve communication with service users

Q 2.15 What could have been done differently to improve the care you received during and after labour? (During labour or soon after birth)



There were 358 responses to this question, 222 (62%) identified an area for improvement. 88 (25%) stated nothing needed to improve and 41 (11%) stated the question was not applicable to their situation. 7 (2%) stated everything needed to improve.



Group	Description
Improvements	Responses received identified improvements = 222
Nothing	Responses received identified no improvement required = 88
Not applicable	N/A entered into field, or response not appropriate = 41
Everything	Responses received identified everything needed to be improved = 7

Q 2.15 What could have been done differently (During labour or soon after birth) - Key Area Groups



222 responses suggested areas for improvement, 337 individual comments were identified from these responses. The most popular group was around quality of care with 87 (26%) comments. 64 (19%) commented on the need for improvement in the attitude of staff.

Groups	No. of comments	%	Description
Quality of care	87	26%	Standards of care need improvement
Staff attitude	64	19%	Improvements in the attitude of staff towards service users
Communication	61	18%	Communication between service users and healthcare professionals needed to improve
Staff Access	50	15%	More staff available with easier access when needed
Environment	43	13%	Mothers and their babies kept together and nursing those who lost a baby in an area other than on the labour or postnatal ward
Emotional support	19	6%	More emotional support provided to parents
More check ups	7	2%	Respondents would like access to more scans and check ups in a more timely manner
Other	6	2%	Other suggestions for improvement in relation to what could have been done differently during labour or soon after birth

Q 2.15 What could have been done differently (During labour or soon after birth) – Quality of care



The quality of care group accounted for 26% of all comments made. It has been broken down into nine groups. 28 (32%) comments were general around how improvements were needed in the attitude of staff.

Quality of care

- "...support and advise bereaved families if they should have any questions and be able to provide the families with the sensitivity needed when they have just lost a baby ."
- "Provide better services for those women having late miscarriages on the gynae ward because the staff clearly did not know what to do."

Group	No. of comments	%	Description
General	28	32%	Improvements needed in the attitude of staff to promote a more compassionate, empathetic and sensitive approach
Personalised	12	14%	More personalised service to be provided, tailored to an individuals care
Postnatal Care	9	10%	Improved postnatal care, including more checks
Continuity	9	10%	More continuity to enable service users to build relationships and not have to repeat the same information to each practitioners
More testing	9	10%	More checks and testing to pick up any problems as early as possible
Pain Management	9	10%	Better pain management, including more choice and medication to be administered quicker
Consistency	5	6%	Consistency in care received, including receive the same advice from staff
Medical Notes	3	3%	Accurate notes and healthcare professionals to read notes and be up to date
Other	3	3%	Other suggestions in relation to what could have been done differently during labour or soon after birth

Q 2.15 What could have been done differently (During labour or soon after birth) - Staff attitude



There were 63 comments relating to staff attitude, 34 (53%) stated that staff should have a more caring attitude. 30 (47%) comments were around how staff should listen more to parents concerns.

Caring Attitude

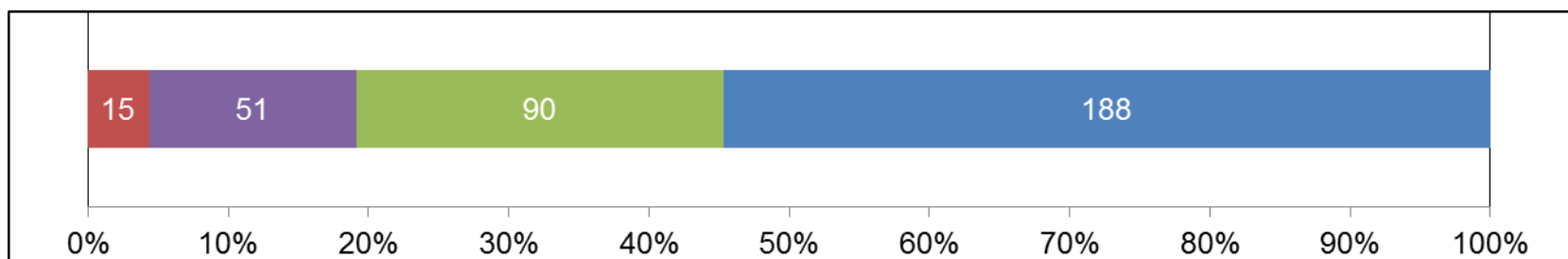
- “Some of the midwives I saw seemed a little blunt about my situation. As if I didn't matter too much as I was having a medical termination.”

Group	No. of comments	%	Description
Caring attitude	34	53%	Improvements needed in the attitude of staff to promote a more compassionate, empathetic and sensitive approach
Listening to parents concerns	30	47%	Service users feeling like decisions were being made for them, concerns being dismissed by staff as just ‘worrying’ and birth plans being ignored

Q 2.16 What could have been done differently to improve your care after the birth of your baby while you were in hospital? (During labour or soon after birth)



There were 344 responses to this question, 188 (54%) identified areas for improvement. 90 (26%) stated nothing could have been improved. 51 responses (15%) stated the question was not applicable to their situation. 15 (<1%) stated everything as an answer.



Group	Description
Relevant response	Responses identified improvement = 188
Nothing	Responses identified no improvement required = 90
Not applicable	N/A entered into field, or response not appropriate = 51
Everything	Responses stated everything need to be done differently = 15

Q 2.16 Care after the birth of your baby while you were in hospital (During labour or soon after birth) - Improvements



There were 188 relevant responses which identified 300 comments on areas for improvement. 85 (28%) said that improvements were needed around environment, 44 (15%) wished for help in creating memories and 42 (14%) suggested more emotional support.

Groups	No. of comments	%	Description
Environment	85	28%	Keeping mother and baby together, nursing those who lost a baby away from maternity areas
Memories	44	15%	Advising, guiding and supporting parents on capturing memories / taking photos and keeping clothing
Emotional support	42	14%	Providing more emotional support to parents
Communication	40	13%	Staff should communicate information to one another and be more transparent with service users
Staff attitude	36	12%	Improvement in staff's attitude towards service users
Quality of care	31	10%	Improving the standard of the treatment and care provided, problems with inaccurate medical notes
Continuous aftercare	8	3%	Improved care provided in the community, including help around breast feeding
More check ups	6	2%	Access to more scans and check ups in a more timely manner
Consent	5	2%	Practitioners should get service user's consent before any procedure and should respect their wishes and privacy
Other	3	1%	Respondents reported unspecific comment or said that "everything" could have been improved

Q 2.16 Care after the birth of your baby while you were in hospital (During labour or soon after birth) – Environment



There were 85 comments made around the environment in which care is delivered. These comments have been broken down into eight groups. The majority of comments suggest that parents who have lost their babies should receive services away from labour and postnatal wards.

Away from labour ward

- “As a mother of a baby who was in neonatal it was very distressing to then be sent into the maternity ward where you are surrounded by healthy new-borns and pregnant women.”
- “I was left on the labour ward for 3 days listening to babies being born, all that time mourning my own baby. This did not do me any good, if anything it made my loss so much harder.”

Group	No. of comments	%	Description
Away from labour ward	59	69%	Care for parents who have lost their babies in areas away from labour or postnatal wards
Privacy	7	8%	Private rooms to spend some time as a family
Partner able to stay	5	6%	Allowing partners to stay with mother and baby and providing them with adequate sleeping provisions
Family and baby together	4	5%	Mothers and babies staying together and not being kept separate
Better food / availability	3	4%	Improvement in the quality of food available and the availability of foods at all times of day and night
Access to neonatal unit	4	5%	Service users want easier access to neonatal wards to see their babies
Better facilities	2	2%	Improve hospital facilities and provide private rooms
Babies together	1	1%	Keep multiple birth babies together

Q 2.17 What was good about your care at this time? (During labour or soon after birth)



There were 357 responses received, 279 (78%) where relevant to the question, with 4 (1%) stating everything about their care was good, 50 (4%) said there was nothing good about the care they received and 24 (2%) were deemed not applicable.

There were 315 comments around more specific aspects of care identified from the 279 responses. 168 (53%) made a positive statement in relation to staff and the care they received. 50 (16%) said they felt well supported during their care and 44 (14%) appreciated the time they were given in hospital and did not feel rushed to go home.

Well supported

- “Very considerate. Everything was explained with lots of support and thoughtfulness.”

Seen regularly

- “We were looked after by one person who checked on us regularly and helped us to form happy memories with our baby.”

Group	No. of comments	%	Description
Staff attitude	168	53%	Caring, compassionate and understanding staff
Well supported	50	16%	Good communication, kept informed and supported throughout
Time given	44	14%	Time given to grieve, not rushed home
Privacy	40	13%	Suitable accommodation away from new mums and their babies or private rooms to spend time with babies
Seen regularly	12	4%	Seen and monitored regularly
Consistency of staff	1	<1%	Seeing the same member of staff

Neonatal care



This section of the survey is for those whose babies were transferred to the neonatal unit. This section is broken down into the following questions:

No	Question
2.18	Do you feel that your baby received good quality care in the transition to and upon admission to the neonatal unit?
2.19	What was good about care in the neonatal unit?
2.20	What could have been done differently to improve your experience at this time?
2.21	Did you feel that the maternity team communicated effectively with the neonatal team?
2.22	Did you feel involved in decisions about your baby's care?
2.23	What did you think about the information you were given about what was happening (i.e. did it give you the information you needed in a way you could understand?)?

Q 2.18 Do you feel that your baby received good quality care in the transition to and upon admission to the neonatal unit? (Neonatal care) – Yes/No



182 people responded yes or no to this question, 144 (79%) said yes, they did feel their baby received good quality care and 38 (21%) said no, they did not feel that their baby received good quality care. 62 of those who said yes and 26 of those who said no left comments. In addition 41 who did not respond yes or no left a comment.

Answer	No. of respondents	%	No. of text responses	%
Yes	144	79%	62	21%
No	38	21%	26	9%
Not answered			41	14%
Total	182	100%	129	100%

Of those who left comments, 78 (60%) were applicable to the question and 51 (40%) were deemed not applicable.

Group	No. of responses	%
Applicable responses	78	60%
Not applicable	51	40%

Q 2.18 Care of your baby during transition and upon admission to neonatal unit (Neonatal care) - Applicable responses



There were 78 applicable responses and 111 comments identified. 59 (53%) reported a good experience of care and said that things went well. 26 (23%) made non specific comments, 16 (14%) said care was not effective.

Good or went well

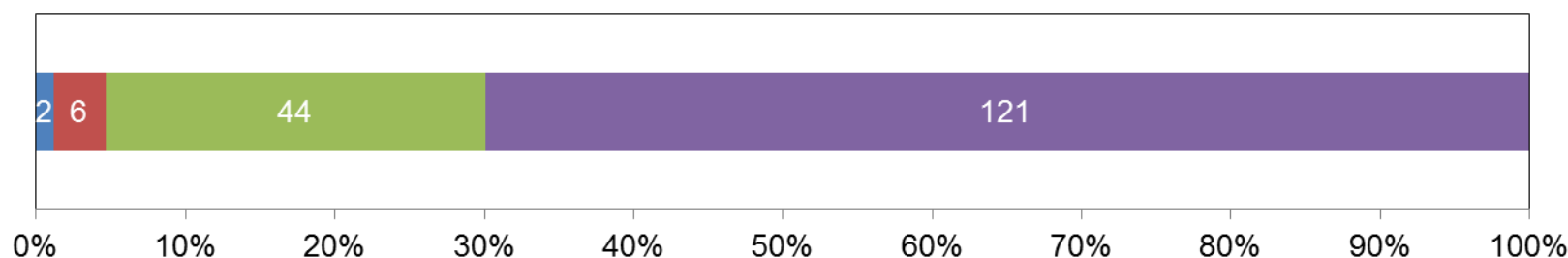
- “The most amazing care from the most amazing people.”

Group	No. of comments	%	Description
Good or went well	59	53%	Had good experience of care or things went well
Care not effective	16	14%	Felt care was substandard or things did not go well
Communication issues	7	6%	Felt communication was not effective
Feeding	3	3%	Comments relating to feeding related issues
Other	26	23%	Non specific comments

Q 2.19 What was good about care in the neonatal unit? (Neonatal care)



There were 173 responses received in relation to this question and 121 (70%) relevant responses, with 2 (1%) stating nothing was good about their care and 6 (3%) stating everything about their care was good. 44 (25%) of responses were deemed not applicable.



Group	Description
Relevant responses	Responses identified improvement = 121
Nothing	Nothing was good about the care received= 2
Everything	Everything about the care was good = 6
Not applicable	Not applicable to the responder or previously answered elsewhere = 44

Q 2.19 What was good about care in the neonatal unit? (Neonatal care) – Applicable responses



There were 121 relevant responses and 196 comments were identified in relation to specific aspects of care. 105 (54%) were around a positive experience of staff, 74 (38%) around being well supported and 7 (4%) stating that they were thankful for the privacy they received.

Good care

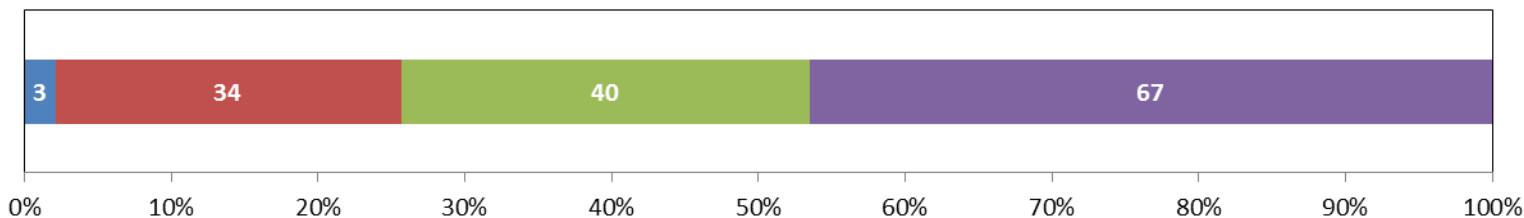
- “I felt that my baby was well monitored and cared for medically.”
- “It was baby and parent centred - it was care and treatment that was explained every step of the way and involved me and my husband. The focus on the family was brilliant.”

Group	No. of comments	%	Description
Positive experience of staff	105	54%	Caring, compassionate and understanding staff
Well supported	74	38%	Good communication, kept informed and supported throughout
Privacy	7	4%	Suitable accommodation away from new mums and their babies or private rooms to spend time with babies
Regular checks	6	3%	Seen and monitored regularly
Help feeding	4	2%	Help feeding including breast feeding and bottle feeding

Q 2.20 What could have been done differently to improve your experience at this time? (Neonatal care)



There were 144 responses to this question, 67 (47%) stated comments which identified an area for improvement . 34 (24%) stated nothing could have been improved. 3 (2%) stated everything needed to improve and 40 (28%) stated the question was not applicable to their situation.



Group	Description
Improvements	Comments received identified improvement = 67
Not applicable	N/A entered into field, or response not appropriate = 40
Nothing	Comments received identified no improvement required = 34
Everything	Comments received everything needed improvement = 3

Q 2.20 Key Area Groups – What could have been done differently to improve your experience? (Neonatal care) - Improvements



67 responses related to improvements, these identified 98 comments which have been broken down into seven groups. The joint top groups for improvement with 22 comments (22%) each were staff attitude towards service users, and communication between healthcare professionals and service users.

Groups	No. of comments	%	Description
Staff Attitude	22	22%	Improvements in the attitude of staff towards service users
Communication	22	22%	Communication could be improved if practitioners were more transparent, shared information more frequently and in more detail
Environment	20	20%	Mothers and their babies kept together and nursing those who lost baby in an area away from maternity areas
Emotional support	12	12%	More emotional support provided to parents
Memories	12	12%	Staff to advise parents on the options available to them to capture memories of their baby
Quality of care	7	7%	Improving the standards of the treatment and care provided and medical notes
Breastfeeding help	3	3%	More advice and guidance on breastfeeding

Q 2.20 What could have been done differently to improve your experience? (Neonatal care) - Staff attitude improvement



There were 22 comments in relation to staff attitude, these have been broken down further into five groups with the majority relating to the attitude of staff and their listening to parent's concerns.

Staff Attitude

- “Not being made to feel like a failure because my son was struggling and had some bad relapses to which I fell apart, staff spoke and treated me like I was an idiot and over reacting when I was just being a loving mum watching her tiny baby struggling to survive.”
- “One doctor was very rude...He stated that I was being cruel to my son by keeping his machine on because he was going to grow up needing carers and ending up in a care home. This was before any tests had been carried out and before we knew the extent of the damage to make any kind of decisions.”

Group	No. of comments	%	Description
Staff attitude – general	10	45%	Improve the attitude of staff to promote a more compassionate, empathetic and sensitive approach
Listening to parents concerns	5	23%	Service users wish to feel more involved in decisions, to have concerns dealt with and not be dismissed when feeling worried
Availability of night time/ weekend staff	4	18%	More staff to attend on service users during evening & weekends
Caring staff	2	9%	Need staff with a caring nature and focus on service users
More staff	1	5%	Increasing the provision of staff to attend on service users

Q 2.21 Did you feel that the maternity team communicated effectively with the neonatal team? (Neonatal care)



155 respondents answered yes or no to this question, 101 (53%) said yes and 54 (28%) said no. 23 of those who said yes and 30 of those who said no left further comments. In addition, 35 respondents left further comments however did not answer yes or no.

