Twins trust.

We support twins, triplets and more...

BeCOME

Better Care Of Multiples - an Exploration

RESEARCH REPORT

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(continued...)

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FOREWORDS

Professor Mark Kilby and Dr Katie Morris: Birmingham Women's Hospital

The BeCOME report is an important piece of work from Twins Trust. It has sampled parents' experiences from using the NHS Healthcare system and their perception of maternity services implementation of the NICE guidance for the management of Twin and Triplet Pregnancies.

Patient participation is now a phrase that is both frequently quoted in the media and used by policy makers, educationalists and practitioners. It can be argued that there is even an industry of 'experts' in patient participation in government organisations and in the third sector willing to offer training and advice in patient participation. It is though essential that patients and users of a maternity healthcare system can give their views and express their feeling relating to the organisation of clinical and supportive care experienced during a pregnancy. This will hopefully reinforce where there is good practice and allow reflection and critically appraisal of areas where we can improve services and care.

In 2011, The first NICE Guideline for the management of Twin and triplet pregnancies was published (www.nice.org.uk/ guidance/cg129) and focused principally on the organisation and standards of care stratified by chorionicity and clinical risk. At its heart, was the formation of multidisciplinary specialist 'Multiples' clinics providing expertise, continuity of care within a designated evidence based care pathway. In 2013, NICE published eight quality standards (NICEQS46) with the aim of improving the quality and consistency of clinical care for multiple pregnancies. Recent data from Twins Trust evaluating the uptake of these 'key standards' have indicated that there is still considerable variation in implementation by NHS healthcare providers across the UK. To provide objectivity to this claim, the Twins Trust Maternity Engagement Project enrolled the participation of 30 maternity units across England to explore the range of uptake and adherence to the NICEQS46 standards during 2017. This interim audit demonstrated a significant correlation between complete adherence to the NICEQS46 standards (thus implementation of guidance outlined in CG129) and improved clinical outcomes. Furthermore, in the centres audited, across hospital units of various size, obstetric and neonatal expertise, and resourcing, there appeared to be a significant association between the implementation of specific elements of the eight quality standards in NICEQS46 and lower stillbirth, neonatal admissions, and neonatal deaths.

The data from the BeCOME study are timely and important as they further outline that there is still variability in clinical practice and maternity service delivery of care in twin and triplet pregnancies. One variation to highlight is the need for care by multidisciplinary teams including involvement of neonatologists antenatally and facilitating continuity of carer throughout the pregnancy, intrapartum and postnatal journey. The NICE guidelines for twin and triplet pregnancy have just undergone a review and re-publication. The prenatal care has been further refined and there are inclusions of clinical standards of care in the intrapartum and postnatal period (www.nice.org.uk/ guidance/NG137). The contents of this report highlight variability of practice and provide further evidence that we cannot be complacent about the clinical care of twin and triplet pregnancies but need to engage with NHS Maternity services regionally and nationally to provide uniformity of care facilitating the reduction perinatal mortality and morbidity.

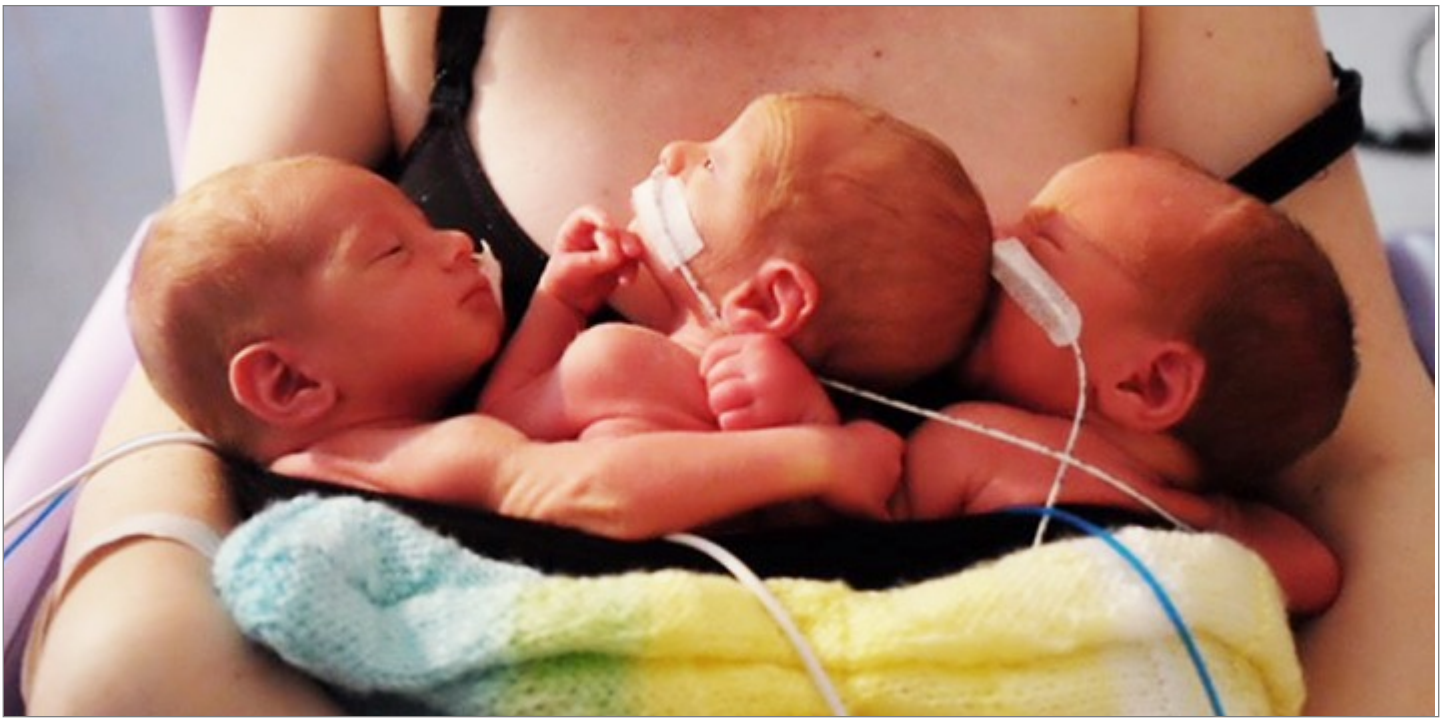
FOREWORDS

Jane Gorringe: Maternity Engagement Manager, Twins Trust

The BeCOME report is really important as it highlights where units could improve the care they offer for multiple pregnancies and improve the outcomes for multiple families. Twins Trust has recently completed a three-year maternity engagement where we worked with 30 maternity units across England to improve the antenatal care for multiple pregnancies, by more closely following the NICE guidelines.

The results were significant in that they showed 40 statistically significant findings which demonstrated that following guidelines improves outcomes for babies. The BeCOME report shows that there are units that could improve the care they offer and so improve the outcomes for babies. Some of the things that we would recommend are that all units use a multiple-specific antenatal care plan – Twins Trust has these available for families and health professionals. Following the correct appointment schedule and delivery timing for each type of multiple pregnancy maximises the chances of a healthy outcome. We also know that continuity of carer is a key factor to improving outcomes so attending appointments at a multiples antenatal clinic and having specialist multiple midwifes provides the best possible care.

Following up with all the original units we'd been engaged with, after 2 years of initial engagement we saw improvements in all outcomes with stillbirths reducing by 7%, neonatal deaths by 18%, neonatal admissions by 23% and emergency C-sections by 6%. Twins Trust is continuing to work with units across the UK to ensure all units offer the best possible care for multiple pregnancies, and we strongly encourage all units to take part. Further information can be found here or by contacting maternityengagement@twinstrust.org



Executive Summary

1.

1.1 Background

In England, multiple pregnancies make up around 1.5% of pregnancies but account for 5% of stillbirths, 10% of neonatal deaths and in the region of 15% of all neonatal admissions[1].

Over several years Twins Trust has conducted research to measure parents' experience of maternity care and the implementation of NICE guidelines (particularly NICE Quality Standards 46) across the UK.

This report contains the findings and recommendations from research to examine the state of maternity care practice in 2019 and progress made in implementation of NICE guidance since previous studies.

1.2 Research undertaken

An online survey, conducted in 2019, amongst parents known to Twins Trust, who had given birth to multiples in the UK since 2015 was conducted - generating 1,003 responses in total. Ten parents were subsequently interviewed in depth over the telephone. An online survey was also sent to health professionals working in multiple pregnancies - this resulted in 76 responses.

1.3 Key findings

1.3.1. Overall satisfaction

- 70% of parents would recommend the hospital where they received their antenatal care to others (13% would not).
- 76% felt confident in the staff caring for them (11% did not).

1.3.2. Adherence to NICE QS46

- Parents report the following levels of adherence with NICE QS46 statements.
  - 89% had a scan between 11-14 weeks to determine chorionicity and amnionicity (QS46.1).
  - 95% were monitored to check for complications in a way appropriate for their pregnancy (QS46.5).
  - 72% had a care plan detailing their antenatal appointments (QS46.4).

69%
saw an obstetrician specialising in multiple pregnancies during their antenatal care

- During their antenatal care 69% saw an obstetrician specialising in multiple pregnancies, 31% saw a midwife specialising in multiple pregnancies and 35% saw a sonographer with specialist training in multiple pregnancies (QS46.3).

only 31%
saw a midwife specialising in multiple pregnancies during their antenatal care

  - 28% discussed the risks and signs of an early (preterm) labour with one or more members of their healthcare team before 24 weeks (QS46.7).
  - 65% discussed the timing of the birth and mode of delivery with one or more members of their healthcare team before 32 weeks (QS46.8).
- Across all these statements except QS46.5, health professionals are more positive about adherence than parents.
- Between 2015 and 2019 there have been slight increases in the proportion of parents agreeing that they received the following aspects of care: a scan between 11-14 weeks, having chorionicity and amnionicity determined at the first scan, seeing a specialist midwife, and seeing a sonographer with specialist training.

89%
had a scan between 11-14 weeks to determine chorionicity and amnionicity (in line with NICE QS46.1)

- Between 2015 and 2019 fewer parents agreed that they had seen a specialist obstetrician, and slightly fewer agreed they discussed mode of delivery. The proportion of parents who discussed preterm labour remained the same.

1.3.3. Continuity of care

- 60% of parents saw the same consultant all or most of the time during their antenatal care, 52% said they saw the same midwife all or most of the time, and 25% said they saw the same sonographer all or most of the time.
- Professionals report higher levels of continuity than parents.

60%
saw the same consultant all or most of the time during their antenatal care

52%
saw the same midwife all or most of the time during their antenatal care

1.3.4. Advice to prepare parents

- Approximately two thirds of parents rated the advice they received from midwives and consultants to prepare for delivery as "very good" or "good".
- Approximately half of parents rated the advice they received from midwives and consultants to prepare for postnatal care as "very good" or "good".

only
28%
had been told before 24 weeks about the risks and signs of an early (preterm) labour

- Approximately 4 to 5 out of 10 parents rated the advice they received from midwives and consultants to care for their babies after discharge from hospital as "very good" or "good". 8 out of 10 rated this advice from neonatal nurses as "very good" or "good".
- Approximately half of parents rated the advice they received from midwives and consultants to prepare for possible admission to a neonatal unit as "very good" or "good".
- Between 2015 and 2019 satisfaction with all the areas of advice above has increased, at times markedly.
- Professionals are often less positive than parents about the advice they feel parents receive, with several feeling the advice could be improved.
- Of those parents whose babies required neonatal care, 38% were offered the opportunity to visit the neonatal unit before birth and 28% were introduced to the neonatal care team before birth.

1.3.5. Postnatal care

- Qualitative feedback reveals several parents did not have a positive experience of postnatal care, especially if one or more of their babies was in neonatal care. This may reflect the move from multiple-specialist antenatal care to more general postnatal care where the level of expertise in caring for parents with multiples may be lower.
- Support for breastfeeding multiples was found to be variable in postnatal care settings. This echoes findings from the 2014/15 report which found that 30% of parents said they were not able to feed their babies as planned, often due to lack of breastfeeding support, pressure to supplement with formula, difficulties with feeding premature babies, separation from one or more babies or the sheer demand of breastfeeding multiples.

38%
of those whose babies required neonatal care were given the chance to visit the unit before birth

28%
of those whose babies required neonatal care were introduced to the neonatal care team before birth

1.3.6. Neonatal care

- Overall satisfaction with neonatal care is high - typically 9 out of 10 parents felt their babies received a high level of care and felt confident in the staff caring for their babies - whether that was in a Neonatal Intensive Care Unit, Local Neonatal Care Unit or Special Care Baby Unit. Satisfaction with transition to, and between, units, was slightly lower.

9 out of 10
felt confident in the staff caring for their babies when they required neonatal care

1.4 Conclusions

1.4.1. Care practice does not always enable parents to make birth planning decisions

This research presents a mixed picture regarding the extent to which parents expecting multiples can make informed decisions about their care and their birth plan. Three out of ten parents did not see (or were not sure that they saw) either an obstetrician, midwife or sonographer specialising in multiple births. 35% did not discuss when and how they wanted to deliver their babies before 32 weeks and, even when a discussion did take place, qualitative responses reveal that consultants' preferences can have a stronger influence on birth planning decisions than those of parents. Some parents feel that they were not listened to and were powerless to challenge staff.

1.4.2. More could be done to prepare parents for premature babies

This research has revealed that, although parents may have prepared themselves for having twins, many parents do not feel prepared for having premature babies. Only 28% of parents had a discussion with professionals about the risks and signs of preterm labour before 24 weeks. 24% of parents reported health professionals did not discuss possible admission to a neonatal unit with them. Of those that did have the discussion roughly half rated the advice they were given positively. Furthermore 36% of professionals feel this advice could be improved.

1.4.3. Continuity of care supports effective decision making

Just over half of parents said that they saw the same consultant and midwife all or most of the time during their antenatal care. This continuity creates the opportunity for more in-depth conversations about concerns or options to take place between parent and professionals. Those who saw different professionals each time report having to describe their situation each time - limiting the effectiveness of the discussion. Reduced continuity also increases the risk of the parent receiving inconsistent and conflicting advice.

1.4.4. Parents' experience of care may not be as positive as professionals may think

Although the sample was small, professionals were consistently more positive about adherence to NICE guidelines than parents. However, professionals are less positive than parents when it comes to the provision of advice. Over half of professionals felt that the advice given to women to prepare for postnatal care could be improved and 44% felt the advice given to women to prepare them to care for their babies after discharge could be improved.

1.4.5. The rate of improvement in adherence to NICE guidelines is slow

Although there has been improvement in adherence to some NICE guidelines in the last four years - progress is slow. Apart from a 29% increase in the proportion of parents seeing a specialist multiple midwife (from 24% to 31%), other increases were small. The proportions of parents having discussions with professionals around preterm labour and delivery options remain at 2014/15 levels.

1.4.6. There is still a wide variation in adherence to NICE guidelines across the country

There is a wide disparity in the adherence to QS46 statements (and overall satisfaction with antenatal care) between Local Maternity Services in England (and also comparing LMS areas in England with Scotland, Wales and Northern Ireland). Considering an average adherence across nine indicators, the scores amongst Local Maternity Services with ten or more parent responses ranged from 50% to 77%.

1.5 Recommendations

This research will be of interest to Local Maternity Systems, individual trusts and maternity teams looking to implement NHS England's Saving Babies Lives Care Bundle which explicitly recommends using the NICE guidance for multiple pregnancies. Considering these findings, Twins Trust makes the following recommendations.

1.5.1. Parents

- Download the Twins Trust multiple antenatal proforma to find out what appointments, scans and tests you should receive during your pregnancy.
- Ask your midwife or consultant if they have a multiple-specific care plan for your type of pregnancy. If they do, check the appointment schedule is the same as in the Twins Trust care plan. If they don't have one, give them a copy of the Twins Trust care plan and make sure the appointment schedule is followed.
- Ensure that the risks and signs of pre-term labour are discussed with you by 24 weeks. Ask if a tour of the neonatal unit is possible.
- Ask if you will be seen by a team that specialises in multiple births.
- Ensure that the mode and timing of delivery (the way that you prefer and is safe to give birth and when this is likely to happen) is discussed with you by 28 weeks. You can also ask to revisit this at any time later in your pregnancy.
- Ask for help on the ward if you need it.
- Before you are discharged ask who to contact if you have any questions.
- Find out what breastfeeding support is available to you.
- If at any time you aren't happy with the care you receive, raise it with your consultant and/or the Patient Advice and Liaison Service (PALS). If the problem remains unresolved, you have the right to self-refer to an alternative maternity unit.

1.5.2. Health Professionals

- Support multiple-birth parents in your care with unbiased information and genuine opportunities to discuss their birth preferences from 24 weeks and by 28 weeks, including offering support to prepare families for pre-term birth and possible neonatal admission. Enable them to make informed decisions, as highlighted by both the 2019 NICE guideline NG137 and the National Maternity Review: Better Births, particularly concerning their delivery and postnatal care.
- Work alongside the maternity safety champions in your trust to identify changes required to improve the care of multiple pregnancies.
- Contact Twins Trust now for resources and practical support. Through our Maternity Engagement Project, we can help develop an action plan and provide practical help to drive change within your hospital.

1.5.3. NHS England and NHS Improvement

- Share the key findings of this research and ensure it is understood amongst Local Maternity Systems and maternity safety champions that the support offered through Twins Trust's Maternity Engagement project is a key contributor to meeting the Ambition, especially improvements in continuity of carer among a vulnerable group, as set out in the Long-Term Plan.
- Ensure that Local Maternity Systems are aware that twin and triplet pregnancies continue to be explicitly recognised in commissioning frameworks, tariff requirements, and care bundles.
- Ensure that there is significant investment in postnatal support for families, including mental health support and infant feeding support as set out in the Long-Term Plan, and that transitions from antenatal to postnatal, neonatal and community care are improved, as recognised in the National Maternity Review: Better Births.

1.5.4. NHS Resolution

- Check that trusts applying for the Maternity Incentive Scheme understand that in order to meet the twin specific requirements of Element Two (risk assessment, prevention and surveillance of pregnancies at risk of fetal growth restriction) of the Saving Babies Lives Care Bundle (2019), they need to implement the standards set out in NICE QS46 or a local variation, and that Twins Trust can support them to do that.

1.5.5. Care Quality Commission

- Ensure the inspection framework for antenatal care continues to focus on care for multiple pregnancies being provided in line with NICE QS46.
- Check feedback to trusts highlights the Twins Trust resources and support that are available to help them make improvements to their care practice where appropriate.

1.5.6. Health Education England

- Provide CPD opportunities for teams to improve their skills and knowledge available in the care of multiple pregnancies and make them aware that Twins Trust provides free CPD to all healthcare professionals involved in multiple pregnancies.

1.5.7. The Department of Health and Social Care

- Ensure Twins Trust's Maternity Engagement Project receives ongoing support both to reach new units and to monitor outcomes achieved by participating units over a longer period.
- Acknowledge that Twins Trust's Maternity Engagement Project is a key contributor to achieving the Better Births ambition, especially improvements in continuity of carer among a vulnerable group, as set out in the Long-Term Plan.

Introduction

2.

2.1 Project context

In England, multiple pregnancies make up around 1.5% of pregnancies but account for 5% of stillbirths, 10% of neonatal deaths and in the region of 15% of all neonatal admissions[2].

The risk of preterm birth is also considerably higher occurring in at least 50% of twin pregnancies[3] with twins facing six times the risk of cerebral palsy[4]. This paints a concerning picture for the growing multiple birth community, one which is compounded by unwarranted variations in clinical care delivered across the UK.

2.2 Better Care Of Multiples - an Exploration (BeCOME) project background

The National Institute for Care and Excellence (NICE) first published antenatal care guidelines for multiple pregnancies (Clinical Guideline 129 - since renamed NG137) in 2011 and followed these with eight quality standards (NICE QS46) in 2013. These guidelines aim to improve the quality and consistency of clinical care provided to those expecting multiples.

In 2015, Twins Trust (formerly Tamba) conducted a survey jointly with the NCT to measure parent experiences of maternity care and implementation of the NICE guidelines across the UK[5]. The survey found that:

- Parents of multiples faced additional challenges in antenatal and postnatal care. Rates of preterm birth were considerably higher for multiples. Multiples were more likely to be born by elective birth and caesarean section, at low birth weight, and in need of neonatal care.
- Parent satisfaction with advice provided by the healthcare team was generally low. Particularly advice on postnatal issues including preparation for admission to a neonatal unit, postnatal care and caring for the babies after discharge.
- Implementation of NICE guidelines varied widely between trusts and regions, and although they were slowly beginning to address the inequalities of care experienced by parents of multiples, further progress was required - particularly in terms of postnatal advice and support and access to a multi-disciplinary team with specialist knowledge of multiple pregnancy.

NICE Quality Standard 46

The quality standard is made up of eight statements that describe high-quality care for patients and are summarised as follows:

1. Women who are pregnant with twins or triplets (referred to as a multiple pregnancy) have an ultrasound scan between 11 weeks and 13 weeks 6 days of their pregnancy. This is to see whether the babies share the same placenta (chorionicity) and amniotic sac (amnionicity). This information is recorded in the woman's notes.[6]
2. Women with a multiple pregnancy have an ultrasound scan between 11 weeks and 13 weeks 6 days of their pregnancy to record the positions of their babies.[7]
3. Women with a multiple pregnancy are cared for by a team of healthcare professionals with different skills and roles (for example, specialist doctors, specialist midwives and ultrasound operators).
4. Women with a multiple pregnancy have a care plan that has the dates and times of all their antenatal care appointments and details of who the appointments are with.
5. Women with a multiple pregnancy are monitored to check the babies for any complications (for example, to check the babies' growth and blood flow) in a way that is appropriate for their pregnancy.
6. Women with a multiple pregnancy have an expert in fetal medicine involved in their care if their pregnancy is higher risk or if there are complications.
7. Women with a multiple pregnancy discuss the risks and signs of an early (preterm) labour with one or more members of their healthcare team. The discussion should take place by 24 weeks of their pregnancy and also cover the possible problems associated with an early birth.
8. Women with a multiple pregnancy have a discussion with one or more members of their healthcare team about the timing of the birth and how they want their babies to be delivered. This discussion needs to take place by 32 weeks of their pregnancy and include agreement of their birth plan.[8]

2.3 BeCOME project aims

Four years on from the NCT/Twins Trust report, Twins Trust were keen to re-examine the state of maternity care, particularly adherence to the NICE guidance, to see how the charity can target their efforts to further reduce stillbirths and neonatal deaths.

