

Network Database Operation Manual

Ver 9.0

(gestational age less than 32 weeks, or birthweight at or less

than 1500g、Year 2026)

The Database is partly supported by grants from
NPO Neonatal Research Network of Japan

Section 1: Introduction

Purpose

- To establish a nation wide database for VLBW infants
- To describe the clinical characteristics and morbidity of VLBW infants
- To identify the factors that affect the morbidity and mortality of the infants

Framework of database

- A large multi-center Neonatal Research Network that included level III and II NICUs from throughout Japan
- One hundred and thirteen variables of the infants were collected and recorded in the database.

Eligibility

- Infants who were born less than 32 weeks of gestation or a birth weight at or less than 1500 g in the participating neonatal centers admitted to participating facilities within 28 days of birth
- Infants who were born alive but died in the delivery room

Definitions

- The day of birth was defined as “day 0”.
- Mortality was defined as death occurring before discharge from a participating NICU.
- Gestational age (GA) was determined in the following order: obstetric examination with ultrasonography, obstetric history based on last menstrual period, and then postnatal physical examinations of neonates.
- Infants weighing less than 10th percentile of the normal birth weight curve at each gestational age were defined as light-for-gestational age.

Section 2: Database Items

Hospital

101 Facility ID (Facility:id)

Provided from the network

Patient

201 Patient Number (Patient:no)

A Mother

301 Maternal age (Maternal:age)

Maternal age at delivery

302 Gravida (Maternal:gravida)

“0” means first pregnancy

303 Parity (Maternal:parity)

304 Maternal comorbidity Maternal:Comorbidity:main)

Use ICD10 coding system (Table 1)

305 Artificial Reproductive Technology (Maternal:ART)

306 Foreigner (Maternal: foreigner)

307 Nationality if other than Japanese (Maternal: nationality)

B Pregnancy

401 Number of fetus (Pregnancy:multiple)

Number of fetus at birth

402 Order of birth (Pregnancy:multiple:order)

If multiple pregnancy, enter the order of birth

403 Plurality (Pregnancy:plurality)

If multiple pregnancy, specify mono- or multi-chorionic.

404 Diabetes mellitus (Pregnancy:DM)

Maternal diabetes mellitus or gestational diabetes mellitus

415 Chronic hypertension (Chronic hypertension)

Materanl hypertension diagnosed before this pregnancy

405 Pregnancy induced hypertension(Pregnancy:hypertension)

Including pregnancy induced renal disease and hypertension, superimposed pregnancy induced hypertension, and eclampsia

406 Clinical chorioamnionitis (Maternal:CAM:clinical)

Diagnosed based on the clinical findings such as maternal fever, leukocytosis, and local pain

407 Histologic chorioamnionitis (Maternal:CAM:pathological)

Diagnosed with pathological examination

408 Grade of histologic chorioamnionitis (Maternal:CAM:pathological:grade)

Defined according to the criteria reported by Blanc

C Delivery

521 Hydrops (LaborDelivery: hydrops)

501 Premature rupture of membranes (LaborDelivery:PROM)

Defined as rupture of membranes before an onset of labor

522 Duration of rupture (LaborDelivery:PROM:duration)

523 Placental abruptio (LaborDelivery:abruptio)

524 Umbilical cord prolapse (LaborDelivery:prolapse)

502 Antenatal steroid usage (LaborDelivery:steroid)

Defined as administration of any corticosteroids to accelerate fetal lung maturity

531 Antenatal steroid courses (LaborDelivery:steroid:course)

540 Maternal MgSO4 (LaborDelivery:steroid:course)

503 Abnormal fetal heart rate monitoring (LaborDelivery:NRFS)

Defined as non-reassuring fetal status

504 Presentation (LaborDelivery:presentation)

Head position or other presentation

505 Delivery mode (LaborDelivery:mode)

Mode of delivery

509 Feto-Maternal transfusion (LaborDelivery:feto-maternal transfusion)

Diagnosed with any method

510 Cord blood transfusion (LaborDelivery:cordblood:transfusion)

Defined as any method of cord blood transfusion at birth

511 Method of cord blood transfusion (LaborDelivery:cordblood:transfusion:method)

D Neonate

602 Age of admission (Neonatal:admission:day)

Must be less than 28 days after birth

603 Gender (Neonatal:sex)

Unknown: 3

604 Outborn (Neonatal:outborn)

An infant was born outside a participating hospital, yes

605 Maternal transfer (Neonatal:inborn)
If mother was transferred from other hospital, select emergency or elected maternal transfer.

606, 607 gestational age (Neonatal:GA:wk)(Neonatal:GA:day)
Unknown: 99

690 Confirmation of gestational age (Neonatal:GA:confirm)
If gestational age was determined by the obstetric examination with ultrasonography

608 Apgar at 1 min (Neonatal:ap1)
Unknown: 99

609 Apgar at 5 min (Neonatal:ap1)
Unknown: 99

651 Apgar at 10 min (Neonatal:ap10)

655 Withhold of aggressive resuscitation at birth (Neonatal:resuscitation:withhold)

610 Oxygen use at birth (Neonatal:resuscitation:oxygen)
Resuscitation with oxygen

611 Endotracheal intubation at birth (Neonatal:resuscitation:intubation)
Resuscitation with an endotracheal tube

652 CPAP use for resuscitation (Neonatal:resuscitation:CPAP)

653 Chest compression for resuscitation (Neonatal:resuscitation:chestcompression)

654 Adrenalin use for resuscitation (Neonatal:resuscitation:adrenalin)

612 Birthweight (Neonatal:birthweight)

613 Body length at birth (Neonatal:length)

614 Head circumference at birth (Neonatal:HC)
If not available, enter the value at the first examination

615 Death at delivery room (Neonatal:livebirth)
If died at delivery room in spite of aggressive resuscitation, go to [1411]
If no resuscitation was attempted, do not register.

