Background and methodology

This survey was designed by Ruth Stevenson (a professional researcher and member of the Market Research Society) in consultation with the MSLC consent working group. Although the survey is about experiences of consent, on Ruth's recommendation the word 'consent' was not used at all in the questionnaire or publicity as it was considered a leading and emotive term. Instead, the wording focuses on 'care and procedures during pregnancy and delivery'. The survey was open during September and October 2017. It was available online via a link distributed electronically and publicised on posters in wards and clinics.

In total, 3,009 responses were received from women that had given birth in the Lothian region in the past five years. Some of these responses were incomplete. For the purposes of robust reporting, analysis was conducted using the 2,363 complete responses.

Profile of respondents

The responding women gave birth in the following locations:

Where was your baby born?	No.	%
Home	55	2
St John's Hospital, Livingston	412	17
Edinburgh Royal Infirmary	1624	69
Birth Centre, Edinburgh	255	11
Elsewhere	17	1

Key findings

Preferences around involvement with care

The majority of women wanted to be involved in their care during pregnancy and delivery:

- 94% agreed that they wanted to play an active part in their care
- 89% agreed that they wanted to have information about all possible procedures, benefits and risks, in advance.
- 78% agreed that they were happy to agree with what the medical professionals recommended (although a noteworthy 16% disagreed)

That said, providing written consent was not a priority for most:

37% agreed that they would like all decisions about any procedure to be done in writing

The experience of making and using birth plans fell into three fairly equal groups:

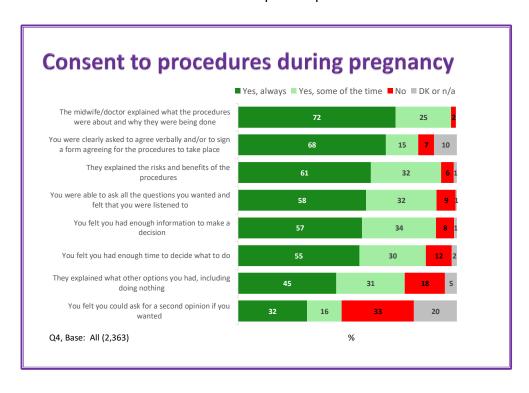
- 28% did not make a birth plan
- 39% made a birth plan and it was used/referred to
- 33% made a birth plan and it was not used/referred to

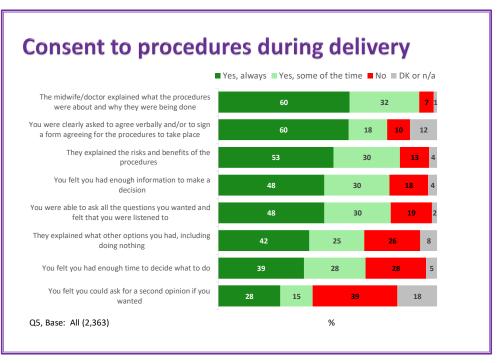
Those that made a birth plan and it was not used/referred to were most likely to:

- Have given birth at the ERI or St. John's
- Have experienced an instrumental delivery, an induction, an epidural or an emergency csection

Experience of consenting to procedures

The women were asked to gauge how often they consented to procedures during pregnancy and delivery. For the purpose of the survey, 'consent' was reduced to its component parts as follows:





For all components, overall incidence of consent was lower during delivery than during pregnancy.

• In both cases, the components of consent experienced most often were: 'the midwife/doctor explained what the procedures were about and why they were being done', 'you were clearly asked to agree verbally and/or to sign a form agreeing for the procedures to take place, and 'they explained the risks and benefits of the procedures'.

In both cases, the components of consent experienced least often were: 'you felt you have enough time to decide what to do', 'they explained what other options you had, including doing nothing' and (by a long way) 'you felt you could ask for a second opinion if you wanted'.

Women most often responded that 'no' they had not experienced the components of consent when:

- They experienced an instrumental delivery, an induction, an epidural or an emergency csection
- They had given birth at the ERI or St. John's
- They had made a birth plan which was not used/referred to
- They were not happy to agree with what the medical professionals recommended

Women most often responded that 'yes' they had experienced the components of consent when:

- They had given birth at the Birth Centre
- They had a planned c-section
- They had made a birth plan which was used/referred to
- They were happy to agree with what the medical professionals recommended

The experience of needing an interpreter

For women that needed an interpreter:

- 46% always had one during their pregnancy and 29% always had one during their delivery
- 36% were always given information in a different language or format if needed during their pregnancy and 27% were always given information in a different language or format if needed during their delivery

In terms of general experience of consent, however, there was no notable difference in response between women who needed an interpreter, and women who did not.

The experience of home birth

Women that delivered at home were more likely than average to feel informed, listened to and to understand their alternative options during delivery.

