British Association of Perinatal Medicine

Implementing a Neonatal Electronic Health Record

A BAPM Toolkit

February 2024

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Glossary of terms

AHP	Allied Health Professional
BAPM	British Association of Perinatal Medicine
EHRS	Electronic Health Record System – a comprehensive health record system covering all patient episodes
EPR	Electronic Patient Record – a digital form of patient notes
FHIR	Fast Healthcare Interoperability Resource
FiCare	Family Integrated Care
HRG	Healthcare Resource Group
ICD10	International Statistical Classification of Diseases 10th edition
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
NEWTT	Newborn Early Warning Trigger and Track
NICE	National Institute for Health and Care Excellence
NIPE	Newborn and Infant Physical Examination
NNAP	National Neonatal Audit Programme
NNRD	National Neonatal Research Database
NMPA	National Maternity and Perinatal Audit
NTG	Neonatal Transport Group
OPCS	Office of Population Censuses and Surveys
OPCS4	OCPS classification of Interventions and Procedures version 4
PBR	Payment by results
PMRT	Perinatal Mortality Review Tool
RCPCH	Royal College of Paediatrics and Child Health
UNICEF	United Nations Children's Fund

Introduction

This toolkit was developed in recognition of the increasing implementation of provider level electronic patient record (EPR) or electronic health record systems (EHRs) and the growing expectation for the involvement of neonatal health professionals in the selection and implementation of electronic records locally and regionally.

Compared to other specialties, UK neonatology has pioneered and benefited from a national collection of data for over a decade. There are concerns that multiple EPR systems without interoperability threatens the current available reliable data capture nationally.

We hope that by equipping the neonatal community with the knowledge and "know-how", this document will serve as a "toolkit" and facilitate meaningful conversations at provider and national level. Where provider-level EHR systems are implemented, due consideration should be given to the impact on existing data entry and flow and clinical teams should not be expected to duplicate data entry.

This document has been written in mind of trusts and neonatal teams around the country that may be at different stages in EHR implementation. Therefore, each section begins with the intended readership who may find this helpful.

Aims and principles

- To ensure that neonatology remains an integral part of any hospital wide EPR.
- To equip neonatal teams with the knowledge to enable neonatal teams across the UK to actively engage with their organisation's digital journey leading to digital solutions appropriate and adequate for the needs of staff, babies and their families.
- To provide a list of **essential**, **highly desirable** and **desirable** capabilities defining the neonatal need for record keeping, local and national audit, quality improvement and benchmarking and research.
- To provide healthcare professionals caring for neonates the understanding and language to discuss their EPR needs with technical and procurement teams from scoping, selection through to implementation.
- To share knowledge and experience from teams that have experienced an EPR configuration and implementation, with teams at different stages of the process.

The agreed principles that have been used throughout the development of this toolkit:

- EPRs should improve clinical care and the experience of staff, babies and their families.
- Data needs to flow in the same way that babies move between providers such that data entered about a baby in one organisation should be available to those caring for that baby in a subsequent organisation delivering care.
- Data should be entered once and used everywhere, so avoiding duplication or conflicting information and ensuring a 'single version of the truth'.
- Data must be captured and stored in a way that it can be used for audit, benchmarking, quality improvement and research.
- Collaborative working across providers is essential to get maximal benefit for all, using expert communities and resourced individuals within teams.
- This document and BAPM as an organisation are vendor agnostic, we do not favour any provider but aim throughout to ensure that systems are fit for purpose.

Background

Electronic patient records and electronic health record systems

An electronic patient record or EPR is defined as an "electronic record of periodic health care of a single individual, provided mainly by one institution"[i]. This contrasts with an Electronic Health Record System (EHRS) which is defined as "electronic longitudinal collection of patient's health and health care from cradle to grave. It combines information from different care settings held in different systems and in some instances, aggregates the data and shows them as a single record. It is a record in digital format that is capable of being shared across different health care settings, by being embedded in network-connected enterprise-wide information systems"[i].

An electronic health record is not limited to an electronic patient record. It is a digital document containing information about a patient's medical and health history, alongside details of encounters with medical providers, diagnoses, medications prescribed and allergies, immunisations, lab test results, involvement in patient registries and research.

Current neonatal digital landscape

The BadgerNet summary care record is currently used by almost all neonatal units in the United Kingdom. Most neonatal units use an additional system (paper or electronic) in parallel with BadgerNet, for additional record-keeping in line with their individual trust policy. There are over 1.3 million neonatal care episodes from over 200 units across the UK stored on the BadgerNet Neonatal database. Over 14 million daily summary forms have been entered into BadgerNet[ii]. The information contained within the summary care record follows the baby as they move between providers as part of the care provided within Neonatal Networks. In addition to inpatient hospital episodes, the record also has the capability of recording neonatal transport episodes.

In addition to providing information for clinical care, data is provided from the BadgerNet Neonatal database to external bodies for reporting, benchmarking, quality improvement, research and registries. As a centrally hosted fully managed service, BadgerNet is updated in line with national data requirement changes.

National digital perspective

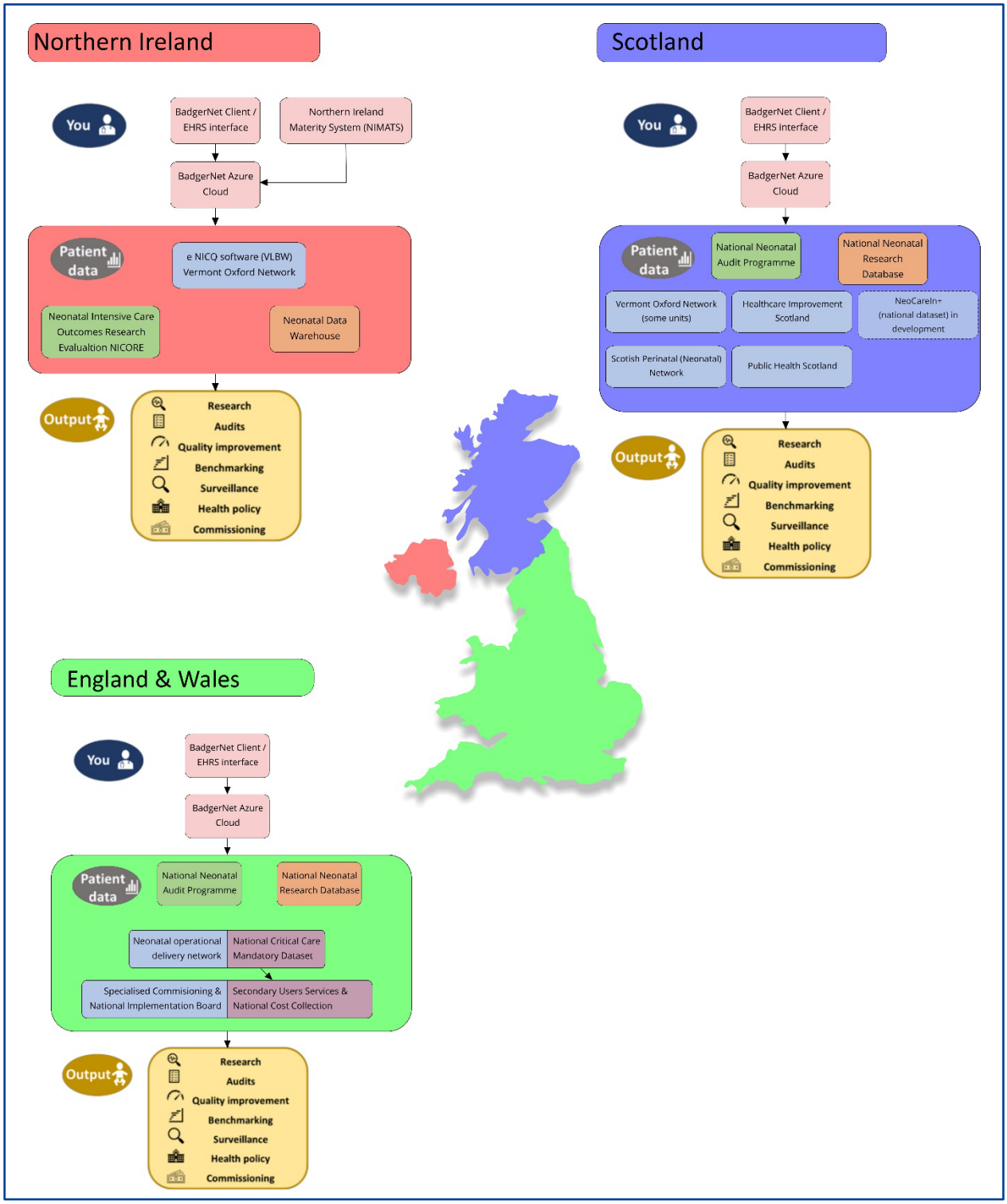
In 2022 the Department of Health and Social Care in England published 'A plan for digital health and social care' [iii] which outlined the aim that all integrated care systems (ICSs) and their NHS trusts in England would have core digital capabilities, including electronic health records, in place by March 2025. The aim is that all NHS trusts will have an electronic patient record (EPR) by March 2025 (90% by December 2023 and 100% by 2025). The policy paper describes a "life-long, joined-up health and care record" – by March 2025, all clinical teams in an ICS will have appropriate access to a complete view of a person's health and social care record that they can contribute to.

To align with this policy paper, hospital providers are procuring 'cradle to grave' EPRs, with trusts at varying stages on their digital journey. Although there is no longer a vision for a single system for use throughout the NHS, there is a Health Systems Support Framework which includes a list of suppliers accredited by NHS England[iv].

In March 2023, NHS England published the 'Three-year delivery plan' for maternity and neonatal services[v]. This contains a specific objective to make better use of digital technology in maternity and neonatal services, recognising that whilst most neonatal services use the BadgerNet summary care record for neonatal data capture, unless adopting the full BadgerNet EPR this is only a summary record and there is a move towards improved neonatal alignment with maternity and paediatrics through local EPR rollouts.

