

## The quality of infant and perinatal mortality statistical data in Albania for the period 2000-2010

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### Abstract

**Aim:** Albania's infant and perinatal health has improved significantly over the past twenty years. Nevertheless, relatively high mortality rates across the country remain a primary health concern and in need of ongoing attention. This study aims to assess the quality of the country's infant and perinatal health reporting system, both internally and in comparison to international standards, in order to ultimately provide recommendations based on the findings.

**Methods:** The study consisted in the collection of infant and perinatal mortality data for the period 2000-2010, from national institutions and hospital facilities in Albania, during a research project between the Berlin School of Public Health and The National Institute of Public Health of Tirana, Albania. The data collected was utilized as a primary tool for conducting a comprehensive quality assessment of the health data.

**Results:** The quality assessment of infant and perinatal mortality data highlights certain inefficiencies with regard to the internal and external comparability of the data. The discrepancy in the collection and reporting of infant and perinatal mortality data in Albania, when compared to international standards, as well as possible gaps in the internal and external data flow, were identified as the key barriers for ensuring the overall quality of the health data generated.

**Conclusions:** Based on findings from this study, ten country-specific recommendations were proposed. The objective of these recommendations is to improve the quality of infant and perinatal mortality reporting in Albania and ensuring both an internal and international comparability of the data.

**Keywords:** Albania, data quality, health-reporting, infant mortality, perinatal mortality.

## Introduction

Infant and maternal health in Albania has improved significantly over the past decades. Nevertheless, national mortality rates remain high, particularly in comparison to Western Europe. In 2010, for example, the national infant mortality rate in Albania was reported as 9.7 deaths per 1000 live births (1), compared to the EU average of 5.93 deaths for the same year (2).

Infant and perinatal mortality rates are vital indicators of both quality and availability of healthcare services provided to mothers and their newborns (3), and are key indices to monitoring and assessing current health trends and driving the necessary policy and investment decisions (4). Possible inefficiencies within a health-reporting system can compromise the quality of health data and the accuracy with which assessments are conducted.

The purpose of this study is to identify prominent discrepancies in regards to the collection, calculation and reporting of infant and perinatal mortality in Albania, particularly when compared to current international standards. This assessment will serve as a basis in providing recommendations for improving the quality of the collection and reporting of health data and data flow, where deemed most appropriate.

## Research questions

1. Are the current definitions and methods of calculation and reporting proposed by the World Health Organization (WHO), currently the ones being used by Albania?
2. What are the main gaps or inefficiencies associated with the reporting of perinatal and stillborn deaths in Albania?
3. What problems can be identified within the data flow process occurring in Albania?

## Methods

### Data collection

Two separate visits to Albania, one during the project period of mid-April to mid-May and a second in late September 2012, provided the opportunity to collect infant and perinatal mortality data for the years 2000 to 2010 on the field. The health data was collected directly and indirectly from the Statistics Sector of the Ministry of Health

(MoH), The National Institute of Statistics (INSTAT), The National Public Health Institute (NPHI), the “Koço Gliozheni” and Lezhë Maternity hospitals, and the “Njësia Bashkiake” Civil Status Office (CSO) in Tirana.

## Study Design

The study design is a data quality assessment, a suitable approach for identifying and assessing potential errors or inaccuracies in the generation of data (5). One component of the assessment compares current definitions and methods of calculation of infant and perinatal mortality rates used in Albania to those proposed internationally using the WHO International Classification of Diseases (ICD-10 Volume 2) as the global standard. Additionally, current methods of health data collection and reporting methods in Albania (specific to infant and perinatal data) were evaluated in comparison to international reporting criteria standards recommended by the WHO. The data used to conduct this assessment included hospital form sheets and national table designs.

A second component of the study focused on assessing the current quality of Albania’s internal and external data flow. To conduct this assessment, data collected from hospitals and CSOs, along with nationally published data obtained from both the MoH and INSTAT, was utilized. Specific to the external data flow, the WHO Health for All Database (WHO HFA-DB), an international health database for the European region, was used to assess the quality and completeness of data transferred by Albania to international organizations. Based on study results, a list of recommendations was presented to improve the overall comparability of data.

