Maternity Services and Multiple Births

A joint report by NCT and the Twins and Multiple Births Association

Background

Multiples make up approximately 3% of babies born each year in the UK with numbers rising significantly over the past 20 years. This is due largely to the increased use of assisted conception techniques such as IVF. Recent figures show that multiples accounted for 7.2% of all stillbirths in England and Wales in 2014 and 6.6% of stillbirths in Scotland. In England and Wales, 10.5/1000 multiple birth babies are stillborn, compared to 4.5/1000 singleton babies. In Scotland 8.5/1000 multiple birth babies are stillborn, compared to 3.9/1000 singleton babies. This means the stillbirth rate for multiples is twice as high as the stillbirth rate for singletons in England, Wales and Scotland. Neonatal death rates in both Scotland and England and Wales are also significantly higher for multiples. In 2013 in England and Wales, neonatal deaths occurred in 11.5/1000 multiple births, compared with 2.4/1000 singleton births. In the same year in Scotland, neonatal deaths occurred in 13.8/1000 multiple births compare with 2.0/1000 singleton births. The risk of preterm birth is also higher for multiples, occurring in at least 50% of twin pregnancies, and twins are six times more likely to have cerebral palsy than a singleton baby.

These figures clearly show that outcomes for multiple pregnancies compare poorly to singletons. National Institute for Health and Care Excellence (NICE) antenatal care guidelines and quality standards, introduced in 2011, aimed to tackle these inequalities and improve quality of care and outcomes for multiple pregnancies. Studies have shown that stillbirth rates, caesarean rates, late admission to neonatal units and patient safety incidents are all reduced as a result of setting up and delivering services in accordance with the NICE guidance. Unfortunately NICE guidance is still not fully or equally implemented across the UK (only fully implemented in 10-18% of units) and there is no specific guidance for intrapartum care for multiples. Therefore, outcomes for multiple pregnancies and patient satisfaction with care remain low. This report seeks to measure parent experiences of maternity care and how well NICE guidelines for multiple pregnancies are being implemented across the UK. In particular, it looks at variation by home nation of the UK and variations in compliance over time, with a particular focus upon the experiences of parents in Scotland.

The Survey

This report describes the findings of the Maternity Services survey distributed by Tamba to parents of multiples in the UK between April and July 2015. The survey covered a variety of topics including place of birth, quality of antenatal and postnatal care, neonatal care arrangements, feeding support, sleeping arrangements and input from Tamba and the Multiple Births Foundation (MBF).

The Sample

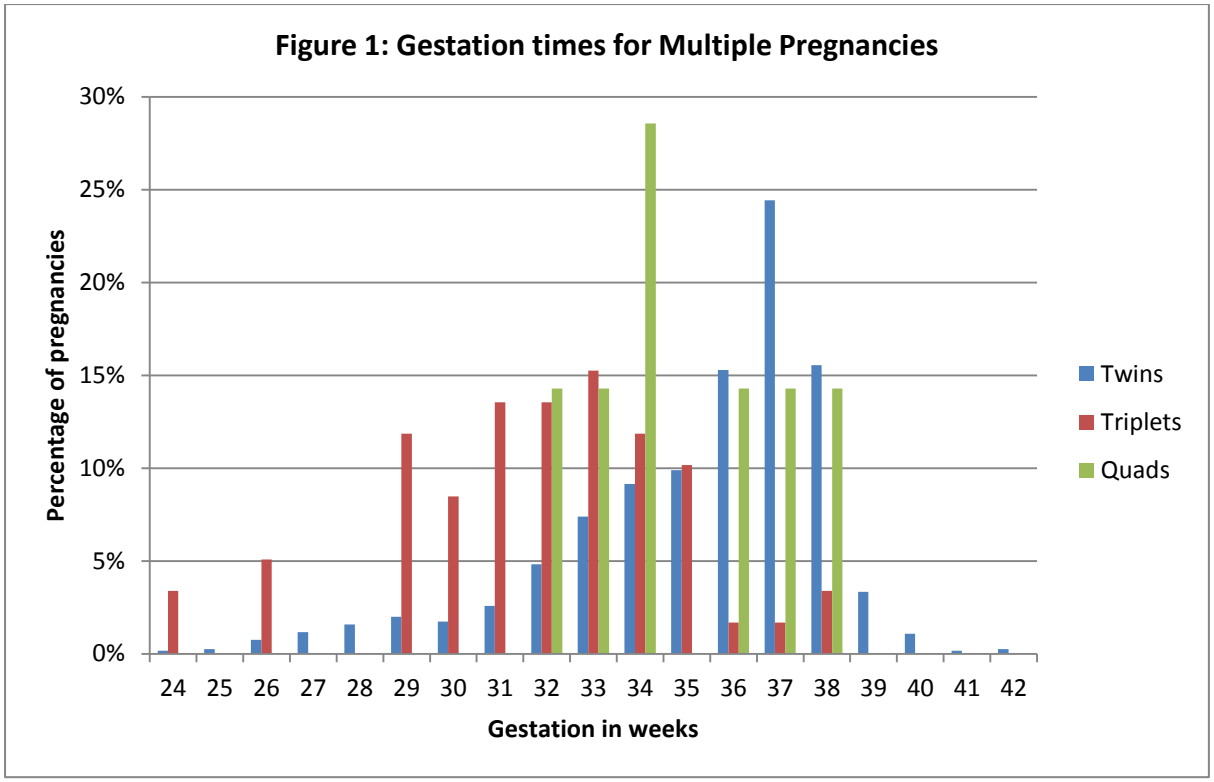
The survey was completed by a total of 1338 respondents. 95.1% were mothers of twins, 3.9% mothers of triplets and 0.2% mothers of quads and 2.4% were fathers. 35.5% had given birth within the last year, 58.5% within the last two years and 91.4% within the last six years. 73.7% had given birth in England, 14.4% in Scotland, 7.6% in Wales and 4.3% in Northern Ireland. In total 185 parents from Scotland responded to the survey. The majority of analysis is based upon the full UK sample. However, where significant differences occur in Scotland these are highlighted in the relevant sections. A more in-depth analysis of variation by Scottish region and over time can also be found in the later sections of the report.

Gestation

Survey results show that gestation times for multiple pregnancies are considerable shorter than the average of 40 weeks for singleton pregnancies. Average gestation times given by the NHS are 37 weeks for twin pregnancies and 33 weeks for triplets[1]. The figures from parents completing the survey are slightly lower at 35.3 weeks for twins and 31.8 weeks for triplets.

Distribution of gestation times for twins, triplets and quads are shown in Figure 1 below. The graph shows that for twin births frequency rises until a peak of 37 weeks, when 24.4% of twins are born. Frequency falls sharply after 38 weeks with only 4.8% of twins born after 39 weeks and just 0.4% after 41 weeks. Triplets births peak at 33 weeks (15.3% of pregnancies) and fall sharply after 35 weeks, with no triplet births recorded after 38 weeks of pregnancy. Numbers for quadruplet births are too low to draw accurate data (n=7) but show all births occurring between 32 and 38 weeks with an average gestation of 34.8 weeks.

Rates of preterm birth (pre 37 weeks) for multiples are considerable higher than the UK average of 8%[2]. Survey data shows that 55.2% of twins and 94.9% of triplets were born pre 37 weeks, with 15% of twins and 41.9% of triplets born before 32 weeks (very preterm).

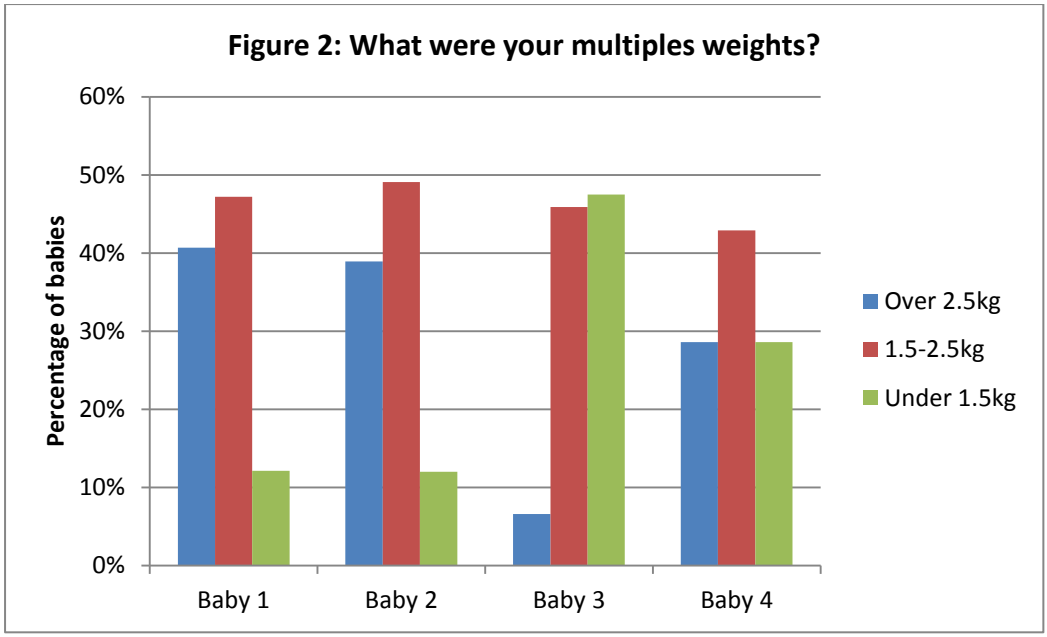


Birth

Due to the high likelihood of premature birth and birth complications amongst multiples, 52.8% of parents completing the survey had an elective birth (meaning they were delivered on a pre-planned date and were either medically induced or delivered through caesarean section) whilst 47.2% had a spontaneous birth. This compares with national averages for all births of 39.1% elective and 60.9% spontaneous birth in 2013/14[3].

