

# National In Vitro Fertilisation, Obstetrics and Perinatal Registry

## Hungarian Perinatal Registry

### *Data collection manual for Neonatal Intensive Care Units*

1 February 2023

All level II and level III Neonatal Intensive Care Units (NICU) operating in Hungary are required to submit data to the Registry, pursuant to Decree 49/2018 (28.XII.) of the Ministry of Human Resources, on the scope of diseases of major public health significance or otherwise associated with significant cost burden, the designation of the authority responsible for maintenance of the disease registry, and the detailed rules for the notification and registration of these diseases.

#### **Criteria for registration:**

Level III NICU-s: (NICU III)

- All neonates admitted to the unit
- All neonates who died in the delivery room of the institution

Level II NICU-s (NICU II):

- Patients also treated in NICU III:  
transferred from a maternity unit or delivery room to NICU III  
and/or received from NICU III
- Infants born with birth weight below 1501 g or before 33<sup>rd</sup> week of gestation
- Need for infusion for more than 12 hours
- Need for respiratory therapy (hood oxygen, nasal cannula oxygen, non-invasive ventilation, invasive ventilation)
- Need for medication to support circulation
- Blood exchange treatment
- Death in the delivery room or in NICU II unit

#### **Endpoint of registry entry:**

- The first discharge from the hospital
- Transfer to a non-NICU II/NICU III institution/facility
- Death
- If continuous hospital treatment is needed, until the age of 1 year.

Exceptions:

- Readmissions: repeated admission within the 44<sup>th</sup> postmenstrual week (28<sup>th</sup> day of life for term newborns) to the NICU II/NICU III from which the discharge took place.
- First admission: admission to NICU II/NICU III within 44 postmenstrual weeks (28 days of life for term newborns) after discharge from the obstetrics ward.
- NICU II/NICU III admission after discharge in case of severe complications, e.g. maximum ROP stage, ROP treatment, acquired hydrocephalus, shunt implantation, NEC.

Post-discharge admission should not be recorded if due to the following complications:  
inguinal hernia surgery, apnoea, RSV pneumonia, bacterial sepsis.

## Data definitions

If a certain information is not available, the field should not be left empty and the 'No data' option must be registered. An information might be unavailable for several reasons – this alone is not a problem, but leaving a field empty is considered as data entry error. In certain cases, it is natural that no substantial data is generated. In these cases, we specifically draw attention in the completion instructions that "No data" should be coded.

Fields marked with an asterisk (\*) are mandatory only for infants weighing below 1501 g or born before 33<sup>rd</sup> gestational weeks, but it is allowed to be filled for other infants as well.

## Common data

Common data refer to unchanging information that is identical across all data providers in case of a patient being treated at more than one institution (such as transportation or transfer from another NICU). The data entered by the first data recording institution will be overwritten by subsequent data entry, resulting in permanent loss of earlier data. Therefore, it is important to carefully edit and supplement already entered data. If we want to change information that significantly affects the patient's health status (e.g. birth weight, Apgar score), it is advisable to consult with the previous institution about the data discrepancy.

Common data includes data from the 'Basic data' table, the 'Obstetrics' table, the 'Delivery room' table and the 'First 12 hours' table.

## Institution-specific data

Institution-specific data include data from the 'First 72 hours' table, 'Risk conditions' table, 'Nutrition' table, 'Medications, blood products' table, 'Invasive devices, interventions' table, 'Ventilation and Surfactant' table, 'Monitoring' table, 'Surgery' table, 'Complications' table and 'ROP – Hearing' table. Care-related data from the own unit should be recorded (and not from another unit within the same institution), unless the instructions given concerning the variable specifies otherwise. In case of children who were transferred between units, only events in the own unit should be recorded. The answer 'No data' means that no record concerning care was available in the own unit.

In the case of a readmitted child, the data should be recorded in summarized form. The previously recorded data are overwritten by subsequent data entry, with permanent data loss of the former. Data already entered must always be carefully corrected and completed.

## Basic data

### Child's ID

The identification number assigned to the registry entry. Assigned by the program in registration sequence.

### Child's surname

A text field to indicate the child's surname at the time of admission. If it changes during care/transfer, the previously recorded name should be in parentheses after the new name.

**Child's first name**

A text field to indicate the child's first name(s) at the time of admission. In case of multiple first names, comma should not be used. If it changes during care/transfer, the previously recorded name should be in parentheses after the new name.

**Child's date of birth**

The child's date of birth, in the format: year, month, day.

**Child's time of birth**

The exact time of birth of the child, in the format: hour, minute. In the case of twins, the birth time should not be identical, there should be at least a 1-minute difference between the birth times of the twins.

**Birth weight (grams)**

The weight of the newborn baby in grams provided by the maternity ward (measurement in the delivery room) or by the sending institution, regardless of any potentially different measurement we may have at the time of admission. If no measurement was taken in the delivery room, the officially certified birth weight based on subsequent measurements should be recorded here. Value range: 250 – 7000 g.

**Birth length (cm)**

The measured body length at birth given in centimetres to one decimal point. If the body length was not measured at birth, the measurement of the following day should be reported. If no body length measurement was taken either at birth or the following day, 'No data' should be recorded. Value range: 20 – 70 cm.

**Head circumference at birth (cm)**

The measured head circumference at birth given in centimetres to one decimal points. If the head circumference was not measured at birth, the measurement of the following day should be reported. If no head circumference measurement was taken at birth or the following day, 'No data' should be recorded. Value range: 17 – 39 cm.

**Gestational age, completed weeks**

The gestational age determined by the obstetrician unit or the sending institution should be given, except if based on the neonatal examination, the previously determined gestational age is unrealistic and the official gestational age is determined and documented based on the result of the neonatal examination. In the case of an undefined value, the lower value should be given, e.g. for 27-28 weeks, 27. In case of an unknown value (e.g. completely uncared pregnancy, concealed pregnancy), the gestational age determined by the neonatologist (e.g. Dubowitz) should be given. Value range: 20 – – 45 weeks.

**Gestational age, completed days**

The gestational age determined by the maternity unit or the sending institution should be given. In the case of completed gestational week, the number of completed days of gestational age is 0.

**First day of last menstruation**

The date of the first day of the mother's last menstruation, in the format: year, month, day.

**Sex of the newborn**

The answer is 'Male' or 'Female' based on the genetic sex, if available. Otherwise, the answer is determined based on external genitalia.

The answer is 'Intersex' if the sex is uncertain.

**Twin status**

The answer is 'Yes' if two or more live fetuses were documented during pregnancy that ended in delivery, regardless of their subsequent fate, including fetal deaths that were not absorbed, and stillbirths. Twin fetuses described in early ultrasound scans that were later absorbed and thus not born shall not be marked.

The answer is 'No' for singleton pregnancies.

**Birth order of twins**

For multiple pregnancies, based on the number and order of live newborns born in the given pregnancy, regardless of the fate of the newborns, the answer is 'twin A', 'twin B', 'twin A triplet', 'twin B triplet', 'twin C triplet', 'twin A quadruplet', 'twin B quadruplet', 'twin C quadruplet', 'twin D quadruplet'.

The answer is 'extreme' for quintuplet or sextuplet births.

The answer is 'No twins' for singleton pregnancies.

**Mother's residence ZIP code**

Mother's permanent address: postal code, municipality, county selected from the 'Municipality' list.

In case of a foreign residence, select '0/Foreign'.

**Address: street, house number**

Mother's permanent address: street, house number. In case of a foreign residence, only the country should be registered.

**Mother's date of birth**

Date of birth of mother, in the format: year, month, day.

**Mother's surname**

Text field to specify the mother's surname at birth (maiden name).

**Mother's first name**

Text field to specify the mother's first name(s) at birth.

**Mother is a Hungarian citizen**

The answer is 'Yes' if the mother is a Hungarian citizen, and in the case of multiple citizenship if Hungarian is among them.

**Own registration number**

The maternal social security number must be recorded.

**Child's final social security number**

The child's final social security number, not a generated social security number. If the child's social security number is not available at the time of recording, 'No data' should be recorded, which must be updated with the final social security number generated in the meantime, to be recorded in this field.

### **Birth in an institution (second stage of labor)**

The answer is 'Yes' if the delivery took place in an obstetrics unit.

The answer is 'No' if the delivery was not in a maternity unit (e.g. at home, in an ambulance, in a public place or in another health facility).

### **Place of birth**

If the birth took place in an institution, select one of the obstetric institutions from the list 'Institution'.

If you cannot find the institution you are looking for, please contact the coordinator.

If the answer to the 'Birth in institution' question is 'No', select one of the following:

'At home without professional assistance'

'At home with professional assistance'

'Emergency ambulance of the National Ambulance Service'

'Ambulance of the National Ambulance Service'

'Public area'

'Other' e.g. Midwife home

### **Place of birth in the current NIC maternity unit**

The answer is 'Yes' if the newborn was born in the maternity unit of the NIC department.

Important: to be completed for the first admission after birth. Do not overwrite during transfer!

## **Obstetrics**

### **Number of previous pregnancies**

The number of previous pregnancies is equal to the sum of the number of previous childbirth events (twin births count as one pregnancy), the number of previous spontaneous miscarriages and the number of previous induced abortions. Example: in the case of previous spontaneous miscarriage and a previous twin birth, the number of previous pregnancies is two. Value range: 0 – 20.

### **Number of previous deliveries**

Number of previous live births and stillbirths. In the case of previous multiple pregnancies, each child is counted separately. The child/children of the current pregnancy should not be counted, including any twins born prior to the child whose data is currently being recorded.

Stillbirth is considered as delivery. Its definition is as follows: delivery occurring after the completion of the 24<sup>th</sup> week of gestation, where the fetus shows no signs of life upon separation from the mother's body. It is also considered a stillbirth, not a miscarriage, if one member of a multiple pregnancy born before the 24<sup>th</sup> week of gestation is born alive. Example: in the case of one previous stillbirth and a twin birth, the number of previous births would be three. Value range: 0-20.

### **Number of previous spontaneous miscarriages**

Spontaneous miscarriage refers to the termination of pregnancy before the 24<sup>th</sup> week of gestation, where the fetus shows no signs of life upon separation from the mother's body. In terms of miscarriages, twin pregnancies count as one event. Value range: 0 – 20.

### **Number of previous induced abortions**

Induced abortion refers to the intentional termination of pregnancy, where the fetus shows no signs of life upon separation from the mother's body. In terms of induced abortions, a twin pregnancy is considered as one event. Value range: 0 – 20.

### **Mother attended antenatal care?**

The answer is 'Yes' if the mother attended antenatal care, regardless of the starting date and the number of visits.

#### **.Start of antenatal care:**

The answer is 'Preconceptionally cared for' if the care started before the beginning of pregnancy.

The answer is 'Early ultrasound performed (before 12<sup>th</sup> week)' if the antenatal care started before the completion of the 12<sup>th</sup> gestational week.

The answer is 'Started in the second trimester (13 – 26<sup>th</sup> week)' if the antenatal care started between the completion of the 12<sup>th</sup> and the 26<sup>th</sup> gestational week.

The answer is 'Started after 26<sup>th</sup> week' if the antenatal care started after the completion of the 26<sup>th</sup> gestational week.

### **Mode of conception**

The answer is 'Spontaneous' if there was no pharmacological or assisted reproductive intervention for achieving pregnancy. Ultrasound examination and tubal flushing are allowed.

The answer is 'Hormonal induction' if the mother received ovulation induction hormonal treatment immediately before the current pregnancy.

The answer is 'IVF' if in vitro fertilization or intracytoplasmic sperm injection (ICSI) was performed.

### **Antibiotic administration/prophylaxis before delivery**

The answer is 'Yes' if the mother received systemic (oral, intramuscular, intravenous) antibiotic therapy at any time during her pregnancy/delivery.

#### **.Time of antibiotic administration to the mother**

The answer is 'Within 4 hours before completion of delivery' or 'More than 4 hours before completion of delivery', as appropriate.

#### **Name of the active substance of the antibiotic given to the mother**

Please provide the name of the active substance of the antibiotic. For example, for Augmentin, the active substances are amoxicillin and clavulanate.

### **\*Tocolysis occurred**

The answer is 'Yes' if the mother received uterine relaxation treatment during her pregnancy.

#### **.Time of initiation of tocolysis**

The answer 'Within 4 hours before completion of delivery', 'Within 24 hours before completion of labor', or 'Initiated more than 24 hours before completion of delivery', as appropriate.

#### **.Intravenous magnesium**

The answer is 'Yes' if the mother received intravenous magnesium for tocolysis during her pregnancy.

#### **.Atosiban (TRACTOCILE)**

The answer is 'Yes' if the mother received atosiban for tocolysis during her pregnancy.

#### **.Terbutaline (BRYCANYL)**

The answer is 'Yes' if the mother received terbutaline for tocolysis during her pregnancy.

### **.Fenoterol (PARTUSISTEN)**

The answer is 'Yes' if the mother received fenoterol for tocolysis during her pregnancy.

### **.Nifedipine**

The answer is 'Yes' if the mother received nifedipine for tocolysis during her pregnancy.

### **.Other medication used for tocolysis**

The answer is 'Yes' if the mother received a medication for tocolysis other than the ones mentioned above.

### **..Name of other medication used for tocolysis**

Text field to indicate the name of the other medication used for tocolysis.

## **Antenatal steroid**

The answer is 'Yes' if steroid administration (intramuscular or intravenous) to the mother commenced more than 24 hours before delivery.

The answer is 'Partial' if steroid administration (intramuscular or intravenous) to the mother commenced within 24 hours before delivery.

The answer is 'No' if the mother did not receive intramuscular or intravenous steroids during her pregnancy. The question is independent of the type, dosage, or route of administration of the steroid treatment.

### **.Number of antenatal steroid treatments**

A planned treatment consisting of multiple doses over a minimum duration of 24 hours counts as one treatment. Enter a number greater than 1 if antenatal steroid treatment was administered weeks before delivery, but delivery did not occur, and repeated steroid treatment was administered. The following questions pertain to the most recent administration of antenatal steroids. Value range: 1-3.

### **.First dose of complete antenatal steroid treatment before delivery**

Considered complete if a total of 24 mg was administered within 24 hours. Fill out only if the answer to the 'Antenatal steroid' question was 'Yes'.

The answer is the time of the first dose administration relative to the time of the delivery, either 'Within 24 – 48 hours', 'Within 48 – 168 hours' or 'After 168 hours' (more than 168 hours elapsed between the first dose and the delivery).

### **.First dose of partial antenatal steroid treatment before delivery**

It is considered partial if the pregnant woman did not receive 24 mg of steroid within 24 hours. To be completed if the answer to the 'Antenatal steroid' question was 'Partial'.

Answer 'Within 24 hours' indicates that the mother received the first dose of antenatal steroid treatment between 3 and 24 hours before delivery.

The answer 'Within 3 hours' indicates that the mother received the first dose of antenatal steroid treatment within 3 hours before delivery.

### **.Drug used for antenatal steroid treatment**

In case of multiple treatments, the steroid used last before delivery should be indicated.

The answer is 'Celestan' if the drug used for antenatal steroid treatment is Celestan.

The answer is 'Dexamethasone' if the active substance of the antenatal steroid treatment drug is dexamethasone.

The answer 'Other' if the drug used for antenatal steroid treatment is neither Celestan nor dexamethasone.

### **..Name of other antenatal steroid**

Text field to specify the name of the other medication used for antenatal steroid prophylaxis.

### **Chorioamnionitis**

The answer 'Yes' if chorioamnionitis is documented in the mother's obstetric or the newborn's neonatal documentation, or if it is later confirmed through placental histological examination. Example of clinical chorioamnionitis: maternal fever without any other explanation, along with at least two of the following criteria: maternal C-reactive protein (CRP) above 20 mg/l, maternal white blood cell count (WBC) above 15 G/l, uterine tenderness, maternal tachycardia above 100 beats per minute, fetal tachycardia above 160 beats per minute, and foul-smelling amniotic fluid.

### **.Diagnosis of chorioamnionitis**

The answer 'Based on clinical symptoms' is selected if the diagnosis of chorioamnionitis is documented in the obstetric documentation (as described above).

The answer 'Based on histology' is selected if the diagnosis of chorioamnionitis is made based on histological examination of the placenta. If there were clinical symptoms and the placental histology is also positive, then the option 'Based on clinical symptoms' should be selected.

The answer 'Other' is selected when there were no clinical symptoms and placental histology was not performed, but diagnosis was established otherwise, e.g. based on the preterm newborn's serum IL-6 level or other inflammatory response.

### **Intrauterine identified congenital anomaly**

The answer 'Yes' is selected if developmental or chromosomal abnormalities have been identified during antenatal care. In this case, the specific developmental or chromosomal disorder should be indicated using the ICD-10 codes. Only diagnoses from the Q main group can be provided. Multiple diagnoses can be indicated. For the "Type" question, the "Pregnancy" option should be selected.

### **Mode of delivery**

The answer is 'Vertex, uncomplicated' if the delivery is spontaneous, vertex (head-first), and vaginal.

The answer is 'Breech, uncomplicated' if the delivery is spontaneous, breech (buttocks-first), and vaginal.

The answer is 'Caesarean section' if the caesarean section was planned in advance.