## Results

### Definition and calculation of health indicators

The infant and neonatal mortality definitions currently used by Albania’s MoH are a translated version of those published by the WHO ICD-9 Volume 2 and are ultimately also in line with current WHO ICD-10 Volume 2 definitions, as confirms the national table designs published by the Statistics Sector of the MoH (Table 1). INSTAT, Albania’s statistical reporting institution, also currently follows the international definition for infant mortality rates,

**Table 1.** Infant mortality rates in Albania for the period 2000-2010

Indicator	Year										
	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Number of Live births	53833	52888	42315	45132	40866	38789	35816	34383	33368	34044	33856
Number of deaths	864	924	730	701	617	569	466	411	372	352	328
Infant mortality (per 1000 live births)	16.0	17.5	17.3	15.5	15.1	14.7	13.0	11.9	11.1	10.3	9.7
Perinatal deaths(per 1000 live births)	13.1	13.4	11.4	12.7	13.1	12.1	12.9	11.7	12.7	10.7	11.4
Neonatal deaths (per1000 live births)	8.9	10.4	8.4	9.8	9.5	10.20	9.10	8.69	8.30	7.40	6.80

Source: Statistics Sector, MoH Albania, 2011a.

citing it in its online definition catalogues as “the number of deaths per year occurring to 1.000 infants (less than one year old) born alive” (6).

With regard to the perinatal mortality indicator, experts confirm Albania’s adherence to the WHO definition of the indicator as being “the sum of fetal deaths and early neonatal deaths” (E. Kakarriqi, August 15, 2012). A set of unpublished data used internally by MoH underlines how the institution currently computes perinatal mortality rates as the *sum* of all ‘ante partum’ (prior to delivery), ‘intra partum’ (during delivery) and ‘post-partum’ deaths (early neonatal period). The data however does not confirm the specific time period from which the ‘ante-partum’ deaths are recorded, and thus it can only be assumed that the term comprises all fetal deaths occurring after the 22<sup>nd</sup> completed week of gestation. Contrary to WHO recommendations, the MoH currently does not provide a separate calculation of stillborn death rates within the table designs.

An analysis of Albania’s primary level perinatal death data, within healthcare facilities, was conducted using unpublished form sheets from the “Koço Gliozheni” Maternity Hospital of Tirana, along with information gathered from the Lezhë Maternity Hospital. Form sheets from the “Koço Gliozheni” hospital define and report perinatal deaths as the sum of all deaths occurring in the facility during the *antepartum*, *intra-partum* and *post partum* period (Table 2). While not explicit within the national table designs, hospital form sheets, on the contrary, were found

to include a detailed reporting of perinatal deaths according to both the weight and weeks of gestation of the dead fetus or newborn. While hospital forms include a detailed collection and reporting of perinatal deaths, there are inconsistencies in how the rates are calculated. Hospital statistical departments calculate deaths as *percentages* (Table 2), as opposed to the internationally recommended calculation of rates as per 1000 births, creating a concern as to how these rates are then adapted at the national level.

**Table 2.** Perinatal mortality data collection by “Koço Gliozheni” Maternity, 2005

Perinatal Deaths		Year 2005
<b>Born</b>	3108	ANTEPARTUM 41 = 1.31%
<b>501&gt; 22 weeks</b>		+INTRAPARTUM 0 = 0%
		+POSTPARTUM 39 = 1.25%
		=PERINATAL 80 = 2.55%
<b>Born</b>	3108	ANTEPARTUM 30% = .96%
<b>1001&gt; 28 weeks</b>		+INTRAPARTUM 0% = 0%
		+POSTPARTUM 27 = 0.86%
		=PERINATAL 60 = 1.83%

### Internal and external comparability of the collection and reporting of data

Hospital form sheets provide essential evidence as to how healthcare facilities collect and report deaths. “Koço Gliozheni” hospital form sheets underscore a comprehensive and detailed procedure for collecting and reporting infant deaths. As one

example of this, form sheets show a registration of neonatal deaths according to duration of life (0-6 days, 7-28 days, and over 28 days), as well as according to weight groups (Table 3).

