



TRAINING MANUAL

Jordan Stillbirths & Neonatal Deaths Surveillance System (J-SANDS)

J-SANDS: Overview

Jordan lacks accurate registration system for reporting stillbirths and neonatal deaths and their causes, and therefore accurate mortality measures and quality indicators are lacking. An electronic surveillance system that automatically transfers the perinatal mortality data to the Ministry of Health and that is linked to a quality improvement system would be invaluable for policy makers. Jordan Stillbirths & Neonatal Deaths Surveillance System (J-SANDS) is a new registration system for capturing comprehensive and consistent data and information on the number and causes of neonatal deaths and stillbirths. The system also provides data on quality indicators through the use of BABIES matrix to determine which intervention package would have greatest impact in preventing these deaths. The system will also register births to use them as denominators for mortality measures.

The system is to be complemented by another intervention "Death Auditing System" to identify the causes and contributing factors to the deaths, followed by making the appropriate actions, and then identifying specific cases for systematic and scientific analysis of the quality of care received, in a no-blame, interdisciplinary setting, with a new vision to improving the quality of care provided to all mothers and babies.

In Jordan, as in many other countries, causes of perinatal deaths (particularly stillbirths) are often inaccurate and underreported. Furthermore, stillbirths are treated as if they had never even existed, being registered as neither a birth nor a death. J-SANDS is an important continuous recording system that can link data from the local to the national level through a networking system to enable benchmarking and monitoring of causes of death to inform policy makers, practitioners and researchers, to help parents understand why the death happened and to assist in future pregnancy planning. The main objectives of J-SAND are:

- To collect accurate data and information on all live births, stillbirths, and neonatal deaths.
- To identify the main and underlying causes of neonatal deaths and stillbirths and determine the socio-economic determinants of these deaths.
- To collect, classify, tabulate and, most importantly, to report cause-of-death data, using ICD-10 codes (ICD-PM), according to different identifiers.
- To calculate, estimate, and report various mortality measures including the neonatal mortality rate and stillbirth rate and other quality indicators.
- To provide data on quality indicators and to link mortality to birth weight and timing of death to determine which intervention package would have greatest impact in preventing adverse outcomes.
- To make evidence-based recommendations to decrease neonatal deaths and stillbirths

ICD-10

J-SANDS record the causes of neonatal deaths and stillbirths using the WHO application of ICD-10 to deaths during the perinatal period (ICD-PM). “ICD-10” is the abbreviated term used to refer to the International Classification of Diseases, Tenth Revision. ICD-10 is a global standard that is used to identify diagnosis and is the basis for determining medical necessity of a procedure or treatment. The ICD-10 is managed by the World Health Organization and classifies thousands of diseases as individual items and groups. By agreement, countries are obliged to report their mortality statistics to the World Health Organization using the ICD-10. These statistics form the basis for international health statistics and for international program priorities. They also form the basis for national and global burden of disease estimates and for decisions about global priorities to improve health.

ICD perinatal mortality (ICD-PM)

The first step in targeting programmes that address perinatal mortality is the accurate capture and classification of the causes of those deaths across all settings, using a globally applicable and comparable system. Perinatal outcomes are also intricately linked to maternal condition, and targeted programmes for reducing perinatal mortality may also affect maternal mortality.

Applying a classification system for perinatal death in such a way that the perinatal deaths are linked to maternal conditions and maternal death will help to improve health of mothers and their babies. The WHO application of ICD-10 to deaths during the perinatal period: ICD perinatal mortality (ICD-PM) is outlined in this document. ICD-PM is based on the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and follows all rules for mortality coding.

In essence, the features of ICD-PM are:

1. It identifies the time of death as antepartum (before the onset of labour), intrapartum (during labour but before delivery) or neonatal (up to day 7 of postnatal life). It can also be used for late neonatal deaths (7 days to 28 days).
2. It is multilayered such that the depth of classification can reflect the locally available intensity of investigation (this reflects the current ICD-10 system where cause of death is assigned in a stepwise process, following the progression of underlying clinical conditions leading to death).
3. It links the contributing maternal condition, if any, with perinatal death.

Ultimately all of these features allow easy identification of where a programme intervention should be targeted to improve both maternal and perinatal outcomes.

