

The International Network for Evaluating Outcomes of very low birth weight, very preterm neonates (iNeo): A protocol for collaborative comparisons of international health services for quality improvement in neonatal care

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Additional file 1: iNeo data variables for collection with explanatory notes

iNeo data variables for collection with explanatory notes
Developed collaboratively by all participating countries

ID	Unique ID assigned by you or we will assign at coordinating center	
Country	Code for country (alphabetical list)	Potential values: 01 = Australia/New Zealand, 02 = Canada, 03 = Israel, 04 = Japan, 05 = Sweden, 06 = Switzerland, 07 = Spain, 08 = UK
Center	Code number only to be sent to iNeo	You need to prepare a list of centers and keep this code with you at your coordination center. In future surveys we will send link with center as code number and then we can link some of physical, organizational, environmental factors to the outcomes. The center assignment will be determined by the network but as a guide we suggest that the center that provided highest level of care (level 3 care) be assigned to that baby. If a baby has been admitted to two tertiary level units before discharge home then the first tertiary level NICU will be assigned to the baby. Potential values: The center number will lie between 001 and 999
Demographics		
Gestational age	Weeks	Potential values: Range from 22 to 44
Gestational age	Days	Potential values: Range from 0 to 6
Birth weight (kg)		For units that can provide exact birth weight we would prefer this information. For units that have limitations or concerns regarding privacy, please provide BW info in 100 g intervals starting at 200-299, 300-399..... etc. Potential values: a. Direct weight

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		<p>b. Range of weight</p> <p>1 = 200-299 2 = 300-399 3 = 400-499 4 = 500-599 5 = 600-699 6 = 700-799 7 = 800-899 8 = 900-999 9 = 1000-1099 10 = 1100-1199 11 = 1200-1299 12 = 1300-1399 13 = 1400-1499 14 = 1500-1599 15 = 1600-1699 16 = 1700-1799 17 = 1800-1899 18 = 1900-1999 19 = >2000</p>
Birth year info	Year	Data will be entered as 2007 onwards
Birth quarter info	Quarter	<p>Potential values:</p> <p>1 = January–March 2 = April–June 3 = July–Sept 4 = Oct–Dec</p>
Age at NICU admission		<p>Potential values: hh:mm If admitted at birth then enter 00.00 Unknown or missing – leave blank</p>

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Sex		Potential values: 1 = Male 2 = Female 3 = Ambiguous 4 = Unknown/missing
Maternal age		In 5 year groups starting at 11 years. Potential values: 1 = 11–15 2 = 16–20 3 = 21–25 4 = 26–30 5 = 31–35 6 = 36–40 7 = 41–45 8 = 46–50 9 = 51–55 10 = 56–60 11 = >61 12 = Unknown
Antenatal details		
Antenatal Corticosteroid use		Potential values: 1 = Yes 2 = No 3 = Unknown/missing
If YES, was it Complete/Incomplete		Potential values: 1 = Complete (at least 2 doses that are 12 hours apart and 12 hours passed since last dose) 2 = Incomplete 3 = Unknown/missing
ROM Duration		Potential values: 1 = <24 hours (includes zero hours or rupture at the time

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		of birth) 2 = 24 hours to 1 week 3 = >1 weeks 4 = Unknown/missing
Maternal High blood pressure	Includes all hypertensive disorders (pregnancy-induced and otherwise)	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Maternal diabetes	Includes all glucose homeostasis disorders (pregnancy-induced and otherwise)	Potential values: 1 = Yes 2 = No 3 = Unknown /missing
Birth details		
Mode of delivery		Potential values: 1 = Vaginal 2 = Caesarean section 3 = Unknown/missing
Presentation	At birth or closest to the time of birth	Potential values: 1 = Vertex 2 = Breech 3 = Other 4 = Unknown/missing
Births this pregnancy	If one fetus dies in-utero, code pregnancy as twin/triplet as appropriate and not singleton or twin based on live births	Potential values: 1 = Singleton 2 = Twin 3 = Triplet 4 = Higher order
Birth order		Potential values: 1 = First 2 = Second 3 = Third

