



**Bliss and TinyLife:
Northern Ireland
Baby Report 2018**



Bliss
for babies born
premature or sick



Contents

Foreword	4
Summary of findings	6
Introduction	8
Health policy and political context	9
Neonatal standards	11
Nursing	12
Specialist nurses and nurse training	14
Community outreach	17
Medical staffing	20
Shortfall in medical staffing	20
Recruitment of medical staff	22
Allied health professionals	24
Occupancy levels	26
Cot closures	30
Avoidable admissions	33
Transfers	34
Support for families	37
Accommodation and meals	38
Communication	41
Psychological support	42
Conclusions and recommendations	46
Methodology	49
Glossary	50
References	52

Acknowledgements

Bliss and TinyLife would like to thank the staff at neonatal units across Northern Ireland and the NISTAR neonatal transport team who took the time to provide us with information for this report. We would also like to thank the parents who responded to our survey and shared their stories with us.

We are grateful to everyone who has given us invaluable advice and help throughout this process, and with interpreting our results.

This report was written by Josie Anderson, edited by Sadie Constable and designed by Chris Beardsall.

Foreword

Over 1,800 babies are born premature or sick each year in Northern Ireland and cared for at one of the country's seven neonatal units. The care these vulnerable babies receive in their first hours, days and weeks of life is crucial both to their survival as well as their long-term quality of life.

It is therefore of great concern that the research presented in this report - on which we were pleased to work in partnership - shows that neonatal services across Northern Ireland are facing a series of significant challenges, including under-staffing across both nursing and medical rotas, set in the context of wider difficulties around recruitment and training. Neonatal staff across Northern Ireland do a fantastic job, but it is hard for them to provide consistent care in such difficult circumstances, and this was reflected in many of the parent stories we gathered as part of this research.

Parents must also be at the heart of their baby's care and decision making, but our research shows parents have access to very limited psychological support and inadequate facilities on neonatal units. This affects their wellbeing as well as how much they can be with their baby in the hospital, which we know is best for both babies and families.

Whilst we acknowledge the work carried out by the Neonatal Network for Northern Ireland, since its foundation in 2013, to improve quality of care and support offered to families of premature and sick babies, we feel there is much that still needs to be put into place. Fundamentally, neonatal services are being held back by the lack of a clear national service specification setting out the standards they need to meet, and an accompanying national plan and investment to provide the resources required to do so.

Disappointingly, there has been no progress on this since the Department of Health published its Strategy for paediatric healthcare services in 2016, despite the fact that the development of a neonatal service specification was included as a key recommendation in the strategy.

Today, at the start of 2018, Northern Ireland is facing a particularly acute period of political upheaval which is reflected in the Assembly at Stormont, where there has been no functioning Executive for over a year and no ministerial leadership. This is directly affecting decision-making, longer-term planning and investment. However, it is unacceptable that political challenges should get in the way of the urgent need to invest properly in the services that are there to ensure that every baby born premature or sick has the best chance at the right start in life, and we call on all those with a say in decision-making to give neonatal services the priority these babies deserve.



A handwritten signature in black ink that reads "Caroline Lee-Davey".

Caroline Lee-Davey
Chief Executive, Bliss



A handwritten signature in black ink that reads "Alison McNulty".

Alison McNulty
Chief Executive, TinyLife

About Bliss

Bliss was founded in 1979 by a group of concerned parents who discovered that no hospital had all the equipment nor the trained staff it needed to safely care for premature and sick babies.

Determined to do something, these volunteers formed a charity to give vulnerable babies the care they deserve. Almost 40 years later Bliss has grown into the UK's leading charity for babies born premature or sick.

Bliss champions the right for every baby born premature or sick to receive the best care. We achieve this by empowering families, influencing policy and practice, and enabling life-changing research.

About TinyLife

TinyLife, formerly known as Northern Ireland Mother and Baby Action, was founded in 1988 by consultants and parents to raise funds to support research in response to the high levels of infant mortality and morbidity.

TinyLife is the only premature baby charity for Northern Ireland, dedicated to reducing premature birth, illness, disability and death in babies. TinyLife provides a range of family support services within neonatal units, at home and in local community settings, which meet the growing need of families with premature and ill babies in Northern Ireland. TinyLife also funds medical research and provides a programme of training and information seminars for professionals and parents.

Summary of findings

Evidence from neonatal units, the neonatal transport service and parents across Northern Ireland has shown that services providing life-saving care to thousands of babies are under significant strain. These difficulties are exacerbated by a turbulent political context which has seen progress to enable much needed transformation across all Health and Social Care services in Northern Ireland stall since the beginning of 2017.

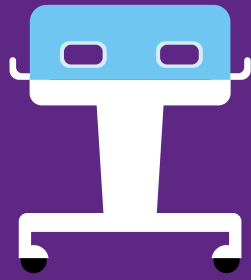
While we recognise that neonatal staff across Northern Ireland do a fantastic job, our findings show that significant additional resources are needed to ensure the sustainability of the neonatal service, as well as investment in family facilities on units to make sure parents can be supported and empowered to take the lead in caring for their baby.

We have found:

- Over half of neonatal units do not have enough nurses in post to meet minimum standards for providing safe, high quality care.
- 55 per cent of the nursing shortfall can be attributed to inadequate funding.
- Five out of seven neonatal units in Northern Ireland have difficulties with at least one aspect of nurse training and development.
- No units in Northern Ireland currently have a neonatal community outreach service provided by neonatal nurses to families after discharge, in place. Despite this, two thirds said they would benefit from having one.
- Four out of seven neonatal units in Northern Ireland do not have enough medical staff in post to meet minimum standards.
- Four out of six units are unable to provide accommodation for all parents of critically ill babies.
- Five out of seven neonatal units have no dedicated access to a mental health professional, and three neonatal units are unable to provide access to any trained mental health professional at all, including by referral to an external service.



Over half
of neonatal units
do not have enough
nurses in post.



**Four out of
seven units**
regularly have to
close their cots.



**Two thirds
of units**
do not have
enough overnight
accommodation for
parents of critically
ill babies.



No units
have a clinical
neonatal community
outreach service
in place.



**Five out of
seven units**
do not have access
to a trained mental
health worker.

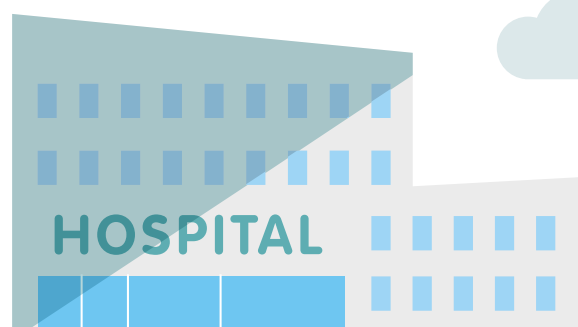


**Four out of
seven units**
do not have enough
medical staff in post.



**Nearly 20
per cent**
of all emergency
transfers are undertaken
due to a lack of
capacity on units.

Neonatal services under pressure in Northern Ireland



Introduction

In 2015, over 1,800 babies were born in Northern Ireland requiring specialist care to help them survive and thrive.ⁱ This means around one in 13 of all babies born in Northern Ireland were admitted to neonatal care due to being born premature or sick.ⁱⁱ

The care these babies receive while in hospital is crucial for both their survival and their long-term quality of life. While many will grow up to have no serious ongoing health conditions, some will face a range of complications in later life.ⁱⁱⁱ However, our findings show that many neonatal services across Northern Ireland do not have the resources to provide care in line with existing standards which are endorsed in other UK nations and followed by neonatal units in Northern Ireland, which set out what safe, high quality care in neonatal units should look like.

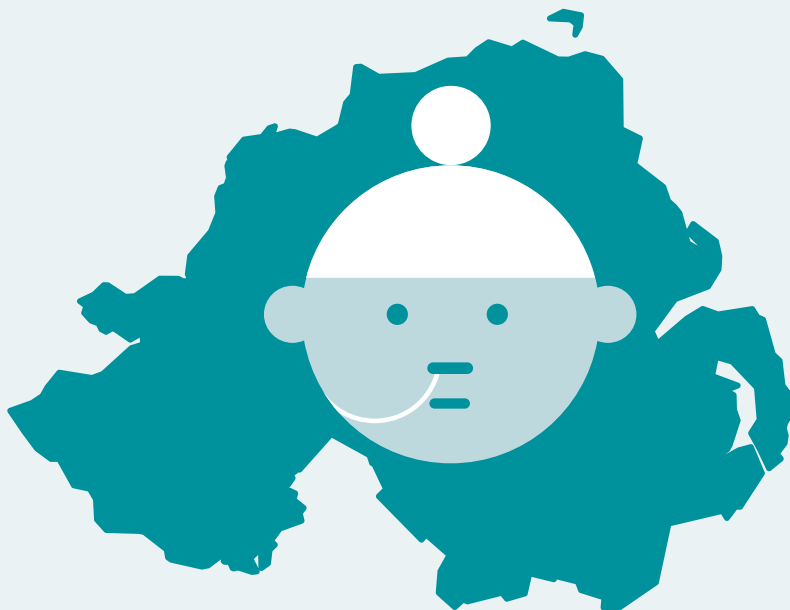
Babies born premature or sick are currently cared for in seven neonatal units across Northern Ireland. The Neonatal Network Northern Ireland (NNNI) leads on the development of safe, high-quality services and works to ensure consistency across units in the network. Central to the work of the network is the input and feedback from families and staff, and they work hard to improve the experience of every family whose baby is born needing neonatal care.

This report is based on information provided by all seven neonatal units and the Northern Ireland Specialist Transport and Retrieval (NISTAR) service neonatal transport team, which operates across the whole of Northern Ireland. Local parents also shared their experiences with Bliss and TinyLife, and their views are included throughout this report.¹

Why are babies admitted to neonatal units?

Over half (52 per cent) of babies that need neonatal care in Northern Ireland do so because they are born premature, at under 37 weeks' gestation.^{iv} These babies are born before they are fully developed, and will often have the longest stays in neonatal care.

48 per cent of all babies admitted to neonatal care in Northern Ireland are born at full term, but with an illness or condition that requires admission and treatment – this ranges from an infection or jaundice to congenital abnormalities and babies requiring surgery.^v



¹ Please see the methodology on page 49 for more information about how this research was conducted.

Health policy and political context

It has been recognised through numerous reviews that there is a need to reform Health and Social Care systems in Northern Ireland to improve the quality, safety and sustainability of services. The challenges highlighted in this report cannot be fully understood without considering the wider Health and Social Care system that neonatal services sit within, and where there are wide-ranging pressures facing services. Leadership and resources from a functioning Executive will be key to overcoming these.

The landmark *Quality 2020: A Ten Year Strategy to Protect and Improve Quality in Health and Social Care in Northern Ireland* (2011), aims to improve safety, effectiveness and cement the role patients and families play in shaping the health services they interact with. The strategy aims to achieve these goals by:

1. Transforming culture across services so staff are willing and able to embrace innovation and change.
2. Strengthening workforce and ensuring staff are equipped with the skills and knowledge they need.
3. Improving data collection to enable better measurement, evaluation and reporting on the effectiveness of services.
4. Developing more coherent and robust standards across services, and for service users to be involved in the development of these.
5. Integrating care across all professional boundaries to benefit patients and their families.^{vi}

While this strategy does not set out service-specific goals, it does identify that Health and Social Care services need to transform fundamentally in order to modernise. The report provides an opportunity for services to reflect on practice, and there has been some improvement at neonatal units with regards to clinical practice and family-centred care as a result of programmes stemming from the strategy.^{vii} However, more recent assessment of the strategy has noted that, while there is commitment to quality improvement at the 'top of the organisation', on the frontline it is 'still viewed as a peripheral activity for a small number of Health and Social Care staff [to do]'.^{viii}

This was followed by *The right time, the right place: an expert examination of the application of Health and Social Care governance arrangements for ensuring the quality of care provision in Northern Ireland* (Donaldson, 2014) report. This report focused on changes to the design of Health and Social Care which could make services safer and more effective, including through reconfiguration of specialist services and standardising clinical practices.^{ix} The report also argued that patients, and their families, should be allowed to have a more powerful voice when it comes to shaping services – especially when things go wrong.^x

Most recently, the *Systems not Structures: Changing Health and Social Care* (Bengoa, 2016) review discusses the urgent need to transform health systems so that they are sustainable for the long term. Among other areas, this report notes the widespread staffing shortfalls across all specialities and the need to re-evaluate investment and spending priorities. The review also called for urgent action to ensure the viability of Health and Social Care services as it estimated that, if the system continues in its current form, it will cost double the amount to fund it simply to maintain current levels of performance; which would amount to 90 per cent of the entire Executive budget.^{xi}

The lack of land border with the rest of the UK adds an additional level of complexity when planning neonatal services and ensuring their smooth running. Occasionally, babies will need to be transferred out of Network to receive care, but the distance to other UK hospitals means it is complex to co-ordinate for staff, and places additional pressures on families. Many babies who need to be transferred out of Network are cared for in the Republic of Ireland. While geographically closer and easier to travel to, there are additional difficulties associated with transfers to a country outside of the UK, for example there are separate systems for birth registration and for information gathering and monitoring.

