THE BEST START

Scottish Perinatal Network NEONATAL

NHS SCOTLAND

National Neonatal Discharge Planning and Follow-up Framework

Principles of Discharge Planning and Neonatal Follow Up

A Framework

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1 Introduction and Context

The review of neonatal and maternity services across NHS Scotland recognised that many babies requiring special care could be discharged home earlier if appropriate neonatal/community services were in place and highlighted that significant variance existed across NHS Scotland.

As some aspects of neonatal care will be required to be delivered in fewer Neonatal Intensive Care Units (NICUs) whilst ensuring families receive as much care and follow-up as possible as close to home, the review also recognised the importance of a consistent approach to repatriation across neonatal services.

Additionally, the review noted that neonatal care should continue after the baby is discharged home and recommended that a consistent follow up process, supported by clear guidelines should be developed to support families at home. This resulted in specific recommendations relating to discharge planning and neonatal follow-up being included within the review report *The Best Start: A Five-Year Forward Plan for Maternity and Neonatal Services in Scotland* (Scottish Government, 2017).

The National Discharge Planning Group Chaired by Dr Morag Campbell, NHS GG&C, and Ms Alison Wright, NHS Tayside, was convened on behalf of the Perinatal Group of Best Start in April 2018 to consider the actions required to fulfil recommendations 47, 48 and 49 of Best Start and to develop a Framework for Practice reporting back to the Perinatal Group and thereafter to the Implementation Board of Best Start.

The Group included multi-disciplinary representation from each Health Board across NHS Scotland with membership specifically targeted at individuals directly involved is this aspect of neonatal care. Recognising the pivotal role of Health Visitors and the need to align with GIRFEC principles representation from Health Visiting colleagues was also secured and comprehensive feedback obtained via the Health Visitors Leads Network.

Four subgroups were identified to contribute to this framework:

1. Discharge Planning
2. Repatriation
3. Models of Liaison
4. Follow–Up

Two well-attended workshops took place to progress this framework with subsequent stakeholder consultation prior to the compilation off this framework.

This Framework describes the overarching principles to support the delivery of the specific recommendations within Best Start. A number of appendices are included to support implementation, sharing of resources and consistency of practice. It is envisaged that Health Boards and individual units will use this framework to support local service delivery recognising that some variation will occur as a consequence of demographics, and geography.

The National Neonatal Network will support units in the implementation of these principles highlighting progress as well as areas of on-going challenge by interval audit. The National Neonatal Network will also be responsible for hosting the accompanying resources and parental information to support the implementation of this framework.

2 Scope

This framework is applicable to all neonatal units and the National Neonatal Transport Service within NHS Scotland. Given the range of possible discharge destinations from neonatal care and acknowledging the key role of Health Visitors the content of this framework is also applicable to Paediatric Services and Health Visitors across Scotland.

3 Principles of Effective Discharge Planning

Discharge is not an isolated event; it is a continuous process that begins at or soon after admission. Parents / carers should be partners in this process, and parental and infant readiness for discharge should be evaluated regularly throughout. Adopting this approach aims to ensure a safe and timely transition to home, whilst reducing re-admission rates.

Core tenets of effective discharge planning

- The "3C's" of discharge planning (adapted from *Discharge Planning Report: Best Practice in Transitions of Care*[1]) are **communication**, **coordination** and **collaboration**.

Communication

- Units should ensure early, regular and effective communication with:
    - Parents / nominated carers
    - Relevant community teams, e.g. community midwives, health visitors, general practitioners, social care
    - Relevant hospital teams, e.g. surgeons, medical specialists, allied health professionals, specialist nursing teams
    - The family's local base hospital
- A provisional discharge date should be identified as soon as feasible by the clinical team and communicated to parents / carers. Parents should be involved in discharge planning alongside the multi-disciplinary team.
- Note that the estimated date of delivery is no longer felt to be an appropriate discharge date for many preterm infants[2].

- Units should ensure that parents / carers should have the following at discharge:
    - Discharge information leaflet appropriate to the diagnosis for their baby and ongoing care package.
    - A copy of the medical discharge summary.
    - Relevant emergency contact numbers
    - Times and dates of planned follow up
    - Details on accessing a trained healthcare professional for emotional/psychological support during and post discharge.