In Scotland, the Digital Health and Care Strategy 2021[vi] and delivery plan 22/23[vii] provide information on the policy position. In particular p27 of the delivery plan sets out commitments to a nationally consistent integrated record, and to implementation of SNOMED and ICD-11:

Figure 1: Neonatal data flow through BadgerNet



Integrating the two perspectives (neonatal and organisation-wide)

To maintain the current neonatal dataflow alongside the requirement for a life-long, joined-up health and care record, it is essential that electronic health record systems can interface and for data to flow between care providers to allow clinical teams the desired access to a person's complete care record.

From a neonatal clinical perspective, this can be achieved by ensuring that all electronic health record systems are able to interface with each other, allowing patient data to flow, as babies move between providers or between departments or areas within an organisation. This approach does not replicate the current centralisation of data for reporting, benchmarking, research and registries, so any external body requiring data would request data extracts, reports, or potentially need to interface with the EPR for data transfer. This may need to be at the individual provider level depending on the EPR architecture.

The alternative solution is to maintain a central summary care record or data warehouse to which each system interfaces. This allows an individual provider to upload data from individual care episodes and then the data can be downloaded to another provider if a baby moves between providers. This approach also allows data to be downloaded from a single source for reporting, benchmarking, research and registries. The benefits of this approach include:

1. Data distribution, where the central summary care record acts as a data spine, a single point of distribution eliminating the need for individual trusts to hold data-sharing agreements and memorandums of understanding, or engage in data transmission etc.
2. Allows for UK-wide research, quality improvements e.g. NMPA, NNAP, NNRD.
3. Service improvement initiatives e.g. GIRFT, neonatal networks.
4. Patient record continuity across all hospital episodes regardless of location.
5. Data continuity (e.g. weights, bilirubin etc).

To maintain this dataflow each EPR will need to be configured to capture the in an agreed dataset, supporting all current outputs. One potential solution would be the establishment of a FHIR (Fast Healthcare Interoperability Resource) standard for extracting the Neonatal Dataset from individual EPR systems. FHIR defines how healthcare information can be exchanged between different computer systems independent of how it is stored in individual systems. Establishing a FHIR standard for all EPR system providers of neonatal critical care would ensure consistency in how the Neonatal Data Set items are extracted. A single FHIR standard would potentially reduce costs as each provider would not have to develop individual extraction with their EPR system supplier.

Case study

The neonatal intensive care unit at University College London Hospital, were the first to attempt an interface between the EPIC EHRS and BadgerNet. A one-way data push was developed lacking the ability for data to flow from BadgerNet to EPIC. Currently there is a programme bringing together all the UK EPIC sites with the EPIC technical support team in an attempt to solve this at a UK-wide level and sharing experience, knowledge and expertise. Bringing teams together to solve problems at a national level reduces the chance of the same work being repeated by multiple teams.

Different EPRs and build architecture considerations

In the current NHS digital journey, there are a significant number of hospital wide and speciality specific EPR providers. Within these options there are also different models of system management and configuration:

- **Fully managed systems**: BadgerNet Neonatal is an example of a remote, fully managed system. The data is held on a remote server fully managed by the vendor. There is minimal end user configuration. There are several advantages of this approach, including central updating and upgrading with no requirement for upgrade support at the provider level. In addition, if such a system is adopted by multiple providers there is no requirement for training as staff move between providers. However, there is no ability for local customisation for specific data capture that has not been built by the vendor.
- **Vendor configured systems**: In this approach there is full specification of the system prior to delivery and go-live. Individual providers can undertake a full specification of their requirements with the system configured by the vendor. This approach has the advantage that the system can be tailored for specific requirements of the provider. However, often the ability to reconfigure workflows and data capture post go-live can be more complicated and often require going back to the vendor which may require additional unforeseen expenditure.
- **User configured systems**: In contrast to a fully managed solution, in a user configured EPR an in-house team is trained to fully configure the EPR to the needs of the provider. This approach allows almost limitless configuration and for the system to continue to be adapted and developed over time. However, there are some challenges associated with this approach. Firstly, to take advantage of the configurability necessitates the development of a large in-house EPR team trained and certified to develop the system. This is expensive in both clinical time and financially. It is essential to recognise that a large in-house EPR team needs to be maintained not only through go-live and optimisation phases but to maintain the system and allow for ongoing development as clinical requirements and benchmarking change. Finally individual workflow configuration means that different clinical builds of the same product may look very different. This means that even with experience using the system, new staff may require considerable training to adapt to an individual provider's build.

Data architecture

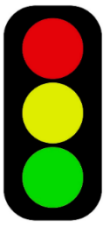
The way the data is stored within an EPR will vary dependent on the individual software architecture, however there are some principles that can potentially help clinicians ensure data is stored in a way that allows it to be captured and stored to fulfil all data and reporting requirements. In the simplest form an electronic patient record can simply function as a digital version of the paper medical record. This approach fails to take advantage of digital transformation and capabilities.
In general, EPRs will use a combination of discrete data elements alongside narrative. Such discrete data elements may exist at patient level (e.g. first name, surname) or episode level (e.g. date of admission) and some data will have a specific time stamp (e.g. weight, length), giving the ability to review data over time and construct charts. Certain aspects of care may benefit from a combination of these approaches, for example a cranial ultrasound needs to record the presence or absence of features such as haemorrhages and measurements such as ventricular indices. In a full EHRS it should be possible to pull together these data into the medical note with the ability to add a narrative, whilst simultaneously populating an underlying data table which allows audit, benchmarking and national reporting.

Defining all the different ways a particular data point may be used can be helpful to consider how that data should be captured, stored analysed and shared.

What does a neonatal EPR need to do?

Who is this section for?

- Essential for anyone considering a user configured system.
- Useful for anyone considering a vendor configured system.
- Not essential for those planning to implement a fully managed system.



In this section, capabilities of EPR documentation will be described as essential, highly desirable and desirable, using the traffic-light colour coding system:
Essential
Highly desirable
Desirable

General considerations

At the heart of specification for an electronic health record system is an understanding of what data needs to be stored and how best to store that data, so that it is available for appropriate clinical and non-clinical use.

National audit and research

The use of data outside of direct clinical care is well-established in neonatal care, from retrospective case reviews as part of mandatory national data-gathering processes (such as the Perinatal Mortality Reporting Tool, or in England the Maternity and Newborn Safety Investigation Programme); UK-wide audit and benchmarking (National Neonatal Audit Programme, NNAP[viii]); and research through the National Neonatal Research Database (NNRD, maintained by the National Data Analysis Unit at Imperial College London[ix]). The use of neonatal data has been used to support all-England policy, for example the NNRD has been used to provide reports to the National Maternity Safety Ambition to reduce brain injury after birth, for the Department of Health and Social Care. In addition, neonatal units and regional neonatal networks routinely use their local neonatal data for audit, governance and service development. Therefore, it is essential that a neonatal EPR can be used for critical clinical documentation, but also store and present data for the wide range of non-clinical applications that occur in neonatal practice.

Neonatal Data Set for England (DAPB1595)

In neonatal medicine, the Neonatal Data Set (DAPB1595) outlines the data items required for English secondary user data set and for the NNRD for both episodic and two-year outcome data[x]. The current BadgerNet summary care record captures these data. It follows that to maintain the dataset and dataflow to the NNRD, any EPR used for neonatal care must capture all the data items in DAPB1595 and must store these data in a way that can be mapped to the NNRD database. A neonatal EPR also must be able to record the items requested for the National Neonatal Audit Programme[xi]. These are subject to review and change over time, therefore the EPR must be able to be amended to record and store these, in a format which allows use by the NNAP and ideally usable and presentable in local audit and governance processes.

Scottish Neonatal Dataset requirements

In terms of Neonatal Data set requirements in Scotland these are (as shown in Figure 1 on page 6): the NeoCareIn+ dataset, NNAP, NNRD, network metrics being co-developed by the Scottish Perinatal

Network (Neonatal Network Data Group) and Public Health Scotland, and patient safety improvement metrics specified by Scottish Patient Safety Programme-Perinatal. Any EPR used in Scotland must be able to support all of these.

Ensuring data capture is family-centred

The framework attempts to define potential digital capabilities and opportunities. Alongside careful defining of data capabilities there also needs to be a sensitive and family-centred approach to EPR implementation at a local level. Provider level discussions about whether and how to implement specific functionality and capabilities benefit from parental involvement. There is risk that EPR systems may act as a barrier to effective communication with teams forming huddles around computers to the exclusion of families. An EPR is a tool for data capture and presentation, it does not remove the need for effective and kind communication with families by health care professionals. There may be unit level or individual family reasons not to implement a particular function or capture specific data points in line with individualisation of care.

Inpatient documentation

All EPRs will need to store a list of active and inactive /past diagnoses as well as procedures and operations. In addition, all clinicians, nurses, allied health professionals (AHP), psychologist and pharmacists will need to be able to document a narrative note within the record. Good record keeping is an integral part of medical, nursing and midwifery practice and is essential to the provision of safe and effective care[xii xiii]. These need to be identifiable to the individual writing the note and to have a full audit trail if there are later changes / corrections. In addition, there needs to be the ability to document specialist reviews, consultations and communication with families. These should ideally be tagged with the note type to allow easy identification when reviewing a patient record retrospectively.

Many EPRs allow system and user defined individualised templates for narrative notes. Specific templates can be developed for medical, nursing, AHPs and psychologists to improve documentation and recording efficiency. These templates will allow data elements (such as corrected age, current weight etc.) to be pulled from various parts of the record alongside current data points such as ventilator settings and most recent observations alongside the narrative of the review. In addition, templates can be used to document procedures such as line insertions (see also under charting lines, feeding tubes, drains and airways below).

Neonatal care relies on communication and interaction not only between neonatal staff but also with other healthcare professionals and other professionals such as social services. These may be face-to-face, via telephone, email, or videoconferencing. In addition, for complex babies, multidisciplinary team meetings may be required. An ideal EPR should allow neonatal staff to document these interactions, with the ability for staff to easily review previous communications and to filter these by category (such as discussions with family, or communication with specialists). It may be useful to be able to attach or link to other documents, such as important documents, photographs or reports that were relevant to a discussion.

