

# By accident or Clesion Control

The record-breaking drop in twin stillbirths by almost 50% and neonatal deaths by 30% in the UK between 2014 and 2016

An insight into work that is likely to have contributed to Saving

505

babies' lives



# External insights

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# Introduction

Tamba trustees adopted a new strategic plan in early 2014 that heavily focused on improving clinical outcomes in multiple pregnancies. This remains a key strand of their existing strategy too. It was based on the learned experience of supporting parents, encouraging research and working with professionals over the preceding decades.

Since then Tamba, along with a range of organisational partners, have built a movement of motivated parents and professionals who have relentlessly campaigned for change. This has been underpinned by a multifaceted approach focusing on eight key areas of activity, which are described in more detail in this paper. Together, they are likely to have contributed to this record breaking fall in twin stillbirths (by almost 50%) and neonatal deaths (over 30%) noted in the latest MBRRACE-UK Perinatal Mortality Surveillance Report 2016.

We are incredibly grateful to the huge number of people and organisations who have been helping to drive this change, and some of the key contributors are listed here. But we are not complacent. According to the latest data, twins are still over one and a half times more likely to end in a stillbirth and over three times more likely to end with a neonatal death. Previous publications highlight that they are still six times more likely to result in a brain injury and contribute towards 10% of

clinical negligence claims 1,2 and around half end up in neonatal care.

While there is still much to do. what is heartening is the growing evidence to suggest that the practice set out in The National Institute for Health and Care Excellence (NICE) guideline CG129, antenatal care in twin and triplet pregnancy, provides a blueprint for further improvements. If maternity units are still yet to implement the guidance, then there are few, if any reasons, to delay any longer. Conversely, commissioners should also be checking to ensure that their money is being well spent. Especially in England, where multiple births receive the highest tariff for antenatal care.

It is hoped that this observational paper is part of a broader discussion about how to continue to improve care in twin, triplet and higher order multiple pregnancies. As set out in the section 'What next?', there are a number of initiatives that will continue to provide additional evidence to provide further clarity on what has happened and needs to change.

It is also hoped that some of these insights might be usefully applied to other populations both in the UK and further afield. Everyone connected with the charity is driven to try and save babies lives so if you think we might be able to help then please do contact us.

 $1.\ \underline{\text{https://ifqlive.blob.core.windows.net/umbraco-website/1311/one-child-at-a-time-report.pdf}$ 

<sup>2.</sup> Multiple Births: Written Parliamentary Question - 217336, 5 December 2014

# Key finds from the MBRRACE-UK Perinatal Mortality Surveillance Report UK Perinatal Deaths for Births from January to December 2016

This report was published on 15th June 2018 with an accompanying conference held in Birmingham, England and streamed live to a conference in Edinburgh, Scotland. It is the third in the series of reports produced by the <a href="MBRRACE-UK team">MBRRACE-UK team</a>. The key finds relating to twins are set out below.

#### **PAGE 113:**

"A small reduction in mortality rates over time can be seen related to most of these characteristics for stillbirths apart from a continued increase in the rate of stillbirth for the Black, Black British ethnic group which was 7.02 per 1,000 births in 2013 and continued to increase from 7.49 to 8.29 per 1,000 total births over the three years from 2014 to 2016. There has been a statistically significant reduction in the rate of stillbirth in twins over the period from 11.07 (95% CI, 9.78 to 12.47) to 6.16 (95% CI, 5.20 to 7.24) per 1,000 total births."

#### **PAGE 114:**

"Most neonatal mortality rates for baby characteristics either remained static or showed a small reduction over the three years presented in Table 25. **The**  reduction in neonatal mortality rates for twin pregnancies was statistically significant reducing from 7.81 (95% CI, 6.73 to 9.01) to 5.34 (95% CI, 4.47 to 6.36) per 1,000 live births. In contrast neonatal rates for the mixed race and Asian, Asian British groups showed a small increase from 1.40 to 1.74 per 1,000 live births and 2.34 to 2.84 live births, respectively."

