



## **Report of a BAPM/RCPCH Working Group**

### **Classification of health status at 2 years as a perinatal outcome**

**Version 1.0; 8 January 2008**

## **Classification of health status at 2 years as a perinatal outcome**

This working group was convened by the British Association of Perinatal Medicine and the National Neonatal Audit Project (NNAP) based in the Royal College of Paediatrics and Child Health in order to re-evaluate current recommendations for the reporting of outcomes of perinatal care for the purposes of Audit and to support research studies.

The Working Group met on 30<sup>th</sup> January 2007 and agreed a work plan. Subsequent activity was carried out by e-mail. The Working group agreed the following terms of reference:

- 1) To agree a classification of health status at 2 years for use in epidemiology, audit and research studies in order to inform current national data collection and current studies.
- 2) In particular to consider:
  - a) Which outcomes are important for parents?
  - b) Which outcomes predict serious disability in middle/late childhood?
  - c) What is meant by "normal outcome at 2y"?
  - d) Which evaluation should we use for research purposes and should this be different to those used for other purposes?
- 3) To define a dataset of outcome categories and indicate how these may be combined into a summary measure(s).

### **Members of the Working Group were:**

- Neil Marlow (Convener, BAPM)
- Jane Abbott (BLISS)
- David Field (The Neonatal Survey)
- Sam Johnson (Psychologist, University of Nottingham)
- Angela Huertas (TRPG/SEND)
- Huw Jones (Portsmouth)
- Maggie Redshaw (NPEU)
- Neil McIntosh (RCPCH)
- Alison Salt (Wolfson Centre)
- Win Tin (Middlesbrough)
- Louise Youle (NNAP)
- Kim Davis (Minutes)
- With thanks and advice from Professor Alistair Fielder

## **Background**

In 1994 A meeting was convened under the auspices of The National Perinatal Epidemiology Unit and Oxford Health Authority, led by Dr Ann Johnson, to consider the definition of disability for outcome studies. The subsequent publication described what was to become known as the Heath Status Questionnaire (HSQ) (1, 2). This has been compared to other classifications (3, 4) and found to be robust. It has been used in high profile publications from the UK but its use has not spread to other countries until recently.

The HSQ defines "severe disability" at 2 years of age (corrected for prematurity) and this category is highly predictive of moderate or severe disability at school age (figure 1).

However there are several drawbacks:

- The HSQ simply describes function but not condition; in particular there is a need to report cerebral palsy to allow comparison with outputs from other international databases.
- Within the severe grouping, particularly for motor problems, there is a need for gradation.
- The developmental cut off (<55) is extreme and, whilst it may be highly predictive, is not commonly used around the world when reporting outcomes for such populations.
- No developmental test is specified - we know from research datasets that unstructured assessment around a cut off is not accurate (<70% agreement; Marlow N Unpublished data from EPICure), similarly screening tests will over-identify children with disability or impairment and different developmental tests may produce different results. A survey from The American Academy of Pediatrics showed that informal measures of development would identify only 30% of children with developmental problems (IDEA programme-AAP 2003).

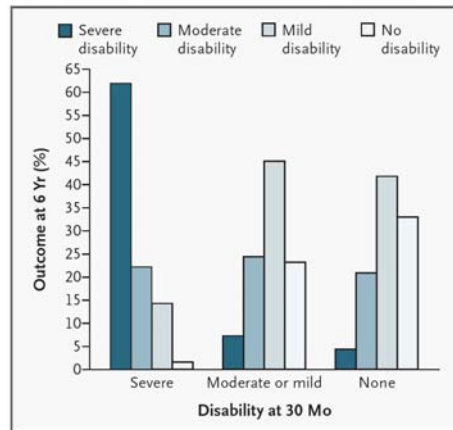


Figure 1: Predictive value of 2½ year assessment using HSQ for outcome at 6 years (5)

Within the UK at present there are several initiatives which involve quantifying outcome at two years, particularly for populations of preterm children. Although some of these have a particular need for precision (for example research studies) in essence the requirements are similar. The widely used SEND neonatal data collection system ([www.neonatal.org.uk/Healthcare+Professionals/SEND](http://www.neonatal.org.uk/Healthcare+Professionals/SEND)) has added a follow up module for completion at 2 years corrected age using the Oxford/NPEU classification; the Neonatal Survey (previously the Trent Neonatal Survey) is currently adding 2 year outcomes and one key question posed by the National Neonatal Audit Project (NNAP) relates to comparative rates of unimpaired outcomes ([www.rcpch.ac.uk/nnap](http://www.rcpch.ac.uk/nnap)). There are several national and international studies organised from or with substantial contributions from the UK (BOOST-II UK; NeoProM; iNOT-27; TRUFFLE) with similar definitions of outcomes. It would be helpful if routine and research outcome evaluation could be brought into line.