Answer	No. of respondents	%	No. of text responses	%
Yes	101	65%	23	26%
No	54	35%	30	34%
Not answered			35	40%
Total	155	100%	88	100%

There were 88 comments in total, 48 (55%) were applicable to the question and 40 (45%) were deemed not applicable.

Group	No. of responses	%
Applicable responses	48	55%
Not applicable	40	45%

Q 2.21 Did you feel that the maternity team communicated effectively with the neonatal team? (Neonatal care) - Applicable responses



There were 48 applicable responses, from this 50 comments were identified. 19 (38%) were around communication and how this was good/effective, 18 (36%) felt that it was not effective and reported an unsatisfactory experience.

Effective communication

- “I was under a consultant and she was excellent in liaising with the neo-natal team before my induction.”

Communication not effective

- “...the maternity and neonatal teams might as well have been in different hospitals - the communication and coordination between them was poor.”

Group	No. of comments	%	Description
Effective communication	19	38%	Felt communication was effective or had a good experience
Communication not effective	18	36%	Felt communication was not effective or had unsatisfactory experience
Other	13	26%	Non specific comments

Q 2.22 Did you feel involved in decisions about your baby's care? (Neonatal care) – Yes/No



This question gave respondents the opportunity answer yes or no to whether they felt involved in decisions about their baby's care. Of the 168 respondents who answered this with a yes or no, 119 (71%) said yes and 49 (29%) said no.

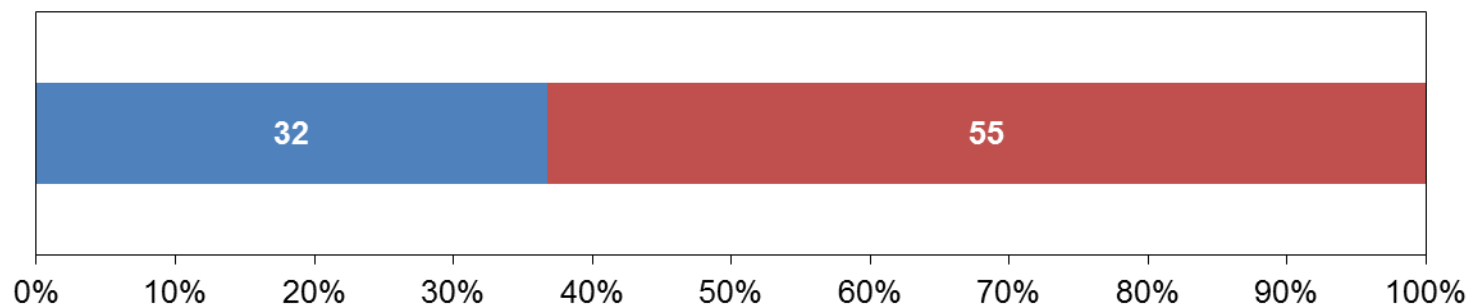
Answer	No. of respondents	% of	No. of text responses	%
Yes	119	71%	35	40%
No	49	29%	26	30%
Not Answered			26	30%
Total	168	100%	87	100%

35 of the respondents who answered yes left comments and 26 of those who answered no left comments. There were 26 respondents who did not answer yes or no however did leave comments.

Q 2.22 Did you feel involved in decisions about your baby's care? (Neonatal care)



There were 87 responders who left further comments, of which, 55 (63%) made a specific response to whether they felt involved in decisions about their baby's care. 32 (37%) respondents did not specifically comment about whether they felt involved or not.



Group	No. of respondents	%	Description
Relevant responses	55	63%	Specific response on how involved they felt in their baby's care
N/A or stated elsewhere	32	37%	Not applicable or stated elsewhere in the survey

Q 2.22 Did you feel involved in decisions about your baby's care? (Neonatal care) - Specific Comments



There were 55 relevant responses identifying 60 comments that were broken down into four groups. 18 (30%) negatively describe how they were not involved in their baby's care. 15 (25%) made general comments on how involved they had been and 14 (23%) described how they had been involved. These three groups are broken down further in the next three slides.

Did not feel involved

- “We just got told things were happening and not informed really why either.”

Level of involvement

- “When it became clear that our son wasn't going to recover, we were given options about whether to take him off the machines that were keeping him alive. And about when that should happen. “

Group	No. of comments	%	Description
Did not feel involved	18	30%	Negative comments about not being involved such as being poorly informed or not given options
Level of involvement	15	25%	General comments on how involved the respondent had felt in decisions
Felt involved	14	23%	Respondents had been involved for example being well informed and given options
Not involved due to circumstances	13	22%	Circumstances mitigated ability to be involved in decision making

Q 2.22 Did you feel involved in decisions about your baby's care? (Neonatal care) - Did not feel involved



There were 18 comments relating to not feeling involved in the care of their baby, 6 (33%) said they felt poorly informed, 4 (22%) comments stated that they were not listened to and 4 (22%) comments said that decisions were made without their involvement.

Poorly informed or poor or no explanation

- “Again I wasn't informed what was happening until it had happened. “
- “The consultant acted as if he couldn't hear me and ignored all my questions”

Sub Group	No. of comments	%	Description
Poorly informed or no explanation	6	33%	Received little advice or information about options, choices or circumstances
Felt not listened to	4	22%	Staff not listening to mother's wishes or concerns
Decisions made without involvement	4	22%	Mother not included in the decision making process
Pressurised into making decisions	1	6%	Mother coerced into decisions without all the facts
Not involved in discharge arrangements	1	6%	Mother not included in the decision making process
Variation between hospitals and services	1	6%	No consistency between providers in the way they deliver services
Pressured into giving formula	1	6%	Moved to formula feeding without providing breastfeeding advice and support

Q 2.22 Did you feel involved in decisions about your baby's care? (Neonatal care) - Level of involvement



There were 15 comments in relation to specific levels of involvement, 10 (67%) said they felt fully involved in all decisions about the care of their baby. 4 (27%) comments stated that they not been involved and 1 (7%) stated that they had been involved most of the time.

Sub Group	No. of comments	%	Description
Involved	10	67%	Felt fully involved in all decisions made about the care of their baby
Not involved	4	27%	Did not feel involved in decisions
Mostly involved	1	7%	Felt involved in some situations however this could be improved

Q 2.22 Did you feel involved in decisions about your baby's care? (Neonatal care) - Felt involved



There were 14 comments from responders who said they felt involved, these have been broken down into three groups. The most commented on sub group was that they were well informed with 12 (86%) comments. 1 (7%) stated that they were given options and 1 (7%) stated they were involved during their time in SCBU (Special Care Baby Unit).

Sub Group	No. of comments	%	Description
Well informed	12	86%	Felt well informed and involved in decisions about the care of their baby
Given options	1	7%	Given options to make decisions around the care of their baby
Involved in Special Care Baby Unit	1	7%	Felt involved when their baby was in the special care baby unit

Q 2.23 What did you think about the information you were given about what was happening? (Neonatal care)



There were 160 responses to this question, 45 were not applicable or stated that they had answered this question already in a previous question. Out of the remaining 115 responses, 122 individual comments were identified and included within the analysis below. There are three overarching groups. 3 (2%) mixed comments, 37 (30%) negative comments and 82 (68%) positive comments. Included within the individual comments were details that were pertaining to a formal complaint which has already been submitted.

Negative

- “Some of the language was difficult to understand- as a parent all we want to know is whether our baby is going to pull through and if so, how well would they be. I had to ask whether our little boy would be in a vegetative state if he survived”
- “When we were told our baby had chronic lung disease it was a terrible shock because we did not understand that the ventilator that was keeping him alive was also damaging his lungs. As mentioned earlier, the information we were given was too much so it didn't get read - there was too much going on.”

Positive

- “All good - we were given information, plus the opportunity to ask questions. We weren't rushed - it felt as though our preferences and values were a real and integral part of the decision making process.”
- “I always felt like every effort was made to help me understand the situation and the care my babies were receiving and all my questions were answered.”

Main Grouping	No. of comments	%	No. of comments	%	Sub- Group
Mixed	3	2%	3	2%	Quality of information was dependant on who was providing it
Negative	37	30%	4	3%	Information was perceived to be withheld or was felt to be misleading
			33	27%	Information was not easy to understand
Positive	82	68%	4	3%	Information was adequate
			7	6%	Information was good and there was an opportunity to discuss
			71	58%	Individuals felt fully informed

Postnatal care



In this section of the survey, respondents were asked to think about the care after they went home following their baby's death. The questions in this section are outlined below:

No	Question
2.24	Did you receive any on-going aftercare from a healthcare professional following discharge from hospital?
2.25	Were you offered bereavement counselling?
2.26	What could have been done differently to improve your care after you left hospital?
2.27	What did you think about the information you were given after your baby died?
2.28	Did you have a follow up appointment with your consultant to discuss the reasons for your baby's death?
2.29	What was good about the process to review the circumstances of your baby's death?
2.30	What could have been done differently to improve the review process?

Q 2.24 Did you receive any on-going aftercare from a healthcare professional following discharge from the hospital? (Postnatal care) – Yes/No



719 individuals answered yes or no to this question, of which, 394 (55%) said that they did receive ongoing aftercare from a healthcare professional following discharge, 325 (45%) said they did not.

Answer	No. of respondents	%	No including text response	%
Yes	394	55%	298	65%
No	325	45%	153	33%
Not answered			10	2%
Total	719	100%	461	100%

An additional 10 respondents chose not to answer the yes/ no question, but did leave a text response.

Of those 461 individuals who did leave text response, there were 455 (99%) which were specific to aspects of ongoing care. 6 (1%) of the responses were deemed not applicable.

Group	No. of responses	%
Applicable responses	455	99%
Not applicable	6	1%

Q 2.24 Aftercare following discharge from the hospital (Postnatal care) - Applicable responses



There were 455 responses and 601 comments were identified from these, 182 (30%) stated that they were supported following discharge by a midwife or community midwife. 83 (14%) said that no or bare minimum care was offered. 79 (13%) received care from a consultant.

Midwife

- “My own community midwife made it her business to continue to see me weekly even after I was medically fit.”

No after care

- “nothing at all, left to navigate grief following pregnancy loss alone.”

Group	No. of comments	%	Description
Midwife	182	30%	Includes references to community midwife providing aftercare
No after care	83	14%	No care offered or bare minimum
Consultant	79	13%	Comments include other care e.g. for infections
Bereavement midwife	69	11%	Role specifically referenced in response
GP	59	10%	Responses relating to local doctor
Counselling	21	3%	Comments include counselling being offered or taken up
Health visitor	20	3%	Contact from a Health Visitor
Usual 6 week check	13	2%	Reference to postnatal checks
Report or investigation	12	2%	Comments include post mortem discussions or review
Referral	11	2%	e.g. to miscarriage or fertility clinic
Telephone	9	1%	Call received or numbers offered
Written information	9	1%	Letter received or leaflet given
Further tests	8	1%	Comments include blood tests
Multiple birth	7	1%	Support given with surviving baby
Planned support	6	1%	Planned visit or check never happened
Support network	6	1%	Includes specific reference to SANDS or Cruse
Other healthcare professional	4	1%	Includes examples such as outreach or psychologist
Informal support	3	0%	Includes assistance from a friend or colleague

Q 2.25 Were you offered bereavement counselling? (Postnatal care) – Yes/No



727 people responded yes/no to this question, 329 (45%) said yes and 398 (55%) said no they were not offered bereavement counselling.

Answer	No. of respondents	%	No. of text responses	%
Yes	329	45%	158	48%
No	398	55%	156	48%
Not answered			12	4%
Total	727	100%	326	100%

158 of those who said yes and 156 of those who said no left comments. An additional 12 respondents chose not to answer the yes/ no question, but did leave comments.

A total of 326 left comments, 324 (99%) were applicable to the question and 2 (1%) were deemed not applicable.

Group	No. of responses	%
Applicable responses	324	99%
Not applicable	2	1%

Q 2.25 Were you offered bereavement counselling? (Postnatal care) - Applicable responses



There were 324 responses relating to the question and from this 381 comments were identified. 78 (20%) said they were not offered counselling, it did not happen or they were not aware of the facility. 64 (17%) arranged alternative support, 45 (12%) said they received counselling from the hospital or other location.

Not offered

- “Told they don't offer for any pregnancy loss under 24 weeks as its not a viable pregnancy-arranged own privately.”

Alternative support

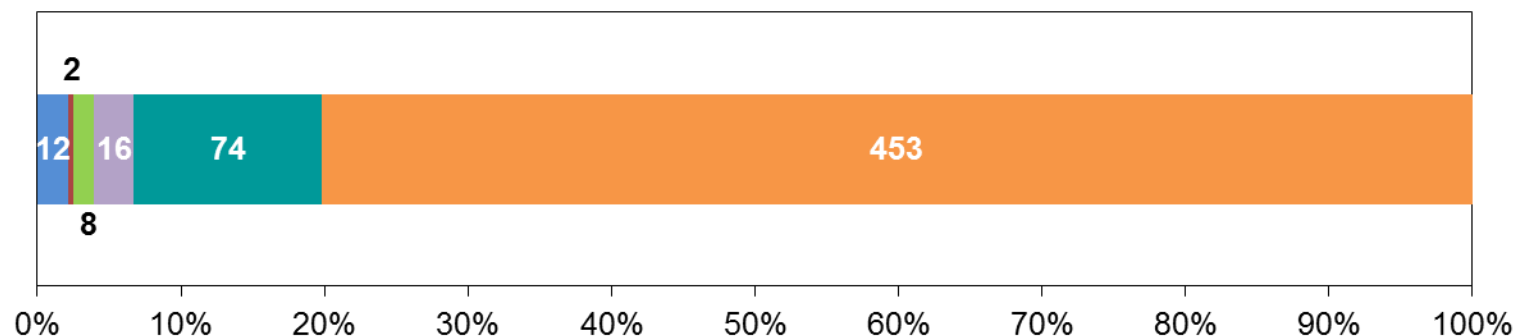
- “Yes we were given information on Cruse and SANDS. Both of which we accessed and have been great.”

Group	No. of comments	%	Description
Counselling not offered	78	20%	Counselling not offered, did not happen or were not made aware of facility
Alternative support	64	17%	Arranged via a charity such as SANDS or given a leaflet
Hospital or other location	45	12%	Counselling available at hospital or other location such as a hospice
Delay	32	8%	Long wait for appointment or counselling too late
Arranged independently	26	7%	Paying privately for counselling or arranged self
Bereavement midwife	24	6%	Counselling provided through a bereavement midwife
Useful	20	5%	Found counselling to be useful or helpful
Initiated contact	17	4%	Had to call or ask for an appointment
Doctor	14	4%	Counselling provided by GP or doctor
Not required	13	3%	Did not require or expect counselling
Telephone number	13	3%	Given a number to call
Venue inappropriate	7	2%	Location not appropriate e.g. maternity unit
Other	28	7%	Non specific comments

Q 2.26 What could have been done differently to improve your care after you left hospital? (Postnatal care)



There were 565 responses in relation to this question, of which, 74 (13%) said nothing could have been done differently and 12 (2%) were deemed not applicable. There were 453 (80%) applicable responses that identified a specific aspect of care that could have been done differently. These aspects are broken down further in the next slide. The remainder were general positive or negative comments that did not identify any specific aspects of care and two others who said they didn't know what could have been done differently.



Group	No. of responses	%	Description
Relevant responses	453	80%	Specific aspects of care that could have been done differently
Nothing	74	13%	Nothing could have been done differently
Positive - general	16	3%	Positive general comment
Not applicable	12	2%	Not applicable / not relevant
Negative -general	8	1%	Negative general comment
Don't know	2	0%	Don't know

Q 2.26 After you left hospital (Postnatal care) - Applicable responses breakdown



There were 453 relevant responses which identified 685 comments that have been broken down into eight groups. There were 229 (33%) comments in relation to support, 162 (24%) comments in relation to bereavement support and 115 (17%) comments said that more information would have improved their care when leaving hospital. These top three groups have been broken down further in the next three slides.

Group	No. of comments	%	Description
More general support	229	33%	More contact with healthcare professionals, better follow up scans/checks, support for partners and a longer period of support
More bereavement support	162	24%	More or better support from bereavement teams and midwives or from specialist counselling
Improved information	115	17%	Explanations of what happened, medical information and practical information on support groups which can be contacted and arrangements
More organisation	70	10%	Better communication between healthcare providers, the need to cancel scheduled appointments and the organisation and location of follow up appointments
Personal experience	58	8%	More personalised experience of care, to feel listened to, have their loss acknowledged and personal preferences supported
Staffing	30	4%	Specific comments on the need for more skilled staff including midwives, GPs and consultants
Memories	18	3%	Access to memory boxes, ability to see the baby and being informed of what is going to happen to the baby
Other	3	<1%	Specific circumstances such as the need for better support for multiple pregnancies where one baby has died

Q 2.26 After you left hospital (Postnatal care) - More general support



There were 209 comments around support and these have been broken down further into nine groups. 114 (50%) comments said that more contact would improve their care after leaving hospital. 46 (20%) comments wished for more midwife contact. A small number of comments related to areas such as support for their partner, support for longer and help with transition.