Coordination & Collaboration

- Units should ensure that discharge planning involves the family and all relevant teams with proactive sharing of key information.
- All units should adopt a standardised approach (pathway), based on established good practice (*Appendix 1*), which may be adapted to reflect local service delivery.
- All units should ensure processes are in place to allow early identification of those babies who require a more formalised multi-disciplinary team / discharge planning meeting:
    - Complex medical or surgical needs.
    - Safeguarding or psychosocial concerns.
- All units should have identified discharge planning co-ordinators within neonatal units and collaborative pathways established with local services to prevent avoidable delays in discharge.
- All units should utilise a standardised discharge checklist to ensure that the planning process is completed (*Appendix 2*).
- All units, with support from the National Neonatal Network, should ensure IT infrastructure is in place or developed to facilitate on-going effective information sharing between hospital and community teams.

4 Principles of Effective Repatriation

'Repatriation' involves the timely return of a baby/babies to their booking unit or to the closest appropriate unit meeting their current care requirements; this may also be to a paediatric ward or a specialised paediatric service. The principles described are applicable regardless of the repatriation destination. Repatriation is integral to the effective delivery of integrated neonatal care across NHS Scotland. To ensure effective, family focused and consistent repatriation across units:

- Neonatal services across Scotland will work collaboratively to deliver these principles to ensure every baby is cared for in the most appropriate unit for their care requirements, underpinned by the philosophy that units work together in a National Neonatal Network, with regular and consistent communication between clinical teams.
- All service users of neonatal care in Scotland should receive standardised written information at the time of initial admission or antenatally where neonatal care is anticipated. This information explains how neonatal care is delivered in NHS Scotland, the concept of the National Neonatal Network, a description of the different types of units and the anticipation of planned repatriation to local units as soon as care requirements allow. This is available from the Scottish Perinatal Network website: perinatalnetwork.scot.
- Individualised assessments of readiness for repatriation must be specific to each baby, recognising the clinical needs, available expertise and facilities and the unit-specific criteria in the preferred Local Neonatal Unit (LNU)/Special Care Unit (SCU).
- Whenever possible multiple births should be repatriated together to minimise separation of families
- Planning should include referral to the Neonatal Transport Team one working day before anticipated repatriation to facilitate planning and workload prioritisation. "Same day" repatriation requests should be reserved solely for capacity emergencies and should be the exception rather than standard practice. All units will follow the agreed national process for arranging repatriation/elective transfers to optimise efficient use of resources and the ScotSTAR team. (*Appendix 3*)
- Ensuring the availability of a maternal bed or a maternal bed within a Transitional Care area should be included within repatriation planning in appropriate cases.

- Robust handover processes for the transfer of clinical information are pivotal to underpin this model of neonatal care. Direct communication between clinical staff in both units should occur during this time period to:
    - facilitate the exchange of clinical information including all contacts/teams and support mechanisms involved with the family. This may include ongoing input from specialised nursing teams, psychology input or family support for example.
    - identify any outstanding investigations, timescales for these and responsibilities for communicating results and decisions about future management
    - clearly document plans for follow-up in keeping with the agreed National Framework
    - Summarise the knowledge and expectations parent/carers/family.
- Families should be involved in repatriation discussions occurring between units (e.g. offered the opportunity to be involved in a videoconference (VC) consultation or to visit the receiving unit). Once repatriation has been agreed and scheduled, families should be provided with information about the destination unit and a designated contact within the receiving unit. If the destination unit is unfamiliar to the family, they should be offered a prior visit to the unit and an opportunity to meet the clinical team.
- All units will follow consistent infection prevention and control policies including the clinical risk assessment for microbiological screening on admission and transfer between units, http://www.nipcm.hps.scot.nhs.uk/content-items/clinical-risk-assessment-for-microbiological-screening-on-admission-or-transfer-to-a-neonatal-unit/ (*Appendix 4*)
- There is no requirement for single room isolation following a transfer/repatriation between units unless:
    - There are known CPE risk factors – isolation is necessary whilst awaiting screening results
    - There is a current outbreak in the referring unit – isolation may be required depending on situation specific advice from IPCT from referring unit.
    - Baby or mother is known to be colonised by a multi-resistant organism –isolation may be required depending on patient specific advice from IPCT from referring unit.
- Receiving units and paediatric services where applicable have a responsibility to create downstream capacity to facilitate the repatriation of a baby within 48-hours of the initial request, to protect NICU capacity for the smallest and sickest babies and to ensure that families are moved closer to home as soon as possible