Data from outcome reports are frequently used to underpin information given to parents during counselling where very preterm birth is anticipated or has occurred. The dataset must be clear in the implications of the categories chosen. A working group of the Nuffield Council on Bioethics has recently recommended that written information be available for parents anticipating extremely preterm birth (6) and a BAPM working group is currently considering this alongside revised guidelines. The two processes will inform each other.

The purpose of this working group is to re-evaluate the relevance of the HSQ today and to specify the dataset which will inform data collection at 2y of age corrected for prematurity for a large section of the UK who subscribe to one of two or three neonatal databases as an extension of the BAPM Neonatal Dataset ([www.bapm.org](http://www.bapm.org)), as recommended in the

published Standards document (7) and the DH External Reference Group Report. (8) The ultimate goal is to provide an outcome measure for the National Neonatal Audit Project ([www.rcpch.ac.uk/nnap](http://www.rcpch.ac.uk/nnap)) and ongoing assessment of disability and impairment that accompany premature birth.

### **The purposes of the dataset**

This definition of health status at two years has a range of purposes:

1. To provide a benchmark for networks and hospitals to evaluate the effectiveness of their care in particular for very premature babies.
2. To provide information concerning the risks following preterm birth to assist in counselling parents.
3. To provide an audit of care across the UK ([www.rcpch.ac.uk/nnap](http://www.rcpch.ac.uk/nnap)).
4. To provide an infrastructure on which perinatal research may acquire 2 year outcome data.

*The working group considered that each of these purposes could be achieved within a single dataset which is described below.*

## Age at assessment

The WG considered that the age of two years (corrected for weeks of prematurity) was still optimal for the assessment of outcome. At this age serious cerebral palsy, sensory deficits and significant developmental impairment may be identified reliably and not confounded by transient neurological syndromes of prematurity. (9, 10) It is appreciated that some international research groups time their assessment at 18-22 months but we consider that there is advantage in basing evaluation on slightly older children and that our system is currently oriented to 24 month assessment, the WG felt that there was no compelling argument for changing it. Correction for prematurity is usually made in determining this age so as not to disadvantage children unnecessarily, although this is not universally agreed.

## Coverage of routine data collection on Health Status

There are wide variations in practice around the country as to follow up schemes. Most neonatal services evaluate children over the first two years. Children who develop neurological or other problems are referred onto appropriate services immediately problems arise or become evident; many neonatal services also re-assess outcome at two years for purposes of their own data collection.

Some services base their category for follow up on gestational age at birth and some on birthweight and some use both criteria. Given the confusion in this area, the WG recommends that follow up evaluations at two years of age corrected for prematurity be carried out for all births at <31 weeks of gestation or <1000g birthweight. The WG further recommends that services should consider a move to the more inclusive category of <32 weeks of gestation or <1500g birthweight. This is consistent with the new RCPCH/RCOphth National Guidelines for Screening for Retinopathy of Prematurity.

## Proposed Structure

The WG considered that the basic format of the HSQ remains a good model. The current definition of severe and other disabilities needed some re-evaluation (see below) and it is envisaged that the 2 year evaluation should be able to identify:

1. A category of “**severe neurodevelopmental disability**” (SND) which would be useful as a descriptor of outcomes which were likely to impair independence throughout childhood and might be useful to parents in the process of perinatal decision making. A child who has any one or more than one impairment in this category is classified as SND.
2. A category of “**neurodevelopmental impairment**” (NDI) as a more inclusive classification, including *in addition to children with severe neurodevelopmental disability*, children with less severely impaired outcome which might serve to use as a comparator across populations and with international studies. In effect this is a category of *moderate neurodevelopmental disability*. A child who has any one or more than one impairment in either category is classified as NDI (equivalent to the outcome in many research reports).
3. A description of **other important disabilities** affecting organ systems other than the brain and sensory organs, for example lungs, kidneys, growth.