The answer is 'Emergency caesarean section' if the caesarean section is performed due to an acute maternal or fetal compromise.

The answer is 'Other, complicated' if the vaginal delivery is complicated (e.g. vacuum extraction, forceps). Complicated cesarean sections should not be recorded here but should be indicated as 'Caesarean section' or 'Emergency caesarean section'.

### **Specify other complicated delivery**

Text field to specify description of the complicated delivery marked as 'Other, complicated' can be provided.

## **Cause of preterm birth**

It should be filled out for neonates born before the 37<sup>th</sup> gestational week according to the obstetric documentation.

The answer 'Abruptio' is selected if placental abruptio occurs before the birth of the fetus.

The answer 'Toxaemia' is selected if maternal toxaemia or eclampsia is the cause of preterm birth.

The answer 'Premature rupture of membranes' is selected if the amniotic sac ruptures before the onset of contractions.

The answer 'Preterm contractions' is selected if labour starts with regular contractions, closed cervix, and intact amniotic sac before the 37<sup>th</sup> week.

The answer 'Other' is selected if preterm birth occurred for reasons not mentioned above.

### **.Other cause for preterm birth**

Text field to provide specific description of the other cause for preterm birth.

## **Delivery room**

### **Delayed cord clamping**

Answer 'Yes' if the umbilical cord was not clamped immediately but was delayed after birth (or extraction).

#### **.Duration of umbilical cord clamping in seconds**

The time elapsed in seconds after birth (or extraction) until the umbilical cord is clamped. Value range: 1- – 60. The value range is outdated, the correction is in progress. In case of duration longer than 60 seconds, the maximum 60 seconds should be indicated.

### **\*Use of plastic bag or wrap**

Answer 'Yes' if any plastic bag or wrap was used in the delivery room to prevent neonatal hypothermia.

### **Apgar score at 1 minute**

The Apgar score at 1 minute, documented in the delivery room.

### **Apgar score at 5 minute**

The Apgar score at 5 minute, documented in the delivery room.

### **Apgar score at 10 minute**

The Apgar score at 10 minute, documented in the delivery room.

### **Umbilical cord blood gas test was performed**

The answer is 'Yes' if an umbilical cord blood gas analysis was performed in the delivery room.

#### **.Sampling site for umbilical cord blood gas test**

The answer 'Artery' is selected if the blood gas analysis in the delivery room was performed on a blood sample from the umbilical artery.

The answer 'Vein' is selected if the blood gas analysis in the delivery room was performed on a blood sample from the umbilical vein.

**.BE with sign (mmol/L)**

The measured value of base excess (BE) with its sign, expressed in mmol/L, from the delivery room blood gas analysis. Value range: -30 to +15 mmol/L.

**.pH**

The measured pH from the delivery room blood gas analysis. Value range: 6.3 – 7.8.

**.pCO<sub>2</sub> (mm Hg)**

The partial pressure of carbon dioxide (pCO<sub>2</sub>) dissolved in blood, measured in mmHg, from the delivery room blood gas analysis. Value range: 10 – 250 mmHg.

**.pO<sub>2</sub> (mm Hg)**

The partial pressure of oxygen (pO<sub>2</sub>) dissolved in blood, measured in mmHg, from the delivery room blood gas analysis. Value range: 0 – 750 mmHg.

**.Lactate (mmol/L)**

The measured concentration of lactate in mmol/L from the delivery room blood gas analysis. Value range: 0 – 30 mmol/L.

**Airway suction in the delivery room**

The answer 'Yes' is selected if airway suctioning (tracheal suctioning) was performed in the delivery room, either using a suction catheter or through an endotracheal tube.

**Oxygen administration in the delivery room**

The answer 'Yes' is selected if the newborn received oxygen supplementation in the delivery room. The oxygen content in the air is 21%.

**. Oxygen administration with FiO<sub>2</sub> setting using a blender:**

The answer 'Yes' is selected if oxygen administration in the delivery room was performed using a blender, i.e. a device used to adjust the ratio of oxygen and air mixture. It helps determine the accurate oxygen concentration in the inhaled gas (fraction of inspired oxygen, FiO<sub>2</sub> value).

**.. Maximum FiO<sub>2</sub> in the delivery room:**

The maximum oxygen concentration in the inhaled gas (FiO<sub>2</sub>) used during stabilisation in the delivery room. Value range: 0.21 – 1.00.

**.. Minimum FiO<sub>2</sub> in the delivery room:**

The minimum oxygen concentration in the inhaled gas (FiO<sub>2</sub>) used during stabilisation in the delivery room. Value range: 0.21 – 1.00.

**Delivery room stabilisation**

The answer is 'Yes' if any resuscitation attempts were made during delivery room care, involving at least one of the following treatments: non-invasive ventilation, intubation, invasive ventilation, surfactant administration, chest compressions, volume administration, medication administration.

**. Separate documentation of the stabilisation**

The answer is 'Yes' if a standardized resuscitation form has been filled out.

### **. Stabilisation with pulse oximeter monitoring**

The answer is 'Yes' if a pulse oximeter was used during the delivery room stabilisation, regardless of the duration.

### **.Any non-invasive ventilation**

The answer is 'Yes' if the newborn received mechanical (e.g. CPAP) or manual (T-piece resuscitator) respiratory support in the delivery room without an endotracheal tube. The administration of free-flow oxygen or burst oxygen administration is not included.

### **..Positive pressure ventilation with CPAP**

The answer is 'Yes' if the newborn received continuous positive airway pressure (CPAP) ventilation through the nose or mask in the delivery room.

#### **...Max EEP (cm H<sub>2</sub>O) with CPAP**

The highest end-expiratory pressure (EEP) should be recorded in cm H<sub>2</sub>O, applied for at least 30 seconds during CPAP ventilation at the time of delivery room stabilisation. Value range: 0 – 30 cm H<sub>2</sub>O.

#### **...CPAP application method**

Answer 'Nasal cannula' or 'Mask' (a face mask covering both the nose and mouth), as appropriate. It is not possible to select both at present – correction in progress -, please indicate the one which occurred in the majority of time.

### **..T-piece resuscitator – Neopuff or similar**

Positive pressure ventilation with T-piece resuscitator – Neopuff, NeoTee or similar device.

Answer 'Yes' if positive pressure ventilation was provided in the delivery room using a T-piece resuscitator, NeoPuff, NeoTee or a similar device.

#### **...Max EEP (cm H<sub>2</sub>O) with resuscitator**

The highest end-expiratory pressure (EEP) should be recorded in cm H<sub>2</sub>O, applied for at least 30 seconds during T-piece resuscitator/Neopuff ventilation at the time of delivery room stabilisation. Value range: 0 – 30 cm H<sub>2</sub>O.

#### **...Max PIP (cm H<sub>2</sub>O) with resuscitator**

The highest peak inspiratory pressure (PIP) should be recorded in cm H<sub>2</sub>O, applied for at least 30 seconds during T-piece resuscitator/Neopuff ventilation at the time of delivery room stabilisation. Value range: 5 – 60 cm H<sub>2</sub>O.

#### **...Resuscitator application method**

Answer 'Nasal cannula or 'Mask', as appropriate.

### **..Self-inflating BVM**

Answer 'Yes' if the newborn was given positive pressure ventilation in the delivery room using a self-inflating bag valve mask (BMV) (using an Ambu or other similar device based on the same principle).

### **...Max EEP (cm H<sub>2</sub>O) during self-inflating BVM ventilation**

The highest end expiratory pressure (EEP) should be recorded in cm H<sub>2</sub>O, applied for at least 30 seconds during self-inflating BVM ventilation at the time of delivery room stabilisation. Value range: 0 – 30 cm H<sub>2</sub>O.

### **...Max PIP (cm H<sub>2</sub>O) during self-inflating BVM ventilation**

The highest peak inspiratory pressure (PIP) should be recorded in cm H<sub>2</sub>O, applied for at least 30 seconds during self-inflating BVM at the time of delivery room stabilisation. Value range: 5 – 60 cm H<sub>2</sub>O.

### **...Self-inflating BVM (Ambu) application method**

Answer either 'Nasal cannula' or 'Mask'.

### **..Other non-invasive ventilation**

Answer 'Yes' if the newborn received any non-invasive ventilation in the delivery room other than the non-invasive ventilation methods listed above.

### **...Name of other non-invasive ventilation**

Text field to specify the other form(s) of non-invasive ventilation.

### **.Intubation in the delivery room**

Answer is 'Yes' if an intratracheal tube was inserted in the delivery room. A 'Yes' response should also be marked if the upper mentioned intubation occurred for the suctioning of meconium or amniotic fluid, if surfactant was administered or preventive intubation was performed. In this case, the answer to the question 'Intubation in the delivery room' from the 'Ventilation and surfactant' table should also be marked as 'Yes'.

### **.Invasive ventilation**

Answer 'Yes' if the newborn received ventilation through an endotracheal tube in the delivery room. In this case, the answer to the question 'Intubation in the delivery room' should also be marked as 'Yes'.

### **..Invasive ventilation with a self-inflating BVM**

Answer 'Yes' if the newborn received invasive ventilation in the delivery room via an endotracheal tube using a self-inflating balloon BVM.

### **...Max EEP (cm H<sub>2</sub>O) during invasive ventilation with self-inflating BVM**

At the time of delivery room stabilisation, the maximum end-expiratory pressure (EEP) in cm H<sub>2</sub>O applied for at least 30 seconds during invasive ventilation using a self-inflating BVM should be recorded. Value range: 0 – 30 cm H<sub>2</sub>O.

### **...Max PIP (cm H<sub>2</sub>O) during invasive ventilation with self-inflating BVM**

At the time of delivery room stabilisation, the highest peak inspiratory pressure (PIP) in cm H<sub>2</sub>O applied for at least 30 seconds during invasive ventilation using a self-inflating BVM should be recorded. Value range: 5 – 60 cm H<sub>2</sub>O.

## **..Mechanical ventilation**

Answer 'Yes' if the neonate received invasive mechanical ventilation via endotracheal tube in the delivery room.

### **...Max EEP (cm H<sub>2</sub>O) during mechanical ventilation**

At the time of delivery room stabilisation, the highest end-expiratory pressure (EEP) in cm H<sub>2</sub>O applied for at least 30 seconds during mechanical ventilation should be recorded. Value range: 0 – 30 cm H<sub>2</sub>O.

### **...Max PIP (cm H<sub>2</sub>O) during mechanical ventilation**

At the time of delivery room stabilisation, the highest peak inspiratory pressure (PIP) in cm H<sub>2</sub>O applied for at least 30 seconds during mechanical ventilation should be recorded. Value range: 5 – 60 cm H<sub>2</sub>O.

## **.Surfactant administration in the delivery room**

Answer 'Yes' if surfactant was administered in the delivery room or before transfer to the definitive care location (NICU) began.

### **..Surfactant administration without intubation in the delivery room**

Answer 'Yes' if the surfactant administration was given without intubation in the delivery room, regardless of whether the newborn infant subsequently required intubation.

Answer 'No' if the surfactant was given into the intratracheal tube in the delivery room. In this case, the answer to the question 'Intubation in the delivery room' should be marked 'Yes'.

### **..Time of first surfactant dose (minutes of life)**

Time of first surfactant dose in minutes of life. Value range: 0 – 100 minutes.

### **..Amount of first surfactant dose (mg)**

Amount of the first surfactant dose in mg. Value range: 50 – 1000 mg.

### **..Surfactant type**

Answer 'Curosurf' if the surfactant treatment given in the delivery room is Curosurf.

Answer 'Other' if the surfactant treatment given in the delivery room is not Curosurf.

### **...Name of other preparation**

Text field to specify the name of the other surfactant preparation.

## **.Volume administration**

Answer 'Yes' if volume administration was given in the delivery room (e.g. physiological saline, albumin solution, blood product, plasma), administered relatively quickly in order to stabilise the circulatory status. 10% glucose bolus, early glucose infusion or IV drug administration due to hypoglycaemia is not included.

## **.Chest compression in the delivery room**

Answer 'Yes' if chest compression was performed in the delivery room.

## **.Administration of drugs in the delivery room**

Answer 'Yes' if medication was given in the delivery room.

**..Epinephrine in the delivery room**

Answer 'Yes' if the newborn was given epinephrine in the delivery room.

**..Bicarbonate in the delivery room**

Answer 'Yes' if the newborn received bicarbonate in the delivery room.

**..Other drugs given in the delivery room**

Answer 'Yes' if the newborn received other medication than epinephrine and bicarbonate in the delivery room. E.g. caffeine, glucose solution.

**...Name of other medication given in the delivery room**

Text field to indicate the name of the other medication given in the delivery room.

**.Time of start of transfer from the delivery room**

The time the transfer from the delivery room started, in the format: year, month, day, hour, minute. It must be later than the date and time of birth.

**.Transfer from delivery room in an incubator**

The answer is 'Yes' if the transfer from the delivery room to the first attending NICU was in an incubator throughout.

**.Transfer from delivery room ventilated**

The answer is 'Yes' if the newborn was ventilated or oxygenated for any length of time during transfer from the delivery room to the first NICU.

**..Name of ventilation during transfer from the delivery room**

The answer is 'ET + self-inflating bag' if self-inflating bag ventilation via endotracheal tube (ET) was given during transfer.

The answer is 'ET + T-piece resuscitator' if a T-piece resuscitator ventilation via endotracheal tube was given during transfer.

The answer 'ET + mechanical ventilation' if mechanical ventilation via endotracheal tube was performed during transfer.

The answer is 'nCPAP/T-piece resuscitator' if ventilation during transfer was performed via a nasal cannula or mask using nasal continuous positive airway pressure (nCPAP) or T-piece resuscitator.

The answer is 'Pharyngeal oxygen' if the neonate received pharyngeal oxygen/pharyngeal ventilation support during delivery.

The answer is 'Hood oxygenation' if the concentration of oxygen in the incubator during delivery is greater than 21%.

The answer is 'Other ventilation' if the neonate received ventilation other than those listed above during transfer.

**Time of arrival at NICU**

The date of arrival from the delivery room to the first admitting unit, in the format: year, month, day, hour, minute. It must be later than the 'Time of start of transfer from the delivery room'.

**Body temperature at discharge from the delivery room**

Body temperature at discharge from the delivery room should be given in degrees Celsius to one decimal point. Method of temperature measurement: thermometer or servo-controlled skin

thermometer. The source of the measurement data may be skin, ear or axillary body temperature data. Value range: 28.0 – 42.0 °C.

### **Body temperature upon arrival at NICU**

Body temperature upon arrival at the NICU should be given in degrees Celsius to one decimal point. Method of temperature measurement: thermometer or servo-controlled skin thermometer. The source of the measurement data may be skin, ear or axillary body temperature data. Value range: 28.0 – 42.0°C.

### **Died in the delivery room**

The answer is 'Yes' if the newborn died in the delivery room or during transport to the NICU.

#### **. Cause of death in the delivery room**

The answer is 'Respiratory failure' if the cause of death in the delivery room is respiratory failure.

The answer is 'Sepsis' if the cause of death in the delivery room is sepsis.

The answer is 'Neurological cause' if the cause of death in the delivery room is a neurological disease but not a congenital anomaly.

The answer is 'Congenital anomaly' if the cause of death in the delivery room is a congenital anomaly. In this case, the specific developmental or chromosomal abnormality should be indicated on the ICD-10 table.

The answer is 'Respiratory failure' if the cause of death in the delivery room is respiratory failure.

The answer 'Not known' if the cause of death in the delivery room could not be determined.

The answer is 'Other' if the cause of death in the delivery room is known but not one of the above.

The answer is 'No data' if no information is available about the cause of death.

#### **.Pathological examination (pathological autopsy) was performed**

The answer is 'Yes' if a pathological examination was performed on the newborn who died in the delivery room.

#### **.Therapeutic interventions were limited in the delivery room**

The answer is 'Yes' if palliative or comfort treatment was initiated, with or without a prior and unsuccessful attempt at stabilisation, due to the presence of an incompatible disorder or acquired condition.

## **First 12 hours**

ONLY data of the first 12 hours of life should be recorded in this table!

The 'First 12 hours' table must be completed by the institution that performed the care of the newborn within the first 12 hours of life. If the care of the newborn is shared by two institutions within the first 12 hours of life, the second institution filling in the form must take into account the data already entered!

Data from the delivery room should only be included (e.g. blood gas analysis date or body temperature) in case the lowest measured values were obtained in the delivery room, or if the measurement was taken in the delivery room only. In such cases, the data should be re-entered in the relevant fields (after having been entered in the 'Delivery room' table).

If the newborn was (also) cared for at a non NICU-II or non-NICU-III facility within the first 12 hours, all available information should be used to complete the fields.

**Min FiO<sub>2</sub>**

The minimal FiO<sub>2</sub> level needed to ensure adequate oxygenation during the first 12 hours of life. The minimum FiO<sub>2</sub> required during resuscitation in the delivery room should not be taken into account! Oxygenation is considered adequate if a pulse oximetry reading of 88-95% is obtained. The lowest FiO<sub>2</sub> value should be recorded that was sufficient to 'ensure adequate oxygenation' for even a short period during the first 12 hours of life after admission to the unit. In the case of an incubator/headbox, if no data were available on the oxygen concentration used, 0.4 FiO<sub>2</sub> should be entered. FiO<sub>2</sub> values should be given in decimal fractions. Value range: 0.21-1.00.