It is within this complex environment that neonatal services operate. Neonatal staff do fantastic work, and are still often able to deliver high-quality care to babies born premature and sick across the country. However, it is difficult to provide care consistently in line with standards of safety and quality when the wider system, as well as the service itself, is under pressure. Further, while these system wide reviews and strategies lead to broad recommendations, it is important that detailed and service specific strategies are developed to implement change on the frontline.

It is therefore welcome that neonatal services are starting to receive greater focus. The 2016 *Strategy for paediatric healthcare service provision in hospitals* and the upcoming review of neonatal services by the Health and Social Care Board on behalf of the Department of Health² provide an opportunity to assess how best to design and operate services to ensure babies receive safe and effective care in a consistent way across all units in the country.

Despite this welcome focus, fundamental service change along with the investment needed to continue to improve both neonatal services and other healthcare systems in Northern Ireland needs to be led by a functioning Government. It is only at Ministerial level that significant changes, and resources to implement programmes now, can be signed off and delivered.

It is imperative that – regardless of the political climate or where decisions on healthcare are being made – the investment and resources are put in place to ensure that every baby born premature or sick in Northern Ireland is cared for in a neonatal unit which is staffed safely, and receives high-quality care from professionals with the right training. A functioning and stable Government underpins the ability of services to transform now - and into the future.

2 The Department of Social Services and Public Safety (DHSSPS) formally changed its name to the Department of Health in 2016.

Changes over Time

2010

NICE publishes the *Specialist neonatal care quality standard*, defining clinical best practice.

2011

Quality 2020 is published, outlining a ten year strategy which aims to improve safety and effectiveness across Health and Social Care.

2014

The right time, the right place report (The Donaldson Report) highlights how reconfiguring specialist services and standardising clinical practice can improve safety and quality across services.

Neonatal standards

Unlike other UK nations, Northern Ireland does not have specific standards setting out the range of services required to ensure high quality care is provided to babies born premature or sick, and their families, while on the neonatal unit

The British Association of Perinatal Medicine (BAPM) *Services Standards for Hospitals Providing Neonatal Care* (2010) are regarded as best practice and applicable across all nations of the UK, and these standards have been used when assessing how neonatal units in Northern Ireland are operating. The NNNI supports the use of BAPM standards, including nurse-to-baby ratios.

Other documents such as the then-Department of Health (England) and NHS *Toolkit for High Quality Neonatal Standards* (2009), *All Wales Neonatal Standards 2nd Edition* (2013), *Neonatal Care in Scotland: A Quality Framework* (2013) and the National Institute of Clinical Excellence (NICE) *Specialist Neonatal Care Quality Standards* (2010) have also been drawn upon in this report. While not formally endorsed in Northern Ireland, they provide an evidence based framework against which to benchmark neonatal services in the absence of a service specification.

The recent Department of Health's *Strategy for paediatric healthcare services provided in hospitals and in the community 2016-2026* specifically recommends that a service specification for neonatal care be established which is consistent and in line with the *Toolkit*. This would put a framework for consistent practice in place – particularly in areas of the service which do not have a whole network endorsed best practice marker; such as the facilities and support available to families on the neonatal unit – and would also support the equitable allocation of funding for neonatal services across trusts, whereas at the moment there can be disparity between trusts in terms of how funds are spent.

It is therefore important that the Health and Social Care Board and the Public Health Agency work to ensure the recommendations of the *Strategy for paediatric healthcare services* are delivered as swiftly as possible.

2016

The *Systems, not structures* (Bengoa Report) review showed the long-term instability of services across Health and Social Care. It warned service reform was needed now to ensure the longevity of services.

2016

The *Strategy for paediatric healthcare service provision in hospitals* recommends a neonatal service specification is developed

2017

The Northern Ireland executive collapses. Projects aimed at reforming services cannot progress.

Nursing

Neonatal nurses provide the majority of care to babies who require treatment on neonatal units, and do a great job of delivering compassionate care to babies and their families. However, it is of course vital that units in Northern Ireland are funded to have enough nurses in order to meet BAPM standards for nurse-to-baby ratios. There is clear evidence that having enough nurses, with the right skills, to provide direct hands on care to babies has a big impact on survival rates and outcomes.

Evidence^{xii}

As early as 1993, research identified the key nurse-to-baby ratios required in neonatal care, which would then be incorporated into standards documents. Williams et al. found, after asking nurses to provide a breakdown of how long they spent doing each task on their shift, that the most unstable babies required continuous attention from one nurse. One nurse could look after up to two ventilated babies, and a single nurse was able to care for up to four babies requiring special care.^{xiii}

More recent studies determined that nurse-to-baby ratios adopted within national standards should be regarded as minimum levels. Milligan et al. concluded that babies who were clinically stable and only in need of special care could require a significant amount of attention when establishing breast or bottle feeding, and a very unstable baby could require the continuous care of more than one nurse.^{xiv} Pillay et al. agreed, concluding in their study of a single neonatal network that “far from being aspirational, [the standards] are practically needed as the bare minimum for adequate service provision.”^{xv}

Nurse staffing levels also directly correlate with mortality rates, with research showing that infants cared for in a setting with higher nurse-to-baby ratios have an improved adjusted risk for survival.^{xvi} It is therefore vital that sufficient numbers of nurses are available on a unit, otherwise babies could be put at risk. The most recent research published in 2016 by Watson et al. established that an increase in mortality rates at Level three units occurred when there was a decrease in the required one-to-one nursing for babies receiving the most intensive level of care.^{xvii}

As well as ensuring the overall nurse-to-baby ratios are sufficient, it is essential that enough nurses with the right skills are available on a unit. Hamilton et al. show in their 2007 study of 54 neonatal intensive care units in the UK that having more nurses Qualified in Speciality (QIS)³ than the standards recommend, reduced the risk of mortality by 48 per cent.^{xviii}

National standards: nurse staffing

The BAPM *Service Standards*, the then-Department of Health's (England)⁴ *Toolkit, All Wales Neonatal Standards* and Scotland's *Quality Framework* and the NICE *Quality Standards* all endorse and consider the following to be the minimum nurse-to-baby ratios which will enable safe and effective care to babies requiring neonatal care:

Special care: there should be a minimum staff-to-baby ratio of 1:4 at all times.

High dependency care: there should be a minimum staff-to-baby ratio of 1:2 at all times.

Intensive care: there should be a minimum staff-to-baby ratio of 1:1 at all times.

The NNNI supports these BAPM ratios, and neonatal units work to adhere to them.

3 This is a nurse or midwife who holds a post-registration qualification in specialised neonatal care.

4 The Department of Health in England formally became the Department of Health and Social Care in January 2018

Over half (four out of seven) neonatal units did not have enough nurses in post to meet minimum standards for providing safe, high quality care. Pressures on neonatal nursing numbers are felt across the system with the NICU, two LNU⁵ and a SCBU⁵ all reporting not having enough nurses in post.

“ While in Intensive Care, it was one nurse to two babies. We were told that it would normally be one on one care but because of understaffing, this wasn't possible. However this does not take away from the fact that the care shown to my baby, both by doctors and nurses was nothing less than 100%. ”

Mum of a baby born at 24 weeks

Bliss and TinyLife calculate, based on the information provided on the snap-shot day we asked about, that at least an extra 28 nurses are needed across Northern Ireland to ensure that all babies born premature or sick get the care they need.⁶

For some units, the shortfall represents a significant proportion of their overall workforce. For example, one unit which currently has 34 WTE (whole time equivalent) nurses in post needs their workforce to increase by over 30 per cent in order to meet demand – this is equivalent to 11 extra nurses.

Most of this shortfall is due to units not being funded to employ sufficient numbers of nurses in order to staff units in a way which will ensure safe nurse-to-baby ratios. In total, three of these four units (one SCBU and two LNU^s) would still be falling short by 15 nurses if all their vacancies were filled – meaning 55 per cent of the nursing shortfall can be attributed to inadequate funding.

“ I feel that there wasn't enough nurses. It [was meant to be] one nurse per baby but the majority of the time each nurse had two babies to look after. This meant having to wait longer if my daughter needed to be suctioned or if her SATS were going down. ”

Mum of a baby born full-term but sick

Challenges with nurse staffing sit within the context of wider staffing gaps facing Health and Social Care Trusts across Northern Ireland. The latest workforce census shows threats to the stability of the nursing and midwifery workforce over the next ten years with 59 per cent of the workforce currently aged over 40, and 32 per cent aged over 50 and approaching retirement.^{xx} The census also reveals the nursing and midwifery workforce has the second highest leaving rate of all specialities (5.9 per cent).^{xx} The recent *Systems not Structures* report revealed that spend on agency staff across the whole of nursing and midwifery grew by nearly 60 per cent from 2010/2011 to 2014/2015.^{xxi} Reliance on bank staffing is expensive and unsustainable, and the emphasis must be on funding, recruiting and training, permanent staff, and retaining them long-term.

5 Please see glossary on page 50 for an explanation of the different levels of neonatal care.

6 Please see methodology on page 49.

“ All care I witnessed was nursing care which was 1:1 or 1:2 in ICU depending on the baby and it was 24/7. Nursing staff provided me with excellent care and updates on my baby. The only issue was they were so busy it was difficult to get skin to skin time. I only got him out of incubator once or twice per day and I feel it would've helped me immensely had I been able to offer kangaroo care as opposed to nursing him a few times per day in ICU.”

Mum of baby born at 33 weeks

Sufficient staffing numbers are also essential for ensuring that staff have the time to talk to families and support them to be involved in their baby's care, as well as have the time for comprehensive handover between shifts. A recent study of parents while on a neonatal unit has shown that a 'universal theme' experienced by parents in Northern Ireland is inconsistency in communication from healthcare professionals, and varying practices between different units.^{xxii}

Nurses are the bedrock of neonatal services and do a fantastic job. But it is harder for them to practice high-quality care consistently which is in line with standards when they are overstretched. It is vital that units receive the investment they need to ensure sustainability of nursing numbers now – and into the future. This is particularly important as it takes at least five years to train a nurse to QIS standard in this highly complex area of care.⁷

“ Neonatal staff often change their duty to accommodate acuity. We also have a small pool of bank nurses to cover shortages and paediatric nurses can also help out when unit is busy and vice versa. We have good communication links with obstetrics through our labour ward safety briefing huddles – and we're able to identify network cot availability through network cot locator.”

Ward manager

Specialist nurses and nurse training

For babies to have the best possible chance of survival and quality of life, it is essential that they are not only cared for by the right number of nurses, but by nurses with a high level of experience and competence to carry out very complex care for the smallest and sickest babies.

It is also important that nurses are given ample opportunity to further their skills through regular training and development opportunities appropriate to their role, to ensure that their skills are maintained against the most up-to-date guidance and best practice.

⁷ Training a nurse to Qualified in Speciality status takes around five years in total. This consists of a nursing degree (generally three years), and then a minimum of six months' experience working in a neonatal unit to be accepted on to the QIS training course. This post-registration qualification then takes a further one to two years.

National standards: specialist nurses and nurse training

The then-Department of Health's (England) Toolkit and Scotland's Quality Framework both state that a minimum of 70 per cent of the registered nursing workforce establishment should be trained to QIS standard for neonatal care. This is an important marker of quality to ensure that a high proportion of the nurse workforce in each unit has proven competence in providing complex care to these babies.

While it was not possible to determine the proportion of QIS nurses in Northern Ireland, it is clear that units across the board are committed to ensuring that staff receive training and have the opportunity to enhance their skills – with one unit, the NICU, commenting that they aim for all of their Band 5 nurses to be QIS.

Despite these welcome commitments, five out of seven neonatal units in Northern Ireland said they had difficulties with at least one aspect of nurse training and development. The remaining units reported having no issues at all.

Units most often reported challenges in releasing nurses for training, with four units indicating this was a barrier which presented itself in different ways. Three of these units, made up of both SCBUs and the NICU, said it was the most common difficulty they faced, with two of these units saying that insufficient numbers of staff on the unit made it difficult for nurses to be released. While no LNUs reported that difficulties releasing nurses prevented training, one did note that this was not an issue only because bank staff are regularly used to backfill in order to facilitate frontline training.

“Some training had to be cancelled due to sick leave.”

Ward manager

In addition to the challenges they face around releasing nurses for training, three of the aforementioned units, one SCBU, the LNU and NICU, also reported vacancies meaning they did not have enough nurses in post in order to meet BAPM standards. This suggests that these shortages may be having a direct impact on the ability of nurses to engage with development opportunities and could result in some staff falling behind in their training, which can affect their skills, or units relying heavily on bank staffing in order to make up the numbers; which is a costly, short-term solution.

“Bank staff are used on a regular basis to facilitate frontline training.”