The overall objectives of the research were:

- To assess current practice regarding the care of multiple pregnancies in the UK from both a parent and clinician perspective
- To compare current practice with the NICE guidance
- To reflect on progress made in implementation of NICE guidance since the 2015 NCT/Twins Trust report.

2.4 Research methodology

To gather the insight of parents an online survey was promoted to Twins Trust members via email and social media. Responses were received between 14/3/19 and 10/5/19. Ten parents were recruited from the survey to be interviewed in more detail over the telephone. Calls were completed between 27/3/19 and 1/5/19.

Twins Trust's professional contacts were also invited to take part in a survey via an online newsletter and at two conferences. Responses were received between 11/3/19 and 28/5/19.

Both surveys were incentivised with entry into a prize draw to win one of two £30 shopping vouchers.

2.5 Acknowledgements

The project benefited from the expertise and support of Professor Mark D. Kilby and Dr R. Katie Morris from the University of Birmingham and Birmingham Women's and Children's Hospital NHS Foundation Trust.

This research was undertaken on behalf of Twins Trust by Fiveways. Fiveways (www.fivewaysnp.com) is dedicated to finding practical solutions to the issues that prevent charities from achieving more, and specialise in insight research and evaluating services to drive future improvement.

The sample (parents)

3.

The parents survey generated 1,003 responses. 96% were mothers of twins, 2% fathers of twins and 2% mothers of triplets.[9] All of the respondents gave birth in the UK in, or since, 2015.

3.1 Type of multiple

For twins (943 respondents), 76% were dichorionic and diamniotic (DCDA) where each baby has a separate placenta and a separate amniotic sac.

20% were monochorionic and diamniotic (MCDA) where babies share a placenta but have separate amniotic sacs, and 4% were monochorionic and monoamniotic (MCMA) where babies share a placenta and share an amniotic sac.

As outlined in QS46, those pregnant with monochorionic twins should expect more frequent scans and monitoring. MCDA twins are at risk of twin-twin transfusion syndrome (TTTS), an abnormality of the placenta. MCMA twins can also experience cord entanglement, which can cause complications.

For triplets (23 respondents) the largest group (43%) was trichorionic triamniotic (TCTA) triplets.

3.2 Gestation and preterm birth

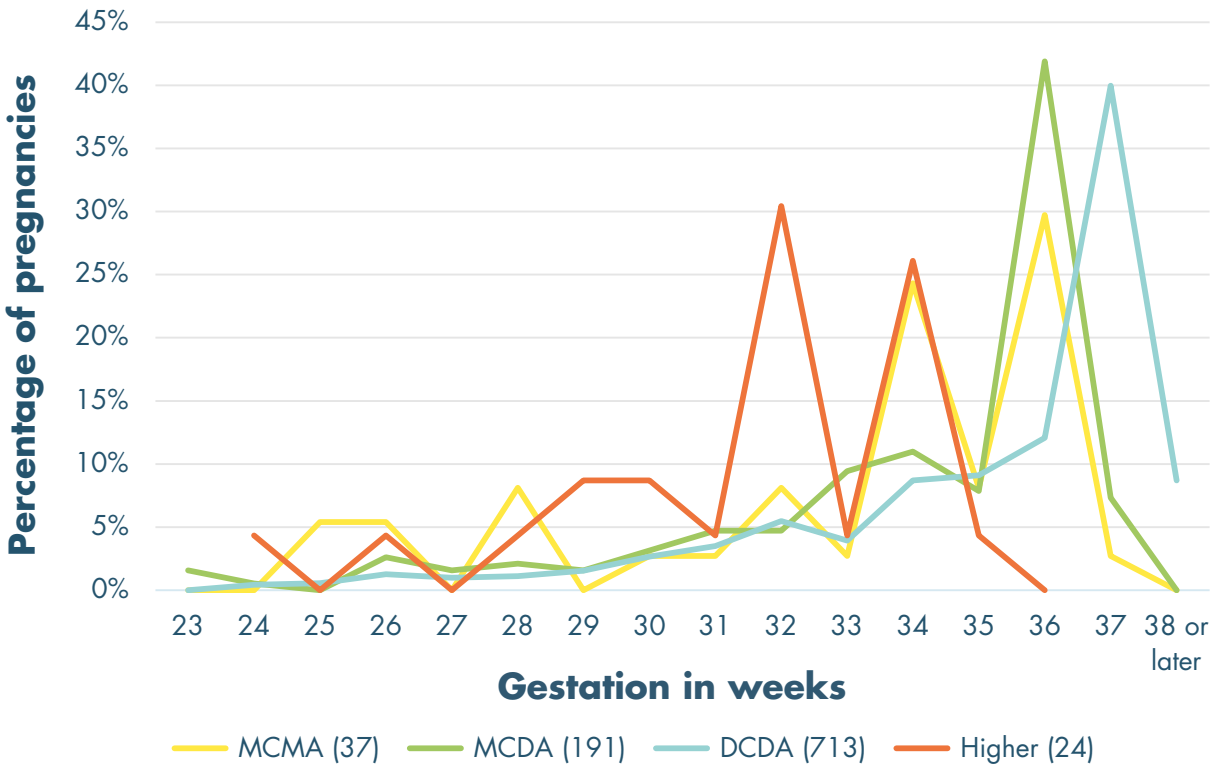
On average a twin pregnancy lasts 37 weeks and a triplet pregnancy 34 weeks[10] - in this sample the averages were lower - 35[11] weeks for twins (941) and 31 weeks for triplets (23).

Average gestation times vary depending on the type of multiple - the higher the consideration of risk, the lower the average gestation. This is mainly due to a few very early births bringing the mean average down - therefore median and mode figures are also considered.

- The mean average gestation for higher order pregnancies (24) was 31 weeks, although 63% were born after that (the median and mode were 32 weeks).
- The mean average gestation for MCMA twins (37) was 33 weeks, although 65% were born after that (the median was 34 weeks and the mode was 36 weeks).
- The mean average gestation for MCDA twins (191) was 34 weeks, although 57% were born after this (the median was 35 weeks and the mode, as with MCMA twins, was 36 weeks).
- The mean average gestation for DCDA twins (713) was 35 weeks, although 61% were born after this (the median was 36 weeks and the mode was 37 weeks).

FIGURE 1

Gestation in weeks by type of multiple



Considering all babies, the rate of preterm birth (labour that happens before the 37th week of pregnancy) in the UK is around 8%[12]. The risk of prematurity for multiple pregnancies is much higher at 57%[13]. In this sample 62% of respondents (978) gave birth before 37 weeks.

- 4% of the sample were extremely preterm (before 28 weeks)
- 10% were very preterm (between 28 and 31 weeks)
- 42% were moderately preterm (between 32 and 36 weeks).

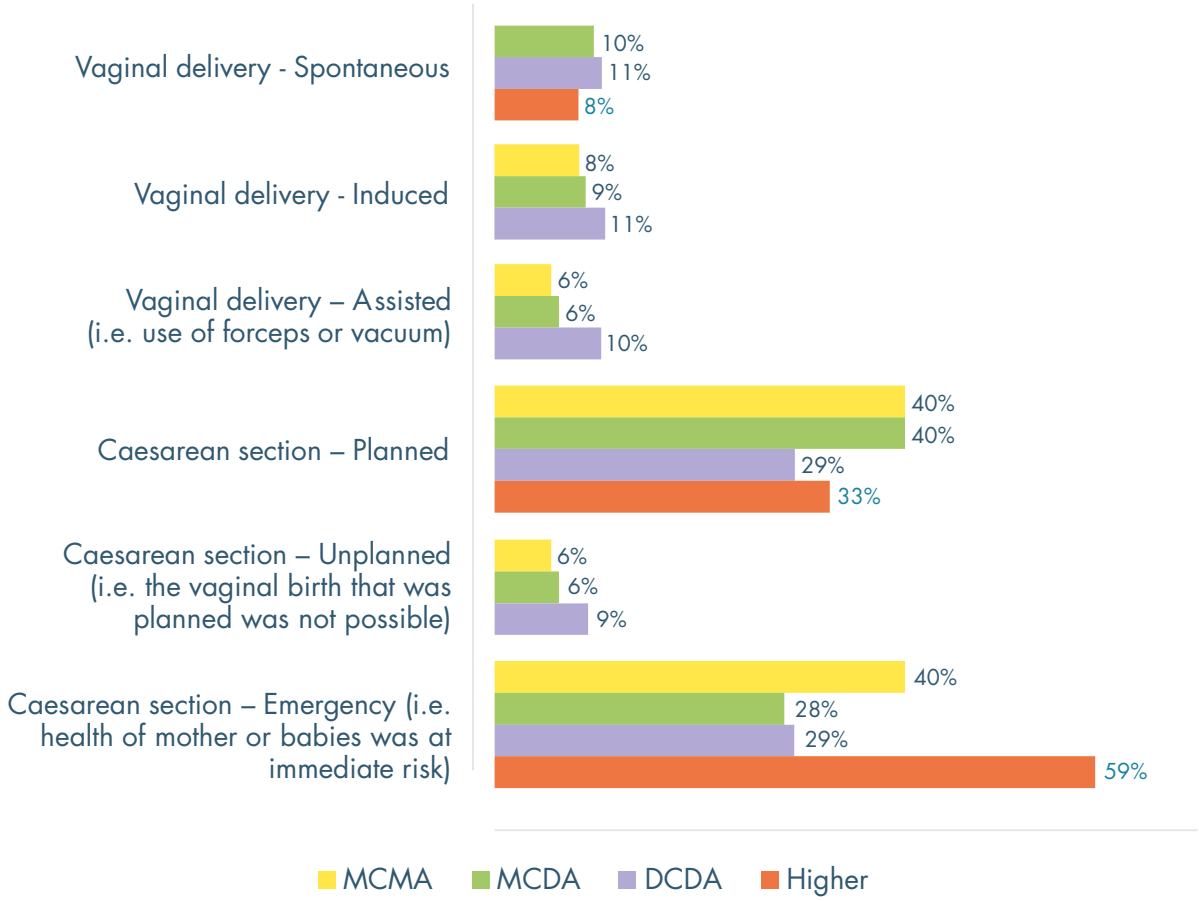
3.3 Mode of delivery

70% of twin babies (973 responses) and 90% of triplet or quad babies (24 responses) were delivered by caesarean section. This compares with 28% for all births[14]. Of those delivered by caesarean section, 42% of twin babies were delivered through emergency caesarean section (64% of triplet or quad babies).

The mode of delivery by type of multiple is shown in the graph below. Vaginal deliveries are more common amongst those expecting DCDA twins (32%) and MCDA twins (25%) compared with MCMA twins (15%) and higher order multiples (8%).

FIGURE 2

Mode of delivery by type of multiple



3.4 Age

Half of the sample of mothers (832) were aged over 35 when they did the survey. As all had given birth to multiples in the last four years, at least 50% would have been over 30 at the time they gave birth and at least 15% would have been over 35. Between 2015-2017 54% of all births in England and Wales were to mothers aged 30 or more and 22% to mothers aged 35 or more[15].

So, broadly the age profile of the sample is in line with that for all births. However, between 2015-2017 4% of births were to mothers under 20, this group is not represented in the sample (we received only 1 response).

3.5 Ethnicity

97% of the sample (821) described their ethnicity as White. In 2017-18 77% of all deliveries were by white mothers.[16] People from Black and Asian ethnicities are significantly under-represented in the sample (1% each), as they represented 5% and 16% of all deliveries in 2017-18.

FIGURE 3

Age of respondent (mothers)

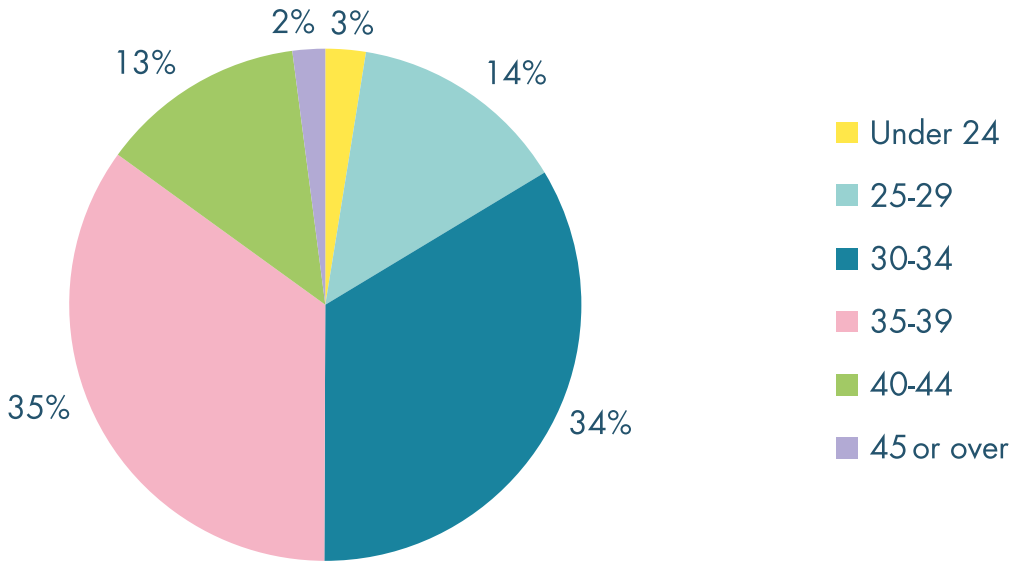
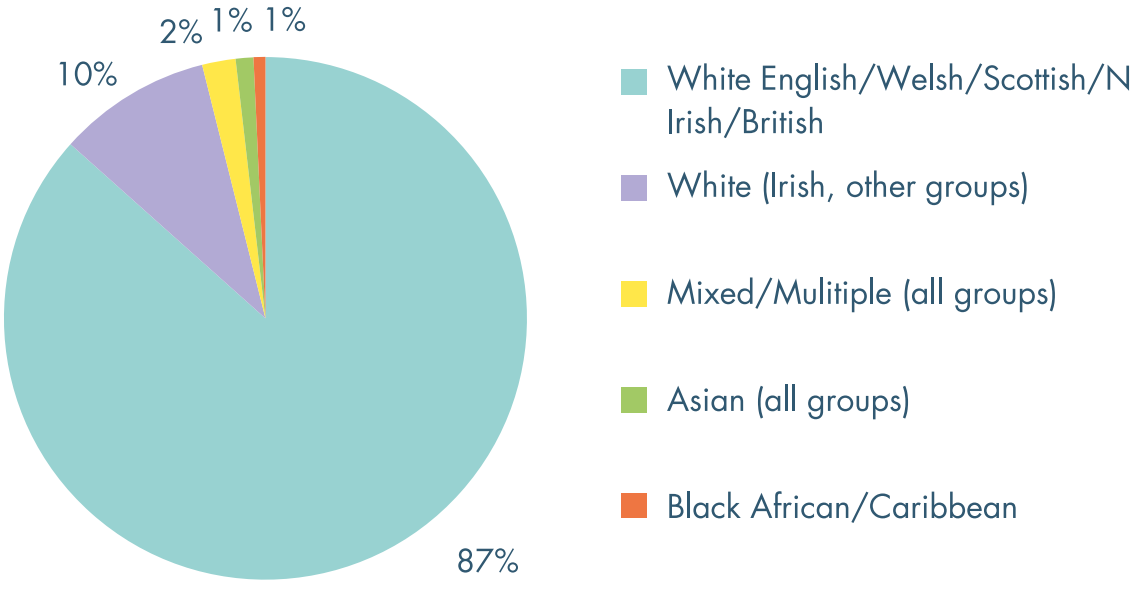


FIGURE 4

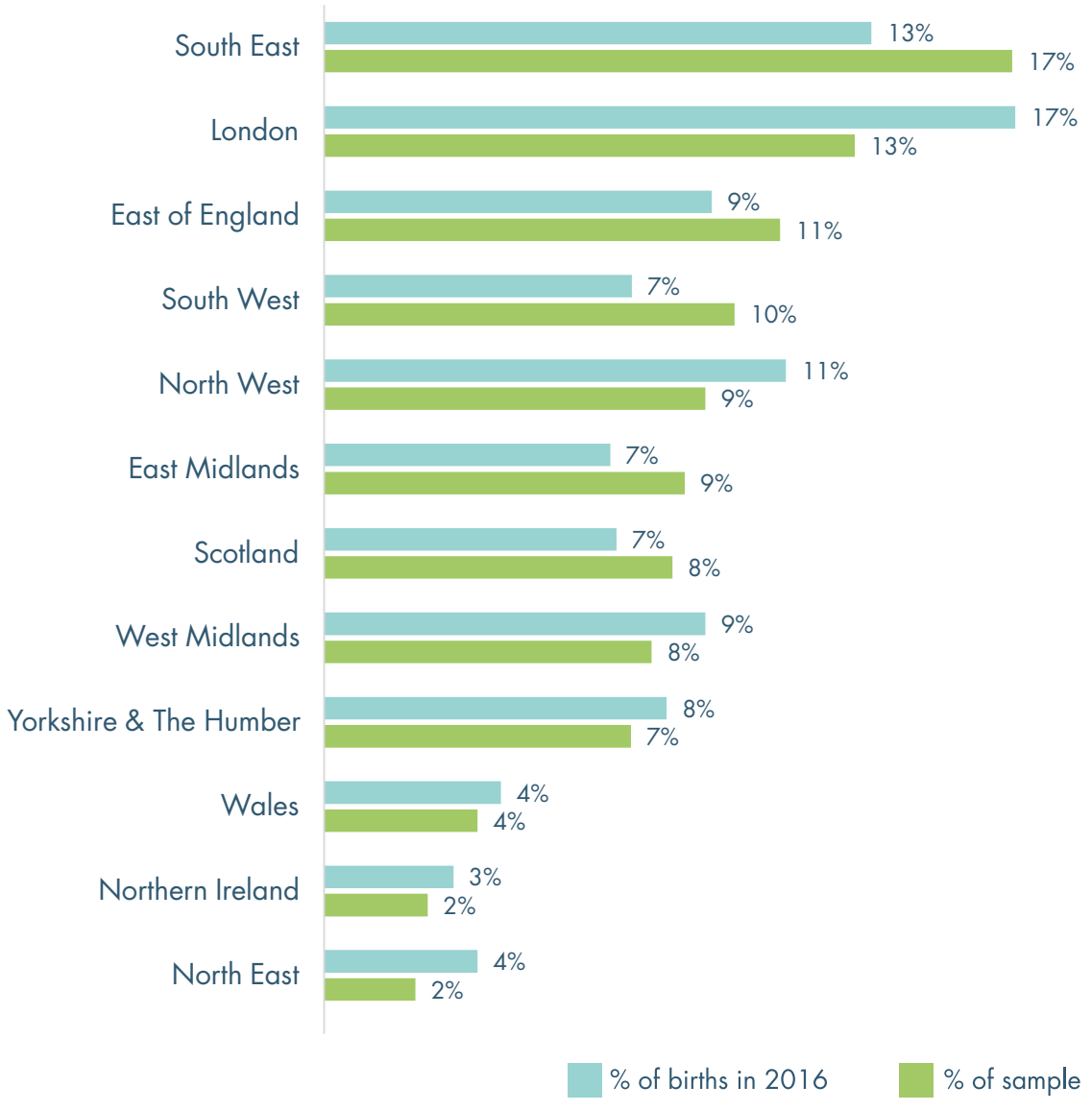
Ethnicity of respondent (mothers)



3.6 Region

The sample is taken from all regions in England as well as Wales, Scotland and Northern Ireland. Compared with the region of residence of mothers in 2016[17], the sample is most over-represented in births in the South East and South West and most under-represented in births in London and the North East.

FIGURE 5
Regional spread



The sample (health professionals)

4.

The health professional survey attracted responses from 76 professionals.

4.1 Role and grade

The most commonly represented job role was midwife (43% of respondents), followed by maternal fetal medicine specialists (11%), sonographers (8%) and obstetricians (8%).

58% of respondents were at Agenda for Change grade 6 or 7, 24% were Consultants.

4.2 Region

The 76 responses were spread over 51 hospitals. In England, 66 responses were spread over 43

hospitals, 39 trusts and 28 LMSs.

4.3 Experience

In terms of maternity/obstetric experience 7 out of 10 respondents had over ten years' experience,

this falls to 3 out of 10 when considering experience of multiple pregnancies.

After your primary qualification, how many years' experience in maternity/ obstetrics do you have?		
	Total	%
Fewer than 5 years	8	11%
More than five years, but fewer than 10 years	14	19%
More than 10 years	53	71%
Total	75	

Approximately how many years have you worked specifically with multiple pregnancies?		
	Total	%
Fewer than 2 years	20	27%
2-5 years	17	23%
5-10 years	15	21%
More than 10 years	21	29%
Total	73	

Most respondents were typically involved in antenatal care - only 3 were typically involved in neonatal care.

	Total	Answered	%
Antenatal	63	76	85%
Intrapartum	25	54	46%
Neonatal	3	51	6%

Professionals were asked "In your current job, approximately how many multiple pregnancies would you personally be involved in the care of each month?" On average professional respondents were involved in 16 multiple pregnancies per month, but there were differences between those who were working in a hospital with a dedicated multiples clinic and those who weren't.

	Average multiple pregnancies per month	Range
Those working in hospitals with a dedicated multiples clinic (44)	21	1-80
Those not working in hospitals with a dedicated multiples clinic (15)	5	1-20

4.4 Organisation of care

62/63 (98%) professionals involved in antenatal care said their unit had a specific guideline for the antenatal care of multiple pregnancies with 1 don't know.