620 Arterial cord blood gas sampling (Neonate:cordbloodgas:sample)
If cord blood gas was analyzed using blood sample obtained from cord artery

622 Cord blood gas pH (Neonate:cordbloodgas:pH)
Measured pH

624 Cord blood gas PO2 (Neonate:cordbloodgas:PO2)
PO2 in Torr

626 Cord blood gas PCO2 (Neonate:cordbloodgas:PCO2)

PCO2 in Torr

628 Cord blood gas BE (Neonate:cordbloodgas:BE)
mmol/L of base excess in negative value

630 Neonatal blood gas sampling on admission (Neonate:neonatalbloodgas:sample)
If neonatal blood sample was analyzed within 6 hours after birth

631 Sampling site of neonatal blood (Neonate:neonatalbloodgas:samplesite)
Sample site of neonatal blood sampl

632 Neonatal blood gas pH (Neonate:neonatalbloodgas:pH)
Measured pH .

634 Neonatal blood gas PO2 (Neonate:neonatalbloodgas:PO2)
PO2 in Torr

636 Neonatal blood gas PCO2 (Neonate:neonatalbloodgas:PCO2)
PCO2 in Torr

638 Neonatal blood gas BE (Neonate:neonatalbloodgas:BE)
mmol/L of base excess in negative value

661 Body temperature on admission (Neonate:admission:temperature)

662 Hemoglobin concentration on admission (Neonate:admission:Hb)

E Respiratory system

701 RDS (Pulmonary:RDS)
Diagnosed by clinical and radiographic findings
ARDS not included

702 Air leak syndrome (Pulmonary:airleak)
Any type of air leak included

720 Thoracocentesis (Pulmonary:airleak:thoracocentesis)

703 Plmonary hemorrhage (Pulmonary:hemorrhage)
Only massive hemorrhage included

705 Persistent pulmonary hypertension of the newborn (Pulmonary:PPHN)
Defined as right-to-left shunt at foramen ovale and/or ductus arteriosus without any anatomical malformation detected by cardiac echocardiography

706 Duration of oxygen use (Pulmonary:oxygen)
Days of age when oxygen supplementation stopped
If still on: 999

707 Duration of CPAPuse (Pulmonary:CPAP)
Days of CPAP or DPAP use including HFNC

708 Duration of mechanical ventilation (Pulmonary:MV)

CPAP and DPAP not included, only invasive mechanical ventilation

709 Use of HFO (Pulmonary:HFO)
 Use of HFO for mechanical ventilation

731 Timing of HFOV use (Pulmonary:HFO:timing)

710 Doses of pulmonary surfactant (Pulmonary:STA)
 Pulmonary surfactant (Surfacten®) given during the acute phase of respiratory Problems

732 Use of NAVA (NAVA)

733 Method of NAVA use (NAVA)

711 Duration of nitric oxide inhalation (Pulmonary:NO)
 Total days of iNO use

741 Purpose of nitric oxide use (Pulmonary:NO:purpose)

712 Chronic lung disease (Pulmonary:CLD)
 Supplemental oxygen with chest X-ray changes on 28th day after birth

713 Type of chronic lung disease (Pulmonary:CLD:type)
 According to the classification by the task force of the Ministry of Health, Labour and Welfare, Japan

734 Chest X-ray finding of CLD (Pulmonary:CLD:Xray)

714 Glucocorticoid use for CLD (Pulmonary:CLD:steroid)
 Steroid given during the hospital stay for prevention or treatment of CLD

717 Inhaled glucocorticoid use for CLD (Pulmonary:CLD:inhaledsteroid)
 Inhaled steroid given during the hospital stay for prevention or treatment of CLD

715 Oxygen or CPAP use for CLD at 36 wk of corrected age (Pulmonary:CLD:36wk)
 Supplemental oxygen or CPAP/HFNC use at 36th week postmenstrual age

751 Respiratory support for CLD at 36 week of corrected age (Pulmonary:CLD:36wk:support)

716 Oxygen concentration at 36 wk of corrected age (Pulmonary:CLD:36wk:O2)
 F₁O₂ at 36th week postmenstrual age

752 Respiratory support for CLD at 40 week of corrected age (Pulmonary:CLD:40wk:support)

753 Oxygen or respiratory support for CLD at 40 week of corrected age (Pulmonary:CLD:40:support:method)

F Circulatory system

801 Symptomatic PDA (Cardiac:PDA)

Diagnosed by both echocardiographic findings and clinical evidence of volume overload due to left-to-right shunt

802 Indomethacin use (Cardiac:PDA:indomethacin)
 Indomethacin use for patent ductus arteriosus, prophylactic use: 3

821 Drug for PDA treatment(Cardiac:PDA:drug)
 1:prophylactic indomethacin,2:rescue use of indomethacin,3:ibuprofen,4:other drugs(multiple choice allowed)

803 PDA ligation (Cardiac:PDA:surgery)
 Operation for PDA

851 Glucocorticoid use for late onset circulatory collapse (Cardiac:adrenal:steroid)
 Defined as steroid use during the hospital stay for treatment of late onset circulatory collapse of prematurity due to impaired adrenal function