If no oxygen was administered, a value of 0.21 should be recorded.

If there was no change in FiO<sub>2</sub> from admission until the end of the 12<sup>th</sup> hour, then the 'Min FiO<sub>2</sub>' and 'Max FiO<sub>2</sub>' values are the same, and the same value should be recorded for both fields.

**Max FiO<sub>2</sub>**

The maximum FiO<sub>2</sub> value applied in the first 12 hours of life. The FiO<sub>2</sub> used during delivery room resuscitation is not taken into account! Oxygenation is considered adequate if a pulse oximetry reading of 88-95% is obtained. The highest FiO<sub>2</sub> value should be recorded that was required to 'ensure adequate oxygenation' for even a short period during the first 12 hours of life after admission to the unit. In the case of an incubator/head box, if no data were available on the oxygen concentration used, 0.4 FiO<sub>2</sub> should be entered. FiO<sub>2</sub> values are given in decimal fractions. Value range: 0.21-1.00.

If no oxygen was received, a value of 0.21 should be recorded.

If there was no change in FiO<sub>2</sub> from admission to the end of the 12<sup>th</sup> hour, then the 'Min FiO<sub>2</sub>' and 'Max FiO<sub>2</sub>' values are the same, and the same value should be recorded for both fields.

**Max EEP (cm H<sub>2</sub>O)**

The value of the maximum end-expiratory pressure (EEP) should be recorded in cm H<sub>2</sub>O, applied during the first 12 hours of life, regardless of the duration of application – whether CPAP, nBIPAP, conventional or HFO ventilation was administered (for HFO, the EEP value is equal to the value of MAP). If none of the above listed types of ventilation were used, a value of 0 should be entered. Value range: 0 – 30 cm H<sub>2</sub>O.

**Max MAP (cm H<sub>2</sub>O)**

The value of the maximum mean airway pressure (MAP) in in cm H<sub>2</sub>O should be recorded, applied during the first 12 hours of life, regardless of the duration of application. This only makes sense in case of conventional, HFO and nBIPAP ventilation. In case of spontaneous breathing, unaided, pharyngeal oxygen, cabin oxygen, nCPAP, the value 0 should be recorded. Value range: 0 – 30 cm H<sub>2</sub>O.

**A blood gas test was carried out**

The answer is 'Yes' if a blood gas analysis was carried out in the first 12 hours of life, even if only umbilical cord blood or other delivery room blood gas tests were performed and there was no subsequent blood gas test.

The answer is 'No' if there was no blood gas test up to and including the 12<sup>th</sup> hour of life, even if there was one thereafter.

**.Total number of blood gas tests in the first 12 hours**

Total number of blood gas tests in the first 12 hours. Cord blood gas tests should be included if performed, but any blood gas tests carried out after 12 hours should not be counted.

### **.Sampling site of the blood gas test with the worst pH value**

The answer is 'Capillary', 'Venous' or 'Arterial', depending on the sampling site of the blood gas analysis showing the worst pH value.

### **Worst BE with sign (-/+ ) (mmol/L)**

Worst base deficit (negative base excess, BE) with sign (-/+) (mmol/L). The worst base deficit (in mmol/L) measured during the first 12 hours of life. The sign must always be marked! If more than one measurement is taken, the worst value should be entered. Value range: -30 to +15 mmol/L. The lower the number, the worse the value, e.g. -12 mmol/L is worse than -6 mmol/L.

### **.Worst pH**

The lowest pH value measured during the first 12 hours of life to the first decimal point. When entering the pH, do not write 0s at the end of the value! Value range: 6.5 - 7.8.

### **.Highest pCO<sub>2</sub> (mm Hg)**

The highest partial pressure of dissolved carbon dioxide (pCO<sub>2</sub>) in mm Hg, measured during the first 12 hours, rounded to the nearest whole number.

If only one measurement was taken, the highest and lowest values are the same and thus the same value should be recorded in both fields. Value range: 5 – 150 mm Hg.

### **.Lowest pCO<sub>2</sub> (mm Hg)**

The lowest partial pressure of dissolved carbon dioxide (pCO<sub>2</sub>) in mm Hg, measured during the first 12 hours, rounded to the nearest whole number.

If only one measurement was taken, the highest and lowest values are the same and thus the same value should be recorded in both fields. Value range: 5 – 150 mm Hg.

### **.Highest pO<sub>2</sub> (mm Hg)**

The highest partial pressure of oxygen (pO<sub>2</sub>) in mm Hg, measured during the first 12 hours, rounded to the nearest whole number.

If only one measurement was taken, the highest and lowest values are the same and the same value should be recorded in both fields. Value range: 5 – 760 mm Hg.

### **.Lowest pO<sub>2</sub>**

The lowest partial pressure of oxygen (pO<sub>2</sub>) in mm Hg, measured in the first 12 hours, rounded to the nearest whole number.

If only one measurement was taken, the highest and lowest values are the same and thus the same value should be recorded in both fields. Value range: 5 – 760 mm Hg.

### **.Minimum blood glucose level in the first 12 hours (mmol/L)**

The lowest blood glucose level measured in the first 12 hours, in mmol/L to one decimal point.

If only one measurement is taken, the highest and lowest values are the same and thus the same value should be recorded in both fields. To be recorded even without a blood gas measurement. Value range: 0.0 – 15.0 mmol/L.

### **.Maximum blood glucose level in the first 12 hours (mmol/L)**

The highest blood glucose level measured in the first 12 hours, in mmol/L to one decimal point.

If only one measurement is taken, the highest and lowest values are the same and the same value should be recorded in both fields. To be recorded even without a blood gas measurement. Value range: 0.0 – 30.0 mmol/L.

#### **.Minimum lactate level in the first 12 hours (mmol/L)**

The lowest lactate level measured in the first 12 hours, in mmol/L to the first decimal point.

If only one measurement is taken, the highest and lowest values are the same, thus the same value should be recorded in both fields. To be recorded even without a blood gas measurement. Value range: 0.0 – 30.0 mmol/L.

#### **.Maximum lactate level in the first 12 hours (mmol/L)**

The highest lactate level measured in the first 12 hours, in mmol/L to the first decimal point.

If only one measurement is taken, the highest and lowest values are the same and thus the same value should be recorded in both fields. To be recorded even without a blood gas measurement. Value range: 0.0 – 30.0 mmol/L.

#### **Lowest measured body temperature in the first 12 hours (°C)**

The lowest body temperature recorded in the first 12 hours, in degrees Celsius to the first decimal point. Method of temperature measurement: thermometer or servo-controlled skin thermometer. The source of the measurement data may be skin, ear or armpit body temperature data. If the measurement taken in the delivery room was the lowest value, that value should be recorded. Range: 28.0 – 42.0 °C.

#### **First 72 hours**

The 'First 72 hours' table must be completed by the facility that cared for the newborn within the first 72 hours of life. In case the newborn was cared for during the first 72 hours, or part thereof, in an institution which is not officially reported to the NICU database (primary obstetrics units, home births, private obstetricians, etc.), an attempt should be made to complete the fields on the basis of the available anamnestic data and consultation with previous providers.

#### **Intrauterine growth restriction**

The answer is 'Yes' if the weight of the newborn is below the standard 10 percentile for age and sex.

#### **Diabetic fetopathy**

The answer is 'Yes' if the consequences of fetal hyperinsulinemia are observed on the newborn of a diabetic mother, irrespective of the type of diabetes (e.g. macrosomia, postnatal hypoglycaemia, polycythaemia etc.), or if it is reported as a diagnosis in the newborn's documentation.

#### **Respiratory disorders**

The answer is 'None' if the newborn had no respiratory distress during the first 72 hours of life.

The answer is 'RDS, HMD, IRDS' if the respiratory distress is due to surfactant deficiency (RDS: – Respiratory Distress Syndrome, HMD: – Hyaline Membrane Disease, IRDS: Infant Respiratory Distress Syndrome).

The answer is 'MAS' if the cause of the respiratory disorder is meconium aspiration syndrome (MAS).

The answer is 'IUP' if the main cause of the respiratory disorder is intrauterine pneumonia (IUP). (Other terms for IUP are 'intrauterine acquired' or "congenital' pneumonia.) In this case, the answer to the question 'Bacterial infection within 72 hours' is 'Yes'.

The answer is 'Wet lung' if the respiratory disorder is caused by slow absorption of the fluid filling the airways during fetal life. Synonym: transient tachypnea (TTP).

The answer is 'Adaptation disorder' if this was indicated as cause for the respiratory distress in the documentation.

The answer is 'Other' if the illness causing the respiratory disorder is not listed above, e.g. asphyxia, neuromuscular disorder, spasm, diaphragmatic hernia, pulmonary hypoplasia or other developmental disorder.

### **Lowest blood pressure in the first 24 hours (MAP mm Hg)**

The lowest mean arterial blood pressure (MAP) measured in the first 24 hours, expressed in mm Hg, regardless of whether invasive or non-invasive blood pressure measurement was performed. Calculation:  $MAP = (2 * DBP + SBP) / 3$ , where DBP is diastolic blood pressure and SBP is systolic blood pressure. Value range: 10 – 100 mm Hg.

### **Shock**

The answer is 'Yes' if occurrence of shock is noted in the patient's documentation (medical records, progress notes, discharge summary).

### **PFC/PPHN (persistent fetal circulation)**

The answer is 'Yes' if one of the terms PFC (persistent fetal circulation), PPHN (persistent pulmonary hypertension of the newborn) or pulmonary hypertension is listed as diagnosis in the patient's final report. Typically, in PFC/PPHN, the pulmonary vascular resistance remains high after delivery. Clinical signs are usually dyspnoea and cyanosis within the first 24 hours, pulse oximetry ( $\geq 10\%$  difference between pre- and postductal  $O_2$  saturation), positive hyperoxia test. Definitive diagnosis: cardiac ultrasound.

### **Postasphyxia**

The answer is 'Yes' if the newborn is hypoxic, hypercapnic and has lactate acidosis due to oxygen deprivation in utero, during delivery or postpartum. The newborn was depressed at birth and therefore required resuscitation of certain intensity. Subsequently, the newborn developed a prolonged multi-organ dysfunction (respiratory, circulatory, nutritional etc. disorder), which was the main reason for intensive treatment.

### **Hypoxic-ischemic encephalopathy**

The answer is 'Yes' if a newborn with asphyxia is diagnosed with encephalopathy within the first 72 hours of life, i.e. is in an abnormal state of consciousness and has at least one of the following: abnormal muscle tone, abnormal tendon reflexes or seizures. In this case, the answer to the question 'Postasphyxia' is 'Yes'.

### **Polyglobulia/polycythemia**

The answer is 'Yes' if the venous haematocrit level is above 65% AND clinical signs associated with microcirculatory disturbance are present (dyspnea, tachypnea, cyanosis, tachycardia, feeding difficulty, vomiting, hypoglycaemia, hyperbilirubinemia, plethora, haematuria, renal vein thrombosis,

priapism, gallstones, hypotension, irritability, abnormal crying, lethargy, irritability, seizures, respiratory distress etc.). Excludes the answer 'Yes' to the 'Anaemia in the first 24 hours' question.

### **Anaemia in the first 24 hours**

The answer is 'Yes' if the venous hematocrit is below 40% within the first 24 hours. Excludes the answer 'Yes' to the question 'Polyglobulia/Polycythemia'.

### **Bacterial infection within 72 hours**

Answer 'Yes' if there is a bacterial infection (e.g. skin, urinary tract) within the first 72 hours of life, even if the source and localisation (affected organ) of the infection remains unclear.

### **Early onset sepsis**

The answer is 'Yes' if based on the clinical symptoms AND inflammatory parameters, the diagnosis of early onset sepsis appears on the newborn's final report or any other medical documents, regardless of whether any blood culture examination confirms the upper mentioned diagnosis. In this case, the answer to the question 'Bacterial infection within 72 hours' is 'Yes'.

### **A blood culture test was performed within 72 hours**

The answer is 'Yes' if a blood culture test was performed within the first 72 hours of life, regardless of when the result was received.

#### **.Blood culture positive within 72 hours**

The answer is 'Yes' if the result of a bacteriological culture of blood taken within the first 72 hours of life is positive.

#### **..Pathogen identification (blood culture)**

Text field for any pathogen identified from a blood culture taken within 72 hours of life.

### **Early onset bacterial meningitis**

Answer 'Yes' if confirmed bacterial meningitis occurred in the first 72 hours of life. In this case, the answer to the question 'Bacterial infection within 72 hours' is 'Yes'.

### **Lumbar puncture occurred within 72 hours**

The answer is 'Yes' if a lumbar puncture occurred for any reason within the first 72 hours of life. In this case, the number of lumbar punctures must also be indicated in the 'Invasive devices, interventions' table.

#### **. Cerebrospinal fluid (CSF) analysis positive within 72 hours**

The answer is 'Yes' if the CSF drawn within the first 72 hours of life has a white blood cell count  $\geq 30/\text{mm}^3$ ; protein  $> 100 \text{ mg/dl}$  (in case of full-term newborn) or  $> 150 \text{ mg/dl}$  (in case of preterm newborn), CSF glucose  $\leq 2/3$  serum glucose.

Answer 'No data' if the presence of blood makes the CSF analysis inconclusive for the diagnosis of infection.

#### **.CSF bacteria positive within 72 hours**

The answer is 'Yes' if the result of the CSF bacteriological culture taken within the first 72 hours of life is positive.

### **..Pathogen name within 72 hours (CSF bacteria)**

Text field for any pathogen identified from the CSF bacteriological culture taken within 72 hours of life.

### **Positive culture result from a bacteriological sample taken on admission**

The answer is 'Yes' if the result of bacteriological culture from samples taken within the first 72 hours of life (e.g. nasal secretions, eye secretions, urine, perianal swabs, ear effusion, amniotic fluid) is positive. The answer is 'Yes' even if the bacteria detected are not considered to be pathogenic.

### **.Pathogen name (positive culture)**

Text field for any bacteria detected via bacteriological culture from sample taken within 72 hours of life.

### **Hydrops syndrome**

Answer 'Yes' if excessive fluid accumulation is present in the newborn due to immune- or non-immune-mediated causes. At least two of the following are present: subcutaneous oedema, pleural effusion, pericardial effusion, ascites, polyhydramnios. The diagnosis is indicated in the documentation.

### **Confirmed congenital virus (TORCH) infection**

The answer is 'Yes' if based on clinical signs, the course of the disease and test results, the diagnosis of congenital TORCH infection is indicated in the final report. TORCH: Toxoplasma gondii, Others (other microbes), Rubella virus, Cytomegalovirus, Herpes viruses. Other microbes: Treponema pallidum, Parvovirus B-19, Hepatitis B virus, Varicella-zoster virus, HIV, Mycobacterium etc.

### **Isoimmunisation**

The answer is 'Yes' if isoimmunisation against any red blood cell antigen occurs, causing clinical symptoms and/or is detected by laboratory methods.

The answer is 'No' even if no specific laboratory test has been performed due to lack of clinical suspicion for isoimmunisation.

### **Direct Coombs test positive**

The answer is 'Yes' if the result of the direct Coombs test is positive.

The answer is 'No' if the result of the direct Coombs test is negative.

The answer is 'No data' if no direct Coombs test laboratory test was performed

### **Rh isoimmunisation, based on clinical signs and laboratory findings**

Answer 'Yes' if Rh incompatibility between mother and newborn occurs AND clinical signs (jaundice, anaemia) or laboratory abnormalities (anaemia, LDH elevation, Coombs positivity) are present. In this case, select 'Yes' for the question 'Isoimmunisation'.

Answer 'No' if Rh incompatibility occurs between mother and newborn without clinical and laboratory abnormalities.

### **Irregular antibodies detectable, except anti-D**

Answer 'Yes' if an irregular antibody to a red blood cell antigen has been detected by laboratory examination which is NOT Rh anti-D but other antibodies (e.g. antibodies to blood group ABO, anti-A1, anti-C, Kell etc.). The presence of an irregular antibody to a non-red blood cell is not to be indicated. For the question 'Isoimmunisation', the answer 'Yes' should be marked.

The answer is 'No data' if no laboratory test for the detection of an irregular antibody has been performed.

## **Risk conditions**

### **Nosocomial non-bloodstream infection**

Answer 'Yes' if the infection occurs more than 72 hours after hospital admission and no evidence suggests it was present at the time of hospital admission.

#### **.Name of nosocomial non-bloodstream infection**

Text field for one-word designations indicating the organ localisation (e.g. pneumonia, urinary tract, skin, conjunctiva).

### **Bacterial infection after 72 hours of life**

The answer is 'Yes' if there is a bacterial infection after 72 hours of life (e.g. skin, urinary tract, eye), even if the source of the infection or the site remains unclear. A 'Yes' answer should also be entered if the answer to the question 'Bacterial sepsis after 72 hours of life' or 'Meningitis/ventriculitis' after 72 hours of life is 'Yes'. In other words, in the case of sepsis or meningitis, the occurrence of infection must also be indicated in this field.

The answer is 'No data' if the newborn was not cared for in the unit after 72 hours of life.