Ward sister

By contrast, the majority of units reported that funding and lack of opportunity were not barriers to training. Only one unit, an LNU, reported funding issues as a barrier to nurse training. This unit reported that they had more staff who wanted to train as an Enhanced Neonatal Nurse Practitioner (ENNP)⁸ than there were funded places available. They also stated that once the ENNP course has been completed, there was no automatic progression to a higher Band. Instead, nurses with this training need to wait for a suitable vacancy before applying for a role where they can fully utilise their skills.

8 Please see glossary on page 50

Similarly, only one unit, another LNU, felt that there was a lack of opportunity for development. This unit stated that, due to their designation, staff had limited opportunity to enhance their skills in caring for extremely premature babies.

It is positive that the majority of units do not feel that funding or lack of opportunity are barriers to training, and this is a departure from other areas of the UK.^{xxiii, xxiv, xxv} It is important that staff continue to have access to training, and that units continue to have resources available to enable high levels of nursing staff to take this up.

The *Strategy for paediatric healthcare services* noted that ‘the increasing complexity of babies being cared for in neonatal units means appropriate training of neonatal nurses to meet future services requirements is essential.’^{xvi} It is important that the significant barriers some units are facing to release nurses for training are addressed. These cannot be resolved without tackling the underlying challenge of nurse shortages, so it is vital that a commitment is given by the Department of Health to give additional funding to the Health and Social Care Board in order to recruit – and train – more nurses.



Community outreach support

Going home is usually an extremely exciting time for families – but it can also be incredibly daunting. It is the first time that parents have to take full responsibility for the care of their baby without the reassurance of having nurses and clinicians at hand. Community outreach, typically provided by neonatal nurses who visit families in their own home after discharge, is important for a family's wellbeing as they get used to being at home.

National standards: community outreach

There are no neonatal standards specific to neonatal community outreach⁹ which cover Northern Ireland.

However, *The All Wales Neonatal Standards* and *Scotland's Quality Framework* state that neonatal units should be able to demonstrate that they have the staff with appropriate training, knowledge and skills available to provide support in the community post-discharge, where this is required.

No unit in Northern Ireland currently has a clinical neonatal community outreach service in place. Despite this, two thirds (five out of seven) said they would benefit from having one. The two services which reported they did not feel a community outreach service would be beneficial were SCBUs.

Of the five neonatal units who said their service would benefit from neonatal outreach staffed by neonatal nurses, two told us they had no formal follow up arrangements in place at all. One LNU noted that while they invite certain babies to be followed up neuro-developmentally in clinic, if parents want support from the neonatal unit staff after discharge they are able to phone the hospital up to one week after going home.

“ I didn't receive a lot of community support. Apart from TinyLife groups there was nothing. ”

Mum of baby born at 34 weeks

The other three units without a neonatal community outreach team to support parents in their homes after discharge, and who said they would benefit from having one, noted they have good relationships with external partners such as the home oxygen team or hospice. As a result, a small number of families whose babies will be discharged in need of these services will receive ongoing support from another agency. However, the vast majority of families, whose babies will be discharged well or with less complex ongoing care needs, have no access to support from neonatal unit staff once they are at home.

“ I didn't access community support as I wasn't aware there was any available to me. I would have welcomed and really appreciated community support as I felt very isolated and traumatised to an extent by my experience. ”

Mum of a baby born full term but sick

⁹ In this section, neonatal community outreach refers to a clinical service provided by neonatal units where nurses support families through discharge and visit them at home. This is separate to community health services provided more widely by GPs and Health Visitors and community support services provided by organisations like TinyLife.

Several units commented on the prevalence of community based services provided by TinyLife. As a result of good links with the charity, many parents of premature babies are able to access face-to-face services including Baby Massage, Baby Sensory Facilities and parent groups after discharge. Families of babies born in the Northern Health and Social Care Trust who meet a set of criteria also have access to TinyGym, a specialist group-based physiotherapy programme that educates parents in basic physiotherapy activities that they can use with their baby at home to improve their child's development. TinyLife Family Support Officers support parents to access this service and, throughout their time engaged in this programme, the physiotherapist helps the parents to understand the difference physiotherapy can make to their baby.

“ The health visitor who came to visit our baby was helpful but not very well informed. She did not have any information relating to premature babies. She did not have premature baby charts for length/weight etc. She did not have any information around the feeding requirements of a premature baby or weaning. ”

Mum of a baby born at 31 weeks

Nearly 40 per cent of Northern Ireland's population live in rural communities so it is important that there are appropriate services for families who may find it difficult to travel frequently to hospital or to services provided by voluntary organisations such as TinyLife.^{xxvii} It is also vital that babies with significant care needs have a care-package and support which suits the circumstances of their families. A lack of clinical outreach services in Northern Ireland means a valuable avenue to provide this is not being utilised.

“ If I am being honest for a long time after leaving neonatal I was pretty much left to my own devices with an extremely sick child who had a lot of complex needs. As a single parent this was very hard for me. If it weren't for the fact I have such a good family network it would have been very hard to cope. ”

Mum of baby born at 23 weeks

It is important that resources are made available to develop clinical outreach services which complement and support existing community based holistic services run by voluntary organisations (which now also include a website designed to support parents of premature babies post-discharge).^{xxviii} *The Strategy for paediatric healthcare services* notes that any development of a neonatal service specification for Northern Ireland must ensure the role of community and voluntary organisations in supporting babies, and their families, must be an important element.^{xxix} It is important that neonatal community services are defined in a service specification, and that clear pathways between clinical and non-clinical outreach services are defined so every family of a premature and sick baby can access support after they have left the neonatal unit.



Medical staffing

Neonatal units need to have the right number and mix of medical staff in order to manage babies' care safely and effectively. There are far fewer medical staff working on neonatal units compared to nurses, so even one or two gaps on a medical rota can have a big impact on babies' care, and how effectively the unit is operating.

National standards: medical staffing

The British Association of Perinatal Medicine (BAPM) *Service standards for hospitals providing neonatal care* (3rd edition, 2010), sets out guidelines for the minimum numbers of medical staff needed at each level of seniority. The NNNI supports the use of BAPM *Service Standards* for medical staffing arrangements.

All units: medical staffing rotas should have a minimum of eight junior (tier one¹⁰) staff members such as doctors new to the speciality and advanced neonatal nurse practitioners (ANNP), eight competent on-site clinicians (tier two) such as speciality doctors and advanced neonatal nurse practitioners, and seven expert (tier three) staff members who are medical consultants. The exact composition of the medical staff needed, and whether these staff should have their time solely dedicated to the neonatal service at each tier, varies between the levels of unit.

Special care baby units: medical staff may be on a shared rota with paediatrics, but at least one consultant should have a lead interest in neonatology. In some settings, tiers one and two may be merged.

Local neonatal units: tier one staff should only cover the neonatal unit, though other staff members may be shared with general paediatrics. A minimum of one consultant should have a lead interest in neonatology and the other consultants covering the service must have expertise in neonatal care.

Neonatal intensive care units: all medical staff should be limited to neonatal care at all levels; there should be no crossover with general paediatrics. There should be 24/7 availability of a consultant neonatologist at tier three, and additional input at tier two, including resident neonatal consultant, where appropriate. The largest units will need many more; BAPM's *Optimal Arrangements for Neonatal Intensive Care Units* (2014) sets out the extra medical staff they need to take on.

Shortfall in medical staff

Based on the information provided by units on the snap-shot day we asked about, four out of seven neonatal units in Northern Ireland did not have enough medical staff in post to meet BAPM minimum standards for safe, high-quality care. This included both SCBUs and two LNUs.

One of these units, a SCBU, reported severe shortages across its tier three (consultant) medical staffing. This is particularly concerning because these doctors are the most experienced and will be needed to make critical decisions about a baby's care. For a baby born in SCBU, this includes making the decision regarding whether to transfer them to a different unit and assessing the extent of their care needs.^{xxx}

The other three units all reported shortages among their tier one (junior) medical staff. Two of these units, both LNUs, used ANNPs to provide medical rota cover, and one noted they also used ENNPs to do the same. While these highly skilled nurses have the skills to cover tier one (junior) roles, removing them from nursing rotas regularly to fill medical rota gaps can exacerbate existing nurse staffing issues (see Page 12). It is imperative that units have the resources available to fully staff their medical rotas without heavy reliance on highly-skilled nursing staff.

¹⁰ Please see glossary on page 50.

“ I only got to speak to a doctor once in the four weeks my child was in NICU and SCBU. ”

Mum of baby born at 31 weeks

Further, while the NICU does meet BAPM standards for safe, high quality care there are only enough medical staff at tiers one and two to meet the minimum required for all neonatal units, and tier three only exceeds the minimum requirement by 1.25 WTE. This is of concern because it is the only unit in Northern Ireland capable of caring for extremely early gestation babies, and babies born with serious congenital abnormalities. Yet, from the data provided by units, it has fewer WTE tier three in post than three of the LNUS. This would still be the same if its tier three vacancies were filled. Indeed, the NICU respondent noted that their medical staffing is below the average for a unit of their size, with comparably-sized NICUs in other UK countries typically having a higher complement of medical staff.

“ You never really saw a lot of senior doctors about, only when they did their rounds. Due to [the ward rounds] being first thing in the morning you were never there due to the journey and other children. ”

Mum of baby born at 28 weeks

Three LNUs also reported having to share their tier one (junior) staff with paediatrics, despite the BAPM standards stating that units of this designation should have a completely separate neonatal rota. Two of these three units shared tier one (junior) rotas with paediatrics for the full 24 hour period, while the remaining LNU only shared partially. Further, all four units shared their tier two (middle grade) and tier three (consultant) doctors with paediatrics. While this is in line with the standards, one unit noted that medical staffing was insufficient when the unit was busy, and could be affected by peaks in paediatric demand.

Adequate medical staffing also helps to ensure that parents and carers receive the right levels of communication and support. Clear and regular communication is important for parents in order to reduce their anxiety^{xxxix}, as well as allowing time for their questions to be answered and for them to be fully involved in the decision making process for their baby.

“ I felt there were not enough doctors or nurses. We barely had any contact with the doctors. ”

Mum of baby born at 34 weeks

The Royal College of Paediatrics and Child Health (RCPCH) *Facing the Future* (2015) standards outline that every parent in a neonatal unit should have a consultation on their baby's condition with a senior member of the team (either a consultant, tier two (middle grade) or ANNP) within 24 hours of admission.^{xxxii} However, the Neonatal Intensive Care Outcomes Research and Evaluation (NICORE) found in their analysis of 2015 data that parents were only consulted within 24 hours by an appropriately graded member of staff 48 per cent of the time.^{xxxiii} While some of this shortfall can be attributed to data collection issues and inconsistent recording, it still provides a useful indicator that this is an area for focus and improvement; and it is welcome that this has been recognised by the NNNI as an area for attention.

“ My experience of senior doctor staffing levels was very mixed - generally positive but there seemed to be a real lack of senior doctor support at the weekend. My son had some serious dips (sepsis and NEC) both of which started at the weekend and I had to demand that a consultant was called to review him - thankfully I pushed for this. On one occasion a junior doctor told me that he 'didn't know what to do next.' However he wasn't immediately keen to call a consultant in. On review, my son was started on treatment both times. ”

Mum of baby born at 30 weeks

Recruiting medical staff

A substantial barrier to units in Northern Ireland providing care which meets BAPM standards is their ability to recruit enough medical staff. Four out of seven neonatal units reported at least one medical vacancy, including one SCBU, two LNUs and the NICU. While the extent of the vacancies varied in their severity across units, vacancies were most common across tier one (junior) and tier two (middle grade).

One LNU had vacancies at every medical tier, suggesting that this unit is facing a particularly chronic situation.

A number of SCBUs and LNUs noted that some of their medical vacancies were being filled temporarily by locums. However, this can lead to instability with one unit noting that two locums left within a month of each other. One LNU also reported using a combined rota across tier one (junior) which included ENNPs. This is potentially placing an increased pressure on nursing rotas at this LNU as it also did not have enough nurses in post to meet BAPM standards, and demonstrates the balancing act units are undertaking to ensure the unit runs as efficiently as possible.

Insufficient funding to recruit the number of doctors needed also contributes to some of this shortfall. If all medical vacancies were filled, two units which failed to meet minimum staffing levels would still not have had enough medical staff in place to meet BAPM standards.