G Central nervous system

901 Neonatal seizure (Neurologic:seizure)
 Seizure during the neonatal period

911 Diagnosis of seizure(Neurologic:seizure:diagnosis)
 1:clinical diagnosis,2:EEG diagnosis(multiple choice allowed)

902 Intraventricular hemorrhage (Neurologic:IVH)
 Diagnosed with cranial ultrasound
 Subependymal and intra choroid plexus hemorrhage included

903 Grade of intraventricular hemorrhage (Neurologic:IVH:grade)
 According to the classification of Papile

921 Grade of IVH right(Neurologic:IVH:grade:right)

922 Grade of IVH left(Neurologic:IVH:grade:left)

904 Post intraventricular hemorrhage hydrocephalus (Neurologic:IVHhydrocephalus)

931 Shunt operation for hydrocephalus(Neurologic:IVHhydrocephalus:shunt)

905 Periventricular leukomalacia (Neurologic:cPVL)
 Only cystic PVL diagnosed by using either head ultrasound or cranial MRI scans, performed after two weeks of age or later

941 White matter lesson(Neurologic:WMlesion)

906 Hypoxic ischemic encephalopathy (Neurology:HIE)
 Diagnosed with abnormal findings by cranial echography, CT or MRI

H Infection

1001 Intrauterine infection (Infection:intrauterine)
 If any inflammatory response was detected in the infants at birth

1002 Sepsis (Infection:sepsis)
 Blood culture proven septicemia or bacteremia at any time during the stay in NICU

1011 Number of episode of sepsis(Infection:sepsis:times)

1012 Onset of 1st episode(Infection:sepsis:onset:1st) days

1013 Pathogen of 1st sepsis(Infection:sepsis:pathogen:1st)
 1:E.Coli,2:CNS(coagulase negative staphylococci),3:GBS,4:Streptococcus sp(other than GBS),5:MSSA,6:MRSA,7:Klebsiella sp,8:Enterococcus sp,9:Enterobacter sp,10:Pseudomonas Aerigonosa,11:Candida sp,12:Fungus,13:others,14:unknown

1004 Early onset sepsis (Infection:sepsis:onset)
 Within 7 days after birth

1021 Onset of 2nd episode(Infection:sepsis:onset:2nd) days

1022 Pathogen of 2nd sepsis(Infection:sepsis:pathogen:2nd)
 1:E.Coli,2:CNS(coagulase negative staphylococci),3:GBS,4:Streptococcus sp(other than GBS),5:MSSA,6:MRSA,7:Klebsiella sp,8:Enterococcus sp,9:Enterobacter sp,10:Pseudomonas Aerigonosa,11:Candida sp,12:Fungus,13:others,14:unknown

1031 Meningitis(Infection:meningitis)

1032 Number of episode of meningitis(Infection:meningitis:times)

1033 Onset of 1st meningitis(Infection:meningitis:onset:1st) days

1034 Pathogen of 1st meningitis(Infection:meningitis:pathogen)
 1:E.Coli,2:CNS(coagulase negative staphylococci),3:GBS,4:Streptococcus sp(other than GBS),5:MSSA,6:MRSA,7:Klebsiella sp,8:Enterococcus sp,9:Enterobacter sp,10:Pseudomonas Aerigonosa,11:Candida sp,12:Fungus,13:others,14:unknown,15:CSF test not performed

1035 Onset of 2nd meningitis(Infection:meningitis:onset:2nd) days

1036 Pathogen of 2nd meningitis(Infection:meningitis:pathogen:2nd)
 1:E.Coli,2:CNS(coagulase negative staphylococci),3:GBS,4:Streptococcus sp(other than GBS),5:MSSA,6:MRSA,7:Klebsiella sp,8:Enterococcus sp,9:Enterobacter sp,10:Pseudomonas Aerigonosa,11:Candida sp,12:Fungus,13:others,14:unknown,15: CSF test not performed

1010 Use of antibiotics (Infection:antibiotics)
 Any type of antibiotics during the stay in NICU

I Digestive system

- 1101 Use of intravenous hyperalimentation (Gastrointestinal:hyperalimentation)
Includes both amino acid and fat infusion
- 1102 Necrotizing enterocolitis (Gastrointestinal:NEC)
Defined according to Bell's classification stage II or greater
- 1103 Idiopathic intestinal perforation (Gastrointestinal:perforation)
Diagnosed if free air was detected in the abdominal cavity by X-ray examination due to other than NEC
- 1104 Meconium related ileus (Gastrointestinal:meconium)
Functional ileus needed aggressive treatment with contrast enema or equivalent procedures
- 1111 Treatment for intestinal perforation (Gastrointestinal:perforation:treatment)
Drainage, laparotomy, ileostomy, or no treatment

J Hearing system

- 1201 Hearing screening (Hearing:screening:result)
Performed by neonatal hearing screening system

K Retinopathy

- 1301 Stage of ROP (ROP:stage)
Worst stage according to the classification by the task force of the Ministry of Health, Labour and Welfare, Japan or International classification
Japan MLHW staging
1:lower than II、2:early III、3:middle III、4: more than lateIII、
5 : not performed
International classification
6: Stage 1、7: Stage 2、8: Stage 3、9: Greater than stage 4 including APROP
- 1302 ROP treatment (ROP:Tx)
If infants were treated with either laser- or cryo-coagulation therapy, or both.
- 1305 ROP treatment with anti-VEGF antibody(ROP:Tx:antiVEGF)
Use of anti-VEGF antibody