Sub Group	No. of comments	%	Description
More contact with healthcare professionals	114	50%	Specialists will only see service users briefly on occasions
More contact with midwives	46	20%	Midwives busy doing things other than educating and guiding mothers
More effective support / care	37	16%	Insufficient level of attention, care and support
More complete follow up scan / checks	9	4%	More scans and check ups required, and in a more timely manner
Support with medical complications after miscarriage	7	3%	When something goes wrong test should establish how to prevent a repeat incident
More effective checks for depression	6	3%	Identify signs of depression early and act upon it
More focus on supporting partners	5	2%	Support should be provide to partners too, not just mothers
Support for longer	4	2%	Support should be extended and also provided within community settings
Greater help with transition	1	<1%	Help with transitions that are taking place in the longer term

Q 2.26 After you left hospital (Postnatal care) - More bereavement support



153 comments were around bereavement support, these have been broken down further into two groups. 127 (78%) comments said that better or more counselling would have improved their experience, the remaining 35 (22%) said that more or a better bereavement midwife team would have helped.

Counselling services

- “An offer of bereavement counselling, someone to talk to both for myself and my husband who was largely forgotten about despite having also lost his child and supporting his wife through a horrendous labour. The whole experience was deeply traumatic and he was offered absolutely no support at all.”
- “I needed someone to talk to outside the family.”
- “The bereavement officer told us she'd be in touch 6 weeks after discharge, we heard nothing. I was a mess, at home alone and had to make my own arrangements and pay for my own counselling. Not a good standard of care at all.”

Sub Group	No. of comments	%	Description
Counselling services	127	78%	More investment into counselling and referral services to identify and treat sooner
Bereavement midwife/team	35	22%	More staff trained in bereavement support to ensure people do not suffer unnecessarily

Q 2.26 After you left hospital (Postnatal care) - Better Information



There were 115 comments relating to better information, these have been broken down into seven groups. 30 (26%) comments said that they would have liked more information on support groups. 28 (24%) wanted a better explanation of what had happened. A smaller number of respondents wished for better medical information or information on the immediate future including funerals and post mortems.

Sub Group	No. of comments	%	Description
Support groups	30	26%	Proactively supply information on support groups
More detailed explanations	28	24%	Answers and explanations into causes of death and how to avoid repeats
More information - general	17	15%	Proactively supply information, or copies of medial records and notes upon request
More information - care and experiences to be expected in the coming weeks	15	13%	Guidance on what to expect and when, reduces shock, surprise and anxiety
More information - medical	12	10%	Explain medical position in plain language so service users understands their situation
More information - funerals	7	6%	Provide funeral advice/options in a timely and sensitive manner
More information - post mortem	6	5%	Provide post mortem advice/feedback in a timely and sensitive manner

Q 2.27 What did you think about the information you were given after your baby died? (Postnatal care)



There were 615 responses to this question, 22 were not applicable or stated that they had answered this question already in a previous question.

Out of the remaining 593 responses, 790 individual comments were identified and included within the analysis below. These have been broken down into three groups. 93 (12%) detailed neutral comments, 227 (29%) made positive comments and 470 (59%) made negative comments.

Group	Description
Positive	Positive comments include those that rated the information either good or excellent = 227
Neutral	Neutral comments include those where information was seen to be adequate or meeting a minimum expectation = 93
Negative	Negative comments include those where no information was received, some information was seen to be more out of date, and where information was not delivered in an appropriate manner = 470

Q 2.27 Relevant responses breakdown - Information given after your baby died (Postnatal care) - Positive



227 (29%) comments stated that the information received was good or excellent. Most comments described care as good and staff as helpful 153 (67%).

Positive

- “I was given lots of information booklets to go through. I was told all the information I needed to know about what was going to happen next. I never left the hospital feeling I didn't know what was happening.”
- “Good. Doctors were professional, compassionate and answered out questions openly”
- “Good to read. SANDS info was brilliant.”

Main Grouping	No. of comments	%	No. of comments	%	Sub Group
Positive	227	29%	4	2%	Information about options available to create memories
			153	67%	Information was described as good, helpful and informative.
			70	31%	Information was described as very good & excellent

Q 2.27 Relevant responses breakdown - Information given after your baby died (Postnatal care) - Negative



There were 470 negative comments, these have been broken down further into nine groups. 199 (42%) comments stated that none or little information was provided, 107 (23%) stated that limited information was received and 81 (17%) stated that the information received was of poor quality.

Negative

- “Very poor. I was given a scruffy leaflet with a phone number on for the hospital church and the SANDS name hand written on it.”
- “It was largely fine - apart from confusion about what to do about registering his birth. I was sent a horrible letter from the registry office accusing me of failing to register his birth, when I had been specifically told that I should wait until the post mortem had been completed so as to register his birth and death at the same time.”

Main Grouping	No. of comments	%	Sub group	No. of comments	%	Descriptions
Negative	470	59%	Poor information	199	42%	None or little information provided
			Limited information	107	23%	Information limited to leaflets and occasionally video
			Poor quality	81	17%	Information quality perceived as generally poor
			Sourced own information	25	5%	Relied on themselves to source information
			Delays receiving	21	4%	Dissatisfied with the delays that occurred
			Staff attitude	15	3%	Staff attitude when delivering information lacked sensitivity
			Incorrect information	11	2%	Received conflicting, irrelevant or out of date information
			Poor information sharing	8	2%	Information sharing was rushed due to the need to make decisions
			Not easy to understand	3	1%	Information not easy to understand

Q 2.28 Did you have a follow up appointment with your consultant to discuss the reason for your baby's death? (Postnatal care)



716 people responded yes or no to this question, with 483 (67%) of individuals saying yes they did receive a follow up appointment and 233 (33%) saying no they did not.

Answer	No. of respondents	%	No. of text responses	%
Yes	483	67%	267	70%
No	233	33%	104	27%
Not answered			10	3%
Total	716	100%	381	100%

267 (70%) of the respondents who said yes and 104 (27%) who said no left further comments. In addition, there were 10 (3% respondents who left comments however did not answer yes or no.

Of the 381 individuals who did leave a text response, 338 (89%) of the response where specific in relation to the question. 43 (11%) were deemed not applicable.

Group	No. of responses	%
Relevant responses	338	89%
Not applicable	43	11%

Q 2.28 Follow up appointment to discuss reason for your baby's death (Postnatal care) - Applicable responses breakdown



There were 388 relevant responses which identified 418 comments, these comments have been broken down further into 11 groups. 171 (41%) stated that they met with a consultant or other doctor, 55 (13%) said they had a long wait or it was too late by the time they did receive an appointment and 38 (9%) said that there was no follow up care offered.

Consultant or doctor

- “The consultant was the doctor who delivered our baby and we had seen him a few times during his life. He was extremely helpful.”

Long wait or too late

- “This took place after the post mortem, around 7 weeks after my baby died. I felt like this was a very long time.”

Group	No. of comments	%	Description
Consultant or doctor	171	41%	Met with consultant or other doctor
Long wait or too late	55	13%	Long wait or too late
No follow up	38	9%	No follow up care or not offered an appointment
Report or investigation	37	9%	Includes post mortem, root cause analysis or other investigation
Appointment scheduled	32	8%	Appointment booked or planned in
Referral	26	6%	Referred to other specialist, clinic or testing
Initiated contact	25	6%	Had to call or ask for appointment
Other contact	13	3%	Contact through letter or telephone call
Other healthcare professional	8	2%	Contact from another person such as a nurse
Venue inappropriate	8	2%	Appointment held in unsuitable location
Contact for other purposes	5	1%	Includes genetic counselling or fertility treatment

Q 2.29 What was good about the process to review the circumstances of your baby's death? (Postnatal care)



There were 490 responses to this question, 169 (35%) were relevant in relation to the question being asked, with 53 (10%) not applicable. 145 (30%) made a general negative comment or said that there was nothing good about the review process and 7 (14%) passed a general positive comment. 116 (24%) received no review following their baby's death.

Group	No. of responses	%	Description
Relevant responses	169	34%	Including communication, staff, support and operations
Nothing or negative comment only	145	30%	General negative comment around the review process
No review carried out	116	24%	No review carried out following the death of their baby
Not applicable	53	11%	Question not applicable to respondents
Positive comment	7	1%	General positive comment around the review process

Q 2.29 Process to review the circumstances of your baby's death (Postnatal care) - Specific response



There were 169 relevant responses which have been broken down further into four groups. 255 (69%) comments were around communication, 64 (17%) made positive comments in relation to the staff, and 35 (10%) received support and were given choices.

Group	No. of Comments	%	Description
Good communication	255	69%	Received answers and explanations around causes of death, receiving information in the right format and given opportunities to express concerns
Positive experience of staff	64	17%	Seen same staff throughout process and staff provided support
Well supported	35	10%	Received counselling, given choices and tests carried out
Well organised processes	16	4%	The review happened quickly, was organised well and was conducted away from other mothers and their babies

Q 2.29 Process to review the circumstances of your baby's death (Postnatal care) - Good communication



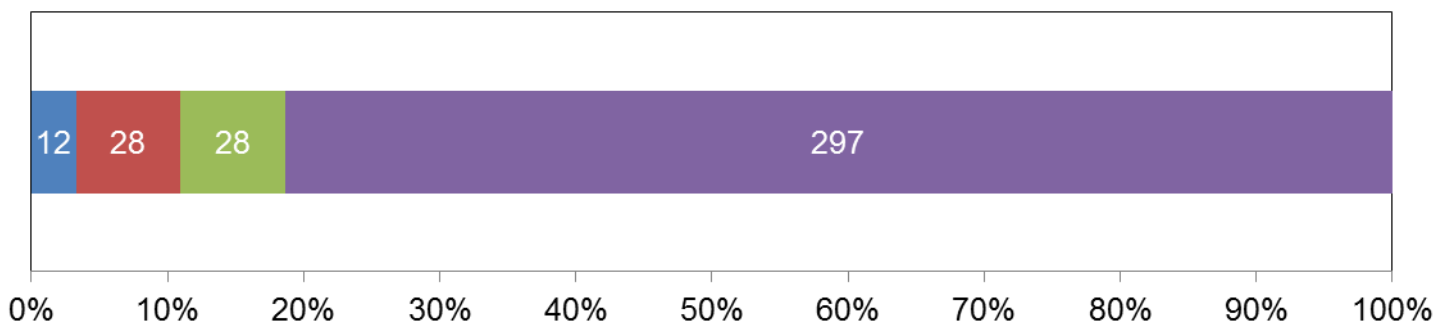
The 255 comments relating to communication have been broken down further into four sub groups, 168 (66%) stated that they were given answers and explanation into causes of death to enable them to understand what had happened. 68 (21%) commented on the discussions they received in relation to long term impact after the death of their baby.

Sub Group	No. of comments	%	Description
Received answers	168	70%	Family given answers and explanations into causes of death to enable understanding of what had happened
Discussion of long term impact	68	22%	Given time to discuss the possibilities of future pregnancies and the how what had happened may impact their future
Easy to understand	12	4%	Information was delivered in a way that was easy to understand
Opportunity to express concerns / criticisms	7	3%	Given time to discuss what future concerns are and constructively receive critical information around their care

Q 2.30 What could have been done differently to improve the review process? (Postnatal care)



There were 408 responses to this question, including 297 (73%) which were relevant in relation to the question. 28 (6%) stated that the question was not applicable to them. 28 (6%) provided comments which were not relevant to the specific question. 48 (12%) stated 'nothing' as a response, and 12 (3%) stated 'everything' as a response.



Group	Description
Relevant responses	Relevant response to the question = 297
Not applicable	Not applicable or answered previously = 28
Nothing	Nothing could have been done differently = 28
Everything	Everything could have been done differently = 12

Q 2.30 What could have been done differently to improve the review process? (Postnatal care) – Relevant responses



There were 297 relevant responses, 386 comments were identified and broken down into four groups. 269 (70%) were around improved patient care and support, 77 (20%) were around systems and processes and 21 (5%) said they were happy with the process.

Group	No. of comments	%	Description
Improved patient care and support	269	70%	Quicker time scales, improving communication and providing the correct information for reviews and providing better care and support for service users throughout
Systems and processes	77	20%	More in-depth reports and reviews, holding reviews in suitable locations and staff being honest and admitting fault/blame
Happy with the process	21	5%	Some comments suggested that the review process was as pleasant as it could have been/ excellent in some cases and staff handled reviews well
No review	19	5%	Comments suggested that in some cases reviews did not take place and some service users were unaware that there was a review process

Q 2.30 Review process (Postnatal care) - Improved patient care and support



There were 269 comments relating to patient care and support, these have been broken down into seven groups. 86 (32%) wished for more information, 78 (29%) wished for quicker response times and 31 (12%) said that staff attitude could be improved.

Group	No. of comments	%	Description
More information	86	32%	More explanation and information provided about miscarriages and receiving a report following review to take away and read in more detail
Quicker response times	78	29%	Reviews taking place sooner, improved time taken to receive results from post-mortems and less waiting time for follow up appointments
Attitude of staff	31	12%	More empathy, compassion and care from staff
Communication	27	10%	Improved lines of communication between medical bodies and ensuring service users are kept informed of developments
Better care and support	25	9%	Suggested improvements including not sending parent back to maternity wards without baby
Feeling listened to	11	4%	Staff to take service users views on board and not dismiss fears
Other	11	4%	Other suggested improvements included proving more choice, bereavement support and involving service users in the review process

Section 3: Questions for families who experienced pregnancy complications (affecting the health of mother or baby), and/or neonatal admission after birth



Twenty six questions were asked in this section. The questions are grouped under five headings. These are:

- Antenatal care -if complications arose during pregnancy related to the mother's health or the health of the baby
- During labour - if your baby suffered harm during labour, thinking about the care you received during and after labour
- Neonatal care - If your baby was transferred to a neonatal unit
- Postnatal care - thinking about your care after you went home.

Section 3 - If complications arose during pregnancy related to the mother's health or the health of the baby



This section of the survey is for service users who experienced complications during pregnancy related to their health or the health of the baby. The questions contained within this part of the survey are broken down below:

No	Question
3.1	Do you feel that you received good quality care specific to your / your baby's health complications?
3.2	Did you feel that any specialists you saw communicated effectively with your existing antenatal care team?
3.3	What could have been done differently to improve your care during pregnancy?
3.4	Did you feel involved in decisions about your care during pregnancy?
3.5	Did you have enough time with your midwife or doctor to talk through decisions and concerns during your pregnancy?
3.6	Did you feel after talking through your decisions and concerns they were acted on?
3.7	What did you think about the information you were given (i.e. did it give you the information you needed in a way you could understand?)?

Q 3.1 Do you feel that you received good quality care specific to you / your baby's health complications? (Complications)



There were 751 responses the yes/no part of this question, 496 (66%) answering yes and 255 (34%) no 229 (52%) of those who said yes and 205 (46%) who said no left further comments including 10 (2%) who did not answer the yes or no part however did leave a comment.

Answer	No. of respondents	%	No. of text responses	%
Yes	496	66%	229	52%
No	255	34%	205	46%
Not answered			10	2%
Total	751	100%	444	100%

There were 444 responders who left comments however 22 (5%) individuals stated that the question was not applicable to them.

Q 3.1 Do you feel that you received good quality care specific to you / your baby's health complications? (Complications) – Relevant responses



From the 422 relevant responses, 613 comments were identified and broken down into four groups. 402 (66%) said that they received poor care and support, 161 (26%) said they were happy with their care and 43 (7%) said they had a negative experience of staff.

Group	No. of comments	%	Description
Poor care and support	402	66%	Better care and support needed. In particular quicker response times to concerns and improved accuracy of the information given
Happy with care	161	26%	Care received was excellent and quality of care from staff was very good
Negative experience of staff	43	7%	Shortage of staff or staff perceived as too busy to provide a good quality of care. Comments also included that test results were misplaced by staff resulting in complications
Lack of resources	7	1%	Lack of available beds and / or space in labour wards impacted the quality of care received

Q 3.1 Do you feel that you received good quality care specific to you / your baby's health complications? (Complications) – Poor care and support



The 402 comments relating to patient care and support have been broken down into six groups. 175 (44%) commented that they would have liked better care and support, 66 (16%) wished for quicker response times in relation to complications and 51 (13%) wished to receive more accurate information.

Group	No. of comments	%	Description
Care - general	175	44%	Additional care needed following premature labour, the need to provide better care for service users and their babies
Response time	66	16%	Complications developing due to delayed monitoring / investigation
Information	51	13%	More accurate information and advice for scenarios such as low lying placentas. The need to receive accurate information during scans preventing unnecessary distress
Listened to	51	13%	Doctors ignoring issues and concerns raised by service users; or individuals had to 'push' to get action
Continuity of care	30	7%	Respondents reported receiving disjointed care including seeing multiple consultants and midwives
Communication	29	7%	Complications not being explained to service users effectively and poor communication from staff relating to ongoing care after delivery

Q 3.2 Did you feel that any specialists you saw communicated effectively with your existing antenatal care team? (Complications) – Yes/No



711 individuals responded yes or no to this question. 415 (58%) said yes and 296 (42%) said no they did not feel that specialists communicated effectively. 88 (28%) of those who said yes and 204 (64%) who said no left further comments, an additional 25 respondents who had not answered the yes/no part also left comments.

