A chance for change

Bliss Baby Report and Manifesto: Scotland 2011

Bliss

for babies born too soon, too small, too sick

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Acknowledgements

We would like to thank the staff at all of the neonatal units who provided us with the information for this report.

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Photographs from: Nicola Kurtz Photography and James Darling Photography.

Printed in the UK by Manor Creative Ltd.

Published in 2011 by Bliss Scotland.

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Executive summary and key findings

Approximately 8,000 babies are admitted to neonatal care in Scotland every year[i] because they are born too soon, too small or too sick. This is equal to one in seven of all babies born in Scotland[ii]. Scotland therefore has the highest rate of admissions in the UK.

This report looks at how services are performing since welcome steps were taken by the previous and current Scottish Governments including:

- Investment into the establishment of three Managed Clinical Networks to coordinate care across Scotland.
- The formation of the Neonatal Expert Advisory Group tasked with drawing up a set of key service standards of care for units in Scotland to meet.
- Investment into neonatal nurse training.

In September 2010 Bliss Scotland sent a survey to all of the 16 neonatal units in Scotland. We received responses from 12 units, an overall response rate of 75 per cent. We found that:

- There is a shortage of nurses to care for Scotland's sickest babies in at least three Level 3 units.
- Some units are facing long term problems recruiting middle-grade doctors and consultants. Two units reported that they each had one consultant vacancy for over six months which they had not yet been able to fill. A further two units reported that they had vacancies which they had been unable to fill for over 12 months totalling five whole time equivalents.
- More than half of units had to close to new admissions at some point in 2009.
- There is a lack of emotional support for parents with fewer than half of units providing access to counselling services for parents.
- There is a shortage of overnight accommodation for parents whose babies are in a unit many miles away from home. Thirty eight more overnight rooms are needed to ensure parents can stay with or near their babies.

The report also sets out a number of recommendations for the NHS, Scottish Government and all of the main political parties in Scotland ahead of the May 2011 elections including:

- To continue investment and support into Managed Clinical Networks to ensure they will meet the needs of their populations, including the needs of families through the provision of accommodation and emotional support where needed.
- To ensure there is a rigorous set of standards for neonatal care, including national staffing standards, fully endorsed by the Scottish Government, which set out clearly the services that need to be in place to deliver the best possible outcomes for babies.
- Health Boards set out comprehensive plans about how they will implement these standards once they are published, and ensure the necessary investment is provided to be able to do so.
- To commit to providing the necessary support for the Scottish Neonatal Transport Service to achieve the recommendations of the Specialist Transport Services Strategic Review, when published later this year.
- Health Boards account for how much funding they provide to neonatal services and ensure that front line services remain supported for vulnerable babies

Introduction

Care for premature and sick babies in Scotland is provided in 16 established neonatal units which are currently being organised into three Managed Clinical Networks. These networks, when they are fully functioning, will co-ordinate the care of babies across a group of neonatal units to ensure that babies receive the care they need, as close to home as possible. The units within each network will provide a range of levels of neonatal care.

Categories of care

Neonatal care includes three categories of care. These are:

- **Special care** – the least intensive level of care and most common. This includes care such as monitoring of a baby's breathing and heart rate, provision of light therapy for jaundice, being fed by tube or supplied with extra oxygen.
- **High dependency care** – this level of care is for babies weighing less than 1,000g, or who are receiving help with breathing via continuous positive airway pressure or intravenous feeding but who do not require intensive care.
- **Intensive care** – highly specialised care for the most seriously ill babies who will often be on a ventilator or need constant care to keep them alive.

Levels of neonatal units

These three categories of care are delivered across three levels of neonatal units in Scotland. These levels are:

- **Level 1 units** – provide special care but do not aim to provide any continuing high dependency care to babies.
- **Level 2 units** – provide high dependency care and some short term intensive care to babies, subject to local agreement.
- **Level 3 units** – provide special care, high dependency and intensive care.

While the British Association of Perinatal Medicine (BAPM) has recently recommended that neonatal unit levels should be redefined to reflect the fact that all unit levels provide a range of categories of care, at least for short periods[iii], services in Scotland have not yet been reclassified.

IT'S A BOY!

Welcome developments

In recent years the previous and current Scottish Governments have taken welcome steps towards addressing some of the key problems facing neonatal services. In 2006 the Maternity Services Action Group (MSAG) was set up to advise the Scottish Government on maternity services from pre-pregnancy through to infancy. MSAG established a neonatal services sub-group to review current provision of care for premature and sick babies and identify recommendations for change. In 2009 the sub-group put forward recommendations[iv], only some of which MSAG endorsed to the Scottish Government.