L Other complications

- 1411 Congenital anomaly (Diagnosis:malformation)
Only major and fatal anomaly

1412 Diagnosis of congenital anomaly (Diagnosis:malformation:disease)

Enter a code for major congenital anomaly

Refer Table 2 in operational manual

1413 Operation for congenital anomaly (Diagnosis:malformation:surgery)

Only operation for congenital anomaly

M Summary

1501 Day of enteral feeding more than 100ml/kg/day (Summary:feeding:100)

If not established: 99

1502 Proportion of breast feeding at discharge(Summary:feeding:breastmilk)

1:100%,2:50~99%,3:1~49%,4:0%

1503 Use of donor milk(Summary:feeding:breastmilk:donormilk)

1504 Use of donor milk bank(Summary:feeding:breastmilk:donormilkbank)

1505 Use of human milk based fortifier (EHMD)(Summary:feeding:breastmilk:ehmd)

1511 Blood transfusion (Summary:anemia:rbctransfusion)

Only RBC transfusion, except cord blood transfusion

1512 Erythropoietin use (Summary:anemia:EPO)

Use of erythropoietin for anemia of prematurity

1513 Purpose of erythropoietin(Summary:anemia:EPO:purpose)

1:anemia,2:protection of neurological damage(multiple choice allowed)

N Discharge

1620 Transfer to upper level hospital during acute period(Transfer)

1630 Reason for transfer(Transfer:purpose)

1635 Days after birth if transferred back from the upper level hospital(Transfer:readmission)

1601 Age of discharge (Discharge:day)

Day of age at disposition

1602 Death at discharge (Discharge:death)

1603 Autopsy (Discharge:autopsy)

1604 Cause of death (Discharge:causeofdeath:code)

Refer Table 3 in operational manual

1605 Disposition to home (Discharge:home)

1606 Place to transfer (Discharge:transfer)

1607 HOT (Discharge:oxygen)

1608 Tracheostomy at discharge (Discharge:tracheostomy)

- 1609 Body weight at discharge (Discharge:weight)
- 1610 Body length at discharge (Discharge:length)
- 1611 Head circumference at discharge (Discharge:HC)

O Predictable outcomes at discharge (Only for the infants discharged alive)

- 1701 Motor disorder inevitable after discharge (Discharge:motor)
- 1702 Visual disorder inevitable after discharge (Discharge:vision)

P Outcomes at 18-24 months of corrected age

- 2010 Follow-up at 18-24 months of age (Followup:1.5)
- 2012 Death after discharging from NICU (Followup:1.5:death)
- 2014 Cause of death after discharging from NICU (Followup:1.5:death:cause)
- 2016 Reason for dropout from follow-up (Followup:1.5:dropout)
- 2018 Hospital name in follow-up currently (Followup:1.5:hospital)
- 2019 Other reason for dropout from follow-up (Followup:1.5:dropout:reason)
- 2020, 2021 Age at follow-up (Followup:1.5:age) (Followup:1.5:age:month)
- 2020, 202 Corrected age at follow-up (Followup:1.5:correctedage)
(Followup:1.5:correctedage:month)
- 2030 Body weight at follow-up (Followup:1.5:weight)
- 2040 Body length at follow-up (Followup:1.5:height)
- 2050 Head circumference at follow-up (Followup:1.5:HC)
- 2060 Home oxygen use at follow-up (Followup:1.5:oxygen)
- 2061 Age in months when home oxygen use stopped, if no longer used
(Followup:1.5:oxygen:duration)
- 2070 Visual impairment (Followup:1.5:vision)
- 2071 Grade of visual disability (Followup:1.5:vision:disability)
- 2072 Use of glasses (Followup:1.5:vision:glass)
- 2080 Cerebral palsy (Followup:1.5:motor)
- 2081 GMFCS (Followup:1.5:CP:GMFCS)
- 2082 Type of cerebral palsy (Followup:1.5:CP:type)
- 2083 Cause of cerebral palsy (Followup:1.5:CP:cause)
- 2085 DQ assessment at follow-up (Followup:1.5:DQ)
- 2088 Reason not assessing DQ (Followup:1.5:DQ:Reason)
- 2100 Scale for DQ assessment (Followup:1.5:DQ:method)
- 2101 DQ score by K scale (Followup:1.5:DQ)
- 2102 DQ score by K scale in corrected age (Followup:1.5:DQ)
- 2103 DQ motor score by K scale (Followup:1.5:DQ:motor)
- 2104 DQ motor score by K scale in corrected age (Followup:1.5:DQ:motor)
- 2105 DQ cognitive score by K scale (Followup:1.5:DQ:cognitive)
- 2106 DQ cognitive score by K scale in corrected age (Followup:1.5:DQ:cognitive)
- 2107 DQ verbal score by K scale (Followup:1.5:DQ:verbal)
- 2108 DQ verbal score by K scale in corrected age (Followup:1.5:DQ:verbal)
- 2111 Scale for DQ assessment other than K scale (Followup:1.5:DQ:othermethod)
- 2112 DQ score by other method (Followup:1.5:DQ)

- 2113 DQ score by other method in corrected age (Followup:1.5:DQ)
- 2114 Developmental assessment by other method (Followup:1.5:DQ:other)
- 2115 Developmental assessment by physician (Followup:1.5:DQ:physician)
- 2120 Hearing disability (Followup:1.5:hearing)
- 2122 Use of hearing aid (Followup:1.5:hearing:aid)
- 2123 Hearing ability with aid (Followup:1.5:hearing:ability)
- 2130 Drug use for asthma (Followup:1.5:asthma)
- 2140 Drug use for epilepsy (Followup:1.5:epilepsy)
- 2150 Use of home health care (Followup:1.5:homehealthcare)
- 2151 Use of respirator (Followup:1.5:homehealthcare:respirator)
- 2152 Tracheostomy (Followup:1.5:homehealthcare:tracheostomy)
- 2153 Tube feeding or gastrostomy (Followup:1.5:homehealthcare:tube)
- 2154 VP shunt (Followup:1.5:homehealthcare:VPshunt)
- 2155 Other home health care (Followup:1.5:homehealthcare:others)
- 2160 Educational training (Followup:1.5:educationaltraining)