Answer	No. of respondents	%	No. of text responses	%
Yes	415	58%	88	28%
No	296	42%	204	64%
Not answered			25	8%
Total	711	100%	317	100%

The 317 responses have been broken down into two groups, there were 288 (91%) that were relevant to the question and 29 (9%) that were deemed not applicable.

Group	No. of responses	%
Relevant responses	288	91%
Not applicable	29	9%

Q 3.2 Specialists communication with existing antenatal team (Complications) - Applicable responses breakdown



There were 288 relevant responses identifying 450 comments. These have been broken down into 9 groups. 191 (43%) reported an unsatisfactory experience of communication between specialists, 86 (19%) made non specific comments and 68 (15%) reported a good experience of communication and said things went well.

Communication ineffective

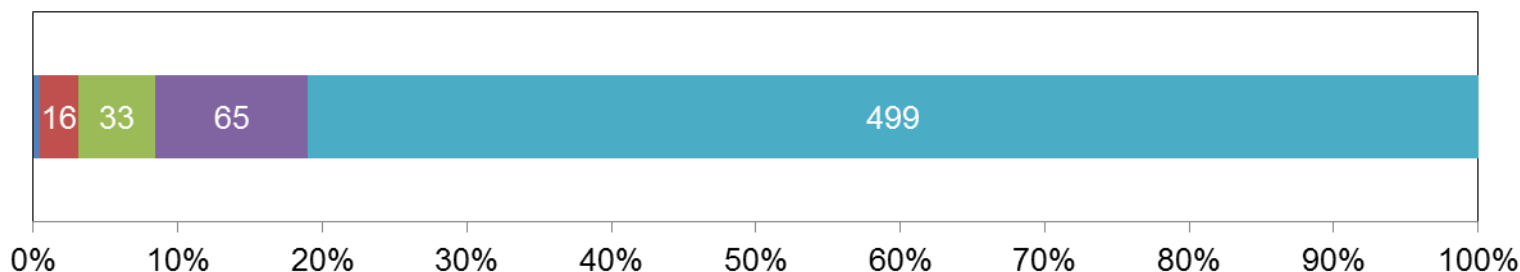
- “...the specialists I saw did not wish to discuss my care plan in respect of the birth with me either in advance or when I presented to labour ward. I felt that it was expected that I would just surrender my power.”

Group	No. of comments	%	Description
Communication ineffective	191	43%	Felt communication was unsatisfactory or lacking
Other	86	19%	Other comments in relation to how improvements could have been made in relation to communication
Good	68	15%	Had good experience of communication or things went well
Continuity of care	65	13%	Issues with continuity of care
Medical Notes	19	4%	Problems with notes
Consistency	8	2%	Issues with variation in care depending on the location
Group B streptococcus	6	1%	More information / testing for group B strep
Communication - Birth plan	4	1%	Issues with communication around birth plans
Communication - Medication	3	1%	Issues with poor communication around medication information

Q 3.3 What could have been done differently to improve your care during pregnancy? (Complications)



There were 616 responses to this question, 499 (81%) stated suggestions for improvements. 65 (11%) responses stated nothing was required to be improved. 33 (5%) responses were generally positive about the care but contained no suggestions for improvements. 16 (3%) responses were not applicable to the question and 3 (<1%) responses stated everything needed to improve..



Group	Description
Improvements	Responses received identified improvement = 499
Nothing	Responses received identified no improvement required = 65
General Positive	Positive responses made but did not include any suggestions for improvement = 33
Not applicable	N/A entered into field, or response not appropriate = 16
Everything	Responses stated everything needed to improve = 3

Q 3.3 Key Area Groups – Care during pregnancy (Complications) - Improvements



There were 499 relevant responses identifying 889 comments relating to improvements. These have been broken down into eleven groups. The most common group related to quality of care, with 249 (28%) comments. 209 (24%) suggested that communication should be better and 96 (11%) stated that staff attitude needs to improve.

Groups	No. of comments	%	Description
Quality of care	249	28%	Improvements around the standards of the treatment and care provided
Better communication	209	24%	Communication could be improved between service users and healthcare professionals
Staff attitude	96	11%	Improvements of the perceived attitude of staff
Staffing	95	11%	Respondents said the care received during pregnancy would have been improved with more staff and better access to staff
More check ups & scans	95	11%	Access to more scans and check ups in a more timely manner
Personalised Care	38	4%	Improvements to the care they received to make more personalised
Environment	15	2%	Keep mothers and babies together and nursing those who lost a baby away from maternity areas
Emotional support	14	2%	More emotional support being provided to parents
Reduce waiting times	10	1%	Lower waiting times for appointments
Breastfeeding support	7	1%	More advice and guidance on breastfeeding and earlier detection of tongue tie
Other	61	7%	Number of individual comments on suggestions for improvement

Q 3.3 Care during pregnancy (Complications) - Quality of care



There were 249 comments in relation to quality of care, these have been broken down further into nine sub groups. 72 (29%) were general comments relating to what could have been done differently, 51 (20%) related to consistency in service delivery and 40 (16%) related to Group B streptococcus testing and the wish for this to be available to all.

Quality of Care

- “I felt that when I raised concerns with regards to losing my mucous plug at 31 weeks and having green discharge I wasn't listened to I was told on three occasions by two midwives and a Dr that it sounded normal despite my baby being born and treated for sepsis.”
- “Midwife taken more [time] to understand my pains as I saw her whilst in early labour and it was diagnosed as a UTI, I was not told to visit the hospital.”

Sub Groups	No. of comments	%	Description
General	72	29%	General comments on what could have been done differently to improve care during pregnancy
Consistency	51	20%	Better consistency in the delivery of the service and an overall provision
Group B streptococcus	40	16%	Proactive group B streptococcus testing to be available to all
Continuity	37	15%	More continuity to enable service users to build relationships and not have to repeat the same information to each practitioners
Monitoring	25	10%	More access to scans and check ups in a more timely manner, particularly in cases of previous miscarriages
Postnatal support	12	5%	More postnatal support
Medical notes	6	2%	More accurate medical notes and the need to keep the information up to date
Antenatal support	4	2%	More antenatal support.
Community	2	1%	More support in the community

Q 3.4 Did you feel involved in decisions about your care during pregnancy? (Complications) - Yes/No



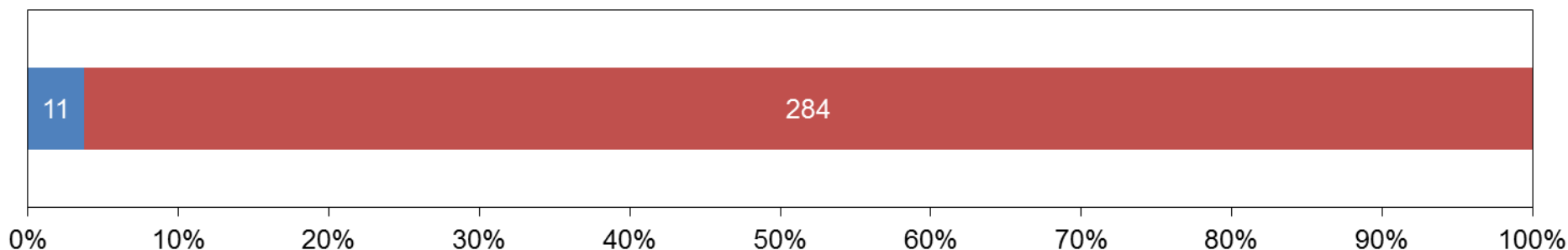
This question gave respondents the opportunity to answer yes or no to whether they felt involved in decisions about their baby's care. Of the 729 respondents who answered, 473 (65%) selected yes and 256 (35%) selected no. A total of 295 respondents went on to provide a text response, including eight individuals who did not answer the yes/no part.

Answer	No. of respondents	% of respondents	No. of text responses	%
Yes	473	65%	115	39%
No	256	35%	172	58%
Not answered			8	3%
Total	729	100%	295	100%

Q 3.4 Did you feel involved in decisions about your care during pregnancy? (Complications)



There were 295 responses to this question. 284 respondents (96%) made a specific comment to whether they felt involved in decisions about their care during pregnancy. 11 (4%) respondents did not specifically comment about whether they felt involved or not.



Group	No. of respondents	% of respondents	Description
Specific comments	284	96%	Specific response on how involved they felt in their care
N/A or stated elsewhere	11	4%	Not applicable or stated elsewhere in survey

Q 3.4 Did you feel involved in decisions about your care during pregnancy? (Complications) - Specific responses



There were 284 relevant responses identifying 338 comments around how involved individuals felt in decisions about their care. These have been broken down into five groups. The most commented group with 193 (57%) comments was around how individuals did not feel involved. A further 53 (16%) made general comments about their level of involvement and 43 (13%) said they felt involved.

Group	No. of comments	%	Description
Not involved	193	57%	Not involved in their decisions, being poorly informed or not listened to
General comments on level of involvement	53	16%	General comments on how involved the respondent had felt in decisions
Felt involved	43	13%	Felt involved in their decisions such as being given options and time
Mitigating circumstances	34	10%	Personal situation meant opportunity to be involved was limited or individual was happy for healthcare professionals to make all decisions
Other experiences	15	4%	Comments made on specific experiences of care rather than made them feel involved or not

Q 3.4 - Did you feel involved in decisions about your care during pregnancy? (Complications) - Not involved



193 comments related to feeling uninvolved, these have been broken down further into eleven sub groups. 32 (17%) felt poorly informed, 30 (16%) comments stated that their concerns were not taken seriously and 27 (14%) comments said that decisions were made without their involvement.

Sub Group	No. of comments	%	Description
Poorly informed	32	17%	Felt uninvolved/uninformed in decisions about care during pregnancy when complications arose
Concerns dismissed	30	16%	Concerns or worries often dismissed
Not involved in decision making	27	14%	Decisions made without discussing fully
No choice	18	9%	No options or choices given
Felt not listened to	17	9%	Felt listened to and that opinions and thoughts were taken on board
Pressurised to make decisions	17	9%	Put under pressure to make decisions quickly
Decisions ignored	15	8%	Choices made however decisions not then respected
Staff inconsistency	8	4%	Not seeing the same member of staff and having to explain same story to different healthcare professionals
Lack of contact	6	3%	Not enough contact or information given from healthcare professionals
Variable involvement	6	3%	Varied levels of involvement throughout the care
Other	17	9%	Other comments in relation to not feeling involved in decisions about care

Q 3.4 Did you feel involved in decisions about your care during pregnancy? (Complications) - General level of involvement



53 comments were made in relation to general levels of involvement. These have been broken down into four sub groups. 19 (36%) comments were from respondents who said they felt involved, 15 (28%) comments stated that individuals were involved but not as much as they wanted or could have been and 11 (21%) said that had to fight to be involved.

Sub Group	No. of comments	%	Description
Involved	19	36%	Felt fully involved and informed throughout care
Partly involved	15	28%	Involved however not always
Had to fight to be involved	11	21%	Was involved but only because this was pushed or requested
Not involved	8	15%	Did not feel involved in care

Q 3.5 Did you have enough time with your midwife or doctor to talk through decisions and concerns during your pregnancy? (Complications) – Yes/No



This question gave respondents the opportunity to answer yes or no. 282 (39%) answered no and 448 (61%) yes as to whether or not they were given enough time to talk through decisions and concerns with their midwife or doctor. 111 of those who said yes and 178 of those who said no left further comments. In addition, 10 respondents left further comments however did not respond to the yes/no part of the question

Answer	No. of respondents	%	No. of text responses	%
Yes	448	61%	111	38%
No	282	39%	178	61%
Not answered			10	3%
Total	730	100%	299	100%

299 respondents then went on to leave comments, including 10 individuals who did not respond to the yes/no part of the question.

From the 299 responses, 34 (11%) were identified as not applicable. The remaining 265 (89%) responses were analysed and 415 comments were identified and broken down into three groups:

Group	Description
Role specific breakdown	Comments specifically identified which healthcare professional groups were and were not available for sufficient time to discuss their concerns during pregnancy = 197
Negative	Negative comments were made by respondents and can be summarised into four sub-groups. The use of time, staffing, availability of time and the manner the professional conducted themselves = 182
Positive	General positive comments were made about enough time with healthcare professionals = 36

Q 3.5 Time with midwife/doctor (Complications) – Role specific breakdown



There were 197 comments in relation to a positive or negative experience with certain healthcare professionals.

There were 74 (38%) positive comments and 123 (62%) negative comments with regards to time spent with certain healthcare professionals. The majority of positive comments and negative comments were around time spent with midwives.

Midwife (positive)

- “My one to one midwife was available 24-7 and visited me on more than 12 occasions”
- “The midwives were all very helpful with answering my concerns, as were the doctors I saw during this period”

Staff Group	Positive		Negative	
	No. of comments	%	No. of comments	%
Midwife	29	39%	70	57%
Consultant	15	20%	15	12%
Doctor (General)	13	18%	18	15%
Hospital Staff	11	15%	15	12%
GP	4	5%	1	1%
Nurse	2	3%	4	3%
Total	74	38%	123	62%

Q 3.5 Time with midwife/doctor (Complications) - Relevant responses breakdown



182 comments were identified relating to a negative experience of time with healthcare professionals. These have been broken down into three sub groups, with the most common being lack of availability of healthcare with 104 (26%) comments. 56 (31%) identified issues with staff attitude and 22 (12%) said there was a lack of person centred care.

Availability and use of time

- “She seemed very rushed and uninterested. Any time she had to do anything outside of box ticking seemed stressful to her and like she didn't really care.”

Main Group	No. of comments	%	Sub- Group	Description	No. of Comments	%
Negative	182	46%	Availability and use of time	Issues with the availability, repetition due to different professionals, professionals appearing conscious of time and feeling rushed	104	57%
			Issues with staff attitude	Respondents used negative descriptors of their professional's conduct during appointments such as blunt or dismissive of concerns and insensitive.	56	31%
			Lack of person centred care	Comments on how additional time not available any support beyond 'normal' requirements e.g. to discuss mental health needs	22	12%

Q 3.6 Concerns acted on (Complications) - Patient care and support



There were 190 comments around patient care and these have been broken down into seven sub groups. The most common sub group with 91 (48%) comments was around individuals not feeling like they were listened to and decisions were made without them. 41 (22%) comments were around more general care and support they received and 18 (10%) said they had to push for decisions.

Sub Group	No. of comments	%	Description
Not listened to	91	48%	Service users feeling as though decisions were made for them, concerns dismissed by staff as just 'worrying' and birth plans being ignored
Care and support	41	22%	Service users felt care and support for them was still lacking even after talking through their concerns
Had to push for decisions	18	10%	Service users felt action was only taken only if they were persistent in their requests
Availability	17	9%	Did not have the opportunity to talk concerns through, decisions were made by professionals
Timing	12	6%	By the time they received help it was too late and staff not acting on concerns resulting in further complications
Continuity of care	6	3%	Constantly faced with conflicting opinions and left out of decisions, concerns not spoken about and decisions overturned by other doctors
Information	5	2%	General confusion about the birth and lack of information provided to service user

Q 3.7 What did you think about the information you were given? - i.e. did it give you the information you needed in a way you could understand? (Complications)



There were 549 responses to question 3.7. 517 (94%) provided comment on the level of information received and 32 (6%) were not applicable.

From the 517 relevant responses, 728 individual comments were identified and included within the analysis below. Of the 728 comments there are three overarching groups. 55 (8%) detailed mixed comments, 367 (50%) made positive comments and 306 (42%) made negative comments.

Group	Description
Positive	Positive comments include those that rated the information either good or excellent = 367
Neutral	Neutral comments include those where information was seen to be adequate or meeting a minimum expectation = 55
Negative	Negative comments include those where no information was received, some information was seen to be more out of date, and where information was not delivered in an appropriate manner = 306

Q 3.7 Information given (Complications) - Relevant responses breakdown (Positive)



There were 367 positive comments and 282 (77%) commented on how easy the information was to understand; and felt they had plenty of information. 43 (12%) said the information was tailored to them and 42 (11%) said they had opportunities to discuss and ask further questions if needed.

Positive

- “Great- especially the breastfeeding video, this really helped when it came to breastfeeding after he was born.”
- “Any information I needed I got it explained in a way that I understood as well as leaflets to takeaway with me.”
- “Good information given honestly and decision made to bring my baby by section 10 weeks early, surgeons were amazing.”

Main Grouping	No.	%	Sub Group	Description	No.	%
Positive	367	50%	Easy to understand	Respondents said they did receive sufficient or plenty of information in a way in which they could understand it	282	77%
			Tailored to individual	Respondents rated the information very good or excellent also referred to the way in which it was delivered, i.e. the information was provided with consideration for them and their circumstances and they felt it was accurate and honest	43	12%
			Opportunity to discuss	Respondents described the information as helpful, informative and that they had the opportunity to ask further questions if needed	42	11%

Q 3.7 Information given (Complications) - Relevant responses breakdown (Negative)



There were 306 negative comments, 163 (22%) of these commented on how individuals were not satisfied on the level of information received. 99(14%) of comments related to the information being not easy to understand due to the overuse of medical terminology. 44 (14%) said that information was of poor quality or out of date.