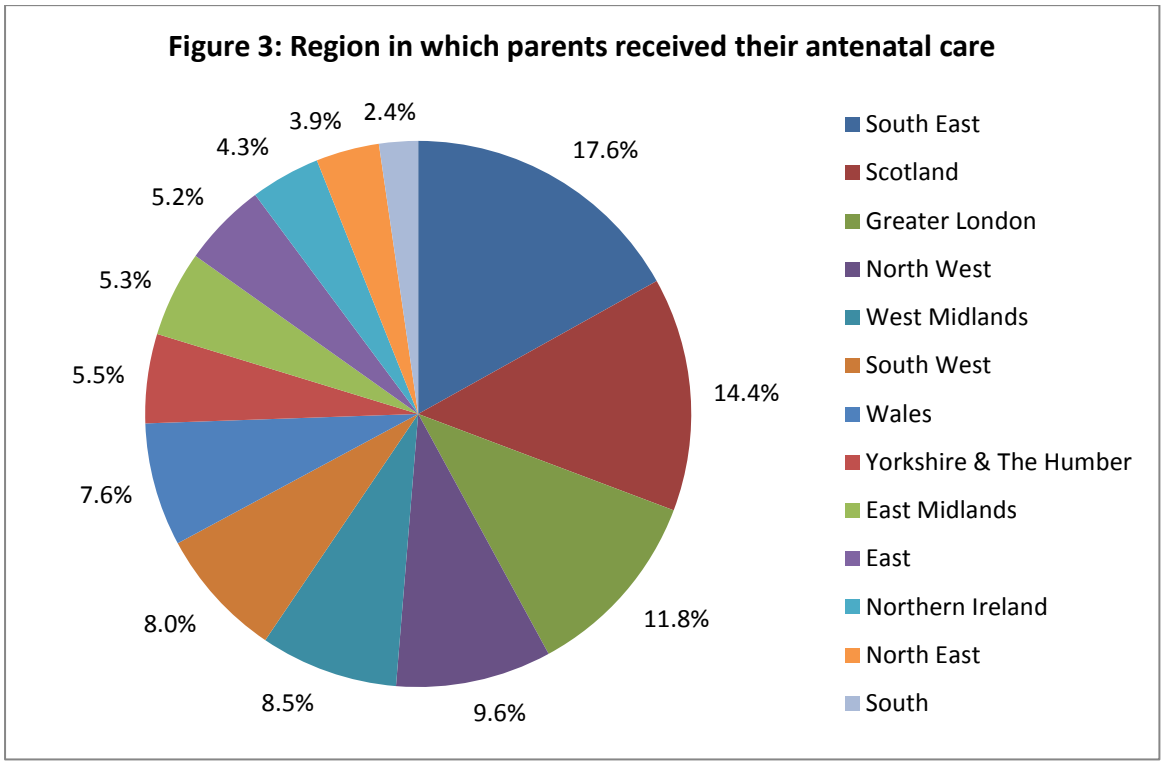
Rates of caesarean birth are also considerably higher in multiple pregnancies, estimated at around 60% by the NHS for twin pregnancies[1] compared with the national rate of 26.2%[3]. The survey reported that 68.1% of all births were by caesarean and 31.9% were vaginal. For twins these rates were 66.9% caesarean and 33.1% vaginal, whilst for triplets rates were much higher at 88.1% caesarean and 11.9% vaginal. Overall caesarean rates in Scotland were slightly higher than the national average, at 74.5%.

Multiple births are also much more likely to have low birthweight babies (under 2.5kg) or very low birth weight babies (under 1.5 kg), particularly for second or subsequent babies and as the numbers of multiples increase. Nationally low birth rate babies account for 7% of live births[4]. The survey shows that 60.9% of multiples were born under 2.5kg and 12.8% were born under 1.5kg. Figure 2 below shows that for twins, both babies are generally above 1.5kg at birth, with the second twin tending to be slightly smaller than the first. For triplets the third baby is very unlikely to be over 2.5kg (6.6%) and much more likely to have a very low birth weight (47.5%). Data for quadruplets seems a little anomalous, though this may be due to the very small numbers involved (n=7).



Region

Parents received antenatal care in all regions of the UK. Numbers were unevenly distributed with the South East (17.6%), Scotland (14.4%), Greater London (11.8%) and North West (9.6%) accounting for approximately half of all care (see Figure 3 below). This is most likely due to relative size and population density of these regions.



Certain hospitals across the UK had relatively higher proportions of parents giving birth to multiples or receiving their postnatal care there. These tended to be located in large population centres or be regional referral units to which mothers of multiples or babies requiring neonatal care may be referred. Four hospitals (Addenbrookes, Royal Infirmary of Edinburgh, Royal Victoria Infirmary and University Hospital of Wales) saw over 2% of cases, whilst a further 24 of the 318 hospitals listed saw over 1% of cases.

Antenatal care

NICE antenatal care guidelines for multiple pregnancies introduced in 2011 list eight quality standards[5] (see below) intended to improve quality of care and outcomes for multiple pregnancies. The current survey sought to measure many of these indicators through questions about mothers' antenatal care. Figures in this section show results compiled from all those completing the survey, whilst subsequent sections seek to measure differences in NICE compliance over time and by region.

NICE Quality Standards (QS46): Multiple Pregnancy: Twin and Triplet Pregnancies

Statement 1. Women with a multiple pregnancy have the chorionicity and amnionicity of their pregnancy determined using ultrasound and recorded between 11 weeks 0 days and 13 weeks 6 days.

Statement 2. Women with a multiple pregnancy have their foetuses labelled using ultrasound and recorded between 11 weeks 0 days and 13 weeks 6 days.

Statement 3. Women with a multiple pregnancy are cared for by a multidisciplinary core team.

Statement 4. Women with a multiple pregnancy have a care plan that specifies the timing of appointments with the multidisciplinary core team appropriate for the chorionicity and amnionicity of their pregnancy.

Statement 5. Women with a multiple pregnancy are monitored for foetal complications according to the chorionicity and amnionicity of their pregnancy.

Statement 6. Women with a higher-risk or complicated multiple pregnancy have an obstetrician from a tertiary level foetal medicine centre involved in their care.

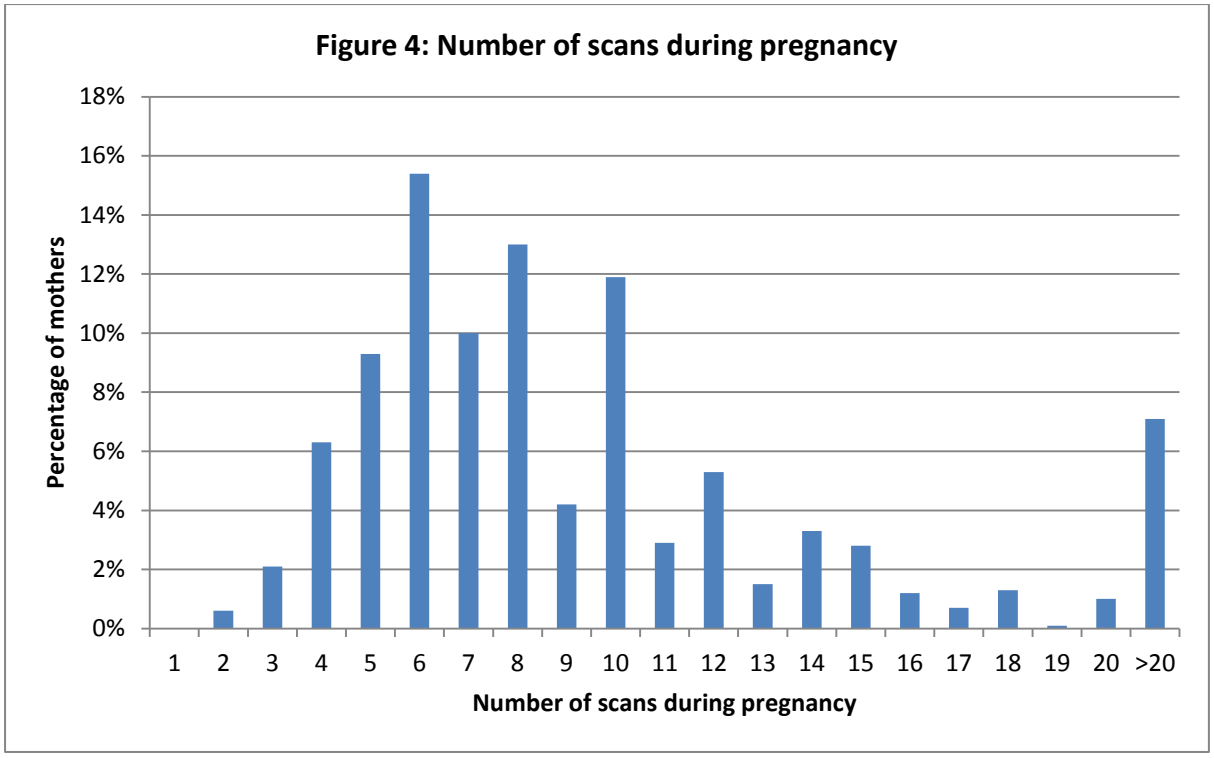
Statement 7. Women with a multiple pregnancy have a discussion by 24 weeks with one or more members of the multidisciplinary core team about the risks, signs and symptoms of preterm labour and possible outcomes of preterm birth.

Statement 8. Women with a multiple pregnancy have a discussion by 32 weeks with one or more members of the multidisciplinary core team about the timing of birth and possible modes of birth so that a birth plan can be agreed.

Ultrasound

The NICE guidelines on multiple pregnancy state that all women should be offered an ultrasound scan by 14 weeks, at which the foetuses should be labelled and the chorionicity and amnionicity of their pregnancy determined. 92% of mothers surveyed had been given an ultrasound scan by 14 weeks and 81.6% had had the chorionicity and amnionicity of their pregnancy determined (with a further 4.9% unsure whether this had been done). Of these 27.5% had a monochorionic pregnancy (where both babies are dependent on a single shared placenta) and 69.1% had a dichorionic pregnancy (where each baby has its own placenta). 78.6% of parents had the chorionicity and amnionicity of their babies explained to them, most commonly by their obstetrician or sonographer.

UK hospitals routinely offer women at least two ultrasound scans during their pregnancy, the first 'dating scan' at around 12 weeks and a second 'anomaly scan' between 18 and 21 weeks, with further scans performed where required. Multiple pregnancies are monitored much more closely, with extra growth scans offered at regular intervals, depending upon the chorionicity, complexity of the pregnancy and the number of multiples. The majority of mothers included in the study (81.7%) had at least 6 scans during their pregnancy, with 39.1% having over 10 and 7.1% of mothers having more than 20 scans. The distribution is shown in Figure 4 below:



Screening, Testing and Advice

Pregnant women in the UK (with the exception of Northern Ireland due to their strict abortion laws) are routinely offered a screening test for Down's Syndrome between 10-14 weeks of pregnancy. This generally involves an ultrasound measurement of nuchal translucency and a blood test. Mothers receiving a higher-risk result are offered further diagnostic testing. 81.7% of mothers surveyed were offered screening for Down's Syndrome, although some stated they were only offered the ultrasound testing, as blood testing would give a false positive result with multiple pregnancies. Only 52.1% of mothers who had received a high risk result said that the options and implications of proceeding to a diagnostic test (which can include a possible risk of miscarriage) had been discussed with them, showing a clear need for further education in this area.

General advice regarding diet, lifestyle and nutritional supplements during pregnancy is given at the first antenatal appointment and throughout the pregnancy as required. Only 60.6% of women in the study reported being given general advice during pregnancy, though it is possible that this advice may have been given very briefly or forgotten. NICE guidelines recommend that full blood counts are performed at 20-24 weeks gestation and again at 28 weeks to screen for anaemia and other blood problems. 76.4% of women said that they had received these blood tests, with a further 10.9% unsure whether they had. Such blood tests may be particularly important with multiple pregnancies where anaemia is more common.

