Title:	Two-year Developmental Follow Up
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Introduction

Premature babies or those born with complex medical conditions are at an increased risk of developmental problems and disorders. Therefore, early detection and early intervention for any adverse long-term event promotes optimal outcomes in these high-risk infants. It is recommended that the families of those babies who have medical conditions or may have development challenges are offered enhanced developmental support and monitoring. This requirement should be in the form of a face-to-face developmental follow up post discharge up to 2 years corrected age. This follow up programme must be provided by a multidisciplinary team (MDT) as an integral part of a neonatal service working together with local health services (1)
Long term follow-up with enhanced developmental surveillance as well as raising awareness of the consequences of prematurity in school are essential in identifying the needs of children born preterm, so that timely interventions can be implemented (2)

Purpose

The guideline aims to provide structure for the 2 year follow up and reporting of health outcomes in line with national standards (1) (3).
Developmental follow-up requires an MDT approach with expertise in neonatal neurodevelopmental assessment. The team should include neonatologists, allied health professionals including dietician, occupational therapist, physiotherapist, speech and language therapist, a psychologist, community liaison staff such as neonatal outreach, paediatric nursing team or health visitors, general practitioners, and paediatricians. The MDT will support and empower families to act as an advocate for their child. The early and coordinated intervention will address parental concerns related to their child's health and development ensuring that their child continues to grow and develop.

Neurodevelopmental follow-up is a critical component of the evaluation of the neurological development and ongoing clinical needs of premature babies or those born with complex medical conditions. This support and surveillance are the foundation of high-quality care provided to newborns at risk of future neurodevelopmental delay and can address the needs of premature and medically complex infants after they are discharged home. Additionally, it provides families with the support and resources they may need from infancy into early childhood.

Criteria for enhanced developmental support and monitoring up to 2 years (corrected age) (1)

- Preterm infants < 30 weeks gestation
- Preterm infants 30^{+1}-36^{+6} weeks gestation and has or had 1 or more of the following risk factors:

    - A brain lesion on neuroimaging likely to be associated with developmental problems or disorders (for example, grade 3 or 4 intraventricular haemorrhage or cystic periventricular leukomalacia)
    - grade 2 or 3 hypoxic ischaemic encephalopathy in the neonatal period
    - neonatal bacterial meningitis
    - herpes simplex encephalitis in the neonatal period.
- Infants with HIE (cooled or not cooled)
- Infants with chronic lung disease (CLD)
- Any infant with significant abnormality on brain imaging
- Infants with significant or multiple congenital anomalies
- Syndromic diagnoses
- Infants at risk of neonatal abstinence syndrome (NAS)
- Other neonatal problem (discussed at discharge planning)

Process

The British Association of Perinatal Medicine (BAPM) and National Institute of Clinical Excellence (NICE) currently recommends that a standardised neurodevelopmental assessment should be carried out at 2 years of age, corrected for prematurity.

Discharge planning and support

Discharge planning should start as soon as possible after the birth of a baby and involve carers and parents at all stages. Information should be provided and discussed with carers and parents about the risk and prevalence of developmental problems and disorders that may occur. The information provided should be tailored to their individual circumstances, considering:

- Their child's potential developmental needs
- Their level of education
- Any social care needs they may have
- Any cultural, spiritual or religious beliefs
- The need for consistency in information sharing among healthcare professionals

Parents or carers should be supported to gain the knowledge, skills and confidence they need to look after their baby in the neonatal unit and then at home following the principles of the model of family integrated care. This enables them to support the baby's developmental and emotional needs.
Emotional and psychological support to parents or carers should be provided on the neonatal unit and upon discharge, recognising the significant impact of having a baby on the neonatal unit on all the family.