### **Bacterial sepsis after 72 hours of life**

The answer is 'Yes' if the diagnosis of late-onset sepsis based on clinical signs AND elevated inflammatory parameters is given in the final report or any medical documentations, regardless of whether blood culture confirms the diagnosis. In this case, the answer to the question 'Bacterial infection after 72 hours of life' is 'Yes'.

The answer is 'No data' if the newborn was not cared for in the unit after 72 hours of life.

### **Blood culture test performed after 72 hours of life**

The answer is 'Yes' if the blood culture analysis was performed between the 72<sup>nd</sup> hour of life and the date of death.

The answer is 'No' if the documentation clearly indicates that no blood culture test was performed.

The answer is 'No data' if the newborn was not cared for in the unit after 72 hours of life or if care was provided after 72 hours of life but it cannot be established with certainty whether a blood culture test was performed.

#### **.Positive blood culture occurred after 72 hours of life**

The answer is 'Yes' if the result of the bacteriological blood culture taken after 72 hours of life is positive, regardless of the pathogen.

#### **..Pathogen name (blood culture after 72 hours of life)**

Text field for the name of the identified pathogen indicated in the 'Positive blood culture occurred after 72 hours of life' question.

#### **..Start of first sepsis episode (after 72 hours of life)**

Date of first positive blood culture sample in the following format: year, month, day.

### **Meningitis/ventriculitis after 72 hours of life**

The answer is 'Yes' if the diagnosis of meningitis or ventriculitis is given in the final report based on clinical signs and/or laboratory and imaging findings. In this case, the answer to the question 'Bacterial infection after 72 hours of life' is 'Yes'.

The answer is 'No data' if the neonate was not cared for in the unit after 72 hours of life.

### **Lumbar puncture/ventricular puncture occurred**

The answer is 'Yes' if a lumbar puncture occurred for any reason after 72 hours of life. In this case, the intervention should also be counted in the question 'Number of lumbar punctures' in the 'Invasive devices, interventions' table.

The answer is 'No data' if the neonate was not cared for in the unit after 72 hours of life.

#### **.Cerebrospinal fluid (CSF) analysis positive after 72 hours**

The answer is 'Yes' if the cerebrospinal fluid (CSF) drawn after 72 hours of life has an abnormally elevated white blood cell count or protein content according to local criteria, or an abnormally low glucose level compared to the blood glucose level. In general, abnormal CSF drawn after 72 hours of life has: a white blood cell count  $\geq 30/\text{mm}^3$ ; protein  $> 100 \text{ mg/dl}$  (in case of term newborn) or  $> 150 \text{ mg/dl}$  (in case of preterm newborn), CSF glucose  $\leq 2/3$  serum glucose.

The answer is 'No data' if the CSF analysis is inconclusive for the diagnosis of infection due to the presence of blood or other reasons (e.g. too few samples).

#### **.CSF bacteria positive**

The answer is 'Yes' if the result of the bacteriological culture of CSF taken after 72 hours of life is positive.

#### **..Pathogen name after 72 hours of life (CSF bacteria)**

Text field for the name of the bacteria identified via bacterial culture of CFS from a sample taken after 72 hours of life.

### **Systemic fungal infection**

The answer is 'Yes' if the result of blood culture, CSF or other bodily fluid taken after 72 hours of life confirms fungal infection.

### **Postnatal virus infection**

The answer is 'Yes' if a postnatally acquired (and not congenital) viral infection has been diagnosed on the basis of clinical signs, course of the disease and test results. The viral infection (usually with the name of the pathogen) is included as a diagnosis in the final report. Transfusion-acquired CMV, hepatitis and RSV infections should also be indicated.

#### **.Name of viral infection**

Text field for the name of the postnatal viral infection.

### **Convulsive state**

The answer is 'Yes' if any seizure, eclampsia, or epilepsy symptom/diagnosis is indicated in the patient documentation or in the final report (Can be short or long, single or recurrent, subtle, clonic or tonic seizure).

### **Recurrent apnoea**

The answer is 'Yes' if least 2 episodes of apnoea (10 seconds) occurred, whether they occurred on the same day or less frequently.

### **Blood glucose level below 2.6 mmol/L on at least two occasions**

The answer is 'Yes' if blood glucose was 2.6 mmol/L or lower on at least two occasions.

The answer is 'No' if the blood sugar level has been determined at least twice, and one or both were higher than 2.6 mmol/L.

The answer is 'No data' if the blood sugar level has only been determined one time or not at all.

### **Thrombocytopenia, mild**

The answer is 'Yes' if the platelet count was between 50 and 100 G/l on at least two occasions. Excludes a 'Yes' answer to 'Thrombocytopenia, severe'.

The answer is 'No' if at least two blood count tests have been performed and the platelet count was higher than 100 G/l on one or both.

The answer is 'No data' if no or only one blood count was performed.

### **Thrombocytopenia, severe**

The answer is 'Yes' if the platelet count was below 50 G/l on at least two occasions.

Excludes a 'Yes' answer to the question 'Thrombocytopenia, mild'.

The answer is 'No' if at least two blood count tests have been performed and the platelet count was higher than 50 G/l on one or both

The answer is 'No data' if no or only one blood count test was performed.

### **Leukopenia**

The answer is 'Yes' if the total white blood cell count was below 5 G/l on even occasion.

The answer is 'No' if the total white blood cell count has been above 5 G/l on each blood count test performed.

The answer is 'No data' if no blood count was performed.

### **Neutropenia**

The answer is 'Yes' if the absolute neutrophil granulocyte count was below 1 G/l on even one occasion.

The answer is 'No' if the absolute neutrophil granulocyte count was above 1 G/l on each blood count test performed.

The answer is 'No data' if no blood count was performed.

### **Congenital malformation**

The answer is 'Yes' if the patient's diagnoses include one or more ICD codes from the Q main group (developmental disorder, chromosomal abnormality). In case of the answer 'Yes', the specific developmental disorder or chromosomal abnormality should be indicated on the ICD table. Multiple diagnoses may be indicated!

#### **.Severity of congenital malformation**

The answer is 'Not life-threatening' if the developmental disorder does not fall into one of the following two categories.

The answer is 'Acutely life-threatening' if urgent surgical or other medical treatment is required due to the anatomical abnormality or consequent physiological dysfunction.

The answer is 'Lethal' if the developmental or chromosomal abnormality is incompatible with life.

## **Nutrition**

### **Enteral feeding**

The answer is 'Yes' if the newborn received enteral feeding at any time in the unit.

#### **.The time of initiation of enteral feeding**

The date of the first enteral feeding (attempt) in the unit, in the format year, month, day, hour, minute, regardless of its subsequent success. It cannot be earlier than the admission date. If the first feeding occurred in an institution or a unit that officially does not report data to the NICU database, the answer to this field should be 'No data'.

#### **.Own mother's milk feeding**

The answer is 'Yes' if the newborn received any amount of its mother's milk at any time, in any way.

##### **..The first day of breastfeeding**

The date of the first day of attempted breastfeeding in the unit, year, month, day.

##### **..The last day of breastfeeding**

The date of the last day of breastfeeding in the unit, year, month, day. If breastfeeding continued until discharge, enter the date of discharge.

##### **..The quality of breast milk**

In cases where multiple options occurred during care, the one that was characteristic for the majority of days, until achieving full enteral feeding.

The answer is 'Fresh ( $\leq 48$  hours)' if the newborn was breastfed or received expressed breast milk directly or within 48 hours of refrigerated storage.

The answer is 'Pasteurized' if the newborn received the breast milk after it was heat-treated at 65 °C for 30 minutes.

The answer is 'Frozen' if the newborn received the breast milk after it was stored frozen.

#### **.\*Collected donor breast milk feeding**

The answer is 'Yes' if the newborn received any amount of collected donor breast milk at any time.

##### **..The first day of collected donor breast milk feeding**

The date of the first day of collected donor breast milk feeding in the unit, year, month, day.

##### **..The last day of collected donor breast milk feeding**

The date of the last day of collected donor breast milk feeding, year, month, day. If the feeding continued until discharge, enter the date of discharge.

##### **..Source of collected donor breast milk**

The answer is either 'From a milk bank' or 'Collected in the unit', as appropriate.

The answer is 'Other', for example, if another mother or acquaintance provides breast milk under a civil contract.

### **..The quality of the collected donor breast milk**

In cases where multiple options occurred during care, you should indicate the one that was predominant for the most days until achieving full enteral feeding.

The answer is 'Fresh ( $\leq 48$  hours)' if the newborn received expressed breast milk directly or within 48 hours of refrigerated storage.

The answer is 'Pasteurized' if the newborn received the breast milk after it was heat-treated at 65°C for 30 minutes.

The answer is 'Frozen' if the newborn received the breast milk after it was stored frozen.

### **.\*Fortified own mother's milk or donor milk feeding**

The answer is 'Yes' if protein, starch, or other nutritional supplement was added to the breast milk or donor milk.

#### **..The first day of fortified milk feeding**

The date of the first day of fortified milk feeding in the unit, year, month, day.

#### **..The last day of fortified milk feeding**

The date of the last day of fortified milk feeding, year, month, day. If the feeding continued until discharge, enter the date of discharge.

#### **..Product used for fortification**

The answer is either 'Starch', 'Complex', or 'Other', as appropriate.

#### **..Name of the product used for fortification**

Text field for entering the name of the product used for fortification.

### **.\*Formula feeding**

The answer is 'Yes' if the newborn received formula at any time.

#### **..The first day of formula feeding**

The date of the first day of formula feeding in the unit, year, month, day.

#### **..The last day of formula feeding**

The date of the last day of formula feeding, year, month, day. If the feeding continued until discharge, enter the date of discharge.

#### **..Name(s) of the formula(s) used**

Text field for entering the name(s) of the formula(s).

### **.\*Continuous tube feeding**

The answer is 'Yes' if the newborn's feeding was continuously and regularly provided through a tube inserted orally, nasally, via gastrostomy or jejunostomy using a pump, or alternatively, if not continuously but with pump feeding sessions longer than 1 hour.

The answer is 'No' if the pump feeding sessions were shorter than 1 hour.

#### **..Start date of continuous tube feeding**

The date of the first day of continuous tube feeding in the unit, year, month, day.

**..End date of continuous tube feeding**

The date of the last day of continuous tube feeding, year, month, day. If they switched to intermittent tube feeding, the day before its start date should be indicated. If the feeding continued until discharge, enter the date of discharge.

**.\*Intermittent tube feeding**

The answer is 'Yes' if the newborn's feeding through a tube inserted orally, nasally, via gastrostomy or jejunostomy was provided intermittently (in boluses), even if the tube remained continuously in place, or if the pump feeding sessions were shorter than 1 hour.

**..Start date of intermittent tube feeding**

The date of the first day of intermittent tube feeding in the unit, year, month, day.

**..End date of intermittent tube feeding**

The date of the last day of intermittent tube feeding, year, month, day. If the feeding continued until discharge, enter the date of discharge.

**.\*Bottle feeding**

The answer is 'Yes' if the newborn was fed from a baby bottle.

**..Start date of bottle feeding**

The date of the first day of bottle feeding in the unit, year, month, day.

**..End date of bottle feeding**

The date of the last day of bottle feeding, year, month, day. If the feeding continued until discharge, enter the date of discharge.

**.\*Breast feeding**

The answer is 'Yes' if the newborn was breastfed.

**..Start date of breast feeding**

The date of the first day of breast feeding in the unit, year, month, day.

**..End date of breast feeding**

The date of the last day of breast feeding, year, month, day. If the feeding continued until discharge, enter the date of discharge.

**.\*Other feeding method**

The answer is 'Yes' if the newborn was fed any other way than a feeding tube, bottle, or breastfeeding.

**..Name of the other feeding method**

Text field to specify the other enteral feeding methods (e.g. cup, spoon).

**..Start date of other feeding method**

The date of the first day of other feeding method in the unit, year, month, day.

### **..End date of other feeding method**

The date of the last day of other feeding method, year, month, day. If the feeding continued until discharge, enter the date of discharge.

### **Full (exclusive) enteral feeding**

The answer is 'Yes' if the newborn received full exclusive enteral feeding, regardless of whether it was sufficient or not. It indicates the absence of parenteral nutrition.

#### **.Full (exclusive) enteral feeding on the first day**

The date (year, month, day) of the first day of 150 ml/kg/day feeding, irrespective of the given answer for the previous question.

### **Infusion fluid intake occurred**

The answer is 'Yes' if the newborn received fluids intravenously for feeding purposes.

#### **.Last day of infusion fluid intake**

The date (year, month, day) of the last day of intravenous fluid intake for feeding purposes. If feeding continued until discharge, enter the discharge date, regardless of other forms of feeding. Temporary reintroduction of IV due to minor surgical interventions should not be considered.

#### **.Body weight on the last day of infusion fluid intake (g)**

The newborn's weight on the last day of intravenous fluid intake for feeding purposes, in grams. Value range: 350 g – 7500 g.

#### **.Body length on the last day of infusion fluid intake (cm)**

The newborn's body length on the last day of intravenous fluid intake for feeding purposes, in centimetres. Value range: 25 cm – 90 cm.

#### **.Head circumference on the last day of infusion fluid intake (cm)**

The newborn's head circumference on the last day of intravenous fluid intake for feeding purposes, in centimetres. Value range: 15 cm – 45 cm.

### **First day free from intravenous devices**

The date (year, month, day) of the day all types of intravenous devices (e.g., cannula, venous catheter) were removed from the newborn. Typically, this is the day after the last day of fluid intake, but it can be later if IV medications, such as antibiotics, are administered through the cannula in the days following the end of parenteral nutrition or infusion treatment.

If the newborn received no infusion at all, the birth date should be entered.

The answer is 'No data' if the newborn was transferred and was handed over to another institution with an intravenous device.

The answer is 'No data' if the newborn was transferred from other hospital/unit, and arrived without an intravenous device.

### **Received probiotics**

The answer is 'Yes' if the newborn received probiotics.

#### **.First day of probiotic administration**

The date (year, month, day) of the first day of probiotic administration in the unit.

**.Last day of probiotic administration**

The date (year, month, day) of the last day of probiotic administration in the unit. If probiotic administration continues after discharge, enter the date of discharge.

**.Name of the given probiotics**

Text field to specify the administered probiotics.

**Medications, blood products****Number of red cell administrations excluding exchange transfusion (occasions)**

Number of occasions red cell concentrate (packed red cells) was administered in the unit. Red cell concentrates used for exchange transfusion should not be counted. If the child patient did not receive a transfusion, enter '0'. Value range: 0 – 40 occasions.

**Number of platelet transfusions (occasions)**

Number of occasions platelet transfusion was administered in the unit. If the child did not receive platelet transfusion, enter '0'. Value range: 0 – 20 occasions.

**Number of FFP administrations (occasions)**

Number of occasions fresh frozen plasma (FFP) was administered in the unit. If the child did not receive FFP, enter '0'. Value range: 0 – 30 occasions.

**Number of Albumin Preparations (occasions)**

Number of occasions albumin preparation was administered in the unit. If the child did not receive albumin preparation, enter '0'. Value range: 0 – 40 occasions.

**IVIG administration**

The answer is 'Yes' if intravenous immunoglobulin (IVIG) treatment was administered.

**Duration of dobutamine treatment (days)**

Number of days of dobutamine (Dobutrex) treatment. Record the number of days the treatment was at all initiated, ensuring that even if treatment was given for only part of a day, it counts as a full day, always rounding up. If the newborn did not receive dobutamine treatment, enter '0'. Value range: 0 – 60 days.

**Duration of dopamine treatment (days)**

Number of days of dopamine treatment. Record the number of days the treatment was at all initiated, ensuring that even if treatment was given for only part of a day, it counts as a full day, always rounding up. If the child did not receive dopamine treatment, enter '0'. Value range: 0 – 60 days.

**Duration of norepinephrine treatment (days)**

Number of days of norepinephrine treatment. Record the number of days the treatment was at all initiated, ensuring that even if treatment was given for only part of a day, it counts as a full day, always rounding up. If the child did not receive norepinephrine treatment, enter '0'. Value range: 0 – 60 days.

**Duration of antibiotic treatment (days)**

Number of days of antibiotic (antimicrobial) treatment. Record the number of days the treatment was at all initiated, ensuring that even if treatment was given for only part of a day, it counts as a full day,

always rounding up. Include all systemic (oral, IV, IM) antibiotics or full-dose therapeutic antifungal treatments, regardless of the type of preparation or any interruptions. Prophylactic doses of antifungal drugs should not be considered here. If there was no systemic antibiotic or therapeutic antifungal treatment, enter '0'. Value range: 0 – 365 days.

#### **Duration of epinephrine treatment (days)**

Number of days of epinephrine treatment. Record the number of days the treatment was at all initiated, ensuring that even if treatment was given for only part of a day, it counts as a full day, always rounding up. If the child did not receive epinephrine treatment, enter '0'. Value range: 0 – 60 days.

#### **Duration of prostaglandin E<sub>1</sub> (alprostit) treatment (days)**

Number of days of prostaglandin E<sub>1</sub> (alprostit) treatment. Record the number of days the treatment was at all initiated, ensuring that even if treatment was given for only part of a day, it counts as a full day, always rounding up. If the child did not receive prostaglandin E<sub>1</sub> treatment, enter '0'. Value range: 0 – 60 days.

