Rapport d'activité du Collège de médecins pour la mère et le nouveau-né (section néonatologie)
Année 2009 et perspectives 2010-2012

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La composition des membres du Collège de néonatologie a été renouvelée en octobre 2008.
Le nouveau Collège s'est appuyé sur le travail accompli au cours des années précédentes et a effectué un **état des lieux** qui est décrit ci-dessous :

1. Il existe une hétérogénéité importante en termes de mortalité et morbidité entre les différents centres NIC.
2. L'adhésion des centres pour l'enregistrement est suboptimal. Le feedback généré par le site web est compliqué et exhaustif.
3. Un nombre significatif d'enfants est retransféré dans des services N*. Les données de sortie de ces patients sont difficiles à tracer.
4. Il existe un enregistrement européen Euroneonet. Les items retenus sont proches mais pas identiques.
5. L'objectif des actions du Collège sont d'ordre qualitatif. Il est dès lors primordial de connaître le devenir à plus long terme des enfants prématurés. Un AR. (7 avril 2008) confie l'organisation du follow-up aux centres NIC.
6. L'outil Nicaudit ne permet pas de connaître la mortalité des prématurés à la limite de la viabilité. En effet certains d'entre eux ne sont jamais admis en NIC mais meurent en salle d'accouchement.
7. L'enregistrement des données Nicaudit sont exploitables pour le peer review uniquement pour les enfants < 1500g car ceux-ci constituent une population homogène.
8. Il existe une demande auprès des services N* de participer plus activement à l'objectif qualité du Collège.
9. Des données importantes sur toutes les naissances sont collectées par le SPE (Studiecentrum Perinatale Epidemiologie) en Flandres et le Cepip (Centre d'Epidémiologie Périnatale) en Communauté française.
10. L'enregistrement des données à des fins multiples demande un encodage répété des mêmes données. Ceci constitue une charge de travail importante et pourrait être optimalisée par un système intégrée d'exploitation de l'encodage des items.

Le Collège a déterminé ses objectifs et ses actions pour les 3 années à venir (2009-2012) :

1. Comprendre la **discordance** entre les centres**.**
Trois indicateurs de qualité parmi les 40 items du Nicaudit montrent une discordance importante:

A. Les infections.
B. Les complications neurologiques.
C. La bronchodysplasie ou maladie pulmonaire chronique.

Cette variabilité de morbidité pouvant être multipliée par un facteur 10 est illustrée dans les 3 graphiques ci-dessous. Afin de vérifier si ces variations étaient dues à la compréhension des définitions où réellement à une discordance entre centres le collège a mis en place 3 groupes de travail. Ceux-ci ont proposé de nouvelles définitions (annexes 1-3). Tous les chefs de service ont été informés de l'adaptation des items. L'application web de l'enregistrement a été adaptée conformément aux nouvelles définitions.

2. Intégrer l'enregistrement **Nicaudit** avec l'enregistrement européen **Euroneonet.**
Les items de Euroneonet ont été intégré dans une nouvelle application web qui comprend à la fois le Nicaudit « new definitions » et les items de Euroneonet. Les items identiques sont automatiquement inclus dans les 2 banques de données sans devoir effectuer un double encodage.
Le lien opérationnel avec Euroneonet est prévu au courant 2010.

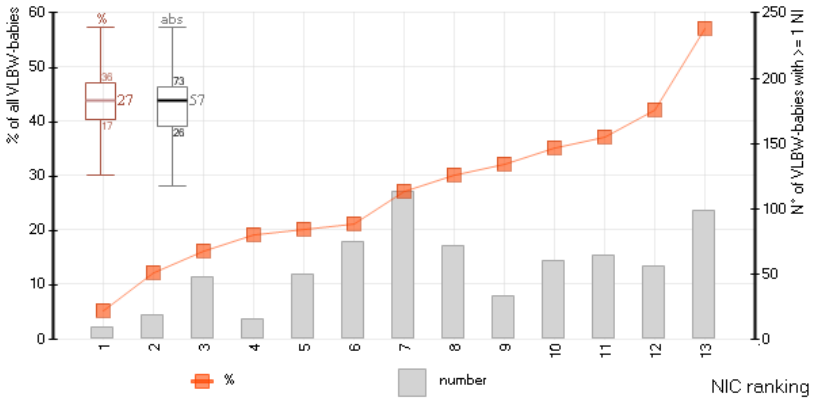
3. Faire une évaluation plus détaillée **des infections nosocomiales.** Les pratiques de maintenance de cathéters centraux et périphériques ainsi que les protocols d'antibiothérapie seront analysés en collaboration avec le **GBN-BVN.**

4. Evaluer la collaboration avec la **plateforme e Health** afin d'optimaliser l'enregistrement de la population des prématurés. Une proposition de collaboration est décrite dans l'annexe 4**.**

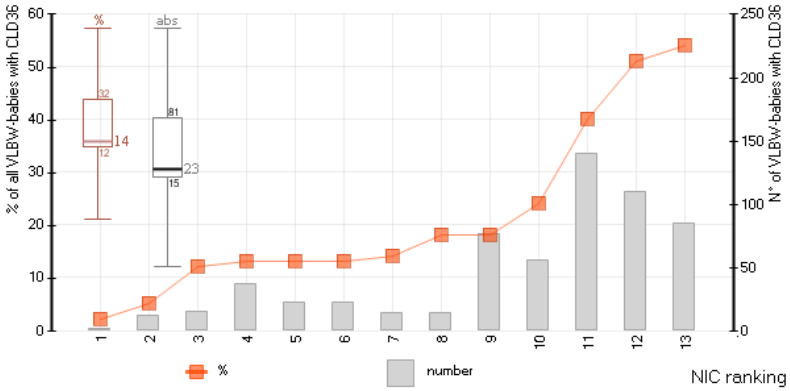
5. Inclure dans l'enregistrement des items de **follow-up**. Un calendrier de suivi a déjà obtenu l'adhésion de l'entièreté des représentants des pédiatres. Le Collège souhaite inclure dans la base de données des marqueurs de morbidité à plus long terme. Le type et le nombre d'items à enregistrer doivent être étudiés**.**