When combined with birth and mortality information, the combined rates of “Death or Severe Neurodevelopmental Disability” and “Death or Neurodevelopmental Impairment” should also be reported.

A sample output from such a dataset is suggested in Figure 2. Data may be reported for hospitals (split by inborn and outborn) or by populations (based on health communities). It is envisaged that the former may be easily done by individual neonatal units but the results will be difficult to interpret because of the inevitable referral bias and potential inclusion bias potentially present when comparing hospitals. However networks could be encouraged to report outcomes for the whole population they serve (excluding transfers in but including transfers out of the network) and these could appropriately be compared with other networks. Clearly other comparisons of results will be performed but it should be stressed that the choice of the denominator population is critically important and should be clearly defined.

Figure 2: Recommended format for reporting perinatal outcomes at 2 years

| Gestational age at birth   | 22w | 23w | ... | 31w |
|--|-----|-----|-----|-----|
| Number of births (exclude terminations of pregnancy) <sup>+</sup>          |     |     |     |     |
| Number of livebirths   |     |     |     |     |
| Number of admissions for intensive care                                    |     |     |     |     |
| number of survivors discharged home  |     |     |     |     |
| No. of deaths between discharge and 2y                                     |     |     |     |     |
|  |     |     |     |     |
| No. of survivors evaluated at 2y   |     |     |     |     |
| No. with cerebral palsy  |     |     |     |     |
| No. with motor impairment GMFCS 2 <sup>*</sup>                             |     |     |     |     |
| No. with motor impairment GMFCS 3-5 <sup>**</sup>                          |     |     |     |     |
| No. with Cognitive score <-2 SD <sup>*</sup>                               |     |     |     |     |
| No. with Cognitive score <-3 SD <sup>**</sup>                              |     |     |     |     |
| No. with hearing aids but not severe hearing impairment <sup>*</sup>       |     |     |     |     |
| No. with severe hearing impairment <sup>**</sup>                           |     |     |     |     |
| No. with speech and language impairment <sup>*</sup>                       |     |     |     |     |
| No. with severe speech and language disability <sup>**</sup>               |     |     |     |     |
| No. with visual impairment but not severe visual impairment <sup>*</sup>   |     |     |     |     |
| No. with severe visual impairment <sup>**</sup>                            |     |     |     |     |
| Total with neurodevelopmental impairment (moderate or severe) <sup>*</sup> |     |     |     |     |
| No. with moderate disability   |     |     |     |     |
| No. with severe neurodevelopmental disability (SND) <sup>**</sup>          |     |     |     |     |
| NDI           % survivors evaluated  |     |     |     |     |
| % admissions for NIC   |     |     |     |     |
| % births <sup>*</sup>  |     |     |     |     |
| Death or NDI   % admissions for NIC  |     |     |     |     |
| % births <sup>*</sup>  |     |     |     |     |
| SND           % survivors evaluated  |     |     |     |     |
| % admissions for NIC   |     |     |     |     |
| % births <sup>*</sup>  |     |     |     |     |
| Death or SND   % admissions for NIC  |     |     |     |     |
| % births <sup>*</sup>  |     |     |     |     |
| No. with other disability  |     |     |     |     |
| Describe   |     |     |     |     |

<sup>+</sup> "Births" may be total births or particular groups (e.g. gestational age) in a defined population – this could be hospital based, network based or population based depending upon the need

<sup>\*</sup> Components of moderate disability (definition see below) – a child with an impairment in any category (but none in the severe category) is classified as having moderate disability.

<sup>\*\*</sup> Components of severe disability (definition see below) – a child with any one severe disability or impairment in any category is classified as having SND

## Definition of impairments and disabilities in the key domains

The definition of outcome is defined across a range of domains as before. These are summarized in Figure 3 and the detailed comments of the working group then follow. These data represent the minimum data that should be recorded for the classification of outcome to populate the table above, in conjunction with core perinatal data.