#### **PAGE 116 - TABLE 26:**

"The ratio of mortality rates for stillbirths has remained fairly constant over time in terms of baby's sex, ethnicity, gestational age and birthweight. However, relative to singletons there has been a significant reduction in the stillbirth rate ratio associated with twin pregnancies, reducing from 2.8 (95% CI, 2.47 to 3.17) to 1.6 (95% CI, 1.36 to 1.88) from 2014 to 2016."

#### **PAGE 117 - TABLE 27:**

"As found in the stillbirths, relative to singletons there has been a significant reduction in the neonatal mortality rate ratio associated with twin pregnancies, reducing from 4.91 (95% CI, 4.20 to 5.73) to 3.33 (95% CI, 2.80 to 3.98) from 2014 to 2016."

I am delighted with this fantastic improvement. Many thanks to all the key organisations which supported our efforts to disseminate the NICE and ISUOG guidelines on the management of twin pregnancies. This has made a huge difference to the health and wellbeing of women and their babies. We must continue our efforts to educate all the staff in our maternity units to enable them to give the best care to mums with twins.

As a Chair of the TAMBA Maternity Engagement initiative, I am very proud of the significant reduction of stillbirth and neonatal deaths in twin pregnancies. We should continue to work with the maternity units in the UK to improve the outcomes of these pregnancies even further."

# Dr Asma Khalil

MD(Res) MRCOG MSc(Epi) MBBCh, Professor of Maternal Fetal Medicine, Lead of the Multiple Pregnancy Service, National Institute for Health and Care Excellence (NICE) Fellow (2013-16), Chair of ISUOG Practice Guidelines: role of ultrasound in twin pregnancy (2016), Chair of UK TTTS Registry, St George's University of London.

# Eight key areas of activity

#### 1. EDUCATING EXPECTANT MUMS

Between 2014-2016, Tamba has supported close to 9,000 expectant parents in direct one to one antenatal and preparing for parenthood classes. The classes coach parents to understand what good care looks like (NICE Clinical guideline 129 antenatal care in twin and triplet pregnancies), how to look after their health in pregnancy and how to articulate any concerns they may have on both fronts. The impact of these classes has been measured in a range of ways but one noticeable effect is a steady flow of questions from parents about querying the clinical care they have received or been offered. Whilst we teach families how to address these points themselves, on occasion we have advocated directly with their clinical teams on their behalf.

These classes have been underpinned with a range of free to access online videos, guides and an online pregnancy countdown tool, which have been accessed over 500,000 times. All the resources, listed at the end of this paper, reinforce these key points.

#### 2. FILLING THE RESEARCH GAPS

We identified that the clinical knowledge gaps highlighted during the production of the NICE guidance wouldn't be filled without ongoing seed funding from ourselves. Intermittent funding for some twin specific projects had been made

available from some public bodies and other charities but prior to 2014, this created peaks and troughs in interest among researchers and teams. We commissioned our first piece of research, which was the production of twin pregnancy growth charts, in 2013/14. We then partnered with the British Maternal Fetal Medicine Society to jointly fund two annual bursaries from 2015 onwar<u>ds</u>. In 2015, we also funded the establishment of a UK wide twin registry - recording complications in twin pregnancies and the staffing to underpin it. We have also noted a steady number of studies published independently, which have focused on the themes identified during the production of the NICE guidance.



# 3. DRIVING UP INTEREST IN THE CARE OF MULTIPLES AMONG CLINICAL TEAMS

While the bursaries were a good platform to raise awareness of the clinical needs of multiples, and resulted in the first year in a 20-fold increase in the number of abstracts published regarding twins, we were relentless in highlighting the importance of good care in multiple pregnancies.

We used a mix of mainstream broadcast and print media but also targeted specialist trade media whenever appropriate. Since 2014, we have created a range of stories to repeat the same message more than 17 times, which is, 'good care according to the NICE guidance' improves multiple babies' outcomes and could save lives.

We supplemented this by attending professional conferences, encouraging and promoting Continuing Professional Development (CPD) opportunities in twin pregnancies and built an email list of more than 1,000 interested professionals who regularly receive information on the latest improvements, news, successes and research opportunities.