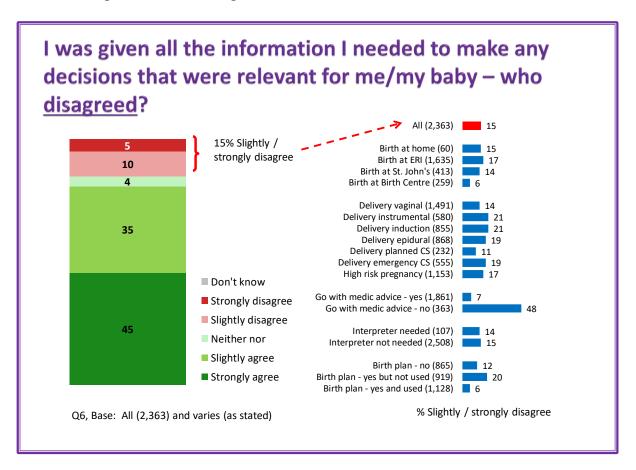
However, they were less likely to say that the midwife/doctor explained what the procedures were about, that they were asked verbally and/or to sign a form agreeing for the procedures to take place, and that the risks and benefits of the procedures had been explained.

It may be that in choosing to give birth at home the women also overtly chose a low-intervention birth where they requested minimal input from any attending medical professionals. This is however speculation and may be worth exploring further.

Overall experience of consent

The women were asked the extent to which they agreed with the statement: I was given all the information I needed to make any decisions that were relevant for me/my baby.

80% agreed and 15% disagreed with this statement

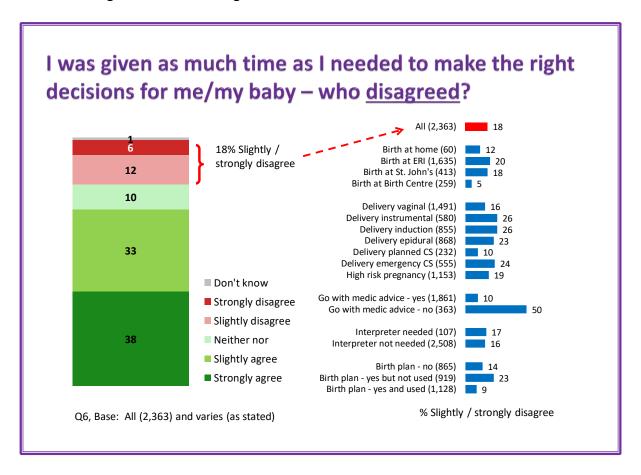


Women most often disagreed - indicating they <u>had not</u> been given all the information they needed to make any decisions that were relevant for me/my baby - when:

- They had given birth at the ERI, St. John's or at home
- They experienced an instrumental delivery, an induction, an epidural, an emergency csection or a high risk pregnancy
- They had made a birth plan which was not used/referred to
- They were not happy to agree with what the medical professionals recommended

The women were asked the extent to which they agreed with the statement: I was given as much time as I needed to make the right decisions for me/my baby.

71% agreed and 18% disagreed with this statement

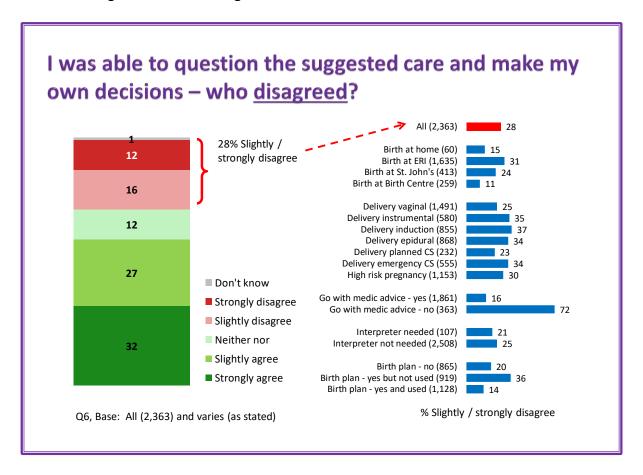


Women most often disagreed - indicating they <u>had not</u> been given all the information they needed to make any decisions that were relevant for me/my baby - when:

- They had given birth at the ERI or St. John's
- They experienced an instrumental delivery, an induction, an epidural or an emergency csection
- They had made a birth plan which was not used/referred to
- They were not happy to agree with what the medical professionals recommended

The women were asked the extent to which they agreed with the statement: I was able to question the suggested care and make my own decisions.