Figure 3 Summary of definitions for recommended outcome categories

| Criteria for   | Severe Neurodevelopmental Disability   | Moderate Neurodevelopmental disability  |
|--|--|---|
| <b>Domain</b>  | <b><i>Any one of the below:</i></b>  | <b><i>Any one of the below:</i></b>   |
| Motor  | Cerebral palsy with GMFCS level 3, 4 or 5  | Cerebral palsy with GMFCS level 2   |
| Cognitive function   | Score <-3 standard deviations below norm (DQ<55)   | Score -2SD to -3SD below norm (DQ 55-70)  |
| Hearing  | No useful hearing even with aids (profound >90dBHL)  | Hearing loss corrected with aids (usually moderate 40-70dBHL) <u>or</u> Some hearing but loss not corrected by aids (usually severe 70-90dBHL)            |
| Speech and Language  | No meaningful words/signs<br><u>or</u><br>unable to comprehend cued command (i.e. commands only understood in a familiar situation or with visual cues e.g. gestures). | Some but fewer than 5 words or signs<br><u>or</u><br>unable to comprehend un-cued command but able to comprehend a cued command                           |
| Vision   | blind<br><u>or</u><br>can only perceive light or light reflecting objects  | seems to have moderately reduced vision but better than severe visual impairment;<br><u>or</u> blind in one eye with good vision in the contralateral eye |
| <b>Other disabilities (included as additional impairments to SND or NDI)</b> |  |   |
| Respiratory  | Requires continued respiratory support or oxygen   | Limited exercise tolerance  |
| Gastrointestinal   | Requires TPN, NG or PEG feeding  | On special diet or has stoma  |
| Renal  | Requires dialysis or awaiting organ transplant   | Renal impairment requiring treatment or special diet  |

## Motor outcomes

Disability in the domain of neuromotor function was classified by function – walking, sitting, head control, hand use (each and together) – in the original database. The original working group considered that these data points could be reliably ascertained, did not need complex definition and reflected a severe restriction in the ability to perform an essential activity.

Despite the difficulty in definition, most reports still quote rates of cerebral palsy, often as “CP with disability” or “non-ambulant CP”.

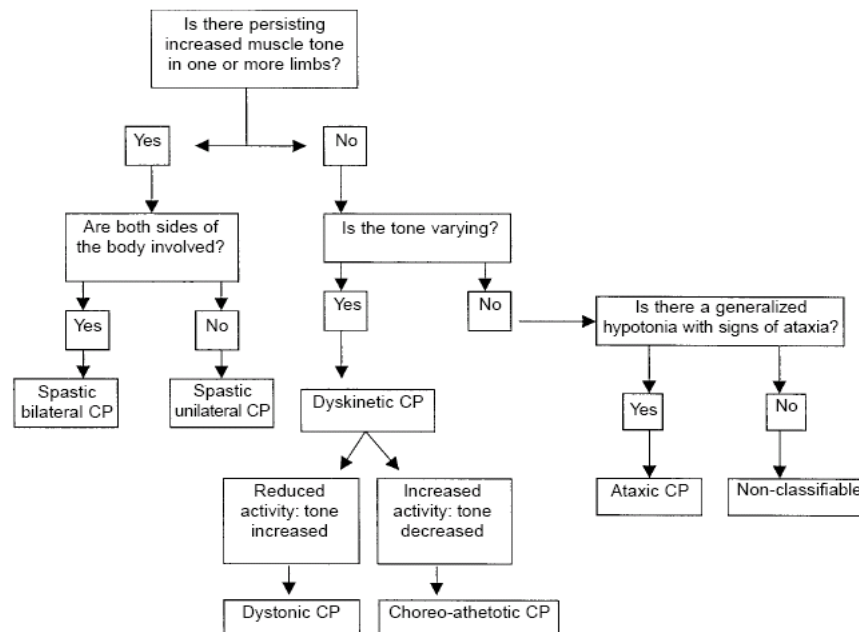
Neuromotor outcome may be determined using developmental scales which place heavy reliance on motor items (using a suitable cut off such as -2SD) or by neurological examination, for which there are a range of standardised procedures available for example the scheme developed by Amiel-Tison and Grenier. (11) From the latter a diagnosis of neurological abnormality may be derived, and a further group identified who have “suspected” abnormality.