#### **Systemic corticosteroid treatment (except for ROP)**

The answer is 'Yes' if systemic (IV, IM, oral) corticosteroid treatment occurred for any reason other than retinopathy of prematurity (ROP).

##### **.Corticosteroid for hypotension**

The answer is 'Yes' if systemic (IV, IM, oral) corticosteroid treatment for hypotension was administered (usually in the first week of life or in connection with sepsis).

##### **..Name of corticosteroid active substance for hypotension**

The corticosteroid active substance given for low blood pressure should be given, 'Hydrocortisone' or 'Dexamethasone', as appropriate.

The answer is 'Other' if the corticosteroid drug given for treatment of hypotension is not hydrocortisone or dexamethasone.

##### **...Name of other corticosteroid active substance for hypotension**

Text field to indicate the name of the other corticosteroid active substance given for hypotension.

##### **..Corticosteroid first dose time for hypotension**

Date, in the format year, month, day, of first corticosteroid administration due to hypotension.

##### **..Corticosteroid first dose (mg/kg) for hypotension**

Dosage of first corticosteroid for low blood pressure, given in mg/kg. The first administered absolute dose should be divided by the body weight (kg) of the day. Value range: 0.1 – 5 mg/kg.

##### **.Corticosteroid for treatment of BPD or CLD**

Answer 'Yes' if systemic (IV, IM, per os) corticosteroid treatment has been given to prevent or treat bronchopulmonary dysplasia (BPD), chronic lung disease (CLD) or to successfully wean off the ventilator (usually after the second week of life). Inhaled corticosteroid treatment is not considered systemic corticosteroid treatment.

**..Name of corticosteroid active substance due to BPD or CLD**

The name of the corticosteroid active substance administered for BPD or CLD should be given, 'Hydrocortisone' or 'Dexamethasone', as appropriate.

The answer is 'Other' if the corticosteroid active substance given for BPD or CLD is not hydrocortisone or dexamethasone.

**...Name of other corticosteroid active substance due to BPD or CLD**

Text field to indicate the name of the other corticosteroid active substance given for BPD or CLD.

**..Time of first corticosteroid dose due to BPD or CLD**

Date of first corticosteroid administration due to BPD or CLD, in the format year, month, day.

**..First corticosteroid dosage (mg/kg) for BPD or CLD**

Dosage of first corticosteroid administration for BPD or CLD in mg/kg. The first administered absolute dose should be divided by the body weight (kg) of the day. Value range: 0.01 – 2.0 mg/kg.

**.Corticosteroid for other reasons (but not ROP)**

Answer 'Yes' if systemic (IV, IM, per os) corticosteroid treatment was given for other reason than ROP, BPD, CLD, hypotension.

**..Reason for corticosteroid administration for other reasons (but not ROP)**

Text field to specify other reason (not ROP, BPD, CLD, hypotension) for corticosteroid treatment.

**..Name of corticosteroid active substance for other reasons (but not ROP)**

Corticosteroid active substance given for other reasons (not ROP, BPD, CLD, hypotension) should be indicated as 'Hydrocortisone' or 'Dexamethasone'. 'Other' if the corticosteroid active substance given for is not hydrocortisone or dexamethasone.

**...Name of other corticosteroid active substance for other reasons (but not ROP)**

A text field to specify the other corticosteroid active substance given for other reasons (not ROP, BPD, CLD, hypotension).

**..Time of first corticosteroid dose for other reasons (but not ROP)**

Date of first corticosteroid dose for other reason (not ROP, BPD, CLD, hypotension), in the format year, month, day.

**..First corticosteroid dosage (mg/kg) for other reasons (but not ROP)**

Dosage of first corticosteroid treatment for other reason (not ROP, BPD, CLD, hypotension), given in mg/kg. The first absolute dose administered is divided by the body weight (kg) of the day. Value range: 0.1 – 5 mg/kg.

**Insulin**

The answer is 'Yes' if insulin treatment has been given.

**.Start of insulin therapy**

The date of the first day of insulin treatment, in the format year, month, day.

**.End of insulin therapy**

The date, of the last day of insulin treatment, in the format year, month, day. If there were time periods when the child did not receive insulin, those periods should not be taken into consideration. Enter the date when insulin administration could be permanently discontinued. If the treatment continued until discharge, enter the discharge date.

**Indomethacin**

Answer 'Yes' if indomethacin treatment has been given.

**.Time of the first dose of indomethacin**

The date of the first administration of indomethacin, in the format year, month, day.

**Ibuprofen**

The answer is 'Yes' if ibuprofen treatment has been given.

**.Time of the first dose of ibuprofen**

The date of the first administration of ibuprofen, in the format year, month, day.

**Paracetamol**

The answer is 'Yes' if paracetamol (acetaminophen) treatment has been given for any reason.

**.Paracetamol first dose time**

Date of first paracetamol administration, in the format year, month, day.

**Caffeine IV**

Answer 'Yes' if intravenous caffeine treatment has been given for any reason.

**.Time of the first dose of caffeine IV**

The date of the first day of intravenous caffeine treatment, in the format year, month, day.

**.Time of the last dose of caffeine IV**

The date of the last day of intravenous caffeine treatment, in the format year, month, day. If there were time periods when the newborn did not receive caffeine or not intravenously, those periods should not be taken into consideration. Enter the date when intravenous caffeine administration could be permanently discontinued. If the treatment continued until discharge, enter the discharge date.

**Caffeine per os (oral)**

Answer 'Yes' if oral caffeine treatment has occurred for any reason. There are some cases of caffeine administration via enema (rectally), but there is currently no separate field for this. The answer 'Yes' should be selected in the case of rectal administration, as well.

**.Time of the first dose of caffeine per os**

The date of the first day of orally administered caffeine treatment, in the format year, month, day.

**.Time of the last dose of caffeine per os**

The date of the last day of orally administered caffeine treatment in the format year, month, day. If there were time periods when the child did not receive caffeine not orally, those periods should not

be taken into consideration. Enter the date when orally administered caffeine administration could be permanently discontinued. If the treatment continued until discharge, enter the discharge date.

### **Thyroxine supplementation**

Answer 'Yes' if thyroid hormone (thyroxine) treatment has been given at least once.

#### **.First day of thyroxine treatment**

The date of the first day of thyroxine treatment, in the format year, month, day.

#### **.Last day of thyroxine treatment**

The date of the last day of thyroxine treatment, in the format year, month, day. If there were time periods when the child did not receive thyroxine or had interruptions in treatment, those periods should not be taken into consideration. Enter the date when thyroxine administration could be permanently discontinued. If the treatment continued until discharge, enter the discharge date.

### **EPO treatment**

Answer 'Yes' if erythropoietin (EPO) treatment has been given at least once.

#### **.First day of EPO treatment**

The date of the first day of erythropoietin treatment, in the format year, month, day.

#### **.Last day of EPO treatment**

The date of the last day of erythropoietin treatment, in the format year, month, day. If there were time periods when the child did not receive erythropoietin or had interruptions in treatment, those periods should not be taken into consideration. Enter the date when erythropoietin administration could be permanently discontinued. If the treatment continued until discharge, enter the discharge date.

### **Barbiturate**

The answer is 'Yes' if intravenous, oral, or rectal barbiturate treatment has been given. Do not mark if intravenous short-acting barbiturate administration took place for intubation or for a short procedure (e.g. thiopental).

### **Analgesic**

The answer is 'Yes' if morphine, morphine derivatives (e.g. Fentanyl, Nubain), or any other analgesic treatment for pain relief has been given.

### **Other anticonvulsant**

The answer is 'Yes' if any anticonvulsant drug treatment, other than barbiturates, has been given.

### **Diuretic**

The answer is 'Yes' if any pharmacological treatment for diuresis (urinary output) has occurred.

### **Inhalation medication**

The answer is 'Yes' if any medication has been administered through inhalation into the airways. Surfactant administration should not be taken into account for this question.

## **Fluconazole prophylaxis**

The answer is 'Yes' if fluconazole treatment was given exclusively for prophylactic purposes in prophylactic doses, regardless of whether a fungal infection occurred. Therapeutic doses of fluconazole should not be accounted for in this question.

## **Vaccinations**

### **Immunisation**

The answer is 'Yes' if the child has undergone active or specific passive immunization.

#### **.BCG**

The answer is 'Yes' if the child has received BCG vaccination.

#### **..BCG date**

The date of the BCG vaccination, in the format year, month, day.

#### **.Hepatitis, active**

The answer is 'Yes' if the child has undergone active immunization against Hepatitis B (HBV).

#### **..Hepatitis, active, date**

The date of the first active immunization against HBV, in the format year, month, day.

#### **.Hepatitis, passive**

The answer is 'Yes' if the child has undergone passive immunization against Hepatitis B (HBV).

#### **..Hepatitis, passive, date**

The date of the first passive immunization against HBV, in the format year, month, day.

#### **.RSV, passive**

The answer is 'Yes' if the child has undergone passive immunization against Respiratory Syncytial Virus (RSV).

#### **..RSV, passive, date**

The date of the first passive immunization against RSV, in the format year, month, day.

#### **.DTPa + IPV + Hib**

The answer is 'Yes' if the child has received DTPa + IPV + Hib (or equivalent) vaccination.

#### **..DTPa + IPV + Hib date**

The date of the first DTPa + IPV + Hib (or equivalent) vaccination, in the format year, month, day.

#### **.Other vaccination**

The answer is 'Yes' if the child has undergone specific immunization against pathogens other than those mentioned above.

#### **..Name of other vaccination**

Text field to specify the name of the other vaccination.

### **..Date of other vaccination**

The date of the first administration of the other vaccination, in the format year, month, day.

## **Invasive devices, interventions**

### **Duration of phototherapy (days)**

Number of days with blue light treatment. Record the number of days the treatment was initiated, ensuring that even if treatment was given for only part of a day, it counts as a full day, always rounding up. If the child did not receive blue light treatment, enter 0. Value range: 0 – 365 days.

### **Umbilical vein catheter (UVC)**

The answer is 'Yes' if umbilical vein catheterization (UVC) was performed.

Answer 'Yes' even if a UVC was inserted for a few hours due to a single intervention (e.g. exchange transfusion or stabilisation in the delivery room).

#### **.Duration of umbilical vein catheter (UVC) (days)**

Number of days with umbilical vein catheterization. Record the number of days UVC was inserted, counting as a full day even if it was inserted for only part of a day, always rounding up. Value range: 1 – 365 days.

### **Other central venous catheter**

The answer is 'Yes' if a central venous catheter (except for umbilical vein catheter) was used. This includes peripherally inserted central catheter, punctured or surgically placed jugular, subclavian, or femoral catheters.

#### **.Duration of central venous catheter, except for UVC (days)**

Number of days with central venous catheterization, except for umbilical vein catheter (UVC). Record the number of days the catheter was inserted, counting as a full day even if it was inserted for only part of a day, always rounding up. If there were multiple central catheters, add the days together and provide the total number of days spent with all central veins (except for UVC). Value range: 1 – 365 days.

### **Umbilical artery catheter (UAC)**

The answer is 'Yes' if umbilical artery catheterization (UAC) was performed.

#### **.Duration of umbilical artery catheter (UAC) (days)**

Number of days with umbilical artery catheterization (UAC). Record the number of days the UAC was inserted, counting as a full day even if it was inserted for only part of a day, always rounding up. Value range: 1 – 365 days.

### **Other arterial catheter**

The answer is 'Yes' if an arterial catheter (except for umbilical artery catheter) was used. The use of the radial artery is primarily considered, but any long-term catheter placed in an artery should be indicated.

### **.Duration of arterial catheter, except for UAC (days)**

Number of days with arterial catheterization, except for umbilical artery catheter (UAC). Record the number of days the catheter was inserted, counting as a full day even if it was inserted for only part of a day, always rounding up. Value range: 1 – 365 days.

### **Chest drain**

The answer is 'Yes' if insertion of a chest drain or thoracentesis was performed, regardless of the reason, duration, or frequency.

### **Exchange transfusion**

The answer is 'Yes' if there was an exchange transfusion, involving the replacement of circulating blood volume with twice the amount of blood, regardless of the number of times the procedure was performed. The answer is 'No' if there was no exchange transfusion, even if the child repeatedly received blood products.

### **Partial exchange transfusion**

The answer is 'Yes' if a partial exchange transfusion was performed due to polycythaemia/hyperviscosity. The answer is 'No' if there was no partial exchange transfusion, even if the child repeatedly received blood products.

### **Number of lumbar punctures**

The total number of lumbar punctures performed in the unit. If no lumbar puncture was performed, enter 0. Range: 0 – 20.

### **Number of ventricular punctures**

The total number of ventricular punctures performed in the unit. Subgaleal shunt surgery-related 'sac puncture' or 'valve puncture' does not count. If no ventricular puncture was performed, enter 0. Range: 0 – 20.

### **Ventilation and surfactant**

If multiple types of ventilation occurred within a single day, mark the day for the type of ventilation in which the most time of the day was spent.

### **Surfactant therapy (not in the delivery room)**

The answer is 'Yes' if surfactant was administered, but not during delivery room care.

The answer is 'No' if, in the case of a non-NICU birth, the newborn transport team participated in stabilisation in the delivery room in the minutes following birth and administered surfactant before departure.

However, answer 'Yes' if the transport team, hours after birth, administered surfactant after the start of transport, or on the unit before their departure and not in the delivery room.

### **.First surfactant within the first hour of life**

The answer is 'Yes' if the newborn received surfactant within the first hour of life on the unit, before reaching 60 minutes of life. Choosing 'Yes' excludes the ability to fill in the field 'Time of the first surfactant dose after 1 hour but within 72 hours (in hours)'.

The answer is 'No' if the newborn received surfactant on the unit after 60 minutes of life. Choosing 'No' excludes the ability to fill in the field 'Time of the first surfactant within the first hour of life (minutes)'.

**.Time of the first surfactant within the first hour of life (in minutes)**

The life age in minutes when the first surfactant dose was administered on the unit if the newborn received it before reaching 60 minutes of life. Value range: 1 – 59 minutes.

**.Time of the first surfactant dose after 1 hour but within 72 hours (in hours)**

The life age in hours when the first surfactant dose was administered on the unit if the newborn received it after 60 minutes but within 72 hours of life. Value range: 1 – 72 hours.

**.Total quantity of the first surfactant dose (mg)**

The total quantity of the first surfactant dose administered on the unit in milligrams. Value range: 50 – 1000 mg.

**.Number of surfactant administrations**

The number of non-delivery room surfactant administrations. Value range: 1 – 20 administrations.

**..Time of the second surfactant dose (in hours)**

The life age in hours when the second surfactant dose was administered on the unit. Value range: 2 – 168 hours.

**..Total quantity of the second surfactant dose (mg)**

The total quantity of the second surfactant dose administered on the unit in milligrams. Value range: 50 – 1000 mg.

**.Surfactant preparation**

The answer is 'Curosurf' if the first surfactant treatment given outside the delivery room was with Curosurf (proactant alfa).

The answer is 'Other' if the first surfactant treatment given outside the delivery room was with a surfactant other than Curosurf.

**..Name of other surfactant preparation**

Text field to specify the name of the other surfactant preparation.

**.Surfactant administration without intubation**

The answer is 'Yes' if surfactant was administered without intubation on the unit, regardless of whether the newborn was later intubated.

The answer is 'No' if surfactant administration was through an intratracheal tube on the unit. In this case, the option 'Yes' should be selected for the 'Intubation' question.

**Intubation**

The answer is 'Yes' if the newborn had an intratracheal tube on the unit, even if intubation did not happen on that specific unit (e.g. a neonatologist from a lower-level unit, or the newborn transport team performed the intubation).

**.Intubation in the delivery room**

The answer is 'Yes' if intubation occurred in the delivery room.

**.Intubation on the unit**

The answer is 'Yes' if intubation occurred on the unit.

**.Intubation only for surfactant administration**

The answer is 'Yes' if intubation occurred only for surfactant administration. In this case, answer 'No' to the question 'Surfactant administration without intubation'.

**.Number of intubations**

The number of intubations that occurred on the specific unit, including elective tube changes. Value range: 1 – 10. If no intubation occurred on the specific unit, the field must be left empty.

**.Number of days spent intubated**

The number of days spent in intubated state on the specific unit, counting a fraction of a day as a whole day. If periods of non-invasive ventilation interrupted the intubated days, sum up the number of days spent intubated and enter the total. If intubation was only for surfactant administration, enter 1 day. Value range: 1 – 365 days.

**Invasive mechanical ventilation**

The answer is 'Yes' if the newborn received mechanical ventilation through an endotracheal tube or tracheostomy on the unit.

**.Conventional mechanical ventilation**

The answer is 'Yes' if the newborn received conventional mechanical ventilation through an endotracheal tube on the unit.

**..Duration of conventional mechanical ventilation (in days)**

The number of days spent on any form of conventional mechanical ventilator. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

**..Days of conventional mechanical ventilation with volume monitoring**

The number of days spent on a conventional mechanical ventilator with volume monitoring. It should be equal to or less than the 'Duration of conventional mechanical ventilation'. Value range: 0 – 365 days.