Negative Comments

- “I did not know anything about GBS. My baby was taken away for 2 hours, and I was taken to my room, post delivery, where I was casually handed a leaflet about GBS, with no explanation. Due to the urgent nature of the delivery, and my brief loss of consciousness on the operating table, I was unaware of what was happening, or the seriousness of it. Only later when my husband went home and researched GBS on the internet, did he become extremely worried for our baby and explained it to me.”
- “There were discussions among the Healthcare professionals about me having a "Ca125" blood test. Due to the nature of my work I knew this was a test for Cancer / tumour markers. That possibility was never discussed with me directly.”
- “Info re Edwards Syndrome given very bluntly by specialist as if reading from a book- no reaction to our reaction. Acted like he hadn't given us possibly life changing information. When you are given news like that you tend to fear the worst and cannot just go with the positive. Had to look up the information online as not given anything to read - impossible to take it all in. Then no one with knowledge to speak to, no helpline etc ,just had to wait for test results.”

Main Grouping	No.	%	Sub- Group	Description	No.	%
Negative	306	42%	Information out of date or poor quality	Content of information shared was felt to be either out of date or of poor quality.	44	14%
			Not satisfied with level of information	Respondents were not satisfied with the volume of information received.	163	53%
			Information not easily understood	Respondents were dissatisfied with the way that information was delivered impacting on understanding, i.e. including medical terminology, language barriers,	99	32%

If your baby suffered harm during labour, thinking about the care you received during and after labour



Within this section of the survey, those parents whose baby suffered harm during labour were asked to think about the care they received. The questions are broken down below:

No	Question
3.8	Did you feel you received good quality care during your labour?
3.9	If you had concerns did you feel they were listened to and acted on?
3.10	What could have been done differently to improve the care you received during and after labour?
3.11	What could have been done differently to improve your care after the birth of your baby while you were in hospital?
3.12	What was good about your care at this time?
3.13	We would like your thoughts on continuity of care. How important would it be for you to be supported by the same midwife before, during and after birth?
3.14	How important was it for you to have the same obstetrician and or midwife throughout the time you gave birth?
3.15	What did you think about the information you were given after your baby suffered harm?
3.16	Did you have a follow up appointment with your consultant to discuss the reasons for your baby's condition?
3.17	What was good about the process to review the circumstances in which your baby was harmed?

Q 3.8 Did you feel you received good quality care during your labour? (If your baby suffered harm during labour) – Yes/No



This question gave respondents the opportunity to answer yes or no. 393 (68%) answered yes and 184 (32%) answered no.

Answer	No. of respondents	%	No. of responses	%
Yes	393	68%	159	50%
No	184	32%	147	46%
Not answered			15	5%
Total	577	100%	321	100%

321 individuals provided further comments, including 15 individuals who did not respond to the yes/no question. 242 (75%) responses were relevant to the question and 79 (25%) responses stated that the question was not applicable to them.

:

Q 3.8 Did you feel you received good quality care during your labour? (If your baby suffered harm during labour) – Relevant responses



From the 242 relevant responses, 365 comments were identified and broken down into four groups. 173 (47%) said that they received poor care and support, 135 (37%) said they were happy with their care and 52 (14%) stated that staff attitudes were negative towards them.

Group	No. of comments	%	Description
Poor patient care and support	173	47%	Quicker response times where concerns are raised, particular for those who have a caesarean
Happy with care	135	37%	Service users were happy with the care they received and staff were reassuring and supportive
Staff attitude	52	14%	Staff perceived to have a negative attitude towards service users
Limited facilities	5	2%	Suggested improvements included providing space for partners to be able to stay and a more beds available

Q 3.8 Care during labour (If your baby suffered harm during labour) - Patient care and support



There were 173 comments relating to patient care and support, these have been broken down into seven sub groups. The most common group with 33 (15%) said they felt a lack of support impacted on the quality of their care. 33 (15%) said they experienced delays in response time and 25 (12%) said that their concerns were dismissed.

Sub Group	No. of comments	%	Description
Lack of support	40	19%	Left alone for long periods even when deemed a high risk
Delays in response times	33	15%	The need for staff to respond more quickly to concerns raised by service user
Concerns dismissed	25	12%	Staff dismissing concerns due to being first time parents and staff ignoring requests
Avoidable complications	19	9%	Complications perceived avoidable if appropriate process followed e.g.. contracting septicaemia
Poor pain relief options	18	8%	Not offered antibiotics and/or pain relief early enough during labour
Poor patient care - general	16	7%	Not being offered food or drink, feeling rushed and receiving poor care during labour
Other	22	9%	Other negative experience of care during labour

Q 3.9 If you had concerns did you feel they were listened to and acted on? (If your baby suffered harm during labour) - Yes/No



This question gave respondents the opportunity to answer yes or no. 329 (62%) answered yes and 200 (38%) answered no. 63 of those who said yes and 130 of those who said no left further comments, including 20 who did not answer yes or no however left a comment.

Answer	No. of respondents	%	No. of responses	%
Yes	329	62%	63	30%
No	200	38%	130	61%
			20	9%
Total	529	100%	213	100%

Of these 159 (87%) included a relevant response to the question, 18 (5%) individuals stated that the question was not applicable to them. 16 (8%) provided comments which were not relevant to the specific question.

Q 3.9 If you had concerns did you feel they were listened to and acted on? (If your baby suffered harm during labour) – Relevant response breakdown



There were 159 relevant responses which have been broken down into three sub groups. 158 (69%) said that they experienced poor care and support, 53 (23%) said they were happy with their care and 17 (8%) made a comment in relation to staff availability and said this was limited.

Group	No. of comments	%	Description
Poor patient care and support	158	69%	Not respected and ignored, care, support & response time to improve
Happy with care	53	23%	Cared and supported, all concerns addressed promptly
Staff availability	17	8%	Limited availability of staff had a negative impact on concerns being acted upon

Q 3.9 Concerns listened to and acted on (If your baby suffered harm during labour) - Poor patient care and support



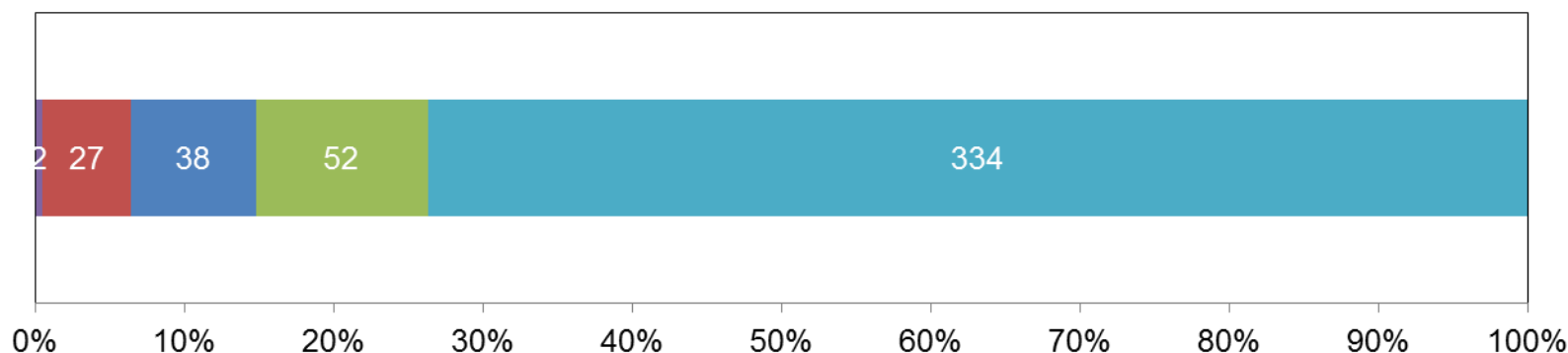
There were 158 comments in relation to poor patient care and support which have been broken down into five sub groups. The most prevalent with 74 (46%) comments is the perception that service users were not listened to by healthcare professionals. 49 (31%) comments felt unsupported and 20 (14%) said staff were slow to respond to concerns.

Group	No. of comments	%	Description
Not listened to	74	46%	Concerns ignored and wishes not respected , or staff making time to listen to service users
Lack of support	49	31%	Poor support for service users in particular around postnatal care
Delays in response times	20	14%	Slow at recognising signs of infection and responding to concerns
Poor breastfeeding information	7	4%	Poor feeding support & advice particularly with premature baby
Other	8	5%	Comments such as the need for quicker / better access to pain relief and not having to push for decisions to be made

Q 3.10 What could have been done differently to improve the care you received during and after labour? (If your baby suffered harm during labour)



There were 453 responses to this question, 334 (74%) identified an area for improvement. 38 (8%) stated nothing was required to be improved. 52 (11%) stated the question was not applicable to their situation.



Group	Description
Improvements	Responses identified improvement = 334
Positive	Responses made on general positive statements = 52
Nothing	Responses identified no improvement required = 38
Not applicable	N/A entered into field, or response not appropriate = 27
Everything	Responses stated everything needed to be improved = 2

Q 3.10 Key area groups – Care during labour - (If your baby suffered harm during labour) – Improvements



There were 334 responses relating to improvements, from this 464 comments were identified and have been broken down into seven sub groups. 189 (34%) related to issues with quality of care, 107 (19%) related to staff perceived attitude and 96 (20%) were about poor communication between service users and healthcare professionals.

Groups	No. of comments	%	Description
Quality of care	189	41%	Improve care & treatment standards, inaccurate medical records and attitude and behaviour of staff
Staff attitude	107	23%	Improve attitude of staff towards service user
Communication	96	21%	Staff should shared information with one another more frequently and be more transparent with service users
Environment	53	11%	Keep mothers and babies together and nurse those who lost a baby away from maternity areas
Consent / respectful of individual	9	2%	Staff should secure service user's consent before any procedures and respecting their wishes and privacy
Emotional support	7	2%	Provide more emotional support to service users
Other	3	1%	Other suggestions in relation to improvements during labour

Q 3.10 Care during labour - (If your baby suffered harm during labour) – Quality of care



There were 107 comments relating to quality of care, these have been broken down further into eight sub groups. 69 (37%) made general comments in relation to improvements however nothing specific. 25 (13%) were around personalised care and 25 (13%) around postnatal support.

General

- “ They were to busy didn't pick up on the fact my sons heart beat had dropped and my blood pressure was extremely high and the urge to push had stopped
- “ The registrar and midwives could have kept a closer eye on timings (they lost track of time!)”

Sub Group	No. of comments	%	Description
General	69	37%	General improvements in care with nothing specific identified
Personalised	25	13%	More personalised service to be provided, tailored to an individuals care
Postnatal support	25	13%	Care and support following the loss of a baby with opportunities to hold them and spend time with them before going home
Testing	21	11%	More checks and testing to pick up any problems as early as possible
Pain management	20	11%	Better pain management, including administering medication quicker and more options being available
C-section specific	16	9%	Improvements for those undergoing a C-section
Continuity	8	4%	Improved consistency of staff and notes, and seeing the same midwife/ staff
Medical notes	4	2%	More accurate medical notes, and staff to ensure they read notes and are up to date

Q 3.10 Care during labour (If your baby suffered harm during labour) – Staff attitude



There were 107 comments in relation to staff attitude, these have been broken down further into seven sub groups. 29 (30%) were around staff listening to parents concerns, 24 (25%) were around how staff should have a more caring attitude and 19 (20%) of comments related to access to staff.

Staff listen to parents concerns

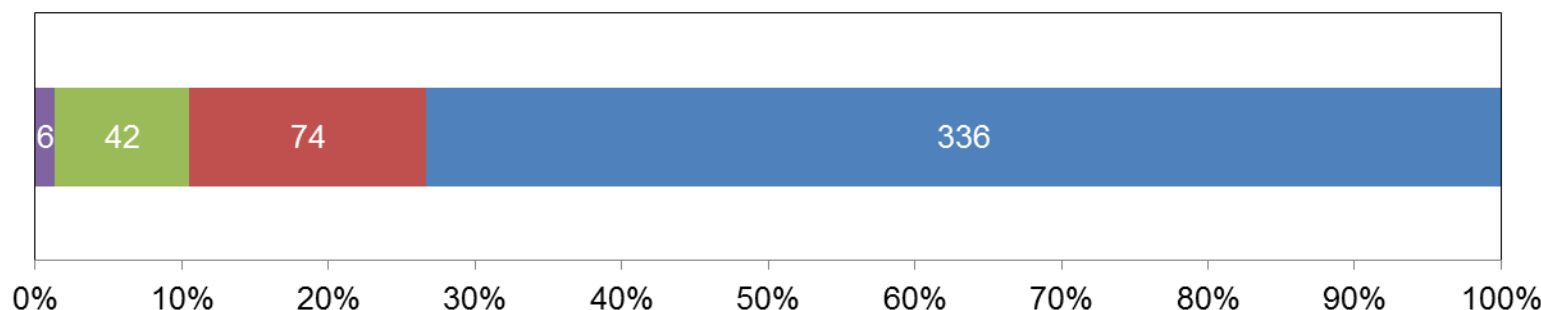
- “Be listened to, be believed when I was having my baby!”
- “I could have been listened to and consulted rather than forced without any other options made available to me”

Sub Group	No. of comments	%	Description
Listening to parents concerns	29	30%	Service users are not involved in making decisions, their concerns are dismissed and choices ignored
Caring attitude	24	25%	Staff should have compassionate, empathetic and sensitive attitude
Access to staff	19	20%	Easier access and availability of staff
Quality of staff	13	13%	Improve skillset of personnel to ensure they can respond to range of situations
More staff	9	9%	Increasing staff on duty
Staff training	2	2%	Staff trained to deal with a wider range of situations
Time to talk things through with staff	1	1%	More time to discuss concerns with staff

Q 3.11 What could have been done differently to improve your care after the birth of your baby while you were in hospital? (If your baby suffered harm during labour)



There were 458 responses to this question and 488 comments were identified. 336 (73%) identified areas for improvement. 74 (16%) stated nothing was required to be improved. 42 (9%) stated the question was not applicable to their situation, and 6 (1%) stated everything had to improve.



Group	Description
Improvements	Responses received identified improvement = 336
Nothing	Responses received identified no improvement required = 74
Not applicable	N/A entered into field, or response not appropriate= 42
Everything	Responses received identified everything needed to improve = 6

Q 3.11 Care after the birth of your baby (If your baby suffered harm during labour) – Improvements



There were 336 responses in relation to improvements, from this 601 comments were identified. These have been broken down further into nine groups. 149 (25%) related to improvements in the environment, 127 (21%) related to staff and 93 (15%) were around communication.

Groups	No. of comments	%	Description
Environment	149	25%	Keep mothers and babies together and nurse those who lost a baby far away from maternity areas
Staff Improvement	127	21%	Improve the attitude of staff towards service users
Communication	93	15%	Staff should discuss matter and explain things to service users
Quality of care	68	11%	Better standards of treatment, care and management of medical records
Emotional support	53	9%	More emotional support for service users
Breastfeeding help	46	8%	More advice and guidance on breastfeeding and detect tongue tie sooner
Communication between healthcare professionals	25	4%	Teams and departments should communicate and coordinate more effectively
Memories	20	3%	Staff should advise and guide mothers on how to capture memories of their baby
Other	20	3%	Other suggested improvements in relation to care after the birth or their baby

Q 3.11 Care after the birth of your baby (If your baby suffered harm during labour) - Environment



There were 149 comments in relation to the environment, these have been broken down further into 8 sub groups. 36 (24%) comments were about receiving care away from the labour ward, 27 (18%) were around keeping the mother and baby together and 18 (12%) were from people wishing for the ability for their partner to stay overnight.

Away from labour ward

- “I was placed into a ward where other mothers had their babies with them. This was a constant reminder that my child was in another part of the hospital, fighting for her life.”

Family and baby together

- “Bring mother and baby together. Awful for the mother to be in intensive care post caesarean at one end of a building, and hours-old baby at the other. This seriously damages attachment for mother and child, and also leaves other family members - especially fathers - torn.”

Sub Group	No. of comments	%	Description
Away from labour ward	36	24%	Nurse those who lost a baby away from maternity wards
Togetherness	27	18%	Keep mother and baby together, not separate
Partner able to stay	18	12%	Provide sleeping provision for partners to stay with mother and baby
Access to neonatal	16	11%	Provide easier access to neonatal wards for mothers to see their babies
Better food / availability	14	9%	Better food available and better availability at all times of day and night
Peaceful	12	8%	Private rooms to get peace and quiet
Not rushed out	12	8%	Do not discharge in a rush, allow mothers more time to remain in hospital
Other	14	9%	Other suggestions for improvement in relation to the environment of which care is provided following the birth of babies

Q 3.11 Care after the birth of your baby (If your baby suffered harm during labour) - Staff Improvement



There were 127 comments and suggestions for improvements in relation to staff, these comments have been broken down further into seven sub groups. 47 (37%) wished for an improvement in staff attitude, 31 (24%) said that more staff would have improved their experience and 22 (17%) wished for staff to listen to their concerns.

Staff Attitude

- “After labour I was looked after amazingly by two wonderful midwives. Unfortunately that was short lived and replaced by another miserable midwife.”
- “Compassion and sympathy of the process of moving neonatal babies around the network, there is a blasé attitude of the unit staff that it happens. When you have experienced premature labour this is a disgusting attitude to have.”

Sub Group	No. of comments	%	Description
Attitude	47	37%	Need to improve staff's attitude towards service users
More staff	31	24%	Increase the staffing provisions
Listen to parents concerns	22	17%	Service users felt that decisions were being made for them, concerns were dismissed and birth plans were ignored
Better training for staff	9	7%	Train staff to deal with a wider range of situations
Time for Questions	5	4%	Staff should ensure they have time to answer any questions
Caring staff (language)	4	3%	Staff should speak with more compassion, empathy and sensitivity
Staff other	9	7%	Various broad statements about the provision and skill mix of staff generally.