A diagnosis of “cerebral palsy” may be derived from this examination; this is purely a descriptive term covering a wide range of outcomes. It is however a useful concept and has recently been redefined thus: (12)

*Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder.*

The definition of this complex condition has an extensive annotation to complete the definition. In this domain we are mainly concerned with motor functions. The distribution of neurological findings may be described using a classification used by a working group of CP Registers - Surveillance of Cerebral Palsy in Europe (SCPE) as outlined in Figure 4. (13)

Figure 4 Classification of cerebral palsy



Two recently developed scales have been developed to quantify motor function *in children with Cerebral Palsy*, the Gross Motor Function Classification System (GMFCS) (14) and the Manual Abilities Classification System (MACS). (15) These are simple to use and reliable descriptors of a *gestalt* of motor performance allowing classification into 5 categories (plus '0' for those without CP). Explanatory notes are provided to make distinctions between grades where difficulties are encountered. The GMFCS is arranged in age bands making it relatively easy to use at 2 years. The MACS was standardised on children from 4 years upwards, but none the less provides a clear classification system which could be adapted to 2 year old children, but still requires validation for that age group.

*The working group considered these options and concluded that defining motor outcome for children with neuromotor abnormality or CP using an internationally accepted scale had value and recommends that classification using the GMFCS be adopted and that cerebral palsy rates be reported classified as recommended by SCPE.*

## Cognitive function

The original dataset acknowledged that cognition is the most difficult area to assess and called for new measures of cognitive function at 2 years of age. Cut-offs of -2SD (reduced 'cognitive' function) and -3SD ('severe disability') were agreed.

Since the publication of this report the Bayley scales have undergone two revisions and the Griffiths Scales have been revised in two forms (0-2y and 2y-8y). The Bayley-III now comprises five scales – Cognitive, receptive and expressive Language, Fine motor, Gross motor – and an observed behaviour scale and parental-report function scale. The whole assessment is lengthy (approximately 1.5h). However the cognitive scale itself is relatively short (taking about 20-30 minutes) and has a correlation coefficient of 0.79 with the WPPSI at 5 years.(16) It is thus possible to use this scale to define cognitive outcome at 2 years; several large randomized trials are currently adopting this strategy.

There is, as yet, less experience with the revised Griffiths Scales and the change in scales at 2 years is a disadvantage for its wider use for this purpose. The closest equivalent to the Bayley Cognitive Scale is the Griffiths "performance" scale but the predictive value and correlation with later IQ is not available. Other developmental scales are available but have less widespread application.

Several parent-based developmental questionnaires are available addressing development, language or cognition. Few have had studies demonstrating utility for the prediction of developmental scores in the abnormal range. Johnson and colleagues have evaluated a revised version of the Parent report of children's abilities (17), the PARCA-r which has high utility to predict a Bayley BSID-II Mental development index (MDI) of <70. (18, 19) Children who have false positives identified using this tool have borderline MDI scores. (19) No correlation with the Bayley-3 cognitive scores has been possible as yet. This is a self completion questionnaire but it is long, comprising both 'cognitive' items from the BSID-II and items from the MacArthur Communicative Development Inventory (MCDI – 100 word vocabulary list and syntax questions).

*The WG recommends that developmental assessment is carried out using a quantifiable standardised scale, for example Bayley Scales or Griffiths Scales, or a quantifiable screening test, such as the PARCA-r, Bayley Screener, etc. The scale used, the cut off applied and the*

*result should be recorded on the form, if appropriate as a "developmental age" to facilitate comparison between different scales.*

*The two cut-offs – of -2SD and -3SD – were confirmed as denoting NDI and severe neurodevelopmental disability (SND) respectively, using a standardised test.*

*Although such questionnaires or other assessment tools may be used in the short term, the working group recommends that all neonatal services plan to develop their follow up service to include a formal developmental assessment using the Bayley-3 cognitive scale.*

## Sensory outcomes and communication

**Auditory Function** – The original dataset was concerned that ‘function’ should be reported and not ‘impairment’, as significant improvement in hearing may be achieved through the use of aids. Hence two categories were defined – children whose hearing remained impaired despite the wearing of aids (i.e. a profound deafness) represents a severe disability and lesser degrees of hearing loss which were helped by aids represents a lesser disability.