Application of ICD-PM in J-SANDS

J-SANDS assign the causes of stillbirth and neonatal death using ICD-PM in a standardized system of definitions and coding rules. This not only allows comparability but, given the widespread use of ICD (117 countries use ICD for mortality reporting), it has great potential to bring to the foreground those deaths that have previously gone unnoticed.

ICD-PM procedures for death registration

Perinatal cause of death and maternal condition on the J-SANDS

The first step in capturing the perinatal death and the maternal condition is undertaken by the care providers at any given health-care facility. This process is not one of coding, but of capturing all of the important clinical aspects of a perinatal death, telling the entire clinical story about both mother and baby. There is no need to have in-depth knowledge of ICD-10 codes to complete this process. Following documentation of the perinatal cause of death and maternal conditions, ICD-PM can be applied using a step-by-step process, whereby components of the clinical story are grouped into ICD-PM groups and linked to the appropriate ICD-10 code without prior knowledge of the codes.

Determining the cause of perinatal death

Cause of death is determined by the medical practitioner or other qualified certifier, who should use his or her clinical judgment in completing the medical certificate of cause of death, including documentation of the morbid conditions and events leading to the perinatal death. Consistent with WHO perinatal death certificate, **J-SANDS** list causes of death into four categories ("a" to "d"):

(a) Main disease or condition in fetus or infant	The " <u>most important or most contributing</u> " main disease or condition in the fetus or infant, which, in the opinion of the doctor in charge, made the greatest contribution to the death of the infant, or fetus.
(b) Other diseases or conditions in fetus or infant	Multiple other contributing conditions in fetus or infant
(c) Main maternal disease or condition affecting fetus or infant *	It is the " <u>most important or most contributing</u> " maternal disease or condition or pathology of the mother, which, in the opinion of the doctor in charge, made the greatest contribution to the death of the infant, or fetus.
(d) Other maternal diseases or conditions affecting fetus or infant	Multiple other contributing conditions in mothers

Application of ICD-PM to the cause of perinatal death

Initially the timing of perinatal death is classified as antepartum (A), intrapartum (I) or neonatal (N). This information is part of the minimum set of perinatal indicators that need to be collected for all births and perinatal deaths. Classifying death by timing still provides valuable information for analysis and targeting of programmes in these areas.

Using the ICD-PM system, J-SANDS groups the main condition in the fetus or infant into a limited number of categories of cause of death under the three headings for timing of death (i.e. A, I or N).

6 groups of antepartum causes of death, designated by a leading “A”;

7 groups of intrapartum causes of death, designated by a leading “I”;

11 groups of neonatal causes of death, designated by a leading “N”.

All of the ICD-10 codes that can be assigned to the perinatal cause of death on J-SANDS are represented in these groupings. The ICD-10 codes have been reordered and clarified to better represent the pathologies at different times of perinatal death. Codes that are not considered to be a cause of perinatal death in these sections have been excluded from the ICD-PM groupings.

The ICD-PM system: perinatal causes of death, separated by timing of death, and maternal condition at the time of perinatal death

Main perinatal cause of death ICD-PM groups

Antepartum death		Intrapartum death		Neonatal death	
A1	Congenital malformations, deformations and chromosomal abnormalities	I1	Congenital malformations, deformations and chromosomal abnormalities	N1	Congenital malformations, deformations and chromosomal abnormalities
A2	Infection	I2	Birth trauma	N2	Disorders related fetal growth
A3	Antepartum hypoxia	I3	Acute intrapartum event	N3	Birth trauma
A4	Other specified antepartum disorder	I4	Infection	N4	Complications of intrapartum events
A5	Disorders related fetal growth	I5	Other specified intrapartum disorder	N5	Convulsions and disorders of cerebral status
A6	Antepartum death of unspecified cause	I6	Disorders related to fetal growth	N6	Infection
		I7	Intrapartum death of unspecified cause	N7	Respiratory and cardiovascular disorders
				N8	Other neonatal conditions
				N9	Low birthweight and prematurity
				N10	Miscellaneous
				N11	Neonatal death of unspecified cause

Application of ICD-PM to the maternal condition in perinatal death

The five existing ICD-10 groups of maternal conditions in perinatal death have been rearranged into five groups denoted with a leading “M” as follows:

