Bliss 30th birthday Baby Report
Neonatal care in Scotland - 2010

Celebrating 30 years

Summary

Around 8,000 babies are admitted to neonatal care in Scotland every year[i]. With 7.3 per cent of all babies born before 37 weeks gestation[ii], Scotland has the highest premature birth rate in the UK.

2010 is Bliss' thirtieth year. Over the last three decades the number of babies surviving at early gestations and after grave illness has greatly increased. New techniques and treatments have transformed the way babies are cared for. As Bliss was founded, a report was published setting out recommendations for improving care for mothers and babies in Scotland[iii]. However Scottish neonatal services have not received the necessary level of political attention and investment to ever make these a reality.

In recent years, the Scottish Government has taken welcome steps towards addressing some of the key problems facing neonatal services. The *Review of Neonatal Services in Scotland,* published in May 2009 set out a range of recommendations on how neonatal care should be provided to ensure the best possible start in life for Scottish special care babies. The recommendations of the review have now started to be implemented, however there is still a long way to go and a number of issues yet to be resolved.

Neonatal care is provided in 15 units across Scotland. The way care is provided, in a relatively small number of specialist centres, ensures babies receive the best standard of care. However it means that every year hundreds of babies and mothers are transferred many miles from home, with significant emotional, social and financial consequences for their families.

While transfers are a necessary part of neonatal care in Scotland, many are as a result of services being overstretched, rather than medical need[iv]. There are huge pressures on nurses and doctors working in neonatal care, and too often units have to close to new admissions. In addition, due to a severe shortage of neonatal nurses, babies are often not receiving the standard of care they need. Neonatal units must be properly resourced to ensure they meet the needs of mothers and babies.

Review of Neonatal Services in Scotland

In the summer of 2006 the Maternity Services Action Group (MSAG) was set up by the Scottish Government to advise ministers on the nature and quality of maternity services from pre-pregnancy through to infancy, and make recommendations on service improvements. Later that year, MSAG established a neonatal services sub-group to review current provision and identify requirements for change. Bliss participated in the review as an active member of the neonatal sub-group.

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for babies born too soon, too small, too sick

The *Review of Neonatal Services in Scotland*, was published in May 2009, two and a half years after it was set up. Its recommendations included:

- Full adoption of the British Association for Perinatal Medicine (BAPM) *Standards for hospitals providing neonatal care*, including standards relating to nurse staffing in neonatal units
- Endorsement of the principle that care should be provided by local services and that efforts should be made to minimise the number of neonatal and '*in utero*' transfers – where the mother is transported to a particular centre before giving birth
- Neonatal services are planned and provided as regional networks of units
- Further action to ensure units provide more long-term accommodation for parents and other practical support including financial support.

Following the review, the Scottish Government has provided some funding towards the establishment of three Regional Managed Clinical Networks to co-ordinate care across Scotland, and recruitment for network managers is currently underway. The Scottish Government is also providing leadership for the further development of neonatal care and how networks should take forward the MSAG recommendations.

Despite this very welcome progress, Bliss has a number of concerns that we believe still need to be addressed.

Neonatal transfers

More than 1500 babies are transferred by the Scottish Neonatal Transport Service's specially designed ambulances or by air ambulance each year[v]. In addition, we estimate there are over 1000 *in utero* transfers each year[vi], although there is little reliable data on the number of *in utero* transfers, which are provided as part of local maternity services rather than by specialist neonatal teams.

There has been a 16 per cent rise in the number of babies being transferred since 2004 when the Scottish Neonatal Transport Service was established, and demand for the service has far exceeded planning assumptions[vii]. Demand is likely to increase further over the coming years, by an estimated 100 transfers each year[viii], as care patterns in some areas change, in line with the recommendations of the *Review of Neonatal Services in Scotland*. This is in addition to any increase that may result from rising birth rates, pre-term birth rates or other social factors. The transfer service must be properly resourced to meet the growing demand, and recommendations set out in the *Review of Neonatal Services in Scotland* to ensure safe and appropriate *in utero* transfers must be addressed without delay.

Hundreds of babies and mothers are transferred long distances to hospitals far from their families' homes every year, and where many babies will need to stay for several weeks or months. In addition to the stress and worry that is inevitable when a baby is admitted to neonatal care, long distance transfers also pose enormous practical, emotional and financial difficulties for families.

A survey of neonatal units carried out as part of the *Review of Neonatal Services in Scotland* showed that while almost all units were able to provide short term accommodation for parents, only half offered longer term accommodation, and less than a third had any transitional care facilities, where parents can sleep overnight and spend time caring for their baby while still under the supervision of specialist staff before discharge[ix].

Bliss has commissioned research to assess the social impact of transfers on families in Scotland, the results of which have just been published[x]. The study was based on a survey of women who had experienced *in utero* transfers. Over half reported feeling socially isolated as a result of being transferred. A fifth reported that their transfer had caused family difficulties – of these, two fifths were difficulties relating to their partner, and just less than a third regarding their other children.