Q 3.12 What was good about your care at this time? (If your baby suffered harm during labour)



There were 428 responses received in relation to this question, 339 (79%) of these were relevant to the question, with 71 (17%) stating that nothing was good about their care, and 18 (4%) of responses deemed not applicable.

There were 444 comments identified from the 339 responses in relation to specific aspects of care. 296 (67%) of these comments were positive remarks in relation to the care received by staff, 63 (14%) commented that they felt well supported and were kept informed and supported.

Regular checks / partner allowed to stay

- “The NICU were fantastic. I was checked on regularly, my son was checked regularly, the staff were approachable and understanding. My husband was also able to stay which made it a lot easier.”

Privacy / Staff

- “Private suite so not too close to other mums and babies on ward. Midwives gave such excellent care and made us feel like parents.”

Group	No. of comments	%	Description
Staff / care	296	67%	Caring, compassionate and understanding staff
Well supported	63	14%	Good communication, kept informed and supported throughout
Partner allowed to stay	14	3%	Partner allowed to stay overnight
Privacy	32	7%	Suitable accommodation away from new mums and their babies or private rooms to spend time with babies.
Regular checks	17	4%	Seen and monitored regularly
Help with feeding	22	5%	Help with breast and bottle feeding

Q 3.13 Same midwife before, during and after birth (If your baby suffered harm during labour) - Scores



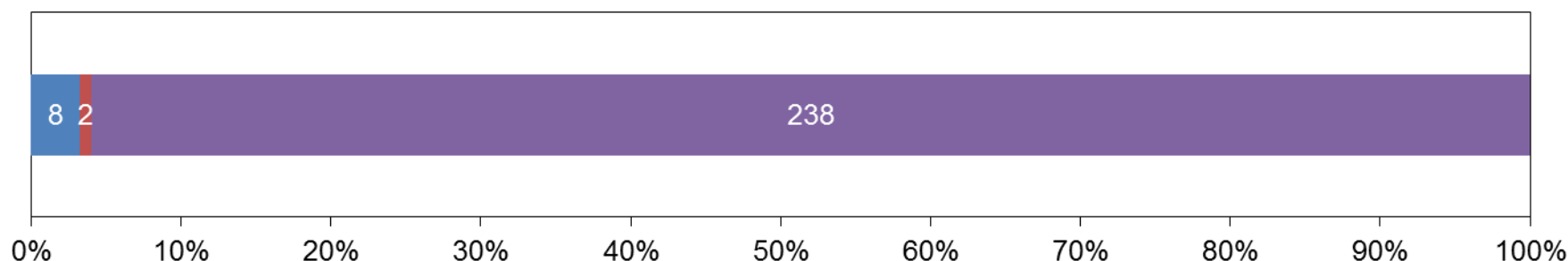
This question gave respondents the opportunity to score how important they thought it was to be supported by the same midwife before, during and after birth with 5 being very important and 1 being not important at all. Of the 572 respondents who scored this question, 353 (62%) scored it 5.

Score	No. of respondents	%
1 = not important	28	5%
2	24	4%
3	73	13%
4	94	16%
5 = very important	353	62%
Total	572	

Q 3.13 How important would it be for you to be supported by the same midwife before, during and after birth? (If your baby suffered harm during labour)



There were 248 responses in relation to this question. 238 (96%) made a relevant response on how important they felt it was to be supported by the same midwife. 8 (3%) respondents stated that the question was not applicable to them. 2 (2%) respondents submitted a number rather than a description.



Group	Description
Relevant responses	Specific comments on how important they considered being supported by the same midwife = 238
N/A	Not applicable or stated elsewhere in the survey = 8
Score	Where people had included a number in the comments box = 2

Q 3.13 Same midwife before, during and after birth (If your baby suffered harm during labour) - Specific Comments



There were 238 responses that were relevant to the question, from this, 286 comments were identified which related to how important they thought it was to be supported by the same midwife before, during and after birth. These comments are broken down into seven group. The most common group with 80 (28%) comments related to the benefits individuals thought this would bring to the care they received.

Group	No. of comments	%	Description
Benefits	80	28%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Positive	58	20%	Seen to be important or a good thing to have if possible
Experiences	55	19%	Personal experience on the benefits of having the same midwife or the negatives if experienced multiple midwives
Problems	40	14%	Identifies some of the problems with attempting to do this such as the fact it would depend on the midwife and questions over the practicality of it
Advice	25	9%	Advice on how to improve the service such as the importance of good handovers, allowing women to change their midwives and the need for good communication
Negative	15	5%	Unimportant or not as important as other areas
Times when it is most important	13	5%	Comments on how at specific times or scenarios it would be most important to have the same midwife

Q 3.13 Same midwife before, during and after birth (If your baby suffered harm during labour) - Specific Comments scores 1 and 2



Breakdown of comments by individuals who scored question 3.13 a 1 or 2:

38 comments were identified which related to how important they thought it was to be supported by the same midwife before, during and after birth. These comments are broken down into seven group. The most common group with 10 (26%) comments related to problems that may arise when doing this.

Group	No. of comments	%	Description
Problems	10	26%	Identifies some of the problems with attempting to do this such as the fact it would depend on the midwife and questions over the practicality of it
Negative	8	21%	Unimportant or not as important as other areas
Experiences	7	18%	Personal experience on the benefits of having the same midwife or the negatives if experienced multiple midwives
Benefits	4	11%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Advice	4	11%	Advice on how to improve the service such as the importance of good handovers, allowing women to change their midwives and the need for good communication
Times when it is most important	3	8%	Comments on how at specific times or scenarios it would be most important to have the same midwife
Positive	2	5%	This was either important or would be a good thing to have

Q 3.13 Same midwife before, during and after birth (If your baby suffered harm during labour) - Specific Comments score 3



Breakdown of comments by individuals who scored question 3.13 a 3:

37 comments were identified which related to how important they thought it was to be supported by the same midwife before, during and after birth. These comments are broken down into seven groups. The most common group with 9 (24%) comments were around how this would be positive in relation to their experience.

Group	No. of comments	%	Description
Positive	9	24%	This was either important or would be a good thing to have
Advice	8	22%	Advice on how to improve the service such as the importance of good handovers, allowing women to change their midwives and the need for good communication
Negative	6	16%	Unimportant or not as important as other areas
Experiences	5	14%	Personal experience on the benefits of having the same midwife or the negatives if experienced multiple midwives
Problems	5	14%	Identifies some of the problems with attempting to do this such as the fact it would depend on the midwife and questions over the practicality of it
Benefits	3	8%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Times when it is most important	1	3%	Comments on how at specific times or scenarios it would be most important to have the same midwife

Q 3.13 Same midwife before, during and after birth (If your baby suffered harm during labour) - Specific comments scores 4 and 5



Breakdown of comments by individuals who scored question 3.13 a 4 and 5:

208 comments were identified which related to how important they thought it was to be supported by the same midwife before, during and after birth. These comments are broken down into seven groups. The most common group with 73 (35%) identified benefits of doing this.

Group	No. of comments	%	Description
Benefits	73	35%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Positive	47	23%	This was either important or would be a good thing to have
Experiences	40	19%	Personal experience on the benefits of having the same midwife or the negatives if experienced multiple midwives
Problems	25	12%	Identifies some of the problems with attempting to do this such as the fact it would depend on the midwife and questions over the practicality of it
Advice	13	6%	Advice on how to improve the service such as the importance of good handovers, allowing women to change their midwives and the need for good communication
Times when it is most important	9	4%	Comments on how at specific times or scenarios it would be most important to have the same midwife
Negative	1	<1%	Unimportant or not as important as other areas

Q 3.13 Same midwife before, during and after birth (If your baby suffered harm during labour) - Benefits



There were 78 comments relating to benefits of having the same midwife. These have been broken down into 6 sub groups. The most commented on sub group was that it would be helpful in knowing history and identifying problems with 24 (30%) comments identifying this as a key benefit. 20 (25%) comments said that the trust / relationship which could be built up with the midwife was a key benefit.

Benefits

- “Someone who knew me, my situation and what my wishes are would have made all the difference. They could have been my voice and supported me to make the right choice in fundamental decisions about care for me and my babies.”

Sub Group	No. of comments	%	Description
Quality of care	24	31%	Perceived to reduce the number of problems or errors
Build up trust	20	26%	You would be able to build up trust more easily
Reduces repeating information	20	26%	Would reduce the need to tell multiple healthcare professionals same information
Support choice	6	8%	Would help choices to be supported as the midwife would have built a relationship and know history
Improve Communication	5	6%	Make it easier for mothers to communicate during labour
Reduces risk of information being lost	3	4%	Information is less likely to be lost in transition between different midwives

Q 3.13 Same midwife before, during and after birth (If your baby suffered harm during labour) - Positive



There were 58 comments around how having the same midwife would have a positive impact. These comments have been broken down further into three sub groups. The most commented on sub group was that it was important with 26 (45%) comments stating this. 24 (41%) comments said that it would be nice and 8 (14%) stated that it would be nice but was not necessary.

Sub Group	No. of comments	%	Description
Important	26	45%	Important to see same midwife
Would be nice	24	41%	Would be nice however not that important
Nice but not necessary	8	14%	Would be nice however not always necessary

Q 3.13 Same midwife before, during and after birth (If your baby suffered harm during labour) - Experiences



There were 55 comments relating to respondents experiences of having/ not having the same midwife. These have been broken down into six sub groups. The most commented on sub group, with 20 (36%) comments, relates to negative experiences in care due to seeing different midwives. 12 (22%) comments were around negative experiences and 6 (11%) were from respondents who said they had limited contact with a midwife.

Different midwives

- “Did not have any one I'd seen before. I had 4 swaps during Labour the middle one liked to flirt with the doctor.”
- “I saw so many different people it was ridiculous”

Sub Group	No. of comments	%	Description
Different midwives	20	36%	Seeing different staff can have a negative impact upon patient experience
Negative experience of midwife	12	22%	Negative experience with a midwife which could be avoided if individual had same midwife throughout
Limited midwife involvement	6	11%	Received little contact from the midwife which impacted quality of care
Same midwife	5	9%	Same midwife attended throughout and was seen as a benefit
Positive experience of midwife	5	9%	Positive experience with a midwife which leads individuals to believe the same midwife throughout would be of benefit.
Other	7	13%	Other comments in relation to experience of seeing the same midwife before/during and after birth

Q 3.14 - How important was it for you to have the same obstetrician and or midwife throughout the time you gave birth? (If your baby suffered harm during labour) - Scores



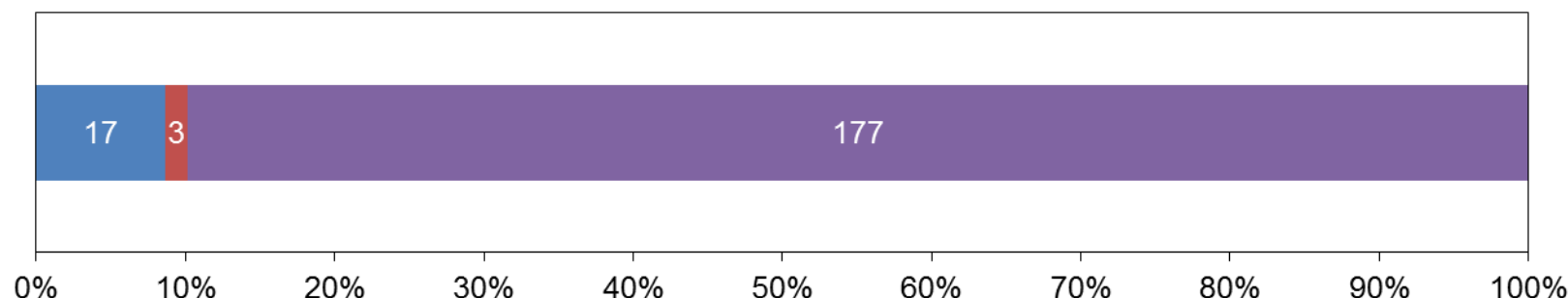
Question 3.14 gave respondents the opportunity to score how important they felt being supported by the same obstetrician and or midwife throughout the time they gave birth was. Of the 569 respondents who scored this question 375 (66%) scored this 5 i.e. very important.

Score	No. of respondents	% of Respondents
1 = Not important	27	5%
2	12	2%
3	63	11%
4	92	16%
5 = Very important	375	66%

Q 3.14 - How important was it for you to have the same obstetrician and or midwife throughout the time you gave birth? (If your baby suffered harm during labour)



There were 197 responses to this question, 177 (90%) responses were relevant to how important it was to be supported by the same obstetrician and or midwife throughout the time you gave birth. 20 (10%) of responses did not or were deemed not applicable or not relevant.



Group	Description
Relevant responses	Specific responses on how important they considered being supported by the same obstetrician or midwife = 177
Score	Where people had included a number in the comments box = 3
N/A or stated elsewhere	Not applicable or relevant comments = 17

Q 3.14 Same obstetrician and or midwife throughout the time you gave birth (If your baby suffered harm during labour) Specific Comments - All



From the 177 relevant responses, 202 comments were identified and broken down into five groups. The majority, 86 (43%) comments were from respondents who said they had a personal experience of having the same midwife/ obstetrician and that this had a positive impact upon their care. 53 (26%) comments stated that this generally would be positive and 25 (12%) explained the benefits that this would have.

Group	No. of comments	%	Description
Experiences	86	43%	Personal experience on the benefits of having the same obstetrician or midwife, or the negatives if experienced multiple obstetrician or midwives
Positive	53	26%	Seen to be important or a good thing to have if possible
Benefits	25	12%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Problems	23	11%	Identifies some of the problems with attempting to do this such as the fact it would depend on the obstetrician or midwife and questions over the practicality of it
Negative	15	7%	Seen as unimportant or not as important as other areas

Q 3.14 Same obstetrician and or midwife throughout the time you gave birth (If your baby suffered harm during labour) - Specific Comments scores 1 and 2



Breakdown of comments by individuals who scored question 3.14 a 1 or 2:

25 comments were identified which related to how important they thought it was to be supported by the same obstetrician and or midwife. These comments are broken down into five groups. The most common group with 10 (40%) comments were around personal experiences on the benefits of having the same obstetrician and or midwife.

Group	No. of comments	%	Description
Experiences	10	40%	Personal experience on the benefits of having the same obstetrician or midwife, or the negatives if experienced multiple obstetrician or midwives
Positive	1	4%	Seen to be important or a good thing to have if possible
Benefits	1	4%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Problems	4	16%	Identifies some of the problems with attempting to do this such as the fact it would depend on the obstetrician or midwife and questions over the practicality of it
Negative	9	36%	Seen as unimportant or not as important as other areas

Q 3.14 Same obstetrician and or midwife throughout the time you gave birth (If your baby suffered harm during labour) Specific comments score 3



Breakdown of comments by individuals who scored question 3.14 a 3:

30 comments were identified which related to how important they thought it was to be supported by the same obstetrician and or midwife. These comments are broken down into five groups. The most common group with 16 (53%) comments were around personal experiences on the benefits of having the same obstetrician and or midwife.

Group	No. of comments	%	Description
Experiences	16	53%	Personal experience on the benefits of having the same obstetrician or midwife, or the negatives if experienced multiple obstetrician or midwives
Positive	2	7%	Seen to be important or a good thing to have if possible
Benefits	2	7%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Problems	5	17%	Identifies some of the problems with attempting to do this such as the fact it would depend on the obstetrician or midwife and questions over the practicality of it
Negative	5	17%	Seen as unimportant or not as important as other areas

Q 3.14 Same obstetrician and or midwife throughout the time you gave birth (If your baby suffered harm during labour) - Specific comments score 4 & 5



Breakdown of comments by individuals who scored question 3.14 a 4&5:

139 comments were identified which related to how important they thought it was to be supported by the same obstetrician and or midwife. These comments are broken down into five groups. The most common group with 53 (38%) comments were around personal experiences on the benefits of having the same obstetrician and or midwife.

Group	No. of comments	%	Description
Experiences	53	38%	Personal experience on the benefits of having the same obstetrician or midwife, or the negatives if experienced multiple obstetrician or midwives
Positive	49	35%	Seen to be important or a good thing to have if possible
Benefits	22	16%	Key benefits this would bring about such as helping ensure problems are identified and building up a relationship of trust
Problems	14	10%	Identifies some of the problems with attempting to do this such as the fact it would depend on the obstetrician or midwife and questions over the practicality of it
Negative	1	1%	Seen as unimportant or not as important as other areas

Q 3.14 Same obstetrician and or midwife throughout the time you gave birth (If your baby suffered harm during labour) - Experiences



There were 86 comments relating to individuals experience with midwives or obstetricians and these have been broken down into six sub groups. The most commented on sub group, with 44 (59%) comments, relates to negative experiences in care due to seeing numerous midwives or obstetricians. 14 (19%) were around the benefits of seeing the same obstetrician and or midwife and 7 (9%) were from those who have had a negative experience.