Q Outcomes at 3 years of age

- 2210 Follow-up at 3 years of age (Followup:3)
- 2212 Death after discharging from (Followup:3:death)
- 2214 Cause of death after discharging from NICU (Followup:3:death:cause)
- 2216 Reason for dropout from follow-up (Followup:3:dropout)
- 2218 Hospital name in follow-up currently (Followup:3:hospital)
- 2219 Other reason for dropout from follow-up (Followup:3:dropout:reason)
- 2220、2221 Age at follow-up (Followup:3:age) 月 (Followup:3:age:month)
- 2222、2223 Corrected age at follow-up (Followup:3:correctedage:year)
(Followup:3:correcteage:month)
- 2230 Body weight at follow-up (Followup:3:weight)
- 2240 Body height or length at follow-up (Followup:3:height)
- 2250 Head circumference at follow-up (Followup:3:HC)
- 2252 Chest circumference at follow-up (Followup:3:CC)
- 2254 Abdominal circumference at follow-up (Followup:3:AC)
- 2260 Home oxygen use at follow-up (Followup:3:oxygen)
- 2261 Age in months when home oxygen use stopped, if no longer used
(Followup:3:oxygen:duration)
- 2270 Visual disability (Followup:3:vision)
- 2271 Grade of visual disability (Followup:3:vison:disability)

2272 Use of glasses (Followup:3:vison:glass)
2280 Cerebral palsy (Followup:3:motor)
2281 GMFCS (Followup:3:CP:GMFCS)
2282 Type of cerebral palsy (Followup:3:CP:type)
2283 Cause of cerebral palsy (Followup:3:CP:cause)
2285 DQ assessment at follow-up (Followup:3:DQ)
2288 Reason not assessing DQ (Followup:3:DQ:Reason)
2300 Scale for DQ assessment (Followup:3:DQ:method)
2301 DQ score by K scale (Followup:3:DQ)
2302 DQ score by K score in corrected age (Followup:3:DQ)
2303 DQ motor score by K scale (Followup:3:DQ:motor)
2304 DQ motor score by K scale in corrected age (Followup:3:DQ:motor)
2305 DQ cognitive score by K scale (Followup:3:DQ:cognitive)
2306 DQ cognitive score by K scale in corrected age (Followup:3:DQ:cognitive)
2307 DQ verbal score by K scale DQ (Followup:3:DQ:verbal)
2308 DQ verbal score by K scale in corrected age (Followup:3:DQ:verbal)
2311 Scale for DQ assessment other than K scale (Followup:3:DQ:othermethod)
2312 DQ score by other method (Followup:3:DQ)
2313 DQ score by other method in corrected age (Followup:3:DQ)
2314 Developmental assessment by other method (Followup:3:DQ)
2315 Developmental assessment by physician (Followup:3:DQ)
2320 Hearing disability (Followup:3:hearing)
2322 Use of hearing aid (Followup:3:hearing:aid)
2323 Hearing ability with aid (Followup:3:hearing:ability)
2330 Drug use for asthma (Followup:3:asthma)
2340 Drug use for epilepsy (Followup:3:epilepsy)
2350 Use of home health care (Followup:3:homehealthcare)
2351 Use of respirator (Followup:3:homehealthcare:respirator)
2352 Tracheostomy (Followup:3:homehealthcare:tracheostomy)
2353 Tube feeding or gastrostomy (Followup:3:homehealthcare:tube)
2354 VP shunt (Followup:3:homehealthcare:VPshunt)
2355 Other home health care (Followup:3:homehealthcare:others)
2360 Educational training (Followup:3:educationaltraining)
2370 Behavior disorders (Followup:3:behavior)
2372 Type of behavior disorders (Followup:3:behavior:abnormal)

C 3 year checkup sheet

c24 Systolic blood pressure mmHg

c25 Diastolic blood pressure mmHg

c26 Occult blood in urine 0:−,1:−+,2:+,3:++,

c27 Proteinuria 0:−,1:−+,2:+

c28 Glucosuria 0:−,1:−+,2:+

c30 Father at home false:no check,true:check (1:yes)

c31 Mother false:no check,true:check

c32 Elder brother false:no check,true:check

c33 Elder sister false:no check,true:check

c34 Younger sister false:no check,true:check

c35 Younger brother false:no check,true:check

c36 Grand father false:no check,true:check

c37 Grand mother false:no check,true:check

c38 Others false:no check,true:check

c39 Paternal education 0:less than 12 years,1:more than 13 years

c40 Maternal education 0:less than 12 years,1:more than 13 years

c41 Child abuse 0:no,1:suspect,2:yes,99:unknown

c42 Group childcare 0:no,1:kindergarten,2:nursery,3:others

c43 Walk 0:normal,1:unstable,2:equine gait,3:unable to walk,99:unknown

c44 Stand 0:normal,1:with support,2:unable,99:unknown

c45 Sit 0:normal,1:with support,2:unable,99:unknown

c46 Muscle tone 0:normal,1:hypertonic (spastic),2:hypertonic (rigid),3:hypotonic,4:undeterminable,99:unknown