Medical shortages in neonatal units have been a long-standing issue in Northern Ireland which has so far been difficult to resolve, and this report demonstrates that these issues persist. The RCPCH *Paediatric Rota Gaps and Vacancies 2017* report showed that Northern Ireland had both the highest level of tier one vacancies at 27.3 per cent compared to a 14.6 per cent UK average, and at tier two with a vacancy rate of 37.4 per cent compared to a 23.4 per cent UK average.^{xxxiv} The vacancy rate in tier one has risen steadily from 19.2 per cent in 2016 and 13.6 per cent in 2015, and a similar pattern is true for tier two.^{xxxv xxxvi}

This has caused long-standing concern among clinicians. Every respondent from Northern Ireland to the 2017, 2016 and 2015 RCPCH workforce surveys said they were either very or moderately concerned about their service's ability to cope over the next six months. ^{xxxvii xxxviii xxxix}

These pressures are not unique to neonatal services. There have been considerable increases in spending on locums in Northern Ireland, rising from £23.6m in 2010/2011 to £38.5m in 2014/2015 across all medical and dental specialities.^{xi}

The 2016 *Systems not Structures* report noted that it was difficult to recruit junior doctors across specialities as they would not be able to get the experience they need to develop and maintain their skills. For junior doctors, working as a locum provides greater exposure to different environments and clinical services than they might get in a permanent position.^{xii}

In this context, it is clear that difficulties with neonatal staffing cannot be resolved in isolation. There needs to be a concerted and focused effort, led by the Department of Health and the Health and Social Care Board to deliver system wide change.

In the short term, the level of concern from neonatal clinicians cannot be ignored. Resource and a clear strategy is needed urgently to maintain the safety and effectiveness of the service.

“ Medical staffing is insufficient when the unit is busy particularly if this occurs out of hours and at weekends. Consultant medical input is reduced because of high general paediatric and administrative workload. ”

Nurse Manager



Allied health professionals

For babies born requiring neonatal care to have the best chance of survival and quality of life, they need input from a whole range of professionals. While neonatal nurses and doctors provide the majority of their care, a multi-disciplinary team including (but not limited to) occupational therapists, speech and language therapists, physiotherapists and pharmacists come together to provide a comprehensive assessment and care plan individualised to each baby's needs.

National standards: allied health professionals

The BAPM *Service Standards* set out the range of professionals with specialist knowledge and skills who babies need to be supported by. These include physiotherapists, occupational therapists and neonatal speech and language therapists. The NICE *Quality Standards* also state that neonatal services should have a 'sufficient, skilled and competent multidisciplinary workforce' which includes input from the aforementioned professionals who are specifically trained in the care of neonates.

Similar standards regarding allied health professional input are endorsed in the then-Department of Health's (England) *Toolkit*, Scotland's *Quality Framework* and the *All Wales Neonatal Standards*.

However, BAPM standards do not set out how much time should be available in Allied Health Professional (AHP) work-plans to support babies or their specific levels of experience and expertise in working with neonates; nor are there specific Northern Ireland standards on this.

It is very positive to note that there has been recent investment in provision of allied health professionals across neonatal services in Northern Ireland: our findings show that all units have access to the vast majority of allied health professional services.

“The pharmacist attended the unit every day, the occupational therapist, physio and speech and language therapist attended once a week for a multidisciplinary team meeting and more often if required. The input of these members of staff was very valuable.”

Mum of a baby born at 28 weeks

The NICU has dedicated access to the full range of allied health professional services. Both SCBUs have no dedicated access to any allied health professional services, but can refer to an external service in most instances. Only two units (a SCBU and LNU) are unable to provide access to any pharmacy and radiography from a neonatal experienced professional, even by referral.

These are largely welcome findings, following investment and development in the 2015/2016 financial year. However, it is important to note that the dedicated time for these professionals is quite small. For example, the NICU, which will care for babies with the most complex care needs who will need the greatest input from a multi-disciplinary team, had 0.5 WTE dedicated in most specialties, and it was noted by the respondent that the unit would benefit from an increase in resourcing across all professions. Allied health professionals need to have sufficient time with the neonatal service in order to become fully integrated into the team. There needs to be enough resource to ensure that all babies benefit from the input of these professionals – and not just those who are extremely premature or very sick.

If babies are unable to receive support from the full range of professionals when they need it, it can have a lasting effect on their long-term development and health. For example, poor nutrition or pain management can have a significant impact on a baby's neurodevelopment as they get older.^{xliii xliiv} An assessment by a multi-disciplinary team prior to discharge can help families overcome difficulties, such as feeding issues, which may reduce a baby's care needs and prevent further hospital admissions.

“Our little man has complex needs so had input from the speech and language therapist and physio. This had to come from the children's hospital and appeared to be difficult to arrange. An onsite team of allied health professionals would be very useful.”

Mum of a baby born at 33 weeks

At the time Bliss and TinyLife received responses from neonatal units, one LNU noted that while they currently only had access to these services via referral, their funding application for increased allied health professional input was being progressed. Another LNU responded that they had funding for dedicated access, but were still recruiting to some of the posts so the allied health professional team was not yet fully operational. Since our research was conducted we've received assurances from the NNNI that these gaps have been filled and both LNUs now have dedicated access to the full range of AHP services.

This recent progress on the funding of allied health professionals to provide input into neonatal units should be celebrated. Several units commented that for the first time they feel like they are working in a multi-disciplinary team and that these professionals are highly valued. It is important that the momentum behind establishing these services does not diminish and that they continue to receive the funding they need Trusts to ensure every unit has sufficient allied health professional presence to meet the needs of all babies born needing neonatal care in Northern Ireland.

“Since the commencement of allied health professional disciplines in neonatal unit we have truly experienced the meaning of a multi-disciplinary team.”

Ward sister

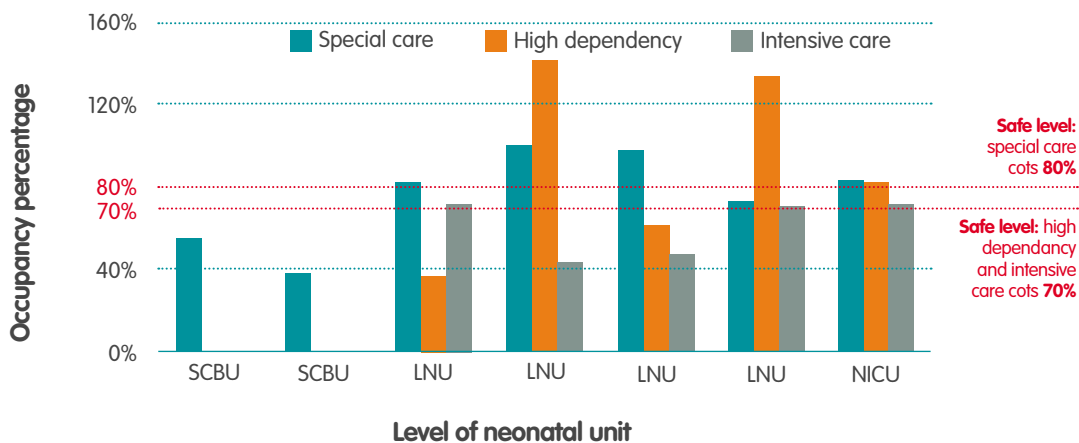
Occupancy levels

A consistently high occupancy rate of cots in neonatal units has been shown to have a negative impact on babies' survival rates, with studies showing that babies cared for in an intensive care unit at 100 per cent occupancy had about 55 per cent higher risk of dying than babies admitted to units with lower occupancy.^{xv}

National standards: occupancy levels

BAPM state that services should be planned for an average occupancy of 70 per cent and the then-Department of Health's (England) *Toolkit* explicitly states that average occupancy should not exceed 80 per cent across intensive care and high dependency. Just as over-occupancy can stretch staff time and put inordinate pressure on units, a unit which is consistently running at low occupancy runs the risk of staff not looking after enough babies to maintain their skills.

While the average occupancy for neonatal units across Northern Ireland is 72 per cent, this masks wide variation. Some units are caring for more babies than is considered safe on a regular basis, while in other units some staff are potentially not caring for enough babies to maintain their skills.¹¹



Graph one: Average occupancy of neonatal units in 2016/2017

As the average occupancy graph shows, four out of seven neonatal units have an average occupancy across their special care cots of more than 70 per cent, including two LNUs who have an average occupancy across these cots of nearly 100 per cent.

LNUs are the units in Northern Ireland which are struggling the most to manage their capacity in line with BAPM and *Toolkit* standards. Two of these units have an average high dependency cot occupancy far above 100 per cent – resting at 143 per cent and 134 per cent across these cots respectively. Being consistently over capacity can make it difficult for units to plan for, and manage, surges of activity. This can lead to units needing to re-designate their cots, or even shut the unit to admissions.

Two further LNUs (including one with occupancy across their high dependency cots of over 100 per cent) also have an average capacity across their intensive care cots of over 70 per cent – which is in line with intensive care cot occupancy at the NICU. This may suggest that some babies who are receiving intensive care at these units might be appropriate candidates to be transferred to the NICU for longer-term intensive care. It is important that protocols for escalation of care transfers are followed to ensure babies receive care in the most appropriate setting for their needs.

¹¹ See methodology on page 49.

“ We had to travel for one week as there was no capacity at a unit closer to home. This was challenging since I had a C-section and my husband had to do all the driving, never mind the strain we were under knowing our baby was sick.”

Mum of a baby born at 34 weeks

Clinical best practice stipulates that the very smallest and sickest babies have improved mortality and morbidity outcomes if they are cared for in a larger, specialist hub. Staff at these units are more easily able to maintain and advance their skills as they will be caring for more very sick babies than those on a smaller unit. It is therefore important that babies who require prolonged intensive care, as set out in the BAPM *Optimal Arrangements for Intensive Care Units*, are transferred to the appropriate setting after birth or, preferably, their mother is transferred with the baby in utero to the appropriate hospital so she can give birth at a unit with tertiary level intensive care on site.^{xvii}

“ I was told there were no incubators available and I would have to move to London, Glasgow or Dublin. A very kind doctor came back and said he had got some babies moved around and had a cot for my baby. The stress and panic I felt at having to move away from people I knew and my family felt awful. Thankfully I got to stay.”

Mum of a baby born at 29 weeks

Issues with maintaining occupancy will be placing pressure on nursing and medical rotas to ensure high-quality care is provided and nurse-to-baby ratios are maintained. Units with over-occupancy in one area can also exhibit under-occupancy in another. For example, one LNU has over 70 per cent occupancy across their intensive care cots and nearly 90 per cent occupancy across their special care cots – but only 37 per cent occupancy across their high dependency cots. Units are regularly reassigning their cots to accommodate the care needs of babies on the unit. A high level of intensive care activity at a non-NICU unit could suggest some babies are not being transferred to the regional centre appropriately.

“ My baby was transferred to another unit as the first unit he was cared for in was full. I was still in recovery from C-section. Being apart for two days was traumatic and I was in shock. Being apart made breastfeeding unachievable for me and I’m lucky we bonded well.”

Mum of a baby born at 32 weeks

At the other end of the spectrum, one special care baby unit has an occupancy rate of just 40 per cent across all of its cots. In order to maintain their safety and efficiency, neonatal care services should be planned for an average occupancy of 70 per cent.^{xvii} It is important that units are able to maintain an average occupancy in line with best practice in order to ensure that staff have enough clinical exposure to babies in order to maintain their skills.

While the NICU maintained an average occupancy across all cots of around 79 per cent, its special care cots and high dependency cots are both regularly over 80 per cent occupancy. As Northern Ireland's only NICU it is vital that they are able to keep cots running in order to receive very sick or extremely premature babies from across the country, while also meeting the needs of all babies born within their catchment area.¹²

“ We live in Belfast. However on the day I went into premature labour there were no neonatal cots available in our local neonatal unit for my twins so we were transferred to Dublin for delivery. We remained there for 11 weeks. We were able to stay in a hotel in Dublin four nights a week and travelled on the airport bus from Belfast to Dublin the other days. This was a very expensive time for us and we were offered no support.”

Mum of a baby born at 24 weeks

These findings indicate that there is an opportunity to reflect on service design to ensure that every baby is receiving the right care in the right setting, and that appropriate pathways and protocols are in place to facilitate this. The upcoming review of neonatal services from the Department of Health and Health and Social Care Board provides a welcome opportunity to further identify ways to improve patient flow and manage peaks in activity.

“ We had triplets who were split up. Two were cared for in one neonatal unit, and one baby in another. It happened unexpectedly one morning as the unit ran out of space and two were well enough for transfer. As a parent you don't have an option or opinion. It was so hard splitting ourselves in two, hard having to work with different doctors, realise different policies and rules in both. Doubles the work load for phone calls etc.”

Mum of triplets born at 29 weeks

¹² Please see glossary on page 50 for more information about the babies neonatal units care for.



Cot closures

Sometimes units have no option but to close their cots (not use cots which are physically available) or close their unit to new admissions altogether as a method of coping with demand or staffing issues.

Only one unit, the NICU, was able to provide details about the number of cot closures they experienced, which totalled 2,190 care days – with the majority of closures being on their special care cots (1,460 days). This suggests they do not have enough staff to man their cots. This could lead to families local to the unit being transferred further afield to receive the care they need.

“During periods of high levels of staff sickness and high cot demand, bank nursing is utilised but there is not a huge pool of bank staff available.”