Digital charting

A full electronic patient record must allow contemporaneous documentation of patient observations including vital signs, weight, input / output and fluid management. These need to be stored in a way to allow interrogation and digital charting.

Demographics

- A neonatal EPR should be able to store the gestation at birth of a baby and provide a real-time corrected gestational age, which can be stored within records and events.

- In a cradle to grave EPR the gestation of the baby will flow from the maternal record. This will ensure both the maternal and neonatal records match. However, as some neonates undergo ex-utero transfer, where the receiving unit do not have a record for the mother, there will need to be a way to manually enter the gestation directly into the neonatal record.
- It is essential to collect accurate data on ethnicity. There is a growing recognition of the inequalities in maternal and neonatal care for people of different ethnic backgrounds. Essential to understanding and reducing these inequalities is accurate data collection with a recognition that the baby may not have the same ethnicity as the mother.

Clinical observations

- Digital charting of patient vital signs including the ability to see observations on a NEWTT2 chart where appropriate for term babies on observations.
- The ability to review patient data in a graphical format is central to good patient care. EPRs allow the ability to see the same parameters on multiple screens / views and offer the potential to zoom in and out to provide a detailed view or an overview of the observations.
- Specific considerations in neonatal care include the ability to record multiple temperature measurements and methods (e.g. for toe-core temperature gap, or rectal temperature for babies undergoing therapeutic hypothermia).
- Grouping the same data elements into different workflows can help with different types of review such as combining information from inflammatory markers, white blood count, temperature, antibiotic use alongside microbiology results can help with infection surveillance and antibiotic stewardship. Additional data fields that may be required depending on the equipment in use on individual NICUs, include end tidal carbon dioxide monitoring, transcutaneous oxygen and carbon dioxide monitoring and near infrared spectroscopy parameters. The ability to record both pre and post ductal oxygen saturations is essential.
- There should be device integration to allow data to transfer from medical devices, point of care testing and patient monitoring to facilitate accurate automated recording of patient data. In general, the attending staff will need to validate the data that has been transferred and form the patient observations. The extent of device integration and parameter mapping will vary between builds, dependent on the investment in this area. Thought must be given to ensuring new devices can be integrated as new equipment is procured, in user configured EPR it may be decided to continue the process of device integration post go-live.
- Whether through device integration or manual data entry any EPRs will need to capture relevant data fields relating to ventilation, including high frequency oscillation, conventional ventilation, nitric oxide, biphasic and conventional CPAP and high flow oxygen therapy depending on what is used in individual neonatal services.
- Other equipment data include the recording of incubator temperature and humidity settings and cooling equipment parameters.

Input / output and growth

- Recording of hourly intake output including enteral and parenteral nutrition, intravenous fluids and feeding (volume, feeding method and type of milk). The input output fluid balance is key to good neonatal care. An EPR allows the hourly recording of fluids, enteral and parenteral feeds alongside the type, volume and method of feeding. This allows fluid balance calculations, nutritional intake calculations and the tracking of breast milk use.
- In support of best clinical care and in line with the 'UNICEF Baby Friendly Initiative'[xiv], consideration is needed for documentation not only donor and maternal breast milk intake but also recording and documentation of lactation. An ideal system would allow the mothers to document expressing and volumes of milk collected potentially through a parent portal to populate a data table within the patient record. This has the potential to support lactation and give opportunities for early intervention to maximise maternal milk provision and breast

feeding. To ensure that such a system is family-centred, parents should be involved in implementation at a local level. It should also be recognised that not families may be unable to or choose not to record these data for a variety of reasons. Such capabilities should be seen as options that some parents may choose to use as part of individualisation of care.

- In addition to fluids and nutrition, special consideration is needed for the additional documentation for blood and blood product transfusions. Whilst in hospital wide EPR the planning and implementation of the blood product transfusion documentation is often defined and specified at hospital level, it is important to consider the procedures that are specific to neonatal services and require additional information, such as dilutional and double-volume exchange transfusions.
- Weight, length and head circumference charting on specific growth charts for term / preterm, male and female babies. Ideally the system will also allow plotting on condition specific growth charts for children with syndromes or skeletal dysplasia. In a comprehensive record particularly if there is associated electronic prescribing, the weight may have to exist in various formats including actual weight, working, or dosing weight and estimated weight when used to prescribe prior to the baby being weighed.

Results

- Automated systems for plotting bilirubin levels correctly according to gestation and to see the rate of rise, in line with nationally agreed Bilirubin jaundice charts[xv] and to provide system support to alert clinicians if results are abnormal. Such charts should where possible also show the actions undertaken.
- Specific consideration is needed as to the recording and documentation of infection / colonisation status, ideally flagging directly from the maternity record if the mother is colonised with *Group B Streptococcus*.
- The ability to record in a structured way ad hoc events within the patient records, such as cardiac echo, retinopathy of prematurity screening and cranial ultrasounds. Storing the data in a structured format in line with the DAPB1595: English Neonatal Data Set, allows simplified data mapping to the NNRD and for auditing processes including NNAP. Ideally ventricular index measurements from cranial ultrasound will be plotted on standardised VI charts. However, relying entirely on templated data points loses the descriptive component of the ultrasound report. Some systems will allow data entry in a way that both populates an underlying timestamped data table and pull into a narrative note forming the report. The data table can then be used for auditing, benchmarking, quality improvement and reporting to national datasets, and the notes form a more contemporaneous record of care whilst the data is only entered once.
- An ideal EPR should automatically identify the dates when key neonatal screening and interventions are due, depending on the gestation of the baby and alert clinicians that they are due, for example ROP screening, cranial ultrasound screening, immunisations and NIPE. Ideally where there may be appropriate variation in local guidelines, a neonatal unit may be able to amend these alerts accordingly.
- An ideal EPR should integrate with other systems to allow investigations to be incorporated into a patient record and stored, without manual input. However, recording investigations performed outside the individual hospital may require manual input or scanning of reports. There may be the ability to link directly to the hospital picture archiving and communication system (PACS) and the opportunity to directly link to point of care testing (see also device integration).

Other documentation

- A defined way to record nursing safety checks, depending on the requirements of individual teams, this should preferably be stored as a data table allowing auditing and benchmarking.

- Clear and appropriate ways to document relating to lines, feeding tubes, drains and airways. A fully integrated ideal approach might involve a way to document the insertion of any device. This has the potential to create a record in the contemporaneous medical record, as well as triggering the generation of a data table to record periodic assessments such as hourly iv-line assessments. Where medical devices have remained in-situ for longer than recommended, ideally an EPR could alert neonatal nursing and medical staff, to encourage regular review and removal of unnecessary devices.
- Clinical assessments that neonatal services may want to consider specific documentation include the Hammersmith Neonatal Neurology Examination (HNNE), Prechtl General Movement Assessment, Bayley Scales and other neurodevelopmental outcomes – (see also outpatient documentation). The storage of these data ideally needs to allow for benchmarking and auditing and consideration if these assessments are single or repeated at varying intervals. This is one area that may benefit from digital data entry forms that can then be used to populate both data tables and creative narrative notes, reports and letters with data entered once.
- It is essential that there is an appropriate way to document child protection issues. These include a clear way to identify that there are child protection concerns, consideration is needed as to the best ways to document child protection matters within the record, particularly if maternal and neonatal records are linked and to ensure the confidentiality and appropriate information sharing, to ensure patient safety.
- An ideal system will also allow documentation of emergency care planning, resuscitation status such as the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)[xvi] process or Coordinate My Care urgent care plans[xvii].
- Activity monitoring: The digital nature of an EPR allows monitoring of activity at unit and healthcare professional level. Some systems allow for patient referrals to be made within the system e.g. referral to a dietician and conversely to capture the number of patients seen by an AHPs or psychologists, including recording the number of new and follow-up reviews. Using these data alongside the demographics of individual patients can ensure the best use of health care resources and evidence the need for additional recruitment. In addition, real time cot occupancy and potentially recording the number of staff on duty at any given time can allow compliance with service specifications and quality benchmarking of neonatal services (see more under informatics).
- Specific consideration should be given to the documentation required for outreach services. An ideal system will allow remote access on portable devices so that documentation can be contemporaneous. Teams may consider developing specific templates for documentation of feeding support, jaundice monitoring, home oxygen care and other support provided by neonatal outreach services.

Outpatient documentation

Babies are often followed-up in neonatal clinics following their discharge from neonatal inpatient care, for example following preterm birth in accordance with NICE guidelines[xviii]. These clinic visits should ideally be able to be recorded using the same EPR and complications arising from the neonatal period, such as developmental delay, should be able to be recorded. The use of a single system for inpatient and outpatient documentation allows the baby's narrative to develop and grow through their childhood. Outpatient records should allow the maintaining of current and past diagnoses, medications, immunisation status, allergies. Single systems also offer the ability to continue growth charts from the neonatal period into childhood follow up for ongoing growth surveillance with growth parameters corrected for gestational age as appropriate.

Other healthcare professionals from the neonatal multi-disciplinary team may also follow-up children following their neonatal stay, for example physiotherapists or speech and language therapists. It would be desirable for EPR to include AHP and psychologist outpatient assessments

and recommendations alongside the medical documentation at follow-up. Increasingly teams follow-up patients in a multidisciplinary clinic, for activity and service monitoring it is desirable to capture who was present in such a follow-up clinic

For sharing of information, it would be desirable for an EPR to maintain a list of community practitioners and AHPs involved in the patient care.

In line with NICE guidance, assessment children born preterm undergoing enhanced developmental surveillance should specifically be assessed for developmental problems and disorders including:

- cerebral palsy
- global developmental delay and learning disability
- autism spectrum disorder
- visual impairment
- hearing impairment
- feeding problems
- sleep problems, including sleep apnoea
- speech, language and communication problems
- motor problems
- problems with inattention, impulsivity or hyperactivity
- emotional and behavioural problems
- executive function problems
- potential special educational needs.

These follow up schedules will often include assessment tools for example PARCA-R, Bayley Scales of Infant and Toddler Development assessments and structured neurological assessments.
In addition, specific variables such as vision or hearing impairment, or death during follow-up may also be collected by the EPR. Consideration should be given to a structured way to capture these outcome measures where appropriate, to allow clinical audit, research and quality improvement programmes.