Multi-disciplinary core team

NICE guidance for twins and triplets states that mothers expecting multiples should be cared for by a multi-disciplinary core team with a specialist knowledge of multiple pregnancies[5]. This team should include a specialist obstetrician, specialist midwife and specialist sonographer, providing continuity of care across hospital and community settings and offering information and support to those with multiple pregnancies. The survey showed mixed results regarding access to such care. Roughly two thirds of mothers (67.7%) had seen an obstetrician with specialist knowledge of multiple pregnancies, whilst only 20.1% had seen a specialist midwife and 28.1% a specialist sonographer (although 23.7% were unsure if the sonographer had specialist knowledge). Such statistics show that many health authorities are clearly failing to provide the required care, particularly in community settings, and provision of much of the specialist advice and knowledge rests with obstetrician, meaning that parents may be missing out on midwife-led care and advice.

NICE guidelines again require that members of the multidisciplinary team discuss the risks, symptoms and signs of pre-term labour and the potential need for steroids for foetal lung maturation in a multiple birth. 64.8% of parents had discussed these risks, most commonly with their obstetrician. The multidisciplinary team are also required to discuss the likelihood of a caesarean or vaginal birth and timing of birth. 86.6% of women had had the opportunity to discuss this with one or more members of their team, most often the obstetrician and / or midwife, although some felt that they had not really been given a choice and had been pushed into a caesarean or vaginal birth against their wishes.

30.5% of hospitals where respondents gave birth ran multiple-specific parent education sessions, most often in the form of a one-off session run by a twin specialist midwife/s. These were most likely to be in larger regional hospitals which had the resources and numbers of multiple pregnancies to make such sessions viable.

Satisfaction with care

Parents were asked about their satisfaction with advice and care provided. Table 1 below shows satisfaction with advice from obstetricians and midwives and access to screening and prenatal education.

Table 1: Parent satisfaction with advice / care provided

	Very **Good**	Good	Reasonable	Poor	Very Poor	**Not Applicable**
Advice given by your obstetrician/doctor to prepare you for birth	30.4%	26.1%	24.9%	11.3%	5.3%	2.0%
Advice given by your obstetrician/doctor to prepare you for post**natal care**	11.3%	13.5%	27.6%	28.3%	12.7%	6.6%
Advice given by your obstetrician/doctor to prepare you for admission to at neonatal unit	15.0%	16.8%	22.3%	19.2%	13.7%	13.1%
Advice given by your obstetrician/doctor to prepare you for caring for your babies after discharge from hospital	8.8%	10.5%	21.3%	29.2%	20.2%	10.0%
Advice given by your midwife to prepare you for birth	16.3%	19.2%	25.8%	17.5%	10.3%	10.9%
Advice given by your midwife to prepare you for post**natal care**	13.2%	16.5%	23.0%	23.6%	13.1%	10.6%
Advice given by your midwife to prepare you for admission to at neonatal unit	9.6%	14.7%	18.1%	22.2%	14.3%	21.2%
Advice given by your midwife to prepare you for caring for your babies after discharge from hospital	11.1%	16.9%	21.7%	22.3%	17.7%	10.4%
Advice given by your midwife on feeding your babies	13.8%	18.4%	20.8%	20.9%	18.7%	7.4%
Access to screening	20.4%	26.8%	24.1%	10.2%	8.8%	9.8%
Access to parent craft/prenatal sessions	8.8%	14.9%	22.5%	22.3%	22.6%	9.0%

Figure 5 below shows satisfaction with obstetrician advice, comparing positive (good or very good) ratings with negative (poor or very poor) ratings. Neutral ratings are not included. The figure shows that parents are generally satisfied with advice from the obstetrician to prepare for birth, with 56.5% of parents rating this positively. Advice on admission to a

neonatal unit is rated fairly equally positively and negatively, whilst over 40% of parents rated advice from their obstetrician on preparing for postnatal care and caring for babies after discharge as 'poor' or 'very poor', showing a clear need for better advice in these areas. Such findings reflect other studies which show that mothers often feel under prepared for the postnatal period[13].

Figure 5: Satisfaction with obstetrician advice

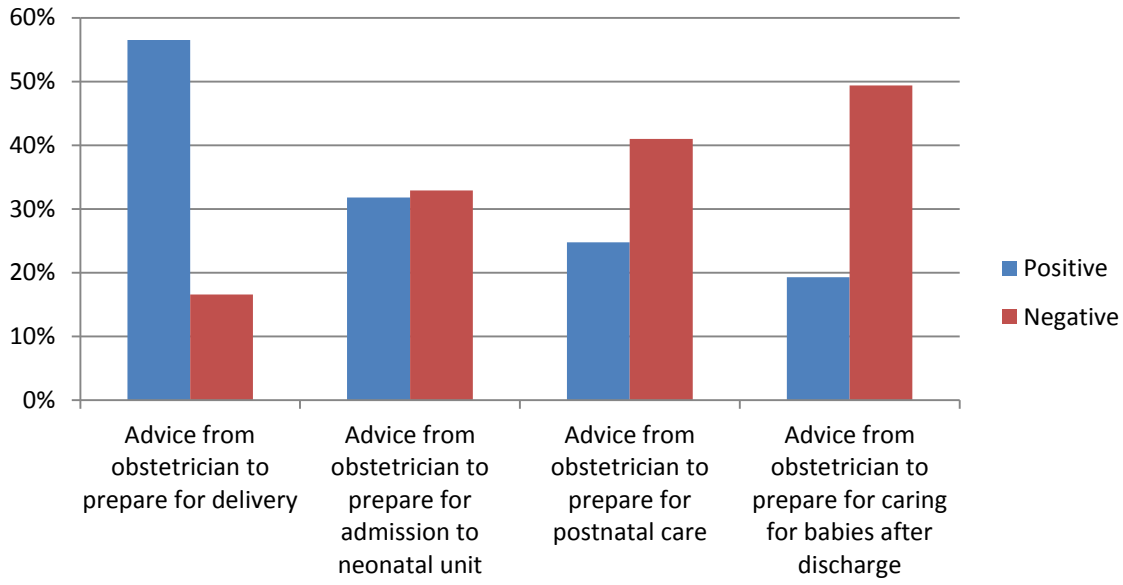
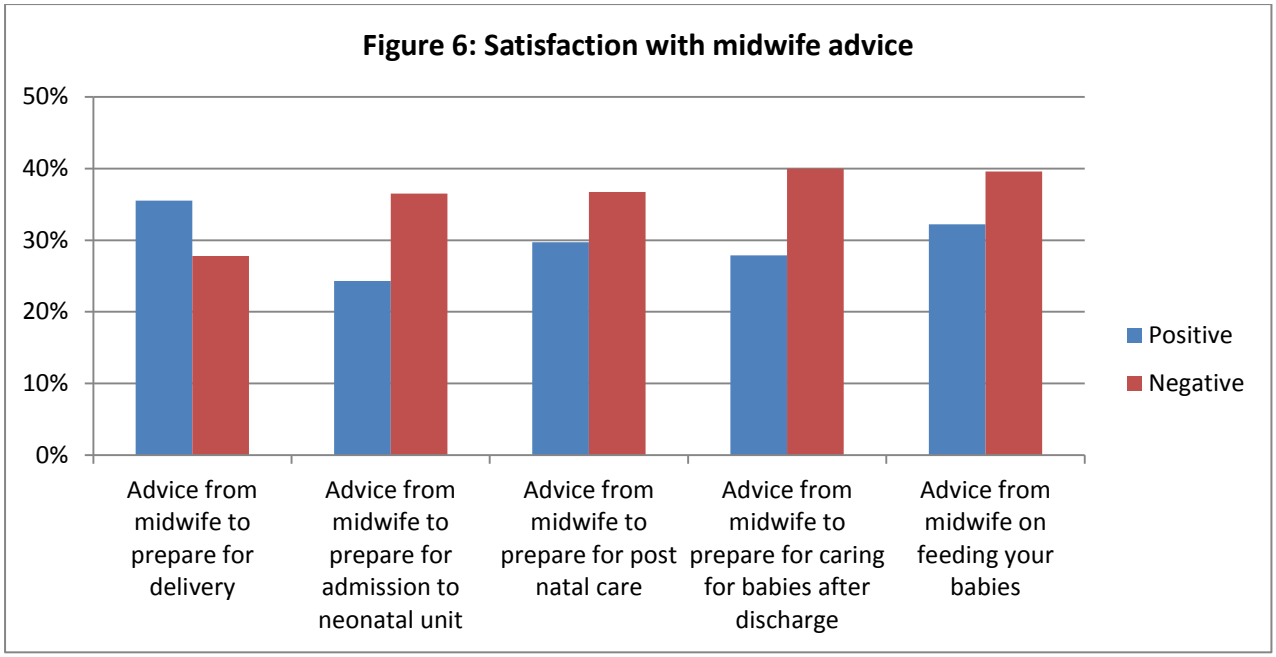


Figure 6 shows satisfaction with midwife advice, showing that again advice on preparation for birth was rated the most positively, with around a third of mothers (35.5%) rating this as good or very good. All other areas showed higher rates of negative satisfaction than positive, with over a third of parents rating midwife advice on admission to neonatal units, postnatal care, and care for the baby after discharge and feeding your babies as poor or very poor. Once again this shows a clear need for further advice and support, particularly in the postnatal period, and better training for midwives on supporting parents of multiples.

Satisfaction with access to screening was rated positively, with 47.2% of parents rating this as good or very good and just 19% as poor or very poor. Parents were less satisfied with access to parent craft / prenatal sessions, with just 23.7% rating this positively, whilst 44.9% rated this negatively. Again this was likely to depend on the area and hospital in which the parents received their care and the facilities available.



Conditions during pregnancy

Women with multiple pregnancies may be at higher risk of developing certain conditions during pregnancy such as high blood pressure, pre-eclampsia, diabetes and hyperemesis gravidarum (extreme morning sickness). They are also susceptible to conditions which only develop in multiple pregnancies, including twin-to-twin transfusion syndrome. 27% of mothers surveyed suffered from high blood pressure during their pregnancy (compared with a national average of 16%[6]), 15.8% developed pre-eclampsia (compared with an average of 2-5%)[6]. 8% suffered from gestational diabetes, whilst 16.4% suffered from hyperemesis gravidarum, compared with an average of just 1% of pregnancies[7]. 9% of mothers reported twin-twin transfusion syndrome. This can only occur in monochorionic pregnancies, which make up under a third (27.5%) of those surveyed, therefore rates are again higher than suggested prevalence of 10-15%[8.]