Information should be shared with parents and carers about universal services and national recommendations for assessing the development of all children through screening and monitoring and that their baby will be offered enhanced developmental support and monitoring with follow up at 2 years corrected age. Neonatal units should consider the making of appointments for the 2 year follow up, upon discharge from the unit with set reminders prior to the appointment. Other health professionals such as GP and health visitors should receive the information about 2 year follow up and appointment as a fail-safe mechanism.
An explanation should be given to parents and carers about their child's developmental (corrected) age and how this will be used for the first 2 years when assessing their functional and developmental skills. The sharing of vital parent information leaflets should be given on discharge (Appendix 4)
A Team Around the Family (TAF) should be considered to support families upon discharge from the neonatal unit. The purpose of the Team Around the Family meeting (TAF) is to share information and to create a solution focussed plan that will support the needs of the child and their family.

Enhanced developmental support and monitoring

Premature babies or those born with complex medical conditions who are having enhanced developmental surveillance must have early assessments with experienced medical and Paediatric Allied Health Practitioners. This is aimed at early detection of developmental problems with early intervention, to optimise outcomes (1). There must be as a minimum 2 face-to-face follow up visits in the first year that focus on development, at the following corrected ages:

- At term (38-42 weeks corrected age or prior to discharge)
- Between 3 and 5 months and
- By 12 months

At each face-to-face follow-up visit and developmental assessment professionals with appropriate skills should:

- discuss with parents or carers whether they have any concerns about their child's development
- include checks for developmental problems and disorders
- measure length or height, weight and head circumference
- carefully evaluate and review any developmental concerns reported by parents or carers or noted during the visit or assessment
- correct for gestational age up to 2 years when assessing development
- consider further investigation or referral if a developmental problem or disorder is suspected or present
- refer the child to the appropriate local pathway if needed.

A multidisciplinary team must provide enhanced developmental support and monitoring up to 2 years corrected age for children who are at increased risk of developmental problems or disorders.

Multidisciplinary teams delivering enhanced developmental support and monitoring for children who meet the criteria for enhanced developmental support must involve the following professionals: (1)

- Community nurse and/or health visitor
- Occupational therapist
- Physiotherapist
- Speech and language therapist
- Dietitian
- Psychologist
- Paediatric neurologist (consider)

Risk and prevalence of developmental problems

Children and young people born as a high-risk newborn, set in the criteria for enhanced developmental support are at an increased risk of developmental problems and disorders. There needs to be an awareness that children who are born high risk and preterm can have an increased prevalence of the following developmental problems: (1)

- cerebral palsy,
- motor function problems with an increased prevalence of developmental coordination disorder.
- learning disability and the prevalence increases with decreasing gestational age.
- special educational needs and risk of low educational attainment at the end of the Early Years Foundation stage and at Key stage 1.
- executive function problems at preschool and school ages
- receptive & expressive speech & language difficulties
- Neurodiversity
- Autism Spectrum Disorder
    - Symptoms of social communication impairment
- Sensory processing disorders
- Increased risk of dyspraxia
- Emotional and behavioural problems
- Eating, drinking and swallowing difficulties
- Sleep problems
- Visual impairment
- Hearing impairment
- Developmental delay

The group of problems that become apparent during child development can often occur together. They are characterised by impairments of personal, social, academic

or occupational functioning, ranging from very specific limitations to global impairments of social skills or cognition, as measured by parents and surveillance tools. The enhanced developmental support for high-risk newborn should be multidisciplinary led with advice and interventions from skilled professionals.