6. Evaluer la population des enfants séjournant en **N*.**

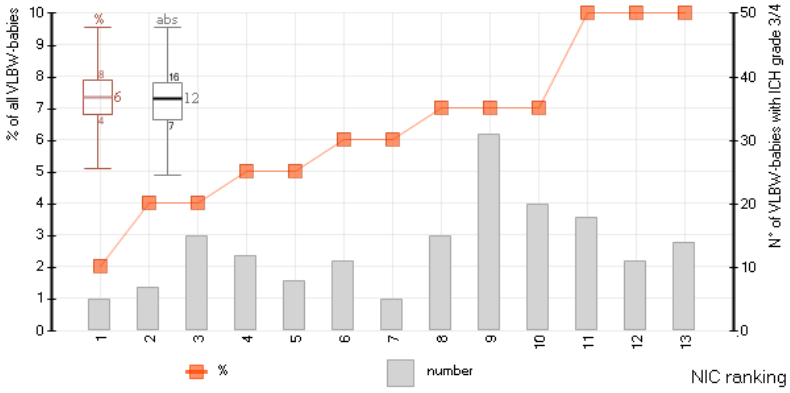
Peer review Nicaudit 2004-2007



A. Infections nosocomiales :
5 à 55% des enfants



B. Bronchodysplasie :
2 à 52 % des enfants



C. Hémorragie intracranienne :
2 à 10% des enfants

Early-onset infection ≤ 72 hours

Proven Early-Onset Bloodstream Infection (PEOBSI)

positive microbiology (blood and/ or CSF)

Clinical Early-Onset Infection (CEOI)

4/4 criteria have to be encountered:

-poor clinical presentation
(T°, apnea, hemodynamic instability or need of respiratory support)

-history of intrapartum AB, neonatalAB before microbiological test
(chorioamnionitis or pPROM, or any maternal infection)

-significant and sustained postnatal increase of CRP (>48h)

-postnatal AB's treatment for at least 7 days

Suspected Early-Onset Infection (SEOI)

all other clinical circumstances

or less than 4/4 criteria in the previous term

NIC AUDIT 40 INFECTION DEFINITIONS

- no early-onset infection at all
- ≤72 h proven early-onset bloodstream infection PEOBSI (please enter pathogen code).
- ≤72 h clinical early-onset infection (CEOI)
- ≤72 h suspected early-onset infection (SEOI)

Late-onset infection > 72 hours

Proven Late-Onset Bloodstream Infection (PLOBSI)

Bloodstream infection: +blood and/ or CSF for recognized pathogens Catheter Bloodstream Infection (CBSI): **+** hemoculture for CONS

(1+ peripheral blood culture if central line but 2+ blood cultures and 7 days AB's if peripheral catheter)

Clinical Late-Onset Infection (CLOI)

3/3 criteria have to be encountered:

-unexpected and unexplained clinical degradation
-significant and sustained increase of CRP (>48h)
-AB's treatment for at least 7 days

Suspected Late-Onset Infection (SLOI)

all other clinical circumstances or less than 3/3 criteria in the previous item

NIC AUDIT 40 INFECTION DEFINITIONS

- no late-onset infection at all
- >72 h proven late-onset bloodstream infection (PLOBSI)
- >72 h clinical late-onset infection (CLOI)
- >72 h suspected late-onset infection (SLOI)

The definitions used are mainly based on cranial ultrasound findings. It is suggested to perform cranial ultrasounds within the first week after birth and to repeat a control ultrasound around day 28. When MRI is performed, it can also be used for these items.

1. **Intracranial hemorrhage**
   (0) No cerebral hemorrhage
   (1) Intraventricular hemorrhage grade 1 : subependymal hemorrhage (germinal matrix hemorrhage)
   (2) Intraventricular hemorrhage grade 2 : intraventricular hemorrhage without dilatation
   (3) Intraventricular hemorrhage grade 3 : intraventricular hemorrhage with dilatation
   (4) Focal periventricular hemorrhagic infarction
   (5) Extensive periventricular hemorrhagic infarction
   (6) Sub- or epidural hemorrhage
   (7) Lobar cerebral hemorrhage
   (8) Thalamoventricular hemorrhage
   (9) Subarachnoidal hemorrhage
   (10) Cerebellar hemorrhage.

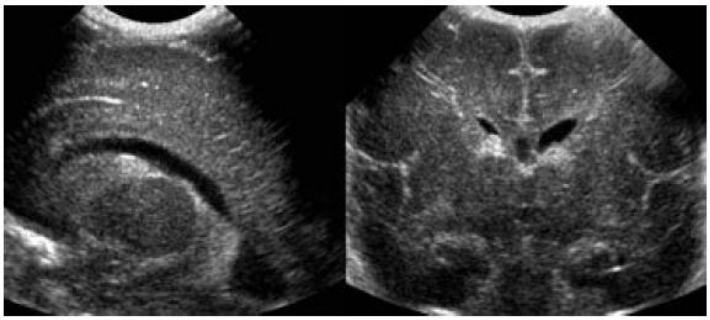
Lesions bilateral : Y/N

It is possible to give three different diagnoses in one patient. A periventricular hemorrhagic infarction should be assigned as first diagnosis with as a second item the grade of intraventricular hemorrhage.

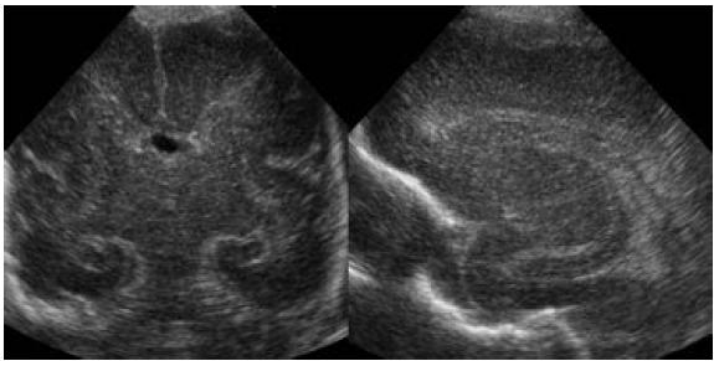
2. **Periventricular leucomalacia**
(0) No periventricular leucomalacia
(1) Periventricular echodense area (isolated flares) more than seven days
(2) Isolated ventriculomegaly
(3) Irregular echodensities, no ventriculomegaly
(4) Grade II : transient periventricular echodense areas evolving into frontoparietal cysts
(5) Grade III : Periventricular echodense areas evolving into multiple cysts in the frontoparietal and/or occipital white matter.
(6) Grade IV : Echodense areas in the deep white matter with evolution into multiple subcortical cysts.