- M1 – the complications of placenta, cord and membranes;
- M2 – maternal complications of pregnancy;
- M3 – complications related to labour and delivery;
- M4 – the medical and surgical conditions which may or may not be related to the present pregnancy (e.g. pre-eclampsia or preexisting hypertension).
- M5 – “no maternal condition”:

ICD-PM maternal condition group	Main maternal conditions included in group*
M1: Complications of placenta, cord and membranes	<ol style="list-style-type: none"> 1. placenta praevia 2. other forms of placental separation and haemorrhage 3. placental dysfunction, infarction, insufficiency 4. fetal-placental transfusion syndromes 5. prolapsed cord / other compression of umbilical cord 6. chorioamnionitis 7. other complications of membranes
M2: Maternal complications of pregnancy	<ol style="list-style-type: none"> 1. incompetent cervix 2. preterm rupture of membranes 3. oligo / poly hydramnios 4. ectopic pregnancy 5. multiple pregnancy 6. maternal death 7. malpresentation before labour 8. other complications of pregnancy
M3: Other complications of labour and delivery	<ol style="list-style-type: none"> 1. breech delivery and extraction 2. other malpresentation, malposition, and disproportion during labour and delivery 3. forceps delivery / vacuum extraction 4. caesarean delivery 5. precipitate delivery 6. preterm labour and delivery 7. other complications of labour and delivery
M4: Maternal medical and surgical conditions	<ol style="list-style-type: none"> 1. pre-eclampsia / eclampsia 2. gestational hypertension 3. other hypertensive disorders 4. renal and urinary tract diseases 5. infectious and parasitic disease 6. circulatory and respiratory disease 7. nutritional disorders 8. injury 9. surgical procedure 10. other medical procedures 11. maternal diabetes including gestational diabetes 12. maternal anaesthesia and analgesia 13. maternal medication 14. tobacco / alcohol / drugs of addiction 15. nutritional chemical substances 16. environmental chemical substances 17. unspecified maternal condition
M5: No maternal condition	<ol style="list-style-type: none"> 1. no maternal condition identified (healthy mother)

*For a full list, definitions, and the other and unspecified conditions that are listed in each group see ICD-10 current version (<http://apps.who.int/classifications/icd10/browse/2015/en>) and ICD-10 volume 2 (www.who.int/classifications/icd/ICD10Volume2_en_2010.pdf?ua=1)

Important Notes to consider when assigning cause of death

1. Maternal disease or condition

Maternal disease or condition affecting fetus or infant: If the woman is assessed by the clinicians as having no recognizable condition, and there were no maternal complications of labour and delivery (e.g. malpresentation), then the maternal condition of “no maternal condition” needs to

be recorded. There are some maternal conditions that occur in mothers who are apparently healthy, and health workers need to consider this when completing the section on the main maternal disease or condition affecting the fetus or infant. For example, a woman may have had no known conditions throughout her pregnancy and may be otherwise clinically healthy when she presents with idiopathic preterm labour and whose baby subsequently dies in the neonatal period from hyaline membrane disease, which is an abnormal occurrence/ complication of labour and delivery. In the interest of linking perinatal and maternal interventions, it is important that this woman is recorded as having the maternal condition of preterm spontaneous labour with preterm delivery.

2. Preterm labour

The contribution of prematurity to perinatal mortality is of great interest to clinicians and researchers alike. It is helpful to be able to distinguish those mothers with apparently idiopathic preterm labour from those with pathology or provider-initiated delivery. Those who review perinatal deaths should remain mindful of this. Preterm labour as a maternal condition applies to those mothers who present prior to 37 completed weeks of gestation with spontaneous onset of contractions and cervical change in the absence of any apparent underlying pathology (e.g. chorioamnionitis or urinary tract infection).

3. Prematurity

Volume 2 of ICD-10 requests that clinicians do not enter prematurity as the main disease or condition in the fetus or infant unless it was the only fetal or infant condition known. It is preferable to only accept the diagnosis of prematurity as the main disease or condition in the infant if further evidence supports this notion, such as if a gestational age of less than 28 weeks was specified.