We also encouraged key clinicians to engage with their peers via national improvement programmes (e.g. Twin stillbirth prevention webinar for Sign up to Safety), international, national and regional conferences, or clinical governance meetings. They have done a fantastic job in this regard. It is also of note that NICE appointed a fellow tasked with embedding the implementation of the guidance during this period who was particularly active and engaged in spreading good practice.

# 4. ENSURING CLINICAL GUIDANCE IS FIT FOR PRACTICE

We pressed for, or supported, the updating and creation of guidance to ensure clinical teams are able to understand what good care in multiple pregnancies looks like. Whilst the NICE guidance is the gold standard, we were involved in it being made into quality standards



in 2013, the RCOG updated its existing green top guidance on monochorionic twin pregnancies in 2016, and ISUOG published its role of ultrasound in twin pregnancies in 2016.

We successfully campaigned for the NICE guidance to be updated to include intrapartum care based on the feedback from nationally recorded patient safety incidents and NHS resolution findings. It will also benefit from new research that settled the questions around timing of birth. We have also lobbied for the Saving Babies Lives Stillbirth Care Bundle to be updated too.

What is clear from our own research outlined below is every time new guidance is issued and supported with an awareness campaign (both at a local and national level) this results in greater uptake among units. This is also likely to be, in part, as a result of going through hospital trust clinical governance structures.

# 5. UNDERSTANDING WHAT CARE IS BEING DELIVERED IN INDIVIDUAL MATERNITY UNITS

It was really important to understand what care was being delivered on the ground and we have produced a series of reports looking at parental experiences since 2009. We also commissioned a report from NPEU looking at the experiences of mothers based on



Care Quality Commission (CQC) feedback in 2011. Whilst very helpful in building the evidence base, the National Perinatal Epidemiology Unit (NPEU) report did not identify what was happening at trust level. All the Tamba surveys and reports have asked parents to give feedback on elements of their care which align with best practice. It has enabled us to check if care is being delivered in accordance with good practice in individual units, and particularly focus on those ones who still have a long way to go to improve. NICE have also used the results of these surveys to monitor the implementation of their guidance.

#### These reports were:

- Twin Pregnancy and Neonatal Care in England - produced by Tamba in 2017. This report is an analysis of data on twin pregnancy and neonatal care in England.
- Tamba and NCT Maternity Services Report: Multiple births in Scotland - produced by Tamba and the NCT in 2016. This report describes the findings of the Maternity Services survey distributed by Tamba to parents of multiples in Scotland and the UK. The survey covered a variety of topics including place of birth, quality of antenatal and postnatal care, neonatal care arrangements, feeding support

and sleeping arrangements.

- Reducing Stillbirths in Multiple Pregnancies and the NHS Stillbirth 'Care Bundle' produced by Tamba in 2016. Tamba's response to the release of the NHS Stillbirth 'Care Bundle.' The report concluded most of the points in the care bundle do not apply to multiple pregnancies.
- Tamba and NCT Maternity
  Services Report: Multiple births produced by Tamba and the
  NCT in 2015. 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
  and sleeping arrangements.
- Tamba Maternity Services
  Survey Report produced by
  Tamba in 2014. Compares and
  contrasts antenatal and
  postnatal services and support
  in several different countries. It
  highlights where excellent
  service delivery occurs and
  where there may be room for
  improvement.
- Healthcare Survey Report -"Making Progress" - produced by Tamba in 2012. This was a follow up to the 2009 survey and asked parents of twins, triplets and more to confirm their recent experience of pregnancy, birth and the early months.
- Maternity Care for women expecting a multiple birth produced by the NPEU and commissioned by Tamba in

2011. Using data from national surveys the report provides an overview of the care mothers of twins and triplets receive during pregnancy, labour and birth and in the early months that follow.

Report - "Multiple Failing" produced by Tamba in 2009.
The survey looked at families'
experience of pregnancy, birth
and their postnatal experience.
It covered a range of topics
including gestational age and
weight of twins or triplets,
access to neonatal care,
postnatal depression, help in
the home and quality of
feeding advice.