Lesions bilateral Y/N

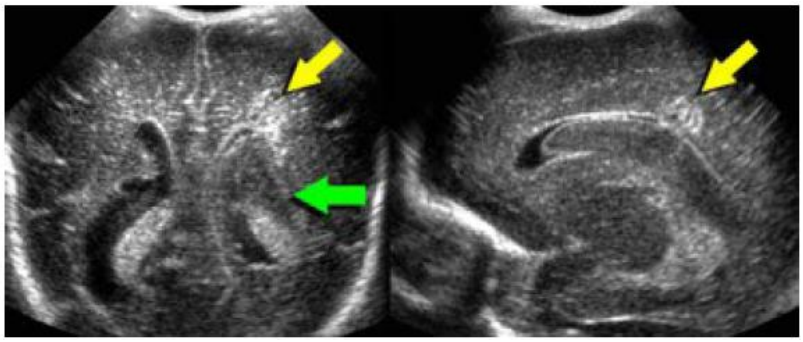
INTRAVENTRICULAR HAEMORRHAGE



IVH grade 1 : an intraventricular hemorrhage confined to the caudothalamic groove.

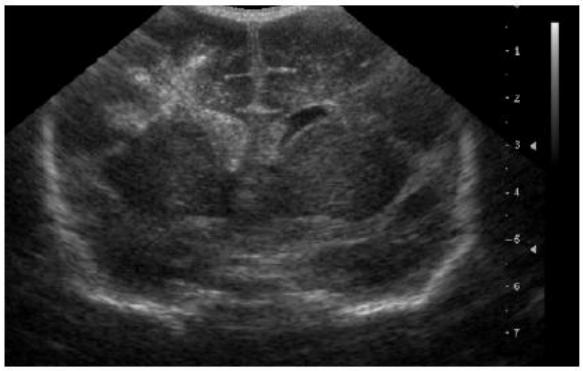


IVH grade 2: both lateral ventricles are filled with blood, but there is no ventricular dilatation.



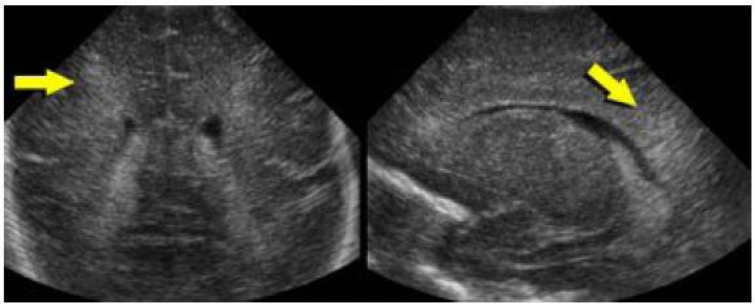
IVH grade 3 : both lateral ventricles are filled with blood. There is also a ventricular dilatation.

Local periventricular hemorrhagic infarction : note the wedge shaped hyperechoic area on the laterosuperior side of the ventricle. This represents a small venous infarction.

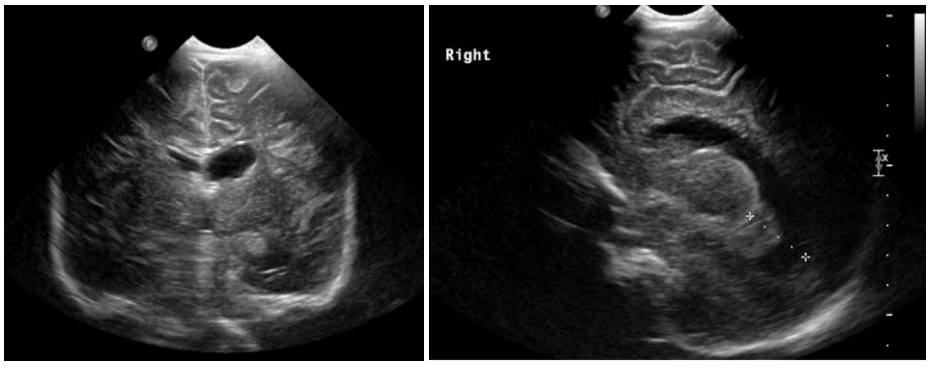


Extensive periventricular hemmorhagic infarction.

PERIVENTRICULAR LEUCOMALACIA

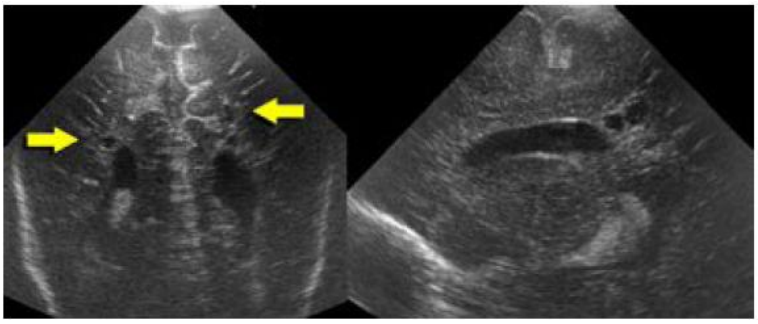


Areas of increased periventricular echogenicity without any cyst formation persisting for more than 7 days.

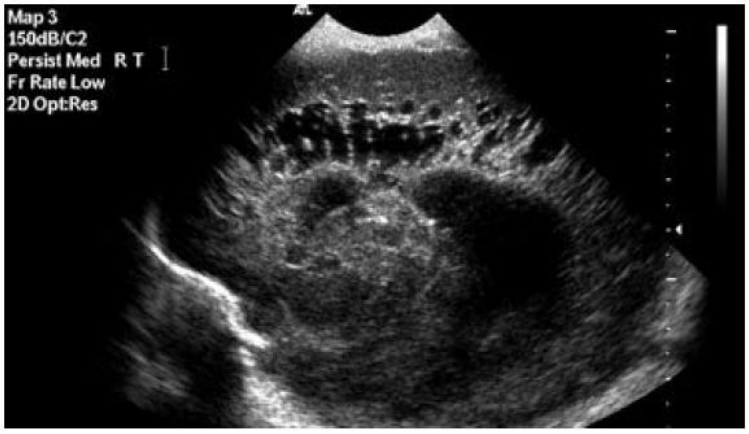


Isolated unilateral ventriculomegaly

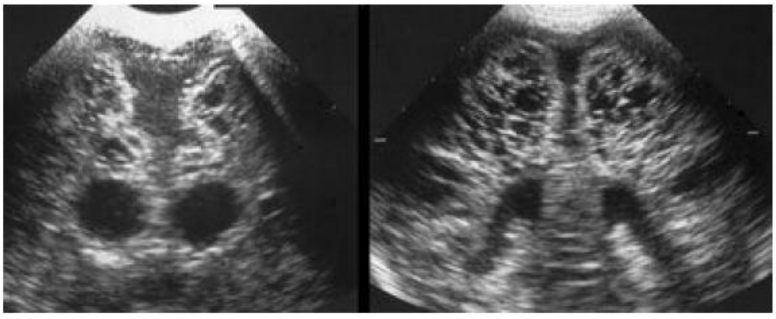
(right side)



PVL grade 2 with small periventricular cysts.



