Audit Risk Level:

(Risk level will be added by EQIA steering group)

3. Rapid Impact Assessment summary report

Each of the numbered sections below must be completed

Interim report ☒ Final report ☐ (Tick as appropriate)

1. Title of plan, policy or strategy being assessed.

‘Neonatal Care: Advice & information from parents who have been where you are now.’

2. What will change as a result of this proposal?

Consultation with a group of parents across South East and Tayside (SEAT) regarding ‘what do we do worst?’ found it was around transitions – between areas/periods of care. Preparation for this is poor. While there are a range of documents, good practice statements and leaflets with advice for parents none have the specific goal of transitional care. This has been written by parents for parents.

3. Briefly describe public involvement in this proposal

A group of mothers from the SEAT Neonatal Managed Clinical Network (MCN) identified a gap, as described above, and agreed to do a focused piece of work to develop a resource guide on transitions in the neonatal unit for parents. As the Guide went through the various phases of development there was also valuable input from
fathers and friends for external review and comment.

A questionnaire was developed to gather feedback from parents as to:

- How useful they found the booklet
- If it was easy to read and understand
- Clearly laid out
- Photos/images used
- If there required to be more detail in any of the sections

The questionnaires were sent out to neonatal units across SEAT and 24 completed questionnaires were returned. These had been completed by mums and dads and the feedback has been overwhelmingly positive. Staff on the neonatal units were also asked to provide feedback and these suggestions have been incorporated in to the Guide.

Clifford Burden, Communications Manager, NHS Lothian has reviewed the Parent Guide and provided guidance and advice on changes to be made to text and formatting which have been made.

4. Date of RIA

5th February 2014

5. Who was present at the RIA? Identify facilitator and any partnership representative present

Name	Job Title	Date of RIA training	Email
Marie Storar	Parent	N/A	
Samantha Wallace	Parent	N/A	
Ian Laing	MCN Clinical Lead	N/A	Ian.laing@nhslothian.scot.nhs.uk
Iona Philp	MCN Manager	N/A	Iona.philp@nhs.net
Margaret Carlin (facilitator)	Senior Health Policy Officer	2010	Margaret.carlin@nhslothian.scot.nhs.uk

6. Evidence available at the time of the RIA

Evidence	Available?	Comments: what does the evidence tell you?
Data on populations in need	Yes	**1. BLISS Parent's Experiences of Neonatal Care (Picker 2011)** -The information needs of parents are better addressed than previously, though not all units have parent booklets, antenatal visits to the unit and written information about discharge home. **2. RCN (2012) Nursing Children & Young People Vol. 24, No.1** – Survey highlights a worrying lack of support in terms of the information parents receive. Evidence of good practice but there was significant variation across units. **3. The POPPY Project (Family Centred Care in the NNU) (Bliss, 2009) -** involved research on three aspects of neonatal care and the provision of services that are important for the parents of premature babies. One of these was: Effective interventions for communication, support and information, as identified by a systematic review of published research evidence. Parents said they needed information and support in order to familiarise themselves with the neonatal unit and to envisage what the future might hold; different formats are

		needed to meet a range of different needs and preferences, including direct conversation, written key points, detailed information packs, useful internet sites, DVDs with real families' experiences. Babies being cared for in neonatal units in the UK usually receive outstanding clinical care. Less consistent attention has been paid to the non-clinical issues and how these affect a family's journey through neonatal care and their experience of the transfer from hospital to home. The POPPY Project Steering Group recommends that all neonatal units provide family-centred care. Family-centred care in a neonatal unit involves health professionals actively considering how it feels for parents to have a premature or sick baby and working within a policy framework to improve the family's experience. This means being willing to 'stand in the shoes of parents'. It involves introducing practices and providing facilities that encourage and support parents and families throughout the care pathway. It is vital that mothers and fathers are included at the centre of the care process, alongside their baby or babies. **Interviews with parents** Interviews with 55 parents in England and Scotland indicated that periods of transition were particularly stressful times. These include the baby's birth and arrival on the neonatal unit, movements between different units or different levels of care and leaving the unit to take the baby home. Parents valued: • consistent, clear information about the unit and caring for their baby, • receiving emotional support, • practical guidance and encouragement in caring for and feeding their baby, including on-going support for breastfeeding. Continuity of care is very important for families, particularly at times of crisis, during transitional care, and at discharge when the parents are assuming full responsibility for their baby's care for the first time. **4. Supporting parents in the neonatal unit – Hazel McHaffie /P.Fowlie (2004) -** Parents find it very stressful when their baby is admitted to the neonatal unit for any reason. Some of the coping strategies