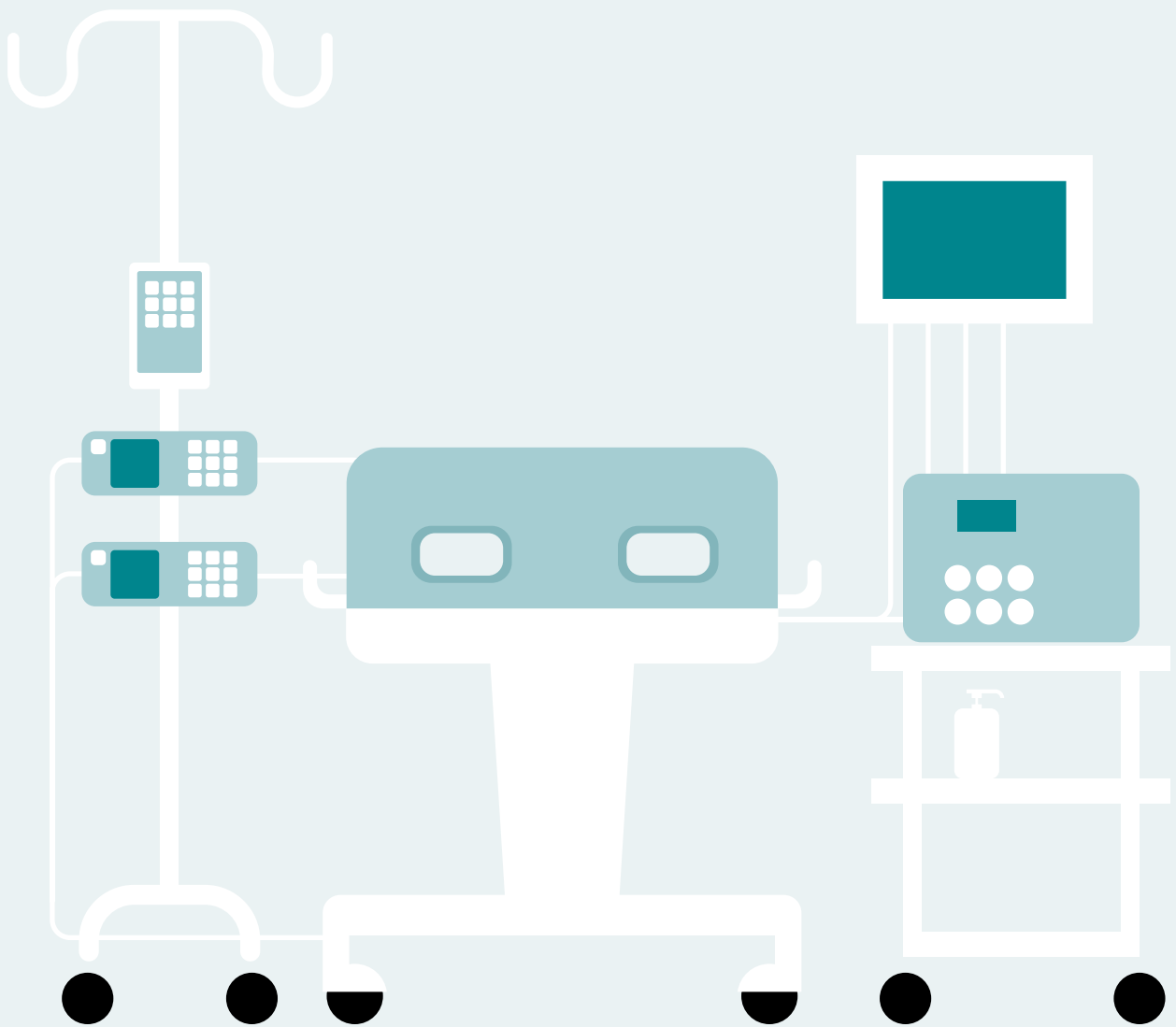
Ward Sister

While only one unit could tell us how many episodes of closure they had, other units noted they also closed their cots even though it was not possible to detail the exact number of closure episodes. In total, four out of seven (three LNUs and the NICU) told us that they regularly had to close cots. Common reasons for closure included short term nursing pressures, recruitment gaps and over occupancy. One LNU told us that staff on the unit frequently change their duty (meaning they fulfill a different job on the neonatal unit to ease pressure from the one they were rostered to do, such as working in a different nursery) in order to accommodate acuity and that they were reliant on using Bank staff and paediatric nurses from the transitional care team to support the unit during particularly busy peaks.

Cot closures can also place additional pressures on the transport service who help ensure that babies receive the care they need at a unit appropriate to their needs. With widespread pressures on cots at the units offering the most specialist care, some babies may have to be transferred out of Network. Due to Northern Ireland having no land-border with the rest of the UK, transfers to other UK hospitals are complicated. While closer, transferring babies to the Republic of Ireland has its own set of complexities associated with planning due to it not being a UK nation. In both circumstances, parents are hit hard; both by the financial constraints of the longer journey, and emotionally as they often have to leave their support network behind to be with their baby.

As well as closing regularly, most units told us that there was more than one factor at play in their unit which contributed to cot closure. All but one unit had multiple factors causing them to close cots and two LNUs had four separate issues which were directly affecting cot closure on their units, including both short and long term staffing shortages.

There are significant and multi-faceted challenges facing units which are resulting in them needing to close cots to try and maintain a safe service. It is of concern that Northern Ireland's only NICU has experienced such a high level of closure of its special care and high dependency cots, which could be resulting in transfers of babies to units further away.





Avoidable admissions

One of the pressures on neonatal services in Northern Ireland is the admission of babies to neonatal units who could be more appropriately cared for in a different setting alongside their mother. From the information provided to Bliss and TinyLife by neonatal units about their admissions for the financial year 2016/2017 it is clear there is variation across the neonatal units in Northern Ireland between babies who are born full term who do not have any serious birth defects or medical disorders (congenital anomalies). While some of these babies are very sick and do need to receive treatment in a neonatal unit, big differences in the numbers of full term babies admitted could highlight inconsistencies in practice.

Six units provided information about their full term admissions, with the remaining SCBU stating that this information was unavailable. While the average proportion of babies being admitted full term but sick without congenital anomalies was 39 per cent across all units, which is lower than evidenced in other UK countries^{xlviii} the incidence of these babies being admitted varied substantially from unit to unit, ranging between 30 and 56 per cent of all admissions.

For neonatal units, unnecessary admissions lead to extra strain as cots are filled with babies who do not need such intensive treatment. This can contribute to problems with units being over-capacity or staff caring for more babies than is considered safe.

An admission to a neonatal unit is frightening for parents. An avoidable admission causes unnecessary stress and anxiety for families which can have a negative impact on babies and their parents. Ideally, babies who are born needing a small amount of additional support, such as help maintaining their temperature or with feeding, should be cared for in a transitional care setting. This allows babies to be kept with their mother, who will provide the majority of the care to their baby, with the support of midwifery and neonatal nursing staff. As a result, transitional care can avoid babies being admitted to special care and avoid the traumatic separation of mother and baby.^{xlix} Implementing transitional care may also ease pressures on busy neonatal units with high numbers of special care cot days.

It is welcome that the NICORE's most recent report states that there is an Admission, Discharge and Transfers Task and Finish Group who will be focusing on decreasing term admissions 'in line with national priorities'.ⁱ The network should be supported with the resources they need to achieve these aims, and the 2017 BAPM transitional care standards should be endorsed and worked towards as they provide a consistent framework on how to best to keep mums and babies together.ⁱⁱ

Transfers

Neonatal transfers are a common and important part of a well-run neonatal service, ensuring that babies get to the right clinical setting safely. The highly skilled and dedicated neonatal transport team, which is part of the Northern Ireland Specialist Transport and Retrieval (NISTAR) service, operates every day across Northern Ireland to make sure babies born premature or sick are receiving the right care, in the right place. The service also covers transfers and retrievals to hospitals in the Republic of Ireland due to changes to the cardiac service and for the purposes of out of region transfers and repatriations.

NISTAR have routine access to a neonatal transfer ambulance as well as routine access to a 4X4 vehicle which is used to move staff and equipment where they need to be.

National standards: neonatal transport

In 2016 the *Quality Standards for Paediatric and Neonatal Specialist Transport Services in Northern Ireland* were published. These standards exist to provide quality assurance and will enable NISTAR to measure the extent to which they are operating in line with best practice.ⁱⁱⁱ

The *Quality Standards* state that the service should be operational on a 24/7 basis for critical care transfers of babies, and there should be a dedicated phone line for referrals with the facility to record and hold conference calls. This is also in line with the requirements of the NICE *Quality Standards*. A high quality service should be able to demonstrate timely arrival to the referring unit and have equipment which is readily available and regularly maintained in order to minimise delays.

Since the introduction of formal *Quality Standards* in 2016, there have been some welcome changes which have supported the operations of the neonatal transport team. Firstly, the transport services have merged and NISTAR is now made up of adult, paediatric and neonatal transport services, which has enabled the neonatal team to access the use of two ambulances, instead of one, on a routine basis, as well as establishing a team base with call takers and administrative staff. There is now also a dedicated consultant rota to cover neonatal transport during day time hours which was not available in the 2014/2015 financial year. At the time Bliss and TinyLife surveyed the neonatal transport team in 2017, there was a two WTE nurse shortage. However, since our research has been conducted, another WTE nurse has been recruited and the process is ongoing to fill the remaining gap, and there are also plans to recruit a clinical director and a lead nurse; which is welcome progress.

“The transfer team were absolutely brilliant! They gave me time with my baby before they took her and rang me when she was safely settled in unit. They made sure all her belongings were with her. The same team transferred her to second unit and again called me as they left one hospital and as they arrived at the next.”

Mum of a baby born at 32 weeks

Despite this positive progress there are still some challenges in meeting the *Quality Standards* and providing a full 24/7 neonatal transport team. Currently, the Neonatal Team is only commissioned to provide day time coverage, from 08:00hrs to 20:00hrs. From 20:00hrs to 08:00hrs neonatal referrals are taken by the NISTAR Paediatric Team and, if they are unavailable, they are passed onto the Independent Sector for transfer as agreed by the Commissioners. While time critical calls which are made overnight should be completed by the referring unit, meaning the transfer will be completed by neonatal staff,

non-urgent transfer calls made overnight which require the input of the Independent Sector will not be undertaken by neonatal staff.

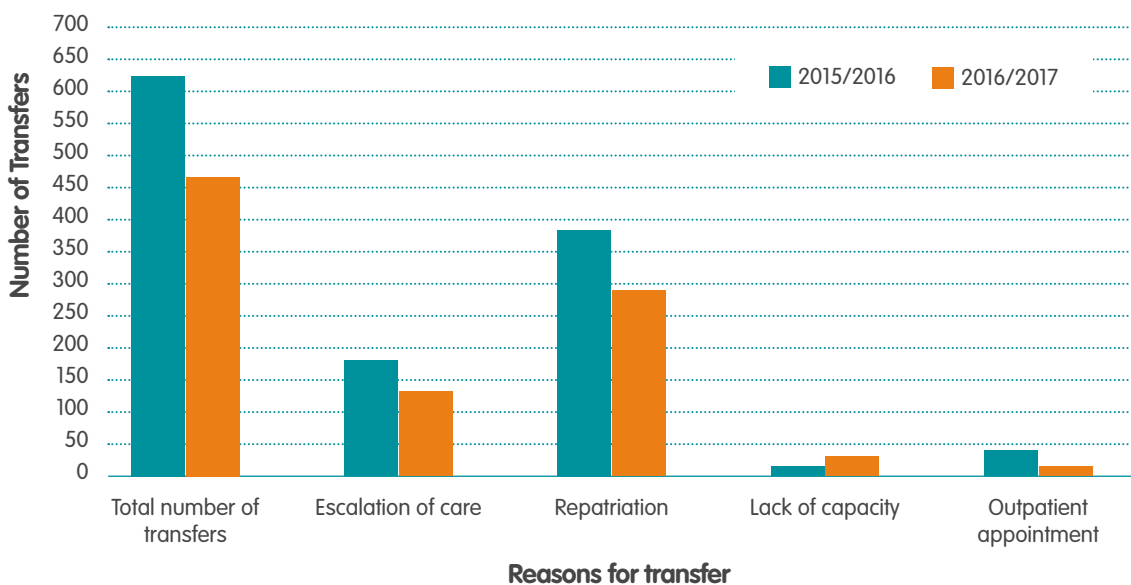
In 2015, the neonatal transport team reported that they did not have a 24 hour dedicated telephone line for clinical advice and to assess cot and maternal bed availability – and this is still the case in 2017. A dedicated phone line is important for units as it ensures time is not wasted by staff members having to make multiple phone calls to different units to find out where a cot is available at the right level of care for their patient.

During the snapshot week our 2016/2017 survey asked about,¹³ all commissioned activity was provided. However, there were two consultant rota gaps as a result of Bank Holidays which fell on this week.

“ I was able to travel with my baby and this made a huge difference to me and made me feel more relaxed about the transfer as I was by her side the whole time! The transport team were fab and were concerned for me and my baby as they knew I was anxious.”