**Table 3.** Infant deaths by days and weight, “Koço Gliozheni” Maternity Hospital, 2009

Infant deaths grouped by day for the year 2009					
Day	0-6	7-28	Over 28	VD-AL	Total
City	11	4	0	2	17
Town	7	5	0	0	12
District	14	5	0	9	28
R-Village	6	6	0	0	11
<b>Total</b>	<b>37</b>	<b>20</b>	<b>0</b>	<b>11</b>	<b>68</b>

Infant deaths grouped by weight for the year 2009							
Weight	500-1000	Weight	1001-1500 g.	1501-2000 g.	2001-2500 g.	>2500 g.	Total
City	2	City	4	3	3	5	17
Town	2	Town	4	2	1	3	12
District	8	District	5	3	3	9	28
R-Village	6	R-Village	4	1	0	0	11
<b>Total</b>	<b>18</b>	<b>Total</b>	<b>17</b>	<b>9</b>	<b>7</b>	<b>17</b>	<b>50</b>

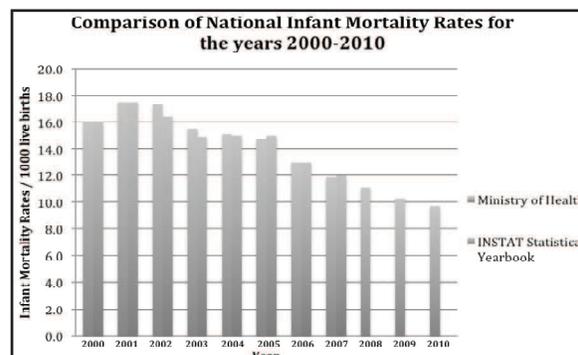
*Courtesy of the “Koço Gliozheni” Maternity Hospital in Tirana, 2009a (unpublished raw data).*

The quality of data collection and reporting procedures at the national level is influenced by the quality of the process at the primary level. As demonstrated in Table 1, Albania’s MoH is currently publishing national infant and neonatal mortality rates as per international standards, however there was found to be no reporting of deaths according to the different neonatal periods (early, late, post) within these tables, as per international recommendations. With regard to the stillborn death indicator, hospital facilities generally report the occurrence of a fetal death as *feto morto*.

As evidenced by Figure 1, fetal deaths are reported in hospitals according to the weight categories of 501g or more, and 1001g or more, slightly diverging from the WHO recommendation of 500g or more (for national data) and 1000 g. or more (for international data) (7). “Koço Gliozheni” form sheets further demonstrate a reporting of antepartum deaths according to weeks of gestation (22-27 weeks, 28-36 weeks, 37-41 weeks, and over 42 weeks) and according to birth weights (500-1000 g., 1001-1500 g., 1501-2000 g., 2001-2500 g., and over 2500g). While the stratification of weight and weeks diverge slightly from WHO standards, hospital data remains the most detailed and comprehensive health data available in the country. At the national level, the MoH and INSTAT do report perinatal mortality rates within their table

designs, however, and of most concern, is the fact that stillborn deaths are omitted completely from these tables (Table 1).

**Figure 1.** Comparison of infant mortality rates for the period 200-2010



*Source: Statistics Sector, MoH Albania, 2011a & the INSTAT Statistical Yearbook, 2009: Graph created by Eleonora Kinnicatt.*

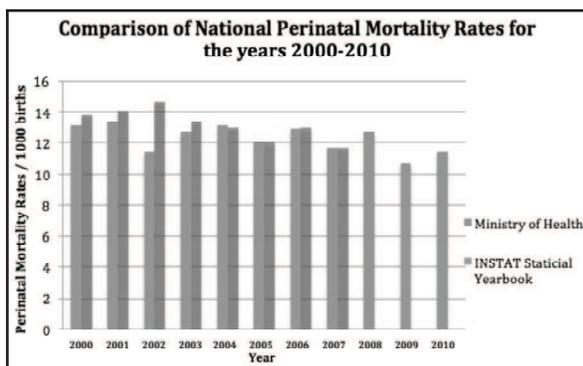
### Internal data flow assessment

The MoH collects and compiles data from health care and hospital facilities, while INSTAT operates using a “dual system” of data flow, utilizing both civil registration data deriving from CSOs and health data deriving from hospitals and primary healthcare facilities (8). Albania’s current birth registration forms requests information regarding length of pregnancy, description of delivery and whether the child is born alive or not. The death of a child, born in Albania