2 year assessment procedure

A face-to-face developmental assessment must be provided at 2 years (corrected age) for all children who meet the criteria, working on the range 22 – 36 months corrected age (1). On discharge from the neonatal unit parents or carers should be provided with a single point of contact within the neonatal service for outreach care.
To identify if the infant is at risk of global developmental delay, learning disability or language problems the Parent Report of Children's Abilities – Revised (PARCA-R) should be completed by the parent(s) or carers prior to the assessment appointment. If the PARCA-R is not suitable (for example, because of poor English language comprehension or the child being outside the validated age range of 22 to 26 months), a suitable alternative parent questionnaire can be used. Caution should be given to its use as there is some evidence from APA that highlights even when screening tools are used a large proportion of potentially eligible infants are not referred for early intervention (4)
vCreate Neuro Neonatal follow up is a useful tool that allows registered parents to securely share smartphone recorded videos and associated metadata with the clinical team to screen for early signs of adverse developmental outcomes prior to attending their 2 year developmental follow up. All neonatal units within the North West have access to vCreate neuro follow up via the NWNODN.
The Bayley Scales of Infant and Toddler Development should be the standard assessment used at the 2 year follow up. This is a standard series of measurements including cognitive, language and motor skills, used primarily to assess the development of infants and toddlers, ages 1–42 months. This measure consists of a series of developmental play tasks and takes between 45 – 60 minutes to administer and derives a developmental quotient (DQ) rather than an intelligence quotient (IQ).
Information from the full MDT must be gained and reviewed with previous assessments to gain a more comprehensive assessment of the child.

Outcomes dataset recording process

It is essential to obtain robust outcomes data of 2 year follow up as this allows determination of the quality of the care and facilitates benchmarking. The BadgerNet system is the current source for inputting of data.

NNAP standard (5)

Developmental standard: Ninety percent (90%) of babies with two-year follow-up data entered.

Inclusion criteria

- Babies born at less than 30 weeks who are not recorded as deceased within their episodic data (including final neonatal outcome).
- The eligible cohort runs for births from July to June each year, for babies who would have reached two years corrected age since the last annual report.

Attribution will be to the neonatal unit of final discharge. When the unit of final neonatal discharge home cannot be ascertained, two-year data is assigned to the last known episode of neonatal care.
Assessment data will be considered for analysis if it took place between 18 and 30 months corrected age for the infant. This is calculated using assessment date, date of birth and gestational age at birth.

Generating a list of babies that require follow up

The BadgerNet system can generate a list of babies that meet the follow up criteria to enable local teams to arrange appointments and liaise with parents and carers. The list can be generated in advance for the whole year if required.
Responsibility for organising and performing the assessment rests with the consultant clinician responsible for ongoing care, even if the assessment itself is delegated to another individual.

How to generate the list:

1. Open BadgerNet front screen by clicking the installed icon.
2. Click on the “Patient Lists” tab.
3. In the “specific groups” section, click on “Two year follow up due” report.
4. All babies that are due a follow up are displayed.
5. These are based on the hospital of final discharge home.
6. This list can be saved or printed by clicking on the down arrow icon on the top right.
7. You can also enter your own criteria by clicking on the “Refine this list” tab

Local neonatal clinicians are required to check that any baby on the list identified as requiring 2 year follow up has not since died and verify removal from the list.

Data recording process

All neonatal units must determine how and by whom data is captured. This can be completed in a few options:

1. The clinician enters the data directly onto Badger at the time of the assessment. This will require the BadgerNet system to be installed on computers where the assessments are being completed.

2. The clinician has a printed form (Appendix 1) that mirrors the data fields on Badger, fills this in at the time of assessment and then enters it on Badger later.
3. The assessment form is completed by the clinician at the time of the assessment but another colleague with Badger access and write permissions, enters it on behalf of them. This may be an administrative colleague such as a secretary, nurse or data clerk trained in how to do so.

Process for entering on to Badger (Appendix 2)

1. Open the BadgerNet front screen by clicking the installed icon
2. Log on using your username and password as above when you generated the patient list.
3. Click on 'select the existing baby care episode…' under the Patient Selection tab.
4. In the search window type either the NHS number or infant surname.
5. Select the infant you need and double click
6. In the 'discharge' window of the chart select '2 year follow up'
7. The assessment page will load and then you need to enter the data;
    a. All assessors should work down it from "Neuromotor" down to "Growth" and then additionally fill out the fields for "auditory", "vision" and "communication" according to your clinical findings.
    b. Infants having a structured developmental assessment, should have this data input as well as the "developmental score" field completed.
8. Once 'saved and closed', click on the badger head in the top left of the screen to return to step 2 above.