Neonatal transport documentation

An ideal comprehensive neonatal EPR will also include the ability to document transport episodes as well as inpatient and outpatient documentation. Transport documentation will need to consider, review and capture the data required for the neonatal transport group dataset[xix]. Although detailed consideration of electronic prescribing is beyond the scope of this document an ideal transport HER or module would allow electronic prescribing using the same formulary and build used on the neonatal unit providing the transport service.

Table 1: Checklist of features for a neonatal EPR

Essential	Highly desirable	Desirable
General Principles		
Store a list of active and inactive / past diagnoses and problems Narrative record keeping, with person-identifiable entries Aim for single entry of data, for single version of the truth Documentation and highlighting of child safeguarding issues Data can be used for activity monitoring, resource allocation, audit, governance and national programmes (NNAP, NNRD)		Tagging of entries to allow easier searching
Admission record		
Structured neonatal admission record, including maternal history, birth history, cord gases resuscitation and birth weight. Admission examination	Details imported from maternity systems, data items such as APGARs shared between systems to avoid discrepancies	Pre-birth discussions and plans able to be documented before baby is born Integration with SMaRT4NIPE (not possible at this time)
Routine Clinical Care		
Observations and vital signs recorded Respiratory support and ventilation data Fluid inputs and outputs, including intravenous and feeding Documentation relating to lines, feeding tubes, drains and airways Record nursing safety checks	Device integration for data transfer from medical devices Recording and documentation of lactation.	Electronic prescribing integrated into EPR including IV fluids, parenteral nutrition and medications. Mothers able to document expressing and volumes of milk
Special documentation for blood transfusion / exchange Data entry for HRG classification and NNAP		
Ward round and clinical assessments		
Structured approach to ward round and clinical assessments, stored as time-stamped entry with contemporaneous data Entry and retrieval of diagnoses, procedures, operations, stored at time of assessment Corrected gestational age automatically calculated Document current medication	Ability to document using structured assessment tools such as Hammersmith Neonatal Neurology Examination (HNNE) Vital signs, ventilation parameters, fluid balance automatically summarised	SNOMED CT codes for diagnoses and procedures Integrated electronic prescribing

Investigations		
Ability to store and present records of investigations	Documentation of parental presence on ward round (for NNAP)	Investigations imported from other integrated systems
Bilirubin data graphed appropriately		Charts show timings of therapy for jaundice
Documentation of infection / colonisation status of baby and positive cultures	Maternal GBS status imported from maternity systems	
Procedures and events		
Ability to document procedures	Structured entry e.g. of echocardiography records	
Ability to document communications, discussions and MDTs	Attach and store documents	Tagging of note types to allow easy reference
Neonatal screening (NIPE, ROP, cranial ultrasounds) and immunisations recorded	Identify and prompts when key screening and interventions are due	Ventricular index charts plotted from results
Discharge documentation		
Discharge summaries of neonatal stays for discharges home or for transfers between healthcare settings**.**	Automatic generation of summaries of stay, e.g. diagnoses, procedures, days of ventilation.	Summaries for neonatal services, parents, community-based health teams using the same data to generate different reports.
Including referral and post-discharge plans and investigations		
Summary includes safeguarding, social and housing needs	Summaries of parent education / clinical competencies	Ability to share summaries with parents through parent portals
Outpatient documentation		
Follow-up assessments performed as part of guidelines to be documented, including developmental disorders	Clinic visits ideally recorded using the same EPR, current and past diagnoses, medications, immunisation status, allergies	EPR to include AHP and psychologist outpatient assessments and recommendations alongside the medical documentation
Documentation of care provided by neonatal outreach teams	Automatic input on appropriate growth charts, including preterm, Down syndrome, etc.	Structured input for assessment tools (PARCA-R, Bayley)
Neonatal transport		
Capture the data required for the neonatal transport group dataset	The ability to document transport episodes	

Workflows

Workflows refer to groups of electronic record activities that can be brought together to facilitate documentation for activities that occur regularly.

Pre-birth workflows

Consideration should be given to the possibility of creating the patient record within the EPR prior to delivery. In a hospital wide comprehensive EPR, this is often achieved by creating a patient record that links to or exists within the maternal record. This has the advantages of:

- Allowing documentation on the electronic record of pre-birth discussions and plans. This is an example of data that should exist and be available from both the maternal and the neonatal record. As such discussions tend to evolve through the pregnancy, one option is for the data to be held within the maternal record and then be pulled into the neonatal record in preparation for the delivery.
- In systems with electronic prescribing (see later), the ability to create the neonatal record and enter an estimated weight can allow for medications to be prepared which need to be started as early as possible after birth, for example prostaglandin for babies with duct dependent cardiac lesions.
- Having a patient record active prior to delivery can also help with documentation around the delivery including safety sign-in and resuscitation documentation (see below).

Admission workflows

When a baby is admitted to neonatal care, the EPR can be used to create an admission summary for the contemporaneous record. In comprehensive systems, much of the demographic and maternal data can be populated automatically.

Although most admissions to neonatal care begin with the birth of the baby, consideration should be given to alternative admission sources to ensure that there is a way to document the necessary information. This is particularly important for systems that populate data from the maternal record; there is a requirement for a way to enter the data when there is no linked maternal record, whilst maintaining the principle of a single version of the truth. For example, if gestation is pulled through from the mother's pregnancy record, there needs to be a way from the neonatal record to enter the data for babies outborn and transferred in. However, if there is a linked maternal record but the data is missing, safeguards need to be in place to ensure the data is corrected in the maternal record, which then populates the neonatal record to avoid data paradoxes.

As a general principle, in a comprehensive EPR, there is often the need for an administrative admission workflow to create the live patient record including birth / admission time, patient location, entering of demographic and parental information etc. This is commonly followed by a more clinically orientated admission workflow, collecting clinical data from the delivery and resuscitation. It can be helpful to consider a simplified rapid admission workflow that can be completed by neonatal staff without the complete midwifery data (if a linked record) to generate a hospital number and allow rapid requesting of imaging, investigations and prescribing in emergency situations.

As part of the birth workflow, it is essential that the EPR interfaces with the National Event Management Service in England and the Community Health Index (CHI) system in Scotland. These ensure new births are registered and NHS numbers (CHI in Scotland) are generated. This is also crucial for the newborn infant physical examination (NIPE) system - S4N in England and the hearing screening systems - S4H in England and Universal Newborn Hearing Screening System (UNHS) in Scotland.

Resuscitation workflow

It is essential to document neonatal resuscitation in such a way that the narrative and details can be used to populate admission summaries, resuscitation documentation and discharge summaries without need for duplication. In addition, depending on local requirements there may be benefit in storing data for intubation, use of cardiac massage and drugs, time of heart rate over 100 beats per minute and time to first gasp, in such a way to allow rapid retrospective searches. Some systems allow a 'real time' documentation of resuscitation with inbuilt timing, so a single click can store resuscitation events (such as intubation or drug administration), both creating a narrative note and discrete datapoints with timings automatically documented based on an initial click when the baby is born.

For systems with linked maternal and neonatal records, consideration will be needed as to where shared data (such as data relating to delayed cord clamping and APGAR scoring) will be held, so that it is available in both records but preventing data paradoxes. Ideally such data can be viewed and entered from either record, but only exist in one place.

Ward round workflow

Whilst not essential to any system the idea of a ward round workflow allows information to be available in a logical manner from various parts of the electronic record for review as part of a ward round. For example, bringing the diagnostic lists where they can be reviewed and updated, followed by data by body system, including ventilation parameters, respiratory observations etc. The presence of parents on the ward round and discussions with them can also be documented. This increases efficiency during the review of a baby. Ad hoc reviews (for example due to clinical concerns) may also follow a similar workflow.

Daily returns for clinical coding

To support activity monitoring, clinical coding and (in England) payment by results, it is essential that a daily entry is made to capture the data required for the HRG classification, with the additional daily fields required for the National Neonatal Audit Programme. Wherever possible, these should be auto populated from data already in the system (such as ventilation modes, weights etc) with the possibility to add data not captured elsewhere (for example parent presence on the ward round).

Newborn and infant physical examination (NIPE)[xx]

Consideration will be needed as to the documentation of the NIPE within the record. At present it is a requirement that the core 4 measures (eyes, heart, hips, testes – if appropriate) are documented on the NIPE national IT system in England (SMaRT4NIPE (S4N)). The newborn physical examination is a much more comprehensive examination encompassing a 'head to toe' exam. It follows that for an electronic record to be considered comprehensive, the full NIPE will need to be recorded within the record, with details of further actions, referrals and outcomes. As the use of S4N is mandatory in England and as there is currently no interfacing option it follows that at least for the core items there is no alternative to double entry.

Discharge workflows

Rather than just considering discharge workflows as something completed at time of discharge for onward information sharing, discharge planning and documentation should be part of the whole neonatal care episode. It may be of value to consider a discharge planning workflow that includes parent education / clinical competencies, social and housing needs, referral and post-discharge plans and investigations. An ideal EPR will allow this to be documented and updated throughout the neonatal stay, such that it is possible for different clinical staff to review the preparedness for discharge and for all the information to then flow through to the discharge summary. It may be possible for the information and education to be shared with parents through parent portals (see

later).

The EPR should be able to create discharge summaries of neonatal stays for discharges home or for transfers between healthcare settings. Included within this discharge workflow will be a process for documenting referral to neonatal outreach / community-based services. Ideally the EPR should assist users by generating summaries of neonatal stays, for example providing lists of diagnoses from the stay, or summarising procedures and interventions, such as the number of days of invasive ventilation. These summaries can be shared with other neonatal services, parents, community-based health teams etc., either in a single format or using the same data to generate different reports.

Death workflows

It is essential that there is a workflow flowing the death of a baby. This will need to include specific items including date and time of death, personnel present at time of death, assessment / examination performed and where possible the medical cause of death. Additional information regarding discussion with the Medical Examiner and referral to HM Coroner is essential. This workflow has the potential to ensure pre-ordered investigations are cancelled, links are made to other reporting bodies such as the Child Death Overview panel and can provide a notification system or check list to ensure that health visitors, general practitioners, referring hospitals, community midwives etc are informed of the death. Ideally information regarding referral for psychological support and bereavement follow-up can be included.