73% professionals involved in antenatal care (63) said they had a dedicated multiples clinic (24% didn't, 3% don't know). The majority (71%) of these clinics run monthly and 63% see fewer than 50 women a month.

95% of respondents working in a hospital with a dedicated clinic said they had a nominated specialist for multiple pregnancies (this compares with a quarter of those who did not have a dedicated clinic). 21 respondents in total were the dedicated specialist (46%).

	Yes	No	Don't know
Dedicated clinic (43)	41 (95%)	1 (2%)	1 (2%)
No dedicated clinic (16)	4 (25%)	7 (44%)	5 (31%)

Excluding those answering "I don't know", all those working in dedicated clinics (42) said they had a specialist obstetrician. 62% said they had more than one. 25% said they did not have a specialist midwife and 29% said they did not have a specialist sonographer.

Number of specialists	None	1	2	3
Area				
Obstetrics (42)	0%	38%	38%	24%
Midwifery (40)	25%	25%	25%	25%
Sonography (31)	29%	23%	16%	32%

Excluding those answering "I don't know", 56% of those not working in dedicated clinics (9) said they did not have a specialist obstetrician. 78% said they did not have a specialist midwife and 90% said they do not have a specialist sonographer.

Number of specialists	None	1	2	3
Area				
Obstetrics (9)	56%	44%	0%	0%
Midwifery (9)	78%	11%	11%	0%
Sonography (10)	90%	10%	0%	0%

Antenatal care: scans and monitoring

5.

This section presents the findings from the parents' survey regarding antenatal scans and monitoring. It includes details on adherence to three of the QS46 guidelines. Findings from the health professional survey are added (in boxes) to the relevant sections.

5.1 QS46.1: Scan between 11-14 weeks to determine chorionicity and amnionicity

NICE QS46. 1 states that women who are pregnant with twins or triplets (referred to as a multiple pregnancy) should have an ultrasound scan between 11 weeks and 13 weeks 6 days of their pregnancy to see and record whether the babies share the same placenta (chorionicity) and amniotic sac (amnionicity).

99% of parent respondents (1003) said that they had an ultrasound scan between 11 and 14 weeks of their pregnancy and for 80% of respondents, those scans correctly determined both chorionicity and amnionicity. 10% did not, 4% had already been determined at an earlier scan (e.g. at a fertility clinic) and 6% of respondents did not know.

Excluding "don't knows" and earlier scans, **adherence to QS46.1 was 89%**.

82% of parents said they had chorionicity and amnionicity explained to them (excluding "don't knows"). In 60% of cases a sonographer was involved in this explanation, with consultants involved in 27% and midwives 8%.

Health professional responses were consistent with the parents.

Excluding “don't knows”, all the 51 professional respondents said that chorionicity and amnionicity was “always” or "usually" determined by scan before 14 weeks and that chorionicity and amnionicity was “always or usually” explained to parents.

However, for professionals, consultants were more likely to be involved in the explanation (46%) than sonographers (31%).

5.2 QS46.5: Scan frequency

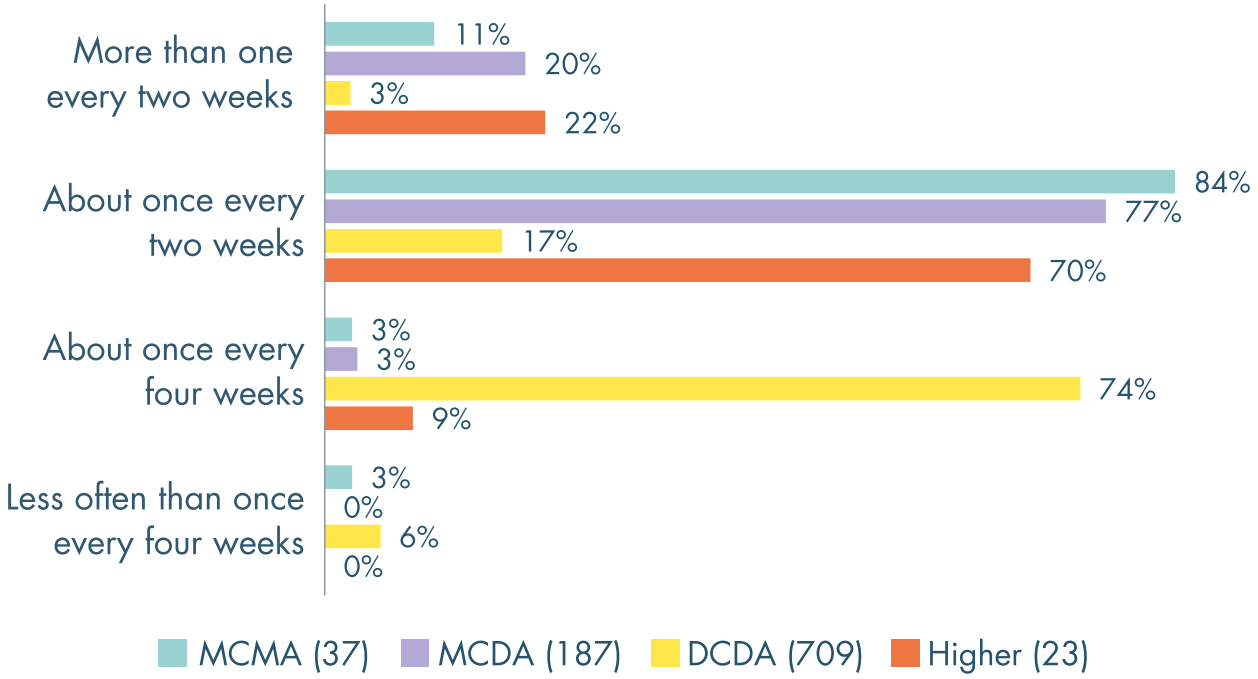
QS46.5 states that women with a multiple pregnancy should be monitored to check the babies for any complications in a way that is appropriate for their pregnancy. This monitoring is reflected in the frequency of appointments. The recommended appointment schedules are as follows[18]:

Type of multiple	Frequency of appointments (after 16 weeks)
MCDA twins, MCTA and DCTA triplets	Every two weeks
DCDA twins and TCTA triplets	Every four weeks

The survey revealed that 97% of MCDA twins (187) and 91% of higher order multiples (23) were scanned every two weeks or more often. 94% of DCDA twins (709) were seen every four weeks or more often. **Overall the adherence to QS46.5 was 95%.**

FIGURE 6

Scan frequency by type of multiple



75% of professionals (55) were “completely” or “very” confident "that women with a multiple pregnancy receive the correct frequency of specialist antenatal appointments with a multidisciplinary core team appropriate for the chorionicity and amnionicity of their pregnancy as defined by NICE guideline 129," 11% were “somewhat” or “not very” confident.

81% of professionals (53) were “completely” or “very” confident "that women with a multiple pregnancy receive the correct frequency of scans appropriate for the chorionicity and amnionicity of their pregnancy as defined by NICE guideline 129," 8% were “somewhat” - no respondents were not confident.

5.3 Interpreting scans

Health professionals (55) were asked which growth charts their unit uses to interpret scan results for multiple pregnancies. 53% used customised charts and 15% twin specific charts.

Type	%
Population	18%
Customised	53%
Twin-specific	15%
I don't know	11%
None	4%

5.4 QS46.4: Care plans

QS46.4 states that women with a multiple pregnancy should have a care plan that has the dates and times of all their antenatal care appointments and details of who the appointments are with.

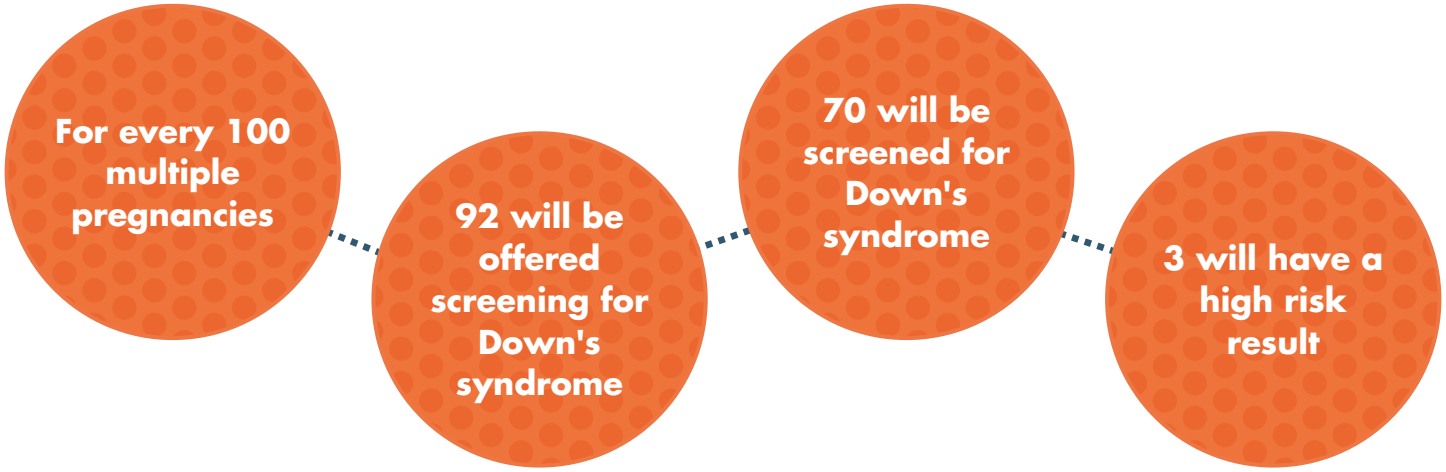
Excluding those answering "I don't know", 72% of respondents (894) agreed with the statement "I had a care plan that specified the timing of my antenatal appointments" with 16% disagreeing (and 12% neither agreeing nor disagreeing). **Therefore, adherence to QS46.4 was 72%.**

62% of health professionals (53) said "a care plan or multiple birth proforma that specifies the timing of appointments with the multidisciplinary core team used for multiple pregnancies" was always used. 28% said "often", 2% "about half the time", 2% "seldom" and 6% "never".

5.5 Screening for Down's syndrome

All pregnant women, regardless of age, are offered screening for Down's syndrome. There is however variation in the type and timing of the screening tests used in England, Northern Ireland, Scotland and Wales.

Excluding those answering "I don't know", 92% of respondents (981) were offered a screening for Down's syndrome. Of those offered (900), 76% had the screening test, along with 15% of those who weren't offered it (81). Of those who were screened (684), 4% had a high-risk result (i.e. higher than a 1 in 150 chance). 89% of these parents (28) had the options and implications of proceeding to a diagnostic test for Down's syndrome explained to them.



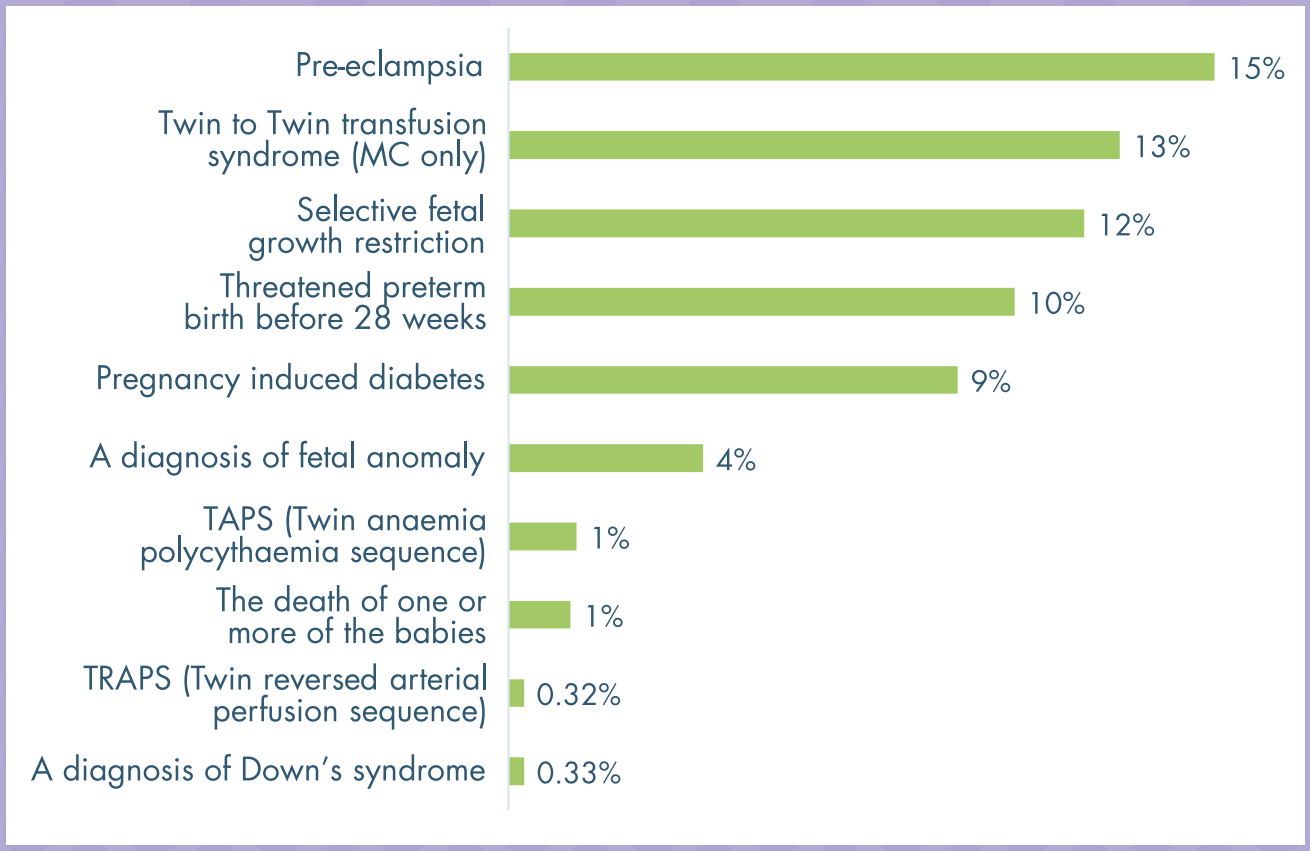
96% of health professionals (48) said parents expecting multiples were "always" or "usually" offered the combined test (scan plus blood test for Down's syndrome).

5.6 Conditions during pregnancy

Pre-eclampsia was the most common complication during pregnancy, experienced by 15% of the sample (1,002). This is higher than the 7-8% average for all pregnancies[19].

FIGURE 7

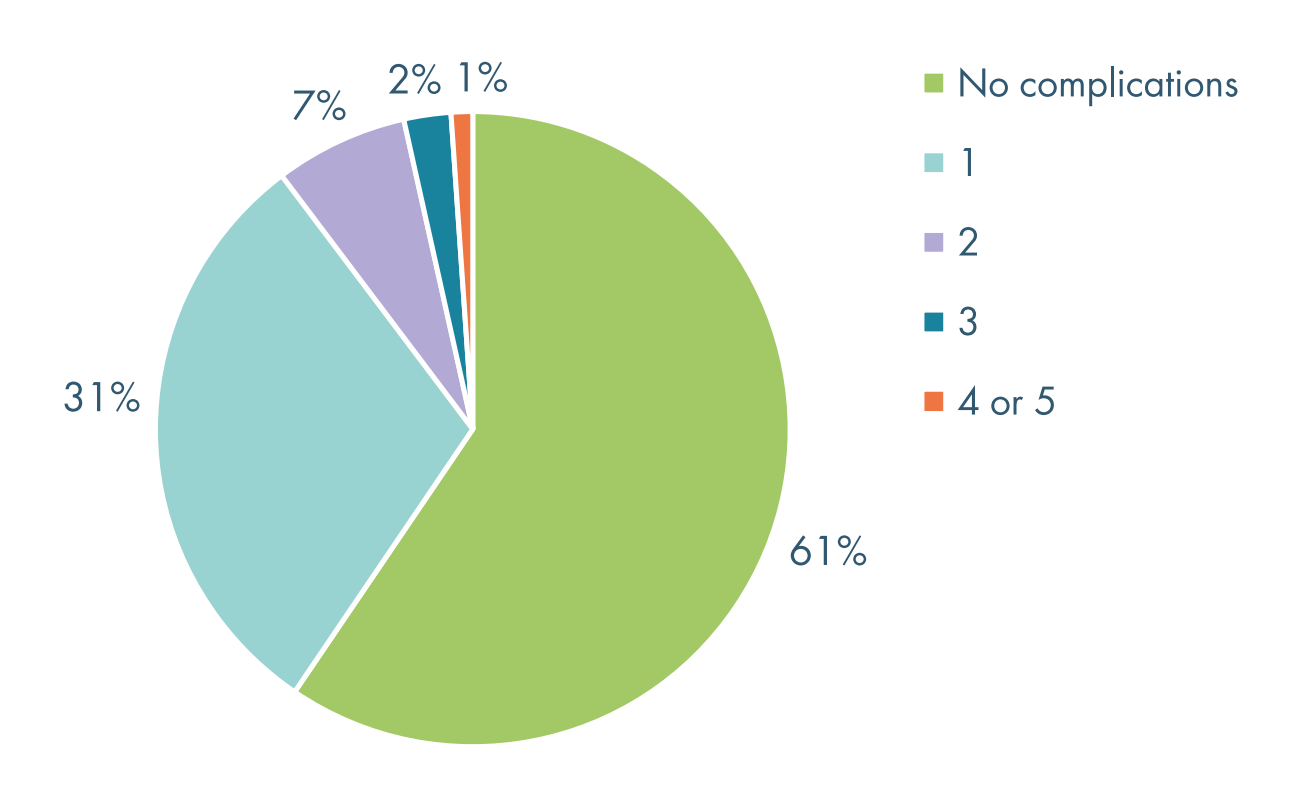
Proportion of complications within respondent sample



61% of respondents did not experience any of the above conditions. 10% experienced two or more.

FIGURE 8

Number of complications per pregnancy



91% of health professionals (54) agreed with the statement "I'm confident that when complications in multiple pregnancies are found they are escalated to the right person quickly" (none disagreed).

Antenatal care: specialist staff and continuity of care

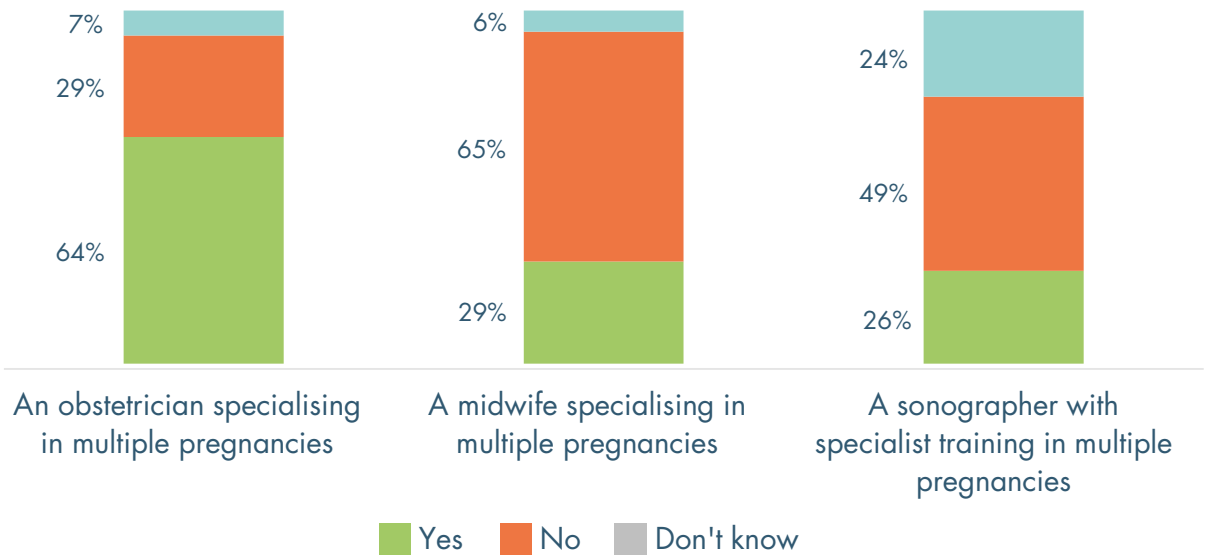
6.

6.1 QS46.3: Seeing specialist staff

QS46.3 states that women with a multiple pregnancy are cared for by a team of healthcare professionals with different skills and roles (for example, specialist doctors, specialist midwives and ultrasound operators).

64% of respondents (991) saw an obstetrician specialising in multiple pregnancies. However less than one in three saw a midwife or a sonographer with specialist knowledge (although 24% did not know if their sonographer had this knowledge).

FIGURE 9
Seeing specialist staff



Adherence to QS46.3 (excluding don't knows) was 69% for seeing specialist obstetricians, 31% for midwives and 35% for sonographers.

The health professionals surveyed report a more positive picture.