Managed Clinical Networks and the Scottish Neonatal Transport Service

Neonatal care is provided in 16 units across Scotland. The way this care is provided, in a relatively small number of specialist centres, ensures babies receive the best standard of care. However it also means that hundreds of babies and mothers have to be transferred for care many miles away from their homes every year, with significant emotional, social and financial consequences for their families.

The 2009 review into neonatal services recommended that Managed Clinical Networks (MCNs) be established to improve the co-ordination of care between different units in a geographical region. MCNs help ensure that babies born premature or sick receive the right care in the right level of unit, as close to home as possible. In 2010 the Scottish Government released some funding to support the establishment of three MCNs. To date, the West MCN is fully established, the South East and Tayside MCN has a Network Manager and Lead Clinician in post and is close to being fully established and the North MCN has a Lead Clinician in post and should be fully established by late March 2011.

A high quality transport service is also needed to ensure the safe transfer of babies in between the different levels of units. While the Scottish Neonatal Transport Service is a good service in many ways, it is now facing a number of challenges, including demand exceeding planning assumptions[v]. However a Government review looking at specialist transport services is currently underway. We urge the review team to address the challenges facing the Scottish Neonatal Transport Service and ensure that it is properly resourced to be able to meet demand. Overall we welcome the progress that has been made by the successive Scottish Governments and the NHS.

Bliss Scotland welcomes the establishment of Managed Clinical Networks and the Specialist Transport Services Strategic Review and urges the Scottish Government and all other political parties to commit to continuing support for this work over the next five years.

Neonatal Expert Advisory Group

The Neonatal Expert Advisory Group (NEAG) was set up by the Scottish Government in the summer of 2010 with the aim of ensuring that neonatal care in Scotland meets minimum clinical standards. The group, which includes Bliss Scotland representation, was given a timeline of two years to draw up key service standards, while also supporting the new Managed Clinical Networks to deliver the best care for their populations.

Bliss Scotland wholeheartedly welcomes this group. However it is vital that the standards the group is producing fully comply with those set out by the British Association of Perinatal Medicine (BAPM), in line with the national standards frameworks endorsed in Wales and England in 2008 and 2009 respectively[vi].

Bliss was disappointed that, in 2009, a key recommendation of the neonatal sub-group that the Maternity Services Action Group did not endorse to the Scottish Government was that units should adopt the BAPM standards on nurse staffing. It is essential that the service standards that NEAG is drawing up endorse these BAPM standards to ensure Scotland's babies born too soon, too small or too sick receive the care they deserve.

It is essential that the Scottish Government and all political parties ensure there is a rigorous set of standards for neonatal care, fully endorsed by Government, which set out clearly the services that need to be in place to deliver the best possible outcomes for babies, as agreed by the clinical experts.

Issues facing neonatal care

While Bliss Scotland welcomes the progress that is currently being made by the Scottish Government in relation to neonatal services, there are still a number of issues that must be addressed to ensure Scotland's most vulnerable babies get the care they deserve.

Nursing levels

Nurses of all levels provide the vast majority of hands-on care to babies born too soon, too small or too sick and therefore form the backbone of our neonatal services.

The British Association of Perinatal Medicine (BAPM)[vii] outlines clinical guidelines for staffing levels that all units should be meeting to ensure premature and sick babies get the care they need:

Staffing of neonatal services

- A nursing ratio of 1:1 is provided for babies requiring neonatal intensive care. The named nurse has a post-registration certificate in neonatal intensive care.
- A nursing ratio of 1:2 is provided for babies requiring high dependency care. The named nurse has training in neonatal care.
- A nursing ratio of 1:4 is provided for babies requiring special care.

Three out of the eight units that provided information on nursing levels and occupancy rates did not have enough nurses to meet BAPM standards, which appears to be an improvement on previous years. However these units that are not meeting BAPM standards are Level 3 units caring for critically ill babies. In addition surveys were not returned from certain units where data is not comprehensively collected. However these are the units where many neonatal staff have told us of nurse shortages.

On top of this, many units are not meeting minimum standards on nurse training levels. Royal College of Nursing standards[viii] state that 70 per cent of the neonatal nursing workforce in intensive care units should have a qualification in specialised neonatal care. However half of the Level 3 units that responded do not meet this standard. Many units report that it is difficult to release nurses for training.

"Generally the staffing does not allow sufficient time for the heavy burden of mandatory training [such as] fire, moving and handling, health and safety, resuscitation, child protection, mentorship…" Clinical Lead

There is strong evidence to support the provision of one to one nursing for babies in intensive care. For example, one study, which observed nurses working in neonatal intensive care units, revealed that a nurse spends on average 56 minutes in every hour providing direct care for the baby[ix]. Further research confirmed that increasing the ratio of specialist neonatal nurses to babies in intensive care and high dependency care is associated with a 48 per cent decrease in risk-adjusted mortality[x].