or to Albanian parents, should, according to the law, be reported in the CSO of residence of the mother. Nevertheless, if the death occurs outside Albania, it is oftentimes difficult to guarantee a registration of the event in the CSO of the mother's residences, as it remains difficult to monitor vital events occurring outside the country ("Njësia Bashkiake", May 2, 2012). INSTAT's demographic health indicators are an important reflection of the population's health status, and are vital tools for monitoring the quality of healthcare provided (8). Today, Albania is witnessing a new migration trend characterized by pregnant women deciding to temporarily leave Albania to give birth abroad. These women however are required by law to return to Albania within three months after giving birth to register their child in their CSO of residence ("Njësia Bashkiake", May 2, 2012). While these births or deaths will be recorded within the national civil registration system, they will be missing from national hospital data, opening up the possibility for an overall discrepancy in health data between hospitals and CSOs.

To further investigate a possible discrepancy in data, national infant and perinatal mortality rates published in the last ten years by the MoH and INSTAT were compared. As is evidenced by Figure 1 and Figure 2, there is currently a difference in the rates being published by the institutions for the same years, a possible cause of the current inefficiencies in Albania's internal data flow.

**Figure 2.** Comparison of perinatal mortality rates for the period 200-2010



Source: Statistics Sector, MoH Albania, 2011a & the INSTAT Statistical Yearbook, 2009; Graph created by Eleonora Kinnicatt.

### External data flow assessment

The quality of the external flow of health data is

critical to ensuring international comparability. The WHO HFA-DB currently publishes a set of core health indicators from all countries in the WHO European Region, and in order to assess the quality of external data flow, infant and perinatal mortality data for Albania (2000-2010) were searched within the database (9). The search resulted in a set of incomplete data, offering only infant and neonatal mortality data for the years 2000–2004, and no data on perinatal mortality rates for Albania. Inefficiencies in the internal and external data flow are underlined by the WHO HFA-DB, stating that: "Particularly high levels of mortality under-registration are observed in countries of central Asia and Caucasus, Albania [...]" (10).

### Discussion

Quality and comparability of health data

The collection and reporting procedures of infant mortality data within hospitals was found, overall, to be in line with international standards; evidenced by the inclusion of neonatal deaths according to duration of life (despite a minor divergence in late neonatal deaths as 7-28 days as opposed to 7-27 days). As the primary national health reporting institution, the MoH currently receives *all* hospital data, however, due to an aggregation of the data; it currently only publishes *total* neonatal mortality rates (Table 1). The omission of deaths according to neonatal periods within national table designs contradicts WHO recommendation that underline the different neonatal periods as important indicators of the quality of antenatal care, care during delivery and postnatal care (11). It is therefore important that Albania prioritize the national reporting of detailed neonatal mortality data, necessary for conducting newborn health evaluations.

While Albanian law currently defines stillborn deaths in accordance with WHO standards, as the death of the fetus weighing 500g or more (E. Kakarriqi, August 15, 2012), there was no identification of a written and translated definition available in the country. Within INSTAT's online catalogue, the sole definition identified was that of *prenatal death*, defined as 'the death of a fetus or child occurring before the delivery, during the delivery and death from 24 hours till 108 hours (seven days) from the delivery of a child born alive' (6). This indicator however remains incomparable to perinatal and stillborn deaths, and also presents a calculation error in that 108 hours is only equivalent to four and half days

and not seven days.

Study results highlight ongoing challenges faced by Albania's health-reporting system in guaranteeing a standardized method of stillbirth reporting across all levels of the healthcare system (E. Kakarriqi, May 3, 2012). The terms *fetal* or *ante partum* death, utilized most often within Albania's hospital forms, lack any indication as to the weeks of gestation or weight of the fetus at the time of death, vital information when coding and reporting stillborn deaths. The complete omission of the stillborn death indicator within national table designs, despite WHO recommendations to do so, further affects the quality of perinatal mortality data, hindering an accurate evaluation of maternal and perinatal health in Albania (12).