# 6. EMBEDDING GOOD CLINICAL PRACTICE IN INDIVIDUAL HOSPITAL TRUSTS

In response to our 2014 Maternity Services Report, we undertook a telephone follow up with every single maternity unit in England. The ring around was predominantly undertaken with Heads of Midwifery in the first instance who in many incidences cascaded engagement to other team members. This compared parental feedback with the team's view of the care they delivered. The results found parental feedback was between 80-90% accurate. Furthermore, in those units with a considerable way to go to implementing the NICE guidance, the Tamba advocate provided coaching on how and where they may like to make improvements.

In 2015, we used the survey findings to undertake a political engagement exercise which included <u>highlighting issues of concern to the Secretary of State</u>

alongside a range of key partners.

However, we also mobilised hundreds of parents to contact their local MPs asking them to check with their local hospital trusts and CCGs if the care being delivered was in accordance with the latest guidance. Nearly 100 MPs positively engaged in the campaign.



The Department of Health maternity team have been consistently supportive of our efforts. They have sponsored the expansion of the UK wide TTTS registry to allow it to capture data on the use of cerclage in certain types of multiple pregnancy. In 2016, they agreed to sponsor a three year quality improvement programme aimed at working with 30 maternity units to statistically prove that good care improves outcomes in multiple pregnancies. But also, the project intends to identify barriers to the delivery of good care and provide sufficient resource to create tools and methods to overcome them. This programme is due to be completed in March 2019. It has statistically proven that good care reduced stillbirths and neonatal deaths and these findings are due to be published in an interim report in July 2018. It has generated strong levels of activity and engagement from the majority of participants. However, the project funding

ends in March 2019 just as the fruits of this work begin to emerge.

Throughout the period there have also been regular updates to maternity networks in England and key stakeholders in Scotland and Northern Ireland. In all countries, we have delivered parenting sessions alongside the main maternity units and in doing so built relationships with clinical teams. Unfortunately due to resourcing pressures our work with key stakeholders has been more ad hoc and is an area for us to address in the future.

In fact, in many regards Northern Ireland was a pioneer in organising itself with a clear care pathway for twins introduced across the country in 2013/14. This is based around clear referral routes for more complex pregnancies and all expectant multiple birth parents being seen by nominated teams.

# 7. BUILDING ALLIANCES AND RELENTLESS CAMPAIGNING

The letter referenced above, to Jeremy Hunt MP, marks the beginning of a concerted effort to build alliances and partnership with key stakeholders.

To this end, the joint baby charities network consisting of: Aching Arms, Action on Pre-eclampsia, ARC (Antenatal Results and Choices), Best Beginnings, Bliss, Child Bereavement UK, CMV Action, The Ectopic Pregnancy Trust, Genesis Research Trust, Group B Strep Support, Kicks Count, Mama Academy, NCT, Parent Infant Partnership UK, The Lullaby Trust, The Miscarriage Association, The Multiple Births Foundation, Sands (Stillbirth & Neonatal Death charity), Tommy's,



and Together for Short Lives. The network has been an endless source of support, advice and encouragement. Our thanks also to Action Against Medical Accidents for their ongoing advice and insights.

Furthermore, thousands of parents to twins, triplets and more have taken action to highlight the need for good care supported by hundreds of families who have been bereaved.

The royal colleges have all been supportive and some of the key individuals are highlighted at the end of this paper. However, of special note is the British Maternal and Fetal Medicine Society (BMFMS), who have supported us throughout this process. Our partnership began under the expert leadership of their president Tim Overton who accompanied us to lots of meetings with key partners, and has continued to this day with their existing president Myles Taylor.

There have been some key parliamentarians who have helped us gather background data for national data sets to help us outline the reasons why care needed to change. These include Lord Nigel Jones, former MP Bob Russell, Baroness Hodgson of Abinger, Dr Alan Whitehead MP and the APPG for Baby Loss led by Antoinette Sandbach MP, Will Quince MP, Victoria Prentis MP, Sharon Hodgson MP, and Patricia Gibson MP.