		include trying to gain a deeper understanding of the problems, establishing a degree of control over the situation, seeking social support from other people. Written information about the neonatal unit and, where appropriate, describing specific conditions or procedures may be useful. **5. NICE Guidelines (2010)** Parents of babies receiving specialist neonatal care can expect to be encouraged and supported to be actively involved in planning and providing care, joint decision-making and to be in regular contact with their healthcare team (Quality statement 5: Encouraging parental involvement in care) **6. 'Information needs of parents of children admitted to a neonatal intensive care unit' (DeRouck, S., Leys, M., 2009)** - Access to information helps parents to gain some control and engage in the care of their baby'. **7. Comparisons of needs, need responses, and need response satisfaction of mothers of infants in neonatal intensive care units. Journal of Paediatric Nursing** (Punthmatharith et al., 2007). 'Research shows that when information giving meets parents needs, their stress is minimised'.
Data on service uptake/access	Yes	There are 17 neonatal units in Scotland. Around 8,000 babies are born prematurely each year in Scotland requiring specialist care in neonatal units.
Data on quality/outcomes	Yes	Poppy Report (Bliss, 2010); Bliss Parent's Experiences of Neonatal Care (Picker 2011) - Picker Survey; How can family centred care be improved to meet the needs of parents with a premature baby in neonatal intensive care? Sarah Cockcroft (2011) Journal of Neonatal Nursing
Research/literature evidence	Yes	As above - Data on populations in need
Patient experience information	yes	Surveys as cited above - Poppy Report (2010); Picker Survey (2011) – parent experience surveys
Consultation and involvement findings	Yes	SEAT Neonatal MCN Parent Survey 2013 - 24 parents (mums & dads). Also mums asked who had not had babies admitted to NNU for comments on Guide. 5 Mums/Dads involved in the SEAT MCN Parent Group to develop Parent Guide. Neonatal unit colleagues across 4 Health Boards and 5 NNU also provided feedback. Neonatal MCN Steering Group (a multidisciplinary/professional group) also consulted on the content of the Parent Guide and feedback provided. The West of

		Scotland MCN contributed comments from NNU staff in that region.
Good practice guidelines	Yes	Neonatal Quality Framework (2013); NHS Scotland Quality Framework (2010); Toolkit for High Quality Neonatal Services (2009)
Other (please specify)		-

7. Population groups considered

	Potential differential impacts
Older people, children and young people	For example - Young mums/grandparents/siblings. Giving information in a clear and unambiguous way.
Women, men and transgender people (include issues relating to pregnancy and maternity)	Women are the key target group. Men have been involved with guide development and questionnaire feedback.
Disabled people (includes physical disability, learning disability, sensory impairment, long term medical conditions, mental health problems)	There are increasing numbers of parents with learning disabilities. Safe guardians of care for a child are identified antenatally. Staff work hard to understand the situation and provide support. This Guide provides information and aims to give parents reassurance. If the Guide is in PDF format parents will be able to access ‘screen reader’ and listen to an audio version and enlarge the print as necessary for ease of reading.
Minority ethnic people (includes Gypsy/Travellers, non-English speakers)	Translators are always available if required in the neonatal units; translation of the Guide into the main foreign languages in the region is being actively considered
Refugees & asylum seekers	These groups are treated no differently as parents on the neonatal unit.
People with different religions or beliefs	This is no reference to this in the Guide. The information is deemed equally valuable and appropriate for parents of any religion or none.
Lesbian, gay, bisexual and heterosexual people	These parents should get equal benefit from reading the Guide.
People who are unmarried, married or in a civil partnership	The information is the same for all, there is no differential impact.