59% agreed and 28% disagreed with this statement

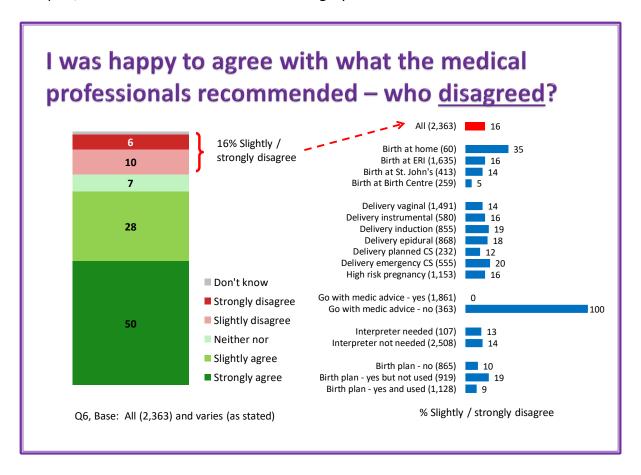


Women most often disagreed - indicating they <u>had not</u> been given all the information they needed to make any decisions that were relevant for me/my baby - when:

- They had given birth at the ERI or St. John's
- They experienced an instrumental delivery, an induction, an epidural, an emergency csection or a high risk pregnancy
- They had made a birth plan which was not used/referred to
- They were not happy to agree with what the medical professionals recommended

The experience of taking the recommendation of medical professionals

The issue of who was not happy to agree with what the medical professionals recommended is complex, and 16% of women fell into this category.



Although there are patterns in who is most likely to fall into this category, they feel a little counterintuitive:

- Those that made a birth plan which was used were similarly likely to have preferred not to follow medical recommendations as those that did not make a birth plan.
- Those that gave birth at home were particularly likely to have preferred not to follow medical recommendations, and those that gave birth at the Birth Centre were the least likely.
- There was no strong variation in experience across the various types of birth, with those that had a planned C-Section least likely to disagree.

It is speculated that how a woman responds to this question might be influenced by a complex interplay of multiple experiences and pre-conceptions, each of which interact and fall along a spectrum, which would explain the unusual pattern in response.

Happy to agree with medic	\leftrightarrow	Not happy to agree with medic	
I always agree with a medical		I was never going to trust the medical	
professional	\leftrightarrow	professional	
Trust was established at some point		Trust was eroded at some point	
during my relationship with the		during my relationship with the	
medical professional	\leftrightarrow	medical professional	
I got the birth I wanted	\leftrightarrow	I did not get the birth I wanted	
← I was not medically able to give consent →			

Each woman will have had a different opinion or experience along each of the four spectrums in the table, in combination influencing how they responded to the question.

So for example, perhaps those that did not make a birth plan made this choice because they knew that they were going to agree with the medical professional, whereas those that made a birth plan that was used were happy to agree with the medic because they got the birth they wanted.

That said, those that were not happy to agree with what the medical professionals recommended were:

- Much more likely to disagree that: I was given all the information I needed to make any decisions that were relevant for me/my baby (48% as compared to 7% of those that agreed)
- Much more likely to disagree that: I was given as much time as I needed to make the right decisions for me/my baby (50% as compared to 10% of those that agreed)
- Much more likely to disagree that: I was able to question the suggested care and make my own decisions (72% as compared to 16% of those that agreed)

This indicates that many of those that were not happy to follow medical recommendations also felt that they were not given enough information, time, or autonomy. These individuals likely fall into a category of women who were not happy to follow medical recommendations because trust was eroded at some point during their relationship with the medical professional. This could potentially affect women across the various types of birth experience.

Again, this is speculation and may be worth exploring further.

Concluding remarks

Almost all of responding women in the Lothians wanted to be involved in their care, and for the most part this was complemented by the vast majority actively consenting in a variety of ways during pregnancy and birth. That said, the women that experienced consent in lower levels told us that they felt they had not been given enough information, enough time, enough autonomy, or that they did not trust the source of information – in some combination. This is a sufficiently broad classification as to ensure that any woman in any pregnancy or birthing situation could potentially have a poor experience.

However, as time was so relevant it is unsurprising that experience of consenting was lowest where women experienced unanticipated or emergency situations, such as:

- Instrumental delivery, an induction, an epidural or an emergency c-section
- Having made a birth plan which was not used/referred to

This naturally corresponds with lower levels of consent amongst women that:

- Had given birth at the ERI or St. John's
- Were not happy to agree with what the medical professionals recommended

Questions to consider

- What are acceptable/realistic levels of consent for NHS Lothian to aim for?
- What can be done to improve levels of consent:
 - o For vaginal births with interventions?
 - o For emergency c-sections?
 - o In ERI / St Johns?
- How can we better understand and improve the experience of consent in relation to:
 - o Home births?
 - o Those that made birth plans that are not referred to?
 - Those that are not happy to take medical recommendations?
- What can be done to ensure that women who need an interpreter get an interpreter?
- What can be done to ensure that women understand that they have a right to ask questions, question care, understand alternative options, and ask for a second opinion?
- What are the best points during pregnancy and delivery to provide information?
- Is it possible to build 'time' (or the illusion of time?) into the experience?
- How is 'trust in the medic' established, and how can this be enhanced and utilised around issues of consent?
- What education for medical professionals might be necessary / appropriate?