Mum of a baby born at 33 weeks

While neonatal transport exists to ensure that babies are in the right clinical setting for their care needs, it also plays an important role in managing capacity across the neonatal network. As Graph two shows the number of overall transfers reduced between 2014/2015 and 2016/2017 with the only exception being for transfers due to lack of capacity at neonatal units, which have increased.



Graph two: Reasons for neonatal transfer in 2014/2015 and 2016/2017

While the overall numbers of unique transfers being undertaken specifically as a result of lack of capacity across the Network remain relatively low, Graph two shows that there has been over a 120 per cent increase in the number of transfers being undertaken for this reason between 2014/2015 and 2016/2017. Further, as a proportion of emergency transfers, those being undertaken for capacity issues accounted for nearly 20 per cent of all transfers in 2016/2017 compared to just seven per cent of total transfers in 2014/2015.

¹³ See methodology on page 49 for more information.

This demonstrates the impact of high occupancy rates (p.26) on the wider service. The pressures of high occupancy on neonatal units in Northern Ireland as they try to cope with demand are in turn impacting on the service NISTAR neonatal transport team can provide.

“At the moment we are experiencing one WTE nursing staff shortage, but we are currently undertaking a recruitment process. We are hopefully going to have a team base at some point with call takers and administration staff. We have also been piloting a single ambulance crew – so we can provide a second daytime ambulance for the Service – which is going well. Further developments are intended to recruit a clinical director and a lead nurse for the combined neonatal, paediatric and adult service.”

Neonatal transport co-ordinator



Support for families

Adequate support and facilities for parents are integral to the provision of family-centred care. Without accommodation near the neonatal unit and access to affordable meals at the hospital, parents have to leave their baby regularly to travel home.

Evidence^{liii}

While there have been huge strides made in medical care for babies born premature or sick over the last 20 to 30 years, leading to more babies than ever before surviving to go home to their families, it is only relatively recently that the role of the baby's family in their care has been seriously studied to see how this impacts on a baby's outcomes and quality of life.

The 2010 NICE *Quality Standards* stipulates that high-quality neonatal services 'require that the physical, psychological and social needs of babies and their families are at the heart of all care given.'^{liv} This family-centred approach places babies firmly within the context of their family, and services should be organised so parents are supported to participate in caring for their baby, including making decisions about their care.

A more recent assessment of parents' views of their neonatal journey and improvements that can be made to it in Northern Ireland has been assessed by Franck et al. Parents felt that a family-centred approach was important throughout their journey, and the majority felt that they should be actively involved in the decision making and care of their baby as early as possible.^{lv} The study concluded that parents can readily identify changes in practice which could have a positive effect on the experience and outcomes for families, and the findings are being used to inform quality improvement within Northern Ireland based initiatives.^{lvi}

Other studies have explored how this approach can improve outcomes for babies. Kaffashi et al. concluded from their study monitoring sleep patterns – between babies who received significant skin-to-skin care and those who did not – that those who did had far better sleep episodes and significantly better brain development as a result.^{lvii} Similarly, greater parental involvement in their baby's care has been shown by other studies to support brain development and improve cognition.^{lviii} Other benefits include improved breastfeeding rates, as mothers are supported to be on the unit more consistently, making it easier to establish breastfeeding, earlier discharge from hospital, and reduced re-admission rates.^{lix, lx}

With this growing body of evidence, a new approach called family-integrated care is developing which facilitates families taking the lead in their baby's care. Spearheaded in Canada, parents are fully supported to be with their baby and to take the lead in their baby's care. They are fully supported with free accommodation, meals and transport and are also trained to carry out basic care such as administering naso-gastric feeds. Parents are involved in all ward round discussions for their baby, and fully participate in decision making. This has been shown to improve parental confidence, communication between parents and professionals, with parents feeling closer and more able to cope with caring for their baby outside of the hospital environment.^{lxi}

National standards: family-centred care

The NICE *Quality Standards* state that parents should be encouraged and supported to be included in the planning and providing care for their baby. The then-Department of Health's (England) *Toolkit*, *All Wales Neonatal Standards* and Scotland's *Quality Framework* all state that a high quality neonatal service will ensure there are dedicated facilities available to families wherever possible. This should include access to food and drink, information regarding support services available and the provision of free overnight accommodation on, or nearby, the neonatal unit.

While there are no Northern Ireland specific neonatal standards which detail the support and information that should be provided to families while their baby is being cared for on the neonatal unit, the NNNI is keen to improve family support on units and all units annually review parent feedback on support given during their neonatal stay which is collated through a discharge survey. Additionally, neonatal staff may benefit from training in family-centred and developmental care to ensure the care they are providing is consistently in line with best practice, such as FINE training.^{lxvii}

Accommodation and meals

The then-Department of Health *Toolkit* (England) and *All Wales Neonatal Standards* both specify that there should be a minimum of one overnight room for parents per intensive care cot. Bliss found in a 2016 report on neonatal services in Wales that the one room per one cot standard was not enough for certain settings, particularly units in rural and hard to reach areas.^{lxviii} Given the numerous rural communities in Northern Ireland, this may also be true for the neonatal units which serve these populations.

Providing sufficient overnight accommodation to enable parents to stay close to their baby and participate in their care is a significant challenge for neonatal units across Northern Ireland. One SCBU was unable to provide any overnight accommodation at all. This is particularly concerning as this unit does not even have the resource to support all families to room-in, which is an important part of the discharge process for families.¹⁴

“ We were only given free meal vouchers if I was expressing for my son. We paid for parking for six weeks and got nothing back. It was only after the six weeks that we got a parking pass which was great but then we were transferred and gave it back so other parents didn't have to pay £5 a day for six weeks for parking and get nothing in return like we did. We now have financial troubles as both my partner and I were out of work so we could see our son. Now my partner is back at work and we are still struggling to make ends meet.”

Mum of baby born at 28 weeks

¹⁴ Rooming-in should be offered by the hospital to all parents before their baby is discharged. This allows parents to stay in a room on or near the unit and care for their baby overnight for a few days. This can help give parents confidence in caring for their baby alone while the unit staff are available to help if necessary.

Many families will have to travel great distances to the hospital, or have prolonged and complicated journeys on public transport, even if their baby does not need such intensive care and is admitted to a local unit. For those living rurally, 'local' units can in reality be far from home and accommodation should therefore be provided to meet the needs of the units' catchment populations so that all parents can be involved in their baby's care.

The financial cost of travelling to see their baby every day in Northern Ireland can also put parents under strain. Some parents are unable to visit their baby as often as they would like as a result, leading to feelings of guilt and difficulties with bonding.^{lxiv} Using the Welsh and English standard of one overnight room per intensive care cot, our findings show that two thirds (four out of six) units^{lxv}, including the NICU and two LNUs, in Northern Ireland are unable to provide accommodation for all parents of critically ill babies.

This is concerning as it means that the units which will care for babies with the most prolonged stays are unable to keep families together. There is also evidence that parent rooms on the units are being used for rooming-in as well as overnight stays. This can lead to units having to prioritise and set criteria regarding which parents are able to stay overnight. If there is an emergency and a baby is in a critical condition or receiving palliative care which requires parents to use an overnight room, this can delay discharge for families who are waiting to room-in. It is vital that there is sufficient overnight accommodation in addition to rooming-in rooms to ensure that neonatal staff are not put in the difficult position of needing to prioritise some families over others.

Four out of six neonatal units which provided information were able to support some families with food and drink costs, including the NICU and three LNUs, either through providing a meal or by offering vouchers for the hospital canteen or shop. However, only one of these units, an LNU, could extend this provision to all families, with the other units only offering support to parents who met a certain criteria. For example, one unit only provides support to mothers who have to travel a long distance, while others can only offer support to mothers who are breastfeeding or expressing. This means support will be out of reach of many families who need it.

Since completing the Bliss and TinyLife survey, construction work has started on the NICU to improve the unit, which will address some of these issues which have been identified. This is positive, and will help staff to better support parents to be involved in their baby's care.

Costs can be a significant barrier to parents being with their baby on the neonatal unit. Bliss and TinyLife previously found that parents spend an average of £65 just on food and drink for every week their baby is receiving neonatal care.^{bvi} It is therefore welcome that nearly all (six out of seven) units have basic facilities, like a kettle or microwave, available to families for use on the unit. The one LNU without these facilities currently available noted that they are in the process of acquiring them.

“ There is no accommodation at the moment. There is a family room (double sofa bed) which is used for rooming in and if baby is ill. Also, we have a hospital bed in an isolation room before for a mum to stay with a palliative care baby.”

Ward manager



Communication

Despite some challenges with providing sufficient access to accommodation, it is positive to note that most units do offer some form of financial support. For example, every neonatal unit in Northern Ireland reported that they are able to offer either free or reduced parking to parents, and as outlined above two thirds of units can support at least some families with food and drink costs.

However, having facilities available only improves parents' experiences if they know they exist, and lack of access to this support has been a longstanding problem.^{bvii} The NNNI have recently published a three-year overview of their *Parents' Experiences of Neonatal Care* annual survey. Only 59.4 per cent of families surveyed in 2016/2017 felt they were given information about help available for travelling expenses, parking costs or food vouchers.^{bviii} Not only was this the lowest scoring question in the whole survey, there has also been a decline in satisfaction over time, from 63.6 per cent of families being satisfied in 2015/2016.^{bix}

“ We got canteen vouchers and parking. This was an AMAZING help, but staff did not tell us about it to begin with. We found out from parents and felt awful having to wait at front reception for it. It should be given to parents from staff if they know they will be staying. ”

Mum of a baby born at 24 weeks

Similarly, Bliss and TinyLife's 2017 parent survey echoed these findings. Many families said that they were only told about free parking or support with food costs a day or two before going home – and some of these families reported that their baby had been receiving care for many weeks before they found out. Some also described how they were told about the support available by other parents, rather than from staff.

Most neonatal units (five out of seven) told us that they provided information about financial support to families. However, many relied on referring parents to social workers who provide information or had leaflets available on the unit.

“ I wasn't offered lunch vouchers and I only got a car park voucher after one week when I asked for it as I heard another parent had got one. The nurses said because I had given birth in the middle of the night, they don't usually ask if parents drive until the morning and they must have forgot. ”

Mum of a baby born at 32 weeks

It is of concern that some units specified that a referral to a social worker for financial advice only occurred if the parent requested it. It is not unusual for parents to feel embarrassed, guilty or ungrateful about admitting that they are having financial difficulties and need to access support.^{bx} This is a significant barrier to parents accessing the support they need and which is often freely available to them. To normalise and encourage parents to access the support they are entitled to, neonatal services need to ensure staff have the time to proactively inform parents about what is available as soon as they are admitted to the unit.

“ It is difficult to assess a personal issue like money with people you do not know and do not want to offend. ”

Ward manager

Having a dedicated family support lead can help prevent parents from falling through the gaps. A named staff member who has responsibility for informing parents about the unit's support package built into their role could be a solution, as can ensuring that financial support information – including details about parking or food vouchers - is included in an admission pack which is given to every family.

“ I was offered canteen vouchers once in 24 days despite exclusively breastfeeding and was so shocked to be offered them and was told by the nurse I should've had it all along. I was also entitled to free parking but each time I enquired nurses were too busy or had no parking passes left and there is a different car park I could have availed of had I been given the pass instead of queuing some times over an hour to see my baby. ”

Mum of a baby born at 33 weeks

Psychological support

Having a baby who is born premature or sick and in need of neonatal care is an extremely stressful and anxiety-filled time for parents. In most instances, parents will not know in advance that their child will require specialist care after birth, and this shock can compound their feelings of stress and loss. It is vital that there is adequate provision and access to psychological support from admission to the neonatal unit, as well as after their baby has been discharged home or if a baby sadly dies.

Evidence^{boxi}

Vigod et al. showed in their study that mothers of babies admitted to neonatal care were up to 40 per cent more likely to suffer from post-natal depression and other mental health conditions compared to the general population of new mothers.^{boxii} Further to this Hynan et al. recommended in their 2015 study that the emotional needs of parents in the neonatal unit were of equal importance to the development of their babies and must have frequent input from experienced neonatal mental health professionals to support them throughout their stay.^{boxiii}

National standards: psychological support

The then-Department of Health's (England) *Toolkit, All Wales Neonatal Standards* and the BAPM *Service Standards* are clear that all parents should have access to psychological and social support, including a trained counsellor. At neonatal intensive care units, parents should have access to a trained counsellor without delay from the time their baby is admitted, and there should be ongoing support during the parents' time on the neonatal unit. Another important part of a psychologist's role is to support other staff on the neonatal unit.

Nearly all (five out of seven) neonatal units have no dedicated access to a mental health professional, and three neonatal units are unable to provide access to any trained mental health professional at all, including by referral to an external service.