Data from the two -year follow-up form will be used to analyse assessment data.

Process for children who are not bought to appointments/ Did not contact

There are many reasons for a child not to be bought for hospital appointments which may include family or environmental factors. Many parents/carers will telephone the hospital to rearrange or cancel appointments, but a significant number just do not turn up.
In a small number of cases, failure to attend raises concerns about safeguarding. In families where there are already safeguarding concerns, Was Not Bought / Did Not Attend should always be taken seriously. There may be a perfectly acceptable reason for the parent's failure to attend for their child's appointment, however, it is also possible that the parent/carer does not share the health professional's concerns, may be hiding injuries or signs of neglect or just unable to put their child's needs first. Where there could be safeguarding concerns, sharing information regarding WNB/DNAs can be vital in protecting the child.
Managing children who are not brought to or do not attend appointments should be individualised and will depend on many factors including how well the clinician knows the family and the level of concern.

However, the opportunity to safeguard children should not be missed. Sharing information on missed appointments may contribute to timely interventions in children whose needs are not being met or who are experiencing abuse.
If the child is known to safeguarding, then assess the long and short term impact upon health and development of the child not being brought to the appointment. There should be liaison with their named Social Worker, the 0-19 service and their GP, to assess the risk and plan the next steps. Consideration needs to be given for meeting the threshold for child protection referral.
If there are no safeguarding concerns, continue to assess the long and short term impact upon health and development of the child not being bought to the appointment. An active management plan needs to be in place for those children to ensure the continuing monitoring of the child's development and is vital that there is liaison with the 0-19 service and their GP for a developmental update, considerations should be given for a further appointment and contact made with parent/carer directly by telephone.
All communications and plans should be documented. There should be correspondence with the 0-19 service, GP and parents/carers.
Please also follow local guidance for when a child Was Not Bought to an appointment or did not attend.

Process for children who move out of area or are discharged out of area

It is important for children who are discharged out of area that their health teams in those areas are contacted. Information sharing is vital to continue to support and monitor the emotional and physical development of the high-risk babies. A discharge letter should be sent to the 0-19 service, their GP and receiving consultant with specific information about the requirement of 2 year follow up. If those details are not available, then the current health visitor or health visitor liaison, should be contacted to gain that information.
To enter the details in to badger, the discharge details page should be accessed and the field 'discharged to' needs to be set to 'home'. The baby must also be eligible for 2 year follow up for the badger field 'Unit responsible for 2 year follow up' to be displayed, as shown in appendix 3.

APPENDIX 1

2-YEAR FOLLOW UP BADGER DATA ENTRY FORM (NNAP)

Name & Designation of person completing form_____
Hospital of birth _____
Current hospital of follow up _____
Infant's name _____ **Infant's NHS No** _____
Date of birth _____/_____/_____ **Date of assessment** _____/_____/_____
Gestation at birth (completed weeks) _____ **Sex: Male / Female**
Birth weight _____ **Full current postcode** _____
Was 2 year examination done: **Yes** **No**
Reason if child not assessed: **Deceased post discharge** **Lost to follow up**
Declined appointment **Responsibility of another unit**
Did not attend appointment **Moved out of area**
Local decision not to follow up

1. **Neuromotor**	**Yes**	**No**	**Unknown**
Does the child have difficulty walking			
Is child unable to walk without assistance			
Is child unstable or needs to be supported when sitting			
Is child unable to sit			
Does this child have difficulty with the use of one hand			
Does child have difficulty with the use of both hands			
Is child unable to use hands to feed self			

2. **Malformations**	**Yes**	**No**	**Unknown**
Malformations at birth or within first 2 years			
Malformation impairs daily activities despite assistance			

3. **Social**	**Yes**	**No**	**Unknown**
Is child on at-risk register, fostered or adopted			