Where a hearing test has been performed it is useful to relate the measured hearing loss to these categories. A child with a profound loss >90dBHL is unlikely to hear normal conversation or to develop good language; a child with a severe loss of 70-90dBHL may hear conversational speech if adequately amplified using a digital hearing aid and children with hearing losses <70dBHL who are aided may hear conversational speech and develop good language. However these cut-offs are dependent upon the configuration of the child's hearing and thus a functional classification is preferred.

*The Working Group agreed that functional hearing rather than a level of hearing impairment were important outcomes and that these definitions were still satisfactory. Where hearing has been recently assessed the degree of hearing loss should also be recorded using the standard definitions of Profound (>90 dBnHL; usually classified as SND), Severe (70-90dBnHL; classified as NDI), Moderate (40-70dbnHL; classified as NDI if requires bilateral amplification).*

**Communication** – The working group reaffirmed the necessity of determining communication disorder in addition to functional hearing impairment. The use of sign language comprises appropriate “language” for assessment in this domain.

For comprehension the original criterion for severe disability was “inability to understand a simple command in a cued situation (i.e. a command such as “give me the ...” in a familiar situation or with visual cues)” and, for expressive language: “the lack of any expressive language or fewer than 5 words or signs”. However to be consistent with performance at -3 standard deviations on current language scales this latter criterion would be no meaningful words/signs.

For other disability category (NDI) the original criteria were “inability to comprehend word/sign out of familiar context” for comprehension and “vocabulary <10 words or single words only with vocabulary >10 words” for expressive language. Again to maintain consistency with -2SD for current language scales this should be changed to fewer than 5 words or signs

*The Working Group agreed that communication disorders should be reported separately to hearing loss and the two categories revised to be:*

*Severe speech and language disability (SND): No meaningful words/signs or unable to comprehend cued command (i.e. commands only understood in a familiar situation or with visual cues e.g. gestures).*

*Speech and language impairment (NDI): some but fewer than 5 words or signs or unable to comprehend un-cued command but able to comprehend a cued command*

**Vision** – The original dataset defined severe visual disability as a child who was “blind or could only perceive light from dark”. Criteria classed as other disability were children whose vision was “not fully correctable”. These criteria are crude functional measures but identify those with the most critical visual disability as severe. Determination of acuity in the follow up setting is impracticable but a clinical evaluation of the child’s vision, including fixation, following, nystagmus in the primary position of the eye and strabismus, is a necessary part of the screening process. The recent WHO classification of severe visual deficit is relevant but difficult to achieve in a 2 year old child without dedicated staff in the setting of a routine follow up service:

|                          |   |
|--------------------------|---|
| Blind (total)            | no perception of light                            |
| Blind (legal definition) | worse than 3/60 (1.3 logMAR)                      |
| Severe vision impairment | worse than 6/60 (1.1 logMAR) to 3/60 (1.3 logMAR) |
| Vision impairment        | worse than 6/18 (0.5 logMAR) to 6/60 (1.0 logMAR) |

*The Working Group agreed with the use of a pragmatic functional classification and adjusted the definition as:*

*Severe visual impairment (SND): blind or can only perceive light or light reflecting objects – usually this will equate to a legal definition of “blind”.*

*Visual Impairment (NDI): seems to have moderately reduced vision but better than severe visual impairment.*

### **Other areas of disability or impairment**

*The working group observed that there were little controversial points in the definition of disability in the domains of respiration, gastrointestinal function, renal function or malformation and that these should stand. Although not addressed in the original text, the presence of seizures was included in the original table, although whether these comprised additional measures of disability was not clear.*

The original classification classified growth as a severe disability where one or more parameters were  $< -3$  standard deviations below population norms. In practice this, by itself, does not confer such significant disability or handicap within the WHO classification.

*The working group recommends that growth parameters (together with their centile or SD scores) should be recorded but that the domain of "growth" should be removed from the list of severe disabilities.*

## **Implementation**

The working group considered that all services could move to accepting this classification of outcome for their routine follow quickly (i.e. by April 2008) but that it should be considered mandatory for the return of information as part of the National Neonatal Audit Project, which was rolled out in April 2007.

We recommend that this database is collected as part of all neonatal computer systems and provides the basis of the NNAP response to answer the question concerning later outcome.