PVL grade 3 with extensive periventricular cysts in the occipital and frontoparietal region.



PVL grade 4 with extensive subcortical cysts.

BPD : PROPOSAL FOR MODIFICATION NIC-AUDIT

The existing item in the NIC-audit database “chronic lung disease at 36 wks PCA” should be adapted as given below (see 1). One additional item: “Oxygen reduction test” should be added (see 2), and another new item should be automatically calculated (see 3) based on the information deducted from those two items and from the already existing item in the database: “last day of continuous oxygen therapy”. Information on *effective* FiO_2 and on how to perform the oxygen reduction test will be provided in the database.

1. Respiratory assessment at 36 w (± 3d)

BPD classification (see 3)

- Not applicable (died <36 w) (discharged <36w) → Not applicable
- On room air (= without any respiratory support) → No BPD (if on room air at 28 d); BPD grade 1 (if on oxygen at 28 d)
- On nasal flow or discontinuous CPAP with *effective* FiO_2 <30% (oxygen reduction test should be performed) → No BPD (if on room air at 28d and if test “Passed”); BPD grade 1 (if test: “Passed”); BPD grade 2 (if test: “Failed”)
- On nasal flow or discontinuous CPAP with *effective* FiO_2 ≥30% → BPD grade 3
- On continuous CPAP or ventilated with FiO_2 <30% → BPD grade 2
- On continuous CPAP or ventilated with FiO_2 ≥30% → BPD grade 3

2. Oxygen reduction test at 36 w (± 3d)

The test should be performed in infants with following criteria:
- <32 w GA or <1500 g BW
- and who were on FiO_2 >21% at 28 d
- and who are on *effective*[5] FiO_2 ≤30 % at 36 w because of chronic pulmonary disease with ventilatory support (oxygen hood, nasal flow cannula, discontinuous CPAP) to obtain saturations of 90- 96%.

The test should not be performed and infants immediately graded as BPD grade 3 (severe BPD) if:

- intubated and ventilated at 36 w with supplemental oxygen (irrespective of the amount of FiO_2 >21%)
- infants on nasal flow with *effective* FiO_2 >30%
- infants on continuous CPAP with FiO_2 >30%

- Not applicable (died <36 w) (discharged <36w) → Not applicable
- Not indicated (*effective* FiO_2 > 30%) (continuous CPAP with FiO_2 >30%) (ventilated) → BPD grade 3
- Passed (= negative oxygen reduction test) → No BPD (if on room air at 28 d); BPD grade 1 (if on oxygen at 28d)
- Failed (= positive oxygen reduction test) → BPD grade 2

3. Grading of BPD[1,2]

(will be automatically generated, according to blue text above)

1. No BPD	no ventilatory support nor oxygen at 28 d and at 36 w
2. BPD grade 1 (mild)	on FiO_2 >21% at 28 d, and off ventilatory support and oxygen at 36 w (or having passed oxygen reduction test at 36 w)
3. BPD grade 2 (moderate)	on FiO_2 >21% at 28 d, and on FiO_2 22-30 % and having failed oxygen reduction test at 36 w
4. BPD grade 3 (severe)	on FiO_2 >21% at 28 d, and on FiO_2 > 30 % at 36 w and having failed oxygen reduction test at 36 w
5. Not applicable	died <36 w, or discharged <36w

Effective inspired oxygen [3]

Effective FiO_2 should be used as criterium to start oxygen reduction test for infants on nasal flow cannula. It can be read in Tables 1 and 2, based on flow (L/min), actual weight of the infant and applied FiO_2. The weight of a neonate and the flow through the cannula yields a factor in Table 1. By combining this factor with the FiO_2 in Table 2, the effective FiO_2 can be read. These effective FiO_2 values were calculated with the equations described by Benaron and Benitz[4] and adapted by STOP-ROP study investigators[5]. They assumed following constant variables: an inspiration time of 0,3 seconds, a constant nasal flow during inspiration, and the upper airway does not serve as a reservoir.

Procedure of oxygen reduction test[6,7]

Eligible infants will be tested in supine position with a pulse oximeter placed on a limb in their usual baseline oxygen 30 minutes after feeding. The test will be performed in 4 stages: baseline, reduction phase, room air observation, and return to usual oxygen.

1. Baseline (5 minutes)

   Record values for heart rate, respiratory rate, oxygen saturation, and frequency of apnea (cessation of breathing for 20 seconds) and bradycardia (heart rate < 80 beats/minute for ≥ 10 seconds) every 60 seconds for a 5-minute period. All occurrences of movement artifact (defined as visible motion of the infant together with loss of plethysmograph signal from the monitor) will be recorded and the corresponding saturation value will be deleted. If all baseline saturation values are 90-96 % with $FiO_2 \leq 0.30$, proceed to oxygen reduction. If saturations are > 96 %, reduce/adjust FiO_2 and redefine effective FiO_2.

2. Oxygen reduction phase (15 – 30 minutes)

   The infant should be under direct observation for the entire period of the oxygen reduction test and room air observation with continuous monitoring of the oxygen saturation.

   - oxygen by hood: reduce FiO_2 by steps of 2% every 5 minutes to room air.

   - oxygen by nasal cannula: maintain flow and reduce oxygen concentration by 2% by blender until 21%. Then reduce flow in 0.5 L/min increments for flow of 1.0-2.0 L/min, and in 0.1 L/min increments for flow of 0.1- 1 L/min to zero. Remove nasal cannula from the nares but leave affixed to the face, so the infant is not disturbed.

3. Room air phase (15 - 30 minutes).

4. Return infant to baseline oxygen support after the completion of the test or immediately at any point when the test “Fails” or when infant experiences several episodes of bradycardia or apnea.

Result of oxygen reduction test

"Pass": if infant tolerates room air for 30 minutes with saturations 90-96% or
if all saturations > 96% during 15 minutes (rapid pass)

→ infant has **no BPD**

"Fail": saturations < 90% during 5 minutes or
saturations < 80% during 15 seconds (rapid fail)

→ infant has **moderate BPD**

References

1. Jobe A, Bancalari E. Bronchopulmonary dysplasia. Am J Respir Crit Care Med 2001;163:1723-9.

2. Kinsella JP, Greenough A, Abman SH. Bronchopulmonary dysplasia. Lancet 2006; 367:1421-31.

3. Walsh M, et al. Oxygen delivery through nasal cannulae to preterm infants: can practice be improved? Pediatrics 2005;116:857-61.