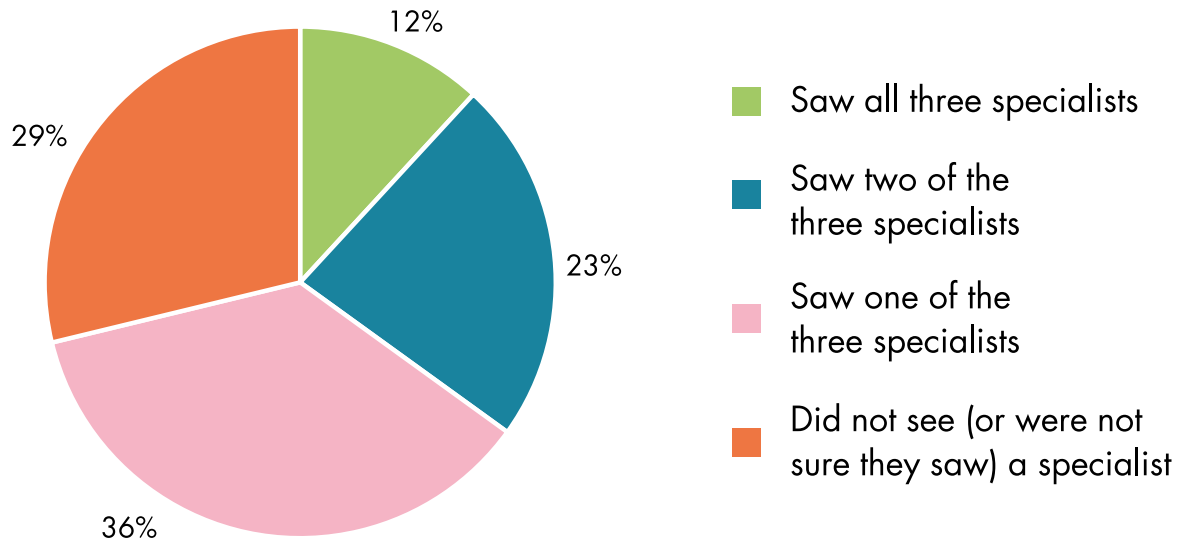
- 81% of professionals (54) agreed with the statement "in my unit, most women with a multiple pregnancy see an obstetrician specialising in multiple pregnancies." 13% disagreed.
- 66% (53) agreed with "in my unit, most women with a multiple pregnancy see a midwife specialising in multiple pregnancies." 30% disagreed.
- 70% (46) agreed with "in my unit, most women with a multiple pregnancy see a sonographer with training in multiple pregnancies." 18% disagreed.

In addition, 77% (53) agreed with the statement "in my unit antenatal care for multiples is provided by an MDT approach" with 19% disagreeing.

12% of parent respondents (1004) saw specialists in all three roles. 29% did not see a specialist in any role (or were not sure they had).

FIGURE 10

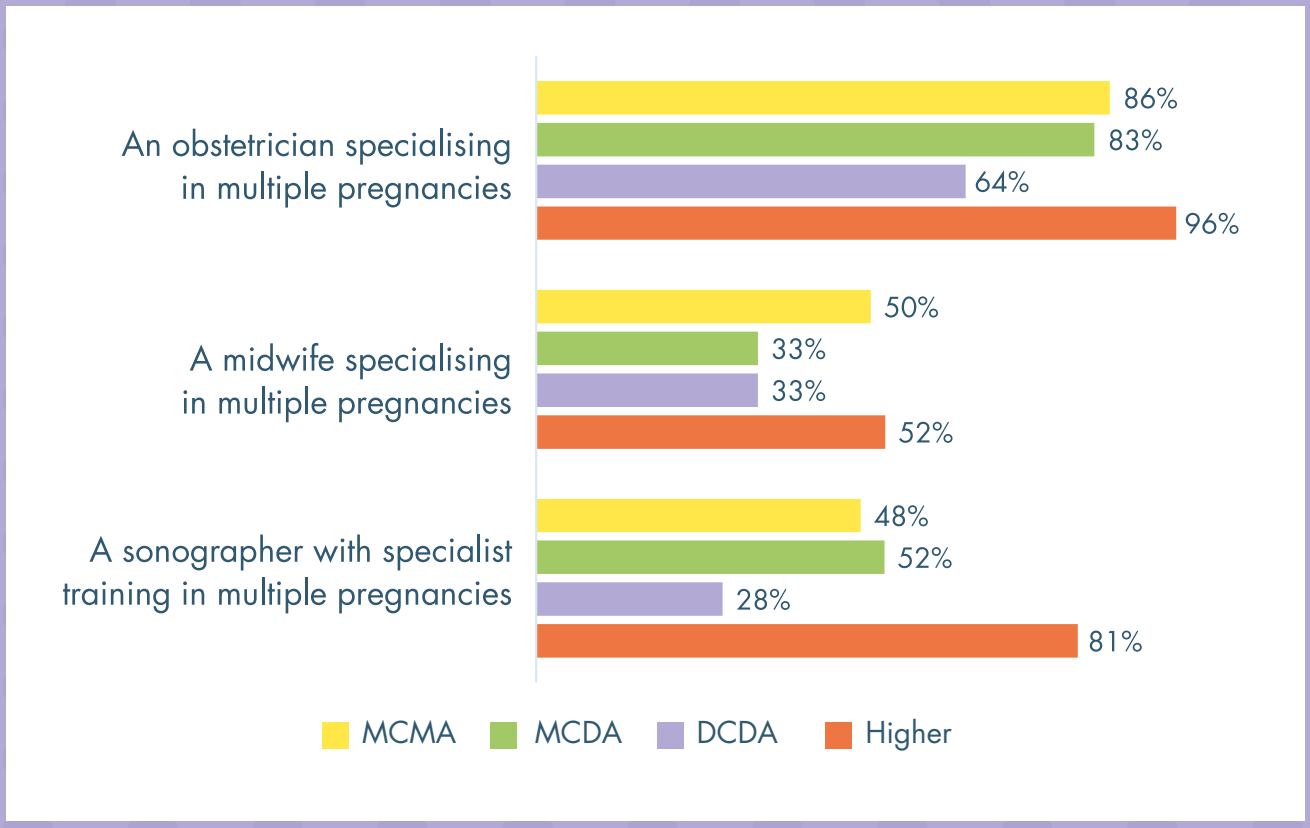
Number of specialist staff seen



Those with higher order multiple pregnancies (23) and MCMA twin pregnancies (37) were the most likely to see specialist staff. However, 13% of higher order multiple pregnancies and 16% of MCMA twin pregnancies were not seen by anyone in, or known to be in, a specialist role.

FIGURE 11

Specialists seen by type of multiple pregnancy



Qualitative responses from parents frequently reveal a perception that there was a lack of multiples experience amongst staff they encountered throughout their pregnancy.

> **"I don't feel I saw anyone who had much experience of twins. I only saw the consultant once, on other visits I saw a trainee or assistant." (DCDA twins)**

> **"I initially saw my main consultant then after that I began seeing registrars instead. After a couple of frustrating experiences (registrars who didn't understand the difference between identical and non-identical pregnancies and another who did not know critical dates on my pathway) I found that I could ask to see the main consultant every time." (MCMA twins)**

> **[The] scan at 29 weeks was with a different obstetrician who was clearly less experienced and caused unnecessary stress as he couldn't locate the membrane showing separate placentas. He wasn't calming and didn't seem interested in how his behaviour was impacting me, the patient." (DCDA twins)**

If the hospital care was consultant-led, women often received midwifery support from their community midwife who may not have had much experience of twins. Some mentioned they missed having access to a specialist midwife in hospital to advise on non-medical aspects of pregnancy.

> **The hospital does not offer a midwife at all if you are consultant led. My consultant appointments focused around the risk of my MCDA pregnancy, but I never had the support of a midwife, which I struggled with." (MCDA twins)**

> **Absolutely awful care. Was supposed to see a twin midwife, but she was never there. The midwives I saw had no idea about twins." (DCDA twins)**

> **Really felt fobbed off by my community midwife. She kept saying the "twins' clinic will explain that". [I] felt she was perhaps less confident advising on a multiple pregnancy." (DCDA twins)**

6.2 Continuity of care

When asked "did you always see the same member of staff at your hospital appointments?" 60% of respondents (979) said they saw the same consultant all or most of the time, 52% said they saw the same midwife all or most of the time. Continuity of care was much lower amongst sonographers with only a quarter of parents saying they saw the same sonographer all or most of the time and over a third saying they saw a different person every time.

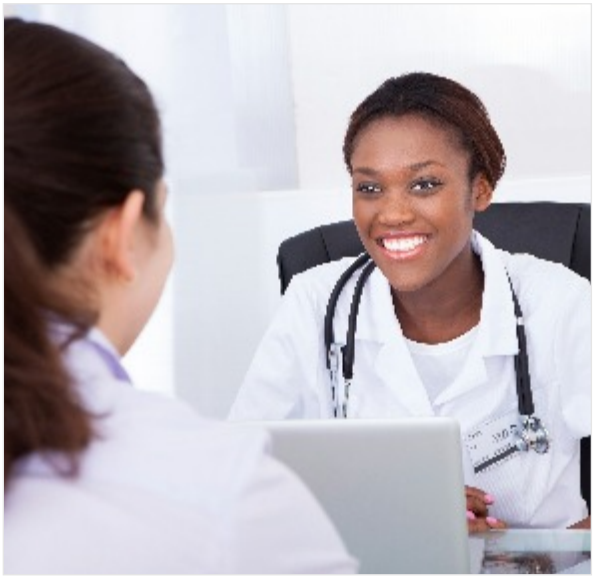


FIGURE 12

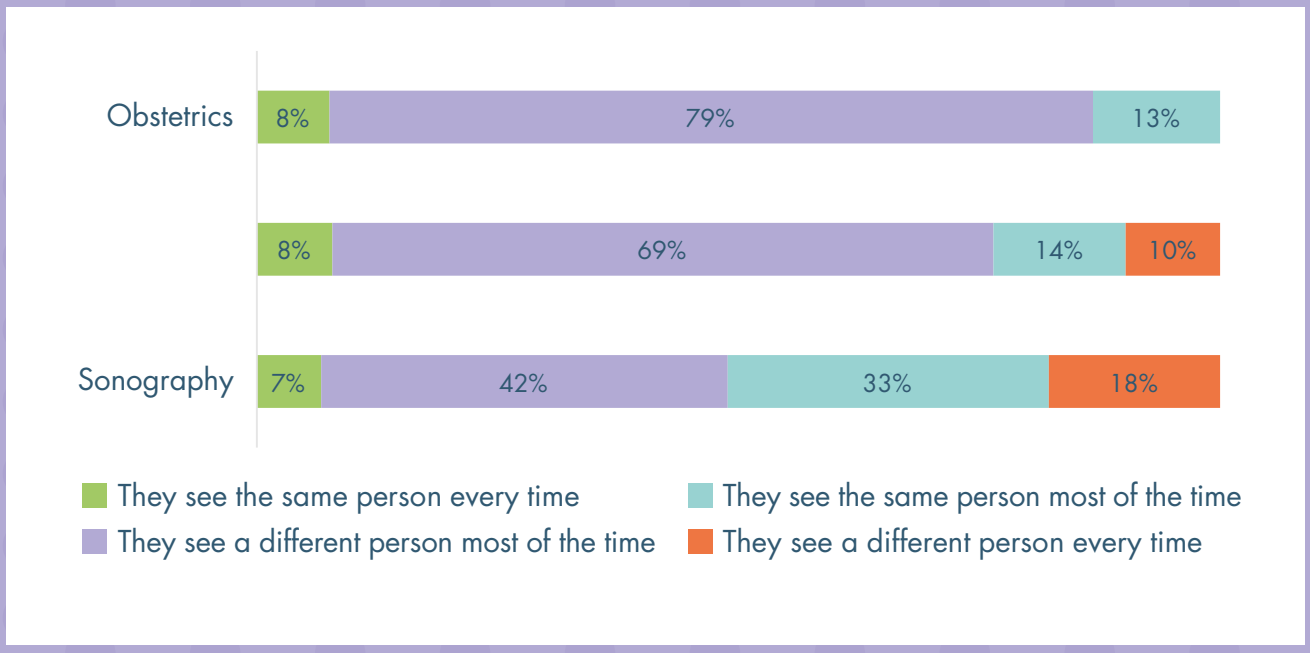
Continuity of care - parents' responses

The health professionals surveyed report higher levels of continuity 78% (54) agreed with the statement "women expecting multiples receive good continuity of care" (9% disagreed).

- 87% of professionals (53) said that parents expecting multiples see the same person in obstetrics "every" or "most of the" time (compared with 60% of parents).
- 77% of professionals (45) said that parents expecting multiples see the same person in midwifery "every" or "most of the" time (compared with 52% of parents).
- 49% of professionals (45) said that parents expecting multiples see the same person in sonography "every" or "most of the" time (compared with 25% of parents).

FIGURE 13

Continuity of Care - health professionals' responses



Those parents expecting higher order multiples or monochorionic twins were more likely to see the same consultant all or most of the time compared with those expecting dichorionic twins. Higher order multiple pregnancies were also more likely to see the same midwife and sonographer all or most of the time compared with twin pregnancies.

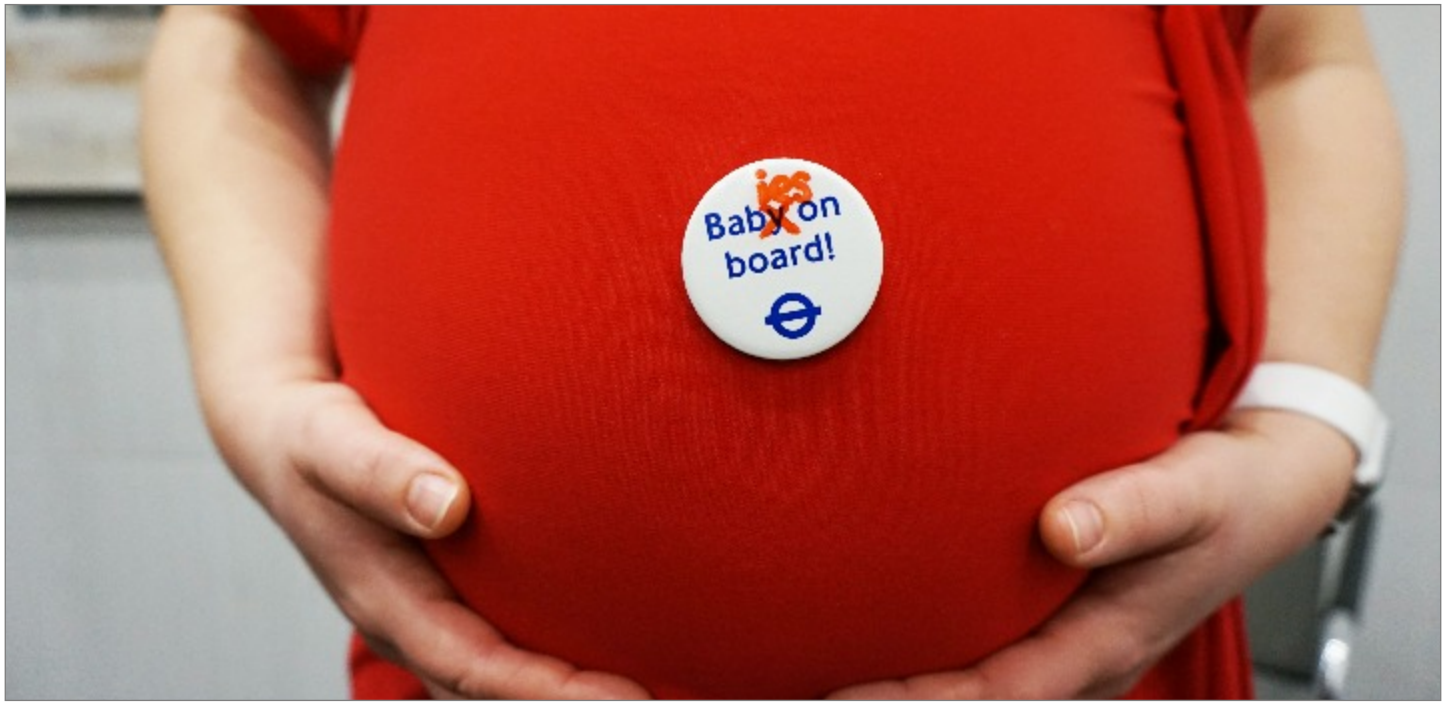
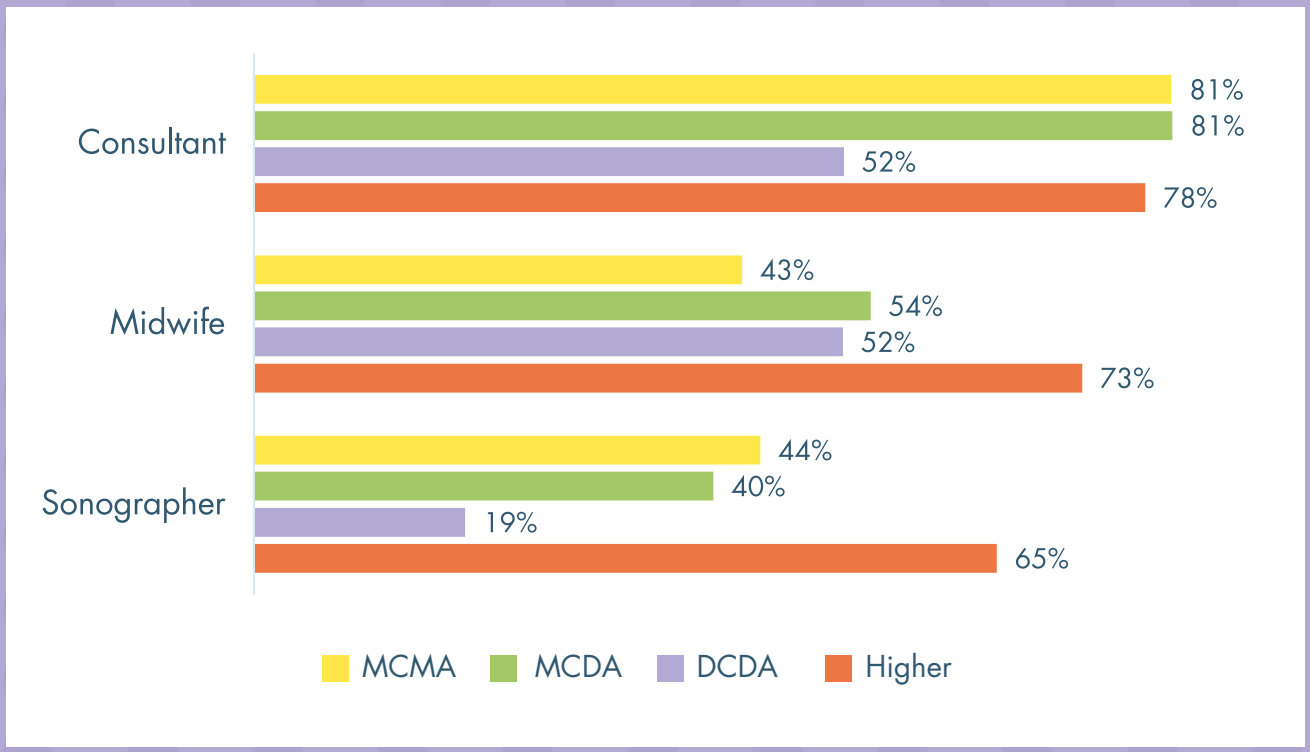


FIGURE 14

Percentage of pregnancies where the professional was seen all or most of the time by type of multiple



Qualitative feedback reveals parents are keen for more continuity in their care. Those parents who saw the same professionals throughout their antenatal care report that it gave them confidence and reassurance - mainly as they were receiving consistent information. The opportunity to have more in-depth conversations with someone who knew their situation also enabled issues and complications to be identified early and dealt with.

> **"I really liked having the same consultant throughout as that gave me more of a personal, one to one [relationship] with him. This also gave me confidence in my consultant as the information I received was consistent especially when issues started to arise in my pregnancy." (MCDA twins, survey)**

“[After the first scan] I saw the same specialist midwife and fetal medicine consultant. The consultant would conduct scans herself and we saw midwife and consultant as a team. They were a well-oiled machine and the level of care was phenomenal. On the one occasion I had an issue, the familiarity and consistency of team really paid off.” (MCDA twins)

“I got to trust the team working with me and they knew what was happening every step of the way. I felt confident they knew what they were doing so when things went wrong, I listened to their advice and trusted they would do all they could for me and the babies.” (DCDA twins)

“In the end delivery decisions were made by my consultant which heavily relied on the fact that she had got to know me over a number of weeks and had consistently assessed me each time. Once delivered it was found my placenta had begun to calcify so it is my belief that this knowledge of me that she had developed by seeing me every appointment led to my babies being delivered safely.” (MCMA twins)

However, it was clear that many women did not have this positive experience. For some not having continuity of care was not an issue - particularly those who had uncomplicated pregnancies, received consistent information, knew the hospital and/or were confident the staff had read their notes.

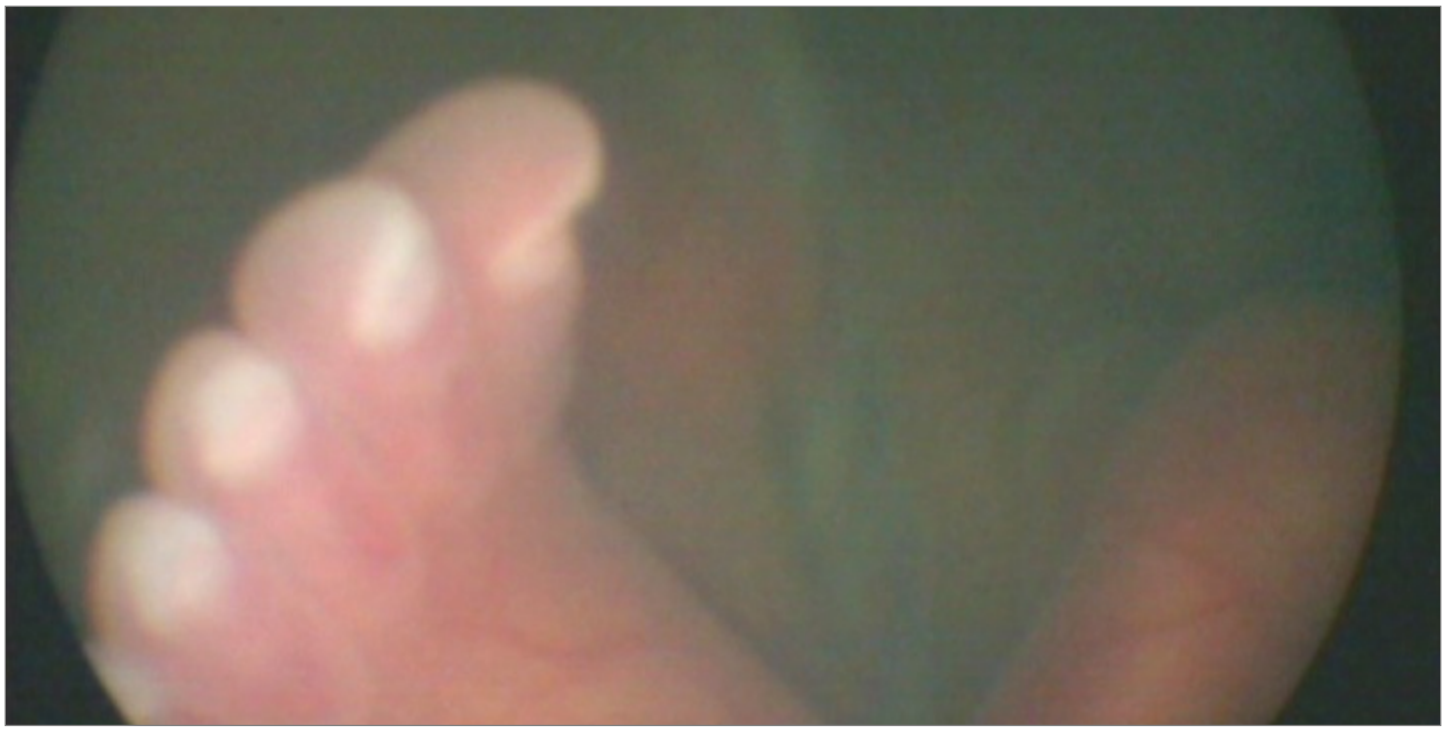
For others, seeing different professionals (and especially consultants and registrars) each time meant they had to "start from fresh" and describe their situation at each appointment "to a stranger"- reducing the time available for discussion and to raise concerns. Furthermore, the chances of receiving confusing and conflicting advice increased. The appointments were described as "upsetting", "unsettling" and "pointless". Some felt that not having continuity of care could lead to conditions not being spotted.