People living in poverty / people of low income	The information is the same for all, there is no differential impact.
Homeless people	These parents will have support in the community- this will have been identified prior to discharge. They will have access to the Guide along with other appropriate support.
People involved in the criminal justice system	Babies in this situation would be fostered- the birth mother could come and visit if deemed safe to do so and the Guide will be available to her as other parents
People with low literacy/numeracy	Clifford Burden, Communications Manager, NHS Lothian has reviewed and commented on this document. Changes have been made accordingly.
People in remote, rural and/or island locations	The information is the same for all, there is no differential impact.
Carers (including parents, especially lone parents; and elderly carers)	This would also include social workers, NNU staff, emergency foster carers.
Staff (including people with different work patterns e.g. part/full time, short term, job share, seasonal)	The information is the same for all, there is no differential impact.
OTHERS (PLEASE ADD):	

8. What positive impacts were identified and which groups will they affect?

Impacts	Affected populations
All families will have the opportunity to benefit from this	

9. What negative impacts were identified and which groups will they affect?

Impacts	Affected populations
Different people will get different things from this. All voices need to be heard on this including families from ethnic groups. Minor gaps which need to be addressed around language used and the	

inclusion of quotes/illustrations reflecting the main black and minority ethnic groups in the SEAT area.	

10. What communications needs were identified? How will they be addressed?

See below.

11. Additional Information and Evidence Required

If further evidence is required, please note how it will be gathered. If appropriate, mark this report as interim and submit updated final report once further evidence has been gathered.

a). Advised that two quotes from parents of ethnic origin, in their own language with a translation to English, would be a useful addition to the Guide. IP to approach neonatal units and ask for their help in obtaining these quotes from parents who currently have babies on the unit.

b). Advised to include more photos of parents/babies from ethnic background in the Guide. IL to obtain permission to use photos previously obtained and send on to IP.

c). Where the word ‘dad’ is used in the Guide change this to ‘partner’. Explain what is meant by using the word ‘parent’ in the foreword. Note at the front needs to say parent/carer.

d). Text to be added to the front of the Guide outlining who this Guide is aimed at – generic application.

e). Add a note to the Guide to indicate that the facility is there to access ‘screen reader’ for those with sensory impairment.

12. Recommendations

As detailed above.

13. Specific to this RIA only, what actions have been, or will be, undertaken and by when? Please complete:

Specific actions (as a result of the RIA)	Who will take them forward (name and contact details)	Deadline for progressing	Review date
Approach neonatal units and ask for their help in obtaining these quotes from parents who currently have babies on the unit.	I.Philp (email as given)	28th Feb 2014	1st March 2014

Obtain permission to use photos previously obtained and search for new photos to include.	I.Philp/I.Laing (email as given)	28th Feb 2014	1st March 2014
Change text in Guide from ‘dad’ to partner. Explain what is meant by the word parent.	M.Storar and rest of parent group to support	28th Feb 2014	1st March 2014
Add text to beginning of Guide – who this Guide is aimed at.	M.Storar and rest of parent group to support	28th Feb 2014	1st March 2014
Indicate how those with sensory impairment can also access the content of the Guide.	M.Storar and rest of parent group to support	28th Feb 2014	1st March 2014

14. How will you monitor how this policy, plan or strategy affects different groups, including people with protected characteristics?

An initial print run of approximately 6000 copies will be made. The Guide will be reviewed 3 years following publication by auditing parents using questionnaires and asking how they would improve it.

Manager’s Name: Iona Philp

Date: 11th February 2014

Please send a completed copy of the summary report to:

Scott.Justice@nhslothian.scot.nhs.uk

Note that you **will** be contacted by a member of NHS Lothian’s impact assessment group for quality control and/or monitoring purposes.