### Quality of data flow

A comprehensive assessment of Albania's demographic data flow could not be conducted due to limited time and resources; nevertheless, a number of possible concerns in the quality of internal data flow were acknowledged. A primary concern over the quality of data flow to INSTAT is in regards to currently high rates of population movement and recognized underreporting of births and deaths in Albania (10). The unquantifiable rate of Albanian women giving birth abroad implies the loss of health data within Albanian hospitals and an ultimate divergence with civil registration data (as births or deaths will be registered in CSO of mother's residence upon return to Albania) ("Njësia Bashkiake", May 2, 2012). The questionable reliability of internal data flow to INSTAT can distort population statistics and directly affect the computation of demographic health indicators produced, including infant and perinatal mortality rates (13).

An internal comparison of infant and perinatal data, conducted specifically for the study, highlights a divergence in mortality rates published by the MoH and INSTAT (Figure 3 & 4). The observed discrepancy may be at least partially caused by inefficiencies in Albania's internal data flow. An underreporting of births and deaths was a factor raised by numerous experts in Albania as a possible reason for the observed divergence in rates between two national institutions (E. Buzali, September 25, 2012). Inefficiencies in the internal data flow were found to ultimately compromise the quality of external data flow, as evidenced by a lack of available

health data for Albania within the WHO HFA-DB.

### Country recommendation proposals

While Albania's health system, like many others, continues to face challenges, the country has already made unquestionable progress, underlining both the ability and concerted effort being made towards responding to the health needs of its population. The findings from this data quality assessment are intended to provide support during this important phase of progress by proposing a number of recommendations:

- a) Albania should adopt all current international definitions for the reporting of infant and perinatal mortality indicators, in line with the WHO ICD-10 Volume 2, across all levels of the system, with a particular focus on standardizing the coding and reporting of stillborn deaths.
- b) Albania should adopt new form sheets and table designs across all levels of its health-reporting system. A reform in data collection will ensure both the internal and external comparability and validity of the health data, necessary for conducting health evaluations at the regional and global level.
- c) It is recommended that Albania include an accurate stratification of deaths according to the duration of life, accordance with international standards. Within hospital forms *and* national table designs, deaths occurring during the early neonatal (0-6 days), late neonatal (7-27 days) and post neonatal (28-364 days) periods should be reported separately (7).
- d) Albania is advised to report the weights of births and deaths according to international recommendations; using the following categories proposed by the WHO ICD-10 Volume 2: *Low birth weight* (up to and including 2499 g.), *Very low birth weight* (up to and including 1499 g.) and *Extremely low birth weight* (up to and including 999 g.) (7).
- e) It is recommended that Albania implement a perinatal death certificate that includes information on the cause of death of the fetus or newborn along with the conditions of the mother. The data registered on this death certificate will provide more detailed information on the perinatal health situation.
- f) To ensure an *internal validation* of data, Albania is advised to implement a protocol procedure for

internal flow of data. A standard protocol will ensure the quality and completeness of health data generated and used for internal and external assessments.

- g) To ensure an *external validation* of data, it is advised that Albania implement a data management system that defines who is responsible for the external delivery of data and for assuring that the quality and completeness of data are in line with international protocols.
- h) It is recommended that Albania prioritize its civil registration data of births and deaths as the primary or “official” set of data. The recommended reform aims to address the inefficiencies identified within the current “dual system” of data flow to INSTAT from CSOs and hospitals.
- i) It is recommended that INSTAT guarantee a yearly publication of demographic data either through its online database or as a statistical demographic yearbook. Additionally, the country should aim to publish yearly health reports, produced by the NPPI, to assess current epidemiological trends, population health status and public health services across the country.
- j) The implementation of national training programs, both in data collection and in statistical training is recommended. These efforts will require particular focus on the training of staff and personnel within government institutions, particularly if there is to be the eventual adoption of the WHO ICD-Volume 2. Training programs should be complemented by the formation of special commission groups, necessary for monitoring infant and maternal health at the district level.

### Limitations

Study limitations included the inability to collect all necessary data for the years 2000-2010, making more difficult the ability to conduct assessments and comparisons. A limited number of English publications, specific to Albania’s infant and perinatal health situation, proved to be another constraint to the study, as there was less evidence available to support certain findings. Lastly, while personal communication with experts proved to be an invaluable asset, the diverse areas of expertise

resulted, in certain instances, in a divergence of information gathered. The subjectivity of some information meant that it could not be included.

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