It is very pleasing to see a significant fall in perinatal and neonatal mortality for twins from these data relating to 2014-2016. This is highly likely to be secondary to increased multidisciplinary working in multiple pregnancy clinics and protocols for screening, surveillance and management outlines in the NICE Guidance on twin and triplet pregnancy and the RCOG Green top guidelines. However, we know that compliance with these guidelines is 'patchy' throughout the UK.

With universal compliance and adherence to management protocols it is probable that further improvements in perinatal survival in twins and triplets could be made. A focus upon screening for preterm birth and intrapartum care in the revised NICE guidelines (for publication in 2019) can only enhance improvements in perinatal mortality and morbidity."

# Mark Kilby

DSc MD FRCOG FRCPI, Professor of Fetal Medicine, Chairman of the NICE Clinical Guideline Group for the Management of Multiple Pregnancy (2011) and expert advisor to the Update Review Group (present), Expert lead for RCOG Green Top Guideline on the management of Monochorionic Twin Pregnancy (2016), University of Birmingham.

# 8. ENCOURAGING AND EMBRACING A POSITIVE POLICY ENVIRONMENT

It has unquestionably been easier to engage with stakeholders as a result of the commitments by Governments in England, Northern Ireland, Scotland, and Wales to reduce stillbirths and neonatal deaths. And credit must go to Sands, and the colleges and other key advocates of this cause who have been making the case for many years.

As outlined above, we have worked with some key politicians who tabled a raft of Parliamentary questions to obtain information from national datasets to build up our evidence base. They also provided the background to much of our local engagement work too.

We adopted the tactic of using the national maternity review in England and the Maternity and Neonatal review in Scotland as opportunities to campaign among clinical teams, networks and politicians to highlight the needs of our families and to press for change. Both Better Births and The Best Start explicitly acknowledge the needs of our families. Our updates to the review teams and other key stakeholders were fairly relentless but they were consistently receptive and encouraging. Once published, we then used these reports to press for further change.

Subsequently, NHS England have been enormously supportive of the need to incorporate all families, ours included, into national commissioning documents and guidelines. Furthermore, the respective Departmental teams in England, Scotland and Northern Ireland have been actively supportive too. In England, the CQC were convinced by the need to focus on these pregnancies and included them in their updated inspection framework. We are grateful for their support (and on occasion patience!).



# The cost of saving 305 twin babies' lives

In 2015 and 2016, there were 305 fewer twin babies lives lost than if the 2014 stillbirth and perinatal death rate in twins had persisted. During this three year period, we estimate that with the kind support of our families and supporters the charity allocated £300k per year towards these activities (£900K in total).

In addition, in 2016 we received £70k from the Department of Health in England and between 2014-16 we received around £63k from the Department of Health in Northern Ireland towards these activities (£133k in total).

Whilst the tools that accompany the NICE guideline to help with implementation suggest that the costs of making changes are minimal, as they mostly involve organisational changes rather than additional resourcing, we estimate from the costs of our Department of Health Quality Improvement programme that supporting each unit to amend

practice is likely to be between £10-15k per unit.

Looking at the NICE maternity impact report, it is unlikely that more than 30 units between 2014-16 undertook a wholescale review and care pathway change. Even at this high estimate, and at the highest cost, this would have amounted to an additional £300k - £450k of cost to health services.

If the additional cost to health services, from government support and to our charity is factored into this then in total this may have been just under £1.6 million - a cost of just over £5,200 per twin baby's life saved. It should also be borne in mind that there are likely to be other costs and cost savings associated with amending practice to implement NICE guidelines 129. However, these costs should therefore be interpreted as a 'best estimate' in the absence of a more formal review.

An almost 50% reduction in stillbirths shown in the latest MBRRACE report in twins is cause for great celebration and testament to the hard work of all those involved in caring for mothers with multiple pregnancy and, of course, to those who look after twins and triplets when they are born.