4. Benaron DA, Benitz WE. Maximizing the stability of oxygen delivered via nasal cannula. Arch Pediatr Adolesc Med 1994; 148(3):294-300.

5. Supplemental Therapeutic Oxygen for Prethreshold Retinopathy of Prematurity (STOP-ROP), A Randomized, Controlled Trial. I: Primary Outcomes. Pediatrics 2000; 105:295-310.

6. Walsh MC, et al. NICHHD Neonatal Research Network. Impact of a physiologic definition on bronchopulmonary dysplasia rates. Pediatrics 2004;114:1305-11.

7. Ehrenkranz RA et al. Validation of the National Institutes of Health consensus definition of bronchopulmonary dysplasia. Pediatrics 2005;116:1353-60.

TABLE 1. Calculation of Effective FIO_2, Step 1

Flow, L/min	Factor With Weight of								
	0.7 kg	1.0 kg	1.25 kg	1.5 kg	2 kg	2.5 kg	3 kg	3.5 kg	4 kg
0.01	1	1	1	1	1	0	0	0	0
0.03 (1/32)	4	3	2	2	2	1	1	1	1
0.06 (1/16)	9	6	5	4	3	2	2	2	2
0.125 (1/8)	18	12	10	8	6	4	4	4	4
0.15	21	15	12	10	8	6	5	4	4
0.25 (1/4)	36	25	20	17	13	10	8	7	6
0.5 (1/2)	71	50	40	33	25	20	17	14	13
0.75 (3/4)	100	75	60	50	38	30	25	21	19
1.0 (1.0)	100	100	80	67	50	40	33	29	25
1.25	100	100	100	83	63	50	42	36	31
1.5	100	100	100	100	75	60	50	43	38
2.0	100	100	100	100	100	80	67	57	50
3.0	100	100	100	100	100	100	100	86	75

Adapted from equations 3 and 4 in ref 1. The rule of thumb (implicit in the table) is that, for most infants in the STOP-ROP study, if flow (in liters per minute) exceeds body weight (in kilograms), then the effective FIO_2 equals the nasal cannula oxygen concentration.

TABLE 2. Calculation of Effective FIO_2, Step 2

Factor	Effective FIO_2 With Oxygen Concentration of						
	0.21	0.22	0.25	0.30	0.40	0.50	1.00
0	0.21	0.21	0.21	0.21	0.21	0.21	0.21
1	0.21	0.21	0.21	0.21	0.21	0.21	0.22
2	0.21	0.21	0.21	0.21	0.21	0.22	0.23
3	0.21	0.21	0.21	0.21	0.22	0.22	0.23
4	0.21	0.21	0.21	0.21	0.22	0.22	0.24
5	0.21	0.21	0.21	0.21	0.22	0.22	0.25
6	0.21	0.21	0.21	0.22	0.22	0.23	0.26
7	0.21	0.21	0.21	0.22	0.22	0.23	0.27
8	0.21	0.21	0.21	0.22	0.23	0.23	0.27
9	0.21	0.21	0.21	0.22	0.23	0.24	0.28
10	0.21	0.21	0.21	0.22	0.23	0.24	0.29
11	0.21	0.21	0.21	0.22	0.23	0.24	0.30
12	0.21	0.21	0.21	0.22	0.23	0.24	0.30
13	0.21	0.21	0.22	0.22	0.23	0.25	0.31
14	0.21	0.21	0.22	0.22	0.24	0.25	0.32
15	0.21	0.21	0.22	0.22	0.23	0.25	0.33
17	0.21	0.21	0.22	0.23	0.24	0.26	0.34
18	0.21	0.21	0.22	0.23	0.24	0.26	0.35
19	0.21	0.21	0.22	0.23	0.25	0.27	0.36
20	0.21	0.21	0.22	0.23	0.25	0.27	0.37
21	0.21	0.21	0.22	0.23	0.25	0.27	0.38
22	0.21	0.21	0.22	0.23	0.25	0.27	0.36
23	0.21	0.21	0.22	0.23	0.25	0.28	0.39
25	0.21	0.21	0.22	0.23	0.25	0.28	0.41
27	0.21	0.21	0.22	0.23	0.25	0.29	0.42
28	0.21	0.21	0.22	0.24	0.26	0.29	0.43
29	0.21	0.21	0.22	0.24	0.27	0.29	0.44
30	0.21	0.21	0.22	0.24	0.27	0.30	0.45
31	0.21	0.21	0.22	0.24	0.27	0.31	0.47
33	0.21	0.21	0.22	0.24	0.27	0.31	0.47
36	0.21	0.21	0.22	0.24	0.28	0.31	0.49
38	0.21	0.21	0.23	0.24	0.28	0.32	0.51
40	0.21	0.21	0.23	0.25	0.29	0.33	0.53
42	0.21	0.21	0.23	0.25	0.29	0.33	0.54
43	0.21	0.21	0.23	0.25	0.29	0.33	0.55
44	0.21	0.21	0.23	0.25	0.29	0.34	0.56
50	0.21	0.21	0.23	0.25	0.30	0.35	0.60
55	0.21	0.22	0.23	0.26	0.31	0.37	0.64
57	0.21	0.22	0.23	0.26	0.32	0.38	0.66
60	0.21	0.22	0.23	0.26	0.32	0.38	0.68
63	0.21	0.22	0.24	0.27	0.33	0.39	0.71
67	0.21	0.22	0.24	0.27	0.34	0.40	0.74
71	0.21	0.22	0.24	0.27	0.34	0.42	0.77
75	0.21	0.22	0.24	0.28	0.35	0.43	0.80
80	0.21	0.22	0.24	0.28	0.36	0.44	0.84
83	0.21	0.22	0.24	0.28	0.37	0.45	0.87
86	0.21	0.22	0.24	0.29	0.37	0.46	0.89
100	0.21	0.22	0.25	0.30	0.40	0.50	1.00

Reference: Walsh M, Engle W, Laptook A, Kazzi SN, Buchter S, Rasmussen M, Yao Q; National Institute of Child Health and Human Development Neonatal Research Network. Oxygen delivery through nasal cannulae to preterm infants: can practice be improved? Pediatrics 2005; 116:857-61.

Collaboration project

College Mother and Newborn (neonatal section) and e-Health

Participants

College

President: Dr. D. Haumont.
Members: Drs L Cornette, JP Langhendries, C Lecart, K Mathé, J Rigo, H Van Hauthem, P Van Reempts.
Expert: president of the Belgian Society of Neonatology: Dr. B Van Overmeire.