4. Obstructed labour

As outlined in ICD-Maternal Mortality (ICD-MM), “obstructed labour may be the start of a sequence leading to death, or may itself be due to some preceding condition such as contracted maternal pelvis or transverse lie”. Where the obstructed labour is the start of a sequence leading to perinatal death, this should be recorded as the main maternal condition. Where the obstructed labour is the consequence of another condition (e.g. malpresentation of the fetus), then this other condition should be recorded as the main maternal condition.

A minimum set of perinatal indicators

J-SANDS reports a collection of a minimum set of perinatal indicators around the time of all births and perinatal deaths, which includes the timing of death.

The development of J-SANDS perinatal health indicators was guided by the following:

- ✓ The Neonatal mortality rate is a key outcome indicator for newborn care and directly reflects prenatal, intrapartum, and neonatal care. Neonatal mortality rate is defined as the number of neonatal deaths (during the first 28 completed days of life) per one thousand live births in a given year or other period (WHO, 2011).
- ✓ Early neonatal deaths are more closely associated with pregnancy-related factors and maternal health, whereas late neonatal deaths are associated more with factors in the newborn's environment.
- ✓ For international comparison, weight-specific ratios and rates in which both the numerator and the denominator of all ratios and rates are restricted to fetuses and infants weighing 1000 g or more will be presented.
- ✓ Indicators will be divided into two groups: Core and recommended perinatal health indicators.
- ✓ Calculation formulas and uses for each indicator are also presented.

Core indicators

- ✓ The fetal death rate
- ✓ Neonatal mortality rate
- ✓ Early Neonatal Mortality rate
- ✓ Late neonatal mortality rate
- ✓ The perinatal death rate
- ✓ Causes of neonatal deaths, perinatal deaths, and stillbirths: Overall and categorized by gestational age and birth weight and for singleton and multiple births.

Mortality Indicators	Numerator	Denominator	Multipli- cation factor
The fetal death rate	Fetal deaths	Total births (live births + fetal deaths)	1000
Neonatal mortality rate*	Number of neonatal deaths	Total number of live births	1000
Early Neonatal Mortality rate	Number of neonatal deaths 0-7 days	Total number of live births	1000
late neonatal mortality rate	Number of neonatal deaths 8-27 days	Total number of live births	1000
The perinatal death rate	Fetal deaths + early neonatal deaths (0-7 days)	Total births (live births + fetal deaths)	1000

Perinatal audit

Consistent information about the nature and cause of death is needed for planning health systems and distributing resources, as well as for improving quality of care at the point of service delivery. These data are necessary for recommendations to be made, so that actions can be taken to prevent similar deaths in the future. Mortality audit is an established mechanism to examine the circumstances surrounding a death and the breakdowns in care that may be preventable. The ICD-PM classification is useful for mortality audit because the focus on the mother– baby dyad highlights areas requiring programmatic intervention that will benefit maternal and perinatal outcomes. It simplifies the certification of perinatal deaths, but it also offers programme officers and public health workers a means to identify solutions that meet the needs of both mother and baby concurrently. The categories on the data collection forms have been collapsed to facilitate ease of data entry and analysis, but they can also be expanded to include more specific causes and categories, depending on the capacity and interest of the facility staff and the perinatal mortality audit team.

Examples/ case-studies

Case 1

A 19-year-old para 1, with a certain gestation of 38 weeks based on early clinical examination, presented in a healthy condition during labour with no significant history. A 2450 g baby was delivered after an 8-hour labour. An early neonatal death on day 2 of life from meconium aspiration syndrome of a 2450 g baby occurred. Factors that are potentially modifiable identified by clinical review of the case were fetal distress not detected in labour and personnel too junior to manage the patient.

Causes of death	Category	Sub-category
I. Main disease or condition in fetus or infant:		Meconium aspiration syndrome
II. Other disease or condition in fetus or infant:		Small for gestational age
III. Main maternal disease or condition affecting fetus or infant:		No maternal condition
IV. Other maternal disease or condition affecting fetus or infant:		

Case 2

A 30-year-old para 1 presented in labour at 39 weeks of gestation, based on a certain last menstrual period, with the fetus alive at admission. The woman was HIV-positive and on long-term antiretroviral therapy. There was poor progress in labour, with incorrect interpretation of the partograph. An acute intrapartum event occurred with a hypoxic intrapartum stillbirth. The fetus was delivered via caesarean section.