- An inability to accept a repatriation transfer within the agreed timeframe and the reason why (unit capacity, staffing, infection control issues) must be escalated to that unit's senior hospital management and will be recorded in a consistent manner using exception reporting at Network level (*Appendix 5*). Reporting on the frequency and reasons for such exceptions will be a core responsibility of the National Neonatal Network.

5 Models of Liaison Services

- Parental preparation

  Throughout the patient journey, there should be a focus on facilitating parents to be the primary carer for their baby from the earliest opportunity. Parents should be supported through appropriate training to be involved in their baby's care and to carry out day-to-day care, to prepare them to meet their baby's ongoing needs at home.
- Neonatal community liaison services must be provided over seven days, ensuring safe transition of babies to the community setting. Depending on clinical demand and geography, a seven-day service may be delivered using telephone, face-to-face visits, utilising e-Health, or any combination of these approaches.

Units will:

- Ensure criteria exist to define eligibility for visits by the neonatal liaison service. Criteria should include those agreed as minimum criteria for visits:
  - <32 weeks gestation
  - an on-going medical need (e.g. domicillary oxygen, NG feeds)
  - consideration if discharge weight < 1.8Kg
- Ensure parents are given the opportunity to meet the community team as early as possible.
- Follow a standard community liaison framework; however, this may be individualised to the needs of each baby and family and relevant to local factors such as expertise, resource and geography.
- Ensure that a process is in place for a handover of information to Health Visiting services that aligns with GIRFEC principles and values where there is no identified need for neonatal community liaison services.

- Ensure there is a robust referral pathway for babies who are being transferred to Community Paediatric Liaison Nurses, where this is applicable locally.
- Ensure the seven-day service meets the local geographical need, utilising technology as appropriate for reviews e.g. "Attend Anywhere" or "vCreate".
- Neonatal community liaison follow-up will be provided by a team of nurses utilising a skill mix and expertise appropriate to the scope of the service dependent on activity and geography.

Units will:

- Have a designated lead for neonatal community liaison services who provides leadership, strategic direction and support to the team.
- Ensure that the skill mix within the team is appropriate to the requirements of the local area to deliver a robust seven-day service, appreciating this can be delivered by various modalities e.g. telephone.

Communication

- Units should establish a multidisciplinary team weekly meeting with a designated Consultant to discuss any concerns about babies out in the community, babies attending clinic and discharge planning of babies in unit.
- Each unit will ensure that information is available to inform parents/carers about the liaison service and the roles of staff within this service.
- Each unit will have clear onward referral pathways in place to escalate concerns noted by members of the community liaison team.
- Each unit will use technology and e-health to provide an efficient and effective community liaison support service.
- Units will undertake telephone/ "Attend Anywhere" consultations where practicable.
- Each unit will engage in audit and benchmarking activities to contribute to the National Neonatal Audit Project (NNAP) as a minimum, and to demonstrate that these key principles are achieved.
- Each unit should have an identified lead for community follow up to ensure optimal data completeness and effective liaison between boards.
- Each unit will reflect on outcome data and service user experience to inform service developments locally and across the Network.

6 Principles of Delivering Neonatal Follow-Up

Preterm infants and infants who have difficulties at the time of birth require a co-ordinated and structured approach to developmental follow-up.