Administration

Drs A Clercx and A Perissino
W Aelvoet

e Health

L Nicolas and F Cammaerts

Abbreviations

NIC: Neonatal Intensive Care
VLBW: Very Low Birth Weight
BSN: Belgian Society of Neonatology
SPE: Studiecentrum Perinatale Epidemiologie
Cepip: Centre d'épidémiologie périnatale

Introduction

The collaboration project proposed is initiated by the neonatal section of the College for Mother and Newborn. The major historical achievement of the Neonatal College is the construction of the NICaudit database, which is a national electronic database with specific interest towards the very low birth weight (VLBW) infants admitted in Neonatal Intensive Care (NIC) units.

Important changes in health care management occurred during the last decades because of the dramatic increasing utilisation of electronic technology. The federal government initiated new electronic platforms aiming a more efficient registration of health care parameters.

The newborn period is the most at risk period in paediatric medicine. Bringing together the new possibilities of a federal e-Health database and the medical motivation to improve neonatal care is the driving trend of this project.

Background clinical aspects

The organisation of neonatal care in Belgium is ruled by a 2 level system:

Level 1: Maternity with a N* function.

Each maternity has to be equipped to care for a sick newborn. If the baby needs specialised staff and equipment which are not available in the local setting he will be transferred to a NIC department. The local team is responsible for the administration of intensive care on a short term basis, until arrival of the NIC transport team. It is recommended that every high risk delivery with potential need for neonatal intensive care is referred antenatally towards a perinatal center including a NIC department.

Level 2: Maternity with a NIC department.

The NIC department is equipped to care for babies with compromised vital functions. The clinical activity for agreement of NIC beds is determined by law in a Royal Decree modified 7 april 2008 (enclosed). Due to historical background some of the NIC departments don't meet the agreement criteria.

In Belgium there are ±120.000 births per year among wich ± 35.000 occur in one of the 19 NIC maternities. The remaining 85.000 are born in 106 hospitals linked to 84 N* . Each hospital with maternity beds does not have a N* function on site. Due to hospital fusions several maternity sites can be linked to one N* function.
The major reason for admission of a neonate in N* or NIC is prematurity (± 2/3 of the patients).

College Mother-Newborn

The Colleges were established by a Royal Decree (15 February 1999).
The tasks of the Colleges are:

-To target quality indicators of care
-To register relevant items
-To give feedback aiming enhanced medical practice

Neonatologists were first involved in a NIC College (2000-2004) and from 2004 in the College of Physicians for "Mother and Newborn".
From start the neonatologists decided to register a selected number of quality-of-care items. A studygroup, members of the College and experts of the Belgian Society of Neonatology (BSN) selected 40 relevant items. Most of them are linked to complications of prematurity. The data base and the different software programs called NICaudit were build under the leadership of the former president of the College Professor Piet Vanhaesebrouck with the technological support of Orbid, a private IT company.

Since april 2005 a website (www.colnic.be) hosts the online feedback. With a private login and password each unit can acces their own data, globalized anonymous data, benchmark profiles, trend and survival analysis.
The Synoptic report was published in may 2008 (enclosure).
The Mother and Newborn College includes 2 sections: neonatology (NIC and N*) and obstetrics. The 2 sections work in parallel sessions but with regular joint meetings. Recently the College of Paediatrics has been created and it is likely that common matters will be discussed in collaboration.

Current situation of registration: feedback from the clinicians

In October 2008 part of the members of the College and the president were replaced by rule. The new college invited the Belgian Society of Neonatology (BSN) and all the responsible physicians of the NIC departments to discuss the registration process.
Following observations and comments were made:

1. Peer review of data concerning VLBW infants is meaningful.
2. The peer review demonstrated a substantial heterogeneity among the Belgian NIC departments in neonatal morbidity and mortality.
3. Compliance of NIC units collaboration is suboptimal. Feedback through the colnic website is perceived by some units as too extensive and complicated.
4. A substantial number of patients are transferred to a N* department. For those infants discharge data are lacking.
5. A European peer review exists: Euroneonet. The items collected are close to the NICaudit items but not exportable as such to the Euroneonet database.
6. The final aim of neonatal care is to improve outcome. Therefore it is of major importance to register follow-up items linked with neonatal data. Particular attention has to be paid to guarantee anonymous registration and protection of private life. A Royal Decree (7 april 2008) imposes the responsibility of the organisation of the follow-up to the NIC departments.
7. The mortality and the decision making processes concerning the patients born at the limits of viability can not be evaluated in the current NICcaudit system because data from the delivery room are lacking.
8. Peer review of all (not only VLBW infants) NIC patients is not relevant due to the absence of entry criteria for a NIC patient and because selected items are mainly related to complications of prematurity.
9. The paediatricians working in N* departments would like to be more involved in the quality evaluation process.
10. The registration of relevant items concerning all births are collected by the **SPE** (Studiecentrum Perinatale Epidemiologie) in Flanders. In the Brussels area epidemiological items are collected by l' Observatoire de la Santé. In Wallonia the registration has recently moved towards a similar model compared to SPE. The data are collected and analysed by the **Cepip** (Centre d'Epidémiologie Périnatale).
11. Hospital Directions are committed to send annual perinatal statistics to the authorities. This substantial workload for the physicians could be reduced by a more user friendly database including the officially required items.

Actions College Newborn and BSN 2008-2009

1. In order to verify if the heterogeneity among NICs was due to a different interpretation of item definitions, study groups were set up by the college. Three major topics with potential long term impact on the infant's health were chosen: neurological abnormalities on cranial ultrasound, chronic lung disease and infection.
   Substantial differences were found in the interpretation of the definitions. The study groups made clear proposals to modify those 3 items.
2. The BSN has conducted a large working group including multidisciplinary collaborators taking care of the follow-up. This working group obtained a national consensus on the minimal requirements on the follow-up calendar and on the composition of the multidisciplinary team for the of the at risk infants. The Belgian Academy of Paediatrics validated the protocol and gave mandate to the Newborn College to monitor the collection of the data: **e-Follow-up** (enclosure).
3. The College defined in collaboration with the Federal Health Government administration the objectives of the actual College. It was clearly stated that registration is important if a specific quality improvement action can be elaborated. The quality of the input is the most important step and should therefore not be too extensive. Financial aspects have to be carefully assessed when electronic applications are elaborated and will be monitored on a long term basis. Minimal registration could be linked to agreement of NIC beds or follow-up teams..
4. The College discussed the possibilities to participate in the national registration platform eHealth-fgov .
5. The private company who elaborated the NICaudit website and applications is Orbid. The minor changes which were asked in the definitions appear to have a substantial cost.