Causes of death	Category	Sub-category
I. Main disease or condition in fetus or infant:		Intrapartum hypoxia
II. Other disease of condition in fetus or infant:		
III. Main maternal disease or condition affecting fetus or infant		Obstructed labour
IV. Other maternal disease of condition affecting fetus or infant:		HIV

Case 3

A 16-year-old para 0 with no medical history presented in spontaneous labour at 29 certain weeks of gestation and subsequently had a forceps delivery of a liveborn baby weighing 1100 g. The baby died on day 2 of life from hyaline membrane disease. The neonatal cause of death is hyaline membrane disease, with the maternal condition of spontaneous preterm labour.

Causes of death	Category	Sub-category
I. Main disease or condition in fetus or infant:		Hyaline membrane disease
II. Other disease or condition in fetus or infant:		Prematurity
III. Main maternal disease or condition affecting fetus or infant:		Spontaneous preterm labour
IV. Other maternal disease of condition affecting fetus or infant:		Forceps delivery

Case 4

A 36-year-old para 5 presented at 35 weeks of gestation determined by clinical palpation, complaining of a headache and decreased fetal movements. A fetal death in utero was diagnosed. Clinical and biochemical investigation revealed maternal proteinuric hypertension. Spontaneous vaginal delivery of a macerated 2100 g stillborn followed induction of labour. The proteinuric hypertension subsequently resolved.

Causes of death	Category	Sub-category
I. Main disease or condition in fetus or infant:		Intrauterine hypoxia
II. Other disease or condition in fetus or infant:		Prematurity
III. Main maternal disease or condition affecting fetus or infant:		Pre-eclampsia
IV. Other maternal disease of condition affecting fetus or infant:		

Case 5

A 37-year-old grand multipara with gestational diabetes mellitus was admitted to hospital at 32 weeks of gestation. She was diagnosed with premature rupture of the membranes and put on antibiotics. Two days later, she delivered a baby boy weighing 1.9 kilograms. The delivery was performed by the house officer. On examination, the baby was found to be premature and was short of breath. He was diagnosed with respiratory distress syndrome of neonates. The baby was sent to the premature baby unit for incubator care. Despite treatment, the baby died 14 hours after birth. Autopsy information may be available later.

Causes of death	Category	Sub-category
I. Main disease or condition in fetus or infant:		Neonatal respiratory distress syndrome
II. Other disease of condition in fetus or infant:		Prematurity or low birth weight
III. Main maternal disease or condition affecting fetus or infant:		Premature rupture of membranes
IV. Other maternal disease of condition affecting fetus or infant:		Preterm labour, gestational diabetes mellitus and grand multipara

Case 6

A primigravida aged 26 years with a history of regular menstrual cycles received routine antenatal care starting at the 10th week of pregnancy. At 30–32 weeks, fetal growth retardation was noted clinically, and confirmed at 34 weeks. There was no evident cause apart from symptomless bacteriuria. A caesarean section was performed and a liveborn boy weighing 1600 g was delivered. The placenta weighed 300 g and was described as infarcted. Respiratory distress syndrome developed which was responding to treatment. The baby died suddenly on the third day. Autopsy revealed extensive pulmonary hyaline membrane and massive intraventricular haemorrhage.

Causes of death	Category	Sub-category
I. Main disease or condition in fetus or infant:		Intraventricular haemorrhage
II. Other disease of condition in fetus or infant:		Respiratory distress syndrome Retarded foetal growth
III. Main maternal disease or condition affecting fetus or infant:		Placental insufficiency
IV. Other maternal disease of condition affecting fetus or infant:		Bacteriuria in pregnancy

Case 7

A 30-year-old mother of a healthy four-year-old boy had a normal pregnancy apart from hydramnios. X-ray at 36 weeks suggested anencephaly. Labour was induced. A stillborn anencephalic fetus weighing 1500 g was delivered.

Causes of death		
Causes of death	Category	Sub-category
I. Main disease or condition in fetus or infant:		Anencephaly
II. Other disease or condition in fetus or infant:		-----
III. Main maternal disease or condition affecting fetus or infant:		Hydramnios
IV. Other maternal disease or condition affecting fetus or infant:		-----