**..Days of conventional mechanical ventilation with volume guarantee**

The number of days spent on a conventional mechanical ventilator with volume guarantee. It should be equal to or less than the 'Days of conventional mechanical ventilation with volume monitoring'. Range: 0 – 365 days.

**.High-frequency oscillatory (HFO) ventilation (while intubated)**

The answer is 'Yes' if high-frequency oscillatory ventilation (HFO) was needed through an endotracheal tube.

**..Duration of HFO ventilation (while intubated) (in days)**

The number of days on which high-frequency oscillatory ventilation (HFO) was provided. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Range: 1 – 365 days.

### **.Non-invasive ventilation preceding invasive ventilation**

The answer is 'Yes' if the newborn received any non-invasive ventilation, either in the delivery room or on the unit, before the initiation of invasive (endotracheal tube-based) ventilation.

The answer is 'No data' if the newborn receiving invasive ventilation was transferred from another institution.

#### **..Start of non-invasive ventilation preceding invasive ventilation**

The date when non-invasive ventilation preceding invasive ventilation started, in the format year, month, day.

#### **..End of non-invasive ventilation preceding invasive ventilation**

The date when non-invasive ventilation preceding invasive ventilation ended, in the format year, month, day.

### **Non-invasive ventilation**

The answer is 'Yes' if the newborn received ventilation without the use of an endotracheal tube (e.g. through a nasal device or a mask) on the unit.

#### **.Non-invasive HFO ventilation**

The answer is 'Yes' if high-frequency oscillatory (HFO) ventilation was administered not through an endotracheal tube or tracheostomy but via a nasal device or a mask.

#### **..Duration of non-invasive HFO ventilation (in days)**

The number of days on which non-invasive high-frequency oscillatory (HFO) ventilation was used. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

#### **.Nasal bi-level positive airway pressure (BiPAP)**

The answer is 'Yes' if the newborn received bi-level positive airway pressure (BiPAP) non-invasive ventilation through a nasal device or a mask.

#### **..Duration of nasal BiPAP ventilation (in days)**

The number of days on which nasal BiPAP ventilation was used. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

#### **.Nasal continuous positive airway pressure (nCPAP)**

The answer is 'Yes' if the newborn received continuous positive airway pressure (CPAP) through a nasal device or a mask on the unit.

#### **..Duration of nasal CPAP ventilation (in days)**

The number of days on which nasal CPAP ventilation was used. The rounded up number of days should be entered, counting a fraction of a day as a whole day. If the ventilation was provided for less than 24 hours, enter 1 day even if it was for half an hour. Value range: 1 – 365 days.

#### **.High flow nasal cannula (HFNC) with air or oxygen**

The answer is 'Yes' if the newborn received humidified, high-flow air or oxygen through a nasal cannula that fits both nostrils with a flow rate greater than 2 liters per minute (HFNC).

### **..Duration of high flow nasal cannula (HFNC) with air or oxygen (in days)**

The number of days on which high flow nasal cannula (HFNC) ventilation was used. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Other respiratory support**

The answer is 'Yes' if the method of respiratory support was neither non-invasive nor invasive ventilation, but was provided rather via nasal cannula with oxygen/air or in form of hood oxygen.

#### **.Traditional nasal cannula with air or oxygen**

The answer is 'Yes' if respiratory support was provided through nasal device through one or both nostrils, with a flow of 2 liters per minute or lower.

#### **..Duration of traditional nasal cannula with air or oxygen (in days)**

The number of days on which traditional nasal cannula ventilation was provided. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

#### **.Hood oxygen**

The answer is 'Yes' if oxygen was administered directly to the incubator or a headbox.

#### **..Duration of hood oxygen (in days)**

The number of days with oxygen supplementation to the incubator or headbox. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

#### **..Hood oxygen administration with hood oxygen concentration measurement**

The answer is 'Yes' if oxygen administration to the incubator or headbox occurred, together with hood oxygen concentration measurement, even if measured only on a single day.

#### **...Duration of hood oxygen administration with hood oxygen concentration measurement (in days)**

The number of days with oxygen supplementation to the incubator or headbox, together with hood oxygen concentration measurement. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Should be equal to or less than the duration of 'Hood oxygen'. Value range: 1 – 365 days.

### **Oxygen therapy**

The answer is 'Yes' if the newborn received oxygen supplementation on the unit through nasal cannula, in the incubator, headbox, or during invasive or non-invasive ventilation. Oxygen received in the delivery room should not be indicated here.

#### **.Duration of oxygen administration (in days)**

The total duration of oxygen supplementation in any form, measured in days. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

## **NO inhalation**

The answer is 'Yes' if the newborn received nitric oxide (NO) inhalation on the unit.

### **.Start of NO treatment**

The date when nitric oxide inhalation therapy was initiated, in the format year, month, day.

### **.End of NO treatment**

The date when nitric oxide inhalation therapy was terminated, in the format year, month, day. If there were periods when NO inhalation did not occur, those should not be taken into consideration. If the treatment continued until discharge, enter the discharge date.

## **Monitoring**

### **Amplitude-integrated EEG (aEEG)**

The answer is 'Yes' if amplitude-integrated EEG (aEEG) monitoring was performed at least once.

#### **.Number of days monitored with aEEG**

The number of days with amplitude-integrated EEG monitoring. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Near-infrared spectroscopy (NIRS)**

The answer is 'Yes' if near-infrared spectroscopy (NIRS) monitoring was performed.

#### **.Number of days monitored with NIRS**

The number of days with NIRS monitoring. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Transcutaneous oxygen and carbon-dioxide (tcpO<sub>2</sub> - tcpCO<sub>2</sub>) monitoring**

The answer is 'Yes' if transcutaneous oxygen and carbon dioxide pressure (tcpO<sub>2</sub> - tcpCO<sub>2</sub>) monitoring was performed.

#### **.Number of days monitored with tcpO<sub>2</sub> - tcpCO<sub>2</sub>**

The number of days with transcutaneous oxygen and carbon dioxide pressure monitoring. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Continuous skin temperature monitoring**

The answer is 'Yes' if continuous skin temperature monitoring was conducted using a sensor attached to the skin.

#### **.Number of days with skin temperature monitoring**

The number of days with continuous skin temperature monitoring. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Continuous core temperature**

The answer is 'Yes' if continuous core temperature monitoring was conducted, e.g. using a sensor placed in the anus or esophagus.

### **.Number of days with core temperature monitoring**

The number of days with continuous core temperature monitoring. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Oxygen saturation level and heart rate**

The answer is 'Yes' if oxygen saturation level and heart rate monitoring were conducted using a pulse oximeter.

#### **.Number of days monitored with a pulse oximeter**

The number of days with oxygen saturation level and heart rate monitoring, using a pulse oximeter. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Electrocardiogram (ECG)**

The answer is 'Yes' if electrocardiography (ECG) monitoring was conducted using skin-adhered electrodes.

#### **.Number of days monitored with ECG**

The number of days with ECG monitoring. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Respiratory rate with ECG electrodes**

The answer is 'Yes' if respiratory rate monitoring was conducted using ECG electrodes.

#### **.Number of days with respiratory rate monitoring using ECG**

The number of days with respiratory rate monitoring using ECG. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Apnea alarm**

The answer is 'Yes' if there were days of care, when pulse oximetry or ECG monitoring were no longer performed, and only apnea monitoring was done using a mechanical device (apnea alarm mat with a sensor placed under the mattress).

#### **.Number of days with apnea alarm**

The count of days with apnea alarm monitoring. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Other monitoring**

The answer is 'Yes' if other types of monitoring besides those listed above took place.

#### **.Name of other monitoring**

A text field to specify the name of other monitoring.

#### **.Number of monitored days (other)**

The number of days with other monitoring. The rounded up number of days should be entered, counting a fraction of a day as a whole day. Value range: 1 – 365 days.

### **Surgery**

## **Surgeries, except for due to ROP**

The answer is 'Yes' if any surgical treatment was performed under general anesthesia or spinal anesthesia, anywhere and at any time, before the most recent discharge from the NICU. The insertion of central venous catheters must be included, if performed under anesthesia.

### **.Patent ductus arteriosus (PDA) ligation**

The answer is 'Yes' if the closure of a patent ductus arteriosus (PDA) was performed through surgical procedure or interventional catheterization. The answer is 'Yes' even if the closure of the ductus arteriosus occurred as part as the surgical treatment of complex congenital heart abnormalities.

#### **..Date of PDA ligation surgery**

The date of the PDA ligation surgery, in the format year, month, day.

#### **..Weight at the time of surgery (grams)**

The weight in grams on the day of the PDA ligation surgery. Value range: 350 – 9000 g.

### **.Surgery due to necrotizing enterocolitis (NEC)**

The answer is 'Yes' if laparotomy, laparoscopy, or peritoneal drainage surgery was performed due to necrotizing enterocolitis (NEC), suspected NEC, or focal bowel perforation.

#### **..Date of surgery due to NEC**

The date of the surgery due to NEC, in the format year, month, day.

#### **..Weight at the time of surgery due to NEC (grams)**

The weight in grams on the day of the surgery due to NEC. Value range: 350 – 9000 g.

#### **..Type of surgery due to NEC**

The answer is 'Only abdominal drain' if the treatment of acute phase NEC was resolved with the insertion of an abdominal drain, and laparotomy/laparoscopy was not required. In this case, answer 'Yes' for 'Abdominal drain due to NEC' in the 'Complications' table.

The answer is 'Laparotomy' if a laparotomy was required due to NEC. In this case, answer 'Yes' for 'Surgery due to NEC' in the 'Complications' table.

#### **..Surgical findings due to NEC**

The answer is 'SIP' (spontaneous intestinal perforation) if during the surgery, focal perforation was detected, and the rest of the intestine was normal. This option excludes the answer 'Only abdominal drain' for the question 'Type of surgery due to NEC'. In this case, answer 'Yes' for 'Focal intestinal perforation' in the 'Complications' table.

The answer is 'Intestinal necrosis' is during surgery, intestinal necrosis was detected, regardless of whether perforation was detected, and whether bowel resection was performed.

#### **..Stoma formation**

The answer is 'Yes' if stoma formation was performed during the surgery, regardless of whether it was later closed.

### **.Subgaleal shunt**

The answer is 'Yes' if a temporary shunt was formed to drain cerebrospinal fluid from the ventricle into a subgaleal pouch, or if a special valve (ventricular access device, VAD) was implanted for periodic drainage of cerebrospinal fluid.

#### **..Time of subgaleal shunt surgery**

Date of subgaleal shunt implantation, in the format year, month, day.

#### **..Weight at the time of subgaleal shunt surgery (grams)**

Weight on the day of subgaleal shunt implantation, in grams. Value range: 350 – 9000 g.

### **.Hernia surgery**

The answer is 'Yes' if surgery was performed due to inguinal hernia. Diaphragmatic hernia or umbilical hernia should not be included.

#### **..Time of hernia surgery**

Date of hernia surgery, in the format year, month, day.

#### **..Weight at the time of hernia surgery (grams)**

Weight on the day of hernia surgery, in grams. Value range: 350 – 9000 g.

### **.Other surgery**

The answer is 'Yes' if any other type of surgery was performed not related to ROP, NEC, patent ductus arteriosus, or inguinal hernia.

#### **..Name of other surgery**

A text field to specify the name of the other surgery, or to provide its ICD-10 code.

#### **..Date of other surgery**

The date of the other surgery, in the format year, month, day.

#### **..Weight at the time of other surgery (grams)**

Weight on the day of the other surgery, in grams. Value range: 350 – 9000 g.

## **Complications**

### **Pneumothorax (PTX)**

The answer is 'Yes' if extrapleural air (pneumothorax, PTX) is diagnosed by chest ultrasound, chest X-ray, or thoracentesis, regardless of whether it required treatment or resolved spontaneously.

The answer is 'No' if clinical symptoms did not suggest pneumothorax, and there were no chest X-ray or ultrasound examinations, or if chest X-ray or ultrasound examinations were conducted, and neither depicted extrapleural air.

#### **.The first day of life with pneumothorax**

The first day of life with pneumothorax diagnosis. Value range: 1 – 365 days.

#### **.Chest drain due to pneumothorax**

The answer is 'Yes' if a chest drain was inserted for the diagnosis or treatment of pneumothorax. In this case, mark 'Yes' for the question 'Chest drain' in the 'Invasive procedures' table.

**.Pneumothorax during spontaneous breathing**

The answer is 'Yes' if pneumothorax occurred while the patient did not require respiratory support.

**.Pneumothorax on CPAP**

The answer is 'Yes' if pneumothorax occurred while the patient was on non-invasive respiratory support (continuous positive airway pressure, CPAP).

**.Pneumothorax during tracheal ventilation**

The answer is 'Yes' if pneumothorax occurred while the patient was under tracheal ventilation, i.e. under intubation.

**Pulmonary haemorrhage**

The answer is 'Yes' if pulmonary haemorrhage is documented in the patient documentation (medical records, progress notes, discharge summary). Minimal bloody secretions occurring during airway suctioning on isolated occasions is not to be considered.

**.First day of life with pulmonary haemorrhage**

The first day of life of the diagnosis of pulmonary haemorrhage. Value range: 1 – 365.

**.Pulmonary haemorrhage after surfactant replacement therapy**

The answer is 'Yes' if the patient experienced pulmonary haemorrhage after receiving surfactant at any time.

**.Pulmonary haemorrhage during spontaneous breathing**

The answer is 'Yes' if the pulmonary haemorrhage occurred while the patient did not require respiratory support.

**.Pulmonary haemorrhage on CPAP**

The answer is 'Yes' if the pulmonary haemorrhage occurred while the patient was on non-invasive respiratory support (continuous positive airway pressure, CPAP).

**.Pulmonary haemorrhage during tracheal ventilation**

The answer is 'Yes' if the pulmonary haemorrhage occurred while the patient was under tracheal ventilation, i.e. under intubation.

**Persistent ductus arteriosus (PDA)**

The answer is 'Yes' if the terms PDA, patent ductus arteriosus, or patent ductus Botalli are mentioned in the patient documentation.

**. ECHO examination was performed**

The answer is 'Yes' if an echocardiogram (ECHO) was performed by a neonatal care provider or a cardiologist.

**.PDA hemodynamically significant**

The answer is 'Yes' if, based on the ECHO examination, there is an entry in the patient documentation indicating a hemodynamically (HD) 'significant' ductus arteriosus. This excludes the answer 'Yes' to the question 'PDA hemodynamically not significant'.

### **.PDA hemodynamically not significant**

The answer is 'Yes' if, based on the ECHO examination, there is a diagnosis of PDA, but the term hemodynamically 'significant' does not appear in the patient documentation. This excludes the answer 'Yes' to the question 'PDA hemodynamically significant'.

### **.Pharmacological treatment for PDA**

The answer is 'Yes' if treatment with indomethacin, ibuprofen, or paracetamol was performed for the purpose of closing the PDA. In this case, the appropriate treatment should also be indicated in the 'Medications, blood products' table.

### **Pneumonia after 72 hours**

The answer is 'Yes' if the newborn had acquired pneumonia during the hospital stay. In this case, mark 'Yes' for the questions 'Nosocomial non-bloodstream infection' and 'Bacterial infection after 72 hours' in the 'Risk conditions' table.

### **Bronchopulmonary dysplasia (BPD)**

The answer is 'Yes' if the term bronchopulmonary dysplasia (BPD) is mentioned in the discharge summary or among the final diagnoses, regardless of the number of days ventilation and oxygen support was provided.

### **.Oxygen requirement on the 28<sup>th</sup> day of life**

The answer is 'Yes' if, according to the medical record/progress notes, continuous oxygen therapy is needed in any form on the 28<sup>th</sup> day of life (1-2 days of omission of oxygen therapy can be disregarded).

The answer is 'No' if the child was transferred to another facility or discharged home, without oxygen therapy, before reaching the 28<sup>th</sup> day of life.

The answer is 'No' if the newborn who previously required no respiratory support, temporarily did require oxygen due to a deterioration in health around the 28<sup>th</sup> day of life.

The answer is 'No data' if the child, with continuous oxygen therapy, was transferred to another facility or died before reaching the 28<sup>th</sup> day of life.

### **..Oxygen requirement FiO<sub>2</sub> on the 28<sup>th</sup> day of life**

The answer is 'FiO<sub>2</sub> 0.22 – 0.3' or 'FiO<sub>2</sub> > 0.3', as appropriate.

### **..Oxygen requirement via nasal device (L/min) on the 28<sup>th</sup> day of life**

The answer is 'Data not available' if the baby did not receive nasal prongs/nasal cannula oxygen on the 28<sup>th</sup> day but received other respiratory support. Value range: 0.1-4 L/min.

### **.Ventilation requirement on the 28<sup>th</sup> day of life**

The answer is 'Yes' if the baby received any form of mechanical respiratory support on the 28<sup>th</sup> day of life. This includes intubated mechanical or non-invasive BiPAP, DuoPAP, nCPAP, HFNC, nasal cannula oxygen (except for hood oxygen!).

The answer is 'No' if the child was transferred to another facility or discharged home without a ventilation requirement before reaching the 28<sup>th</sup> day of life.

The answer is 'No data' if the child, with mechanical respiratory support, was transferred to another facility or died before reaching the 28<sup>th</sup> day of life.