“I saw a different consultant every time, who were not familiar with me or my pregnancy. They made me feel like I couldn't confide in anyone or ask in depth questions as they didn't know my pregnancy at all.” (MCDA twins)

> **It would have been nice to have a consistent midwife; it was different almost every time. Therefore [you have] the same conversations over and over. Being told you are high risk every single time by a new midwife was horrible and created even more anxiety around my pregnancy." (DCDA twins)**

> **I wish I had had a designated midwife to be able to open up a bit more and say things one would not normally tell a stranger. I had to check with each new person that they had read my notes and knew my background, which was embarrassing. I didn't feel confident to question them because they are professionals" (DCDA twins, interview 9)**

> **[There was] no continuity of midwives or sonographers - so no reassurance that they knew what they were looking for. Things might have been picked up earlier in scans."**
>
> **(Triplets, type unknown, interview 4)**



Antenatal care: discussions on preterm labour and delivery 7.

7.1 QS46.7: Preterm labour discussion

QS46 states that women with a multiple pregnancy should discuss the risks and signs of an early (preterm) labour with one or more members of their healthcare team. The discussion should take place by 24 weeks of their pregnancy and cover the possible problems associated with an early birth.

Excluding those answering "I don't know", 70% of parents (959) had a discussion about "the risks, symptoms and signs of preterm labour and the potential need for steroids to speed up lung development in a multiple birth." 40% of these parents (671) representing 28% of all parents had the discussion before 24 weeks. **Therefore, adherence to QS46.7 was 28%**.

Consultants were involved in 78% of these discussions, with midwives involved in 20%.

Those expecting higher order multiples or monochorionic twins were more likely to have the discussion and have it before 24 weeks, than those expecting dichorionic twins.

Professionals surveyed felt that these discussions happened more regularly than parents report. 32% of health professionals (47) said that discussions before 24 weeks, about the risks, symptoms and signs of preterm labour and the potential need for steroids for fetal lung maturation “always” take place, 57% said that they “usually” take place, 4% said they take place “about half the time” and 6% said they seldom take place.

FIGURE 15

Preterm labour discussion by type of multiple

Some parents felt unprepared for premature birth:

> **"Strange as it may seem I was fairly unprepared mentally and practically for going into labour early. And the consultants never really discussed this with me or what might happen." (Twins, type unknown)**

> **"I didn´t know what to expect when I had a premature birth. I ended up giving birth in a hospital that I didn´t know existed. They kept saying 'we need to find you Level One care'... what's that?" (MCMA triplets, interview 3)**

7.2 QS46.8: Delivery option discussion

QS46 states that women with a multiple pregnancy should discuss the timing of the birth and delivery options with their healthcare team. This discussion needs to take place by 32 weeks of their pregnancy and include agreement of their birth plan.

Excluding those answering "I don't know", 89% of parents (966) said that the team looking after them discussed if they were likely to have a caesarean section or vaginal delivery. 74% of these parents (839) representing 65% of all parents had that discussion before 32 weeks[20]. **Therefore, adherence to QS46.8 was 65%.**

Consultants were involved in 85% of these discussions, with midwives involved in 15%.

52% of health professionals (47) said that discussions before 32 weeks about the timing of birth and possible modes of delivery place "always" take place. 38% said they "usually" take place, and 10% said they take place "about half the time."

Birth planning and the influence of staff (particularly consultants) was a common theme in the qualitative responses. Several women commented on being confused and concerned by the different "agendas" of consultants concerning delivery and the timing of the discussion about the birth plan.

> **"Seeing different staff every time was very confusing, one doctor pushing for C-section, one doctor pushing for vaginal delivery, a very confusing time." (DCDA twins)**

> **"One consultant in particular was extremely abrasive and tried to talk me out of an elective C-section when my mind was made up already." (DCDA twins)**

> **"The first consultant at twin clinic told me "I only deliver twins via C-section" - serious alarm bells rang for me as both babies head down and DCDA no indication of section required. I didn't trust her and made sure I didn't give birth in that hospital." (DCDA twins)**

> **They bully you into doing what's best for them and not the patient... I don´t think they give you all the information, which takes choices away from you."**
>
> **(DCDA twins, interview 2)**

> **My consultant was very blasé about it being a multiple pregnancy. Just told me that as twin one was head down, a vaginal birth would be fine. I was concerned twin two was breech, he wasn't. Option for caesarean never discussed. As my first babies, we didn't really question him. Ended up with emergency section under general anaesthetic." (DCDA twins)**

> **The consultants refused to discuss a vaginal birth versus a caesarean with me and said they would discuss this at 36 [weeks] of pregnancy. I knew I wanted a caesarean because of the risks to myself and the babies having done my research on potential interventions such as forceps. However, the consultants absolutely refused to discuss it with me and even after I had told them that I wanted a caesarean they wrote 'aim for vaginal birth' on my notes. My opinions were not respected or given any sort of priority. This caused massive anxiety and was a contribution to my postnatal depression." (DCDA twins)**

> **I wish I knew I didn´t need to be induced and that I could have a say in the delivery: nobody ever said to me, "ultimately it's your choice". I couldn´t make decisions, it was all about following the hospital's protocols." (DCDA twins, interview 8)**

Several women felt these discussions should have happened earlier.

> **I only met a consultant once and it was because I insisted at 32 weeks that I didn't want to wait until 36 weeks to do the birth plan. I was told that there was no reason to do a birth plan before 36 weeks and because twin 2 was transverse I would be booked in for a caesarean. In actual fact babies were born vaginally spontaneously at 33+6... with no birth plan." (DCDA twins)**

> **I felt my hospital care was minimally useful and that my concerns were not taken onboard. I tried to discuss my birth options at 32 weeks, was fobbed off and told to wait for the next appointment at 36 weeks. I pointed out that I could have delivered by then, and indeed I had my twins at 35 weeks." (DCDA twins)**

> **We were always told that they wouldn't discuss the birth plan until it was closer to 36 weeks. I was also told I would get a tour around the neonatal department. Although there were a lot of indications that I would go into preterm labour and I was kept in hospital for two weeks prior to going into labour, this was all left too late and I went into labour with no clue what would happen to me or my babies." (MCDA twins)**

Lack of a plan, or an agreed approach, sometimes caused difficulties on the day of delivery.

> **It was awful. When I talked to two different consultants, they both agreed I could have a vaginal birth, but they would book a C-section just in case I would change my mind. I didn't, but when I got to the hospital thinking I was having an induced delivery, they almost forced me to have a C-section. They judged me and I was told I was going to put my babies' lives at risk. Nothing to do with what I discussed with the two consultants." (DCDA twins)**

“The consultant who was conducting my caesarean challenged me on the morning of the delivery as to why I wanted the surgery. She suggested I could get induced instead. It didn't change my mind, but I did find it a little inappropriate and poor timing. I was never challenged about my choice until then.” (DCDA twins)

Antenatal care: advice given and satisfaction with care

8.

8.1 Preparing for delivery

98% of respondents (956) rated the advice they received from either a consultant/doctor or a midwife to prepare themselves for delivery. The remaining 2% said neither member of the team discussed preparation for delivery with them.

Of those who rated the advice, roughly two thirds of respondents rated it as "very good" or "good" from each role. There was very slightly more dissatisfaction with the advice from midwives with 13% rating it "poor" or "very poor" (compared with 11% for consultants or doctors). This suggests that some of the negative experiences highlighted in the previous section are likely to represent an important but minority view, and that most people are satisfied with their preparation for delivery.

FIGURE 16

Ratings for advice to prepare for delivery

50% of health professionals (46) rated “the advice we give women with a multiple pregnancy to prepare them for delivery” as “good”, 28% felt it was “adequate” and 29% felt it could be improved.

8.2 Preparing for postnatal care

81% of respondents (883) rated the advice they received from either a consultant/doctor or a midwife to prepare themselves for postnatal care. The remaining 19% said neither member of the team discussed preparation for postnatal care with them.

Discussions with midwives were rated slightly more highly (53% "very good" or "good") than those with consultants/doctors (50% "very good" or "good").

FIGURE 17
Ratings for advice on postnatal care

Roughly 20% of parents described this advice as "poor" or "very poor". We will see below (section 13) that people's experience of postnatal care was not always positive.

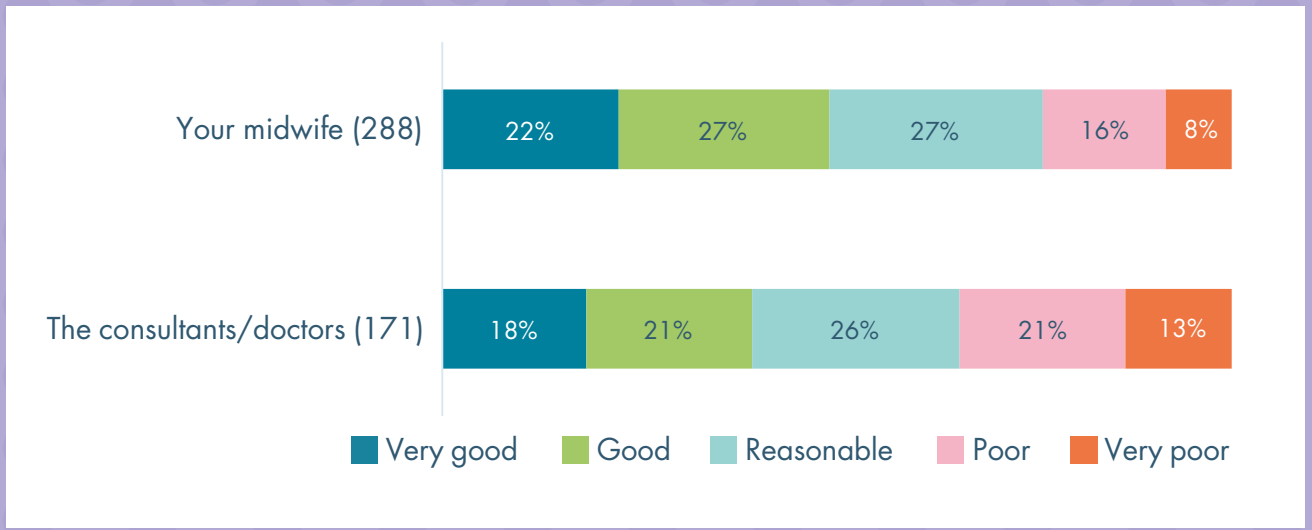
27% of health professionals (45) rated “the advice we give women with a multiple pregnancy to prepare them for postnatal care” as “good”, 22% felt it was “adequate” and 51% felt it could be improved.

8.3 Caring for babies after discharge from hospital

For those respondents whose babies did not require neonatal care (413), 28% did not receive advice for caring for their babies after discharge from either a midwife or a consultant/doctor. Those that did, rated the advice from midwives more positively than that from consultants or doctors with 49% stating the midwife's advice was "very good" or "good" compared with 39% for consultants/doctors. Also 34% of respondents rated the advice from consultants/doctors as "poor" or "very poor" compared with 24% for midwives.

FIGURE 18

Ratings for advice on caring for babies after discharge (those not requiring neonatal care)



For those respondents whose babies did require neonatal care (434), all respondents received advice for caring for their babies after discharge from either a midwife, a consultant/doctor or a neonatal nurse. 21% only received this advice from a neonatal nurse.

Advice from neonatal nurses was rated much more positively than that from consultants/doctors or midwives, with 80% stating the neonatal nurse's advice was "very good" or "good" compared with 53% for consultants/doctors and 48% for midwives.

FIGURE 19

Ratings for advice on caring for babies after discharge (those requiring neonatal care)

30% of health professionals (44) rated "the advice we give women with a multiple pregnancy to prepare them for caring for their babies after discharge..." as "good", 27% felt it was "adequate" and 44% felt it could be improved.

Some parents would agree that this advice could be improved.

> **[I was] discharged at midnight-ish with zero advice on what to expect when we got home." (DCDA twins)**

> **Whilst pregnant my care was good. Upon discharge I was sent home with some print outs about exercises post c-section but very little else. It's incredibly overwhelming coming home with two babies as a new mother and I felt incredibly lost and scared once home as to what we should even do." (DCDA twins)**

8.4 Preparing for possible admission to a neonatal unit

76% of respondents (916) rated the advice they received from either a consultant/doctor or a midwife to prepare themselves for a possible admission to a neonatal unit. The remaining 24% said neither member of the team discussed preparation for admission to a neonatal care unit with them. Discussions with midwives and consultants were rated similarly.

FIGURE 20

Ratings for advice on possible admission to a neonatal unit

Some qualitative feedback from parents also highlights room for improvement:

> **Nobody discussed the possibility of preterm birth other than saying "there is no reason they will be born early". Nobody discussed SCBU or NICU. They ended up in SCBU for 2 weeks and I had no idea why, I thought they might be seriously ill, but they were just early and small." (DCDA twins)**

> **I was not given any information to prepare me for what would happen after the birth, so it was all unknown. I didn't know anything about NICU so when my boys were born, they were just taken straight off me and I didn't see them for ages. It would've been nice if someone would've told me that that might happen!" (DCDA twins)**

> **I was told about the injections to help the lungs develop about an hour before I was given the first one. I was 'briefed' very quickly about delivery when I was being wheeled to the delivery room. Someone came in to talk to me about the neonatal unit in between contractions - about 30 minutes before giving birth to premature twins! This was ridiculous as I had absolutely no idea about neonatal care and what was ahead of us and obviously couldn't pay attention to someone discussing it with me while in labour! It would have been nice to know at least some of this a few weeks earlier." (DCDA twins)**

> **The neonatal staff were fantastic but I had never visited the unit or met staff. I was very shocked by the appearance of my babies as at no stage had I ever been prepared for this. I was sent home away from my babies for almost 5 weeks and I think I spent a time in shock. I was so unprepared for birth and what to expect afterwards." (TCTA triplets)**

51% of health professionals (47) rated "the advice we give women with a multiple pregnancy to prepare them for possible admission to a neonatal unit" as "good", 13% felt it was "adequate" and 36% felt it could be improved.

8.5 Introduction or visit to the neonatal unit before birth

Of those parents whose babies required neonatal care (494), 38% were offered the opportunity to visit the neonatal unit before birth.

42% of professionals (49) reported that women with a multiple pregnancy are "always" or "usually" offered the opportunity to visit the neonatal unit before giving birth. 18% said "about half the time", 35% "seldom" and 4% "never".

28% were introduced to the neonatal care team before birth although this rises to 37% when considering those respondents who ended up delivering their babies before 35 weeks.

38% of professionals (47) reported that women with a multiple pregnancy are "always" or "usually" introduced to the neonatal care team before giving birth. 26% said "about half the time", 32% "seldom" and 4% "never".

Those parents who mentioned having a tour of the neonatal unit found it useful, others would have valued the opportunity.

> **"The midwife team were superb in taking us in groups to the neonatal unit and explain the room and process for multiple births. This experience and knowledge was crucial in keeping us calm only a week later when the babies arrived at 28 weeks." (DCDA twins)**

> **"I requested a tour of the NICU through my midwife. I found this appointment extremely helpful and feel I should have automatically been offered it (as it was almost guaranteed that the babies would be admitted as they were triplets). Without that tour I would have felt clueless about what was ahead of us." (DCTA triplets)**

> **"Our babies arrived at 27+4. We hadn't seen a NICU or SCBU, so our first visit was to see our boys. I appreciate we were a minority in delivering this early but seeing a unit as early as possible would have been helpful." (DCDA twins)**

8.6 Other advice and education

Excluding those answering "I don't know":

- Two thirds of respondents (965) report being given advice about diet, lifestyle and nutritional supplements.

88% of health professionals (50) said parents expecting multiples were "always" or "usually" given advice about diet, lifestyle and nutritional supplements.12% said this "seldom" happened.

- 29% of respondents (898) said their hospital offered multiple-specific parent education sessions.

56% of health professionals (48) agreed with the statement "In my unit we offer multiple-specific parent education session(s)". 40% disagreed.

Some parents mentioned the role Twins Trust had played in preparing them, some others undertook a lot of research themselves.

> **"To be honest most of the information we got was from a Twins Trust antenatal course. Very limited information was given from the hospital. The Twins Trust website was a great source of information for us at an overwhelming time." (MCDA twins)**

> **"My husband and I attended a Twins Trust antenatal class. It was invaluable. I felt that expecting twins we didn't learn anything relevant at our local antenatal classes. It was at the Twins Trust class that we were made aware of the very real possibility of preterm birth. This really helped me when I went into labour at 27 weeks." (MCDA twins)**

> **"I received inaccurate information. I read the NICE guidelines and found out important information I should have received. The first consultant did not label my file as a multiple pregnancy so the midwife didn´t offer blood tests because they were following the pathway for singletons, I had to request them myself. I felt my babies were being put at unnecessary risk. I felt that I had to look into things myself or the babies would not get the care that they needed, which I found really frustrating." (DCDA twins, interview 2)**

8.7 Overall satisfaction with antenatal care

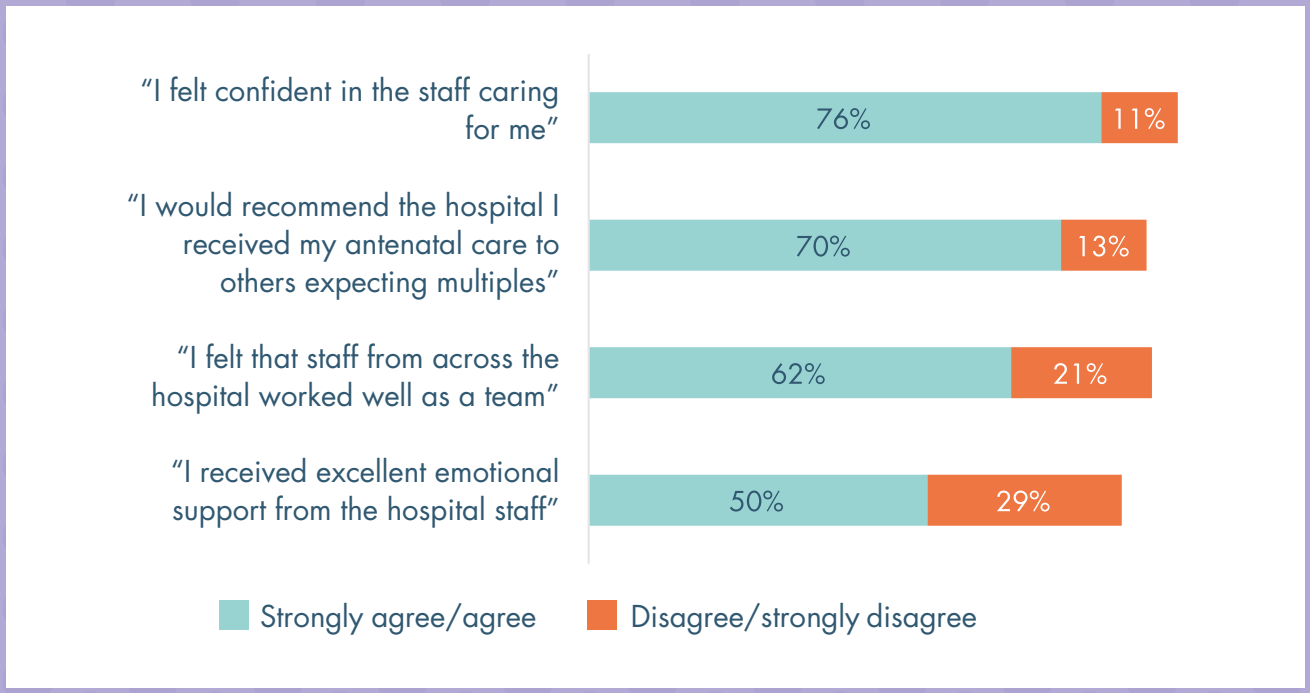
Respondents (924) were asked to agree or disagree with four statements relating to their overall experience of their antenatal care.

Over three quarters (76%) felt confident in the staff caring for them (with 11% disagreeing) and 7 out of 10 would recommend the hospital where they received their antenatal care to others (with 13% disagreeing).

6 out of 10 parents agreed that staff worked well as a team, though 2 out of 10 disagreed. Emotional support was the area that divided parents the most - 5 out of 10 agreed they had received excellent emotional support, but 3 out of 10 disagreed.