4. **Respiratory / CVS system**	**Yes**	**No**	**Unknown**
Limited exercise tolerance with or without treatment			
On supplemental oxygen or any respiratory support			

5. **Gastro-intestinal tract**	**Yes**	**No**	**Unknown**
Is child on a special diet			
If yes, what diet			
Does child have a stoma			
Does child require TPN, NG or PEG feeding			

6. **Renal**	Yes	No	Unknown
Renal impairment, no treatment			
Renal impairment, on dietary or drug treatment			
Renal dialysis or awaiting renal transplant			

7. **Neurology**	Yes	No	Unknown
Has the child had a seizure or fit in the past 12 months			
Is the child on anticonvulsants			
More than 1 seizure a month despite treatment			
VP shunt inserted or insitu			

Growth				
Date of measurements				
Weight				
Length / height		Measured how?	Standing	Lying
Head circumference				

1. **Development score**	Yes	No	Unknown
Is development normal (<3 months delay)			
Is there mild delay (3-6 month delay)			
Is there moderate delay (6-12 month delay)			
Is there severe delay (more than 12 month delay)			
8. Development score cont.	**Yes**	**No**	**Unknown**
Was child difficult to test			
Will you refer for detailed neurodevelopmental assessment			

What development test(s) used

☐ Bayley III ☐ Griffiths
☐ Schedule of growing ☐ Other(specify)
☐ Unknown

9. Auditory	Yes	No	Unknown
Does child have a hearing impairment			
Hearing impairment corrected by aids			
Hearing impairment, uncorrected by aids			

10. Vision	Yes	No	Unknown
Any visual problems. Inc squint			
Visual defect not fully correctable			

11. Communication	Yes	No	Unknown
Does child have difficulty with communication			
Does child have difficulty with speech			
Does child have <5 words, vocalisations or signs			
Unable to understand word or sign out of familiar context			
Unable to understand words or signs			

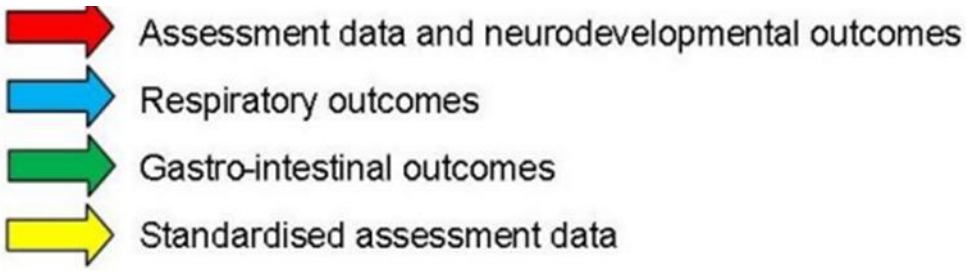
12. Neurological diagnosis	Yes	No	Unknown
Does child have a diagnosis of cerebral palsy			