“ Access to such individuals was not offered to me until my son returned home. I have suffered severe PND before and the trauma of my son's arrival really affected me and I was extremely anxious all the time. [To have had] someone to chat to about it all while still in hospital would have helped a lot. ”

Mum of a baby born at 30 weeks

It is deeply concerning that the NICU, which will be caring for babies with the most complex needs and which is likely to have higher levels of bereavement than other neonatal units, is one of the units which is unable to offer **any** access to a mental health professional. The unit noted that they have been actively seeking input from psychological support services 'for a number of years', but they have had difficulties in securing funding. It is essential that Northern Ireland's only NICU is prioritised for the development of a psychological support service due to its position in caring for the country's most vulnerable babies – and their families.

“ I was staying in the unit as I was a breastfeeding mum and was making slow but steady progress with my preemie. One thing I wish there had been was access to mental health staff, I had severe postnatal depression and the wards are very isolating for parents at the best of times. Some of the nurses definitely picked up on it and were as supportive as they could be but it wasn't their role and they weren't trained. I believe if I had had support from an earlier stage my depression would not have developed to the stage it did. ”

Mum of a baby born at 34 weeks

Of the two neonatal units, both of which are LNUs, which are able to provide some dedicated access to psychological support services, neither are able to provide support to all families who might need it. One is able to provide access to psychotherapy and counselling, but only for families who are bereaved, and the other is only able to provide support to families with a baby who is an inpatient on the unit, and not post-discharge except in exceptional circumstances. This unit also notes that their psychological support services are new and that they hope to develop them further. This is welcome and units which have services should be supported to continue to extend their reach so all families who need support can benefit from it.

“ I had no psychological support. The whole experience was a rollercoaster of emotions. Especially when [my baby] was transferred from one unit to another. Even when she passed away I was not told of any help.”

Mum of a baby born at 34 weeks

The lack of support available to families whose baby requires neonatal care is having a real impact. In Bliss and TinyLife's 2017 survey, of the 147 parents who left comments about the psychological support they received, over three quarters (114 out of 147) stated that they had no access to any professional support.¹⁵ Many of these parents stated that they felt some professional support would have been beneficial and a number described the long-term consequences of their neonatal experience, including post-traumatic stress and post-natal depression.

It is of particular concern that some respondents reported that they already had a diagnosis of severe mental health issues before their baby was born, with one mother explaining that she had experienced a stillbirth only a year before her twin daughters were born needing neonatal care – and yet none of these particularly vulnerable parents had any professional psychological support offered to them throughout their time on the neonatal unit, or after discharge.

“ We did not receive any psychological support during the girls' hospital stay. We had lost our son the year before the girls were born, he was born sleeping at 41 weeks and was our first son. I was supposed to receive psychological support from the hospital in relation to his death but never received my referral. I think psychological support would have helped me contain my emotions when the girls were in hospital, I was continuously asked if the girls were my first babies and I found it extremely hard answering the question as I didn't always want to explain about my little boy.”

Mum of twins born at 27 weeks

¹⁵ The Bliss and TinyLife parent survey asked parents open-ended questions about different aspects of their neonatal journey. One question asked parents about the psychological support they received. There were 147 respondents to this question who had had a neonatal experience within the last five years (2013-2017).

Published in 2015 by the then-DHSSPS, the *Regional Bereavement Guidance on evidence based, holistic care of parents and their families after the experience of miscarriage, stillbirth and neonatal death* report discusses the importance of a specialist bereavement midwife in supporting families with grief, as well as the need to refer some women for further counselling. It also highlights the need for privacy and 'suitable rooms' for families to spend with their baby. It is important that units are supported to develop these facilities and services so every family whose baby sadly dies receives the very best support.^{xxiv} Despite this, there are only two bereavement suites available in Northern Ireland.

Many parents noted that while there were no formal services, the unit staff provided good emotional support on a day-to-day basis. However, nursing staff are not trained mental health professionals and they should not have to provide intensive support to parents who would benefit from professional input. Further, the neonatal unit is a stressful environment for neonatal staff as well. The death of a baby or other particularly emotive and stressful experiences can be difficult for staff to process and come to terms with. It is essential that trained psychological input is also available to frontline staff.

The lack of support available for families, and staff, is extremely troubling. Parents, particularly those whose baby is receiving intensive care, need to have good psychological support available to them from admission to the unit. While there has been difficulty with securing funding, it is essential that these services are developed as a matter of priority.

“ Our first son was born at 24 weeks and lived 13 days. The doctors and nurses were amazing and gave updates fully every several hours. But there could have been a room for bereavement, especially for when we were saying goodbye to our baby. They had to clear out an equipment room. Then the family were all taken to the breast pump room so it wasn't the best setting for our last few precious moments. ”

Mum of baby born at 24 weeks



Conclusions and recommendations

Neonatal staff across Northern Ireland do an incredible job, but their already demanding and challenging workload is being made all the more difficult as a result of a lack of vital resources needed to meet nationally recognised standards. Neonatal units across Northern Ireland are unable to meet standards of best practice across a range of areas, including staffing levels and psychological and practical support for families.

These challenges are exacerbated by the turbulent political and health policy context that neonatal services have to operate within, and are reliant on for cohesive funding and planning. Further, a lack of land border with the UK can make it difficult to plan services effectively due to the complexities associated with transferring to other UK nations and to the Republic of Ireland with its separate jurisdiction.

While there are elements of the service to celebrate, such as the recent focus on ensuring allied health professional presence on the neonatal unit, now is the time address the significant challenges facing neonatal services today, to ensure they are able to cope into the future.

1 Babies born premature or sick in Northern Ireland must receive care in neonatal units which are safe, well organised, staffed and funded, and the continuation of this must transcend political turbulence. It is imperative that the required funding is available and plans for service development are still executed wherever decision making power is held.

National service specification

Neonatal services are unable to meet NNNI supported markers of a safe, high-quality service on a range of factors, including nurse-to-baby ratios. To ensure progress can be made, and services can continue to be developed to meet the needs of Northern Ireland's population it is essential that:

2 The Department of Health, Health and Social Care Board and the Public Health Agency must work together to produce, and commit to meeting, a Northern Ireland Neonatal Service Specification which includes measurable standards of care which reflect the specific needs of neonatal services in Northern Ireland.

3 In line with the 2016 *Strategy for paediatric healthcare services*, the service specification should explicitly include the valuable contribution of community and voluntary sector organisations, and their role in the provision of expert advice and support for parents and families of every baby born premature or sick.

Funding

It is clear that not enough funding is reaching neonatal services in order for them to recruit the staff they need, and provide the facilities and support to parents so that they can be with their baby every day and feel fully supported throughout their journey from admission to post discharge.

4 The Department of Health, Health and Social Care Board and the Public Health Agency must invest in neonatal care so that services can recruit the nurses, medical staff and other professionals they urgently need, and ensure that staffing and training gaps are addressed.

5 The Department of Health, Health and Social Care Board and the Public Health Agency must work to develop clinical neonatal outreach services which are delivered by neonatal staff, with input from the Neonatal Network Northern Ireland.

Support for families

Family-centred care improves babies' outcomes, helps families to bond and shortens hospital stays. Despite welcome attention and progress driven by the NNNI and neonatal units, investment and further support is required to enable parents to be at the centre of their baby's care, including facilities that allow them to be near their baby and emotional and psychological support to help them cope with the stress and trauma of their baby being admitted to neonatal care.

- 6 The Department of Health, Health and Social Care Board and the Public Health Agency must invest in developing onsite facilities for families so they can be with their baby, including overnight accommodation, with clear timescales for implementation of these changes.
- 7 The Department of Health, Health and Social Care Board and the Public Health Agency must commit to investing urgently to ensure every neonatal unit can provide families access to psychological support. Psychological support services must be established at the Tertiary centre as a matter of priority so families of the very sickest babies have access to trained psychological support from the time of admission, including access to counselling.
- 8 The Neonatal Network Northern Ireland should audit the parent support packages available in units across Northern Ireland, and work with neonatal units to develop strategies to ensure these are communicated to families from admission to the unit. Each unit should have a dedicated member of staff to ensure parents are aware of all practical and financial support available.
- 9 The Neonatal Network Northern Ireland should support the use of the BAPM Framework for Neonatal Transitional Care.
- 10 Neonatal units, with the support of the Neonatal Network Northern Ireland, should identify ways to embed a family-centred care approach into the ethos of their units, including through training programmes such as those offered by FINE.





Methodology

In July 2017, Bliss and TinyLife sent a survey to the seven neonatal units that were operational in Northern Ireland during 2016/2017. All of these units responded.

The survey included questions about admissions, activity levels, staffing, training, facilities for families on the neonatal unit and other family support, including access to psychological services.

Questions about admissions and activity levels were for the financial year 2016/2017. Nurse and medical staffing questions related to a single day in March 2017 to get a snapshot of staffing, and to provide an indication of the current staffing situation across units in Northern Ireland.

Nursing requirements were calculated according to the nurse-to-baby ratios which are endorsed in the NICE *Quality Standards* and BAPM *Service Standards*. This calculation took into account annual care days and occupancy rates for different categories of care at each unit.

Occupancy levels were calculated according to the levels defined in the *Toolkit* using the activity levels provided for the financial year 2016/2017, and the number of declared cots units told us they had for each level of care.

The survey also included space for comments, from which the quotes from health care professionals in this report are drawn.

In June 2015 Bliss surveyed NISTAR, neonatal transport team, and their response is used in this report. Information they provided is also included in the UK-wide Transfers of premature and sick babies report published by Bliss in April 2016. Further information was very kindly provided by the transport service in 2017 which has also been included in this report.

Parents whose babies were cared for in neonatal units across Northern Ireland also shared their stories with Bliss and TinyLife. The parent survey was widely promoted through social media channels over an eight week period, and received 351 responses in total. In order to ensure the examples cited were relevant, we used a 2013 cut-off for neonatal experience, with 181 respondents falling into this category. We have used quotes from these 181 respondents within this report.

Parents whose babies were cared for in neonatal units across Northern Ireland also shared their stories with Bliss and TinyLife, and we have used their quotes in this report.

Glossary

Categories of care

- **Special care** is the least intensive level of neonatal care and is the most common. Babies receiving special care may need to have their breathing and heart rate monitored, be fed through a tube, supplied with extra oxygen or be treated for jaundice.
- **High dependency care** is provided to babies who need continuous monitoring, for example those who weigh less than 1,000g, or are receiving help with their breathing via continuous positive airway pressure or intravenous feeding, but who do not require intensive care.
- **Intensive care** is highly specialised care for the smallest and most seriously ill babies who require constant care and, often, mechanical ventilation to keep them alive.
- **Transitional care** is another type of care babies may receive in hospital. It allows babies who need some extra help, but do not need to be admitted to a neonatal unit, to stay with their mother with support from neonatal staff.

Medical tiers

- **Tier one** medical staff are junior staff members such as doctors new to the speciality and advanced neonatal nurse practitioners (ANNPs) or Enhanced Neonatal Nurse Practitioners (ENNPs).
- **Tier two** medical staff are middle grade staff members such as speciality doctors and more experienced ANNPs.
- **Tier three** medical staff are medical consultants.

Neonatal units

- **Special care baby units** provide special care for their local population. Depending on local arrangements, they may also provide some high dependency care.
- **Local neonatal units** provide special care and high dependency care and a restricted volume of intensive care (as agreed locally). Babies who require complex or longer-term intensive care will be expected to transfer to a Neonatal Intensive Care Unit
- **Intensive care units** provide the whole range of medical (and sometimes surgical) neonatal care for the local population from a larger intensive care unit. Additional care will be provided for babies and their families referred from the neonatal network in which they are based. Admission of babies from other networks may occur to deal with peaks of demand or requests for specialist care not available elsewhere. Many will be sited within perinatal centres that are able to offer similarly complex obstetric care. These units will also require close working arrangements with all of the relevant paediatric sub-specialties.

The Neonatal Network Northern Ireland leads on the provision of safe, high quality services for specialist neonatal care through good practice and the development of outcome-led services. The engagement and participation of staff and families are central to the work of the Neonatal Network ensuring that their contribution to continuous service improvement is addressed through the Network's work plan. When babies in the Network need to be transferred, they will usually be moved to another unit within Northern Ireland, though some babies are cared for at units in the Republic of Ireland or other UK nations.

Enhanced Neonatal Nurse Practitioners (ENNP) are nurses who have already QIS trained and have undergone additional training and education which allow them to safely take on added responsibilities for practice and clinical decision making, for example intravenous cannulation). While highly trained nurses, they have the skills to fulfil tier one medical roles.

Advanced Neonatal Nurse Practitioners (ANNP) are nurses who acquire skills beyond QIS and ENNP. The education and training of ANNPs exists typically within a Masters framework and nurses qualified to this level will have skills including the stabilisation and transfer of sick babies across networks, independent prescribing, initiation of complex procedures and case load management. While highly trained nurses, ANNPs have the skills to fulfil tier one, and some have the skills to fulfil tier two, medical roles.