Sub Group	No. of comments	%	Description
Different midwives or obstetricians	44	59%	Seeing different staff can have a negative impact upon patient experience
Same midwife or obstetrician	14	19%	Seen by the same staff throughout and was seen as a benefit
Negative experience of midwife or obstetrician	7	9%	Negative experience which could be avoided if individual had same midwife or obstetrician throughout
Shift changeover	7	9%	No staff available during shift changeover causing an impact on quality of care
Positive experience of staff	3	4%	Positive experience with staff which leads individuals to believe the same midwife or obstetrician throughout would be of benefit.
Other	11	15%	Other comments describing experiences in relation to seeing the same obstetrician and or midwife

Q 3.14 Same obstetrician and or midwife throughout the time you gave birth (If your baby suffered harm during labour) - Positive



There were 53 positive comments in relation to seeing the same obstetrician and or midwife. These comments have been broken down further into four sub groups. 24 (45%) comments were from respondents saying that it was important, 23 (43%) said that it would be nice and 3 (6%) said it would be nice but not necessary.

Sub Group	No. of comments	%	Description
Important	24	45%	Important to see same midwife
Would be nice	23	43%	Would be nice however not that important
Nice but not necessary	3	6%	Would be nice however not always necessary
Same obstetrician important	3	6%	Important to see same obstetrician

Q 3.14 Same obstetrician and or midwife throughout the time you gave birth (If your baby suffered harm during labour) - Benefits



There were 25 comments in relation to the perceived benefits of seeing the same obstetrician and or midwife, the most commented on sub group was that it would help develop trust and relationship with 10 (40%) comments. 9 (36%) comments stated that it was helpful in knowing history and recognising problems, 5 (20%) were around how having the same obstetrician and or midwife reduces the need for repeating information.

Sub Group	No. of comments	%	Description
Build up trust	10	40%	You would be able to build up trust more easily
Quality of care	9	36%	Perceived to reduce the number of problems or errors
Reduces repeating information	5	20%	Would reduce the need to tell multiple healthcare professionals the same information
Support choice	1	4%	Would help choices to be supported as the midwife would have built a relationship and know history

Q 3.15 What did you think about the information you were given after your baby suffered harm? (If your baby suffered harm during labour)



There were 402 responses to this question, 113 (28%) were not applicable or stated that they had answered this question already in a previous question. The remaining 289 (72%) responses provided comment on the information individuals were provided with after their baby suffered harm.

From the 289 responses, 322 individual comments were identified and these have been broken down into three groups. 80 (25%) were positive comments, 71 (22%) were neutral, and 171 (53%) were classed as negative comments.

Group	Description
Positive	Positive comments include those that rated the information either good or excellent = 80
Neutral	Neutral comments include those where information was seen to be adequate or meeting a minimum expectation = 71
Negative	Negative comments include those where no information was received, some information was seen to be more out of date, and where information was not delivered in an appropriate manner = 171

Q 3.15 Information you were given after your baby suffered harm (If your baby suffered harm during labour) - Positive



There were 80 positive comments, which have been broken down into two sub groups. 46 (58%) commented on how easy the information was to understand; and felt they had plenty of information, 34 (43%) were around how care tailored to the individual was received.

Positive

- “Clear, given in bite sized chunks with full explanations on why decisions were being made.”
- “Sensitively and calmly delivered to me. I knew what was happening...”
- “Fantastic, they couldn't have armed me with anymore information and even gave me books about dealing with a premature baby.”
- “Excellent, the neonatal consultant kept me fully informed and explained all procedures and reasons as well as reassuring me.”
- “Excellent, even after my baby suffered a major overdose of Gentamicin after notes got confused. They monitored my daughter for 2 years.”

Main Grouping	No. of comments	%	Sub group	Description	No. of comments	%
Positive	80	25%	Easy to understand	Respondents said they did receive sufficient or plenty of information in a way in which they could understand it	46	58%
			Tailored to individual	Respondents rated the information very good or excellent also referred to the way in which it was delivered, i.e. the information was provided with consideration for them and their circumstances and they felt it was accurate and honest	34	43%

Q 3.15 Relevant responses breakdown - Information you were given after your baby suffered harm (If your baby suffered harm during labour) - Negative



There were 171 negative comments, these have been broken down into four sub groups. 95 (56%) commented on how information received was either out of date or a poor quality. 57 (33%) comments related to individuals who received no information and 11 (6%) said that information was not easily understood.

No information received

- “Absolutely nothing. No information or closure was given to us until we received our sons post mortem.”
- “Given no information at all, had to chase for info and wasn't told very much at all. Also given inconsistent information by different health care professionals. “

Main Grouping	No. of comments	%	Sub- Group	No.	%
Negative	171	53%	Information out of date or poor quality	95	56%
			No information received	57	33%
			Information not easily understood	11	6%
			Comments relating to liability	8	5%

Q 3.16 Did you have a follow up appointment with your consultant to discuss the reasons for your baby's condition? (If your baby suffered harm during labour) – Yes/No



510 individuals responded to the yes or no part of question 3.16. 226 (44%) said yes and 284 (56%) said no they did not receive a follow up appointment with their consultant. 97 of those who said yes, and 117 of those who said no, went on to leave further comments. In addition, 29 respondents left a comment who had not responded yes or no.

Answer	No. of respondents	%	No. of text responses	%
Yes	266	44%	97	40%
No	284	56%	117	48%
Not answered			29	12%
Total	550	100%	243	100%

Out of the 243 responses 60 (25%) were deemed not applicable. The remaining 183 (75%) responses included relevant information around follow up appointments.

Group	No. of responses	%
Relevant responses	183	75%
Not applicable	60	25%

Q 3.16 Follow up appointment to discuss reasons for your baby's condition (If your baby suffered harm during labour) – Relevant responses



There were 183 relevant responses, from this 191 comments were identified. 58 (31%) were positive about the follow up. 81 (42%) were negative about the follow up appointment, and 26 (14%) related to the actual outcome of the follow up appointment.

Unsatisfactory experience

- “I had various doctors look at my baby but nobody ever admitted to the injury being the fault of the medical staff.”

Discussed with consultant or other professional

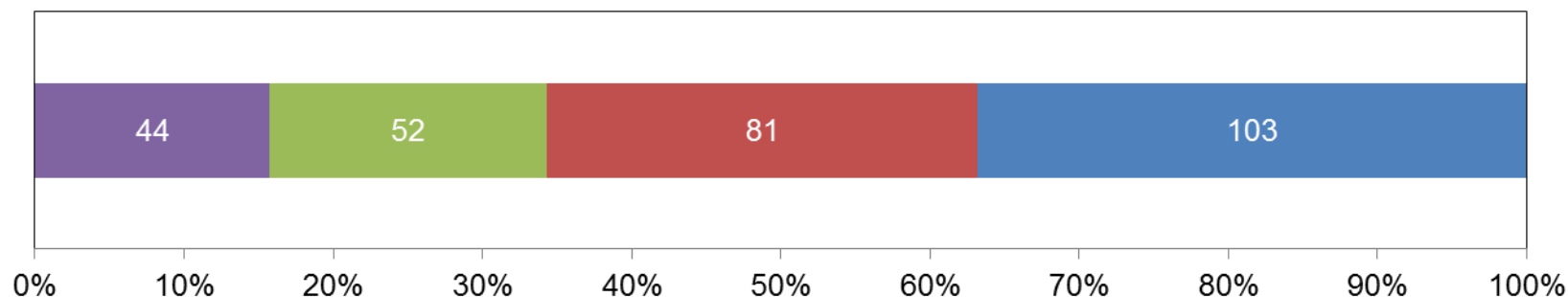
- “With Consultant who was honest and listened.”

Group	No. of comments	%	Group	No. of comments	%	Description
Positive	58	31%	Discussed with healthcare professional	30	16%	Includes GP, midwife or other hospital teams
			Continued involvement	28	15%	Regular contact with clinicians
Negative	81	42%	Unsatisfactory experience	36	19%	Process was not open
			No support or discussion	24	13%	Not supported or no discussion
			Delayed response	16	8%	Long wait for appointment
			Not useful	5	3%	Appointment not helpful
Outcome	26	14%	No reason or cause not known	12	6%	Unable to identify reason for condition
			More tests	6	3%	Other tests carried out or planned
			Investigation	5	3%	Includes post mortem or review
			Premature birth	3	2%	Related to premature birth
Other	26	14%	Other	26	14%	Other comments relating to the follow up appointment

Q 3.17 What was good about the process to review the circumstances in which your baby was harmed? (If your baby suffered harm during labour)



There were 280 responses received for question 3.17. 81 (29%) of these responses were specific in relation to what was good about their care. 103 (37%) responses were deemed not applicable. 52 (18%) made a general negative comment around the review process and 44 (16%) said that no review took place.



Group	Description
Not applicable	Response not applicable or does not relate to the question = 103
Specific response	Specific response in relation to certain aspects of the review process = 81
Negative comment	General negative comment in relation to the review process = 52
No review	No review undertaken = 44

Q 3.17 Review process (If your baby suffered harm during labour) – Relevant responses



There were 81 responses that were relevant to the question, from this, 97 comments were identified. 40 (41%) of these related to good communication during the review process. This included comments relating to receiving honest information at regular intervals with clear explanations. 35 (36%) said that staff were fully supportive, with individuals receiving counselling and information on prevention in future pregnancies.

Group	No. of comments	%	Description
Communication	40	41%	Honest information given at regular intervals, with clear explanations of what had happened
Medical and emotional support	35	36%	Staff fully supportive, provided with counselling and information on prevention in future pregnancies
Identification	10	10%	Issues and causes were identified
System improvement	8	8%	Changes were made to systems or procedures, so that others do not suffer from the same problem
User involvement	4	4%	Staff listened and parents given time to express concerns, kept fully involved in the process

Q 3.17 Review process (If your baby suffered harm during labour) - Communication



There were 40 comments in relation to communication, these have been broken down further into six sub groups. 13 (33%) said they were kept informed and regularly given updates, 7 (18%) said they were given chance to ask questions and 12 (30%) said that they staff fully explained what had happened.

Sub Group	No. of comments	%	Description
Informative / kept informed	13	33%	Given updates regularly throughout the review process
Explained what happened	12	30%	Staff provided explanations of what had happened during the review process
Ability to ask questions	7	18%	Time offered to ask questions around what happened
Transparent	5	13%	Honest throughout and transparent throughout the review
Explained reason for medication / tests	2	5%	Received rational reasons why medication and tests were undertaken
Consultation with specialists	1	3%	Time with the specialists during review process to fully understand what had happened

Neonatal Care



No	Question
3.18	Do you feel that your baby received good quality care in the transition to and upon admission to the neonatal unit?
3.19	What was good about care in the neonatal unit?
3.20	What could have been done differently to improve your experience at this time?
3.21	Did you feel that the maternity team communicated effectively with the neonatal team?
3.22	Did you feel involved in decisions about your baby's care?
3.23	What did you think about the information you were given about what was happening (i.e. did it give you the information you needed in a way you could understand?)

Q 3.18 Do you feel that your baby received good quality care in the transition to and upon admission to the neonatal unit? (Neonatal care) – Yes/No



541 individuals responded yes or no to this question, of which, 496 (92%) people said yes and 45 (8%) people said no. 158 of those who said yes and 32 of those who said no left further comments. In addition, there were 26 respondents who left comments however did not answer yes or no.

Answer	No. of respondents	%	No. of text responses	%
Yes	496	92%	158	73%
No	45	8%	32	15%
Not answered			26	12%
Total	541	100%	216	100%

From the 216 responses, 196 (91%) were relevant to the question and 20 (9%) were deemed not applicable.

Group	No. of responses	%
Relevant responses	196	91%
Not applicable	20	9%

Q 3.18 Your baby's care in the transition to and upon admission to the neonatal unit (Neonatal care) – Relevant responses



There were 196 relevant responses and from this 234 comments were identified. 143 (59%) said they had a good experience, 23 (9%) said they did not receive good quality care and 18 (7%) said that the communication was ineffective.

Good or went well

- “I couldn't fault the SCBU team they were fantastic and did everything they could to help our baby.

Group	No. of comments	%	Description
Good or went well	143	59%	Had good experience of care or things went well
Not good quality of care	23	9%	Felt care was not of good quality or things did not go well
Ineffective communication	18	7%	Felt communication was not effective
Breast feeding issues	4	2%	Comments relating to feeding related baby being in neonatal unit
Other	46	19%	Other comments relating to the kind of care received during the transition to the neonatal unit

Q 3.19 What was good about care in the neonatal unit? (Neonatal care)



There were 483 responses received for question 3.19. 434 (90%) were specific in relation to an aspect of their care; 8 (2%) stating that nothing was good about their care and 11 (2%) stating everything about their care was good. There were 30 (6%) responses deemed not applicable.

From the 434 relevant responses, 677 comments around specific aspects of care were identified. 429 (63%) related to the good care received by staff. 179 (26%) comments were about how supported individuals felt throughout their baby's time in neonatal care.

Staff attitude

- “The staff were fantastic. Communication and explanation was fantastic and we were always involved in decisions and their care plan.”

Environment

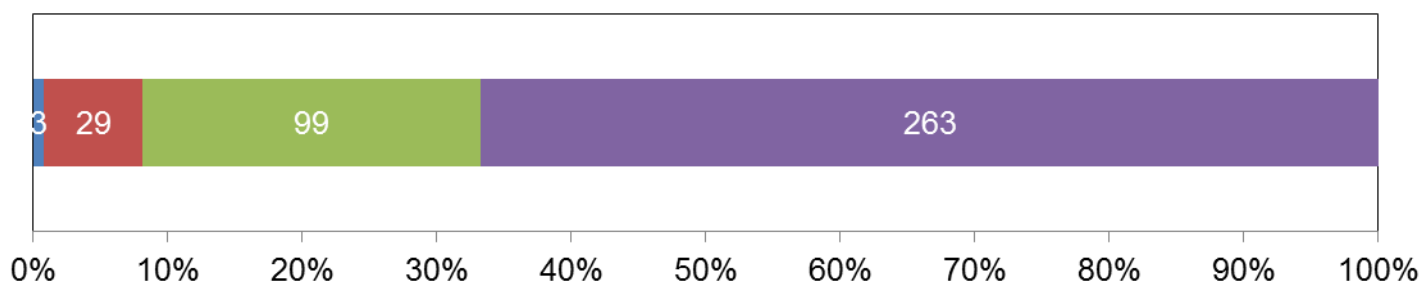
- “Private room. Accessible and approachable staff. Peace and quiet.”

Group	No. of comments	%	Description
Staff Attitude	429	63%	Caring, compassionate and understanding staff
Communication	179	26%	Good communication, kept informed and supported throughout
Feeding support	30	4%	Advice and support feeding, including breast feeding and bottle feeding
Regular checks	29	4%	Seen and monitored regularly
Environment	10	1%	Suitable accommodation away from new mums and their babies or private rooms to spend time with babies.

Q 3.20 What could have been done differently to improve your experience at this time? (Neonatal care)



There were 394 responses received for this question. 263 (67%) identified areas for improvement, 99 (25%) stated nothing was required to be improved. 29 (7%) stated the question was not applicable to their situation and 3 (1%) stated everything needed to improve.



Group	Description
Improvements	Comments received identified improvement = 263
Nothing	Comments received identified no improvement required = 99
Not applicable	N/A entered into field, or response not appropriate = 29
Everything	Comments received identified everything needed to improve = 3

Q 3.20 Key Area Groups - What could have been done differently (Neonatal care)



There were 263 relevant responses which identified 378 comments relating to what could have been done different when they were in neonatal care. 87 (23%) comments related to improvement to the overall environment, 75 (20%) were around communication and 64 (17%) were about emotional support.

Top Groups	No. of comments	%	Description
Environment	87	23%	Keep mothers and babies together and nursing those who lost a baby far away from maternity areas
Communication	75	20%	Communication could be improved if there was more transparency, information was shared
Emotional support	64	17%	Provide more emotional support to parents
Staff attitude	50	13%	Staff should improve their attitude towards service users
Memories	24	6%	Staff should advise and guide parents on capturing memories of their baby
Breast feeding help	25	7%	More advice and guidance on breastfeeding and detecting tongue tie
Communication between healthcare professionals	15	4%	Better communication between teams and departments to ensure care is coordinated
Quality of care	24	6%	Improving standards of treatment and care
Other	14	4%	Other suggestions for improvement in relation to neonatal care

Q 3.20 What could have been done differently (Neonatal care) - Environment



There were 87 comments in relation to the environment and these have been broken down into seven sub groups. 36 (41%) related to the family and baby being together, 18 (21%) were about access to neonatal wards and 7 (8%) were about the availability of peaceful accommodation.

Family & baby together

- “I would have liked to have been able to stay with my babies in hospital during the time that they were in the neonatal unit”
- “Leaving my baby was agony, I wish that I could have stayed with him.”

Sub Group	No. of comments	%	Description
Family and baby together	36	41%	Keep mother and baby together not separate
Access to neonatal	18	21%	Mother should have easier access to neonatal wards to see baby
Peaceful accommodation	7	8%	Service users want private rooms to get peace and quiet
Partner able to stay	7	8%	Provide adequate sleeping provisions so partners can stay with service user and baby
Babies together	5	6%	Keep multiple born babies together
Better environment - general	4	5%	General comments in relation to providing better facilities
Other	10	11%	Other suggestions for improvements in relation to environment

Q 3.21 Did you feel that the maternity team communicated effectively with the neonatal team? (Neonatal care) – Yes/No



This question gave respondents the opportunity to answer yes or no. 520 people responded with 298 (57%) selecting yes and 222 (43%) selecting no. 47 of those who said yes and 131 of those who said no went on to leave further comments. In addition, 38 respondents who had no answered yes or no left further comments.