c47 Fine motor function 0:normal,1:borderline,2:clumsy,99:unknown

c48 Motor disturbance 0:no,1:yes,99:unknown

c49 CP 0:normal,1:suspected,2:CP,99:unknown

c50 Type of CP 1:spastic,2:rigid,3:athetoid,4:flaccid

c51 Type of paralysis 1:quadriplegia,2:diplegia,3:paraplegia,4:hemiplegia

c52 Cause of CP Text

c53 PVL false:no check,true:check

c54 IVH false:no check,true:check

c55 unknown false:no check,true:check

c56 Others false:no check,true:check

CPSonota Cause of CP others Text

c58 Epilepsy 0:no,1:yes,99:unknown

c59 Visual ability 0:normal,1:blindness,2:hemi lateral
blindness,3:amblyopia,4:esotropia,5:exotropia,6:myopia,7:hyperopia,8:others,99:unkno
wn
Gankashindanmei Ophthalmic diagnosis 0:no,1:yes
c61 Eyeglasses 0:no,1:yes,99:unknown
c62 Hearing 0:normal,1:abnormal,99:unknown
Choryokushindanmei Otorhinolaryngological diagnosis 0:no,1:yes
c64 Hearing aid
c65 Asthma 0:no,1:yes,99:unknown
c66 Recurrent upper respiratory tract infection 0:no,1:yes,99:unknown
Zaitakuiryo Home healthcare false:no check,true:check
c68 Home oxygen false:no check,true:check
c69 Mechanical ventilation false:no check,true:check
c70 Tracheostomy false:no check,true:check
c71 Tube feeding false:no check,true:check
c72 VP shunt false:no check,true:check
c73 Anti-epileptic drug false:no check,true:check
c74 Others false:no check,true:check
Zaitakusonota Other home healthcare Text
c76 Duration of home oxygen Months
ShintaitekiIjyo Physical disturbance Text
c78 CT/MRI examination 0:no,1:yes,99:unknown
c80 Normal false:no check,true:check
c81 Bilateral PVL false:no check,true:check
c82 Hemi lateral PVL false:no check,true:check
c83 Multicystic encephalomalacia false:no check,true:check
c84 Severe ventricular dilatation false:no check,true:check
c85 Hydrocephalus false:no check,true:check
c86 Others false:no check,true:check
MRISonota Other MRI/CT findings Text
c88 Behavior 0:normal,1:hyperkinetic,2:ADHD suspected,3:Autism
suspected,99:unknown
KodohyokaSonota Behavioral disorder others Text
c89 Method of DQ measurement 0:Kyoto,1:Others
C89others Method of DQ measurement others
c 90 DQ by chronological age

c 91 DQ by corrected age
c 92 DQ motor by chronological age
c 93 DQ motor by corrected age
c 94 DQ cognitive by chronological age
c 95 DQ cognitive by corrected age
c 96 DQ verbal by chronological age
c 97 DQ verbal by corrected age
c 98 Method of DQ measurement others
c 99 Method of DQ measurement other than new Kyoto scale
c100 DQ assessed by physician 0:normal (DQ>85) ,1:borderline (DQ 70-84) ,2:delay (<70)
c101 DQ other methods by corrected age 0:normal,1:borderline,2:unable,99:not tested
c102 Bayley cognitive
c103 Bayley language 0:normal,1:borderline,2:unable,99:not tested
c104 Bayley motor 0:normal,1:borderline,2:unable,99:not tested
c105 DQ evaluated by other methods 0:2 word sentence,1:single word,2:no word,99:unknown
c106 Verbal recognition 0:normal,1:unable,99:unknown
c107 Educational training 0:no,1:yes,99:unknown

R Outcomes at 6 years

2410 Medical followup 1:yes,2:no

2412 Death after discharged from NICU 1:yes,2:no,3:unknown

2414 Cause of death

2416 Reason for not receiving medical followup
1:followed at different hospital,2:admitted at facility for handicapped children

2418 Hospital name

2419 Reason for not receiving medical followup others

2420 Chronological age at followup years

2421 Chronological age at followup months

2422 Corrected age at followup years

2423 Corrected age at followup months

2430 Body weight kg

2440 Body height cm

2450 Head circumference cm

2452 Chest circumferencecm

2454 Abdominal circumferencecm

2455 Systolic blood pressuremmHg

2456 Diastolic blood pressuremmHg

2550 Home health care1:yes,2:no

2551 Tracheostomy1:yes,2:no

2552 Mechanical ventilation1:yes,2:no

2460 Tracheostomy1:yes,2:no

2553 Tube feeding1:yes,2:no

2554 VP shunt1:yes,2:no

2555 Others1:yes,2:no

2560 Duration of home oxygen useAge in months

2570 Visual impairment 1:yes,2:no

2572 Visual impairment severity
1:blindness or light perception,2:Amblyopia • finger movement of
nystagmus,3:strabismus,4:others

2572 Visual impairment others

2574 Eyeglasses1:yes,2:no

2580 Hearing disability1:yes,2:no

2582 Hearing aidAge in months

2584 Hearing ability

1:normal,2:moderate hearing loss (40 d B~) ,3:deaf • severe hearing loss (90 d B~)

2600 Motor disturbance1:yes,2:no

2610 Motor disturbance severity1:mild,2:cerebral palsy,3:unkown

2612 Motor disturbance mild typetext

2620 GMFCS1:I,2:II,3:III,4:IV,5:V

2630 Type of CP1:spastic,2:athetoid,3:mixed,4:flaccid,5:others ()

2640 Lesion of CP

1:quadriplegia,2:diplegia,3:paraplegia,4:hemiplegia,5:monoplegia,6:unknown

2650 Cause of CP IVH1:yes,2:no

2651 Cause of CP PVL1:yes,2:no

2652 Cause of CP others1:yes,2:no

2652 Otherstext

2660 DQ measurement1:yes,2:no

2670 Reason for not measuring DQ

1:normal development by physician diagnosis,2:severe delay by physician

diagnosis,3:refuse by parents,4:unable to perfome,5:failed to

performe,6:others()