References

- i. Neonatal Intensive Care Outcomes Research and Evaluation (2017) Neonatal Care in Northern Ireland, 2015: Data Report
- ii. The proportion of babies born who require neonatal care in Northern Ireland was calculated using figures available in the NICORE (2017) Neonatal Care in Northern Ireland
- iii. For example, children born extremely prematurely are more likely than other children to have cerebral palsy, learning difficulties, behavioural problems and breathing difficulties. More information can be accessed at: epicure.ac.uk/overview/main-challenges
- iv. NICORE (2017) Neonatal Care in Northern Ireland
- v. NICORE (2017) Neonatal Care in Northern Ireland
- vi. Department of Health, Social Services and Public Safety (2011) Quality 2020: A 10-Year Strategy to Protect and Improve Quality in Health and Social Care in Northern Ireland
- vii. Health and Social Care Board and Public Health Agency (2017) Annual Quality Report 2016/2017
- viii. Bengoa, R, Stout, A, Scott, B, McAlinden M, Taylor, M A,(2016) Systems, not Structures: Changing Health & Social Care
- ix. Donaldson, L, Rutter, P, Henderson, M (2014), The Right Time, The Right Place: An expert examination of the application of health and social care governance arrangements for ensuring the quality of care provision in Northern Ireland
- x. Donaldson, L, et al. (2014), The Right Time, The Right Place
- xi. Bengoa, R et al. (2016) Systems, not Structures
- xii. Evidence box first published in *Bliss Scotland baby report 2017: An opportunity to deliver improvements in neonatal care*, (2017)
- xiii. Williams, S, Whelan, A, Weindling, A M, Cooke, R W (1993) 'Nursing staff requirements for neonatal intensive care', *Archives of Diseases in Childhood*, 68(5), pp.534-538
- xiv. Milligan, D W, Carruthers, P, Mackley, B Ward Platt, M P, Collingwood, Y Wooler, L, Gibbons, J, Draper, E, Manktelow, B N (2008) 'Nursing workload in UK Tertiary Neonatal Units', *Archives of Disease in Childhood*, 93(12), pp.1059-1064
- xv. Pillay, T, Nightingale, P, Owen S, Kirby D, Spencer, S A (2011) 'Neonatal Nursing Efficacy: practical standards of nursing care provision in a newborn network', *Archives of Disease in Childhood*, 96(Suppl 1), A36
- xvi. Callaghan, L, Cartwright D, O'Rourke, P Davies, M (2003) 'Infant to staff ratios and risk of mortality in very low birthweight infants,' *Archives of Diseases in Childhood – Fetal and Neonatal Edition*, 88(2), F94-F97
- xvii. Watson, S I, Arulampalam, W, Petrou, S, Marlow, N, Morgan, A S, Draper, E S, Modi, N on behalf of the Neonatal Data Analysis Unit (NDAU) and the Neonatal Economic, Staffing and Clinical Outcomes Project (NES COP) Group (2016) 'The effects of a one-to-one nurse-to-patient ratio on the mortality rate in neonatal intensive care: a retrospective, longitudinal, population-based study', *Archives in Disease and Childhood – Fetal and Neonatal Edition*, 101(3), F195-200
- xviii. Hamilton, K E, Redshaw, M E, Tarnow-Mordi, W (2007), 'Nurse staffing in relation to risk-adjusted mortality in neonatal care', *Archives of Diseases in Childhood – Fetal and Neonatal Edition*, 92(2), F99-F103
- xix. Department of Health and the Information Analysis Directorate (2017) Northern Ireland Health and Social Care Workforce Census March 201, available online at: <https://www.health-ni.gov.uk/sites/default/files/publications/health/hscwc-march-17.pdf>
- xx. DH & IAD (2017) Workforce Census March 2017, available online at: <https://www.health-ni.gov.uk/sites/default/files/publications/health/hscwc-march-17.pdf>
- xxi. Bengoa, R (2016) Systems, not Structures
- xxii. Franck, L S, McNulty, A, Alderice, F, (2017) 'The Perinatal-Neonatal Care Journey for Parents of Preterm Infants: What Is Working and What Can Be Improved', *Journal of Perinatal and Neonatal Nursing*, 31(3), pp.244-255
- xxiii. Bliss (2015) Bliss baby report 2015: Hanging in the balance, England
- xxiv. Bliss (2016) Bliss baby report 2016: A time for change, Wales
- xxv. Bliss Scotland (2017) Bliss Scotland baby report 2017: An opportunity to deliver improvements in neonatal care
- xxvi. Department of Health (2016) Providing High Quality Healthcare for Children and Young People: A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community (2016-2026)
- xxvii. Northern Ireland Department of Agriculture and Rural Development (2016), Northern Ireland Rural Statistics accessed online at: <https://www.dardni.gov.uk/sites/default/files/publications/dard/rural-statistics-infographic-2016-final.pdf>
- xxviii. Life at home with your premature baby was written and developed in April 2017 in partnership between Queen's University Belfast and TinyLife. It can be accessed online at: <http://lifeathome.tinylife.org.uk/>
- xxix. Department of Health (2016) A Strategy for Paediatric Healthcare Services (2016-2026)
- xxx. Tubman, R, McGuinness, S (2016) Quality Standards for Paediatric and Neonatal Specialist Transport Services in Northern Ireland
- xxxi. Franck, L S, et al.(2017) 'The Perinatal-Neonatal Care Journey for Parents of Preterm Infants'
- xxxii. Royal College of Paediatrics and Child Health (2015) Facing the Future: Together for Child Health
- xxxiii. NICORE (2017) Neonatal Care in Northern Ireland
- xxxiv. Royal College of Paediatrics and Child Health (2017) Paediatric Rota Gaps and Vacancies 2017: Findings of a survey carried out between January and April 2017
- xxxv. Royal College of Paediatrics and Child Health (2016) Paediatric Rota Gaps and Vacancies 2016: Findings of a survey carried out between January and March 2016
- xxxvi. Royal College of Paediatrics and Child Health (2015) Rota vacancies and compliance survey December 2014-April 2015
- xxxvii. RCPCH (2017) Paediatrics and Rota Gaps and Vacancies 2017
- xxxviii. RCPCH (2016) Paediatrics and Rota Gaps and Vacancies 2016
- xxxix. RCPCH (2015) Rota vacancies and compliance survey, Winter 2014/2015

- xl. Bengoa, R (2016) Systems, not Structures
- xli. Bengoa, R (2016) Systems, not Structures
- xlii. Granua, R E, (2013) 'Neonatal Pain in Very Preterm Infants: Long-Term Effects on Brain, Neurodevelopment and Pain Reactivity,' *Rambam Maimondes Medical Journal*, 4(4) e0025, available online at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3820298/#>
- xliii. Ranger, M, Grunau R E, (2014) 'Early repetitive pain in preterm infants in relation to the developing brain', *PMC Free Article* 4:57–67 available online at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3975052/>
- xliv. Prado, E L, Dewey K G, (2014) 'Nutrition and brain development in early life', *Nutrition Reviews*, 72(4) pp.267-284 available online at: <https://academic.oup.com/nutritionreviews/article/72/4/267/1859597>
- xlv. UK neonatal staffing study group (2002) 'Patient volume, staffing and workloads in relation to risk-adjusted outcomes in a random stratified sample of UK neonatal Intensive care unit: a prospective evaluation,' *The Lancet*, 359(9301), pp.99-107
- xlvi. British Association of Perinatal Medicine, Service Standards for hospital providing neonatal care (3rd Edition) available online at: https://www.bapm.org/sites/default/files/files/Service_Standards%20for%20Hospitals_Final_Aug2010.pdf
- xlvii. NHS England & Department of Health (2009) Toolkit for High Quality Neonatal Services.
- xlviii. NHS Improvement (2017) Reducing harm leading to avoidable admission of full-term babies into neonatal units: Findings and resources for improvement. This report found almost 60 per cent of all neonatal admissions in England were of full-term babies. Similarly, the Wales Neonatal Network (2016) Annual Report 2016 (Report on achievements, transport, staffing, activity and outcomes) found 50 per cent of all neonatal admissions in Wales were of full-term babies.
- xlix. Forsyth P, 'New practices in the transitional care centre improve outcomes for babies and their families'. *J Perinatal*, 18(6 pt 2 SU), S13-7
- I. NICORE (2017) Neonatal Care in Northern Ireland
- li. British Association of Perinatal Medicine (2017) A Framework for Neonatal Transitional Care
- lii. Tubman, R, McGuinness, S (2016) Quality Standards for Paediatric and Neonatal Specialist Transport Services in Northern Ireland
- liii. Evidence box first published in Bliss Scotland baby report 2017: An opportunity to deliver improvements in neonatal care, (2017)
- liv. National Institute of Clinical Excellence (2010) Neonatal specialist care Quality standard (QS4)
- lv. Franck, L S, et al.(2017) 'The Perinatal-Neonatal Care Journey for Parents of Preterm Infants'
- lvi. Franck, L S, et al.(2017) 'The Perinatal-Neonatal Care Journey for Parents of Preterm Infants'
- lvii. Kaffashi F, Scher M, Ludington-Hoe S, Loparo K (2013), 'An analysis of the kangaroo care intervention using neonatal EEG complexity: a preliminary study,' *Clinical Neuro physiology*. 124(2):238-46
- lviii. Flacking R, Lehtonen L, Thomson G, Axelin A, Ahlqvist S, Hall Moran V, Ewald U, Dykes F. (2012) 'Closeness and separation in neonatal intensive care,' *Acta Paediatrica* 101:1032–1037
- lix. Flacking et al. (2012) 'Closeness and Separation'
- lx. O'Brien, K., Bracht, M., Macdonell, K., McBride, T., Robson, K., O'Leary, L., Christie, K., Dicky, T., Levin, A., Lee, S.K., (2013), A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. *BMC Pregnancy and Childbirth*, 13(Suppl 1):S12
- lxi. O'Brien et al. (2013) 'Family Integrated Care'
- lxii. The Family and Infant Neurodevelopmental Education (FINE) programme is a unique educational pathway in family centred developmental care that is suitable for all disciplines in any neonatal centre. More information can be found at www.bliss.org.uk/the-fine-course
- lxiii. Bliss (2016) Baby report Wales: time for change
- lxiv. Franck, L S, et al.(2017) 'The Perinatal-Neonatal Care Journey for Parents of Preterm Infants'
- lxv. This figure for units meeting the Welsh and English one overnight room to intensive care cot is represented as being out of a smaller number of units than gave details about their accommodation. This is because one unit did not give enough information to determine whether the accommodation they had was equal or in excess of their intensive care cots.
- lxvi. Bliss and TinyLife (2014), It's not a game: the very real costs of having a premature or sick baby in Northern Ireland
- lxvii. Bliss and TinyLife (2014), It's not a game
- lxviii. Neonatal Network Northern Ireland (2017) Parents' Experiences of Neonatal Care: A 3-Year Journey available online at: <https://www.qub.ac.uk/schools/SchoolofNursingandMidwifery/FileStore/Fileupload,777900,en.pdf>
- lxix. NNNI (2017) Parents' Experiences of Neonatal Care, available online at: <https://www.qub.ac.uk/schools/SchoolofNursingandMidwifery/FileStore/Fileupload,777900,en.pdf>
- lxx. Franck, L S, et al.(2017) 'The Perinatal-Neonatal Care Journey for Parents of Preterm Infants'
- lxxi. Evidence box first published in Bliss Scotland baby report 2017: An opportunity to deliver improvements in neonatal care, (2017)
- lxxii. Vigod, S.N., Villegas, L., Dennis, C.L., Ross, L.E. (2010) Prevalence and risk factors for postpartum depression among women with preterm and low-birth weight infants: a systematic review, *BJOG*, 117(5), pp.540-50
- lxxiii. Hynan, M.T., Steinberg, Z., Baker, L., Cicco, R., Geller, P.A., Lassen, S., Milford, C., Mounts, K.O., Patterson, C., Saxton, S., Serge, L., Stuebe, A.,(2015) 'Recommendations for mental health professionals in the NICU,' *Journal of Perinatology*, 35 S14-S18
- lxxiv. Department of Health, Social Services and Public Safety (2015) Regional Bereavement Guidance on evidence-based, holistic care of parents and their families after the experience of miscarriage, stillbirth or neonatal death





“ My baby was extremely ill but the doctors and nurses never gave up hope even when they didn't know what was wrong with him or how to fix him. They are the hardest working people I have ever met. I will never forget what they did for my little boy. They saved his life by not giving up. Superheroes the lot of them. ”

(Mum of a baby born full term but sick)

We rely on donations to fund our vital work and your support could be life changing to premature and sick babies in Northern Ireland.

e ask@bliss.org.uk

w bliss.org.uk

a **2nd Floor, Chapter House,
18-20 Crucifix Lane,
London SE1 3JW**

e info@tinylife.org.uk

w tinylife.org.uk

a **The Arches Centre
1st Floor, 11-13 Bloomfield Avenue
Belfast BT5 5AA**