All units should:

- Introduce the concept of neonatal follow-up early in the patient journey and revisit the conversation throughout the admission.
- Apply a structured follow-up framework; however, this may be individualised to the needs of each baby and family and reflect local service delivery.
- Provide enhanced surveillance and support as per NICE (2017) guidance for all babies <30 weeks gestation and those with additional risk factors *as a minimum*.
- Recognise that babies born at <32 weeks gestation or with a birth weight <1500g are considered at high risk of neurodevelopmental sequelae and a multidisciplinary program of neonatal follow-up is recommended (British Association of Perinatal Medicine, 2010).
- Recognise that babies born at 32+0 to 33+6 weeks gestation remain at elevated risk of neurodevelopmental sequelae and tailored care pathways should be designed to support developmental surveillance in this group.
- Ensure that babies born at 34+0 or above with no additional risk factors will follow the Universal Screening Pathway provided by the Health Visiting service in line with developmental follow-up guidance (NICE, 2017) and the postnatal care guideline (NICE, 2015).
- Ensure the principles and approach of GIRFEC underpins the communication between health professionals and planning of follow-up arrangements for all babies.
- An example of neonatal follow-up triage is provided in *Appendix 6 and 7*.

Neurodevelopmental follow-up will be provided by a multidisciplinary team with expertise in neonatal neurodevelopmental assessment. The multidisciplinary team could include neonatologists, allied health professionals, community liaison staff, general practitioners and paediatricians. The team will support and empower families to act as an advocate for their child.

- Professionals who provide services to neonates require a highly complex set of skills including enhanced assessment, observation, intervention, evaluation and interpretation of findings for the preterm and high-risk infant population in a follow-up setting. This includes advanced

clinical training in the neonatal setting and sound theoretical and evidenced based knowledge underpinning their practice.

- Some professions will have additional supporting documents detailing skills and experience required more specifically (Association of Paediatric Chartered Physiotherapists (APCP), 2011; Royal College of Occupational Therapists (RCOT), 2017; British Dietetic Association (BDA), 2018; Royal College of Speech and Language Therapists (RCSLT).
- Health Visitors, General Practitioners and family nurse practitioners will have access to specific support and resources to enhance understanding of preterm development and common developmental problems encountered by high-risk infants.

Standardised information is available to compliment the discharge process, supporting parents in the transition to home and promoting ongoing development

- All parents whose babies will be returning to a neonatal follow-up clinic will receive the national leaflet 'Ready for Home'. This is available from the Scottish Perinatal Network website: perinatalnetwork.scot.
- The 'Ready for Home' leaflet may be supported by further information about specific follow-up pathways in local areas if required.
- All parents of babies not returning to clinic will be signposted to resources to allow them to support development of their baby. A selection of resources are available to support health care professionals and families. These can be found at the Scottish Perinatal Network website: perinatalnetwork.scot.

Each unit will have clear onward referral pathways where developmental concerns are identified (e.g. ophthalmology, neurology, AHP's, Community Paediatrics).

Each unit will consider how technology and eHealth can be used to support the implementation of effective support and surveillance.

Each unit will engage in audit and benchmarking activities and demonstrate that these key principles are achieved. Each health board will contribute to the National Neonatal Audit Project (NNAP).

Each unit should have an identified lead for follow-up data to ensure optimal data completeness, which may include liaising with other Health Board leads (a list of neonatal outcome data leads to be hosted on National Neonatal Network website).

Each unit will participate in data sharing events to share experiences and learning between units.

All units will reflect on outcome data and service user experience to inform service developments locally and across networks.

7 References

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9. *Getting it right for every child* (GIRFEC). Available from: https://www.gov.scot/polices/girfec/.
10. Scottish Government (2017) *The Best Start: A five-year forward plan for maternity and neonatal care*.

8 Group Membership

Discharge Planning Group		
Judith Simpson (Lead)	Consultant Neonatologist	NHS GGC
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9 Acknowledgement

With acknowledgement to Dr Claire Smith, Consultant Neonatal Medicine, NHS Lothian, for her assistance in producing the recommendations relating to infection control requirements in the context of repatriation and transfer between units.

10 Appendices

Appendix 1: Discharge Planning Pathway

Appendix 2: Example of Discharge Checklist

Appendix 3: ScotSTAR Repatriation Transfer Documentation and Booking Process

Appendix 4: Infection Control Recommendations relating to Transfers between Neonatal Units

Appendix 5: Exception Reporting Tool Repatriation Transfers Neonatal Services NHS Scotland

Appendix 6 and 7: Triage Process for Follow Up

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