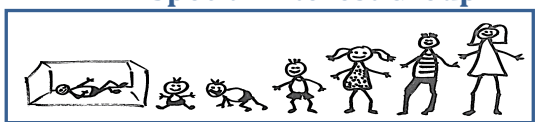
BANNFU

British Association of Neonatal Neurodevelopmental Follow up

BAPM Special Interest Group



31st March 2020

Guidance for phone /video follow up clinics during Covid19 Pandemic

The neurodevelopmental follow up service for your high-risk patients during this Covid19 Pandemic although not urgent, is extremely important for infants and families. This short document aims at providing a suggestion for a guideline on how to run a neurodevelopmental follow up service at a distance either by phone or video conference.

Population (WHO)

High risk patients are premature <30 weeks, birthweight <1500g, FGR <2nd centile, any encephalopathy (term or preterm), any brain lesion likely to be associated with developmental delay, bacterial meningitis or HSV encephalitis

Aims (WHAT)

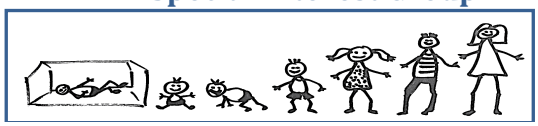
The aims of the service continue to be early identification of problems, early intervention, and provision of outcome data for research and for evaluation of neonatal services.

1. Early identification

Timely referrals to therapies or other services are dependant on the prompt identification of physical or behavioural problems. Instruments that can be used for early identification of delay or abnormalities include the structured developmental assessments, such as Bayley Scales of Infant Development or Denver Developmental Screening Tests, any neurology examination, such as Amiel Tison or Hammersmith Infant Neurological Examination (HINE), and the video assessments of General Movements (Prechtl). Parents are excellent observers of their own children. Asking parents a selection of questions from the tests by phone or video link will help the professional infer a developmental age equivalent and determine whether there are any developmental concerns requiring referrals to specialist services. The Neonatal Neurodevelopmental Follow up service should aim to cover the initial 2 years at the minimum, and ideally extend into early school age.

2. Early Intervention

Starting from admission to the neonatal unit, early intervention continues throughout discharge and first few years of life and is very important for optimising developmental outcomes.. Much of the advice on Early Intervention is provided by the literature published on sensory-motor development by therapists around the world, and this is usually demonstrated to families in group or one-to-one sessions. In the current situation where face to face contact must be minimised, a very good summary and evidence-based approach is provided by EI SMART which has age adequate recommendations on leaflets that are downloadable from their website. (www.eismart.co.uk)



3. **Provision of outcome data for Research/clinical purposes**

Without the option of an assessment in person, it is not possible to obtain objective scores for formal developmental test. Outcome data must therefore be characterised in a qualitative manner, such as "normal" or "concerns", "complex communication issues" or "behavioural problems". For assessments at two years of age (corrected), there is a validated tool, the PARCA-R Questionnaire, (https://www2.le.ac.uk/partnership/parca-r/docs/parca-r-manual), currently recommended by NICE for the children born prematurely. It is administered between 23.5-27.5 months of age corrected for prematurity and has two scales, the non-verbal cognitive scale and the verbal scale. Parents can be sent the questionnaire by email, score and email back, or it can be completed during the telephone consultation.

Timing (WHEN)

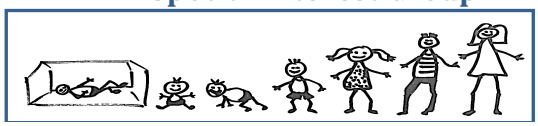
The recommendation by NICE is a minimum of 2 face to face F/u visits in the first year at 3-5 months and by 12 months and a detailed developmental assessment at 2 years.

We suggest,

1. **Term assessment-** Video and Neurology examination before discharge. If the patient is discharged before term, parents could send the video for the team to review according to local arrangements. Questions asked should include hearing screening, concerns about vision, behaviour, asymmetries, Diagnosis is given (ie progressing well, concerns on…) Referrals as appropriate and Early Intervention with EI SMART. See appendix.

2. **Three months' review**- Home video by parents sent to the MDT as per local arrangements. Remember to ask for consent for sharing with other professionals. Questions as per Bayley, Griffiths, SGS or other forms – Identify concerns, needs and practices to avoid. Diagnosis of F (-) should be urgently referred to local MDT and physiotherapy. See appendix for information for parents on how to video, EI SMART and positioning leaflets for illustration on Early Intervention.

3. **Two years' review-** Bayley III is a face-to face assessment so it won't be possible to use it for telephone or video reviews. We would recommend that the PARCA-R questionnaire is to be sent in advance to parents and have ready for the clinic or could be completed during the consultation. Scores should inform research and clinical service. Fine and Gross motor are not covered by PARCA-R, so professionals are expected to ask questions on their observation of neurology (asymmetries, abnormal tone or posture, vision, hearing, behaviour) and to take this opportunity for completing the 2y questionnaire on Badger, indicating that development (question 10) is based on PARCA-R. Please see Appendix for Two-year questionnaire, developmental checklists and my motor-baby chart.



4. **Other reviews** Ideally for Early Intervention at 3,6,12 months should be offered as per clinical need and unit programmes, subject to staff availability. For early intervention recommendations please see appendix on infant positioning, developmental checklists and EI SMART.

Important- These patients may not have been in contact with any other medical professional. Take the opportunity to enquire about general health, immunisations, feeding, medication, etc. and intervene or refer appropriately.

Coordination (HOW)

Coordination of telephone/video consultation should ideally be done by a service coordinator when possible, who calls the family before the appointment and ask for consent for a telephone appointment receives videos and completed questionnaires and sends out reports and leaflets after clinic.

Ideally, relevant forms should be sent to the family by email or post prior to the clinic (ie PARCA-R) so are ready for discussion at the appointment. If this is not possible then forms should be completed by phone during the consultation. The clinic letter generated together with relevant leaflets are to be encrypted and sent by email to the families who have given consent, or by post.

Notes on Documentation

- All clinical encounters should be documented on the respective trust system including date and time of the phone/video call. A clinic letter is to be produced for the GP, the child's parents and the referees clearly indicating that the information provided is based on observation from parents.
- Where observation is not clear, or professionals are unsure of the information provided by the family it would be recommended to refer for a face-to-face appointment – clarifying that this may be delayed because of the Covid19 Pandemic.
- Please remember that the 2y outcomes form in Badger should also be completed online.

Appendix – Useful Resources

- PARCA-R manual (https://www2.le.ac.uk/partnership/parca-r/docs/parca-r-manual)
- Copy of Denver forms to extract relevant questions at specific ages
- HINES Neurology examination form to be used as a guide
- Two-year Badger questionnaire
- My Baby Motor by Olsen-Puttkammer chart for motor progression
- Developmental checklists for all ages
- Infant Positioning advice for parents
- Information on how to video a baby and how to send the video
- www.eismart.co.uk for leaflets on Early Intervention recommendations according to age