FIGURE 21

Overall satisfaction with antenatal care



Professionals surveyed were more confident about the levels of effective teamwork than parents, 85% (54) agreed with the statement "When it comes to multiple births, professionals from different disciplines work effectively as a team" (4% disagreed).

Adherence to QS46 by local maternity system

9.

Local Maternity Systems (LMS) were introduced in England in 2017 to plan the design and delivery of maternity services for populations of 500,000 - 1,500,000 people and realise the vision of "Better Births", the report of the National Maternity Review (2016). The aim of Better Births is to make maternity services across England "safer, more personalised, kinder, professional and more family friendly; where every woman has access to information to enable her to make decisions about her care; and where she and her baby can access support that is centred on their individual needs and circumstances."[21]

Responses to the parents' survey were analysed by LMS (alongside Scotland, Wales and Northern Ireland) with each receiving an adherence score for eight QS46 indicators[22] and one overall satisfaction indicator[23]. Details of the results for each indicator are in the Appendix.

The table below shows the average for each LMS across all nine indicators. This shows a wide variation of average compliance which ranges from 41% to 77%

Rank	LMS	Average %	Responses
1	Northumberland, Tyne & Wear & North Durham	77%	14
2	Northern Ireland	77%	23
3	Durham, Darlington, Tees, Hambleton, Richmondshire & Whitby	76%	7
4	SW London	75%	30
5	Surrey Heartlands	75%	17
6	Birmingham and Solihull	72%	19
7	NE London	72%	13
8	Devon	69%	15
9	Sussex and East Surrey	69%	24
10	Scotland	69%	76
11	West Yorkshire	67%	32
12	Gloucestershire	66%	11
13	Hertfordshire and West Essex	66%	17

(table contiued...)

Rank	LMS	Average %	Responses
14	Cheshire and Merseyside	66%	23
15	NC London	63%	23
16	Kent & Medway	63%	22
17	NW London	63%	16
18	Herefordshire and Worcestershire	62%	6
19	Coventry and Warwickshire	61%	15
20	Mid and South Essex	61%	21
21	Lancashire and South Cumbria	61%	18
22	Bath, Swindon and Wiltshire	60%	23
23	SE London	60%	31
24	Buckinghamshire, Oxfordshire and Berkshire West	60%	34
25	South Yorkshire and Bassetlaw	59%	21
26	Frimley Health	59%	28
27	Derbyshire	58%	10
28	Hampshire and the Isle of Wight	57%	22
29	Cambridgeshire and Peterborough	57%	23
30	Bristol, North Somerset, South Gloucestershire	57%	23
31	Wales	56%	33
32	Norfolk and Waveney	56%	17
33	Nottinghamshire	55%	24
34	Humber, Coast and Vale	55%	14
35	Greater Manchester	55%	35
36	Northamptonshire	54%	25
37	Staffordshire	53%	7
38	Suffolk and North East Essex	53%	10
39	Lincolnshire	52%	8
40	Cornwall & The Isles of Scilly	51%	5
41	Milton Keynes, Bedfordshire and Luton	51%	14
42	The Black Country	50%	13
43	Leicester, Leicestershire and Rutland	50%	12
44	Dorset	49%	7
45	Somerset	43%	4
46	West, North and East Cumbria	41%	4
47	Shropshire, Telford and Wrekin	41%	8

Changes to adherence to NICE guidelines over time

10.

It is possible to measure changes in adherence of some NICE guidelines over time by comparing the results of this survey with data collected in 2010/11 (before their introduction), 2013/14 and 2014/15[24].

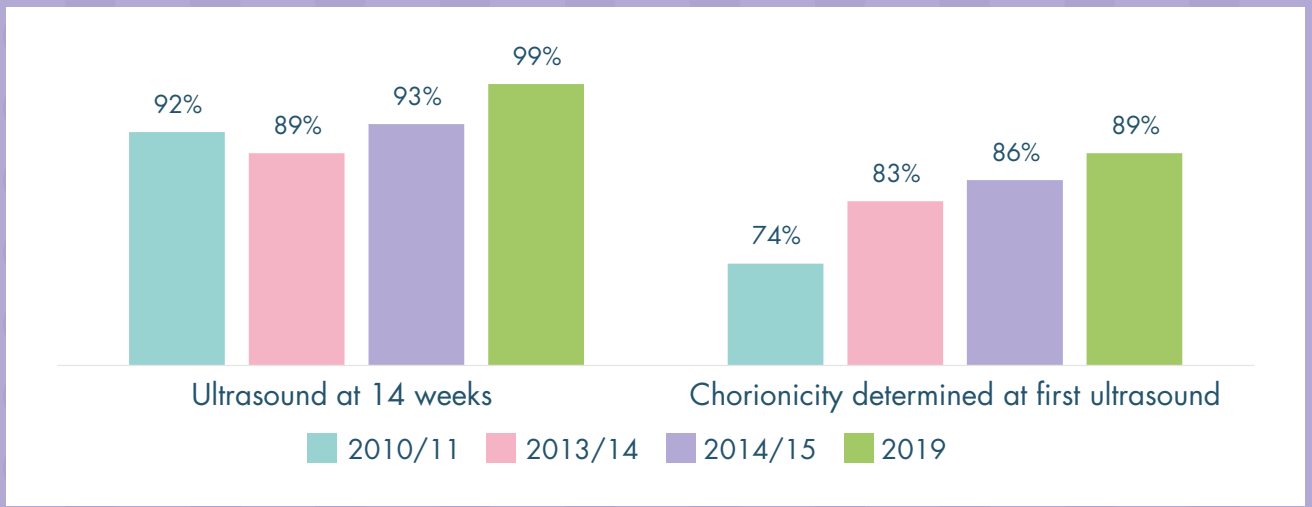
This analysis reveals positive increases with regards to the first ultrasound scan and the proportion of parents seeing specialist midwives and sonographers. The proportion of parents having the preterm labour and mode of delivery discussion has remained the same. The only indicator to show a decrease was the proportion of parents seeing a multiple specialist obstetrician.

10.1 First scan

The proportion of respondents having a scan by 14 weeks (an aspect of QS46.1) has increased to 98.7% in 2019 from 93.2% in 2014/15 (an increase of 6%). The proportion of those who have the chorionicity determined at that scan has also risen from 85.5% to 89.2% (an increase of 4%).[25]

FIGURE 22

First scan results over time

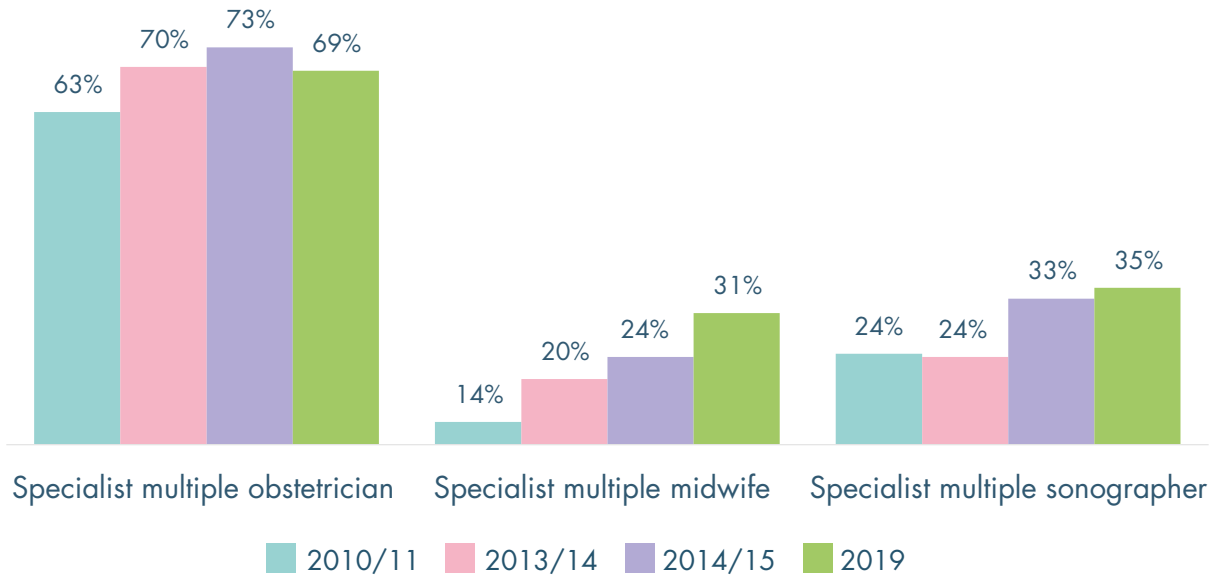


10.2 Seeing specialist staff

Although there have been increases in the proportion of parents seeing specialist midwives (up 29% from 2014/15) and sonographers (up 5%), the proportion of parents seeing specialist obstetricians has decreased by 5% since 2014/15.

FIGURE 23

Seeing specialist staff over time

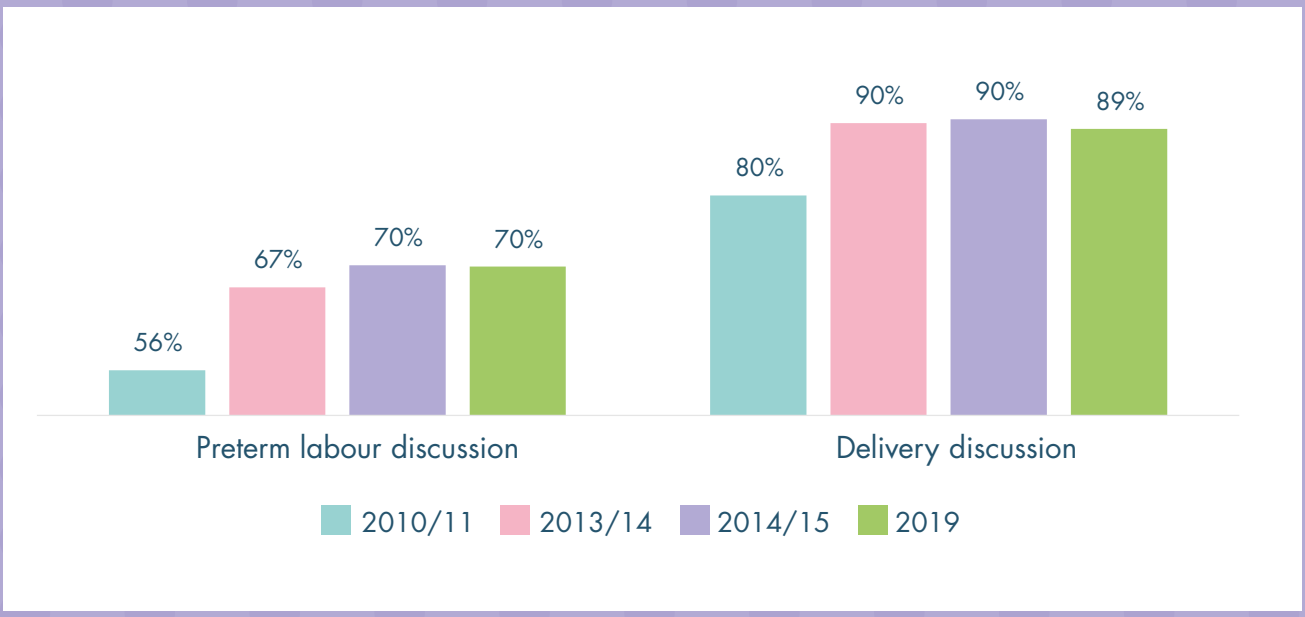


10.3 Preterm labour and delivery discussions

The proportion of parents having discussions with a member of their healthcare team about preterm labour or mode of delivery has remained similar to that of 2014/15 - both have shown very slight falls (the preterm labour discussion decreased by 0.3% and the mode of delivery discussion by 1.3%).

FIGURE 24

Discussions over time



Changes to satisfaction with advice over time

11.

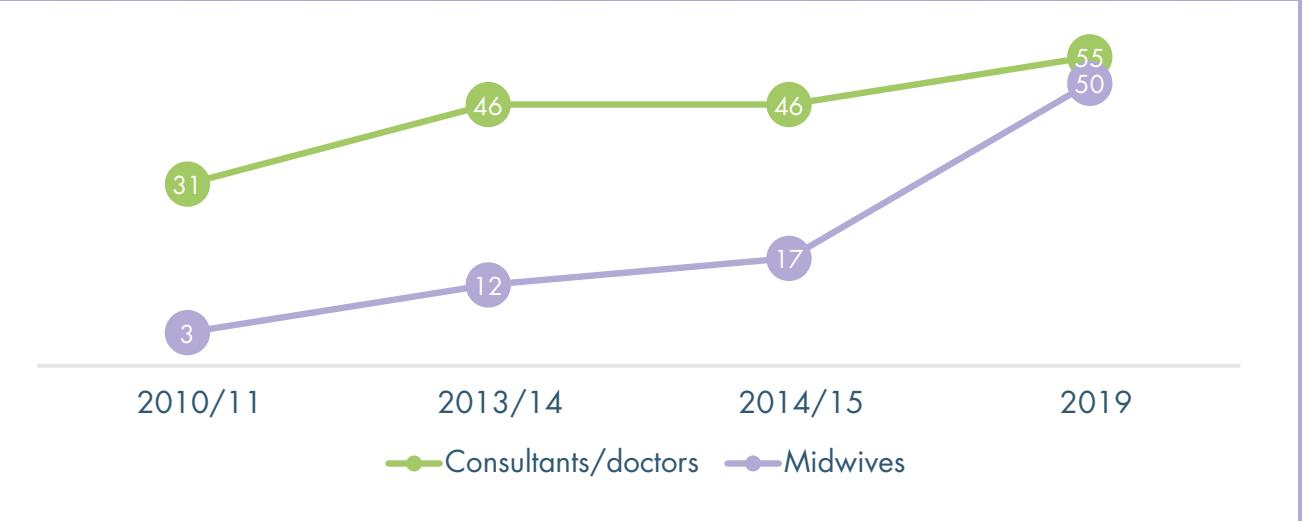
The following charts use "net satisfaction" to measure parental satisfaction with advice over time. Net satisfaction is the difference in percentage points between those that are positive about the advice and those that are negative. For example, if 50% are positive and 20% negative the net satisfaction is 30. If 25% are positive and 60% negative the net satisfaction is -35. The higher the net satisfaction the more people are positive about the statement and fewer are negative about it.

11.1 Advice to prepare for delivery

Net satisfaction with advice to prepare for delivery from midwives has increased significantly since 2014/15.

FIGURE 25

Advice to prepare for delivery (net satisfaction over time)

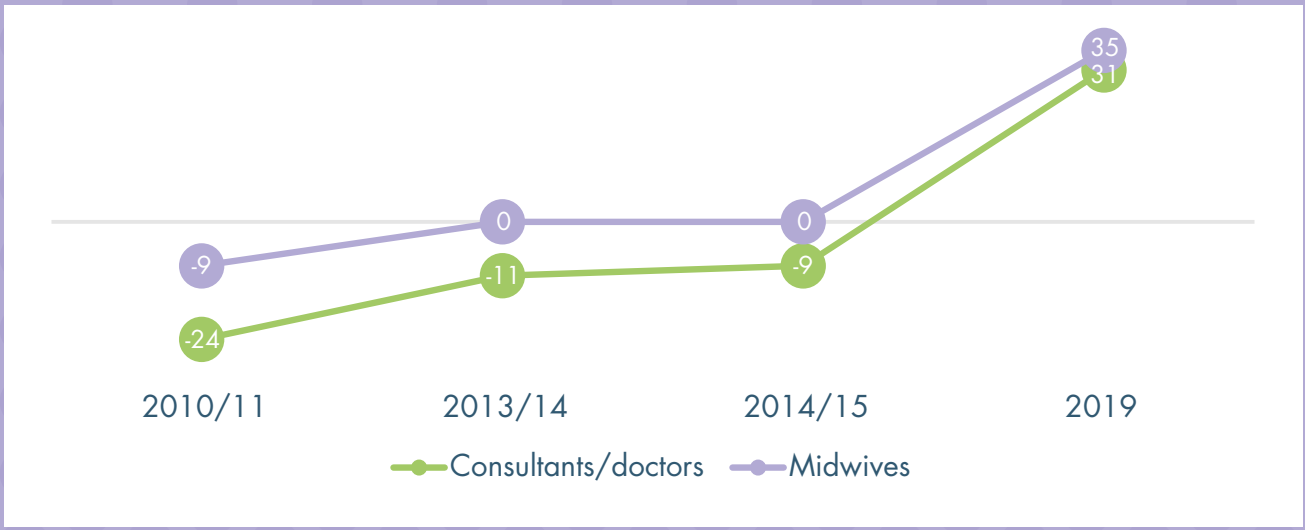


11.2 Advice to prepare for postnatal care

There have been significant increases in parents' satisfaction with the advice they receive to prepare for postnatal care. In previous years there was a net dissatisfaction with this advice (i.e. more people were negative about it than positive). In 2019 there are healthy net satisfaction levels (of over 30 percentage points) with advice from both consultants and midwives.

FIGURE 26

Advice to prepare for postnatal care (net satisfaction over time)

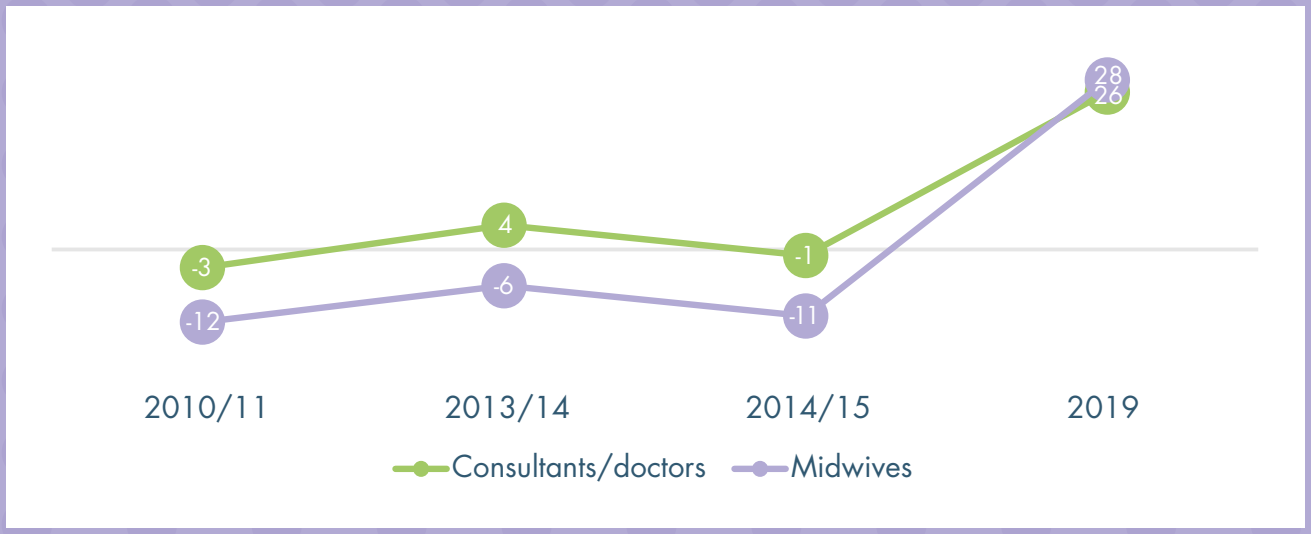


11.3 Advice to prepare for possible admission to a neonatal unit

As above, despite net dissatisfaction with this advice in previous years, many more parents are now satisfied with this advice from both consultants and midwives. For example, in 2014/15 26% of parents were positive about this advice from midwives, with 36% negative (a net disagreement of -11), however in 2019 50% were positive and 22% negative (a net agreement of 28).

FIGURE 27

Advice to prepare for possible admission to a neonatal unit (net satisfaction over time)

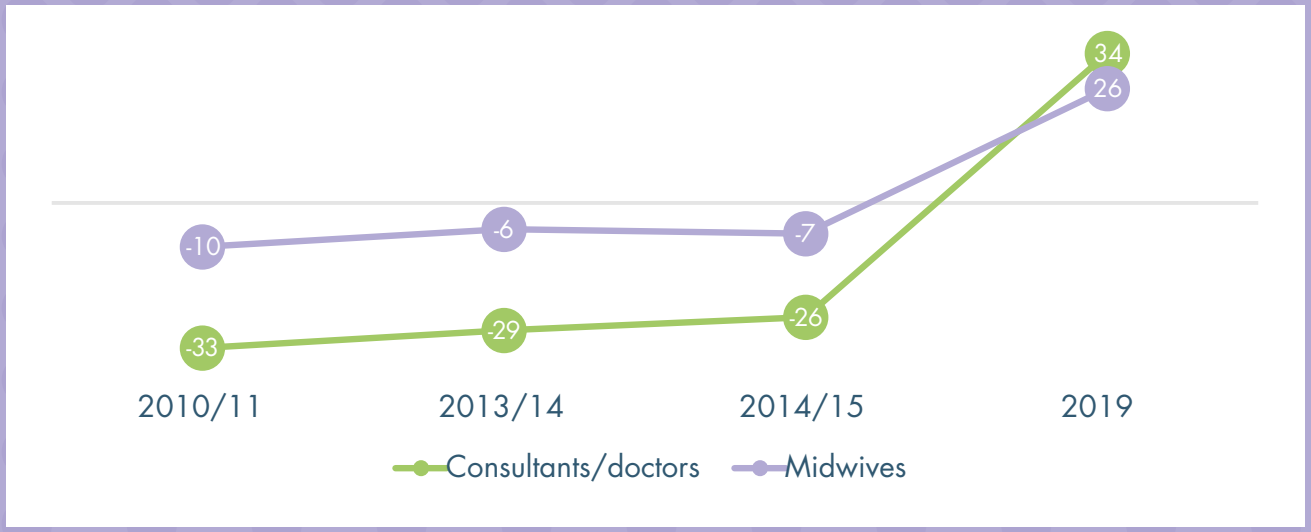


11.4 Advice to prepare for caring for the babies after discharge

The increases in satisfaction are mirrored in the advice to prepare for caring for babies after discharge. The increase in parents' positive opinions of advice from consultants/doctors is striking. In 2014/15 21% of parents were positive about this advice, with 47% negative (a net disagreement of -26), however in 2019 53% were positive and 19% negative (a net agreement of 34).