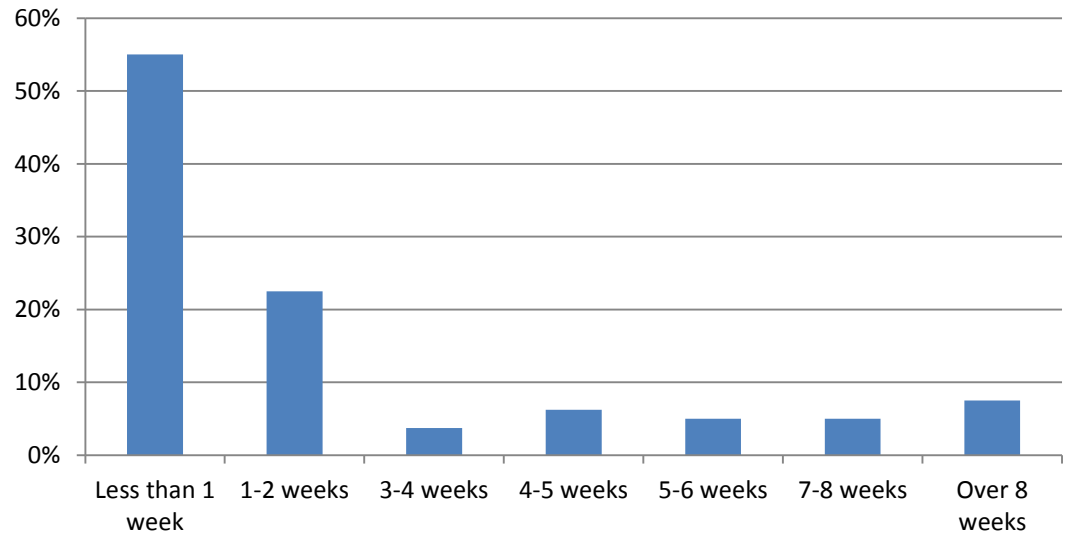
Neonatal care

Multiple births are far more likely to require neonatal care than singletons, due to high levels of prematurity, low birthweight and other complications. This is reflected in the survey findings with over half (51.5%) of respondents stating that one of more of their babies required some kind of additional care in a neonatal unit after birth. Of these 42.2% were in a Level I Special Care Baby Unit (SBCU), 25% were in Level II High Dependency Unit and 28.4% were in Level III Neonatal Intensive Care Unit (NICU).

The majority of parents whose babies required neonatal care (84.2%) were all able to stay together at the same hospital. The survey comments show that those parents who were separated from one or more of their babies often found it very traumatic and difficult to divide their time between the babies, particularly if the hospitals were geographically distant or they themselves were still hospitalised and too ill to travel, making this a priority for care wherever possible.

Over half (55%) of parents who had to be in a separate hospital from their babie(s) were separated for less than one week and a further 22.5% for between one and two weeks. 7.5% of parents were separated from their babies for over 8 weeks. 21.4% of babies were transferred to a secondary or primary level neonatal unit nearer to home prior to discharge.

Figure 7: Number of weeks that parents were separated from their babie(s) in neonatal care



60.2% of parents of multiples receiving neonatal care (in a NICU) were able to stay at the hospital or nearby in temporary lodging such as a hotel, Ronald McDonald house or similar overnight accommodation. Many other parents stated that they were offered this option, but chose to stay at home after they were discharged from hospital as they lived nearby.

Neonatal Care in Scotland

In Scotland 82.4% of those baby(ies) who needed neonatal care were able to stay together at the same hospital as their mother and sibling(s), however some of the qualitative comments alluded to the fact that neonatal cot distribution did not always match where mothers were planning to give birth, leading to babies being transferred.

> ‘During my labour I was moved from RAH to Royal Infirmary and back to RAH again within a 24 hour period due to insufficient beds available for my twins in SCBU. I was 30 minutes away from being flown to Belfast by helicopter as this was the nearest available hospital with 2 available beds in SCBU. RAH juggled their available incubators and therefore we were transferred back before delivery’.
>
> ‘Babies born in Dundee before being transferred to Aberdeen. We were able to stay at parent suite at hospital’
>
> ‘Twin 2 was taken to a hospital an hour away when born. Two days later we all went to the same hospital’
>
> ‘Was advised during labour that there were no 2 incubators together in the West of Scotland. Due to complications during birth, emergency treatment was needed so the SCBU went above capacity to treat them’

In most cases (82.5%) parents reported that the hospital automatically offered to keep all their babies together, although 3.2% had to argue for places for all of their babies. A further 6.5% had been told that they would be spilt up but luckily places became available at the right time, whilst a further 3.5% had been told they would be spilt up and places did not become available. For 4.4% clinical needs meant that all the relevant services and treatments services could not be provided at a single hospital.

Feeding

Feeding multiples provides additional challenges and mothers may find that they are unable to feed their babies in the way that they intended. 29.6% of parents said they had not been 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/more babies, or the sheer demand of breastfeeding multiples. 33.2% were able to breastfeed, whilst 27.3% were able to express feed. 21.5% decided to mixed feed, 20.3% to use formula milk and 2.8% to use donor milk.

Babies born at an early gestation are often unable to breastfeed straight away and need assisted feeding. 68.7% of mothers whose babies were unable to feed said that they had been taught and given help with expressing breastmilk. Others said that they had been offered a breast pump, but not shown how to use it adequately, or their babies had been given formula milk and they had not been given the option. For those whose babies were able to breastfeed at birth, only 57% were given advice about expressing, sometimes only upon their own request. Some mothers reported being pressurised to top up with formula milk, whilst others reported being ‘bullied’ to breastfeed when they did not want to. Such findings correspond with current research on infant feeding which shows that women often feel pressure and guilt regarding their feeding decisions[10], which may be intensified in the

case of multiples and those with premature or sick babies who often feel their choice is taken away from them.

Parents were asked whether they were supported to achieve their feeding preference, with around a third (35.1%) saying they were not supported in any way. Around two-thirds (62%) said that they had been supported by health professionals, with smaller numbers supported by various voluntary organisations including the Breastfeeding Network (5.9%), NCT (3.9%), Tamba Breastfeeding Peer Supporters (2.3%), La Leche League (2.2%), Twinline volunteers (1.1%) and The Multiple Births Foundation (0.5%). Such figures clearly show scope for further support for breastfeeding multiples, both from health professionals and voluntary organisations, who may have more expertise and time available to support mothers with establishing feeding and overcoming difficulties.

Co-bedding and sleeping arrangements

Advice on safe sleeping for multiples is similar to that for singletons, in that they should be placed on their back, feet to the foot of the crib and share a room with their parents for the first six months of their lives. However it is also advised that 'co-bedding' (placing two or more babies together in the same cot / crib) is safe while space permits and may help to soothe the babies and regulate body temperatures and sleep cycles[11]. Only 42.1% of parents completing the survey had been given advice on safe sleeping for multiples, showing room for improvement in this area.

The majority of families had their babies all discharged from the hospital at the same time (87.9%), although this was not always possible where one multiple required further medical treatment.

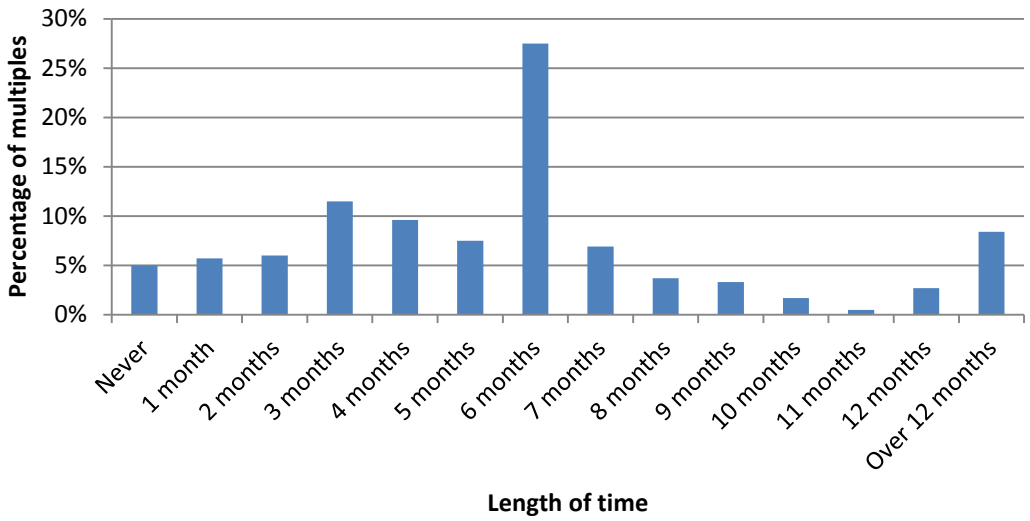
Over half of multiples were co-bedded in the hospital with 49.5% placed in the same cot and 4.5% placed in the same incubator at birth. 22.6% were undergoing treatment and could not be placed together, whilst 16.8% were placed in different cots in the same ward and 23% were placed in separate incubators in the same ward. This seemed to depend upon the preferences of the parents or those providing the care, although the small numbers co-bedded in incubators may be due to the lack of availability of suitable facilities. Clear guidance on best practice in this area would be useful.

The majority of parents co-bedded their infants when they got home, with 57. 7% placing them in the same cot / crib and 19.8% placing them in the same Moses basket / bassinet. 32.6% placed them in separate Moses baskets / bassinets and 8.2% placed them in separate cots / cribs, with many parents moving between different forms of sleeping arrangements as their babies grew, or placing them differently during the day / night.

Rates of co-bedding in hospital seemed slightly lower in Scotland compared with UK averages, with 38.3% co-bedded in the same cot and 1.3% in the same incubator. This may again be due to differences in facilities or practices at different hospitals. However once parents got their babies home 50.7% co-bedded them in the same cot/crib and 18.9% in the same Moses basket / bassinet.

The majority of parents (95%) slept in the same room as their babies for some period of time, most commonly for the recommended 6 months (27.5%). The amount of time babies spent in the parents room is shown in Figure 8 below, with 8.4% of parents sharing a room with their babies for over 12 months.

Figure 8: Length of time multiples shared a room with parents



Only 21% of parents reported that their babies had shared a bed with them during the first 6 months of their lives, with many stating that this was only occasionally when they were having trouble sleeping. Such numbers seem low compared to other studies with Ball (2002) reporting that approximately 50% of UK infants had shared a bed with their parents at some point during the first 3 months of their lives[12]. This may be due to the self-report nature of the survey (with parents not wishing to be seen to be engaging in 'unsafe' sleeping practices), the fact that many multiples are born preterm (a risk factor for bed-sharing), or the additional practical challenges of bed sharing with more than one infant.

Zygosity

28.4% of multiples born to parents completing the survey were monozygotic (identical), 66.65% were dizygotic (fraternal) and 6.7% did not know the zygosity. The majority of parents said that they knew this either from looking at the physical features of their babies (41.6%) or because the team at the hospital had confirmed it from the scan as they shared one placenta (40.4%). A further 6.4% had the zygosity confirmed by the hospital team from a shared placenta in the afterbirth, 5.8% had a DNA test performed privately, 2.6% had a test during pregnancy for medical reasons, 3.6% had studied the behaviour of their babies and 18.4% were unsure how they knew the zygosity. 3.9% of parents had been told at birth that their multiples were one type of zygosity, only to be confirmed later by DNA testing that they were the other.