2860 DQ assessed by physician1:normal,2:borderline,3:delay

2680 Method of DQ or IQ measurement

1:WISCIV,2:WPPSI,3:Tanaka-Binet,4:new Kyoto

scale,5:K-ABC,6:Tsumori-Inage,7:Others

2690 Method of DQ or IQ measurement others

2700 WISCIV full IQ

2702 WISCIV VCI

2704 WISCIV PRI

2706 WISCIV WMI

2708 WISCIV PSI

2720 WISCV full IQ

2722 WISKV VCI

2724 WISKV VSI

2726 WISKV FRI

2728 WISKV WMI

2730 WISKV PSI

2732 WISKV QRI

2734 WISKV AWMI

2736 WISKV NVI
2738 WISKV GAI
2740 WISKV CPI
2710 WPPSI full IQ
2712 WPPSI VCI
2714 WPPSI PRI
2716 WPPSI PSI
2718 WPPSI GLC
2820 New Kyoto scale DQ
2830 Tanaka-Binet DQ
2840 K-ABC scale
2850 Others
1:normal,2:borderline,3:delay
2870 Asthma1:yes,2:no
2880 Epilepsy1:yes,2:no
2890 Behavioral disorder1:yes,2:no
2892 Behavioral disorder ADHD1:yes,2:no
2893 Behavioral disorder ADHD suspected1:yes,2:no
2894 Behavioral disorder ASD1:yes,2:no
2895 Behavioral disorder ASD suspected1:yes,2:no
2896 Epilepsy1:yes,2:no
2900 Educational training1:yes,2:no

Checkup sheet at 6years

F

F001 Occult blood in urine 0:-,1:+/-,2:+,3:++
F002 Proteinuria 0:-,1:+/-,2:+
F003 Glucosuria 0:-,1:+/-,2:+
F011 Father at home 1:yes
F012 Mother at home 1:yes
F013 Elder brother at home 1:yes
F014 Elder sister at home 1:yes
F015 Younger sister at home 1:yes
F016 Younger brother at home 1:yes
F017 Grand father at home 1:yes

F018 Grand mother at home 1:yes
F019 Other member at home 1:yes
F020 Years of education father 1:less than 12 years,2:more
F021 Years of education mother 1:less than 12 years,2:more
F022 Maltreatment 1:no,2:yes,3:suspect,99:unknown
F023 Level of school 1:regular elementary school,2:special
F024 Name of the school
F031 Ability of walk 1:normal,2:unstable,3:equine gait,4:u
F032 Abnormal movement of extremities 1:no,2:yes,3:borderl
F033 Equinus foot 1:yes
F034 Genu recurvatum 1:yes
F035 Abnormal extension or flexion of elbow 1:yes
F036 Supination or pronation of forearm 1:yes
F037 Adduction of fingers 1:yes
F038 Others 1:yes
F039 Unknown 1:yes
F040 Involuntary movement 1:no,2:yes,3:unknown
F041 Muscle tone 1:normal,2:spastic,3:right,4:decreased
F042 Tendon reflex normal 1:yes
F043 Tendon reflex increased 1:yes
F044 Tendon reflex decreased 1:yes
F045 Tendon reflex borderline 1:yes
F046 Tendon reflex asymmetry 1:yes
F047 Tendon reflex unknown 1:yes
F048 Babinski reflex 1:no,2:yes,99:unknown
F049 Muscle clonus 1:no,2:yes,3:unknown
F050 Fine motor movement 1:normal,2:borderline,3:poor,99:unkown
F061 Tandem gait walk 1:yes,2:no,3:not tested
F062 Stand on right foot 1:yes
F063 Stand on left foot 1:yes
F064 Supination or pronation of upper limbs 1:no mirror motion,2:mirror motion,3:mirror motion from non-dominant arm to dominant arm,4:not tested
F065 Right-left orientation 1:yes,2:no,3:not tested
F066 Dominant arm 1:right,2:left,3:not fixed,99:unknown
F067 Copy of figures 1:yes,2:imcomplete,3:unable to evaluate
F071 motor impairment 1:normal,2:mild impairment,3:cerebral palsy,99:unknown

F072 Mild motor impairment
F073 Type of cerebral palsy 1:spastic,2:athetoid,3:mixed,4:flaccid,5:others
F074 Lesion of cerebral palsy
1:quadriplegia,2:diplegia,3:paraplegia,4:hemiplegia,5:monoplegia
F075 Cause of CP PVL 1:yes
F076 Cause of CP IVH 1:yes
F077 Cause of CP unknown 1:yes
F078 Cause of CP others 1:yes
F079 Other cause of CP
F080 Cerebral palsy GMFCS 1:I,2:II,3:III,4:IV,5:V,99:unkno
F091 Epilepsy 1:yes,2:no,99:unknown
F092 Epilepsy diagnosis
F093 Febrile convulsion 1:yes,2:no,99:unknown
F094 Visual impairment 1:no,2:amblyopia,3:strabismus,4:blindness or light perception,5:finger movement or nystagmus,6:others,99:unknown
F095 Visual impairment others
F096 Visual impairment diagnosis
F097 Visual acuity right
F098 Visual acuity left
F099 Eyeglasses 1:yes,2:no,99:unknown
F100 Reason for eyeglasses
F101 Hearing impairment 1:no,2:mild,3:severe,99:unknown
F102 Hearing impairment diagnosis
F103 Hearing aid 1:no,2:yes,99:unknown
F104 Asthma 1:no,2:yes,99:unknown
F106 Home healthcare 1:no,2:yes,99:unknown
F107 Mechanical ventilation 1:no,2:yes,3:unknown
F108 Tracheostomy 1:yes
F109 Home oxygen 1:yes
F110 Tube feeding 1:yes
F111 VP shunt 1:yes
F112 Others 1:yes
F113 Home healthcare others
F114 Duration of home oxygen use in months
F115 Other abnormal physical findings
F121 MRI/CT 1:normal,2:abnormal,99:unknown