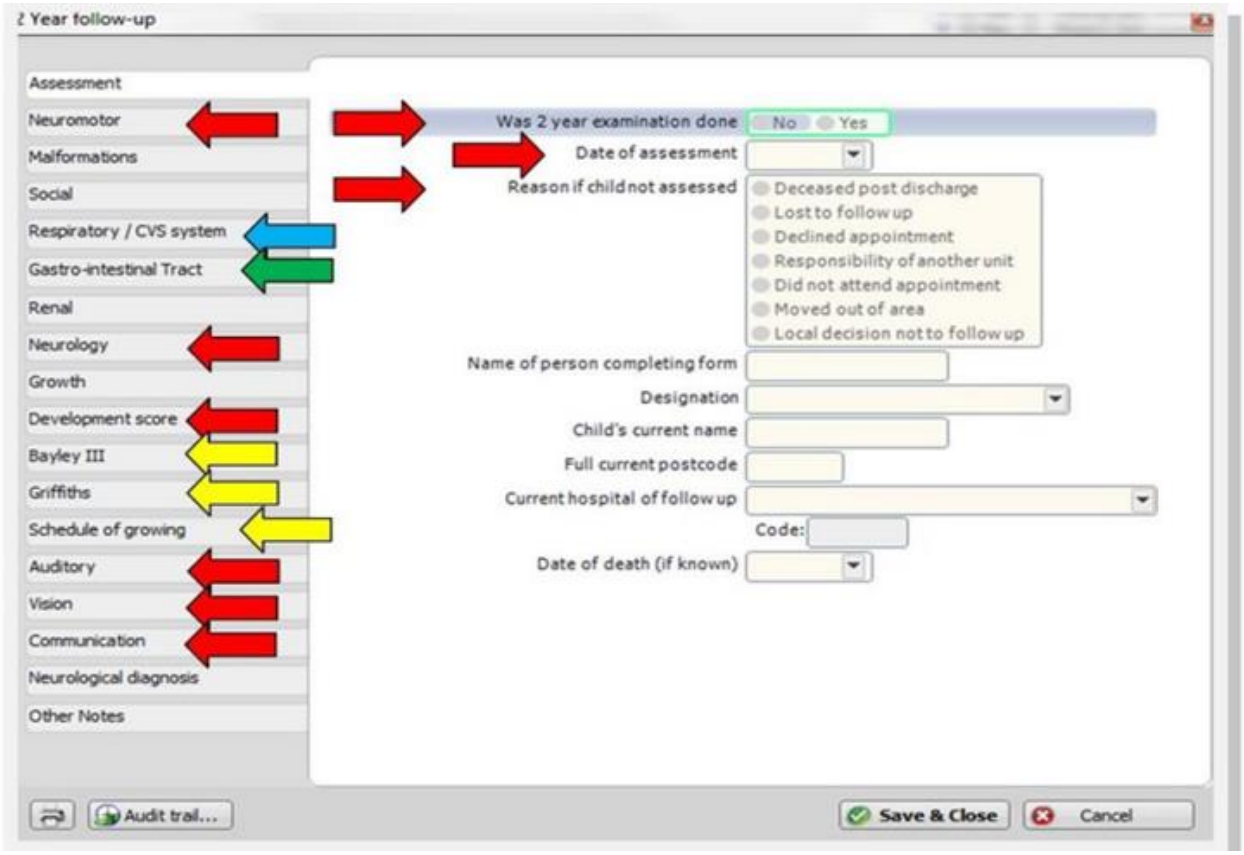
Type of cerebral palsy	☐ Spastic bilateral: 2 limb involvement	☐ Spastic bilateral: 3 limb involvement
	☐ Spastic bilateral: 4 limb involvement	☐ Hemiplegia: Right sided
	☐ Hemiplegia: Left sided	☐ Dyskinetic / Dystonic / Choreo-athetoid
	☐ Not classifiable	
Other diagnosis notes		