What has caused this welcome change? This has been no accident. In part, they have been a result of national guidance informed by both clinical research and expert opinion. TAMBA has played a crucial role in this success story. Without TAMBA's efforts, national guidance may not have been adhered to. In addition, TAMBA continues to provide invaluable help and support to mothers and families with twins but also to professionals involved in their care.

The BMFMS has enjoyed working closely with TAMBA and currently co-sponsors two twin research fellows. Improvements, however, are still required and further research into twins, encouraged by today's announcement, is still required if we are to continue to improve the outcome of twins and multiple births. The BMFMS is therefore delighted to join with TAMBA in celebrating the results of the MBRRACE report.

# **Myles Taylor**

President of the British Maternal and Fetal Medicine Society



# **Tim Overton**

Past President of the British Maternal and Fetal Medicine Society

# What next?

We are at the planning stage of creating new resources for expectant mothers to cover place of birth decisions and to provide more information on complications in multiple pregnancies (e.g. Twin anaemia polycythaemia sequence).

It is pleasing to note that there are still significant clinical research studies underway including STOPPIT 2 led by Professor Jane Norman looking at trying to reduce pre-term births, and the use of non-invasive ultra sound to treat Twin to Twin Transfusion Syndrome by Professor Christoph Lees, which have been supported by National Institute of Health Research (NIHR) and Medical Research Council (MRC) respectively. These are in addition to the studies jointly funded by the BMFMS.

There is the ongoing production and testing of twin pregnancy specific growth charts, which have just been validated and were developed as a result of a recommendation during the production of the national guidelines. The modelling for the charts continues to suggest they will be important in helping to reduce unnecessary pre-term deliveries. An online portal making them available to everyone for free, worldwide, is in the planning phase.

In 2016, the Department of Health recognised and approved Tamba's strategy to reduce stillbirths, neonatal deaths and pre-term admissions by awarding the charity a grant to conduct a high quality improvement programme. This project will provide units with far more insight into how good practice can be achieved as well as highlight how common barriers to achieving good care can be removed. This project is due to end in March 2019 with an end of project conference scheduled for early April 2019. However, we are actively looking for support to continue this excellent work.



The quality improvement tools (audit templates, pathway pro formas, multiples clinic team role descriptions, CPD resources and videos) produced as part of the Department of Health project are to be made freely available to every unit in the UK shortly. There will be an online guide on how to use them and units who wish to participate should contact support-team@tamba.org.uk.

We are hoping to shortly commission a national audit of clinical practice, building on previous Tamba reports involving both patients and clinical teams this time. Meanwhile, the National Maternity and Perinatal Audit (NMPA) have also committed to publishing an insight into the care

received by twin mothers and MBRRACE are about to begin a confidential enquiry into twin pregnancy losses.

NHSE have kindly committed to updating the Saving Babies Lives Care bundle to include specific interventions to support the care of twins. And the importance of the NICE guidance is due to be outlined in soon to be published Reducing Pre-term Admissions Guideline for Commissioners and Providers.

In Scotland, the Department of Health have agreed to fund a national conference to bring clinical teams together to share best practice and identify areas of future development, and the Department in Northern Ireland have expressed an interest in something similar. The Scotlish Multiple Births Best Practice Conference is scheduled for Friday 28th of September 2018.

If you would like to attend please contact

helenpeck@tamba.org.uk

The reduction in the rate of stillbirths and neonatal mortality in twins reported in the MBRRACE-UK Perinatal Mortality Surveillance Report is excellent news and reflects the greater awareness of the complexities of multiple births and changes in clinical practice which have achieved significantly improved outcomes for multiple birth babies. I have no doubt that the NICE Guideline has played a critical part in this as well as the work undertaken by Tamba and the Multiple Births Foundation to raise professional awareness of the need for improved care for these families. However much remains to be done to fully implement the NICE Guideline. In addition more research is needed to help us have a greater depth of understanding about all aspects of multiple births and the impact on families and education for health and allied professionals to enable them to give the care required."

# Jane Denton

CBE FRCN Director Multiple Births Foundation, Co-lead Elizabeth Bryan Multiple Births Centre - Birmingham City University.