Data quality and completeness

Whatever EPR system is implemented by individual providers it is essential that neonatal data continues to flow for secondary purposes as outlined in figure 1. In addition to the challenges outlined previously regarding interfacing between different EPR systems, the underlying information within each EPR needs to be complete and accurate. The ability to run data quality and data completeness reports is essential to maintain the data integrity needed for research and benchmarking. Such reports in practice often occur at both provider level and by the secondary user once a data extraction has occurred. For example data in the National Neonatal Research Database undergo both quality and completeness checks with provider clinical teams issued with quality reports so that any checks and corrections can be made into the EPR.

Interfacing and informatics

Who is this section for?

- Essential for all considering any form of device integration and for those implementing a non-managed system.

Device integration

Integration of medical devices directly with an EHR presents multiple benefits but also presents significant challenges. Neonatal services use multiple devices that are unique including incubators, neonatal ventilators all of which require significant investment of both time and money to ensure they are successfully integrated into the EPR. Device integration can improve the accuracy of the data captured by reducing transcribing errors as well as reducing the medical and nursing time required to document vital signs, results etc. Intelligent device integration can improve clinical decision-making as there is no longer the need to search for patient data across devices. Bringing all the relevant information into a single digital workspace and allowing health care professionals to view the information in various tabulated or graphical views can reduce the time needed for information analysis and improve the speed and accuracy of clinical decision making.

The integration of medical devices on a NICU requires the devices to 'talk' to the EPR and for specific data points to be mapped to where they will be stored within the EPR. This requires consideration of the device itself and what communication options are available. Devices such as vital signs monitors, incubators, ventilators and smart pumps will differ in their communication abilities which may be wireless, wired or both. Legacy equipment may not have communication capabilities preventing integration with the EPR. Connection of a medical device to an EPR potentially requires various stages, including developing software and building a network of gateways for data exchange. The final pipeline may use multiple protocols for communication with hospital devices and often requires middleware sitting between the output of the device and the input of the EPR. Within this process it is essential to ensure confidentiality, security and integrity of clinical records.

In addition to transfer and storage of the raw data output of medical devices, the potential for integration of data analysis and artificial intelligence, provides huge potential for improvement in patient care. For example, learning algorithms can identify hidden patterns and abnormalities that may be difficult for health care professionals to rapidly identify.

With the potential to store increasing amounts of data within the EPR through device integration, it is essential to consider the accuracy and reliability of such data which may impact on the validity and utility of automated physiological tracking and early warning systems. Many EPRs will use a human validation step with clinical staff reviewing data at specific intervals and will show whether specific data points have been validated or not. In practice it is not uncommon for data to be marked as reviewed and validated whilst still containing errors.

Legacy systems

A full hospital EHRS will replace most digital platforms within a hospital. However even with a comprehensive EHRS, there will be legacy systems that will remain in use after implementation. At a hospital level, consideration will be needed as to how the EHRS will sit alongside legacy systems without losing the key benefit of having all information in a single space. This is a bigger consideration for teams considering a specialty specific EHRS, as to how information may be able to transfer from maternity systems, laboratory results and PACS (picture archiving and communication

system). As previously described, nationally mandated systems such as the newborn and infant physical examination IT portal (SMaRT4NIPE) and the hearing screening system (S4H) will have to sit alongside the EHRS, as interfacing is not currently possible.

Informatics

Much of the focus during design and implementation of an EPR is focused on data entry and review. It is however essential that consideration is given to data review at a local level for audit, quality improvement, activity monitoring and other local, regional and national reporting. Depending on the design of the EPR dashboard, report generation may be available through the live clinical system or may be performed on the underlying data using Structured Query Language (SQL). This latter approach is useful if the data request involves large volumes of data but generally requires informatic specialists to undertake the search requests.

The BadgerNet platform contains a set of reports and dashboards designed specifically for neonatal care. These are preconfigured but allow the end-user to change various parameters to provide the data required. If improved interfacing between other EPR and the BadgerNet data spine is achieved, this gives individual users the opportunity to revert to the BadgerNet platform to undertake searches and data quality reviews without needing to configure these within the EPR itself.

Alternatively, dashboards and reports can be configured within the EPR itself, which does not rely on the interfacing between systems. If this approach is adopted, the following considerations should be given to configuring reporting capabilities and dashboards prior to go-live:

- **NNAP dashboard:** real time patient quality metric tracking is essential to ensure unit performance against the NNAP measures. It is essential that there is potential to change, adapt and reconfigure this dashboard as the NNAP measures change.
- **Local quality dashboards:** individual services may have specific governance measures in addition to those used as part of the national neonatal audit project. The ability to refine and change these measures is essential in the planning of the implementation.
- **Patient flow:** Searches of admissions, discharges and transfers to an individual provider and within services e.g. transfers from neonatal care to transitional care, allow for patient flows to be reviewed and supported.
- **UNICEF UK Baby Friendly compliance dashboard**: to support providers to comply with the UNICEF UK Baby Friendly initiative consideration should be given to a rolling dashboard including:
  The percentage of mothers who are expressing within the first 24 hours after admission.
  The percentage of babies who receive human milk within the first 24 hours after admission.
  The percentage of babies who are receiving human milk when they leave the unit.
  The percentage of mothers expressing when the baby leaves the unit.
  The percentage of mothers who are breastfeeding their baby when they leave the unit.
- **Patient searches:** this includes demographic data, gestation, diagnoses and treatments. Some EPRs allow patients to be included in defined registries to facilitate rapid searching. For example, creating a registry of preterm babies prevents the need to search entire hospital patient populations. Along with searches of admissions, discharges and transfers, these capabilities may aid local audit, governance and service improvement projects.
- **Activity tracking:** this is essential as part of ‘payment by results’ or similar processes. The ability to quantify patient care alongside criteria such as HRGs is essential for clinical coding where such processes exist.
- **Data quality and completeness reports:** this is essential to give the opportunity to improve data capture and to provide all data necessary for reporting bodies.

Clinical case record downloads

In addition to data extraction for audit, benchmarking, quality improvement and research, consideration is needed as to how clinical records can be accessed for review. This type of review can be for second opinions, medicolegal cases or as part of a wider service review. There is also increasing requirement for external case reviews for example as part of MBRRACE-UK Confidential Enquiry panels, or PMRT reviews.

The architecture of an electronic record does not follow the linear structure of a paper record, and consideration is essential as to how the electronic case record can be extracted and reviewed in a logical coherent way. A downloaded record needs to be presented with a coherent clinical narrative with medical, nursing, allied health professional and psychology notes aligned. Nursing observations and charting provides a particular challenge as electronic record charting occurs at the time of access based on data held in tables. In electronic form this is a powerful tool allowing the same data to be viewed in almost infinite combinations and at differing levels of detail. However, if all the data is downloaded and presented as tables or in chronological order alongside clinical notes, the record becomes unintelligible and the ability to forensically interrogate a record is lost. One potential solution to this problem would be data to be presented in a standardised hourly observation chart, replicating those in paper records that can be downloaded and reviewed alongside the narrative notes, investigation results, imaging and medication record. An alternative would be the ability to allow external reviewers specific electronic access to review records using a simplified read-only interface.

A standardised read only interface would prevent reviewers needing to undertake training on different EPR systems. To date this area appears to have received little attention, however consideration will be needed with the increasing requirement for external oversight and case reviews.

Overview of desirable features

Who is this section for?

- Useful for all teams implementing a new EHRS to recognise the possibilities.

Digital transformation of healthcare can include additional features to support clinical care and communication, this section aims to give an overview of some of the features that may be available and some considerations as to how these relate to neonatal EPR implementation.

Electronic prescribing

Detailed description of electronic prescribing is beyond the scope of this framework, however there are some specific neonatal considerations when hospital wide EPR implementation includes electronic prescribing. As a general principle sharing of electronic build between NHS providers should be strongly encouraged. For a new EHR implementation not to start a completely new pharmacy build but to learn and develop an existing build from another provider has the potential to save time, money and reduce build errors.

Formulary Considerations

It is essential to consider where there is the ability to have a separate formulary from other areas of the hospital. If this is possible within an electronic prescribing model, this will help avoid drug errors caused by prescribers selecting the wrong preparation, for example an adult ITU setting might use a different muscle relaxant than the neonatal setting. If a system does not allow separation of the neonatal part of the formulary, consideration should be given to the use of naming conventions, preference lists and other tools to signpost the correct neonatal formulation. Other features that may help reduce drug errors include dosing guard rails (which prevent prescribing outside an agreed range). It is important to ensure that all the common neonatal mediations used are built on the electronic system to minimise any need for an “unconfigured drug” prescription.

Dosing and Weights

Neonatal patients need special consideration around weight-based dosing. There may be multiple weights stored within the EPR including estimated weight, actual weight, working weight and potentially dose-specific weights. Consideration is needed as to how to manage different weights and weight changes during a baby’s neonatal stay.

For certain medication groups for instance intubation drugs, the establishment of weight-based dose bands, in conjunction with dose-rounding tolerances, could be of fundamental importance in developing neonatal medicine catalogues in line with HSIB recommendations[xxi]. Electronic prescribing systems can also manage ‘reasonable’ volumes for dilution and administration prevent prescriptions and formulations that are too small or too large.

It may be beneficial for trusts to evaluate the use of the free-text fields in electronic prescribing and medicines administration systems and to define their purpose, to ensure they are used in the way intended and used consistently to prevent unintentional consequences.

There should be a standardised system to prescribe both flushes of sodium chloride 0.9% and 0.45% and all medical gases including oxygen and nitric oxide. You should be able to administer the flushes in ml which can be used to calculate total volume used. It may be difficult to take into account the

bolus drug volumes of infusions on an electronic prescribing system.

Medication Scheduling

When considering regular scheduled medications, it is essential that the prescribing module fits the clinical practice of the unit. Some neonatal services do not use specific drug rounds / times but individualise to the baby, other services will need the drug schedules to default to the appropriate drug round time with special consideration of antibiotics. There also needs to be the ability to 'hold' drug administration whilst waiting for drug levels.