Future perspectives of registration- collaboration with e-Health

What is the demand of the individual clinician, the college, the BSN and the health authorities?

INPUT
The actual registration systems require most of the time repetitive input of items in the different databases. There is an important demand coming from the caregivers to simplify the registration systems. Ideally each item which is needed for several databases should be introduced once and redistributed to the different databases.
There is an ongoing debate around the declaration of newborn infants at the limit of viability. Belgian law and medical practice are not compatible.
There is an international agreement to declare every birth of a baby with a birthweight equal or above 500g and a gestational age equal or above 22 weeks.
A minimal set of follow-up items of the VLBW infants to be registered in the database has to be identified.

OUTPUT

At present the NICaudit database is a major tool to assess quality of care in VLBW infants who are at risk for developmental problems and other health outcomes. They represent 1-1.5% of all life births.

The aim of the Newborn College and the BSN is to continue to register relevant items of these babies in the neonatal period and during follow-up. Epidemiological data on this vulnerable population has to be carefully assessed. The NICaudit definitions will be adapted according the conclusions of the study groups (**e-NICaudit**). An important improvement would be to integrate the Euroneonet registration with a feedback from other European countries. The financial aspects have still to be discussed according the annual support given to the College

Besides the NICaudit items there is a need to collect more information about the mother and the pregnancy. These data are registered in the different birth registration systems: birth certificate, SPE, Cepip..

The follow-up items which will be included in the registered database will be defined in agreement with the consensus calendar (**e-Follow-up**). The College will discuss the elaboration of an informed consent document to the parents. This document is particularly important concerning the anonymous aspect of individual data. Registration on the e Health platform gives all the guaranties in terms of confidentiality and protection of private life.

Besides the data concerning the VLBW infants admitted in the NICs , we need information concerning the total newborn population. The data and the output collected by SPE and in the future by Cepip are already a substantial support to analyse the evolution of perinatal care. The construction of the **e-Birth** platform as part of the e-Health project is possibly a response to the need of a global view on neonatal care.

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Three examples of the potential improvements with an integrated e-Birth; SPE; Cepip; e-NICaudit and e-Follow-up database

1. One of the most difficult matters in perinatal care is the prognosis of the infants at the limit of viability. Our current registration system does not allow to predict survival. The NICaudit database includes only the patients who are admitted in the NIC. If the baby is dying in the delivery room he will not be included. Bringing together the information collected by SPE-Cepip and NICaudit will allow an accurate risk calculation for mortality and morbidity at those very low gestational ages.
2. Recently the medium preterm population gained more and more attention and could possibly be more vulnerable than initially taught. Registration could be a major tool to follow these infants
3. The evolution of the medical studies with the numerus clauses and the trend towards part time practice has an impact on the organisation of care, especially in perinatal medicine where permanent trained staff has to be available. Registration of activity could help to define needs and verify the possibilities of adequate medical staffing.

Methodology: To be defined…..

Enclosures:

NICaudit synoptic report. P. Vanhaesebrouck et al:
https://portal.health.fgov.be/pls/portal/docs/PAGE/INTERNET_PG/HOMEPAGE_MENU/GEZONDHEIDZORG1_MENU/OVERLEGSTRUCTUREN1_MENU/COLLEGESVANGENEESHEREN1_MENU/NEONATHOLOGIE1_MENU/PUBLICATIES169_HIDE/PUBLICATIES169_DOCS/ACTIVITYCOLLEGENIC2000-2007_0.PDF
Royal Decree 7 April 2008
Consensus document: follow-up preterm infants. B. Van Overmeire et al.
Approval Belgian Academy of Paediatrics, P Alliet

Consensus rapport of Working group Follow-up of preterm infants in Belgium (dd 22-4-09)

Members of working group: Cornette Luc, Debauche Christian, Dewulf Laurence, François Anne, Goossens Luc, Hasaerts Danielle, Haumont Dominique, Laroche Sabrina, Lecart Chantal, Oostra Ann, Ortibus Els, Rigo Jacques, Van Overmeire Bart.

1. Content of follow-up program

Agreement has been reached about a follow-up protocol for all infants with birthweight < 1500 g and/or gestational age < 32 weeks. The proposal on pages 2-7 represents the time schedule and items (questionnaire & examinations) that minimally have to be completed at each prescheduled visit. Financing will be coupled with the registration of a limited number of follow-up items (5-10) linked to the Nicaudit database under supervision of the Nic College. Written informed consent of the parents is required. The college will make a proposal for the items as well as for the consent document.

2. Organization

There was consensus in the working group that the follow-up consultations at the key time points should be performed by a multidisciplinary team, composed of at least a neuro-pediatrician, a physical therapist, psychologist and or pedagogue with secretary support. A minimal activity for the team of 50 new infants/year at the 3-4 month visit is required, in order to allow efficiency and quality. Each of the 19 NICs has to contract one multidisciplinary follow-up team (e.g. at own institution, external, or COS center). Financing should be based on each infant visit, with reimbursement of travel costs for the parents, and an additional 15% overhead costs.

3. Timecourse per visit

	Discharge from NIC-N*	3-4 m	12 m (10-13)	22 m (21-24)	5 y (4,5-5,5)	8 y (7-9)
Pediatrician	60’	60’	60’	60’	60’	60’
Physical therapist	-	60’	60’	60’	1h30’	-
Speech therapist	-	-	-	-	1h15’	-
Psychologist/pedagogue	-	60’	60’	60’	120’(*1)	60’
Social worker	30’	30’	30’	30’	30’	-
Secretary	30’	45’	45’	45’	120’	30’
Team discussion & parent communication	-	60’	60’	60’	90’	60’
Total	2 h	5 h 15’	5 h 15’	5 h 45’	9 h 55’	3 h 30’

*(*2 including WIPPSI)*

PROPOSAL NATIONAL FOLLOW-UP PROTOCOL (<1500G AND/OR <32 W)

At discharge (from NIC or N*)

ANAMNESE

- Family languages and most spoken language at home ?
- Family structure ? (e.g.: mother-father living together, divorced parents with alternating custody, single parent, recomposed family, …)
- Psychosocial support provided during stay at the NIC ? (No / Yes)
- Synagis® (Not eligible / Eligible, not yet administered / Eligible and 1st dose administered)
- Written informed parental consent for registration of follow-up items in the national Nicaudit database under supervision of the College of physicians.