The Elizabeth Bryan Multiple Births Centre (EBMBC) is delighted to note the reduction in the rate of stillbirths and neonatal mortality in twins as reported in the MBRRACE - UK Perinatal Mortality Surveillance Report (2018). The success in reducing these rates highlights the benefits of professionals and parents working together to improve health care. Tamba has excelled in making the voice of parents a significant influence on changing practice. As we develop our research and education programmes at the Elizabeth Bryan Multiple Births Centre we look forward to working with Tamba to do even more to help and support multiple birth families."

# Dr Merryl Harvey

Professor of Nursing and Family Health / Co-lead the Elizabeth Bryan Multiple Births Centre, Birmingham City University.

# Key contributors

Our thanks to all the parents and our partners who have been involved in pressing for change. Furthermore, we are hugely grateful to all the individual professionals and teams that have striven to improve the work they have done. And a special thanks to all the units across the UK, who have partnered with us in delivering parenting sessions to expectant mums and dads.

We have listed below some of the stand out contributions that come to mind but there are many more who could be listed.

Belfast Royal Jubilee Twins Clinic - started by Dr Samina Dornan and now led by Dr Mary Murnaghan who have flown the flag and provided endless support across the region.

#### Birmingham Women's Twins Team

 led by Professor Mark Kilby who chaired the NICE & RCOG guideline committees and provided expert input in a number of Tamba resources.

Glasgow Twins Clinic team - led by Janice Gibson and Marie Anne Ledingham who have been instrumental in driving forward improvements in care locally. Supported by Alan Cameron who has provided endless encouragement for all our work and especially during his time as VP at RCOG.

The Leeds Twins Clinic team - who have introduced the only example of continuity of carer through pregnancy to postnatal care.

Liverpool Women's Twins Clinic team - past and present who have been involved in establishing one of the oldest clinics in the UK and continue to deliver excellent care.

#### Newcastle RVI Twins Clinic team -

and surrounding network - who introduced a standardised pathway and guidance in their region before anyone else. Supported by the Northern Twins Registry and based on the research by Debbie Sen - they were one of the first to introduce a specialist midwife, Sandra Bosman, to support women.

St George's (London) Twins Clinic team - led by Professor Asma Khalil who was the chair of the ISUOG guideline team, NICE fellow for the implementation of Twin clinics, and chair of UK TTTS registry and Department of Health funded QI programme.

Southern Health & Social Care
Trust and Northern Health & Social
Care Trust in Northern Ireland who have contributed so much to
improving the care of families
expecting twins in their area.

Multiple Births Foundation - based at Queen Charlotte's Hospital, our sister charity has long contributed and campaigned for clear guidelines and professional development to improve outcomes in twin pregnancies.

**NICE** guideline and quality

standards committees and the **RCOG** and **ISUOG** guideline contributors.

30 maternity units engaged in the DH funded QI programme and the partners on the steering committee.

UK TTTS registry steering committee

Royal Colleges for their ongoing support and interest and the BMFMS - presidents past and present and their fellow committee members.

The whole research community in this area including the ONS and the MBRRACE teams and NIHR women and children's team.

Finally we want to say a massive thank you to our dedicated staff and volunteer team, both past and present.

With only a few days' notice to put this insights paper together, we are sorry if you should be here but are missing.

# **Appendix**

# Tamba resources produced since 2014

# Factsheets produced

- One parent family
- Same sex couples
- Partners
- Grandparents
- Triplets
- Safe sleeping for twins, triplets or more
- PND and multiple birth families
- Health visitor advice guide
- Weaning
- Potty training
- Individuality

# Specifically for professionals

- Health Professionals Free CPD Area includes a total of 45 video learning sessions (12 Antenatal care, 5 intrapartum care, 10 best practice plus south study day 7 and north study day 11), NICE endorsed multiple antenatal care pathway.
- Growth charts flyer
- CPD flyer
- Bereavement Support Group flyer
- Butterfly cot cards
- Helping Hands flyer
- Courses poster
- Breastfeeding peer support poster