Infusions

When considering infusions many services now use standardised infusion strengths which will allow an electronic prescription module to automatically calculate the infusion rate. It would be good practice for all neonatal units especially in the same network to adapt the same standardised infusions as this would help minimise errors if there were inter hospital transfers. The alternative approach of standardised infusion rates with variable infusion strengths is likely to increase the risk of drug errors. Although many services used standardised parenteral nutrition and premade standardised fluid infusions it is essential that neonatal teams can prescribe bespoke fluids / parenteral nutrition when needed.

Neonatal infusions can be complex and an electronic system can help reduce manual calculations that might be needed, for example the use of a bespoke fluid of sodium electrolytes in a bespoke glucose base fluid, where an electronic system can calculate the mmol of electrolyte needed to add to a base fluid.

Complex prescriptions

Consideration is needed regarding complex dosing regimens such as variable dose / sliding scale insulin, infusions that are gradually increased such as intravenous immunoglobulin and weaning regimens such as steroids.

Administration and validation

Additional features that may be available within electronic prescribing, include prescribing groups of medications in a single prescription (e.g. vaccinations, intubation medication), prescribing and requesting investigations in a single activity (e.g. a neonatal admission set – this can help prompt the prescribing of intravenous flushes and oxygen) and the use of barcodes for medication and patient checking to reduce administration errors. Such barcoding can often also be applied to expressed breast milk to facilitate checking and reduce the risk of wrong baby administration. There needs to be a suitable governance process in place to ensure the build is safe for use, including the input of an experienced neonatal pharmacist; validation of complex prescriptions and infusions should be completed by a pharmacist with the relevant experience. Ongoing support of the electronic medication library is essential; sufficient resources for maintenance and for new developments is essential to continue to maintain and develop the system. Vaccinations should be linked or interfaced with the national systems, in England there is plans for a federated data platform to facilitate this.

Parent portals

Electronic Health Record Systems have the potential to enhance care, improve communication and to further promote parents as partners in their baby's care. At the heart of parent and patient digital engagement is the use of portals.

In the simplest form, families can be given access to the medical record through the portal, this can be limited to specific note-types such as family discussions. This is similar to units giving parents access to the written medical notes prior to digitisation. Many systems allow notes to be shared either as default, or to require the release of individual notes or note types to the portal. Specific consideration needs to be given to the sharing of child protection information, to ensure safety of children and families. It may also be possible share the results of investigations. This could be executed by having an option to 'release' results to the portal manually, or automatically for certain result types, with the option of building in a delay, so that results are not released immediately. At the end of a neonatal stay the ability of a portal to store and share a summary of the care provided has the potential to ease the burden on families to retain and recount the medical history, and to improve subsequent care.

When considering providing access to aspects of the clinical record specific consideration is needed to maintain safe child protection and confidentiality. In general, only those with parental responsibility should be considered for access. As most units will have some form of family support / psychosocial meeting proxy record access could be reviewed and considered within this multidisciplinary setting. This allows consideration from multiagency professionals on a case-by-case basis to help ensure safe and appropriate access to information.

One feature of parent portals is the ability to provide information leaflets through a digital platform. This can be automated, for example if a baby has a diagnosis of ventricular septal defect, the clinician can be given the option to send a patient information leaflet (in a language based on the parents recorded preference). Parent information can be part of parent education, family integrated care and discharge planning with associated records of competencies within the baby's record. Information flow though portals is a two-way process. Families can have the option to send as well as receive information, such as updating demographic details. Questionnaires or tools can be developed to allow discrete data entry into the baby's record. Post-discharge, questionnaires can be used as part of clinical and neurodevelopmental follow up as well as ongoing feeding support.

Portals also allow appointment reminders, scheduling and may include embedded video clinics. Clinic letters can be shared with parents electronically reducing workload and improving sustainability. If video storage is included within the EPR portals, this can allow parents to securely upload videos, such as for Prechtl assessments. It may also be possible to support family connection with babies on NICU through video sharing, baby diaries and virtual consultations with families where appropriate.

It is however essential to recognise that there will be barriers for some families accessing information in a digital format and consideration is essential to ensure digital transformation does not exacerbate health and information inequalities. Specific plans are needed to support those families with barriers to digital engagement including language, cultural, literacy, health literacy and digital poverty to ensure they receive the same level of care, engagement and information as those accessing digital platforms[xxii]. It is also essential that digital capabilities and communication should be considered as enhancements and do not remove the need for effective and compassionate direct communication with families by health care professionals. As these portals are aimed at improving parent information, engagement and empowerment it follows that decisions to develop and / or implement different functionality should be made at a local level and involve or be led by parents.

Multimedia integration

Digital platforms allow the medical record to hold multimedia elements in addition to that possible within paper medical records. Capturing of clinical images may be possible directly through the EPR, resolving issues regarding image capture and data transfer. In this way, images of skin lesions or wounds can be taken, tracked and shared in a secure environment.

If there is integration of video data, this may be used to document abnormal movements and clinical movement assessments e.g. Prechtl.

Many EPRs also allow data entry using embedded voice recognition software for data entry, this may be particularly valuable for staff that find the use of EPR and digital technologies challenging.

Standardisation of data coding

Who is this section for?

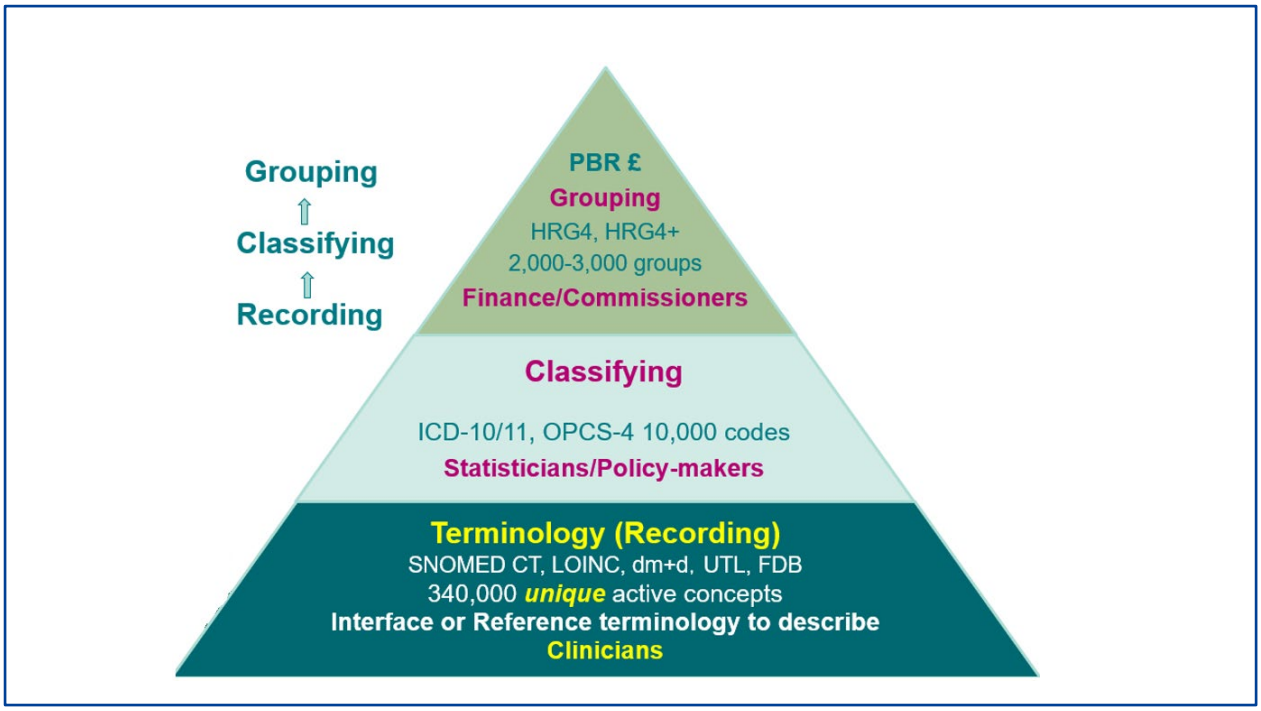
- Of interest to those wanting to understand the standard coding systems that have been adopted within the NHS

A number of standardised coding and classification systems have been developed to help with interfacing and communication between different electronic systems.

SNOMED CT[xxiii] is a structured clinical vocabulary for use in an electronic health record. All NHS healthcare providers in England must now use SNOMED CT for capturing clinical terms within electronic patient record systems.

The Office of Population and Surveys (OPCS) Classification of Interventions and Procedures version 4 (OPCS4) and the International Statistical Classification of Diseases and Related Health Problems version 10 (ICD10) are clinical classifications standards. Both are mandated nationally (in England and Scotland) for use across the NHS. Healthcare Resource Groups (HRGs) are the 'currency' of Payment by Results (PBR) in England for inpatient care, outpatient procedures and A&E attendances. HRGs are also used in England as a key measure of unit activity, e.g. where NICUs are required to undertake at least 2000 IC days per year and LNUs 500 IC / HD days?