FIGURE 28

Advice to prepare for caring for the babies after discharge (net satisfaction over time)



Intrapartum care

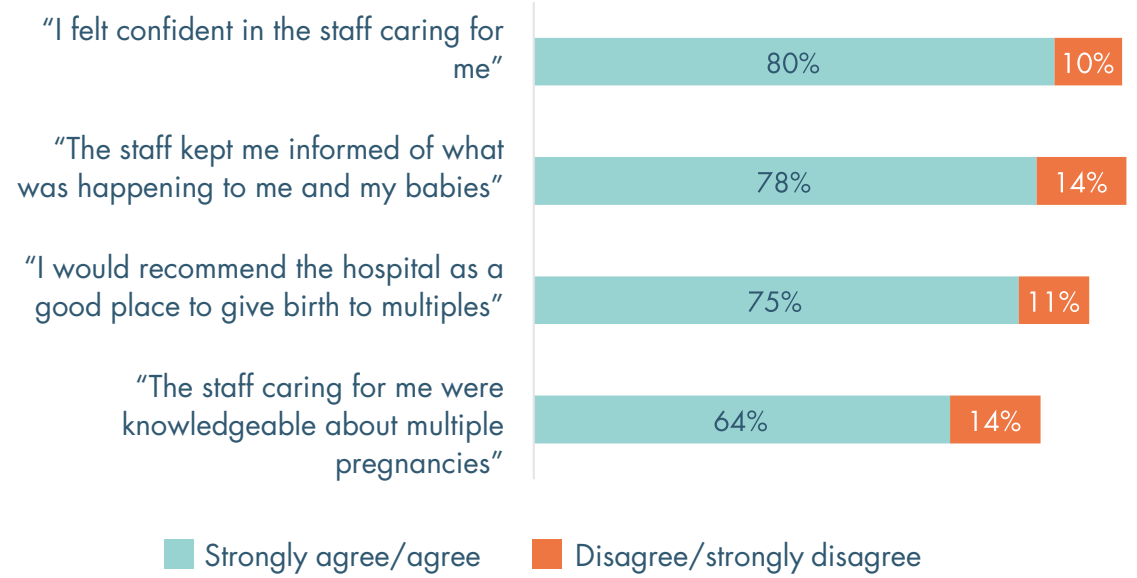
12.

Respondents (913) were asked to agree or disagree with four statements "about the care they received when giving birth."

8 out of 10 respondents felt confident in the staff caring for them (with 1 in 10 disagreeing). Three quarters would recommend the hospital as a good place to give birth to multiples (with 11% disagreeing). Respondents were positive about being kept informed of what was happening (78% agreed, 14% disagreed) and about whether they felt the staff caring for them were knowledgeable about multiple pregnancies (64% agreed, 14% disagreed)

FIGURE 29

Overall satisfaction with intrapartum care



Postnatal care

13.

Although not explicitly covered in the survey, parents' experience of postnatal care was commented on frequently. Some had positive feedback:

> **"We stayed in hospital for a week after the births. We had our own room. The staff were supportive without being intrusive. Lots of advice on breastfeeding and caring for the babies. The NHS is amazing." (DCDA twins)**

> **"I don't remember much with me being so unwell, but I do remember being looked after by an amazing team, I felt 100% supported and looked after along the way and my partner and I couldn't have asked for better care!" (DCDA twins)**

> **"The midwives were so helpful. I stayed 4 days and each midwife I met made me feel at ease and cared for. They taught me so much about how to look after my babies - it gave me the confidence I needed when I left. I couldn't praise them enough." (MCDA twins)**

However, more parents recounted more difficult experiences:

> **"[The] postnatal ward was shocking. I just felt like they wanted us out. I suffered severe complications during birth and afterwards, the care was appalling. The neonatal care was excellent however." (DCDA twins)**

“The level of care and consistency of the team for the antenatal care was phenomenal. Once the babies arrived, we defaulted from fetal medicine back into the normal protocol. The level of care drastically reduced here with many midwives out of their depth on any questions relating to multiples. Each time I asked they said, “I don't know, will find out” and never came back.” (MCDA twins)

“I was forgotten about! My twins stayed in SCBU for three weeks whereas I was discharged after two nights. I didn't see a midwife or health visitor until a month after birth when the babies were discharged. No midwife ever came to my house, I had to struggle all the way to a children's centre on my own with newborn twins. To leave a new mum without postnatal care for a month was negligent of the hospital.” (DCDA twins)

“The days in the maternity ward were a nightmare. I remember it like a torture. The senior midwife in the night shift complained about having too many sets of twins, she told me she was going to call somebody to tell her not to send her anymore. We were too much work, she said. They managed to make my birthing experience a bad dream. I remember the day my twins were born as the best but also the worst day of my life thanks to all of them.” (DCDA twins)

“Postnatal care in the hospital was horrible, I was accused of starving my twins by insisting I should be trying to breastfeed them, I was ignored when I had issues and they just tried to push me into using formula. I got an infection from the operation and was again ignored and ended up in an ambulance back at the hospital one week after birth, during this time I was also ignored, no help was offered, no explanation or information given about what had happened.” (DCDA twins)

In several cases, clear and accessible breastfeeding advice was found to be lacking:

> **"There was no twin specific advice on breastfeeding, the infant feeding lead was very difficult to access and did not come back to see me despite requesting. Every medical professional assumed I would formula feed and was surprised or even advised against breastfeeding." (DCDA twins)**

> **"I had no breastfeeding support and consequently failed to breastfeed my twins which was heart-breaking." (DCDA twins)**

> **"Special care and postnatal ward were disjointed, and it was difficult to understand what was going on. There was a clash in terms of breastfeeding, which was strongly encouraged by midwives whereas the special care staff were more concerned about the quantities the babies were taking no matter how that happened, the approach was not as holistic." (MCDA twins, interview 10)**

> **"The midwives made me feel like I was such a bad mum, like obstructive and not wanting to do the right thing for my child... I was just shocked they were completely not listening to anything I said."**
>
> **(DCDA twins, interview 7)**

Neonatal care

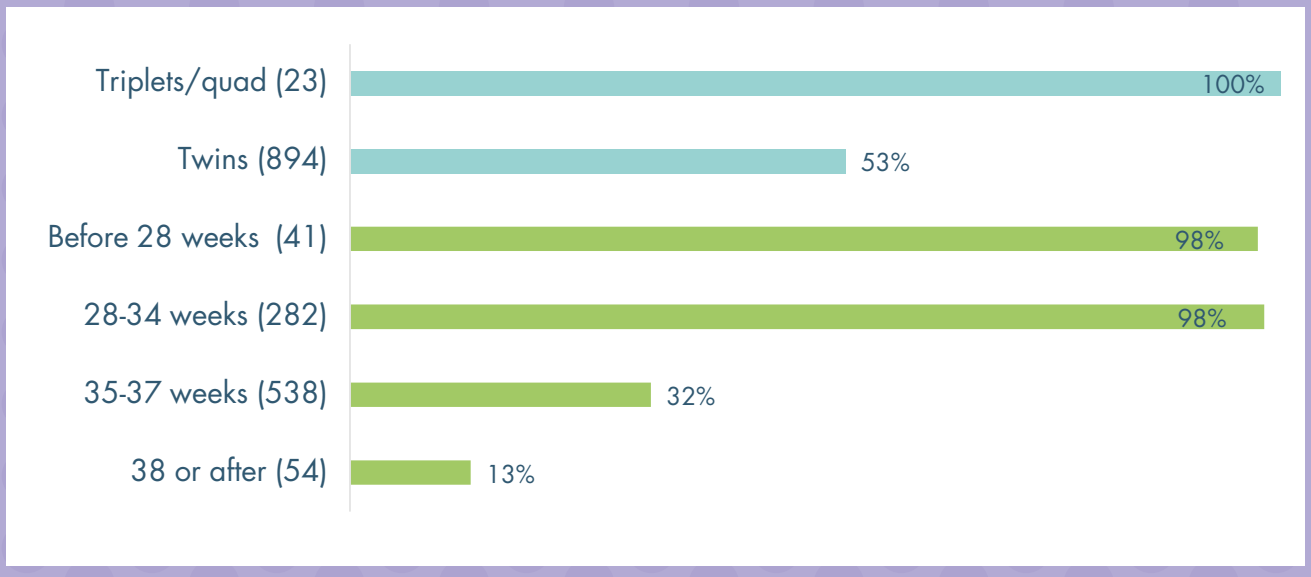
14.

14.1 Those requiring neonatal care

In total 55% of respondents (916) had a baby or babies that required neonatal care. Triplets and those born before 34 weeks were the most likely to need neonatal care.

FIGURE 30

Admission to neonatal care by twins/triplets and gestation



Respondents were asked if their baby or babies spent time in one of the following types of neonatal unit.

Unit	Description
Neonatal Intensive Care Unit (NICU)	Providing the highest level of care to babies requiring the most medical intervention at birth, NICUs support babies who need surgery, ventilation, CPAP (help with breathing when born less than 28 weeks), or who have a very low birth weight.
Local Neonatal Unit (LNU)	For babies who need short term intensive care support following apnoeic attacks, continuous positive airway pressure (CPAP) or tube feeding. Sometimes babies can be transferred to an LNU from a Neonatal Intensive Care Unit (NICU).
Special Care Unit (SCU) or Special Care Baby Unit (SCBU)	For babies who need monitoring of their breathing or heart rate, additional oxygen, tube feeding phototherapy (for neonatal jaundice) or recovery from other care. Sometimes babies can be transferred to a SCU or SCBU from a Neonatal Intensive Care Unit (NICU) or a Local Neonatal Unit (LNU).

Of those respondents experiencing neonatal care, just over three quarters had babies admitted to NICU (representing 700 babies) and/or SCBU (640 babies). Only a third had babies in an LNU (274 babies).

14.2 Staying together

For every unit type, most respondents were able to stay with their baby or babies in the same hospital. The proportion was lowest in NICUs.

FIGURE 31

Proportion of respondents able to stay with babies by unit type

In the vast majority of cases the hospital automatically offered to keep the babies together (88% for NICU, 96% for LNU and 93% for SCBU). Parents rarely had to argue for places for all their babies (5% for NICU, 2% for LNU and SCBU).

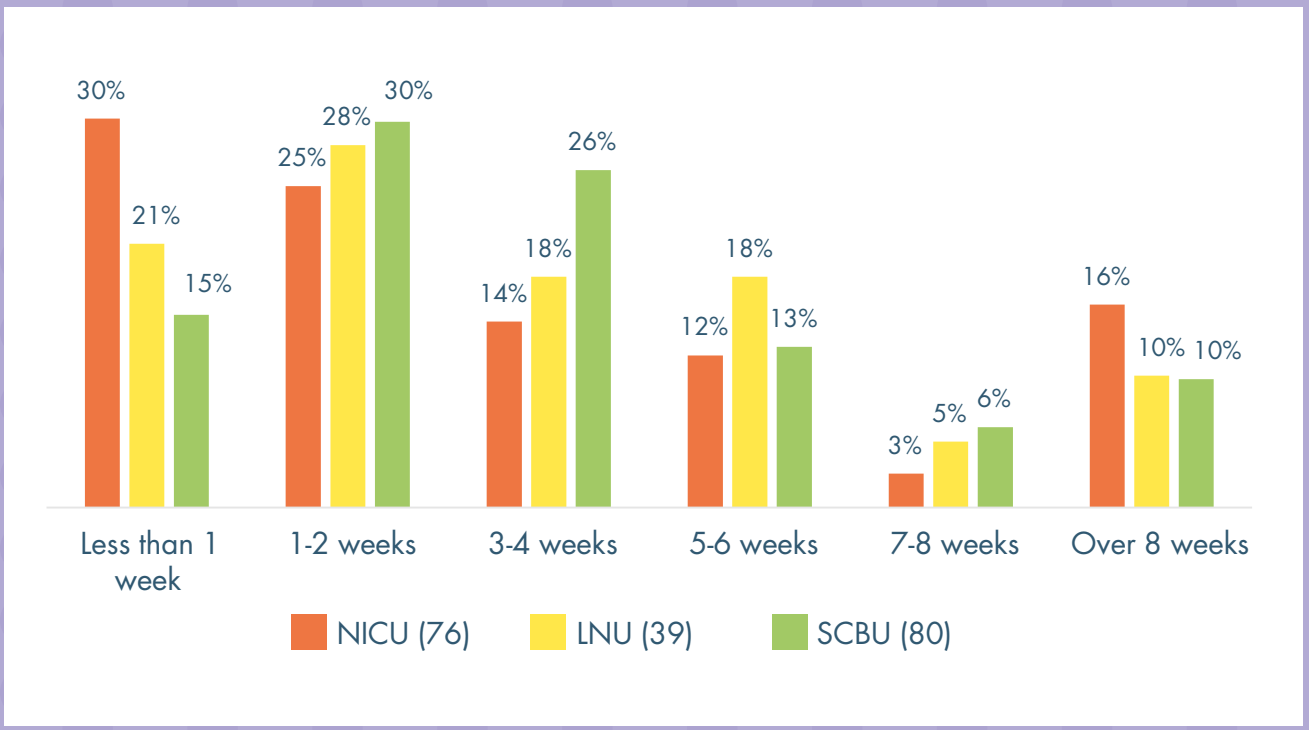
The main reasons given as to why families were not able to stay together were that there were not enough places available and that the mother was discharged (and usually lived nearby).

Reason for not being able to stay together	NICU (77)	LNU (38)	SCBU (76)
Not enough places were available to keep us all together	42%	32%	38%
Mother discharged	17%	37%	38%
Clinical needs meant that the relevant treatments and services could not be provided at a single hospital	10%	11%	8%
One baby healthy/less ill	10%	11%	4%
Not offered	5%	5%	4%

For those respondents not able to stay together, periods of separation range considerably. For each type of unit roughly 7 out of 10 parents are separated for four weeks or less. 1 in 6 of those parents not able to stay with their child in NICU are separated for over eight weeks.

FIGURE 32

Periods of separation for those not able to stay with the baby/babies in hospital



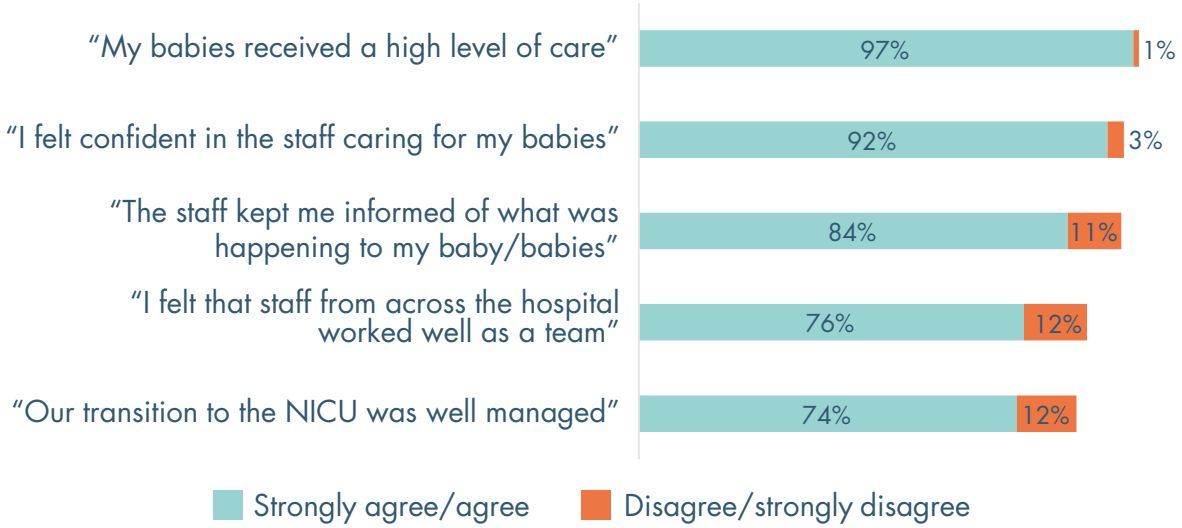
14.3 Overall satisfaction with NICU care

Respondents (372) were asked to agree or disagree with five statements about the care their baby/babies received in a NICU.

All the statements received many more positive responses than negative ones. 97% of respondents felt their babies received a high level of care (with only 1% disagreeing) 92% felt confident in the staff caring for their babies (with 3% disagreeing). Of all the statements the one concerning transition was agreed with least often (72%).

FIGURE 33

Overall satisfaction with care in NICU



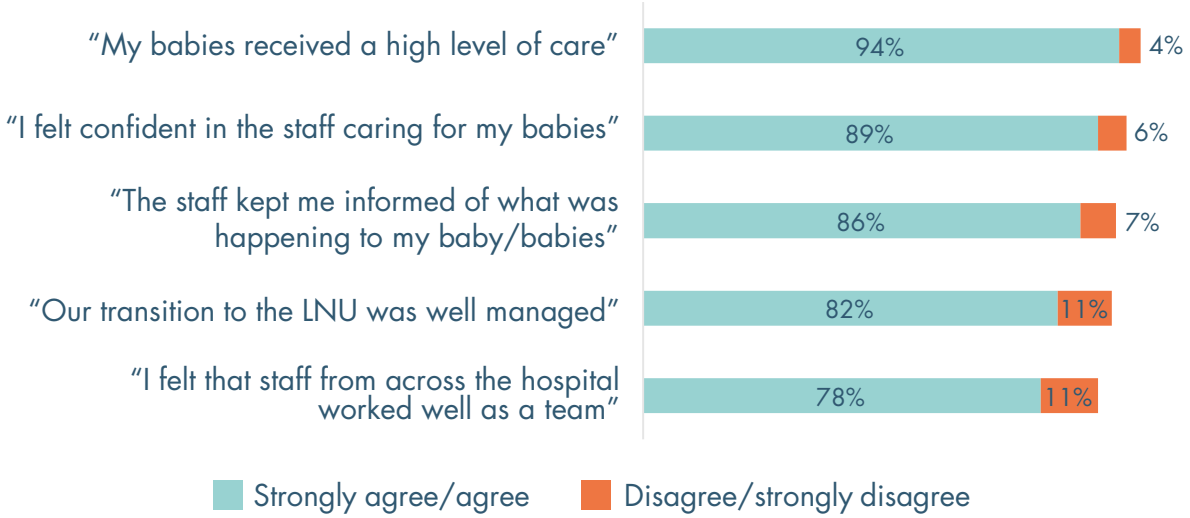
14.4 Overall satisfaction with LNU care

Respondents (143) were asked to agree or disagree with five statements about the care their baby/babies received in an LNU.

As with NICUs, all the statements received many more positive responses than negative ones. Statements relating to level of care and confidence in staff were agreed with most, with low levels of disagreement. Statements relating to transition and teamwork were agreed with slightly less and disagreed with slightly more, though even here roughly 8 out of 10 agree and 1 out of 10 disagrees.

FIGURE 34

Overall satisfaction with care in LNU



14.5 Overall satisfaction with SCBU care

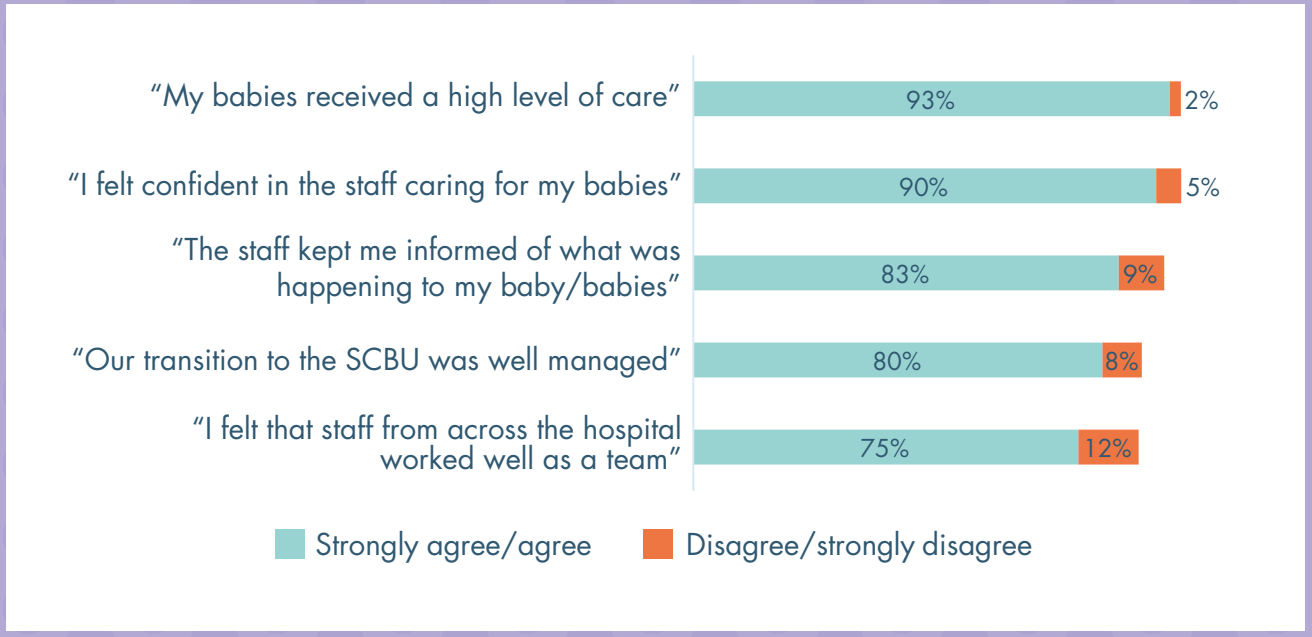
Respondents (327) were asked to agree or disagree with five statements about the care their baby/babies received in a SCBU.

The findings mirror those for the other units, with all statements receiving many more positive responses than negative ones. Parents are especially positive about levels of care and confidence in staff, again transition and teamwork attract slightly less agreement.

