

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 with 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 (Meternal: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:plurarity)
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 to 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 Pulmonary 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 CPAP use (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(Pulmonaray: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)
 - F_IO₂ 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 lesion(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 late III、
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, 2022 Corrected age at follow-up (Followup:1.5:correctedage)
(Followup:1.5:correcteage: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:vison:disability)
- 2072 Use of glasses (Followup:1.5:vison: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 scare 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 checklist

- 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:unknown

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 circumferencem
- 2454 Abdominal circumferencem
- 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:hemiplagia,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:rigid,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:diplegis,3:parplegis,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:strabisumus,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 1:yes
 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 nponrm-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	Oligoamnios
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	Meningomyelocele
103	Hydroanencephaly
104	Congenital hydrocephalus
105	Holoprocencephaly
Heart	
201	Tricus
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	Hydropus fetalis
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