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		4 = Forth 5 = Unknown/missing
Place of birth	Inborn applies to tertiary care hospital where NICU is located. Outborn includes those babies who needed to be transferred to NICU after birth for ongoing neonatal care from facility other than hospital in which they are cared for	Potential values: 1 = Inborn 2 = Outborn 3 = Unknown/missing.
Immediate postnatal care		
Need for intubation	Within first 30 minutes of birth	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Need for CPAP	Within first 30 minutes of birth	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Need for CPR during initial stabilization	CPR includes chest compression and/or epinephrine within first 30 minutes of birth	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Apgar at 1 minute		Potential values: 0–10, Unknown/missing = Leave blank
Apgar at 5 minutes		Potential values: 0–10 Unknown/missing = Leave blank
Admission status		

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Re-admission		Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Admission Head Circumference (cm)	Up to one decimal point	Potential values: 15.0 cm to 99.9 cm Unknown/missing = 0.0
Admission length (CM)	Up to one decimal point	Potential values: 15.0 cm to 99.9 cm Unknown/missing = 0.0
Admission temperature (°C)	Up to one decimal point	Potential values: 20.0 ⁰ C to 45.0 ⁰ C Unknown/missing = 0.0
Severity of illness score used	Whatever score is used by network	SNAP, SNAPII, SNAPPE, CRIB, CRIB II, TRIPS Data will be collected on all scores. Analyses will be performed based on standardized scores to compare severity of illness on admission scores as adjusted data Please enter score in your range
Neonatal course		
Duration of Supplemental O₂	Days or hours (use midnight as cut-off)	Number range from 0–10000 (depending upon unit: hours or days) If not applicable as infant did not receive it then put zero If missing/unknown then leave blank
Duration of CPAP	Days or hours (use midnight as cut off)	Number range from 0–10000 (depending upon unit: hours or days) If not applicable as infant did not receive then put zero If missing/unknown then leave blank
Duration of mechanical ventilation	Days or hours (use midnight as cut off)	Number range from 0–10000 (depending upon unit: hours or days) If not applicable as infant did not receive it then zero

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		If missing/unknown then leave it blank
Duration of TPN in days	Days/hours (use midnight as cut off)	Number range from 0–10000 (depending upon unit: hours or days) If not applicable as infant did not receive then put zero If missing/unknown then leave blank
Surfactant	Yes/no	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Diagnoses/Procedures		
PDA	Clinical or echocardiographic diagnosis. We will collect information on method most commonly used in separate survey.	Potential values: 1 = Yes 2 = No 3 = Unknown /missing
Indomethacin or other NSAID for PDA treatment		Potential values: 1 = Yes 2 = No 3 = Unknown /missing
Surgical ligation		Potential values: 1 = Yes 2 = No 3 = Unknown /missing
RDS	Clinical and/or radiological criteria	Potential values: 1 = Yes 2 = No 3 = Unknown /missing
Air leak	Includes Pneumothorax, Pneumomediastinum	Potential values: 1 = Yes 2 = No

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		3 = Unknown /missing
Air leak requiring drainage	Needle paracentesis or chest tube to be included	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
BPD at 28 days (need for supplemental oxygen)	X-ray is not mandatory	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
BPD at 36 weeks (need for supplemental oxygen)	X-ray is not mandatory	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Postnatal steroid use for BPD	Only systemic use (Not inhaled steroid use)	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
NEC (diagnosed using Bell's criteria)	Stage 2 or higher only	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Surgery for NEC (laparotomy/drainage)		Potential values: 1 = Yes 2 = No 3 = Unknown/missing
IVH (most severe grade) prior to discharge	Classification could be SEH/GMH, IVH, VE, IPE	Potential values: 0 = No hemorrhage 1 = Grade 1 hemorrhage or subependymal hemorrhage or subependymal cyst or germinal matrix hemorrhage 2 = Intraventricular hemorrhage without ventricular