CLINICAL EXAMINATION

- Weight, length, head circumference (plot on standard curve, and Z-scores)
- Neurologic assessment (Normal / Suspect / Abnormal: …)

- Audiologic assessment performed? (Yes / No) (if yes: result ? & type of test ?)
- Ophtalmologic examination performed ? (Yes / No) (if yes: result ?)
- Cerebral assessment by ultrasound or MRI (Normal / IVH / PVL / other: …., cfr NicAudit)

PLAN

1. Follow-up assessment visit 3-4 months (corrected, postterm age) by multidisciplinary follow-up team or COS
2. Additional referral to :
   - Primary paediatrician
   - Pediatric neurologist
   - Ophthalmologist
   - Otorhinolaryngology referral center
   - Other support (paramedical, home intervention)
   - Pediatric ward / intensive care (prolongation of hospitalization)
   - Center for infants with chronic illness

3-4 month (corrected postterm age)

ANAMNESE

- Family languages and most spoken language at home
- Family structure (e.g.: mother-father, single parent, …)
- Was any psychosocial support provided during stay at the NIC ? (No / Yes)
- "onthaalmoeder" / "kribbe" – "crèche" - day care center / kindergarten - kleuterschool / basic school

- Synagis® (Not eligible / Eligible, not administered / Eligible and administered)
- Audiologic assessment performed? (Yes / No) (if yes: result ? & type of test ?)
- Ophtalmologic examination performed ? (Yes / No) (if yes: result ?)
- Chronic disease for which a therapeutical intervention or a re-hospitalization was needed since discharge ? (No / Yes) (if yes: specify)
- Feeding difficulties ? (No / Yes) (if yes: specify)
- Sleep disturbances ? (No / Yes) (if yes: specify)
- Ongoing support since discharge ? (No / Yes) (if yes: specify)

CLINICAL EXAMINATION

- Weight, length, headcircumference (plot on standard curve)

- Neurological assessment:
  Test that has been used (check applicable)
  - standard neurological examination
  - specialized neurological examination (Amiel Tison, Bayley 2, Bayley 3,…)
  - additional investigations / tests : specify: …
  Test result: - normal
  - suspect
  - abnormal

- Mental / psychomotoric assessment
- Audiologic assessment
- Visual assessment

PLAN

1. No specific action required , next follow-up assessment scheduled at 12 months (10-13) (corrected, postterm age)

2. Referral to :
   - Multidisciplinary follow-up team or COS
   - Pediatric neurologist
   - Ophthalmologist
   - Otorhinolaryngology referral center
   - Primary paediatrician
   - Tertiary care center - hospitalization
   - Other support (paramedical, home intervention)

12 month (10-13) (corrected, postterm age)

ANAMNESE

- Family languages and most spoken language at home
- Family structure (e.g.: mother-father, single parent, …)
- Synagis® vaccination completed ? (Ineligible / Yes / No)
- "onthaalmoeder" / "kribbe" – "crèche" - day care center / kindergarten - kleuterschool / basic school
- Audiologic assessment performed ? (Yes / No) (if yes: result ? & type of test ?)
- Ophtalmologic examination performed ? (Yes / No) (if yes: result ?)
- Chronic disease for which a therapeutical intervention or a re-hospitalization was needed since previous follow-up assessment ? (No / Yes) (if yes: specify)
- Feeding difficulties ? (No / Yes) (if yes: specify)
- Sleep disturbances ? (No / Yes) (if yes: specify)
- Ongoing support ? (No / Yes) (if yes: specify)

CLINICAL EXAMINATION

- Weight, length, head circumference (plot on standard curve)
- Neurological assessment (and IMOC (infirmité motrice d'origine cérébrale) or CP classification)
- Mental assessment
- Audiologic assessment
- Visual assessment

PLAN

1. No specific action required , next follow-up assessment scheduled at 22 month (22-24) (corrected, postterm age)
2. Referral to :
   - Multidisciplinary follow-up team or COS
   - Pediatric neurologist
   - Ophthalmologist
   - Otorhinolaryngology referral center
   - Primary paediatrician
   - Tertiary care center - hospitalization
   - Other support (paramedical, home intervention)

22 month (21-24) (corrected, postterm age)

ANAMNESE

- Family languages and most spoken language at home
- Family structure (e.g.: mother-father, single parent, …)
- "onthaalmoeder" / "kribbe" – "crèche" - day care center / kindergarten - kleuterschool / basic school
- Chronic disease for which a therapeutical intervention or a re-hospitalization was needed since previous follow-up assessment ? (No / Yes) (if yes: specify)
- Feeding difficulties ? (No / Yes) (if yes: specify)
- Sleep disturbances ? (No / Yes) (if yes: specify)
- Ongoing support ? (No / Yes) (if yes: specify)
- Behavioural assessment ? (Normal / Suspect / Abnormal)

CLINICAL EXAMINATION

- Weight, length, head circumference (plot on standard curve)
- Neurological assessment:

- Mental assessment
- Auditory assessment
- Visual assessment

PLAN

1. No specific action required, next follow-up assessment planned at 5 year (4,5-5,5)
2. Referral to :
   - Multidisciplinary follow-up team or COS
   - Ambulatory rehabilitation
   - Pediatric neurologist
   - Ophthalmologist
   - Otorhinolaryngology referral center
   - Primary paediatrician
   - Tertiary care center - hospitalization
   - Other support (paramedical, home intervention)

5 year (4,5-5,5) (before first grade)

ANAMNESE

- Family languages and most spoken language at home
- Family structure (e.g.: mother-father, single parent, …)
- "onthaalmoeder" / " day care center / kindergarten - kleuterschool
- Chronic disease for which a therapeutical intervention or a re-hospitalization was needed since previous follow-up assessment ? (No / Yes) (if yes: specify)
- Feeding difficulties ? (No / Yes) (if yes: specify)
- Sleep disturbances ? (No / Yes) (if yes: specify)
- Ongoing support ? (No / Yes) (if yes: specify)
- Behavioural checklist ? (with conclusion into: Normal / Suspect / Abnormal)

CLINICAL EXAMINATION

- Weight, length, head circumference (plot on standard curve)
- Physical exam
- Neurological and neuromotor assessment:

- Mental assessment
- Auditory and visual assessment (to perform or to collect data from PMS-CLB)
- Language, intelligence and visual motor coordination

PLAN

1. No specific action required, next follow-up assessment planned at 8-9 year
2. Recommendations to parents / pediatrician.
3. Referral to other specialist / center

8 year (7-9)

Cfr 5 year program

Kind regards,
Bart Van Overmeire, President BVN-GBN