We recommend that Specialist Commissioners should require NHS Trusts to collect such information about at risk groups based upon hospital populations as part of the contract for providing neonatal care and adjust their baseline contract appropriately to facilitate the provision of resources for neonatal follow up. We also recommend that Neonatal Networks collate such data for the Commissioners and present the data by hospital Trust and by Primary Care Trust boundary. This will require inter-network collaboration where there are significant cross boundary flows of patients through patient choice or as a result of the geographical location of services.

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Appendix

## Example of form for classifying health status Follow up assessment at 2years of age

*Note this form may be expanded to include a standardised respiratory history (such as the ISAAC questionnaire) and other aspects of medical history or to include a formal neuro-assessment. Similar other forms are available, such as the TRPG form via the SEND website ([www.neonatal.org.uk/Healthcare+Professionals/SEND](http://www.neonatal.org.uk/Healthcare+Professionals/SEND))*

Name of Examiner

Date of Assessment

Place of Assessment

### Identifiers

Child's NHS/Hosp Number

Child's Name

Child's Sex

Child's Date of Birth

Gestational Age at birth

weeks

Age at assessment

months

Age corrected for  
prematurity

months

Main language spoken at  
home

## Developmental Assessment

Assessment complete?

yes

no

If not, please describe reasons in Notes, below

### Developmental assessment results

Name of test applied

Score

Test score achieved (DQ or standardised score)

| Subscales scores if appropriate<br>(please label) | Subscale | Score |
|---|----------|-------|
|   |          | _____ |
|   |          | _____ |
|   |          | _____ |
|   |          | _____ |

Notes: ***If unable to carry out formal or screening assessment, please record reasons and your estimate of developmental level below***

- Normal development (DQ > 85 or < 3 mo delay)
- Mild delay (DQ 70-84 or 3-6mo delay)
- Moderate delay (DQ 55-69 or 6-12mo delay)
- Severe delay (DQ < 55 or > 12mo delay)

Please tick one box below

Assessed

Estimated


Unknown

## Clinical Assessment and Cerebral Palsy

Please tick one

***NO CEREBRAL PALSY***

**Classification of Cerebral Palsy (SCPE classification)**

|  |                    |                          |
|--|--------------------|--------------------------|
| Spastic bilateral                              | 2 limb involvement | <input type="checkbox"/> |
|  | 3 limb involvement | <input type="checkbox"/> |
|  | 4 limb involvement | <input type="checkbox"/> |
| Hemiplegia                                     | Right sided        | <input type="checkbox"/> |
|  | Left sided         | <input type="checkbox"/> |
| Dyskinetic                                     | Dystonic           | <input type="checkbox"/> |
|  | Choreoathetoid     | <input type="checkbox"/> |
|  | Ataxic             | <input type="checkbox"/> |
| Non-classifiable <i>(comment below please)</i> |                    | <input type="checkbox"/> |

*What do you think is the cause of this child's motor impairment (if present)?*

### Ventricular shunt

*Is there a ventricular shunt present?*  yes  no

### Seizures

*In the past **12 months** has the child had a fit or seizure?*  yes  no

If yes, when was the last seizure?

*Within the – last 24h=1; last 48h=2; last week=3;  
last month=4; last 6 mo=5; last year=6*

*Is the child receiving anticonvulsant medication?*  yes  no

### Other neurological problems

*Please describe any other neurological problems*

## Functional Disability - MOTOR

### Gross Motor Function Classification Scale for Cerebral Palsy (GMFCS)

Record the level of *gross motor ability* you have observed

Record 0 if the child does not have cerebral palsy

- Level 1** Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device
- Level 2** Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture
- Level 3** Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs
- Level 4** Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone
- Level 5** Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll

*Note:*

***Distinction between Level I and Level II:*** Compared with children in Level I, children in Level II have limitations in the ease of performing movement transitions; walking outdoors and in the community; the need for assistive mobility devices when beginning to walk; quality of movement; and the ability to perform gross motor skills such as running and jumping.

***Distinction between level II and level III:*** Differences are seen in the degree of achievement of functional mobility. Children in Level III need assistive mobility devices and frequently orthoses to walk, while children in Level II do not require or are unlikely to require assistive mobility devices after age 4.