APPENDIX 2

Process for entering on to Badger

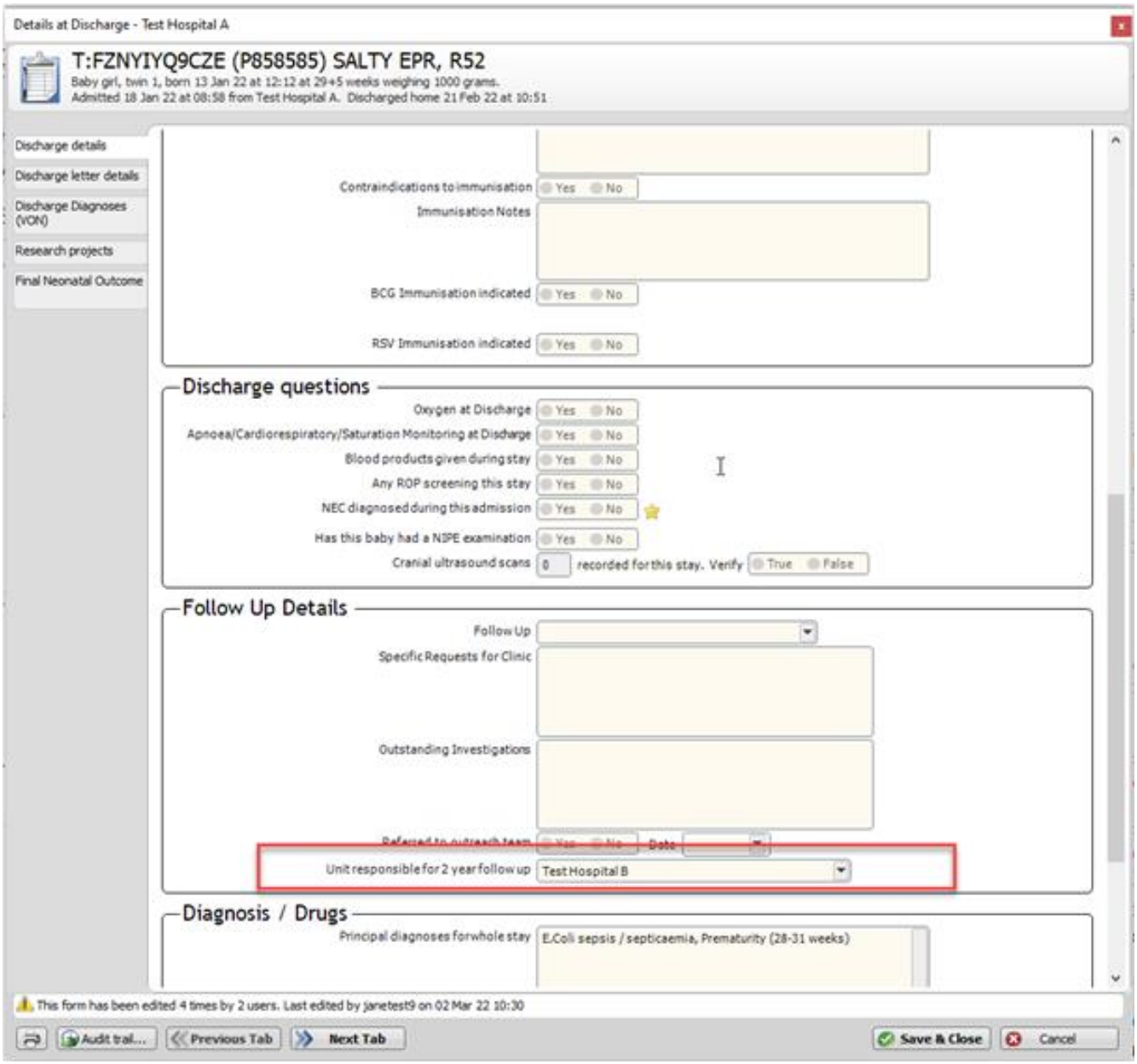
Data from the two -year follow-up form will be used to analyse assessment data. Which sections are used for each part of the analysis is indicated below by the coloured arrows (NNAP audit measures, 2022)





APPENDIX 3

Process for children who move out of area or are discharged out of area



Parent leaflet for 2 year follow up

BANNFU_Leaflet.pdf (amazonaws.com)

References

1. **National Institute for Clinical Excellence.** *Developmental follow up of children and young people born preterm.* 2017.

2. **Francesca Seregni, Joanna Coghill, Hilary S. Wong.** *School-age developmental needs in children born preterm.* 2021.

3. **Department of Health.** *Toolkit for high quality neonatal services.* 2009.

4. *Missed opportunities in the referral of high risk infants to early intervention.* **Tang BG, Feldman HM, Huffman LC, Kagawa KJ, Gould JB.** 2012.

5. **RCPCH.** *National neonatal audit programme.* 2022.