The correct number of nurses on a unit can also mean that they have more time to spend with parents explaining medical procedures and equipment, helping provide skin-to-skin care* and generally supporting families during such a difficult and emotional time. Bliss Scotland urges NEAG to fully endorse the BAPM nurse staffing standards.

"We appreciate everything that everyone did in looking after our baby… however, staffing issues were obvious, breastfeeding help was very poor, and general updates on progress… were only really explained if you asked." Parent

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* Which, among other developmental care techniques, have been proven to have a positive effect on the health of a premature or sick baby: *POPPY steering group, Family-centred care in neonatal units: A summary of research and recommendations from the POPPY project*, London: NCT, 2009

"The experience was frightening. The doctors and nurses were professional but did not communicate with the families adequately. Procedures were at times carried out without enough explanations." Parent

Medical staffing

There are significant problems with recruiting consultant level doctors in neonatal units in certain units in Scotland. Five units reported current vacancies in their consultant grade rotas, totalling 7.5 whole time equivalent posts. Two of these units reported that they each had one consultant vacancy for over six months which they not yet been able to fill. A further two units reported that they had vacancies which they had been unable to fill for over twelve months totalling five whole time equivalents.

"We cannot fill the posts due to a lack of applicants and a lack of funding." Nurse

Units also reported, unprompted, that they have significant problems recruiting middle grade doctors:

"We have a major issue [with] middle grade/resident cover." Senior Nurse

"Medical middle grade rota relies heavily on locum cover. There is a lack of neonatal trained staff to fill vacant posts." Specialist

It is vital that these shortages are addressed to ensure consistent quality of care for premature and sick babies across Scotland.

Unit closures and occupancy levels

Because of the pressures facing neonatal services, many units are having to close their doors to new babies born needing specialist care. Five out of the nine units that responded to this question had to close to new babies born in their hospital for a total of 208.5 days in 2009, and closed to babies in other hospitals for 269.5 days in 2009. Scaled up to all 16 units, we estimate that units were closed for 507 days to babies born within their own hospital grounds, and for 675 days for babies born elsewhere. It is worth noting that units often try to overcome these closures by borrowing equipment, drafting in staff for extra shifts or getting agency staff and only close to admissions as a last resort.

"This is the first year we have seen significant closures, probably due to occupancy capacity." Senior Nurse

There is evidence that babies' health outcomes are better when neonatal units have average occupancy levels of no more than 80 per cent[xi]: this means that, for example, if a unit has ten staffed cots, on average only eight of the cots should be filled. This additional capacity provides a safety net to ensure that if there are sudden peaks in the number of babies admitted to the unit, all babies will get the care and attention they need.

Our survey showed that occupancy rates in the 11 units that responded to this question were highly variable. For example, one Level 3 unit reported running at 40 per cent one month and 365 per cent a few months later in their high dependency cots. In addition the findings showed that special care and high dependency cots are working at a much higher occupancy rate than intensive care cots with five units' special care or high dependency cots working at over 80 per cent occupancy rate.

Access to therapy services

BAPM's recently published clinical standards also set out that all babies cared for in neonatal units should have access to a wide range of other health professionals known as allied health professionals to provide services such as physiotherapy, specialist feeding and nutritional support[xii].

We asked units if they had provided any access to a range of allied health professionals in the month of June 2010, to establish a snap shot of babies' access to these services at a recent point in time.

Access to occupational therapists to assess babies' daily activities to help detect any developmental issues was minimal: only three units out of the 11 that responded to this question reported that babies had access in the month of June.

Only four units provided any specialist nutritional support. However more positively six units said babies had access to speech and language therapy, to assess and provide specialist care for babies with feeding and swallowing problems. Plus babies had access to physiotherapy in seven units.

Emotional and practical support for families

Over the month of June 2010, fewer than half of units provided parents with access to counselling. Parents who have been through the traumatic experience of having a baby in neonatal care are at a higher risk of developing depression or anxiety[xiii]. It is therefore important that parents are given the opportunity to speak to a counsellor.

Eleven out of 12 units told us that they have some overnight accommodation either on the unit or within hospital grounds to enable parents to be close to their babies when they are critically ill. However there is a shortage of around 38 beds in total, meaning that some parents will not be able to stay with their babies[xiv]. Because of Scotland's geography and the fact that there are only 16 specialist units to cover the whole of Scotland, many parents will find that their baby is transferred many miles away from their home. It is therefore essential that they are given the opportunity to stay within or close to the hospital. One unit has an arrangement with a local hotel which provides free rooms to parents in need of accommodation if they do not have enough rooms in the hospital. Bliss Scotland highly recommends other units to look into this as an innovative way of providing extra capacity.