Change over time

The report seeks to measure change over time in terms of compliance with NICE guidelines for multiple pregnancies, which were introduced in September 2011. In order to do so we compared three time points – current 2014/15, data from 2013/14 and data from 2010/11 (pre NICE guidelines). The measures of NICE implementation used are shown below:

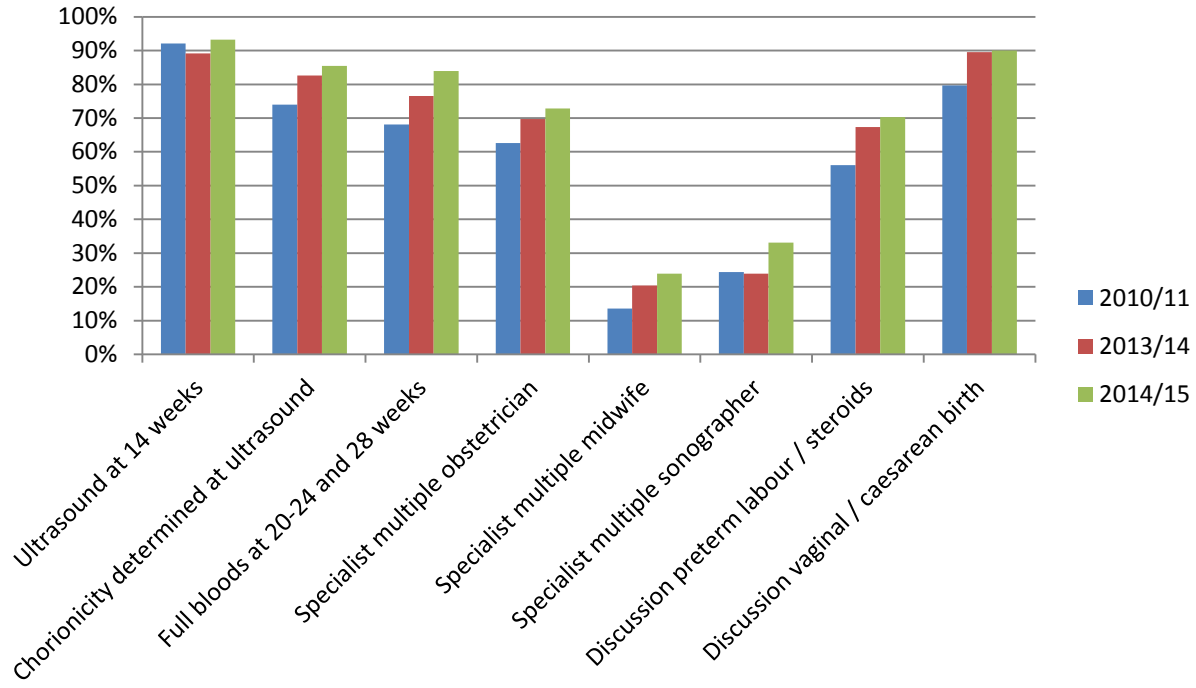
1) Ultrasound by 14 weeks of pregnancy
2) Chorionicity of pregnancy determined at first ultrasound
3) Full blood count taken at 20-24 weeks and again at 28 weeks
4) A multidisciplinary core team with a specialist knowledge of multiple pregnancy
    a) An obstetrician with a specialist knowledge of multiple pregnancy
    b) A midwife with a specialist knowledge of multiple pregnancy
    c) A sonographer with a specialist knowledge of multiple pregnancy
5) Discussion of the risks, symptoms and signs of pre-term labour and potential need for steroids for foetal lung maturation
6) Discussion of the likelihood of caesarean / vaginal birth

The results show that average levels of compliance with NICE measures have increased from 58.8% in 2010/11, to 64.9% in 2013/14 and 69.1% in 2014/15, showing a 10% improvement over the past four years. Whilst this is a positive step, rates of improvement are slow and at current levels it could potentially take another twelve years to achieve full compliance, with associated negative outcomes and experiences for parents and babies during this time.

All measures of NICE implementation have shown an improvement in compliance over time with the exception of ultrasound at 14 weeks, which was already at high rates of compliance (92.1%) pre 2011. All other standards have shown a steady improvement of +10-15% over the four year period that the guidelines have been in operation, with smaller improvements over the last year, although two standards maintain very low levels of compliance – the availability of a midwife with specialist knowledge of multiple pregnancies (23.9%) and the

availability of a sonographer with specialist knowledge of multiple pregnancies (33.1%). Discussion of the signs of pre-term labour also remains relatively low at 67.3% compliance, whilst the availability of an obstetrician with specialist knowledge of multiple pregnancies stands at 72.8%. Ultrasound before 14 weeks pregnancy (93.2%) and discussion of the likelihood of vaginal / caesarean birth (90%) both are both above 90%, whilst chorionicity determined at first ultrasound (85.5%) and full blood counts at 20-24 and 28 weeks (83.9%) show greatly improved compliance (see Figure 9 below).

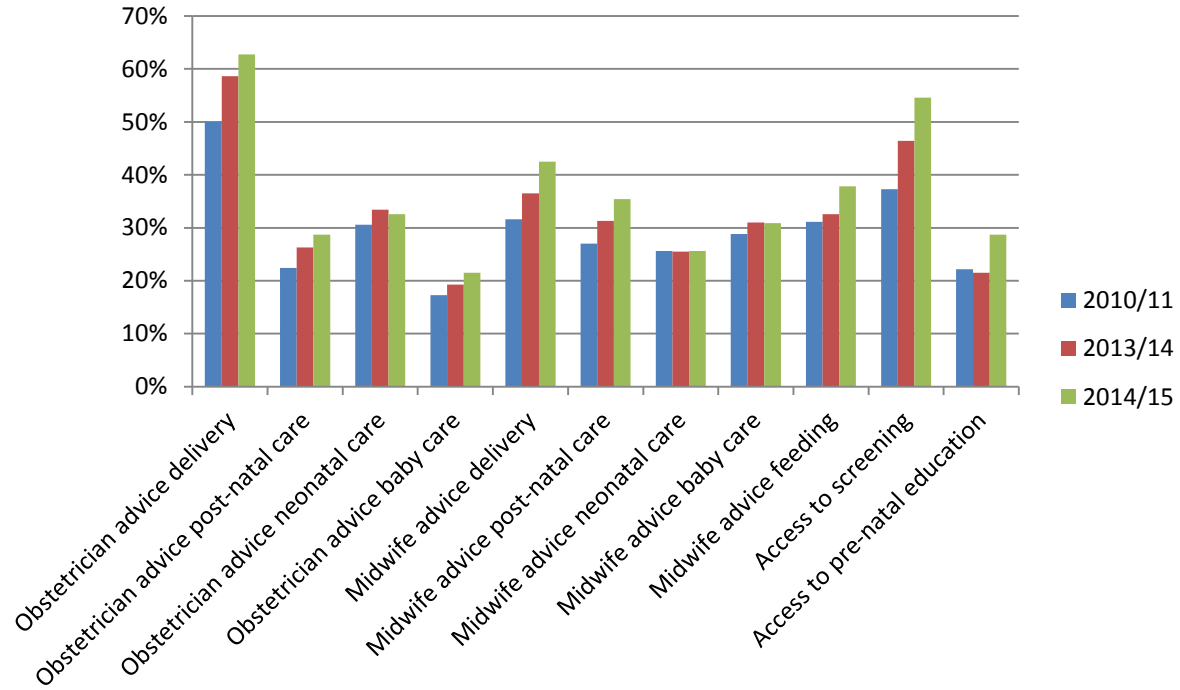
Figure 9: Percentage compliance with NICE guidelines 2010/11, 2013/14 and 2014/15



Satisfaction with quality of care also generally shows improvement over time (see Figure 10 below), although positive ratings of satisfaction remain below 50%, except for obstetrician advice to prepare parents for birth (62.7%) and access to screening (54.6%), which have both seen significant improvements in satisfaction over time, most likely linked to the implementation of NICE guidelines. All other measures of satisfaction have seen some improvements, with the exception of midwife advice on neonatal care, which has remained static at around 25.5%. Satisfaction with obstetrician and midwife advice in preparation for birth have both increased by more than 10% over time, whilst obstetrician and midwife advice on postnatal care has seen modest improvements, as has midwife advice on feeding and access to prenatal education / parent craft classes. However overall levels of positive (good or very good) satisfaction remain relatively low, with much further room for

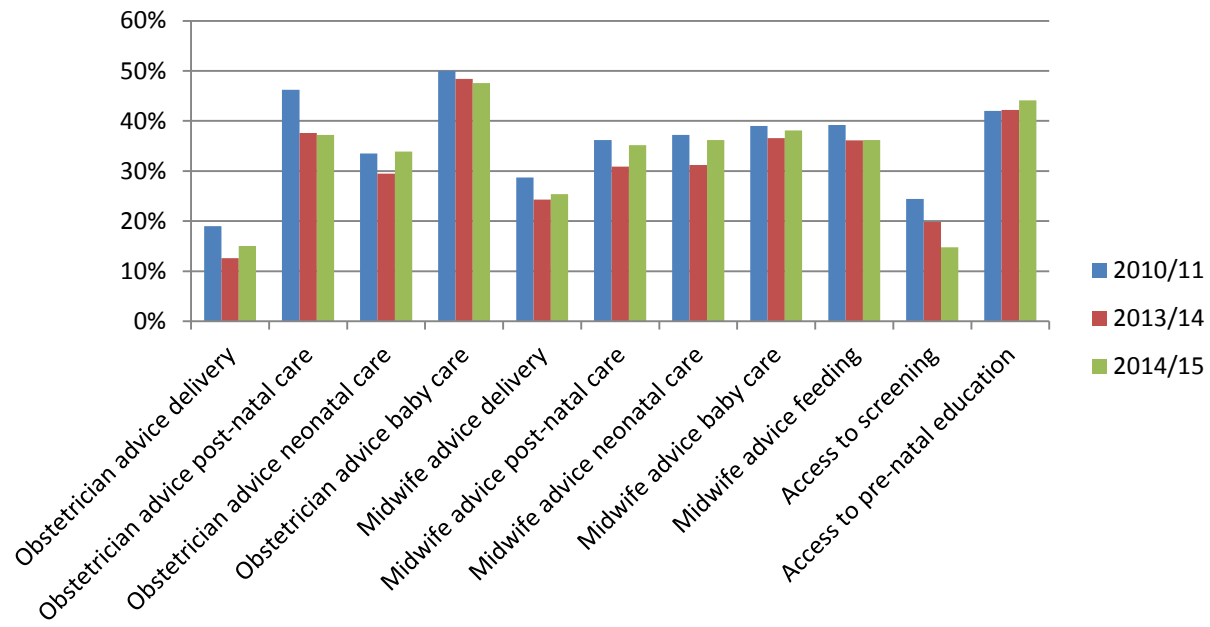
improvement, particularly with regard to obstetrician advice on post-natal and practical baby care and midwife advice on neonatal care. It is possible that these areas are seen as the domain of the other specialist (midwife / obstetrician) so little advice is provided.

Figure 10: Positive satisfaction with antenatal care 2010/11, 2013/14 and 2014/15



Levels of negative satisfaction (poor or very poor ratings) remain relatively high (see Figure 11 below) particularly with regard to obstetrician advice on baby care (47.6%) and access to pre-natal education (44.1%). Most areas had seen some small improvements over time, although these tended to be by only a few percentage points and perhaps highlight the areas where NICE standards are not being met (e.g. lack of midwives with specialist knowledge of multiple pregnancies). Such high levels of negative satisfaction show there is clearly room for further improvements in many areas of antenatal care with only obstetrician / midwife advice in preparation for birth and access to screening scoring below 30% for negative satisfaction (meaning more than a third of parents are dissatisfied with most areas of their care).