## Functional Disability – SENSORY and COMMUNICATION

### Problem with vision or eye defect

|  |                          |     |                          |    |
|--|--------------------------|-----|--------------------------|----|
| Is there a visual or eye defect of any type present? | <input type="checkbox"/> | yes | <input type="checkbox"/> | no |
| Does the child wear spectacles?                      | <input type="checkbox"/> | yes | <input type="checkbox"/> | no |
| Is there a squint present?                           | <input type="checkbox"/> | yes | <input type="checkbox"/> | no |

#### Usual vision (with spectacles if worn)

Please tick one

|   |                          |
|---|--------------------------|
| <i>Normal or near normal</i>                                  | <input type="checkbox"/> |
| <i>Reduced vision but not blind as below</i>                  | <input type="checkbox"/> |
| <i>Blind: No useful vision - sees light only or no vision</i> | <input type="checkbox"/> |

### Problem with Hearing

|  |                          |     |                          |    |
|--|--------------------------|-----|--------------------------|----|
| Is there a hearing impairment of any type present? | <input type="checkbox"/> | yes | <input type="checkbox"/> | no |
| Does the child normally wear hearing aids?         | <input type="checkbox"/> | yes | <input type="checkbox"/> | no |

#### Usual Hearing (with aids if worn)

Please tick one

|   |                          |
|---|--------------------------|
| <i>Normal or near normal</i>  | <input type="checkbox"/> |
| <i>Hearing loss corrected with aids (usually moderate 40-70dBHL)</i>          | <input type="checkbox"/> |
| <i>Some hearing but loss not corrected by aids (usually severe 70-90dBHL)</i> | <input type="checkbox"/> |
| <i>No useful hearing even with aids (profound &gt;90dBHL)</i>                 | <input type="checkbox"/> |

### Problem with Speech or Language

*\*exclude isolated articulation defects*

|  |                          |     |                          |    |
|--|--------------------------|-----|--------------------------|----|
| Are there communication difficulties of any type present?* | <input type="checkbox"/> | yes | <input type="checkbox"/> | no |
|--|--------------------------|-----|--------------------------|----|

#### If yes – how does the child usually communicate?

Please tick one

|  |                          |
|--|--------------------------|
| <i>Speech</i>  | <input type="checkbox"/> |
| <i>Speech + other formal systematised methods (e.g. signing)</i> | <input type="checkbox"/> |
| <i>Formal systematised methods only</i>                          | <input type="checkbox"/> |
| <i>Not communicating by speech or other method</i>               | <input type="checkbox"/> |

#### Comprehension Is the child able to understand a simple command

|                             |                                    |                          |     |                          |    |
|-----------------------------|------------------------------------|--------------------------|-----|--------------------------|----|
| (such as "give me the ...") | <i>In an unfamiliar situation?</i> | <input type="checkbox"/> | yes | <input type="checkbox"/> | no |
|                             | <i>Only in a cued situation?</i>   | <input type="checkbox"/> | yes | <input type="checkbox"/> | no |

#### Expressive language

Please tick one

|                                     |                          |
|-------------------------------------|--------------------------|
| <i>&gt;5 words or signs</i>         | <input type="checkbox"/> |
| <i>fewer than 5 words or signs</i>  | <input type="checkbox"/> |
| <i>No meaningful words or signs</i> | <input type="checkbox"/> |

*Comments (including level of hearing impairment if known)*

## FUNCTIONAL DISABILITY – SOMATIC PROBLEMS

Please rate the following areas of somatic function:

### Respiratory

*No concerns (may be on medication)*

*Limited exercise tolerance*

*Requires continued respiratory support or oxygen*

Please tick one

### Renal Function

*No concerns*

*Renal impairment requiring treatment or special diet*

*Requires dialysis or awaiting organ transplant*

Please tick one

### GI Function

*No concerns*

*On special diet or has stoma*

*Requires TPN, NG or PEG feeding*

Please tick one

### GROWTH

Weight  *kg*

Height  *cm*

Head circumference  *cm*

Office use

 sd  
 sd  
 sd

Please describe any other disability not covered above, explaining how it affects daily life

**Thank you for completing this assessment**

**Please return to:**

**Xxx**