### **.Oxygen requirement at 36 postmenstrual weeks**

36 postmenstrual weeks = gestational age in weeks + age in weeks

The answer is 'Yes' if the newborn received any respiratory support and/or oxygen therapy on the 36<sup>th</sup> postmenstrual week.

The answer is 'No' if the child was discharged or transferred to another institution without oxygen treatment before reaching the 36<sup>th</sup> postmenstrual week.

The answer is 'No data' if the child, before reaching the 36<sup>th</sup> postmenstrual week, was discharged or transferred with oxygen therapy to another institution, or died, and information about therapy needs after discharge and transfer is not available.

The answer is 'No data' if the newborn's gestational age is greater than 36 weeks and 6 days.

### **..Oxygen requirement FiO<sub>2</sub> at 36 postmenstrual weeks**

The answer is 'FiO<sub>2</sub> 0.22 – 0.3' or 'FiO<sub>2</sub> > 0.3', as appropriate.

### **..Oxygen requirement via nasal device (L/min) at 36 postmenstrual weeks**

The answer is 'No data' if the baby did not receive oxygen through a nasal device/nasal cannula on the 36<sup>th</sup> postmenstrual week, but received other respiratory support. Value range: 0.1 – 4 L/min.

### **.Ventilation requirement at 36 postmenstrual weeks**

The answer is 'Yes' if the newborn received invasive or non-invasive ventilation on the 36<sup>th</sup> postmenstrual week.

The answer is 'No' if the child was discharged or transferred to another institution without invasive or non-invasive ventilation before reaching the 36<sup>th</sup> postmenstrual week.

The answer is 'No data' if the child, before reaching the 36<sup>th</sup> postmenstrual week, was discharged or transferred with invasive or non-invasive ventilation to another institution, or died, and information about therapy needs after discharge and transfer is not available.

The answer is 'No data' if the newborn's gestational age is greater than 36 weeks and 6 days.

## **Necrotizing enterocolitis (NEC)**

The answer is 'Yes' if the diagnosis of necrotizing enterocolitis (NEC) is documented in the patient records or discharge summary.

### **.Bell stage**

The answer is 'Stage I' if the radiological findings show normal gas shadow or mild distension.

The answer is 'Stage II' if the radiological findings show dilated bowel loops, pneumatosis, or portal venous gas.

The answer is 'Stage III' if the radiological findings show pneumoperitoneum.

The answer is 'No data' if no abdominal X-ray and/or abdominal ultrasound examination were performed.

### **.Perforation**

The answer is 'Yes' if free intraperitoneal air is detected on radiological findings, during surgery, or during insertion of abdominal drains.

### **.The perforation was focal gastrointestinal perforation**

The answer is 'Yes' if focal perforation was visible during surgery or autopsy, and the rest of the bowel was normal.

### **.Abdominal drain due to NEC**

The answer is 'Yes' if ONLY abdominal drain insertion occurred for treatment of NEC during the acute phase. The answer is 'No' if abdominal drains were inserted and left in during surgery or laparotomy.

### **.Surgery for NEC**

The answer is 'Yes' if laparotomy was performed due to NEC.

### **Cerebral/cranial imaging**

The answer is 'Yes' if cerebral/cranial imaging (ultrasound, US) or magnetic resonance imaging (MRI) was performed.

### **.Intraventricular haemorrhage (IVH)**

Based on the results of cranial US/MRI, mark the stage of the most severe intraventricular haemorrhage (IVH) ever observed, even if the condition later improved.

The answer is 'No' if cranial imaging did not show germinal matrix or intraventricular haemorrhage.

The answer is 'Stage I' if the bleeding is localized to the germinal matrix.

The answer is 'Stage II' if the bleeding into the ventricle fills less than 50% of the ventricular lumen and does not cause ventricular dilatation.

The answer is 'Stage III' if the bleeding into the ventricle causes significant ventricular dilatation.

The answer is 'Stage IV' if, in addition to the previous stage, haemorrhagic infarction is evident in the periventricular white matter and/or other brain regions.

### **Acquired hydrocephalus (non-congenital)**

The answer is 'Yes' if cranial imaging (US, MRI) revealed ventricular dilatation that was not present until 1 week of age. Congenital hydrocephalus should be categorized under developmental abnormalities, and should not be marked here.

### **Cystic periventricular leukomalacia**

The answer is 'Yes' if the term periventricular leukomalacia (PVL) is mentioned in the findings of cerebral/cranial imaging (US, MRI).

The answer is 'No' if cerebral/cranial imaging (US, MRI) was performed, and periventricular leukomalacia was not detectable.

The answer is 'No data' if the preterm infant died or was transferred before the 2<sup>nd</sup> week of life, and PVL was not visualized in the US examinations until then.

### **Decubitus – tissue necrosis**

The answer is 'Yes' if pressure ulcers or pressure-induced injuries were visible on the skin.

### **.Severity of decubitus**

In the case of multiple pressure-induced injuries, indicate the most severe condition detected.

The answer is 'Mild, transient' if there is an erythema that does not blanch upon pressure to the affected skin area. The skin is moist, feels persistently warm, and there may be painful swelling or induration.

The answer is 'Moderate, transient' if there is partial skin loss on the skin surface, subcutaneously or both (loss of both epidermis and upper layers of dermis). The ulcer is superficial and clinically equivalent to an abrasion or blister.

The answer is 'Severe, transient' if there is total skin loss, with damage or necrosis of subcutaneous tissues, extending down to the fascia but not involving it.

The answer is 'Severe, permanent' if there is extensive destruction, tissue necrosis, or muscle, bone or tendon injury with complete or partial skin loss.

**.Decubitus on limb**

The answer is 'Yes' if pressure-induced injuries were on the limb.

**.Decubitus on ear**

The answer is 'Yes' if pressure-induced injuries were on the ear.

**.Decubitus on nose**

The answer is 'Yes' if pressure-induced injuries were on the nose.

**.Decubitus on other location**

The answer is 'Yes' if pressure-induced injuries were on a location other than the limb, ear, and nose.

**..Other location of decubitus**

Text field to specify the location of pressure-induced injuries in other areas.

**.Related to body positioning, clothing, immobility**

The answer is 'Yes' if the cause of pressure ulcers is related to clothing or immobility.

**.Related to intratracheal tube or its fixation**

The answer is 'Yes' if the cause of pressure ulcers is related to the intratracheal tube or its fixation.

**.Related to nCPAP nasal device or its fixation**

The answer is 'Yes' if the cause of pressure ulcers is related to the nasal device or its fixation during nCPAP ventilation.

**.Related to cannula or needle**

The answer is 'Yes' if the cause of pressure ulcers is related to any cannula, needle, or their fixation.

**.Related to surface disinfectant, chemical impact**

The answer is 'Yes' if the cause of pressure ulcers is of chemical origin.

**.Related to heat impact**

The answer is 'Yes' if the cause of pressure ulcers is heat exposure.

**.Related to other devices**

The answer is 'Yes' if the cause of pressure ulcers is not among those listed above.

**Discontinuation of medication due to side effects**

The answer is 'Yes' if the medication was discontinued earlier than planned, due to an adverse change in condition associated with the discontinued medication, whether this was merely a suspicion or considered to be proven.

**.Name of discontinued medication**

Text field to specify the generic or brand name of the discontinued medication due to real or suspected side effects.

**.Side effect of discontinued medication**

Text field to describe the side effect(s) constituting the reason for discontinuing the medication.

**Complication related to medication**

No need to record, deletion in progress.

**.Description of complication related to medication**

No need to record, deletion in progress.

**.Complication due to which side effect**

No need to record, deletion in progress.

**Other complication**

The answer is 'Yes' if a complication occurred that cannot be classified into the previous fields.

**.Description of other complication**

Text field to describe the other complication.

**CT scan performed**

The answer is 'Yes' if a CT scan was performed.

**.Name of CT scan**

Text field to specify the body part(s) for which a CT scan was taken.

**Cranial or brain MR imaging performed**

The answer is 'Yes' if cranial or brain MR imaging was performed.

**.Other MR imaging performed**

The answer is 'Yes' if MR imaging of a body part other than the head was performed.

**.Name of other MR imaging**

Text field to specify the body part(s) for which MR imaging was taken.

**ROP and hearing test**

**Ophthalmological examination was performed**

The answer is 'Yes' if a fundus examination was performed by an ophthalmologist. The red reflex examination performed by a neonatologist is not to be considered.

**.Maximal stage of ROP in the left eye**

Enter the maximal (most severe) stage of retinopathy of prematurity (ROP) as described in the ophthalmologist's written report. If there is no ROP, enter 0. Value range: 0 – 5.

**.Additional symptoms in the left eye**

The answer is 'Yes' if any additional symptoms were described in the left eye during ophthalmological examinations. The answer 'Yes' cannot be chosen if the maximal stage of ROP in the left eye is 0.

### **.Maximal stage of ROP in the right eye**

Enter the maximal (most severe) stage of retinopathy of prematurity (ROP) as described in the ophthalmologist's written report. If there is no ROP, enter 0. Value range: 0 – 5.

### **.Additional symptoms in the right eye**

The answer is 'Yes' if any additional symptoms were described in the right eye during ophthalmological examinations. The answer 'Yes' cannot be given if the maximal stage of ROP in the right eye is 0.

## **Surgery for ROP**

The answer is 'Yes' if laser coagulation, cryotherapy, or vitrectomy was performed for ROP.

### **.ROP laser coagulation**

The answer is 'Yes' if laser coagulation was performed for ROP.

#### **..Laser coagulation on the left side**

The answer is 'Yes' if laser coagulation was performed on the left eye for ROP.

#### **..Laser coagulation on the right side**

The answer is 'Yes' if laser coagulation was performed on the right eye for ROP.

#### **..Date of first laser coagulation**

The date (in the format year, month, day) of the first laser coagulation performed for ROP, regardless of whether the operation had to be repeated or was performed later on the other eye.

#### **..Body weight at laser coagulation (grams)**

Body weight in grams on the day of the first laser coagulation for ROP. Value range: 350 – 9000 grams.

### **.Cryotherapy**

The answer is 'Yes' if cryotherapy was performed for ROP.

#### **..Cryotherapy on the left side**

The answer is 'Yes' if cryotherapy was performed on the left eye for ROP.

#### **..Cryotherapy on the right side**

The answer is 'Yes' if cryotherapy was performed on the right eye for ROP.

#### **..Date of first cryotherapy**

The date (in the format year, month, day) of the first cryotherapy for ROP.

#### **..Body weight at cryotherapy (grams)**

Body weight in grams on the day of the first cryotherapy for ROP. Value range: 350 – 9000 grams.

### **.Vitrectomy**

The answer is 'Yes' if vitrectomy was performed for ROP.

#### **..Vitrectomy on the left side**

The answer is 'Yes' if vitrectomy was performed on the left eye for ROP.

### **..Vitrectomy on the right side**

The answer is 'Yes' if vitrectomy was performed on the right eye for ROP.

### **..Date of first vitrectomy**

The date (in the format year, month, day) of the first vitrectomy for ROP.

### **..Body weight at vitrectomy (grams)**

Body weight in grams on the day of the first vitrectomy for ROP. Value range: 350 – 9000 grams.

## **Medication for ROP**

The answer is 'Yes' if intraocular or systemic (IV, IM, per os) medication was administered for ROP. Eye drops should not be included.

### **.Intraocular drug treatment**

The answer is "Yes" if the medication was given into the vitreous humour of one or both eyes to treat ROP.

#### **..Name of intraocular medication**

Text field to indicate the active substance of the intraocular drug.

#### **..Date of first dose of intraocular medication**

Date of first dose of intraocular medication, in the format year, month, day.

### **.Systemic medication for ROP**

The answer is 'Yes' if systemic (IV, IM, per os) medication was administered for ROP. Eye drops should not be included.

#### **..Steroid for ROP**

The answer is 'Yes' if systemic (IV, IM, per os) steroid treatment was administered specifically for ROP.

#### **...Steroid agent administered for ROP**

The answer is 'Hydrocortisone' or 'Dexamethasone' if the administered steroid for ROP was either of these. The answer is 'Other' if a different steroid was used.

#### **....Other steroid agent for ROP**

Text field to specify the name of the another steroid agent administered for ROP.

#### **...Start of steroid for ROP**

The date (year, month, day) of the first dose of steroid administered for ROP.

#### **...First dose of steroid (mg/kg) for ROP**

The dose of the first administration of steroid due to ROP in mg/kg. Divide the administered amount by the weight (kg) on that day. Value range: 0.1 – 5 mg/kg.

#### **..Other systemic treatment for ROP**

The answer is 'Yes' if non-steroid systemic (IV, IM, per os) drug treatment was administered for ROP. Treatment with eye drops is not included here.

### **...Name of other systemic treatment for ROP**

Text field to specify the active ingredient of the non-steroid drug given systemically for ROP.

### **...Start of other systemic treatment for ROP**

The date (in the format year, month, day) of the first start of other systemic drug treatment for ROP.

### **Objective hearing screening was performed**

The answer is 'Yes' if the mandatory newborn hearing screening was carried out with the automated auditory brainstem response (ABR) device in the unit.

#### **.Result of objective hearing screening**

The answer is 'Normal' if the first hearing test result screened using the ABR device was satisfactory. The answer is 'Follow-up needed' if the first screening test result using the ABR device was not satisfactory, requiring a corrected follow-up examination until 1 month of age (with the ABR device).

### **Logistics**

Common data, a new form must be filled out for each new admission. A new form must be filled out in case of readmission, as well. The existing form should not be overwritten because the last save is stored in the database, and previous data will be lost.

#### **Logi ID**

The logistics identifier. Assigned by the program in recording order.

#### **Current institution**

From the 'Institution' list, the name of the NICU III or NICU II should be selected, for which data is currently recorded.

#### **Method of admission**

The answer 'First admission' should be avoided, when possible; try to specify more accurately where the newborn was transferred from – see below. This option is to be deleted in the future.

The answer is 'Transfer' if the child was transferred from another NICU III or NICU II (i.e. from another data recording institution).

The answer is 'Readmission' if the child was readmitted after being transferred.

The answer is 'First admission from the institution's delivery room' if the newborn was admitted from the institution's delivery room or the maternity observation unit.

The answer is 'First admission from the institution's neonatal unit' if the newborn was admitted from the institution's neonatal unit.

The answer is 'First admission from another institution's delivery room' if the newborn was admitted from another institution's delivery room or maternity observation unit.

The answer is 'First admission from another institution's neonatal unit' if the newborn was admitted from another institution's neonatal unit.

The answer is 'First admission from home or from public place' if the newborn was admitted from a non-healthcare institution, e.g. in the case of an out-of-hospital birth, or if a previously discharged newborn was readmitted.

### **Reason for transfer to unit or readmission**

In the answer to the question 'Method of admission' is either 'Transfer' or 'Readmission', the following possible answers can be selected:

The answer is 'Continuation of therapy' if the reason for the child's transfer or readmission is to continue previous medical treatment to facilitate discharge.

The answer is 'Surgery' if the reason for the child's transfer or readmission is surgical treatment to be performed at the institution.

The answer is 'Other diagnostics or treatment' if the reason for the child's transfer or readmission is to perform a diagnostic procedure or treatment that was not available at the sending institution. E.g. laser coagulation for ROP.

The answer is 'Chronic care, continuation of therapy' if the reason for the child's transfer or readmission is the need for long-term care. The designation 'continuation of therapy' in the name of this option is a program error, correction is in progress.

The answer is 'Other' if the reason for the child's transfer or readmission is not among the options listed above. E.g. for social reasons.

#### **.Specify other logistical reasons**

Text field to specify other reasons for transfer or readmission.

### **Time of admission**

The date (in the format year, month, day, hour, minute) of admission to the unit.

### **Birth weight (grams) at admission**

The child's weight at the time of admission, given in grams. Value range: 250 – 9000 g.

### **Length (cm) at admission**

The child's length at the time of admission, given in centimetres with decimal precision. Value range: 25 – 70 cm.

### **Head circumference (cm) at admission**

The child's head circumference at the time of admission, given in centimetres with decimal precision. Value range: 12 – 50 cm.

### **Method of discharge**

The answer is 'Discharge' if the newborn was discharged before the age of one, whether to the birth parents, adoptive parents, or an infant home.

The answer is 'Transfer from unit' if the newborn was transferred to another hospital department (even within the same institution) before the age of one. In this case, the 'Reason for transfer from unit' question must be filled out.

The answer is 'Death' if the newborn passed away in the unit before the age of one.

The answer is 'Requires hospital care at the age of one' if the child still requires continuous and previously uninterrupted hospital care on their first birthday.

#### **.Cause of death**

The answers 'Respiratory disease' or 'Sepsis' are self-explanatory.

The answer is 'Neurological cause' if the cause of death is an acquired neurological disease that is not a congenital disorder.

The answer is 'Congenital disorder' if the cause of death is a congenital malformation or chromosomal abnormality. In this case, the specific anomaly must be specified on the ICD table.

The answer is 'Other' if the cause of death is not among the above.

**..Specification of other causes of death**

Text field to specify other causes of death.

**.Autopsy performed**

The answer is 'Yes' if a pathological examination was performed on the deceased newborn.