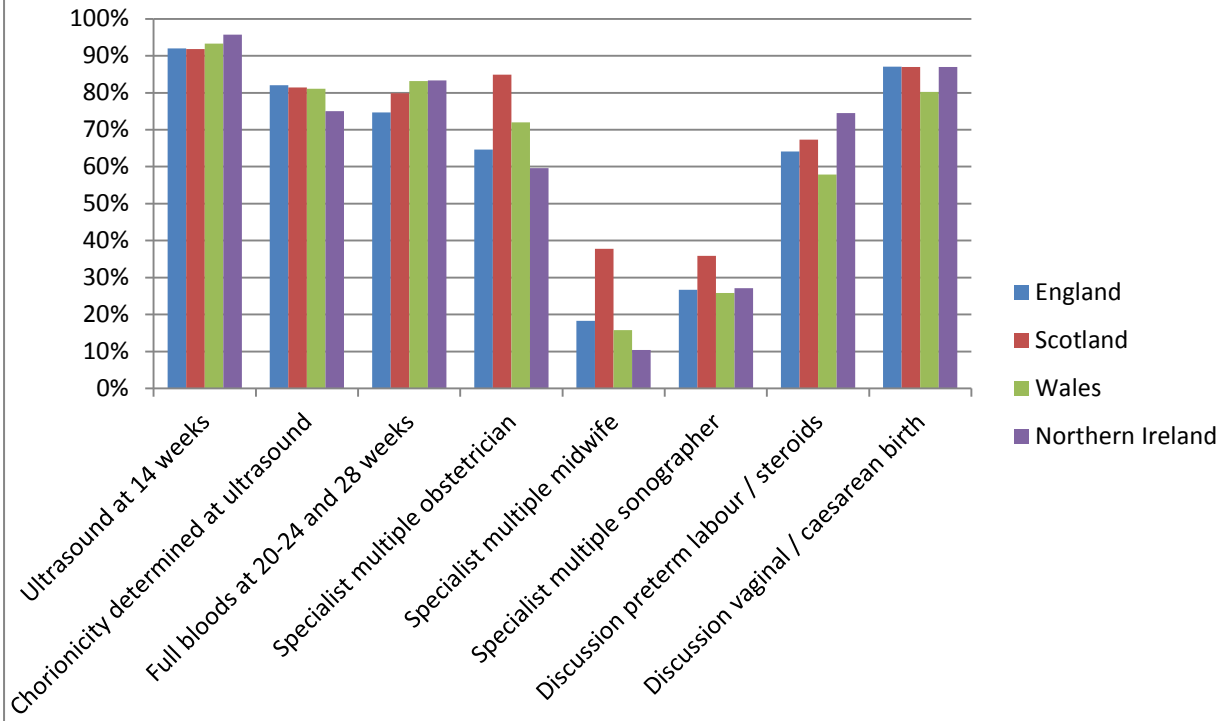
Figure 11: Negative satisfaction with antenatal care, 2010/11, 2013/14, and 2014/15



Variation across the UK

In addition to variations over time, care can also vary according to location. The six measures of NICE implementation were measured across the four home nations of the UK (England, Scotland, Wales and Northern Ireland). Overall scores for implementation of NICE standards were found to be broadly similar across England (63.7%), Wales (63.7%) and Northern Ireland (64.1%) and significantly higher in Scotland which scored an average of 70.8% overall. Looking at the NICE recommendations individually, scores were broadly similar for all four nations across five of the measures, with Northern Ireland scoring highest for ultrasound by 14 weeks (95.7%), full blood counts at 20-24 and 28 weeks (83.3%) and discussion of the signs and symptoms of preterm labour (74.5%) and England for determining chorionicity at the first scan (82%) and discussion of the likelihood of vaginal / caesarean birth (87.1%). However Scotland scored significantly higher on the measures relating to care by a specialist multidisciplinary team, with 84.9% of Scottish parents seen by an obstetrician with specialist knowledge of multiple pregnancies (compared to a low of 59.6% in Northern Ireland), 37.8 % seen by a specialist midwife (compared with 10.4% in Northern Ireland) and 35.9% seen by a specialist sonographer (compared with 25.8% in Wales).

Figure 12: Implementation of NICE guidelines for multiple pregnancy across the UK



Parent satisfaction with care /advice also varied across the UK, with Scotland and Northern Ireland scoring consistently higher than England and Wales on all measures of satisfaction (except access to screening in Northern Ireland) and Wales scoring consistently the lowest. The highest satisfaction scores were for obstetrician advice to prepare parents for birth in Scotland (61.6%), Northern Ireland (58.4%) and England (56.4%), whilst satisfaction in Wales was only 48.9%. Access to screening also scored highly in Scotland (55.1%) and England (49%). Greater satisfaction with care and advice in Scotland is likely to reflect higher levels of NICE compliance. Scotland and Northern Ireland also had consistently lower levels of negative satisfaction compared with England and Wales. Lowest levels of satisfaction were with obstetrician advice on practical baby care, midwife advice on neonatal care and access to prenatal education, with overall lowest levels of satisfaction all occurring in Wales. The exception to this was satisfaction with access to screening in Northern Ireland, which scored only 20.5%. This is likely due to strict abortion laws, which prevent abortion for foetal abnormalities, therefore screening for Down's Syndrome was only offered to 21.3% of parents compared with 81.7% across the UK.

Figure 13: Positive satisfaction with care / advice across the UK

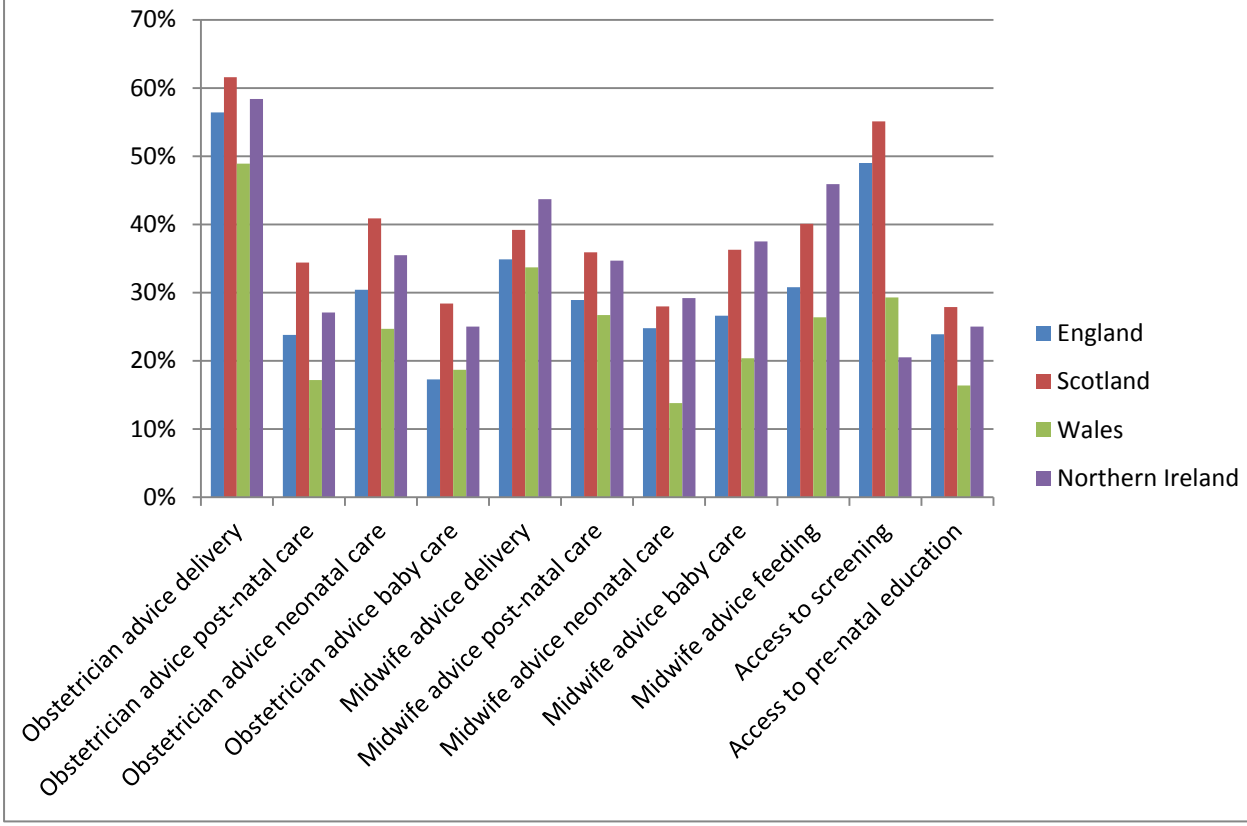
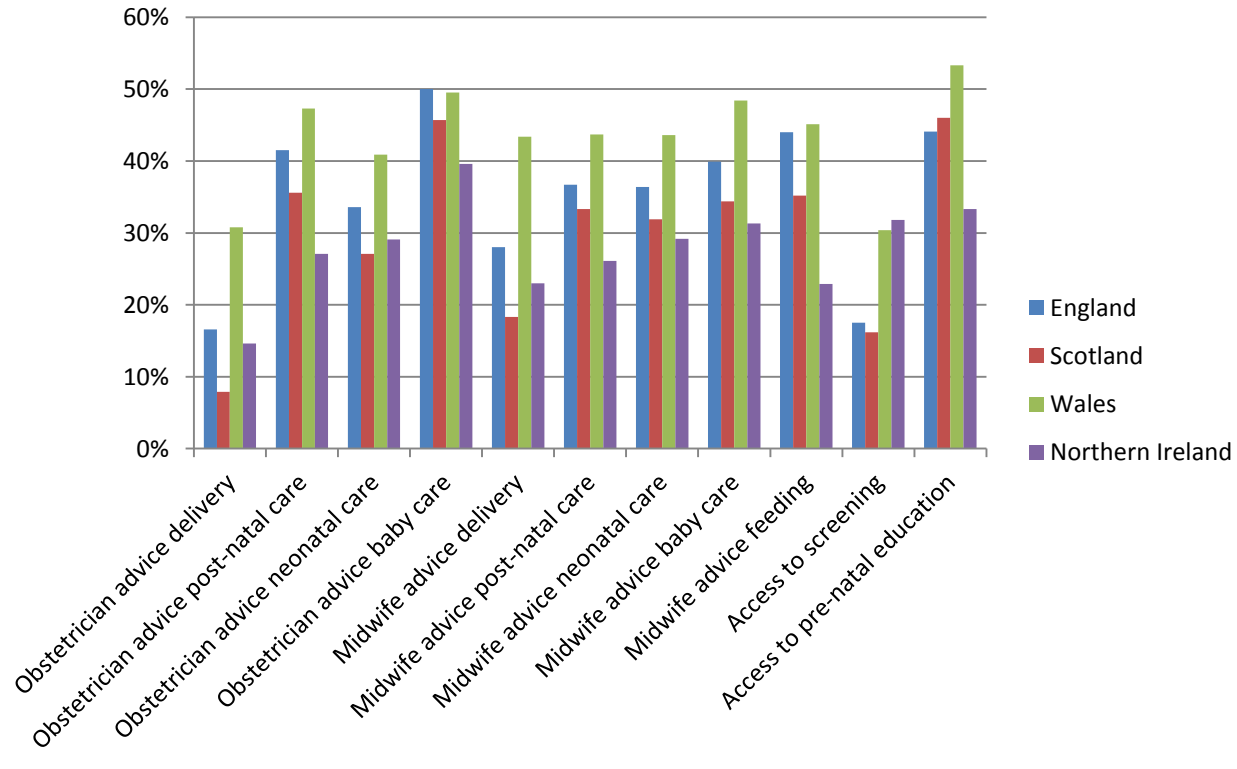