# **Booklets updated**

- Healthy Multiple Pregnancy Guide
- Practical Preparing for Parenthood
- Breastfeeding
- Neonatal Guide
- Bereavement Support

### Webinars launched

- Ask the midwife
- Preparing for parenthood
- Breastfeeding
- Triplet parents to be
- Behaviour
- Sleep
- Weaning

# Pregnancy Countdown Tool

Registered via our website, including in Welsh and shorter by trimester versions in Urdu, Bengali, Gujarati, Polish and Indian Punjabi.

https://www.tamba.org.uk/pregnancy/ pregnancy-countdown-toolintroduction?tab=1

# **Appendix continued**

# Tamba resources produced since 2014

### Videos added to Tamba's website

#### **Bottle-feeding**

- How do you bottle feed more than one?
- with Claire Burgess

<u>www.tamba.org.uk/Parenting/First-Year/</u> <u>Feeding</u>

#### Crying

- How do you cope with two or more babies crying? with Claire Burgess
- Is it normal to feel anxious when your babies are crying? with Claire Burgess

<u>www.tamba.org.uk/Parenting/First-Year/Concerns</u>

#### **Activities**

- Activities with your babies with Claire Burgess
- Being a father of multiples with Claire Burgess

<u>www.tamba.org.uk/Parenting/First-Year/</u>
Bonding

#### **Routines**

What can you do to help develop a routine - with Claire Burgess

www.tamba.org.uk/Parenting/First-Year/ Coming-Home

#### **Preparing siblings**

■ How can you prepare siblings for new babies? - with Claire Burgess

www.tamba.org.uk/Parenting/First-Year/ Coming-Home

#### Sleep - Newborn to 12 months

Vicki from the Children's Sleep Charity talks about what you might expect with regards to sleep in the first 6 months

<u>www.tamba.org.uk/parenting/sleep/</u> 0-12-months

#### Sleep - 12 months plus

■ Vicki from the Children's Sleep Charity answers a series of questions about sleep for children 12 months plus

www.tamba.org.uk/parenting/sleep/ 1yearplus

#### Safe sleeping

- Sleep and safe co-bedding of multiples with Prof Helen Ball
- Why is it important to ensure that babies sleep on their backs?
- What else can we do to reduce SIDS risks?
- Guidance on co-bedding triplets
- Will the babies get too hot if they are sleeping side-by-side?
- Babies sleeping with parents
- Is it ok to co-bed and if so how should it be done?
- Does everyone co-bed in the same way?
- Why do some parents put their babies together in the same cot?
- Should I use dummies?
- Does sleep develop the same way for all babies regardless if they are multiples?
- Once my babies start to sleep through the night does it stay that way?
- How do parents cope with disturbed nights?
- Sleep patterns 6-12 months

www.tamba.org.uk/parenting/sleep/0-12months

## **Appendix continued**

# Tamba resources produced since 2014

# Videos added to Tamba's website (continued)

#### **Triplets**

- How did you feel when you found out that you were expecting triplets?
- Were you offered selective reduction?
- What was your pregnancy like?
- Do you have any top tips on coping with a triplet pregnancy?
- What was the birth like?
- What were your experience of SCBU
- Do you have any top tips for parents with babies in SCBU?
- What were your breastfeeding experiences?
- What were the early days like?
- How did/do you get out and about?
- How do you cope with people stopping you and asking personal questions?
- What did you find hardest to cope with?
- What are your top tips?
- Dad what is it like to be a father of triplets?

www.tamba.org.uk/pregnancy/triplets

#### A parent's experience

A mum talks about her journey of helping her children to get a good night's sleep

www.tamba.org.uk/parenting/ sleep/1yearplus

#### **PND**

■ Inspirational mothers speak to us about their experience of PND, how they cope and their tips for other parents.

<u>www.tamba.org.uk/parenting/under-1s/pnd-experiences</u>



TAMBA, Manor House, Church Hill, Aldershot, Hants, GU12 4JU www.tamba.org.uk support-team@tamba.org.uk

Twinline - freephone helpline: 0800 138 0509 (10am-1pm and 7pm-10pm seven days a week)