**.Limitation of therapeutic interventions occurred**

**The answer is 'Yes' if, with no prior attempt or after an unsuccessful attempt for stabilisation due to a disorder incompatible with life or an acquired condition, palliative or comfort care was initiated. Reason for transfer from unit**

The answer is 'Surgery' if the reason for transferring the child from the current unit is surgical treatment performed in the receiving institution.

The answer is 'Other diagnostics or treatment' if the reason for transferring the child is the performance of a diagnostic procedure or treatment that was not available in the current (sending) institution. This includes laser coagulation for ROP.

The answer is 'Chronic care, continuation' if the reason for transferring the child is the continuation of previous medical treatment to facilitate discharge or long-term care.

**Time of discharge**

The date of discharge from the unit, in the format year, month, day, hour, minute.

**Weight at discharge (grams)**

The child's weight on the day of discharge, or if not measured, then on the previous day, given in grams. Value range: 250 – 9000 g.

**Length at discharge (cm)**

The child's length on the day of discharge, or if not measured, then on the previous day, given in centimetres with decimal precision. Value range: 25 – 70 cm.

**Head circumference at discharge (cm)**

The child's head circumference on the day of discharge, or if not measured, then on the previous day, given in centimetres with decimal precision. Value range: 12 – 50 cm.

**Use of apnea or other respiratory monitor at discharge**

The answer is 'Yes' if the newborn is discharged with monitoring, e.g. with pulse oximetry or apnea alarm.

**Feeding method at discharge**

To be filled out based on the feeding in the 24 hours before departure.

The answer is 'Breastfeeding' if the newborn was predominantly or exclusively breastfed in the last 24 hours.

The answer is 'Expressed breast milk feeding' if the newborn was predominantly fed with expressed breast milk from the mother in the last 24 hours.

The answer is 'Donor breast milk feeding' if the newborn was predominantly fed with donor breast milk in the last 24 hours.

The answer is 'Mixed feeding: breast milk + formula' if breast milk was a smaller proportion than formula.

The answer is 'Mixed feeding: donor milk + formula' if donor milk was a smaller proportion than formula.

The answer is 'Formula feeding' if the newborn was predominantly formula-fed.

The answer is 'Other' if the newborn received total or partial parenteral nutrition.

### **Oxygen requirement at discharge**

The answer is 'Yes' if the newborn received oxygen supplementation at the time of discharge.

### **Institution after transport**

In the case of transfer, select the receiving institution from the 'Institution' list. If you cannot find the desired institution, please inform the coordinator.

### **ICD codes table**

Common data. In the case of multiple ICD codes, multiple tables must be completed.

#### **ICD code**

Currently, diagnoses from the Q main group can be specified. Multiple diagnoses can be indicated!

#### **ICD type**

The answer is 'Pregnancy', 'First 72 hours of life', 'Discharge', 'Autopsy', 'Follow-up at 2 years' or 'Other', as appropriate based on the time of diagnosis.

### **Follow-up at two years of age**

Common data. The test should be performed at the corrected age of two years for children with a birth weight <1500 g.

#### **Date of 2-year-old follow-up examination**

Date of 2-year-old follow-up examination, in the format year, month, day. If the infant died after care at NICU, either in an institution or at home, the date of death should be recorded, in the format year, month, day.

#### **Corrected age in weeks at 2-year-old follow-up**

Corrected age in weeks at the time of the follow-up examination.

Calculation of the corrected age: subtract from the actual age the number of weeks between the birth and the 40<sup>th</sup> gestational week. Value range: 0 – 160 weeks.

#### **The test was performed at the corrected age of two years**

The answer is 'Yes' if the follow-up test was performed at a corrected age of 100 – 108 weeks.

#### **.If no, what was the reason for no follow-up, or not at 2 years**

The answer is 'Died' if the child died any time after being cared for in the NICU.

The answer is 'Relocated/moved' if the child does not live at the given address, and cannot be contacted.

The answer is 'Other' if the reason for the child's no follow-up examination, or not at their 2 years of age, is another than the above listed reasons.

#### **..Other reason for no follow-up, or not at 2 years**

Text field to specify the reason for not having a follow-up examination, or not at the corrected age of two.

#### **..Place of death**

The answer is 'Hospital' if the child died in any inpatient care health facility.

The answer is 'Other' if the child did not die in an inpatient health care facility.

#### **..Age at death (in months)**

The actual age at death in months. Value range: 0 – 48 months.

#### **..Cause of death**

The answer is 'SIDS' if the child died of sudden infant death syndrome (SIDS).

The answer is 'Accident, violence' if the child died due to an external cause.

The answer is 'Other' if the cause of death of the child is not one of the above.

#### **...Other cause of death**

Text field to specify the other causes of death of the child.

### **Body weight at time of examination (grams)**

Weight of the child on the day of the follow-up the examination, in grams. Value range: 4000 – 25000 g.

### **Body length at time of examination (cm)**

The child's body length on the day of the follow-up examination, in centimetres. Value range: 60 – 120 cm.

### **Head circumference at the time of examination (cm)**

The child's head circumference on the day of the follow-up examination, in centimetres. Value range: 30 – 60 cm.

### **Congenital malformation**

The answer is 'Yes' if one or more ICD codes from the main group Q (malformation, chromosomal abnormality) are included in the diagnoses.

In this case, any developmental or chromosomal abnormalities not yet recorded should be entered in the ICD codes table. Multiple diagnoses may be indicated!

### **Continuous oxygen demand**

The answer is 'Yes' if the child requires continuous supplemental oxygenation at home or any institution, by any means.

### **Need for respiratory therapy**

The answer is 'Yes' if the child requires continuous or intermittent mechanical ventilation support (non-invasive ventilation) at home, is a – participant in a home ventilation programme.

**Apnea or ALTE at home**

The answer is 'Yes' if apnea or apparent life-threatening events (ALTE) occurred at home, i.e. respiratory arrests either with an apnea monitor or without monitoring, leading to medical examination, or respiratory arrest resulting in resuscitation and subsequent hospital admission of the infant. –

**More than 3 hospital admissions for lung disease in the first year of life**

The answer is 'Yes' if the child was hospitalized for lung disease three or more times in the first year of life, after being discharged following birth.

**More than 3 hospital admissions for lung disease in the second year of life**

The answer is 'Yes' if the child was hospitalized for lung disease three or more times in the second year of life.

**Received passive immunisation against RSV**

The answer is 'Yes' if the child received passive immunization for respiratory syncytial virus (RSV).

**Confirmed RSV infection with hospitalisation in the first year of life**

The answer is 'Yes' if the child was hospitalized for RSV infection in the first year of life, after being discharged following birth.

**Medication for chronic lung disease**

The answer is 'Yes' if the child has been on continuous (or ongoing at the time of the follow-up examination) medication for chronic lung disease.

**.Name of medication for chronic lung disease**

Text field for the name of the medicine received for chronic lung disease.

**Under care for congenital heart defect**

The answer is 'Yes' if the child is under care for congenital heart defect.

**Surgery for congenital heart defect was performed**

The answer is 'Yes' if the child underwent an operation for a congenital heart defect.

**Awaiting surgery for congenital heart defect**

The answer is 'Yes' if the child is scheduled for surgery due to a congenital heart defect.

**Medication for congenital heart defect**

The answer is 'Yes' if the child is receiving continuous (or ongoing at the time of the follow-up examination) medication for a congenital heart defect.

**.Name of medication for congenital heart defect**

Text field for the name of the medicine received for the congenital heart defect.

**Need for feeding via gastrostomy**

The answer is 'Yes' if the child continuously required total or partial feeding through a gastrostomy either at the time of the follow-up examination, or in the last 3 months.

**Parenteral feeding requirement**

The answer is 'Yes' if the child required total or partial parenteral nutrition continuously (at the time of the follow-up examination, or in the last 3 months).

**Medication due to GOR**

The answer is 'Yes' if the child required medication for gastroesophageal reflux (GOR) continuously (or at the time of the follow-up examination).

**.Name of medication used for GOR**

Text field to specify the name of the medicine received for gastroesophageal reflux (GOR).

**Special formula requirement**

The answer is 'Yes' if the child required special formula (e.g. anti-reflux formula, reduced phenylalanine formula) continuously (or at the time of the follow-up examination).

**.Special formula used**

Text field to specify the name of the special formula.

**Dialysis requirement**

The answer is 'Yes' if the child required dialysis continuously (or at the time of the follow-up examination).

**Hearing confirmed as intact (previously tested by objective method)**

The answer is 'Yes' if the child's hearing is confirmed to be intact by objective testing. Excludes the answer 'Yes' for the questions 'Use of hearing aid', 'Under care for hearing loss, not currently requiring instrumental correction' and 'Hearing loss not correctable with a bilateral device'.

Answer 'No data' if the child's hearing has not been assessed by an objective method.

**Use of hearing aid**

The answer is 'Yes' if the child is using any form of hearing aid (e.g. implant or hearing aid) continuously (or at the time of the follow-up examination). Excludes the answer 'Yes' to the questions 'Hearing confirmed as intact', 'Under care for hearing loss, not currently requiring instrumental correction' and 'Hearing loss not correctable with a bilateral device'.

**Under care for hearing loss, not currently requiring instrumental correction**

The answer is 'Yes' if the child's hearing is determined as not intact by objective testing, and is therefore under care, but does not require a hearing aid. Excludes the answer 'Yes' for the questions 'Hearing is confirmed as intact', 'Use of hearing aid', 'Hearing loss not correctable with a bilateral device'.

Hearing loss not correctable with a bilateral device. The answer is 'Yes' if the child has hearing loss detected by objective testing, and is not correctable using a bilateral device. Excludes the answer 'Yes' to the questions 'Hearing is confirmed as intact', 'Use of hearing aid', 'Under care for hearing loss, not currently in need of instrumental correction'.

**Use of vision aid**

The answer is 'Yes' if the child uses a visual correction device (glasses) continuously (or at the time of the follow-up examination).

**Total bilateral blindness or light perception only**

The answer is 'Yes' if the child has been diagnosed with total bilateral blindness or only light perception in both eyes. Excludes the answer 'Yes' to the question 'Unilateral blindness'.

**Unilateral blindness**

The answer is 'Yes' if the child has been diagnosed with blindness in only one eye, or only light perception in only one eye. Excludes the answer 'Yes' to the question 'Total bilateral blindness or light perception only'.

**Last ophthalmological examination (months of life)**

Age at the last ophthalmological examination, expressed in months. Value range: 0 – 99 months.

**Disfiguring or cosmetically significant scars**

The answer is 'Yes' if the child has disfiguring or cosmetically significant scars.

**.Description of significant scars**

Text field to describe the disfiguring or cosmetically significant scars.

**Foot deformity**

The answer is 'Yes' if the child has a foot deformity that makes walking difficult.

**Hip dysplasia**

The answer is 'Yes' if the child previously (or at the time of the follow-up examination) received orthopaedic care and treatment for hip deformity.

**Deformity due to fracture**

The answer is 'Yes' if the child had a bone fracture in neonatal life (mostly due to osteopenia), which healed with deformity.

**Hemihypertrophy**

The answer is 'Yes' if the right or left side of the body is more asymmetrical than normal. This difference may be visible on a finger, a hand, foot or the face, or may affect half of the body, including the brain, tongue, or internal organs.

**Other musculoskeletal or dermal abnormalities**

The answer is 'Yes' if there is a significant musculoskeletal or dermal abnormality which cannot be categorized in the previous fields.

**History of CNS seizures, convulsion in the last 12 months**

The answer is 'Yes' if any central nervous system (CNS) seizure, convulsion, eclampsia, epilepsy symptom diagnosis occurred in the last 12 months (may be short or long, single or recurrent, subtle, clonic or tonic seizure condition.)

**Epilepsy diagnosis**

The answer is 'Yes' if the child has been diagnosed with any form of epilepsy.

**VP, VA, SG shunt**

The answer is 'Yes' if the child has a ventriculo-peritoneal (VP), ventriculo-atrial (VA) or subgaleal (SG) shunt.

### **Hemiparesis**

The answer is 'Yes' if the muscles of one side of the body's limbs and other body parts are weakened or paralysed.

### **Tetraparesis**

The answer is 'Yes' if muscle weakness or paralysis affects all four limbs, usually with hypotonia of the trunk.

### **Spastic unilateral paresis**

The answer is 'Yes' if involvement with increased muscle tone is observed on one side of the body (two types are monoparesis and hemiparesis).

### **Spastic bilateral paresis**

The answer is 'Yes' if involvement with increased muscle tone is observed on both sides of the body (two types are tetraparesis and diparesis).

### **Hypotonic cerebral palsy**

The answer is 'Yes' if muscle weakness or paralysis are accompanied by reduced muscle tone, affecting mainly the trunk (this is a 'historical' type of cerebral palsy, no longer differentiated, as it later progresses into the above categories, usually tetraparesis).

### **Other cerebral palsy**

The answer is 'Yes' in case of ataxic paresis (a form characterised by coordination problems of muscle movements and motor difficulties in speech) and dyskinetic paresis (a form characterised by involuntary movement patterns).

### **Walks without assistance**

The answer is 'Yes' if the child walks independently without a cane, walker, etc.

### **Stands up without assistance**

The answer is 'Yes' if the child stands up independently without being pulled or supported.

### **Sits without assistance**

The answer is 'Yes' if the child sits independently without support.

### **Eats independently with hands**

The answer is 'Yes' if the child eats independently with his/her hands.

### **Holds head without assistance**

The answer is 'Yes' if the child holds his/her head unaided, without support.

### **Gross Motor Function level according to GMFCS**

GMFCS – Gross Motor Function Classification System

**Level 1:** Can walk indoors and outdoors and climb stairs without using their hands for support. Can perform usual activities, like running and jumping. May have decreased speed, balance, and coordination.

**Level 2:** Can walk indoors and outdoors and climb stairs using a railing. Experiences difficulty with uneven surfaces, inclines, or while in crowds. Can minimally run or jump.

**Level 3:** Walks with assistive mobility devices indoors and outdoors on level surfaces. May be able to climb stairs using a railing. May propel a manual wheelchair; may require assistance for long distances or uneven surfaces.

**Level 4:** Walking ability is severely limited, even with assistive devices. Uses a wheelchair most of the time and may propel their own power wheelchair. May participate in standing transfers.

**Level 5:** Has physical impairments that restrict voluntary movement control and the ability to maintain head and neck position against gravity. Experiences impairment in all areas of motor function. Can't sit or stand independently, even with adaptive equipment. Can't independently walk, though may be able to use powered mobility devices.

### **Examination by objective test**

The answer is 'Yes' if the child's development has been quantitatively assessed using an objective, validated developmental test.

#### **.Date of objective test**

The date (in the format year, month, day) when the objective developmental test was carried out. It does not necessarily have to coincide with the two-year follow-up examination, but efforts should be made to conduct it between 100 – 108 corrected weeks of age.

#### **.Name of the objective test**

Text field for the name of the objective test performed.

#### **.FQ result**

Functional quotient (FQ) or developmental level, to be filled in if the objective test was Brunet-Lézine.

Calculated as  $FQ = (\text{developmental age} / \text{age}) \times 100$ .

### **Communicates verbally or other means**

The answer is 'Yes' if the child communicates with words or signs.

### **Can produce more than 5 different sounds**

The answer is 'Yes' if the child is capable to produce more than 5 different sounds.

### **Can understand words and signs**

The answer is 'Yes' if the child understands words or signs.

### **Shows interest in familiar people and objects**

The answer is 'Yes' if the child shows an interest in, or pays attention to familiar people and objects.

### **Eye contact is made**

The answer is 'Yes' if eye contact can be made with the child.

### **Tolerates stroking**

The answer is 'Yes' if the child tolerates stroking without a negative reaction.

### **MQ (motor quotient)**

Motor quotient (MQ), as determined by Brunet-Lézine test. In Hungarian, abbreviated as PQ.

**CQ (coordination quotient)**

Coordination quotient (LQ), as determined by Brunet-Lézine test. In Hungarian, abbreviated as KQ.

**LQ (language quotient)**

Language quotient (LQ), as determined by Brunet-Lézine test. In Hungarian, abbreviated as BQ.

**SQ (social quotient)**

Social quotient (SQ), as determined by Brunet-Lézine test. In Hungarian, abbreviated as SZQ.

**MDI**

Mental developmental index (MDI), as determined by Bayley II test.

**PDI**

Psychomotor developmental index (PDI), as determined by Bayley II test.

**Cognitive scale**

Cognitive scale score, as determined by Bayley III test. Value range: 55 – 145.

**Language scale**

Language scale score, as determined by Bayley III test. Value range: 47 – 153.

**Motor scale**

Motor scale score, as determined by Bayley III test. Value range: 46 – 157.

**Attended early developmental intervention**

The answer is 'Yes' if the child attended early developmental intervention or developmental therapy sessions multiple times.

**.Start of early developmental intervention**

Age of the child when developmental therapy was started, expressed in actual months of life. Value range: 0 – 99 months.

**.Currently attending early developmental intervention**

The answer is 'Yes' if the child was still attending developmental therapy sessions at the time of the follow-up test.

**..Length of early developmental intervention**

If the child is no longer attending developmental therapy sessions at the time of the follow-up test, the age of the child at the last attended session should be given, expressed in actual months of life. Value range: 0 – 99 months.

**.Name of early intervention**

Text field to specify the applied developmental therapy method(s).