Figure 2: Diagram Credit: Leilei Zhu, Clinical Data Standards Lead / Advisor, UCLH

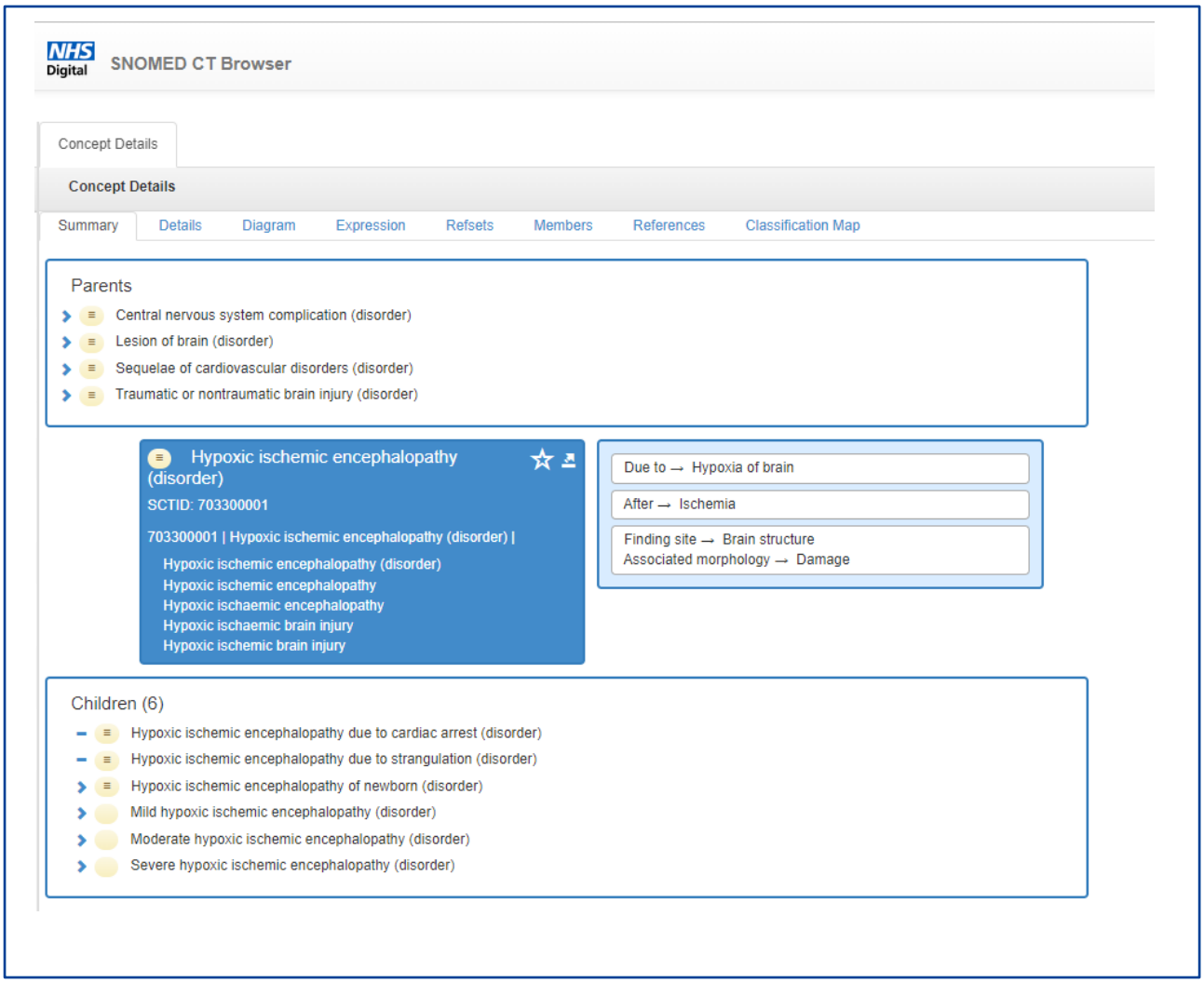


In combination with the mandated English dataset described in DAPB1595, any EPR will provide real time, contemporaneous recording of daily events. These will include workflows for documentation and data capture at admission, ward rounds, discharges as well as ad hoc events and reviews, consultations, AHP and psychologist documentation. In a hospital wide EPR or a fully interfaced system, data entered for the mother of the baby will, where appropriate, be available within the neonatal unit, such that there is a single version of the truth. This is a concept of either a single

centralised database, or a distributed synchronised database, which stores all the data from an organisation in a consistent and non-redundant form. So that for example data entered into the maternal record regarding antenatal steroid administration will also be available in the neonatal record without the need for double entry and removing the risk of the same clinical data being recorded differently in different parts of the record.

All EPR will need to store a list of active and inactive / past diagnoses as well as procedures and operations. As previously described, the agreed data standard for recording these within the NHS is SNOMED CT. The huge number of diagnostic and procedure concepts within the SNOMED CT vocabulary are arranged in a hierarchical structure where a given concept is related to less specific termed (parent) and more specific (termed child) concepts. To standardise documentation, it may be beneficial for local or national teams to develop preference lists of preferred SNOMED CT concepts to harmonise documentation between providers.

Diagram showing the relationship between the SNOMED CT concept of hypoxic ischemic encephalopathy to more and less specific concepts.



Developing a business case

Who is this section for?

- Essential for anyone procuring a unit level EHRS
- Not needed if a hospital wide procurement underway

This section is not meant to be exhaustive as each trust / system will have different requirements. It is meant to be a chapter full of suggestions gathered through experience of clinicians in implementing different models of EPR and some of the things they wished they had known before embarking on the journey!

To start: Engagement piece

Start a conversation with your local team - what are the challenges to their current way of working. There may be improvements you can make to that whilst you embark on this digital journey as creating a business case and getting a new system online takes some time. There may be staff who have worked for other providers who have seen and worked with different systems.

Start a conversation with your local digital team - establish what their ambitions are. They may have project managers (PMs) who could help you construct a business case. They may have access to funding. They may have plans to develop an in-house system. Many EPRs have been built with adult services in mind so it is important to get across to your digital team why the neonatal environment is different – range of weights, gestations, screening criteria etc.

Start a conversation with your own management team - where does a neonatal EPR fit strategically? It is important early on, to start discussions about possible avenues of funding. This may be from the capital budget or even charity investment.

Start a conversation with other units who have moved to a digital system - aim to visit and see the system in action. This will enable you to get real feedback on how it works and what the challenges are, without the possible bias of a provider being present.

Start a conversation with potential providers - this will enable you to scope what is out there already, get some baseline costs and review basic levels of system integration.

Useful evidence to collate to provide the case for change

Prior to embarking on a business case for an EPR within your service it is important to create the argument for change from what you have already.

Listed below are a few areas that we would suggest you consider:

Cost savings - Investing in an EPR is going to create a cost pressure within your department initially so it is important to be clear about the “spend to save” opportunities that it will bring. Things to consider are the amount of money currently spent on stationary, time spent filing notes, storage of notes or even scanning paper records into electronic systems.

Consideration needs to be given as to whether you are going to invest in an “off the shelf” package or an in-house build. An “off the shelf” package may require a large initial outlay, but this should be reviewed considering software developers time in developing your own bespoke system.
It is beneficial to complete a time in motion study looking at how your current process works and try

and quantify what time could be saved by progressing to a more digital workplace. This may not be cash releasing but would have a direct improvement in the quality of clinical care staff can deliver.

Activity data and service income - Any system that is going to be used needs to have the ability to record information relating to nurse staffing and also acuity of care delivered. This is how (in England) the trusts, ODNs and Specialist commissioning work together to agree on budget setting, staffing quotas.
It is also important to be able to demonstrate this data for business cases for other aspects of your service e.g. consultant workforce, response to the Neonatal Critical Care Review.

Quality of care - It is important to articulate how important quality metrics are in the field of neonatal care and the role they play in benchmarking our services regionally and nationally. The ability to collate and share our data is an essential component of any clinical service specification. This is one of the fundamental differences between the requirements of a neonatal EPR and other systems in use.

Any business case needs to deal with how this data is utilised locally, regionally and nationally. There should be a brief explanation articulating all of the areas where neonatal data is shared and utilised. This will vary according to your own networks and organisations; NNAP data is standard across the UK.

If your unit has ambitions to contribute to the Vermont Oxford network, then this also needs including.

Research opportunities - All trusts are keen to raise their research profile and so including some basic detail relating to that and the opportunities should be included. Any EPR should have the capability to integrate with national research studies within the NNRD.

Family engagement - Family integrated care is a key part of all our work and this also makes a neonatal EPR different from other systems. There needs to be documentation of the benefits of any neonatal EPR that allows more parental involvement from diary functions to sharing of videos of their infants. There could also be the role of utilising it as a parent educational platform. Parental involvement in decisions regarding functionality and implementation is essential. This may be an area which would benefit from being parent led.

Staff engagement - Staff recruitment and retention is high on all trusts' agendas. A neonatal EPR that would allow single entry of data and avoid all the duplication of documentation would go a long way to improve that. Many systems built with adult services in mind necessitate additional workarounds for smaller services. This often creates added work for staff.

When you can work in an environment where there is only one system in action it increases the quality of the data that is inputted, removing much of the needs for retrospective data cleaning and inaccuracies in reports. This also has a positive impact on staff morale as you can believe your more reliable data and respond to changes in outputs in a timely fashion.

Funding

This is always a challenge in the current financial climate of the NHS but we have listed some areas for consideration below that we hope will help.

Outlay for procuring the EPR - This will likely include a licence fee and then also a "per episode" usage cost. It is important to establish what this looks like and the likely increases in annual costs over the duration of the contract. This cost needs to be balanced against any current outlay for other systems e.g. BadgerNet summary record.

Hardware - Implementing a new EPR is likely to also require the procurement of significantly more hardware for your service. It would be best practice when working with a full EPR, that each infant in the critical care area of service has a device to themselves. It may be possible to share a device in SCBU or transitional care settings where the need for full integration of monitoring and results is less important.

These could be in the form of laptops, desktops or tablet devices. Consideration needs to be given to who will maintain all this additional equipment and how it will be cleaned. It is also of value to consider where they will be stored – wall mounted, on wheels, in patient drawers.

Infrastructure - If you work in a new building then it would be hoped that the network infrastructure would be there to support all the integration of systems, pumps, monitors that you may want to occur with an EPR.

It is important to involve a project manager and a solutions architect from your digital team to review the requirements with you as getting the infrastructure right is costly but would ensure you got maximal output of your EPR.

It is also worth considering how your neonatal EPR will connect to your local maternity digital system**.** This may contribute to the need for a joint business case so you can utilise the same provider or there will be integration costs to enable basic data to be transferred from one system to another. This automatic transfer of data reduces the workload on clinical staff and also ensures good quality data as there is only one source of it. This integration should be encouraged.

For full integration you may want to have data downloaded from your monitors, ventilators and pumps. It is important to have conversations with your providers for these things as to whether that information could be shared via Bluetooth transmitters or needs to be hard wired into your unit.