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		dilatation 3 = Ventricular dilatation with intraventricular hemorrhage 4 = Intraparenchymal echogenicity suggestive of hemorrhage or infarction with or without IVH 5 = Unknown/missing 6 = No exam
PVL or persistent parenchymal opacity	Persistent intraparenchymal echolucency or cysts identified on US or MRI	Potential values: 1 = Yes 2 = No 3 = Unknown/missing 4 = No exam
International ROP criteria	In either eye, record the worst stage	Potential values: 0 = No ROP 1 = Stage 1 ROP 2 = Stage 2 ROP 3 = Stage 3 ROP 4 = Stage 4 ROP 5 = Stage 5 ROP 6 = Unknown/missing 7 = No eye exam done
Treatment for ROP	Anti-VEGF or laser	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Early onset sepsis	Infection within 72 hours (3 days) of birth – positive blood and/or CSF for pathogenic organism	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Early onset sepsis	If yes – organism	Potential values: 1 = E Coli 2 = GBS

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		<p>3 = Other Gram negative bacteria 4 = Other Gram positive bacteria 5 = Fungal 6 = Viral 7 = Other 8 = Unknown</p>
Late onset sepsis	Infection after 3 days (or 72 hours of age) – positive blood and/or CSF for pathogenic organism	<p>Potential values: 1 = Yes 2 = No 3 = Unknown/missing/ Not applicable in case of death prior to 3 days</p>
LOS episode 1	Organism If multiple organisms are grown in culture consider most virulent: Virulence should be counted as: Fungal – Gram negative (including E coli), Gram positive (including GBS), viral, mycoplasma, other, in that sequence.	<p>Potential values: 1 = E Coli 2 = GBS 3 = Other Gram negative bacteria 4 = Other Gram positive bacteria 5 = Fungal 6 = Viral 7 = Other 8 = Unknown/missing</p>
LOS episode 1	Postnatal age in days	<p>Value range from 3 to 500 Leave this blank if only one episode of sepsis</p>
LOS episode 2	Organism If multiple organisms are grown in culture consider most virulent: Virulence should be counted as: Fungal – Gram negative (including E coli), Gram positive (including GBS), viral, mycoplasma, other, in that sequence.	<p>Potential values: 1 = E Coli 2 = GBS 3 = Other Gram negative bacteria 4 = Other Gram positive bacteria 5 = Fungal 6 = Viral 7 = Other 8 = Unknown/missing</p>

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LOS episode 2	Postnatal age in days	Value range from 3 to 500 Leave this blank if only one episode of sepsis
LOS episode 3	Organism If multiple organisms are grown in culture consider most virulent: Virulence should be counted as: Fungal – Gram negative (including E coli), Gram positive (including GBS), viral, mycoplasma, other, in that sequence.	Potential values: 1 = E Coli 2 = GBS 3 = Other Gram negative bacteria 4 = Other Gram positive bacteria 5 = Fungal 6 = Viral 7 = Other 8 = Unknown/missing
LOS episode 3	Postnatal age in days	Value range from 3 to 500
LOS episode 4	Postnatal age in days	Value range from 3 to 500
LOS episode 5	Postnatal age in days	Value range from 3 to 500
Congenital anomalies	Major congenital anomaly – defined as those life-threatening or likely to affect quality of way to a significant degree	Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Specified list to be developed based on ICD-10	If yes to above	Please mention all congenital anomalies you have for a particular infant. If they are coded, please give code number (ICD code). Centrally we will separate them in major and minor groups
Discharge Information		
Age at Discharge/death	Postnatal age in calendar days	Number varies from 1 to 1000 If died before 24 hours – enter duration in hours and add “h” at the end
Delivery Room Death		Potential values: 1 = Yes 2 = No
Death	Prior to discharge from NICU	Potential values: 1 = Yes

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		2 = No
Cause of death if available		Again any free text would be acceptable for this item and we will group them centrally.
Discharge destination		Potential values: 1 = Home 2 = Level 2 or HDU 3 = SCBU 4 = Pediatric ward 5 = PICU 6 = Out of area/country 7 = Rehabilitation/palliative care 8 = Unknown/missing 9 = Other 10 = Unknown
Breastfeeding/breast milk at discharge		Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Oxygen at discharge		Potential values: 1 = Yes 2 = No 3 = Unknown/missing
Weight at discharge/death		In Kg, range 0.000 to 20.000 Leave blank if unknown (especially in case of death)