Answer	No. of respondents	%	No. of text responses	%
Yes	298	57%	47	61%
No	222	43%	131	22%
Not Answered			38	18%
Total	520		216	

From the 216 text 169 (78%) left specific information relating to the communication, 47(22%) responses were deemed not applicable.

Group	No. of responses	%
Relevant responses	169	78%
Not applicable	47	22%

Q 3.21 Communication between maternity team and neonatal team (Neonatal care) - Relevant responses



There were 169 applicable responses and from these 193 comments were identified relating to communication between the neonatal and maternity teams. 121 (63%) comments described how communication was ineffective or below their expectation. 32 (17%) comments described how communication in their experience was good between the two teams and 115 (8%) were around how breastfeeding was impacted by poor communication.

Communication ineffective

- “I think there is definitely a divide between midwives and neonatal. I think many of the midwives didn't expect or understand how distressed I was. It might be their day job, but this is my whole life! A bit of understanding might have made it better.”

Communication effective

- “Very much so, it was clear they worked as part of a team.”

Group	No. of comments	%	Description
Communication ineffective	121	63%	Felt communication was not effective or did not meet their expectation
Communication effective	32	17%	Felt communication was effective or had a good experience
Breastfeeding	15	8%	Breastfeeding perceived to be impacted by poor communication between the two teams
Other	25	13%	Other comments in relation to the communication between the maternity team and the neonatal team

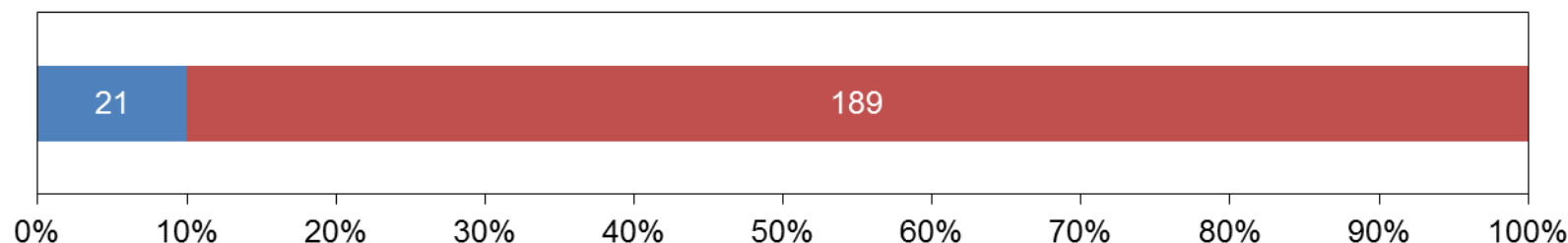
Q 3.22 Did you feel involved in decisions about your baby's care? (Neonatal care) - Specific Comments



This question gave respondents the opportunity to answer yes or no to whether they felt involved in decisions about their babies care. Of the 578 respondents who answered this yes or no, 408 (71%) selected yes, 170 (29%) selected no. 92 of those who said yes, and 96 of those who said no left further comments. In addition, 22 respondents who did not answer yes left further comments

Answer	No. of respondents	%	No. of text responses	%
Yes	408	71%	92	44%
No	170	29%	96	46%
Not Answered			22	10%
Total	578		210	

Of the 210 responses, 189 (90%) made specific comments as to how involved they felt in decisions about their baby's care. 21 (10%) respondents did not specifically comment on how important they considered it to be.



Group	Description
Relevant responses	Specific response on how involved they felt in their baby's care = 189
N/A or stated elsewhere	Not applicable or stated elsewhere in the survey = 21

Q 3.22 Did you feel involved in decisions about your baby's care? (Neonatal care) – Relevant responses



There were 189 relevant responses and from these, 239 comments were identified and broken down into three groups. 104 (44%) comments describing how they were not involved. 104 (44%) provided comments on how involved they had felt. 31 (13%) described how involvement was either mitigated by circumstances or personal choice e.g. happy to let healthcare professionals make all the decisions.

Group	No. of comments	%	Description
Not involved	104	44%	Descriptions of how respondents had not been involved in decisions such as consent not being requested, decisions being made without their involvement or decisions not being respected
Involved	104	44%	Descriptions of how respondents had been involved for example being well informed or through good communication
Mitigating circumstance	31	13%	Service users had limited involvement either through choice or due to their personal circumstances.

Q 3.22 Did you feel involved in decisions about your baby's care? (Neonatal care) - Not involved



There were 104 comments from respondents who said they did not feel involved, these were broken down into eleven sub groups. The most commented on sub group was that decisions were made without their input or consent with 38 (41%) of comments. 23 (25%) comments related to individuals feeling that they only had limited information so unable to be involved in decision making. 12 (12%) of the comments related to respondents not feeling involved.

Sub group	No. of comments	%	Description
No input or consent	38	37%	Decisions made without respondents input or consent
Limited information	23	22%	Service users poorly informed or provided with minimal choice
Not involved	12	12%	General comments stating the service user was not involved in decision making
Not listened to	7	7%	Service users concerns not listened to or taken into account
Felt excluded or uncomfortable	5	5%	Felt excluded or uncomfortable in front of healthcare professionals and unable to be involved
Had to push to be involved	4	4%	Service users involved in decision making, but after 'fighting' to be involved
Involvement inconsistent	3	3%	Too much variation in involvement between different units or healthcare professionals
Too hurried	3	3%	Decision process felt rushed which limited service user's involvement
Communication ineffective	3	3%	Poor communication with healthcare professional impacted involvement
Choices not respected	2	2%	Choices or decisions not respected by healthcare professionals
Other	4	4%	Other comments in relation to feeling uninvolved

Q 3.22 Did you feel involved in decisions about your baby's care? (Neonatal care) - Involved



There were 104 comments from respondents who said they felt involved. These have been broken down into four sub groups. 27 (26%) said they felt very involved, 35 (34%) said they felt involved and 3 (3%) felt mostly involved.

Sub Group	No. of comments	%
Very involved	27	26%
Involved	35	34%
Mostly involved	3	3%
Partly involved	16	15%

The 23 (22%) comments remaining relate to specific actions which enabled service users to be involved in the decision making process.

Sub Group	No. of comments	%	Description
Involved a specific units	10	10%	Service users described specific units within hospital where they felt involved in decision making
Good communication	4	4%	Good communication between service users and healthcare professionals
Rounds were beneficial	4	4%	Involvement in decision making was facilitated by the medicals rounds
Consent was requested	3	3%	Consent was requested from the service users
Informed	2	2%	Service users felt well advised and informed

Q 3.23 What did you think about the information you were given about what was happening? - did it give you the information in a way you could understand? (Neonatal care)



There were 475 responses, 28 (6%) of which were not applicable. The remaining 447 (94%) responses provided comment on the information individuals were given.

From the 447 responses, 497 individual comments were identified and these have been broken down into three groups. 290 (58%) were positive comments on the information received. 187 (38%) were negative about the information given, with 20 (4%) comments stating the level of information was what was expected.

Group	Description
Positive	Positive comments include those that rated the information either good or excellent = 290
Neutral	Neutral comments include those where information was seen to be adequate or meeting a minimum expectation = 20
Negative	Negative comments include those where no information was received, some information was seen to be more out of date, and where information was not delivered in an appropriate manner = 187

Q 3.23 Information given about what happened (Neonatal care) Relevant responses breakdown



There were 290 positive comments, 210 (72%) commented on how easy the information was to understand; and felt they had plenty of information. 80 (28%) comments were related to how information received was tailored to them.

Positive

- “I have a high need for detailed information and the consultants were very good about understanding this and providing the required detail.”

Main Grouping	No. of comments	%	Sub- Group	Description	No.	%
Positive	290	58%	Tailored to individual	Respondents rated the information very good or excellent also referred to the way in which it was delivered i.e. the information was provided with consideration for them and their circumstances and they felt it was accurate and honest	80	28%
			Easy to understand	Respondents said they did receive sufficient or plenty of information in a way in which they could understand it	210	72%

Q 3.23 Information given about what happened (Neonatal care) Relevant responses breakdown



There were 187 negative comments and these have been broken down into three groups. 86 (46%) commented on how information received wasn't trusted as appeared either out of date or perceived poor quality. 85 (46%) were around how they experienced a negative attitude from staff and 16 (8%) were around how the information was not easy to understand.

Negative

- “As I was very poorly myself at the time I felt very numb and that nobody really took the time from the neonatal unit to come and explain to me what was happening whilst I was on the maternity unit, I found out more info from my husband.”
- “I would have preferred more written information so I could digest it and reassess it later rather than just once off verbal communication.”
- “A lot of the information was simplified as I am a young parent, but this was unnecessary and I often had to ask more probing questions to get to the truth of the matter.”
- “There was a lot of doctor talk to the point where I had to sign something to say it was ok for my mother to talk to the doctors because we didn't understand what was going on.”

Main Grouping	No. of comments	%	Sub- Group	Description	No.	%
Negative	187	37%	Information not easily understood	Respondents were dissatisfied with the way that information was delivered impacting on understanding, i.e. including medical terminology, language barriers,	16	8%
			Staff attitude	Staff attitude when delivering information lacked sensitivity	85	46%
			Information out of date or poor quality	Content of information shared was felt to be either out of date or of poor quality.	86	46%

Postnatal Care



No	Question
3.24	Did you receive any on-going aftercare from a healthcare professional following discharge from hospital?
3.25	What could have been done differently to improve your care after you left hospital?
3.26	What could have been done differently to improve the review process?

Q 3.24 Did you receive any ongoing aftercare from a healthcare professional following discharge from hospital? (Postnatal care) – Yes/No



817 individuals responded yes or no to this question, 480 (59%) said “yes” they did receive ongoing aftercare from a healthcare professional and 337 (41%) said “no” they did not.

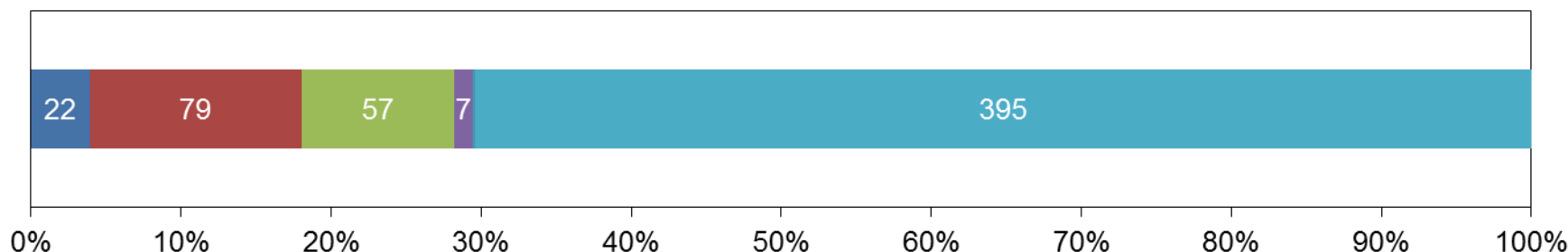
Answer	No. of respondents	%
Yes	480	59%
No	337	41%
Not Answered		
Total	817	100%

Please note, there was no opportunity in the questionnaire for individuals to leave a descriptive or free text comment in relation to this question.

Q 3.25 What could have been done differently to improve your care after you left hospital? (Postnatal care)



There were 560 responses question 3.25. 395 (71%) responses stated suggestions on what could have been done differently to improve their care after they left hospital. 79 (14%) responses stated nothing could have been done differently. 57 (10%) made general positive statements about the postnatal care, but no suggestions for improvement. 7 (1%) responses were negative about postnatal care, but provided no suggestions for improvement. 22 (4%) responses stated that the question was not applicable or relevant to their situation.



Group	Description
Relevant responses	Specific aspects of care that could have been done differently = 395
Negative	Negative general comment = 7
Positive	Positive general Comment = 57
Nothing	Nothing could have been done differently = 79
Not applicable	Not applicable / relevant = 22

Q 3.25 What could have been done differently to improve your care after you left hospital? (Postnatal care) - Specific Comments



There were 395 specific responses and from this 562 comments were identified and broken down into nine groups. 245 (44%) comments were around how better support would have improve their care when leaving hospital. 68 (16%) comments were about improvements to staffing and 68 (12%) were around emotional support.

Group	No. of comments	%	Description
Improved care	245	44%	Improvement postnatal care, including suggestions for more contact with healthcare professionals and more follow up appointments
Staffing	68	12%	Care delivered by specific staff and general comments on staff competency
Emotional support	68	12%	Access to counselling, mental health specialists and people to discuss the birth
Communication	43	8%	Staff communicating with one another to ensure coordinated care between hospital and community services
Information	39	7%	Explanations of what happened, medical information and practical information on support groups and funerals
Organisation	30	5%	Better organisation of visits and appointments, and the addressing medical issues before discharge.
Personal	29	5%	Personal experience of care such as whether or not they felt listened to or emotionally supported
Care at home	15	3%	Provide more care at home, including home appointments / visits
Other	25	4%	The care they received in hospital such as the need for appropriate discharge as well as specific comments such as access to a dietician

Q 3.25 What could have been done differently to improve your care after you left hospital? (Postnatal care) – Improved care



There were 245 comments in relation to how care could be improved. There have been broken down into seven sub groups. The most commented on sub group was more contact with healthcare professionals with 74 (30%) comments. There were also a significant number of comments on improvements around follow ups and checks with 41 (17%) comments. A further 35 (14%) comments who specifically stated that more contact from midwives would improve care.

More contact

- “People should have kept a better eye and contact with me but because my baby was damaged I was so depressed plus I had damage to my own body.”
- A follow up appointment to discuss what happened during my pregnancy and the immediate aftercare would have been useful.

Sub Group	No. of comments	%	Description
More contact with healthcare professionals	74	30%	Increased contact with health professionals after leaving hospital
Follow up appointments	41	17%	More detailed examination and more follow up appointments to improve care offered after leaving hospital
Midwife contact	35	14%	More contact with midwives after leaving hospital
Care - mother	30	12%	Improvements in care given to mothers after leaving hospital
Care - general	27	11%	General comments on improvement to postnatal care
Feeding support	19	8%	Feeding support after leaving hospital could be improved
Other	19	8%	Improvements in care, specifically services focussed at the babies, could be improved

Q 3.25 What could have been done differently to improve your care after you left hospital? (Postnatal care) - Staffing



There were 68 comments in relation to staffing, these have been broken down into six sub groups. 28 (19%) comments requested access to more skilled or experienced staff would improve their care, 15 (22%) comments stated that having the same staff throughout postnatal care would improve the overall level of care received and 14 (21%) wished for staff better trained in premature births.

Access to expertise

- “I have found that healthcare professionals that follow you up after birth are not as knowledgeable as midwives.”
- “A doctor that I felt I could have asked questions.”

Sub Group	No. of comments	%	Description
Access to expertise	28	42%	More skilled or experience staff available
Continuity	15	22%	Better continuity of staff
Better training - premature births	14	21%	More staff trained in premature births
Staff attitude	9	13%	Improved attitude of staff
More staff	1	1%	More staff available
Staff better trained in multiple births	1	1%	More staff trained in multiple births

Q 3.26 What could have been done differently to improve the review process? (Postnatal care) – Specific responses



There were 335 responses to this question, 226 (84%) responses were relevant to the question on what could improve the review process. Out of the remaining responses 18 (5%) stated that the question was not applicable to them, 36 (11%) provided comments which were not relevant; 51 (15%) stated 'nothing' as a response, and 4 (1%) stated 'everything' as a response.

From the 226 specific responses, 237 comments were identified and broken down into four groups. 128 (54%) comments were related to how patient care could be improved, 19 (8%) said they were happy with the process and 17 (7%) said that systems and processes could be improved.

Group	No. of comments	%	Description
Patient care	128	54%	Better communication, more info, more inclusion and consistency in the care
Happy with the process	19	8%	Found the review process was helpful and informative
Systems and processes	17	7%	Better information sharing and joint working, unbiased investigations and learning from mistakes
Staff attitude	15	6%	Staff to show more empathy and understanding transparency with service users
No review took place	58	24%	Not offered chance of review, however this process would have been useful

Q 3.26 What could have been done differently to improve the review process? (Postnatal care) – Patient care



There were 128 comments relating to patient care and these have been broken down into eight sub groups. The most common sub group with 49 (38%) comments was how the care and support for those involved in a review process could be improved. 22 (17%) said that communication could have been improved and 12 (9%) said that there could be improvements in continuity of care.

Sub groups	No. of comments	%	Description
Better care and support	49	38%	Better support for those who have experienced a premature birth, requiring mental health support and receiving follow up appointments
Communication	22	17%	More joined up communication between staff, maternity care, GP and neonatal and improving communication with service user
Continuity of care	12	9%	Improved consistency of staff and notes involved in the review process
More information	10	8%	Service users would like to receive copies of maternity notes and records
Listened to	9	7%	Being offered the chance to speak to a professional and have the service user's experience listened to
Review sooner	8	6%	Quicker processes, debriefs and reviews to avoid errors occurring
Other	18	14%	Other suggestions for improvements in the review process



END