Figure 14: Negative satisfaction with care / advice across the UK



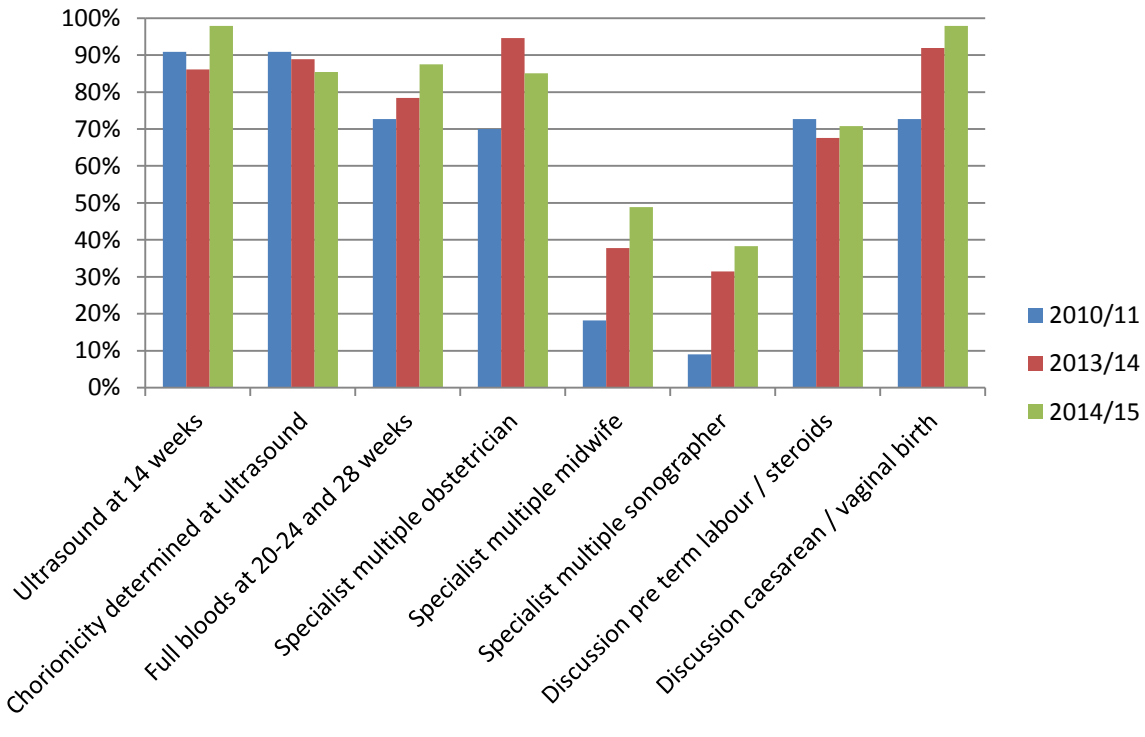
Negative satisfaction with care / advice showed a similar pattern, with higher levels of negative satisfaction occurring in Wales (and to a lesser extent England) across almost all indicators (with the exception of access to screening in Northern Ireland). Satisfaction scores can partly be explained by higher overall rates of NICE compliance in Scotland, although it is unclear why Northern Ireland shows much higher rates of satisfaction than England / Wales and why Wales has the lowest rates of satisfaction overall, showing a need for further investigation in this area.

Maternity services in Scotland - change over time

Healthcare Improvement Scotland has issued guidance that NICE guidelines on antenatal care in multiple pregnancy should be adopted in Scotland.

Average levels of compliance with NICE guidance in Scotland have improved over time from 62.1% in 2010/11 (pre-implementation) to 72.1% in 2013/14 and 76.5 % in 2014/15. These results are significantly above the UK averages of 58.8% in 2010/11, 64.9% in 2013/14 and 69.1% in 2014/15, however further work is needed. Compliance with each of the individual quality standards is shown in Figure 15 below, showing that, as elsewhere, access to midwives and sonographers with specialist knowledge of multiple pregnancy remains limited, though these measures have seen significantly more improvement in Scotland than across the UK (improving by approximately 30% over the past four years).

Figure 15: Percentage compliance with NICE guidance in Scotland 2010/11, 2013/14 and 2014/15



Stillbirth and neonatal death rates: Scotland

Stillbirth and neonatal death rates for multiples remain significantly above those for singletons. Tables 2 and 3 below compare stillbirth and neonatal death rates for singletons versus multiple births in Scotland from 2010 to 2014. Whilst both stillbirth and neonatal death rates have seen a small reduction over this time period, stillbirth rates for multiples remain more than double those for singletons. Neonatal death rates show an even greater discrepancy at more than five times those for singletons in 2014.

Stillbirth rates for multiples in Scotland have dropped somewhat from 12.8 per 1000 births in 2010 to 8.5 per 1000 births in 2014, most likely due to the units which implementation of best practice following the introduction of NICE antenatal care guidelines in 2011. However neonatal death rates have not shown a consistent decrease and remain at 11.5 per 1000 live births, perhaps reflecting the continued lack of specific intrapartum care guidelines for multiples.

Between 2010 and 2013 multiple births accounted for 6.7% of all stillbirths and 16.7% of neonatal deaths in Scotland, whilst in 2014 they accounted for 6.6% of stillbirths and 14.6% of neonatal deaths, despite making up just 3.1% of all births. Therefore it is vital to ensure that these and other high risk pregnancies are taken into account and specific measures taken to improve patient safety

Figures for 2013 – 14 show a small improvement in both stillbirth and neonatal death rates for singletons and significant improvement in neonatal death rates for multiple births from 13.8 per 1000 in 2013 to 11.5 per 1000 in 2014. However stillbirth rates for multiples actually rose from 7.1 per 1000 in 2013 to 8.5 per 1000 in 2014 (although small numbers make accurate statistical comparison difficult).

Table 2: Live births, stillbirths and neonatal deaths in Scotland 2010 – 2014 (singletons)

Year	Total live births	Stillbirths	Neonatal deaths	Stillbirth rates per 1000 births	Neonatal death rates per 1000 births
2010	56,941	267	127	4.7	2.2
2011	56,877	278	136	4.9	2.4
2012	56,288	257	119	4.5	2.1
2013	54,347	222	108	4.1	2.0
2014	54,981	213	117	3.9	2.1

Table 3: Live births, stillbirths and neonatal deaths in Scotland 2010 – 2014 (multiple births)

Year	Total live births	Stillbirths	Neonatal deaths	Stillbirth rates per 1000 births	Neonatal death rates per 1000 births
2010	1,850	24	23	12.8	12.4
2011	1,713	21	23	12.1	13.4
2012	1,739	17	29	9.7	16.7
2013	1,667	12	23	7.1	13.8
2014	1,744	15	20	8.5	11.5

Comparative figures for England and Wales (Tables 4 and 5) show a similar picture, although stillbirth rates for multiples have not fallen as sharply as in Scotland, remaining at 10.5 per 1000 in 2014. This may reflect overall lower rates of NICE compliance, or other cofounding socio-demographic factors such as age, ethnicity or socio-economic status. Between 2010-2013 multiple births made up 6.8% of all stillbirths and 15.3% of neonatal deaths in England / Wales, compared with 6.7% of stillbirths and 16.7% of neonatal deaths in Scotland. This shows slightly higher neonatal death rate in Scotland. Neonatal death rates for 2014 are not yet available in England / Wales, however 2013 figures show that these remain high (11.5 per 1000) for multiple births. Stillbirth rates for 2014 show multiple birth babies still made up a high percentage of stillbirths, accounting for 6.6% of stillbirths in Scotland and 7.2 per cent in England and Wales. These figures show there is much further work to be done.

Table 4: Live births, stillbirths and neonatal deaths in England and Wales 2010 – 2014 (singletons)

Year	Total live births	Stillbirths	Neonatal deaths	Stillbirth rates per 1000 births	Neonatal death rates per 1000 births
2010	696,213	3455	1,746	5.1	2.5
2011	696,785	3556	1,761	5.1	2.5
2012	706,470	3304	1,676	4.7	2.4
2013	676,609	3078	1,639	4.5	2.4
2014	673,337	3020	Not available	4.5	Not available

Table 5: Live births, stillbirths and neonatal deaths in England and Wales 2010 – 2014 (multiple births)

Year	Total live births	Stillbirths	Neonatal deaths	Stillbirth rates per 1000 births	Neonatal death rates per 1000 births
2010	22,212	259	321	11.4	14.5
2011	22,797	255	355	11.1	15.6
2012	22,812	254	309	11	13.5
2013	21,521	206	247	9.5	11.5
2014	21,896	234	Not available	10.5	Not available

Variation by Scottish region

Whilst numbers of respondents completing the survey in Scotland are relatively low, making statistical comparison difficult, we looked at measures of patient care / NICE compliance by Scottish NHS health board region. Two of the fourteen Scottish NHS regions (NHS Orkney and NHS Shetland) had no patients receiving their care in that region, most likely to due the remote nature of these areas which would have meant that multiple pregnancies were referred to larger specialist centres on the mainland. Other areas also had relatively low numbers of patients receiving their care (NHS Ayrshire and Arran, NHS Borders, NHS Dumfries and Galloway, NHS Fife, NHS Forth Valley, NHS Highlands and NHS Western Isles) whilst larger population centres such as NHS Grampian, NHS Greater Glasgow and Clyde, NHS Lanarkshire, NHS Lothian and NHS Tayside received greater numbers of patients. 34 patients received their care outside of Scotland, most commonly in neighbouring North-East or North-West England (or in other areas where they had moved in the intervening period). These patients are excluded from the analysis.

Table 6 below shows levels of NICE compliance by NHS health board. Whilst it is difficult to draw statistically significant results from areas with few patients the results show that some areas are clearly performing better than others with regards to patient care. NHS Lanarkshire shows the highest overall levels of compliance at 78.6%, followed by NHS Glasgow and Greater Clyde at 74.6%, NHS Forth Valley at 74.4% and NHS Lothian at 73.8%. NHS Borders, NHS Fife and NHS Highland all also scored above 70% compliance. Low scoring health boards included NHS Grampian at 58.9%, where only 11.1% of patients had access to a midwife with specialist knowledge of multiple pregnancies, compared with 78.6% in Lanarkshire. Areas with small numbers of patients were also underperforming, such as NHS Western Isles (50%), NHS Dumfries and Galloway (56.3%) and NHS Ayrshire and Arran (62.5%), most likely due to the fact they were small regional hospitals with lack of access to specialist staff / facilities.