F122 Age at MRI/CT examination
F123 MRI/CT findings
F124 EEG examination 1:normal,2:abnormal,99:unknown
F125 Age at EEG examination
F126 EEG findings 1:normal,2:abnormal,99:unknown
F127 ABR 1:normal,2:abnormal,99:unknown
F128 Age at ABR examination
F129 ABR findings
F131 Gaze 1:able to gaze,2:incompletely,3:unable,99:unknow
F132 Eye contact 1:yes,2:imcomplete,3:no,99:unknown
F133 Move around 1:yes
F134 Rush suddenly 1:yes
F135 Touch everything 1yes
F136 Hesitate to perform 1:yes
F137 Forget many things immediately 1:yes
F138 Ignore turns 1:yes
F139 Restless always 1:yes
F140 Fight to others 1:yes
F141 Answer questions without understanding them 1:yes
F142 Not response to call 1:yes
F143 Over familiar to others 1:yes
F144 Selfishness 1:yes
F145 No friend 1:yes
F146 Obsessive 1:yes
F147 Repeat somebody's words 1:yes
F148 Finger flapping 1:yes
F149 Behavioral disorder 1:no,2:yes,99:unknown
F150 No behavioral disorder 1:yes
F151 ADHD 1:yes
F152 ADHD suspected 1:yes
F153 ASD 1:yes
F154 ASD suspected 1:yes
F155 Behavioral disorder others 1:yes
F156 Unknown type of behavioral disorder 1:yes
F157 Other type of behavioral disorder
F161 IQ/DQ measurement 1:yes,2:no,99:unknown

F162 Reason not measuring IQ/DQ 1:normal evaluated by physician,2:delay evaluated by physician,3:refusal from parents,4:unable to perform due to delay,5:failed to perform,6:others,99:unknown

F171 Educational training 1:no,2:yes,99:unknown

F172 Name of educational training facility

F173 Age when educational training startedYear

F181 Free comment

If you have any questions, email to nponrn-office@umin.org.

Table 1 Code for maternal complications (ICD10 code)

ICD-10	Disease
A560	Chlamydia infection
A630	Condylomata acuminata
B009	Herpes simplex infection
B069	Rubella infection
B259	CMV infection
B343	Parvovirus infection
B373	Candidiasis
B589	Toxoplasmosis
D259	Myoma
D27	Ovarian cyst
D693	ITP
E039	Hyperthyroidism
E059	Hypothyroidism
I499	Arrhythmia
J459	Asthma
K769	Hepatitis
M320	SLE
N189	Renal failure
N390	Urinary tract infection
N61	Mastitis
N760	Vaginosis
O141	HELLP
O262	Repeated abortion
O343	Cervical incompetency
O360	Rh incompatibility
O361	Other blood type incompatibility
O40	Hydroamnios
O410	Olygoamnios
O418	Amniotic fluid turbidity
O430	TTTS
O441	Placenta previa
O459	Abruptio placenta

O690	Umbilical cord prolapse
O692	Cord around neck
O711	Uterine perforation
O721	Atonic bleeding
O723	DIC
O757	Previous C/S
O85	Puerperal fever
O990	Anemia
Z225	HB carrier
Z940	Kidney transplantation

Table 2 Congenital anomaly

Code	Congenital anomaly
Central nervous system	
101	Anencephaly
102	Meningomeylocele
103	Hydrocephaly
104	Congenital hydrocephalus
105	Holoprocencephaly
Heart	
201	Tricuspid atresia
202	TGA
203	Tetralogy of Fallot
204	Single ventricle
205	DORV
206	ECD
207	Pulmonary atresia
208	Tricuspid atresia
209	HLHS
210	IAA
211	TAPVR
Digestive system	
301	Cleft lip
302	Tracheo-esophagus fistula
303	Esophagus atresia
304	Duodenal atresia
305	Jejunum atresia
306	Ileum atresia
307	Colon atresia
308	Atresia anus
309	Umbilical hernia
310	Gastroschisis
Urinary tract	
401	Bilateral renal agenesis
402	Bilateral dysplastic or polycystic kidney
403	Hydronephrosis

404	Bladder exstrophy
Chromosomal anomaly	
501	13 trisomy
502	18 trisomy
503	21 trisomy
504	Another chromosomal anomaly
Others	
601	Systemic bone disease
602	Congenital diaphragmatic hernia
603	Hydrops fetus
604	Potter syndrome
605	Congenital error of metabolism
606	Congenital myopathy
Undefined	
999	Other fetal congenital anomaly

Table 3 Cause of death

Code	Cause
10	Congenital anomaly
25	CLD
26	CLD+infection
27	CLD+hypoxia
30	Sepsis(unknown bacteria)
31	Sepsis (known bacteria)
40	NEC
41	NEC+sepsis
50	Severe IVH
90	Others
99	Unknown