The research also revealed:

- Almost half had insufficient time to organise alternative childcare
- A fifth had partners who experienced difficulties getting time off work
- Two fifths reported that their families had experienced travel difficulties
- Three out of ten women reported financial problems as a result of the transfer. The key issues associated with this were partner's employment status; child care difficulties; travel difficulties; accommodation problems; duration of hospital admission
- 15 per cent reported that families had difficulties in finding local accommodation. Only 13 per cent received help from hospital staff with finding family accommodation, but over half of all those surveyed expressed the desire for hospital accommodation to be available to them.

A final key finding of the research was that according to the understanding of those surveyed, one in four transfers were as a result of a lack of cot availability for the baby at a unit closer to home, rather than medical need. The impact that transfers can have on family life is clear. There is a pressing need to ensure that services are better planned to meet the needs of families, and minimise the occurrence of such avoidable distress and disruption.

Staffing of Neonatal Services

Bliss was disappointed that MSAG did not accept the neonatal sub-group's recommendation to adopt the BAPM standards on nurse staffing, instead saying only that "in practice a unit has the responsibility to look after safely the babies in its care."

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[xi]. 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[xii].

Bliss research from 2008 found that an extra 100 neonatal nurses were needed in Scotland to meet the BAPM standards. While we welcome the introduction of the neonatal nursing workload and workforce tool, which takes into account the BAPM guidelines, we would urge the Scottish Government to ensure that this leads to real improvements in staffing ratios so that all babies in Scotland receive the care they need. While adults and children in intensive care receive one to one nursing, in many areas babies do not. We believe that this level of care should be provided to the most vulnerable babies in our society as a right, and call on the Scottish Government to take a lead on this and endorse the BAPM standards in full.

There are also concerns about shortages in properly trained doctors in Scottish neonatal services. The *Review of Neonatal Services in Scotland* identified 'deep concerns amongst clinical staff' about medical staffing levels. These concerns were particularly in light of the European Working Time Directive coming into force from August 2009, which reduces the availability of junior doctors, and the roll out of Modernising Medical Careers, which will also impact in a reduction in junior doctors from 2011. We urge the Scottish Government to carefully plan how shortages in appropriately trained doctors working in neonatal care can be addressed.

Recommendations

- The introduction of neonatal networks must end inappropriate transfers of mothers and babies long distances because units closer to home are closed to new admissions. Networks must be properly resourced to ensure that they can meet the needs of their populations, including the needs of families through the provision of long term accommodation and financial support where needed.
- The Scottish Neonatal Transfer Service must be properly resourced to ensure it can meet growing demand, and *in utero* transfers should be provided as part of a safe and co-ordinated service.
- Neonatal care must be provided in compliance with BAPM standards. The Scottish Government should endorse the standards and ensure that there are enough trained nurses and doctors to provide the care that vulnerable babies need.

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References

i *Directory of Critical Care*, CMA Medical Data (2008). There is some discrepancy between different sources over neonatal admission figures. ISD Scotland use the figure of 6,000 admissions each year, while the survey of neonatal units carried out as part of the *Review of Neonatal Services in Scotland* and Directory of Critical Care both highlight c.8000 admissions each year. However, as the *Review* concluded: "It is not possible to conclude which data source is more accurate: there are acknowledged issues over the completeness of the returns used by ISD, and around the quality of self reported data." (Appendix F.)

ii ISD Scotland (2009).

iii Walker J (Chairman) *National Medical Consultative Committee, Report of the Joint Working Party on Standards of Perinatal Care in Scotland* (1980).

iv Skeoch C et al *The Perinatal Collaborative Transport Study* (CoTS) NHS Quality Improvement Scotland (2008)

v *Scottish Neonatal Transport Service 2009 Review*, NHS Scotland (2009)

vi 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 utero* transfers per calendar month.

vii *Scottish Neonatal Transport Service 2009 Review*, NHS Scotland (2009)

viii *Scottish Neonatal Transport Service 2009 Review*, NHS Scotland (2009)

ix *Review of Neonatal Services in Scotland Maternity Services Action Group (MSAG)* Neonatal Services Sub Group, (2009)

x Jackson L, McLean D, Wilson AM, Skeoch C, *An evaluation of the financial and emotional impact of in utero transfers upon families: a Scotland-wide audit.* Infant, Volume 6 issue 2 (March 2010)

xi Milligan DWA, Carruthers P, Mackley B, Ward Platt MP, Collingwood Y, Wooler L, Gibbons J, Draper E, Manktelow BN 'Nursing Workload in UK tertiary neonatal units' in *Archives of Disease in Childhood* published online (2008).

xii Hamilton KE, Renshaw ME, and Tarnow-Mordi W, 'Nurse staffing in relation to risk-adjusted mortality in neonatal care', *Archives of Disease in Childhood, Fetal and Neonatal Education*, (2007: 92; 99-103).

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