Table 6: Levels of NICE compliance by Scottish NHS Health Board 2014

	Number of respondents	Ultrasound at 14 weeks	Chorionicity at ultrasound	Full bloods at 20-24 and 28 weeks	Specialist obstetrician	Specialist midwife	Specialist sonographer	Discussion pre-term labour and steroids	Discussion vaginal / caesarean birth	Overall NICE compliance
NHS Ayrshire and Arran	7	100.0%	60.0%	80.0%	80.0%	40.0%	0.0%	80.0%	60.0%	62.5%
NHS Borders	4	100.0%	75.0%	75.0%	75.0%	75.0%	33.0%	50.0%	100.0%	72.9%
NHS Dumfries and Galloway	2	100.0%	50.0%	100.0%	100.0%	50.0%	0.0%	0.0%	50.0%	56.3%
NHS Fife	5	100.0%	100.0%	50.0%	100.0%	50.0%	25.0%	50.0%	100.0%	71.9%
NHS Forth Valley	8	80.0%	100.0%	100.0%	75.0%	60.0%	0.0%	80.0%	100.0%	74.4%
NHS Grampian	19	81.2%	64.7%	58.8%	77.8%	11.1%	44.4%	38.9%	94.4%	58.9%
NHS Greater Glasgow and Clyde	51	97.6%	90.7%	74.4%	95.0%	45.2%	40.0%	72.1%	81.4%	74.6%
NHS Highland	10	100.0%	100.0%	88.9%	55.6%	22.2%	44.4%	88.9%	77.8%	72.2%
NHS Lanarkshire	15	92.3%	92.9%	100.0%	100.0%	78.6%	15.4%	57.1%	92.3%	78.6%
NHS Lothian	37	97.0%	81.8%	87.9%	87.5%	30.3%	33.3%	75.7%	96.9%	73.8%
NHS Tayside	24	79.0%	73.7%	73.7%	72.2%	42.1%	57.9%	68.4%	84.2%	68.9%
NHS Western Isles	1	100.0%	100.0%	100.0%	0.0%	0.0%	0.0%	0.0%	100.0%	50.0%

CONCLUSIONS

The report shows that parents of multiples still face additional challenges in preparation for labour and birth, antenatal and postnatal care. Recent figures show that multiples accounted for 7.2% of all stillbirths in England and Wales in 2014 and 6.6% of stillbirths in Scotland. Between 2010 and 2013, multiples accounted for 16.7% of neonatal deaths in Scotland and 15.3% of neonatal deaths in England and Wales.

The risk of preterm birth is also considerably higher occurring in at least 50% of twin pregnancies, with twins facing six times the risk of cerebral palsy. These outcomes compare poorly to singleton births and the discrepancy has existed for decades.

Rates of preterm birth are considerably higher for multiples, with the survey showing average gestation times of 35.3 weeks for twins and 31.8 weeks for triplets. Multiples are more likely to be born by elective birth (52.8% compared with 39.1% nationally) and caesarean section (68.1% compared with 26.25% nationally) and some parents may feel they are given little choice over their birth experience. The survey showed higher caesarean rates in Scotland than UK average at 74.5%, although it is unclear why this may be the case.

Multiples are also more likely to be born at low birthweight (73.7% compared with just 7% nationally) and to require some form of additional neonatal care (51.5% of babies in this survey). Qualitative evidence suggests that uneven distribution of neonatal cots may be leading to unnecessary transfer of babies in the immediate post-natal period and separation from parents and siblings. Parents may also be more likely to experience problems with feeding their babies due to difficulties of prematurity, illness, separation, lack of feeding support, or the sheer demands of feeding multiples, with 29.6% of parents saying they were unable to feed their babies as planned.

Such additional challenges have been recognised in the NICE guidelines for multiple pregnancies introduced in September 2011, which aim to provide parents with a level of care suitable for the complexity of their pregnancy, including additional monitoring, advice and care by a multidisciplinary core team with specialist knowledge of multiple pregnancies. However parent experiences of antenatal care remain mixed and unevenly distributed across the UK, with variable implementation of NICE guidelines.

Parent satisfaction with access to antenatal screening is generally good, with 47.2% of parents rating this as ‘good’ or ‘very good’. 92% of parents nationally had received an ultrasound by 14 weeks of pregnancy and 81.6% had the chorionicity and amnionicity of their pregnancies determined at the first ultrasound. Multiple pregnancies are monitored much more closely than singletons, with 81.7% of parents having at least six scans and 7.1% having more than twenty. 81.7% were offered screening for Down’s Syndrome and 76.4% were offered full blood tests at 20-24 and 28 weeks pregnancy.

Access to care by a specialist multi-disciplinary core team is much more limited, with approximately two-thirds (67.7%) of mothers seeing an obstetrician with a specialist knowledge of multiple pregnancy, but just seeing 20.1% a specialist midwife and 28.1% seeing a specialist sonographer. Such statistics show that many health authorities are clearly failing to provide the required level of care, and identify a clear need for further availability and training of suitable staff.

Parent satisfaction with advice provided by the healthcare team is also generally low. Advice from both obstetricians and midwives in preparation for birth is rated positively, with 64.8% of parents reporting that they discussed the risks, signs and symptoms of pre-term labour and 86.6% that they had the opportunity to discuss the timing of birth and likelihood of vaginal / caesarean birth. However, advice on postnatal issues including preparation for admission to a neonatal unit, post-natal care, caring for the babies after discharge and advice on feeding the babies were all rated negatively, reflecting previous studies which show that parents often feel unprepared for the realities of the early post-natal period and abandoned by health professionals at this time[13].

Such findings show a clear need for further advice and preparation for potential postnatal complications (which are more common in multiple pregnancies) and general postnatal advice and support. Over a third of parents (35.1%) said that they were not supported in any way to achieve their feeding preference and 57.9% had not received advice on safe sleeping for multiples. Such figures show a need for further postnatal input from health professionals, but also a possible role for voluntary organisations such as Tamba which may have more time and expertise to dedicate to such issues. The survey shows that health professionals are poor at signposting to such organisations, with over half (55.4%) of parents not informed about Tamba or the MBF's services and just 24.5% attending their parent education sessions. Feeding support is another area where voluntary organisations may play a key role, with only a minority of parents (15.9%) currently accessing support in this way.

The report shows some positive improvements in access and satisfaction with services over time. Overall measurements of NICE implementation have increased from 58.8% in 2010/11 to 69.1% in 2014/15, showing a 10% improvement over the past 4 years. However, progress is slow and at current rates of improvement it could be estimated to take a further 12 years to achieve full compliance, with associated risks of continued negative outcomes for multiple births and patient safety incidents. Access to a specialist midwife (23.9%) and sonographer (33.1%) remain particularly low, showing clear needs for further improvements. Rates of satisfaction with care / advice have also shown some improvement over time, although satisfaction with post-natal advice and access to pre-natal education remain particularly low.

The report also shows variations in access to care across the four nations of the UK. Scotland has considerably higher overall scores for NICE implementation (70.8%) than the rest of the UK, with England (63.7%), Wales (63.7%) and Northern Ireland (64.1%) all broadly similar. Scotland also shows highest levels of satisfaction with care / advice, followed closely by Northern Ireland, with Wales scoring consistently lowest on satisfaction, despite similar levels of compliance to NI. Parents in Northern Ireland were particularly dissatisfied with their access to screening, whilst scoring highly in all other areas, due to their strict abortion laws.

Whilst rates of NICE compliance in Scotland have increased relatively more quickly than elsewhere in the UK from 62.1% in 2010/11, to 72.1% in 2013/14 and 76.5 % in 2014/15, there is still much further work to be done. Access to a midwife with specialist knowledge of multiple pregnancies (48.9%) and specialist sonographer (38.3%) remain low, as does the discussion of pre-term labour and the potential need for steroids of foetal lung maturation (70.8%). There also remains a problem with the uneven distribution of neonatal cots, leading to transfer and separation for some multiples and their parents.

Stillbirth rates in Scotland have seen significant improvement over the past five years from 12.8 per 1000 births in 2010 to 8.5 per 1000 in 2014. However this is still more than double the national rate of 3.9 per 1000 for singletons. Neonatal death rates have not shown a similar improvement, standing at 11.5 per 1000 in 2014 from 12.4 per 1000 in 2010, more than five times the rate of 2.1 per 1000 for singletons. Multiples accounted for 6.6% of all stillbirths and 14.6% of neonatal deaths in Scotland in 2014, despite making up just 3.1% of births, therefore it is vital to ensure that these and other high risk pregnancies are taken into account in order to meet these targets. Such figures clearly show the need for further improvements in patient safety and specific guidance for multiple births, particularly in the intrapartum period.

Access to services also varies by Scottish region, with many of the more remote areas having limited access to specialist services. Patients requiring more specialist care may have to travel longer distances to bigger population centres or even neighbouring English regions. Larger health boards also differ in standards of care, with NHS Lanarkshire performing the best at overall 78.6% compliance, alongside NHS Glasgow and Greater Clyde at 74.6%, NHS Forth Valley at 74.4% and NHS Lothian at 73.6%, whilst NHS Grampian is underperforming at 58.9%, scoring particularly poorly on access to a specialist midwife, sonographer and the discussion of potential pre-term labour.

Overall the report shows that implementation of NICE guidelines is slowly beginning to address the inequalities of care experienced by parents of multiples and recognise their additional needs. However much further progress is required. Parents generally have good access to screening and advice in preparation for birth, but have further needs in terms of post-natal advice and support and access to a multi-disciplinary team with specialist knowledge of multiple pregnancy. Whilst Scotland has shown more improvement than other areas of the UK, high stillbirth and neonatal death rates for multiples show the need for further progress.

Access to an appropriately trained team during both pregnancy and birth would improve quality of care, patient safety and outcomes for multiple pregnancies and ensure that all families were able to access the range of options available to them. Studies have shown that where services are implemented in compliance with NICE guidance stillbirth rates, caesarean rates and patient safety incidents are reduced. A recent Australian study[15]

showed that after the implementation of a specialist twin clinic, caesarean rates, late preterm births (34-37 weeks) and maternal inpatient stay were all reduced.

We would therefore call for more full and rapid implementation of NICE guidance to drive improvement for multiples and their families. This involves acknowledging that multiples (along with other distinct groups e.g. women from some ethnic backgrounds) have specific needs that are easily overlooked, which can result in poorer outcomes and should be explicitly addressed through national, regional and local policy initiatives.

Planned extension of NICE Multiple Pregnancy guidelines to cover the intrapartum period would also help to ensure continuity of care and improve outcomes for babies and parents during this time, when the majority of clinical negligence claims occur. Clear guidelines for the postnatal period would help to ensure best practice in postnatal and neonatal care and provide families with the additional support they require in caring for their multiples.

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