Neonatal transfers

Transport services are an important aspect of neonatal care to ensure that babies and their mothers receive the level of care they need. In Scotland more than 1,500 babies are transferred every year[xv] and around 1,000 mothers who are having complications before birth are transferred every year[xvi].

However there has been a 16 per cent rise in the number of babies being transferred between 2004, when the Scottish Neonatal Transport Service was established, and 2009. Demand for the service has therefore far exceeded planning assumptions and is likely to increase further over the coming years, by an estimated 100 transfers per year[xvii]. The transport service must be properly resourced to meet growing demand.

Conclusions

There have been a number of welcome developments in recent years that are starting to have a real and positive impact on neonatal services in Scotland. Bliss Scotland welcomes these developments and urges the Scottish Government and all political parties to pledge to continue this good work.

However there are still a number of issues that units are facing, particularly the recruitment of doctors, a shortage of nurses to care for Scotland's sickest babies in Level 3 units and a lack of emotional and practical support for parents. These need to be addressed urgently by the Scottish Government and Health Boards to ensure Scotland's most vulnerable babies get the care they deserve.

Recommendations

We recommend

- **The Scottish Government, all political parties and Health Boards commit to continuing investment and support into Managed Clinical Networks to ensure they can meet the needs of their populations, including the needs of families through the provision of accommodation and emotional support where needed.**
- **The Scottish Government and all political parties ensure there is a rigorous set of standards for neonatal care, including national staffing standards, fully endorsed by Government, which set out clearly the services that need to be in place to deliver the best possible outcomes for babies.**
- **Health Boards set out comprehensive plans detailing how they will implement these standards once they are published, and ensure the necessary investment is provided to be able to do so.**
- **The Scottish Government, all political parties and Health Boards commit to providing the necessary support to the Scottish Neonatal Transport Service to achieve the recommendations of the future Specialist Transport Services Strategic Review when published later this year.**
- **Health Boards account for how much funding they provide to neonatal services and ensure that front line services remain supported for vulnerable babies.**

Methodology

In September 2010, Bliss Scotland sent a survey to all 16 neonatal units in Scotland. We received responses from 12 units: a response rate of 75 per cent. One of the twelve responses was from a Level 3 unit with surgery, seven were Level 3 units, three were Level 2 units and one was a Level 1 unit.

We asked 21 questions about the units' facilities, designation, staffing and occupancy, with a further two sections where respondents could add comments. Some questions related to the current staffing of the unit at the time of completing the survey, others referred to data for 2009. Further questions were focussed on a particular month/week to get a snap shot of how services across the country are working at one time.

To calculate the number of nurses needed to care for the babies admitted in 2009, we used the average monthly occupancy rate for each level of care the hospitals provides, taken from their response to our survey. We divided this figure by 30.42 to work out the average number of occupied cots per day. We then applied the following formula to calculate the number of nurses needed according to the BAPM 2001 standard:

((number of intensive care cots) + (number of high dependency cots/2) + (number of special care cots/4) +1) x 5.75

The survey did not ask whether the unit's staffing levels included uplift for training, sickness and maternity leave. This is something we will seek to address in future surveys.

All posts in this report refer to whole time equivalent positions.

Parent quotes are from a survey posted on our website asking parents to tell us about their experiences of having a baby in neonatal care. Over 600 people responded to this request. Of these 39 were parents who have had a baby or babies admitted to Scottish neonatal units between January 2007 and July 2010.

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[ii] There were 58,243 live births in Scotland in the year ending March 2009 according to the *Births in Scottish Hospitals*, ISD Scotland (Aug 2010)

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[xii] *Service Standards for Hospitals Providing Neonatal Care (Third Edition)*, British Association of Perinatal Medicine (August 2010)

[xiii] National Health and Medical Research Council, *Postnatal depression: A systematic review of published scientific literature to 1999*, (1999)

[xiv] This calculation is based on there being one overnight room per intensive care cot plus two extra per unit for rooming in.

[xv] *Scottish Neonatal Transport Service 2009 Review,* NHS Scotland (2009).

[xvi] Skeoch C, Jackson L, McLean D, Wilson AM, *The Perinatal Collaborative Transport Study (CoTS)* NHS Quality Improvement Scotland (2008). CoTS collected data from Scottish maternity units on in utero transfers over a six month period in 2006/7. It identified 94 in uterotransfers per calendar month.

[xvii] *Scottish Neonatal Transport Service 2009 Review,* NHS Scotland (2009).

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