44% of health professionals (45) rated "the transition of women with multiple babies after delivery into NICU or SCBU" as "good", 11% felt it was "adequate" and 45% felt it could be improved.

FIGURE 35

Overall satisfaction with care in SCBU



In qualitative feedback neonatal care is often described as "excellent" and "outstanding":

> **My girls were admitted to SCBU as they lost a lot of weight after birth, they were cared for by the SCBU staff for almost 2 weeks. If it wasn't for that unit they wouldn't be here." (DCDA twins)**

> **The neonatal staff were amazing they kept us informed all the way I could see the babies any time or call any time... emotionally they were there when I needed to speak to someone." (DCDA twins)**

> **The neonatal care we received was of the highest quality. The nurses looking after my baby let us know every progress made, every setback, they were very knowledgeable and very caring to me my babies and partner. We felt comfortable and confident. They made a difficult situation so much easier." (MCDA twins)**

“The support we received from the midwives in the hospital was world class. After the delivery of our twins, the midwives were our biggest support unit as our twins were separated (one in NICU, one with mum). We cannot thank/praise their support and care enough.” (MCDA twins)

Being able to understand the ways of working in neonatal units was a recurring theme with parents' reporting mixed experiences:

“We knew we were going to go there [to a neonatal unit] so I did a full tour, I met all the doctors and nurses, and I knew what to expect. The best thing was that at the start of each shift for the babies' care, the nurse would come to my ward and plan the day with me -whether I was going to breastfeed, etc I felt free to go and see my eldest for a couple of hours knowing that we had agreed who was going to be there. It was amazing, that it was so organised. That really helped because we could get into a routine. Shifts took place always at the same time of day so everyone knew when things would happen.” (DCDA twins, interview 6)

“Visiting hours were strange. You'd think partners would be allowed to stay with the mum and the baby for as long as they wanted to but that isn't the case. I also didn't feel I could see my son whenever I wanted because I couldn't take my daughter with me. I felt prepared to have both babies together in the unit, but it was a shock that they ended up in different places, I wasn't prepared for that. The visiting hours of both places were not aligned so I only saw my son's doctor once because I couldn't be there, and my partner wasn't allowed to be there either. Therefore, I missed out on information on my son's progress during doctors' rounds. It was all very disjointed.” (DCDA twins, interview 9)

> **In special care they seem to forget that you've never been there before and they assume much more knowledge on your part than you have, and coming out of an emergency caesarean you are not really 'with it'. It was a steep learning curve and I wasn't prepared at all." (DCDA twins, interview 10)**

> **It would be good to have some of the information printed, a little handy guide of 'this is what happens at the neonatal unit', because some people might forget some of the details that they are given before the birth." (DCDA twins, interview 6)**

Some parents reported struggling to perform a parental role. In some cases, this extended to a feeling that they were not welcome and that the babies did not feel like theirs:

> **There was little opportunity to 'parent' my twins while in the NICU. I felt like I was in the way a lot of the time and I didn't feel very involved in their care. Therefore, when the twins were discharged it was a huge and steep learning curve with no support other than a health visitor available." (Twins, type unknown)**

> **Counselling support in all NICU hospital units would be great, it's an awful experience, and I would go back to my ward or home once discharged and would cry so much and had no support from midwives when on the ward, they left me to it, just shrugged their shoulders. I had no one to turn to. Also, the babies felt like they were not mine, I had to ask if I can pick my babies up, when caring for my babies like nappy changes or changing clothes I felt being watched. I know how to care for my babies, I understand the nurses were doing their job, but give parents a little more space to be parents to their babies. If the parents need help, then the nurses are there on hand to help." (DCDA twins)**

Others mentioned a disconnect between neonatal units and maternity wards:

> **Whilst I was in hospital, I felt stressed and upset, as I wanted to be with my babies, but at times I had to go back to the ward to have obs done and for medication, the thing that hurt me is I would get back to the ward and they would tell me off, I said you know where I am, I'm with my babies! The same with NICU staff, if I was on the ward receiving care myself, the staff of NICU would do the same asking me where I have been etc... I became very emotional and stressed." (DCDA twins)**

> **I couldn't walk after my C-section so needed to arrange a wheelchair each time I wanted to visit him, and I was also caring for my daughter. The NICU team were requesting me to be there with my son at times for feeds or to support him with tests which clashed with the routine of feeding and pumping that the ward team were wanting me to establish for my daughter. The two teams did not communicate at all for the first few days. No one seemed to be responding when I said I did not know how to physically manage it all. I felt at times like I was losing my mind with the sleep deprivation, my own recovery, the emotion of my son's diagnosis, and the feeling that I was torn between both children, not giving either of them what they needed." (DCDA twins)**

> **The separate teams made me feel very torn in that they didn't seem to work together. As I was still a patient on maternity and visited neonatal, I was chastised for visiting neonatal then told off for not visiting my babies enough." (MCDA twins)**

The challenge of neonatal transfers, and having to become accustomed to a new unit with new processes, was also mentioned by some parents:

> **My twins had to be transferred to another hospital straight after delivery, as there were not enough neonatal cots available for them at the current hospital. I was informed of this on the operating table as they were preparing me for my caesarean. This was very distressing." (DCDA twins)**

> [The babies were moved to a unit of the same level]
> **They didn´t need to move to have better care, they moved to have the same care... the whole thing when you dig into it is about funding, it has absolutely nothing to do with care whether it is at the time or in the future... I had to keep going to one hospital for my care, while the babies were in another, which was very inconvenient and there was no medical reason for it... when you are completely new to the whole hospital environment you just about got yourself understanding how everything works, and then you are moved and it's a completely new game with new staff and a new set of rules... when you are a brand new mum with twins that you are worried about, it is horrific." (DCDA twins, interview 1)**

> **Discussions about transfers were stressful, but the staff were compassionate and caring and also sensible." (DCDA twins)**

> **My twins were transferred to another NICU soon after birth, and then a SCBU at yet another hospital a day later but the staff handled it brilliantly and my babies were really well cared for. Sometimes NICU units are full through no fault of the staff and it is much safer for babies to be transferred to another unit, rather than them being cared for in a unit that is too full. The staff who handle the ambulance transfers are also brilliant and provide excellent care for the journey." (DCDA twins)**

Conclusions

15.

15.1 Care practice does not always enable parents to make birth planning decisions

"Better Births", the report of the 2016 National Maternity Review aimed to make maternity services across England "safer, more personalised, kinder, professional and more family friendly; where every woman has access to information to enable her to make decisions about her care; and where she and her baby can access support that is centred on their individual needs and circumstances."

This research presents a mixed picture regarding the extent to which parents expecting multiples can make informed decisions about their care and their birth plan. Being informed relies on having useful discussions with the right people. Three out of ten parents did not see (or were not sure that they saw) either an obstetrician, midwife or sonographer specialising in multiple births.

Furthermore, although two thirds of parents rate the advice they received from consultants, doctors and midwives to prepare them for delivery positively, 35% did not discuss when and how they wanted to deliver their babies before 32 weeks and, even when a discussion did take place, qualitative responses reveal that consultants' preferences can have a stronger influence on birth planning decisions than those of parents. Some parents feel that they were not listened to and were powerless to challenge staff.

15.2 More could be done to prepare parents for premature babies

If quality discussions with health professionals don't always take place, and plans are made without effective parental input, it is difficult for some parents to feel prepared for what might happen. This is most evident when it comes to preparation for preterm birth and neonatal care. This research has revealed that, although parents may have prepared themselves for having twins, many parents do not feel prepared for having premature babies.

Only 28% of parents had a discussion with professionals about the risks and signs of preterm labour before 24 weeks. 24% of parents reported health professionals did not discuss possible admission to a neonatal unit with them. Of those that did have the discussion roughly half rated the advice they were given positively. Furthermore 36% of professionals feel this advice could be improved. Visits to neonatal units and introductions to staff help parents to prepare, and are positively received, however both parents and professionals report that these visits do not always routinely take place.

15.3 Continuity of care supports effective decision making

Continuity of care supports informed decision making and preparation for future eventualities. Just over half of parents said that they saw the same consultant and midwife all or most of the time during their antenatal care. This continuity creates the opportunity for more in-depth conversations about concerns or options to take place between parent and professionals. Those who saw different professionals each time report having to describe their situation each time - limiting the effectiveness of the discussion. Reduced continuity also increases the risk of the parent receiving inconsistent and conflicting advice.

15.4 Parents' experience of care may not be as positive as professionals may think

Although the sample was small, professionals were consistently more positive about adherence to NICE guidelines than parents. This may be explained by timing - professionals will have been referring to current processes and parents may have been recalling processes that have been superseded. However, this is an interesting disparity and one that might be explored further with a larger professional sample.

However, professionals are less positive than parents when it comes to the provision of advice. Over half of professionals felt that the advice given to women to prepare for postnatal care could be improved and 44% felt the advice given to women to prepare them to care for their babies after discharge could be improved. More research may be needed to explore what improvements professionals feel might be made in these areas.

15.5 The rate of improvement in adherence to NICE guidelines is slow

Although there has been improvement in adherence to some NICE guidelines in the last four years - progress is slow. Apart from a 29% increase in the proportion of parents seeing a specialist multiple midwife (from 24% to 31%), other increases were small. The proportions of parents having discussions with professionals around preterm labour and delivery options remain at 2014/15 levels.

15.6 There is still a wide variation in adherence to NICE guidelines across the country

There is a wide disparity in the adherence to QS46 statements (and overall satisfaction with antenatal care) between Local Maternity Services in England (and also comparing LMS areas in England with Scotland, Wales and Northern Ireland). Considering an average adherence across nine indicators, the scores amongst Local Maternity Services with ten or more parent responses ranged from 50% to 77%.

Recommendations

16.

This research will be of interest to Local Maternity Systems, individual trusts and maternity teams looking to implement NHS England's Saving Babies Lives Care Bundle which explicitly recommends using the NICE guidance for multiple pregnancies. Considering these findings, Twins Trust makes the following recommendations.

16.1 Parents

- Download the Twins Trust multiple antenatal proforma to find out what appointments, scans and tests you should receive during your pregnancy.
- Ensure that the risks and signs of pre-term labour are discussed with you by 24 weeks. Ask if a tour of the neonatal unit is possible.
- Ask if you will be seen by a team that specialises in multiple births.
- Ensure that the mode of delivery (the way that you prefer and is safe to give birth) is discussed with you by 28 weeks.
- Ask for help on the ward if you need it.
- Before you are discharged ask who to contact if you have any questions.
- Find out what breastfeeding support is available at your hospital.

16.2 Health professionals

- Support multiple-birth parents in your care with unbiased information and genuine opportunities to discuss their birth preferences from 24 weeks and by 28 weeks, including offering support to prepare families for pre-term birth and possible neonatal admission. Enable them to make informed decisions, as highlighted by both the 2019 NICE guideline NG137 and the National Maternity Review: Better Births, particularly concerning their delivery and postnatal care.
- Work alongside the maternity safety champions in your trust to identify changes required to improve the care of multiple pregnancies.
- Contact Twins Trust now for resources and practical support. Through our Maternity Engagement Project, we can help develop an action plan and provide practical help to drive change within your hospital.

16.3 NHS England and NHS Improvement

- Share the key findings of this research and ensure it is understood amongst Local Maternity Systems and maternity safety champions that the support offered through Twins Trust's Maternity Engagement project is a key contributor to meeting the Ambition, especially improvements in continuity of carer among a vulnerable group, as set out in the Long-Term Plan.
- Ensure that Local Maternity Systems are aware that twin and triplet pregnancies continue to be explicitly recognised in commissioning frameworks, tariff requirements, and care bundles.
- Ensure that there is significant investment in postnatal support for families, including mental health support and infant feeding support as set out in the Long-Term Plan, and that transitions from antenatal to postnatal, neonatal and community care are improved, as recognised in the National Maternity Review: Better Births.

16.4 NHS Resolution

- Check that trusts applying for the Maternity Incentive Scheme understand that in order to meet the twin specific requirements of Element Two (risk assessment, prevention and surveillance of pregnancies at risk of fetal growth restriction) of the Saving Babies Lives Care Bundle (2019), they need to implement the standards set out in NICE QS46 or a local variation, and that Twins Trust can support them to do that.

16.5 Care Quality Commission

- Ensure the inspection framework for antenatal care continues to focus on care for multiple pregnancies being provided in line with NICE QS46.
- Check feedback to trusts highlights the Twins Trust resources and support that are available to help them make improvements to their care practice where appropriate.

16.6 Health Education England

- Provide CPD opportunities for teams to improve their skills and knowledge available in the care of multiple pregnancies and make them aware that Twins Trust provides free CPD to all healthcare professionals involved in multiple pregnancies.

16.7 Department of Health and Social Care

- Ensure Twins Trust's Maternity Engagement Project receives ongoing support both to reach new units and to monitor outcomes achieved by participating units over a longer period.
- Acknowledge that Twins Trust's Maternity Engagement Project is a key contributor to achieving the Better Births ambition, especially improvements in continuity of carer among a vulnerable group, as set out in the Long-Term Plan.

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6. This survey was conducted between January and April 2019 when NICE guidance recommended the dating scan take place between 11 weeks and 13 weeks 6 days, therefore adherence has been assessed on this basis. Since then, the guidance has been updated to recommend that this scan takes place between 11 weeks 2 days and 14 weeks 1 day.
7. This survey was conducted between January and April 2019 when NICE guidance recommended the dating scan take place between 11 weeks and 13 weeks 6 days, therefore adherence has been assessed on this basis. Since then, the guidance has been updated to recommend that this scan takes place between 11 weeks 2 days and 14 weeks 1 day.
8. This survey was conducted between January and April 2019 when discussions about timing and mode of delivery were recommended before 32 weeks of pregnancy, therefore adherence has been assessed on this basis. Since then the guidance has been updated to recommend that this discussion takes place between 24 and 28 weeks of pregnancy.
9. In addition, there was one father of triplets and one mother of quads.
10. Tamba www.twinstrust.org/let-us-help/pregnancy-and-birth/preparing-for-birth/birth-plans.html Accessed 24/7/19
11. This is a minimum - 62 respondents answered 38 weeks or more, these have been treated as 38 weeks for the purpose of calculating mean averages.
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20. This calculation includes those who may have given birth before 32 weeks as there is an expectation that the conversation should still have taken place before 32 weeks if the mother was likely to give birth earlier.
21. NHS England, Maternity Transformation Programme www.england.nhs.uk/mat-transformation Accessed 27/07/19
22. QS46 1, 3 (obstetrician), 3 (midwife), 3 (sonographer),4,5,7 and 8
23. Agreement that they would recommend the hospital where they received their antenatal care to others
24. The results for the 2019 exclude those answering "I don't know". It is not known how these were treated in previous years.
25. The 2019 question asked, "Was the chorionicity and amnionicity of your babies determined at the first ultrasound?" so those who had the chorionicity determined but not the amnionicity may have answered "no". For the 2019 result those answering "I don't know" and "I had an earlier scan" have not been included.

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Appendix

QS46 adherence and overall satisfaction by LMS

Results by indicator divided into approximate thirds. Green indicates the top third, yellow the middle third and pink the bottom third. Figures in red indicate fewer than 10 responses.

Top third | Middle third | Bottom third | RED = fewer than 10 responses

	QS1 - Chorionicity and amnionicity confirmed at scan before 14 weeks	QS3.1 Seen by specialist obstetrician	QS3.2 Seen by specialist midwife	QS3.2 Seen by specialist sonographer	QS4 - Had a care plan that specified the timing of antenatal appointments	QS5 - Monitored for complications according to chorionicity and amnionicity (not MCMA twins)	QS 7 - Discussion by 24 weeks about the risks, signs and symptoms of preterm labour and possible outcomes of preterm birth.	QS 8 - Discussion by 32 weeks about the timing of birth and possible modes of delivery	"I would recommend the hospital I received my antenatal care to others expecting multiples"	Average adherence across nine indicators
Northumberland, Tyne and Wear and North Durham	73%	79%	86%	80%	93%	100%	50%	50%	86%	77%
Northern Ireland	78%	88%	64%	50%	100%	100%	38%	88%	84%	77%
Durham, Darlington and Tees, Hambleton, Richmondshire and Whitby	86%	71%	50%	60%	100%	100%	43%	88%	88%	76%
SW London	86%	90%	75%	62%	90%	94%	24%	66%	87%	75%
Surrey Heartlands	93%	83%	56%	70%	89%	100%	38%	61%	83%	75%
Birmingham and Solihull	79%	94%	60%	47%	65%	100%	32%	80%	89%	72%
NE London	93%	80%	15%	54%	85%	100%	50%	86%	75%	71%
Devon	94%	73%	20%	31%	93%	100%	60%	81%	69%	69%
Sussex and East Surrey	96%	75%	38%	31%	79%	100%	33%	87%	77%	69%
Scotland	90%	91%	49%	39%	68%	99%	36%	70%	75%	69%
West Yorkshire	86%	75%	56%	56%	69%	97%	31%	68%	62%	67%
Gloucestershire	100%	58%	0%	43%	91%	100%	40%	82%	83%	66%
Hertfordshire and West Essex	94%	63%	47%	40%	71%	100%	31%	78%	71%	66%
Cheshire and Merseyside	71%	78%	61%	45%	71%	95%	45%	54%	71%	66%

(table continued...)

	QS1 - Chorionicity and amnionicity confirmed at scan before 14 weeks	QS3.1 Seen by specialist obstetrician	QS3.2 Seen by specialist midwife	QS3.2 Seen by specialist sonographer	QS4 - Had a care plan that specified the timing of antenatal appointments	QS5 - Monitored for complications according to chorionicity and amnionicity (not MCMA twins)	QS 7 - Discussion by 24 weeks about the risks, signs and symptoms of preterm labour and possible outcomes of preterm birth.	QS 8 - Discussion by 32 weeks about the timing of birth and possible modes of delivery	"I would recommend the hospital I received my antenatal care to others expecting multiples"	Average adherence across nine indicators
NC London	85%	78%	44%	56%	65%	95%	17%	68%	61%	63%
Kent & Medway	91%	62%	64%	33%	76%	90%	33%	52%	65%	63%
NW London	100%	63%	22%	27%	87%	100%	29%	76%	60%	63%
Herefordshire and Worcestershire	80%	50%	17%	60%	67%	100%	33%	83%	67%	62%
Coventry and Warwickshire	93%	69%	40%	17%	64%	93%	29%	60%	87%	61%
Mid and South Essex	94%	55%	36%	47%	68%	100%	38%	55%	57%	61%
Lancashire and South Cumbria	83%	78%	19%	47%	72%	100%	28%	58%	61%	61%
Bath, Swindon and Wiltshire	95%	76%	26%	13%	64%	96%	29%	61%	84%	60%
SE London	88%	63%	19%	52%	75%	83%	25%	66%	71%	60%
Buckinghamshire, Oxfordshire and Berkshire West	83%	81%	15%	38%	79%	88%	27%	65%	65%	60%
South Yorkshire and Bassetlaw	95%	48%	14%	13%	85%	100%	29%	64%	81%	59%
Frimley Health	100%	56%	11%	15%	81%	89%	25%	72%	78%	59%
Derbyshire	80%	50%	44%	25%	60%	90%	60%	50%	60%	58%
Hampshire and the Isle of Wight	81%	57%	26%	23%	82%	83%	19%	74%	68%	57%
Cambridgeshire and Peterborough	79%	74%	24%	33%	60%	96%	21%	80%	45%	57%
Bristol, North Somerset, South Gloucestershire	100%	76%	5%	25%	52%	90%	22%	74%	67%	57%
Wales	84%	56%	15%	31%	78%	97%	22%	62%	62%	56%
Norfolk and Waveney	83%	65%	0%	14%	88%	100%	29%	71%	56%	56%

(table continued...)

	QS1 - Chorionicity and amnionicity confirmed at scan before 14 weeks	QS3.1 Seen by specialist obstetrician	QS3.2 Seen by specialist midwife	QS3.2 Seen by specialist sonographer	QS4 - Had a care plan that specified the timing of antenatal appointments	QS5 - Monitored for complications according to chorionicity and amnionicity (not MCMA twins)	QS 7 - Discussion by 24 weeks about the risks, signs and symptoms of preterm labour and possible outcomes of preterm birth.	QS 8 - Discussion by 32 weeks about the timing of birth and possible modes of delivery	"I would recommend the hospital I received my antenatal care to others expecting multiples"	Average adherence across nine indicators
Nottinghamshire	80%	54%	17%	29%	54%	96%	27%	67%	76%	55%
Humber, Coast and Vale	100%	67%	7%	18%	77%	93%	27%	60%	50%	55%
Greater Manchester	78%	67%	17%	16%	74%	97%	22%	56%	72%	55%
Northamptonshire	87%	59%	0%	22%	58%	90%	23%	62%	80%	53%
Staffordshire	88%	63%	13%	29%	33%	100%	33%	50%	71%	53%
Suffolk and North East Essex	82%	64%	27%	25%	75%	89%	18%	50%	44%	53%
Lincolnshire	100%	38%	0%	29%	63%	100%	25%	56%	63%	52%
Cornwall & The Isles of Scilly	80%	20%	20%	20%	33%	100%	60%	80%	50%	51%
Milton Keynes, Bedfordshire and Luton	87%	40%	27%	15%	58%	80%	23%	60%	67%	51%
The Black Country	100%	50%	7%	25%	50%	85%	29%	47%	62%	50%
Leicester, Leicestershire and Rutland	100%	54%	8%	10%	55%	93%	18%	57%	58%	50%
Dorset	86%	50%	0%	14%	63%	100%	17%	63%	50%	49%
Somerset	100%	50%	0%	0%	60%	100%	20%	0%	60%	43%
West, North and East Cumbria	80%	40%	0%	25%	50%	100%	0%	25%	50%	41%
Shropshire, Telford and Wrekin	86%	50%	0%	0%	38%	100%	11%	38%	44%	41%
Total	**88%**	**69%**	**31%**	**35%**	**73%**	**95%**	**30%**	**66%**	**70%**	

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