Staged approach - It may be that investment in a full EPR, its infrastructure and hardware is outside the scope of your organisation. It is worth discussing with potential suppliers what a staged approach to implementation may look like. This would ease the financial burden and may make it a more appealing journey to embark on for the finance teams.

Annual costs - When considering the costs of any EPR it is important to factor in the ongoing annual licence fees and maintenance costs.

Digital project manager costs - It is possible to implement an EPR without a digital project manager but this needs to be balanced against the impact utilising dedicated experienced nursing or medical time in leading the project. It is important to identify early on if there is the possibility of having a digital PM or if you would need to pay for their time. An early conversation with your digital team would help this.

Sources of funding

Neonatal service budget - In any neonatal service budget there is already a cost for utilising the BadgerNet summary care record and the licence associated with that. Any added costs for an EPR could be added to this. It is important to be clear as to what the added benefits are.

Charitable funding - There may be interest from local charities that support your trust in funding this kind of development. They may be focused on one particular patient group (e.g. cardiac infants) rather than the whole service, but this may enable you to progress with the idea of matched funding from the trust. Charities with a focus on parent support may be able help if the system you will procure has a real family integrated care focus with diary functions, videos, education.

Digital development grants - These may be available from time to time to cover the costs of the initial outlay of implementation or the costs of a digital PM. They are unlikely to involve recurrent funding though, so that needs to be considered.

Implementation

Clinician and nursing leaders - In the implementation of any system, it is essential to have dedicated clinical leaders of the project who have significant time allocated to this role. This enables them to become champions, troubleshoot the system and train staff in the clinical environment. These need to have specific funded hours to avoid affecting the clinical service. The amount of time required will vary but in general this is underestimated. In the lead up to go-live it is essential that enough time and resources are allocated for the leads and superusers to provide the support for the project. In addition, it must be remembered that ongoing clinical digital leadership is essential and needs adequate resourcing. As digital becomes central to delivery of healthcare both ongoing support for clinicians in digital roles alongside good working relationships between clinical and digital teams are essential.

Digital project manager - It is possible to implement a system without the need for a digital project manager, as long as you have enough investment of time from the clinical workforce. This can be hard to achieve and it may be that a hybrid model of part digital PM working alongside a member of the clinical team leads to the most effective implementation team.

Support from software company - With any digital system there is the possibility that there may be issues out of hours that need urgent attention. In procuring a system and negotiating a contract it is important to be clear as to what the support package looks like and any other maintenance / upgrade costs that may be necessary.

Challenges

Niche specialty - We are a small speciality within larger provider – articulating our specific needs can be hard. There may be an ask for you to simply use the standard provider EPR. There may be an ask to utilise a combined critical care EPR. It is important that any business case can articulate the potential pitfalls of these different routes.

Business continuity plan - It is essential with the development of any EPR that there are contingencies in place for times of potential digital failure. Ensuring that a robust plan is in place is key. There is likely to be one related to the BadgerNet summary care record, where a failure can remain part of business as usual, but a full EPR that is fully digitally integrated will need to be a cohesive plan of how to manage a failure.

Afterwards

Ensure you have an evaluation plan and share your experiences widely so all can learn from your success (and failures!)

Education and training

Who is this section for?

- Essential for all implementing a new EHRS

Introducing a new EPR into a complex healthcare environment is challenging. Alongside changes in documentation are often changes in workflows that mean the go-live day is a unique challenge for healthcare teams. Training an entire multidisciplinary workforce is challenging and recognising that there are significant variations within a diverse team is essential.

High-quality training for healthcare staff around the time of EPR implementation is a key facilitator to successful implementation, conversely, inadequate training can act as a barrier[xxiv].

Training methodologies

A variety of training and combination of education methodologies including one-to-one training, peer-coaching, classroom training, e-learning and EPR simulation may be appropriate[xxv]. While studies have identified benefits in confidence, knowledge and skills, as a result of training, there is no evidence that any specific methodology is optimal and a combination of approaches may be most effective[xxvi]. Each organisation implementing an EPR will need to design a training and education programme, based on the existing knowledge and skills of their healthcare staff, experience of current systems and the educational skills and resources available for the transition.

Neonatal EPR implementation provides specific challenges due to the unique neonatal workflows which make generic hospital wide EPR training programmes of limited value. Similar to championing the neonatal requirements at the time of EPR procurement, it is also essential that there is a strong neonatal voice when considering training and implementation. In this situation, consideration of bespoke or additional training for neonatal teams is essential**.** When designing the delivery of a training programme for neonatal staff it is helpful to draw on training opportunities that may be provided by different teams.

EPR Training Teams

Training may be provided to staff directly by the EPR vendor - this may be to end-users or train-the-trainer cascading models. In addition, the EPR vendor may offer technical support to staff in-person or electronically (e.g. support line, or in-person visit to the neonatal unit during the time of implementation and at training sessions).

Trust-level EPR staff should be trained and experienced to provide support both through the pre-go-live training phase and through implementation. Developing expertise within the hospital helps ensure adequate technical support can be provided during implementation, in a sustainable way. At time of go-live, there may be value having additional members of staff specifically available in the neonatal unit to support the clinical team with the EPR. This may include experts from the EPR vendor and staff from other sites that have implemented the same EPR, ideally from a neonatal service.

Local EPR Champions

Local EPR champions can be an extremely effective model involving all members of the neonatal multidisciplinary team. Such programmes can include super-users, with enhanced training and experience as well as expert communities who may have the ability to undertake limited

reconfiguration of the EPR (where possible). There is clear evidence that the degree of post go-live end-user satisfaction is directly related to the engagement of the multidisciplinary team during configuration, training and implementation.

EPR champions may have a specific role offering refresher training for relevant staff groups to ensure they are kept up-to-date and continue to develop their understanding of the EPR. In addition, EPR clinics led by different champions and superusers can provide an opportunity for staff to raise queries or troubleshoot difficulties, as well to support personalisation of the EPR for individuals if available.

Training materials

It is important to recognise that the neonatal workforce is diverse in discipline, digital experience and in learning styles. As well as using combinations of training methodologies, a variety of training materials may also be beneficial to support differing learning styles and speeds.

Training manuals with generic information and specific use of the EPR and workflows are commonly developed. They can be tailored to a different member of the MDT relating to their data requirements and include sections on troubleshooting / frequently asked questions. They can provide a valuable reference resource but require regular reviews as the EPR is updated. For this reason, having large quantities of printed material may be time consuming and not sustainable. It may be preferable to keep this as a digital manual, for example on the provider intranet which can be updated as required.

Short tip sheets for reminders and for updates or new developments can be valuable, produced rapidly and circulated widely. There may be benefit of printed copies at workstations as new updates and features are introduced.

E-Learning platforms

To support classroom face-to-face learning, **electronic learning platforms** can be a valuable way to help staff training. These often work as training modules dedicated to different needs of the MDT. The ability to develop e-learning resources locally may be limited and will need to be revised and updated.

Video resources

Short / bite-sized 'how to' videos can be an effective way to teach established users on advanced features and updates. Availability of a video library for ongoing / refresher training may help maintain a skilled workforce overcoming the shift nature of clinical work and differing needs of individuals. Producing these videos using the recording feature in video conferencing software has made this option, a quick, easy and effective training option.

Simulation

Neonatal units run regular simulation programmes to simulate the impact of human factors on the management of clinical scenarios. **Simulation leads should consider incorporating the use of EPR within these scenarios**, so that members of the MDT can learn how to use these electronic systems under simulated and controlled environments. Some EPRs offer environments which simulated patients can be created and used for simulation without affecting the live clinical system.

Monitoring training

There will need to be a **training log** to ensure that all staff have completed the agreed basic level of EPR training prior to go-live. Detailed records including those **accessing e-learning, video resources and refresher training** can both help support individual staff members and assess the perceived value of different training materials and methodologies. This will ensure that the training package evolves in a way that is defined be the needs of the end-users, allowing training to recognise the needs of different team members.

Ultimately, the success of EPR implementation within neonatal units is dependent on ensuring a fully trained workforce, anticipating the challenges and how to overcome these. Particularly with extensively end-user configured systems, many of the challenges and problems will only become evident post go-live.

It is also essential to recognise that some staff members find the use of the EPR challenging, despite training. It is important to continue to offer additional support to staff members making use of different training methodologies and materials described above.

Maintaining data and clinical quality

EPR systems are able to store huge amounts of data automatically and to process data into summarised records. As well as ensuring health care professionals are trained to use the EPR effectively it must also be recognised that the automation may both impact on the health care professional's clinical review and their learning and training in the specialty. The human response to an apparently well-presented clinical note which has been automatically derived but not really considered can be an increasing problem. Interestingly some EPRs now allow notes to be reviewed showing which sections have been written, templated, or copied from previous notes. EPRs also allow remote access either onsite or remotely.

The concept of a remote review must not be considered commensurate with a cotside clinical review. Auditing of quality of reviews and documentation is as essential in electronic as paper medical records. Finally reviews of individual interactions with EPRs may help define future education and training. Studies already show significant variability between individual's interactions with EPRs with, for example, huge variation in the number of mouse clicks to achieve the same activity. Such analyses can help to understand human EPR interactions and support ongoing user interface development as well as guiding future training.

Case study

The local neonatal unit at Newham University Hospital, London, identified that their existing use of EPR did not include nursing staff and that there was no model documentation template to use as a framework to maintain structured notes. Following this they implemented a four-stage Quality Improvement Project to address these concerns, led by a team including senior and trainee medical staff and Advanced Nurse Practitioner input. Nursing staff were supported as EPR for nursing notes was implemented, using structured templates to allow consistent records of patient care. The unit is now planning to implement full electronic records of patient observations and electronic prescribing.

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Leading Excellence in Perinatal Care

This document was produced by the British Association of Perinatal Medicine (BAPM).

BAPM a membership organisation that is here to support all those involved in perinatal care to optimise their skills and knowledge, deliver and share high-quality safe and innovative practice, undertake research, and speak out for babies and their families.

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British Association of Perinatal Medicine (BAPM)
is registered in England & Wales
under charity number 1199712 at
5-11 Theobalds Road, London, WC1X 8SH